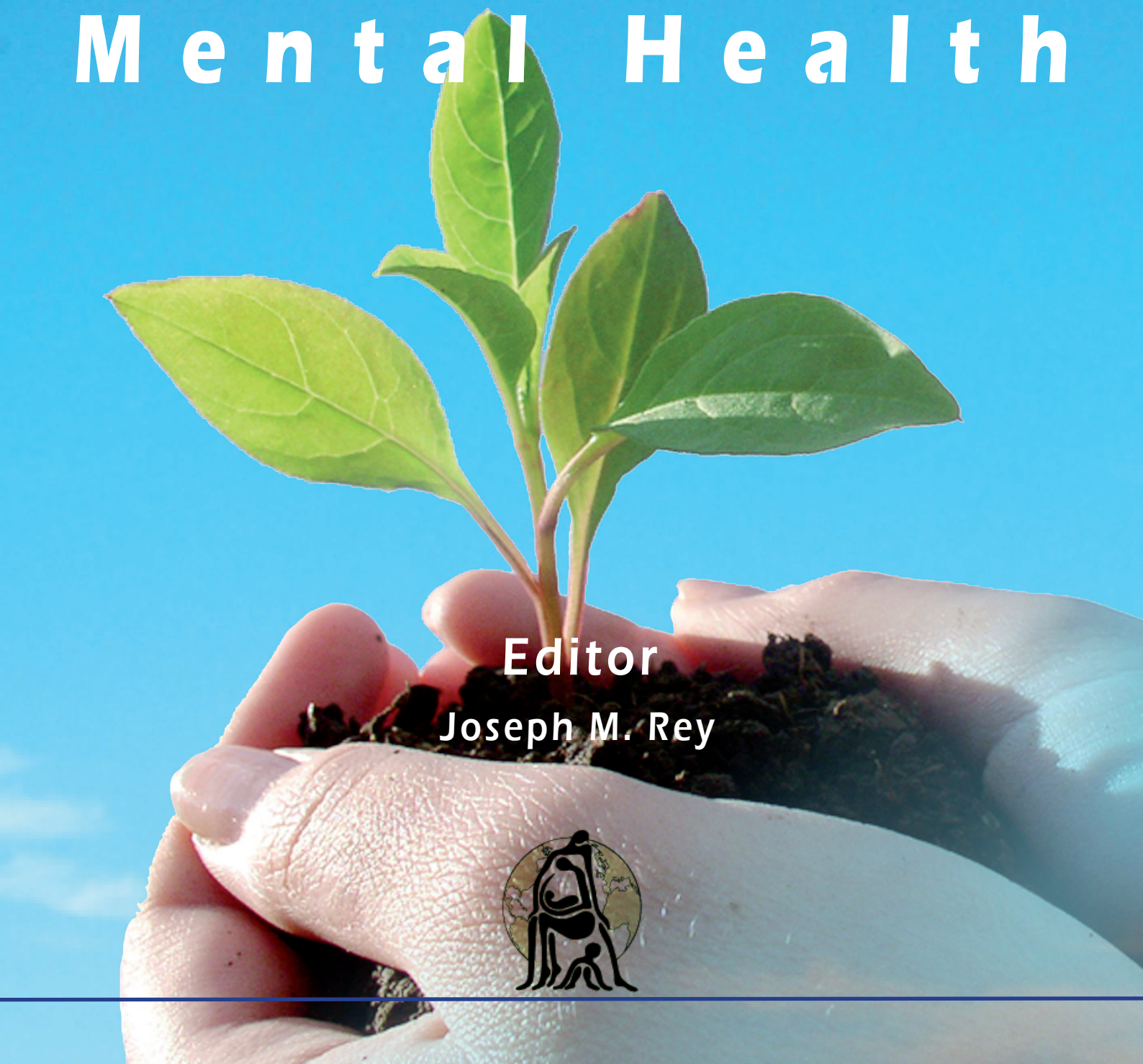
INTERNATIONAL ASSOCIATION FOR CHILD AND ADOLESCENT PSYCHIATRY AND ALLIED PROFESSIONS • ASSOCIATION INTERNATIONALE DE PSYCHIATRIE DE L'ENFANT, DE L'ADOLESCENT, ET DES PROFESSIONS ASSOCIEES • ASOCIACIÓN INTERNACIONAL DE PSIQUIATRÍA DEL NIÑO Y EL ADOLESCENTE Y PROFESIONES AFINES • 国际儿童青少年精神医学及相关学科协会 • ASSOCIAÇÃO INTERNACIONAL DE PSIQUIATRIA DA INFÂNCIA E ADOLESCÊNCIA E PROFISSÕES AFINS •

IACAPAP Textbook of Child and Adolescent Mental Health



Editor
Joseph M. Rey

Knowledge is the enemy of disease... Applying what we know already will have a bigger impact on health and disease than any drug or technology likely to be introduced in the next decade.

(Pang et al *The Lancet*, January 28, 2006).

Mental illnesses are different to most other illnesses. The overwhelming burden of mental illnesses falls upon the young.

(Healthcare Information for All 2015).

Supporting the mental health of children and adolescents should be seen as a strategic investment that creates many long term benefits for individuals, societies and health systems.

(WHO, 2005).

IACAPAP Textbook of Child and Adolescent Mental Health



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IACAPAP Textbook of Child and Adolescent Mental Health

ISBN: 978-0-646-57440-0

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The opinions expressed are those of the authors and do not necessarily represent the views of IACAPAP or the Editor.

This publication seeks to describe the best treatments and practices based on the scientific evidence available at the time of writing as evaluated by the authors and may change as a result of new research. Readers need to apply this knowledge to patients in accordance with the guidelines and laws of their country of practice. Some medications may not be available in some countries and readers should consult the specific drug information since not all the unwanted effects of medications are mentioned.

Organizations, publications and websites are cited or linked to illustrate issues or as a source of further information. This does not mean that authors, the editor or IACAPAP endorse their content or recommendations, which should be critically assessed by the reader. Websites may also change or cease to exist.

Unless stated otherwise, the case vignettes are fictional and seek to highlight specific issues, although they are based on the authors' clinical experience.

Suggested citation: Rey JM (editor). *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

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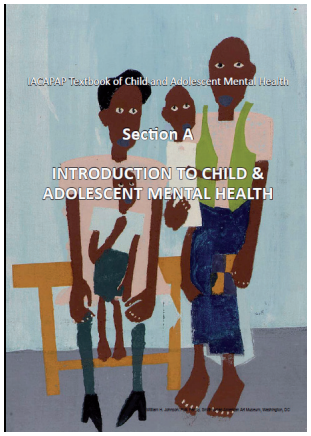
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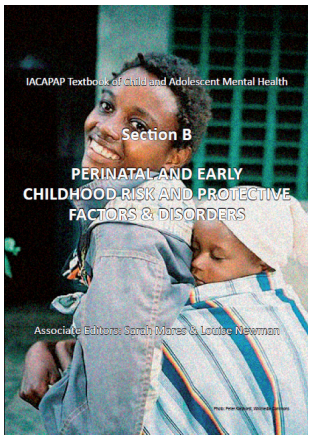
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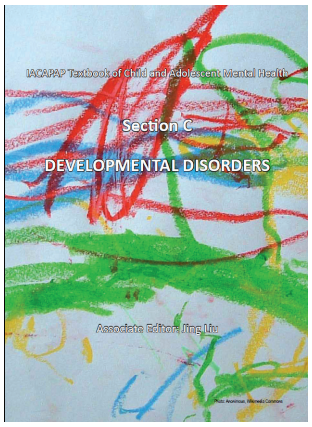


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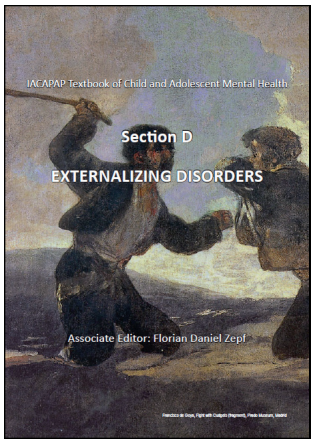
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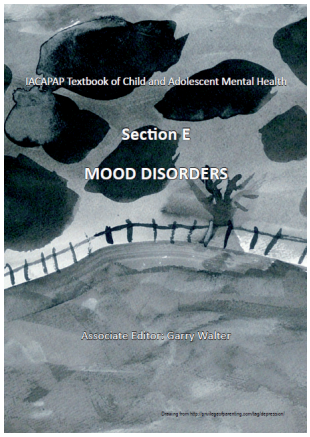
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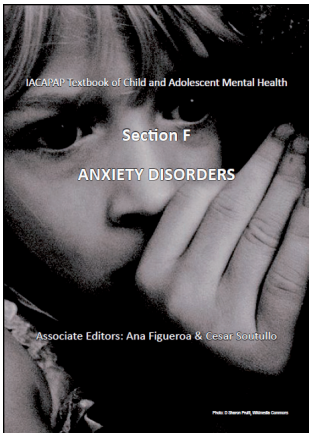
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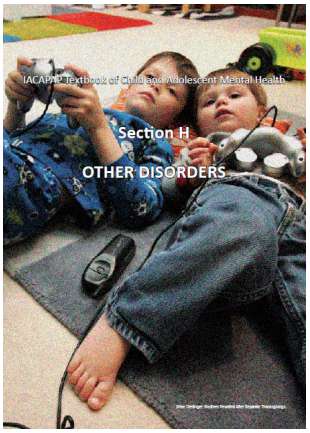


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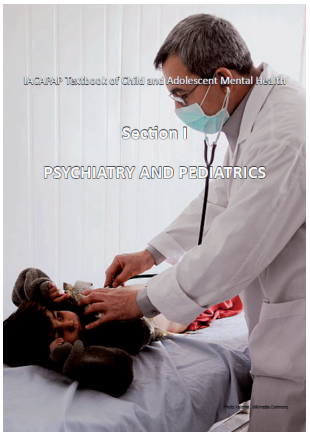
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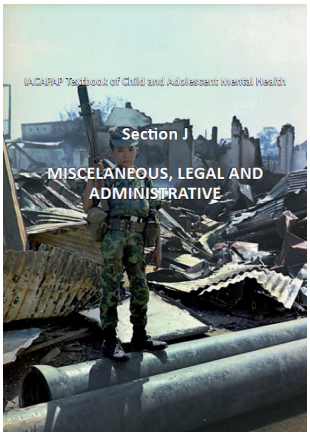
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FOREWORD

A Child and Adolescent Mental Health Guide in Every PALM

An electronic textbook on child and adolescent mental health (CAMH) that is free of charge and downloadable is now available on the website of the International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP). It is based on best clinical practice, reflects the latest research, will be updated regularly and strives to be culturally sensitive.This feat clearly reveals the commitment of IACAPAP to make knowledge about CAMH widely available, whilst advocating for access to quality CAMH care globally.

This e-book is a joint venture between child and adolescent psychiatrists and allied professionals in better-resourced parts of the world and the awfully few CAMH professionals in resource-poor regions working together. This arrangement fulfils another of IACAPAP's objectives of facilitating partnerships between developed and developing countries for the purpose of education and training, encouraging learning and growth on both sides and helping to reduce the disparity in accessibility of CAMH resources.

On the 6th of December 2010, the IACAPAP Bureau received a proposal from Professor Joseph Rey for the creation of an electronic book for CAMH to be launched at the Paris Congress in July 2012. We were thrilled about the leap forward this project could mean for CAMH worldwide. At the same time, it seemed a nearly impossible task. Now we can look back with amazement. We are fully aware that this innovation was primarily achieved with the sacrifice, doggedness, brilliance and sometimes sharpness of Professor Rey, the Editor. Seemingly impossible tasks need unusual interventions to bring them to fruition.

We were also conscious of the urgent need to have this project completed because a majority of the health professionals in the areas of the world where more than 80% of children and adolescents live have had no formal CAMH training. This book is an excellent starting point to ensure that no health professional who has to care for children is left without CAMH information. I have witnessed, first-hand, the difficulty of obtaining CAMH textbooks in developing countries due to high costs of purchase and difficulties with shipping. I have also experienced the pressure involved in having to loan a CAMH textbook for just a few days or having to make photocopies of portions of books in order to obtain needed information for patient care, research and training. This e-book will bring tremendous relief to CAMH professionals caught in this kind of web. Estimates suggest that there are now almost 6 billion mobile phone subscribers, a figure that would include a majority of the world's population. Most of the growth in the subscriber base has come from the developing world. This e-book enables IACAPAP to put current information on best practices for CAMH into the palm of every health professional.

Finally, with a comprehensive textbook for CAMH in the palm of every CAMH professional around the world, children, adolescents and their families can have better CAMH care. Change has definitely come to the world of CAMH through access to IACAPAP's new e- textbook of Child and Adolescent Mental Health; a truly welcome change!

Olayinka Omigbodun

PREFACE

One of IACAPAP's commitments is to ensure that child and adolescent mental health workers everywhere in the world have access to the best up-to-date information to treat their patients. Thus IACAPAP provides regular world congresses, a parallel book series, educational courses in disadvantaged regions, the Donald F Cohen fellowship program, and the Helmut Remschmidt research seminars. This book is a further contribution in this undertaking.

IACAPAP's electronic book brings together available technologies and resources to make learning more accessible, more efficient and more fun. For example, readers of the chapter on normal development can click and watch no less than the famous developmental psychologist, Jean Piaget, explain and illustrate his theories of cognitive development. While reading the chapter on other substances of abuse, view a clip from *Samson and Delilah,* an Australian feature film which graphically depicts the deleterious effects of petrol sniffing in an aboriginal teenager. Learn how to identify and rate the early manifestations of autism by watching a series of video clips, or listen to lectures by the best experts, or view video clips that can be used to educate parents and patients. The most recent and authoritative practice guidelines, free-to-use rating scales and questionnaires and the full text of hundreds of key publications are only a click away from your screen (text in blue signals a hyperlink). In our case, we are privileged to have not only a variety of media forms but also highly instructive text, but what you have on your screens today is only the beginning, a beta version, a skeleton: much flesh is to be added yet.

What comes next? Apart from updating the book every year, specialized chapters dealing with specific issues will be added to make the textbook increasingly more comprehensive. This may include, for example, chapters dealing with specific treatments, both psychological and pharmacological, and chapters about illnesses and problems not yet covered in this edition such as HIV/AIDS and PTSD.

How can you contribute to this project? You can provide feedback about specific chapters: what is useful and what is not; which aspects are not well described; important gaps and issues not discussed; errors; and information about specific needs or problems in your country or culture that should be mentioned. All these comments will be sent to contributors who will be asked to take them on board for the new editions. You may also suggest topics for chapters as well as the names of experts who could write them. Regrettably, the book is only available in English and, so far, the included resources in other languages are very few. So please alert the editor about resources in languages other than English.

Much remains to be done, but IACAPAP is committed to continue supporting this project to which so many people have selflessly contributed. I thank the IACAPAP Executive for their support and foresight, particularly the president, Professor Olayinka Omigbodun. Many busy experts from the five continents have contributed chapters and responded creatively to the demands made on them, for which I am grateful. I also thank the Editorial Advisory Board and the Associate Editors—who helped with some of the sections—for their advice and suggestions. Of these, Professors Garry Walter and Florian Daniel Zepf deserve special mention. Dr Jenny Bergen and Helen Rey assisted with the more unrewarding tasks of proof reading and in many other practical ways. Finally, Josephine Pajor-Markus helped with design and layout and Sherri Corrie made it easy to deal with website issues.

Joseph M Rey

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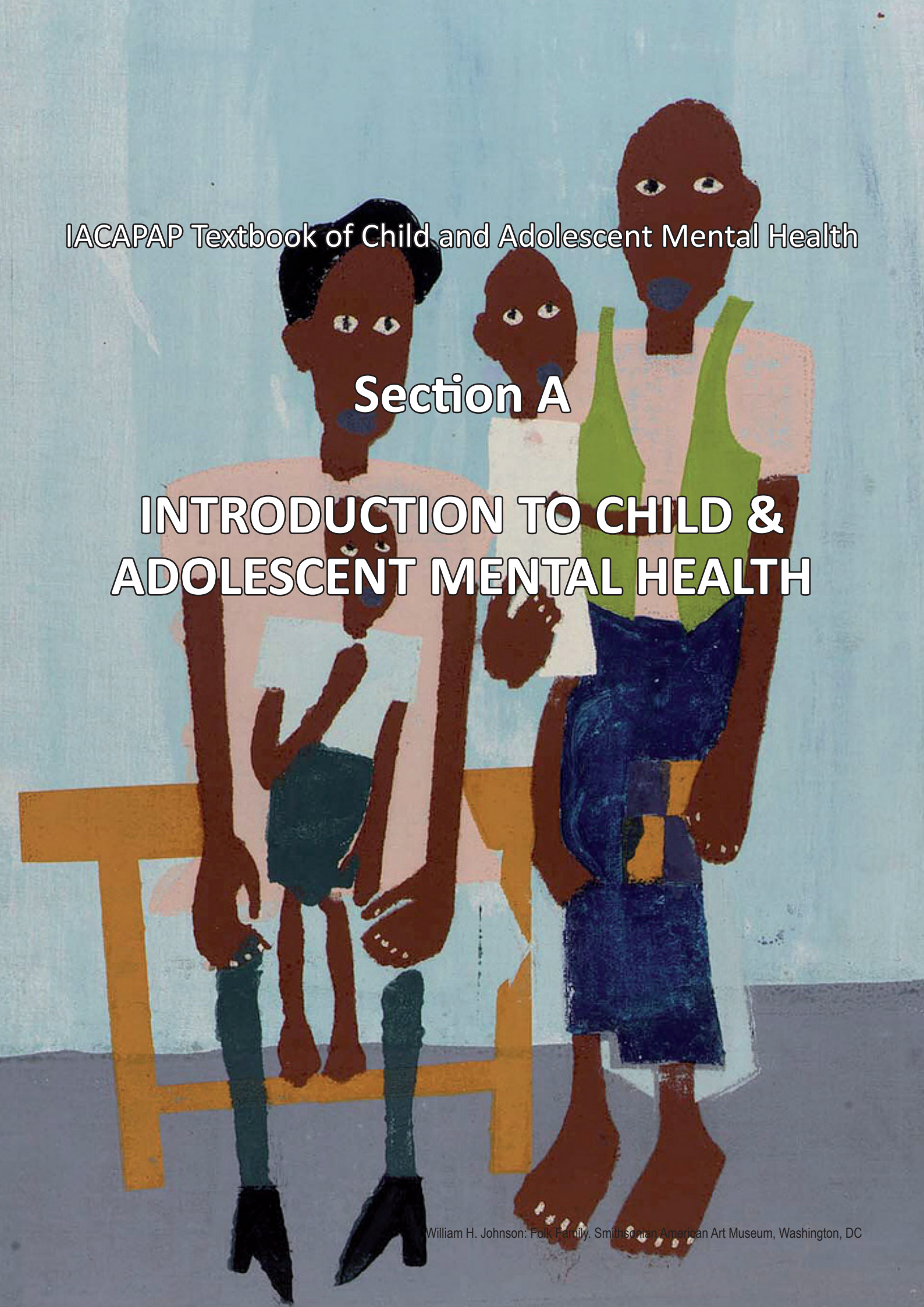
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IACAPAP Textbook of Child and Adolescent Mental Health

Section A

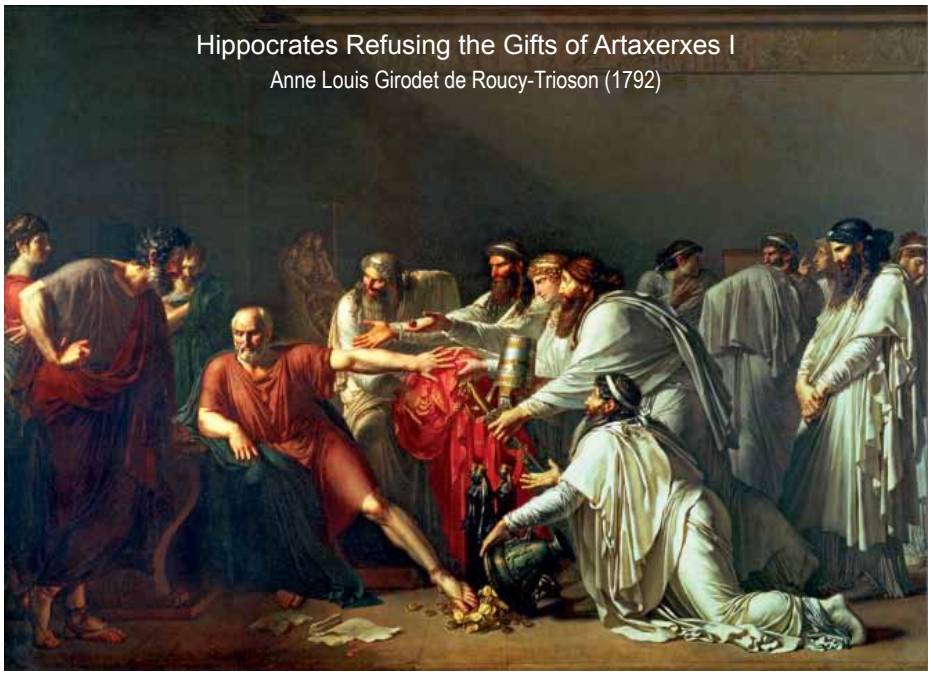
INTRODUCTION TO CHILD & ADOLESCENT MENTAL HEALTH



William H. Johnson: Folk Family. Smithsonian American Art Museum, Washington, DC

ETHICS AND INTERNATIONAL CHILD AND ADOLESCENT PSYCHIATRY

Adrian Sondheimer & Joseph M Rey



Hippocrates Refusing the Gifts of Artaxerxes I
Anne Louis Girodet de Roucy-Trioson (1792)

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Conflict of interest: none declared

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Conflict of interest: none declared

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Suggested citation: Sondheimer A, Rey JM. Ethics and international child and adolescent psychiatry. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

In a thoughtful and deliberate move, the opening chapter of the first IACAPAP textbook of child and adolescent mental health focuses on the relationship between ethics and the field. While this chapter focuses on medical practitioners, most of the ethical issues discussed apply to all mental health professionals (e.g., psychologists, social workers, nursing personnel, therapists) treating children and adolescents. Unless otherwise specified, "child" is used to mean all people younger than 18 years, "parent" represents parents and guardians, "child psychiatrist" means child and adolescent psychiatrists, and "child psychiatry" means the discipline of child and adolescent psychiatry.

"Of moral purpose I see no trace in Nature. That is an article of exclusively human manufacture – and very much to our credit"

Thomas Huxley



Thomas Henry Huxley (1825-1895) by Carlo Pellegrini ("Ape") 1759-1840. Dibner Library, Smithsonian Institution.

Child psychiatry is a subspecialty of psychiatry, and psychiatry is a medical specialty. The profession of medicine is intrinsically designed to do battle with whatever ails the human body and mind, and it attracts practitioners who are so inclined. If one were to define ethics as that intellectual line of inquiry focusing on the rightness and wrongness of human behaviors (American Heritage New Dictionary of Cultural Literacy, 2005) then medicine is an exemplar among the professions in that, as a vocation devoted to benefitting both the individual and collective human condition, it is founded and based on trying to do "the right thing". Thus, the medical profession and its practice seem clearly based on an ethical perspective. If only, however, matters could be viewed so simply. In fact, the study of ethics most commonly focuses on the complexities of the human condition which, by definition and experience, is usually composed of gray, complicated and murky areas. Only rarely does an ethical inquiry seem to offer stark black and white contrasts. That makes the examination of ethical questions interesting.

Psychiatry, more than any of the other medical specialties, attempts to focus equally on mind and body (Slavney, 1993). Ideally the specialty strives to integrate the two, as their functions are both mediated by the brain. Thus, psychiatry's perspective embraces the individual patient's cognitive, affective, interpersonal and behavioral processes, while simultaneously functioning in familial, social, cultural, economic, religious, educational and political contexts. Child psychiatry, a subspecialty of general psychiatry, focuses on individuals spanning the ages of infancy through adolescence, with many practitioners extending that range through young adulthood. The development of the child implies growth and maturation in various spheres, including the physical body, cognitions, affects, behaviors, and abilities to judge situations. Insofar as children have not as yet attained adult capacities in these areas, they require the protection and nurturance of guardians. In the main parents fill that role, but at other times familial relatives, government agencies, or other designated individuals provide the settings for youngsters to mature. Unlike their counterparts who limit their work to the treatment of adult patients, child psychiatrists usually devote their efforts not only to the youngsters but to the caregiving adults as well, who often provide information that the child is unable or unwilling to do. Working with two generations and their interactions, however, often provides witness to mutual conflicts which, in turn, can trigger ethical dilemmas.

ETHICS AND THE LARGER CONTEXT

Theoretically, solutions to ethical quandaries would be distinguished from other responses to these dilemmas by two distinct features. First, the solutions

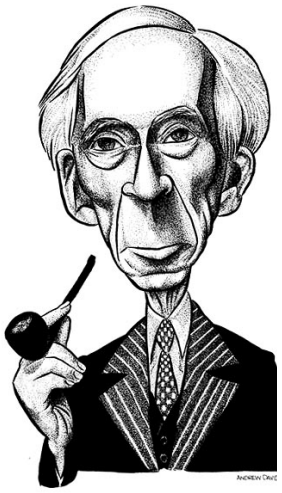
would be universalizable, i.e., arrived at independent of the circumstances in which they emerge and thus applicable in all contexts. Secondly, these objective "universalist" resolutions would trump personal and group motivations.

But, in fact, are these assertions axiomatic? In order to arrive at a well-reasoned and just resolution, in contrast to the judicious or prudent one, can one legitimately ignore context, be it political, economic, cultural or religious? On the face of it, that would seem unlikely. When contrasting, for example, the environments in which citizens of technologically-advanced democracies live with those of poverty-ridden, war-dominated, totalitarian autocracies, it is difficult to imagine applying identical ethical reasoning approaches in both settings and arriving at identical resolutions. Adding to the confusion are countries that have mixes of these elements, e.g., those whose current economic development may outstrip that of the established industrialized democracies but whose political architectures are largely dominated by "top down" perspectives. Stark examples of contrasts facing child psychiatrists serve to illustrate this: the luxury of the ethical dilemma of whether to prescribe a proprietary medication rather than a generic one, when for-profit insurance companies or government-approved formularies bring pressure on the child psychiatrist to prescribe the latter, contrasting with a child psychiatrist's desire to prescribe an antidepressant – any antidepressant – in a country that lacks many basic necessities, not to mention an adequate supply of psychotropic medications; the ethics of resisting the subtle pressure of a prosecutor's office to "waive" a juvenile offender's family court case to adult criminal court versus the threat from a government's military arm of a child psychiatrist's loss of livelihood, or worse, should a child psychiatrist refuse to admit a psychiatrically healthy individual, who has run afoul of political or police officialdom, for treatment to a psychiatric hospital (LaFraniere & Levin, 2010); the ethics of providing care to a recently bereaved child, surrounded by loving relatives with adequate or better financial resources, versus the provision of care to orphans, whose parents and adult relatives were murdered by a warring faction, now sheltered and living together in a youth dormitory (Stover et al, 2007; Williamson et al, 1987).

Writing about the ethics of child psychiatry with an international perspective means considering an enormous range of administrative, political, religious, cultural and economic contexts (Leckman & Leventhal, 2008). Do these stark differences in turn imply that ethical reasoning should be approached differently depending on context? In theory, the answer is no. It would appear that identical reasoning methods ought to be used in all contexts. The settings, however, most definitely need to be considered in the attempt to arrive at the most useful resolutions, and those considerations might well result in contrasting final choices in seemingly similar cases.

"I think we ought always to entertain our opinions with some measure of doubt. I shouldn't wish people dogmatically to believe any philosophy, not even mine"

Bertrand Russell



Bertrand Russell (1872-1970)

andsuchandsuch

It would appear that identical reasoning methods ought to be used in all contexts. The settings, however, most definitely need to be considered in the attempt to arrive at the most useful resolutions, and those considerations might well result in contrasting final choices in seemingly similar cases.

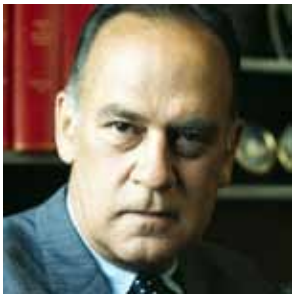
HISTORY OF CHILDHOOD

Optimal development of children is crucial to all societies, as the offspring will become the societies' adults who, they hope, will carry on the groups' traditions and values. According to predominating views of Western history, after infancy, children were viewed for millennia as little adults (Aries,1962; DeMause, 1974). They were considered the property of their parents who, in return for providing the youngsters with food and shelter, were entitled to the proceeds of their labor. Inklings of the need for education, beyond that of vocational apprenticeships,

began to be felt during the 17th century. Accompanying that development, conceptualization of childhood as a stage of human development separate from that of adulthood began to emerge. During the past 100+ years, concentration on childhood as a unique developmental stage has proceeded apace. During this time laws have been established mandating school attendance, protecting against child labor, facilitating and supporting the functioning and health of families, creating juvenile justice systems with unique approaches to legal procedures, and mandating reports of the abuse and/or neglect of children to governmental authorities (Enzer, 1985; Graham, 1999). As governments progressively took on responsibilities for children's welfare, the medical profession similarly evolved. Pediatrics first appeared as a specialty in the late 1800s; child psychiatry, as a subspecialty of psychiatry, began to emerge in the 1930s/40s (Musto, 2007). In the USA, the American Academy of Child Psychiatry was founded in 1953. During the past half-century, childhood itself has been subdivided more narrowly, while expanding its purview to now include the stages of infancy, toddlerhood, preschool, school-age, and adolescence (this last time frame further subdivided into early, middle and late stages). Thus, the conception of childhood has evolved over time from that of a relatively undifferentiated mass to the current one of substantial differentiation, distinguished by narrow age spans and differing needs and abilities. While all the stages share in common the requirement for adult-supplied nurturance, these fine-tuned differences, as will be seen later, often play a significant role in ethical considerations.

"Ethics is knowing the difference between what you have a right to do and what is right to do"

Potter Stewart



Potter Stewart (1915-1985) was an Associate Justice of the US Supreme Court

PROFESSIONALISM AND CHILDREN

Medical ethics comprises a large subset of medical professionalism. The concept of professionalism extends beyond matters directly affecting patient care, and speaks to the general comportment of the physician (Gabbard et al, 2011; Wynia et al, 1999). As much of a physician's behavior affects patient care, indirectly if not directly, the boundaries between ethics and professionalism can become hazy. Taking a broad view of the child psychiatry practitioner, child psychiatrists possibly are attracted to their work with children because they sense a vulnerability in youngsters that draws on their latent desires to nurture, protect, and educate. While those factors undoubtedly work in the youngsters' favor by facilitating good patient-doctor relationships, the potential pitfalls in those relationships also are many. For example, practitioners may find themselves physically or emotionally attracted to patients' guardians or to the patients themselves; indulging in rescue fantasies; feeling the urge to provide special favors for specific patients or their families; or desirous of soliciting patients' families for funding of designated projects. While such thoughts and fantasies should be understood as not unusual accompaniments of practice, acting on them in ways that prove deleterious to the patient would be unprofessional. By contrast, as the cardinal principle of ethical medical practice, the child's safety, welfare and interests must be the practitioner's paramount concern. Such a principle mandates that, under no circumstances, should a child psychiatrist exploit a child patient or the child's relatives by violating professional boundaries. These boundaries are both literal and figurative limits, created precisely to forestall such behaviors (Gabbard & Nadelson, 1995; Schetky, 1995). Instead, the child and its guardians should be able to expect, with certainty, that the child psychiatrist will conduct all mutual exchanges honestly, transparently, with integrity and fidelity.

CODES OF ETHICS

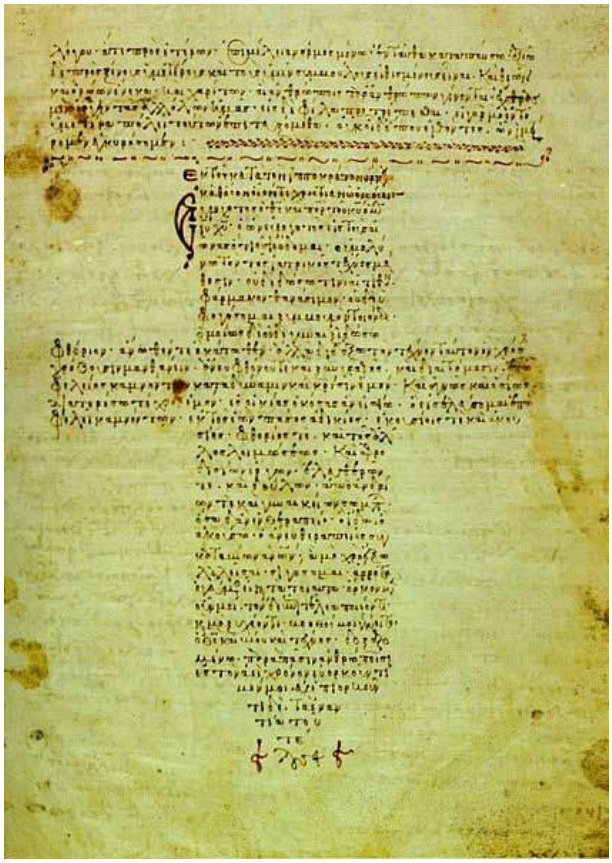
Throughout the millennia of existence, all human societies have designated certain citizens as its healers. More recently, these individuals were titled its physicians, or doctors. Throughout these many centuries, the medical practitioners, inhabitants of disparate societies situated in countries encompassing the entire globe, have created innumerable codes of ethics to guide their professional behaviors. The vast majority of these codes, despite emanating from societies differing starkly from each other along ethnic, religious and geographic lines, share common foci and concerns. Thus, the following principles are addressed in most of the codes:

- Primacy of respect for human life
- Physician responsibility for the well-being of the patient
- Admonition to help or, at least, do no harm; and
- An emphasis on virtue and duty.

Attention is often directed as well toward these specific issues:

- Equality of care independent of the patient's financial standing
- Expectation of setting appropriate fees
- Employment of legitimate methods to establish diagnoses, including clinical observation and sound reasoning
- Consideration of whether, and when, to provide treatment; if treatment, the employment of legitimate therapies
- The confidential nature of the patient-physician relationship
- Prohibition against sexual relationship between physician and patient; and
- Imposition of punishment or sanctions in the event of inept technical performance or code violation.

International codes, adopted by medical organizations, initially appeared in formal mode during the 20th century. The World Medical Association's International Code of Medical Ethics, first produced in 1949 and revised most recently in 2006, outlines the general duties of physicians as well as their responsibilities to patients and colleagues (World Medical Association, 2006). Emphasis is placed on the need for competence, honesty, dedication, avoidance of bias and/or exploitation, respect for confidentiality, collaboration, and, interestingly, the obligation of physicians to obtain care for themselves in the event of personal mental or physical illness. Similar global thinking led to the establishment of several psychiatric codes and declarations on a pan-national scale. The World Psychiatric Association's Declaration of Madrid (1996), building on the prior Declarations of Hawaii (1977) and Vienna (1983), created international ethical standards and guidelines for psychiatric practice (World Psychiatric Association, 1996). In addition to the discussion of such basic elements as the practitioner's responsibility to the patient, the need to maintain knowledge of current scientific developments, protection of participants in research, confidentiality, and maintenance of professional boundaries, specific attention is also paid to prohibition of participation in torture, death penalty, sex selection, and ethnic and/or cultural discrimination procedures; avoidance of industry- and politically-induced conflicts of interests;



The Hippocratic Oath is an oath historically taken by physicians and other healthcare professionals swearing to practice medicine ethically. It is widely believed to have been written by Hippocrates or by one of his students.

A 12th-century Byzantine manuscript of the Oath (Wikimedia Commons)

and the expectation that sound treatments must be based on valid diagnoses, following the patient's receipt of complete pertinent information and subsequent provision of uncoerced consent. In 1989, the United Nations Convention on the Rights of the Child, with the collective weight of the member countries behind them, established the rights of children to survival, development, protection and participation, including the rights to voice their views freely, be given commensurate deference, and live with their families (United Nations, Centre for Human Rights, 1990) (see Chapter J.7). The United Nations Convention on the Rights of Persons with Disabilities (2006) emphasizes that respect and dignity are to be accorded to disabled individuals of all ages, including children, and embraces the psychiatrically ill, among many others (United Nations, 2007; Stein et al, 2009). The document highlights nondiscrimination and equal access to health care, and emphasizes the right of all disabled individuals to equal inclusion in all aspects of life and its fundamental freedoms. Despite the impressive provenance of these declarations, it is obvious that their implementation varies enormously among the signatory countries. That is to be expected, given grossly differing systems of government. Reassurance, however, comes from the continuing global ethically-based thrust in the direction of greater protections for children and the disabled, and an increased awareness of forces that promote or impede their implementation. In 2006, the International Association for Child and Adolescent Psychiatry and Allied Professions (IACAPAP) created guidelines and principles for practitioners in its document entitled Ethics in Child and Adolescent Mental Health, which in turn derived from IACAPAP's resolution "Assuring Mental Health for Children", promulgated in 1992 and further revised in 1996 and 2004 (IACAPAP, 2006). IACAPAP's document itemizes basic ethical principles;

addresses rights of both children and their parents/legal caregivers; reviews consent and assent; and addresses topics including confidentiality, potential exploitation, sexual encounters, honesty, involuntary treatment, gifts from patients or industry, presentation of patient material in publications and professional meetings, research ethics, multidisciplinary collaboration, and the association's guidelines for its acceptance of financial support.

The initial efforts and subsequent revisions noted in these various declarations and guidelines are a function of circumstances and influences that change over time. The American Academy of Child and Adolescent Psychiatry's (AACAP) Code of Ethics serves as an example. Promulgated initially in 1980, revised slightly in 2007 and greatly in 2009, the Code reflects changes in medical knowledge, modes of clinical practice, payments for services, understandings of psychological dynamics, and practices of the pharmacologic and manufacturing industries that evolved over three decades (American Academy of Child and Adolescent Psychiatry, 2009). The most recent revision addresses, directly and comprehensively, issues of third-party influence, expectations of publication of all research study results – positive and negative, conflicts of interest, romantic and/or sexual entanglements with patients and their families, risks of research with children, practitioner self-aggrandizement, and expectations that practitioners will have knowledge of the laws prevailing in the professional's jurisdiction as well as tensions that might exist between the law and ethical considerations. As Beauchamp (2009) notes, "the law is not the repository of our moral standards and values". By contrast, codes of ethics are guidelines for professional behavior and they differ from laws by providing greater flexibility and choices of action. The codes embody standards of professional conduct and the current AACAP code is an example of one that clearly, rather than vaguely, indicates preferred behaviors. For the practitioner who has questions about his or her own or a fellow professional's motivations, inclinations or behaviors, consultation with colleagues and referral to a code's guidelines are arguably the most useful and potentially helpful options.

CHILDREN, ETHICS, AND ETHICAL PRINCIPLES

Children and adults differ from each other in discernible ways. Children are usually smaller, have narrower understandings of historical and external events, are engaged in a continuous process of rapid development and maturation, and require protection by and nurturance from others. Children, however, are not a monolithic group – e.g., the toddler and the late adolescent differ greatly from each other in many of the above-cited spheres, even as they also share these traits in common. Consequent to their ongoing dependence on adults, however, usually they are legally regarded as minors. Thus, significant decisions, e.g., where and with whom they will live, their ability to roam or travel, locales of secular and nature of religious educations, and access to medical care, all reside by law in the hands of their parents/guardians. In countries endowed with effective legal systems, the state has the legal right to intervene in such decisions only in the event that guardians are derelict in providing their children with the basic necessities, i.e., food, shelter and education, or are abusive of the youngsters under their care. These seemingly "self-evident" and generally accepted legal rules are in fact based on the employment of basic ethical understandings which in turn are combined with extensive knowledge of childhood development. While several approaches to moral thought vie for supremacy (Bloch, 2007), fundamental principles undergird

the ethics of endeavors with children. Thus, the individual clinician is expected to work toward outcomes that would prove best for the child (*beneficence*), avoid practices that are likely to cause the child harm (*nonmaleficence*), grant respect for the choices and wishes of the individual patient (*autonomy*) and treat all patients under care fairly, equally, and with fidelity (*justice*). This same ethical structure holds for the creation of administrative approaches designed to provide care and protection for large groups of children (Sondheimer, 2010). For example, when planning measures to foster improved mental health efforts in schools (Bostic & Bagnell, 2001; Brener et al, 2007), provide care for children traumatized by war (Betancourt, 2011; Panter-Brick et al, 2011), or innovate programs for juvenile offenders (Holden et al, 2003), it is reasonable to expect that authorities would design their efforts in such ways that the children experience benefit, are not hurt, feel respected, and receive help and protection equally.

These sentiments and approaches envision the ideal, and some clinical and administrative conditions might readily lend themselves to stark and clear right or wrong choices. But reality generally presents conflicts that exist in shades of gray. Viewing children along maturational continua is an obvious illustration. Thus, what may be beneficial for a 16 year old (e.g., respecting the autonomous right to refuse treatment) may not be helpful for the recalcitrant seven year old. Other gray area dilemmas commonly assert themselves as well. For example, given differing perspectives between child and guardian, to whom does the child psychiatrist defer, without ignoring the concerns of the other? When a group (e.g., a family) wants to pursue an agenda favored by the majority of its members, is the minority's dissenting view (not infrequently that of the child patient) to be accorded respect, and how? When does the child psychiatrist pay attention to the needs of an individual patient in the context of limited resources if, from a public health perspective, attention to the community's needs could ultimately benefit a greater number of patients? Often, the ethical principles employed to pursue answers to such clinical or administrative questions conflict with each other, and a reasoning approach must be employed to achieve a desirable resolution. Notably, this process should never imply a pre-ordained outcome.

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ETHICAL REASONING

Clinicians usually perform their work with patients without stopping to question the ethical bases of their actions. This makes perfect sense. The average child psychiatrist is conscientious, has received adequate training and, over time, acquired clinical experience, all of which foster the child psychiatrist's provision of good care in relatively routine fashion. On occasion, however, the child psychiatrist is confronted with confusing or unsettling situations that leave the practitioner feeling uneasy and uncertain as to how to proceed (Sondheimer, 2011). The child psychiatrist's hesitation or discomfort could be due to, e.g., a parent's request to order a urine toxicology screen for her adolescent child while stipulating that the child not be informed of the test's purpose; a child's ambiguous self-harm verbalization that leaves the child psychiatrist uncertain regarding the patient's potential safety; or, an agency's innocent and appropriate request for information about a child which, if divulged, might prove injurious to the patient. When the child psychiatrist consciously focuses on, and does not ignore, his or her own discomfort, the psychiatrist can use the sense of unease as a salient signal to

recognize the presence of an ethical dilemma and the need for clear and discerning thought.

The ethical reasoning process follows a consistent pattern. As ethics "is the enterprise of disciplined reflection on moral intuitions and moral choices" (Veatch, 1989), perhaps the most important step in the process is the initial recognition of the presence of ethical conflict and an acknowledgment of the need for a response. Commonly, this recognition follows the child psychiatrist's almost instantaneous affective response of unease or dread, itself followed by a fleeting desire to flee the problem or to hand responsibility for its solution to a colleague. This response comes on the heels of the realization that none of the possible options for intervention stands out as strikingly superior to others, and all potential choices inherently harbor problems. As soon as the "immature" responses pass, it becomes incumbent on the child psychiatrist to rationally examine the matter. Several approaches are useful. In other than extreme situations calling for immediate action, the child psychiatrist should temporize, ask questions, obtain information, and delay choosing an ultimate clinical or administrative option. The psychiatrist is encouraged to reflect on the personal values he or she employs in the reasoning process. Self-inquiry can lead to cognizance of the roles played by the child psychiatrist's upbringing, education, and nonprofessional personal experiences, for better or worse, in his or her considerations of the dilemma. Third, consultation with colleagues is often helpful. While the problematic matter may be new to the child psychiatrist, it is likely to have been encountered by colleagues or addressed in the professional literature. Further, it may help to include the patient and other pertinent principals in the discussion of the ethical conflict, in order that they contribute responsibility for the outcome. Finally, after employing the above stratagems, the child psychiatrist should consider relevant choices and possible consequences, while performing risk/benefit analyses on all. The four core aforementioned ethical principles, and the guidelines provided by the child psychiatrist's national and international codes of ethics, can aid in arriving at an ultimate choice of action. This resolution often proves to be the least harmful, but not necessarily the seemingly optimal.

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SAFETY

Primum non nocere – above all do no harm – is a cardinal tenet of proper medical practice (Smith, 2005). Translating its application to psychiatric care, this fundamental rule emphasizes that the child psychiatrist's paramount concern is the safety of the child (patient). For example, the depressed child recently engaged in suicidal behaviors, whose self-harm ideation continues unabated, is best cared for in a psychiatric institution that provides close and constant supervision, despite the actual and implied infringements on the youngster's autonomy and freedom of movement. Another child, who is depressed but not suicidal, would likely benefit from outpatient care while living at home with his or her family. In both scenarios safety must be addressed as the primary concern, but the respective potential threats to well-being are differentiated, resulting in treatment provision in dissimilar settings. Parenthetically, ethical child psychiatric practice would require that the practitioner be fully aware of the legal protections available to the child that are operative in the practitioner's jurisdiction, in order that infringements on the child's rights are kept to a minimum.

CONTEXT – CULTURE, HISTORY AND ECONOMICS

Context can play a significant role in ethical considerations as differing cultures may regard similar behaviors differently. In the US, for example, the adult who develops garbled and incoherent speech at her suburban, middle-class home, whose previous similar episodes resulted in psychiatric hospitalizations, is likely to again be hospitalized at her family's urging; her similar-aged counterpart, engaged in the same behavior while "speaking in tongues" in a rural, fundamentalist church, is likely to receive solicitous and supportive responses from fellow worshipers. Analogously, the child who verbally disputes a teacher's provocative assertion in a "progressive" school, located in an industrialized society, is likely to receive plaudits for her behavior; by contrast, the student living in a traditional tribal setting, challenging her elders by requesting education ordinarily not permitted to girls, may well be seen as obstreperous, a discipline problem, or spiritually disordered (Robertson et al, 2004). These examples indicate that it is ethically incumbent on child psychiatrists to bring awareness of context, or "cultural competence" (Bass et al, 2007; DeJong & Van Ommeren, 2005; Kirmayer & Minas, 2000), to their clinical considerations. Similarly, available resources often play a significant role. For example, where they are limited, largesse might be considered the institutionalization of a brain-damaged youngster, despite that support being limited to custodial care. A more well-to do environment, by contrast, might be able to provide a variety of educational, recreational and interpersonally stimulating resources, while simultaneously enabling the child to live at home with his family. In each case, the ethically optimal intervention is utilized, but the available resources dictate different choices.

Knowledge of the history of psychiatry is yet another important factor in ethical deliberations. Over the course of the past 100+ years, different large-scale psychiatric movements have held sway. At distinct times psychoanalytic theory, somatic therapies (e.g., electroconvulsive treatment, insulin shock, psychosurgery), pharmacotherapy, community psychiatry, systems theory, institutionalization, deinstitutionalization, and both prevalent and fleetingly present psychotherapies (e.g., group, family, cognitive-behavioral, primal scream, milieu) have vied for visibility with or primacy over the others. Frequently, the integration of several modalities proffered simultaneously has proved most efficacious (The MTA Cooperative Group, 1999; March et al, 2004), the opinions of single therapy adherents notwithstanding. Recent changes in the scientific development of child and adolescent psychiatry have produced an intense current focus on molecular influences and the nature of their interplay with the environment (Rutter, 2010). National economic systems have also changed. Public and private funding of care, including health insurance and payments for clinics and programs provided by both sectors, have varied over time, within and across national borders. These changes constantly affect resources available for the psychiatric needs of children, thus affecting ethical considerations. The gradual or sudden economic changes do not alter the fundamental ethical reasoning approaches, but they do impact the breadth and scope of the child psychiatrist's available clinical considerations and choices.

ETHICS – THE GLOBAL AND THE PARTICULAR

Discussions of ethical dilemmas commonly focus on situations encountered by clinicians during the care of an individual child and/or family. For the practitioner, it is easiest to concentrate on and conceptualize one case at a time. The application of ethical thought, however, embodies the universal, and initial consideration of children from a global perspective is therefore in order. Studies performed in disparate countries indicate a prevalence of mental disorders in 5% to 20% of child populations (Giel et al, 1981; Malhotra, 1995; Patel et al, 2007). Large numbers of children live as displaced refugees (Forbes, 1992), are homeless (Raffaelli & Larson, 1999), have become orphans due to the deaths of parents from AIDS (UNICEF, 2000), and are victims of physical or sexual abuse. On the occasions that well-structured epidemiologic studies are performed, significant numbers of these children are found to suffer with stress-related, depressive, and anxiety-based symptomatology. The majority of these children live in resource-poor countries, harboring few available trained mental health personnel. Beyond addressing the needs of these youngsters for food, mental health and life skills training of educators and primary care providers by child psychiatry consultative personnel is arguably, from an ethical perspective, the most beneficial approach for the children and their often clinically depressed mothers (Fombonne, 2005; Graham & Orley, 1999; Lewis et al, 2001; Omigbodun, 2008).

Clearly, in resource-poor countries, the needs of the many are great. Child psychiatry practitioners world-wide, however, tend to be found predominantly in resource-rich environments. The ethical dilemmas they encounter most commonly arise in the context of care provision for a single child, while the dilemmas themselves are universal and transcend national boundaries. Issues of assessment, diagnosis and treatment; assent/consent/dissent; parent-child conflicts; confidentiality; agency; physician responsibility; boundaries; and advocacy, are among many that deserve examination.

ASSESSMENT AND DIAGNOSIS

Prior to the advent of the third edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-3) in 1980, psychiatric diagnosis in the US was often based on psychoanalytic musings ascribing etiologies to disorders that were purported to stem from disturbed unconscious intrapsychic processes. As these diagnoses were based on theoretical constructs and not on consensually observed phenomena, diagnoses of individuals by the practitioners of those eras commonly conflicted. Furthermore, the "disorder" concept itself, in the absence of biologic tests that might confirm diagnoses (contrasted with, for example, elevated glucose levels associated with diabetes mellitus; elevated troponins, elevated cardiac enzymes, and specific EKG tracings associated with myocardial infarcts), raised the concern of "the eye of the beholder". For example, the disruptive behavior of a child might be viewed by different examiners as a normal variant, symptomatic of an oppositional or conduct disorder, or a reaction to a stressor. Even with well-outlined diagnostic criteria, it is conceivable that diagnostic disagreement could exist among conscientious clinicians, raising questions about the fundamentals of the diagnostic process and accurate definitions of "illness" (Pies, 2007). The lack of confidence in psychiatric diagnoses and poor diagnostic concurrence prior to the 1980s, coupled with fears of "labeling" and

prevailing stigma associated with mental illness, led to a sizable number of vocal proponents of diagnostic nihilism. In addition, the opprobrium earned by the misuse of psychiatric diagnoses for political purposes (e.g., the former Soviet Union's creation and employment of the novel diagnosis of "sluggish schizophrenia" in order to forcibly hospitalize and treat political opponents of the regime against their will) highlighted on an international scale the need for a considerably more rigorous diagnostic consensus (Wilkinson, 1986).

The last 30 years, however, have witnessed consensual agreement by psychiatric researchers on progressively more rigorous approaches to groupings of observed phenomena. These have led in turn to more carefully defined diagnostic categories. Close collaboration between the consultants producing editions of the International Classification of Diseases (ICD) and subsequent DSM volumes has been the rule, leading to considerable compatibility between these two "official" versions of psychiatric diagnoses (Sartorius et al, 1993). Thus, the diagnostic process has undergone a transformation permitting collaborators on transnational studies to more comfortably assume that study subjects from countries other than their own satisfy the same inclusion and exclusion criteria. Cautions remain, however, regarding inadequate sensitivity to culture-bound variables (Belfer & Eisenbruch, 2007; Van Ommeren, 2003).

Rigorous diagnostic criteria permit the development of treatments that are tailored to specific diagnoses. When used in this fashion – for the good of the patient – the diagnostic process clearly satisfies a cardinal ethical principle. However, the potential problems of "labeling" and stigma remain as possibly harmful to the child (Pescosolido et al, 2007). The practitioner has little control or influence over how people, other than immediate family, might misuse this information. Particularly in the current era of electronic transmission a diagnosis theoretically could attach to an individual "forever", and relatively unsophisticated societies could become fearful of and devalue a child carrying a psychiatric diagnosis. Ultimately, it is the child psychiatrist's responsibility to provide an accurate assessment and diagnosis in order to better the patient's condition; follow procedures guarding the confidentiality of written materials; and contribute to the education of local societies concerning the prevalence of mental disturbance, prognostic accuracy, treatment efficacy, and the need for familial and community support (Rosen et al, 2000; Thara et al, 2001).

Child psychiatrists should be mindful of various influences that could play roles in the diagnostic process, while maintaining awareness that their efforts will significantly impact the near- and possibly longer-term futures of their child patients.

In recent years, the US has witnessed a striking increase in the incidence of childhood autistic and bipolar disorders. While it appears that, in both cases, these increases are due to a combination of closer scrutiny and greatly expanded diagnostic definitions of these disorders, these developments remind that scientific progress does not occur without struggle, controversy, conflict and mistakes (Angell, 2011; Carey, 2007; Kim et al, 2011; Moreno et al, 2007). In the course of proposed and revised definitions, some children might receive a diagnosis in error while others may benefit from expanded criteria. In addition, increased awareness of the diagnoses of childhood ADHD and bipolar disorder in the international domain may be related to heightened professional education and sensitization of practitioners to these disorders, promoted in part by pharmaceutical companies. Their efforts might well be motivated by the desire to provide benefit to a previously undetected but substantial number of affected children; that the companies stand to gain financially from the marketing of relevant medications in new and



When Rebecca Riley died in December 2006, pediatricians and psychiatrists in the US and across the world were already debating whether preschoolers like the 4-year-old Hull girl could be diagnosed with bipolar disorder and attention deficit hyperactivity disorder (Lambert, 2010). In a lawsuit settlement, the Medical Center defendant agreed to pay $2.5 million to the estate of 4-year-old Rebecca, who died of an overdose of medications, prescribed by a psychiatrist, and over-the-counter remedies (Baker, 2011).

"Riley… was exceptionally young when she was diagnosed [with bipolar disorder], just 2½." "Rebecca was prescribed an antipsychotic medication, a drug used to treat bipolar disorder in adults, and a blood pressure medication that is sometimes used to help hyperactive children sleep." "The psychiatric controversy is over diagnosing children before their teen years. There is virtually no scientific research on children younger than 6" (Goldberg, 2007).

emerging markets is also a pertinent factor. In the end, it is incumbent on child psychiatrists to perform their diagnostic work accurately and with care. They should be mindful of various influences that could play roles in the diagnostic process, while maintaining awareness that their efforts will significantly impact the near- and possibly longer-term futures of their child patients.

TREATMENTS – SOMATIC AND VERBAL

Treatments of the individual child, when indicated, should follow an adequate diagnostic process. Leaving preventive efforts aside momentarily, the current psychiatric knowledge base is limited to the provision of somatic- or psycho- therapies or, often ideally, both. Treatment provision, however, is frequently limited by the locale, surrounding culture, resource availability, and practitioner knowledge. It is incumbent on practitioners to be aware of available resources, the degree of psychological flexibility or rigidity of the individuals to who they provide care, the harm that might befall a child if care is not provided, and the limitations of their own knowledge. The last factor is best dealt with by consultation and possible collaboration with professional colleagues.

Evidence-based medicine should function as the primary foundation for prescribed treatments, but due to a lack of extensive studies focused on children it has limited reach. Studies indicate that certain chemical classes of medications are useful for specific disorders – e.g., stimulants for ADHD; mood stabilizers for bipolar disorder; selective serotonin reuptake inhibitors for major depression and obsessive-compulsive disorders. Such pairings hold similarly true for certain psychotherapeutic approaches, e.g., cognitive-behavioral therapy for phobic disorder; inpatient psychiatric milieu treatment for severe suicidal behavior/ideation. But variability and blended treatments are the norm in the provision of verbal therapies. As well, treatments frequently prove culturally and locale dependent. A recent study of the diagnosis and treatment of ADHD in three resource-rich countries serves as a good example, as it found great differences between the nations with regard to incidence, views of illness severity, and treatment approaches (Hinshaw et al, 2011). Other studies produced findings strongly suggestive of benefits that accrue when psychotropic medications and

psychotherapy are both provided in tandem, in contrast to just one or the other, though the ability to provide the two is conditional on the presence of available resources and personnel (The MTA Cooperative Group, 1999; March et al, 2004).

Not infrequently, ethical concerns about somatic and verbally-mediated treatments are approached as if they present dissimilar dilemmas when, in fact, similar concerns apply to both. They each have the potential to produce benefit or harm; risk/benefit analyses should precede the choice of either or both; the potential for uncalled-for clinician aggrandizement is inherent to the provision of either; and the inept provision of the one or the other could easily cause harm. Psychotropic medications, electroconvulsive therapy, and complementary or "natural" medicines all may directly impact developing brain structure, cerebral neurotransmitter receptor complexes, and other body organ systems. The more immediate potential side effects are well-recognized, but the possibility of unleashing long-term ill effects is unclear. Similarly, beneficial or poor psychotherapeutic care is likely to have obvious positive or negative near-term psychological impact, while the long-term effects on psychological functioning, via cognitive incorporation of the experience, is difficult to determine.

Off-label prescribing of medications is common in child psychiatry practice due to the paucity of relevant child-based studies (Baldwin & Kosky, 2007; Bucheler et al, 2002 ; Efron et al, 2003; Hugtenburg et al, 2005). Its consequent potential for benefit or harm is uncertain and variable. Examples include alpha-agonists used as second-line treatments for ADHD; neuroleptics used to treat severe disruptive behavioral presentations; and the use of lithium, anticonvulsants, and neuroleptic medications in the treatment of vastly increased numbers of patients diagnosed, in the recent past, with bipolar disorder of childhood. Similarly, the application of a single psychotherapeutic modality for a range of disorders; difficulties in psychotherapy provision due to a diminished emphasis in training (Tucker et al, 2009); focus on the individual patient at the expense of the family or vice versa; and incorporation of corporal rather than structured restraint methods (even in the context of cultural approval of the former) are all examples of verbally- and environmentally-mediated therapeutic impediments or approaches that could have deleterious impact on some children while nevertheless benefitting others. The innovations and the liabilities contribute to the development of the field by adding to its knowledge base, as they underscore the need for ever-improved training and expansion of the treatment armamentarium. Simultaneously, they highlight the limits of the profession's expertise and the need to rein in diagnostic and treatment hubris.

Off-label

Off-label prescribing means prescribing a medication for a condition or age group or using a form of administration (e.g., oral, parenteral) not formally approved by the appropriate regulatory agencies (e.g., FDA, EMEA). This may vary from country to country.

Off-label prescribing of medications is common in child psychiatry practice due to the paucity of relevant child-based studies. Its consequent potential for benefit or harm is uncertain and variable.

In addition to remedies for diagnosed psychiatric illness, preventive treatment approaches warrant comment (Layne et al, 2008; Sanders, 2002; Silverman et al, 2008). While numerous studies describe treatments of post-traumatic disorders in children, stress inoculation training was designed to block post-traumatic stress responses by its introduction in advance of anticipated stress-inducing situations. Studies describe teacher-mediated group interventions, guided by the instruction of child psychiatrists and other mental health professionals, that employ the stress inoculation training goals of fostering resiliency and psychological strength in groups of children who formerly experienced trauma en masse (Wolmer et al, 2003). While these studies raise an ethical concern, i.e., the withholding of a putatively therapeutic intervention for students comprising the control groups, it

appears that child psychiatry involvement in the training of the educators clearly created benefits for the treated youngsters. When preventive and potentially therapeutic undertakings are performed in this manner, larger numbers of children are likely to obtain benefit than would otherwise be impacted in after-the-fact one-to-one care. This approach adheres to the ethical principle of social justice, i.e., by providing benefit to the many in essentially equal fashion. It also provides a clear contrast, in the child setting, for the ethical thought underlying public health models of care with the more traditional perspective of care provision for the individual.

ASSENT, CONSENT, DISSENT AND AGENCY

Assessment, diagnosis and treatment should, with the exception of emergencies, be performed solely with the assent of the child and the consent of the parent/guardian. Legal systems in many countries distinguish between the mental capacities of children and adults, though the chronological age defined as dividing the one stage from the other may vary between different jurisdictions and within nations. Adults are defined as individuals competent to make decisions for themselves and those for whom they are designated as having primary custodial responsibility. Consequently, only they can give *consent* for treatment of the children under their care (Macbeth, 2002). Children, by legal definition, are perceived as lacking the necessary competence to give consent, but they have the psychological capacities to voice *assent* or *dissent* (United Nations Centre for Human Rights, 1990), though how meaningful assent can be assessed is open to question (Koelsch & Fegert, 2010). When parents desire treatment for their child, and the latter assents, psychiatric care ordinarily proceeds without a hitch. However, it is not unusual for parent/guardian-child conflicts to exist about the need for care, with the parent commonly asserting that need while the child resists or refuses outright. It is universally understood that the safety of the child dwarfs all other considerations, thus supporting professional decisions that may abrogate a child's autonomy rights. Typical scenarios include the suicidal youngster or the physically and mentally debilitated anorectic adolescent, psychiatrically hospitalized against their wishes.

It is always incumbent on the child psychiatrist to consider the degree of emotional development and cognitive maturation of the child in question. For example, an oppositional eight year old, who frequently engages in physically assaultive behavior in the school setting, might be brought by parents for a psychiatric evaluation against his will. By contrast, the 17 year old who upsets her parents, by refusing to attend a religious rite, would not seem to require professional services and, rather, her dissent from participation in a proposed psychiatric evaluation would appear to warrant respect and deference. In sum, a child's chronologic age, degree of cognitive and emotional maturity, and concerns about his or her safety require evaluation when weighing the degree of respect to be paid to the youngster's autonomous decision-making capacity. These considerations contribute in turn to the child psychiatrist's goal of choosing the most beneficial approach to a clinical situation. (Parenthetically, it should be noted that similar deliberations prevail with regard to children who might be involved as subjects in psychiatric research, an issue discussed in the research section below).

Age of consent

In most countries, the age of majority is 18 (although it fluctuates between 14 and 21). Age of majority is when the law recognises that minors cease to be considered children (and the responsibility of their parents) and assume control over their own persons and actions. However, in some countries (e.g., Australia, UK), minors (people younger than 18) are able to consent to treatment and to participate in research from the age of 16 or even earlier ("mature minors"). See also Chapter J.3.

Child psychiatrists often field requests or demands from a variety of players with stakes in clinical outcomes. For example, child psychiatrists providing care to juvenile offenders, who were living in foster care prior to placement by the judicial system in a psychiatric facility, will likely field inquiries and demands from involved courts, social service agencies, hospitals and residential treatment facilities, the offending children and their biological and foster families. Often, each entity will have differing and possibly opposing goals and objectives. It is likely that the child psychiatrist would feel a degree of obligation to all – in ethical terms, the psychiatrist could experience a crisis of *agency*, i.e., to which of these entities does one owe allegiance? Ultimately, the principle and concept of *fidelity* dictates that the child psychiatrist's primary responsibility and charge is to engage in *advocacy* for the patient, by pursuing the best or least detrimental outcome for the youngster. Often, that result requires the child psychiatrist to facilitate communication among the various interested parties and possibly to mediate between them. The child psychiatrist's major ethical obligation, however, is to advocate for the patient's interests.

Parents, and countries, periodically engage in highly authoritarian stances. An illustration on the family level is parents who blame their child for familial dysfunction, refuse to engage in family therapy, and subsequently "solve the problem" and defuse the situation by sending the child to a boarding school (Salinger, 1951). An example on the macro level is the city administration that expels a large number of its residents, including the "unstable" mentally ill, to points unknown, describing the citizens as threats to public safety (Spegele, 2011). In both cases, the autonomy rights of relatively defenseless individuals are ignored. Of course, forces exist that are beyond a child psychiatrist's ability to control, but the child psychiatrist as advocate can give professional voice to those interventions more likely to be respectful of individual choice and to produce clinically better outcomes for both small and large groups of patients.

CONFIDENTIALITY

Ordinarily, individuals are accorded privacy rights, implying that they control ownership of their personal information. When such material is communicated to physicians in the course of evaluation or treatment, the physician is ethically (Winslade, 1978) and legally (Simon, 1987) obligated to regard the information as confidential, not to be revealed to anyone without the patient's, i.e., the owner's, permission. Such professional behavior is respectful of a patient's *autonomy*, and avoids the harm (*nonmaleficence*) that would easily ensue, directly to the patient and indirectly to the therapeutic relationship, should a deliberate breach occur.

Maintenance of confidentiality under all circumstances, however, is not an inherent good – such rigid devotion to the concept could conceivably cause harm. Several matters warrant consideration. First, differences between adult and child cognitive abilities suggest that adults have achieved a cognitive maturity that children only attain following continuous maturation through adolescence. Thus, children are perceived as lacking the breadth of understanding presumably available to adults – in the current instance, a solid understanding of confidentiality rights and their possible limits. Consequently, just as children, using identical reasoning, cannot legally *consent* to treatment, only their adult guardians can consent to the release of children's confidential information to third parties. Second, children's psychiatric

treatments are most commonly initiated by parents or guardians, presumably with beneficent intent. The parents naturally desire feedback from the physicians about their children, may themselves be directly involved in the treatment, and often express their rights to access information about their children, including possibly confidential material. Third, an understanding of confidentiality, its desirability and its benefits, develops gradually, concomitant with the child's developing sense of autonomy. The preschool and early school-age child would likely be shocked and upset if a practitioner did not provide pertinent information to her parent on the grounds of guarding the child's confidences. For a practitioner to do so could well upset the emotional stability of the patient. It is only as the child matures that it becomes more likely for the child and adolescent psychiatrist to hear patient requests that specific material not be divulged to the parent.

Most commonly, such parent-child struggles over information control come to the fore during adolescence. Adolescents often raise issues that conflict with prevailing parental or societal attitudes and mores or provoke safety concerns. Rhetorically, how is the child and adolescent psychiatrist to address a patient's expressed intent to break into a school's computer system; engage in forbidden sexual activity; experiment with illicit drugs; break curfews; venture with friends into unsafe communities; or engage in covert, potentially dangerous, political activity? Such instances sorely test the clinical muscles of the practitioner, and the internal conflict of respecting or violating the patient's autonomous confidentiality rights is placed front and center.

Several principles hold sway. Safety considerations are foremost. Should a psychiatrist perceive an adolescent's imminent threat of danger to self or others, adherence to confidentiality must be violated and guardians or other protective entities informed in order to ensure maintenance of the patient's life and safety of the environment. Short of such frank expressions of suicidal and homicidal intents or behaviors, gray area situations, involving the potential for varying degrees of risk (Ponton, 1997), call for a sensitive evaluation of circumstances with, at best, uncertainty concerning the maintenance or violation of confidentiality rights.

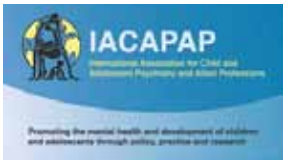
In addition, practitioners can best aid their patients by avoiding entrapment by rigid rules regarding the observation of confidentiality rights. Rather, adoption at the outset of a family- versus an individual-based treatment approach, with "mutual trust" rather than the administration of paternalistic advice serving as the underpinning for the therapeutic relationship, encourages the use of reason, persuasion, tact, and clinical judgment to dictate the degree to which confidential information might be transmitted, if at all, and by whom. Similar collaboration is called for with children and their parents concerning the nature and content of written material to be transmitted to agencies and other care providers. Caution is indicated in light of concerns regarding the potential longevity of such material (Alessi, 2001), as well as its occasional inappropriate release to unintended recipients (e.g., Conn, 2001), both of which should be discussed with the patient and guardian.

Traditional families, living in resource-poorer settings or having immigrated to resource-richer locales, often contrast with families in developed settings by paying less attention to the autonomy of the individual child as they, by contrast, put greater emphasis on the need for the youngster's will to blend into the goals

and desires of the family's or clan's adults. In these families, the notion of a child's confidentiality rights may therefore experience great challenge. For example: "Anything my child wants to say can be said, and must be said, with me present – we have nothing to hide from each other." Directly confronting such a stance by trumpeting confidentiality rights is likely to end in a failure to persuade. Rather, acknowledgement of the parent's desire for pertinent information while promoting the potential benefits stemming from respect of individual autonomy, in a model that emphasizes the inclusion of all family members, is more likely to result in the most efficacious and beneficent care for the child. In contrast to differing families, a related study, determining the responses of psychiatrists in three countries to confidentiality scenarios, revealed no significant differences between the practitioners (Lindenthal et al, 1985).

RESEARCH

Because children cannot give consent by themselves, research involving young people poses particular ethics challenges. Notably, there has been a growing appreciation that it is in children's best interests that good-quality research is undertaken – the lack of evidence about the effectiveness of many treatments in the young has already been highlighted and extrapolating to children results found in trials conducted in adult populations is not necessarily valid. To obviate this problem some governments (e.g., the US) provide financial incentives (e.g., by extending the patent period of a drug) if research in children is undertaken. This notwithstanding, research in young people needs to carefully adhere to ethical principles and requirements because of the risks of exploitation. These principles are spelled out in a variety of documents anchored on the Nuremberg Code (which contains research ethics principles for human experimentation set as a result of the Nuremberg Trials following the Second World War) and the 1974 Declaration of Helsinki (Chapter J.7 in this book describes in some detail the implications for research of the United Nations Convention on the Rights of the Child, particularly in low income countries and in communities enduring war or civil strife).



Click on the picture to access IACAPAP's declarations on ethical practice

The IACAPAP's Declaration of Berlin (2004) – Principles of Ethics in Child and Adolescent Mental Health (revised in Melbourne, 2006) – states that "Informed consent to being a research subject should be based on the following Principles:

- It is essential that clinical research involving human subjects is dedicated to promoting health
- The well-being of the research subject has priority over the interests of science and society
- The performance of a research project involving human subjects should be based on a clearly written proposal that is approved by an independent ethical committee which includes representatives of parents and the law
- Participation is voluntary. Any subject can refuse or discontinue participation without pressure, penalty or loss of benefit
- Children and adolescents may not have the capacity to give informed consent to being research subjects. However, their assent must be obtained. Assent should take into account the age, maturity and

psychological state of the child involved. If the child is unable to give assent, the "proxy consent" of a parent or legal guardian is required

- Informed consent requires a statement that a study involves research, and information about the purposes, duration and procedures of the study. It should include a description of the foreseeable risks and discomforts involved, and of the benefits to the subject expected as a result of the research. Alternative treatments should be discussed
- Today much of the prescription of psychotropic medication in children is "off-label". There is an urgent need for pharmacological research in children. It is an ethical mandate that drugs be properly studied in children and their efficacy empirically established before they are widely used. The results of clinical trials should be available to the public even when the trial fails to establish effectiveness empirically. 'No clinical trial is finished until the data are made available'."

Research involving children as participants should always be reviewed and approved by appropriately constituted ethics review committees; this is a requirement for publication in most scientific journals. In the US, Federal Regulations specify the circumstances in which research with children may be approved; i.e., if research:

- *Does not involve greater than minimal risk*
- *Involves greater than minimal risk but presents the prospect of direct benefit to the individual subjects.* In this case the risk is justified by the anticipated benefit and the relation of the anticipated benefit to the risk is at least as favorable to the subjects as that presented by available alternatives
- *Involves greater than minimal risk and no prospect of direct benefit to individual subjects, but is likely to yield generalizable knowledge about the subject's disorder if* :
  - The risk represents a minor increase over minimal risk
  - The intervention presents experiences to subjects that are reasonably commensurate with those inherent in their actual or expected medical, psychological, social, or educational situations, and
  - The intervention is likely to yield generalizable knowledge about the subjects' disorder which is of vital importance for the understanding or amelioration of the subjects' condition.
- *Research which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children if*:
  - The research presents a reasonable opportunity to further the understanding, prevention, or alleviation of a serious problem affecting the health or welfare of children, and
  - The research will be conducted in accordance with sound ethical principles.

The use of placebo has been more controversial in children than in adults. While the need for placebo controlled trials is acknowledged, placebos should not be used if there is risk of harm to participants or when an equally safe treatment is available.

Assent

Assent means (Committee on Bioethics of the American Academy of Pediatrics, 1995):

- Helping children gain a developmentally appropriate understanding of the nature of their illness
- Explaining what they can expect (good and bad) with the treatment
- Evaluating children's understanding of the situation, including whether they are being inappropriately pressured, and
- Seeking an expression of the child's willingness to accept the treatment

In the case of participation in research, if children do not have a choice and their refusal or dissent does not count, it should not be pretended that a requirement for assent is to provide a choice. Children need to know if they do or do not have a choice. A requirement for assent protects children from psychological or other harm. Children benefit from knowing what will happen, having a say and being listened to even though they do not have the final authority to make decisions. Seeking assent also respects the child as a person. Part of that is to provide opportunities for children to develop autonomy. However, assent by itself is not sufficient to authorise participation in research.

Dissent

Means that children's objections and distress are taken into account even when the child is incapable of taking part in discussions or deciding. In the case of participation in research trials, dissent does not function only at the point of enrollment. Dissent can be about a child wanting to withdraw from research.



Click on the picture to access "Understanding Consent in Research Involving Children: The ethical Issues"

Parents are the main decision-makers for their children, including participation in research. Parental decision-making is a critical factor in the study of pediatric research ethics, even though it is recognized that parents, as well as researchers, may have interests that conflict with the best interests of the child. The legitimate role of the child in decisions about research participation is also recognized. The ethical concept of assent provides a framework to assist investigators and parents with efforts to incorporate the views of children who are recruited as research subjects. Assent is analogous to consent where participants have a reduced capacity to understand the matter to which they are assenting.

While the general principles about consent to research are widely accepted, there are variations between countries and the issues become more complex in special situations. For example, in Australia and the UK minors can in some circumstances consent to research without additional parent consent when the child is "mature enough to understand". When the young person is of developing maturity and the risk of research participation is no more than discomfort and the aim is to benefit young people and there are additional good reasons not to involve parents (e.g., some internet research), then minors can also consent. Moreover, parent's consent is not always required, for example in situations where seeking parental consent is inappropriate (e.g., if parents are neglectful or abusive) or offers no protection (however, consent from another adult might be required if that adult has responsibility for the child's safety and wellbeing).

Another potentially troubling issue is whether it is acceptable to offer money or benefits to children for participating in research and, if so, in which circumstances (this only arises when cash or valuables are above reimbursement of expenses). Policies about rewards also vary between countries but it would be considered unethical if rewards could lead participants – or those deciding for them – to ignore or significantly undervalue serious risks.

POTPOURRI

As ethical thinking undergirds the structure and practice of child and adolescent psychiatry in its entirety, the range of subjects potentially available for discussion is vast. The most salient have been addressed, and the topics that follow, discussed in brief, are open to investigation in much greater detail.

Conflicts of interest

Third party influence has received considerable media attention in the recent past, stemming primarily from the efforts of the pharmaceutical industry to promote sales of its products, via overt and subtle subsidies and other inducements to physicians (Schowalter, 2008). Such external attempts at influence are exerted as well by health insurance providers, school system personnel, governmental agencies, guardians, colleagues, and financial investors. Internal competing loyalties can stem from interpersonal rivalries, relationships, and intellectual passions, resulting in biased rather than dispassionate judgments (Walter et al, 2010). Commonly, these conflicts emerge in research and publication contexts as well as interpersonal. In all instances, the child psychiatrist is obligated to prioritize the welfare of the patient above the other interests competing for attention. The child psychiatrist's internal conflicting impulses are best handled via transparency, honesty, notification, disclosure, self-examination and self-scrutiny. The acid test is putting oneself in the patient's place and examining the matter from that perspective (Brewin, 1993).

Teaching, training and enforcement

The teaching of ethics is mandated by residency training accrediting bodies (Dingle & Stuber, 2008). Topics commonly reviewed include advocacy, consent/assent, agency, autonomy, research concerns, boundaries, confidentiality, practitioner relationships with health care providers and industry, and the relationship and distinctions between ethics and the law (Sondheimer, 1998).

Conflicts of interest

Conflicts of interest may be inevitable for clinicians because of the multiple responsibilities and relationships that are part and parcel of medical practice. Being subject to competing interests, however, is not necessarily unethical. Maintaining ethical practice is determined by how one handles them. Knowledge of professional standards, recognition of potential conflicts and appropriate disclosure are key steps in this process.

Research funded by the pharmaceutical industry reported in psychiatric journals has been steadily increasing. Moreover, positive outcomes are reported much more often in trials so funded (78%) than in those without industry sponsorship (48%) or those financed by a competitor (28%) (Kelly et al, 2006). The obvious issue arises as to the extent to which industry-funded research influences findings and to what degree one can trust such work.

Conflicts of interest are not restricted to drug trials. For example, The Lancet published in 1998 a study which suggested a link between autism and the measles-mumps-rubella (MMR) vaccine. The report sent shockwaves around the globe as well as frightening parents and medical practitioners. As a consequence, MMR vaccination rates in England declined by 10% in the following 5 years while cases of measles almost quadrupled. A journalist later established that the principal author had not disclosed that the Legal Aid Board had commissioned him to determine, for a sizable fee, if evidence sufficed to support a legal action by parents of children allegedly harmed by the vaccine. The Lancet subsequently retracted the article and the UK's General Medical Council found the lead author unfit to practice. Subsequent research has conclusively refuted any link between the vaccine and autism (Demicheli et al, 2005).

Authorship

The International Committee of Medical Journal Editors (2006) explains that authorship should be based on all the following criteria:

- Substantial contributions to the study's conception and design or acquisition of data or their analysis and interpretation
- Drafting the article or revising it critically; and
- Approval of the final draft.

'Guest', 'honorary' or 'gift' authorship are all considered unethical. A guest author is one who is knowingly listed as an author to influence reviewers or to seek some benefit or professional favor.

Study of one's child and adolescent psychiatry's national code of ethics is recommended. Resources for child psychiatrists faced with ethical dilemmas include ethics committees, institutional review boards, state or country medical accrediting bodies, and individuals with known expertise in ethics. Periodically, complaints of an ethical nature are raised against practicing physicians by a patient's family member or, rarely, colleagues. Such complaints should be channeled in the direction of individuals and committees with ethics expertise, who can then advise concerning the best manner to pursue subsequent steps.

Administration

Child and adolescent psychiatrists treat individual patients. They also direct inpatient and outpatient units, hospitals, and residential treatment facilities; are responsible for small and large research enterprises; and plan care for defined demographic populations of hugely varying sizes. In these roles they are accountable, albeit indirectly, for the welfare and working conditions of patients and staff. To varying degrees, these child psychiatrist administrators will have responsibility for budgeting; determining the needs for various services; credentialing and privileging employees; creating smooth supervisory processes with clear lines of authority; ensuring documentation in medical and other administrative records; and supervising the entire gamut of investigational research, including subject recruitment, obtaining consent, safeguarding confidentiality, data collection and analysis, and dissemination of findings (Sondheimer, 2010). Ethical problems often arise in these spheres of activity. How to fund a new clinical service that is liable to impact negatively on another in the face of limited institutional or governmental financial resources; how to respond to individual staff members who observe organizational protocols to grossly differing degrees; how to approach an institutional review board, some of whose members may be friendlier to a research proposal than others? An ethical reasoning process helps to sort out the conflicts; frequently, concentration on the principle of (distributive) justice helps resolve the conflicts between difficult choices (Sabin & Daniels, 1994).

RECENT AND EMERGING CONCERNS

Genomics

The past two decades have witnessed explosions in knowledge of genetic information, having the potential for decoding children's entire DNA sequences. Much effort has been expended to determine relationships between specific gene sequences and psychiatric disorders. While results to date have not yielded consistent findings, continued investigations will likely produce usable results in the future, possibly leading to changes in diagnostic nomenclature and the introduction of gene therapies. Confidentiality, assent/consent, rights to know and not know of disease presence, authorized versus unauthorized screenings for disorders, and predictions of disease onset are among the ethical concerns raised by the new technologies that will demand ever-closer examination (Appelbaum, 2004).

Psychiatric prodromes

Analogous to the potential of molecular-based genomics to predict the eventual development of psychiatric illness, examination of family trees and

clinical observation have led to studies of treatment interventions with adolescent populations at risk for the expression of schizophrenia (McGorry et al, 2009). Similarly, expanded definitions of bipolar disorder have led to the exposure of very young children to mood stabilizing medications, as already highlighted. While such preventive efforts are superficially admirable as they, in theory, have the potential to stave off the development of and suffering from serious mental illness, these efforts are open to much question given the profession's current stage of relative ignorance (Cornblatt et al, 2001). Reliable predictive tools of illness development are not available, determination of preventive treatment effectiveness is not possible, treatment interventions with (neuroleptic) medications could conceivably cause more harm than benefit (especially when prescribed for individuals who, in the first place, would not have need for them), and non-psychotic individuals might be stigmatized (Frances, 2011).

Neuroenhancement

Pharmacologic augmentation of normal function raises related but different issues. Child psychiatrists are comfortable treating illness or distress (e.g., antidepressants for depression; neuroleptics for severe thought disorder) thus improving mood, cognitions and relatedness. While diagnoses are usually based on meeting designated criteria, at times they are employed because signs suggest the possible presence of a disorder. For example, parents seeking to create academic advantages for their child may seek treatment – based on a loose aggregate of attentional impairments – with stimulant medications in order to help their youngster focus all the more intently on tasks. Are these parents seeking unfair advantage? Do such maneuvers diminish the esteem derived from hard work and self-improvement? Will the child psychiatrist consider the potentials for harm, e.g., side effects or fostering of an initial reliance on drugs as aids? Or, might enhancing the child's performance be of overall benefit to the youngster and the larger society (Farah et al, 2004)? Do enhancements of mood and cognitions via prescribed medications differ from the improvements in physical and emotional functioning stemming from joint replacement surgery, Botox injections, and morning cups of caffeinated coffee? Does society distinguish between body and mind, feeling more comfortable with enhancing the former and queasy regarding the latter (while conversely bearing in mind the majority's antagonism toward the use of steroids and "cell-doping" in competitive sports)? Neuroenhancement brings questions of identity, self, free will, and responsibility to the fore, and these questions will surface with ever-greater frequency for parents concerned about their children (Cheung, 2010).

Electronics, social media, and bullying

Psychiatry, following some initial trepidation, has become immersed in the world of electronics (Huang & Alessi, 1996). Practitioners and institutions employ computers for record-keeping, prescribing, billing, scheduling appointments, and communicating; the profession reacts electronically to media coverage; and practitioners design personal web pages, blog, and deal with the use and misuse of a variety of electronic instruments by patients. These new worlds of technology, as was true of all prior eras ushering in wide-spread technological innovations, have the potential for positive and negative impacts for its users. They are best judged by old, traditional ethical criteria; the dilemmas the new technologies raise remain

the same, they simply are garbed in novel fashions. In addition to the technologies' heuristic use to child psychiatrists in daily administration, education, research and clinical practice, they offer specific benefits for patients, e.g., the opportunity for pervasive developmentally disordered spectrum children, socially awkward and fearful, to engage socially with others electronically rather than face to face (Panyan, 1984). For many such youngsters, these communications provide a sense of comfortable engagement and, for some, lead to later meetings in person with their contacts. Similarly, many computer programs provide assistance to children with learning and communication disorders.

As with all new technologies, however, they are also open to misuse. Bullying of children by peers is a millennia-old problem, but the perpetrator of the past could always be readily identified. With the advent of current technology, by contrast, cyberbullying permits anonymous harassment of unsuspecting and vulnerable peers, commonly leading to considerable distress and the occasional front-page news article following the suicide of a bullied or "outed" youngster (Boyd & Marwick, 2011). Preventive and post-incident interventions have been created in response but, given children's immature understanding of consequences and the anonymity afforded by electronic communications, these malicious behaviors are likely to continue in a world that currently contains 800 million Facebook members. Psychiatric ethics requires child psychiatry practitioners to be aware of these developments, the potential of electronics to be used for both good and ill, the need to advocate and care for those who have suffered, to educate communities concerning potential benefits and dangers, and to aid in the implementation of relevant school-based intervention programs.

CONCLUSION

Child and adolescent mental health professionals, whether located in well-to-do, poverty-stricken, or middle-class areas or countries, share the same responsibilities – to advocate and provide care for youngsters, commonly the least protected and most vulnerable age group, independent of locale. Ethical considerations, principles, and the ways of thinking about dilemmas, whether arising in clinical, administrative or research contexts, remain the same, independent of locale as well. Available resources in these locales differ markedly, however, resulting in different resolutions to these dilemmas in different geographic settings. The fundamental ethical goals of providing protection and beneficial interventions to children remains the overarching societal and professional expectation of the child psychiatrist. This chapter, focusing on such basic matters as assent, dissent, diagnosis, treatment, confidentiality, and research, coupled with a look at recent developments in the field, has hopefully provided useful food for thought about ethical matters which impact on child and adolescent mental health practitioners, independent of their country of citizenship.

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NORMAL DEVELOPMENT

INFANCY, CHILDHOOD AND ADOLESCENCE

Nancy G Guerra, Ariel A Williamson & Beatriz Lucas-Molina



Watoto Wema boys enjoying a game in Kenya
(Photo: Dennis Machio-Michezo Afrika)

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Suggested citation: Guerra NG, Williamson AA, Lucas-Molina B. Normal development: Infancy, childhood, and adolescence. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

A 15-year-old girl starts throwing nightly tantrums if she doesn't get desert after dinner. Her mother is justifiably concerned and seeks the help of a mental health professional. Yet when her three-year-old son does the same thing, she sends him to his room, convinced this is a passing phase he will outgrow in due time. The mother probably is right—the same behavior has very different meanings for toddlers and teenagers. Without a working knowledge of *normal development* the same mother might send the three-year-old to a therapist or the teenager to her room.

For parents, this knowledge comes from multiple sources including experience, friends, cultural traditions, magazines and books, support networks, and more recently electronic sources such as websites and chat rooms. Parents also rely on guidance counselors, social workers, therapists, and physicians to help them understand typical and atypical behaviors. Yet health professionals often are more versed in the language of abnormality and psychopathology than in the language of normal growth and development. For example, the Diagnostic and Statistical Manual for Mental Disorders (DSM-IV-TR) and the International Statistical Classification of Diseases and Related Health Problems (ICD), provide clinicians with a compendium of criteria and categories for aberrant psychological development. However, these systems provide little information about normal development, which is not simply the absence or opposite of psychopathology.

The purpose of this chapter is to give a brief overview of normal child development, defined as average or "on-time" growth based on the attainment of specific physical, cognitive, linguistic, social-emotional, and behavioral milestones across specific stages. A focus on normal development suggests what is likely based on population averages, with clear historical, cultural, and international variations to be expected. A foundational understanding of average development can be useful to practitioners in many ways, from assisting clinicians in history taking or planning diagnostic work at intake to augmenting case conceptualization and the selection of developmentally-appropriate treatments (Holmbeck et al, 2010).

This chapter begins with a review of key developmental principles or themes, including nature versus nurture, developmental timing and plasticity, critical and sensitive periods, and the role of culture and context. Following this brief introductory section, age-specific milestones in cognitive, linguistic, social-emotional, and behavioral development from infancy through adolescence are reviewed. Although it is also important to understand normative milestones in the area of physical development, this typically is covered in medical and health publications and is beyond the scope of this chapter.

UNDERSTANDING NORMAL DEVELOPMENT

Several recurring developmental principles or themes are important to keep in mind when defining normal development and identifying growth processes and milestones.

Nature versus nurture: the origins of development

There has been a long history of debate about the influence of nature versus nurture on development, often referred to as the "nature-nurture debate." Are we born a certain way or does our behavior depend on how we are raised? A focus on *nature* highlights the role of genes and biology in predetermining developmental

outcomes from conception onward. In contrast, a focus on *nurture* emphasizes the role of life experiences across different contexts including the family, school, peer group, community, and culture.

Recent advances in behavior genetics have provided compelling evidence for the *relative* contributions of both nature and nurture. In light of these scientific advances, few current theories of development embody an either/or position in this debate, but emphasize the interplay of both over time (Berk, 2006). Stated simply, a key issue is not *whether* development is due to nature or nurture, but *how much* and *how* each contributes to outcomes across multiple characteristics and domains. Rather than consider nature *versus* nurture, it is more accurate to consider both nature *and* nurture and how they interact (Plomin et al, 1995).

The empirical evidence on the relative contribution of nature and nurture comes largely from family, twin, and adoption studies, as well as from more recent DNA analyses. Much of the research on the genetic roots of behavior has focused on disorders or problem behaviors, including mental retardation, schizophrenia, autism, alcoholism, aggression, and criminality. A strong relation between biology and development has been found for chromosomal and single-gene disorders such as Trisomy 21 (Down's Syndrome). The genetic contribution for disorders involving multiple genes is more complex to determine with estimates varying widely across studies. For example, heritability estimates for alcoholism have been found ranging from 0.32 to 0.98, depending on symptoms (McGue, 1994). In any case, the influence of environmental factors such as parenting styles, socioeconomic status, and neighborhood characteristics on mental illness, behavioral disorders, and other individual differences looms large (Meier et al, 2008; Turkheimer et al, 2003; Tuvblad et al, 2006).

What do we know about the role of nature and nurture in children's normal development? Much of this work has focused on two areas: temperament and intelligence. Studies of infants and young children have examined temperamental characteristics such as reactivity, mood, shyness, sociability, emotionality, attention/persistence, and adaptability. Because temperament is defined as stable and early appearing individual differences in behavioral tendencies, it is presumed to have strong biological roots. Clearly identifiable and enduring patterns of behavior such as shyness have been observed in very young infants, suggesting children are born with these tendencies. Twin studies generally confirm this genetic contribution, with heritability estimates ranging from 0.20 to 0.60 (Saudino, 2005). Intelligence also has a high heritability factor, typically estimated to be about 0.50 (Plomin et al, 1995); however, this may vary according to environmental differences like socioeconomic status (Turkheimer et al, 2003).

But findings for both temperament and intelligence also mean that much of what differentiates individuals is *not* accounted for by a child's biological birth certificate. Some of these environmental influences vary between contexts. For instance, communities vary in terms of resources and families differ in terms of typical parenting practices. However, it is also important to remember that environmental influences within a given setting may be non-shared. For example, parents may treat their children differently within the same family—this is called the "non-shared environment."

As mental health professionals consider the extent of their child clients' normal or atypical development, it is important to recognize this complex interplay of nature and nurture and how this contributes to the clients' clinical presentations.

Additionally, educating youths' primary caregivers about the biological and environmental influences on development may dispel the misconception that children are products of *either* nature *or* nurture in isolation. A boy who is "just like his father" may have been born with some genetic similarities, but he also is equally likely to be modeling his father's behavior based on what he sees at home and elsewhere.

Developmental timing and plasticity

A second overarching theme within the developmental literature is the sequencing and variation within normative development. A *continuous* view of development holds that humans grow and change through a gradual process, growing at a relatively even pace and acquiring more complex cognitive, linguistic, social-emotional, and behavioral skills in a linear fashion as they age, much like gradually climbing a hill. *Discontinuous* theories conceptualize development in a stage-specific pattern, where individuals experience rapid change when transitioning from stage to stage, but experience relatively little change during one developmental period, much like climbing stairs.

Just as the nature versus nurture debate shifted towards a nature *and* nurture perspective, theories of development have increasingly blended continuous and discontinuous models of development. The end result is that development is seen as a dynamic process that can be characterized as both continuous and discontinuous in its pattern and rate of change. Accordingly, normal child development occurs on a continuum, ranging from children whose physical, cognitive, social-emotional, and behavioral development may lag behind those of their peers, to children who are precocious, meeting or surpassing developmental milestones before most children their age. Even still, a majority of children who develop slightly earlier or later than their peers may do so within a "normal" timeframe.

As opposed to either maintaining a steady developmental pace or maturing through a rapid series of developmental "bursts," children demonstrate considerable



Imitation: a quick way of acquiring skills

heterogeneity in their rate of development. Such variation occurs within and between different developmental domains, with varying rates of development in cognitive versus social-emotional domains, for example, as well as across different periods of youth development, such as in toddlerhood versus adolescence (Holmbeck et al, 2010). Whereas one child may demonstrate advanced linguistic development during toddlerhood, he or she may lag behind some children in developing motor coordination at this time. During adolescence, this same child could have verbal abilities that are commensurate with peers, while also demonstrating highly advanced motor coordination compared to others.

It is useful to keep in mind that, barring early mental or physical disorders, lapses in development and deviations from the norm at different points in time are not necessarily predictive of subsequent developmental deficits or delays. Instead, children typically continue to grow and change. Traits or skills can be altered throughout the lifespan although they typically are more malleable earlier in development. This notion of *plasticity* is an important characteristic of normal child development.

Critical and sensitive periods

One of the most famous cases in the developmental literature is about a child named Genie who was locked in a closet until she was discovered by authorities at age 13. Although Genie was the subject of intensive intervention, she was never able to regain normal cognitive, physical or social skills. Studies of Genie and other *feral children,* individuals who have lived isolated from human contact from an early age, have yielded important information about *critical periods* for normal development. A critical period is a limited time that begins and ends abruptly during which a specific function develops. If the conditions for development are not available during that time, it may be extremely difficult or even impossible to develop these functions later in life. For example, the first five years of life are a particularly critical period for language acquisition. The early years are also critical for the development of vision—studies of babies born with cataracts left unrepaired have found that they do not develop normal vision even if cataracts are removed later in life.

Critical period

A critical period is a limited time that begins and ends abruptly during which a specific function develops. If the conditions for development are not available during that time it may be extremely difficult or even impossible to develop these functions later in life.

Sensitive period

A sensitive period is a time when it is easiest for children to acquire certain skills. It is similar to a critical period in that it is a time of optimal development, but it is best understood as a time of maximum sensitivity that begins and ends more gradually and is more amenable to recovery.

A *sensitive period* is a time when it is easiest for children to acquire certain skills. It is similar to a critical period in that it is a time of optimal development, but it is best understood as a time of maximum sensitivity that begins and ends more gradually and is more amenable to recovery. For example, second language learning is easier before age 6, but not impossible at any age (although most older learners do not speak with a native accent). The difference between critical and sensitive periods has also been the subject of much debate, particularly in the area of language. It is sometimes blurred, particularly because critical periods have been defined as times when individuals are most "sensitive" to stimuli. Critical and sensitive periods are best understood as optimal "windows of opportunity" and are important for encouraging positive developmental outcomes that are most likely (and possibly can only occur) during certain ages.

The role of culture and context

Normal development can only be understood within the context and culture where it occurs. These factors can influence normal development and may promote or hinder it. Thus, another important principle of normal development

is that average population rates for on- or off-time development may vary considerably within and across racial/ethnic and cultural groups. They may also vary according to other contextual differences including historical era, community, or socioeconomic status. For example, during the colonial period in the US, parents considered babies crawling to be something abnormal and to be avoided at all costs. Doctors at that time even recommended that parents tie their children to a cradle to prevent crawling as this movement was thought to be reflective of animal and not human behavior. Now, most American parents are delighted when they see their children beginning to crawl and try to encourage it.

The nature and timing of some capabilities is less likely to vary across context, particularly in physical and cognitive domains. Skills and behaviors—such as cooing and babbling, initiation of speech, or the ability to use abstract reasoning—develop in a more species-specific pattern; they are all capabilities that are unlikely to differ cross-culturally. For example, children in India, China, Sweden, and Peru all are likely to begin to talk during the second year of life, although cultural practices may encourage or discourage the precise timing of language development. Similarly, if a child grows up in a culture that does not encourage abstract thinking, although this potential develops during adolescence, it may never translate to actual behavior.

This means that normal development must always be understood within a specific culture or context that regulates its expression. However, this framework can also present challenges. For example, immigrant parents often expect their children to conform to standards of normal behavior in their home country while children try to assimilate to their new culture. Children and parents must also conform to standards that may be considered normal in their home country that may even be illegal in their new country. For this reason it is important for practitioners to understand the cultural norms of their clients and how they can best align with acceptable practices.

Child development is organized into:

- Infancy: 0 to 2 years
- Toddlerhood and preschool: 2 to 5
- Childhood: 6 to 11
- Adolescence: 11 to 18.

STAGES AND DOMAINS OF DEVELOPMENT

The following sections describe age-graded milestones across different domains of development. Child development is organized into *infancy* (ages zero to two), *toddlerhood and preschool years* (ages two to five), *childhood* (ages six to 11), and *adolescence* (ages 11 to 18). Although in this chapter we do not discuss development during *emerging adulthood* (ages 19 to 29), in many cultures, particularly in higher income Western countries, this period is considered to be a continuation of adolescence as part of an extended transition to adulthood.

Cognitive development focuses on changes and growth in internal mental processes, such as concrete and abstract thinking and reasoning, problem-solving, memorizing and recalling, planning, imaging and creating. Cognitive development also refers to the proliferation of internal cognitive scripts or patterns of thinking and understanding, as well as larger schemas, or overarching beliefs about the self, others, and how the world works. Milestones that are categorized as part of the *linguistic* development domain reference the child's communication skills, developing speech patterns, and sentence structuring, much of which relates to the sequencing of cognitive development.

The *social-emotional domain* involves the development of relationships with others and the learning of social norms and customs, as well as growth in the ability to identify, understand, express, and modulate one's feelings. *Behavioral milestones* refer broadly to the child's development of age-appropriate behavior, such as following rules or regulating deviant behavior. Throughout infancy, toddlerhood, childhood, and adolescence, normally developing youth negotiate certain tasks or milestones that occur at specific time points, in each of the cognitive, linguistic, social-emotional, and behavioral domains.

NORMAL DEVELOPMENT IN INFANCY AND EARLY TODDLERHOOD: AGE ZERO TO TWO

From birth to age two, interactions and patterns of attachment between the infant and the primary caregiver are an important catalyst for cognitive, linguistic, social-emotional, and behavioral development. Noticeable developmental changes occur rapidly during the infancy period, particularly when comparing the completely dependent child at birth to a child at age two who is able to put words together, walk alone, and navigate the social environment with purpose.

For this reason, milestones within each domain in the following sections are organized according to the period of birth to six months, seven months to 1 year, 13 months to 18 months, and 19 months to two years, to better reflect the sequencing of change during the infancy and early toddlerhood periods. Recall that the descriptions and temporal placement of these milestones generally reflect normal development, but that infants who complete these milestones slightly before or after their same-age peers can still do so within the bounds of what is considered to be normal development.

Cognitive and linguistic milestones

Birth to six months

During this period, the infant's use of sight, sound, taste, touch, and smell facilitates cognitive and linguistic growth as well as social interaction with primary caregivers. From birth to six months, infants' perceptual acuity begins to improve, leading to the increased differentiation of external stimuli, such as patterns, colors or sounds, as well as the recognition of facial expressions. As they navigate their new world, babies are attracted to stimuli that help them in this quest—brightly colored mobiles, clear sounds like bells and whistles and easy to distinguish shapes and patterns.

These perceptual changes coincide with the infant's growing preference for familiar people and stimuli. At birth, most babies tolerate being held by a number of different adults without showing too much distress. However, closer to age six months, babies may cry or whimper more often when held by unfamiliar adults or family members, developing a particular preference for the face, vocal sounds and smell of the primary caregiver, typically the mother in most cultures. In some sense, normal developmental processes during infancy suggest it might be easier for a child to start communal care arrangements like day care at a relatively younger age (earlier than six months) before developing clear preferences for caregivers or settings.

During this stage, infants also develop a preference for face-to-face interactions and are able to recognize and imitate adult facial expressions. This recognition and imitation typically is quite pleasing to parents and increases the parent-child bond as reciprocal interactions become possible. The infant's memory and attention skills likewise improve, so that the infant can efficiently remember and attend to certain people, physical locations or objects, such as a bottle or a preferred toy. In essence, during these very early months, the infant is constructing a blueprint for life—filled with familiar objects, people and experiences.

A common concern for parents during this stage is why their babies cry so frequently—during the night, multiple times per day and even after being fed. Yet, without the ability to talk, *crying* is a normal and primary venue for communicating discomfort to caregivers—babies are born crying. Infants cry primarily to express basic needs, such as hunger, thirst, or the desire for comfort, as well as to express negative emotional or physical states, such as anger or pain. Indeed, as parents become more synchronized with their infants, they soon are able to recognize different types of cries, based on the crying pattern, intensity and rhythm. For example, *basic crying* is a cry that increases in intensity and rhythm in response to hunger, whereas *angry crying* and *pain crying*, are characterized by a long cry followed by a period of silence and rapid inhalations, usually beginning suddenly and in response to physical discomfort (Hetherington et al, 2006).

Crying

Crying is a normal and primary venue for communicating discomfort to caregivers. Infants cry to express basic needs, such as hunger, thirst, or the desire for comfort, as well as for anger or pain.

Cultural and contextual differences may also impact babies' crying patterns. It has been reported that infants from non-Western countries are quieter than their counterparts from Western countries (Zeifman, 2001). An examination of infant caregiving practices in these societies suggests that the greater amount of physical contact and the more frequent feedings typical of non-Western parenting habits may physiologically prevent infants from crying. Contextual stressors, such as poverty, can impact important child rearing necessities like food and housing, which may influence parental responsiveness and, in turn, babies' crying. A lack of food, housing, or financial security can make it difficult for parents to provide sensitive, responsive and stimulating care to their children. Therefore, the extent to which parents effectively perform their caregiving roles depends not only on their ability to recognize and respond successfully to their babies' cries, but also on stresses and supports they are provided contextually. For this reason, practitioners and health workers should be especially aware of such stressors in order to support parents who are learning to respond to crying newborns, so as not to become an additional source of stress for the family.

To the relief of many parents, by about two months of age babies also begin *cooing*, making noises that are characterized by short vowel sounds, and move into *babbling* by four months, when consonant sounds are added and speech becomes repetitive, for example, "babababa." Although crying does not stop at this time, cooing and babbling noises are pleasant and fun for parents to hear. They also serve as precursors to language development.

In addition to a preference for the voice of the caregiver, the infant also prefers to hear his or her native language and may begin communicating about the same items or events as the primary caregiver in a process called *joint attention* (Berk 2006). At the infant's birth, a new mother may point to an older sibling and tell the infant, "That's your brother!" At that early age, the infant typically

would not direct attention towards the brother at that time. When the parent utters this same sentence when the infant is closer to six months, the infant may look at the brother and babble or coo, showing interest in the same subject as the primary caregiver. This joint attention with the caregiver can enhance vocabulary development, and also demonstrates the infant's growing and related cognitive abilities. Parents at this time may start pointing out various environmental objects, people or events, directing the infant's attention and integrating new vocabulary words. Although at this stage, the infant will only change visual attention and make cooing or babbling noises while engaging in joint attention, this process becomes more established in later months and throughout toddlerhood. This also points to the importance of social stimulation and interaction as a primary means for early development.

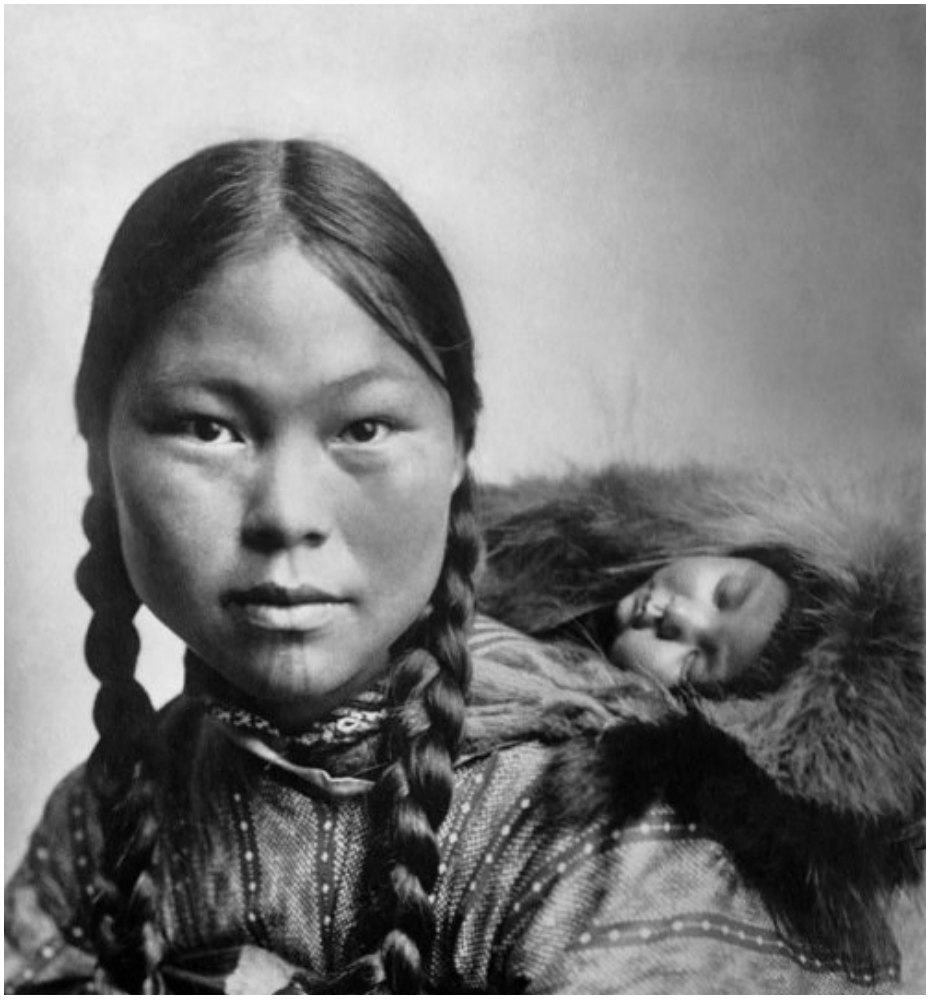
Age seven months to one year

Infants continue to use their growing perceptual and sensory capabilities to inform cognitive and linguistic development during this period as they approach one year of age. At this time, infants' memory and attention skills continue to improve, although memory in these early stages is contingent upon the familiarity of the situation or person or the infant's motivation, for example, to interact with others or use a toy.

A milestone of this developmental period is *object permanence*, an understanding that objects or people still exist when these items are not readily

Object permanence

Is the understanding that objects or people still exist when they are not readily seen or heard. Object permanency emerges around 8 months of age.



Infants need to develop a relationship with at least one primary caregiver for social and emotional development to occur normally. Proximity between infants and an attachment figure facilitates this process.

Inuit mother and baby

seen or heard, that emerges around eight months (Piaget, 1954). As an example, imagine that two eager parents are playing with their three-month-old infant on the floor, using a popular jack-in-the-box toy where the doll figure is hidden in a box and pops out again to surprise the infant. The parents notice that the infant acts as if the toy is gone when it is not directly in sight and only seems frightened when the toy pops out. They wonder whether their baby is unable to play with this toy or even whether something is wrong with their baby. Perplexed, they put the toy in the closet. They decide to try again when their baby is about eight months old and are pleased to see that their infant now searches for the jack-in-the-box doll, babbles excitedly when it pops out and appears to remember the game and where the doll went time and time again. This baby will now also engage in turn-taking and "peek-a-boo" games with caregivers, and will search for toys or other items that are out of sight, for example, when an item or toy is placed under a blanket or cloth.

At this stage, babies use babbling in conjunction with play through the manipulations of different sounds when interacting with the parent and in combination with gestural requests for objects. Infants may babble or make noises to suggest they want something, such as a toy or food, and begin to point at objects around age 1, as another form of communicating their desires. Some babies will speak their first word during this period or during the 13 to 18 month stage. Finally, infants will learn and respond to their own name at this point, which also reflects social-emotional gains in differentiating the self from those around the infant, and especially from the primary caregiver, although this process (self-other differentiation) is more apparent after 13 months of age.



Click on the picture to access a 2-hour roundtable discussion about the development of temperament.

Age 13 months to 18 months

During this time period infants expand their repertoire of earlier cognitive skills. Most babies not only search for objects hidden from sight—characteristic of object permanence—but look for these items in more than one location, such as under the couch and in other rooms, making organized games like hide-and-seek possible.

Memory storage and retrieval continues to advance—babies at this age can imitate others with increasing delays between the time of the observed behavior and the imitation of this behavior in other contexts. For example, at home, a father may put a toy cup on his head playfully, using it like a hat. Later in the week, at daycare or at the home or a relative, the 15-month-old infant may do the same thing when presented with a toy cup while in a playroom, showing a delayed imitation of the father's home behavior. Infants at this age also begin to store prior experiences in memory and are aware of times when present situations are not in accordance with prior events or their pre-existing expectations. For example, while changing a 13-month-old baby's diaper, the mother may give the baby a certain object to keep the infant occupied, like a specific stuffed animal the baby likes to hold and squeeze during diaper change time. If the stuffed toy is unavailable one day, the infant might still look expectantly at the mother and reach toward her, looking for the toy. The infant became accustomed to this routine and has noticed that this diaper change is different from their typical routine.

Infants typically say their first word at 12 or 13 months, although the average range is between eight and 18 months. Many parents may expect their

child to say "mama" or "dada" first, both of which are similar vowel-consonant combinations to early babbling. However, infants' first words may be based on context or the repetition of particular words that the caregivers say frequently throughout the day. One mother wanted to teach her infant daughter to avoid dangers and repeatedly said "no" during the day. Unfortunately, she was dismayed when her daughter's first word was "no" instead of "mama"—in fact, the daughter started to call her mother "no" for some time.

After the first word, vocabulary will grow to about 200 words during this period, although this can vary substantially by the infant's developmental environment. Socioeconomic status and cultural background are two important variables that can impact language development and content, for example, how many words children learn and whether these words are predominantly object-based (referential) or expressive. For example, the infant who learned the word "no" soon went on to learn the parents' names, calling them "mama" and "dada." Whereas referential words primarily are used to name things, expressive language describes people, feelings or social events. Children of different demographic or cultural groups may use either more referential or more expressive language during early development, depending on their external environment in combination with other individual characteristics.

Age 19 months to two years

As the infant approaches toddlerhood, cognitive advances continue in the areas of memory, problem solving and attention (executive functioning). Beginning at this stage, infants can develop and carry out action plans, such as building a specific type of structure with blocks. Whereas 10-month-old children cannot typically sustain play together—typically sit side by side in a playroom (called parallel play)—the play of infants at this stage becomes more interactive. When a pair of 20-month-old infants plays together, they might engage in *pretend* or *make-believe play*. A common theme for make-believe play is engaging in everyday tasks that the infants have observed others perform, such as eating, cooking, sleeping, or feeding household pets. This type of pretend play is also indicative of more advanced working memory and imitative skills—and perhaps another venue for constructing a blueprint for life.

Cultural differences in children's play themes have been well documented (Rogoff, 2003). Although most children will engage in ordinary chores like sweeping or food preparation cross-culturally, North American toddlers tend to participate more frequently in make-believe play that includes managing household machines such as vacuum cleaners and dishwashers, or using a mobile cell phone. In contrast, Mayan children from Guatemala have less involvement with machines but many have roles in adult activities, such as running errands to a corner store or weaving household items. The differences in themes of play across cultures highlight the fact that cultures and communities may vary considerably in the skills that are considered important or a normal part of one's household. Likewise, practitioners should note that parents who are more informed about the benefits of pretend play may take a more active role in introducing complexity and diversity into play themes. Other parents may either be uninformed about play or it may not be culturally relevant to be involved in children's play activities. Overall, the themes of play and the degree to which parents are involved in play differ

Click on the pictures below to watch developmental theorist Jean Piaget discuss and illustrate his theory about intellectual development (in French and English with subtitles in English).



Part 1 (12:25)



Part 2 (13:05)



Part 3 (11:30)



Part 4 (4:49)

across cultures, and should be taken into account before making assumptions about "normal" pretend play.

Along with the cognitive gains at this stage, this period brings several advances in linguistic skills. Infants at this age start combining two or more words, like "no mom!" or "want that," and the infant's vocabulary also grows noticeably. Because children at this stage are learning and practicing word pronunciation, they often replace certain parts of a word with vowels of consonants that are easier to say or leave off the end of words. During his first day of daycare, one infant constantly asked for "ju" during lunchtime and became upset when the preschool teachers tried to ask what this meant. When this infant's father picked him up from daycare that afternoon, he was able to explain to the teachers that this meant "juice," reflecting the infant's routine at home, where he got juice every day with his lunch. In a Spanish-speaking country, such as Mexico, an infant might initially say "melo etá" instead of "caramelo está" in Spanish ("the candy is there," in English) to her granddad as she is trying to find the candy her granddad has playfully hidden away from her. This infant has mispronounced part of the words and left off several sounds. Although parents may express concern that their infant cannot form full words, this type of word replacement or shortening is typical for infants at this stage.

Social-emotional and behavioral milestones

Is it OK for parents and children to sleep together?

How long should they share a bed?

Just as infants depend primarily on caregivers to facilitate their exploration of the external environment and, by extension, their cognitive and linguistic development, much of the infant's social-emotional and behavioral milestones are negotiated in the context of the infant's relationship with the primary caregiver. A critical milestone during this period is the development of the *attachment relationship*, or the infant's emotional bond to the primary caregiver (Ainsworth, 1979). The strength of this bond indicates the extent to which the infant can use the caregiver as a *secure base* from which to explore the world, return to during times of distress, and use as a framework for social-emotional development.

Birth to six months

At this early stage, infants are learning to regulate their emotions and behavior, although they may not seem to be very good at it. Part of self-regulation includes the formulation of regular behavioral patterns in the areas of eating and sleeping, for example, as these behaviors can also impact the infant's level of emotional arousal and degree of affect regulation. Although most babies will not sleep through the night until they reach their first birthday, infant sleep cycles become more predictable by the age of eight weeks, when infants are sleeping for longer periods at night than during the day. It is important during this period for parents to establish regular activities and routines—it is easier to learn to wait for something that comes at the same time each day than for something that is random.

Sleeping routines are often difficult for parents to establish and may vary considerably by culture. Is it OK for parents and children to sleep together? How long should they share a bed? Although the majority of American infants typically sleep separately from caregivers in a crib, other cultures prefer *co-sleeping* arrangements, where the infant sleeps with one or more caregivers in the same bed, often with other siblings as well. For some cultures, co-sleeping is seen as

an important indication of the infant-caregiver bond and is presumed to have health benefits over sleeping separately. These cultural variations are likely to be reinforced in other practices—the important thing to remember is that infants need routines, and that appropriate routines do vary cross-culturally.

Regardless of the varying sleep and wake cycles or patterns in a particular culture, infants at this stage will begin to exhibit more predictable sleeping habits and cycles. Similarly, eating schedules will become more predictable, with the infant transitioning from feeding five to eight times per day in the first couple of months after birth, to feeding three to five times per day, at relatively equal intervals, by the sixth month of life.

Just as routines are important for babies, infants can easily become overwhelmed by new experiences, taxing their emerging self-regulation skills. For example, imagine that a caregiver is dangling a brightly colored mobile over her three-month-old infants' face, making whooshing noises as she moves the mobile parts above and around the infant's head. After cooing and smiling for a few seconds, the infant suddenly looks away, disengaging from the caregiver's play. Should the caregiver be upset? Did she do something wrong? Is there something wrong with the infant?

Such behavior is normal at this stage of development. It is called *gaze aversion*, and is a normal reaction to overstimulation and arousal. In this case, the infant will look away from the stimuli—for example, turning away from the mother's play with the mobile—as a method to regulate arousal. Over time, through appropriate and sensitive interactions with caregivers, infants' tolerance for emotional arousal and regulation of this arousal will increase. After becoming habituated to the caregiver's play with the mobile, this infant may begin to track the mobile and coo at the caregiver for a longer period of time, eventually maintaining this play.

Gaze aversion

Gaze aversion, looking away from a stimulus, is a normal reaction to overstimulation and arousal and is an infant's attempt to regulate arousal.

The infant's range of emotions increases during this period from the dichotomous states of either pleasure (relaxation) or pain (discomfort) to the differentiation of various feeling states within these broad categories. Emotional expression becomes more varied, organized and specific to the infant's external environment and/or internal feeling state. During these months, the infant also begins to match the caregiver's feelings during face-to-face interactions. By the age of six weeks, the infant develops a *social smile* in response to human faces and particularly the face of the primary caregiver. At three or four months, the infant also begins to laugh, especially in response to the laughter of other adults or the surprise at discovering a fun, novel situation, such as the caregivers making funny faces at the infant. Frustration and the closely related emotional state of anger become more distinguishable by about six months, at which point the distinct state of sadness also emerges. Infants will typically withdraw when feeling sad, although crying and its distinct patterning can accompany a range of negative emotional states. In truth, the multiple emotions infants display only six months after birth are striking!

Parents often are surprised to learn that infants (and people) vary greatly in *temperament*, defined as a biological predisposition to patterns of behavior and interaction (Wachs, 2006). Imagine that several new mothers are sitting together at a weekly playgroup with their six-month-old infants when one mother brings

Photo: Linda Cronin



up several eating and sleeping issues she has been having with her baby. Her baby has yet to develop routine sleeping and eating patterns and often cries in response to new toys or situations that he is exposed too. Another mother mentions that she has not had this experience at all, that her infant sleeps through the night and loves exploring new objects and meeting new people. A third mother comments that she is not sure whether her baby will be a social child later in life because the mother remembers being told that she was shy when she was a baby.

Temperament is a biological predisposition to patterns of behaving and interacting.

The three mothers wonder which of these babies is the most "normal". They all are! They are normal, just different. The first baby would be classified as having a difficult temperament, the second as easy, and the third as slow-to-warm up. Babies who exhibit difficult temperament are those who are highly reactive to external stimuli, expressing more negative emotions, such as anger, fear, or anxiety, and are less likely to effectively manage or regulate those emotional states. Irregular sleeping and eating habits are also associated with this category (Thomas & Chess, 1977). Easy infants are thought to have more regular eating and sleeping habits and to adapt well to new situations or people; these infants are also less emotionally reactive and express and regulate emotions and arousal states without a predominance of negative emotionality. Finally, slow-to-warm-up infants may initially appear more withdrawn than others, with mildly negative responses to novel situations, but eventually exhibit positive and adaptable characteristics and patterns of social responding to others.

Although temperament is thought to be a relatively stable and biologically-influenced trait that can predict later social-emotional development, only 60% of infants can be classified into a temperament category, and infant traits may change over time. Indeed, temperament style has been found to interact with elements of the external environment, such as maternal responsiveness or family chaos, making

it difficult to reliably predict how temperament styles in infancy and toddlerhood relate to later social-emotional development (Essex et al, 2011; Rubin et al, 2002). Remember, the settings where children grow up will influence how they turn out—nature and nurture join forces to make us who we are and who we become.

Additionally, cross-cultural studies have shown differences in infant temperament when comparing Western and non-Western populations (Ahadi & Rothbart, 1993). For example, North American infants typically score higher on measures of activity level (intensity and frequency of motor movements), approach tendencies (degree to which a child accepts new people, objects or situations), and positive mood (extent to which a child expresses positive emotions) when compared to Chinese infants. Conversely, this line of research has shown that Chinese infants are, on average, more easily consoled during a crying episode than their North American counterparts.

Age seven months to one year

The most apparent social-emotional and behavioral milestones during this period are the development of the *attachment relationship*, and the occurrence of *stranger wariness* and *separation anxiety*. Infant-caregiver attachment refers to the infant's bond with the primary caregiver, and the extent to which the infant can use the caregiver as a *secure base* for exploration and for comfort. Researchers initially classified attachment styles through a series of interactions called the "Strange Situation task", involving short separations from the primary caregiver and exposure to another adult in the context of an unfamiliar playroom (Ainsworth, 1979).

Secure attachment refers to infants who cry when the primary caregiver is absent, but allow themselves to be comforted upon the caregiver's return; these infants also use their caregiver as a secure base which they periodically "check in with," by physically toddling back to or visually glancing over at the caregiver, during their exploration of new environments or situations. *Separation anxiety* can be an overt sign of secure attachment, although not all infants evidence this type of behavior and it may occur regardless of attachment classification (Berk, 2006). Many primary caregivers express concern that at this age their children cannot tolerate minor separations and begin crying inconsolably when the caregiver leaves, whether parents are leaving their child with unfamiliar adults in a new daycare setting or in the care of familiar family members. This anxious behavior peaks around one year of age, along with *stranger wariness*, in which the infant displays discomfort in the presence of unfamiliar people. Although separation anxiety may persist even after the infant develops a regular routine of separations from the primary caregiver, for example, attending daycare five days per week, this behavior is normal up until toddlerhood.

Insecurely attached infants fall into several categories, all of which reflect disruptions in the infant-caregiver bond. *Avoidant attachment* characterizes infants who do not become distressed when the caregiver leaves the room and react to both strangers and the caregiver in a similarly unresponsive fashion. Infants who exhibit *resistant attachment* are hesitant to explore an unfamiliar playroom while the caregiver is present, become upset when she leaves and are angry and sometimes aggressive with the caregiver when she returns, showing some resistance to being comforted. *Disorganized attachment*, a category created after several years

Insecure attachment

Disruptions in the infant-caregiver bond can result in insecurely attached infants. This can manifest in:

- Avoidant attachment, when infants do not become distressed when the caregiver leaves the room and react to both strangers and the caregiver in a similarly unresponsive fashion.
- Resistant attachment, which is characterised by hesitancy to explore an unfamiliar playroom while the caregiver is present, become upset when she leaves and are angry and sometimes aggressive with the caregiver when she returns, showing some resistance to being comforted.
- Disorganized attachment, when infants appear confused, contradictory or emotionally labile in their behavior, with some of these infants showing signs of disassociation (frozen facial expression and total unresponsiveness).

of initial attachment research, represents infants who are confused, contradictory, or emotionally labile in their behavior, with some of these infants showing signs of disassociation (frozen facial expression and total unresponsiveness); this category reflects the most severe form of insecure attachment.

Although a healthy infant-caregiver relational bond is important, the attachment relationship and its influence on later development depend on multiple individual and contextual factors. These include maternal sensitivity and responsiveness, infant temperament, home environment, socio-economic status, racial/ethnic background, and other influences in the infant's life (Seifer et al, 1996; Wong et al, 2009).

The biological mother also is not necessarily the primary attachment figure; the infant may bond with other important adults, including fathers, extended family members and foster parents. Attachment classifications also depend a great deal on the infant's cultural context. Attachment classifications and the Strange Situation task are culture-bound phenomena, and may not adequately describe infant-caregiver attachment in other cultures. For example, suppose a Japanese infant and his mother are placed in a Strange Situation task and the infant does not appear to be distressed when his mother leaves the room. When a stranger comes in to play with the infant, the infant is somewhat non-responsive and continues playing on his own. This pattern persists when his mother returns to the room. Should this infant be classified as having an avoidant attachment pattern? Not necessarily; infants in non-Western societies may display behavior that North Americans would characterize as avoidant, but in reality these patterns are normative in other cultural groups (Marcus & Kitayama, 1991). Finally, attachment patterns, like temperament, are not always stable over time and can change according to changes in the infant's temperament, home life, and environmental context.

Social referencing

Social referencing is the term used to describe the way that infants take their cues from others in deciding what emotions and actions are appropriate in a specific situation.

Social referencing, another social-emotional milestone, also begins during this period. Imagine a baby at this age falls down while playing with siblings and the parent in the grass at the park. The infant has fallen on a relatively soft surface and is not hurt. The infant appears surprised at the fall, but looks quickly at the caregiver, who smiles and tells the infant, "Oops! You fell down." The infant smiles in return and continues to play. This interaction is indicative of social referencing, which occurs when the infant looks to either the primary caregiver or other important adults before reacting to ambiguous or novel situations. Another example of this situation would be if an unfamiliar dog approached the infant, siblings, and caregiver while they were playing in the park. When the infant sees his sibling and parent petting the dog and guiding the infant in interacting with the dog, the infant will use these behavioral and emotional responses to appraise the nature of the situation and respond accordingly. Although infants will be wary of strangers or new animals, they are more likely to respond positively if they view their caregiver exhibiting positive emotions in response to the stranger's or the animal's presence.

Social referencing can also give children opportunities to discover and imitate how to react to aspects of their social environment—in other words, social referencing provides a basis for acquiring knowledge about culture-bound social nuances. For example, in a context where different castes co-exist, an infant from a lower caste may witness, and subsequently learn to imitate, submissiveness in

the presence of high-caste persons from watching interactions between primary caregivers and high-caste individuals. Additionally, if this toddler grew up in India, he might learn through social referencing at an early age to only use his right hand for eating—in India, the right hand is the "clean" hand while the left is the "dirty" hand, used for cleaning oneself after defecation. This premature right-hand dominance might then lead the child to an earlier knowledge of left and right compared to children his age in other countries, showing how social referencing can promote the learning of culture-bound social nuances and can lead to additional cultural differences.

Social referencing continues to develop throughout toddlerhood and beyond, as individuals take cues from others to learn how to appropriately respond to different emotionally stimulating situations or use others' responses in comparison with their own emotional states and preferences. This milestone also indicates that the infant is becoming aware of the difference between the self and others, as well as of the desires and feelings of others. Corresponding with this growing realization, another important milestone during this period is the infant's ability to follow simple directions given by others, which appears at nine to ten months of age and continues to advance later in infancy. In this case, the infant playing with the dog may be able to follow the mother's command to give the dog a stick to play with, and the infant will most likely be able to comply, following the directions of the primary caregiver.

Age 13 months to 18 months

During this stage, more concrete signs of *self-awareness* develop. Infants now are aware that their body, emotions and behaviors are separate entities from those of their primary caregiver and from others. Infants at this stage begin to recognize themselves, a critically important step in development. A compelling example of this self-awareness is illustrated by an infant's first look in the mirror. Although initially surprised, most infants quickly learn that they are looking at themselves and not someone else. Importantly, cross-cultural studies have shown that there are significant differences in the responses of Western and non-Western infants when looking at their reflection in a mirror (Broeschet al, 2010). While mirror recognition may be a marker of growing self-concept in Western infants, this is not necessarily the case for non-Western infants. As such, the consideration of the mirror self-recognition as an index of self-awareness in children's development is influenced by the cultural context in which the child is embedded.

The changes during this period also show advances in emotional development, as infants are now able to play with peers through imitation or mutual play tasks and can also demonstrate empathy towards others. *Empathy* is the capacity to reflect and feel the emotions demonstrated by another person. When infants see displays of emotion in their caregiver, particularly negative emotionality, infants may show their own personal distress or comfort the caregiver, although the latter empathic response typically occurs around the age of two. At this stage, infants continue to differentiate their emotional experiences from others as their sense of self-awareness grows, but also show signs of prosocial behavior.

Age 19 months to two years

As toddlerhood approaches, the infant becomes aware of the names for various emotional states and starts to use language and other behaviors to regulate

Table A.2.1 Summary of developmental milestones from zero to two years

	Cognitive and linguistic milestones: Social stimulation and interaction	Social-emotional and behavioral milestones: Attachment relationships
Birth to six months	• Better differentiation of external stimuli (sounds, colors, etc.) • Recognition of facial expression • Preference for familiar people, stimuli and face-to-face interactions. • Improvement of memory and attention skills (infants can remember and attend to certain people, physical locations or objects) • Use of crying to express basic needs (hunger, thirst, comfort, etc.) • Emergence of language precursors: Cooing (2 months) and babbling (4 months) • *Joint attention*: Caregiver and baby take turns exchanging facial expressions and noises.	• Early behavioral and emotional self-regulation based on establishment of regular activities and routines (e.g., eating, sleeping, etc.) • Sleep cycles become more predictable by the age of eight weeks • *Gaze aversion*: Normal reaction to overstimulation and arousal • *Social smile*: As a response to familiar human faces (6 weeks) and as initiated by the baby (3 or 4 months). • Multiple displays of emotions by age six months (e.g., frustration, anger, sadness, etc.) • Individual and contextual differences in *temperament*
Seven months to one year	• Growing perceptual and sensory capabilities. • Improvement of memory and attention skills: Dependent on the familiarity of the situation, person, or infant's motivation • *Object permanence* (eight months): Objects and people still exist although not seen or heard • Emergent language skills: Babbling when interacting with the caregiver, some will speak their first word at 12 months or in the next stage • Can point to an object (e.g., a toy) around one year • Will learn and respond to own name.	• Development of *attachment relationships*: Infant's bond with the primary caregiver • *Separation anxiety*: Displays anxiety when the caregiver leaves • *Social referencing*: – How to react to ambiguous or novel situations – Facilitates acquisition of culture-bound social nuances – Differentiation between self and others.
13 months to 18 months	• Expansion of their repertoire of earlier cognitive skills: – Object permanence: Will look for the hidden item in more than one location – Memory and retrieval: Increasing delays between the observed behavior and its imitation in other contexts – After the first word (eight-18 months): Vocabulary grows to about 200 words.	• *Self-awareness*: Recognition of oneself • First demonstrations of *empathy*: Capacity to reflect and feel the emotions demonstrated by another person (e.g., when infants see displays of negative emotionality in their caregiver, they may show their own personal distress or attempt to comfort the caregiver).
19 months to two years	• Cognitive advances in memory, problem solving, and attention: – Development and execution of action plans (e.g., building a structure) – Pretend or make-believe play (20 months) and daily life play themes • Advanced linguistic skills: – Combining two or more words – Replacement of parts of a word with vowels or consonants that are easier to say – Vocabulary growth.	• Use of language and other behaviors to regulate emotional experience • Growing awareness of others • Emergence of more complex emotions (e.g., embarrassment, guilt, shame, etc.) • Lower intensity of separation anxiety • First signs of self-control: Able to delay engagement in an enjoyable task • Play: Imitation of others, use of language and play choices based on gender stereotypes.

his or her emotional experience. For example, the infant may be able to name an internal feeling state and tell the caregiver about it ("I'm mad!") or offer the sad caregiver a hug, showing an increasing capacity for empathy. Consistent with the growing awareness of others during these later stages of infancy, the more complex emotions emerge at this time, such as embarrassment, guilt, and shame, all of which are emotional responses to others' perspectives of the child's behavior. For example, when one family's two-year-old was caught with her hands in the cookie jar, she appeared to respond with embarrassment to her mother's scolding and started to cry when she realized that this action was not allowed. In earlier stages, this same infant may have only cried out of surprise and anger when her mother took the cookies.

Behaviors indicative of separation anxiety decrease in their intensity during this stage and infants begin to show higher-level emotional regulation skills, such as delay of gratification. Although self-control at this age varies according to individual differences, some infants nearing toddlerhood can delay engaging in an enjoyable task or wait to receive a prize if asked to do so. Play behaviors during this time period revolve around imitation of other children, although language is also introduced to describe or direct the play and infants begin to make choices about play items based on gender stereotypes.

Infancy at a glance

The period of birth to two years is an exciting time of incredible advances in cognitive, linguistic, social-emotional and behavioral development, summarized in Table A.2.1. During the first few months, the infant relies primarily on the caregiver for the provision of basic needs and the facilitation of different developmental advances across multiple domains, by age two the infant shows signs of self-awareness, independence, social coordination, and empathy, which continue to develop during toddlerhood and preschool, setting the groundwork for social engagement and learning.

NORMAL DEVELOPMENT IN LATE TODDLERHOOD AND PRESCHOOL: AGE TWO TO FIVE

Late toddlerhood generally refers to ages two to three. Preschool years typically are between ages three and five. However, due to temporal overlaps within these developmental periods it is also reasonable to discuss cognitive, linguistic, social-emotional, and behavioral milestones throughout toddlerhood and preschool ages as one developmental period spanning ages two to five. During this stage, children continue to negotiate and balance their reliance upon the primary caregiver with their desire for independence. They become more self-reliant in preparation for the school-age years, often their first venture into the world beyond their immediate family and community.

Cognitive and linguistic milestones

Cognitive milestones between ages two and five largely reflect the child's growing capacities in the areas of working memory, sustained attention, problem-solving, and organization, which facilitate the child's early learning and school readiness. Piaget's theory of cognitive development terms this period the

preoperational stage, wherein the toddler makes advances in his capacity to represent events or stories mentally, but remains *egocentric*, or self-focused, in his thinking (Piaget, 1954). However, recent research suggests a more flexible view of cognitive development at this age, with the toddler and preschooler making some gains in their abilities to empathize with or take the perspective of others.

A concerned parent of a three-year-old boy seeks the advice of a mental health professional. The parent is worried because the toddler often talks at length about an imaginary friend with whom the child says he plays many games. The boy has named the imaginary friend, insists that the friend come everywhere with the parent and the rest of the family, and becomes upset when other family members challenge the existence of this friend. While this behavior would not be considered typical at the age of seven or eight, beginning in toddlerhood and preschool, normally developing children will engage in more complex *sociodramatic play*, including developing imaginary friends, reflecting a growing capacity for mental representations.

Make-believe play with peers begins at age two or 2½, and increases in complexity until age four or five, when preschoolers begin to mutually build upon their make-believe play (Davies, 2004). Make-believe play indicates that children are able to mentally represent their world both with and without play objects, and can create imaginary sequences or representations of real or pretend life events. The development of an imaginary friend is normal at this age and is only one of many variants on sociodramatic play, which can also include playing house or doctor, pretending to be a superhero, or pretending that stuffed toys or other items can talk. Although at this stage children often pretend that inanimate objects can talk or think, toddlers and preschoolers increasingly differentiate animate from inanimate items. Sociodramatic play also involves and strengthens other cognitive and social-emotional capacities, such as working memory, attention, reasoning, self-control and cooperation, and perspective-taking, all of which grow and develop during this period.

At age three or four, toddlers also come to understand *dual representation*, or the recognition that a symbolic object, such as a photograph or model of a train station, is both an object and a symbol of something else, such as a family member or a train. Along with these advances in mental representation, children during this period also transition from believing in magic and imaginary beings, such as fairies, witches, vampires, or goblins at ages two and three, to searching for logical explanations for make-believe persons such as Santa Claus at ages five or six. However, magical thinking or belief in otherworldly figures will vary according to cultural beliefs and norms, and continued belief in these figures is not necessarily atypical in certain cultural contexts. For example, in modern Chile, many Mapuche communities believe witchcraft to be the primary cause of illness and misfortune. Among the Mapuche, is not strange to find children, adolescents and adults who believe in the existence of witches and their magical powers. Therefore, health practitioners working with these communities should take these beliefs into account when conceptualizing normal development.

Whereas cognitive problem solving during infancy relied mostly on trial and error, problem-solving during this stage is enhanced by the child's greater ability to sustain attention, engage in planning behaviors and use cognitive *scripts*



Photo: San Jose Library

or internal models of prior behavior and experiences for everyday problem-solving or interpretive purposes. For example, a toddler may learn how to build a taller and more stable structure with his blocks after learning how to do so from watching peers or caregivers and will integrate this learning into building larger block structures in the future. In terms of interpreting everyday experiences, children between the ages of two and five can typically relay the steps or actions involved in activities such as visiting a relative ("we drive to grandma's, she makes us dinner, we watch a show, we go home") or a day at preschool. Thinking at this stage also becomes more oriented around cause and effect relationships, and memory span can grow to up to four items. Problem solving can also occur through parental scaffolding or support, and through the developing child's use of *private speech.* Private speech occurs when toddlers and preschoolers talk to themselves out loud, providing themselves with guidance when solving problems, such as thinking through or planning their behavior (Berk, 2006). This milestone may also inform the development of more advanced memory, categorization and self-reflective processes.

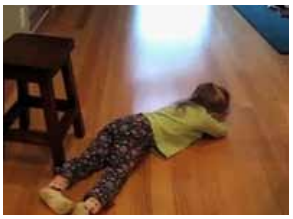
Cognitive and linguistic gains in school-based tasks become apparent during these ages, when children learn early literacy and numeracy skills. Although the learning of such skills will vary substantially according to language exposure in the home, socioeconomic status and cultural context, many children during their toddlerhood and preschool years learn to count and recite the alphabet. Children also can usually relate details of a story to others and ask questions to clarify their understanding by age five. Other language skills that continue to develop

and improve between the ages of two and five are in the areas of vocabulary and sentence construction. Important milestones include the growth of the child's vocabulary to about 2,000 words by age five, their ability to define known words and integrate new words into sentences upon hearing them toward the end of the preschool period. Two-year-olds will put sentences together with only two or three words. By age four or five the child can typically communicate with sentences that are more grammatically complex, utilizing different verb tenses, and can speak in coherent verbal exchanges with others.

Social-emotional and behavioral milestones

Many social-emotional changes occur during the toddler and preschool years. While younger children may comply with parental demands or requests, children at this stage are more likely to be resistant, as they balance their simultaneous desires for parental scaffolding and increased autonomy. Toddler and preschooler transition through a time of increased, and then decreased aggression and temper tantrums, and make overall gains in their understanding of emotions—in both their own emotional expression and that of others.

One afternoon, a mother comes to pick her child up from a relative's home and finds that her toddler bit one of her same-aged cousins in response to the cousin pushing the toddler while they were engaged in play. The mother is shocked, embarrassed and wonders how this could happen—her daughter has never bitten anyone at home and has been taught to use her words when she is upset. As her family member asks the mother where the toddler learned this behavior, the mother begins to feel concerned about whether this is age-appropriate or reflects the beginning of a behavioral problem. This type of aggressive behavior is quite normal for toddlers and even preschoolers. At age two, there is a universal increase in physically aggressive behavior, which can include biting, hitting of peers, family members and the primary caregiver. *Temper tantrums* are also normative during late toddlerhood. These intense emotional outbursts usually originate with the child's resistance to parental requests, frustration with external events, or feeling state of being tired or hungry. Temper tantrums typically appear between the ages of one and three, when children are still acquiring language skills to describe their emotions and desires; they should decrease significantly, along with physically aggressive behavior, by ages four or five, when children increase their emotional vocabulary, self-regulation skills and knowledge of socially appropriate displays of emotion. Although behaviors like biting, hitting or temper tantrums can be embarrassing for parents—particularly when these behaviors happen in a public setting like at preschool or in the supermarket—this behavior is normal for children this age, within reason.



Researchers have recently deconstructed the patterning of temper tantrums. Click on the link to view (1:54)

While physically aggressive behavior decreases over the course of this period, verbal aggression and other subtypes of aggression, such as *instrumental* aggression, begin to increase. Whereas the aggressive behavior of most two-year-old children is *reactive* in nature (in response to an external event), as children age, their aggressive behavior can become more instrumental, or calculated and goal-oriented, between ages three and four (Berk, 2006). For example, four-year-olds may act aggressively in order to gain access to a wanted toy, whereas the two-year-old in the previous example bit her cousin in response to being pushed. On the other hand, children also may become more competent social-problem solvers at this time, especially

given appropriate modeling by adults and other peers. Overall, aggressive behavior is normative during this period, but should decline as children enter their school-aged years, by about five or six years of age.

Other social-emotional milestones in emotional expression and in understanding the emotions of others occur during this period. In particular, more complex behavioral and linguistic expressions of emotion, including empathy and sympathy, develop during this time. For example, when seeing his mother become sad and upset one evening, a two-year-old might hug this distressed parent. In contrast, an older preschooler will use physical actions as well as words to provide comfort, asking, "What's wrong mommy?" hugging his mother and even repeating soothing phrases he has heard from his mother or other caregivers, like "It will be OK." Over the course of this developmental period, children come to rely more on words than behavior to express how they feel and to understand the feelings of others. By age three or four, toddlers and preschoolers become more accurate in their appraisal of emotions and emotion-related behaviors in others, including peers. This period is also when children develop their first friendships, which increase in importance as children reach school age. An understanding of cultural norms for emotional expression, or *emotional display rules*, becomes more engrained, and children become more aware of when to display certain emotions. Part of the normative decrease in temper tantrums by the end of this period is due to an increase in linguistic abilities, but a contributing factor is also the preschooler's recognition that these emotional displays are not appropriate for most, if any, situation. Other display rules, such as when to show excitement and when to laugh (playing games, after dad tells a joke) and when to be quiet (when mom is on the phone, at religious ceremonies or services) also become more entrenched and understood. Both emotional display rules as well as *moral beliefs*, which also begin to emerge at this time, are largely influenced by peers, caregivers and the child's larger cultural context.

Children's capacity to describe mental states and the characteristics of others also grows in accordance with increasing self-awareness and language skills. When a two- or three-year-old is asked to describe his best friend, this toddler will use the friend's name, but will rely on physical appearances, such as gender or age, or behavioral competencies to describe the friend. By contrast, children in the later preschool years will describe others by labeling the emotions, attitudes and characteristics of others. At this age, along with a description of physical traits and gender, a child might describe his best friend as someone who is "funny, and good at soccer, and comes over a lot." During this period, children also come to recognize cultural and racial differences between groups. Finally, children reach the milestone of *gender constancy*, or the idea that gender cannot be changed, and also become more aware of gender stereotyped behavior by age five or six, adhering more frequently to gender-based expectations of play and social behavior, which may vary across cultures and environmental contexts. While a three-year-old American toddler might enjoy playing house and dress-up with his female peers, by age five this preschooler might choose to play with cars or other action-oriented games with his male peers instead, adhering to gender stereotyped behavior that is common in North America. Gender constancy can also impact the way children think about their future roles in the world of work, although this varies cross-culturally. Consider a five-year-old North American boy who used to tell his

father he wanted to be a teacher. One day, the child surprises his father telling him he doesn't want to be a teacher anymore. When his father asks him about his new resolution, he simply states, "I can't—all teachers are women." In contrast, a Cameroon child of the same age might have a different experience, as in his school there are only male teachers.

Certain behavioral changes that are related to physical maturation are also important to acknowledge in the realm of behavioral development during toddlerhood and preschool ages. Between the ages of two and five, children become more competent at feeding themselves, while *toileting* oneself also typically emerges and becomes part of the child's behavioral repertoire at this time, with the majority of children reaching relative independence in this area by age four or five. While puberty, or sexual maturation, does not begin until age 11 or 12, with toddlers and preschoolers' continuing growth in self-awareness, they may become more curious about, and begin to explore themselves sexually. In the realm of normative behavior, children at this age may touch themselves, ask caregivers or peers questions about genitalia and show peers genitalia. While many parents are concerned to see their child's behavior becoming more sexualized, this behavior is normative to some extent. However, forceful or sexually coercive behavior, and knowledge or imitation of adult sexual acts is usually atypical behavior and may indicate instances of sexual abuse or overexposure. As with other developmental milestones, physical and behavioral changes during this period should be considered in the context of children's individual and contextual differences.



Click on the picture to view a short video (6:18) illustrating some of Piaget's stages of intellectual development.

Toddlerhood and preschool years at a glance

Toddlers and preschoolers show significant changes in their understanding of the self and others, evidenced by the completion of developmental milestones in the areas of mental representations, problem solving, and other cognitive skills, as well as in the areas of language, social-emotional process and behavior; this is summarized in Table A.2.2. For many cultures, the successful completion of toddler and preschool milestones indicates readiness for formal educational learning or schooling, which usually begins at age six or seven.

NORMAL DEVELOPMENT IN CHILDHOOD: AGE SIX TO 11 YEARS

Cross-culturally, the developmental periods from age six and to 11 is a time when children become more involved in the social world and learn skills for later use in adulthood, through their transition to either formal schooling or in societies without schooling, through apprenticeships related to future work or familial roles. Children become more attuned to cultural norms, rules and laws, and gradually begin to shift their focus and attention from parental relationships to social and peer-oriented activities, particularly as they reach age 11 and the beginning of adolescence.

Cognitive and linguistic milestones

Between the ages of six and 11, children make important information processing advances in the areas of attention, automatization and memory, as well as other mental operations. By about age seven, children are typically able to direct their attention toward one set of stimuli or one task while simultaneously ignoring

Table A.2.2 Developmental milestones in late toddlerhood and preschool: Age two to five years

Cognitive and linguistic milestones: Mental representation	Social-emotional and behavioral milestones: Balance between parental demands and child's need of autonomy
• *Sociodramatic play* (by age three): – Reflection of a growing capacity for mental representations (imaginary friends, etc.) – Involves and strengthens other cognitive and socio-emotional capacities (e.g., working memory, attention, reasoning, self-control, cooperation, perspective-taking, etc.) • *Dual representation* (age three or four): The recognition that a symbolic object (a photograph) is both an object and a symbol of something else (a family member) • Continuously searches for logical explanations and cause/effect relationships ("why" period) • *Cognitive scripts*: Internal models of prior behavior and experiences that guide child's behavior • Memory span grows up to four items • *Private speech:* Children talk to themselves out loud, providing themselves guidance when solving problems • Learning of early literacy and numeracy skills • Growth of child's vocabulary to about 2,000 words by age five • Grammatically complex sentences by age four or five (use of different verb tenses, etc.)	• Normative *temper tantrums*: – Appears between the ages of one and three, and decreases along with physically aggressive behavior, by ages four or five – Related to language and self-regulation skills achievement • Decreased *reactive aggression* (in response to an external event) and increased verbal and instrumental (goal-oriented) aggression • Aggressive behavior is normative during this period, but should decline by about five or six years of age • More complex behavioral and linguistic expressions of emotion (empathy and sympathy) • Development of first friendships. • Emergence of *moral beliefs* and motional display rules: cultural norms for emotional expression • Growth of children's capacity to describe mental states and characteristics of others: – By age two or three, descriptions will rely on physical attributes – By age four or five, the description will rely on the emotions, attitudes and characteristics • *Gender constancy*: Gender cannot be changed; becomes more aware of gender-stereotyped behavior at ages five or six • Physical maturation: Feeding and toileting oneself. • Sexual curiosity and self-exploration: Normative to some extent.

extraneous stimuli. Whereas a five-year-old child has great difficulty focusing on academic tasks while hearing other children talk or play outside the classroom window, by age eight or nine most children can focus on their material, or are easily redirected. This *selective attention* is necessary for critical thinking and the learning of new skills or information (Berk, 2007). Self-control also plays a role in the child's attention skills, as do societal expectations, communicated through school or other learning environments.

A father tells his two children, ages six and 10, to get ready to leave the house quickly, as they are late for the 10-year-old's soccer game. The father says, "Both of you please put on your shoes, go get your jackets, take a snack with you, and fill up your water bottles while I put the gear in the car". When the father comes back in the house, the 10-year-old is ready to go, but the six-year-old has to be reminded of several steps by his father and older brother, such as getting his snack and filling up his water bottle. "My six-year-old is really out of it," thinks the father, wondering whether his younger son has an attention or memory problem.

Although during this period of time, the child's memory capacity and skills in both storing and retrieving information increases and improves, becoming faster and more efficient, age 11 marks when the child is able to hold sequences of steps in mind and follow instructions more efficiently than in the early school years. In this example, the six-year-old has not developed the memory capacity and efficiency that his older brother has. During these years, the child can also rely on *gist-based memory*, or the basic components of what they learned or what happened (Berk, 2007). While the six-year-old may remember some parts of his brother's game, his older brother will likely come home with a more comprehensive memory; yet both children will remember the overall "gist" of what happened—that the older brother's team won the game.

Children also become aware of various skills to improve or increase memory during this period, spontaneously beginning to use cognitive rehearsal strategies like the creation of mental cues and categories, or the repeating of information to help themselves recall important tasks or processes. When he first learned the rules of soccer at age eight, the older child in our example often repeated several rules to himself during practice or after being reminded of them by his coach as a method to improve his memory. Soon, the knowledge of these rules became more automatic, as memory is involved in the process of automatization. *Automatization*, or *automaticity*, refers to the act of practicing or repeating new information and related thoughts or behaviors until these processes become more routine (Davies, 2004). Automaticity is a necessary component in learning virtually any new task or skill, such as academic tasks like reading, writing, completing mathematics operations, or other skills like learning to play soccer.

Along with gains in information processing, children between the ages of six and 11 meet many milestones in several different cognitive operations. During the preschool years, asking a child to differentiate their right and left will leave most children confused and the vast majority will not understand when a parent tells them that they have to "wait five minutes" before having a snack. Preschoolers have a limited orientation to time and spatial organization while, beginning at age six, children become more advanced in these areas. By this age a child can distinguish their own right from left and can note the right or left side of others around age seven or eight. Time and calendar dates become more meaningful after age seven, when most children can usually identify when their birthday is, and will understand when they are told to "wait five minutes" for a snack. Other mental operations include more sophistication in the seriation and categorization of objects according to specific characteristics such as shape, size, length, color, as well as increasing capacity for the processing of auditory and visual information. It is important to note than not all children classify objects in the same way across cultures. Children in many communities, especially if they have not had much schooling, might sort objects according to their function rather than according to other dimensions such as size, shape, or color. For example, children with more experience working on a family farm may classify a hoe and a potato in the same group because a hoe is used to dig a potato.

Seriation

Refers to the ability of sorting objects or situations according to characteristics such as size, color, shape, or type. This capacity is developed during the concrete operations stage, usually from seven to 12 years of age.

Problem solving and reasoning also improve during childhood as thinking becomes more organized, creative and flexible, and the capacity for *metacognition*, or "thinking about thinking" develops. As a related process, *cognitive self-regulation*, or the process of monitoring one's thoughts and actions in learning new skills

or solving problems, also occurs during this period and continues to develop during adolescence to inform more abstract problem-solving. Finally, emerging literacy and numeracy skills at age six and seven evolve and become increasingly sophisticated as the child engages in school-based academic tasks, with the child moving from learning to read in the early elementary years to using reading skills to learn new information by the end of middle childhood, at age 11.

As in other periods, cognitive development influences the degree of the child's language capacity. For example, as children make gains in their information processing skills, particularly in the areas of selective attention and memory, they are better able to learn new words, integrate these words in sentences, and adhere to grammatical structures they have learned in school or conversationally. An important linguistic milestone between the ages of six through 11 is vocabulary growth, which typically increases to an average of 10,000 words during this period. By age nine to 11, children can also understand the double meaning of some words, such as when words are used metaphorically. For example, when given a sticker at school for good behavior that says "You are a shining star!" a child during this stage will understand that they have done a good job and are being compared to the brilliance of a star.

When one child's grandparents used to call him during his toddlerhood and preschool years, the child would stare into the telephone, saying a few words at times and talking somewhat reluctantly into the speaker. Around age six, this child appeared more comfortable using the phone and began to speak even more clearly on the phone between the ages of seven and eight. Children also make important advances in their conversational skills at this time, acquiring *shading* skills, or communication skills related to gradually changing the topic of the conversation (Berk, 2007). Whereas conversations with his grandparents used to involve the child answering a series of questions, during the stage from age six to 11, this child began to spontaneously offer his grandparents new information and ask questions of them that were relevant to their conversation. However, the extent of the child's vocabulary growth and other linguistic skills during this period will depend on cognitive abilities and will additionally vary by cultural context and societal norms.

Social-emotional and behavioral milestones

Childhood is also a time to develop mastery of self and others, including self-esteem, emotional regulation, perspective taking, moral development, and peer relationships. As children begin to compare themselves to others and receive feedback from teachers or other adults, *self-esteem*, or beliefs about self-worth, begins to drop in comparison to its higher levels during the toddler and preschool years. One day after coming home from school, a 10-year-old girl remarked to her mother, "I'm not good at dance anymore…so I'm not gonna go to class today." This surprised the mother, as typically her daughter loved her afternoon dance class and always wanted to practice her routines in front of others. After some questioning about this statement, her daughter said that she saw another group of girls practicing a popular dance at recess and felt she wasn't as good as those girls based on what she saw, and based on how positively her peers reacted to this display. This 10-year-old's self-esteem was modified through her interactions in the social world, which holds more weight than in previous years.

Self-esteem during this period is increasingly based on the child's self-perceived competence or peer group status, or through identification with primary caregivers, teachers, and other youth (Schaffer & Kip, 2010). Cultural factors and gender differences influence both the development of self-esteem and the degree to which children make social comparisons to others. For example, children from Asian cultures have been found to have lower self-esteem despite higher mastery of various academic tasks. Girls in North America have also demonstrated lower levels of self-esteem during this period compared to boys.

The need for self-control increases during this developmental stage as children engage in purposeful actions that are often in larger groups (such as formal schooling). This engagement requires two important self-control skills: *delay of gratification* and *impulse control*. Whereas a very young child wants immediate gratification, between the ages of six and 11, children learn to wait for a reward, engage in activities other than play, and conform behavior to the norms of the peer group and context. In part this is facilitated by watching peers use self-control. Self-control also varies by temperament—some children are better able to control desires and impulses than others regardless of what peers do or specific reward structures.

Children between the ages of six and 11 are even more aware of gender stereotypes and roles than in previous developmental periods. Exploration of gender roles occurs during this period, with youth increasingly identifying with same-sex role models, whether peers, caregivers, relatives, teachers, or celebrities. This developing sense of gender identity can also impact self-concept and facilitate gender socialization. Although girls and boys can certainly have cross-gender friendships between the ages of six and 11, a look around an elementary school recess yard will show that groups of children are generally gender-segregated,

Sri Lankan children playing in a beach
(Photo: Dhammika Heenpella)



with girls and boys separately playing or talking together in same-gender groups. Groups of girls may stand around and socialize more frequently than engaging in a game of sports or tag, for example, while at recess, which is what many boys prefer to do while on a break during their school day. Such gender segregation has been consistently found across cultures as well.

Emotional development and regulation continues during middle childhood, both of which are facilitated by simultaneous advances in cognitive and linguistic domains. Beginning at age eight, children start to realize they can experience more than one emotion at once, and also become more adept at appraising the range and combinations of emotions in others. Although children become aware of emotions such as pride, shame, guilt, and embarrassment during the preschool years, awareness of these more complex emotions becomes more sophisticated and children change their behavioral responses to such emotions as they develop in their maturity. When a three-year-old doesn't get to play with a certain toy she wants, she may scream and cry out of frustration. Her mother may realize that the three-year-old is not only upset but is also over-tired and needs to take a nap. An 11-year-old in middle childhood may become similarly upset when she doesn't get to stay up as late as older siblings to watch a television program, but may have a better understanding that she is also tired and has to get up early for school the next day. The 11-year-old will not typically scream and cry because she isn't getting what she wants and may be able to go to bed after some discussion about this instead of arguing with her parents (although in adolescence, arguing with caregivers may be a more probable outcome).

During this period, children also learn to regulate and manage their emotions and behavioral responses through two types of adaptive coping strategies, which most children use by about age 10. Although it is unlikely that the 11-year-old in the example above will need to employ coping strategies to regulate her upset about not staying up late, this same child will likely draw upon coping skills when she finds out that she hasn't been invited to the birthday party of a popular girl at school. *Problem-focused coping* occurs when children identify if the issue they are facing is changeable or not, think about possible solutions, and then carry out their chosen solution. The 11-year-old in this case thinks about asking if she can attend the party anyway, or contemplates telling a friend who was invited to ask the birthday girl why the 11-year-old didn't receive an invitation. However, these options don't feel comfortable to the 11-year-old. When this type of problem-focused coping strategy does not work or is not applicable, children typically engage in *emotion-centered coping*, which involves the child working to manage or control distressing responses through different strategies, such as seeking social support when problems cannot be immediately solved. The 11-year-old decides to talk to another friend about the party and tell the friend how she feels; their talk about this over the phone makes the 11-year-old feel better about not receiving an invitation to the party.

Empathy is another complex emotional state that continues to develop during this period. Children become more sophisticated in their ability to think about the thoughts or emotions of others, showing increased *perspective taking* that also informs their capacity to demonstrate empathy. They can simultaneously think about their own thoughts and feelings at the same time as they appraise and empathize with the thoughts and feelings of others and, by age 10, they start to

recognize the views of an impartial third party as well. In the example above, when the 11-year-old girl calls her friend to seek support due to her being excluded from a birthday party, the friend she calls is able to empathize with her friend's distress, examine her own feelings about the party and discuss what the birthday girl is likely to be thinking and feeling by not inviting everyone to the party.

Moral development during this period is also related to the development of children's empathy, in that youth are increasingly able to integrate the perspectives of others into their worldview and sense of morality. Children's *moral views*, or sense of "wrong" versus "right," during this stage are typically rule-governed, reflecting a heightened awareness of societal or cultural norms, laws, and customs. However, children's moral development is also dependent upon immediate environmental contexts and interactions they see in their families and neighborhood, even if these differ or are deviant in comparison to larger societal/cultural laws and customs. *Normative beliefs*, or the child's beliefs about the bounds of appropriate behavior, can vary substantially based on children's exposure to aggressive or deviant behavior, with the development of normative beliefs in early childhood predicting the extent of youths' aggressive behavior during later childhood (Huesmann & Guerra, 1997).

An increased focus on rules and laws also impacts on children's peer relationships and chosen play activities between the ages of six and 11. During this period, children form friendships on the basis of trust in one another, kindness, support and a mutual enjoyment of similar hobbies or activities. Many children become involved in rule-oriented games, such as sports or activities that require planning or strategy, and children sort themselves into various peer groups during free play activities. Children at this age who behave in a prosocial and non-aggressive manner are usually more popular or socially accepted than those who are either aggressive or socially withdrawn and awkward.

Peer victimization or bullying also begins to occur more frequently during this period. Typically, bullies are socially rejected, aggressive children who physically or verbally target and attack victims who are less assertive, physically weaker, and usually socially withdrawn, or those who exhibit marked differences from peers in their physical or other characteristics. Categories of bullies and victims are not mutually exclusive as many victims can bully others and vice versa, resulting in a bully-victim category of youth who engage in both of these behaviors (Cook et al, 2010). For example, one eight-year-old boy is constantly pushing another same-aged peer around on the playground. This eight-year-old is taller and stronger than the smaller eight-year-old that he pushes around, often allowing the bullying eight-year-old to take the weaker child's money for lunch. Most of the other kids at school don't socialize with the eight-year-old bully, as he seems angry most of the time, and his behavior causes him to get in trouble frequently with the school principal. After he leaves school, the eight-year-old usually walks home through the same couple of neighborhood streets, and is almost always confronted by a bigger and stronger 11-year-old, who pushes the eight-year-old to the ground nearly every day, asking him for his lunch money. In this case, the eight-year-old who bullies on the playground is also a victim of bullying by an older child.

As children continue to physically mature, sexual curiosity and self-exploration also continues, within the bounds of age-appropriate behavior, as

Table A.2.3 Developmental milestones in childhood: Age six to 11 years

Cognitive and linguistic milestones: Gains in information processing	Social-emotional and behavioral milestones: Development of self and others mastery
• Better self-control and use of divided, focused, and *selective attention* • *Gist-based memory*: Basic components of what was learned or what happened • Better use of skills to improve or increase memory, and *automatization* • Time and spatial orientation and organization: Differentiation of right from left • *Seriation* and categorization of objects • Increasing capacity for processing auditory and visual information • Development of *metacognition*, or "thinking about thinking," and *cognitive self-regulation*, the process of monitoring one's thoughts and actions. • Emergency of more sophisticated literacy and numeric skills • Vocabulary growth: Up to 10,000 words • Understanding the double meaning of words and metaphors • Advances in conversational skills: Acquirement of *shading* skills, related to gradually changing the topic of the conversation	• Self-esteem or beliefs about self-worth: – Diminution as a result of interpersonal comparison. – Based on perceived competence or peer group status, or identification with significant adults. – Influenced by cultural factors and gender differences. • Better self-control: – Related to delay of gratification and impulse control. – Facilitated by watching peers use self-control. – Influenced by child temperament. • Greater awareness of gender stereotypes and roles: – Developing sense of *gender identity* can impact self-concept and facilitate gender socialization. – Social groups are generally gender-segregated. • Increasing emotional development, regulation, and coping: – Problem-focused coping: Based on trying to solve the problem. – Emotion-centered coping: Based on trying to manage or control distressing responses. • Progress in empathy and moral development: Due to increases in children's perspective taking abilities. • Friendships based on the trust in one another, kindness, support and mutual enjoyment of similar hobbies or activities. • Peer victimization begins to occur. • Sexual and/or romantic interests may begin to develop at this stage.

described above in the toddlerhood and preschool years' section. Although males and females at this age typically sort themselves into same-sex peer groups, sexual or romantic interests may begin to develop at this stage, although these interests become more overt with the onset of puberty, in adolescence.

Childhood at a glance

As children develop, between the ages of six and 11, they negotiate critical milestones related to their entrance into the social world, summarized in Table A.2.3. Between these ages, children work to develop a sense of mastery over academic and social domains and become more interested in and involved in their peer group. By the end of this period, the cognitive, linguistic, social-emotional, and behavioral changes youth have made prepare them for their transition to adolescence and their development of personal identity during this period.

NORMAL DEVELOPMENT IN ADOLESCENCE: AGE 12 TO 18 YEARS

Adolescence has long been thought of as a time of change across multiple domains, particularly in the physical and social-emotional realms. With pubertal

changes beginning for most children at age 11, hormonal changes impact youths' functioning and negotiation of developmental milestones in the areas of cognition and language, as well as in their social-emotional skills and behavior. Adolescence also marks a shift from a relatively equal focus on both caregivers and peers, to increased attention on the peer group. Adolescence also is a period when youth may increase in their risk-taking behavior and experimentation (Guerra & Bradshaw, 2008), and become more susceptible to peer influences. Overall, adolescence is a period that prepares youth for the transition into adulthood and the formulation of their adult identity (Erikson, 1968).

Cognitive and linguistic milestones

Cognitive milestones between the ages of 12 and 18 can be characterized by the adolescent's growing self-consciousness and *metacognition*, or increased attention to and awareness of their own thought processes. During this time, adolescents are increasingly self-focused and may also improve in their cognitive self-regulation strategies. However, due to the hormonal changes that come with the onset of puberty, despite their greater sophistication in complex reasoning and formal mental operations, adolescents may also become more impulsive and less attentive at times, and may also struggle to effectively make decisions and plan for the consequences of their behavior.

Cognitive distortions about the self also appear with adolescents' increased self-consciousness—called the *imaginary audience* and defined as a belief that they are the main focus of other people's attention (Berk, 2006). Consider this example. Before leaving the house for a family holiday party, a mother tells her 13-year-old son and 15-year-old daughter that they have to wear some of their nicest clothes, and suggests her daughter wear a new long dress and her son wear the sweater his grandmother gave him. When the family is ready to leave, the 15-year-old comes downstairs wearing a short dress and lots of makeup, which her mother asks her to remove. The 15-year-old becomes immediately upset, arguing with her mother and exclaiming that the long dress is "babyish" and that "*everyone* will notice that I'm not allowed to wear makeup!" Shaking her head, the mother instructs her daughter to go back upstairs, take off her makeup and change into the longer dress. When her 13-year-old son comes down, she is equally surprised to see he isn't wearing the sweater and wants to wear his basketball jersey instead. Her son tells her that, "*all* of the other cousins get to wear their jerseys and *all* of them will see this dumb sweater and make fun of me!" The mother wonders how her children became so self-involved; her kids never acted like this when they were younger.



Click on the picture to view a short video (12:02) on developmental theorist Eric Erikson's stages of psychosocial development.

Another common cognitive distortion of this period is the *personal fable*, a result of the imaginary audience. Thinking of themselves as the center of attention, adolescents come to believe that to be the case because they are special and unique. Thanks to this personal fable, young adolescents also believe that their feelings and emotions are different, often more intense and terrible, than those of others. It is quite common for an upset teenager to exclaim to family members that they will "*never* understand" how the teenager feels. The personal fable may also give rise to a sense of invulnerability and singularity, creating a propensity for behavioral risk-taking. For example, a 15-year-old adolescent who is experimenting with drugs and alcohol might think, "other people will get hooked on drugs but not me," or a 16-year-old girl who is engaging in high risk sexual practices can think "other

women will get pregnant or get infected with HIV, but that stuff would never happen to me."

Despite these cognitive distortions and difficulties with rational decision-making and impulsivity, teenagers become more advanced in their performance of mental operations and their information-processing skills and cognitive self-regulation improve overall. Important cognitive milestones in this regard include greater planning and problem-solving abilities, abstract thinking and reasoning, and the capacity to understand, compare, or integrate advanced theoretical perspectives.

The majority of linguistic advances in adolescence are a continuation of previous milestones, such as vocabulary growth in middle childhood, and the refinement of grammatical structures. The adolescent's vocabulary can grow to over 40,000 words by age 18, and will likely include a number of abstract terms, with adolescents mastering the syllable stress and intonation of these more difficult words (Berk, 2006). With their improvements in vocabulary and grammatical skills, by age 18 adolescents can typically read and understand adult literature. Finally, adolescents evidence skill improvement in the area of pragmatics. By age 14, adolescents will use and understand conversational nuances, such as sarcasm or irony, and by age 18, their communication patterns are increasingly patterned according to specific contextual cues or societal expectations across a variety of environmental situations.

Social-emotional and behavioral milestones

Adolescents are more self-aware and self-conscious than younger children and may engage in more frequent risk-taking or experimentation behaviors (Guerra & Bradshaw, 2008), particularly when encouraged to do so by peers. Social-emotional and behavioral development during this period are characterized by a struggle to assert one's own identity and autonomy, although often in a context that maintains dependence on caregivers for basic needs (food, clothing, finances, transportation). Over the course of adolescence, youth negotiate many milestones related to social-emotional and behavioral development, all in preparation for the transition to adulthood.

With greater self-awareness and self-discovery in adolescence comes marked fluctuation in the adolescent's self-esteem, emotional regulation, and overall identity formulation. Adolescents have increased self-esteem or an inflated sense of self-importance and uniqueness at times, but also tend to experience more frequent self-criticism, sadness and anger. The intensity of such high and low emotional experiences is linked to adolescents' hormonal changes during puberty, to their growth in metacognition and to the increase in the dimensionality of self-esteem, which now includes academic or work performance, social competencies, peer relationships and romantic relationships and appeal.

Mild to moderate variations in mood and behavior are normal and to be expected. A teenager may come home one day in a good mood after doing well on a test, act cheerfully and talk with his mom about his day. Two days later, the very same teenager may be irritable, ignore his family and refuse to talk to his mother at all, only to be very pleasant at dinner, leaving his mother completely confused. It may be that he had a fight with a girlfriend, who called to apologize before dinner, or any number of momentary disappointments.



The desire to fit in or conform to the standards of one's clique or peer group becomes more marked during early adolescence.

Unfortunately, this type of moodiness is common among adolescents, which can lead to frequent disagreements with others, most often primary caregivers. Disagreements with parents typically increase between the ages of 12 and 14, but by age 18 adolescents usually exhibit less moodiness and engage in fewer disagreements with caregivers, on average.

In terms of peer relationships, youth tend to sort themselves into selective groups or *cliques* between the ages of 12 and 18, with each clique exhibiting different group norms, attitudes and value systems. The importance of *peer group conformity* also emerges during early adolescence. The desire to fit in or conform to the standards of one's clique or peer group is more apparent in younger adolescents between the ages of 12 and 14, as these youth tend to look to the peer group for direction in their dress, choice of recreational activities and taste in various media (movies, TV, music), all of which are shorter-term behaviors and features of identity. One father is confused by his 14-year-old daughter's new tastes and clothing style; all of a sudden she dresses in all black, exactly like two of her peers, and asks repeatedly whether she can dye her hair purple. The music coming from her room sounds different than it used to and the father notices that his daughter has started to paint her nails black as well. When asked about her new taste in clothes and music, the daughter appears annoyed and tells her dad that she's becoming her "own person". Her father teases that she looks like a carbon copy of her friends and the 14-year-old becomes even more upset, telling her dad that he just doesn't understand her and that she is more "alternative" than any of her peers.

Six months later, the 14-year-old visits her older cousin and comes back wearing a new flower-print top, brightly colored jewelry, and pink nail polish. "What happened to all the black?" her father asks. The 14-year-old rolls her eyes, tells her father that "black is so over" and continues in her new style of dress for the rest of the year, which her friends soon conform to as well. However, by the age of 18, the father notices that his daughter's "style" and tastes have solidified

and fluctuate much less than earlier in adolescence. At 18, when his daughter looks back at pictures of herself in all black, she laughs and says she remembers how important it was for her to dress exactly like her friends or her older cousin.

Such peer influences, like taste in clothing or music, usually do not conflict with the adolescent's preexisting moral beliefs and attitudes, although some peer group norms may be more deviant than others. For example, aggressive youth may sort themselves into antisocial peer groups that are involved in delinquent behavior. Some adolescents may join a formal street gang, or may just hang out with other peers who enjoy similar antisocial behaviors, such as "tagging" or putting graffiti on public buildings, drinking alcohol or using drugs. These antisocial peer groups can also influence less aggressive youth that join such groups in a process called *deviancy training*, in which aggressive or delinquent peers mutually "train" or socially reinforce the development of antisocial behavior in one another or in less aggressive youth with whom they associate (Dishion et al, 1996; Poulin et al, 1999). For example, a less deviant adolescent who occasionally associates with a group of more antisocial peers, may receive social praise, physical protection from other aggressive youth, or invitations to exclusive parties after he steals his parents' alcohol to bring to his peers, all of which reinforce his developing problem behavior. *Peer pressure* to conform to peer group norms or behaviors also influences adolescents' involvement in both prosocial and antisocial behavior, depending on the nature of the peer group, although peer pressure and influence decrease somewhat in strength by age 18, when personal identity and moral beliefs become more solidified (but not yet stable).

Deficits in adolescents' rational decision-making skills and increases in impulsivity during this time can lead to greater experimentation in general problem behaviors, such as cutting school or persistent truancy, drug and alcohol use and abuse, sexual-risk taking, and acts of violence or aggression (Guerra & Bradshaw, 2008), especially when taking part in such behaviors is sanctioned by the adolescent's peer group. In the example above, the adolescent is more likely to steal alcohol from his parents to give to his friends because his peer group often drinks together. For this reason, many prevention programs occur in middle and high schools to address this universal increase in problem behavior. However, involvement in problem behaviors will depend a great deal on the adolescent's individual and group-based social and environmental differences. Bullying also continues during adolescence, although it is less physical in nature when compared to bullying in middle childhood.

A 15-year-old girl sits at her computer and starts to cry quietly, shaking her head at the screen and trying to close her web browser quickly before her older, 20-year-old sister walks over to see what is going on. The 15-year-old looks down, appears embarrassed, and finally admits that a boy she had liked posted a picture of her on a social networking site that he had taken on their first date together. Although the picture was not sexually explicit, he wrote some suggestive comments under the photo that insinuated that they had "gone all the way" together, which was not true. Another girl in the 15-year-old's peer group had commented on the post and called the 15-year-old some derogatory names, leading others to do the same, all based on the rumor that the boy's social networking post had started. This type of event is indicative of the peer victimization that can take place during adolescence: it may become sexualized in nature, may occur indirectly and is more

likely to take place while teens use the internet (called cyberbullying; Williams & Guerra, 2007).

Victimization in adolescence may also be more social or relationally focused in content, reflecting *relational* or *verbal* as opposed to *physical aggression.* Further, whereas deviant or aggressive peers were once rejected in childhood, these youth can sometimes become popular in adolescence. For example, the above situation in which an adolescent steals alcohol from his parents could lead to increased respect from others in his peer group and could increase his popularity at school. However, popular adolescents typically continue to reject highly antisocial youth, and friendship quality between youth usually depends on prosocial characteristics, like mutual trust, loyalty and support. If the adolescent stealing alcohol had also forced another adolescent to drink the alcohol until he or she passed out, the larger and more popular peer group would likely reject this adolescent and his more deviant behavior.

As adolescents work to develop their identity, they may reach a greater understanding of their own moral beliefs, and continue to improve in their perspective-taking abilities. Adolescents will also behave more in accordance with their personal value system over time, which can include religious, cultural, and other influences apart from those of the peer group, particularly as they near age 18. However, social-emotional and behavioral development does not conclude with adolescence and continues to inform identity development in early adulthood.

Table A.2.4 Developmental milestones in adolescence: Age 12 to 18 years

Cognitive and linguistic milestones: Complex reasoning and formal mental operations	Social-emotional and behavioral milestones: Assertion of one's identity and autonomy
• Improvement of information-processing skills, metacognition, and cognitive self-regulation strategies • Growth in self-consciousness and cognitive distortions • Imaginary audience: Belief that they are the main focus of other people's attention • Personal fable: Belief that one's experiences and feelings are unique from others • Difficulty with rational decision-making and impulsivity • Vocabulary growth (over 40.000 words by age 18) and refinement of grammatical structures • Progress in conversational skills.	• Frequent and intense fluctuation in self-esteem and emotional experiences linked to hormonal changes • Self-esteem increases in dimensionality: Academic or work performance, social competencies and peer relationships, romantic relationships and/or appeal, etc. • Mild to moderate variations in mood and behavior: – Normal and to be expected – Can lead to frequent disagreements with others, especially primary caregivers • Importance of *peer group conformity*: – Adaptation to the group norms, attitudes, and value systems – Possible processes of *deviancy training* and peer pressure • More likely to participate in risk behaviors: drug and alcohol use and abuse, acts of violence and aggression, bullying behavior, etc. • Peer victimization becomes more social or relationally focused in content • Friendship quality depends on prosocial characteristics such as mutual trust, loyalty, and support • Greater understanding of their own moral beliefs • Improvement in their perspective-taking abilities.

In many traditional societies, the transition from childhood or adolesence to adhulthood is usually accompanied by culture-specific rituals. Although there is great variation across cultures, there is a tendency to mark children's rupture with their previous life through various rites of passage or shifts in the individual's social behavior, which demarcate the beginning of adulthood. For example, within the Kurnai community in Australia, a boy's relationship with his mother changes considerably from the moment he is recognized as a man, as he has to give up his childhood games and take on different responsibilities. Also common to Aboriginal Australian communities is the rite of passage called a "walkabout," in which adolescent males separate from their tribe and live in the wilderness for a period of time, marking the transition to adulthood, among other shifts at this time.

Similarly, in modern societies one may find activities that resemble these rites of passage, although modern rites of passage may be markedly different in nature. For example, the numerous exams and the multiple admission tests that many adolescents have to endure in order to gain entrance to college or graduate school may constitute an initiation into adult society. In the same way, for some cultures it is common to celebrate such academic achievements through graduation parties after the adolescent completes different stages of his or her studies (such as high school). Religious ceremonies, such as the Bar or Bat Mitzah in Judaism, or the Confirmation in Catholicism, may also mark the passage from chilhood to adulthood. In Hispanic/Latino communities, the "Quinceañera," a celebration at age 15 that represents the entry of young girls into adulthood, is when girls gain certain social privileges, such as going to dances, watching more adult movies, using makeup, and having a significant other. These rites of passage and markers of the transition from adolescence to adulthood vary substantially both across and within various cultures and racial/ethnic groups. Practitioners and other healthcare providers should be aware of the culture and context in which their clients are embedded and should practice cultural sensitivity, both when examining adolescent transitions to adulthood and when considering the previous developmental stages.

Adolescence at a glance

Normal adolescent development across cognitive, linguistic, social-emotional, and behaviors domains reflects the child's increased involvement in the social world, growing sense of identity, and preparation for the transition to adulthood. Common patterns in adolescent development include the development of higher-order cognitive and linguistic skills, an initial increase in moodiness, caregiver-child conflict, and conformity with group norms, with a decrease in these behaviors by age 18. Although identity and social roles do not solidify during this stage, the milestones that occur in adolescence greatly inform later adult functioning across multiple developmental domains.

CONCLUSIONS

It is important to understand the timing and progression of normal developmental milestones throughout the periods of infancy, childhood and adolescence, and within cognitive, linguistic, social-emotional and behavioral domains. Normal development is defined as not only the absence of psychopathology, but also the negotiation of important milestones in a timely fashion. However, the definition of "normal" development must always be contextualized according

Other useful Internet resources

- Centers for Disease Control and Prevention
- University of Michigan Health System (with videos and information in Spanish)
- Child & Family Webguide – Tufts University
- Child Developmental Institute
- Palo Alto Medical Foundation (information available in English and Spanish)
- Medline Plus: Trusted Health Information for You
- National Institute Of Child Health and Human Development
- Center of the Developing Child

to the myriad of racial, ethnic, cultural and environmental differences that exist both within and across different groups of youth. For mental health professionals, this review of normal development can assist in history-taking and assessment, treatment planning and the appropriate choice of evidence-based and developmentally appropriate interventions. Although deviations from average or on-time development are not specifically discussed in this chapter, other chapters in this volume provide thorough information about the presentation of and evidence-based treatments for various physical and mental health disorders that occur in youth. The applied professional is encouraged to use the following discussions of atypical behavior as well as this chapter's review of normal development to inform future conceptualizations of youths' functioning during infancy, childhood and adolescence.

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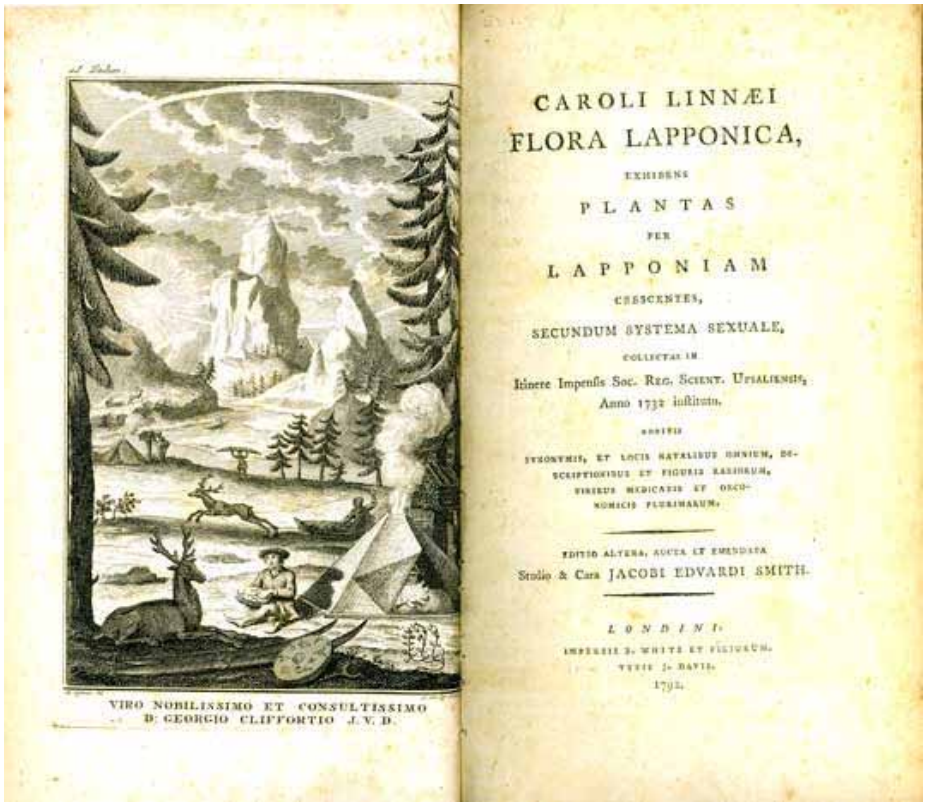
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CLINICAL MODELS FOR CHILD AND ADOLESCENT BEHAVIORAL, EMOTIONAL AND SOCIAL PROBLEMS

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Suggested citation: Achenbach TM, Ndetei DM. Clinical models for child and adolescent behavioral, emotional, and social problems. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

This chapter presents models for distinguishing among various kinds of behavioral, emotional, and social problems manifested by children. (For brevity, we use "child," "children," and "childhood" to include ages from birth through 18 years.) We use the term "models" to include official nosologies (i.e., classifications of diseases) such as the World Health Organization's (1992) *International Classification of Diseases* (ICD) and the American Psychiatric Association's (2000) *Diagnostic and Statistical Manual of Mental Disorders* (DSM). We also use "models" to include alternative nosologies, such as the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, Revised* (DC:0-3R; Zero to Three, 2005), plus empirically based models derived from data on large samples of children.

The term "model" has become widely used to designate systematic representations of phenomena. It implies that particular phenomena can be represented (i.e., modeled) in multiple ways. It also implies that different models for particular phenomena can be evaluated in terms of their utility for particular purposes, rather than requiring forced choices between one model as right versus other models as wrong. Thus, for example, a DSM model may use different terms and criteria than an ICD model for attention problems, but both may be useful for different purposes and/or in different systems of care.

Some models are designed to represent relations among particular phenomena without representing causes of the phenomena. Other models are designed to represent the causes of phenomena. At their present stage of development, the clinical models presented in this chapter do not include specific causes of behavioral, emotional, or social problems. (This chapter does not address mental retardation or disorders such as Down Syndrome, Prader Willi Syndrome, Williams Syndrome, and phenylketonuria for which genetic or other physical causal factors are well documented – see Chapter C.1.) Although genetic and other physical factors are apt to affect many behavioral, emotional, and social problems, the paucity of knowledge about specific causal pathways means that clinical models must focus on phenotypic characteristics that practitioners can identify and work with. To collaborate with practitioners in advancing our understanding of etiologies, treatment effects, and outcomes, researchers also need to use similar phenotypic models to link their work to cases seen by practitioners.

ICD AND DSM

Because the ICD-11 and DSM-5 nosologies are still being developed, we cannot be specific about the formats, categories, or criteria for these nosologies. Consequently, we must base our presentation on aspects of the existing ICD and DSM models that may continue in the pending editions as well.

The ICD and DSM models are based on inputs from committees of experts who negotiate the diagnostic categories to be used and the criteria to be specified for determining whether individuals qualify for the diagnoses modeled by each category. The experts span a broad range of clinical, administrative, public health, and research experience. Drafts of the proposed categories and criteria are widely circulated for comment and are revised on the basis of the comments. Field trials may be conducted to test the criteria. For the DSM-IV-TR child diagnostic categories that are defined mainly in terms of behavioral, emotional, and social problems (e.g.,

Emil Kraepelin (1856-1926)



The putative father of psychiatric nosology

Emil Kraepelin is credited with constructing clinical models for psychopathology that laid the foundations for psychiatric nosologies. During his medical training at the University of Leipzig in the 1870s, Kraepelin became a disciple of Wilhelm Wundt, who is regarded as the founder of experimental psychology. Using Wundt's experimental methods to study the psychological functioning of patients, he included psychological characteristics in his clinical models, and he wrote his doctoral dissertation on the place of psychology in psychiatry.

Kraepelin initially believed that careful documentation of different psychopathological phenotypes would eventually guide discovery of a particular brain disease underlying each phenotype. In 1883, Kraepelin published the very small first edition of his Compendium der Psychiatrie, which was followed over the next 43 years by eight more editions of progressively greater heft. Among other achievements, Kraepelin is credited with breaking what had been a single category of all psychoses into separate categories of manic-depressive disorders and dementia praecox (early dementia), later re-named schizophrenia. In the later editions of his Compendium, Kraepelin added psychogenic disorders, plus personality disorders that he considered to be on the border between illness and common idiosyncrasies.

As revealed in a cartoon drawn by Kraepelin, he did not take psychiatric diagnoses too seriously. Reproduced below from the Bierzeitung (Beer Newspaper) of 1896, the cartoon is captioned (in English translation) "Psychiatrists of Europe! Protect your most sacred diagnoses!" Kraepelin thus warned against becoming overly awed by diagnoses.



attention problems, conduct problems, oppositional defiant problems, anxiety, depression), the criteria include a list of symptoms and a diagnostic threshold for the number of symptoms from the list that must be judged present to justify a diagnosis (American Psychiatric Association, 2000). Additional criteria include the duration of symptoms, age of onset, and impairment. The criteria are similar for children of all ages and both genders. The criteria are also similar for information obtained from different sources, such as parent, teacher, and child reports, tests, and clinical observations. If there are inconsistencies or contradictions between different sources (e.g., a teacher reports attention problems but the parent and child do not), the practitioner must ultimately make a yes-versus-no judgment about whether each diagnostic criterion is met. The practitioner must then make a yes-versus-no judgment about whether the child qualifies for a diagnosis.

DSM dimensional diagnostic criteria

In preparation for DSM-5, the American Psychiatric Association appointed a task force to consider possibilities for "dimensional" (i.e., quantitative) diagnostic criteria. The task force has published a great deal of support for dimensionalizing criteria for many kinds of child and adult diagnoses (Helzer et al, 2008). However, it is not clear at this writing whether or how DSM-5 criteria might be dimensionalized. One possibility appears to be that criteria for clinical diagnoses will retain the yes-versus-no format of DSM-IV-TR but that separate research diagnostic criteria may include some kind of dimensionalization.

ICD-10 research diagnostic criteria

The ICD-10 *Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research* (World Health Organization, 1993) added research criteria to the criteria that were previously published for clinical diagnoses (World Health Organization, 1992). The ICD-10 research diagnostic criteria resemble DSM-IV-TR criteria in that they specify symptoms and other features that must be judged yes-versus-no. After users make yes-versus-no judgments of each criterion, they must make a yes-versus-no judgment of whether a child qualifies for a particular diagnosis.

Differences between ICD-10 and DSM clinical diagnostic criteria

The ICD-10 clinical diagnostic criteria (World Health Organization, 1992) differ from DSM-IV-TR criteria in that they lack explicit statements of specific symptoms, other features, and decision rules for making yes-versus-no judgments to decide whether a child qualifies for a particular diagnosis. The ICD-10 and DSM-IV-TR also differ considerably in their descriptions of diagnostic categories and in some of the categories themselves. For example, the ICD-10 has diagnostic categories for sibling rivalry disorder, hyperkinetic conduct disorder, and disinhibited attachment disorder that lack counterparts in the DSM-IV-TR.

ICD-10 differs from DSM-IV in that ICD-10 lacks explicit statements of specific symptoms, other features, and decision rules for making yes-versus-no judgments to decide whether a child qualifies for a particular diagnosis.

The ICD-10 and DSM-IV-TR additionally differ in their subdivisions of certain diagnostic categories. For example, DSM-IV-TR divides its category for attention deficit hyperactivity disorder (ADHD) into predominantly inattentive type, predominantly hyperactive-impulsive type, and combined type. By contrast, the ICD-10 category most similar to ADHD is designated as hyperkinetic disorder, which is not subdivided into categories like those of the DSM-IV-TR. On the other hand, the ICD-10 subdivides conduct disorder into conduct disorder confined to the family context, unsocialized conduct disorder, and socialized conduct disorder.

Although the DSM-IV-TR Appendix H lists ICD-10 code numbers for many DSM diagnostic categories, practitioners should not expect much agreement between particular DSM diagnoses and ICD diagnoses made for the same children, even when the DSM and ICD diagnoses have the same code numbers.



Click on the picture to access the DSM-5 website that gives details of proposed changes to the classification and their rationale.

DIAGNOSTIC CLASSIFICATION FOR INFANCY AND EARLY CHILDHOOD

The *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* (DC:0-3) was first published in 1994, followed by a revised edition (DC:0-3R) in 2005 (Zero to Three, 1994, 2005). A key purpose was to respond "to the failure of the DSM system to include (1) sufficient coverage of syndromes of early childhood that needed clinical attention or (2) sufficient consideration of developmental features of early disorders" (Zero to Three, 2005, p 4). Like the DSM and ICD, the DC:0-3 was developed by having experts negotiate diagnostic categories and criteria.

DC:0-3R Axes

The DC:0-3R includes the following five axes:

I. Clinical disorders
II. Relationship classification
III. Medical and developmental disorders and conditions
IV. Psychosocial stressors
V. Emotional and social functioning.

Some of the Axis I clinical disorders, such as *posttraumatic stress disorder*, *separation anxiety disorder*, and *generalized anxiety disorder*, have counterparts in DSM-IV-TR. However, as they are designed for ages 0-3, the DC:0-3R criteria are quite different from DSM-IV-TR criteria and are illustrated with clinical examples for ages 0-3. Other DC:0-3R disorders do not have clear counterparts in DSM-IV-TR. Examples include *deprivation/maltreatment disorder*, which "occurs in the context of deprivation or maltreatment" (p 17); *prolonged bereavement/grief reaction*; *mixed disorder of emotional expressiveness*, "characterized by a child's difficulty in expressing a developmentally appropriate range and intensity of emotions over at least a 2-week period" (p 27); and *hypersensitive*, referring to hypersensitivity to sensory stimuli. A diagnostic category designated as *multisystem developmental disorder* is designed for children less than 2 years old who manifest problems like those specified for pervasive developmental disorder in the DSM-IV-TR.

DC:0-3 was developed to respond to the DSM system not including sufficient coverage of syndromes of early childhood and of their developmental features.

The DC:0-3R Axis II *Relationship Classification* has no counterpart in DSM-IV-TR, but is considered to be especially important for young children. As a basis for classifying relationships, the DC:0-3R provides the 100-point Parent-Infant Relationship Global Assessment Scale (PIR-GAS), on which clinicians rate parent-infant relationships. PIR-GAS ratings of 81-100 indicate *adapted relationships*, ratings of 41-80 indicate *features of a disordered relationship*, and ratings of 0-40 indicate a *disordered relationship*. The DC:0-3R also provides the Relationship Problems Checklist for clinicians to rate the following qualities of parent-infant relationships: overinvolved, underinvolved, anxious/tense, angry/hostile, verbally abusive, physically abusive, and sexually abusive. For each of these qualities, clinicians are to indicate whether there is no evidence, some evidence needing

further investigation, or substantial evidence, based on their judgments of the behavioral quality of interaction, affective tone, and psychological involvement.

The DC:0-3R Axis V *Emotional and Social Functioning* might be considered somewhat analogous to the DSM-IV-TR Axis V Global Assessment of Functioning. However, the DSM-IV-TR Axis V is assessed with a single 100-point scale for rating psychological, social, and occupational functioning. By contrast, the DC:0-3R Axis V comprises clinicians' 6-point ratings of the following capacities for emotional and social functioning (p. 62):

- Attention and regulation
- Forming relationships/mutual engagement
- Intentional two-way communication
- Complex gestures and problem solving
- Use of symbols to express thoughts/feelings
- Connecting symbols logically/abstract thinking

The DC:0-3R Axis III *Medical and Developmental Disorders and Conditions* and Axis IV. Psychosocial Stressors are roughly analogous to the DSM-IV-TR Axis III General Medical Conditions and Axis IV Psychosocial and Environmental Problems, although the content and clinical examples for the DC:0-3R axes are specific to ages 0-3.

For practitioners who work with infants and young children, the DC:0-3R certainly touches on many more relevant aspects of functioning, problems, and issues than the ICD or DSM-IV-TR. However, proper use of the DC:0-3R's five axes requires extensive training of practitioners, as well as extensive interactions with each child and its caregivers under multiple conditions. Further research is needed to determine how to train practitioners to use the DC:0-3R with adequate reliability, validity, and utility.

GAPS BETWEEN NOSOLOGICAL MODELS AND CLINICAL ASSESSMENT

The ICD, DSM, and DC:0-3R nosologies are intended to embody concepts of disorders distilled from inputs by many experts. Except for use of standardized cognitive tests to determine whether children meet diagnostic criteria for mental retardation or learning disorders, the nosologies do not specify clinical assessment procedures on which to base judgments of each criterion for making diagnoses of particular disorders. As an example, the DSM-IV-TR criteria for ADHD list nine symptoms of inattention (e.g., "is often forgetful in daily activities") and nine symptoms of hyperactivity-impulsivity (e.g., "often talks excessively"). For a child to meet the overall diagnostic criterion for ADHD, the practitioner must decide that at least 6 of the 9 symptoms from at least one list "have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level." The practitioner must also decide that some symptoms caused impairment before the child was 7 years old, that the symptoms currently cause impairment in at least two settings (e.g., home and school), and that there is clear evidence "of clinically significant impairment in social, academic, or occupational functioning" (American Psychiatric Association, 2000, pp92-93).

To diagnose children, practitioners must decide what information to obtain for making yes-versus-no judgments of each criterion for all disorders that the



Uniformed letter carrier with child in mailbag (c 1900)

This postman posed for a humorous photograph with a young boy in his mailbag. After parcel post service was introduced in the US in 1913, at least two children were sent by the service. With stamps attached to their clothing, the children rode with railway and city carriers to their destination. The Postmaster General quickly issued a regulation forbidding the sending of children in the mail after hearing of those examples (National Postal Museum, US)

children might have, how to obtain the information, and from whom. In most cases, practitioners would want to interview the child and at least one parent figure. However, interview time is precious and is seldom sufficient to assess all potentially relevant symptom criteria. For each ADHD symptom that they report to the practitioner, children and parents may not be able to accurately say whether the symptom caused impairment before age 7 and whether it currently causes impairment in at least two settings.

If a child attends school, the practitioner would typically want to obtain information from the child's teacher(s) to provide a picture of the child's functioning in school. In fact, to judge whether the child meets criteria for ADHD, the practitioner typically needs to know whether at least 6 of the 9 symptoms from one or both lists cause impairment in the school setting. Because teachers often instigate referrals for help and because many child problems interfere with functioning in school, teachers' input can be valuable in multiple ways, in addition to being needed to judge whether particular symptoms cause impairment in school. Because practitioners are seldom able to interview teachers, other methods are needed to obtain information from them.

Whatever the assessment methods, reports by parents, teachers, and children often differ with respect to criteria required for diagnoses (De Los Reyes, 2011). Consequently, practitioners may find it hard to make yes-versus-no diagnostic judgments on the basis of conflicting information from different sources. Practitioners may also be handicapped by the failure of nosologies to

specify procedures for assessing behavioral, emotional, and social problems in different settings and by gaps between what parents, teachers, and children are able to report versus the diagnostic requirements for yes-versus-no judgments. Practitioners therefore need practical methods for assessing children's problems in multiple settings and for dealing with discrepancies between different sources of information.

Standardized diagnostic interviews

Various standardized diagnostic interviews (SDIs) have been developed to obtain assessment data from informants in order to determine whether criteria for diagnoses are met. Parallel versions of several SDIs are available for administration to children and their parents, although agreement between diagnoses made from child and parent interviews is typically low.

Among the SDIs for diagnosing children, the *Diagnostic Interview Schedule for Children* (DISC; Shaffer et al, 2000) is perhaps the most widely used. The DISC is highly structured. This means that it comprises narrowly focused questions for obtaining yes-versus-no answers as to whether each DSM diagnostic criterion is met. Because the respondent's yes-versus-no answers are the basis for determining whether each criterion is met, highly structured SDIs like the DISC are called "respondent-based" interviews. Neither clinical skills nor clinical judgments are needed to administer the DISC. However, intensive training is needed to learn how to ask the questions properly, to record the answers, and to respond flexibly when answers cannot be clearly coded as yes-versus-no. To cover all the criteria for symptoms, impairment, occurrence in multiple settings, duration, age of onset, etc. for all the DSM diagnoses relevant to children, the DISC contains thousands of questions. There are "skip-out" options for skipping questions for some diagnoses if it appears that a child will not meet criteria for those diagnoses. However, administration of the DISC usually takes at least an hour for each informant (e.g., each parent and child) and may take several hours for interviews regarding clinically referred children who have many problems.

In addition to respondent-based SDIs like the DISC, a second type of SDI is known as "interviewer-based." These SDIs must be administered by clinically trained interviewers who can phrase the SDI's semistructured questions in ways that are appropriate for each interviewee. The interviewers must also be trained to judge the interviewee's responses as indicating whether the child does or does not meet each criterion for each diagnosis. The most widely used interviewer-based SDI is the *Kiddie Schedule for Affective Disorders and Schizophrenia* (K-SADS; Kaufman et al, 1997).

A third type of SDI combines aspects of respondent-based and interviewer-based SDIs. An example is the *Development and Well-being Assessment* (DAWBA; Goodman et al, 2000). The DAWBA includes structured interviews for administration to parents and 11- to 16-year-olds. The DAWBA's interviews include some open-ended questions for following up on the interviewees' responses to the structured questions. A brief questionnaire is used to obtain data from teachers. The data from parents, teachers, and youths are brought together by a computer program that generates likely diagnoses. Experienced clinical raters then view the computer output and decide whether to accept or overturn the computer-generated diagnoses.

Relations between standardized diagnostic interviews and clinical diagnoses

SDIs are now widely used in research on both child and adult disorders. Consequently, many published findings about associations between diagnoses and other characteristics are based on diagnoses made with SDIs. However, owing to the cost and time required to train interviewers and to administer SDIs, they are seldom used in clinical practice. We must therefore ask, would children receiving particular diagnoses from SDIs receive the same diagnoses from clinical evaluations? To answer this question, a meta-analysis was performed on data from 38 studies that reported agreement between diagnoses made from SDIs and from clinical evaluations of the same patients (Rettew et al, 2009). Agreement was expressed in terms of the percentage of cases that received the same diagnoses from SDIs and from clinical evaluations. The *kappa* statistic (Cohen, 1960) was used to correct for chance agreement. The agreement between children's SDI diagnoses and their diagnoses made from clinical evaluations averaged 39%, after correction for chance. In other words, SDIs and clinical evaluations yielded the same diagnoses for 39% of children but different diagnoses for 61% of children. The agreement percentages varied considerably among diagnoses, with a low of 19% for generalized anxiety disorder and a high of 86% for anorexia nervosa (to obtain large enough numbers, data for children and adults were combined when computing these percentages). For some disorders, such as anorexia nervosa, the high agreement indicates that findings with SDI diagnoses can be applied to clinical diagnoses. However, the low agreement for other diagnoses, such as generalized anxiety disorder, indicates that findings with SDIs cannot be applied to clinical diagnoses.

Because various SDIs have been used to obtain the diagnoses reported in published studies, we also need to ask whether each child would receive the same diagnoses from different SDIs. Surprisingly little research has been published on this important question. In what may be the only published study of agreement between child diagnoses made from the most widely used SDIs, only 3% of the diagnoses made from DISC interviews of children and their parents agreed with diagnoses made from K-SADS interviews of the same children and their parents (Cohen et al, 1987). Thus, for many children, we cannot expect different SDIs to yield the same diagnoses nor can we expect SDIs to yield the same diagnoses as clinical evaluations.

Instruments for rating children's problems

To help practitioners obtain information from parents, teachers, and children, various standardized rating instruments have been developed. Many of these instruments are designed to be self-administered by people who can read, but they can also be administered by lay interviewers who read the items aloud and enter the respondent's answers on a rating form or computer keyboard. If a practitioner looks at the results of rating instruments completed by one or more parent figures, the practitioner can then tailor precious interview time to focus on problem areas revealed by the results and on issues not tapped by rating instruments. By using instruments that provide parallel forms completed by parent figures, teachers, and the child, the practitioner can compare results to identify agreements and discrepancies. The practitioner can then use interviews and other means to investigate further. The use of parallel rating instruments completed by parents, teachers, and children enables practitioners to obtain and compare a great

deal of information from multiple informants at little cost in practitioner time. Rating instruments are also available for completion by people who provide day care for young children, observers who rate children's behavior in group settings such as classrooms, and practitioners who administer clinical interviews and/or standardized ability tests (Achenbach, 2009).

The items of some rating instruments are intended to approximate the symptom criteria embodied in official nosologies. An example is the *ADHD Rating Scale* (DuPaul et al, 1998), which has 18 items approximating the nine inattention and nine hyperactivity-impulsivity symptom criteria for DSM-IV-TR ADHD. Unlike the DSM-IV-TR criteria, however, each ADHD Rating Scale item is rated *0 = Never or rarely, 1 = Sometimes, 2 = Often,* or *3 = Very often*. The ratings are summed to yield separate scores for scales comprising the inattention and hyperactivity-impulsivity items. Clinical cutpoints have been established on distributions of scale scores obtained from parents' and teachers' ratings of samples of children in the US. Thus, although the items approximate the DSM-IV-TR symptom criteria, the raters are not required to make yes-versus-no responses and practitioners can see how scale scores compare with normative distributions of scale scores and with cutpoints on those distributions of scale scores.

Other rating instruments also focus mainly on a particular diagnostic category such as ADHD but include additional problems as well, e.g., the *Conners Rating Scales-Revised* (CRS-R; Conners, 2001). Still other rating instruments include more diverse items that are scored on scales constructed by a combination of statistical analyses and the authors' decisions about which items to assign to particular scales. The *Strengths and Difficulties Questionnaire* (SDQ; Goodman, 1997), for example, has 25 items, which are scored on five scales constructed by the author. The *Behavior Assessment System for Children-2* (BASC-2; Reynolds & Kamphaus, 2004) is a much longer instrument that is scored on numerous scales based on a combination of statistical analyses and the authors' decisions about which items to assign to particular scales. Instruments such as the ADHD Rating Scale, CRS-R, SDQ, and BASC-2 are useful for obtaining informants' ratings of various kinds of problems, but they do not close the gaps between clinical assessment and nosological models any more than SDIs do.

CLINICAL MODELS DERIVED FROM RATINGS OF CHILDREN'S PROBLEMS

The nosological models have been constructed largely via "top-down" procedures. In other words, construction of the nosological models has started "at the top" with diagnostic categories proposed by experts. For each category, the experts have then proposed criteria for determining whether a child's problems fit the category. Although input from other experts and from field trials has been used to adjust some criteria, the diagnostic categories and criteria have not been derived from data on actual samples of children. Furthermore, the diagnostic criteria are the same for boys and girls, all ages, all sources of information, and all societies.

Just as multiple nosological models may co-exist, so too, alternative kinds of models may co-exist with nosological models. One alternative has involved using "bottom-up" procedures to derive clinical models from ratings of many children. This has been done by having parents, teachers, and children rate diverse problems

as *0 = Not true, 1 = Somewhat or sometimes true,* and *2 = Very true or often true* for thousands of children referred for mental health services and thousands of children sampled from general populations (Achenbach & Rescorla, 2000; 2001). The items were iteratively selected and refined on the basis of input from practitioners in fields related to mental health, from research on problems reported for children referred for mental health services, and from analyses of ratings and suggestions provided by parents, teachers, and children on successive pilot editions of the rating instruments. Rather than being selected on the basis of experts' diagnostic concepts, the final sets of items have been selected on the basis of their ability to discriminate significantly between children who were referred for mental health or special education services versus demographically similar children who were not referred for services. Important criteria for retention of problem items were that (a) they could be understood and rated by parents, teachers, and/or children, and (b) they were rated significantly higher for referred children than for demographically similar non-referred children.

Although many of the items have counterparts among the nosological criteria, other items were also found to discriminate between referred and non-referred children even though they were not among the nosological criteria. Equally important, the items were worded so that parents, teachers, and children could rate them, rather than being worded in terms of nosological criteria that parents, teachers, and children may not understand. The final versions of the rating instruments can be completed in about 15 minutes and include assessments of competencies as well as problems. The instruments include the *Child Behavior Checklist* for ages 1½-5 and 6-18, the *Caregiver-Teacher Report Form* for ages 1½-5, the *Teacher's Report Form* for ages 6-18, and the *Youth Self-Report* for ages 11-18 (Achenbach & Rescorla, 2000; 2001).

Syndrome models

After the rating instruments were developed, ratings of thousands of children were statistically analyzed to identify actual patterns (i.e., syndromes) of problems that tend to occur together. The syndromes were given names that summarize their constituent problems. For ages 6-18, the syndromes are designated as *Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints* (without known medical cause), *Social Problems, Thought Problems, Attention Problems, Rule-Breaking Behavior,* and *Aggressive Behavior.* Counterparts of several of these syndromes were found for ages 1½-5, but syndromes designated as *Emotionally Reactive* and *Sleep Problems* were also found. Children's scores on each syndrome are computed by summing the 0-1-2 ratings of the syndrome's items. To make it easy for practitioners to compare a child to non-referred peers, the syndrome scores are displayed on profiles in relation to norms for the child's age and gender, the type of informant (parent, teacher, self), and the relevant society (explained later).

Additional statistical analyses have identified associations among subsets of the syndromes that are designated as *Internalizing* (anxiety, depression, social withdrawal, somatic complaints) and *Externalizing* (rule-breaking and aggressive behavior). Scores for Internalizing and Externalizing are computed by summing the 0-1-2 ratings of the items comprising these broad groupings. A *Total Problems* score is also computed by summing the 0-1-2 ratings of all the problem items on a form. Scores for Internalizing, Externalizing, and Total Problems are displayed on

profiles in relation to norms for the child's age and gender, the type of informant, and the relevant society.

DSM-oriented scales

The items of the rating instruments were selected through bottom-up procedures that started with ratings of children rather than top-down procedures that started with diagnostic categories. Nevertheless, some of the problem items have counterparts among diagnostic criteria and some of the statistically identified syndromes comprise problems like those of certain diagnostic categories. For example, the Attention Problems syndrome includes many problem items analogous to the symptom criteria for ADHD. Furthermore, significant associations have been found between certain diagnoses and high scores on certain syndromes (Achenbach & Rescorla, 2001).

In order to help practitioners see relations between diagnostic categories and the data obtained with the rating instruments, expert psychiatrists and psychologists from many cultures were asked to identify rating instrument items that they considered to be very consistent with DSM-IV-TR diagnostic categories. The items identified by large majorities of experts for particular diagnostic categories were then grouped into DSM-oriented scales corresponding to the diagnostic categories. For ages 6-18, the DSM-oriented scales are designated as *Affective Problems, Anxiety Problems, Somatic Problems, Attention Deficit Hyperactivity Problems, Oppositional Defiant Problems,* and *Conduct Problems.* For ages 1½-5, the experts' judgments yielded several DSM-oriented scales analogous to those for ages 6-18, but also a scale designated as *Pervasive Developmental Problems* (Achenbach & Rescorla, 2000). This scale has been found to identify children diagnosed as having autism spectrum disorders (Muratori et al, 2011; Sikora et al, 2008). A child's score on each DSM-oriented scale is computed by summing the 0-1-2 ratings of the problem items comprising the scale. To enable practitioners to compare the child's scores with scores for non-referred peers, the scale scores are displayed on profiles in relation to scores for the child's age and gender, the type of informant, and the relevant society, as illustrated in Figure A.3.1 for self-ratings by 16-year-old Richard (not his real name). The DSM-oriented scales, the syndrome scales, and their respective profiles thus provide alternative models for understanding and using informants' ratings of children's behavioral, emotional, and social problems on the same rating instruments.

Cross-informant comparisons

Because parents, teachers, and children are aware of different aspects of children's functioning, discrepancies are often found between the problems reported by different informants. When discrepancies are found, it is tempting to conclude that one informant is right while another is wrong. However, different informants may provide useful information about differences in how a child functions in different contexts and with different people. Discrepancies between informants' reports may also reflect differences between the informants' perceptions and evaluations of children's functioning. These differences need to be considered when deciding whether a child needs mental health services, what kind of services, and how parents, teachers, and the child may participate in the services.

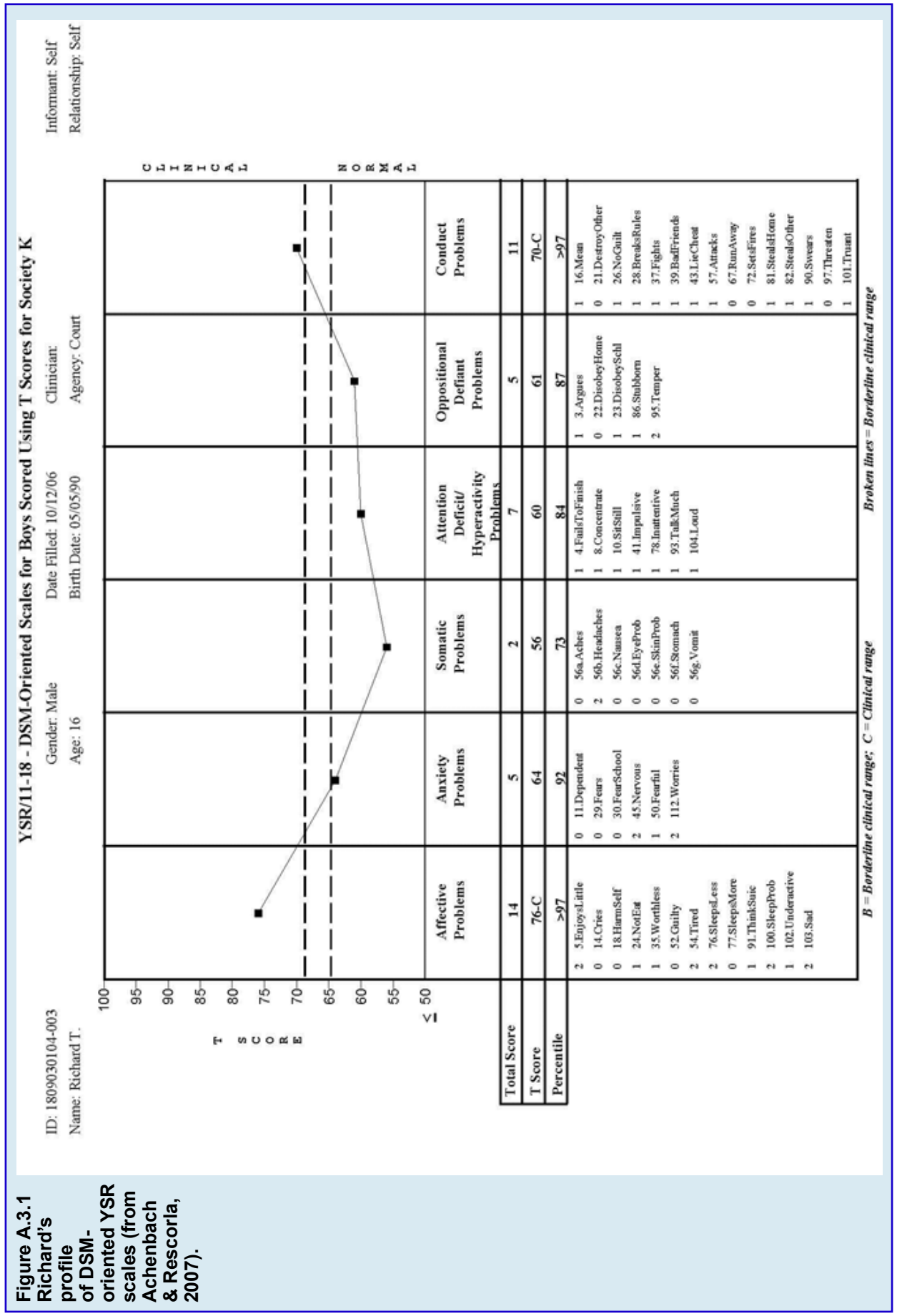
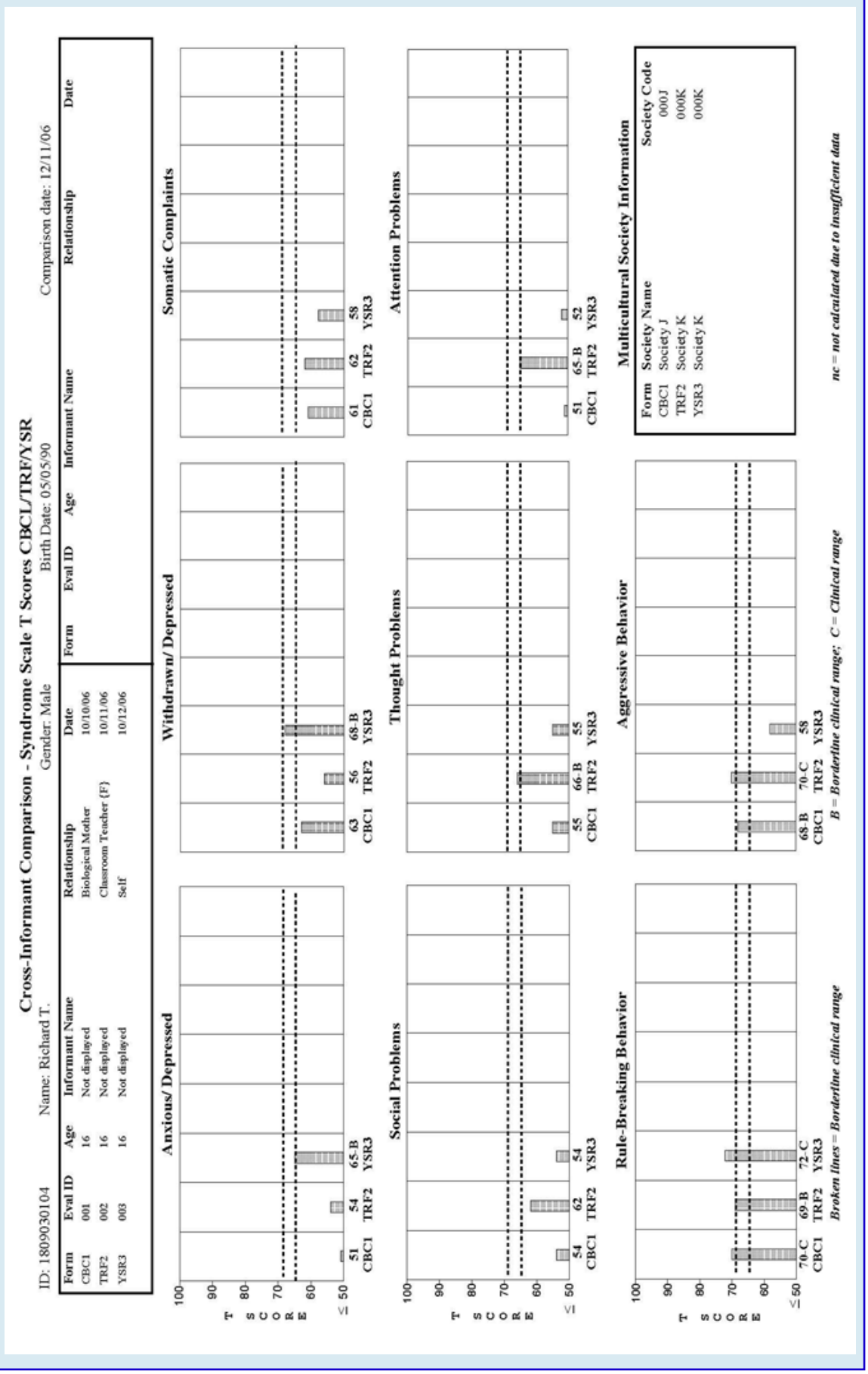


Figure A.3.1 Richard's profile of DSM-oriented YSR scales (from Achenbach & Rescorla, 2007).

Figure A.3.2 Cross-informant comparisons of Richard's scores on syndrome scales in relation to Society J norms for the CBCL and Society K norms for the TRF and YSR (from Achenbach & Rescorla, 2007).



To make it easy for practitioners to detect similarities and discrepancies between problems reported by parents, teachers, and children, the computer software for using the rating instruments produces side-by-side displays of the 0-1-2 ratings of each problem item by any combination of up to eight informants. The side-by-side displays of item ratings enable the practitioner to quickly identify problems that are endorsed by all informants, problems that are not endorsed by any informants, and problems that are endorsed by some informants. As an example, if certain problems are endorsed only by teachers, this would suggest that these problems are specific to the school context. On the other hand, if certain problems are endorsed only by parents, this would suggest that these problems are specific to the family context.

In addition to the side-by-side displays of problem ratings, the computer software also displays bar graphs of syndromes and DSM-oriented scales scored from each informant's ratings. As an example, Figure A.3.2 shows the bar graphs of DSM-oriented scales scored from ratings of 16-year-old Richard by his mother, teacher, and Richard himself. By looking at the bar graphs, the practitioner can quickly see whether any scores are in the borderline clinical range (between the two broken lines) or in the clinical range (above the top broken line). The practitioner can also see whether there are important differences between scores obtained from different informants.

Multicultural applications

The ICD, DSM, and DC:0-3R models have not been extensively tested outside a handful of societies. Consequently, much remains to be learned about how well their symptom criteria, diagnostic thresholds (i.e., the number of symptoms required for diagnoses), and other features apply to children from the many societies where the nosological models have not been tested. As significant changes are likely in ICD-11 and DSM-5, it is to be hoped that drafts of the new criteria will be subjected to multicultural tests before the criteria are finalized.



Click on the picture to access the ASEBA website.

Meanwhile, clinical models derived from data on problems rated for ages 1½-18 have been tested in 47 societies, and translations of the rating instruments are available in the 86 languages listed in Table A.3.1. The syndrome models were tested by statistically analyzing ratings of tens of thousands of children by their parents, teachers, daycare providers, and—for ages 11-18—the children themselves (Achenbach & Rescorla, 2012). Nearly all of the analyses supported the syndrome models that were originally derived from ratings of Anglophone children from Australia, Jamaica, the UK, and the US. The findings mean that the patterns of co-occurring problems embodied in the syndromes scored from the parent, teacher, and self-rating instruments were also found in the other societies.

To provide norms appropriate for children in the 47 societies, distributions of Total Problems scores were compared for the samples of children from all the societies. Based on these comparisons, societies with relatively low, medium, or high problem scores were identified. To enable practitioners to compare a child's scores with scores obtained by peers in the appropriate society, norms have been constructed for low-scoring, medium-scoring, and high-scoring societies. The three sets of multicultural norms are available in computer-scoring software that enables practitioners to display a child's syndrome, DSM-oriented, Internalizing,

Table A.3.1 Translations of the Achenbach System of Empirically Based Assessment (ASEBA) forms[a]

Afaan Oromo (Ethiopia)	Georgian	Portuguese (Brazil)
Afrikaans	German	Portuguese (Portugal)
Albanian (Albania, Kosovo)	Greek	Portuguese Creole
American Sign Language	Gujarati (India)	Punjabi (India)
Amharic (Ethiopia)	Haitian Creole	Romanian
Arabic	Hebrew	Russian
Armenian	Hindi	Samoan
Auslan (Australian Sign Language)	Hungarian	Sepedi (Northern Sotho, South Africa)
Bahasa (Indonesia)	Icelandic	Serbian
Bahasa (Malaysia)	Italian	Sesotho (Southern Sotho, South Africa)
Bangla (Bangladesh)	Japanese	Sinhala (Sri Lanka)
Bengali	Kannada (India)	Slovak
Bosnian	Khmer (Cambodia)	Slovenian
Braille	Kiembu (Kenya)	Somali
British Sign Language	Kiswahili (Kenya)	Spanish (Castilian)
Bulgarian	Korean	Spanish (Latino)
Catalan (Spain)	Laotian	Swedish
Chinese	Latvian	Tagalog (Philippines)
Croatian	Lithuanian	Tamil (India)
Czech	Macedonian	Telugu (India)
Danish	Malay	Thai
Dutch (Netherlands, Flanders)	Malayalam (India)	Tibetan
Estonian	Maltese	Turkish
Farsi (Persian, Iran)	Marathi (India)	Ukrainian
Finnish	Nepalese	Urdu (India, Pakistan)
French (Belgian)	Norwegian	Vietnamese
French (Parisian)	Papiamentu (Curacao)	Visayan (Philippines)
French (Quebecois)	Pashto (Afghanistan, Pakistan)	Xhosa (South Africa)
Ga (Ghana)	Polish	Zulu

[a]Languages into which at least one ASEBA form has been translated (from Achenbach & Rescorla, 2012).

Externalizing, and Total Problems scores in relation to norms for the appropriate society, as well as for the child's age and gender and the type of informant.

OVERVIEW OF CLINICAL MODELS

We have outlined several models for distinguishing among various kinds of behavioral, emotional, and social problems. At this stage of mental health science, no single model can be regarded as totally correct, with the others being regarded as wrong. Instead, the different models may have different strengths and weaknesses for different purposes. Consequently, for the foreseeable future, it may be helpful to think in terms of multiple models for guiding the collection and use of clinical data for evidence-based practice.

The ICD and DSM models for childhood behavioral, emotional, and social problems are components of nosologies that cover many kinds of problems across the lifespan. Like the models for other age groups, the models for children's problems comprise diagnostic categories proposed by experts who then specify criteria for determining which categories a child's problems match. The criteria require the same yes-versus-no judgments for children of both genders, different ages, and different cultural backgrounds, as well as for data obtained from different sources. In evaluating DSM-IV and ICD-10, the world's most famous child psychiatrist, Sir Michael Rutter (2011), concluded that "there are far too many diagnoses, and a ridiculously high rate of supposed comorbidity" (p. 647), and that "the use of dimensions could reduce the extent of misleading supposed comorbidity" (p. 655).

> "*There are far too many diagnoses, and a ridiculously high rate of supposed comorbidity*."
> "*The use of dimensions could reduce the extent of misleading supposed comorbidity*."
>
> Sir Michael Rutter (2011, p 655)

Like the ICD and DSM, the DC:0-3R is a nosology whose categories were proposed by experts who then specified criteria for determining which categories a child's problems match. Unlike the ICD and DSM, however, the DC:0-3R was designed to provide better coverage of early childhood syndromes and developmental features. Also unlike the ICD and the DSM, the DC:0-3R provides rating scales for parent-infant relationships, which are regarded as especially important for understanding the problems of very young children.

The failure of the ICD and DSM to specify procedures for assessing behavioral, emotional, and social problems has spurred the development of various SDIs. In recognition of the need for data from parents as well as from the child, SDIs designed for diagnosing children include interviews for parents. Some SDIs also provide questionnaires for teachers. However, differences between parent, teacher, and child reports make it hard to draw yes-versus-no conclusions about each diagnostic criterion.

As SDIs are widely used to make diagnoses for research purposes, many publications report findings for diagnoses made with SDIs. However, the extensive training and large blocks of time needed to administer SDIs limit their use in clinical practice. Consequently, it must be asked whether research findings for diagnoses made from SDIs can be applied to diagnoses made from clinical evaluations. Meta-analyses indicate good agreement between certain diagnoses—such as anorexia nervosa—made from SDIs and clinical evaluations, but poor agreement for some

common diagnoses, such as generalized anxiety disorder. Across all diagnoses in the meta-analyses, SDIs and clinical evaluations yielded the same diagnoses for 39% of the child patients but different diagnoses for 61%, after correction for chance.

In addition to SDIs that yield yes-versus-no judgments about diagnostic criteria, various instruments have been developed for rating children's problems. Some rating instruments comprise items approximating the symptom criteria for a particular diagnostic category, such as ADHD. Other instruments include more diverse items that may approximate certain diagnostic criteria but do not include one-to-one counterparts of diagnostic categories.

Another approach to constructing clinical models is by working from the bottom-up by starting with informants' ratings of diverse problem items for thousands of children. The ratings are then analyzed statistically to identify syndromes of co-occurring problems. For use in clinical evaluations, children's syndrome scores are computed by summing the ratings of the items comprising each syndrome. To enable practitioners to determine whether scores are in the normal range, borderline clinical range, or clinical range, the syndrome scales are displayed on profiles in relation to norms for the child's age and gender, as well as for the type of informant, such as parents, teachers, and children themselves. To take account of differences between problems reported for children in different societies, the practitioner can select norms based on multicultural data from many societies. And to help the practitioner make cross-informant comparisons, item and scale scores from multiple informants can be displayed side-by-side. The scale scores from each informant are standardized for the child's age and gender, the type of informant, and the multicultural norm group selected by the practitioner.

Pediatric clinic in Kenya



An 8-year-old Kenyan boy was brought to a local medical clinic by his mother. About 2 years earlier, she had noticed that he seemed very restless and that other children refused to play with him. He was very distractible and had to be supervised carefully. Home helpers employed by the mother often quit because they could not put up with him. He sustained a variety of injuries, including bruises, fractures, and burns. His teachers complained that he was very careless, had poor handwriting, and did not complete his work. He blurted out answers when it was not his turn and was very disruptive in class. Although he appeared bright, he was easily distracted and was quarrelsome during playtime, wanting to be in the center of all the children's activities. He lost important school items, prompting his mother to visit the school often in order to look for lost property and to attend disciplinary meetings.

To provide model-based assessment data, the mother was asked to complete the Conners Parent Rating Scale (CPRS). Based on elevated scores on multiple CPRS problem scales, the mother's interview reports, and a brief session with the boy, the clinic pediatrician recommended that the boy be seen by a psychiatrist for a more extensive evaluation than the local medical clinic could provide.

When the psychiatrist evaluated him, he noted that the boy was well-groomed but that he had multiple bruises at different stages of healing. The bruises appeared to be the results of falls and bumping into objects rather than having been inflicted by other people, however, he said that he was often punished at home because of his behavior and asked the doctor to talk to his parents about these punishments. A mental status examination revealed he was well-oriented in time and place, his memory was good, and there was no evidence of perceptual disturbances. However, he was easily distracted and made many inappropriate noises. He could not sit still, walked around the room, and asked the doctor questions about pictures on the office walls. His language skills were poorly developed, and he did not express ideas clearly.

In reviewing the CPRS results forwarded by the boy's pediatrician, the psychiatrist saw that scores were elevated on multiple scales, with especially high scores on the ADHD Index. Although the boy clearly needed help in multiple areas, the psychiatrist concluded that the high scores for ADHD argued for a trial of medication to see whether it would reduce problems of inattention and hyperactivity sufficiently to make the boy amenable to help with other problems.

When discussing his conclusions with the boy's mother, the psychiatrist found that she had already learned about ADHD from a friend whose child had similar problems. Consequently, the mother was not surprised by the psychiatrist's conclusions and was willing to have a trial of medication. With the mother's permission, the psychiatrist also communicated his conclusions and plan to the boy's teacher, who was also concerned about his behavior. The psychiatrist prescribed 10 mg of methylphenidate twice daily and asked mother and teacher to complete the CPRS at monthly intervals to evaluate response to treatment and as a basis for deciding on possible further interventions. Mother was also given information about ADHD and about more appropriate disciplinary measures.

The statistically derived syndromes provide bottom-up models for understanding children's problems. However, top-down models are also provided for scoring the same rating instruments in terms of DSM-oriented scales based on clinical judgments by experts from many cultures.

THE NEED FOR MODEL-BASED ASSESSMENT IN DEVELOPING COUNTRIES

The needs for mental health services in developing or low income countries are apt to be at least as great as in developed countries, but low income countries have far fewer skilled mental health workers. The photo shows one of the authors in a clinic in a low income country where children are waiting to be seen by a nurse – who is overwhelmed by the sheer number of patients. There is thus an urgent need to use assessment instruments that may assist overworked health care providers. These instruments should be able to obtain reliable information from parents and – whenever possible – teachers and the children themselves. Such instruments can serve, at least, the following purposes: (a) to increase awareness of mental disorders in children; (b) to integrate data about these problems into health information systems; and (c) to assist in identifying cases for referral to specialists, if needed. The case vignette above illustrates a model-based assessment in a developing country.

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THE CLINICAL ASSESSMENT OF INFANTS, PRESCHOOLERS AND THEIR FAMILIES

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Photo: http://www.dean.be

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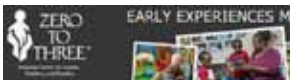
Conflict of interest: none reported.

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Suggested citation: Mares S, Graeff-Martins AS. The clinical assessment of infants, preschoolers and their families. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Health professionals encounter families with infants and young children in a broad variety of settings and circumstances. Consideration of mental health, social and emotional issues should be a necessary part of all health and welfare assessments. The extent to which mental health is the focus will be determined by the setting and the purpose of contact with the infant, toddler, preschooler and family.



A series of podcasts, videos and print handouts about early development are available at the Zero to Three website. Click on the picture to view.

This chapter outlines a framework for assessing infants, young children and their families and provides an approach to *understanding* and *formulating* their difficulties. No matter what the presenting problem, a comprehensive assessment always includes consideration of factors in the child, the parents and wider family, and the social and cultural context that contribute to vulnerability and resilience. These factors are used to inform and focus interventions. *Assessment of risk* (e.g., developmental risk, or risk of harm to the infant or the caregiver) is part of all infant and early childhood mental health assessments, which includes assessment of parenting capacity. This framework can be adapted to a range of clinical settings. The aim of this chapter is to enhance the interest and ability of health professionals to consider mental health and developmental issues in all their dealings with families who present during this period of rapid developmental change.

The developmental importance of early relationships

There is increasing evidence of the infant's capacity and motivation to interact with the environment (people and objects), organising the self and learning from birth. Most accounts of early development stress the infant's move from dependency towards self-organisation alongside the development of identity.

A psychologically healthy infant is characterized by:

- The ability to form close and secure interpersonal relationships
- Drive to explore the environment and learn
- All within the context of family, community, and cultural expectations for the child
- Synonymous with healthy social and emotional development

Development does not occur in a vacuum but in the context of a caretaking relationship, and the carer is vital in supporting the unfolding of the infant's capacities. The family (infant, caregivers and siblings) also exists within a network of relationships and culture. This network includes the social and physical circumstances of the family, which can either enhance and support the family's quality of life and relationships, or undermine them. Even if the infant is genetically and biologically programmed for development, certain environmental experiences are required at specific times – known as *critical periods* – in development.

Infants are born ready to relate, not just to anyone but to specific caregiving individuals. They develop in the context of these relationships and the quality of parenting has a developmental impact. The human baby is born extremely vulnerable and remains dependent for longer than the young of any other species, and so the role of parent or caregiver is intense and prolonged. The family has a crucial part in facilitating and supporting infants' development throughout the early years and their capacity to do this affects the strengths and vulnerabilities infants will carry for their lifetime.

A brief introduction to the science of early childhood development can be found at the *In Brief* series from Harvard University's Center on the Developing Child. Click on the picture to view.



The *first year* involves the development of the basics for language and the establishment of attachment relationships. The *second year* of life involves two major achievements (i) language and symbolic play, and (ii) mobility. Mobility allows children to explore and develop cognitively and to develop independence from the caretaker. The toddler experiments with separation and develops a sense of identity and autonomy. During *the third and fourth years* of life children consolidate, refine and expand these abilities into a sense of self in relation to others and their place in the world (see Chapter A.2).

Attachment

The quality of attachments developed between a young child and their caregivers has a significant impact on social, emotional and cognitive development across the lifespan. Attachment can be defined as an enduring emotional bond characterised by a tendency to seek and maintain proximity to a specific figure(s), particularly when under stress. Attachment theory understands the nature of infants' attachment to their caregivers as a primarily biologically determined phenomenon upon which survival depends. The infant develops internal working models of relationships from the quality and nature of early experience with caregivers, and this influences ongoing social and emotional development. Evidence from longitudinal studies of attachment indicates that security of attachment during infancy is linked to the young child's developing capacity for self-regulation, reciprocity and collaborative social interactions (Sroufe et al, 2005).



Click on the picture to access the NSW Institute of Psychiatry, which has a variety of training videos for sale.

ATTACHMENT PATTERNS AND DISORDERS

Attachment theory describes three types of organised attachment and a pattern of disorganised or disoriented attachment. Attachment disorders (reactive attachment disorder) are also described (DSM-IV TR; American Psychiatric Association, 2000) but there is disagreement about the utility of current diagnostic categories and alternatives have been proposed (Boris et al, 2005; Chaffin et al, 2006; Newman & Mares, 2007; Zerotothree.org).

Attachment

An enduring emotional bond characterised by a tendency to seek and maintain proximity to a specific figure or figures, particularly when under stress.

Attachment can be:

- Organised
  - Secure
  - Insecure/ambivalent
  - Insecure/avoidant
- Disorganised

Organised attachment refers to strategies for managing oneself (and displays of affect) in relation to others that children develop in response to the relationship with their caregiver. These are classified as secure, insecure/ambivalent or insecure/avoidant. Disorganised attachment refers to the child who fails to develop coherent or effective strategies to deal with attachment anxiety, usually where the caregiver is simultaneously the source of comfort as well as the cause of distress or anxiety, for example in situations of child maltreatment (see Howe, 2005; Lyons-Ruth et al, 2005).

Attachment theory – developed initially by John Bowlby from a range of previously separate and diverse areas of knowledge – is an integrated body of theory and practice that enables links to be made between behaviour and inner representations of relationships, and between the experiences of one generation and the care they will provide to the next – that is, the transgenerational aspects of parenting. It provides explanations for the link between observed parenting behaviour, the quality of parent and infant relationships and the later functioning of the child, socially and emotionally. Attachment theorists and researchers have developed methods to elicit and evaluate aspects of the inner representational world of the infant, child and adult. Currently there are limitations to the application of these research-based approaches which cannot yet be easily utilised in the clinical situation.



Click on the picture to view a brief introduction to John Bowlby, the development of attachment theory and transgenerational issues in attachment.

ASSESSMENT

A good knowledge of attachment theory allows clinicians to assess emotional and behavioural problems from a relationship perspective. This is not to say that all infant and early childhood mental health interventions require formal assessment

of attachment status. Research-based methods for assessing attachment such as the *Strange Situation Procedure* (Ainsworth et al, 1978) – are time consuming and require extensive training. A universally accepted clinical and diagnostic protocol for assessing attachment at different ages as well as for diagnosing disorders of attachment does not currently exist. This partially explains the limited research and inconsistent approaches to assessing attachment in clinical settings. Many clinicians when consulted about children's attachments are handicapped by having little formal training in and much uncertainty about assessing attachment clinically (Crittenden et al, 2007). For this reason, outside a research context, it is advisable to describe what is observed between child and carer rather than to use language that may imply an attachment classification or diagnosis when formal assessment has not been undertaken. Assessment of attachment in clinical settings requires a focus on problems and strengths in the relationship between caregiver and child, rather than a focus on strengths of difficulties as existing within the individual child alone (Zeanah et al, 2011). The principles of assessment are summarised in Table A.4.1.

The Circle of Security (COS) website contains useful information for parents and clinicians about the importance of attachment, attachment quality and approaches to parenting and interventions. It is based extensively upon attachment theory and current neuroscience. The COS is a user-friendly, visually based approach (with extensive use of both graphics and video clips) to helping parents better understand the needs of their children. Information about the core elements of this approach, as well as training opportunities can be accessed and downloaded by clicking the picture.



Attachment-informed assessment

While a formal assessment of attachment is not usually conducted in clinical settings, an *attachment-informed* assessment can be undertaken. This includes:

1 *A history of the child's attachments*. It is important to focus on a chronological account of the significant attachment figures available to the child since birth, particularly disruptions in care, abandonment or losses, alternate caregivers, neglect of care and abuse. Availability of the current primary carer and contact with other caregivers should be noted, as well as the child's behaviour with each and response to changes of carer. In older children, relationships with peers and siblings should be described.

2 *Details and observations of the infant or child's current behaviour*. Of particular interest in relation to attachment quality and disruptions or disorder are:

- Help or comfort-seeking behaviour, including response to pain or distress (e.g., who do they go to if they fall and hurt themselves; do they show distress; are they discriminating about who can comfort them? are they shy with strangers?)
- Quality of interaction and ability to use caregiver or another adult for comfort, including ability to explore and play in a new setting, response to limit setting and the nature of the interaction with the clinician.

This needs to be understood within a developmental framework. A six-month-old is less likely to show shyness or fear of strangers than a 12-month-old. A three-year-old may be able to use verbal information from the carer (e.g., "I am going out for a minute, I will be back soon") to tolerate a separation while an 15-month-old is less able to do this.

There are a number of core principles and issues that need consideration in any assessment of a family with an infant or young child, independent of the setting in which the assessment occurs or the background of the clinician; these are summarised in Table A.4.1. These principles are drawn from clinical experience and are informed by research and theoretical understandings of infancy, early childhood and family processes. An approach informed by these core principles

Table A.4.1 Principles of Assessment

1	**Assessment of risk**
	Assessment of the immediate and longer term safety or risks to the infant, young child, and other family members is a necessary and inevitable aspect of all assessments. This focus may or may not be clear to the family, but is a key component of clinicians' responsibilities and obligations.
2	**Parents want the best for their children**
	Almost always, parents want the best for their children and family. The clinician's role is to assist them in providing this.
3	**Biopsychosocial framework**
	A biopsychosocial approach ensures that physical, psychological, interpersonal, social and cultural factors that contribute to the presentation of the family and infant are examined. The physical and psychosocial wellbeing of the infant cannot be considered separately.
4	**Developmental context**
	The perinatal and early childhood period is a time of transition and enormous growth for infant and family, Children develop at differing rates across a range of normal parameters and difficulties need to be understood in a developmental context. Emotional, behavioural and developmental problems presenting in infancy can have lifelong consequences but some are the manifestation of normal developmental transitions: over time, with adequate support, they will resolve.
5	**A relational approach**
	Early development can only be understood within the caregiving context. As described above, this includes attachments and the quality of the infants' primary relationships. Although individual factors in the child or parent may contribute to current difficulties, the interaction or "fit" between the needs and capabilities of each family member and the sources of stress and support in the family context, could determine outcome.
6	**Vulnerabilities and strengths**
	Identifying vulnerabilities and strengths (also called risk and protective factors) helps shape and target interventions.
7	**The transactional model of development**
	The transactional model of development (Sameroff & MacKenzie, 2003) emphasises the interaction between genetic and environmental factors over time and 'the development of the child is seen as a product of the continuous dynamic interactions of the child and the experience provided by his or her family and social context' (Sameroff & Fiese, 2000, p10).

A thorough assessment is necessary:

- For accurate diagnosis and formulation
- To help the family maximise their child's developmental potential
- For appropriate, targeted intervention and management planning
- To collect data for research and statistical purposes.

enables the clinician to develop an understanding of the presenting problem, and where intervention and assistance are best targeted.

The Setting for the Assessment

Assessment of infants and their families is undertaken in a number of ways and can occur in a wide range of settings and circumstances. Visiting a family at home provides very different information from that obtained in a clinic setting. Where a family is seen depends on the clinician's professional role, practice and the aims of the assessment. For example, a family may present only once to their local

emergency department late at night when the parents are concerned their baby is unwell and won't sleep. If seen at home, the practical and financial difficulties (for example, a one-room house and noisy neighbours) that affect their ability to focus on and settle their baby might become more evident. This would alter the focus of the assessment and require a very different use of the clinician's time. Assessment may occur in a mental health setting over two or three sessions because there is concern about parental depression. Alternatively, a family may be seen regularly in an early childhood clinic, allowing observation over time as their relationships develop and the infant grows. Concerns about abuse or neglect require evaluation and inevitably involve the clinician in the difficult task of establishing rapport and cooperation with parents who feel threatened, afraid or criticised. A developmental assessment or follow-up of a family with a child with medical or developmental problems may require a more direct medical or biological focus, but nonetheless needs to include consideration of the familial and social context. There are no clear right or wrong ways but every clinician needs to think about the advantages and limitations of the approach they take and how this may impact on the information they obtain.

A comprehensive assessment is based on an understanding of the developmental tasks of the period and observations of the child–carer relationship. It includes:

- The clinical assessment interview
- Observation of parent–child interaction and relationship
- Developmental assessment of the child.

Aims of the assessment

The essential aim of assessment, whatever the context or setting, is to identify and understand the problems facing the family, their strengths and vulnerabilities, in order to assist them in maximising their parenting capacity and the developmental potential of their child (assessing parenting capacity is discussed below). Information obtained during the assessment may also be used for other purposes, such as research into clinical or social conditions that affect parenting and child development.

Sources of information

During the assessment process a range of information is obtained from different sources, determined in part by the clinical setting and the purpose of the assessment. Direct sources of information include:

- Clinical history provided by the referring agent and the family
- Observations of family members and their interactions
- Medical and developmental tests and investigations
- Other sources (for example, the referring agency or other services involved with the family, the day care, the school).

Other information may include:

- Written documentation of past history and interventions
- Emotional or "affective" information – including the clinician's response to and feelings about the family and their presentation
- Information (knowledge, skills and attitudes) drawn from the clinician's professional experience.

The Assessment Process

Enabling parents and caregivers to explore the complex emotions related to parenting and identifying obstacles that may impede their best parenting efforts is an important part of the assessment. Non-judgemental listening and genuine curiosity about the problem, the family and the child are all essential. Effective assessment enables observation of more than what is spoken, through

The parents of a two year-old girl brought her to a mental health outpatient clinic complaining that she had been "very nervous and agitated since she was one year old". Her parents said she often became aggressive, hit her head on the wall at home and scratched herself. She would wake up stressed, refusing the bottle and scratching her mother. Her behaviour worsened when in contact with other children, so parents kept her at home. She was aggressive with adults, throwing toys on the floor or at people. They reported that she was calm when near her maternal grandfather, who did everything she wanted including things the parents considered dangerous. With strangers she was very shy, keeping her head down and not talking. The parents could not identify a precipitant for the symptoms but the onset had coincided with the child learning to walk and therefore becoming more independent. She lived with her parents and her eight year old brother.

It was apparent that parents had very different approaches to managing her. The mother had difficulty setting limits, while the father, when he was at home, punished the girl physically (hitting her with slippers). The mother said she always wanted to have a daughter whom she could "dress like a princess" and this girl had not been what she expected. The brother was very calm and obedient and had never been a problem.

The psychologist assessed the family during four weeks, interviewing the parents, observing the child alone and the interaction between children and parents. She referred the parents to a parent training program. After a few sessions, the parents found better ways to set limits and parent more consistently and the girl's behaviour improved. The next step was to support parents in sending the child to daycare for a few days a week, giving her the opportunity to be with other children and adults.

an understanding of the rich and essential information conveyed in interactions between children and their caregivers. Advice and intervention should not precede a thorough understanding of the issues.

The interview

The goal of the interview process is not only to gather information and objective data, but also to form a therapeutic relationship within which the problem can be understood and progress made towards resolving it. Whether a family is seen only once or the initial meeting is the first in a series of ongoing contacts, the process of developing a *therapeutic alliance* runs parallel to and determines success in eliciting the *facts* of the history. Just as parenting is primarily about relationships so contact with distressed families needs to be understood as a professional relationship within which the family can feel heard and understood, and therefore better able to care for their child. Even when assessing concerns about child abuse or neglect or providing a medico-legal report, it is important to be aware of the importance of the therapeutic alliance while also being clear and direct about the purpose of the interview, professional role and responsibilities, and any limits to confidentiality. Equally central is the importance of listening to the family: Why have they come? What are their concerns? What do they want help with?

A unique aspect of assessing families with an infant or young child is that frequently the "patient" has no words to tell their side of the story. In this case, what is observed about the child, their behaviour, their responses and the interaction between family members is crucial in helping the clinician and family to understand the child's experience and their part in the current difficulties.

The process of assessment, of listening and observing, and of asking questions, allows clinicians and parents to begin to develop a clear and focused understanding of the core of the problem – or problems – underlying the family's presentation.

Information gained helps the clinician and parents together to organise and understand the experience of the family in order to construct a narrative or "story", an account of the family's experience with the child. This is constantly updated and modified through the duration of assessment and intervention, as development

and change occur. During the interview there are opportunities to observe the infant or toddler and their interactions with the adults.

The history

During the interview – at which the child and, when possible, both parents and other significant caregivers are present – the clinician will explore with the family their hopes and fears, their expectations of themselves and this child, as well as their experience, if any, with medical and psychological services in the past. Using a bio-psycho-socio-cultural approach, information is obtained about:

1. The current problem
2. The background and developmental history of
   a. Child
   b. Parents and family
3. Current supports and stressors.

The current problem

- How do family members understand and describe what is concerning them?
- Has this happened before?
- Was there a precipitant?
- Why have they sought help now?
- What have they tried and what has been helpful?
- What made them decide to seek help from you and your service?
- What do they want help with? What are their priorities?

The background history

This includes information about:

- The individual parent's history of their own family and relationships
- Parents as a couple
- Conception, pregnancy and delivery
- Child's development since birth.

The information obtained will include risk and protective factors in the child, parent(s) and their relationship, social and cultural context. This material will include consideration of biological, psychological and socio-cultural factors.

The bio-psycho-social framework

The infant is born with a genetic endowment, including what is sometimes called temperament, and at birth has already been affected by their environment in utero (for example, the adequacy of nutrition, drug or alcohol exposure, prematurity or other medical illness) (see Chapter B.1). These are biological contributions to the presentation.

The quality of parenting may alleviate or exacerbate a child's constitutional difficulties. This is often described as *goodness of fit* between parental expectations and capabilities and infant aptitudes and needs. It includes psychosocial and interpersonal factors, as well as biological aspects of the parents' and infants' health that affect their ability to meet their baby's needs.

The place of the child in the family, including gender and birth order, the meaning of this child to these parents at this time in their lives and their place

- Assessment of infants or young children and their families will vary depending on the clinician's role, the purpose of the assessment, the setting and the professional relationship with the family
- All assessments are greatly enhanced when a biopsychosocial approach is taken, to enable the integration of information from a range of sources.
- Children's physical and mental health are not separable, just as infant well-being and safety cannot be considered outside the context of primary caregiving relationships and the family context
- The focus of an assessment will vary but the clinician's obligation is to keep in mind the bigger picture, in order to work with the family and other professionals to optimally facilitate infant or young child development and potential, and the quality of family life and relationships.

in the sociocultural context should also be considered. Information should be obtained about biological, psychological and social factors that have helped or hindered the family now and in the past.

Biological factors. These include genetic vulnerability, past and current health, and any significant family history of illness. In the young child this includes intra-uterine exposure to drugs or other toxins, and other factors affecting development and physical health.

Psychological and relational factors. *Intra-psychic factors,* such as current psychiatric illness, personality issues and attachment style and interpersonal factors, such as the history and quality of current relationships.

Social, cultural and contextual factors. Factors in the social context, the degree of cultural and social isolation or support, financial security and parental employment. Socioeconomic status is a powerful predictor of infant developmental outcome (Zeanah et al, 1997), but the family's ability and willingness to access and use support is crucial. Factors to be considered here, identified by Reder et al (2003), include:

- The context and the interaction between the family and the social environment
- Family functioning, for example, poverty, unemployment, responses to stress, social or cultural isolation
- Potential for stability in relationships and social circumstances
- Relationship with others and the ability to use interventions and community support.
- The extended networks that support or abandon the family at this time of rapid developmental change
- The social and cultural factors that impinge on the family
- Relationship quality and interactions
- Family violence
- Practical issues and circumstances; the practical reality of the family situation, including housing, poverty, employment, and educational opportunities.

What parents bring to parenting?

- Their psychological and social strengths and resources
- Their phantasies of what and who the child will be for them
- The history that precedes conception and birth, including their experiences in their own family and their experiences of being parented
- Their expectations of themselves as parents, influenced by their own experiences of family life
- Their psychopathology – the parents' past and family psychiatric history and current difficulties including parental substance abuse
- Parental age and life stage

Transgenerational issues in parenting

Having a baby to care for is a powerful trigger for feelings, thoughts and memories about the parents' own upbringing. Many aspects of parenting are determined by how we were parented ourselves, who held us, how we were

Examples of risk and protective factors

Tammy was born slightly premature and narcotic dependent as her mother had used heroin during pregnancy (biological risk). Her mother was thought to be unable to care for her because of ongoing substance use and Tammy was placed with her aunt and uncle when she was one month old (the quality of care she receives in this kinship placement will determine whether it is a developmental risk or a protective factor for Tammy). She was initially a very irritable and unsettled baby but then developed well and established an organised attachment to her aunt (psychologically protective).

When she was aged three, a severe tornado lashed the town where the family lived destroying the house (contextual risk). Although no one was hurt, the family had to live in a shelter for several months, the uncle lost his job and there were a lot of stressors, resulting in him becoming depressed (psychological/ relational risk). In order to find work they had to move from the area they had always lived in to another district where they were socially isolated (socio-cultural risk). They were a resourceful family and developed close relationships with other families who were also new to the town and who helped them settle in the new community (contextually protective).

Table A.4.2 Rating scales and questionnaires

Instrument	Comments
Child Behavior Checklist (CBCL)) for 1.5 -5 yrs (Achenbach & Rescorla, 2000)	• Two questionnaires to assess adaptive and maladaptive functioning of 1½-5 year-olds. Rated by parents, day care providers and teachers • A recent international project using the CBCL identified consistencies in aggregations of emotional and behavioural problems in preschoolers across the 24 societies participating in the study (Ivanova et al, 2010; Rescorla et al, 2011). • Proprietary
Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997)	• It rates 25 attributes, some positive and other negative. The SDQ has an impact supplement that helps in the assessment of impairment related to behaviours the child is presenting with. Parent and teacher versions for three and four year-olds in several languages • Free of charge
The Ages and Stages Questionnaire (ASQ-3) (Squires & Bricker, 1999)	• Developed to identify infants and young children (0-5) with potential developmental problems. Five areas are screened: communication, gross motor, fine motor, problem solving, and personal-social. Completed by parents/carers • Proprietary
The Ages and Stages Questionnaire: Social Emotional (ASQ:SE) (Squires et al, 2003)	• A culturally versatile tool for clinicians to identify and monitor children at-risk for social, emotional and behavioural delays. The ASQ-SE rates a child's development in the behavioural areas of self-regulation, compliance, communication, adaptive, autonomy, affect and interaction with people • Proprietary
Preschool Age Psychiatric Assessment (PAPA) (Egger & Angold, 2004)	• A structured parent interview for diagnosing psychiatric disorders in preschool children (two to five years old). Used as a research tool, it can be used in also clinical work. • Proprietary; formal training required. For more information
The Parenting Stress Index – Short From (PSI-SF) (Abidin, 1995)	• Screens for stress in the parent-child relationship, dysfunctional parenting, parental behaviour problems and child adjustment difficulties within the family. • Available in several languages. • Proprietary. More information at

comforted, how our needs were met. This information is stored in procedural memory, memory for actions, not in verbal memory. The earliest experiences with our parents occurred long before we were able to put emotions in words. As Winnicott (1987) puts it: "… she was a baby once, and she has in her the memories of being a baby; she also has memories of being cared for, and these memories either help or hinder her in her own experience as a mother'"(p 6).

Parents with a personal history of abuse or neglect enter parenthood at a disadvantage. This is because of the inadequate internal models they have to draw on, the effect of early neglect or abuse on their own capacity for self-regulation and reflection, and often limited current family and social support. Only about one third of children who have been abused go on to be abusive parents (Egeland et al, 2002), but this is clearly a risk factor for difficulties in parenting. Assessment of risk is discussed further below.

Questionnaires and interviews

Besides the history and clinical observation of the child, questionnaires, rating scales and structured interviews can be used to help in the assessment



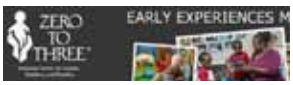
John Bowlby (1907 – 1990), a British psychiatrist, was the main theorist behind the concept of attachment.

process. Standardized instruments pose questions about the child's behaviour that can be easily rated. They are designed to be completed by parents, child-carers and teachers, giving information about the child's functioning in different contexts. These are summarised in Table A.4.2.

ASSESSING INTERACTIONS BETWEEN PARENTS AND INFANTS OR YOUNG CHILDREN

Even in a brief interview with a family, many observations can be made that provide information about the *quality* of the interaction and relationships. Observation of the quality of the relationship with the child is also a central part of assessing risk. Interactions reflect the parents' nurturing capacity, their ability to respond sensitively and appropriately to their child's cues as well as the child's ability to accept and respond to parental care.

The daily routines of feeding, sleeping and changing are the setting for important social exchanges, and also times of increased risk for the child if the caregiving system is stressed or inadequate. What parents actually do is more important than what they say or think they do. Parents' sensitivity to the child's communications is central to the development of the relationship between them and is predictive of the kind of attachment relationship that is developing with each parent. Observation of the parents' responses to their child's emotional signals and communications, and the parents' capacity to interpret these and respond appropriately, is the basis of the assessment.



An extensive list of potential psychosocial and environmental stressors identified in the DC:0-3R: Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood, (Zero to Three Press; 2005) can be found and downloaded at the website (click on the picture).

Observation provides information about:

- Parental sensitivity to the child
- Child responsiveness to parental care and attention
- The *fit* between them
- Child and parent safety

- Parents' capacity to work together to care for the child and the quality of their relationship.

The relationship and interaction with the child is affected by:

- Immediate contextual factors
- Individual aspects and characteristics of the caregiver and child
- Events in the past, especially the parents' experience of being parented.

The behaviour of the parents and child while they are with you is as important as what is said. It is recommended that clinicians pay as much attention to what parents and infants are *doing* as to what they are *telling* you. With the infant in the room you will see how easily they settle, how responsive they are to parental voice and touch, how they indicate their needs and how these are responded to. With a toddler present, you will learn a great deal about how free he feels to explore the room, how much proximity he seeks from his parent and the behaviours that gain parental attention.

The language used by parents, the way they talk to and about their child also provides information. You may notice for example:

- Offhand remarks and nicknames
- Stories, when a parent may consciously or unconsciously be talking about other people or situations but is describing something about the child, or their interactions with the child
- Non-verbal communication between parents, and between parent and child, particularly facial expression and touch
- What parents say to the child, what they say about the child and how these compare.

Ideally, communication between parent and infant or young child is:

- *Contingent*: the parent is responsive to the child's cues, rather than intrusive and insensitive
- *Collaborative*: both parties are active participants in the interaction and build or *repair* their communication together to restore optimal and comfortable levels of arousal
- *Emotionally attuned*: the parent is able to identify and *tune into* the child's emotional state and to organise their response appropriately.

All this depends on the capacity of the caregiver to be empathic, and to be *attuned to the mind of the child*. It requires parents to reflect on their own experiences and inner state and to acknowledge their child as an *experiencing being*: to *be with* rather than *do things to* their child. This is known as *reflective* or *metalising* capacity.

Reflective or mentalising capacity

Mentalising or reflective capacity refers to the activity of understanding behaviour in relation to mental states, or "holding mind in mind" (Allen et al, 2008, p3). Mental states include thoughts, feelings and intentions; mentalising involves "the capacity to think about feeling and to feel about thinking" in oneself and in others (Slade, 2005; p271). Fonagy and colleagues (1991) propose

Assessing interaction

- A mother, who was having treatment for a postpartum psychosis, said proudly that she was breastfeeding her baby and it was going well. When the baby started moaning she picked him up and positioned him well to feel but did not open her shirt or give the baby access to her breast, just holding him against her shirt where the baby vainly attempted to latch onto the breast. The mother seemed unaware of his struggle until he grizzled loudly. She still did not open her shirt until the clinician suggested it.
- A two year old boy fell off the chair during the assessment and bumped his head quite hard. His mother had described him as "independent". Instead of crying or going to his mother, he walked to the window and looked outside. It was striking to the interviewer that he did not seek parental confort or show distress.
- A five year-old boy is brought by his mother to a consultation with a primary care psychologist. The boy was referred by his teacher because he was not able to do the activities proposed in class. He was always quiet and alone, refusing peers' invitations to play. The mother could not understand his behaviour. In their second consultation, the psychologist invited the boy to play offering him some toys. The boy only could play when the mother came into the room and gave him verbal instructions about what to do. He only moved or changed toys after she gave him *permission*. After that, the psychologist enquired more about his habits and noticed that he was not allowed to do anything the mother had not planned.

A comprehensive assessment is based on an understanding of the developmental tasks of the period and observations of the child–carer relationship. It includes:

- The clinical assessment interview
- Observation of parent–child interaction and relationship
- Developmental assessment of the child

that the parent's capacity to hold the child's experience in mind is linked to the intergenerational transmission of attachment security (Slade et al, 2005).

There are formal assessments of reflective capacity available, for example the *Parent Development Interview* or PDI (Slade, 2005). In relation to clinical assessment, the focus is on the parent's capacity to take the child's perspective to appreciate that the child has an experience separate from their own. Children are at higher risk of maltreatment if parents consistently misperceive or misinterpret their behaviour (Howe, 2005).

Semi-structured play assessment

Some services use a structured or semi-structured process for assessing the parent child relationship. An example is the *Modified Crowell Procedure* (Crowell & Feldman, 1988), which was developed for use with children aged 12-60 months and takes between 30 and 45 minutes to administer. The parent is asked to undertake a series of activities with the child. This usually includes: to play "as you would at home" (free play); to follow the child's lead in the play; asking the child to clean up; playing with bubbles, a series of puzzles or problem-solving tasks and a brief separation/reunion. At the end, the carer is asked how representative these interactions were of what happens at home. The purpose of this assessment is to observe the carer and child interacting together in a series of slightly different tasks as a way of identifying strengths and weaknesses in their relationship. The focus is on problem solving, play and enjoyment and on an informal assessment of attachment. It gives an opportunity to observe the child's persistence, their use of the carer for support, their ability and willingness to ask for help, their fine and gross motors skills, and the degree of enjoyment, ease and pleasure in the interactions. The quality and nature of each participant's behaviour as well as of their interactions is important, as is the transition between tasks (e.g., do children have difficulty shifting from one activity to another? Is their attention span limited? Do they cooperate with the request to tidy up? How clearly do parents communicate with the child?). How children use the caregiver for support

Parents of infants and toddlers frequently are worried about developmental delays and behaviours related to autism spectrum disorders (ASDs). It is important that clinicians keep this in mind to recognize the early signs of ASDs; children with ASD whose conditions are diagnosed early and who participate in appropriate intervention programs have better outcomes (Johnson et al, 2007). The American Academy of Pediatrics has resources to support paediatricians in the identification and care of children with ASD.

during transitions between activities and the separation and reunion is especially important because these changes represent mild stressors to young children. More discussion about the use of observational measures in assessment can be found in Aspland & Gardener, 2003, Crowell 2003; Crowell & Feldman,1988; Miron et al, 2009.

DEVELOPMENTAL ASSESSMENT

A developmental assessment can be included, when appropriate, as part of the therapeutic intervention. Many kinds of developmental assessment can be undertaken depending on the purpose of the assessment, the clinician's skill and the family's needs and concerns. Involving parents in the assessment process provides them with useful information about their child's abilities and needs and also allows the clinician to see what use parents make of this information. Advisability for a developmental assessment can arise from the history and observations of the child as well as from the results of rating scales or questionnaires such as the *Ages and Stages Questionnaire* mentioned above.

Conducting a developmental assessment

General principles

- First, as in any assessment, ask what information the parents *want* to receive. This helps build rapport and indicates to the family that the process is for the benefit of the child and family. Respecting parents' requests at this stage may enable more sensitive or difficult information to be discussed at a later stage
- Provide a safe, comfortable environment for the child
- Assess infants' optimal level of functioning and what they can do with support
- Involve one or both parents (in the room for infants, or behind a one-way mirror for older children) in the process of assessing their child's skills, interests, behaviour and adaptive capacities.
- Be aware of and sensitive to cultural differences, respecting and appreciating these

Some of the instruments used for developmental assessments are:

- The *Neonatal Behavioural Assessment Scale (NBAS)* (Brazelton & Nugent, 1995). The NBAS was designed to capture the early behavioural responses of infants to their environment, before their behaviour is shaped by parental care. Brazelton and Nugent's assumption is that a baby is both competent and complexly organised and an active participant in the interaction with caregivers. The assessment seeks to help understand the infant's side of the interaction
- The *Bayley Scales of Infant Development (BSID)* (Bayley, 1993). Applicable to children 1-42 months of age, provides information about the child's language development, problem-solving skills, gross and fine motor development, attentional capacity, social engagement, affect and emotion, and the quality of the child's movement and motor control
- The *Wechsler Preschool and Primary Scale of Intelligence (WPPSI)* (Wechsler, 2002). Neuropsychological assessment that can be useful

The 4 Ps

The 4 Ps is a way of summarising the factors contributing to the problem as:

- *Predisposing*: what made this family vulnerable?
- *Precipitating*: why have they come now?
- *Perpetuating*: what makes it hard for things to get better?
- *Protective*: what strengths can we identify and build on in our intervention in the child, the family and the social and cultural context?

for children from 30 months of age onwards. It evaluates children's verbal comprehension, perception, organization and processing speed abilities, giving clinicians a developmental perspective of the child's intelligence.

- The *Vineland Adaptive Behavior Scales* (Sparrow et al, 1984). A parent interview that obtains information on children's adaptive functioning in real-life situations covering the domains of daily skills, communication, socialization, motor functioning and maladaptive behaviour.

FORMULATION

The aim of assessment is to understand why *this family* is presenting with *this problem* at *this time*, and what are the impediments or obstacles that have prevented them from resolving their difficulties without professional help. This information forms the basis for what is called a *formulation*. Formulation is an integrative statement that provides an aetiological understanding of the problem and of the factors contributing to the presentation. It can take different forms, but ideally includes consideration of biopsychosocial factors. This summary informs the development of a comprehensive intervention plan. Another way of thinking about formulation is to identify or organise the information obtained in the assessment into what can be called the *4 Ps*.

Ideally, during the process of assessment, the family and clinician come over time to a new, shared understanding – a story – about the meaning and nature of the presenting difficulties and also the way forward. Developing an intervention and anticipating prognosis requires the clinician to think about and identify protective factors and resources that can be built on.

The role of diagnosis

When possible, establishing a diagnosis contributes to a more complete formulation. For example, a diagnosis can help clinicians to decide which treatment is appropriate. It can also facilitate communication between the various professionals taking care of the child. With these purposes in mind, efforts are been made to elaborate a diagnostic classification for mental health problems in infants, toddlers and preschool children. The most important systems currently available are the *Diagnostic Classification of Mental Health Disorders of Infancy and Early Childhood* (DC: 0-3R) (Zero to Three, 2005) and the *Research Diagnostic Criteria-Preschool Age* (Task Force on Research Diagnostic Criteria: Infancy and Preschool, 2003).

Symptoms of concern in young children

- Very frequent tantrums
- No tantrums at all, too quiet and compliant
- Role reversal:
  - Controlling and punitive
  - Compulsive caregiving
- Self-soothing, masturbating
- Self-harming, head banging
- Persistent regression, loss of toileting, more clingy
- Persistent precocity and over-maturity (little adult).

Toddler and preschool presentations are discussed further in Luby (2006) and Banaschewski (2010).

ASSESSING RISK IN INFANCY AND EARLY CHILDHOOD

Assessment of risk is an implicit – and sometimes explicit – aspect of every assessment of infants or young children and their caregivers. In many countries, health workers are required by law to report children who are at risk. Like all other assessments, risk assessment requires a detailed history, observation of relationships and information from a range of sources. Risk to the infant or to the relationship with the infant occurs whenever the caregiver's resources are overstretched. In considering risk in infancy and early childhood we are considering risk *within a relationship*. Infants can also be at risk developmentally or physically because of medical illness or prematurity, but the caregiving relationship and the social

Table A.4.2 Indicators that an infant/child is at possible physical, psychological or developmental risk.

In the infant/child	In the parents	In the context
• Failure to thrive • Failure to meet expected milestones • Hypervigilant or startling easily • Excessively quiet and withdrawn • Marked aggression in a toddler • Basic needs not met • Role reversal or caregiving behaviour towards parent • Emotion regulation problems • Unexplained bruising or medical injury	• Inability to recognise or prioritise the child's needs • Untreated or inadequately treated psychiatric illness or substance abuse • Lack of insight and lack of engagement with treatment services • Child incorporated in parental delusional system, including positive delusions • Insensitivity to child's signals and needs (emotionally unavailable) • Thoughts of self-harm or fear of harming child • Scared of infant, ignores infants cries • Frightening or looming behaviour, rough handling of infant • Hostile or negative attributions ("he is out to get me") • Unrealistic developmental expectations • Lack of parenting skills	• No other available and protective adult • Significant cultural or social isolation • Minimal social supports • Domestic/family or community violence • Multiple social risks (e.g., homelessness, itinerancy) • Chronic stress

Developed in conjunction with Nicholas Kowalenko, Sarah Mares, Louise Newman, Anne Sved Williams, Rosalind Powrie, and Karin van Doesum.

context of that relationship are major determinants of the psychological outcome for the child.

There are various degrees and types of risk, which range from physical illness or disability in the infant, to those associated with child abuse and neglect. As well as prematurity and medical illness, factors that contribute to developmental risk include child temperament, problems with attachment, parental mental illness, exposure to violence, socioeconomic status, poverty and adolescent parenthood (Zeanah et al, 1997).

Here the focus is on the assessment of risk to the child within the caregiving relationship. When one or both parents have psychiatric illness, substance abuse histories or the domestic situation is unsafe, it is also necessary to assess the risk (of self-harm or violence) to the child's caregivers. When the caregiver is at risk, the child is also at indirect risk because of the centrality of the caregiving relationship to the child's wellbeing. Therefore domestic violence, even in the absence of violence directed towards the child, represents a significant developmental risk. The cumulative developmental impact of multiple risk factors must also be considered (Appleyard et al, 2005).

Rajni's parents both used drugs and alcohol regularly after her birth and possibly also during the pregnancy. She was neglected, physically abused and there was considerable violence between the parents. She was removed from her parents aged 11 months after an unexplained leg fracture. At that time her milestones were a little delayed and she was small for her age. She was placed with an older relative who cared well for her and her growth and development improved.

When she was 2½ years, her carer developed cancer and Rajni was returned to her parents. Another period of neglect and exposure to violence followed. Rajni was again placed with a foster family when she was 3½. They reported frequent tantrums, often scratching and hitting her head. She hoarded and stole food and was indiscriminate socially, attaching herself to relative strangers, climbing on their laps and holding their hands, and she would "go blank" when told off or reprimanded or if there was a loud noise, particularly shouting or arguing.

Rajni's difficulties could be understood as survival strategies she had developed in response to her early neglect and abuse. Her behaviour began to settle after a period in a safe and loving home environment but she remained sensitive to noise and had difficulties with sleeping, feeding and regulating her emotions.

Risk

- Risks can be identified within the individual, the caregiving relationship and the social context
- Assessment involves weighing up risk and protective factors
- The greatest developmental impact is from cumulative risks, in particular those that operate long term
- Risk assessment requires history, observation of interactions and information from a range of sources

Types of Risk

In general, risk can be defined as the probability of an event occurring, including consideration of the losses and gains associated with it. In this context (infant development and child protection) risk assessment is not free from cultural and moral judgements. There is a high degree of uncertainty when predicting risk in child-protection matters and inevitably this contributes to the anxiety felt by even very experienced clinicians working in this area.

In this context, different types of risk can be identified:

- Risk to the child's immediate physical or emotional safety
- Risk to the child's optimal development. This acknowledges the importance of early experience for later outcome. Genetic, in-utero and physical factors such as illness may be present
- Indirect risk, such as repeated separation from a parent hospitalised with a psychiatric or medical illness. Parental mental health problems are a significant risk factor.
- Cumulative risk occurs when a child and family are exposed to multiple risk factors. For example, a premature infant born to a young single mother with a narcotic addiction with little family support is clearly at greater risk than a premature infant with similar medical and biological risk factors, born to a couple with adequate financial and practical support.

The greatest developmental risks are those that operate long term, for example:

- Chronic neglect
- Chronic instability in the family's personal and social circumstances
- Exposure to parental personality disorder or dysfunction and ongoing mental health problems.
- Ongoing hostility towards the child

Consequences of maltreatment

Children who have been abused or neglected may have physical, emotional and behavioural sequelae, which may then make caring for them more difficult. For example, traumatised children may continue to show avoidant or disruptive behaviour for some time after being placed in safe fostering environments. Abuse and neglect may have long-term effects on the child's understanding of feelings and relationships. A child with brain damage after head trauma may have long-term physical and emotional symptoms, meaning that caring for them is particularly difficult and challenging. This presents parents (including foster and adoptive parents) with challenges that they may not have anticipated, requiring them to demonstrate more patience or perseverance than with a less traumatised child.

Infants in high-risk situations are more likely to develop insecure or disorganised attachment relationships with their caregivers. There is evidence that disorganised attachment during infancy is linked to emotional and behavioural difficulties in childhood, adolescence and adult life. Therefore, although an infant may not be at an immediate physical risk, an erratic, neglectful or unstable caregiving environment is a threat to their social and emotional development. In child neglect, chronic unresponsiveness to the child's physical or emotional needs can have profound developmental consequences but may be harder to detect than physical abuse. Unfortunately, many infants at risk suffer both neglect and abuse, and neglect.

Risk in Infancy

- There are degrees of risk
- Risk factors may be cumulative—there is rarely a linear correlation between any one risk factor and later developmental outcome. There is a linear correlation between number of risk factors and developmental impact
- Risk may be direct or indirect
- Risk may be to immediate physical safety or to longer term psychosocial development.

PARENTING AND PARENTING CAPACITY

Many definitions of parenting and parenting capacity have been suggested over time (Jones, 2001; Reder et al, 2003). The core elements of parenting as defined by Hoghughi (1997) are:

- *Care*: meeting the child's needs for physical, emotional and social well-being, and protecting the child from avoidable illness, harm, accident or abuse
- *Control:* setting and enforcing appropriate boundaries; and
- *Development:* realising the child's potential in various domains.

Knowledge, motivation, resources and opportunity are necessary to be an effective parent.

Parenting capacity

Parenting capacity can be described as the capacity to recognise and meet the child's changing physical, social and emotional needs in a developmentally appropriate way, and to accept responsibility for this. Parenting capacity is determined by:

- *Parental factors* (and the parent-child relationship), including the parent's models and understanding of their parenting role, and ability to understand their infant's emotional and psychological needs
- *Child factors* (and the child–parent relationship)
- *Contextual sources of stress and support* (and the family-context interaction) (Reder et al, 2003).

Recently, there has been consideration of the relative weight or emphasis to be given to each of the above factors in considering risk to infants and children.

Donald and Jureidini (2004) argue that parenting capacity assessment should centre primarily on the parent's ability or potential to provide empathic, child-focused parenting; in other words, on the "adequacy of the emotional relationship between parent and child", specifically "on the parental capacity for empathy" (p7). They describe factors in the child or the relational and social context as "modulating effects" upon the primary domain of parenting capacity. While their approach is untested in practice, it has the advantage of focusing the clinician on the quality of the relationship and the parents' potential for an adequate emotional relationship with their child, and links with the growing literature on parental reflective capacity as a core factor mediating risk. Farnfield (2008) proposes a theoretical model for assessment of parenting, identifying seven core dimensions and a number of modifying variables. This model uses an ecological framework informed by attachment theory and a systemic approach, identifying the parent's own history of being parented as the first of these core parenting dimensions.

Factors that promote resilience in the child (Ferguson & Horwood, 2003; Sameroff et al, 2003)

- A well-functioning parent or other involved adult
- Social supports
- Professional intervention when it is indicated
- Consistency in other relationships and activities
- Having a skill or talent.

Capacity for change

Assessing the parents' capacity for change in situations where risk to the infant or caregiving system has been identified, or abuse or neglect has occurred is a necessary but difficult task.

For example, an adolescent mother has been unable to help her infant into organised patterns of sleeping, waking, eating and playing. The infant is failing to gain adequate weight and is fussy and restless. This parent may lack adequate information about infant development but is otherwise motivated and has just enough resources to meet the infant's needs. Support and education may reduce the risk to this infant, allowing her to get on with her development. However, if there is a lack of motivation from the parent, then provision of resources and information will not be enough to protect the infant from the consequences of neglect.

Repetition of abuse occurs in 25%–50% of families in the UK where children are returned to their parents after removal following abuse or neglect (Reder, 2003). Difficulty in identifying when it is appropriate to provide care or nurture, or when protection or control (limit setting) is required, are common for parents with histories of maltreatment. This can affect their capacity to parent adequately and to use available resources and support services.

Concerns about the immediate or long-term safety of an infant or a caregiver need to be addressed openly and directly with the caregivers and referral agency. Appropriate intervention must follow, and processes be put in place for monitoring the ongoing safety and wellbeing of all family members. Where possible, this involves establishing a network of support for vulnerable families and assessing their capacity to use services and relationships, to parent safely and effectively, to reflect on past experience, and to give priority to their child's needs for care and protection.

CONCLUSION

Assessment of families with infants and young children occurs in a variety of contexts and for many different reasons. Nonetheless, a comprehensive assessment should always include a relational and developmental focus, with consideration of both strengths and vulnerabilities that parents' and child bring to their current

circumstances, and attention to biopsychosocial factors that help or hinder the family at this time of rapid developmental change.

A working alliance between the family and the clinician supports any proposed interventions. Concerns about the immediate or long-term safety of the child or caregivers need to be addressed openly and directly with the caregivers and referring agency. Appropriate intervention must follow, and processes put in place for monitoring the ongoing safety and wellbeing of all family members.

All assessments of young children involve consideration of risk. The notion of risk in infancy and early childhood is complex and multifactorial. It includes consideration of immediate risks to child and parent safety, of the impact of single and cumulative risk factors, and the notion of developmental risk and psychopathology following early adversity. The vulnerability and dependence of young children on the availability of their caregivers means that risk is always considered within the caregiving context, and that threats to the safety of either or both parents inevitably impacts on the child's wellbeing.

Risk increases whenever the child's needs outweigh the capacity of the carers and their supports to meet these needs. As described, this can occur because of factors in the child, the caregiving system (parents), or the social context, and many at risk children and families have vulnerabilities in all three areas.

Situations of high risk are distressing for all concerned, particularly when the clinician is required to recommend the removal of an infant or young child from their home. A comprehensive assessment that includes a careful history, consideration of the coherence of the history provided, observation of interactions between child and caregiver(s), and corroborative history are central to an adequate assessment of risk. This ensures that decisions are based on sound information obtained from a variety of sources and are made in the best interests of the child and the family.

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THE CLINICAL EXAMINATION OF CHILDREN, ADOLESCENTS AND THEIR FAMILIES

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Sherlock Holmes statue at Meiringen, Switzerland (Wikipedia commons)

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Suggested citation: Lempp T, de Lange D, Radeloff D, Bachmann C. The clinical examination of children, adolescents and their families. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

WAYS OF READING THIS CHAPTER

- You are a *beginner in the field* of pediatric mental health:

  Welcome to this exciting subspecialty! We are inviting you to sit back and read the whole chapter.
- You are already *experienced and trying to improve* your examination skills:

  We suggest that you read the clinical pearls in the right column and try them out in your practice. If you wish, you may collect more of them and share them with clinicians all over the world by sending them to the authors for the next edition of this chapter.
- You are *experiencing difficulties* with a specific patient's diagnostic assessment:

  We suggest that you read the troubleshooting box at the end of this chapter (pages 23-24). If this does not help, check our reading recommendations in the references section (pages 24-25).

Conflict of interest: none reported

Acknowledgements: our gratitude to Friderike Fornoff (University of Frankfurt) and Joseph Rey (University of Sydney) for their help in preparing this chapter.

Would you like to share your "clinical pearls"?

If you have comments regarding this chapter, especially more clinical pearls from your own work you are cordially invited to send us your suggestions to lempp@em.uni-frankfurt.de

The Sherlock Holmes illustrations are from Sidney Paget (1860-1908), who illustrated Conan Doyle's stories in The Strand magazine.

Why should I read this chapter?

In many respects it seems worthwhile giving special attention to the clinical examination process in child psychiatry (except when otherwise specified, "child" refers to "child" and "adolescent"):

- It is obvious that there has to be a thorough and comprehensive *diagnostic evaluation before treatment* can be considered. If the diagnosis is wrong, incomplete, not understood or accepted by all parties involved, the chances of treatment failing are fairly high. The planning and initiation of a treatment regime in child and adolescent psychiatry is usually time-consuming and costly. Therefore, the time spent in the diagnostic process to create a valid and solid foundation for effective treatment planning is wisely invested.
- There are *distinctive developmental aspects* in the mental health examination of children and adolescents, which deserve special attention. Children and adolescents are not little adults. They cannot be assessed in isolation, speak a "different language" to the clinician and rarely seek help by themselves.
- Especially for beginners in the field, it is easy to get confused by the amount of information and by inconsistent reports. To minimize this, it is helpful to be *clear about the aims* of the evaluation process. The art in daily practice is in finding the balance between standardization and individualization when using different methods to reach these aims.

"I like to think of myself as Sherlock Holmes during this time. I use the more obvious clues (usually the presenting complaint) to begin the investigation, as well as "digging deeper" to understand the nature of the symptoms and behavior, and the biological, psychological and social factors, which are precipitating and maintaining the impairing symptoms." (Stubbe, 2007).

"Whatever the age of the child, and whatever the clinical issue, it is important that the interview combines an appropriate degree of structure and standardization (which are essential for comparability across children) and sensitivity to the unexpected and to the individual issue." (Rutter & Taylor, 2008).

Be clear about the aims and flexible in the methods.

Distinctive aspects of the mental health examination in children and adolescents

- Children rarely initiate psychiatric assessment and the *referral is typically requested by someone other* than the patient (e.g., parents, teachers, pediatricians, courts). This can be of paramount importance in the interpretation of the case. Perhaps the adult's expectations for the child exceed the child's abilities, or the parenting style may result in a poor fit between parents and this particular child, and parents seek to

change the child in order to remedy this poor fit. In other cases, parents or teachers have mental health problems of their own, which alter their perception of the presenting child in a negative way. In summary:

- It is necessary to consider both the child's and adults' contribution to the distressing behavior for which examination is being sought
- We need to pay explicit attention to the child's perception of the problems and what the child desires to change.

No child can be assessed in isolation!

- Children need to be *evaluated in the context* of the family, the school, the community and the culture, which means that no child can be assessed in isolation. Moreover, most children function differently in different settings and it is helpful to know which surroundings improve or worsen the distressing behavior – also to identify the child's areas of strength. Thus, the simultaneous examination of parental and family functioning is crucial, as is the need for multiple informants. Building rapport with all the parties relevant to the case who may have information or who could play a helpful role in furthering the child's progress is essential. Parental permission should also be obtained. For example:
  - Parents living apart from the child (it is often helpful to involve both parents to the greatest extent as early as possible)
  - Teachers (by phone or email, examination of school records and obtaining teacher rating scales). A teacher will have seen hundreds of children of a given age or grade level to serve as a basis of comparison, in contrast to the parent of an only child.
  - General practitioners and pediatricians
  - Any past and current mental health provider
  - When appropriate: siblings, grandparents, child caretakers, stepparents
  - For inpatient children: nursing staff, social workers, teachers, physical- and occupational therapists.



"There should be no combination of events for which the wit of man cannot conceive an explanation." (Sherlock Holmes, "The Valley of Fear")

- The presenting problems must be considered in a *developmental context*. Developmental factors often influence the presentation of psychiatric symptoms (e.g., depression presents differently at different ages). While some disorders look quite similar in children and adults (e.g., obsessive compulsive disorder), other disorders are notably different in younger children as compared to adolescents or adults (e.g., PTSD). Behavioral problems in children can be due to a delay in skill development (e.g., enuresis or bedwetting), the loss of previously attained skills (e.g., consequence of a serious disorder, loss or trauma), or inability to select appropriate skills from an existing repertoire (e.g., conduct disorder). In summary, one needs to be aware of normal and abnormal child development, including the range of behaviors that can be observed at different ages, contexts and the various forms of disturbance in each developmental stage (see Chapter A.2).
- Children's ability to reflect and discuss their feelings or experiences is influenced by maturational factors. This means that *child and clinician are at different developmental levels* and speak "different languages". Moreover, stage-specific developmental features can impede communication. For instance, younger children may not trust

unfamiliar adults, adolescents often perceive clinicians as simply another adult imposing expectations or judging them. Therefore, information-gathering from the child often requires modes of communication other than question and answer or verbal discourse. Children of different ages need different methods of collecting data and interviewing (e.g., observing a baby, playing with preschool children, talking directly about symptoms to articulate children or adolescents, drawing with anxious or uncommunicative children)

- The clinical assessment of children typically *requires more time than adults* (about 2 to 5 hours), thus using time efficiently is an important consideration. Rating scales and questionnaires is a way of increasing efficiency (see below), but can never replace a thorough face-to-face evaluation.



"It is a capital mistake to theorize before one has the data. Insensibly, one begins to twist facts to suit theories, instead of theories to suit facts"
(Sherlock Holmes, "A Scandal in Bohemia")

AIMS OF THE EXAMINATION

Before beginning the examination it is essential to be clear about its aims. While the methods to reach this goal might differ in individual patients and families, the aims are quite consistent, namely to:

- Create a *good therapeutic relationship*. The need to develop a good alliance between the multiple parties, especially between the clinician and the child, the clinician and the parents and with other, possibly helpful, family members as well as outside agencies. A rupture in these relationships can dramatically interfere with treatment efforts
- Understand the exact *reason for referral* ("Whose problem is it?" "Why now?")
- Identify the child's and parent's implicit and explicit *expectations and concerns* about the evaluation
- Identify the *main complaint* of the child and the family
- *Evaluate the child in the context* of his or her *current functioning* in the family, the school, and with peers, with sensitivity to cultural or community influences and the extent this has been impaired by the current problem(s)
- Obtain an accurate picture of the *child's developmental functioning from birth to now* and to obtain *a picture of the parents and family functioning*, and family history concerning medical and psychiatric disorders
- Identify individual, family or environmental factors that may be causing, accelerating or ameliorating the presenting difficulties
- Condense all the information obtained into a *clinical formulation*. That is, the clinician's distillation of the data put together in a coherent fashion to understand the multiple factors which are contributing to the presentation. This understanding will inform diagnosis, prognosis, and treatment recommendations
- *Communicate this clinical formulation* and recommendations to the parents and the child in an understandable and constructive way
- Establish target symptom priorities and *clarify the focus of treatment*

In short, the aims of the evaluation are the integration of the complex (and sometimes disparate) information gleaned from the examination process, putting it into a certain context to understand the child's behavior and to clarify the treatment focus and appropriate interventions for this individual case.

The first diagnostic steps are observation and collection of facts.
It is a mistake to move quickly relying on single symptoms.

- Discuss with the patient and the family the relative *benefits and risks of the proposed treatments* and to identify and discuss all relevant environmental factors which may influence adherence to treatment
- Achieve all this in a *time-efficient* manner.

BRINGING BUILDING BLOCKS TOGETHER

There are no specific biological or radiological markers for the diagnosis of psychiatric disorders (yet). In their absence, the *multimodal diagnostic process* is the gold standard for the examination of mental health problems. This means that we cannot trust one specific method to make a valid diagnosis (e.g., to give a family a definitive diagnosis after one interview or after filling out a couple of questionnaires). Instead, it is necessary to collect different diagnostic *building blocks* (e.g., separate interviews with parents and child, rating scales from teacher, psychometric assessment). If these blocks fit together (i.e., point in the same direction) we can build a *diagnostic wall* out of them (i.e., the diagnosis). Standing on this more or less solid wall we can see a picture of the whole problem. Only then are clinicians in a position to make appropriate recommendations. The final diagnosis, treatment recommendations and prognosis must only be made in light of all these circumstances.



"We balance probabilities and choose the most likely. It is the scientific use of the imagination."
(Sherlock Holmes, "The Hound of the Baskervilles")

Before you start to build the diagnostic wall (see below: Setting the stage), we suggest collecting at least four basic building blocks:

1. Parents and child interview
2. The mental status examination
3. The medical history and the physical examination
4. Rating scales and psychometric assessment.

Combining these blocks usually helps to find the suitable diagnosis according to one of the two major classification systems: the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 2000), and the International Classification of Diseases (ICD-10; World Health Organization, 1996).

Comorbid problems

Parents and teachers usually describe the most prominent symptoms in their children or those that cause them the most concern, with the result that some problems can be easily overlooked. *Internalizing* symptoms, such as anxiety or depression, can be difficult for children to describe and tend to be less troublesome or apparent to adults than *disruptive* or *externalizing* symptoms (e.g., those seen in ADHD or conduct disorder). Comorbidity (the presence of more than one concurrent disorder) is extremely common in child mental health; the co-occurrence of several disorders has implications for treatment and prognosis.

Differential diagnosis

Differential diagnosis is the method used to systematically identify the presence of a disorder when several alternatives are possible. Psychological symptoms are often equivocal diagnostically in that they often occur in various disorders (e.g., irritability can be found in depression, bipolar disorder, ADHD,

Be as transparent as possible with the patient and the family, especially at the beginning of the examination.

anxiety etc.) thus, disorders that share similar symptoms should be considered and some excluded.

Setting the stage

The aim of this part of the examination is to build a good therapeutic relationship with the child as well as the parents – right from the beginning – and to clarify all relevant *administrative aspects*, the *reason for referral* and *expectations* of all relevant parties.

The right place

To reduce possible fears of the patients it is helpful to evaluate them in a room with enough space, pleasant lighting, colored pictures on the walls and to have at hand toys, pencils and paper.

A good therapeutic relationship from the beginning

Building of a good therapeutic alliance is a key consideration right from the start. Most families and children are intimidated by the prospect of seeing a clinician in a mental-health setting. Increasing the degree of transparency usually helps lessen this difficulty. Often, it is effective to explain in advance every step of the process, especially at the beginning – what you will do, why and how long it will take.

Example of how to explain your profession:

"I am a child and adolescent psychiatrist – a medical doctor who is specialized in understanding and treating emotional and behavioral problems in children and teenagers. My first job is to try to understand the problems you have…"

Young children may need to be reassured about where they are going and which kind of doctor they will meet (e.g., "a feelings doctor", "a talking doctor", "a hospital for emotional problems") and that there will not be needles or painful physical procedures. Children usually have no idea, or a false idea, of what occurs in a mental health examination and may be afraid of being hospitalized, taken away from the family or otherwise punished, especially if their difficulties have been a source of recrimination within the family. Parents and relatives are often misinformed and may share some of these beliefs; it is also helpful to explain to them what type of professional you are.

Administrative aspects

Make clear what the psychiatric examination entails, how long it will take and what the family can expect at the end (e.g., a verbal recommendation, a written report). The cost (if fees are involved) needs to be clarified at the onset. It is important to ascertain also if there are financial or insurance limitations, which may influence the diagnostic process or treatment options. Scheduling, confidentiality, and permission to contact other people to obtain information should also be discussed right at the start. Parents should be asked to bring copies of as many school reports as possible.

School reports should be routinely checked for:

- Sudden or gradual decline in output or performance
- Large differences in marks in different school subjects
- Comments about social and behavioral problems.

Clarifying the reason for referral

Before you start, consider the purpose of the evaluation so that you structure the examination to fit the reasons for referral. For example, assessment will differ if the purpose is to prepare a court report in a custody dispute, if the evaluation is requested by social services, or the consultation is sought by parents concerned that their child may be suicidal. This minimizes the chances of frustrating and disappointing your patient, the family or other people.

Children often do not understand why they are going to see a mental health practitioner because they do not feel ill – they may be attending because

of promises of ice cream or other treats after the appointment. School teachers may want the child to show more self-control and push parents to manage the child differently or consider medication. The mother may want the examination to validate her parenting efforts; the father may want a diagnosis that would allow access to additional school resources to improve the child's school performance, while the grandmother may wish for a totally different ("old-style") parenting approach.

"Whose idea was it that your child might need this evaluation?"

Important questions in this part of the examination are:

- Who initiated the referral and why? (e.g., parents, pediatrician, school, court, the patient, emergency department)
- Who else is concerned about the child and for what reason?
- Why now?
- What are the key concerns or questions for which people want a response?

Two crucial questions one needs to ascertain at the beginning of the examination:

- Whose problem is it?
- Why now?

If there are conflicting reasons for the referral and you become confused, remind yourself that, when in doubt, you are the child's clinician. Try to keep your examination focused on what you believe will ultimately lead to the best possible outcome for the child.

"What do you hope this examination will accomplish?"

Handling expectations

A common source of frustration is wrong or inflated expectations. It is helpful to check the expectations of the family at the beginning of the interview. This helps to build rapport and understanding. Preparing families for what to expect diminishes parent and child anxieties. Managing expectations may require clarifying what the examination process can or cannot fulfill.

PARENT AND CHILD INTERVIEW

Who should I talk to and in which sequence?

It is informative and reasonable to have the child together with the parents at the beginning of the diagnostic process. Later on, it is helpful to interview the patient and parents separately. While there are no hard and fast rules about how to do this, it is mandatory to interview patients by themselves at some stage, particularly to clarify issues that patients may not feel comfortable talking about when parents are present such as suicidal thoughts, abuse or sexuality issues.

The child is usually the best information source for internalizing symptoms whereas parents can give reliable information about externalizing ones.

In most cases, parents will have limited knowledge about their child's inner feelings, experiences outside of home and performance at school. Disagreements between parents, child and teachers are common. Studies have shown that agreement between parents and child are low to moderate (e.g., Achenbach et al, 1987; Salbach-Andrae et al, 2009). School-age children and adolescents are themselves the best informants for anxious or depressive feelings, suicidal ideation, and behaviors the parents may not be aware of – such as sexual activity, sexual identity issues, sexual abuse, drug use, obsessive thoughts, and hallucinations. On the other hand, parents are a good source of information for behaviors such as deceitfulness, overactivity, inattention, impulsivity, non-compliance, and aggression.

How should I formulate my questions?

Using parents' actual words in the interview can help ensure that parents feel heard.

It is adequate in almost all cases to start with one to three *open-ended questions*. This helps to establish rapport and avoids premature narrowing of focus. In addition, it is useful to allow parents to tell their version of the problem for at least several minutes. This helps to clarify what truly concerns them, allows them to feel heard and understood by the clinician. It is helpful and improves communication to later on use parents' actual words (e.g., "You talked about the *special hours* of your *little lion* in the evening. When did they first happen?")

As the interview progresses you can use more and more *follow-up questions* to clarify details, and *screening questions* to check areas not yet mentioned. If these do not reveal significant information, move on to another topic.

Who is truthful?

As already mentioned, disagreements between observers' descriptions of children's behavior are common and have several potential sources:

- Disagreement actually reflects differences in the behavior of the child in different settings or with different observers
- Different standards when judging the child's behavior
- Ignorance about how other children of the same age behave
- Observers' biases.

To manage discrepant reports, it is useful to collect information from as many sources as possible giving more weight to those that appear more reliable in the clinicians' opinion. In most cases disagreements are more the result of looking at the child from different perspectives or in a different contexts than of truthfulness. The more perspectives from which you obtain information, the more complete your understanding will be and the more accurate the assessment.

Important topics to ask about

There are five key areas of interest in the clinical examination; you may use the acronym **SIRSE** to remember them:

- **S**ymptoms
- **I**mpact
- **R**isk factors
- **S**trengths
- **E**xplanations.

Many parents become distressed when describing their child's deterioration. Giving parents the opportunity to narrate this history in their own words, even if it is initially confusing, may help.

Symptoms

The initial focus should be on the symptoms that led to referral and those that cause most distress to the patient and the family (main complaint). Important characteristics about the problematic behavior that need to be elucidated are:

- Frequency (changes over time?)
- Intensity (changes over time?)
- Duration
- Context in which the behavior emerged
- Progression of the problem.

The next step is to obtain a detailed *history of the problem(s).* A good understanding of their evolution is necessary to ascertain the right diagnosis. For this, it is important to clarify whether a problem:

- Has been present since early childhood (e.g., symptoms of autism)
- Is intermittent or recurrent (e.g., depressive or manic symptoms, tics), or
- Represents a deterioration from a previously higher level of functioning (e.g., schizophrenia).

Check the impact of symptoms on the patient, family, school and peers.

In this part of the examination one also gathers information about all previous treatments including medication, counseling, hospitalization, or use of traditional, complementary and alternative medicine (see Chapter J.2).

Impact

Next is to ask about the impact of these symptoms on the daily life of the child and family members: effect on the patient's quality of life, siblings, parents' relationship, extended family, school class, academic performance, contact with peers, and development. This includes finding out in what context(s) the problems occur and in which they do not or occur to a lesser extent (an example of marked symptoms in the absence of impairment is frequently seen in specific phobias). Remember that problem behavior may reflect:

- An underlying disorder in the child
- A mismatch between the child and the environment
- A problem within the child's environment, or
- Usually, a combination of all the above.

Risk factor
A risk factor is something that increases the chances of developing a disease. This may come from what one does (e.g., using cannabis increases the risk of psychotic symptoms). Other times, there is nothing one can do about the risk. It just exists. For example, adolescent females are more likely to suffer from depression than males. So, gender is a risk factor for depression.

Risk factors

The next step entails screening for relevant risk factors, currently, in the past, and in the extended family (family history). Important risk factors are genetic, developmental, familial, and social. Most of the presumed *causes* of mental health disorders in children are better understood in terms of *risk factors*. There are three different kinds of risk factors and it is useful to divide them into "*the 3 P's*":

- ***P**redisposing* factors, which render the child vulnerable to a disorder (e.g., genes, birth weight, gender)
- ***P**recipitating* factors, which are associated with the emergence or worsening of symptoms (e.g., onset of puberty in anorexia nervosa)
- ***P**erpetuating* factors, which maintain the symptoms (e.g., inadequate parenting style, lack of professional intervention, no access to health services).

Before beginning to ask questions about the developmental history it is helpful to explain to the parents why this is necessary. Otherwise they might get confused about these issues.

A matching analogy is the wind, which blows through a hole in a window. Before the hole existed, the glass might have been fragile in one spot (*predisposing*). The glass was then hit by a stone (*precipitating*) and there were no craftsmen to seal the hole *(perpetuating).* So the wind is still blowing (*symptoms of the disorder*) (Goodman & Scott, 2005).

Developmental history. This is a detailed account of the child's development from the beginning of the pregnancy to birth and early development. It is helpful and time efficient to use a structured approach with screening questions about

important milestones (see Table A.5.3) and follow-up questions, if necessary. Parents often vary in their recollection and timing of developmental milestones. Check for problems in:

- Basic functions (sleeping, eating, toilet training)
- Psychomotor milestones: walking, sitting, fine and gross motor skills, handwriting skills
- Cognitive development and school functioning: history of the child's language development, reading, writing and math skills. Progress at school requires some innate cognitive abilities but also reflects the child's motivation, capacity to concentrate, attitude towards authority, capacity for peer relations, tolerance for frustration and delayed gratification, and a degree of parental support for learning
- Interpersonal development: reaction to separation early in life, ability to play with other children, stability of relationships, number of friends, types of activities shared
- Emotional development and temperament
- Trauma history: physical, sexual, emotional, neglect, acute or chronic, intra- or extra-familiar, violence, natural disaster
- Harmful behavior: head banging or self-injurious behavior, thoughts or comments about death, self-mutilation, cutting, and harmful acts toward other people or animals.

Possible trauma screening question to parents: "Has your child ever witnessed anything really bad or frightening?"
Possible trauma screening question to the child: "Has anyone ever tried to hurt you?"

Particular attention should be paid to changes or discontinuities in the developmental progress.

Family history. This includes (screening) questions about current and past family functioning and about neuro-psychiatric disorders in other members of the family (e.g., alcohol dependency, substance abuse, suicide, and unusual or odd behavior in relatives). Knowing about mental health disorders in the family can help in finding the right diagnosis (e.g., a mother with alcohol dependency could lead to the consideration of a fetal alcohol syndrome).

It should be routine to ask about the neuro-psychiatric disorders on both sides of the family.

The possible parental genetic contribution to the disorder of the child should be assessed (e.g., the existence of bipolar disorder in the father would cast his son's depressive symptoms in a different light), but almost no psychiatric disorder appears through genetic transmission alone, although increased vulnerability to various disorders is likely (Luthar & Prince, 2008). Though unspoken during the psychiatric evaluation, many parents fear that their other children may be destined to be affected when one sibling has a disorder, so clarification of the genetic contribution to the expression of disorders can often be helpful in reducing fear, guilt, and distress among parents and siblings.

The clinician should be attentive throughout the interview to parents' psychopathology (e.g., a depressed mother will often give more negative reports about a child's behavior than a parent who is not depressed.)

Strengths

It is a capital mistake to focus only on the patient's and family's deficits and to neglect the almost always existing strengths, which can give important hints for treatment. Such an approach supports the self-esteem of both the child and the parents and provides information about factors that may help to ameliorate or compensate areas of vulnerability.

"It is important that the tenor of diagnostic inquiry should convey an appreciation that the child is not merely a patient or bearer of symptoms" (King, 1997)

Explanations

It is very informative to ask about the ideas parents have about the nature and causes of their child's behavior in order to know what psychoeducation

interventions may be necessary. To understand how parents and the child understand the evolution of their symptoms can also give important references to the cultural background of this specific family (Sholevar, 2007).

Concluding the interview

Allowing the interview to end in a collaborative fashion increases the likelihood that child and family will feel positive about it and any subsequent clinical encounters. Suitable questions at this stage are:

- *"What else have I not asked about that is important?"*
- *"I have asked you a lot of questions. Do you have any questions for me?"*

"When I meet the parents of a child who suffers from a mental disorder, the first thing I ask them is to tell me what is the most special thing about their child, which abilities, resources, feelings, and talents they recognize in him/her." (Giovanni Bollea, Italian child psychiatrist)

INTERVIEW WITH PARENTS

Aims of the interview with parents

The parental interview seeks to clarify:

- Which aspects of their child's behavior is of greatest concern to them
- What they have tried in order to deal with the problem
- The impact of the child's disturbance on the rest of the family
- If the problem behavior is situation-specific or pervasive (e.g., restlessness and inattention at school but not anywhere else could cast doubt on the presumptive diagnosis of ADHD)
- If there are neuropsychiatric disorders in the family.

Parents sometimes fear that they are the only ones who have a problem with their child. It can be a relief to hear from the clinician that such problem is not uncommon and that he or she has seen and helped many families with this type of problem.

Standardized interviews

Standardized interviews (diagnostic tools with specific questions in a given sequence) are often used in research but can also be an effective help in daily practice. On the one hand, especially for beginners, standardized interviews (especially for developmental and family history) can help cover the key domains of psychopathology. They ensure that clinicians inquire systematically about a broad range of symptoms, particularly those that may be clinically significant but are not the presenting complaint. Using these instruments makes it less likely that comorbid disorders will be missed. On the other hand, these tools can never take the place of an individualized psychiatric interview; they cannot be relied upon as the sole basis for establishing diagnosis or planning treatment. Further, many are only symptom inventories and do not ask for important symptom-related information like situational context, ways of coping, feelings etc (Le Couteur & Gardner, 2008).



"It is of the highest importance in the art of detection to be able to recognize, from a number of facts, which are incidental and which vital. Otherwise, your energy and attention must be dissipated instead of being concentrated." (Sherlock Holmes, "The Reigate Puzzle")

THE CHILD INTERVIEW

The aims of the child interview are to:

- Gain the child's trust. In general, the younger the child, the more time is needed to achieve this
- Obtain the child's perception of the problem
- Get a good understanding of the child's current developmental stage
- Obtain information about emotional symptoms, traumatic events, delinquent acts, drug use, sexual problems
- Collect data for the mental status examination (see below).

Children can often indicate an acceptable point for the parents to leave the room, usually within a matter of minutes, and transitional objects (blankets, teddies) may ease this transition, although this may be impossible in cases of separation anxiety. The older the child the sooner you should be able to finish the conjoint session. Children often find it embarrassing to listen to their problems being discussed in front of them.

"The clinician must be aware of the impact on the interview process of perceived differences or similarities between the clinician and the child (or parents) in terms of gender, age, and ethnic or social background." (King, 1997)

How to start?

Once parents have left the room, it is wise to begin the interview with neutral topics that may interest the child such as talking about favorite hobbies, animals, holidays, Christmas or birthday presents. The next step is to inquire about what the child has been told or understands about the purpose of the interview; this often provides information about the relationship and openness of communication between child and parents as well as on the cognitive development of the child. Some children need encouragement to express their *own* concerns, instead of the worries of parents or teachers. Be aware of how you word your questions: younger children are particularly open to influence of suggestion.

Without trust and rapport, valid information is less likely to be obtained.

Developmentally appropriate interview techniques

Preschool children should not be expected to sit still during the interview and the interviewer needs to decide what play material will be made available for the child. Developmentally appropriate techniques include drawing, playing and direct questioning. The appropriate method for each case will depend on the age of the child (the developmental age more than the chronological age) and the presenting problems (e.g., selective mutism). Inviting the child to draw a picture is almost always a good start. Direct questions should be short, in simple, precise vocabulary and deal with one concrete issue at a time (Jones, 2003). For example, not "Do you get into trouble at school, get along with other students and like sports?" but "Are you getting into trouble at school?"

The child's description of feelings, mood, levels of distress, and significant events contribute to a better understanding of the child's predicament.

Getting involved in the child's play can help to:

- Empathize with them
- Assess their affective state
- Ascertain their coordination and motor skills
- Evaluate speech and language development
- Test attention span
- Understand their capacity for complex thinking
- Assess their capacity for interactive play and "as if" games (especially important when a pervasive developmental disorder is suspected)
- Collect information for the mental status examination (see below).

Generic toys are preferable since they are more likely to evoke the child's specific concerns rather than the prefabricated scripts associated with toys based on TV shows or movies. (Bostic & King, 2007)

Questions to explore children's inner feelings include:

- "What animal would you most/ least like to be?"
- "Who would you take with you to a desert island?"
- "What would you ask for if you were granted three magic wishes?"

Interviewing adolescence patients

The overall sequence is similar to when interviewing other children. However, one would spend considerably more time with the adolescent alone. It is crucial to avoid the perception that parents and clinician are allied against him.

The purpose, duration, confidentiality issues, and the role of the clinician should be discussed early in the child interview in developmentally appropriate terms. Sample questions:

- "What did your parents tell you about coming here today?"
- "How do you feel about being here?"

A suitable way to begin the interview with adolescents is to review and clarify what the adolescent believes and has been told about the purpose of the interview. Adolescents are very sensitive to beliefs that they are perceived as weak, weird or different, about being included or excluded, and about fairness and justice. In this line, useful questions for adolescents include:

- "What do you see as fair or not fair in your life?"
- "What would you most like to change in your school/ family/ the world?"
- "What are your plans for the next 10 years?"

Contrary to popular beliefs, asking about suicide will not induce or trigger it. A caring clinician may be the only adult able to talk about these thoughts with the adolescent.

Confidentiality: "*will you tell my parents?*"

One of the key concerns among adolescents in relation to seeking medical help is confidentiality. Adolescents should always be informed of the confidential nature of the doctor-patient relationship and its limits at the outset: that confidentiality would be broken without the patient's consent only if the patient's safety or the safety of others is at risk. Many countries impose statutory obligations on mental health practitioners to report instances of abuse. Laws in this regard vary and clinicians need to be up to date with the local requirements. The best way to discuss confidentiality is at the beginning of the interview, when the parents and adolescent are present, thus educating parents that what their child discloses is kept confidential.



"Never trust general impressions, my boy, but concentrate yourself upon details."
(Sherlock Holmes, "A Case of Identity")

Special areas of interest for the interview with adolescence patients

- Antisocial or delinquent behavior (e.g., *"Have you done anything that you now look back on and think that was pretty dangerous?")*
- Sexual identity and activity (e.g., *"Have you ever had romantic feelings toward anyone?"* Try to avoid asking questions to a male/female teenager like *"Is there a girl/boy whom you like?"* that may be interpreted by them that you assume heterosexuality when adolescents may be struggling with homosexual feelings
- Alcohol and substance abuse (start with previous exposure, context use – parents, friends, effects of substances – whether they believe that substances alleviate their symptoms, e.g., self-medicate).
- Suicidal ideation or behavior, including non-suicidal self-injury (e.g., *"Do you sometimes feel an urge to hurt yourself?", "Have you ever thout that your life was not worth to live?")*

"The day may come when there are drugs that are specific to particular diagnoses but that day is a long way off at the moment. Both psychological and pharmacological treatments need to focus on particular patterns of symptomatology rather than the diagnosis as such" (Rutter & Taylor, 2008)

MENTAL STATUS EXAMINATION

The aim of the mental status examination (MSE) is to be an objective description, not interpretation, of the child's appearance, symptoms, behavior and functioning as manifested *during the examination*. A well-written MSE enables another clinician or the same clinician weeks, months or years later to have a clear picture of the patient's mental state at the time of assessment. The MSE is an essential part of any psychiatric examination (see Table A.5.1). Strictly speaking, the MSE is purely descriptive, includes no judgment of whether the appearance and behavior is normal or abnormal, clinically significant or non-significant.

Most disorders do not show abnormal feelings or behaviors that cannot be found in normal children or adolescents in some circumstances. The severity

Table A.5.1 Mental status examination

MSE component	Take notice of:	Example
Physical appearance	• Age (actual and apparent) • Age-appropriate clothes, • Grooming and cleanliness • Dysmorphic features, bruises, scars	"Stephanie is a pleasant looking, well groomed and appropriately dressed 9-year-old girl who looks older than her age (like a 12 year old)"
Manner of relating to examiner and parents, including ease of separation	• Eye contact • Ability to cooperate and engage with examination • Behavior towards parents and siblings	"She avoids eye contact but cooperates with the examination process."
Mood and affect	• Type, range and appropriateness of affect (e.g., depressed, elated, irritable)	"Stephanie looks depressed (e.g., cries often, does not enjoy activities and pastimes, feels hopeless), her affect shows limited variation (i.e., within a narrow range) and she describes a depressed mood"
Anxiety	• Fears • Phobias • Obsessions • Compulsions or rituals • Separation difficulties	"She shows no evidence of unwarranted fears or anxiety symptoms"
Psychomotor behavior (including activity level and unusual motor patterns)	• Tics, mannerisms • Activity level • Coordination	"Activity level seems reduced"
Form and content of thinking	• Hallucinations • Delusions • Thought disorder	"Thinking is slowed down but coherent. There is no suggestion of hallucinations or delusions."
Speech and language	• Fluency • Volume • Rate • Language skills,	"Her speech is age-appropriate. There is no pressure of speech."
Overall cognitive functioning	• Developmentally appropriate vocabulary • Fund of knowledge • Appropriate drawings	"Her cognitive ability seems impaired and her vocabulary is below average for her age."
Attention and concentration	• Attention • Concentration	"Becomes easily tired and appears to have difficulty following conversations over a long period."
Memory	• Short-term • Long-term	"Shows no deficits in recalling events."
Orientation	• Orientation in time, place, person	"Is oriented in time and place."
Judgment and insight	• Acknowledgement of problems • Capacity to judge hypothetical situations • Attitude towards receiving help • Compliance with treatment	" patient is aware of the fact that she has a problem, wants to be helped and cooperate with treatment"
Examination of risk	• Suicidal thoughts or behavior • Self-harming behavior • Thoughts or plans of harming others • Risk-taking behavior	"There is no evidence suggesting suicidality or threats to others."

Source: King (2007) modified.

(amount), pervasiveness and nature (quality) of the symptoms determines their clinical significance.

Although presented as a separate component that is distinct from the history-taking, in reality much of the MSE takes place implicitly as the clinician interacts and observes the child during the individual and family interviews. While some components of the examination may require specific inquiry or examination (e.g., orientation, memory, specific symptoms such as hallucinations or obsessions) most will be noted as the interview progresses.

Clinicians should use every opportunity to observe the patient and his interaction with others, particularly with the family. For example behavior:

- In the waiting room (e.g., how did they choose to sit? Are they talking to each other? Arguments?)
- During the initial greeting and introduction
- In the office
- Upon separation (e.g., when parents leave the room)

Describe before interpreting

Since any given symptom may have different meanings, functions and clinical implications in different children it is important not to jump from symptom to diagnosis.

Table A.5.2 Psychiatric symptoms and examples for corresponding somatic differential diagnoses

Symptom	Differential diagnosis
Depression	• Neurological disorders (e.g., tumor, epilepsy, trauma, cerebral atrophy) • Endocrine disorders (e.g., hypo-/ hyperthyreosis, Addison's disease, Cushing's disease) • Kidney diseases (e.g., chronic nephritis) • Metabolic diseases (e.g., hypoglycemia) • Infectious diseases (e.g., AIDS, Lyme borreliosis) • Intoxication (e.g., alcoholism) • Malignant disorders (e.g., chronic leukemia) • Pharmacologic: antihypertensives (e.g., beta blockers), antiepileptic drugs, psychotropic drugs (e.g., neuroleptics, barbiturates), steroids (e.g., glucocorticoids), analgesics • Other: tuberculostatics, antibiotics, cytostatics, antimycotics
Psychosis	• Neurologic disorders (e.g., brain tumor, epilepsy, encephalitis, infections, multiple sclerosis) • Illegal substances (e.g., marijuana, cocaine, LSD) • Intoxication (e.g., alcohol) • Pharmacologic: psychotropic drugs , anticonvulsants, anticholinergics, steroids, antibiotics
Anxiety	• Substance-use disorders: drugs, amphetamine, cocaine, hallucinogens, alcohol, nicotine, caffeine, ecstasy, opioids • Neurologic disorders: organic seizures, migraine, multiple sclerosis, increased intracranial pressure, reduced cerebral perfusion • Other medical disorders: hypoglycemia, hypoxia, hyperthyroidism, carcinoid, dysrhythmia, pheochromocytoma
Anorexia nervosa	• Cancer • Endocrine disorders (e.g., hyperthyroidism, diabetes mellitus) • Gastro-intestinal disorders(e.g. Crohn's disease, ulcerative colitis, gastritis, gastric ulcer) • Malabsorption (e.g. coeliac disease)
Enuresis	• Urological and genital abnormalities (e.g., urethral valve, labial fusion) • Urinary tract infection • Neurologic disorders (e.g., myelomeningocele, spina bifida, tethered cord) • Other medical disorders (e.g., diabetes mellitus)

Source: Herpertz-Dahlmann & Bachmann (2007), modified.

- During psychological testing
- During physical examination

MEDICAL HISTORY AND PHYSICAL EXAMINATION

The aim of the medical history and physical examination is to identify causative, associated or exacerbating medical problems; it has the potential to uncover a treatable somatic condition. Medical conditions can:

- Increase the child's risk for psychopathology
- Be relevant for treatment
- May explain the current psychopathology.

While physical illness mimicking psychiatric disorder is relatively rare in daily practice, knowledge of these possible "diagnostic traps" is important (Table A.5.2.). If there are hints in the medical history that medical conditions or treatments play a role in this patient, further investigations should be done.

Don't forget the somatic part of your diagnostic process, but mental health clinicians also need to know when to accept that a child has been adequately examined and investigated.

We suggest a *stepwise approach* to this part of the examination (time and cost-effective):

- Step 1: brief medical history
- Step 2: basic physical examination.

If steps 1 and step 2 are unremarkable, it seems reasonable to avoid further examination and investigations. If further examination is necessary:

- Step 3 (if indicated by steps 1 or 2): investigations and specialist referral.

Past medical history

A systematic history-taking approach should be used as a guide to the possibility that somatic problems might be relevant with respect to the presenting symptoms. This includes a clinical history of medical disorders in the patient and in the family. Studies have shown that medical history-taking often influences management while physical examination only rarely does (Dooley et al, 2003).

Red flags that would suggest the need for a more detailed physical examination (step 3) include:

- Atypical presentation of symptoms or atypical age of onset (e.g., hallucinations in a 7-year-old girl)
- History of seizures
- History of head trauma or central nervous system infection
- Regression in development
- Over the 97th or under the 3rd percentile in any of the growth curves
- Suggestions of child abuse or factitious illness (e.g., Münchausen by proxy)
- Sudden onset of new and odd behavior (e.g., hand flapping in Rett syndrome)
- Altered level of consciousness, severe fatigue, cognitive changes, and physical symptoms such as sore throat, fever, headache, nausea, and weight changes

Parents will occasionally report a loss of previously acquired skills; this always needs to be taken seriously and should lead to suspicion of neurodegenerative disorder and specialist referral.

- Acute onset of obsessions and compulsions and or motor or vocal tics, particularly following pharyngitis (PANDAS, see Chapters F.4 and H.5).

The following checklist lists all relevant parts of a medical history in child mental health:



"The little things are infinitely the most important." (Sherlock Holmes, "A Case of Identity")

Pre- and perinatal development

- Consanguinity of the parents?
- Use of assisted reproductive technologies?
- Pregnancy (full range of teratogens: alcohol, tobacco, illicit substances, medications; history of rashes and fever during pregnancy – may indicate exposure to congenital viral infection)
- Previous neonatal deaths or acute life-threatening episodes in siblings (could be a pointer towards inborn error of metabolism)
- Previous spontaneous abortions (two or more) – one in 20 of these parents will carry a chromosome translocation or inversion (Gardner & Sutherland 1996)
- Birth and neonatal history: gestational age at birth; weight; APGAR score, if available (difficult birth is a risk factor for developmental problems).

Table A.5.3 Overview of developmental milestones

Age	Motor skills	Language
3 months	Holds head steady	Imitates sounds
6 months	Can roll over	
9 months	Sits without support	Combines syllables into word-like sounds
12 months	Stands alone	Uses 20 single words
15 months	Walks alone Plays with ball	
18 months	Carries items while walking	Can make two-word sentences
2 years	Can run Can kick a ball forward	Child uses own name Asks "Why?" Can name at least six body parts
3 years	Jumps, balances on one foot	Uses four to five words in a sentence Uses singular and plural
4 years	Bounces	Uses past tense, recounts experiences
5 years		
6 years	Bounces cross-step	Language development completed

*Use only as rough reference.

Accidents or illnesses with a potential for central nervous system impact deserve specific inquiry.

- Lead exposure
- Seizures
- Head trauma
- Loss of consciousness.

Postnatal development

Early developmental history (up to 5 years). Encourage bringing parent-held records of vaccinations etc to the first examination if available. A general view of the milestones of development is given in Table A.5.3.

History of past illnesses

Common disorders in childhood (e.g., asthma) should lead to an enquiry into medications that the child takes, both prescribed and over-the-counter. All extended hospital stays after birth; surgical procedures; vaccination; states of loss of consciousness and seizures; hearing or vision difficulties; allergies (particularly to medications); and response or side effects to previous medications should be collected.

The clinician should be especially alert to the mentioning of diseases that can affect the central nervous system including HIV/AIDS, tuberculosis, lupus erythematosus, epilepsy, migraine, traumatic brain injury thyroid disorders, diabetes.

Basic physical examination

Who should do medical examination?

Physicians who keep up their skills to perform a physical examination (for which they usually worked hard in medical school) this can provide an additional opportunity to learn more about the child's concerns (especially about body-related

Table A.5.4 Skin inspection in child psychiatry

Dermatologic symptoms	Possible hints for:
• Needle tracks, abscesses or hyperpigmentation on the arms	• Substance use disorder
• Bruises, hematomas of different age	• Child neglect • Physical abuse
• Signs for non-suicidal self-injury (e.g., scars)	• Borderline personality disorder[a]
• "Café-au-lait" marks after age of 1 year >1.5cm • Freckling in armpits after 3 years	• Neurofibromatosis type 1[b] (rare)
• Ash-leaf depigmented macules • Adenoma sebaceum • Periungual fibromas	• Tuberous sclerosis[c,d] (rare)
• Port wine stain usually in the trigeminal region	• Sturge Weber syndrome[b] (rare)

[a]The most common location for non-suicidal self-injuries is the inner part of the left under arm.
[b]Neurofibromatosis Type 1, tuberous sclerosis, and Sturge Weber syndrome are neurocutaneous syndromes (phakomatoses). These disorders affect the central nervous system, the skin and the eye. All these tissues have a common ectodermal origin.
[c]0.4%-3% of children with autism are found to also have tuberous sclerosis (Smalley et al, 1991).
[d]The best diagnostic test is a cerebral MRI.



Click on the picture to access an 8-minute crash course on neurocutaneous disorders.

issues) and about the mental status. For psychologists and other mental health professional with a non-medical education it is practical to find out if there had been a physical examination of the child in the recent past or to refer the patient to a physician (optimally, a pediatrician).

A screening neuro-developmental examination is sufficient and does not require the child to fully undress.

The following parameters should be assessed:

- Height and weight (centile charts)
- Head circumference (centile charts; the most common cause of large and small heads is simply familial, and thus comparison of mid-parental head centiles should precede interpretation of a single measurement)
- Blood pressure (use an appropriate cuff for the size of the child – e.g., one that covers two-thirds distance from the elbow to shoulder; interpret with age-appropriate values)

The following procedures should be undertaken:

- Skin check (see Table A.5.4)
- Basic neurological examination:
  - Stance and gait
  - Tests for cerebellar function (e.g., check for dysdiadochokinesia)
  - Tone, power, reflexes
  - Abnormal movements (fasciculations, tics, myoclonus, dystonia, athetosis, hemiballismus, tremor).

Of all the aspects of the neurological examination, observing the child's gait is the most valuable. A normal gait depends on intact and delicately balanced motor, sensory, and coordination systems. A normally walking child is unlikely to have a severe neurological impairment (Wolf et al, 2008).

Investigations, tests and specialist referral

The range of investigations, tests and specialist referrals available may vary substantially from country to country. What is described here is the optimal situation but many of these investigations will not produce positive findings in the immense majority of cases:

- Blood tests
- Urine tests (toxicology screen, pregnancy testing)
- Brain imaging (first choice: MRI; second choice: CT)
- Genetic investigation (key pointers in physical examination: noticeable dysmorphy of the face, hands and feet; over the 97th or under the 3rd percentile in any of the growth curves).
- Metabolic investigation (key pointers in history: consanguinity, failure to thrive, episodic decompensations, often during minor illnesses; hepatosplenomegaly, coarse facial features). A general metabolic screening is more useful than a genetic investigation, EEG or cerebral imaging, and may therefore be more worthwhile.
- Electroencephalography (EEG)



If you suspect a rare metabolic or genetic disease and you do not have the option of referral to a specialist, click on the picture to access "orpha.net" and check the "search by signs" function. This portal (for rare diseases and orphan drugs) is available in English, Spanish, German, Italian, French and Portuguese.

Use any chance you have to see children with rare disorders. Knowledge of what phenotypes exist is a precondition for their recognition. Phenomizer is a site with useful information that allows clinicians to enter a patient's clinical features and obtain probabilistic differential diagnoses. For a tutorial on how to use Phenomizer click here.

Rating scales are tools to complement an evaluation, not to replace it.

- Electrocardiogram (EKG)
- Hearing examination
- Eye examination.

RATING SCALES AND PSYCHOMETRIC ASSESSMENT

The aim of this section is to give readers a brief overview of tools that may assist in finding the right diagnosis and in individualizing treatment.



"There is nothing more deceptive than an obvious fact."
(Sherlock Holmes, "The Boscombe Valley Mystery")

Rating scales

Rating scales are instruments (paper and pencil or computer-based) used to collect data about the presence (qualitative measurement) and severity (quantitative) of symptoms. Rating scales can be used as a source of additional diagnostic information, to monitor and measure the effectiveness of treatment (outcome), and as research tools. They can also be used for screening, to ascertain whether a child should be evaluated more thoroughly for mental health disorders (Verhulst & Van der Ende, 2008).

Pros and cons of rating scales

Pros:

- Helping to detect problems that are clinically significant but not part of the presenting problem
- Helping to conduct a comprehensive examination
- Some parents and adolescents may reveal concerns in writing that they do not verbalize
- Rating scales can be completed by parents, teachers, and patients outside the interview and so help to make the interview more effective and efficient
- Scales that rate severity can be useful to quantify a baseline to later assess response to treatment (e.g., ADHD-symptom checklist before and after treatment with methylphenidate).

Cons:

- Require time and literacy
- May be disliked by parents or children

Table A.5.6 The Strengths and Difficulties Questionnaire (SDQ)

Purpose	Languages	Comments
Screening for mental health disorder in children and adolescents (Goodman et al, 2000)	Available in 73 languages	• Free for noncommercial purposes • High SDQ-scores –upper 10% in a community sample – were associated with increased psychiatric risk • Used worldwide • Very brief: 25 items all in one page • High specifity but low sensitivity (use only as a screening instrument) • Can be completed by the patient on-line and get immediate feedback.

Source: Carandang and Martin (2009).

- Require time to rate and analyze
- Clinicians may over-rely on them.

There are rating scales for completion by the patient, the clinician, the parents, teachers and other informants (e.g., youth workers). A combination of these tools is used in everyday practice. An example of a rating scale used worldwide – available free in numerous languages for noncommercial purposes – is the Strengths and Difficulties Questionnaire (SDQ), presented in Table A.5.6. Completed by parents, teachers, the child, or all of them, the 25 SDQ items were designed to include both strengths and difficulties. The SDQ is a generic scale to rate a wide range of problems. In many cases, however, particularly if a specific disorder is suspected (e.g., depression, ADHD) using a more detailed, targeted rating scale in addition to a generic one is useful (see the diagnosis section of the respective chapter in this e-book).

Psychometric assessment

The art of an effective psychometric assessment is the accurate use and valid interpretation of psychometric tests. Test results may help clinicians to:

- Find the diagnosis or comorbidity
- Identify the individual's profile of cognitive strengths and weaknesses
- Plan treatment (e.g., the level of communication in future psychotherapy).

There are a huge number of psychological tests for children and adolescents and the choice depends on the individual patient, the suspected diagnosis and the knowledge and experience of the tester. Assessment of the patient's cognitive functioning is often helpful for diagnosis and treatment planning (see Chapters C.1 and C.3).

Intelligence: "the sum of all higher mental processes"

There is disagreement among experts on what exactly *intelligence* is but there is strong empirical evidence that intelligence tests measure something meaningful about development, cognitive abilities and adaptive behavior (Charman et al, 2008). The *intelligence quotient (IQ)* shows moderate to high stability over time and correlates highly with real-life outcomes, such as academic achievement, employment and income.

Suitable IQ-Tests have age-graded norms and are well standardized (see Chapter C.1). *When* a test was normed is relevant because there has been a modest increase in scores over time in some countries, possibly due to improvements in diet and education. Standardized intelligence tests produce scores with a mean of 100 and standard deviation of 15. Standard scores are then used to define average, below average or superior ability depending on how many standard deviations above or below the general population mean a child's performance lies. An IQ below 70 is a strong indicator for the existence of an *intellectual disability* (see Chapters C.1).

Observation of the child in the test situation is an important part of assessment. The following characteristics should be documented and considered when interpreting the test results:

- Degree of cooperation with the examiner

Testing the theory of mind: the Sally/Anne test

The Sally/Anne test is a psychological test with dolls, used in developmental mental health to measure a person's social-cognitive ability to attribute false beliefs to others (i.e., the theory of mind, for more details see Chapter C.2). The clinician uses two dolls, "Sally" and "Anne". Sally has a basket; Anne has a box. Clinicians show the children a simple sketch, in which Sally puts a marble in her basket and then leaves the scene. While Sally is away and cannot watch, Anne takes the marble out of Sally's basket and puts it into her box. Sally then returns and the children are asked where they think she will look for her marble. Children are said to "pass" the test if they understand that Sally will most likely look inside her basket before realizing that her marble isn't there. Children under the age of four, along with most autistic children (of older ages), will answer "Anne's box," seemingly unaware that Sally does not know her marble has been moved.



Click on the picture to access a video clip explaining the Sally/Anne test.



"There is nothing more stimulating than a case where everything goes against you."
(Sherlock Holmes, "The Hound of the Baskervilles")

- Activity and concentration level
- Social and communication skills
- Specific areas of difficulties

Test results may be influenced by:

- Language problems
- Motor coordination problems
- Medications
- The current psychopathology (e.g., depression)
- Vision and hearing problems.

If there are major discrepancies between the test results and the child's performance described by parents or teachers or with the clinical observations, this will always require further study.

The examination is not complete until findings are communicated to parents, the child and referring agency.

COMMUNICATING FINDINGS AND RECOMMENDATIONS

The aim of this last but essential part of the examination process is to summarize the findings into a clinical formulation, a clinical diagnosis and to communicate them in a clear and helpful way to all relevant parties. This may require one or more sessions where treatment recommendations and options are discussed and decided upon.

In most cases it is useful to spend some time processing all the information collected, scoring rating scales and considering the differential diagnoses and recommendations. Parents may be anxious to hear what is wrong with their child (and family). So, much sensitivity is required. Disappointment, sadness or grief, denial and other emotions are common, especially when the diagnosis destroys expectations about the child's future.

Guiding principles for feedback:

- Plain, non-technical language
- Nonjudgmental
- Strength-orientated
- Sensitive
- Practical.

You need to be aware that *very little* of the information you give *will be retained*, especially if the session is highly emotive. So, in some cases you may

provide a report or a succinct written summary for the parents. If appropriate and feasible, offer further sessions to discuss issues once the family has had the chance of working through the information.

Never let a family go with just the diagnostic information. Always present them with treatment options and hope.

An explicit emphasis on the child's and the family's *strengths and abilities* facilitates the feedback process and gives a more realistic picture of the patient as an individual rather than a mere illness-oriented diagnosis. Avoid technical terms and psychiatric jargon (instead of: "*The theory of mind of your daughter is insufficient*" it seems better to say: *"Sally has some problems understanding that others have beliefs, desires and intentions that are different from her own."*). Just naming the diagnosis is never enough. Explain the rationale for the diagnosis and influencing factors. The formulation is more helpful than a simple clinical diagnosis in understanding and helping the child and the family. Explain if *areas of uncertainty* remain, including whether diagnosis can change over time and what the likely outcome, treated and untreated, might be. If the diagnosis is provisional, be clear that you are not sure.

"To cure sometimes, to relieve often, to comfort always." (Edward Livingston Trudeau, 1848-1915)

With or without the child?

- Depending on the nature of the problem and the developmental stage of the child it may be appropriate for the child to be present. If yes, take a few minutes and explain your findings to the child directly. A good strategy is to start describing the strengths of the patient, then talk about the difficulties and the options to reduce them, and end again talking about the strengths and instilling hope that the current situation will get better
- Provide a clear focus for therapeutic intervention.

Clinicians have to ensure that findings and recommendations are:

- Heard
- Understood and
- Experienced as helpful.



"Nothing clears up a case so much as stating it to another person."
(Sherlock Holmes, "Silver Blaze")

To enhance compliance with future treatment, rather than experts, clinicians should become partners with the patient and family in the decision-making process. In most cases it is possible to outline several treatments, with their risks and side effects, and help parents decide which one they wish to follow. If parents are eager to pursue treatments that are unhealthy, unproven or dangerous, the clinician should highlight the risks of such a decision.

When discussing prognosis, it is necessary to combine instilling hope with a realistic view of the long-term outcome of the disorder. In many cases the long-term therapeutic goal will be finding ways to live with the illness (including the risk of recurrences), than a cure.

There is an imperfect match between the neat diagnostic descriptions given in textbooks and the clinical presentations seen in clinical practice. Clinicians must always be on the alert for unusual patterns that do not fit existing diagnostic conventions.
(Rutter & Taylor, 2008).

TROUBLESHOOTING

The following advice is in case you feel lost in the evaluation process and have no idea about the right diagnosis in a particular child. The sequence should be applied flexibly:

- Ignore the DSM and ICD constructs for a moment and go back to the description of the problems. Just try to describe as well as you can what is unusual in this patient. After that, think again about which diagnosis(es) match this pattern of symptoms

- Talk with a colleague about this case, especially experienced ones
- If possible, videotape an examination (with the permission of patient and parents), show it to colleagues and ask for their opinion
- Maybe there is nothing wrong with the child. For whatever reason the child is presented seeking help when a family member is the one with mental health problems
- It is often not possible to conduct the whole diagnostic process in one appointment
- If you get stuck in the differential diagnosis, remember that common disorders are frequent and rare disorders are rare
- Symptoms can present atypically in cases with multiple comorbidities (e.g., depression in an autistic child)
- If you have a prime suspect diagnosis but you are still unsure, then check the differential diagnosis part of the respective chapter in this or another good-quality textbook (see References)
- Do not ignore possible somatic diagnosis, side effects of medications or effects of illicit drugs
- Think about the possibility of factitious or shared disorders (e.g., a mother with schizophrenia makes her young child believe that both are being pursued by the secret service)
- There will always be cases in which symptoms do not fit in with a specific diagnosis because classification systems are not perfect and presumably will never be. As Leo Kanner, a pioneer child psychiatrist, put it in the title of his paper on differential diagnosis: "The children haven't read those books" (Kanner, 1969).
- There will be cases in which there is no suitable diagnosis, because the illness is not yet described or, more likely, because the patient has no psychiatric or medical illness but a problem of living and is more in need of advice than of complex therapy.

"When you hear hoof beats behind you, don't expect to see a zebra" (Theodore E Woodward MD)

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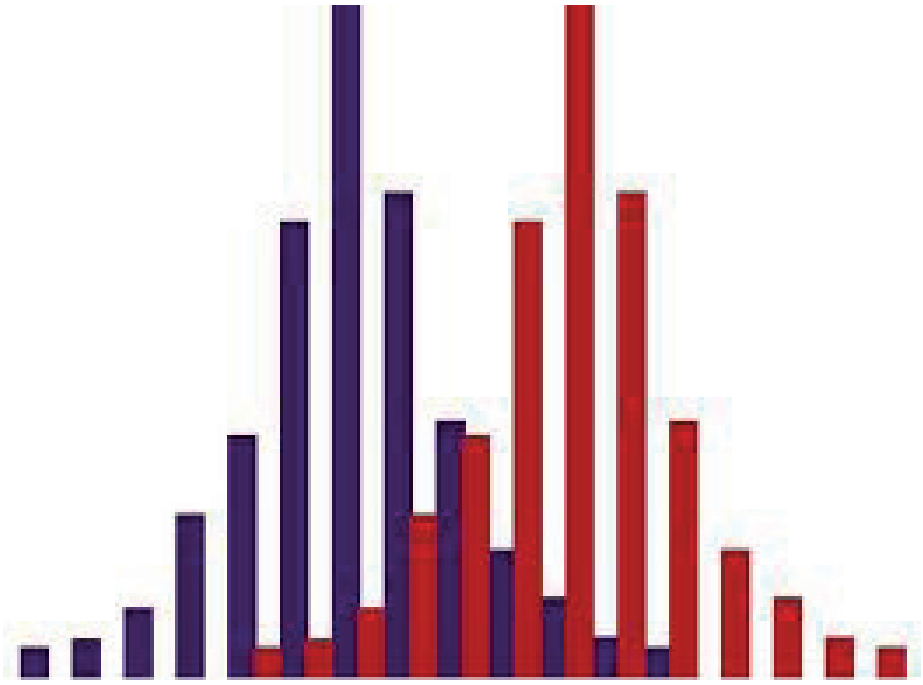
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*Recommended reading.

EVIDENCE-BASED PRACTICE IN CHILD AND ADOLESCENT MENTAL HEALTH

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Acknowledgments. Professor Eric Youngstrom, University of North Carolina, Professor Peter Szatmari, McMaster University, and Dr Eric Daleiden, PracticeWise LLC, were very helpful reviewers in correcting

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Suggested citation: Hamilton J, Çuhadaroğlu-Çetin F. Evidence-based practice in child and adolescent mental health. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

This chapter shows you how to use data from those studies with less bias and less random error in order to make good clinical decisions to help youth seeking clinical treatment for mental health problems. Specifically, this chapter shows you how to:

- Think about bias and random error as undesirable
- Understand those statistical concepts most relevant to aligning your clinical work with good evidence
- Search databases electronically available at no cost to anyone with an Internet connection
- Use good diagnostic interview techniques to show that the youth does or does not meet criteria for well-defined syndromes
- Find the treatments most likely to be effective for those syndromes.

In brief, this chapter shows clinicians how to align what they do with *what works*: actions that will facilitate a higher proportion of youth to improve their functioning more substantially and more quickly than alternative actions. But to get at the truth about what works, it is first necessary to do battle with two great enemies of the truth: *bias and error*.

and adding to earlier drafts. The final responsibility for the manuscript, including errors, belongs to the authors. You may contact the corresponding author at john.hamilton@kp.org

Error

All experiments or clinical decisions are subject to either random error, systematic error or both. *Random errors* are due to unknown and unpredictable changes in measuring instruments or in the environmental conditions. *Systematic errors* (or bias), by contrast, are inaccuracies that are consistently in the same direction. They may occur because there is something wrong with the measurement instrument (e.g., a rating scale, diagnostic criteria) or because the instrument is wrongly used by the experimenter (e.g., a clinician who systematically over-estimates − or under-estimates − suicide risk).

BIAS AND RANDOM ERROR

The problem of bias

Bias interferes with validity – the degree to which a study measures what it intends to measure – by creating systematic (non-random) deviations from the underlying truth (Guyatt & Rennie, 2002). Bias is different from *random error*. Random error is diminished by increasing sample size, whereas bias can remain in a sample of any size. Consider the targets (a) through (d) in Figure A.6.1 where the bull's eye in the center marks the true effect. In study (a), there was little or no systematic deviation from the true effect (little or no bias), as well as little scatter (random error). In (b), there was also little bias but much random error, and in (c) much bias but little random error. In (d) there was much bias and random error.

Figure A.6.1 Examples of bias and of random error in data samples (Kabai, 2011a).

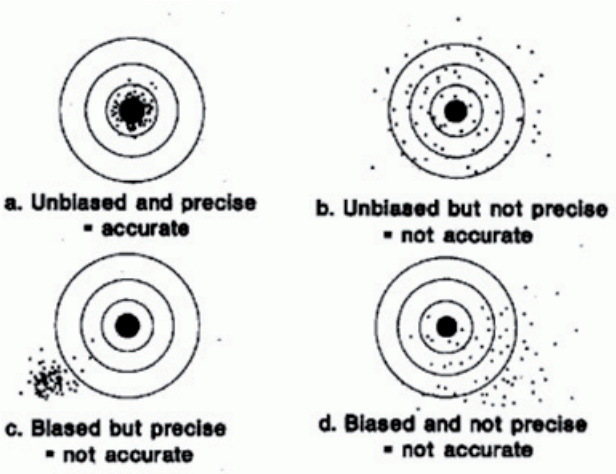
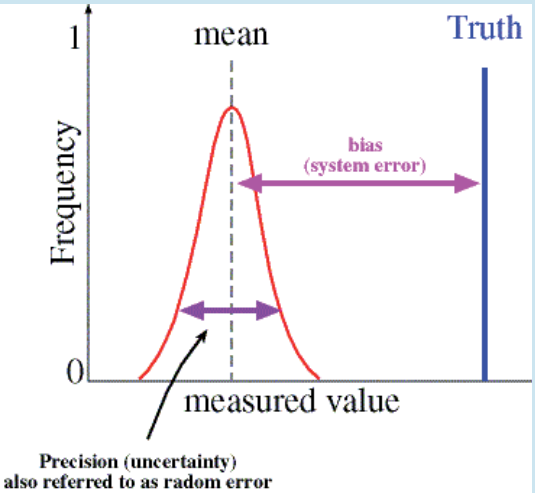


Figure A.6.2 Schematic representation of random error and bias (Kabai, 2011b).



Finding evidence with low bias and low random error

The most useful evidence in guiding clinical decisions is evidence *with minimal bias and minimal random error.* Figure A.6.2 is a schematic representation of random error and bias. Table A.6.1 shows common sources of bias and strategies for reducing each while Table A.6.2 shows common sources of random error and strategies for reducing it.

Bias

Bias is an ever-present risk in research, even in well-designed RCTs. For example, positive outcomes are reported much more commonly in trials funded by the pharmaceutical industry (78%), compared to those without industry sponsorship (48%) or those financed by a competitor (28%) (Kelly et al, 2006).

Table A.6.1 Common sources of bias and strategies to reduce them.

Source of bias	Strategy to reduce the source of bias
• Treatment and control patients differ in prognosis	• Random allocation to treatment or control
• Placebo effects of treatment	• Patients blinded to active treatment or control
• Caregivers add other treatments	• Caregivers blinded to treatment or control
• Assessors of outcome are biased	• Assessors of outcome blinded to treatment or control status of cases they assess
• Loss to follow-up	• Follow-up of all or at least a high proportion of cases entering the study

Table A.6.2 Two common sources of random error and strategies for reducing each.

Sources of Random Error	Strategy to Reduce It
• Imprecise measuring instruments	• Improve precision of instruments
• Small sample size	• Increase sample size

USEFUL EVIDENCE-BASED PRACTICE CONCEPTS

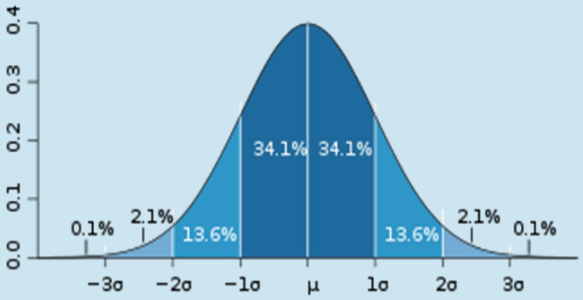
Mean

A few basic statistical concepts are all that is needed to understand many core ideas used in evidence-based approaches. First, recall the basic *normal* or Gaussian curve which describes the distribution of many aspects of nature, and which can be derived mathematically using probability theory. The most common value is the same as the *mean* value, represented here by the Greek letter *mu* (μ).

Standard deviation (SD)

SD is a measure of variability: it reflects how much variation or "scatter" there is from the mean value (average). A small SD relative to the mean indicates a distribution where the data points are closely clumped together. A large SD relative to the mean indicates a distribution where data points are spread out over a large range. SD is sometimes described as the *typical amount that cases differ from each other*. Two out of three cases are expected to fall within plus or minus one SD of the mean.

Figure A.6.3 Plot of a normal (Gaussian) distribution having a mean value represented by the Greek letter *mu* (μ) and a standard deviation, *delta* (σ), represented by each colored band. Note that slightly over one-third (34.1%) of the population of this distribution lies within one standard deviation above the mean; slightly over one-third (34.1%) also lies within one standard deviation below the mean. Only about 2% of the population lies within 2 or more standard deviations above the mean, and only about 2% lies within 2 or more standard deviations below the mean (Wikipedia).



Effect size

Effect size in a research study measures how big the effect of a treatment is, relative to the differences between cases in general. It is the standardized mean difference between the two groups in a study. Technically, this is measured as the ratio of the difference due to treatment compared to what is called the *pooled* standard deviation. *Pooled* refers to combining figures from both the control and experimental group to create a pooled standard deviation.

$$\text{Effect size} = \frac{[\text{Mean of experimental group}] - [\text{Mean of control group}]}{[\text{Pooled standard deviation}]}$$

Figure A.6.4 shows a typical representation of data from an experimental treatment in child psychiatry with an effect size of 0.73. Note that the two curves overlap considerably.

How to calculate the pooled standard deviation can be found at statistical sites (e.g., http://www.leeds.ac.uk/educol/documents/00002182.htm). Effect size places the emphasis on the most important aspect of an intervention − the size of the effect − rather than its statistical significance, which is determined by both effect size and sample size.

Example of effect size

A study (McCracken et al, 2002) sought to examine whether an atypical antipsychotic (risperidone) was more effective than placebo in reducing aggression, tantrums or self-injurious behavior in children suffering from autism aged 5 to 17 years. Scores after 8 weeks on a measure of irritability were 11.3 (SD 7.4) for the treatment group and 21.9 (SD 9.5) for the control group. What is the effect size?

Effect size = (11.3-21.9) / 9.5, that is 1.1. This is a large, highly significant effect size. Effect sizes above 0.5 are often considered clinically significant, but smaller effects can still have clinical significance if the treatment can easily be applied to large populations (e.g., the use of aspirin to prevent heart attacks, where the effect size is small but when this occurs over large populations, the public health consequences are significant).

Absolute risk reduction (ARR)

Absolute risk reduction is a measure used to compare two different alternatives: *how much does one treatment reduce the risk of a specified "bad" outcome (like a depressed youth staying depressed) compared to either an alternative treatment or placebo?* For example, in the Treatment for Adolescents with Depression Study (TADS), at 12 weeks, 65.2% of adolescents receiving placebo were not rated as improved or very much improved compared with only 39.4% of adolescents receiving fluoxetine. Therefore, the ARR of not improving for youth with major depressive disorder who took fluoxetine compared to placebo was 65.2 - 39.4 = 25.8%. In other words, fluoxetine reduced the risk of not improving considerably: 25.8%, or about 1 out of 4.

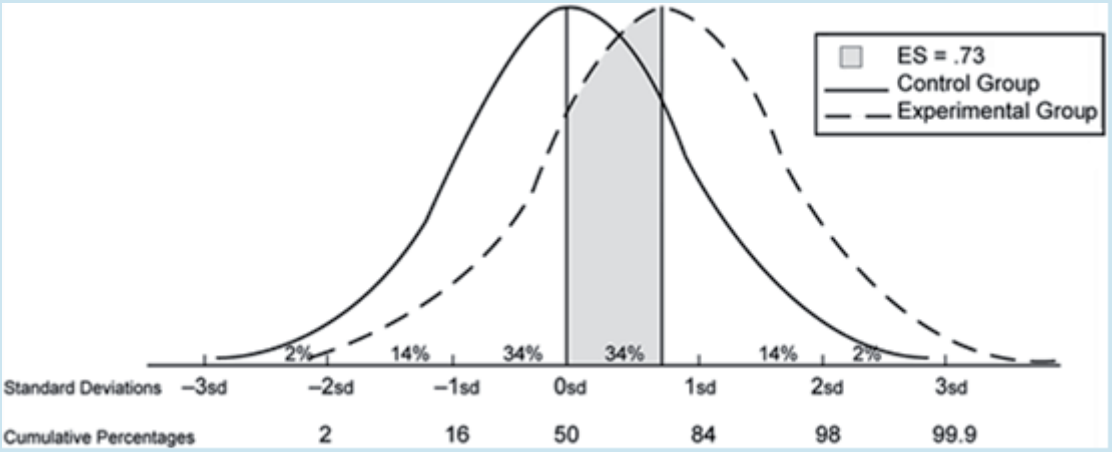


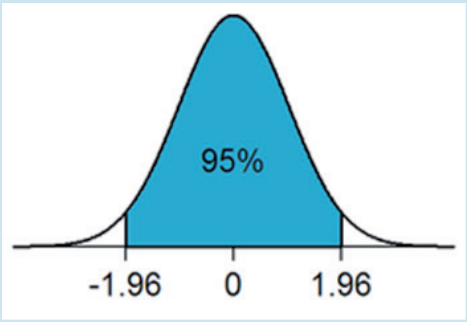
Figure A.6.4 Data from this randomized controlled trial shows that, relative to the control group, the experimental group after treatment has improved: it has moved to the right 0.73 standard deviation units. Therefore the effect size is 0.73.

Absolute risk reduction is helpful for two reasons. First, as discussed below, the ARR can be used to compute the *number needed to treat* (NNT). The formula is simply NNT= 1/ARR with the answer rounded up to the next whole number. Second, the ARR does not exaggerate the treatment effect as does the *relative risk reduction* (RRR) which is simply computed as the risk in the treatment group divided by the risk in the control group. In TADS the RRR when comparing outcome for youth receiving fluoxetine to youth receiving placebo is the risk of depressive symptoms being rated as not significantly improved in the treatment group receiving fluoxetine divided by the risk for youth not being significantly improved in the placebo group, or 39.4 / 65.2 = 0.60, generally expressed as 60%. Note that this figure is quite different from the absolute risk reduction as calculated in the paragraph above (25.8%). In general, ARR is a more useful statistic than the RRR.

Confidence interval (CI)

Rather than beginning with a definition, a specific example might be more useful to gain a feel for this important concept. Suppose the Minister of Health tells you she is concerned about depressed teenagers and she asks you to determine the *average* (i.e., mean) level of symptoms of depression in 13 year old children in the large city where you live. You accept the challenge and begin the project by arranging for 13-year olds from all over the city to complete an inventory of depressive symptoms. The mean score is 39.8 on the 49 completed questionnaires. You calculate the standard deviation and it is 9.0. The Minister of Health wants you to estimate, based on your data from the 49 returned questionnaires, how close is your mean to the *true* value, also called the *population* value. That is, if it were possible to assess *all* 13-year old children in the city with this depression scale, this would presumably be very close to the *true* value. You can see, therefore, that the *true* or *population* value is a useful concept, but in reality, it is often not practical to test all the children. Simply by chance you may have ended up with a higher proportion of unhappy children or of unusually happy children in your sample than is present in the city in general, even if you managed to avoid being biased in your sampling (like choosing only students from the same school, or only students in a certain class).

Figure A.6.5 An important fact associated with the "1.96" in the formula for calculating 95% confidence intervals: 95% of the area of a normal distribution is within 1.96 standard deviation units of the mean.



You tell the minister the mean score in your sample is 39.8, as a rough estimate. She, however, wants to know more, and asks, "How rough an estimate is that? What is the highest true value? And the lowest?" You answer, "Yes, I can give you a range or interval but it depends on how often you want me to be right. Do you want me to be right like 80% of the time that I give you these estimates? Or 95%? Or even 99%? The more you insist that the answer I give you does contain the true answer for the population, the wider the interval will be." The minister says, "OK. I want your answers on these kinds of estimates to be correct 95% of the time." The minister has just asked for the 95% confidence interval of your calculated mean.

Confidence intervals can make you a data wizard



A statistician can now help. She tells us that a good estimate for calculating confidence intervals in normal distributions is as follows, where N is the number of subjects generating the data (49 in this case) and SQRT means square root:

Confidence interval, upper bound = Calculated mean + 1.96 x SD/ SQRT N

Confidence interval, lower bound= Calculated mean - 1.96 x SD/ SQRT N

Therefore the confidence intervals are:

CI_{upper} = 39.8+1.96x9.0/SQRT 49 = 39.8+1.96x9.0/7 = 39.8+2.52 = 42.32

CI_{lower} = 39.8-1.96x9.0/SQRT 49 = 39.8-1.96x9.0/7 = 39.8-2.52 = 38.28

Now you have an answer for the Minister.

In summary, CIs are expressed with three numbers, the first being the mean, our best estimate of the true value. The other two numbers are of course the numbers stating the lower bound of the interval and the upper bound. The more certain we want to be, the wider the confidence interval will be: wide confidence intervals *make sure* the correct number is in there somewhere. *Confidence intervals are important because statistical analysis of studies is based on the central idea that, despite making observations on a limited sample of subjects, the inferred truth to be drawn from the study will apply to the population of all such subjects.* The main purpose of a confidence interval is to indicate the precision or imprecision of the study sample as an estimate of the true population value. Confidence intervals are therefore useful and even necessary whenever an inference is made from the results of one study to the wider world. In the first example, there were only 49 children completing the depression questionnaire, but the Minister hopes to generalize the findings to all 13 year old children in the city. Also note that even if you and the Minister chose your sample wisely – e.g., from very different schools in different



How high should be the hurdle researchers require for a youth to be considered "improved" when they calculate NNT?

Higher hurdles will raise NNT because fewer youth will get over them.

parts of the city to avoid bias – the problem of random variation in the level of depression symptoms remains. Merely by chance, you may have come across children with notably higher or notably lower depression levels than exist in the entire population of children of that age in the city, even though there was no significant systematic bias in your sampling method.

Number needed to treat

The number needed to treat, often abbreviated NNT, can be used to summarize in a single number how effective a specific treatment is compared to placebo. NNT is defined as *the number of people we must treat in order to prevent one additional bad outcome*. A *bad outcome* is defined by specific criteria. Therefore low NNTs (like 3 or 4) indicate an effective treatment, because it is common for the treatment to *convert* a patient to a successful outcome who would not have improved without the treatment. Typical successful outcomes are improved mood or improved functioning, often defined with a cutoff point on a scale.

Note, though, that NNT depends very much on the *hurdle* that needs to be cleared in order to be considered "better" or "cured." *How high or low this hurdle is will impact on the NNT hugely.* Always note, therefore, what hurdle authors have chosen when reading a paper and noting an NNT.

High NNTs (like 25, 30 or even higher) suggest either a treatment that is not very effective or an outcome that is difficult to achieve. For example, if we require that a successful outcome in a depressed adolescent is an outcome without a single depressive symptom, then it will be difficult to achieve this outcome and the corresponding NNT will be higher than if we had chosen a more modest outcome.

Number needed to harm

Number needed to harm is abbreviated NNH and summarizes how frequently a specific side-effect occurs with a specific treatment. NNH is defined as the number of people we must treat in order that a single person is harmed by the treatment who would not have been harmed if he had received only a placebo intervention. For example, with medications, an undesirable effect or side effect occurs that would not have occurred if the patient had received a placebo. Therefore high NNHs indicate a safe treatment: many individuals must receive the treatment before a single individual is harmed by the treatment. Decisions to recommend a specific treatment will therefore require balancing the benefits (NNT) with the risks (NNH).

Mann et al (2004) conducted a meta-analysis to estimate the effectiveness of acamprosate in achieving abstinence among alcoholics. They reported that across studies 36.1% of participants taking acamprosate had achieved abstinence at 6 months compared with 23.4% of those on placebo. What is the NNT?

In this case NNT = 1/ (0.234-0.361) = 7.9. That is, eight patients (it is customary to round to the next whole number) will need to be treated with acamprosate for one additional patient to abstain from alcohol at 6 months compared to those not receiving treatment.

Number needed to harm (NNH)

NHH equals one divided by the rate in non-exposed minus rate in exposed individuals.

In the Treatment for Adolescents with Depression Study (TADS) Team (2004) study the authors reported that 11.9% of participants treated with fluoxetine alone had reported some harm-related event, compared with 5.4% for placebo. What is the NNH?

In this case NNH = 1 / (0.119 - 0.054) = 15.4. That is, fifteen depressed patients will need to be treated with fluoxetine for one additional patient to suffer a harm-related event attributed to the medication.

UNDERSTANDING A STUDY BY LOOKING AT ITS BASIC STATISTICS

Now consider the results from a study examining the response of children and adolescents with an anxiety disorder using these core statistical concepts. Called the Child/Adolescent Anxiety Multimodal Study (CAMS), this study recruited children and adolescents from multiple sites with common anxiety disorders – generalized anxiety, social phobia, or separation anxiety disorder – and randomized these youth into receiving one of four possible treatment strategies: CBT alone, sertraline alone, combined CBT and sertraline, and placebo.

The graph in Figure A.6.7 shows Pediatric Anxiety Rating Scale (PARS) scores for the 4 groups, each receiving a different treatment. Scores greater than 13 are consistent with an anxiety disorder. Combining sertraline and CBT, based on these data, is the most effective treatment. The *error bars* on the PARS figures show how much *scatter* there is in those numbers. The top of an error bar is most easily understood as the mean plus the standard error of the mean (calculated as the standard deviation / square root of the number of participants), and the bottom of the error bar is the mean minus the standard error of the mean. More complex methods of calculating *standard error* represented by the error bars also exist.

In this case, the clinical magnitude of the impact of treatment on outcome was evaluated by calculating effect sizes for each of the 3 intervention groups compared to the placebo group: how different were each of the 3 intervention groups on the PARS compared to the placebo group? Based on improvements on the scale the authors used to measure anxiety in youth, the PARS, the effect size at 12 weeks was 0.86 for combination therapy, 0.45 for sertraline alone and 0.31 for CBT alone.

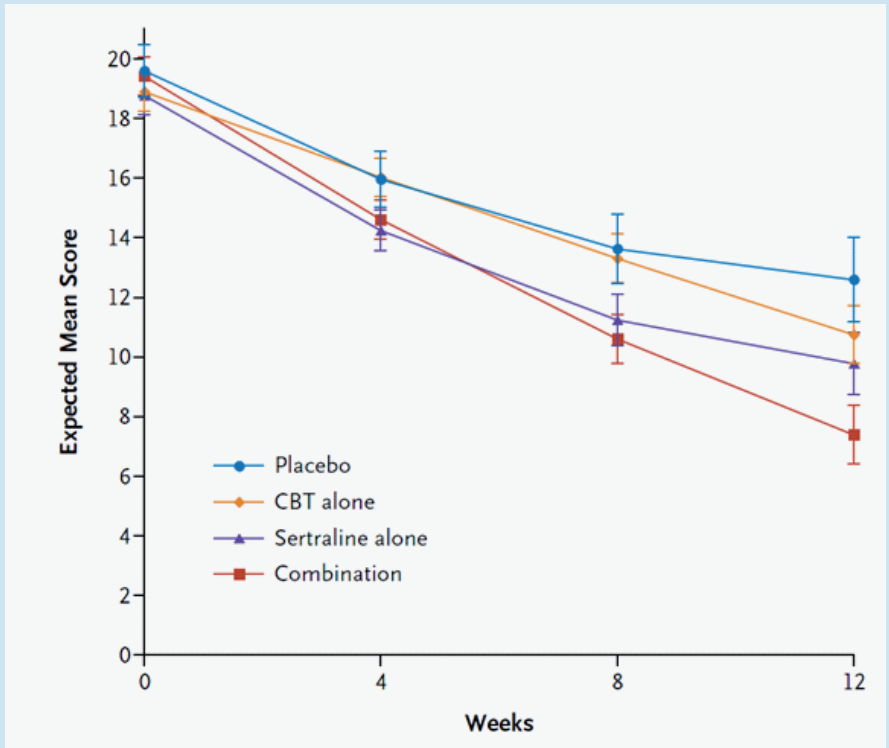


Figure A.6.7 Results from the Child/ Adolescent Anxiety Multimodal Study, a trial randomizing anxious youth into one of 4 different treatments. (Reproduced with permission from Walkup JT et al. Cognitive behavioral therapy, sertraline, or a combination in childhood anxiety. N Engl J Med 2008; 359:2753-2766. Copyright ©2008 Massachusetts Medical Society).

The authors also calculated the number needed to treat. Recall that to calculate an NNT, we must choose a "hurdle" for each subject to "clear". Higher hurdles are more difficult to clear and therefore will generate higher NNTs; lower hurdles will generate lower NNTs. The authors chose as a hurdle that the youth must be rated as either improved or very much improved on the PARS by the end of treatment at 12 weeks. Using this criterion, the authors calculated the NNT for sertraline alone as 3.2 and for cognitive behavioral therapy alone as 2.8, and for the combination of both treatments the NNT was 1.7. This low NNT is encouraging because it demonstrates that effective treatments exist for many youth with anxiety disorders.

The authors also used statistics to convey to readers how certain they are that their results were not a lucky fluke caused by random events that together resulted in improvements in those youth receiving sertraline and CBT. To assess this possibility, the authors calculated the confidence intervals for each effect size and for each number needed to treat. The confidence intervals for 95% certainty around the calculated effect size of 0.86 were 0.56 to 1.15 for youth receiving the combination of sertraline and CBT compared to youth receiving placebo, which is a good, robust effect in child psychiatry. Effect sizes of 0.8 and higher indicate a large effect, 0.3 and below a small effect according to Cohen's (1988) conventions.

RELIABILITY AND VALIDITY OF DIAGNOSTIC METHODS

THE FOUNDATION OF EVIDENCE-BASED PRACTICE

Aligning the diagnostic methods in your practice with the diagnostic methods used by researchers is important because then youths in your practice who you define as having, for example, major depressive disorder, will tend to have similar constellations of depressive symptoms to those youth whom researchers studied when testing treatments for major depressive disorder. You can then confidently import their results about what helps such youth into your own practice.

So, how reliable are the procedures you use to identify syndromes in youth? Reliable means first that the test when used repeatedly yields consistent results. For example, if a well-defined, structured diagnostic interview produces identical or very similar results when re-administered a short time after the first administration, this suggests the test is reliable (test-retest reliability). Reliable also means it yields the same or very similar results when used by different observers on the same youth (inter-rater reliability)?

And how valid are the diagnostic systems you use to identify syndromes in youth? A valid diagnostic system is one that truly measures what it claims to measure. For example, a valid diagnostic system to assess the severity of depression is one that actually measures the severity of depression. Evidence supporting the validity of a diagnostic system for the severity of depression might include data showing that self-reports of depression severity from adolescents are highly correlated with reports from trained interviewers who interview the same adolescents using that diagnostic system. Diagnostic agreement between structured diagnostic interviews of the type often used in research studies and clinical evaluations vary widely by disorder and is low to moderate for most disorders (Rettew, 2008).

Reliability

Reliability is the consistency achieved by a measuring instrument (e.g., a diagnostic test or questionnaire) across individuals, times and clinicians. Reliability is measured using the kappa (κ) statistic for categorical variables (e.g., diagnosis) and intraclass correlation coefficient (ICC) for continuous variables (e.g., scale scores). Common values for both range from 0 (not better than chance) to 1 (perfect agreement). Reliabilities above 0.5 are acceptable and above 0.7 are excellent.

Validity

Validity is the extent by which a diagnostic system measures what it claims to measure. Assessment of validity is often indirect, relying on the capacity of a measure to agree with other measures of the same construct, or to predict course, outcome, response to treatment etc. Correlation coefficients and factor loadings are both common ways of quantifying at least some types of validity.

TABLE A.6.3 Examples of reliable measurement instruments* (see also Chapter A.5)

Disorder	Instrument
Anxiety disorders including generalized anxiety disorder and separation anxiety disorder	• Screen for Child Anxiety Related Emotional Disorders (SCARED) • See also Chapters F.1 and F.2
Depressive disorders including major depressive disorder and dysthymia	• Hamilton Rating Scale for Depression (HAMD-21) • Johns Hopkins Depression Checklist for Children (HDCL-C) • See also Chapter E.1
Attention deficit/ hyperactivity disorder	• Swanson Scale for ADHD (SWAN ADHD) • The SNAP-IV Teacher and Parent Rating Scale • Vanderbilt ADHD Diagnostic Parent Rating Scale • See also Chapter D.1
Obsessive-compulsive disorder	• Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) • See also Chapter F.3

*These instruments were developed and tested in Europe and the US. Syndromes in countries far-removed from these geographic areas may be substantially different. In addition, remember that the results of a single instrument are only one aspect of coming to a conclusion, or even an initial hypothesis, about diagnosis; many other sources of data such as the interview with the youth, his parents, as well as historical information and medical and psychiatric records are also useful.

In summary, a reliable and valid diagnostic system is an essential foundation to clinical practice. Unfortunately, unstructured clinical interviews have a poor track record for reliability and validity in diagnosing youth with psychiatric disorders. Diagnostic interviewers proceeding with no structure tend to jump to conclusions, often fail to assess important co-morbidities, and produce diagnostic results that are not reliable. This is a major problem but one that can fortunately be solved.

Reliable and valid diagnostic instruments

Creating a reliable and valid diagnostic system is a difficult challenge. The most useful aids to create such a system are specific diagnostic instruments for specific classes of disorders. Diagnostic aids are often available free on the Internet, are highly useful in defining disorders and their severity and, importantly, serve as a baseline which may allow you to measure change in symptoms during treatment. Some examples of what is available for some of the most common disorders can be found in Table A.6.1.

An example of using diagnostic tools to assess an adolescent

Correctly "translating" symptoms described by young persons, their parents and teachers into a psychiatric syndrome or, at least, part of a syndrome (*subsyndromal condition*) is important. This step takes the unique complaints of an individual child and family, translates them into a recognized disorder, and tries to avoid the many possible sources of error in the process. Consider, for example, Sam, a 14 year old boy whose parents complain he is constantly irritable and having trouble sleeping. He has falling grades and withdraws socially. His constellation

of symptoms may fit into more than one syndrome. Adolescents may become irritable when feeling anxious or oppositional but irritability also suggests the possibility of a mood disorder; his social withdrawal similarly has many possible origins. Fortunately, widely available and inexpensive broad-based assessment tools are useful in getting the diagnosis right (see Table A.6.1).

Whereas these instruments help us zoom in and define more precisely symptom levels in the domains suggested by the clinical history, we also need a way to zoom out and screen Sam for other, less obvious syndromes such as being a victim of trauma or abuse, or using substances, or having a behavioral disorder he has neglected to tell us about.

Screening questions from a well-recognized comprehensive assessment of psychopathology can be helpful here. The Kiddie-SADS (K-SADS) is a widely used semi-structured diagnostic interview procedure generously placed in the public domain for non-profit use and ethical research (Kaufman et al., 1997). Note that the K-SADS is not a structured interview – one in which the interviewer repeats written questions verbatim – but rather a semi-structured interview in which the interviewer has the choice of several possible questions trying to probe the same domain. Interviewers do *not* have to ask every question, but rather stop when they have sufficient information. Here are some K-SADS screening questions designed to probe for possible alcohol abuse:

- *How old were you when you had your first drink?*
- *What's your favorite thing to drink?*
- *Do you have a group of friends you usually drink with, or do you usually drink alone?*
- *Where do you usually drink? At home? Parties? A friend's house? The street? Bars?*
- *Are there special times when you are more likely to drink than others? School dances or other parties?*
- *How old were you when you started to drink regularly, say two drinks or more per week?*
- *In the past six months has there been at least one week in which you had at least two drinks?*

What is a good way to screen for trauma?

Here is a sampler of how the semi-structured interview K-SADS asks about trauma, but only after a "warm-up" period to gather basic information and put the youth at ease. Note that proper use of the K-SADS requires training and the list below includes only some of its questions about trauma (Kaufman et al, 1997)

1. Traumatic Events

Probe: I am going to ask you about a number of bad things that often happen to children your age and I want you to tell me if any of these things have ever happened to you. Be sure to tell me if any of these things have ever happened, even if they only happened one time.

a. Car Accident: Have you ever been in a bad car accident? What happened? Were you hurt? Was anyone else in the car hurt?

b. Other Accident: Have you ever been in any other type of bad accidents? What about a biking accident? Other accidents? What happened? Were you hurt?

c. Fire: Were you ever in a serious fire? Did your house or school ever catch on fire? Did you ever start a fire that got out of control? What happened? Did anyone get severe physical injuries? Was there a lot of damage?

The K-SADS continues from this point with questions about witnessing a disaster like a bad storm or a violent crime, domestic violence, or physical or sexual abuse.

The authors of the K-SADS suggest a clear threshold for further assessment: either the youth or parent reports the youth has 2 or more drinks per week for at least 4 weeks. The explicit thresholds of the K-SADS for "counting" a symptom as present or absent are useful, as are its suggested questions. They are clear and direct, yet offer the interviewer multiple ways of getting the information needed. The specificity of the K-SADS questions, their clear thresholds, and the presence of screening questions are useful for clinicians trying to improve the reliability and validity of their clinical interviews. Using the entire interview requires specific training and may be unrealistic in many clinical settings, but its probes, suggested questions and thresholds are useful.

Once a good – reliable and valid – diagnostic evaluation of the adolescent has been completed, the task of choosing a treatment is next.

CHOOSING A TREATMENT

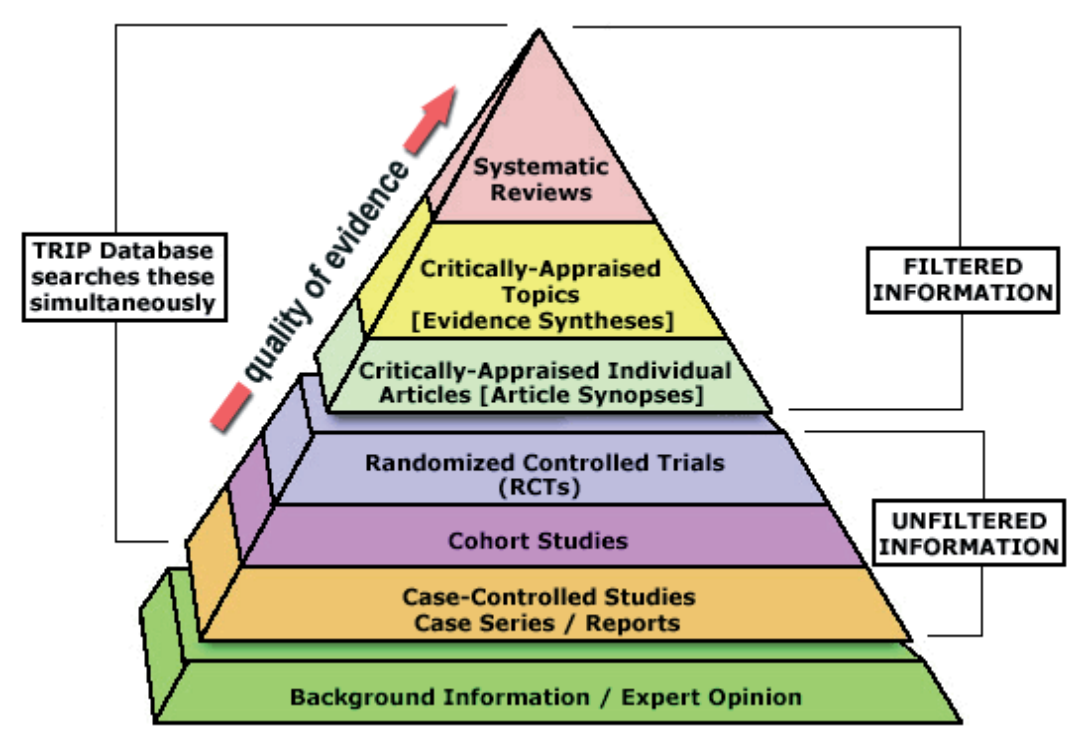
The concept of a pyramid of evidence

A *pyramid of evidence* is a useful way of summarizing what is the *best* evidence – that is, closest to a precise statement of the truth. Sources of evidence with less bias and less random error are placed higher up, towards the top of the pyramid as the most credible. Pyramids are a good shape to represent the transition from the hundreds or even thousands of sources of "lower level evidence" such as case studies, non-controlled trials and even expert opinion rightly placed close to the base of the pyramid – to the relatively few systematic reviews of randomized controlled trials and meta-analyses that synthesize all the most credible evidence – rightly placed at the top of the pyramid. Since there are many case reports and other studies likely to contain bias and random error and relatively few that thoughtfully synthesize all credible evidence, the broad base and narrow peak shape of a pyramid is especially appropriate (Figure A.6.8).



Pyramids are a good shape to represent different kinds of evidence, since they are broad at the base and narrow at the top. Our goal is to get to the top, where the view is good, minimizing distorting biases and random error.

Figure A.6.8 A pyramid of evidence where higher-up on the pyramid means more freedom from bias and random error.



Source: University of California, San Diego, library system and its TRIP database which uses 'filters' (software programs) to select published evidence most free from bias and random error.

Background information

At the bottom, background information on the subject, such as the neurophysiology of depression or autism, for example, and the opinion of experts with experience provide only weak evidence. Background information only sets the stage for what might happen: many possible dramas can occur using the same stage set. If, for example, imaging studies show changes in blood flow in frontal cortical areas in depression, this does not necessarily help us choose the most effective treatment for depression.

Expert opinion

Similarly, *expert opinion* can be dead wrong. The expert may be employed by a drug company and feel pressure to favor a specific drug, or may feel shame about negative outcomes, or pride about positive outcomes and subconsciously slant the results in a positive direction, or simply be loyal to a certain treatment because it is familiar. The main point is that a single individual's opinion unsupported by systematic data gathered using recognized methodology represents weak evidence. Familiar humor states this conclusion as "In God we trust. Everyone else, bring data."

Cases series

Case series and case reports are also near the bottom of the evidence pyramid. A single practitioner assessing a single case, carrying out the treatment, and then assessing the results is highly vulnerable to biases. Case series produce

weak data because there is no comparison group, although their data may be useful to investigators generating hypotheses for future studies.

Case-control studies

Case-control studies can be useful in showing an association between exposure to a risk factor and an outcome. In case-control studies, the outcome is known, such as adolescent suicide. The investigator then creates a control group of individuals without the outcome but with similar characteristics as the individuals with the known outcome and determines the rate of exposure to a risk factor in the controls compared to those with the known outcome. Using this methodology, the accessibility and availability of a gun in the home has been shown to be associated with increased risk of adolescent suicide (Brent et al, 1993). This is useful evidence when advising parents of a potentially suicidal adolescent.

Cohort studies

Cohort studies can be useful in demonstrating prospectively an association between exposure to a specific risk factor and outcome. Here sampling is by exposure, not by outcome. Children exposed to certain kinds of abuse, for example, are known to be at higher risk of developing depression. Some cohort studies use very large databases, even including all children in an entire country, and therefore generate great statistical power (the ability to detect even a small effect).

Randomized controlled trials

Individual randomized controlled trials (RCTs) are the principal building blocks of higher levels of the pyramid. With their unique advantages of a control group chosen at random and often deliberate blinding of subjects, treating clinicians, and assessors as to assignment to the active intervention or control group, RCTs have unique advantages. Higher levels of the pyramid are designed to wring out limitations on RCT data, such as eliminating data from poorly done RCTs, while combining data from multiple well-done RCTs to generate a larger number of subjects studied in order to minimize random error. Beware of ignoring unpublished RCTs.

CONSORT stands for Consolidated Standards of Reporting Trials.

Click here to access the CONSORT checklist of information to include when reporting a randomized trial.

Critical appraisal

The critical appraisal of individual articles eliminates data from trials with significant flaws. Perhaps such a flawed trial did not adequately blind raters, for example, or lost a large proportion of the sample to follow-up. If so, then the results may contain significant bias and the studies are excluded. The results of critically-appraised individual articles on the same topic, now known to be free of obvious sources of bias, can then be pooled to increase sample size in order to reduce random error. Consider using specific convenient checklists of criteria when appraising a study, such as the Consolidated Standards for Reporting Trials (CONSORT) checklist, if and when you have time to do so.

The flow diagram in Figure A.6.9 (page 20) shows how some critical steps in running an RCT are worth keeping in mind as you read a paper. At times, for example, an author may describe a study as a "randomized trial" even though it is clear in the methods section that assignment was not truly random. There are many potential sources of bias in doing an RCT, but most practitioners simply don't have the will, the time or the statistical and research expertise to read through a published RCT. Critical appraisal implies having a critical look at each step of

a study to ensure that no bias is passed through to the final results. Attending a course in EBM and participation in a journal club for people interested can help to improve critical appraisal skills.

Evidence synthesis and systematic reviews

Evidence synthesis pools data from individual RCTs that have been critically-appraised for possible sources of bias. Pooling data tends to decrease random error to produce a more precise result.

Finally, systematic reviews are an especially organized method of evidence synthesis relying on agreed-upon standards of synthesis. With this methodology, perhaps best exemplified by the Cochrane Library's electronic library of Systematic Reviews, the method used to combine data and draw conclusions is well-established prior to beginning the review. This methodology is also transparent, in that the reader can review how the results were obtained. A meta-analysis is a type of systematic review that considers data from several studies to arrive at a single estimate of the effect size or NNT.

USING THE INTERNET AND THE PYRAMID TO FIND EFFECTIVE TREATMENTS

Answering questions relevant to your practice using the Internet

Try to remain curious when doing clinical work: ask questions relevant to caring for the patients you see that day. This means asking questions relevant to the specific case and trying to answer them by using the Internet to look through the published literature, focusing on evidence free from bias and random error.

The first step is to ask a question. To achieve this, begin the question with "What is the evidence that…?" This ensures that the question can be answered: you will either find there is no evidence, in which case the answer is "none," or you will find at least some evidence.

The goal of a search is a practical result, good enough to inform care without claiming to be definitive, within the time and resources available. Technology allows searching databases for valid and relevant results. Software has made sensitive and specific searching easy on PubMed, the Internet site of the National Library of Medicine in the United States. PubMed is maintained by the United States government at no cost to users and no subscription is necessary. PsycINFO, the Internet site for psychological studies, is maintained by the American Psychological Association and offers *abstracts* at no cost to users. CENTRAL, the Cochrane Library's database of controlled trials, is based in the United Kingdom. CENTRAL is the abbreviation used for The Cochrane Central Register of Controlled Trials; it contains summaries of nearly 700,000 controlled trials both from PubMed and EMBASE, a database especially strong in European journals. EMBASE is accessible only to subscribers and is maintained by Elsevier, a corporation based in Amsterdam. PubMed is a good place to start for questions related to medication and includes studies that were not RCTs. PsycINFO is good for questions related to psychosocial issues. CENTRAL is good to search exclusively for results from RCTs.

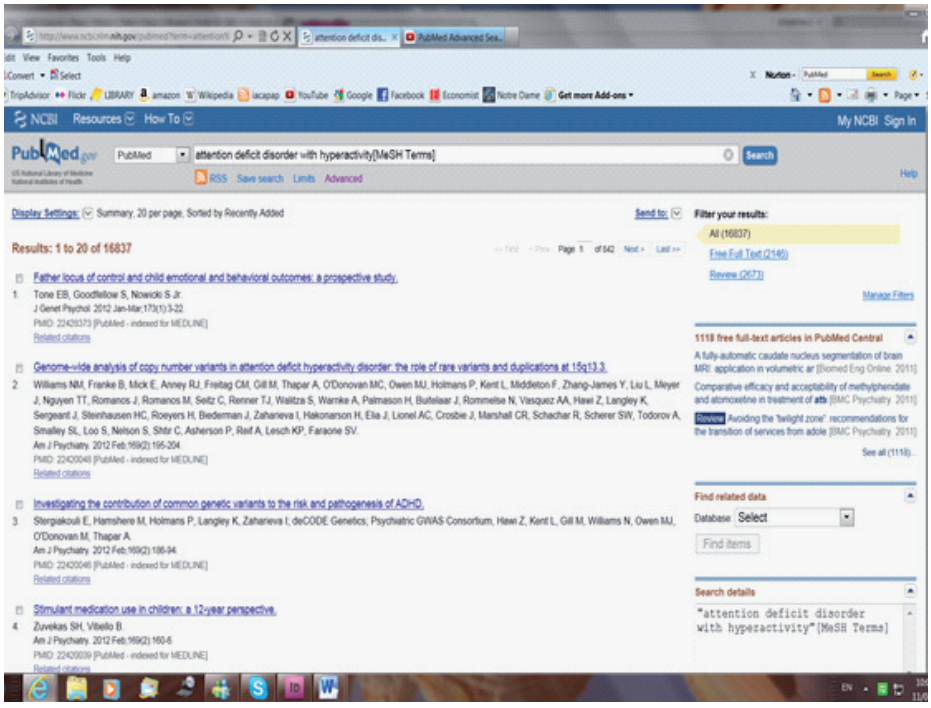


The logo of PubMed, a free source of evidence. It has filters to find systematic reviews, useful as summaries of high-quality evidence

Terry: a 10-minute search for a solution for a boy with inattentive type ADHD

A child psychiatrist is trying to help a 10-year-old boy with inattentive type ADHD (ADHD-I). Based on SWAN scores (see Table A.6.3) from his teacher, he required methylphenidate 15 mg three times daily to achieve a substantial improvement (a teacher rating of less than 9 on the first nine SWAN questions, the inattentive items). But he lost so much weight on this regimen that it had to be stopped. Now his parents are increasingly frustrated and are seeking a solution: "Isn't there anything else?" His child psychiatrist wants an agent other than a stimulant or atomoxetine – both suppress appetite. Our doctor recalls how helpful guanfacine has been in the past treating ADHD boys with ODD and hyperactive/impulsive symptoms. But is guanfacine effective in ADHD-I? What is the evidence that guanfacine is effective in 10-year boys with ADHD-I? If it is effective, what is the effect size?

1. As a reasonable place to begin, go to PubMed. Click on "Advanced", select in the drop down menu "MeSH term" (MeSH stands for Medical Subject Headings), type "attention deficit hyperactivity disorder" in the search box and click "Search". The result should look like the figure below.



There are too many resulting "hits" to be able to read through them yourself – over 16,000! We need a way to limit the results to a manageable number by choosing only those results from the top of the pyramid in order to see the *best* evidence. Here's how.

2. Begin at the top of the pyramid: search for any *meta-analyses* published. Go back to the search page and, after repeating the previous step, type "guanfacine" in the serach box "AND" and "All Fields" and click "Search". This results in 94 "hits". Now click on "Limits" and select "Meta-Analysis" in the new menu and clik "Search"; 2 hits result but this boy does not belong to the population studied by either article: one concerns adults,

Searching PsycINFO

PsycINFO is an excellent database choice for searches of constructs like "bullying" or "identity" because it has a thesaurus of index terms. Searching the term "bullying", for example, shows the following Index Terms listed in a column to the left of the abstracts, along with the number of hits for each index term.

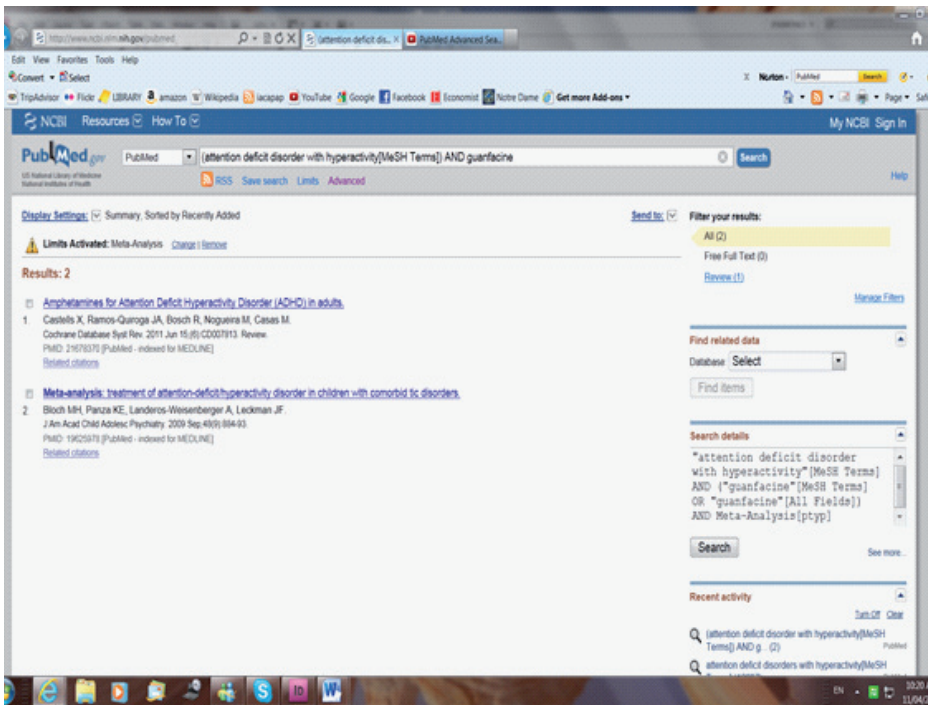
Index Term:

- Bullying (2,808)
- Victimization (1,175)
- Aggressive Behavior (845)
- Peer Relations (543)
- Schools (437)
- 5 more...

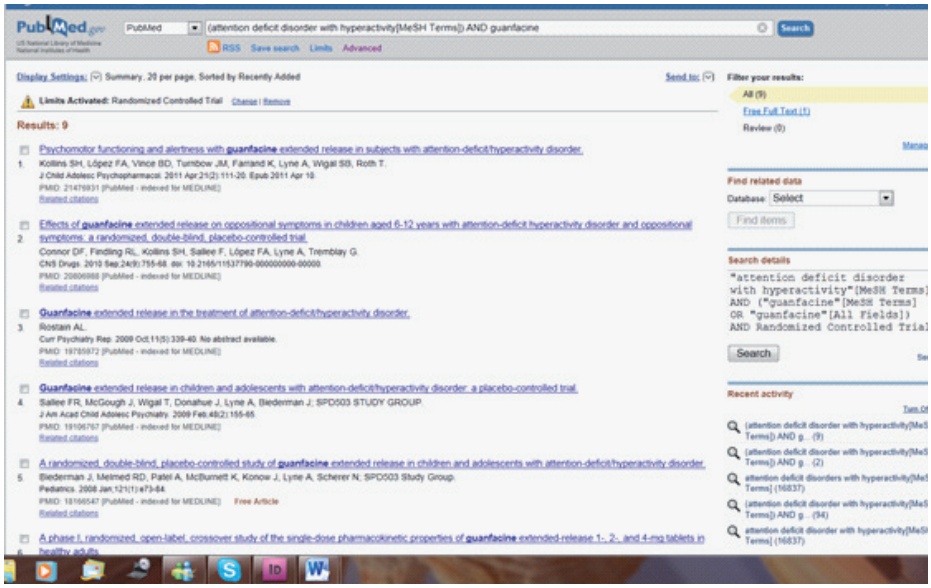
Clicking on the hypertext on the website brings you to those abstracts which are available at no charge. Use the "Advanced Search" tab to search "bullying" and also choose "Only Show Content Where…" to include the dropdown menu choice "Treatment Outcome/ Randomized Controlled Trial." This reduces 2808 hits to only 10 (October 28, 2011).

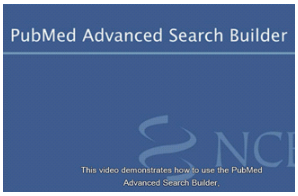
For an exercise, try finding all randomized trials studying the effect of relaxation training in adolescents.

the other, children with ADHD and tics, and our patient has ADHD without tics (see Figure below). We have become too selective and need to broaden the search.



3. Move down a step in the pyramid to RCTs by changing the "Limits" box from "Meta-analysis" to "Randomized controlled trials", and 9 articles appear (see Figure below).





Click on the picture to view a video tutorial on how to search using PubMed (2:27)

Articles 4 and 5 are the only ones directly relevant to a 10 year old boy, and only article 5 is available in full text at no charge (Biederman et al, 2008). This article was funded by pharmaceutical companies, a potential source of bias, and concerns extended-release guanfacine, which is expensive and not available to this boy. A quick Internet search, however, finds that guanfacine's half-life in children and adolescents is 13 to 14 hours, suggesting that it is possible to mimic the extended-release preparation with an affordable preparation – guanfacine itself – taken at least twice daily (Strange, 2008).

How big was guanfacine's effect on inattentive symptoms in youth with the combined type ADHD among the children studied? The authors note "Effect sizes in the GXR treatment groups calculated *post hoc* were 0.58, 1.19, and 1.34 for the 0.05 to 0.08 mg/kg, 0.09 to 0.12 mg/kg, and 0.13 to 0.17 mg/kg groups, respectively." However, these effect sizes were for the changes in ADHD total scores (inattentive and hyperactive/impulsive symptoms). Fortunately, the authors clarify "All groups of children taking GXR showed significant improvement on both the hyperactivity/impulsivity and inattentiveness subscales of the ADHD-RS-IV [a rating scale] compared with placebo. Mean changes from baseline in hyperactivity/impulsivity in the placebo and GXR 2-mg, 3-mg, and 4-mg groups were –4.06, –6.94, –7.09, and –9.46, respectively. *Mean changes from baseline in inattentiveness were –4.78, –8.46, –8.71, and –9.51, respectively.*[italics added]" Even though no effect size is offered concerning changes in inattentiveness alone, these data suggest that the effect size will be at least equal to the effect size for inattentive and hyperactive/impulsive symptoms combined.

It is reasonable to conclude that the 10-year old boy with inattentive type ADHD may respond with a significant reduction in symptoms to guanfacine titrated to a dose of 1.0 to 1.5 or 2.0 mg twice daily.

Internet strategies to find information about a broad subject area

Rather than looking for evidence on a specific clinical question about one youth, imagine that you are writing a guideline for your country on how to treat children and adolescents with schizophrenia. One relevant question might be, "What is the evidence there are effective treatments for youth with schizophrenia?" Begin by finding the most current, relevant data from randomized trials. Begin searching PubMed for treatment studies in children and adolescents with schizophrenia. Here's how to do it (note that the number of hits will change with time as new studies are added).

1. *Find the medical subject heading for your search topic*. Enter "Schizophrenia" in the PubMed search box after using the dropdown menu to change the setting to "MeSH". This means you are now searching the Medical Subject Headings used by the National Library of Medicine in the United States. These Medical Subject Headings are used to categorize every article published in the medical literature, making it possible to retrieve all articles on the same subject. In this case, multiple (12) MeSH terms are retrieved, commonly described as 12 hits. Each contains the word "schizophrenia" either in the title or the description.
2. *Send the relevant terms to the Search Builder box, combining them with "OR."* Only 6 appear relevant since the final 6 concern an unusual protein. After selecting these 6, click on "Add to Search Builder".
3. *Add a truncated version (tw) of the central concept as a text word to the search with an "OR*". In this case, add "Schizophren*"(tw) to the search box with the "OR" operator. This step will retrieve any article containing any word beginning with the letters "Schizophren" in the title or abstract. This additional term can help find any articles which may have not been correctly classified under one of the MeSH terms as containing information about schizophrenia, as well as articles only using such terms

Searching the Cochrane Library's CENTRAL database

Searching CENTRAL for "bullying" yields 36 hits, all RCTs studying bullying. One done in Australia, for example, in 2009 shows promise in adolescent boys, and did not appear in the PsycINFO search for RCTs of "bullying." (Berry K and Hunt CJ (2009), Evaluation of an intervention program for anxious adolescent boys bullied at school. Journal of Adolescent Health 45:376-382). CENTRAL is useful in retrieving RCTs from around the world and making abstracts available at no cost to everyone.

as "schizophrenic" or "schizophrenics"

4. *Search PubMed with this string of "OR" terms.*

   125889 hits occur. It is time to now get more specific and begin carving this large set of references into only the most relevant.

5. *Click on "Limits" and check the box "Children 0 to 18"*

   22545 hits remain

6. *Click on "Limits" and check the boxes "Meta-analysis" and "Randomized controlled trial".*

   945 hits remain. This may be a reasonable number to look through for a major position paper for an entire country. Two or three individuals could scan the titles and abstracts and choose the most relevant. Alternatively, you could go back to "Limits" and choose the box "Published in last 5 years", further reducing the number of references. Note also that many references only concern adults, not children or youth, and can be dropped immediately.

Here is an alternative if you don't have the time to look through so many hits:

1. Return to step 1 and note that one of the MeSH terms returned is "Schizophrenia, childhood." Send only the term "Schizophrenia, childhood"[MeSH] to the search box, ordering the search engine to only search that single MeSH term. 1434 hits appear.
2. Now apply the limits "Meta-analysis" or "Randomized controlled trial". 8 hits remain. These hits are mandatory reading, but the limits seem to have eliminated too many hits.
3. Return to step 2 with 1434 hits and apply the limits "Last 10 years." 59 hits remain. Scanning these hits reveals a series of highly relevant articles with topics like "Effects of clozapine and olanzapine on cortical thickness in childhood-onset schizophrenia," and "Asymmetry loss is local rather than global in childhood-onset schizophrenia."Note the dramatic falloff in the number of hits, suggesting that – as the PubMed sites notifies us – "Schizophrenia, childhood" as a MeSH term is primarily an historical term; yet the 59 hits retrieved from the last 10 years appear mostly highly relevant and interesting for a position paper.

The take-home message is to *keep search strategies transparent and clear, and always monitor how many hits result; these data allow you to be continually adjusting your search to your purposes, time, and interest.*

Keep track of how many hits a strategy produces in the context of the purposes of your search: are the results manageable and adequate for your purposes? If you sense they are not manageable (too many hits and too little time), continue to carve out new results with further limits. If you sense they are not sufficient, change your initial search strategy to be more sensitive. In this example, adding the term "Schizophren*" (tw) added more than 20,000 hits. Another alternative to increase sensitivity is to click on the "Related citations" hypertext below the citations which seem especially useful; the software reports a series of citations similar in subject matter to the citation you find useful.



Keeping up with evidence-based medicine

More than 5000 biomedical articles and the results of about 100 treatment trials are published worldwide every day and the number continues to grow. Keeping up with this tide of information is daunting. To facilitate that task, you may subscribe at no cost to the Evidence Updates website run by the BMJ Group and McMaster University's Health Information Research Unit. These institutions collaborate to provide clinicians with access to current best evidence from research, tailored to one's own health care interests, to support evidence-based clinical decisions. This service scans more than 120 top medical journals and more than 50 000 articles each year, rating them according to validity and relevance, and regularly sends subscribers an email with the key articles in their specialty.

CLASSIC EBM AND THE 'ANSWERABLE QUESTION'

"EBM classic" is our phrase for the approach developed originally by David Sackett and colleagues at McMaster University in Canada and later at many other sites. Their work was fundamental to the approach discussed here. We distinguish our approach, however, which is tailored to fit the reality of doing work in child mental health, from "EBM classic," which was originally developed in the context of internal medicine. It's important to know about "EBM classic" as the bedrock precursor of what is discussed here.

"EBM classic" can be summarized as a five-step model:

1. Posing an "answerable" question about a clinical situation, usually beginning "What is the evidence that..." a specific *patient or problem*, treated with a specific *intervention* yields in *comparison* to another intervention or placebo yields what *outcomes*? These are sometimes called PICO questions (Patient/Intervention/Comparison/Outcomes).
2. Searching for evidence to answer the PICO question.
3. Critically appraising the evidence by asking questions about how well the studies were done.
4. Integrating clinical expertise and the patient's values with the evidence to make a decision about treatment.
5. Evaluating the result.



Click on the picture to access the Centre for Evidence Based Medicine website, which has information and training on EBM

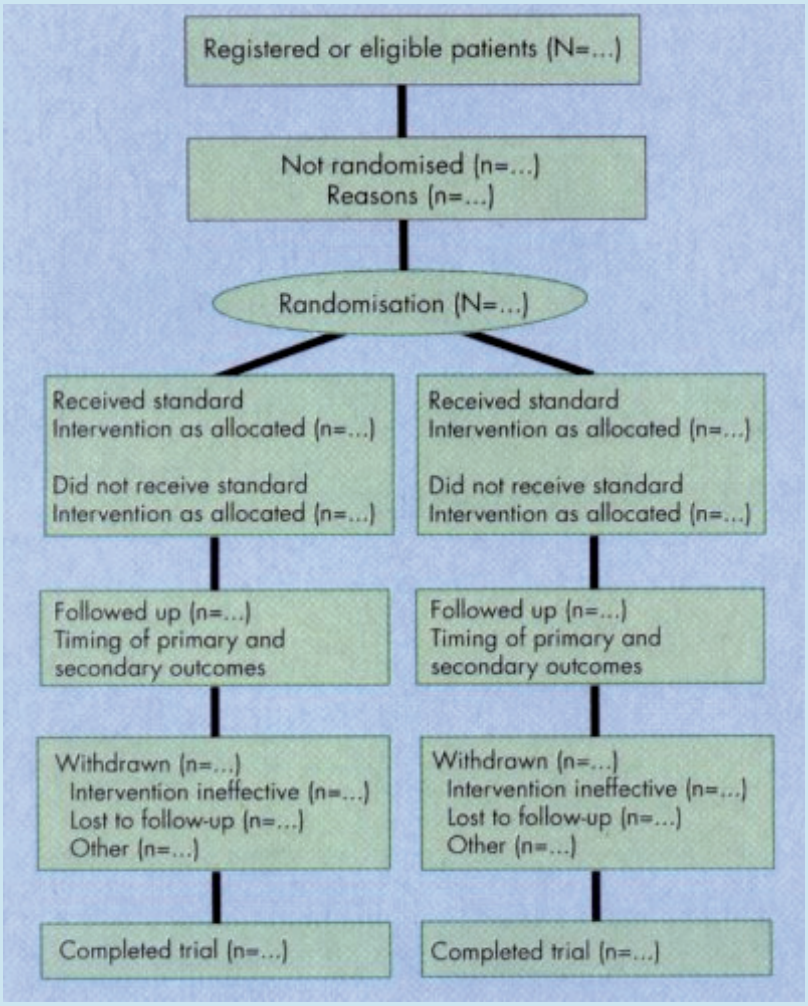


Figure A.6.9

A flow diagram of an RCT showing how subjects 'flow' though the study.

Checking a paper through each step is a good start in doing a critical appraisal of the quality of a study. Try to imagine what biases can occur at each step (e.g., less than random randomization, biases in follow-up between the two paths or 'arms,' etc.)

Source: British Dental Journal 186: 258 (1999).

"EBM Classic" also takes on such important issues as the sensitivity and specificity of diagnostic tests and how to apply the evidence (Sackett et al, 2000).

EVIDENCE-BASED PRACTICES AND LOCAL CULTURE

Culture – left undefined for our purposes – is an important factor coloring how the ideas discussed in this chapter are received by clinicians and patients alike. Cultural components affecting our practices include beliefs and values, child rearing practices, the role of the extended family, and the impact of the Internet.

Beliefs and values

Beliefs regarding the treatment of mental illnesses are important, and it is crucial that clinicians understand the culture where they work in order to enable the acceptance of effective interventions. In societies where there is more severe stigmatization of the mentally ill, it can be very difficult to convince a child and family to even attend an initial psychiatric interview. Even if they attend, it may be very difficult for them to accept the diagnosis as well as the suggested treatment. In some cultures mental illnesses are believed to be spiritual and therefore spiritual treatments are the first choice. Families may comply with the treatment only if the spiritual healer approves. In one such case a Turkish spiritual healer had prepared a *muska* – a magical necklace of wrapped paper and cloth to get rid of the illness – for a psychotic teenager who the healer had sent for hospitalization. In the process of his treatment the adolescent opened the *muska*. He found only one scrawled word: *Haldol*!

Yet clients often look for magical, immediate cures. It is very difficult at times to explain, and have them accept, the time required for good treatment, or the advisability to use a medicine in spite of its potential side effects. In cultures where people first ask their neighbors or relatives about the problem and rely on their personal or third party experiences, EBT suggested by a clinician may not always fit with the neighbors' suggestions and often acquires "not-to-be used" status (the neighbor's child got well with another medicine, thus this may not be the right one).

Assumptions in child rearing practices

Assumptions like "boys normally show high motor activity" can be a reason for a family to refuse medication to treat ADHD, because the family thinks the drug slows down the child and makes him "abnormal." Another common assumption is that "children should not be given pills for a long time." This often disrupts medication treatment. Or, "Grandma says he is just like his father as a child, and his father is doing OK. Are you sure he needs treatment?"

Role of the extended family

In traditional cultures, grandparents or elder brothers or sisters of the parents may be in charge of treatment decisions. They may refuse to allow the parents to administer the suggested treatment. On some occasions parents who believe in EBT are faced with the conflict of administering the treatment secretly. Family members may also interfere with the dosage prescribed, based on their personal opinions.

The influence of the Internet

Parents or adolescents checking the Internet may well refuse treatment. Since the Internet may misinform as well as inform, patients and their families often find more misinformation than guidance. For example, they may Google a word and read whatever is displayed, often the information found emphasizes side-effects, ignores benefits, and opposes medications for mental illness. Providing parents and teens with information about Internet sites with fewer biases and more accurate and complete information may improve adherence to treatment.

To summarize, a key role of the clinician is to understand both the cultural system of beliefs and values of her patients as well as the fundamental ideas of epidemiology and clinical research that make up the first part of this chapter. The successful combination of both, as applied to the patient and family in the office, is the essence of evidence-based practice.

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PRINCIPLES IN USING PSYCHOTROPIC MEDICATION IN CHILDREN AND ADOLESCENTS

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Conflict of interest: none reported.

*The opinions and assertions contained in this chapter are the private views of the author and are not to be construed as official or as reflecting the views of the US National Institute of Mental Health, the National Institutes of Health, or the Department of Health and Human Services.

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Suggested citation: Vitiello B. Principles in using psychotropic medication in children and adolescents. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Medications to treat mental conditions (psychotropics) have become increasingly used in child and adolescent psychiatry. From the serendipitous discovery by Bradley of the effects of amphetamines in child hyperactivity in 1937 to the multisite clinical trials of the 2000s, pediatric psychopharmacology has gradually become both an active area of research and, at least in some countries, common clinical practice. It has also been the subject of debate and controversy in the general public and among mental health experts, especially with respect to the appropriateness and safety of using medication for treating emotional and behavioral problems during development. With the notable exception of medications for attention deficit hyperactivity disorder (ADHD), which were first introduced for pediatric use and then applied to adults, psychotropic medications were first developed to treat depression, anxiety, mania, or psychosis in adults, and then used also in children suffering from these conditions. Concern has been raised about both the validity of applying adult diagnostic categories to children and the safety of extrapolating information collected in adults to children.



In 1937, Charles Bradley, a psychiatrist, administered dl-amphetamine to "problem" children at the Emma Pendleton Bradley Home in Providence, Rhode Island, in an attempt to alleviate headaches. However, Bradley noticed an unexpected effect upon the behavior of the children: improved school performance, social interactions, and emotional responses. Bradley's studies went largely ignored in the field of child psychiatry for nearly 25 years. However, they proved to be an important precursor to studies on the use of amphetamines in conditions such as attention deficit hyperactivity disorder (Strohl, 2011).

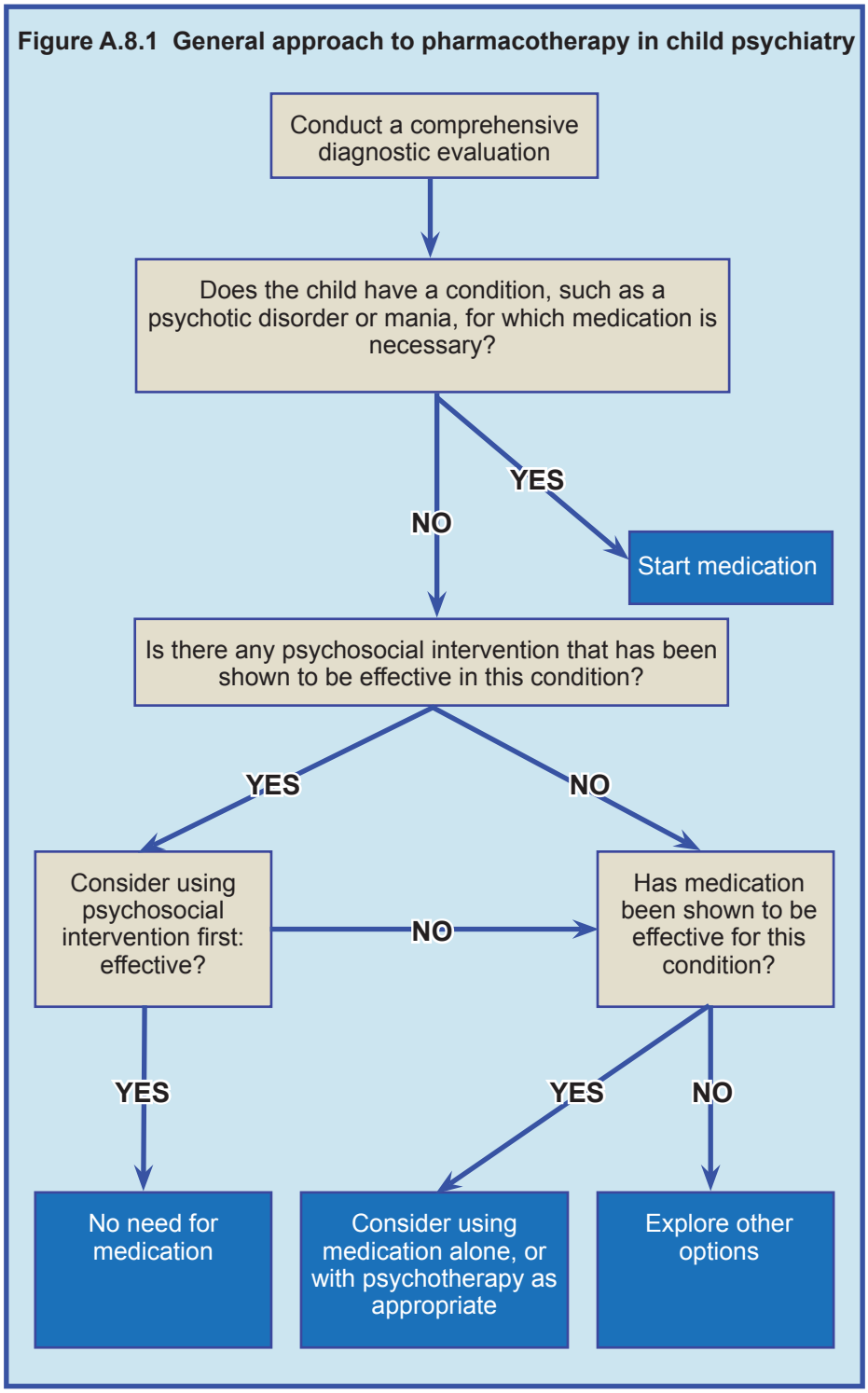
Pediatric pharmacology research has provided a better understanding of the benefits and risks of the pediatric use of several psychotropics, such as stimulants and antidepressants. For many other medications, however, the current knowledge base is still incomplete. The inadequacy is especially evident with respect to the long-term use. In psychiatry, medications are seldom curative and, since many disorders tend to persist or recur, long-term treatment is often required, thus raising concerns about both the persistence of the therapeutic effect and the safety of prolonged exposure to psychotropic agents at a time of rapid development. A related question is whether treatment in childhood will lead to a better functional outcome and improve the ultimate prognosis. Unfortunately, controlled clinical trials are usually limited to just a few months of treatment, and documenting long-term treatment effects is methodologically very difficult.

The purpose of this chapter is to review the key elements relevant to the therapeutic use of psychotropic medications in children and adolescents. The aim is to provide clinicians with a general framework for approaching the pharmacotherapy of psychiatric disorders during development. For detailed information on specific medications, the reader is referred to the chapters covering the relative disorders.

WHEN TO USE PSYCHOTROPIC MEDICATION IN YOUTH?

A number of factors come into play when choosing a treatment. A comprehensive diagnostic evaluation is the necessary first step (Figure A.8.1). Patients with psychotic disorders typically require pharmacological treatment to control symptoms and restore functioning. Patients with other disorders, on the other hand, may be often successfully treated with non-pharmacological interventions, and medication is just one of several therapeutic options whose potential benefit and risks need to be considered by the treating clinician, the family, and, whenever possible, the young persons themselves. For example, psychotherapy can be effective in the management of patients with attention deficit/hyperactivity disorder (ADHD), major depression, and anxiety disorders. Not all children, however, improve on purely psychosocial interventions and, for

Figure A.8.1 General approach to pharmacotherapy in child psychiatry



"But family and many friends were judgmental: How could we start a five-year-old on medication, especially one as smart as our son, who had taught himself to read before age four? They seemed to assume that he was different because he was so smart. Anyway, the logic went, a lot of boys are a handful at that age, and that's not a reason to put a five-year-old on medication. They concluded that the problem was that I was a psychiatrist. Clearly, I was pathologizing a boy who was just being a boy. How else would you expect a mom who is a psychiatrist to handle a rambunctious, precocious five-year-old besides putting him on medication?" (Gold, 2010).

them, medication may be necessary to improve mood, behavior, and functioning. It should be noted that psychotherapy and medications are not mutually exclusive treatment modalities: in some conditions, combined use was found to be more beneficial than monotherapy (Vitiello, 2009a).

A key consideration in choosing among therapeutic options is the strength of the evidence supporting the efficacy and safety of the treatment for the specific condition and the age of the child. As in other areas of medicine, also in child psychiatry the standards of evidence-based medicine apply (Gray, 1997). Thus, the

strongest level of evidence comes from at least one systematic review of multiple, well-designed, randomized controlled trials (Type I), followed by evidence from at least one properly designed randomized controlled trial (Type II). Thanks to clinical research conducted in the last decade, there is now evidence for the short-term efficacy of a number of medications in children (Table A.8.1).

Evidence of the long-term effectiveness and safety of pharmacological treatments in children and adolescents is largely lacking.

Much less strong is the evidence of the long-term effectiveness and safety of treatments. There are, however, a few placebo-controlled discontinuation studies that have shown that long-term treatment can be effective in maintaining improvement and preventing symptoms recurrence. For example, in youth suffering for depression, continuing antidepressant treatment significantly reduces the risk of relapse (Emslie et al, 2008). Likewise, discontinuing risperidone in children with autism and severe behavioral disturbances increases the risk of recurrence of aggression, self-injury, and tantrums as compared with continuing treatment (Research Units on Pediatric Psychopharmacology Autism Network, 2005a). In addition, a number of naturalistic follow-up studies provide useful information on the long-term outcome of youths treated for several years, even though treatment effects are difficult to determine due to the lack of a control condition.

PHARMACOKINETICS

Drug absorption, distribution, metabolism, and excretion can be influenced by development, so that trying to determine doses and frequency of administration for children based on data obtained from adults can lead to inappropriate treatment. Although children have smaller body size than adults, the relative mass of liver and kidney tissue is greater when adjusted for body weight. Children also have relatively more body water, less fat, and less plasma albumin to which drugs can bind. Consequently, the volume of distribution of a drug tends to be greater in children than in adults. In general, children have greater drug extraction during the first pass through the liver, lower bioavailability, and faster metabolism and elimination. This means that simply decreasing adult doses based on child weight may result in under-treatment. In adolescence, together with a marked growth in body size, there is a redistribution of the body compartments. In males, the percentage of total body water increases and that of body fat decreases, while the opposite occurs in females.

Once absorbed, most drugs undergo biotransformations (metabolism) that turn the parent compound into more polar, and therefore easier to eliminate, by-products (metabolites). Typically, medications undergo first an enzymatic oxidative or hydrolytic transformation (phase I), and then are conjugated with glucuronic acid, sulfate, glutathione, or acetate to form products that are eliminated via the kidney or the bile. The Phase I oxidative processes are mediated by cythocrome 450 (CYP450) microsomal enzymes, which are concentrated primarily in the liver. The CYP 450 system is immature at birth but its metabolizing capacity increases rapidly, so that by one month of age it is already about 20% of the mature level, which is achieved by three years of age. Because children have proportionally more liver parenchyma than adults, they have greater weight-adjusted metabolic capacity.

The two most important CYP 450 enzymes in pediatric psychopharmacology are the CYP3A4 and the CYP2D6, which are involved in the metabolism of most psychotropics. For example, the 3A4 system metabolizes sertraline, citalopram,

Table A.8.1 Selected psychotropic medications and level of evidence for efficacy in children (<18 years)

Medication	Condition	Evidence for efficacy[1]	US FDA-approved indication and age, in years, for which it is approved
Methylphenidate and dexmethylphenidate	ADHD	Type I	6 and older
Amphetamines	ADHD	Type I	3 and older
Atomoxetine	ADHD	Type I	6 and older
Clonidine	ADHD	Type I	6 and older
	Tourette's disorder	Type I	
Guanfacine	ADHD	Type I	6 and older
Fluoxetine	Major depression	Type I	8 and older
	OCD	Type II	7 and older
	GAD/SP	Type II	
Sertraline	OCD	Type I	6 and older
	Major depression	Type II	
	GAD/SP	Type I	
Citalopram	Major depression	Type II	
Escitalopram	Major depression	Type I	12 and older
Fluvoxamine	OCD	Type II	7 and older
	GAD/SP	Type I	
Venlafaxine	Major depression	Type V	
Bupropion	ADHD	Type II	
	Major depression	Type V	
Clomipramine	OCD	Type II	10 and older
Haloperidol	Tourette's disorder	Type I	3 and older
	Psychosis	Type II	3 and older
	Hyperactivity, severe behavioral problems, explosive hyperexcitability	Type II	3 and older
Pimozide	Tourette's disorder	Type I	12 and older
Risperidone	Schizophrenia	Type II	13 and older
	Bipolar disorder	Type I	10 and older
	Aggression	Type I	"Irritability" in autism: 5-16 years of age
	Tourette's disorder	Type I	

Table A.8.1 Selected psychotropic medications and level of evidence for efficacy in children (<18 years) (Continuation).

Medication	Condition	Evidence for efficacy[1]	US FDA-approved indication and age, in years, for which it is approved
Quetiapine	Schizophrenia	Type II	13 and older
	Bipolar disorder	Type II	10 and older
Aripiprazole	Schizophrenia	Type II	13 and older
	Bipolar disorder	Type II	10 and older
	Aggression	Type I	"Irritability" in autism: 5-16 years of age
Olanzapine	Schizophrenia	Type II	13 and older
	Bipolar disorder	Type II	10 and older
Lithium	Bipolar disorder	Type III	12 and older
	Aggression	Type II	
Valproate[2]	Bipolar disorder	Type II	
	Aggression	Type II	
Carbamazepine[2]	Bipolar disorder	Type V	
Oxcarbazepine[2]	Bipolar disorder	Type V	
Lamotrigine[2]	Bipolar depression	Type V	

ADHD: attention deficit hyperactivity disorder; OCD: obsessive compulsive disorder; GAD: generalized anxiety disorder; SP: social phobia.

[1]Strength of the evidence: Type I: strong evidence from at least one systematic review of multiple well-designed randomized controlled trials. Type II: strong evidence from at least one properly designed randomized controlled trial. Type III: evidence from well-designed trials without randomization, single group, pre-post, cohort, time series or matched case-control studies. Type IV: evidence from well-designed non-experimental studies from more than one center or research group. Type V: opinions of respected authorities, based on clinical evidence, descriptive studies or reports of expert committees (Gray, 1997).

[2]Aproved for the treatment of epilepsy from infancy.

escitalopram, bupropion, mirtazapine, aripiprazole, quetiapine, ziprasidone, alprazolam, and zolpidem. The 2D6 system metabolizes fluoxetine, atomoxetine, risperidone, olanzapine, and haloperidol. Some psychotropics can also act as inhibitors of these enzymes so that concurrent administration of another drug that is a substrate for the enzyme results in reduced metabolism and higher medication concentration in the body. For example, the 3A4 enzymes can be inhibited by fluoxetine or fluvoxamine. Concomitant administration of fluvoxamine (inhibitor of 3A4) and pimozide (metabolized by 3A4) could lead to high levels of pimozide and prolongation of the QTc interval. An additional complexity is that some medications, such as carbamazepine and phenobarbital, can induce the 3A4 activity, thus potentiating its metabolizing capacity. The concomitant administration of carbamazepine and a medication metabolized by 3A4 can result in lower levels of the medication. In sexually active female adolescents, use of oral contraceptives can induce CYP enzymes and thus increase drug metabolism and elimination.

Genetic polymorphism has been identified for CYP2D6. About 7-10% of Caucasians, 1-8% of Africans, and 1-3% of East Asians are poor metabolizers. Poor metabolizers have higher drug concentrations in plasma and other body tissues. For example, the mean elimination half-life of atomoxetine is about 5 hours in children or adults who are extensive metabolizers, but 22 hours in poor metabolizers (Sauer et al, 2005). While the clinical implications of these metabolic differences do not seem to be significant for atomoxetine, some cases of toxicity have been reported with other psychotropics. For example, one case of death in a child with a 2D6 genetic deficiency was associated with unusually high plasma levels of fluoxetine (Sallee et al, 2000). Assay for genetic polymorphism is not routinely done in current child psychiatry practice, but it may be considered for individual patients who do not respond to adequate doses of medication, or present with unusual reactions to medications metabolized by enzymes with genetic polymorphism (e.g., 2D6 and 2C19).

The main route of drug elimination is through the kidneys. Absolute clearance is usually lower in children than in adults, but weight-adjusted clearance is greater. Because of the faster elimination, the drug plasma half-life can be shorter in children than in adults (Daviss et al, 2005). A shorter elimination half-life means that plasma steady-state is reached sooner during repeated administration, and that elimination is faster so that withdrawal symptoms upon discontinuation are more likely. In these cases, a more frequent dosing is needed to maintain consistent therapeutic levels and prevent withdrawal symptoms between doses.

For some medications, the dose and duration of treatment can influence the pharmacokinetics. After a single dose of sertraline 50 mg in adolescents, the mean half-life was about 27 hours, but, after repeated administrations, it decreased to about 15 hours (Axelson et al, 2002). Moreover, the steady-state half-life was longer (about 20 hours) after administration of higher doses (100-150 mg). Based on these data, lower doses (50 mg/day) should be given twice a day to ensure consistent treatment and prevent withdrawal, while higher (100-150 mg) doses could be given once a day.

The pharmacokinetics of many psychotropics has been studied in children and adolescents. For escitalopram, aripiprazole, quetiapine, risperidone, and lithium, the pharmacokinetics was found to be similar in youths than in adults (Rao, 2007; Findling et al, 2008; Thyssen et al, 2010; Findling et al, 2010). However, considerable inter-subject variability was observed, so that major individual differences in the time-course of pharmacological effects can occur in clinical use.

For methylphenidate and amphetamines, whose short half-life results in short duration of action and in the need for multiple daily administrations, a variety of extended release formulations have been developed. The first generation of extended release formulations of methylphenidate consisted of tablets with different coatings of immediate and slower release medication. With these preparations, however, the onset of action was at times delayed in the morning or the therapeutic effect faded in the afternoon. Consequently, a second-generation of biphasic extended release formulations has been introduced. These formulations allow an initial bolus of medication to be absorbed immediately, followed by a second, more gradual release. The plasma pharmacokinetics curve thus shows an

Pharmacokinetics
What the body does to the drug: absorption, distribution, metabolism, and excretion.

Pharmacodynamics
What the drug does to the body: the biochemical and physiological effects of drugs on the body.

Half life
The time required to reduce the plasma concentration to one half of its initial value

Plasma steady state
Steady state occurs when the rate of drug absorption into the blood equals the rate of elimination from it. The time to reach steady-state concentrations is dependent on the half-life of the drug.

acute initial peak at about 1.5 hours after dosing, followed by a second peak about 3 hours later (Swanson et al, 2003). With these extended release preparations, only a once-a-day morning administration is needed to provide therapeutic effects up to 8-10 hours.

PHARMACODYNAMICS

Most psychotropics act through neurotransmitters, such as dopamine, serotonin, and norepinephrine, whose receptors undergo major changes during development (Rho & Storey, 2001). Receptor density tends to peak in preschool years and then gradually declines towards adult levels in late adolescence (Chugani et al, 2001). The impact of these developmental changes on drug activity and possible implications for efficacy and safety are still not well understood. However, differences between children and adults in efficacy and safety have been observed thus suggesting that development can significantly influence the effects of these medications. For example, tricyclic antidepressants, though proven effective in adult depression, have no demonstrable antidepressant effect in children (Hazell et al, 1995); amphetamine-like stimulants are more likely to induce euphoria in adults than in children; antipsychotics tend to cause stronger metabolic effects in youth than in adults (Correll et al, 2009); and serotonergic antidepressants were found to increase the risk for suicidal ideation and attempts in children, adolescents, and young adults, but not in the middle-aged or the elderly (Hammad et al, 2006; Stone et al, 2009).

Clearly the developmental stage influences the response to a number of psychotropics. This is evident also in the lower tolerability and efficacy of methylphenidate in children with ADHD between 3 and 5 years of age as compared with older children (Greenhill et al, 2006). When brain development is abnormal, such as in autism, the effects of medication can be impacted, as shown by the lack of benefit from selective serotonin reuptake inhibitors for compulsive and repetitive behaviors in autism (King et al, 2009). Thus, information derived from data from adolescents may not be applicable to children who are younger or suffer from pervasive disorders of development. This underscores the need for research directly in the patient populations likely to be treated with these medications.

EFFICACY

The term *efficacy* is broadly used to indicate that a treatment has a demonstrated therapeutic benefit when tested in fairly tight experimental conditions, usually involving carefully selected samples of patients. The term *effectiveness* is typically applied to treatments that have shown to have benefit in usual clinical settings for patients broadly representative of the population likely to receive the treatment. Often, however, these two terms are used interchangeably.

The most convincing evidence of the efficacy of a treatment comes from controlled clinical trials showing the superiority of the treatment over a control in modifying a clinically meaningful outcome. Double-blind trials are methodologically more convincing than open studies because they control for expectation biases. A number of well-designed placebo-controlled clinical trials have been conducted in pediatric psychopharmacology. The results of these studies provide the foundation for evidence- based pharmacotherapy in child psychiatry,

which is currently summarized in a number of practice guidelines and treatment algorithms (National Institute for Health and Clinical Excellence, 2005 and 2008; Pliszka et al, 2007; Birmaher and Brent, 2007; McClellan et al, 2007).

One critical element in evaluating the efficacy of a treatment is the chosen outcome. A treatment can be effective at decreasing symptoms (*improvement*), eliminating the key manifestations of the disorder (*remission*, in the short-term, and *recovery*, if sustained over time), restoring functioning (*functional recovery*), or decreasing the risk for relapse or recurrence of the symptoms. Thus, when stating that a certain treatment is *effective*, one should also specify the particular outcome being considered. Typically, medications are approved for clinical use based on studies showing efficacy at decreasing symptoms. In fact, proving treatment effects on remission, recovery, or functioning requires longer term controlled trials, which are more difficult and expensive to conduct. There are, however, a few studies showing effectiveness on remission and recovery for a number of medications, such as stimulants in ADHD (Swanson et al, 2001) or serotonergic antidepressant in adolescent depression (Kennard et al. 2006; Vitiello et al, 2006).

Efficacy

A term used to indicate that a treatment has a demonstrated therapeutic benefit when tested in rigorous conditions, usually involving carefully selected samples of patients.

Effectiveness

Typically means that the treatment has shown to be beneficial in usual clinical settings for patients broadly representative of the population likely to receive that treatment.

The need to document symptom reduction and remission brings forward the importance of measuring the behavioral, emotional, and functional manifestations of mental dysfunction. In the absence of biological markers of disease and treatment effects, clinicians must rely on symptoms in order to gauge treatment response. Suitable rating scales have been developed for all the more common conditions in child mental health (e.g., Conners et al, 1998; Poznanski & Mokros, 1996; Birmaher et al,1997; March et al, 1997; Research Units on Pediatric Psychopharmacology Anxiety Study Group 2002; Bernstein et al, 2010; Shaffer et al, 1983; Wagner et al., 2007; see also Chapter A.5). These scales can be broadly divided into those that are completed by the clinician based on direct observation and informants (*clinician-rated scales*), and those that are completed directly by the informant (*self-administered scales*). Respect to adults, a distinctive characteristic of pediatric psychopharmacology is that, in addition to the child, the clinical information is usually derived from parents and teachers. Assessing and monitoring medication effects is therefore more complex and time consuming in children than in adults because clinicians must collect and integrate information from multiple sources.

When comparing treatments or making clinical decisions, it is useful to quantify the size of the treatment effect (see also Chapter A.6). Using data from controlled clinical trials, the magnitude of the treatment effect relative to a control can be expressed in standard deviation units. One of the most commonly used way of computing an effect size is the Cohen's *d* or the Hedge *g*, which is in the difference in outcome measure between the study groups divided by the pooled standard deviation at the end of treatment (Rosenthal et al, 2000). Compared with a placebo condition, stimulants usually have a large effect size (0.8 and above) in decreasing symptoms of ADHD (Greenhill et al, 2001). In the trials that have detected a separation between SSRI and placebo, the SSRI had a moderate effect size (0.5-0.7) when used in the treatment of major depression (TADS Team, 2004) or obsessive compulsive disorder (Pediatric OCD Treatment Study, 2004). However, meta-analysis of all available databases of clinical trials in pediatric depression indicate that the effect size of antidepressant medication vs. placebo is small (0.25, 95% C.I. 0.16-0.34) (Bridge at al, 2007).

The effect size calculation can be applied also for quantifying the pre-post treatment difference within the same group of patients, rather than the difference between treated group and control. In these cases, however, due to the lack of a parallel control, the effect due to the treatment cannot be separated from the effect due to the mere passage of time. For this reason, a within-group pre-post effect size cannot be taken as an estimate of the effect of treatment but rather of the combined effects of time and treatment.

It is also useful to express the strength of the therapeutic benefit using the *number needed to treat* (NNT), which is the number of patients who need to be given the treatment in order to add one more improved patient to the number of those who are expected to improve in the control condition. Thus, in the Treatment for Adolescents with Depression Study (TADS), 61% of fluoxetine-treated patients improved at the end of the 12-week treatment as compared with 35% of the placebo patients (TADS Team 2004). Based on these rates, the NNT for fluoxetine is 4 (i.e., 1/61-35), which indicates that one needs to treat on average 4 patients in order to improve one patient more than the placebo condition. The smaller the NNT, the greater is the relative efficacy of the treatment. The NNTs of psychotropic medications, though variable among studies, is often quite favorable and compares well with other non-psychiatric drugs used in pediatrics.

Assessing and monitoring medication effects is more complex and time consuming in children than in adults because clinicians must collect and integrate information from multiple sources.

Most of what is currently known about the effects of treatments is limited to the short- (i.e., a few weeks) and intermediate-term (i.e., a few months). Relatively few studies have addressed the long-term effectiveness of pharmacotherapy in child psychiatry (MTA Cooperative Group, 2004; TADS Team, 2007; Vitiello et al, 2011). More research is needed to see whether control of symptoms leads to long-term benefits and better prognosis. For example, it would be good to know if improvement in ADHD symptoms translates into a lower risk for motor vehicle accidents, higher academic and occupational achievement, and better social adjustment, in the same way that the control of hypertension has been found to decrease cardiovascular morbidity and mortality. Unfortunately, we still do not have the data for drawing this type of conclusions. Research on the long-term effects of treatments poses many challenges from a practical and methodological perspective. In fact, long-term randomized controlled trials are difficult to implement, and merely observational studies are usually insufficient for proving causality.

SAFETY

Ensuring safety is especially important when treating children. Pharmacological treatment during a period when the organism undergoes rapid development may result in toxicities that are not seen in adults. A general concern is that agents acting on neurotransmitter systems in rapid development may interfere with normal processes and result in unwanted long-lasting changes. Some studies in developing animals have been conducted. For example, administration of fluoxetine to newborn mice transiently inhibits the serotonin transporter during early development; this is associated with behavioral abnormalities such as reduced exploratory behavior and slower adaptation to novel environments or stimuli in adult age (Ansorge et al, 2004). Even though the relevance of these data to children is unclear, a high level of suspicion is warranted when treating children with medication, especially when the treatment is at an early age (under age 6) or

prolonged in time.

Medications may cause a variety of adverse effects (Vitiello et al, 2003a). Some effects, such as dystonias with anti-dopaminergic agents or appetite suppression with stimulants, become evident acutely, after a brief period of drug exposure, while others, such as tardive dyskinesia or metabolic syndrome with antipsychotics, emerge slowly with chronic treatment. Some adverse effects are related to drug dose or plasma concentrations, such as lithium-induced tremor, while others emerge after drug discontinuation, such as antipsychotic withdrawal dyskinesias. Some adverse effects can be anticipated based on the mechanism of action of the medication, while others are completely unexpected, such as increased suicidality with antidepressant treatment. Like for efficacy, assessment of safety depends in large part on adult monitoring and reporting. Identification of adverse effects is contingent on a thorough and detailed evaluation by a clinician familiar with the medication.

In recent years, more information has become available on the long-term safety of several psychotropics in children. For example, it is now better recognized that stimulants, such a methylphenidate and amphetamines, can cause a dose-related delay in physical growth, in both weight and height. After 14 months of treatment, children treated with stimulant medication for ADHD grew on average 1.4 cm less in height than peers treated with behavior therapy (MTA Cooperative Group, 2004). A growth deficit was found to persist in future years in children who are continuously medicated (Swanson et al, 2007). The mechanism underlying the interference of stimulants with skeletal growth is still unclear, but recent data suggest that chronic treatment with methylphenidate leads to transient inhibition of testosterone levels and delay in puberty (Mattison et al, 2011).

Some adverse effects can be anticipated based on the mechanism of action of the medication, while others are completely unexpected, such as increased suicidality with antidepressant treatment.

Because stimulants have adrenergic activity, concern has been raised about unwanted cardiovascular outcomes, including sudden death (Gould et al, 2009). However, recent analyses of large patient population data have not identified any association between therapeutic use of stimulants and increased cardiac death or cardiac events leading to emergency department visits (Cooper et al, 2011; Schelleman et al, 2011). Moreover, a prospective study of children treated for up to 10 years did not find an increased risk for hypertension, although stimulants have a detectable effect on heart rate even with chronic use (Vitiello et al, in press).

As stimulants are drugs of potential abuse, concerns have been raised about the possibility that treatment in childhood may sensitize the brain and thus make substance abuse and dependence more likely in adolescence and adulthood (Vitiello, 2001). The feasibility of mounting randomized, well-controlled studies to address this issue is questionable, and researchers have relied on naturalistically treated samples. Most of these studies have not found an increased risk of substance abuse after treatment with stimulants (Biederman et al, 2008; Wilens et al, 2008).

Differences in tolerability have been observed across age and type of development. Preschoolers with ADHD show lower tolerability to methylphenidate than older children (Greenhill et al, 2006; Wigal et al. 2006). Likewise, children with autism or other pervasive developmental disorders with ADHD symptoms are more sensitive to the adverse effects of methylphenidate as indicated by an 18% treatment discontinuation due to intolerable adverse events (most commonly irritability) (Research Units on Pediatric Psychopharmacology Autism Network,

2005b). Youths exposed to second generation antipsychotics are more prone to gaining weight than adults (Correll et al, 2009).

Antidepressants have been found to increase the risk for certain suicide-related events, such as thoughts about suicide and suicidal attempts, although an effect on completed suicide could not be determined (Hammad et al, 2006). In a meta-analysis including 13 placebo-controlled trials in children and adolescents with major depression, the suicidality rate (suicidal thoughts, attempts and self-harm) was 3% on antidepressant and 2% on placebo (Bridge et al, 2007). Similar meta-analyses of clinical trials in adults have documented an interaction between age and risk of suicidality with antidepressant use: the risk was increased for individuals under age 25, not affected between 25 and 64 years, and actually decreased in older patients (Stone et al, 2009). These data provide an example of interaction between development and pharmacological effect, even though the biological underpinning of this interaction remains unknown. The mechanism through which antidepressants may trigger suicidality remains a matter of speculation. It is possible that some youths become abnormally activated by the antidepressant, displaying akathisia, agitation, anxiety, insomnia, and impulsivity. However, this explanation remains a theory based on anecdotal reports as systematic analyses of treated patients have not confirmed it (Vitiello et al, 2009b).

Preschoolers with ADHD show lower tolerability to methylphenidate than older children. Likewise, children with autism or other pervasive developmental disorders with ADHD symptoms are more sensitive to the adverse effects of methylphenidate.

Safety is a relative concept and the possible risks of pharmacotherapy must be weighed against the possible risks of untreated psychopathology. Decisions about prescribing medication must also take into account the availability of effective non-pharmacological interventions. Though generally found less effective at decreasing symptoms of ADHD or depression in children and adolescents, psychotherapy can be considered in lieu of medication for mild depression, or in combination with medication for more severe cases. Psychotherapy, used either sequentially (i.e., start first with psychotherapy, then add medication if insufficient) or in combination (i.e., start both psychotherapy and medication concurrently), may be able to reduce the dose of medication needed to control symptoms.

ETHICAL AND REGULATORY CONSIDERATIONS

Children should be explained about their condition and the choice of possible treatments to the extent allowed by their cognitive and emotional developmental stage. However, before the age of 14 or 16 years (the legal age for consent to treatment varies according to country; see also Chapter A.1) they cannot give legal permission for treatment, which must come from their parents. It is the responsibility of the prescribing clinician to inform the parents of the expected benefits and risks of the medication. Parents are also instrumental for implementing pharmacotherapy by ensuring appropriate administration of prescribed medication and for reporting treatment-emergent adverse effects.

Research in children

Progress in pediatric psychopharmacology depends on direct participation of children in research (see also Chapter J.7). In the US and some other countries, child research is subject to special regulations that are in addition to those for adult research participation (United States Department of Health and Human Services; Food and Drug Administration, 2001). Only scientifically sound research that utilizes valid methodology and is posited to add new knowledge about important

health issues may be ethically acceptable (Vitiello, 2003b). Pediatric research can be divided into two broad categories based on whether it does or does not have the *prospect of direct benefit* to the individual participant. "Prospect of direct benefit" means that each participant has the potential of deriving a health benefit from participation. General acquisition of knowledge relevant to the child's condition does not satisfy the requirement of *direct benefit*. To be ethically acceptable, research with prospect of direct benefit must also have a favorable balance between anticipated benefits and foreseeable harms. Usually, studies of the efficacy of treatments have potential for direct benefit to the research participants. In these cases, the main criterion for determining if the study is ethically acceptable is the risk/benefit ratio. The presence of a placebo arm in randomized clinical trial is usually considered acceptable in child psychiatry conditions. Placebo does not equal absence of treatment and has been associated with substantial improvement, especially in the case of mood and anxiety disorders.

Pharmacological research that does not offer a prospect of direct benefit includes pharmacokinetics and pharmacodynamics studies. In order to examine the acceptability of a study in this category, it must be determined whether such a study does or does not have the potential for generating essential knowledge relevant to the disorder or condition of the research participant. If the information is not relevant to the child's disorder or condition (e.g., a pharmacokinetics study in healthy children at no increased risk for the condition being targeted by the treatment), the research can be conducted only if it entails no more than *minimal risk*. Minimal risk is defined as "risk for harm not greater than ordinarily encountered in daily life, or during routine physical or psychological examinations or tests" (section 46.102(i) in U.S. Department of Health and Human Subjects 1991). The prevailing interpretation is that the daily life, exams and tests of a normal child are to be used as reference, but a precise quantification of risk in ordinary daily life is not easy and remains a matter of discussion.

If the study aims to acquire information relevant to the child's condition (e.g., pharmacokinetics of a medication for ADHD being studied in children with ADHD), the research risk cannot be greater than *a minor increase of minimal risk*. According to the current US regulations, a *minor increase over minimal risk* can be considered acceptable only if:

a) It presents "experiences to the subjects that are commensurate with those inherent in their actual or expected medical, dental, psychological, social, or educational situations" and

b) The study has the potential to generate new knowledge considered of "vital importance" for understanding or treating the child's disorder or condition.

Research not approvable based on these criteria but which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children, can be referred to the Secretary of Health for further review under the HHS regulations at 45 CFR 46.407 (U.S. Department of Health and Human Subjects 1991) and FDA regulations at 21 CFR 50.56 (Food and Drug Administration 2001). Studies where psychotropic medications are given to normal children in order to better understand their mechanism of action on the brain usually fall into this category since non-therapeutic administration of a

A number of public and private websites provide detailed information about child participation in research and the process of determining if a particular project is ethically acceptable. Click on the picture below to access the website of the Office for Human Research Protection.



Click on the picture below to access the Children's Hospital Boston's interactive parents' guide to medical research.



psychotropic drug would generally be considered to pose more than minimal risk. Similar, although not identical, regulations are in place in the European Union and in other countries.

The process of informing parents and children about the aims, procedures, potential risks and benefits of research participation, existence of alternative treatments, and the rights of research participants is critical for obtaining their informed permission and assent. In general, children age 7 and above are able to provide assent, which is often documented in writing with an appropriate "assent form". With proper communication and explanation by researchers, parents can achieve a good understanding of both the research procedures and the rights of participant. By age 16, adolescents have a level of understanding similar to that of their parents (Vitiello et al, 2007).

A number of psychotropics have received approved pediatric indications by the drug regulatory agencies (the FDA in the US), but others are used *off-label*. Use of a drug *off-label* is not in itself an inappropriate practice as it is often supported by considerable empirical evidence and consistent with treatment guidelines. However, it is important for parents to be aware that a medication is going to be prescribed off-label so that they can make fully informed decisions about the treatment of their child.

PEDIATRIC PSYCHOPHARMACOLOGY IN CLINICAL PRACTICE

Practicing evidence-based pharmacotherapy in child and adolescent psychiatry requires the integration of knowledge and expertise at different levels, including developmental psychopathology, pharmacology, current drug regulatory policies, bioethics relevant to vulnerable patients, and at least enough familiarity with psychosocial interventions to allow an informed and balanced decision making process. Research typically provides information at the group level. This is certainly useful for preparing general practice guideline and algorithms, but the information needs to be interpreted and adapted to the needs of the individual child, a process that relies on the skills of the clinician.

The first few weeks of treatment are devoted to determining if and at which dose the medication is effective and tolerated. During this phase (*acute treatment*), frequent monitoring is needed in order to titrate the dose based on clinical response (Table A.8.2). Depending on the type of medication, clinical response can take just a few days to emerge or may require several weeks. As previously discussed, the use of standardized rating scales can be especially useful in this phase. It should be noted that, even for the most effective medications, such as stimulants in ADHD, the chance that an individual patient will derive a clinically significant benefit is about 70%, thus leaving about a third of patients without sufficient improvement. This means that the clinician must be ready to recognize non-response and change the treatment plan accordingly. In many cases, a second-step medication can be considered. For example, if a child with ADHD has not improved from methylphenidate, an amphetamine product may be effective. Likewise, depressed adolescents who have not improved on an antidepressant have about a 50% chance to respond to another antidepressant (Brent et al, 2008).

Table A.8.2 Key steps in implementing pharmacotherapy in child and adolescent psychiatry

1. Complete a comprehensive diagnostic evaluation documenting the presence of a condition for which medication is indicated
2. Inform parents and child (to the extent allowed by developmental level and cognitive functioning) of the potential benefits and risks of medication as compared with alternative options
3. If the medication does not have a regulatory-approved indication for use in children with the condition, inform parents and child that the medication is being used "off-label"
4. Identify and measure the target symptoms and functions that medication is expected to improve
5. Based on the medication, obtain baseline clinical or laboratory parameters (e.g., weight, height, blood pressure, pulse rate, cholesterol level, renal function)
6. Start medication at a dose in the lower end of the usually effective dose range aiming at identifying the lowest possible dose that produces the desired outcome
7. Monitor effects, side effects and, if appropriate, plasma levels (e.g., lithium levels) in the first few weeks of treatment, and adjust the dose as appropriate
8. If there is improvement, optimize the dose aiming at maximum resolution of symptoms and improvement in functioning
9. Determine the maintenance dose and, based on the condition and medication, establish a tentative duration of treatment
10. As appropriate, periodically consider the need for continuous treatment vs. discontinuation
11. When discontinuing treatment, examine the need for gradual taper, which is recommended for most medications after chronic treatment (e.g., antidepressants, lithium, antipsychotics), vs. abrupt discontinuation, which can be appropriate for some medications (e.g., methylphenidate)

Once a medication has been found to be of benefit and well tolerated by the patient, the treatment continues with the goals of optimizing it, achieving remission and functional recovery (*continuation phase*). Finally, after achieving recovery, the treatment typically continues with the purpose of maintaining improvement and preventing relapse or recurrence (*maintenance phase*). The duration of maintenance treatment depends on the condition being treated and the history of illness of the individual patient. For example, ADHD is a chronic condition, so that long-term treatment is usually indicated. However, the phenotypic manifestations of ADHD may change with time, as hyperactivity tends to decrease or fade away in adolescence or young adulthood, so that a periodic reassessment of the need for pharmacological treatment is advisable on an annual basis or so. This can be accomplished by discontinuing treatment and monitoring for symptoms at home and in school. In the case of depression, it is recommended that effective treatment be continued for 6-12 months after reaching remission, after which a

gradual tapering off of the medication over a 2-3 month period can be considered (Hughes et al, 2007). For patients who had had recurrent episodes of depression, a more prolonged treatment is usually advisable.

CULTURAL AND ETHNIC INFLUENCES

The use of pharmacotherapy for children and adolescents with mental disorders varies widely across countries. This variability cannot be fully accounted for by differences in nosology or prevalence of psychopathology, thus suggesting that cultural, economic, regulatory, and other contextual factors play a major role in the decision by clinicians and parents to medicate children with emotional and behavioral disorders (Vitiello, 2008). Use of psychotropic medications is substantially higher in the US than in other developed countries. More than 80% of the world usage of stimulant medications occurs in the US. It is estimated that about 3.5% of US children are treated with stimulant medication for ADHD, and use has been consistently increasing over the years (Zuvekas & Vitiello, in press). Likewise, antidepressant and antipsychotic use is many times greater in the US than in other countries (Fegert et al, 2006).

There are also differences within countries. For example, use of stimulants for ADHD treatment in the US is greater among the white population than among children of African American or Hispanic background. These ethnic differences appear to be independent of economic factors. Furthermore, stimulant medication use is lower in the US West Coast than in the rest of the country (Zuvekas & Vitiello, in press). One needs to recognize that approaches to mental health vary considerably based on cultural factors. The implications of this variability for disease outcome and patient prognosis are unclear.

CONCLUSIONS

When properly used, medications can have an important role in the treatment of children and adolescents with several mental disorders. There is evidence that some medications can help not only manage symptoms, but also improve functioning and speed up recovery. The critical role of a thorough and complete diagnostic evaluation before considering medication cannot be overemphasized, as well as the need for consistent monitoring during treatment. The therapeutic value of a number of psychotropics is now well documented in both the short- and intermediate-term, while more research is needed to better understand the long-term impact of pharmacotherapy. Pediatric psychopharmacology is a field in rapid development and clinicians need to remain informed as new data become available.

Use of psychotropic medications is substantially higher in the US than in other developed countries.

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Section B

PERINATAL AND EARLY CHILDHOOD RISK AND PROTECTIVE FACTORS & DISORDERS

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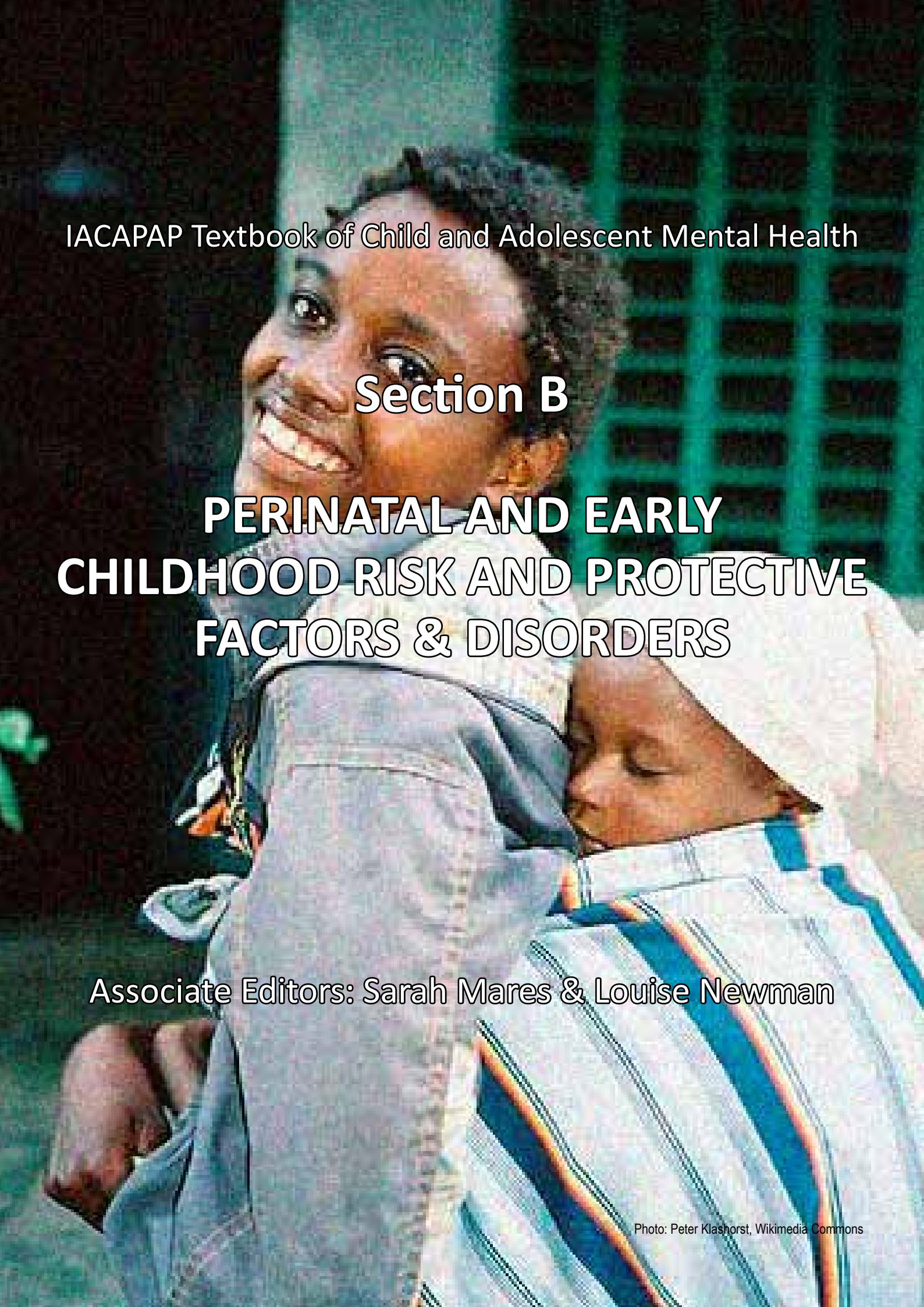


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EARLY MALTREATMENT AND EXPOSURE TO VIOLENCE

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Children Playing London Bridge, by William H. Johnson

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Suggested citation: Tan Susan MK, Kamal Nor N, Loh SF, Wahab S, Marimuthu S, Chan LF. Early maltreatment and exposure to violence.. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

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Acknowledgements: Our thanks to Ms Madeleine Yong and Ms Lois Engelbrech, Founding Director s of Protect and Save the Children (PS the Children) Malaysia for their contribution. Also to Dr Irene Cheah for reviewing the draft, Ms Siti Haidah Mohd Ijam and Ms Siti Suraya Mansor for their secretarial help

Children need a safe and secure environment that they can call home. Besides providing shelter, home needs to be a place of both physical and emotional safety where children can find comfort, protection and security. Thus, optimum development depends on the interaction of positive environmental influences and inherent genetic disposition starting even prenatally (Shonkoff et al, 2000). Negative experiences at an early age have been shown to have long term consequences for children, including changes in brain structure (National Scientific Council on the Developing Child, 2004). These stressors are not necessarily just physical insults such as injury or infection; psychological or emotional ones are equally "toxic" for the process of growing up healthily, especially if there are no supportive adult attachment figures to help the child buffer the stress. When the immediate environment in which a child lives – his home – becomes a "war zone" with verbal and physical aggression, the suffering of the child is not only limited to the point in time when it occurs but has repercussions for the rest of his life. Research has shown that exposure to violence in the household has a lasting developmental impact (US Department of Health and Human Services, 2003). In this chapter the term "child" is used for human beings aged less than 18 years, "he" is used to describe both girls and boys and "parent" is used to describe parents, carers, guardians and other individuals who have parental responsibilities.

HISTORICAL NOTE

Dr Henry Kempe created the terminology and concepts which are now universally recognized. The "shaken baby syndrome" was identified in1972 by American pediatrician and radiologist John Caffey (American Academy of Pediatrics, 2001). However, it was not until the 1970s that sexual abuse began to be acknowledged and the 1980s and 1990s that emotional abuse was recognized.

CHILD MALTREATMENT

The definition (see Table B.1.1) of child maltreatment varies across continents and cultures but the focus is on similar salient points, which are:

- *Ill treatment* (i.e., the opposite to nurturing)
- *The potential to cause harm to the child*, including threats to harm as well as neglect (failure to provide the basic necessities required for normal development)
- It usually involves parents or other people in the context of a relationship of responsibility, trust or power (this includes teachers, religious leaders etc.)
- *Exposure to (witnessing) violence*, especially between parents.

In 1873 animals had rights but children did not

In 1873, a church worker, Mrs Etta Wheeler, who had been asked to visit the family, found a 9 year-old-girl, Mary-Ellen, shackled to her bed, grossly malnourished, scarred and badly beaten. Mrs Wheeler was so appalled by what she saw that she went to the authorities to report this horrifying child abuse.

The authorities turned her away. Mrs Wheeler refused to take no for an answer and petitioned the American Society for the Prevention of Cruelty to Animals (ASPCA). She was appalled that animals were protected but children were not. Mrs Wheeler appealed to the ASPCA that children were members of the animal kingdom and must therefore be protected. It was on these grounds that the ASPCA did finally intervene. Mary-Ellen was removed from her abusive home and placed in foster care, where she thrived. She went on to marry, have 2 daughters, and lived to the age of 92.

Table B.1.1 The various types of child abuse*

Physical abuse	Physical harm or injury
Neglect /negligent treatment	Failure to provide for a child's basic needs and development in all spheres
Emotional abuse	Failure to provide a developmentally appropriate, supportive emotional environment which results in impairment of a child's emotional development or sense of self-worth
Sexual abuse	The involvement of a child in sexual activity that he (by virtue of his age or stage of development): • Does not fully comprehend • Is unable to give informed consent to • Is not developmentally prepared for. Sexual abuse may be by adults or children who are in a position of responsibility, have obtained children's trust, or have power over the victim.
Exploitation	The use of the child in work or other activities for the benefit of others, for financial gain, e.g., child labor.

*World Health Organization and International Society for Prevention of Child Abuse and Neglect (2006).

The "father" of child abuse

Serendipitously, the advent of radiology, took the diagnosis of child abuse to a new level. Dr Henry Kempe, a US pediatrician, used X-rays to prove non-accidental injuries in a large number of children admitted to his care. The

X-rays changes of old fractures and abnormal skeletal changes led to the identification and official recognition of physical abuse and child neglect by the medical community through his seminal work "The Battered Child Syndrome" bringing the issue of child abuse to the fore of modern medicine in the 1960s.

The diversity of legal definitions, practices and laws represents a wealth of models to choose from to develop a suitable legal framework and practice in one's own country. One can thus model on what is deemed most appropriate for a particular society. International organizations, which span countries and cultures, usually adopt definitions and legal guidelines from the country most appropriate for their practice. The World Health Organization (WHO) distinguishes several types of child maltreatment: physical abuse; sexual abuse; neglect and negligent treatment; emotional abuse; and exploitation.

Cultural values, standards of care in a community and poverty are important considerations in determining the presence of maltreatment and how it is addressed. What are *reasonable* standards of discipline may change with time as well as between societies. For example, physical punishment, which was considered an aspect of appropriate parenting in days gone by – spare the rod, spoil the child – is now widely seen as harsh or inappropriate (Creighton, 2004). Although non-violent approaches to disciplining children are the most commonly reported method (Runyan et al, 2010), violent disciplinary practices still occur worldwide (UNICEF, 2010). A higher level of education in primary caregivers is associated with lower levels of violent disciplining. Research in Sweden has shown that legislation banning corporal punishment, if used in conjunction with public promotion of alternative non-violent parenting methods, may reduce the use of violent disciplining (Ziegert, 1983).

So, how do we know if a child is being maltreated? If the universal principles of children's rights are violated or the child is at risk, at that time or at a later time, to suffer negative consequences as a result of that action or lack of action, alarm bells should ring. However, it was only with the Universal Declaration of Human Rights (1948) and the Convention on the Rights of the Child (UNICEF, 1989) that international legal instruments for the promotion and protection of children's

Children's Rights (see also Chapter J.7)

The Convention on the Rights of the Child states that children everywhere are entitled to basic human rights which include the right to:

- Survival
- Develop to the fullest
- Protection from harmful influences, abuse and exploitation
- Participate fully in the family, cultural and social life.

rights became available (see Chapter J.7). In 1873 animals had rights but children did not. Mary-Ellen, the 9 year old child in the vignette, did not suffer in vain. As the first recognized child abuse victim in North America, her case led to the founding in 1874 of the Society for Prevention of Cruelty to Children (Finkelhor, 1984).



In 1873 animals had rights but children did not. In 1989, children had rights too! (CRC,1989)

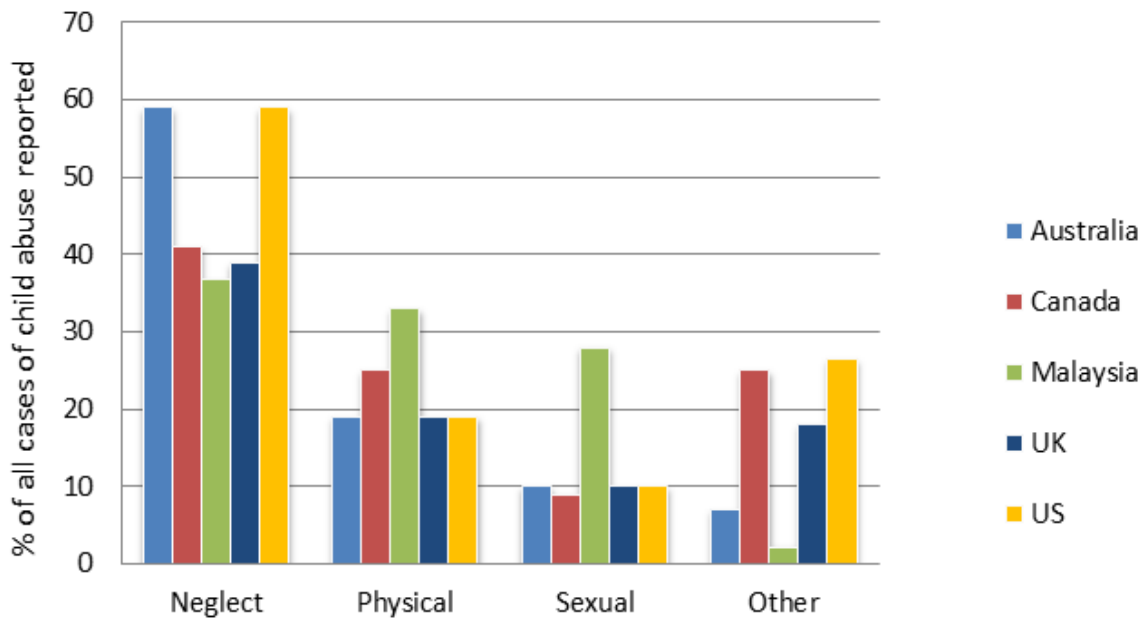
EPIDEMIOLOGY

Globally, there is a lack of reliable estimates of the prevalence of child maltreatment, especially for low- and middle-income countries. Most prevalence and incidence studies have been conducted in Western countries (Figure B.1.1). Estimates vary widely depending on the country and the method used; hence, comparisons between countries should be interpreted with caution. Increasing awareness amongst professionals and the public has resulted in greater reporting of abuse.

Approximately 40 million children globally are estimated to suffer abuse each year (WHO, 2001). Between 25% and 50% of all children report having been physically abused. Many are also victims of emotional abuse or neglect and what is reported may only be the tip of the iceberg. There is potentially a large pool of undetected maltreatment which may not have been recognized to be due to abuse. For example, there are approximately 31,000 homicide deaths/ year of people younger than 15years. Many children who die are classified as "accidental deaths" – falls, burns, drownings – which may have been died due to maltreatment. Further:

- The International Labor Organization reports that there are 250 million child laborers aged 5 to 14 years in developing countries. 15 million

Figure B.1.1 Rate* of child maltreatment in several countries according to type.



*Estimates vary widely depending on the country and the method used; comparisons between countries should be interpreted with caution. Sources: Australian Institute of Health and Welfare (AIHW, 2004); Canada (Trocme & Wolfe, 2001) in Creighton, 2004; UK: Department of Education and Skills (DES 2004); US: Department of Health and Human Services (US DHHS, 2003).

children in India are bonded laborers, working to pay off family debts (Human Rights Watch, 2001).

- Approximately one million children are introduced to commercial sexual exploitation worldwide (Casa Alianza, 2001)
- In armed conflict and refugee settings, girls are particularly vulnerable to sexual violence, exploitation and abuse by combatants, security forces, members of their communities, aid workers and others (WHO, 2010)

Table B.1.2 Features of risk factors of abuse*

	Risk factors	Features of risk factors	Common presentations
Child	• Younger age • Constitutional vulnerabilities (e.g., cerebral palsy, mental retardation, prematurity etc) • Difficult temperament • Chronic illness • Gender – for school aged children, female gender higher risk for sexual abuse while male gender higher risk for physical abuse	• Vulnerable & dependent state • Attachment issues	• Fractures • Shaken baby syndrome (especially below 3 y/o) • Bruises • Internal bleeding • Choking • Smothering
Family	• Low socioeconomic status (poverty, unstable housing, low education, unemployment, single parenthood, young parental age) • Criminal history • Substance abuse • Chronic physical illness and disabilities • Psychosocial factors (mental health problems, poor coping skills; lack of support from spouse, family, community; marital disharmony; domestic violence) • Parents victims of abuse • Violence within the family	• Lack of resources and education • Increased caregivers' burden • Lack of parental supervision • Ineffective coping skills and parenting skills	• Malnourishment • Inadequate health care • Emotional Abuse • Harsh physical punishment • Lack of supervision • Exposure to pornographic materials
Society	• High local unemployment • Social isolation • Socio-cultural • Legal aspects • Disasters: natural or man-made	• Cultural practices that condone certain types of abuse • Policies, or lack of, leading to child exploitation • Lack of enforcement	• Sanctioned physical and sexual abuse (e.g., genital mutilation) • Child soldiers • War rape • Prostitution

*Sources: Herrenkohl et al (2008); Mersky et al (2009); Stith et al (2009); Whitaker et al (2008).

RISK FACTORS

Table B.1.2 shows there are certain children, parent and family characteristics that increase the likelihood of children being abused or neglected. Early identification of such unmet needs with timely and sensitive intervention to meet them could avoid the situation from becoming more serious and many children being abused.

Mother's poor health or compromised nutritional status (for example teenage mothers with an unwanted pregnancy living in poverty) may result in inadequate nutrition and in preventable problems such as folic acid deficiency (increasing the risk of *spina bifida*), rubella, exposure to environmental toxic substances such as mercury, lead and organophosphate insecticides, and both legal and illegal drugs.

Parental factors associated with child abuse

- Unemployment
- Poverty
- Family and marital conflict
- Domestic violence,
- Drug or alcohol use,
- Trouble with the law
- Previous involvement with child protection services
- Parental exposure to physical abuse or family violence in their childhood.

CONSEQUENCES OF MALTREATMENT

For child survivors of maltreatment the suffering happens not just at that point in time; the deleterious impact, without adequate intervention, lingers on decades later into adulthood. Mental health and physical health problems occur during childhood as well as when they have grown up. Certain types of abuse may cause long-term injuries, for example when the brain is directly damaged as in the "*Shaken baby syndrome*". Maltreated children with bone fractures may have a higher risk of developing cancer (Fuller-Thompson et al, 2009).

Beside social problems, children who survive abuse or neglect are more likely to have cognitive difficulties affecting learning, language development and academic achievement. They are more likely to develop antisocial behavior with subsequent delinquency, and teenage pregnancy (Johnson et al, 2006). They are more likely to smoke cigarettes, use alcohol or illicit drugs (Dube et al, 2001); up to two-thirds of people in drug treatment programs reported having been abused as children (Swan, 1998).

Childhood maltreatment is strongly associated with poor physical and mental health outcomes in adulthood. As young adults, victims are at increased risk of depression, anxiety, eating disorders, obesity and attempted suicide (Silverman et al, 1996), are more likely to have physical symptoms (both medically explained and unexplained) and to engage in health-risk behaviours such as smoking, risky sexual behaviors, alcohol and drug misuse. The greater the severity of maltreatment the stronger is the association with poor outcomes in adulthood.

Science has refuted the belief that infants and young children are too young to be affected by stressors. Exposure to stress during critical developmental periods can have long term damaging effects to the developing brain resulting in structural changes (National Scientific Council on the Developing Child, 2010). Adverse early infant experiences such as neglectful maternal care has been shown to have a negative impact on the developing brain. Drug and alcohol exposure in pregnancy may also lead to neurobehavioral and neurohormonal changes in the offspring that could have long-term adverse effects on memory, learning, and behavior (see Chapter G.1).

Mechanisms

Maltreatment causes stress. Stress responses include activation of hormonal and neurochemical systems, the sympathetic adrenomedullary system, producing

adrenaline, and the hypothalamo-pituitary-adrenocortical system, which produces cortisol. Sustained or frequent activation of these hormonal systems can have serious developmental consequences. For example, when children experience severe or prolonged stress, their cortisol levels remain elevated for prolonged periods. This toxic stress can turn specific genes "on" or "off" (Gunnar et al, 2006). The relationship children have with their caregivers play a critical role in regulating stress hormone responses. For example, children who have secure attachment relationships have a more controlled stress hormone response when upset or frightened; the contrary occurs in children whose attachment relationships are insecure or disorganized (Loman et al, 2010).



Click on the picture to view a video describing how toxic stress derails healthy development (1:52)

EVALUATION

Concluding that child maltreatment has taken place has important implications for the child and the family (e.g., a child may be removed from a family or a person may be imprisoned). While in some cases child abuse can be clearly seen to have occurred (e.g., if the child has evidence of physical injuries or of being prostituted in the presence of witnesses), this is not clear cut in the majority of cases, when ascertaining whether maltreatment has taken place is usually difficult. This is because, depending on their stage of cognitive development, children are often unable to remember events, are very suggestible and experience conflicting emotions. For example, it has been shown that up to one-third of three year olds misidentify their own father in a photo-lineup – casting doubt on their ability to correctly identify a potential perpetrator (Lewis et al, 1995).

It needs to be distinguished between a mental health evaluation of children in which maltreatment is suspected (e.g., in which a disclosure has been made or if the clinician suspects that maltreatment has taken place) and the forensic interview – to elicit facts with a view to legal action. Optimally, once clinicians form the view that maltreatment has occurred, they should report it to the appropriate authorities according to their local law; in these circumstances it is not the role of clinicians to investigate whether maltreatment has actually occurred. Therapists should never be the forensic examiner in those specific cases; not separating both roles (investigation and treatment) will cause problems and hinder prosecutions because therapists would not be objective and could be accused of contaminating the child's memories or planting new ones. The clinical – therapeutic – assessment would not differ greatly from the clinical assessment of other children (see Chapter A.5) and is not repeated here. This section focuses on the forensic evaluation (however, in societies where the luxury of adequate number of specialists is not available, forensic evaluation needs to be completed before intervention by the same person for the reasons described above).

The age of the child and cognitive development needs to be kept in mind and should influence the way in which the interview is conducted and the type of information that can be obtained:

- *Toddlers* have difficulties identifying time and place and will probably not be able to say how often something has happened, when it happened, or even where it happened
- Three to five year olds cannot think abstractly, may be easily distracted during the interview or become restless. They may be able to date things in relation to events such as before or after birthdays, bedtime,

Behaviors that that may indicate that a child may be abused

- Unexplained delay in seeking medical help, especially following a fracture, serious burn/ scald
- Explanation offered by child or guardian is not consistent with the injury
- Discrepant explanations given by members of the family and other caregivers
- History of ingestion of poison, alcohol or drugs, suicidal attempts or running away
- Inappropriate response of caretaker to child's injuries such as denial that child is in pain, or minimizing of symptoms
- Repeated presentations with injuries, often to different doctors or health care facilities.

etc. Asking them to draw or demonstrate what happened might be easier for them than verbal communication

- *Six to nine year olds*, although concrete thinkers, are increasingly capable of understanding concepts, able to orient themselves in time and space and draw simple floor plans. They can deceive more convincingly than younger children and are more capable of keeping a secret. They usually feel conflicted, confused, guilty and embarrassed, and may be afraid they may be punished. They are reluctant and tentative in their disclosures and withdraw if the interviewer is perceived as unsupportive. Role play, drawing and the use of dolls by trained personnel can be helpful
- *Preadolescents* (aged 10-13) are typically more comfortable with an interviewer of the same gender; feel awkward and self-conscious about their bodies and about discussion of sexual issues. They normally understand that what has happened to them is wrong but are likely to feel responsible for the abuse; overwhelming guilt and shame often leading to denial. They may respond better to brief, clinically oriented questions and to a more formal approach to the interview. They need reassurance that they are not to blame for what has happened.
- *Teenagers* are more likely to respond to an honest, open and direct approach, showing respect for their concerns and support for their needs; avoiding coming across as critical or judgmental (Craig, 1998).



Click on the picture to view a slide show on child abuse (warning: extremely graphic) (8:54)

Disclosure of abuse, particularly sexual abuse is gradual. Most children go through stages, which include denial-disclosure-recantation-reaffirmation. Up to 70% of sexually abused children may initially deny the abuse. Younger children are more likely to disclose the abuse accidentally through inappropriate statements or actions such as sexualized play. Older children and teenagers are more likely to disclose the abuse purposefully because they are angry at the perpetrator or are influenced by their peers.

The interview should be conducted by someone experienced in this area in a child-friendly and non-threatening setting. The number of interviews should be kept to a minimum by having as many of the multi-disciplinary professionals involved as possible present. Ideally this should be done in a viewing room with a one way mirror or by videoing the interview, so as not to overwhelm the child.

The clinical history is most important and includes obtaining a history from the child, in particular the social history, as well as corroborating evidence from others. Family and social history are important to understand the family background, living arrangements and support systems. As already highlighted, certain risk factors are strongly associated with child abuse.

While the forensic interview aims to clarify *who, what, where* and *when,* this does not mean that a good understanding of the child's and family's background is not important. Questions should be open ended, backing off when sensing the child is uncomfortable. Walking the child through familiar routines so the child can describe them spontaneously is often helpful.

According to Craig (1998), the basic format should include:

- A short rapport-building phase
- An attempt to determine the child's developmental level, communication skills, and knowledge of truth/lie, pretend/real

Shaken baby syndrome: a 'hidden' abuse

This is a preventable cause of long-term neurological damage and disability in a previously healthy child. It can be caused by vigorous shaking of a baby (usually younger than 2 years) by the carer resulting in rupture of intracranial blood vessels when sheared against the skull. It can present with:

- Drowsiness, lethargy and fits
- Subdural hemorrhage or generalized cerebral edema
- Retinal hemorrhages
- Fractures, for example rib fractures.

- The child's knowledge of body parts and ability to use words such as “on top of”, “under”, “in front”, “behind” etc
- Next, the main part of the interview (who, what, where and when) by asking open ended questions like: "Do you know why you are here?" "Your Mommy told me you've been having a problem with…”
- Avoid teaching the child about sexual activity, correcting the child's statements, or giving judgments (e.g., the alleged perpetrator being a bad person)
- Don't use words the child does not understand
- Don't ask complicated or double-barreled questions
- Avoid questions that can be answered with “yes” or “no”
- Good ways to elicit information include questions such as: “Tell me more”; “What makes you think so?” “Then what happened?” “Is there anything else you want to tell me?”

Details that need elucidating include events that preceded the injury or abuse, when and who first noticed the child was injured, how the child’s symptoms developed and in what order. Certain circumstances are highly suspicious of abuse (refer to Box).

Key features in the physical examination of abused children

- General demeanor and appearance
- Cleanliness, signs of neglect, emotional disturbance
- Edema, bruises and redness of the scalp
- Infant’s fontanelle for fullness
- Fundoscopy findings of retinal, pre-retinal or vitreous hemorrhages
- ENT: bleeding, tears of the frenulum, bruising or abrasion inside the lips or pharynx
- Rib tenderness, lung contusions; ruptured spleen or viscous, duodenal hematomas on chest and abdominal examination
- Bony or joint tenderness or swelling

The physical examination

A thorough pediatric physical examination is imperative in all cases of suspected child abuse and many countries have their own guidelines setting out how this is to be performed. The physical examination should be conducted in a comfortable, child friendly environment, where the child can be put at ease. If appropriate and available, the presence of a person known to the child may help. The examination should be non-threatening, starting with the routine measurements normally carried out on pediatric patients such as height, weight and head circumference. As the child is being examined for evidence of injury, assessment of language and social skills can also be done as one interacts with the child. Physical examination findings such as bruises, burns, abrasions or skin lesions should be documented accurately, including descriptions, measurements, diagrams and photographs. Use simple diagrams to accurately draw and label correctly the site of injury, left or right.

Suspect maltreatment if the answer is yes to any of the following questions (Mcdonald, 2007):

- Is there an unusual distribution or location of lesions?
- Is there a pattern of bruises or marks?
- If there is a bite or handprint bruise, is it adult size?
- If there is a burn, are the margins clearly demarcated with uniform depth of burn?
- If there is a burn, is there a stocking and glove distribution?
- Are there lesions at various healing stages or ages?
- Is the reported mechanism of injury inconsistent with the extent of trauma?

Careful documentation is vital as doctors examining the child might be asked to testify in court regarding the evidence obtained and can refer to their

Farah, a 15 year old girl, was brought to hospital by police for attempting to jump off the 4th floor of a shopping mall after her boyfriend broke off with her. She admitted to feeling sad for a "long, long time" – since her parents divorced when she was seven years old. Of all the four siblings she missed her father the most as he used to spoil her. After the divorce he remarried, had other children, stopped visiting and ceased maintenance payments.

Farah's grades deteriorated as she started to skip classes going from an A-level student to the bottom of her class. Her mother remarried a businessman three years ago. He seemed to be the father figure and provider they all longed for until his business failed and he turned to drugs. He became increasingly violent towards her mother and all the siblings and started raping Farah and her 10 year old sister when their mother was working. He silenced them with threats that he would kill their mother if they told anyone. Farah tried to escape stepfather's abuse by staying away from home at a shopping centre till late at night when her mother came home. Farah began mixing with the boys in the shopping complex and became a "girlfriend" to a "kind" 20 year old convenience store worker because he listened to her problems. She started having intimate relations with this boyfriend 10 months ago; she felt the need to please him to keep his support.

She stopped having periods seven months ago and guessed she was pregnant because she "felt something moving inside" although her periods had been irregular for about a year. She told her boyfriend that she might be pregnant and he refused to have anything to do with her anymore. She now wants to die or have an abortion.

own notes, which can be subpoenaed. All the information gathered should be clearly written up immediately to prevent errors and should be factual, concise and accurate (in the child's own words as far as possible), signed with the name of the doctor, clearly written and dated (with an official stamp if required by local procedures).

Investigations

A skeletal survey is recommended for children under the age of two years. All children with head injuries should have X rays, CT or MRI scans, depending on availability. Ultrasound examinations can detect excessive free fluid and hematomas to help diagnose intra-abdominal injuries. Blood tests needed include a full blood count and coagulation tests to diagnose bleeding disorders in patients who present with bruising; drug screens are useful if poisoning, accidental or otherwise, is suspected.

SEXUAL ABUSE

There is no universal definition of child sexual abuse. The WHO defines it as the involvement of children in sexual activity (a) that they do not fully comprehend, (b) to which they are unable to give informed consent or for which children are not developmentally prepared and cannot give consent, or (c) that violate the laws or social taboos of society. Other definitions include the use of a child for sexual gratification by an adult or significantly older person (Tomison, 1995 p2). In practice, identifying child sexual abuse is complex and what is considered sexual abuse may vary depending on local customs (e.g., female genital mutilation), legislation (criminal or child protection laws), and the relationship between the child and the perpetrator. While some behaviors would be considered sexually abusive by almost everyone (e.g., the rape of a 10-year-old child by a parent), others are more ambiguous (e.g., consensual sex between a 19-year-old and a 15-year-old). Legal age of consent also varies between countries. Unlike in other types of maltreatment, whether sexual abuse has occurred or not varies depending on the relationship between victim and perpetrator:

- *Adults with no familial relationship to the child*. Any sexual behavior between a child under the age of consent and an adult is abusive

Physical indicators of child sexual abuse (not necessarily present):

- Bleeding from the vagina, external genitalia or anus
- Injuries such as tears or bruising to the genitalia, anus or perineal region
- Sexually transmitted diseases (STD), vaginal discharge
- Trauma to the breast, buttocks, lower abdomen or thighs
- Adolescent pregnancy

- *Family members of the child*. Any sexual behavior between a child and an adult family member is still abusive (consent, equality and coercion concepts are usually inapplicable in instances of intra-familial abuse)
- *Adults in a position of power or authority over the child* (e.g., teachers, health professionals). Age of consent laws are usually not applicable due to the imbalance of power that exists and the breach of personal and public trust when professional boundaries are violated
- *Adolescent or child perpetrators*. Existence of abuse would depend on whether the activity is consensual, the age differential and whether there is an imbalance of power (e.g., sexual activity between two 15-year-olds where one suffers from an intellectual disability). Sexual exploration between consenting adolescents at a similar developmental level is not considered abuse.

Forms of child sexual abuse include physical contact (such as touching, fondling or any form of contact with breasts or genitalia, including using objects, vaginal intercourse, and sodomy) and nonphysical abuse (such as exposing children to pornography, erotic talk, and exhibitionism); this may occur in dyads, groups, sex rings, as sexual exploitation, and as ritual abuse.

Child sexual abuse may be uncovered in various ways. A child may disclose the sexual acts directly or indirectly with age inappropriate behavior, particularly overtly sexualized behavior. Older children may present with self-destructive behaviors, drug use, suicide attempts, self-mutilation or running away from home. These children may also have an unexplained accumulation of money and gifts. There are indicators peculiar to child sexual abuse listed in the Box.

Examining victims of child sexual abuse

Once sexual abuse has been uncovered, there is a need to protect the child from further harm and help in treatment and rehabilitation. It is important to emphasize again that the therapist *should not be* the forensic examiner unless there is no one else available, in which case the forensic examination and legal procedures should precede the therapy.

Physical examination is no different from that of maltreated children, as described above, although the emphasis would be on those aspects and areas relevant to sexual abuse. The absence of abnormal physical findings *does not* exclude the possibility of abuse – less than 10% of substantiated child sexual abuse cases have physical findings on examination. This may be due to, among other reasons, the type of abuse (e.g., nonphysical) or the timing of the examination in relation to the abuse. In the physical examination of females one should keep in mind the possibility of normal and abnormal variants of external genitalia (e.g., hymeneal cleft) and non-specific findings including erythema, labial adhesions (normally found in 17%-39% of prepubertal girls), vaginal discharge, condyloma acuminatum or anal fissures in a young child.

For the proper procurement of medico legal evidence, timely and accurate collection of samples is needed. Forensic issues to be mindful of include *not* allowing the child to bath or clean up, although the child may feel disgusted and dirty, until the physical examination is completed and samples taken. To reduce distress, perform the physical examination as soon as possible after the incident (also seminal DNA degenerates after 72 hours). Label correctly each item of

The role of the physician

The role of the physician (as separate from the therapist) in child sexual abuse cases

- To identify any injury (including ano-genital, extra-genital trauma, other physical signs of abuse or neglect)
- To detect the presence of STD, pregnancy (pregnancy prevention may be indicated in some countries)
- To consider post-exposure prophylaxis for HIV.
- To identify any other forensic evidence that may corroborate the existence of abuse (e.g., body fluids)
- To accurately record any physical findings and the result of investigations (e.g., through photographs)
- To explain and initiate any necessary treatment
- To rule out psychiatric emergencies (e.g., suicidality).

Examination in sexual abuse cases

Never use any type of force or coercion to perform the medical examination, which may re-traumatize the child. Sedation (with the appropriate consent) may be necessary to facilitate proper examination as well as to procure medico legal evidence.

clothing packed in bags provided with the child's name in the presence of police and utilize a "rape kit" to obtain samples (individual countries may have different kits, like they have different guidelines as to how the forensic examination should be conducted).

LEGAL ISSUES

Each country has its own legislation about child protection. Many countries have legislated mandatory reporting to child protection bodies; a police report may also be required. For example, in Malaysia (Child Act 2001), Child Protectors (social welfare officers) are authorized to conduct home visits and place victims in a safe environment and it is mandatory for all doctors to report to the Child Protectors once child abuse is uncovered.

MANAGEMENT

Regrettably, even in high income countries such as the US, a very large proportion of the victims of maltreatment do not receive any treatment or services – apart from investigation. Thus, given the frequency of this problem, the unmet need is enormous; welfare services dealing with maltreatment are stretched if not overwhelmed everywhere in the world.

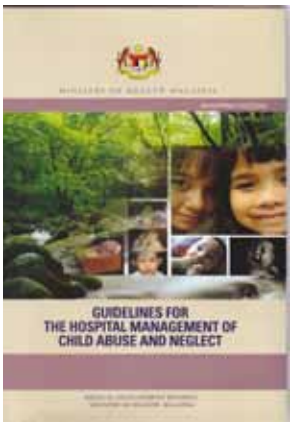
Treatment will require different targets depending on the type of abuse (e.g., physical, sexual, neglect), the symptoms and their severity, whether the child has been removed from the family (e.g., it is in foster care or in an institution) and what treatment seeks to achieve (e.g., family preservation or reunification). There is very limited evidence about what treatments are effective (Wathen & MacMillan, 2005). In practice, the parents and not the child are often the main focus of intervention. In these cases, the stronger effects are achieved by targeting parents and the parent-child interaction context in home-based settings during early childhood, designing multicomponent interventions delivered by professionals for teaching parenting competency skills, and targeting families of higher risk children (Thomlison, 2003). For example, a controlled trial in the US involving 192 parents in child welfare – with an average of six prior referrals and most with all of their children removed – in which parents attended a program of "parent-child interaction therapy" found a significant reduction in future child welfare reports (Chaffin et al, 2011). Trauma-focused cognitive behavior therapies and parent-child interaction therapy appear to be superior to general psychotherapeutic treatments.

The first step is to ensure that the effects of maltreatment are not worsened by the subsequent management delay as the child's development marches on, which regrettably often happens due to poor coordination of services and care planning (system abuse). While the focus should be on the welfare of the child, the traditional practice of managing child maltreatment by physically removing the child to a place of safety focuses primarily on the physical well-being of the child alone. This protects the child from further harm from the same perpetrator but might not address his emotional and psychological needs vital for healing.

In general, psychiatric management can be divided into acute and long term. During the initial presentation, a full assessment of the victim's condition is needed. In severe cases, inpatient admission might be considered, for example, in cases of severe depression, high suicide risk or acute psychosis. Admission may

Issues to keep in mind following sexual abuse in adolescents

- Teenage pregnancy, parenthood and abortion (illegal in some countries), abandoned babies
- Culturally unacceptable sexual practices (e.g., homosexual practices)
- Impact of sexual abuse and exploitation
- Implications of chronic illness (e.g., pelvic inflammatory disease)
- Chronic psychological and emotional complications
- Stigma
- Impact on academic and occupational functioning and opportunities.



Click on the picture to access the Malaysian Guidelines for Hospital Management of Child Abuse and Neglect (2009). Most countries have their own guidelines.

also be required for treatment of physical injuries or for the protection of the child. Acute and short term problems often observed include: fear and anxiety, sleep problems and nightmares, somatic problems, anger/acting out, lowered self-esteem, social withdrawal or isolation, school difficulties, feelings of powerlessness, stigmatization, and symptoms associated with trauma. Ongoing problems such as depression, post-traumatic stress disorder, relationship issues, juvenile delinquency and substance abuse have to be anticipated. Factors affecting the consequences of child abuse and neglect include the:

- Child's age and developmental stage at the time of abuse
- Type of abuse (physical abuse, neglect, sexual etc.)
- Frequency, duration, and severity of abuse
- Relationship between the victim and abuser (English et al, 2005).

"It is easier to build strong children than to repair broken men."

Frederick Douglass (1817–1895)

In the long term, there is a considerable body of evidence showing that maltreatment during childhood is a factor that increases the risk for almost all psychiatric conditions, and these should be appropriately managed as described in other chapters of the book. Another important aspect of management is to support the child with the help of an attachment figure, e.g., helping the child deal with non-supportive family members and cope with court proceedings (Center on the Developing Child, 2007).

Effective interventions for children and families at risk of poor outcomes

- Early and intensive support by skilled home visitors for vulnerable families who are expecting a first child
- High-quality, center-based, early education programs for young children from low-income families
- Two-generation programs that simultaneously provide direct support for parents and high-quality, center-based care and education for young children from families experiencing significant adversity
- Interventions that provide specialized services matched to the problems they are asked to address for young children experiencing toxic stress from abuse or neglect, severe maternal depression, parental substance abuse, or family violence
- Parent management training programs.

PREVENTION

Preventing child maltreatment before it occurs is as important as treatment (Finkelhor, 2009). Reducing child abuse is possible but requires a coordinated multi-sectorial approach. Effective prevention programs support parents and teach positive parenting skills. Ongoing care of children and families can reduce the risk of maltreatment reoccurring and can minimize its consequences. Longitudinal data from the Perry Preschool Project research shows that successful intervention results in decreased expenditure in the juvenile and criminal justice systems, decreased special education costs, increased tax revenue from higher incomes, and decreased reliance on government assistance. Cost-savings from reductions in crime were the primary saving mechanisms observed (Rolnick & Grunewald, 2003).

While some prevention programs are universal (e.g., education about parenting through advertisements or media programs, creating awareness of the evil of family violence, universal home visitation for new mothers), most are targeted to families with the risk factors highlighted. These would include more intensive home visitation, screening, detection and treatment of maternal depression, and parenting programs. The last, based on the principles of social learning theory, deliver lower intensity modalities of parent management training programs such as "Triple P" (Positive Parenting Program) (Graaf, 1998) (see Chapters A.9 and D.2). Both home visitation and parent training programs have been shown to be effective but much more work and resources are required in this area. Policymakers, NGOs and important community figures (e.g., religious, academic) have role to play in this endeavor.

Policymakers

Using the information gathered over decades of research, it is imperative that policy makers be convinced of the importance of implementing policies to

Prevention strategies from an NGO's perspective

P.S. The Children, a non-profit organization in Malaysia built its framework on research from the US, UK and Australia and adapted it to the Malaysian context. Research indicates that far more children are abused than actually reported. Thus, preventing sexual abuse is paramount and it seeks to:

- Educate adults to better protect children
- Galvanize communities to develop support systems for children
- Teach all children appropriate protective behaviors
- Teach high risk children how to use support systems
- Teach abused children who are too afraid to tell that what abuse was not their fault and help with other emotional health issues to minimize long-term negative effects of the abuse
- Prevent child abuse victims of today from becoming offenders of tomorrow.

meet the needs of vulnerable children. They need to be aware that:

- No single program, approach or mode of service delivery has been shown to be a "magic bullet". There are ways to promote the healthy development of young children. The key is to select strategies that have documented effectiveness, assure they are implemented well, and recognize the critical importance of a strong commitment to continuous program improvement
- Successful large-scale programs require rigorous assessment and periodic monitoring of the quality at individual implementation sites, as well as training and technical assistance for continuous quality improvement
- Return on investment is more important than up-front costs. Long-term societal benefits are of greater importance than short-term costs. Four key challenges of note are:
    1. Matching support and services to the needs and strengths of the children and families to be served
    2. Paying careful attention to the quality of implementation when effective model programs are taken to scale
    3. Developing new intervention strategies for children and families for whom conventional approaches appear to have minimal impact
    4. Providing an environment that supports ongoing, constructive evaluation and continuous program improvement
- "Contexts" for policy consideration include:
    1. The nuclear family
    2. Out-of-home settings
    3. Multi-generational programs
    4. Family economics and maternal employment
    5. Environmental contamination.



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Children celebrating eid Mubarak in Malaysian traditional costumes.

FAILURE TO THRIVE OR WEIGHT FALTERING IN A PRIMARY HEALTH CARE SETTING

Astrid Berg



A Javanese family at Tasik Malaya, Java (Photo: CH Graves, c1902)

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Conflict of interest: none declared.

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Suggested citation: Berg A. Failure to thrive or weight faltering in a primary health care setting. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions, 2012.

A mother's first concern is about whether she can maintain the life and growth of her baby (Stern, 1995). Feeding the infant and seeing it develop is a primary task which all parents wish to fulfil. Most mothers want only the best for their offspring. In turn, the child possesses an inborn drive to move forward, to grow and to progress – children are meant to thrive. Sadly, this fundamental right is missing for many infants all over the world. When things go wrong, when the growth of the baby is impeded for whatever reason, it becomes a serious and profound problem for the parents. It is worth reflecting on the meaning of naming this condition "failure to thrive": does it not imply failure on the part of the caregiver? Could this not do an injustice to the parent? In future we may consider "faltering weight" as a better, less pejorative term to describe this condition.

Feeding varies considerably among children during infancy and feeding problems are very common, affecting up to 30% of infants depending on how feeding problems are defined. However disorders of feeding are still poorly understood. The causes of infant feeding problems are multifactorial, not well known and overlapping the fields of paediatrics and mental health, although physical causes need to always be excluded.

Research has shown that in developing countries children under the age of 5 years are prevented from reaching their full potential because of exposure to multiple risk factors. Poverty plays a central role in mental health in general for adults (Lund C et al, 2010), but particularly it does so for young children. Malnutrition in the early years has serious consequences for brain development (Grantham-McGregor et al, 2007) which could adversely affect children's later ability to learn and progress in school. The long term adverse effect of failure to thrive on cognitive ability should not be underestimated; it has been estimated to be around 4 IQ points. (Corbett & Drewett, 2004)

Feeding

The term "feeding" implies a two-way relationship, a delicate interplay between mother and child in the feeding situation.

It is important for infant and child health workers to know that malnutrition is not simply a matter of inadequate food intake or physical illness, but that it can be a manifestation of things having gone wrong in the relationship between mother and child. The term *feeding* does imply that a two-way relationship is part of eating in early childhood (Chatoor, 2002) – a delicate interplay exists between mother and child in the feeding situation. While the World Health Organization recognizes the importance of *stimulation* for young children, there is insufficient emphasis on the centrality of the caregiver-child relationship in the actual feeding situation.

This chapter focus specifically on how priority can be given to the relationship between caregiver and child within the context of a primary health care setting in a developing country such as South Africa. The categories which describe the various reasons for faltering weight are described. The focus throughout shall be on the very young child, under 12 months, bearing in mind that the effects of early problems in this domain extend far beyond the first year of life. The word "mother" is used to denote the adult who is the main caregiver and who fulfils the traditional "mothering" functions. It does not exclude other caregivers such as father, grandparents, day carers and foster parents.

DEFINITIONS AND CLASSIFICATION

Failure to thrive can be regarded as a descriptive umbrella term which refers to inadequate growth due to a nutritional deficiency. Failure to thrive is often used in clinical practice to mean that the current weight or rate of weight gain of a child are significantly below that expected of similar children of the same sex and age. There is no definite accepted measure to diagnose the condition; most practitioners diagnose failure to thrive when a child's weight for age falls below the fifth centile of the standard growth chart (see Appendix B.2.1). Although failure to thrive was once classified into organic and nonorganic, it is now seen to be the result of the interaction between the environment and the child's health, development and behaviour (Gahagan, 2006). Successful feeding is necessary not only for physical survival but is also tied in with the infant's general development.

Failure to thrive can be regarded as a descriptive umbrella for infants or toddlers who have difficulty in establishing regular feeding patterns and do not gain the expected weight.

DSM-IV and the DC: 0-3R classification systems

DSM-IV-TR (American Psychiatric Association, 2000) defines "feeding and eating disorders of infancy or early childhood" as a persistent failure to eat adequately resulting in significant failure to gain weight or significant loss of weight over at least one month, and the disturbance is not due to an associated gastrointestinal or other general medical condition. This definition however is limited as it does not include the subcategories or groupings which are evident when working with very young children who exhibit faltering weight.

The *Diagnostic Classification: Zero to Three Revised Edition* (DC0-3R) (Zero to Three, 2005) re-dresses this problem and makes use of the categories originally described by Chatoor (2002). According to DC0-3R, the diagnosis of *feeding behaviour disorder* should be considered when an infant or toddler has difficulty in establishing regular feeding patterns. As has been already stated, the intake of food at this early stage of life is not an isolated activity but part and parcel of the relationship that exists between the caregiver and the baby. Four stages of feeding behaviour disorder are described – these can become evident during specific developmental phases from the first weeks of life until toddlerhood:

- *Feeding disorder of state regulation*. Difficulty with feeding becomes evident during the neonatal period. Young infants must reach a state of calm alertness in order to feed successfully. Vulnerable infants may have difficulty in reaching this state of calm alertness – an attuned caregiver will be able to help her infant reach and maintain an optimal state for feeding. However if the caregiver is overwhelmed or depressed, she may have difficulty in helping her child attain this state of calm alertness.
- *Feeding disorder of caregiver-infant reciprocity*. Between 2 and 6 months of age the infant affectively engages with the caregiver. Reciprocal vocalizations, eye contact and physical closeness are the hallmarks of this phase, which Daniel Stern has called the "most exclusively social period of life" (Stern, 1985). It is thus to be expected that if the caregiver is unable to respond to the infant's cues, feeding may become affected. According to Chatoor (2002), these infants could be called "neglected" in that their mothers often suffer from psychiatric conditions, such as affective illnesses and substance abuse. Because of the turmoil in their minds, they are unable to be sufficiently attuned to the cues of their infants. However, the association of serious



Photo: Kent Page, UNICEF, DRC, 2003.

mental disorders with feeding disorder of caregiver-infant reciprocity may be more applicable to high income countries. In low to middle income countries, mothers' disturbance is often a more reactive one – reactive to very real stressful life events they have to contend with on a daily basis. These hardships are the cause of preoccupation and depressive affect which in turn may account for a lack of sensitivity to her child's cues and thus giving rise to a feeding disorder of reciprocity. It does not necessarily imply neglect or serious mental disturbance in the mother.

- *Infantile Anorexia*. This disorder becomes apparent between the ages of 6 months and 3 years. Chatoor (2002) links it to difficulties in the developmental phase of separation-individuation, as described by Margaret Mahler (1972). If the infant's cues have not been understood and bids for comfort have been responded to by feeding, the infant confuses hunger with emotional experiences and learns to eat or not to eat in response to negative feelings. Eating can then become a battleground resulting in feeding being externally regulated by the parents. This condition causes enormous anxiety in parents who may resort to extreme measures in order to coax their child into eating.
- *Sensory food aversions*. These become apparent when the infant transitions from baby food to table food. These children are very aware of various sensory stimuli and may respond to the taste, texture, smell and appearance of certain foods. They may show aversive reactions when specific foods are placed in their mouths and are generally reluctant to try out new foods, often resulting in a restricted diet.

Feeding disorder associated with concurrent medical condition and *feeding disorder associated with insults to the gastrointestinal tract* will not be dealt with here as they are not developmentally based and can thus be seen at any age.

FAILURE TO THRIVE, ATTACHMENT AND MATERNAL SENSITIVITY

DSM-III (American Psychiatric Association, 1980) included *growth failure* under the diagnosis of *reactive attachment disorder*; however, by the time DSM-III-R (American Psychiatric Association) appeared in 1987, the link between failure to thrive and reactive attachment disorder was eliminated (Boris & Zeanah, 2005). Subsequent research has shown that most children with failure to thrive do not meet criteria for reactive attachment disorder. Irene Chatoor and colleagues (1998) came to the conclusion that feeding problems and growth deficiencies can occur within the context organized and secure attachment relationships. However, a broad link between failure to thrive and the relationship between mother and baby can readily be made, even if the criteria for attachment disorder are not met.

The attachment relationship is built to a large degree on the ability of the mother to be attuned to her child. From her Uganda study Mary Ainsworth formulated the concept of maternal sensitivity to infant signals, which she correlated with later attachment security (Bretherton, 1992). Mothers who are depressed or preoccupied are likely to be less available to respond to their infants promptly and appropriately (Patel et al, 2004). This lack of sensitivity can be manifest in the feeding situation – which during the first year of life is the mother's main task and the infant's main physical need. What is then needed is for mothers to be made aware of this link and to help them become responsive to their babies in the daily feeding situation.

RESPONSIVE FEEDING

Nutrition and primary health care programmes place emphasis on concrete feeding practises and on the actual diet given (Bourne et al , 2007; Bowley et al, 2007; Cattaneo et al, 2008), often with no mention of the fact that feeding in young children is embedded in the relationship with the care-giver. However it is encouraging to note that over the last decade there has been an increasing awareness of the need a child has for a responsive care-giver, also in the feeding situation. Thus the concept of *responsive feeding* has been developed and is being

A child rearing context in Mozambique*: Madzawde*

Once born a baby was considered to have madzawde - during this period the mother had to breastfeed her child for 2 years and a symbiotic relationship between mother and infant was unconditionally guaranteed by this state of madzawde. The mother used the breast for comfort, the child was carried on the back and she would sleep with the child. This provided an opportunity of optimal physical and psychological care during the early phase of life. Two years after the birth of the baby the parents performed a madzawde ritual which marked the point of separation between mother and child and allowed for the re-establishment of the marital relationship. If this ritual was not performed according to the custom a set of physical symptoms could ensue which would affect the child and could even lead to death. This phase and ritual is rooted in the deep cultural knowledge of what a child needs in the first years of life and has been transmitted from one generation to the next. However, the war experiences in this region disrupted the ability of parents to carry out this ritual and it is postulated that the etiology of the Protein-Energy-Malnutrition subsequently seen in this area is elated not so much to lack of food, but with the disorganization of madzawde (Igreja, 2003).

incorporated in the scientific literature as well as nutrition programming (Bentley et al, 2011).

Parents and caregivers vary in the way they feed their children – this depends not only on the socio-economic context but also the cultural milieu in which the child is being raised. However, generally speaking, positive verbalizations and attentive mothers are associated with greater acceptance of food and better growth. While breastfeeding is the norm in most non-western cultures, times of weaning can be marked by specific rituals, which, if disturbed can lead to faltering weight (see Box in Page 5).

When planning nutritional intervention programmes for young children, simple and basic messages need to be given, messages which are easily conveyed and which make sense across different cultural settings. Black and Aboud (2011) conceptualized a four-step process between caregiver and child that reflects reciprocity and mutuality and is at the heart of responsive feeding:

1. The caregiver creates a context which promotes interaction – this would include having a routine, a structure, expectations and a positive emotional atmosphere.
2. The child responds and gives their signals to the caregiver.
3. The caregiver in turn responds promptly in a manner that is supportive, contingent and tailored to the child's developmental abilities and needs.
4. The child will then experience a predictable response.

While the above steps are clear and, on the face of it, easy to implement, much depends on the caregiver's ability to be attuned to the child and to be able to respond contingently. The third step in the above sequence is the one most dependent on, and reflective of the caregiver's state of mind. Chronic lack of resources, which includes not only material but also the lack of supportive relationships, makes people more vulnerable to additional stress, which contributes to further resource loss (Hobfoll, 2001). In developing or low income countries this chronic lack of resources is more prevalent. It is thus not surprising that growth stunting is a significant link in the chain of events that lead to ultimate poor educational outcomes for children in the developing world (Grantham-McGregor et al, 2007).

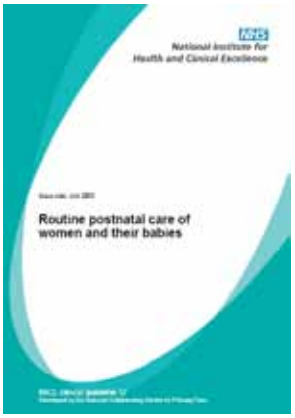
Concepts such as *responsive feeding* are helpful in articulating the possible mechanisms that are at play in the feeding situation. However it must be remembered that most parents are able to keep their infants alive and feed them well without having been taught how to do it. It is knowledge that has been passed on through the generations and, whatever the methods used, it has worked, otherwise that particular group of humans would not have survived. Daniel Stern's (2002) words ring true: "*A mother's caregiving repertoire need not be taught, in fact cannot be taught, but it can be disinhibited*."

The question then is how can a mother, father or other caregiver be *disinhibited* so as to become a responsive feeder of her baby? And, if we step further back, how do we identify caregivers who are struggling? Given that there might be millions of such children in developing countries, how do we find them and their parents? One possible point of entry will be put forward here.

PRIMARY HEALTH CARE SETTING FOR INFANTS IN A DEVELOPING COUNTRY

It is usual practice that all infants and toddlers are weighed on their scheduled immunization clinic visits. Growth monitoring has been used as a screening tool to identify vulnerable children during these visits. The child health chart used in South Africa contains a graph which incorporates the weight for age of the child at every clinic visit. Children who deviate from their trajectory are considered to be at risk and are referred for nutritional support. Clinical experience has shown that faltering weight can be associated with a variety of socio-emotional factors and can be a useful entry point for mental health practitioners.

If mental health services are available, these children and their caregivers are also referred to an infant mental health practitioner. It would be the task of this practitioner to ascertain whether factors relating to the child's socio-emotional development could be contributing to the faltering weight. It must be noted that for many caregivers anywhere, let alone in developing countries, the notion of an infant being affected by psychological factors such as family conflict or maternal depression is novel and care has to be taken to introduce this possibility in a gentle and understandable way (Berg, 2007). The following steps are guidelines which are useful when meeting a mother and an infant with faltering weight in a primary health care setting.



Click on the picture to access the NICE clinical guideline Routine Postnatal Care of Women and their Babies.

Background information of family and child

- *The mother's trust has to be gained*. She may come from a setting where she has been blamed for her child's poor weight gain and thus may be angry or closed in her attitude to health professionals. Trust is established by having a non-judgmental attitude and giving a simple explanation about the finding that often children's problems with feeding and gaining weight have to do with factors other than provision of food. Such factors are mother's emotional problems caused by difficulties within families, stressful life events and the like. Usually this makes sense to the caregivers and they are willing to talk about their lives. In addition, confidentiality needs to be stressed. Most

The toddler NB was referred at the age of 14 months with the problem of faltering weight, which started when she was 3 months of age. While the history was taken in terms of the family and day care arrangements, it was noted that NB was very hesitant in approaching the biscuit that had been placed in front of her. She took a long time to approach it and, once she had it in her hand, examined it with great care. Only then did she put it in her mouth and started chewing on it. This observation of long hesitancy and careful examination made the health care provider ask more details about her weaning. This turned out to have been a traumatic time for mother and NB who, at the age of 3 months, was not ready to be taken off the breast – for at least one month mother battled to get her to accept the bottle; mother had no choice as she had to return to work.

NB's sensitivity and temperament was explained to mother who agreed with the observations. When she returned 2 weeks later her weight had increased from 8.3kg to 9.1 kg and mother spontaneously said that she was happy that she had been referred to us.
This simple case vignette illustrates how much information can be gleaned by observing the infant and what relief can be provided to the mother that she and her child can be understood and not judged.



Faltering weight in primary health care

The University of Cape Town Parent-Infant Mental Health Service is based at the local children's hospital and as part of its outreach programme provides a clinical service to a large township on the outskirts of the city. A child psychiatrist, together with a community counsellor who also acts as interpreter and cultural broker, visit the same well-baby clinic on a weekly basis. It is known as the "Mdlezana Centre".

Infant mental health is a concept that is new and unknown in many communities. Even though it is central, mental health as such is not high on the list of priorities that have to be dealt with in these communities, which are struggling to cope with the daily tasks around survival. Mental health in infants is even more foreign. A way had to be found whereby at risk mother-infant dyads could be identified and referred. It also had to be done in such a way as to not frighten or alienate mothers who might experience such a referral to an outside doctor in a negative or threatening way.

Over time it became evident that faltering weight could constitute a sign that all was not well, and that this was not necessarily due to food insecurity, but due to maternal inhibition. Infant weight is recorded at each visit and plotted on the "Growth monitoring chart". In many clinics supplementary food is given in cases where growth has been unsatisfactory. However, despite this, many babies fail to respond, underlining the point made earlier that feeding hinges on the relationship between mother and infant. The centre's mission statement can be seen in page 9.

mothers come from tight communities where there is much observation and gossip, which results in many not feeling safe to openly discuss their concerns.

- *Information about the family constellation*. Relevant information here is the whereabouts of the father of the baby and the presence or absence of the maternal grandmother. Clinical experience attests to the fact that frequently mothers harbour negative feelings and thoughts towards the father of the baby; this may play itself out in the mother rejecting the infant because of the conscious or unconscious association of her child with its father. The support of the maternal grandmother is crucial, particularly with very young mothers. Traditionally, maternal grandmothers perform central advice giving roles and when this is disrupted for whatever reason, the young woman feels abandoned, both physically and emotionally.
- The third task is to look closely at *the weight trajectory* of the baby and to note when the weight dropped. Enquiries can then be made as to changes

The MDLEZANA CENTRE MISSION STATEMENT

Molweni BooMama!





We are the team from the Mdlezana Centre and would like to talk to you about your babies. While most other people talk about the healthy body of the babies, we also talk about the happiness of you and your baby.

Babies do not just need food, but they need love – this is not always so easy to give, especially when you are feeling heart-sore, upset or angry. Sometimes we feel that something is just not right, and then we cannot enjoy our children.



You must know that even new- born babies are able to hear and see. They pick up from the environment far more than we ever thought they would. If the mother is unhappy, she cannot smile at her baby when the baby is looking at her. If the mother is angry, she will not talk to her baby. So, it can happen that the baby too becomes sad, because it is not being looked at and spoken to the way it needs to. A sad baby will not eat properly and then will be behind in his/her development.



We are taking the first 3 years of life very seriously because it is during this time that the foundation is laid down for the future development of the child. Not just whether the child will be happy or unhappy, but whether the child will be able to learn and concentrate in school.



We thus ask you to come to us and talk with us if you feel something is not right between you and your baby. We cannot offer food or employment, but we can offer a listening ear and advice. Whatever you discuss with us is confidential and remains only with us. We have the time and the knowledge to listen to your troubles.

If you are feeling well then your baby will feel well and develop in the way you want it to. Just as you pay attention to your baby's physical needs, like food and immunisation, so you must pay attention to your own and your baby's emotional needs.



or difficulties either within the mother or her family, separations or losses that occurred during that time. It is important to explain to the mother the impact these events could have had on her and her child. The time of weaning needs to be noted as the weight loss often occurs at that time. Prolonged breast feeding may be a sign of difficulty in separation and could affect the acceptance of solid food – it could be the beginning of infantile anorexia.

- A *physical examination* may be necessary if there are dysmorphic features or suggestions of underlying diseases that may affect growth. Things to look for include skin rashes, cleft palate, symptoms of respiratory or cardiac

disease (e.g., cyanosis, tachypnoea), abdominal distension or organomegaly, evaluation of suck-swallow coordination, presence of dysmorphic features suggestive of a genetic disorder, such as Down's syndrome; intellectually disabled children often have feeding problems.

However, the point that is made in this chapter is about the emotional connectedness or dis-connectedness between caregiver and child and that it is this that affects the feeding relationship. The purpose of gathering information and talking about facets of the mother and baby's life is to enable the mother to have a space in which to think, make links and find meaning, and thus to produce a greater awareness of how her mind and her actions impact on her child. It also provides the mother with the only opportunity she may have to share her hardships with an empathetic listener. Most caregivers understand that concrete help in the form of employment, grants, and food cannot be given in such a service and appreciate the fact that there is a safe space in which they can be heard.

Assessment of child and caregiver-child interaction

While the above information is being gathered, note is taken of the manner in which mother gives information, the way in which she handles and holds her child. In particular it is noted how mother interacts with her infant – is she aware of his needs? Is she attuned to what he is doing? This naturalistic observation, as opposed to using formal observation measures, has the advantage that it allows an open-ended approach.

In primary health care settings and in developing countries standardised assessment scales are often difficult to use as they require specialized training and are mostly based on samples from developed countries. The *parent-infant relationship* can be rated according to the Parent-Infant Relationship Global Assessment Scale (PIR-GAS) of DM0-3R (Appendix B.2.2). The *emotional and social functioning of the child* can be assessed using the Description of Capacities for Emotional and Social Functioning of the Zero to Three System (2005) (Appendix B.2.3).

A biscuit is useful to observe the infant's behavior more closely.

Besides these naturalistic observations and assessments, there is one technique which may be particularly useful in a resource-poor setting. As Winnicott used the spatula game in order to assess the infant's level of anxiety, so a *biscuit* can be used in order to observe the infant more closely. The biscuit is placed within reach of the infant and a close observation is made as to how the infant approaches this new object. Is there curiosity to feel, to mouth it? Is there a long period of hesitation or does the infant grab it with confidence and spontaneity? Does the infant show interest in it at all? Observing the use of the biscuit is a technique similar to the observation of the manner in which an older child would engage with a toy and is a useful adjunct to the overall assessment of the infant. A baby who grabs the biscuit with confidence, who explores it with his mouth and who can play with it, is of less concern than an infant who barely notices the new object or who is too inhibited to venture forth and take hold of it. That infant may be physically not well, but it may also mean that the child has become withdrawn, lacking in energy and vitality – either way, this baby requires our attention (Berg, 2010).

Working with a cultural counsellor and interpreter

The majority of health care interactions in a developing country such as South Africa take place in the presence of a third party. This person, who may

be a nurse or a lay individual, is expected to serve a function that is well beyond that of a mere language interpreter and should be regarded as a *cultural broker* and co-therapist. If the health care provider comes from a different culture, then it is incumbent to ensure that there is proper translation. It is imperative that cultural norms and values be understood and, if there is a disjunction between western bio-medicine and traditional healing methods, then mediation and explanation is essential. The close working together between the health care provider and the cultural broker ensures that communication is clear and respectful. The primary health care clinic is a system in itself and has its own culture. It is wise to adjust to this where possible and not to alienate staff by making extra demands on their time.

CONCLUSION

Faltering weight in an infant is a sign that all is not well. This does not necessarily mean that insufficient protein and calorie intake is the cause, nor does it mean that the child is physically ill. Both these factors need obvious exclusion before other influences are considered. This Chapter addresses these other influences of which the most important may be maternal depression and preoccupation which may be the cause of non-responsive feeding of the child.

Offering a space in which confidentiality is assured, and where the mother is able to think and make links is often all that is needed to gain awareness and insight. In this way behaviour changes and the child is provided with a predictable, developmentally appropriate response in the feeding situation. Not only may this lead to a more robust weight gain, but it will also lay the basis for a more secure relationship between infant and caregiver which is the beginning of mental health for all.

The author working with an interpreter (and cultural broker) in a South African clinic.



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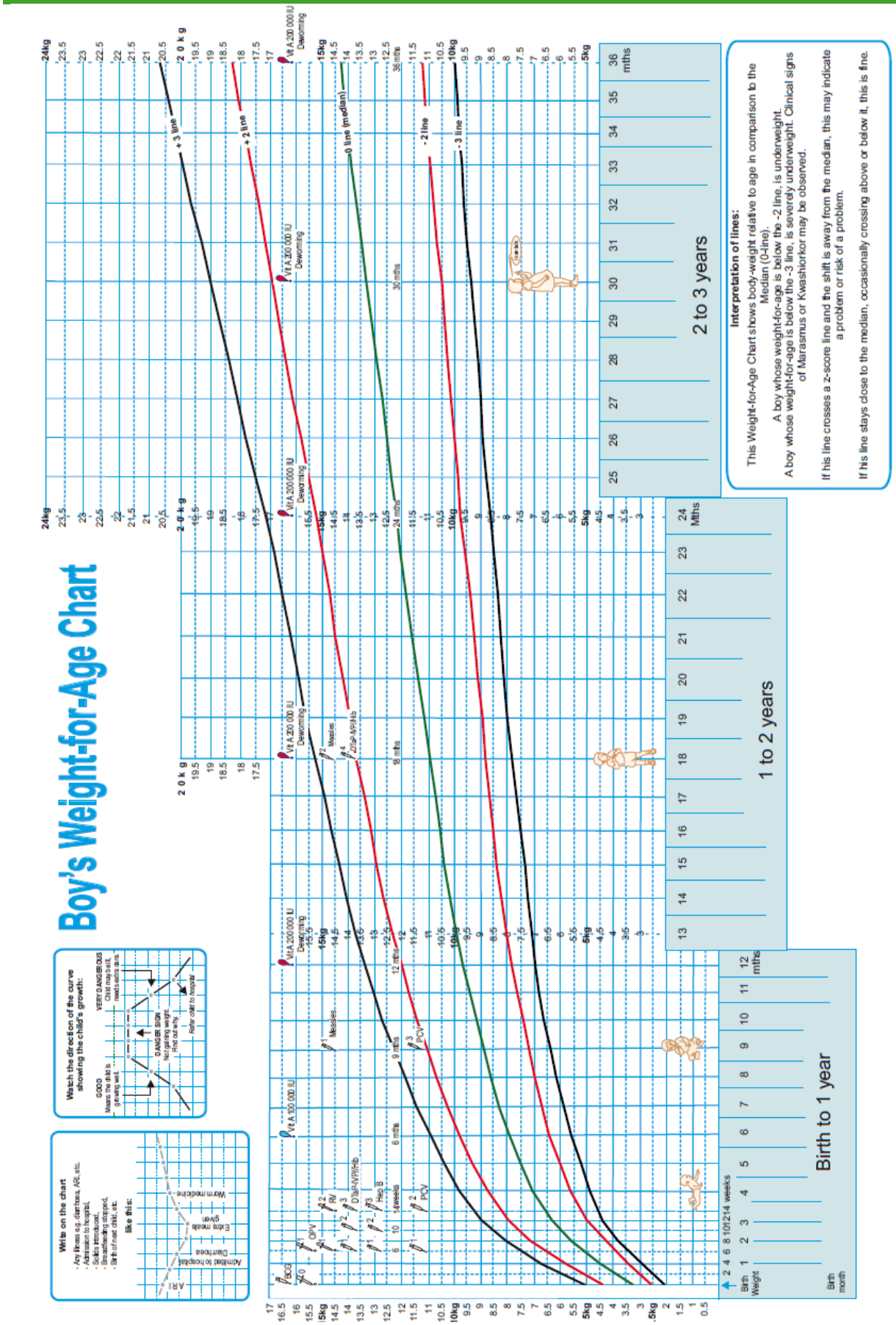
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Appendix B.2.1



Appendix B.2.2

The Parent-Infant Relationship Global Assessment Scale

PIR-GAS Ratings according to DC: 0-3 R

91-100 Well Adapted

Mutual enjoyment without sustained distress or conflict

81-90 Adapted

At times there may be conflict but it does not persist longer than a few days; interactions are mostly reciprocal and synchronous

71-80 Perturbed

Some aspect in the overall functioning is less than optimal; child and parent may experience transient distress lasting up to a few weeks. The disturbance is limited to one domain of functioning

61-70 Significantly Perturbed

Relationships are strained but still largely adequate. Conflicts are limited to one or two problematic areas. Both parent and child may expreince distress and difficulty for a month of more.

51-60 Distressed

Conflict may spread across multiple domains of functioning and resolution is difficult. The developmental progress of the dyad seems likely to falter if the pattern does not improve

41-50 Disturbed

The relationship is beginning to be overshadowed by problematic features. Dysfunctional patterns are more than transient, and developmental progress may temporarily be disrupted

31-40 Disordered

Rigidly maladaptive interactions, conflicted interactions are evident. Developmental progress of the child is likely to be influenced adversely

21-30 Severely Disordered

Relationships are severely compromised. Both parent and child are significantly distressed by the relationship itself. Interactive patterns seem to have been in place for a long time. Developmental progress of the child is influenced adversely and the child may lose previously acquired developmental skills

11-20 Grossly Impaired

Relationships are dangerously disorganized and the infant is in imminent danger of physical harm

1-10 Documented maltreatment

Documented neglect and physical or sexual abuse that is adversely affecting the child's physical and emotional development

Appendix B.2.3

Child's Capacities for Emotional and Social Functioning Rating Scale

According to DC: 0-3 R

Emotional and social functioning capacities	Functional rating 1	2	3	4	5	6	n/a
Attention and regulation							
Forming relationships/mutual engagement							
Intentional two-way communication							
Complex gestures and problem solving							
Use of symbols to express thoughts/feelings							
Connecting symbols logically/abstract thinking							

Functional rating

1. Functions at an age-appropriate level under all conditions and with a full range of affect states
2. Functional at an age-appropriate level, but is vulnerable to stress or with a constricted range of affect
3. Functions immaturely (i.e., has the capacity, but not at an age – appropriate level)
4. Functions inconsistently or intermittently unless special structure or sensorimotor support is available
5. Barely evidences this capacity, even with support
6. Has not achieved this

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Section C

DEVELOPMENTAL DISORDERS

Associate Editor: Jing Liu

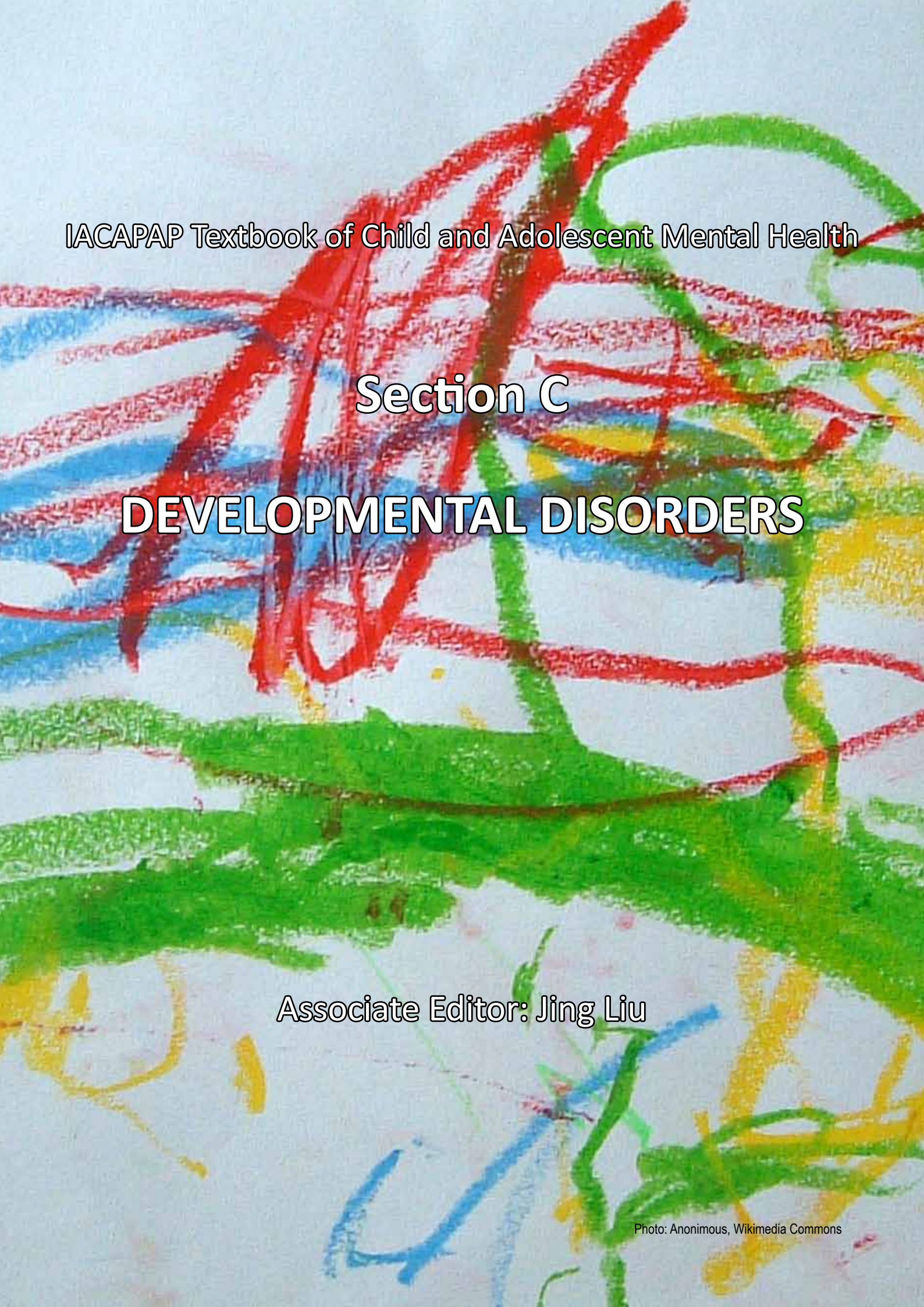


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INTELLECTUAL DISABILITY

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Conflict of interest: none declared

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Suggested citation: Ke X, Liu J. Intellectual disability. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

The term *intellectual disability* (ID) is increasingly being used instead of *mental retardation.* ID or mental retardation is defined as *a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor, and social abilities* (World Health Organization, WHO, 1992). The American Association on Intellectual and Developmental Disabilities (AAIDD) describes ID as *characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills*. This disability originates before age 18. In general, ID applies to the same individuals who were previously diagnosed with mental retardation in kind, level, type, duration and the need for services and supports. Every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of ID (Schalock et al, 2007).



What is a normal development?

There is a wide range of what can be considered "normal" but growth follows a certain sequence. Particular kills are expected to emerge at more or less a specific age. For a detailed description of normal developmental milestones go to Chapter A.2 or click on the picture to go to the National Dissemination Center for Children with Disabilities .

EPIDEMIOLOGY

There have been many surveys to ascertain the prevalence of ID across the world with estimates ranging from 1% to 3% (Harris, 2006). A recent meta-analysis concluded that the average prevalence of intellectual disability across all the studies is 1%. Prevalence is higher in males in both adult and child and adolescent populations. Among adults, the female-to-male ratio varies between 0.7:1 and 0.9:1, while in children and adolescents it ranges between 0.4:1 and 1:1. Rates vary according to income; the highest prevalence occurs in low and middle income countries where rates are almost twice those in high income countries (Maulik et al, 2011). Another meta-analysis, which considered studies published between 1980 and 2009 in European countries, found overall estimates ranging from 0.4% and 1.4% (Wittchen et al, 2011). The prevalence of ID across Asia is broadly consistent with estimates in western countries: 0.06%-1.3% (Jeevanandam, 2009). The most recent Chinese national survey on disability, conducted in 2006, estimated a prevalence of ID of 0.75%. Prevalence in urban areas was lower (0.4%) than in rural areas (1.02%) (Kwok et al, 2011)

ETIOLOGY AND RISK FACTORS

Etiology of ID is heterogeneous. Injury, infections and toxins have become less prevalent causes because of improved antenatal care, while genetic factors have become more prominent. No specific etiology can be found in up to 40% of cases, particularly in mild ID. Environmental influences (e.g., malnutrition, emotional and social deprivation experienced, for example, in poorly run orphanages) can also cause or aggravate ID. Understanding the etiology of ID raises the possibility of treatment or prevention in some cases, while it may allow predicting specific difficulties in others.

Many factors have been confirmed to cause or be associated with ID. These factors, which influence the development and function of the child's brain prenatally, perinatally or postnatally, can be divided into three groups: organic, genetic and socio-cultural. Trisomy 21 and fragile X are the commonest diagnosable genetic causes of intellectual disability. It is unlikely that all intellectual disability will fit neatly into these three groups – overlapping genetic, environmental and socio-cultural factors are likely to be relevant in many cases. Conversely, in up to two-thirds of mild cases and one-third of severe cases, no causes are found,

Table C.1.1 Common causes of intellectual disability

Category	Type	Examples
Prenatal (before birth)	Chromosomal disorders	• Down's syndrome* • Fragile X syndrome • Prader Willi syndrome • Klinefelter's syndrome
	Single gene disorders	• Inborn errors of metabolism, such as galactosemia* • Phenylketonuria* • Mucopolysaccaridoses • Hypothyroidism* • Tay-Sachs disease • Neuro-cutaneous syndromes such as tuberous sclerosis and neurofibromatosis • Brain malformations such as genetic microcephaly, hydrocephalus and myelo-meningocele* • Other dysmorphic syndromes, such as Laurence-Moon-Biedl syndrome
	Other conditions of genetic origin	• Rubimstein-Taybi syndrome • Cornelia de Lange syndrome
	Adverse environmental influences	• Deficiencies* such as iodine deficiency and folic acid deficiency • Severe malnutrition in pregnancy* • Substances use* such as alcohol (fetal alcohol syndrome), nicotine and cocaine during early pregnancy • Exposure* to other harmful chemicals such as pollutants, heavy metals, abortifacients, and harmful medications such as thalidomide, phenytoin and warfarin in early pregnancy • Maternal infections such as rubella*, syphillis*, toxoplasmosis, cytomegalovirus and HIV • Others, such as excessive exposure to radiation* and Rh incompatibility*
Perinatal (around the time of birth)	Third trimester (late pregnancy)	• Complications of pregnancy* • Diseases* in mother, such as heart and kidney disease, diabetes • Placental dysfunction
	Labour (during delivery)	• Severe prematurity, very low birth weight, birth asphyxia • Difficult or complicated delivery* • Birth trauma*
	Neonatal (first four weeks of life)	• Septicemia, severe jaundice*, hypoglycemia
Postnatal (in infancy and childhood)		• Brain infections such as tuberculosis, Japanese encephalitis, and bacterial meningitis • Head injury* • Chronic lead exposure* • Severe and prolonged malnutrition* • Gross under stimulation*

*Definitely or potentially preventable.

highlighting the need for further research. A more detailed list of causes is available at the WHO website (see Table C.1.1). A few are described below in more detail.

Intelligence quotient (IQ)

IQ is a score derived from one of several tests. There are many types of IQ tests that seek to measure general or specific abilities: reading, arithmetic, vocabulary, memory, general knowledge, visual, verbal, abstract-reasoning etc. Well-known IQ tests include the Wechsler Intelligence Scale for Children, Stanford-Binet, Kaufman Assessment Battery for Children, and Raven's Progressive Matrices. Traditionally, an IQ score was obtained by dividing the mental age of the person taking the test (the age group which on average scored such a result in a random sample of the population) by the chronological age multiplied by 100. However, this method has shortcomings (e.g., it cannot be used in adults). Currently the test results are standardised against a representative sample of the population; IQ scores for children are relative to children of the same age. The median result is defined to be 100 and one standard deviation is 15 points, therefore, 95% of the population have scores within two standard deviations of the mean (i.e., within an IQ range of 70 to 130). For IQ to be accurate needs to be standardised against a population culturally similar to that of the person being tested. For example, using norms obtained in a Brazilian population would produce biased results if the person taking the test is Burmese.

Although IQ can change to some extend with increasing age, it is a surprisingly robust construct that is strongly predictive of achievement. IQ has a large inherited component but environmental factors have a strong effect as well. Heritability increases with increasing age: it can be as low as 0.2 in infancy, 0.4 in middle childhood, and up to 0.8 in adulthood. What appears to be a straightforward concept has been marred by controversy over the years. For example, some scholars believe that intelligence is a learned combination of many different skills and abilities while others assume that intelligence is a single trait that is heavily determined by genetics, even others believe that there are large ethnic or racial differences.



Hashan is a four year old boy. He still can't walk independently but can take a few steps with support. He recognizes family members but cannot show where his ear and nose are. He can babble (say ba-ba-ba) but has not learnt to say any meaningful word. He can't indicate toileting needs. His parents say that he is like a one-year-old child.

Does Hashanm suffer fom ID? If so, how severe?

IQ tests are different from achievement tests, the latter seek to measure the skills and knowledge learned (e.g., language, arithmetic), usually through schooling; IQ tests measure aptitude rather than actual achievement (see Chapter C.3). While in the past there was an emphasis on the so-called "general intelligence" current theories view intelligence as a more complex ensemble of aptitudes in a variety of areas (musical, mechanical, physical, social) which can differ substantially in the same individual.

Table C.1.2 illustrates the attainment in adulthood of people with different degrees of ID (WHO). It is clear that even those with severe ID can become at least partly independent in looking after themselves through proper supervision, care and training.

MANIFESTATIONS AND SUBTYPES

The manifestations of ID are mainly developmental delay in intellectual functioning and deficits in social adaptive functioning. According to the severity of the delay in intellectual functioning, deficits in social adaptive function and IQ, the psychiatric classifications describe four levels of severity:

Table C.1.2 Adult attainment according to the degree of intellectual disability

Degree	IQ range	Adult attainment
Mild	50-70	• Literacy + • Self-help skills ++ • Good speech ++ • Semi-skilled work +
Moderate	35-50	• Literacy +/- • Self-help skills + • Domestic speech + • Unskilled work with or without supervision +
Severe	20-35	• Assisted self-help skills + • Minimum speech + • Assisted household chores +
Profound	Less than 20	• Speech +/- • Self-help skills +/-

Note: +/- sometimes attainable; + attainable; ++ definitely attainable

- *Profound*

  IQ is usually below 20; profound intellectual disability accounts for 1% to 2% of all cases. These individuals cannot take care of themselves and have no language. Their capacity to express emotions is limited and poorly understood (Adams & Oliver, 2011). Seizures, physical disabilities, and reduced life expectancy are common.

- *Severe*

  IQ is usually between 20 and 34; severe intellectual disability accounts for 3% to 4% of all cases. Every aspect of their development in the early years is distinctively delayed; they have difficulty pronouncing words and have a very limited vocabulary. Through considerable practice and time, they may gain basic self-help skills but still need support at school, home and in the community.

- *Moderate*

  IQ is usually between 35 and 49, accounting for about 12% of all cases. They are slow in meeting intellectual developmental milestones; their ability to learn and think logically is impaired but are able to communicate and look after themselves with some support. With supervision, they can perform unskilled or semiskilled work.

- *Mild*

  IQ is usually between 50 and 69 and account for about 80% of all cases. Development during their early life is slower than in normal children and developmental milestones are delayed. However, they are able to communicate and learn basic skills. Their ability to use abstract concepts, analyze and synthesize are impaired but can achieve reading and computing skills to grade three to six level. They can

perform house-work, look after themselves and do unskilled or semi-skilled work. They usually require some support.

CLINICAL SYMPTOMS

Speech

Children with ID usually have delayed language development and difficulties speaking and expressing themselves. The degree of severity varies with the level of impairment of intellectual ability. Mild cases can achieve language skills that are only a little poorer than children in the normal range of development. Severe or profound cases can't communicate at all or speak only a few words.

Perception

Children with ID are slow in reacting and perceiving environmental stimuli. They have difficulties distinguishing small differences in the shape, size and color.

Cognition

Capacity to analyze, reason, comprehend and calculate, and for abstract thinking is often impaired to a greater or lesser extent according to severity. Children with mild ID are capable of achieving reading and mathematics skills to approximately the level of a typical child aged 9 to 12 (Daily et al, 2000). Individuals with severe or profound ID lack the capacity to read, calculate or even understand what others say.

Concentration and memory

Ability to concentrate is low and narrow. By and large, memory is poor and they are slow at remembering although there are exceptions (e.g., savants). They have difficulties recalling and their memories are often inaccurate.

Emotion

Emotions are often naive and immature but may improve with age. Capacity for self-control is poor and impulsive and aggressive behavior is not uncommon. Some are timid, withdrawn and shy.

Movement and behavior

Children with ID often lack coordination, may be clumsy or show excessive movement. Meaningless or stereotyped movements (e.g., rocking, head-banging, teeth-biting, shouting, tearing clothes, pulling hair, playing with the genitals) are frequent in severe ID. Destructive, aggressive or violent behavior can also be observed. Self-injurious behavior (e.g. self-slapping or biting) may occur in moderate and severe ID.

Health problems associated with intellectual disability

Compared with normal children, children with ID are at a higher risk of having other health problems. The most prevalent health conditions are: epilepsy (22%), cerebral palsy (20%), anxiety disorders (17%), oppositional defiant disorder (12%), and autistic disorder (10%) (Oeseburg et al, 2011).

Epilepsy

- Between 1% and 13% of children with Down syndrome have epilepsy (Arya et al, 2011)
- Epilepsy, often severe and hard to control, is present in 85% of

Angelman syndrome patients within the first three years of life (Fiumara et al, 2010)

- Patients with fragile X syndrome are highly prone to develop epilepsy (Qiu et al, 2008)

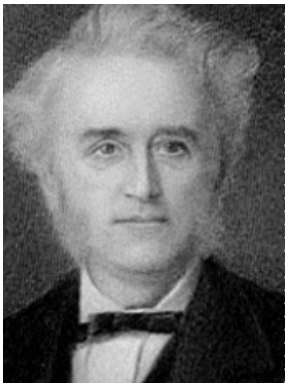
Behavior problems

Symptoms like restlessness (continuously moving around, unable to sit in one place), poor concentration, impulsiveness, temper tantrums, irritability and crying are common. Other disturbing behavior, like aggression, self-injurious behavior (such as head banging) and repetitive rocking may also be seen (see section on challenging behaviors below). When such behavior is severe and persistent, it can become a major source of stress for families. Therefore, attention should be paid to reduce such behavior while providing treatment and care.

Sensory impairment

Visual and hearing problems are present in about 5%-10% of persons with ID. Sometimes these problems can be resolved by using hearing aids or glasses, or undergoing surgery for cataracts

As noted earlier, other developmental disabilities, such as cerebral palsy, speech problems and autism can occur along with ID. Persons with multiple disabilities pose a big challenge in terms of providing care.



John Langdon Haydon Down (1828 -1896), a British physician, was the first to describe a relatively common genetic disorder that is now called Down syndrome.

COMMON CONDITIONS ASSOCIATED WITH INTELLECTUAL DISABILITY

Down syndrome

Down syndrome, also known as trisomy 21, is a chromosomal disorder caused by an additional copy of genetic material on chromosome 21, which affects the development of the body and brain. This syndrome was first described by the British physician John Langdon Down and identified in 1959 as caused by a 21 trisomy by Jérôme Lejeune.

Maternal age and Down syndrome

A woman's risk of having a baby with Down syndrome is:

- At age 25, 1 in 1,250
- At 30, 1 in 1,000
- At 35, 1 in 400
- At 40, 1 in 100
- At 45, 1 in 30
- At 49, 1 in 10

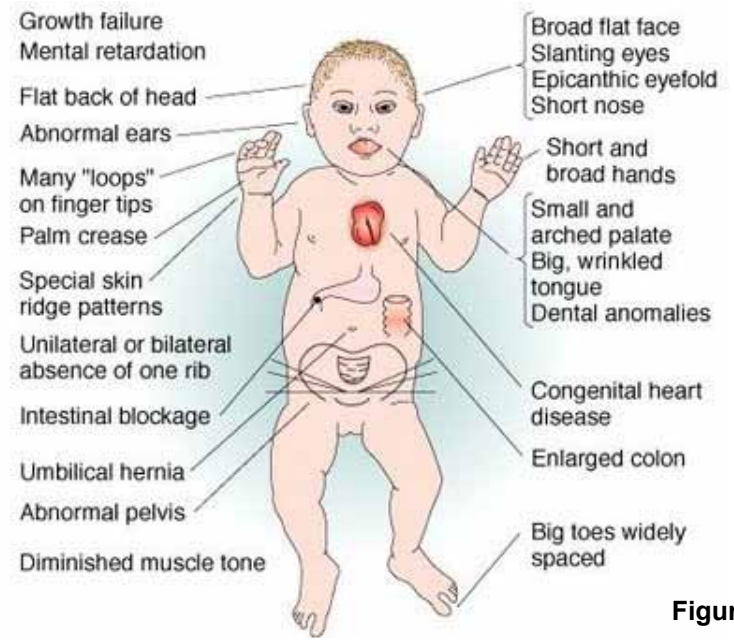


Figure C.1.1 Symptoms of Down syndrome

The incidence of Down syndrome is approximately one per 1000 newborns (Roizen & Patterson, 2003) and is influenced by maternal age. Women aged 35 and older have significantly higher risk.

Down syndrome can be diagnosed by chromosome analysis either prenatally or postnatally, according to which it can be grouped into four types: trisomy 21, mosaicism, translocation and duplication of a portion of chromosome 21.

Clinical features of Down syndrome include (Figure C.1.1):

- Intellectual disability, usually mild; they possess good social skills
- A characteristic appearance including brachycephaly, epicanthal folds, upslanting palpebral fissures, strabismus, Brushfield spots on iris, flattened nose, low-set and rounded ear, macroglossia, open mouth, short neck, brachydactyly, fifth finger clinodactyly, atypical fingerprints, wide 1-2 toe gap known as sandal foot
- Impaired physical growth such as short stature, short limbs and lax ligaments
- Often accompanied by different medical problems including congenital heart disease, duodenal atresia, hearing loss, ophthalmological problems, hypothyroidism, early-onset dementia, and leukemia.

Down syndrome can be detected through prenatal screening. Common screening procedures include: (a) measurement of maternal serum alphafetoprotein (AFP), human chorionic gonadotropin (hCG), unconjugated oestriol, and inhibin-Alpha (INHA) at 15-20 gestational weeks; (b) fetal ultrasound testing for a thickened nuchal fold with measurement of maternal serum free Beta hCG and pregnancy-associated plasma protein A (PAPPA) at 10-13.5 gestational weeks; both (a) and (b). For families with a high risk of having a child with Down syndrome, an invasive diagnostic test, such as amniocentesis, chorionic-villus sampling, or percutaneous umbilical cord blood sampling, performed in the late first trimester or early second trimester, is most accurate.

Premutation

Premutation is a change in a gene that precedes a mutation without altering the function of the gene. In disorders caused by trinucleotide repeat expansions, such as fragile X, premutation is an abnormally large allele that is not associated with clinical symptoms but that can expand into a full mutation when transmitted to the offspring. Full mutations cause clinical symptoms of the disorder.

Fragile X syndrome

Fragile X syndrome (also known as Martin-Bell syndrome and Escalante's syndrome) is an X-linked disease that is one of the most common inherited forms of ID. It is also associated with autism. Martin and Bell first described this disorder in 1943, and Herbert Lubs identified an associated fragile site on the X chromosome in 1969.

The fragile X syndrome is characterized by an expansion of a single trinucleotide gene sequence to over 200 copies of a CGG repeat in the 5'-untranslated region of the fragile X ID 1 (FMR1) gene located at band q27.3 on the long arm of the X chromosome (Xq27.3), which silences the transcription of the gene.

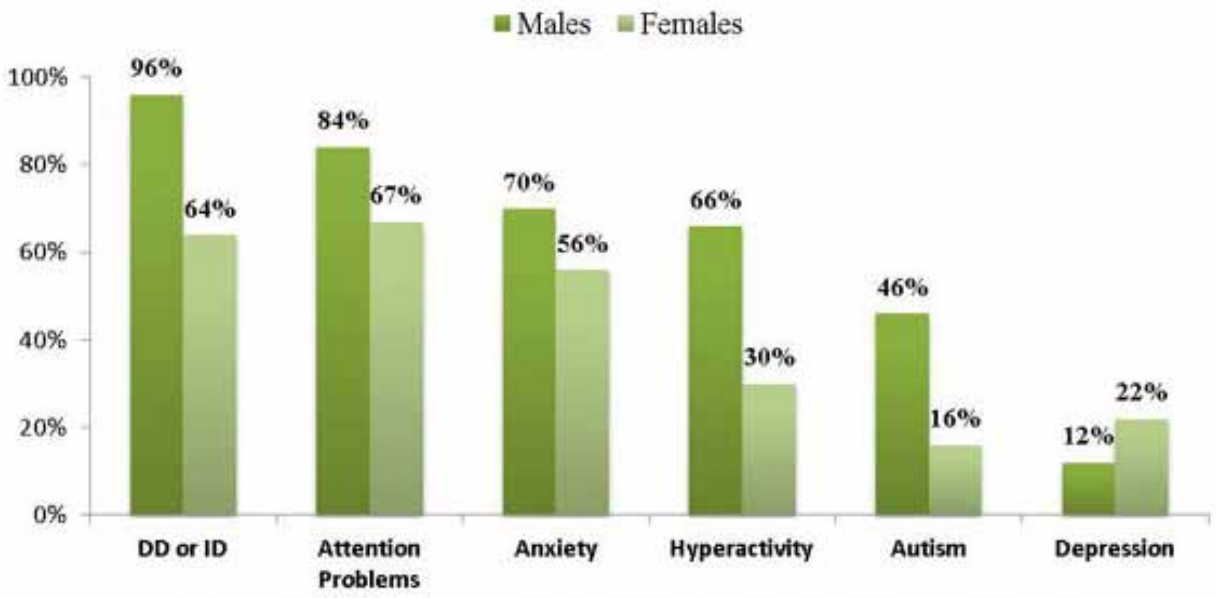
Incidence is about 1 per 2000-5000 persons and is 30% more frequent in males than in females (Hessl et al, 2002; Ridaura-Ruiz et al, 2009). Fragile X syndrome is an X-linked dominant condition with variable expressivity and possibly reduced penetrance that is largely transmitted by females but affecting males more often because males normally have only one copy of the X-chromosome.

Prevalence of fragile X

Approximately:

- 1 in 3600 to 4000 males are born with the full mutation for fragile X and will have fragile X syndrome
- 1 in 4000 to 6000 females are born with the full mutation for fragile X but only 50% of them will show some features of fragile X syndrome
- 1 in 800 men are carriers of the fragile X premutation
- 1 in 260 women are carriers of the fragile X premutation.

Figure C.1.2 Percentage of children with fragile X syndrome diagnosed or treated for other conditions



Source: CDC

Clinical manifestations of the fragile X syndrome vary from mild to severe in physical, cognitive, emotional and behavioral features. Generally, females have a less severe form of the disease than males. Physical phenotype includes a long, narrow face with a prominent forehead and protuberant ears, joint hypermobility associated with connective tissue dysplasia, double-jointed thumbs, flat feet, and macro-orchidism after puberty in males. Individuals with fragile X syndrome usually have cognitive deficits – IQ ranging from normal or borderline to severely low – such as problems with working memory, executive function, and mathematic and visuospatial abilities. Language delay is also evident in early childhood. Emotional and behavioral disturbances are common, including anxiety and mood disorders, features of attention deficit hyperactivity disorder, obsessive compulsive-like symptoms (e.g., repetitive actions or phrases), aggressive and self-injurious behavior, and a difficult temperament. Fragile X syndrome is a common cause of autism. Neurological problems such as seizures may also be found. In addition, persons carrying a premutation (CGG repeat number ranges from 55 to 200) are believed to have a clinical disorder characterized by mild learning disability, emotional problems, premature ovarian failure, and a neurodegenerative disorder called fragile X-associated tremor/ataxia syndrome in older people.



Prominent characteristics of Fragile X syndrome include an elongated face, large or protruding ears, and low muscle tone.

Genetic tests for CGG repeat expansions in FMR1 gene using PCR and southern blot analysis is diagnostic for fragile X syndrome and should be provided to all persons with developmental delay, borderline intellectual abilities, ID and autism. Sequencing of FMR1 gene should be considered as well to exclude deletions of this gene if normal CGG-repeat length is found (Garber et al, 2008).

Genetic counseling is recommended for the whole family if a positive fragile X syndrome premutation or full mutation is detected, and cascade testing should be planned for family members. Although genetic counseling cannot prevent fragile X syndrome, it is still important to give at-risk families accurate reproductive counseling and allow for appropriate intervention beginning in infancy.



Click on the picture to view a short description of PKU (6:02)

Phenylketonuria

Phenylketonuria (PKU) is an autosomal recessive single gene disorder discovered by the Norwegian physician Ivar Asbjørn Følling in 1934. It is caused by mutations of the phenylalanine hydroxylase (PAH) gene or genes coding for enzymes involved in the cofactor tetrahydrobiopterin (BH4) biosynthesis or recycling, which result in dysfunction of phenylalanine metabolism leading to excessive phenylalanine and related substances in the blood, the brain and the urine. Increased phenylalanine concentrations in the brain are toxic and cause disruption of neuropsychological function. The prevalence of phenylketonuria varies widely around the world due to ethnic and social reasons (e.g., frequency of consanguinity). In Europe the prevalence is about one case per 10000 live births, but it is one in 4000 in Turkey, one in 25000 to one in 50000 in Latin America and one in 100000 live births in some regions of China (Blau et al, 2010).

PKU is diagnosed if blood amino acid analysis reveal a raised concentration of phenylalanine (>120 umol/L). To clarify whether the patient with hyperphenlalaninaemia is deficient in BH4 synthesis or regeneration, measurement of urinary pterins or red blood cell dihydropteridine reductase through a filter paper-dried blood specimen, or BH4-load test should be done (Blau et al, 2005). Urinary pterins patterns can differentiate several types of PKU:

- *Classical PKU with PAH deficiency*: total pterins are high but the ratio between neopterin and biopterin is normal
- *GTP cyclohydrolase (GTP-CH) I deficiency:* total biopterins are very low or not detectable
- *6-pyruvoyl-tetrahydropterin synthase (6-PTS) deficiency*: neopterin is increased but biopterin is decreased
- *Pterin-4a-carbinolamine dehydratase deficiency*: neopterin is high while biopterin is low or borderline, and primapterin is high
- *Dihydropteridine reductase (DHPR) deficiency*: neopterin is normal and biopterin is raised.

Inherited metabolic disorders

Chromosomes in human cells contain genes which control growth and maturation. Some of these are responsible for chemical (metabolic) reactions, which are essential for brain growth. If such a gene is abnormal, it can lead to a derangement of metabolic reactions and cause problems such as mental retardation. Phenylketonuria is one such condition. Babies with phenylketonuria, in addition to mental retardation, have light-colored hair and skin, a small head, and are prone to convulsions.



Blood is taken from a two-week old infant to test for PKU
Photo: Nando Peretti Foundation

Babies with PKU seem normal at birth but progressively show developmental disabilities frequently accompanied by lighter skin, hair, eyes, eczematous rash, "mousy" odor, motor deficits, seizures, behavior problems and autism. Early screening, diagnosis and prompt intervention can prevent individuals with PKU from further damage to the brain. Newborn blood screening test for PKU is usually performed three to seven days after birth and a repeat test at approximately two weeks of age to verify the initial test, followed by further diagnostic tests if positive.

Iodine deficiency (which causes hypothyroidism) is the single greatest preventable cause of mental retardation and an important public health problem. This condition can be prevented with iodine supplements in the diet such as by using iodized salt.

Intervention should be started as soon as PKU is confirmed. Restriction of dietary phenylalanine is still the most important and effective management: phenylalanine-free formula with low protein; avoiding foods rich in protein (such as meat, fish, milk, eggs, standard bread, most cheeses, nuts and seeds) and containing aspartame (flour, soya). For patients with the BH4-responsive type, identified by BH4-load test, preparations containing BH4 may be prescribed. Other approaches, such as large neutral amino acids treatment, use of phenylalanine ammonia lyase and gene therapy are under investigation (Blau et al, 2010). For best outcomes, serum phenylalanine should be monitored regularly throughout life in case changes are needed to maintain target therapeutic blood levels.

Congenital hypothyroidism

Congenital hypothyroidism is an endocrine disease caused by thyroid hormone deficiency after birth. It can be classified into permanent and transient. Permanent congenital hypothyroidism is usually associated with thyroid dysgenesis, dysfunction of thyroid hormone biosynthesis or metabolism, or deficiency of thyroid stimulating hormone (TSH), while transient congenital hypothyroidism is due to iodine deficiency, maternal intake of antithyroid drugs, or transplacental maternal thyrotropin receptor blocking antibodies (TRB-Ab). Congenital hypothyroidism occurs in approximately one per 2000 to 4000 live births (Rastog et al, 2010).

Congenital hypothyroidism is diagnosed by measuring serum TSH and either free T4 or total T4 combined with T3 resin uptake. According to age-normative reference ranges, primary congenital hypothyroidism is confirmed with increased TSH and decreased or normal free T4 or total T4, while secondary (central) congenital hypothyroidism is likely if T4 is low but TSH is not elevated. There are other diagnostic tests to further determine the underlying etiology including measurement of urinary iodine, radionuclide uptake and scan, thyroid ultrasonography, serum thyroglobulin measurement, antithyroid antibody determinations, evaluation for other pituitary hormone deficiencies, brain MRI, and genetic testing.

Clinical features of congenital hypothyroidism in infants include: persistent jaundice, poor feeding, quiet, excessive sleeping, constipation, low body temperature, abnormal cry, umbilical hernia, bradycardia, hypotonia with delayed reflexes. Some may have a palpable goiter. The typical appearance includes a wide posterior fontanel, puffy face, flattened nose, eyes exhibiting pseudohypertelorism, and open mouth with macroglossia. If untreated, congenital hypothyroidism can result in growth failure, permanent mental impairment and cardiac problems.

Newborn thyroid screening tests and early management are very important to prevent the development of ID in congenital hypothyroidism. Blood sampled from a heel-prick between two and five days of age is screened by special filter

paper cards to detect TSH levels. A second test is performed, especially for preterm and acutely ill term infants with "delayed TSH rise", between two and six weeks of age. If initial TSH >30mU/L serum or >15mU/L whole blood, confirmatory serum thyroid testing should be performed (Rastog & LaFranchi, 2010).

Once congenital hypothyroidism is diagnosed, oral thyroxine treatment should be initiated immediately with close follow up, particularly in the first two to three years of life, crucial for positive neurologic outcome. High dose levothyroxine is recommended to normalize serum T4 and TSH as rapidly as possible, monitoring closely in order to adjust levothyroxine dose promptly if results are abnormal. For infants with central congenital hypothyroidism, however, low dose levothyroxine should be started and increased slowly, with addition of physiological doses of cortical hormone meanwhile to prevent sudden hypocorticism from happening. Treatment of transient congenital hypothyroidism takes several years, whereas it is lifelong in permanent congenital hypothyroidism. Genetic counseling and antenatal diagnosis should be considered for families at risk of having a baby with congenital hypothyroidism.

Prader-Willi syndrome

Prader-Willi syndrome is an uncommon genetic disorder of chromosome 15q11-13. It was first described by Andrea Prader and Heinrich Willi in 1956. Symptoms include weak muscle tone, feeding difficulties, short stature, incomplete sexual development, cognitive disabilities, and a chronic feeling of hunger that can lead to excessive eating and obesity. Incidence is approximately one in 25,000 to one in 1,000 newborns (Killeen, 2004). Individuals with Prader-Willi syndrome are at risk of learning and attention difficulties. Research suggests that most (50%-



The children depicted here have a genetically confirmed diagnosis of Angelman syndrome. Happy expression and an unstable gait accompanied by uplifted arms are commonly observed. At times, the facial appearance can suggest the diagnosis, but usually facial features are not distinctive. Source: Gene Reviews.

65%) fall within the mild/borderline/low average intelligence range (Curfs & Fryns,1992; Cassidy,1997).

Traditionally, Prader-Willi syndrome was diagnosed by clinical characteristics but it can now be diagnosed by genetic testing. Prader-Willi syndrome has no cure. Early diagnosis allows for early intervention. Children should receive treatment to improve muscle tone. Speech and occupational therapy are also indicated. School aged children will benefit from a highly structured learning environment as well as special education. Daily recombinant growth hormone injections are helpful (Carrel et al, 2002).

Angelman Syndrome

Angelman syndrome is a complex genetic disorder characterized by intellectual and developmental delay, severe speech impairment, seizures, ataxia, hand-flapping, and a happy, excitable demeanor with frequent smiling and laughter. It was first described by Harry Angelman in 1965. Prevalence is approximately one in 10,000 to one in 20,000 live births (Petersen et al,1995; Steffenburg et al,1996).

Angelman syndrome is caused by the loss of the normal maternal contribution to a region of chromosome 15, most commonly by deletion of a segment of that chromosome. Diagnosis relies on a combination of clinical features, molecular genetic testing or cytogenetic analysis. Consensus diagnostic criteria for Angelman syndrome are available (Williams, 2006). Analysis of parent-specific DNA methylation imprints in the 15q11.2-q13 chromosome region detects approximately 78% of individuals with Angelman syndrome; fewer than 1% have a cytogenetically visible chromosome rearrangement. UBE3A sequence analysis detects mutations in an additional 11%. Accordingly, molecular genetic testing identifies alterations in approximately 90% of individuals with Angelman syndrome (Dagli & Williams, 2011). Currently, Angelman syndrome has no cure; treatment is symptomatic (e.g., epilepsy can be controlled with anticonvulsant medication).

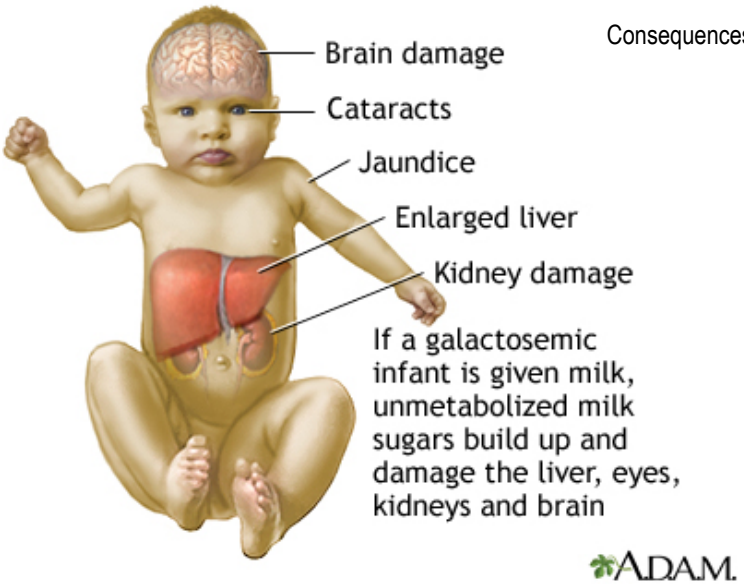
Galactosemia

Galactosemia is an autosomal recessive single gene disorder associated with a dysfunction of the enzymes that convent galactose into glucose, leading to the accumulation of toxic amounts of galactose in the blood and body tissues, resulting in ID and multiple organ damage. It was first reported by Goppert in 1917, and identified as a defect of galactose metabolism by Herman Kalckar in 1956. Its prevalence is about one per 60,000 live births.

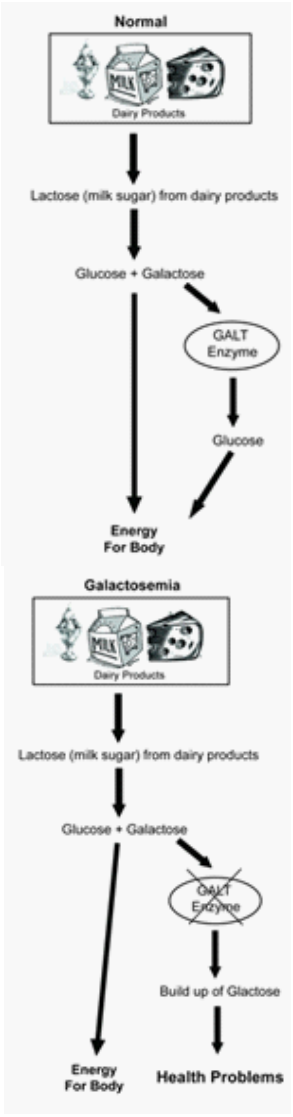
- According to the enzymes affected, galactosemia can be classified into three type*Type I, classic galactosemia*, is due to galactose-1-phosphate uridyltransferase (GALT) deficiency
- *Type II, galactokinase (GLK) deficiency*
- *Type III, UDP-galactose epimerase (GALE) deficiency*.

Diagnosis of galactosemia is established by a test using blood or urine to detect activity of the three enzymes mentioned above and to quantify galactose levels. In addition, molecular genetic testing is now available (Elsas, 2010).

Infants with galactosemia present nonspecific symptoms including vomiting, diarrhea, poor feeding, prolonged jaundice, hepatomegaly, failure to



Consequences of galactosemia



thrive, lethargy, and bleeding diathesis. If not treated promptly, sepsis, liver failure, cataracts, intellectual disabilities, growth delay and death may occur. However, chronic or secondary complications are probable in older children and adults even with early and adequate therapy, including delayed growth, poor intellectual functioning, speech defects, motor problems, learning disabilities and ovarian failure.

To prevent the primary manifestations of galactosemia, it is very important to perform newborn screening tests for all infants and immediate restrictions on all lactose-containing foods and medicines in those affected. Symptoms resolve quickly and prognosis is good if dietary therapy is started in the first three to ten days of life. Routine monitoring of galactose accumulation is necessary to make adjustments to treatment. Other interventions include calcium supplements, ophthalmologic examination, developmental evaluation, and speech assessment. For families at risk of having an affected child, genetic counseling and prenatal diagnosis are recommended.

Fetal alcohol syndrome

Fetal alcohol syndrome, the most severe form of fetal alcohol spectrum disorders, is a preventable cause of intellectual disability. Fetal alcohol syndrome is the result of high alcohol consumption during pregnancy, especially in the first three months of gestation, which can inflict considerable harm to the developing fetus, particularly to the brain. Rates vary according to alcohol consumption in a population; in the USA, it is estimated at 0.2 to 1.5 per 1000 live births have fetal alcohol syndrome (Centers for Disease Control and Prevention, 2009).

Medical practitioners' knowledge about this condition is low and detection is very poor, with many sufferers going undiagnosed. Together with a history of maternal alcohol intake, currently physicians still rely heavily on three clinical characteristics for diagnosis (Centers for Disease Control and Prevention, 2009):

- Facial abnormalities
- Central nervous system abnormalities
- Growth deficits.



Click on the picture to view a one-hour educational video on fetal alcohol syndrome.

More effective diagnostic tools for early detection using biomarkers, such as fatty acid ethyl esters in the meconium (Bearer et al, 2005), are under investigation.

Clinical symptoms vary depending on the amount, frequency and timing of alcohol exposure, maternal and genetic influences. Infants with fetal alcohol syndrome usually show growth retardation and a mixture of characteristic craniofacial anomalies, which are the hallmarks, including a flat philtrum, thin upper lip, short palpebral fissures, epicanthal folds, low nasal bridge, short upturned nose, ear malformations, and flattened maxilla. Central nervous system abnormalities are also commonly seen in fetal alcohol syndrome, which may include microcephaly, seizures, poor motor coordination, neurosensory hearing loss, cognitive and functional impairments. Furthermore, fetal alcohol syndrome may predispose to the development of mental health problems and substance use.

The only way to prevent fetal alcohol syndrome is to keep away from alcohol during pregnancy. Education for pregnant women or who are planning pregnancy is essential. In addition, screening questionnaires and biochemical markers for detection of maternal alcohol use are useful to detect risk behaviors and intervention to prevent further damage to the fetus. More research on this area is sorely needed (Ismail et al, 2010).

DIAGNOSING INTELLECTUAL DISABILITY

According to both the DSM and ICD, three basic criteria should be met for a diagnosis of intellectual disability (or mental retardation):

- Significantly sub average intellectual functioning (IQ of 70 or below)
- Concurrent deficits or impairments in adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety
- Onset is before age 18 years.

The subtypes and their characteristics have already been described earlier in the chapter. Diagnosis requires a full professional assessment of intelligence and adaptive behavior. Children with ID are usually brought to professional attention because of their behavior rather than their low intelligence. Moderate and severe

Intellectual disability and DSM-5

The revision of the DSM classification is proposing to change the name of this group of disorders to "intellectual developmental disorder" and less reliance on IQ for diagnosis. According to this proposal, a diagnosis of intellectual developmental disorder would require:

- Deficits in general mental abilities such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning and learning from experience with an IQ two or more standard deviations below the population mean for a person's age and cultural group (IQ below 70).
- These deficits significantly impair functioning by limiting participation and performance in one or more aspects of daily living, such as communication, social participation, functioning at school or at work, or personal independence at home or in community settings. These limitations result in the need for ongoing support at school, work, or independent life.
- Onset during the developmental period.

forms are identified early because developmental milestones are markedly delayed. Milder forms often become apparent during primary school as a result of academic difficulties, or even later, during adolescence.

A comprehensive assessment should include detailed questioning about:

- The medical history of parents and family: genetic conditions, infections during pregnancy, prenatal exposure to toxins, perinatal injury, prematurity, and metabolic disorders
- Development: language and motor skills, socialization, understanding and calculation
- Environment in which the child is raised: education, resources and the family environment

Physical examination, by the mental health clinician or pediatrician, focusing on symptoms associated with ID. For example, appearance of the face (e.g., the flat, broad face of Down syndrome) (Conor, 1999) or Brushfield spots (small white or grayish/brown spots on the periphery of the iris also common in Down syndrome) that may alert the clinician to the possibility of ID.

IQ measurement is mandatory in all cases in which ID is suspected. IQ should be measured using, if at all possible, widely accepted tests that have been standardized for the specific – or culturally similar – population (e.g., normative data obtained in a German population should not be used for Chinese children). Widely used tests include the *Wechsler Intelligence Scale for Children* and the *Stanford-Binet Intelligence Scales*.

It is also useful to evaluate adaptive behavior. To do that professionals compare the functional abilities of a child to other children of similar age and education. There are many adaptive behavior scales available, such as *Vineland Adaptive Behavior Scales* and *Adaptive Behavior Assessment System-II,* but an accurate assessment of children's adaptive behavior requires clinical judgment as well.

Laboratory investigations (e.g., genetic testing) are indicated in all patients with ID, seeking to ascertain its etiology, which may have significant implications for treatment, prognosis and prevention. The extent of these investigations will largely depend on parents' resources and availability of these tests in the specific country.

Differential diagnosis

Another term "developmental delay" is a broader concept than ID. It indicates that children show difficulties in one or more areas of adaptive functioning; this does not necessarily imply that they have significantly impaired cognitive abilities. In other words, although individuals with ID also show developmental delays, not all developmentally delayed children are intellectually disabled.

Among the most common conditions that can be misdiagnosed as ID are specific developmental disorders and school underachievement. In the former, children may appear developmentally disabled because they perform poorly in one or several academic skills (e.g., reading, arithmetic) when in fact they have an average IQ. In the latter, poor school performance mimicking ID may be due to other factors such as depression or school non-attendance (see Chapter

C.3). Although rare, the possibility of severe environmental deprivation, which may present with similar symptoms to ID (e.g., in severely deprived and under-stimulated children in orphanages), should also be excluded. Many children with autism spectrum disorders also have ID, however, they show the specific symptoms of the autism spectrum disorder. In these cases both diagnoses should be made.

Borderline intellectual functioning

The boundary between "normal" and "below average" IQ is not rigid, as highlighted by the fact that psychosocial impairment is also required for a diagnosis of ID. Individuals with an IQ in the range of 71-85 – *borderline intellectual functioning*, about 7% of the population – are not impaired enough to warrant a diagnosis of ID, nevertheless they face considerable difficulties due to their limited cognitive ability. They may be able to perform day to day activities and a simple job without assistance but are more vulnerable to stressful life events and more likely to develop a psychiatric disorder as a result.

MANAGEMENT

In all cases of ID, the crux of treatment is early detection and early intervention. As no specific etiology can be found in up to 40% of cases and many known causes cannot be cured, in the majority of cases, the aim of treatment is not a "cure" but to minimize symptoms and disability through reducing risk (e.g., helping individuals to be safe at home or school), teaching life skills, improve life quality and support families and carers. Detailed goals and modalities of treatment for each individual will largely depend on the cause and severity of ID and comorbid conditions.

Etiological treatment

If the cause of ID is detected in a newborn, usually through screening, etiological treatment should be administered (e.g., in diseases such as PKU, congenital hypothyroidism and galactosemia) as already described.

Challenging behaviors and behavior intervention

Challenging behaviors is a term used to describe comportment that interferes with the daily life of individuals with ID and their carers, reduce their quality of life and survival. These represent a wide range of problems that includes, among others, aggression, self-injury (such as head banging or ingestion or inhalation of foreign bodies), destroying objects, non-compliance, idiosyncratic habits (e.g., restricted range of foods), and socially inappropriate behavior. These problems frequently result in carers seeking medical help and can easily overwhelm families' ability to cope with and care for these young people, often resulting in rejection or, in more severe cases, institutionalization.

As in non-ID individuals, challenging behaviors serve a function and they are maintained or reinforced if the person with ID is successful in altering their internal or external environment through their behavior – such as by gaining attention, avoiding duties or demands, achieving access to preferred activities or objects or control over their own life, sensory feedback (e.g. hand flapping, eye

poking), and reduction of arousal and anxiety. The causes of challenging behavior are complex and include:

- Medical
  - Unrecognized pain or discomfort
  - Side effects of medications
  - Substance abuse
  - Physical illnesses such as epilepsy
  - Behavioral phenotypes specific for a syndrome
- *Dual diagnosis*. As already highlighted, intellectually disabled young people have higher rates of psychiatric disorder. A comorbid psychiatric illness (often referred to as "dual diagnosis") occurs in about half of individuals with ID, the more frequent being ADHD, depression, autism and conduct problems, but schizophrenia and bipolar disorder also occur at least as often as in the non-ID population. Psychiatric illnesses like schizophrenia, depression and obsessive compulsive disorder present with roughly the same features in those with mild ID as in other people. However, recognition can be difficult in youth with moderate and severe ID, who tend to display more disorganized, unpredictable and difficult to understand symptoms, compounded by inability to describe their experiences:
  - Depression may present as withdrawn behavior, irritability and aggression
  - Manic episodes may present as distinct periods in which the youth with ID absconds, becomes boisterous, irritable or disinhibited
  - Aggression without clear precipitants and associated with bizarre behaviors suggestive of hallucinations or suspiciousness could suggest schizophrenia.

  The existence of a family history of psychiatric illness such as schizophrenia or mood disorders may raise the suspicion. Timely identification and treatment of these comorbid conditions reduce disability, family burden and improve quality of life. There are questionnaires available that can help clinicians in the assessment of comorbid psychiatric problems such as the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 2002) a 96-item inventory, and the Aberrant Behavior Checklist (ABC; Aman et al, 1985), a 58-item questionnaire.
- Environmental
  - Problems in the living and working environment (e.g., lack of stimulation, family conflict, bullying)
  - Life events (e.g., change of school, death or separation)
  - Communication issues (e.g., inability to communicate, carers not attuned to the young person's needs, inappropriate management that reinforces challenging behavior)
  - Life stages (e.g., puberty)

– Behavior serves a function or purpose for the person. Challenging behaviors are maintained if the person is successful in altering their internal or external environment through their behavior.

Management of challenging behaviors

People with ID and challenging behaviors or dual diagnosis are one of the most disadvantaged groups in most countries, very often receiving substandard care. One of the key roles of mental health professionals dealing with people with ID is the management of challenging behaviors. This requires considerable time, experience and skill. The starting point is to ascertain whether there are treatable causes (as listed above) and to conduct a behavior analysis. The settings in which problems occur can be the home, school or vocational training place, respite care facility or institution. Behavior analysis includes:

- A detailed description of the challenging behavior
- When and where does it take place (time, place, activity, context)
- The sequence of events and interactions with others: possible triggers, how others respond, do these responses reinforce the behavior?
- Skill factors (or lack of) involved
- Potential needs met by the challenging behaviors.

Once this is understood, a behavior intervention plan can be designed to address the problem. The first goal will be to ensure the safety of the child with ID and of the family or carers. The second would be to extinguish the undesirable behavior. In most cases this will involve families, teachers or workers in institutions, taking into consideration the family's needs, strengths and weaknesses, and often supporting and empowering them. Educating, helping and engaging the support network is essential for success.



Click on the picture to watch a video about education programs in people with ID (Cantones with English subtytles; 8:01).

Medication

Medication is often used (probably overused; Branford, 1994) in the treatment of people with ID. Because mental health professionals are often consulted in crisis situations, medication may be prescribed in an ad hoc basis to deal with the crisis, when medication should optimally be used after a comprehensive assessment and as part of an overall treatment plan in which behavioral management and involvement of the family are essential (see above). The particular issues of informed consent in this population should also be taken into account.

Smaller doses than those typical in non-ID patients should be used – people with ID generally have more medical problems and are more sensitive to the side effects of drugs. Therefore it is wise to start with a very low dose and gradually increase it according to response and side effects.



Click on the picture to watch a video on the US "Individualized Education Program" (IEP) (2:38).

Use of medications in this group is largely based on clinical experience rather than trial data. In the absence of controlled trial data, antipsychotics, antidepressants, mood stabilizers and other psychotropic medications should be used for the same indications as for children without ID, with the precautions listed above. The growth in the use of second generation antipsychotics, particularly for the management of challenging behaviors, is of concern. While some trial data in children (Snyder et al, 2002) – not replicated in adults (Tyrer et al, 2008) – suggest

that they may be useful in the short term, there are growing concerns about their long-term use because of side effects (e.g., metabolic syndrome).

Agents that reduce sexual desire are of special relevance to adolescents with ID because they occasionally display inappropriate, difficult to control sexual behavior. This can cause alarm and may result in restrictions to their freedom. Although the use such medications (e.g., cypropterone, testosterone antagonists) pose significant ethical challenges, they are increasingly prescribed for this purpose (Reilly et al, 2000).



Click on the picture to watch a video about children with disabilities' transition from school programs.

Education

In general, children with ID are less efficient at learning than other children. As they grow up and master activities of daily living, they need to attend school like other children. In high income countries such as the US, every child with ID from age three through 21 have access to free public education through an individualized education program. In a developing country such as India, there has been noticeable progress in addressing the challenges posed by ID. However, there is still a long way to go in low income countries in terms of developing effective, accessible, and affordable interventions (Girimaji & Srinath, 2010).



Click on the picture to watch a video about opening pathways to training and employment for people with intellectual disabilities in Africa

Overall, attending school is essential for children with ID to learn not only academic skills but also self-discipline, social and practical skills for community living. Though they have more difficulty learning, experience and research has shown that by applying the right educational techniques, many are capable of acquiring the basic skills of reading, writing, and arithmeth ic.

Inclusion versus segregation

The current trend is to educate children with ID as far as possible in normal rather than special schools (inclusive education). This especially applies to those with milder forms of ID. However, there is limited evidence to compare the school experience of children with mild to moderate ID in mainstream and segregated education (Cooney, 2006). Another approach is to conduct special classes for children with ID in normal schools (opportunity classes). More severely retarded children may benefit from special schools. Whatever the approach, children with ID need education – even more so than other children – to maximize their development and chances in life.

Physical and occupational therapy

Physical therapy and occupational therapy may contribute to treatment because ID is often accompanied by poor muscle tone, lack of coordination and slow development of motor skills. A therapist will be able to set up an individualized treatment plan that may be conducted at home, school or institution.



Click on the picture to watch a video clip from the the US Centre for Disease Control and Prevention about early detection of developmental disabilities (4:32).

Speech therapy

Speech and language are very important and highly specialized functions. They serve the crucial purpose of communicating one's own feelings and thoughts to others. Children with ID often show significant limitations in speech and language. Research has shown that a systematic application of speech therapy

techniques is effective in promoting speech, language and communication ability in ID children. Additionally, augmentative and alternative communication strategies can be used to help children with all levels of ID (Wilkinson & Hennig, 2007).

Family education and support

Children with ID have the same basic human rights and fundamental freedoms as other children, including the rights to grow up in a family environment (United Nations, 2006). But the enhanced education and care needs of children can challenge the family's capacity to fulfill their functions and the ability to cope with exhaustion and isolation. Parents of children with ID generally reported needing more relevant information, psychological support and respite care services (Bailey et al, 1992). Support for families should meet these needs and prevent parents or other family members from feeling overwhelmed. To this effect, the WHO suggests that family support need to include communication of the diagnosis and information about it, emotional support, family counselling and training, involvement in health care decisions and respite care (World Health Organization, 2010).

PREVENTION

Since ID is a life-long condition that cannot be "cured", prevention is very important. Prevention opportunities are summarize in Table C.1.3. Three levels of prevention can be distinguished: primary, which refers to a set of approaches that reduce or eliminate the risk of ID; secondary, which aims at an early diagnosis and treatment; and tertiary, which seeks to limit disability.

Primary Prevention

Genetic counseling

Prospective parents, especially couples who already had a child with ID are usually keen to know the risk of future children being affected. Sensitive and accurate professional advice may help them make informed decisions about having other children. Such counseling can be as simple as telling parents who have a child with ID caused by a brain infection that the risk for their next child is very low, or it could be a very complicated matter needing costly tests when a genetic cause is suspected.



Click on the picture to watch a one-hour long video from the US Centre for Disease Control and Prevention about early detection of developmental disabilities.

There have been rapid advances in the field of genetics. A set of techniques for the detection of genetic disorders called molecular genetics has evolved in the last decade. Though currently costly, the techniques are likely to become less expensive and applicable for wider use. One example is the possibility of detecting the presence of Down syndrome by performing a blood test on the mother during early pregnancy.

Prenatal

- Avoiding pregnancy before 21 years and after the age of 35 to reduce complications of pregnancy and labor. The risk of Down syndrome and other chromosomal disorders also increases after the age of 35. Prenatal screening/diagnosis of parents at risk.
- Abnormalities in the growing fetus can often be detected during early pregnancy. When a serious abnormality is found, parents may have

the option of terminating the pregnancy. Some of these procedures are relatively safe, inexpensive and widely available (e.g., ultrasound). Others, such as genetic testing, are expensive, technically complex, not widely available and have their own risks.

Perinatal

- Pregnant women should add iodized salt to their diet to prevent iodine deficiency and avoid exposure to harmful chemicals and substances including alcohol, nicotine and cocaine.
- Neonatal screening. There are some causes of ID for which definite treatment is available in the form of medicines or special diets (e.g., PKU, galactosemia and hypothyroidism). Tests are available to detect these conditions at birth. If they are detected and treatment is started immediately, the occurrence of ID and other problems can be prevented.

Postnatal

- Universal immunization of children with the WHO schedule of recommended vaccines
- Prompt treatment for severe diarrhea and brain infections during childhood
- Providing a safe, caring, enriching and stimulating environment for children from infancy to ensure proper intellectual development.

Secondary prevention

Some medical conditions associated with ID can be detected at birth. It is also possible to define a group of babies who are at risk of having a greater chance of developing ID as they grow up. These are children born prematurely, with a low birth weight (less than 2 kg), who have suffered asphyxia during birth, or have had a serious illness in the neonatal period. Following these infants up and monitoring whether they start to lag behind can be helpful in preventing ID.

By and large, most children with severe ID can be recognized by the age of 6-12 months. Mild ID usually becomes evident by the age of two years. Intelligence and social adaptation tests for the early detection of ID are now available, and can be adapted to any culture with appropriate modifications. Once a baby is suspected of or identified as having ID, it is necessary to provide appropriate stimulation for optimal development within that child's potential. These are techniques by which parents encourage and teach babies to use and develop their sensory (vision, hearing and touch) and motor (grasping, reaching, manipulating, and transferring) faculties. Such stimulation is necessary for normal development. Children with developmental delay need it all the more. Many manuals and guides have been developed for early stimulation, for instance, Portage Guide to Early Stimulation and Preschool Intervention for Developmentally Delayed Children (published by the National Institute for the Mentally Handicapped, Secunderabad, India). Some of these models have been successfully adapted (WHO, 2004).

Tertiary prevention

Family

The best place for children with ID to grow up in is with their own families. Organized support services are definitely needed for families to adapt well and face the situation with confidence and the least amount of stress. Parents need

Associations and links

- American Association on Intellectual and Developmental Disabilities
- Australian Institute of Health and Welfare
- Australasian Society for Intellectual Disability
- Center for Effective Collaboration and Practice
- Council for Exceptional Children (CEC)
- Down's Syndrome Association (UK)
- European Association of Intellectual Disability Medicine
- Independent Living Canada
- National Center on Birth Defects and Developmental Disabilities (US)
- National Dissemination Center for Children with Disabilities (US)

Table C.1.3 Levels of prevention

Level	Approach	Interventions
Primary Prevention (preventing the occurrence intellectual disability)	Health promotion	• Health education, especially for adolescent girls • Improvement of nutritional status in the community • Optimum health care facilities • Improvements in pre, peri and postnatal care
	Specific protection	• Universal iodization of salt • Rubella immunization for women before pregnancy • Folic acid administration in early pregnancy • Genetic counseling • Prenatal screening for congenital malformation and genetic disorders • Detection and care for high-risk pregnancies • Prevention of damage because of Rh incompatibility • Universal immunization for children
Secondary Prevention (halting disease progression)	Early diagnosis and treatment	• Neonatal screening for treatable disorders • Intervention with "at risk" babies • Early detection and intervention of developmental delay
Tertiary Prevention (preventing complications and maximizing functioning)	Disability limitation and rehabilitation	• Stimulation, training and education, and vocational opportunities • Mainstreaming / integration • Support for families • Parental self-help groups

to learn appropriate ways of rearing and training the child. They will continue to need assistance, guidance and support as the child grows up, especially during adolescence, early adulthood and during periods of crisis.

Community

No program is likely to succeed without community involvement and participation. Services for individuals with ID include: medical and psychological (clinical) services. The first requirement is for appropriate facilities for a good medical/health evaluation and accurate diagnosis. Doctors should be in a position to recognize and manage treatable disorders such as hypothyroidism. Associated problems such as convulsions, sensory impairments and behavior problems can be corrected or controlled with proper medical attention. There are many claims that some drugs and herbal preparations can improve intelligence. But no drugs or any other treatment can cure ID. It is desirable to have facilities for psychological assessment of strengths and weaknesses in the child which can form the basis for future training. Adequate parental counseling in the initial stages is essential. Doctors, nurses, psychologists and social workers can make a big difference to parents by correctly explaining the condition, options for treatment, likely outcomes as well as by clarifying their doubts and helping them come to terms with having a handicapped child. Parental counseling also involves providing emotional support and guidance. Communities need to be educated also about the right of people with ID to lead their lives with respect and dignity, without discrimination. It is possible to achieve this goal by bringing about positive changes

in societal awareness, attitudes and beliefs about this condition. Individuals with ID should become an integral part of society, should not be isolated, segregated or discriminated against in any fashion.

Governments have the responsibility to provide optimum services to adequately address the needs of individuals with ID. This includes strengthening and effective utilization of existing services in the health, education and welfare sectors.

PROGNOSIS

Many individuals with ID, particularly those of mild or moderate severity, are able to live independently and make a contribution to their community. Individuals with mild to moderate ID are frequently able to achieve some self-sufficiency and to lead happy and fulfilling lives. Individuals with severe ID are usually not able to live independently. Most people with Down syndrome who live into their 40s and 50s develop an Alzheimer's-like dementia (McPhee et al, 1999).

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AUTISM SPECTRUM DISORDERS

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Clay art by Santiago, an 11 year old with autism spectrum disorder. Photo: Lynn Albrink

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Suggested citation: Fuentes J, Bakare M, Munir K, Aguayo P, Gaddour N, Öner Ö, Mercadante M. Autism spectrum disorders.In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

The term autism spectrum disorders (ASD) refers to a group of neurodevelopmental conditions defined by impairment in three areas: social interaction, communication or use of verbal and non-verbal language, and a stereotyped, restricted or repetitive pattern of behavior, interests and activities. Symptoms are generally obvious before the age of three years, but in most areas of the world these conditions are not diagnosed until a few years later. The increased identification of these disorders, the emotional impact they have in families and the challenging financial demands associated with their treatment and support currently make ASDs an important illness at the scientific, public health and human rights level. The treatments now available can achieve a far better quality of life for sufferers than was the case just a few years ago, but it must be recognized that ASDs cannot yet be cured and most people with ASD, particularly in developing countries – with a few fortunate exceptions – are not receiving specialized treatment or any treatment at all.

This chapter seeks to describe the current knowledge in the classification, epidemiology, etiology, clinical picture, assessment, prognosis and treatment of ASD. It is hoped this material will be useful for clinicians committed to changing global health practices involving these patients and their families.

HISTORY

Eugen Bleuler (1857–1939), a Swiss psychiatrist, coined the terms *schizophrenia* and *autism*. He derived the latter from the Greek word *autos* (meaning "self"), to describe the active withdrawal of patients with schizophrenia to their own fantasy life in an effort to cope with intolerable external perceptions or experiences (Kuhn, 2004). The use of the term *autism* in its current sense started 30 years later when the Austrian pediatrician Hans Asperger adopted Bleuler's terminology of *autistic psychopaths* in a lecture he delivered at the Vienna University Hospital (Asperger, 1938). Asperger subsequently published his second PhD thesis in 1944 (first transcribed in 1943) (Asperger, 1944) where he described a group of children and adolescents with deficits in communication and social skills and also with a restricted, repetitive pattern of behaviors.

At the same time, in 1943 – separated by distance, the Second World War and apparently unaware of each other's work – Leo Kanner, at Johns Hopkins University Hospital in the US, described 11 children with striking behavioral similarities to those depicted by Asperger in his classical paper *"Autistic disturbances of affective contact"* (Kanner, 1943). Most of the characteristics described by Kanner such as *"autistic aloofness"* and *"insistence on sameness"* are still part of the criteria to diagnose autism in current classifications. Children described by Asperger differed from those of Kanner in that they had no significant delays in cognitive or language development.

Asperger's paper, published in German, remained largely unknown until Uta Frith translated it into English (Asperger, 1944), which made it widely available. These ideas were further disseminated by Lorna Wing (Wing, 1997) in the UK. As a result, there has been a gradual acknowledgement that autism constitutes a spectrum with a continuum from mild to severe symptoms and that Asperger's disorder is part of that continuum.

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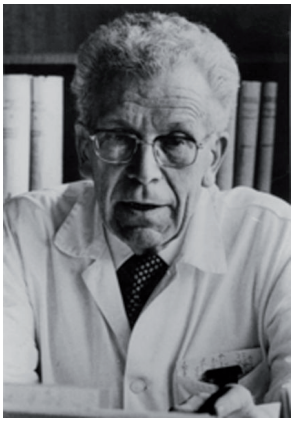
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**In memoriam*



Hans Asperger (1906-1980), Austrian pediatrician, described the symptoms of autism in 1938. An autistic syndrome of high functioning autism was named after him.

It was a misfortune that the original meaning of Bleuler's term and its theoretical relationship with schizophrenia, combined with the psychoanalytic theories dominant in the mid twentieth century, amalgamated ASDs with psychotic disorders, classifying them under the rubric of *childhood schizophrenia*. The apparent withdrawal of ASD patients was misinterpreted as the same mechanism as that seen in schizophrenia, a defensive retreat from an intolerable external situation, the result of a pathogenic family (as it was them widely conceptualized). Unfortunately, some of these discredited ideas are still held by some. The relative importance of ASDs in relation to other health conditions continues to be underestimated by governments and international agencies. In Africa, for example, clinical work on ASDs did not start until three decades after Kanner and Asperger had published their work (Lotter, 1978; Bakare & Munir, 2011).



Leo Kanner (1894-1981), American psychiatrist, described autism in 1943. His work laid the foundations for modern child psychiatry.

DEFINITION

ICD-10 (World Health Organization, 1990) classifies autism under the *pervasive developmental disorders*, a group of conditions characterized by qualitative abnormalities in reciprocal social interaction, idiosyncratic patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a feature of the sufferer's functioning in all situations. DSM IV (American Psychiatric Association, 2000) also uses the term *pervasive developmental disorders*, although its subdivision is different in the two classifications. Both taxonomies utilize a list of behaviors, require that a number of criteria be met to warrant a diagnosis and are periodically reviewed to incorporate new research data. In fact, both are currently undergoing a detailed review; DSM-5 is expected to be released in 2013 and ICD-11 in 2015. Important changes to DSM-5 are expected while up to this point, ICD-11 does not seem to be planning major modifications.

The changes proposed for DSM-5 have been polemical in scientific and lay circles. DSM-5 proposes to eliminate the division existent in DSM-IV between autism, Rett´s disorder, Asperger´s disorder, childhood disintegrative disorder, and pervasive developmental disorders not otherwise specified. According to the DSM-5 proposal, there will be a unique category of ASD, characterized by:

- Persistent deficits in social communication and social interaction across contexts not accounted for by general developmental delays
- Restricted, repetitive patterns of behavior, interests, or activities
- Presence from early childhood (but may not become fully manifest until social demands exceeds the child's limited capacities), and
- Limitation and impairment in everyday functioning.



Click on the picture to access the latest information about ASDs in DSM-5

DSM-5 will thus eliminate the diagnosis of Asperger's disorder while formalizing the "spectrum" concept espoused by Lorna Wing, who favored considering Asperger's disorder a sub-category of a unified ASD construct (Wing et al, 2011).

Clinicians will find the classical symptoms grouped in these two areas (deficits in social communication and restricted, repetitive patterns of behavior) with the addition of hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment. Also, there will be a complementary

classification of severity, categorized as "requiring support", "requiring substantial support" and "requiring very substantial support".

A recent study by Frazier et al (2012) supports the validity of the proposed criteria. They report increased specificity compared with DSM-IV and suggest that a relaxed algorithm should be considered to improve identification and decrease cost, thus maximizing intervention resources. William et al (2012) tested the construct validity and reported the DSM-5 model was superior to DSM-IV, and the model fit in their sample was good, stable across age and gender and in those with clinical and sub-threshold autistic presentations.



Lorna Wing is an English psychiatrist and physician who promoted the concept of an autism spectrum. She is also one of the founders of the National Autistic Society in the UK

EPIDEMIOLOGY

Autism was once considered a relatively rare condition. Recent epidemiological data have radically altered this perception. Based on large surveys in the US, the Centers for Disease Control and Prevention (CDC), estimates the prevalence of ASD as 1 in 88 children, occurring in all racial, ethnic and socioeconomic groups, although it is five times more common among boys (1 in 54) that girls (1 in 252). The CDC website also offers data from numerous studies in Asia, Europe and North America showing an average prevalence of ASDs of about 1%. A recent survey in South Korea, which screened children in the schools, reported a prevalence of 2.6% (3.7% among boys and 1.5% among girls) (Kim et al, 2011). Another study in England estimated a prevalence of ASD at almost 1% in adults (Brugha et al, 2011).



Click on the picture to access the CDC (2012) document: Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. Morbidity & Mortality Weekly Report Surveillance Summaries.

However, epidemiological studies are difficult to compare. They vary in the composition of the population surveyed, recruitment mechanisms, sample size, design, awareness, participation rates, diagnostic criteria, instruments used as well as whether impairment criteria are included (Fombonne, 2009). Nevertheless, using the same methodology over a period of eight years, the CDC's Autism and Developmental Disabilities Monitoring Network has found increasing rates of ASDs in the US.

Table C.2.1 Prevalence of autism spectrum disorders, Autism and Developmental Disabilities Monitoring (ADDM) Network 2000-2008 (combining data from all sites)

Survey year	Year of birth	Prevalence per 1,000 children (range)	Frequency
2000	1992	6.7 (4.5–9.9)	1/150
2002	1994	6.6 (3.3–10.6)	1/150
2004	1996	8.0 (4.6–9.8)	1/125
2006	1998	9.0 (4.2–12.1)	1/110
2008	2000	11.3 (4.8–21.2)	1/88

Source: CDC website

Although studies do not rule out temporal or external demographic factors (such as being born to older parents; survival of premature or high risk low birth weight babies; earlier diagnosis of young children with higher IQ who spontaneously make progress over time that would not have been diagnosed years ago; or only counting older children receiving special support), experts in the field explain this rising in prevalence by increased awareness and improvement in the recognition and detection of the disorder. This may explain why the prevalence of ASD is reported to be lower in China (6.4 in 10.000) (Li et al, 2011). While there is much research on ASD in Europe and North America, there is not a single epidemiological study of ASD in sub Saharan Africa (Bakare & Munir, 2011), but a significant increase of ASD among children of Ugandan mothers (Gillberg et al, 1995) and of Somali women living in Sweden (Barnevick-Olsson et al, 2008) has been reported.

EARLY DETECTION

It is acknowledged that early detection constitutes a major advancement in that it enables prompt intervention that may improve prognosis in a significant proportion of children with ASD, but also because it clarifies the doubts and anguish of parents and allows adequate public planning for future school placements and community support.

It was known that there was a higher incidence of ASD among siblings of already identified cases; this observation has led to a more detailed examination of newborn siblings and follow up during their first years of life. Trying to identify early developmental signs that precede a diagnosis of ASD in siblings that eventually develop the disorder has been a fruitful area of investigation. This change, from a retrospective view of abnormal development to a prospective follow-up of children at risk, constitutes a remarkable scientific advance. It has been shown in these high-risk infants that there were no notable findings during the first six months in those later classified as ASD; however, in the following six months, social interaction problems started to unfold (Zwaigenbaum et al, 2005). By two years of age, toddlers in the spectrum had clear problems in social communication, play, language and cognition, as well other sensory and motor difficulties (Zwaigenbaum et al, 2009). These findings confirm the notion that ASD can be identified earlier than usual in some cases and that for many children 24 months of age coincides with a peak in new symptoms that would facilitate recognition. The same authors reported (in an oral presentation at the 2011 IMFAR-San Diego) that 25% of the 277 siblings followed up in their study were diagnosed with ASD at 36 months of age, but cautioned that in 46% of those there had been no diagnosis assigned in their evaluation at 24 months of age. Therefore, at least in this probably non-representative sample, trajectories are quite different from what was considered retrospectively.

Relevant information to guide clinicians comes from the longitudinal research conducted by the First Words Project (Florida State University) that identified *red flags* for ASD, although they insist there is not a pathognomonic symptom that guarantees the presence of ASD. Not all children with ASD show all and every one of the symptoms all the time; and this should prevent clinicians from saying "*this child does not have autism, because I saw him looking at the eyes of others"* or similar. The First Words Project came up with nine red flags that helped

Figure C.2.1 Red flags to identify autism spectrum disorders and developmental delay



Source: First Words

to distinguish children with ASD from children with developmental disabilities and typically developing children, and four red flags that distinguished children with ASD and developmental disabilities from children with typically developing children (Wetherby et al, 2004).

Many questionnaires have been developed as possible screening tools for developmental assessment of children as well as for ASD screening. Information, sound practical advice and a description of the most useful ones can be found in the ASD website of the US Centers for Disease Control and Prevention. Common myths shared by many professionals and policy-makers about developmental screening are summarized in Table C.2.2. A variety of practice flowcharts are also available, largely produced by national societies, but the one produced by the American Academy of Pediatrics represents the current gold standard for screening ASD in developed countries (Johnson & Mayers, 2007).



Click on the picture above to access the M-CHAT official website. M-CHAT is freely available in a variety of languages for clinical, research and educational purposes. Click on the picture below to access an instant-scoring, on-line, free, English version, with all the required materials and references



Screening instruments

Among the many instruments available (click here for an exhaustive list), there are currently two that merit special mention since they are free, tackle different age groups (one younger children and the other older ones), have gone through cross-cultural adaptation and appropriate translation to many languages, and have been researched in various countries. These are the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al, 2001) and the Childhood Autism Spectrum Disorders Test (CAST) (formerly known as Childhood Asperger Syndrome Test).

The M-CHAT can be complemented with the M-CHAT Follow-Up Interview, also available at the M-CHAT website. It is recommended that M-CHAT

Table C.2.2 Myths about developmental screening

Myth # 1	*"There are no adequate screening tools for preschoolers"*
Fact	Although this may have been true decades ago, today sound screening measures exist. Many screening measures have sensitivities and specificities greater than 70%
Myth # 2	*"A great deal of training is needed to administer screening correctly"*
Fact	Training requirements are not extensive for most screening tools. Many can be administered by paraprofessionals
Myth # 3	*"Screening takes a lot of time"*
Fact	Many screening instruments take less than 15 minutes to administer, and some require only about 2 minutes of professional time
Myth # 4	*"Tools that incorporate information from the parents are not valid"*
Fact	Parents´ concerns are generally valid and are predictive of developmental delays. Research has shown that parental concerns detect 70% to 80% of children with disabilities

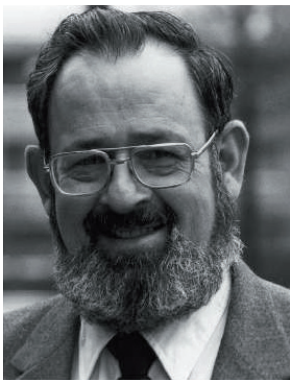
Source: CDC / Autism website

users also incorporate the M-CHAT Follow-up Interview into the screening, given recent findings demonstrating that use of the interview greatly reduces false positive cases, avoiding unnecessary referrals. The CAST is also available free for non-commercial purposes and in many languages at the website of the Autism Research Centre of the University of Cambridge.

There are practical and ethical difficulties in screening for ASDs and it is questionable whether screening should be routinely implemented worldwide

The American Academy of Pediatrics recommends screening for ASD of 18 and 24 months old children using a staged procedure (Johnson & Meyers, 2007). However, there are practical and ethical difficulties to do so and it is questionable if this screening should be routinely implemented worldwide. First, the psychometric properties of these instruments are not perfect. Some, like M-CHAT, identify a proportion of *false positive* cases that indeed do not have ASD. Health authorities may not consider this a problem since it detects children that require support for other conditions (e.g., developmental delays, speech problems). There are also *false negatives*: children having the condition who are not identified by the screening – there is no screening instrument with perfect sensitivity and specificity. Al-Qabandi et al (2011) challenge the belief that screening should be done because there is an effective treatment (e.g., early behavioral intervention) – although promising, treatments are not equally effective in all children with ASD and we are just beginning to understand who will be best served with what treatment but many questions remain. It is widely recognized that screening for a condition without having the resources or treatments (as it happens for ASDs in most regions of the world) may be unethical. In the same line, it is not clear whether young children with ASD are more easily recognized using universal screening instruments administered by professionals than, for example, through a culturally sensitive, community campaign. Despite all these controversies it is accepted that increasing information, educating families, teachers and medical staff to recognize ASD is a step forward.

The mechanisms to detect ASD are likely to be different for each country and region, depending on culture and child rearing practices, but mainly depending on the availability of developmental surveillance (not isolated "checking" for a specific condition). Most children in the world do not have access to *well-baby programs* and to developmental surveillance. Access to health should include empowering communities and health systems to identify the most prevalent disabilities in a given community. In developed countries these include intellectual disability, cerebral palsy, deafness, blindness, and ASD. In other parts of the planet, the priorities for surveillance might be very different. In summary, we propose that context-friendly developmental surveillance should be conducted for all children with administration of screening instruments to those suspected of having ASDs.



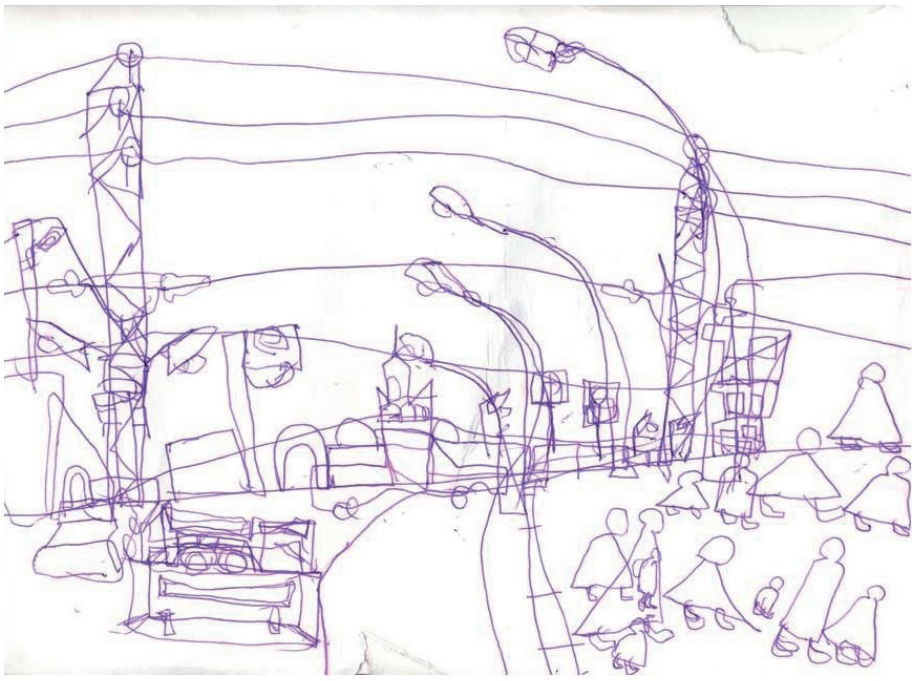
Bernard Rimland, PhD (1928-2006), American psychologist, was the founder and director of the Autism Research Institute and founder of the Autism Society of America. He opened the way for the current understanding of autism by introducing the notion that it was a disorder of brain development.

ETIOLOGY AND RISK FACTORS

In the US, in the 1950s and early 1960s, autism was thought to be due to the defective upbringing of children by cold and rejecting parents, thereby leaving the child with no alternative but to seek comfort in solitude, as once claimed by Bruno Bettelheim. He compared autism to being a prisoner in a concentration camp (something he had experienced himself in Germany during WWII) (Finn, 1997) in his book "*The Empty Fortress: Infantile Autism and the Birth of the Self*". In 1964, Bernard Rimland opened the way for the current understanding of autism by introducing the notion that it was a disorder of brain development with his seminal book "*Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*" (Rimland, 1964),

Genetic factors

Evidence for the importance of genetic factors in the etiology of autism comes from many sources, including twin and family studies (Muhle et al, 2004). Autism is, for example, 50 to 200 times more prevalent in siblings of autistic probands than in the general population. Among probands' relatives who do not



Drawing by Khalil, an 11 year old child with ASD

have autism, there is also an increased prevalence of milder forms of developmental difficulties related to communication and social skills. Concordance rates for autism range from 36% to 96% in monozygotic twins but only 0% to 27% in dizygotic twins (Shadock & Shadock, 2008).

Although the heritability of autism has been estimated to be as high as 90% (Freitag, 2007), genetic factors are heterogeneous, complex and for the most part poorly understood. The precise mechanisms are being explored through whole-genome screening, cytogenetics, and evaluation of candidate genes (Muhle et al, 2004). In studies of candidate genes, there are replicated findings of increased risk for autism associated with variants in single genes on chromosomes 2, 3, 4, 6, 7, 10, 15, 17 and 22 (Freitag et al, 2010). Cytogenetic studies have implicated abnormalities at the 15q 11-q 13 locus in individuals with autism (Muhle et al, 2004; Smalley, 1991). Genome-wide association studies have found slight effects on autism risk with genetic variants at the 5p14.1 and 5p15 loci (Ma et al, 2009; Weiss et al, 2009). Also, replicated copy number variations, found in genome-wide association studies to be more common in individuals with autism than in controls, are located on chromosome regions 1q21, 2p16.3, 3p25-26, 7q36.2, 15q11-13, 16p11.2 and 22q11.2 (Freitag at al, 2010). Future directions for genetic research in autism lie in identifying specific gene-environment interactions.

Neuroanatomic and neuroimaging findings

Neuroanatomic and neuroimaging findings, though not diagnostic, have consistently revealed increased cerebral volume that affects both gray and white matter, as well as enlarged ventricles. Neuroimaging findings also include abnormalities in brain chemistry, serotonin synthesis, and brain electrophysiology (Courchesne et al, 2004; Hazlett et al, 2005; Lainhart, 2006).

The autism "spectrum" is now understood to be neurodevelopmental, meaning that there are differences in the pattern of brain development. For example, early brain overgrowth has been documented in the first two years of life (Courchesne et al, 2001) and, in later development, there are clear differences in the function and structure of the "empathy circuit" of the brain (amygdala, ventromedial prefrontal cortex, temporo-parietal junction, orbitofrontal cortex, anterior cingulate, and other related brain regions) (Lombardo et al, 2011). There are also differences in connectivity between frontal and parietal lobe functions that are thought to relate to cognitive style, in particular an over-reliance on processing details and a relative under-reliance on processing gist or holistic information (Belmonte et al, 2004).

Environmental factors

A number of environmental factors have been claimed, particularly in the Internet, as playing a role in etiology of ASDs, including mercury, cadmium, nickel, trichloroethylene, vinyl chloride (Kinney et al, 2010). It is important to note that the previously suggested link between MMR vaccines and autism spectrum disorders (Wakefield et al, 1998) had been debunked by international agencies that included Centers for Disease Control and Prevention, Institute of Medicine of the US National Academy of Sciences, the UK National Health Service and the Cochrane Library. The Wakefield et al (1988) article published in Lancet that suggested the association between the MMR vaccine and autism has since been declared fraudulent and officially withdrawn (Goodlee et al, 2011).

Etiology

Interested readers can learn about ongoing studies on the etiology of ASDs by checking the following websites:

- Childhood Autism Risks from Genetics and the Environment (CHARGE)
- Autism Birth Cohort Study (ABC)
- Avon Longitudinal Study of Parents and Children (ALSPAC)
- Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)
- Markers of Autism Risk in Babies - Learning Early Signs (MARBLES)

Associations between different environmental factors contributing to vitamin D deficiency and increased risk of autism has also been proposed (Grant & Soles, 2009). This requires further studies.

Epigenetic factors

There are indications that, in addition to genetic and environmental factors, epigenetic factors also play some role through the fact that several genetic syndromes that are co-morbid with ASD show dysregulation of epigenetic marks that help regulate gene expression (Grafodatskaya et al, 2010). The epigenetic line of research also holds promise in offering an explanatory model to understand the putative increased incidence of autism suggested by epidemiological findings.

Risk factors

The NICE (2011) guideline "*Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum*", while stressing the low quality of evidence found, lists the risk factors for ASDs that are clinically and statistically important as:

- A sibling with autism
- A sibling with another ASD
- Parental history of schizophrenia-like psychosis
- Parental history of affective disorder
- Parental history of another mental or behavioral disorder
- Maternal age older than 40 years
- Paternal age between 40 and 49 (ASD)
- Paternal age older than 40 years (autism)
- Birth weight less than 2500 g
- Prematurity (under 35 weeks)

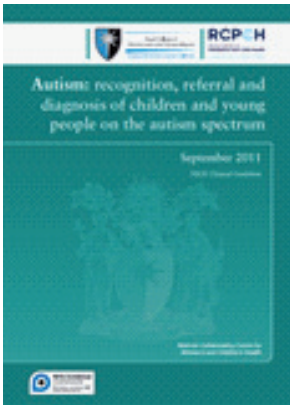


Clay art by Santiago, an 11 year old with autism spectrum disorder. Photo: Lynn Albrink

- Admission to a neonatal intensive care unit
- Presence of birth defects
- Male gender
- Threatened abortion at less than 20 weeks
- Residing in a capital city
- Residing in suburb of a capital city.

In relation to medical conditions associated with ASD, with the same proviso of low quality of the evidence, the NICE guideline lists the prevalence of ASDs in several medical conditions (prevalence of ASDs between parentheses):

- Intellectual disability (8%-27.9%)
- Fragile X syndrome (24%-60%)
- Tuberous sclerosis (36%-79%)
- Neonatal encephalopathy/epileptic encephalopathy/infantile spasms (4%-14%)
- Cerebral palsy (15%)
- Down syndrome (6%-15%)
- Muscular dystrophy (3%-37%)
- Neurofibromatosis (4%-8%).



Click on the picture to access the NICE guideline: "Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum"

Neonatal physical illnesses such as post-encephalitic infections and sepsis had been documented to precede the onset of symptoms of ASDs, especially in sub-Saharan Africa. Autoimmune factors have also been claimed as a possible etiological factor in ASDs. This would result, if finally demonstrated, from reactions between maternal antibodies and the fetus (Bakare & Munir, 2011).

In summary, although heritability of autism has been estimated as extremely high, the challenges faced in understanding the etiology of autism lie in the observation that genetic factors are heterogeneous, complex, and the interaction between genes and environment are poorly understood. There are on-going and ambitious individual and familial longitudinal studies that promise to give us useful data in this regard.

Future directions for genetic research in autism lie in identifying specific gene-environment interactions. Research must overcome the challenges of elucidating the roles of genetic heterogeneity, epigenetic mechanisms and environmental modifiers. It is hoped that technological advances, combined with longitudinal projects, will help us understand in the near future the etiological complexities of these disorders and will advance specific ways to treat and to prevent them.

CLINICAL ASPECTS

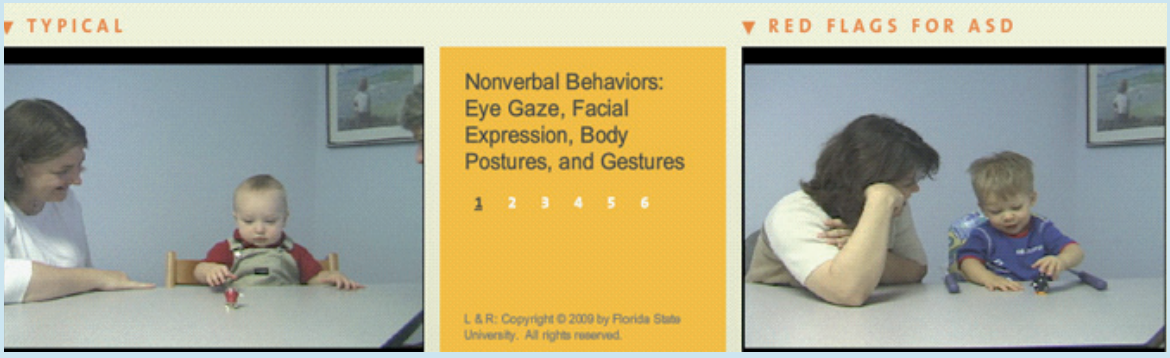
Qualitative impairments in social interaction

Of the three core symptom domains that define autistic disorder, impairment in social interaction is central. This includes impairments in nonverbal behaviors used to regulate social interactions, failure to develop peer relationships appropriate to the child's developmental level, and lack of spontaneous seeking to share enjoyment, interests or achievements with others (e.g., by a lack of showing, bringing or pointing objects of interest to the attention of others). Children with impairments in these areas lack social or emotional reciprocity.

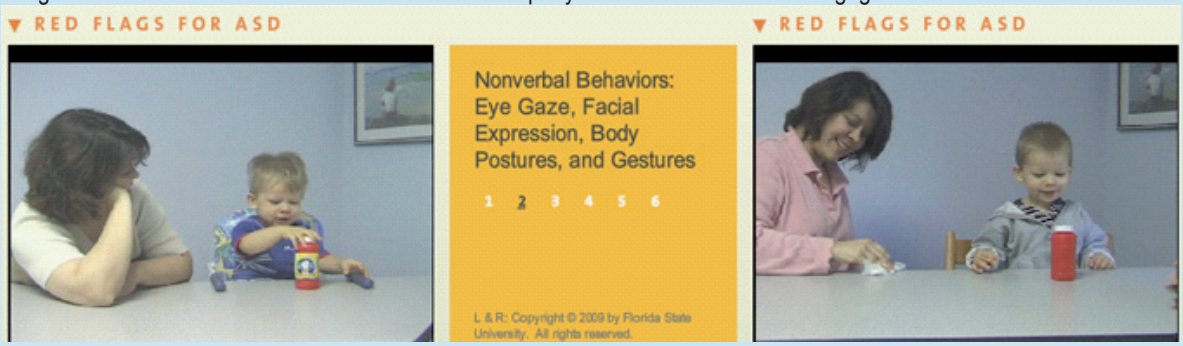
Responding to joint attention and initiating joint attention is very important in social learning and is associated with language and cognitive development. Impairment in joint attention is a very important early symptom that can be seen even in very young children with autism.

Research on the *theory of mind* has shown that children's ability to imitate others lies at the origin of understanding the perspective of others. Theory of mind enables one to have an idea of the mental state of others and, to some extent, predict their actions. This is also related to the ability to understand deception and other people's emotions (empathy). Theory of mind impairments negatively affect pretend play, empathy, sharing, social and emotional reciprocity and peer

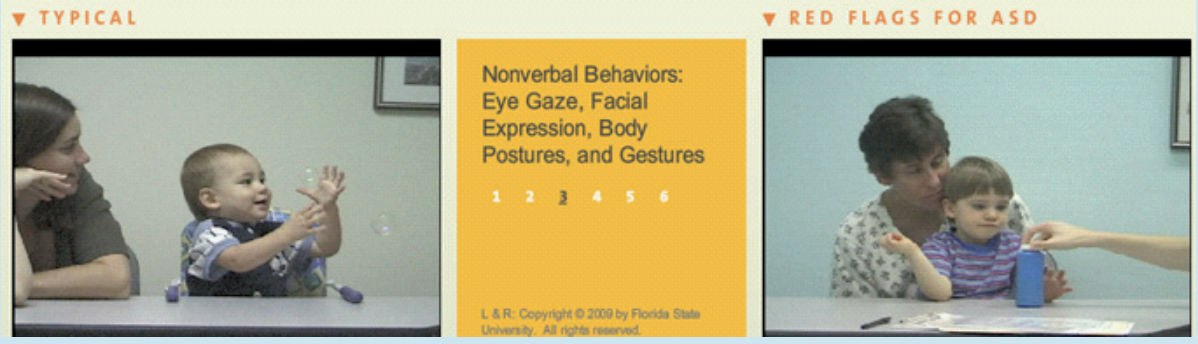
Figure C.2.2 Photographs illustrating "red flags"; video clips available at the Autism Speaks video glossary



A typical child at 12 months shifts his eye gaze from the windup toy to the clinician and then coordinates his eye gaze with smiling. A child with ASD becomes focused on the windup toy and does not look at or engage in interaction with adults.



A child with ASD at 18 months looks at the bubble jar and his mother's hands but does not shift his eye gaze from the jar to his mother's face to convey what he wants. The same child at 27 months has been in an early intervention program and, although he still has significant language challenges, he is now able to look at his mother's face in coordination with a sign or gesture and word.



A typical child at 15 months demonstrates facial expression; the movements of the face are used to express his emotions and to communicate with others nonverbally. A child with ASD at 20 months has a marked impairment in the use of facial expressions and other nonverbal behaviors.

relationships. Theory of mind impairments can be seen in all individuals with ASD regardless of age and intelligence when mental-age-appropriate tests are used (Baron-Cohen, 2009). However, theory of mind deficits are not exclusive to ASD and can be seen in schizophrenia and in some personality disorders.

Another important concept is *stimulus overselectivity*: children with ASD exhibit overly selective attention. This is also not unique to ASD and can be seen in children with intellectual disabilities.

Stimulus overselectivity can be due to restricted attention or bias towards non global, local information. The latter has been described as the "*weak central coherence theory*" (Happe & Frith, 2006). The bias explanation allows individuals with ASD to have superior local information processing ability. *Enhanced perceptual functioning theory* (Mottron et al, 2006) posits that individuals with ASD have biased perception, which is more locally oriented; detail perception is enhanced and movement perception is reduced. Baron-Cohen and associates (2009) argue that sensory hypersensitivity leads to excellent attention to details and "hyper-systemizing" leads to law-based pattern recognition, which can produce talent.

Children with ASD use nonverbal behaviors such as eye contact, gestures, body postures and facial expressions less often than typically developing children. One of the most important findings in recent years has been the observation that two-year-olds with autism fail to orient towards biological motion – human bodies in motion (Klin et al, 2009) – and they do not preferentially look to the eyes of approaching adults (Jones et al, 2008).

Children with ASD show several atypical behaviors, probably due to *sensory hypersensitivity*, that can be observed in visual, auditory and tactile modalities and can be specific to certain stimuli (Baron-Cohen et al, 2009). Visual hypersensitivity may lead to lateral vision – staring at objects with pupils at the corner of the eyes (Mottron et al, 2006). Lateral vision has been interpreted as an attempt to limit excessive information or to focus on optimal information. Auditory and tactile hypersensitivities can be very stressful. On the other hand, sensory hypersensitivity may also lead to exceptional attention to detail.

Even high-functioning individuals with ASD may have problems in peer relations. While some of the subjects do not have any interest at all in relating to peers, others may have impairments in playing in different sides of a game (both seeking and hiding). Some children with ASD may want to have peer relations but they may have problems in interpreting other's actions and responding accordingly. Many subjects with ASD do not have insight into the nature of social relations, particularly in their part and role in relationships. Many individuals with ASD may fail to develop empathy. All of these difficulties lead to impairments in social relations.

Joint attention

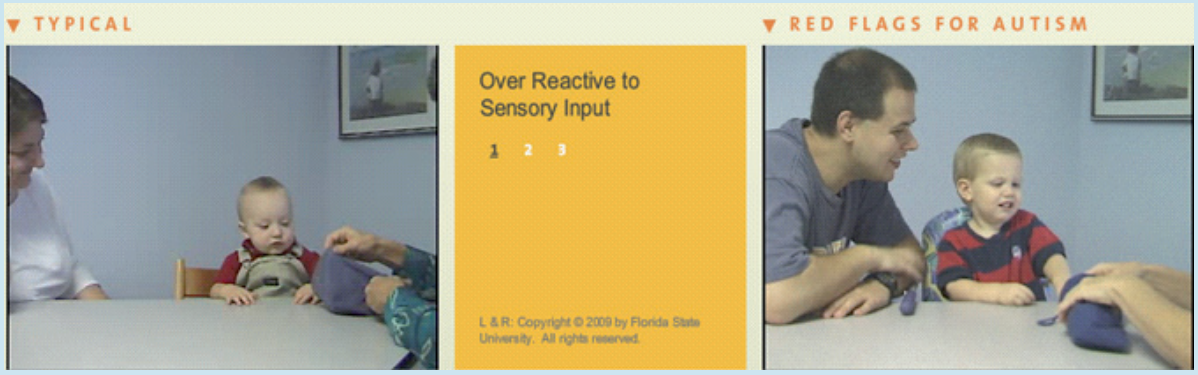
This term describes children's capacity of being able to look at another person's eyes and face in order to get information such as how that person feels, what that person is looking at, or what that person is trying to do. It is also being able to follow another person's eye-gaze to then look at the same thing and being able to sustain joint attention, which is harder in an activity where you cannot predict what the other person will be doing, feeling or planning. Certain social situations require shifting attention frequently to monitor the other person.

Qualitative impairments in communication

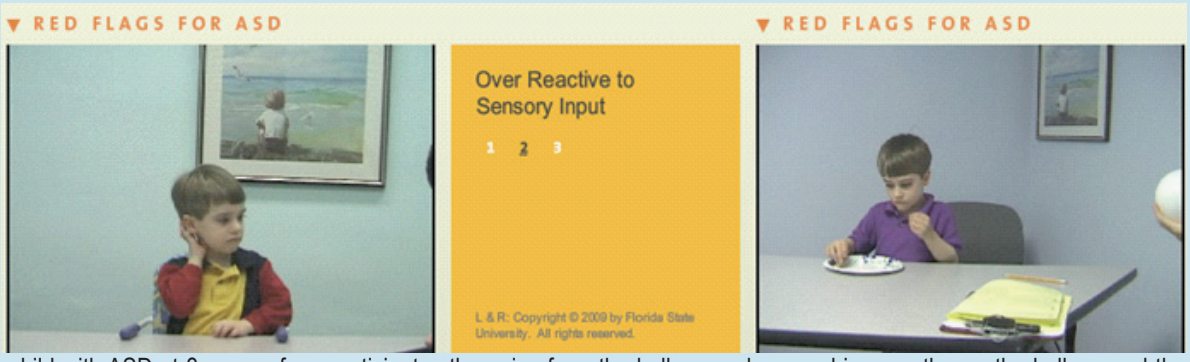
This core symptom domain includes delay in, or total lack of development of spoken language, which is not accompanied by compensatory attempts; marked impairment in the ability to initiate or sustain conversations; stereotyped, repetitive or idiosyncratic language; and lack of varied, spontaneous imitative or make-believe play. Language delays, lack of language, and peculiarities in spoken language are common in ASDs and they are often the parents' initial concern.

The important distinction lies in the compensation attempts; children with other developmental and sensory disabilities usually use non-verbal means – such as gestures – for communication. In children with speech, functionality and social directedness of the speech is very important. Repetition of another person's words, echolalia is frequent in ASDs. The rate, volume and intonation of speech can be abnormally high, low, fast, slow, jerky, monotonous, etc. Individuals with ASDs may invent their own words or phrases and language can be repetitive, may repeat the same phrases even when they are inappropriate to the context. Even high-

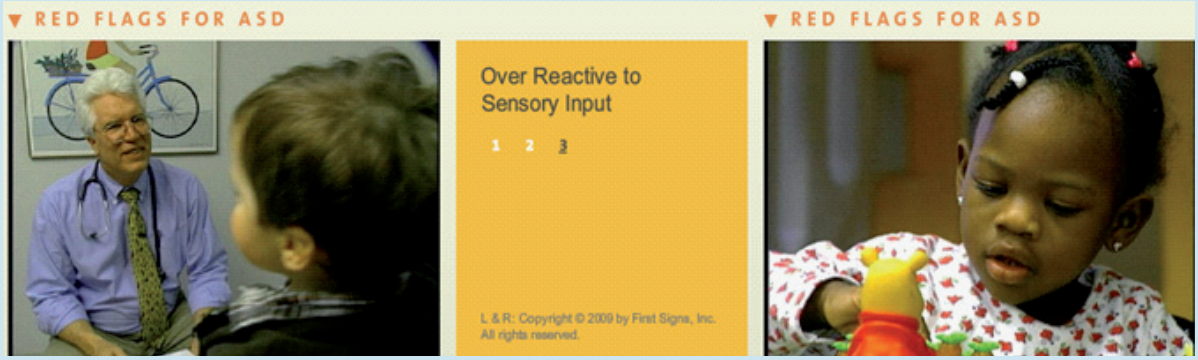
Figure C.2.3 Photographs illustrating "red flags"; video clips available at the Autism Speaks video glossary



A typical child at 12 months reaches cautiously into the bag, looks at the clinician for reassurance and actively explores the Koosh "cat" ball by touching and mouthing it, and shows it to his mother. A child with ASD at 20 months has good eye gaze, however he is very reluctant to touch the Koosh "cat" ball. His strong negative reaction is known as "sensory defensiveness".

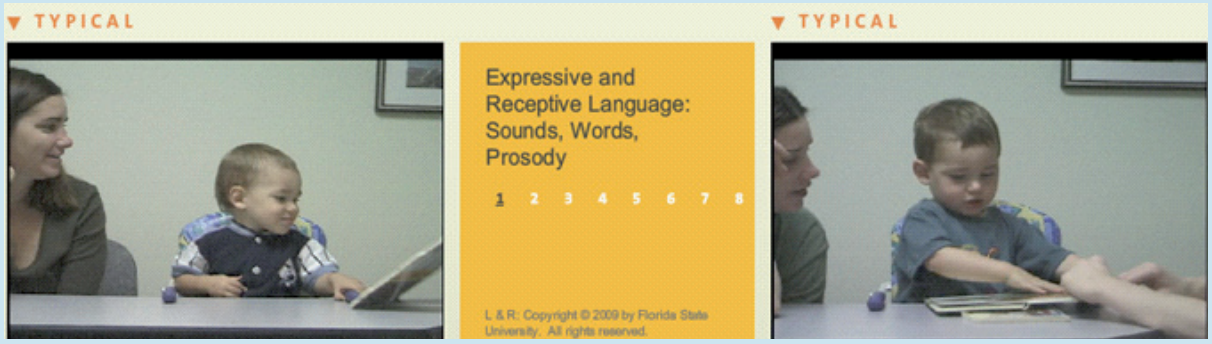


A child with ASD at 3 years of age anticipates the noise from the balloon and covers his ears, throws the balloon and then gives it to his mother to protest. The same child at 5 years again covers his ears in anticipation of the balloon being shot into the air. Although over-reactive to sensory input, he is now able to tell the clinician that he does not want her to let the air out.

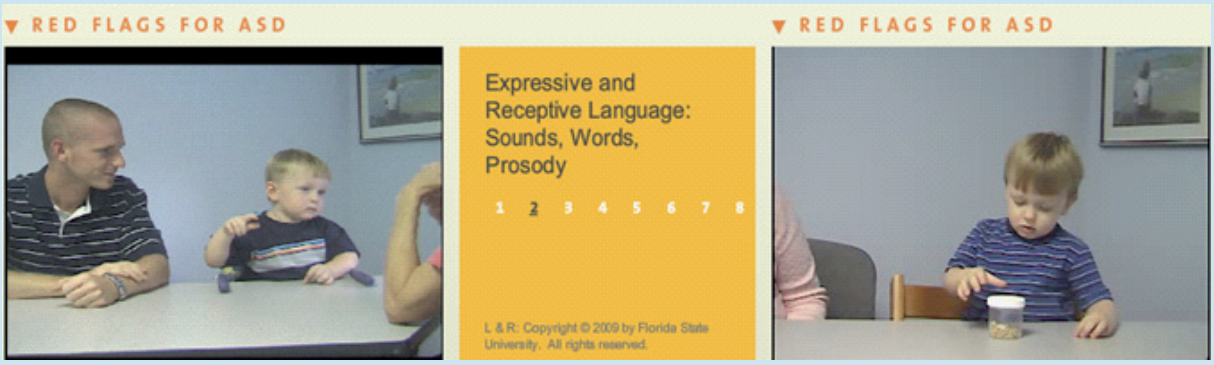


A child with ASD at 2 years is very over-reactive to light and starts engaging in self-stimulating behavior to soothe or comfort himself. A child with ASD at 3 years is very reactive to loud noises, like hand clapping. This child puts her hands over her eyes and reaches to her mother for comfort.

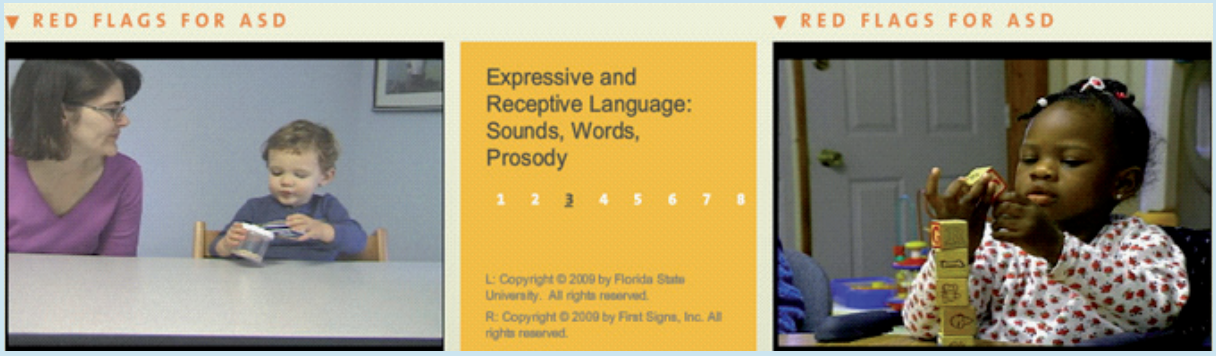
Figure C.2.4 Photographs illustrating "red flags"; video clips available at the Autism Speaks video glossary



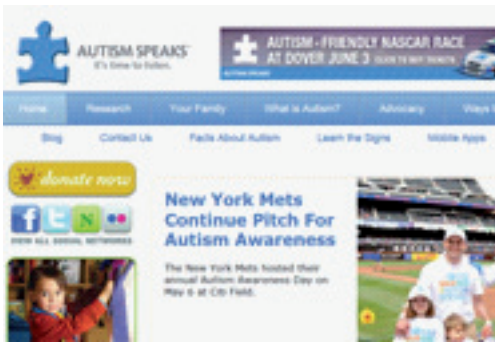
A typical child of 15 months uses speech-like sounds or babbling in a meaningful, interactive way. The same typical child at 22 months uses clear words to name animals while pointing to pictures in the book.



A child with ASD at 22 months has desire and shows effort to communicate with a lot of gestures and minimal vocalization, but he does not have words yet. The same child at 28 months is trying to imitate the words "more" and "open" verbally.



A child with ASD at 28 months produces unusual sounds for language. A child with ASD at 36 months has unusual sounds for language. It seems more like self-talk since she never looks at others.



Click on the picture to access the Autism Speaks website. This is an excellent resource documenting all the symptoms and signs. The facility is free; information cannot be downloaded but can be used online by professionals who want to show these symptoms (video clips) to families or in training sessions. The video clips contrast the behavior seen in children with ASDs with that of typically developing children. The Video Glossary was created by Amy M. Wetherby, PhD, director of the Florida State University Autism Institute and Nancy D. Wiseman, founder and president of First Signs®.

functioning individuals with ASD can have problems initiating and sustaining a conversation. This includes lack of *small-talk*, not providing enough information, not asking for information and not building on other people's comments. When combined with restricted interests, conversation with persons with ASD can be very difficult to sustain.

Play can be functional or imaginative. Functional play is when toys are used as intended, for example using a toy fork as a fork or pressing the buttons of a cause-and-effect toy. Problems in make-believe and imitative play are apparent in many children with ASD. Typically developing children play with several materials in a flexible and creative way. For example, in typical make-believe play children can use a puppet as a general and a wooden block as the car of the enemy soldier (imaginative play). Everything can be used in an imaginative way.

Repetitive, restricted, stereotyped patterns of behavior, activities and interests

According to DSM-IV, this third core symptom domain includes preoccupation with stereotyped and restricted patterns, inflexible adherence to routines, stereotyped and repetitive motor mannerisms, and persistent preoccupation with parts of objects. It has been suggested that this domain is very broad and contains at least two subtypes of behaviors: (a) repetitive sensory motor behaviors (lower-order) and insistence on sameness – and possibly circumscribed interests – (higher-order). Repetitive sensory motor behaviors are more frequently seen in young children and are associated with lower non-verbal intelligence.

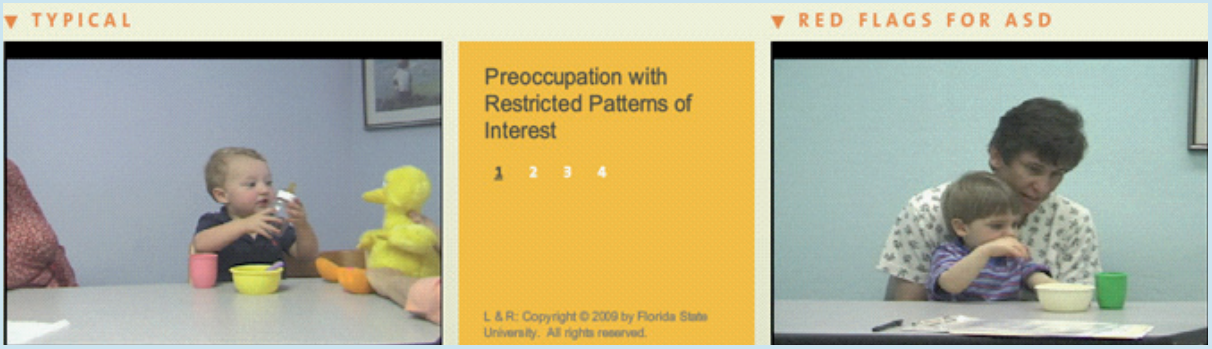
Many individuals show strong interests in some topics; they read extensively about them, collect items related to them, can talk on that subject for hours, and may proceed as young adults to join interest groups or societies dedicated to their interest. The difference between these *normal* behaviors and those of individuals with ASD can be explained in terms of narrowness of the focus, inflexibility, perseveration and lack of social quality. Individuals with ASD can focus on a very specific part of the object of their interest; for example, only the number of teeth in dinosaurs. They can have problems in switching to other topics even when other people are clearly not interested in what they are talking about. They keep focusing on the topic when they are supposed to do other tasks and may become distressed or even agitated when they are interrupted. They may show less interest in sharing their hobby in social ways, like joining a club.

Inflexible adherence to specific, non-functional routines or rituals is also a typical symptom of ASDs. Difficulties with minor changes in personal routine and resistance to even small changes in the environment can cause significant problems in their and their families' daily lives.

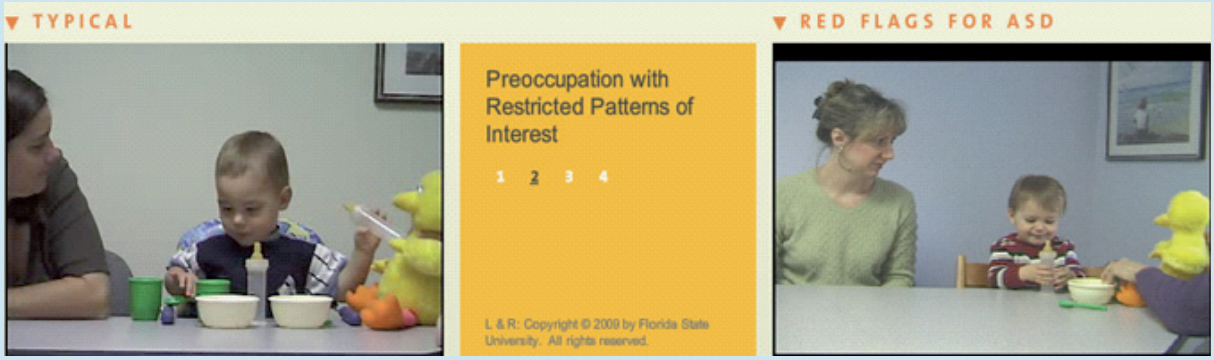
Stereotyped and repetitive motor mannerisms and persistent preoccupation with parts of objects may be more evident in younger children and individuals with intellectual disability. These include hand and finger flicking, mannerisms, rocking, toe walking, sniffing and licking non-food objects, spinning, and unusual visual gaze, among others. Persistent preoccupation with parts of objects can be seen, for example spinning wheels, flickering the eyes of dolls, among others.

Stereotyped behaviors can be observed in several other conditions including Tourette's Disorder, Fragile X syndrome, Rett's disorder, obsessive compulsive disorder, deafness, blindness, schizophrenia and a variety of intellectual disabilities

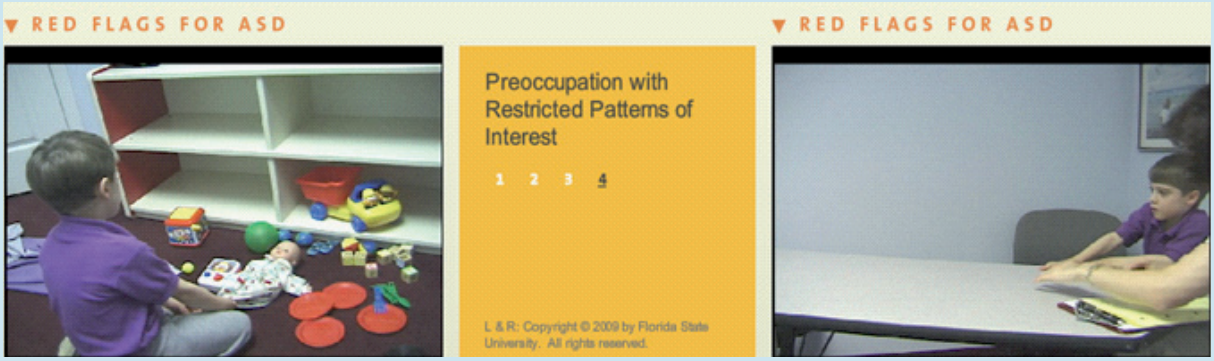
Figure C.2.5 Photographs illustrating "red flags"; video clips available at the Autism Speaks video glossary



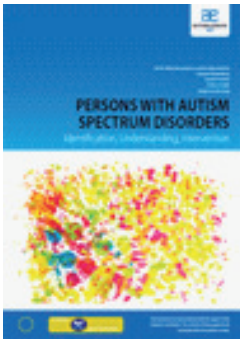
A typical child at 20 months engages in make-believe play by offering "coffee" to everyone and scooping food for Big Bird and himself. A child with ASD at 20 months does not engage in make-believe play but instead explores objects by turning them over and rolling them.



A typical child at 15 months engages in make-believe play by hugging and feeding Big Bird with the bottle, and stirring, pouring, and blowing on food. He shifts his focus from one toy to another and from the toy to people. A child with ASD at 16 months does not engage in make-believe play but instead is very focused on wobbling the bowl and cup.



A child with ASD at 5 years zeroes in on (and gets stuck on) a ball that looks like a globe. He has been intensely interested in planets for a few years, so he was particularly drawn to the ball, to the exclusion of all the other toys. Same child with ASD at 5 years gets stuck on the camera. He has shown an interest in the camera and other mechanical or electronic things for a few years.



Click on the picture to access Autism Europe's "Persons with Autism Spectrum Disorders: Identification, Understanding, Intervention"

without ASD. It seems that the frequency but not the pattern – which is related to the developmental level – of the behavior is what is distinctive for ASDs (Bodfish et al, 2000).

DIAGNOSIS

There is a wide agreement that, once the presence of ASD is suspected, the child should be referred for a multi-disciplinary assessment in which all members of the team should have some ASD training and at least one member should be trained in the assessment and diagnosis of ASD using standardized instruments. Also, it is recommended that the child should be ideally observed in several different settings, both structured and unstructured. It needs to be recognized, however, that the vast majority of child and adolescent mental health services worldwide do not have the state-of-the-art instruments used in specialized clinics in wealthy countries such as the Autism Diagnosis Observation Schedule, the Autism Diagnostic Interview, the Diagnostic Interview for Social and Communication Disorder or the Developmental, Dimensional and Diagnostic Interview. This highlights the need for dissemination, training and development of multi-cultural, multi-language, cheap, reality-oriented, user-friendly, instruments.

The NICE guideline is freely available and considers all the aspects of the ASD-specific diagnostic assessment, provides recommendations about its core elements, autism-specific diagnostic tools and how best to communicate to parents a diagnosis of autism for their child. In summary, the NICE guideline reiterates what has been established in other guidelines including a detailed enquiry into the specific concerns raised by family and teachers; medical history; home life, education and social care; and history and observation focusing on the developmental and behavioral features specified ICD-10 and DSM-IV. This core information is usually sufficient to establish a diagnosis of autism when diagnosis is straightforward. Beyond the diagnosis of ASD, a diagnostic assessment should also include a profile of strengths, needs, skills and impairments. The instruments needed for this will depend on the age of the patient and the developmental level, but should be instrumental in helping to identify:

- Intellectual ability and learning style
- Academic skills
- Speech language and communication skills
- Fine and gross motor skills
- Adaptive (including self-help) skills
- Socialization skills
- Mental and emotional health including self-esteem, physical health and nutrition
- Sensory hyper- and hypo-sensitivities
- Behavior likely to affect participation in life experiences, future support and management.

Physical examination

A comprehensive physical examination should also be undertaken. Findings from the physical examination may be useful to detect coexisting conditions or symptoms of disorders that may have a causative role or increase the suspicion of an ASD. Particular attention should be given to identifying skin stigmata of

neurofibromatosis and tuberous sclerosis, as well as congenital abnormalities and dysmorphic features including micro and macrocephaly. The examination should also look for signs of physical injury, such as self-harm or maltreatment.

Differential diagnosis

Autistic disorder, when presenting in its full typical form, is not difficult to recognize by a professional with experience. However, clinicians should rule out medical, genetic, neurological or sensory dysfunctions or disorders. The situation is different for clinical pictures that do not fit the traditional descriptions of the disorder, which are becoming more frequent due to the widening of the construct into the autistic spectrum and this can lead to diagnostic disagreements.

Infants and toddlers

Differential diagnosis at this age should rule out disorders that interfere with normal development of language and social skills:

- *Hearing loss* can be suspected if the child has lost his babbling, shows poor vocalizations or indifference to auditory stimuli. Routine exam in very young children who cannot be expected to cooperate include otoacoustic emissions and impedance audiometry. If they are normal, there is no need for further testing. If they are abnormal, the external ear should be examined and both tests should be repeated in two-three months. If the results are again abnormal, auditory evoked potentials should be studied.
- *Severe psychosocial deprivation*. It is well known that severe emotional deprivation in childhood leads to serious psychological impairments including pseudo-autistic clinical pictures (Rutter et al, 1999). The autistic-like symptoms in these cases usually consist of a relative indifference to the environment, communications delay, restricted interests and repetitive behaviors. Unlike in autism, social reciprocity is not completely abnormal – although bonding may be affected – and deficits can be reversed quickly in the majority of cases if environment improves.
- *Intellectual disability* (formerly known as mental retardation). It is often a difficult diagnosis to exclude in the early years of life because evaluation of cognitive functioning is more difficult (see Chapter C.1). Some symptoms (e.g., facial dysmorphy, microcephaly) may suggest the existence of genetic or neurological problems known to cause intellectual disability may be suspected. It is also documented that severity of intellectual disability is positively correlated with social interaction deficits (Wing & Gould, 1979). Therefore, attributing communication and socialization defects, self-injurious or stereotypic behaviors to autism or severe intellectual disability can be challenging. This can be provisionally solved if there is evidence of an abnormal development in social, communication and imaginative skills discordant with the general level of intelligence (very difficult to clarify when mental age is below 18 months). It is important here to highlight that the association of AUDs and intellectual disability is very common and that many known causes of intellectual disability, such as

The National Institute for Health and Clinical Excellence (UK) is currently in the process of producing much needed guidelines on autism in adults. The draft copy is now undergoing consultation.

chromosomal abnormalities often present with autistic symptoms (e.g., Fragile X syndrome, Prader-Willi syndrome) (see Chapter C.1).

- *Rett's disorder*. DSM-IV includes this condition among the pervasive developmental disorders. However, DSM-5 proposes not to include Rett's disorder because although patients often have autistic symptoms they are apparent only for a brief period during early childhood, so inclusion in the autism spectrum is not appropriate for most individuals. Rett's disorder is an X-linked neurodevelopmental disorder that affects girls almost exclusively. Typically, there is normal development until 6–18 months of age, then development stops and a regression appears (loss of speech and of purposeful hand use) with specific hand stereotypies and social withdrawal, which mimic an autistic picture. Besides, there is a deceleration in head growth leading to acquired microcephaly and seizures may appear. Research has led to identification of a gene (MECP2) on the X chromosome (explaining the higher frequency in girls, but some male cases have been reported) (Amir et al, 1999).
- *Receptive-expressive language disorders*. Expressive language disorder is very common in children and usually consists in a simple delay in mastering phonology, lexicon and syntax that looks very selective in the context of a typical development of social skills, non verbal communication, cognitive skills and imagination. The situation is more challenging in a minority of non-autistic children of normal non-verbal intelligence who have severe receptive-expressive language impairment. This situation has been described as "semantic-pragmatic disorder" with problems in the social communication aspects of conversational interchange, including echolalia. However, unusual preoccupations and rituals are much less common than in autism. It is of note that this disorder is not included in DSM-IV or ICD-10,
- *Landau–Kleffner syndrome*. Acquired aphasia with epilepsy or Landau–Kleffner syndrome is characterized by a normal development until age three to four followed by a massive regression of receptive and later expressive language, typically in conjunction with the development of seizures or sleep electroencephalogram abnormalities. The regression may be associated with transient social withdrawal but a complete autistic picture is not observed. There is a sub-type of pervasive developmental disorder, childhood disintegrative disorder, where regression is evident, but the regression occurs earlier (18 to 24 months of age).
- *Selective mutism and separation anxiety*. Withdrawal, anxiety and communication problems are common. However, it can be easily distinguished from autism because of the existence of normal communication and social skills at home or in other familiar environments.

Older children

Differential diagnosis in typical autistic presentations is easier in older children, but it can be difficult in cases within the broader phenotype: cases in the "periphery" of the spectrum, especially in high functioning children or cases with



Clay art by Santiago, an 11 year old with autism spectrum disorder. Photo: Lynn Albrink

a partial disorder. An accurate medical history, establishing the onset of symptoms before or after the age of three years, is often an important indicator.

Clinicians should consider *childhood schizophrenia* (see Chapter H.5). The potential confusion between this rare condition and ASD may arise from poor expression of emotions and negativism. However, hallucinations and delusions are specific to schizophrenia. Furthermore, most children with early onset schizophrenia do not show the language delay or abnormalities and the social deficits that are typical of ASDs.

Other psychiatric conditions to be excluded are *attention deficit hyperactivity disorder* especially as both can coexist, and *obsessive compulsive disorder* because of the rituals and selected interests, but the differential diagnosis can easily be made on the bases of the history and the global clinical presentation. It is of interest to highlight that some authors refer to a disorder not included in the current classifications: *multiple complex developmental disorder* (Towbin et al, 1993), which consists of impaired regulation of affective state, with primitive anxieties, impaired social reciprocity and thought disorders, but failing to meet criteria for ASDs.

PROGNOSIS AND ADULT OUTCOMES

ASDs are disorders that start in infancy; therefore, significant changes occur with development that will impact adult outcome. These changes should not be overlooked and require on-going monitoring and individualized adaptation to optimize support programs. Baghdadli et al (2007) have stressed the high variability in short-term outcomes of preschoolers, emphasizing the importance of considering individual characteristics and adaptive strategies. They suggest that these differences may be due to certain initial characteristics like speaking skills and severity of autistic symptoms.

The more severe the comorbid intellectual disability the poorer is the outcome. It is generally accepted that speech before the age of six and a higher IQ are associated with a better outcomes (Billstedt et al, 2011). However, there is limited research data about the whole spectrum across the life cycle. Therefore,

clinicians must be cautious when predicting the distant future of their patients. ASDs are lifetime disorders and cannot be cured. Nevertheless, disability depends not only on the characteristics of the individual but also on the environment that is offered to that person, adapted or not, to minimize the disabilities.

In this regard, uncertainty comes from three sources. First, little research has been done about the role played by the supports provided. Second, there is a younger and less severely affected group of individuals now diagnosed with ASDs in industrialized countries; their prognosis and response to treatment may be better than traditionally expected. Finally, there is limited epidemiological data on adults, particularly those with Asperger's disorder. Marriage and Wolverton (2009) showed that despite adequate academic achievement, work, living and mental health status can be poor in this population. Lehndardt et al (2011) estimate that the lifetime rate of psychiatric consultations for this group can be as high as 78%.

Overall, it can be said that the vast majority of children with ASD will continue to show deviance and difficulties in social interactions throughout their lives. It should be assumed that they will need support and help in many areas. However, their quality of life can be improved when adequate programs are available in their communities. Community based programs should be adapted to each individual, taking into consideration areas of difficulty and strengths, as well as the resources that the community has to offer. People with autism will need structure, clarity and predictability throughout their lives.

Behavior and adaptive skills tend to improve with age. Nordin and Gillberg (1998) found that measures of flexibility and cognitive shifting abilities tend to be predictors of good social outcome. Unfortunately, more research is needed on the adult population, so programs may be adequately tailored to meet their needs as well as supporting transition into adulthood.

Prognosis should be discussed with the family to avoid unrealistic expectations and focus all efforts on early intervention and fostering family involvement and knowledge, as well as community participation. It is important to underline that current efforts in treatments and creation of services (nonexistent in most countries), will shape the future functioning of the children diagnosed and treated now, as they grow and become adults.

TREATMENTS

The key strategies in the treatment of ASDs are to:

- Personalize
- Contextualize.

Treatment of ASDs depends on factors that make description of "the treatment" inadequate. Differences in age, degree of impairment, comorbid disorders, family and social situation, level of resources and community development, provision of education (or lack of it), health and welfare assistance, opportunities for sheltered employment and availability for inclusive living in the community in adult life will make a huge difference. If there are two words that would underline what should be done for ASDs, those two concepts would be "to personalize" and "to contextualize".

Despite accepting these commonsense ideas, there is a tendency to search for a "cure" for ASD, as if there was a single cause, a unique mechanism and a single condition underlying the syndrome that, if identified, would lead to cure for all the ASDs. The Internet allows families and professionals to hear about many "treatments" – some based on current knowledge but others based on sheer

Table C.2.3 Treatments for autism spectrum disorders, evidence supporting their effectiveness and recommendation about their use

Effectiveness	Intervention	Recommendation
Not supported by evidence	• Doman-Delacato therapy • Irlen lenses • Facilitated communication • Psychodynamic psychotherapy • Secretine • Antimycotic therapy • Chelation • Immunotherapy • Craniosacral therapy • Animal assisted therapies	**Not recommended**
Weakly supported by evidence	• Auditory integration • Sensory integration • Expressive psychotherapies (art and music) • Vitamins and dietetic supplements • Gluten and/or casein free diets	**Recommended only in controlled research studies**
	• Social skills programs • Augmentative / alternative communications systems • TEACCH (Treatment and Education of Autistic and Related Communication-Handicapped CHildren) program • Cognitive behavioral therapy • SSRIs in adults with ASDs (if comorbid obsessive compulsive disorder) • Stimulants in persons with ASD and comorbid ADHD	**Recommended**
Supported by evidence	• Behavioral interventions • Risperidone (for comorbid severe irritability or challenging behaviors)	

Source: Fuentes-Biggi et al (2006)

superstition or false beliefs – that most people feel confused about what to do. The worst aspect is that families (and professionals) feel that there is something else they should be doing and by not doing it, they are not providing the best treatment for the person with ASD. In the same line, very often there is a disregard for local limitations and possibilities. Thus, programs developed over the years in wealthy countries are copied or applied in completely different areas of the world without regard for the local circumstances, opportunities and feasibility of future maintenance.

While there is no cure for ASDs, there is strong evidence that appropriate, lifelong educational approaches, support for families and professionals, and provision of high quality community services can dramatically improve the lives of persons with ASD and their families. There are up to date practice guidelines in many countries such as Spain and the UK, which have reviewed the available evidence for a great variety of treatments advocated for ASD. The UK departments for Education and Skills and for Health have also produced guidance for the education of students with ASDs. Much has been learned about the practices

that are supported by evidence and those that are not, and about which programs make a real difference to the lives of individuals with ASD. Unfortunately, this knowledge has not yet been incorporated into clinical practice around the world, even in more affluent societies. Thus, there remains a gap between knowledge and opportunity; it is evident that very few people with ASDs receive state-of-the-art support.

Recent reviews of the evidence conclude that relatively few treatments meet the necessary criteria when assessing the value of interventions. Nevertheless, evidence is improving, with growing numbers of well-conducted studies. Randomized control trials are also increasing in number. However, even when outcome is positive, most research still focuses on very short-term goals and on a limited number of outcome measures. There is little attempt to address questions such as whether treatment succeeds in maximizing the long-term potential of the individuals involved or if it truly improves their quality of life. Such issues may require very different research strategies such as audits and reviews, systematic analysis of problems, and measures of satisfaction. It is also crucial to collect the views of individuals with ASD themselves.

To date, programs involving behaviorally based interventions, those designed to improve parent-child interaction, and those with an emphasis on developing social and communication skills appear to have the strongest supporting evidence, at least in the short term. As Autism Europe states, there are many other elements that are essential to improve longer-term outcome:

- Education, as early as possible, with special attention to social, communication, academic and behavioral development, provided in the least restrictive environment by staff who have knowledge and understanding of both autism and the individual student.
- Accessible community support in terms of appropriate, well-informed, multi-agency services that will help each individual to realize their potential and life-time goals (either chosen by the individuals themselves, or those who know, love and legally represent them).
- Access to the full range of psychological and medical treatments (adapted as necessary to meet the needs of individuals with ASD) that are available to the general population.

According to Autism Europe, interventions that are best supported by evidence as examples of good practice include four principles:

- *Individualization*. There is not a single treatment that is equally effective for all persons with ASD. Diversity in the manifestations of this spectrum as well as individual skills, interests, life vision and circumstances mandate personalization.
- *Structure*. That is, adapting the environment to maximize each individual's participation by offering varying degrees of predictability and stability, more effective means of communication, establishing clear short and long-term goals, defining the ways in which these goals can be met and monitoring outcomes.
- *Intensity and generalization*. The interventions used should not be sporadic or short term, but applied in a systematic manner on a daily basis, across different settings, and by all those living and working



There are a variety of strategies that can augment autistic children's communication ability. New technologies are expanding greatly the capacity and sophistication of these communication aids. One example is "e-Mintza", a free application to generate a personal communication board on a computer or tablet (currently available in the Basque and Spanish languages). To view a short video about e-Mintza (in Basque and Spanish), click on the picture above. Click **here** to download the application.

with the person with autism. This will ensure that the skills acquired in more structured settings can be maintained in real life situations as well. Those responsible for carrying out the intervention should also have access to appropriate support and guidance from professionals with expertise in ASDs.

- *Family participation*. Throughout childhood and beyond, parents must be recognized and valued as the key elements of any intervention. Information, training and support, always within the context of family values and culture, should be the common denominator of any professional intervention. Other important sources of support, such as babysitting, respite care, short breaks, or tax benefits should be available to avoid the discrimination that many of these families still face. Adequate support for social, medical and educational services is necessary to ensure that these families are able to enjoy the same quality of life as everyone else.

Globally, given that the vast majority of people with ASDs are not receiving specialized treatment – more often than not, they are not receiving what could be considered adequate generic treatment – child mental health professionals should be devoting their efforts to the development of resources in the community where they practice and to support these children's families. Regardless of their age, most people with ASDs around the world live with their families. It is of these families that one needs to ask how they want to be supported, what are their priorities, what are their dreams, what life project they would like for their child. The person with ASD should participate in this dialogue, directly or helped trough interpersonal support and augmentative communication means; in the minority (at least 25%) that cannot express themselves at all, by delegation from people who know them well. Families are the essential support networks that cannot be replaced by governments. Their role should be gratefully recognized, our task being to maximize their potential in their own terms. We are talking not only about a health goal but also about fighting ignorance and discrimination.



Clay art by Santiago, an 11 year old with autism spectrum disorder. Photo: Lynn Albrink

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SCHOOL UNDERACHIEVEMENT AND SPECIFIC LEARNING DIFFICULTIES

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Finishing lessons at home

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Acknowledgements: We would like to acknowledge Elinor Saiegh-Haddad for commenting on the Arabic section of Table C.3.2 and Ying Wang for the Chinese language stimuli in Table C.3.7.

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Suggested citation: Nag S, Snowling MJ. School underachievement and specific learning difficulties. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

A child struggling in school causes concern. Difficulties with school tasks can leave children frustrated and parents and teachers wondering about the barriers that are preventing learning. Indeed, school underachievement is one of the most common reasons for referral to a visiting specialist in school or to a child guidance clinic. Underachievement may however be a symptom of any number of cognitive, emotional and social difficulties. In this chapter we will first review definitions of learning disorders and discuss issues surrounding their diagnosis. Although there is a growing body of evidence about mathematical and other non-verbal learning difficulties, our focus will be on *literacy learning difficulties* for two reasons. First, they pose a significant barrier to achievement across the curriculum and second, because substantial cross-linguistic information is becoming available about their behavioral manifestations in different language contexts, methods of assessment and intervention. We will also consider *school underachievement* when it is secondary to other conditions and, for a small selection of such syndromes, we discuss why this may be the case. We end the chapter with a discussion about priorities that low income communities can set, both for the identification of children with specific learning difficulties and remedial support.

Literacy

The ability to derive and communicate knowledge and meaning from written language.

CORE CONSTRUCTS

- There are many core skills that support learning. These different skills can be seen as multiple foundations for learning
- A child's performance can be examined in relation to each of the multiple foundations. We can expect the child's profile of skills to show a mix of strengths and difficulties
- When children's development is delayed in relation to at least one of the factors contributing to learning, they may be considered *at risk* for a learning difficulty. Conversely, when skills are generally available or present to above average levels, they may act as protective factors
- The criteria used for the diagnosis of learning difficulties are moderated by the learning context
- *Learning difficulties* are a dimensional construct – children with difficulties fall along a continuum, some show less difficulty and others more
- Criteria used for diagnosis may separate children who have a learning difficulty from those who do not. This is a categorical approach to understanding learning difficulties. The approach is popular, but it is important to note that cut-off criteria differentiating at-risk/not-at-risk children are arbitrary.
- There are distinct and specific learning difficulties that comprise a cluster of recognisable behaviours. Examples of specific learning difficulties (SLDs) are *dyslexia* (a difficulty with reading-related skills) and *dyscalculia* (a difficulty with numerical skills)
- SLDs can be present with other co-occurring problems or co-morbidities. Examples of co-morbid problems include speech and sound disorders, attention deficit disorders and emotional disorders.
- The manifestations of a learning difficulty can change over development. What appears to be mild at one age can become a significant problem in another life stage.



Many people suffer from dyslexia. Albert Einstein, Harrison Ford and George Washington are said to have had the condition

DEFINITION AND CLASSIFICATION

For many years, the most popular approach to identifying specific learning difficulties (SLDs) was to use *discrepancy criteria* – that is, to identify a child as having an SLD if their attainment was below that to be expected based on general cognitive ability. Indeed, the two main classification systems used in clinical practice at the time of writing – ICD-10 (World Health Organization) and DSM-IV (American Psychiatric Association) – follow the discrepancy model to classify children with learning difficulties. However, the use of the discrepancy approach in educational settings has gradually declined because there is little evidence of differences in etiology or prognosis for children with SLDs who have higher or lower IQ (Snowling, 2008). Accordingly, the proposal for DSM-5, which we will discuss below, moves away from this approach. An alternative approach to classification, known as the *response to intervention* approach, is gaining interest and because there are merits in this approach for low and middle income countries, it will also be considered.

For a discussion about issues surrounding classification see: Changing concepts of dyslexia: nature, treatment and co-morbidity, November 2009; Journal of Child Psychology and Psychiatry Virtual Issue on-line

The diagnostic systems differ in their approach to the identification of SLDs (see Table C.3.1). When compared to ICD-10, DSM-IV is less explicit about the extent of delay that must be recorded before a diagnosis is considered, and in DSM-5 it is proposed that the discrepancy formula be abandoned altogether. Diagnostic systems also differ in their treatment of co-morbidities. In DSM-IV and DSM-5, co-occurring difficulties receive parallel diagnoses. In ICD-10 co-occurring difficulties are placed on a hierarchy with the diagnosis pegged to one nodal difficulty or cluster of difficulties. Sometimes the status given to a co-occurring difficulty has implications for understanding the etiology of the difficulty (e.g., literacy difficulties and language difficulties occurring in parallel, or one following from the other).

All these diagnostic systems are fashioned after medical models and there is sometimes a mismatch between clinical diagnosis and the labels for various learning-related difficulties commonly used in educational settings. Below are examples of clinical diagnoses that do not easily fit into what is seen in regular classrooms:

- *Specific* difficulties with spelling. Poor spelling usually co-occurs with difficulties in reading, but in some writing systems (where reading is regular but spelling-sound mappings are inconsistent), spelling difficulties are more common than reading difficulties
- *Disorder of written expression*. There is an under-diagnosis of this disorder. This is not so much because poor written expression skills are difficult to identify but because written expression is seen as following on from a more fundamental difficulty with reading and spelling.

Phonemes/ phonological skills
Phonemes are the smallest sound units in a language that are capable of conveying a distinct meaning (i.e., the m in mat or b in bat). Phonological skills concern an individual's ability to identify, categorize or manipulate these sounds, and include skills such as segmentation, blending, rhyming, and alliteration.

In addition, some diagnostic labels are umbrella terms and therefore uninformative for intervention. For example, both DSM-IV and ICD-10 classify together reading comprehension difficulties and reading accuracy difficulties. However, these are disorders which require different interventions: whereas interventions for reading comprehension focus on developing broader oral language and inferential skills, interventions for reading accuracy primarily target phonological skills.

TABLE C.3.1 Approaches to classification

ICD-10	DSM-IV	Proposed for DSM-5*
• Disorders include reading disorders (81.0), spelling disorders (81.1), disorders of arithmetic skills (81.2) and mixed disorder of scholastic skills (81.3) • Conservative about extent of distance between age/intelligence and attainments for making a diagnosis • On individually administered tests, differences in child's performance must be two or more standard errors below prediction based on age and general intelligence • The lowered attainment must not be attributable to poor opportunity for qualified literacy instruction or other external factors such as disrupted schooling and recent entry into regular schooling • Difficulties must be evident from the earliest stages of acquisition of the particular skill. This criterion is suggestive of abnormality in foundational cognitive skills and indicative of a difficulty that may have a biological basis rather than a socio-cultural/environmental basis.	• Disorders include developmental reading disorder (315.00), mathematics disorder (315.1) and disorder of written expression (315.2) • The child's extent of learning must be substantially below that of peers who have received equivalent opportunity • The lower levels of achievement must be seen to be interfering with academic achievement and daily living • When a known sensory deficit such as nystagmus or low vision accompanies the underachievement, the extent of learning delay should be far in excess of the known contribution of the sensory deficit. The co-occurring difficulty must also be coded • All co-morbidities should be recorded such as attention deficits, emotional difficulties and behavioral disorders • Other associated social-emotional difficulties are known to occur including reduced self-esteem and self-efficacy for academic performance, and increased barriers for entry into school and post-school training as well as in the world of work. DSM-IV encourages that this and similar other associated difficulties be recorded.	• Learning disorder is the generic term to describe disorders characterized by difficulties in learning academic skills – accurate and fluent reading, writing and arithmetic – which significantly affect academic achievement or daily functioning if accommodations are not made • Learning disorders are grouped together with communication disorders (as neurodevelopmental disorders) to reflect their onset during the pre-school or early school years • Learning disorders described in DSM-5 are dyslexia, dyscalculia and disorder of written expression • DSM-5 proposes to drop the discrepancy criterion. For the first time reading fluency will be recognized as an area of assessment for diagnosis (earlier manuals only mentioned reading accuracy). This change reflects the current understanding of the clinical picture of dyslexia – poor reading fluency is known to be a persistent problem into adulthood in most languages, and poor reading fluency (rather than reading accuracy) is a defining feature of dyslexia in many languages • Specific difficulties with reading comprehension (previously classified within reading disorder) will not be clearly accounted for. Thus, diagnosis for two categories of children remains unclear: (i) those with exceptional decoding skills but poor reading comprehension, and (ii) those who begin with poor oral language and go on to have poor reading comprehension. The poor comprehender profile is noted as a feature of language impairment and perhaps will be classified in a new category called learning disability.

*Expected publication date is May, 2013.

Discrepancy criteria qualified by local conditions

For most childhood and adolescent disorders the process of arriving at a diagnosis must be sensitive to local culture and ways of living. Such sensitivity is critical for SLDs since many different factors affect the learning of basic skills, particularly literacy. For example, some children learn to read in their home language, others in a neighborhood language or a language imposed by socio-political forces, yet others achieve literacy in an entirely foreign language, having heard very little of the language at home, in the community and sometimes even in school. In other instances, children may learn to read in two or three languages, and become bi-scriptal or multi-scriptal. Learning how to read and write these multiple languages may happen simultaneously or sequentially, with children being introduced to additional languages at different stages in their school career. Any understanding of the specific literacy difficulties needs to be sensitive to the multiple pathways to literacy.

A strong relationship also exists between socio-economic conditions and literacy outcomes. In a survey of 672 high school children in the UK tested during the standardization of the *York Assessment of Reading and Comprehension*, a clear association was found between reading ability and social deprivation. The survey used the postal codes of children's homes to rank them for social deprivation. A lower rank was for localities (postal codes) in which children experienced many forms of deprivation relative to the UK norm. The trends in the data are presented in Figure C.3.1. About 33% of children in the deprived neighborhoods were poor readers, close to double when compared to the more advantaged neighborhoods, where between 5% and 18% of children were classified as poor readers.

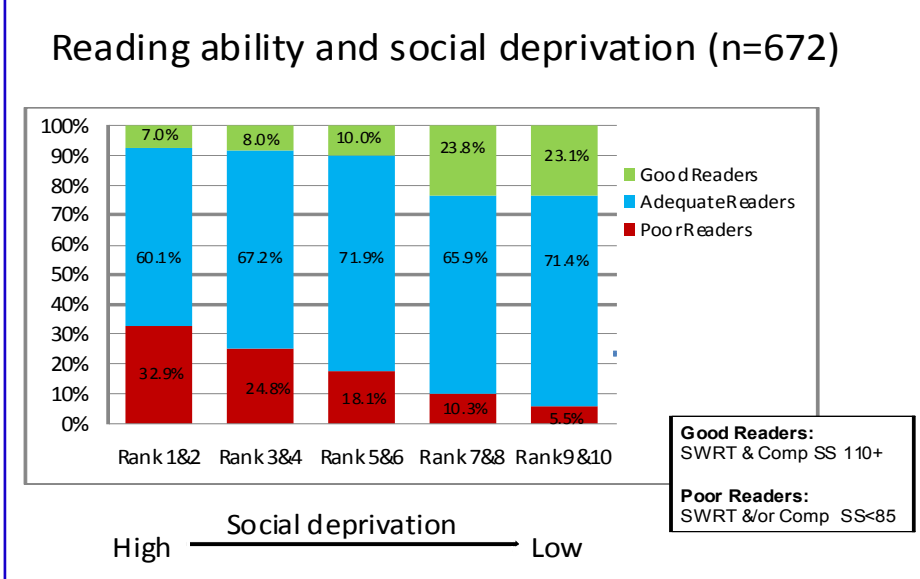
Reading fluency
The ability to read quickly, accurately and effortlessly, with appropriate expression and meaning.

Reading accuracy
The ability to correctly decode the written language, especially when reading aloud.

Reading comprehension
Knowledge and understanding derived from text.

Reading attainment
Level of achievement in any or all reading skills, usually estimated by performance on a test.

Figure C.3.1 Reading ability is modulated by local conditions
(SWRT = single word reading; Comp = reading comprehension, SS = standard score)



Bi-scriptal, multi-scriptal
The ability to read or write the scripts of two (bilingual) or more languages.

The influence of social deprivation on literacy attainments is also found among children gaining literacy in a second language although, similar to monolingual groups, the impact appears to be uneven across cognitive domains. The annual surveys of the Uganda National Education Board, for example, documented better language and literacy attainments in the relatively more advantaged localities in the capital city of Kampala and the surrounding urban area than in more deprived rural areas (NAPE, 1999-2008), while a pre-school survey of Spanish-English bilinguals in the US (Bohman et al, 2010) showed vocabulary learning to be more vulnerable to the influences of social deprivation than acquisition of basic grammar.

The discrepancy formula, which is favored by ICD-10 and DSM-IV but not DSM-5, is particularly difficult to apply when there is variable opportunity and the literacy environment leaves children far behind in their attainments. In such situations, the learning difficulties and low level attainments mimic the difficulties and skills profile seen among children with dyslexia. For example, when large numbers of children in a class are below the expected level for their grade and age, not all the underachievers will show a cognitive profile that is typical of dyslexia. Such children may be said to show a *dyslexia-like picture* but are certainly not eligible for a clinical diagnosis. Clarity about the distinction between the disorder and environmentally induced underachievement, that mimics the disorder, is essential. Without such a distinction there will be an over-diagnosis of the disorder and an unacceptable use of a deficit/disorder perspective for all interventions.

Dyslexia

A developmental disorder affecting the skills involved in the reading and spelling of words, in the absence of any intellectual impairment. Symptoms range from mild to severe, and various subtypes have been proposed.

In many countries there are no locally standardized tests. In such contexts, test results can be difficult to interpret and there is a genuine concern that test findings can mislead. In other words, test results in the absence of normative data are an unreliable metric for deciding who has a learning difficulty and who is free of learning problems.

The discrepancy formula is problematic on several other fronts as well. For example, a formula using a child's age and predicted attainment for that age assumes a mono-grade classroom, with a pre-specified age band in each class. But in many communities the age-grade arrangement is quite different. Schools may be multi-grade with children from several grades in one class. In such schools learning targets may not follow a year-wise framework. Sometimes, the age criteria for school admission may be flexible with older children entering lower classes.

The discrepancy index between intelligence and attainment has also turned out to be problematic. The assumption here is that a higher IQ is associated with better reading scores, and when this is not the case then it is an indication of a learning difficulty. Evidence is now available from several large scale studies that the correlation between IQ and reading skill is modest, thus the simple intelligence-reading attainment discrepancy formula is not very useful and it is unclear what exactly a discrepancy index based on IQ can say about the nature of a learning difficulty.

Given all the above, the criteria used for "diagnosis" must be agreed within the context of the local educational setting. Such sensitivity can correct the mainly acultural nature of descriptions in diagnostic systems. It can ensure that there is a clear distinction made between learning difficulties attributable to poverty, deprivation and insufficiency of school-related experiences, and learning

difficulties that follow from biologically-based cognitive deficits. But, even after we have smoothed out the jagged edges of our definitions and created a diagnostic system that is contextually appropriate, there remains one further difficulty with this approach – it is not grounded in educational practice and instruction. A diagnosis does not in itself indicate what may be the best way to intervene to help the child. Moreover, the diagnosis gives no indication of the cognitive deficits that underpin the disorder, nor does it highlight potential risk factors. Some of these concerns are addressed in the next section.

Response to intervention as an approach to diagnosis

In this approach to classification, children are said to have a specific learning difficulty if they *continue to struggle even after substantial individualized help has been given, and this is documented* through a continuous monitoring of their response to the intervention. The term *individualized help* means any teaching program motivated by the child's specific learning needs. The individualizing of the program can be at the level of worksheets, teaching targets, time given to the child to finish an assignment and the ways in which the assignment is assessed. Individualized help may be through a mainstream program that is suitably adapted (the child remains in class and is given what everyone else is receiving but with some changes). Alternatively, the individualized program may be offered through remedial teaching in small groups or on a one-to-one basis. The term *continuous monitoring* means that there is a predetermined time plan for repeated evaluation of the child's skills and attainments. This could be at the end of every school term or every academic year or at any other natural transition point in the school system. The scope of what is monitored is also flexible. The areas can cover foundation skills for learning as well as the main curriculum areas that are important for the child to show improvement in school.

The *response to intervention* approach recommends a postponement of diagnosis till after a *proven* intervention has been offered to the child. School under-achievement is a serious possibility for many children, not least because of poor quality teaching and long gaps in teaching input. An essential first step in such contexts is to defer the diagnosis and first arrange for a period of focused teaching support. The essential ingredients of such an approach are laid out in a recent report to the UK government (The Rose Review; 2009).

Models for response to intervention depend on how many layers of support are made available to the child. Each layer of support may be referred to as a "tier" or a "wave". Figure C.3.2 below summarizes three responses to intervention models.

One concern about the response to intervention approach is that it is expensive. Another concern is whether the intervention on offer is indeed the best suited for the child. This is mainly because any intervention, by its very attempt to be focused and specific in its targets, may inadvertently neglect an important domain that needs remediation and skill-building. Thus, an intervention may be focused on reading-related skills while neglecting other skills such as language. If a child has a primary language difficulty, information gained from response to a reading intervention may be misleading. The intervention may simply not have addressed the skills the particular child lacked. Further, core curricular areas such as handwriting, math and expressive writing are often prone to neglect.

Expressive writing

Writing which explores the personal feelings, experiences and opinions of the writer.

Figure C.3.2 Models that allow for assessment of Response to Intervention

Single-tier model: all children receive a fairly long quality program and then assessment is conducted.



Two-tier model: children receive a second intervention if they still struggle some time after a first module.



Three-tier model: children who are below expected level at each tier receive a progressively more intensive remedial program.



Summary

- School underachievement is often the reason for referral to child and adolescent clinics and allied settings. School underachievement is a visible feature for a number of different underlying difficulties.
- A diagnosis of one of the specific learning difficulties is heavily dependent on the educational, socio-economic and socio-cultural context.
- Popular approaches to diagnosis use discrepancy criteria – discrepancy is assessed between a child's age/grade/IQ-expected and actual performance on a specified learning task.
- Such a discrepancy formula is neither informative for intervention nor a description of underlying causes for the difficulty.
- An alternative approach to identification is to allow the child to *first* receive quality teaching (*quality-first*) which can assure the assessor that the symptom picture is not because of lack of opportunity. Following the intervention, those children who remain behind are the ones who qualify for a diagnosis.
- However, the *response-to-intervention approach* can be misleading if the intervention itself is of poor quality or the area of intervention is other than the specific difficulty of an individual child. In such instances measuring response-to-intervention is a futile exercise.

LITERACY LEARNING

Literacy learning is directly dependent on the writing system that a child is taught. Figure C.3.3 shows a map locating some of the scripts in which children are learning to be literate across the world. The map covers the Latin-derived scripts like English, German and French, the Cyrillic scripts of languages like Russian and Ukrainian, the alphabet systems of Arabic and Hebrew, the Asian scripts of Hindi, Bengali and Tamil, the mixed scripts of Japanese and Korean, the Chinese scripts of Hong Kong, Taiwan and other varieties on mainland China, the syllabaries of the native American languages and the *abugida* of Ethiopia. This list is by no means exhaustive (for example, some children are learning through the tactile modality – Braille), but underlines the sheer diversity in scripts and how easy it is to overlook the fact that understanding how specific learning difficulties impact literacy requires an understanding of the writing system of a region. In the following section, we discuss three aspects of writing systems: the direction of writing, the number of symbols in the writing system and the level of spoken language that is encoded in the symbols of the writing system.

Some defining features of writing systems

Writing direction is the reading direction

Modern day writing mostly lays out the symbols left to right (e.g., Bengali, English, German and Tamil), right to left (e.g., Arabic, Divehi, Hebrew and Urdu) or top-down (some forms of Chinese and Japanese). But there are several other symbol arrangements that are possible and that have been used successfully by literate societies down the centuries. Figure C.3.4 below gives two examples of symbol arrangements, no longer in use, but used by large communities for several centuries. Literacy instruction for these ancient writing systems would have perhaps focused on ensuring that learners understand the logic of the writing direction.

Figure C.3.3 A selection of scripts in which children gain literacy



Source: Wikipedia GNU free documentation license.

Figure C.3.4 Writing direction in the ancient scripts of early Greek and Egyptian Hieroglyphic.



One can only speculate on what the clinical picture of a specific literacy difficulty might have been in these contexts!

Writing systems have a symbol register

The symbol units in English, French and Italian are called *letters*, the Bengali, Hindi and Tamil symbols are called *akshara* and the Chinese symbols, *characters*. The symbol sets in each of these and other systems have unique contours and visual features that distinguish them from others.

The number of symbols in a writing system can be as little as in the 20s to as many as 2500 or more. We refer to the small symbol registers as *contained orthographies* and those with hundreds of symbols as *extensive orthographies*. The European languages for example have symbol sets of less than 35 and are examples of contained systems. The Asian alphasyllabaries, with 300+ symbols, and the Chinese systems, with 2000+ symbols, are extensive systems. The pace of learning the different number of symbols varies as a consequence. Among contained systems, children quickly master the basic symbol set, typically within one school year. Among the extensive systems, new symbols continue to be learnt in middle and high school, and beyond. Any attempt at making comparisons about symbol learning across the two types of writing systems is therefore not straightforward. And, as can be expected, when symbol learning demands are different, there is a knock on effect on how word reading, spelling, reading comprehension and expressive writing are developed within each system.



Click on the picture to access a website with a fascinating collection of scripts down the ages.

The differences between contained and extensive orthographies have another outcome that is of direct interest to understanding children who fall behind in literacy. In the extensive systems, because new symbol learning takes place over a protracted period of time, children vary in their level of symbol knowledge in middle school and even high school. Symbol knowledge thus becomes a robust concurrent predictor of individual differences in literacy development (for Indian *akshara* systems: Nag, 2007; for Chinese: Tong et al, 2010). Children who begin with lesser symbol knowledge are less accurate in reading words correctly and quickly (reading accuracy and reading speed). In the contained systems however, knowledge about the small number of symbols is easily gained by all children. Individual variations in letter knowledge disappear after an exceptionally short time, often confined to the first year of literacy instruction. Thus symbol

knowledge (or letter knowledge) is a useful concurrent index for understanding individual differences in literacy attainments only within the first few years of primary school. Nonetheless, symbol knowledge is a *good longitudinal predictor of literacy attainments* in both contained and extensive orthographies; children who are slow to learn the symbols of their language often remain slow in literacy development in the following years.

Writing systems represent sounds

A primary function of written language is to capture the words and meanings of the spoken language. However, writing systems vary in the level at which the symbol units capture spoken language. Below are four examples of differing levels of representation.

- The *alphabet* captures sound at the level of small sub-syllabic sound units called phonemes. English is an example of an alphabetic writing system. The sound /*p*/ for example is represented by the letter *"p"* (*"pin", "pot"* and *"picture"*) and the sound */s/* by the letters *"s"* and *"c"* (*"sun"* and *"sign"*, *"cell"* and *"center"*). In the alphabetic systems, there is thus a correspondence between the symbols (letters or graphemes) and phonemic sounds. Several European languages including Dutch, Finnish, Greek, Icelandic, Norwegian and Spanish, use letters to represent phonemes. Other examples of alphabetic scripts are Hebrew, Arabic and Cyrillic.
- The *alphasyllabary* is another type of writing system. Alphasyllabic scripts have a *dual representation*; their symbols stand for syllable-level sounds such as /ka/ and /ko/ but can be further segmented to reveal the phonemic sound components (called phonemic markers). Thus an alphasyllabic symbol such as /ko/ can be pulled apart to represent which segment of the symbol represents the /k/ and which part the /o/. Several alphasyllabic writing systems are concentrated in and around the South and South East Asia region. These are Indic scripts that have their roots in the ancient Brahmi writing system, and some examples are Bengali, Gujarati, Hindi, Tamil, Thai and Sinhala. Other examples of alphasyllabaries are the *abugida* of Ethiopia and neighboring regions of North Africa, and the writing systems found in the northernmost parts of North America.
- In the *syllabary*, another closely similar writing system, the symbols map onto sounds only at the level of the syllable. The syllabaries are distinguishable from alphasyllabic symbols because they cannot be de-constructed visually below the level of the syllable to reveal smaller sound-bearing features. Examples of syllabaries are the Cherokee script and the Japanese *hiragana*.
- The *character* is the symbol unit of the Chinese writing systems, and is commonly called a *logograph*. The characters represent abstract ideas. They carry specific lexical information, often representing meaningful units of the language called *morphemes*. Thus, the symbols of the Chinese systems are meaning-bearing units rather than merely notations of the sounds of a language, as in the alphabetic, alphasyllabic and syllabic systems described above. Chinese characters, however, have distinct visual features called phonetic radicals which give clues to the sounds that the symbols represent. In other words, the characters of Chinese carry both lexical and phonological information and thus the writing system is more appropriately called a semanto-phonetic or morpho-phonemic.

Alphabetic systems

Writing systems in which letters, symbols or signs, usually arranged in a fixed order, are used to represent one or more phonemes in the language transcribed.

Alphasyllabic systems

Writing systems in which symbols and signs represent sounds at the level of both the syllable and the phoneme.

Chinese systems

Logographic writing systems, in which complex signs or characters are used to represent words or morphemes in the Chinese languages.

Contained and extensive orthographies

Contained orthographies are writing systems in which a relatively small number of symbols are used to represent sounds throughout the language (i.e. alphabetic systems, spanning around 24-36 letters). By contrast, extensive orthographies are writing systems in which a vast number of symbols or characters are used to represent sounds throughout the language (i.e., alphasyllabic systems; the Chinese system – spanning over 2,500 characters).

The cognitive processes that underpin literacy learning in each of the four writing systems described above are subtly different. But there is also growing research evidence to show that there are some commonalities involved in the foundation skills required for learning to read across writing systems. We turn next to describe these skills, as well as to highlight some script-specific cognitive demands.



Click on the picture to access "Developing Early Literacy: Report of the National Early Literacy Panel"

The foundations for learning to read

*Oral language skills are critical for the development of literacy***.** Teachers are often told that it is vital they trust the adage "speaking and listening help reading and writing". This is exceptionally sound advice that has been borne out by literacy research. Children who have better language proficiency in the language of reading instruction are at an advantage. They have more language tools for the task of understanding the written material. Oral language supports several aspects of literacy including decoding words, making meaning of texts, and expressive writing. There is also evidence to show that when teaching specifically focuses on improving oral language, the gains are twofold: children get better at multiple skills associated with oral language *and* they show improvement in their literacy skills.

Oral language is an overarching term for several skill domains, namely *phonology*, *semantics*, *syntax* and *pragmatics*. *Phonology* refers to the speech sound system and how it maps to meaning, *semantics* refers to the meaning relationships between words (how our vocabulary knowledge is structured), *grammar* to the formal structure of the language (syntax and morphology) and *pragmatics* to the use of various cues which make communication meaningful (e.g., use of information, intonation, emphasis and gesture). Each of these skills supports the development of literacy but, among them, phonology has been a lead candidate for defining the core deficit in specific reading difficulties/dyslexia. In this section we discuss semantics, grammar and pragmatics under the umbrella term *broader oral language skills.* We then proceed to examine the role of phonology in more detail.

Morphology
The study of the structure and content of a given language's word forms and linguistic units.

Pragmatics
The study of the use of language in social contexts and the ways in which people produce and comprehend meanings through language.

Semantics
The study of meaning in language.

Syntax
The study of the rules governing the ways in which words combine to form phrases, clauses, and sentences (i.e., grammar).

Broader oral language skills support literacy in various ways, and there is evidence that better oral language skills are associated with better performance on specific sub-components of literacy. It is important to note that we are discussing here the oral language skills that are specifically in the language in which literacy is being taught. When the literacy language is the child's less proficient language then the child may lack these vital strategies.

Word recognition

- *Exception words* are words that do not show predictable symbol-sound associations. Examples of exception words in English are 'knife' with a silent 'k' and 'whistle' with an unusual letter string for the ending sounds. A straightforward decoding strategy cannot suffice and word recognition draws upon broader oral language skills. The role of semantics and syntax (together affording a linguistic context) in learning exception words has been shown in several languages.
- *Polymorphemic words* are words with more than one meaning unit yoked together. Broader oral language skills help decode polymorphemic words probably because better oral language allows children to "see" the embedded morphemic units more readily. Examples of polymorphemic words are

compound words like *butterfly, sunshine* and *somewhat*, words with prefixes like *un-conscious, non-sense* and *poly-morphemic* and words with suffixes like *comb-ing, amuse-ment* and *electri-cian*. A language where lexical compounding is frequent is Chinese. An example of Chinese word formation through compounding is the three character word for *giraffe* (*chang2.jing3.lu4*) which represents the three morphemes *long.neck.deer* (Chenet al, 2009). We now have good evidence to show that those children who have insights into the internal morphemic structure of Chinese words are better at word reading.

- Some languages are densely inflected using many varieties of grammatical markers to communicate meaning. *Inflections* include case markers and person-number-gender markers which are either attached or closely associated with specific nouns, verbs and other grammatical units in sentences. In these languages, knowledge of inflections (inflectional morphology) helps to predict upcoming information in sentences and thus may facilitate word decoding. Examples of inflections in English are the past tense inflection *–ed* (*test- tested*) and the plural inflection *–s* (*result-results*).
- In some languages such as Japanese, the same symbols may change in sound value depending on whether it is a single character word or part of a multi-character word. Thus, the same symbol (called *kanji*) is the first symbol in *flower* and in *pollen*, but they each have a different pronunciation: /*hana*/ and /*kafun*/ (Wydell, 2003). The underlying rule for choice of sound has to do with whether the word is a native Japanese word (called *Kun*-reading) or a loan word from Chinese (called *On*-reading). Such changes in symbol-sound correspondences based on the native-foreign roots of words are seen in other languages as well, such as Tamil and Bengali, and the role of vocabulary knowledge is thus essential to decode the word.
- In some languages such as Arabic, texts for skilled readers do not represent the vowels (*unvowelised writing*). It is therefore the sentence context and broader oral language skills that allows the reader to recognize the word. Indeed, knowledge of morpho-syntax is crucial for reading because when vowel units are left unrepresented in the writing, a given consonant string can stand for any number of words.



Click on the picture to access a website (Reading for Meaning) with activity ideas for an oral language program.



Children's artwork in Arabic, preschool in Indonesia. (Picture: S. Nag).

- In some languages, words with multiple morphemes undergo subtle phonological changes particularly at the point where the morphemes join. In English the suffix *-tion* can cause phonological changes at the boundary – *connect* to *connection, separate* to *separation.* Knowledge of these morpho-phonemic aspects of internal boundaries of words can help decoding.
- Broader oral language skills can help to recognize a word that is proving difficult to decipher using a straightforward phonological decoding strategy. They are particularly used for reading less transparent words, words with multiple meaningful units and lesser known words, for example for learners in a non-dominant language.

Spelling

- In some languages, broader oral language skills (especially morphological knowledge) can help in deciphering the spelling of a word. Thus in English, knowing that *drama* and *dramatist* are morphologically related words, can help spelling them. Examples of other words in English, for which derivational rules make spelling simpler, are words with suffixes *–ment (involvement), –ness (wetness), –ion (connection)*. Morphemic rules are used in word spelling in several other languages including Dutch, Kannada and Arabic.
- In some languages, different word forms are *homophones* (words with same sound but different spelling). It is only knowledge of how morphology maps to the written form of the word (meaning-symbol linkages) that can assure correct spelling. In French for example, conjugations of the verb *manger* (eat) are pronounced in the same manner even though they have different spellings: *je mange (I eat); tu manges (you eat); ils mangent (they eat).* In Cantonese, the syllable */fu/* is written with a different character depending on its tonal value: */fu1/* (skin), */fu2/* (tiger), */fu3/* (trousers), */fu4/* (symbol), */fu5/* (woman) and */fu6/* (father) (Tong et al, 2010).
- Morphological knowledge has been found to be particularly useful in languages such as Arabic, Japanese and Bengali where phonological values of symbols change depending on context. In Bengali for example, word medial consonant clusters are realized in spoken form quite differently from the written spelling - the word *podda* (lotus) is written as *padma* and *sotto* (truth) as *satya*. Knowing the rule that *consonants in word medial positions, even if geminated in spoken form, will be a mixed cluster,* however implicit this knowledge may be, helps in spelling these words.
- The use of morphological knowledge to read symbols is particularly important in morpho-phonetic writing systems like Cantonese and Mandarin. This is because the same tonal syllable in different polysyllabic words can be written with a different character. Take the Cantonese syllable */laan4/.* It has a different spelling (character form) when it represents different meanings such as *block*, *column, orchid, waning* and *wave* (Tong et al, 2010).
- Some words carry unusual internal phonemic changes making spelling these words as demanding a task as reading them. Once again, morpho-phonemic knowledge about word internal boundaries helps in the decoding of such words.



Chinese is an example of an extensive orthography.

Reading comprehension

- Reading comprehension is closely linked with listening comprehension; therefore, children with better oral language skills are better at reading comprehension. Broader oral language skills help extract context-related information. Both context and word-level meanings combine to support comprehension of the written text.
- Individual words may carry both meaning and grammar-related information (morpho-syntactic information). In such instances, greater awareness of the roots and inflected markers for various grammatical functions has been found to be associated with better reading comprehension. In Kannada, a language of South India, the phrase *biijagaLu nungidanu* (swallowed seeds) comprises the following morphemic units*: biija* (noun + plural) *nungu* (verb + past, masculine, singular, 3rd person).
- Sentence processing depends quite critically on the mechanism of prediction. When children have a better idea of sentence structures they are better able to comprehend what they read. Better knowledge of syntax and grammar can therefore help to more accurately predict, and thus more quickly recognize, upcoming words in a sentence. For example in English, when there is an accurate interpretation of the word order, reading comprehension is supported.

Each of these interactions between broader oral language and the sub-components of literacy are critical right from the outset of literacy and are likely to affect literacy learning into adulthood. For example, findings from a survey of close to 40,000 households in the US found that young adults between the ages of 21 and 25 years who struggled with reading comprehension were also poor in spoken language tasks.

Mappings between cognitive domains support literacy development

The process of learning to read entails becoming skilled at mapping the symbols of the writing system (orthography) on to the sounds that they represent in the language (phonology). In addition, written words and sentences need to be mapped on to meanings (semantics). The schematic drawing in Figure C.3.5 is a simple illustration of how the three cognitive domains interact. Skilled reading, spelling and expressive writing require that connections across the domains are accurate and efficiently executed. For example, the process of decoding words commonly requires linkages to be made between orthography and phonology: from symbols to sounds for reading, and sound to symbols for spelling. But in many languages, such as Arabic, Bengali, Chinese, English and Tamil, the same symbol may have different sounds depending on the context in which it appears. In such cases, decoding additionally requires making links between orthography and semantics+grammar. These different types of links across multiple domains are the "glue" that hold written and spoken language together.

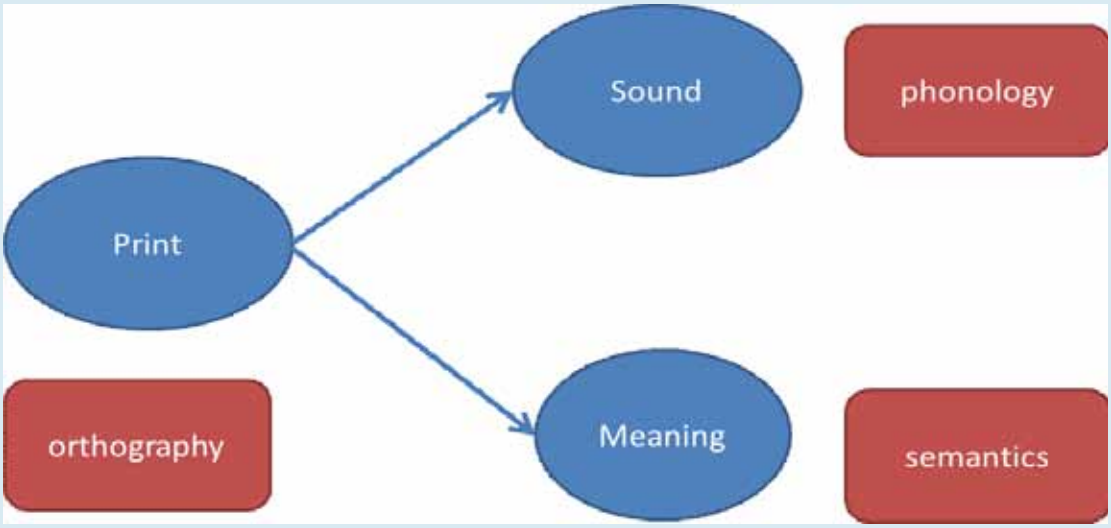
Transparent writing system
A writing system in which only one letter (or symbol) is used for each phoneme (e.g., Finnish).

Opaque writing system
A writing system in which single letters (or symbols) can represent multiple phonemes (e.g., different vowel sounds in the English language), or where a single phoneme can be represented by multiple letters (i.e., *c* and *k* in the English language).

Mappings between phonology and orthography

The linkages between phonology and orthography are more or less predictable in different writing systems. For example, if we take the letter string "*tea*", in English it means a hot beverage and the written word maps on to the spoken syllable */te/*. In Finnish, the same letter string "*tea*" is a name, and is sounded out exactly as it is written, making it a two syllable word */te/+/a/*. The

Figure C.3.5 A schematic representation of three cognitive domains involved in literacy.



difference between English and Finnish is one of "transparency", which refers to that feature of writings systems "where it is approximately true that individual letters correspond reliably to individual sounds" (Seymour, 2005 p299). Finnish is a *transparent language* whereas English is an *opaque language*. Other examples of transparent languages are Italian, Serbian, Kannada and Divehi, while examples of more opaque languages are Bengali, Danish, Portuguese and Urdu.

We now know that when the mappings are regular, consistent and hence transparent, children learn to read faster. One of the biggest cross-linguistic studies to confirm this was initiated by a network of European researchers, the COST A8 Consortium (1995-1999). The COST A8 Consortium assessed children in grade 1, who were under what the authors called "standard teaching conditions" for the particular country (Seymour, 2005). Children were asked to read aloud lists of words and non-words (letter strings that are not meaningful). While decoding of words can draw upon both sound-symbol linkages as well as semantic knowledge, reading of non-words cannot draw upon meaning or context related strategies, and is thus often considered a pure indicator of phonological decoding skills, requiring detailed knowledge of what sounds the individual letters map on to. The comparison across countries confirmed the advantage that transparency of a writing system brings to the process of learning to read. In the more transparent languages, children in grade 1 were already accurate more than 90% of the time when decoding words. On non-words too these children were high in their accuracy, reading more than 80% of items on the list correctly. The exception was English, where the inconsistency of the mappings slowed down children's mastery of decoding skills. Their accuracy rates fell to below 40%.

Decoding skills

Skills necessary to analyze and correctly interpret the graphic symbols of a familiar language (e.g., the ability to connect a printed word to the spoken word it represents).

The languages compared by the COST A8 Consortium were all contained orthographies with symbol sets between 24 and 32 symbols. Similar effects of transparency on reading accuracy are also seen in the extensive orthographies. In a comparison of adult Hindi-Urdu bilinguals for example, reading was faster

and better in Hindi (more transparent) than Urdu (less transparent) (Rao et al, 2011). In another comparison between two Japanese scripts, a similar difference was found between the more transparent Hiragana and the less transparent Kanji (Chen et al, 2007).

There are a number of possible explanations for the differences in speed and accuracy observed across writing systems:

- Transparent writing systems allow for ease of assembling sounds because once the individual symbols are decoded in these systems, a mere assembly of the sounds will reveal the word. The less transparent systems on the other hand need other layers of knowledge to work out the word. The phonological assembly route to decoding and the route via other layers (usually lexical) broadly differentiate the more and less transparent systems.
- The processes involved in learning about the mappings between symbols and sounds differ. This is a slightly different learning challenge from the end-processes that support decoding outlined above. Transparent systems have a straight forward mapping which allows for faster grasp of the symbol-sound linkages. This is essentially statistical association learning between visual and verbal codes. Less transparent systems require many more instances of exposure to learn the variations in the system. In other words, it is easier to learn that the sound of "*p*" is always */p/* (transparent) than to learn that the sound */ai/* may be represented though */i/*, */eigh/*, */ai/* or */aye/* (not transparent).

The role of phonology in literacy learning

Phonological processing skills refer to knowledge about the sounds of a language and the skill to manipulate these sounds. An example of a phonological skill is the ability to drop the first sound in words like "*meat"* and "*shut"* (to get *"eat"* and *"ut"*), or the skill to replace their first sounds with "*l"* (thus *"leat"* and *"lut"*). There is good evidence from across languages and different age groups that learning to read continuously draw upon such phonological skills. In turn, developing reading skills re-shapes phonological skills. Awareness of phonemes, for example, is a robust predictor of single-word reading attainment in several alphabetic and alphasyllabic languages – for example, English (Muter et al, 2004), Arabic (Abu-Rabia et al, 2003) and Kannada (Nag, 2007). Importantly, difficulties with phonological skills are a defining characteristic of many poor readers, in different types of writing systems and languages and across age groups into adulthood.

What is the reason for such a close associations between phonology and literacy? First, writing systems directly represent phonology and hence learning to read immediately draws upon this cognitive domain. Second, in the process of reading, the segmental units in spoken sounds become better represented because the symbols are visual representations of phonological units. However, the level at which the specification occurs varies across writing systems because, as discussed above, writing systems differ in the level of spoken language they represent:

- For alphabetic systems, the specification is at the level of the phoneme.
- For alphasyllabic systems, the specification begins with the syllable and moves onto the phoneme.
- For Chinese systems, the specifications are mainly at the level of the syllable.

Visuo-motor skills and visual processing skills

These are two areas that have not been included in the schematic diagram in Figure C.3 5. There is, however, reason to believe that both of these skills are important foundation skills in the visuo-spatially complex writing systems such as the Japanese *kanji*, the Chinese systems and perhaps also some of the Indian alphasyllabaries. Research in this area is ongoing but initial data from both cross-sectional as well as longitudinal studies suggests that visuo-motor skills and visual processing skills are associated with individual differences in reading skills (Nag & Snowling, 2010; Tong et al, 2010; McBride-Chang et al, 2005; Wydell, 2003).

Summary

- Typical literacy development draws upon multiple cognitive domains. Of these, phonology, vocabulary and syntax, as well as the skill for mapping efficiently between visual and verbal codes, are the best researched foundation skills for literacy development
- When the symbol system is visuo-spatially complex, visual processing skills appear to be important predictors of early literacy attainments
- Children are learning to be literate in a variety of orthographies and these writing systems differ on several counts including the number of symbols they carry and the level at which they represent spoken language. The cognitive demands of learning to be literate are therefore subtly different in each writing system
- However, behind the script-specific details are some common cognitive processes that are essential for literacy learning in all writing systems. These critical foundations include oral language skills and skilled mapping between sounds and symbols.

Table C.3.2 opposite lists the broadly similar foundation skills across writing systems, but note the specificities of each of the typologically very different systems.



School, Maputo, Mozambique.
Photo: Peter Reid

Table C.3.2 Foundation skills are broadly similar across writing systems.

	Arabic[1]	Kannada[2]	Chinese[3]	English[4]
Phonological skills	Phonemes	Syllables and phonemes	Syllables and lexical tones	Phonemes
Orthographic knowledge	Letters and diacritics, symbol form according to position in word	Akshara, diacritics and ligaturing rules, knowledge of akshara-syllable mappings	Characters, phonetic radicals, knowledge of specific characters for homophones	Letters and legal letter sequences
Sound-symbol mappings	Level of word & morphemes especially for unvowelled text and homographs	Level of syllable, phoneme and onset-coda	Level of word, morpheme, syllable and phonetic radicals	Phoneme and rime level
Vocabulary knowledge	Knowledge of inflections, derivatives and compounds	Knowledge of derivational morphology, morpho-phonological rules in polymorphemic words	Knowledge of homophones, structure of polymorphemic words and rules of lexical compounding	Knowledge of exception words, inflections, derivatives and compounds
Grammar knowledge	Knowledge of markers for case, person, number, gender, awareness of agreement features	Knowledge of markers for case, person, number, gender, awareness of agreement features	Knowledge of acceptable word order	Knowledge of tense markers, constraints of word order

Note: based on work by Elinor Saiegh-Haddad[1], Sonali Nag[2], Catherine Mcbride-Chang[3] and Margaret Snowling[4]



Ancient rock art and inscriptions, Edakkal, India. (Picture: G. Arulmani)

LITERACY DIFFICULTIES

In this section we will review what we know about literacy difficulties: how common are they in the population, what their clinical picture is and what we know about their etiology. We will also discuss current trends in assessment and intervention. The literacy difficulties we focus on are not just limited to those children who fulfill the criteria laid out in the diagnostic manuals. We also focus on children who are in the mild to moderate range for literacy delays, reflecting the knowledge that reading (and spelling) is a continuous trait. This is in keeping with the view that both the risk factors for specific learning difficulties and the manifest clinical picture are dimensional in nature rather than simple, categorical entities (see Chapter A.3).

Epidemiology

Information from epidemiological studies helps us understand how common a particular difficulty is by checking its frequency in a population. Such studies also gather information about the distribution of the problem – whether it predominantly occurs in a particular location, in which age groups the problem is observed, what are the circumstances under which the clinical picture changes, and whether there are differences in occurrence over time. Analyses of this kind help us gain a better understanding of the multiple factors that shape the manifestations of a difficulty, as well as to develop appropriate policies for people who are affected.

A review of published epidemiological studies suggests similar trends across countries; this is not surprising since prevalence rates depend upon the precise criteria used to define these disorders and different studies tend to adopt similar cut-offs – e.g., lowest 5% or 15%: USA (Shaywitz, 1998), India (Nag, 2000; Nag & Snowling, 2010). Accordingly, narrow band definitions of reading disorders based on conservative cut-offs place the prevalence rates of specific learning difficulties between 4% and 8%. In contrast, broad based surveys that identify poor readers *due to multiple underlying causes* show prevalence rates of up to 18%. Incidence rates appear to increase over the early school years, with estimates showing a peak around the end of primary school (age 8-10 years), and new "cases" continuing to be identified through middle and high school, higher education and beyond.

The components of literacy that are prioritized for surveillance of literacy difficulties change over the school years, usually reflecting prominent concerns of community leaders, parents, teachers and clinicians for each level of schooling (see Box in next page). In the primary school years, the focus is on children's difficulty with word-level decoding skills. By middle school, in addition to the children who already show an early disadvantage because of poor word decoding attainments, a second group of late-emerging poor readers also begins to be identified. These are poor readers with more or less adequate word-level decoding skills but substantially poor reading comprehension skills. From this level of school onwards, difficulties with spelling and expressive or narrative writing also attract diagnosis. In older children, adolescents and adults, more "cases" may be identified depending on the formula adopted by the particular survey for categorizing low achievement. However, when a consistent cut-off is used, estimates appear to be more stable. For example, in a longitudinal study over a three year period, the number of poor readers was 16% (Vellutino et al, 2008) though this need not imply that the same children are affected at each stage.

An example of a framework for monitoring reading attainments: The SACMEQ* II surveys

A group of countries in Africa have been conducting cross-national surveys since the 1990s. Called the *Southern and Eastern Africa Consortium for Monitoring Educational Quality* (SACMEQ), the group comprises the ministries of education in southern and eastern Africa[1]. Given below are the levels of reading assessed in the SACMEQ II Surveys (2000-2003):

Level 1. **Prereading**: matches words and pictures involving concrete concepts and everyday objects.

Level 2. **Emergent reading**: matches words and pictures involving prepositions and abstract concepts; uses cuing systems to interpret phrases by reading forward.

Level 3. **Basic reading**: interprets meaning (by matching words and phrases completing a sentence) in a short and simple text.

Level 4. **Reading for meaning**: reads forward and backward to link and interpret information located in various parts of a text.

Level 5. **Interpretive reading**: reads forward and backward to combine and interpret information from various parts of a text in association with (recalled) external information that completes and contextualizes meaning.

Level 6. **Inferential reading**: reads through longer (narrative, expository) texts to combine information from various parts of a text to infer the writer's purpose.

Level 7. **Analytical reading**: locates information in longer (narrative, expository) texts to combine information to infer the writer's personal beliefs (value systems, prejudices, biases).

Level 8. **Critical reading**: locates information in longer (narrative, expository) texts to infer and evaluate what the writer has assumed about both the topic and characteristics of the reader (for example, age, knowledge, personal beliefs, values).

*SACMEQ member countries are Botswana, Kenya, Lesotho, Malawi, Mauritius, Mozambique, Namibia, Seychelles, South Africa, Swaziland, Tanzania (mainland), Tanzania (Zanzibar), Uganda, Zambia, and Zimbabwe.

Multiple contexts

Epidemiological data are sensitive to local conditions. For example, in an epidemiological survey in the city of London, UK, the prevalence of dyslexia was put at 3% in the metropolitan area while in another survey using exactly the same tools and criteria for identification, prevalence rate was 6%. The second survey was in the more deprived inner city schools (for a review see Rutter & Yule, 2006).

A similar picture of the impact of socio-economic disadvantage is available from surveys in the Southern Indian city of Bangalore where socio-economic circumstances were more crucial in explaining prevalence rates than children's language of literacy learning. Among schools catering to families belonging to the middle socio-economic classes and offering reading instruction in a non-dominant language (English), the prevalence rate was 18%. However in an institutional home for children in conflict with the law who were learning to read in their home language (Kannada), the prevalence rate jumped to 60% .

It is important also to note that most currently available epidemiological information is from high income countries. What this means is that data come from a particular type of schooling environment that typically subscribes to a mono-grade organization and strict age-grade stratification, class sizes are small to moderate and teacher: student ratios are healthy. Many of these schools are able to offer literacy instruction in the child's home language, or have well developed

bridge programs for transition from the home language into the school language. However, in many low and middle income countries, school arrangements may be quite different. Schools may have multi-grade classrooms (e.g., children between the ages of 5 and 8 studying in one group, with instruction spanning grades 1 to 3). Age range within a class may be quite large. For example, in a survey of about 8000 children in Uganda, the average age in grade 3 was around 10 years and the age range was between 6 and 15 years (UNEB, 2008). Schools may be informal or non-formal, with school timing being customized to the target group in the region (e.g., children who work with their families for a living). In these countries, the language of literacy instruction is often not the same as the home language, and language programs to ease the transition into the school language may be by-passed. In addition, teacher: student ratios may be unreasonably large (even up to 1:120 in some cases). It is clear that in these settings, prevalence rates cannot be easily predicted from what is documented in high income countries.

Further complicating the picture are the multiple sources of influence on the pace of literacy learning. The nature of the writing system, the child's proficiency in the language of literacy instruction and the effectiveness of the instruction program can all change the rate at which children become skilled in literacy. The variable trajectories of literacy learning need to be factored in when making definitions of who has a literacy difficulty. Table C.3.3 lists some of the parameters that can change the estimates of school learning and therefore define the local conceptualization of school underachievement.

Table C.3.3 Some influences on the pace of literacy learning.

Parameters that can influence the pace of learning	Likelihood of longer learning time
• Are the links between the symbols and the sounds clear and consistent? • Is the writing system transparent or opaque?	• With opaque writing systems (e.g., Portuguese, English, Japanese kanji, Tamil, Bengali, Arabic, Hebrew)
• How many symbols are there in the writing system? • Is the symbol set contained or extensive?	• With extensive writing systems (e.g., Chinese, Indian akshara)
• What is the morpheme length of most words in the language of literacy?	• When words contain many morphemes and there are word internal changes either at the level of one morphemic unit or a morpheme boundary
• What are the types of inflections in the language of literacy?	• With less productive inflections, greater distance between agreement features
• Is literacy learning occurring in the first, second, third or another later-learnt language for the child?	• When literacy is in the less dominant language (e.g., in many parts of the Asia Pacific, Africa and Central Europe)
• Is the child learning to read in more than one language? • Is the child receiving literacy instruction to become bi-scriptal or multi-scriptal?	• When literacy instruction is simultaneous in more than one language (e.g., many parts of South Asia)
• Is the literacy instruction of appropriate quality and adequate duration?	• With poor quality teaching and insufficient duration of teaching
• Is the home and community environment nurturing of literacy?	• In non-nurturing environments for literacy development

Epidemiological data not available

It should be clear by now that the cut-offs used for epidemiological surveys of literacy difficulties are externally defined by the context, and rates reported from epidemiological studies in one context must be interpreted cautiously in other contexts. Keeping this in mind, we suggest that it is best to begin with a brief survey in locations where epidemiological data are not available. A survey can help to understand the local prevalence rates of the literacy difficulty in different age bands and its distribution across locations (e.g., public vs. private schools, mother tongue schools vs. other language schools, poorly functioning schools vs. well functioning schools). The following are examples of tools for surveys:

- Progress in International Reading Literacy Study (PIRLS) – Student Questionnaire (2001)
- The Child Development Index (Nag & Arulmani, 2006 p30). This questionnaire is for village community workers.

Clinical picture

Dyslexia

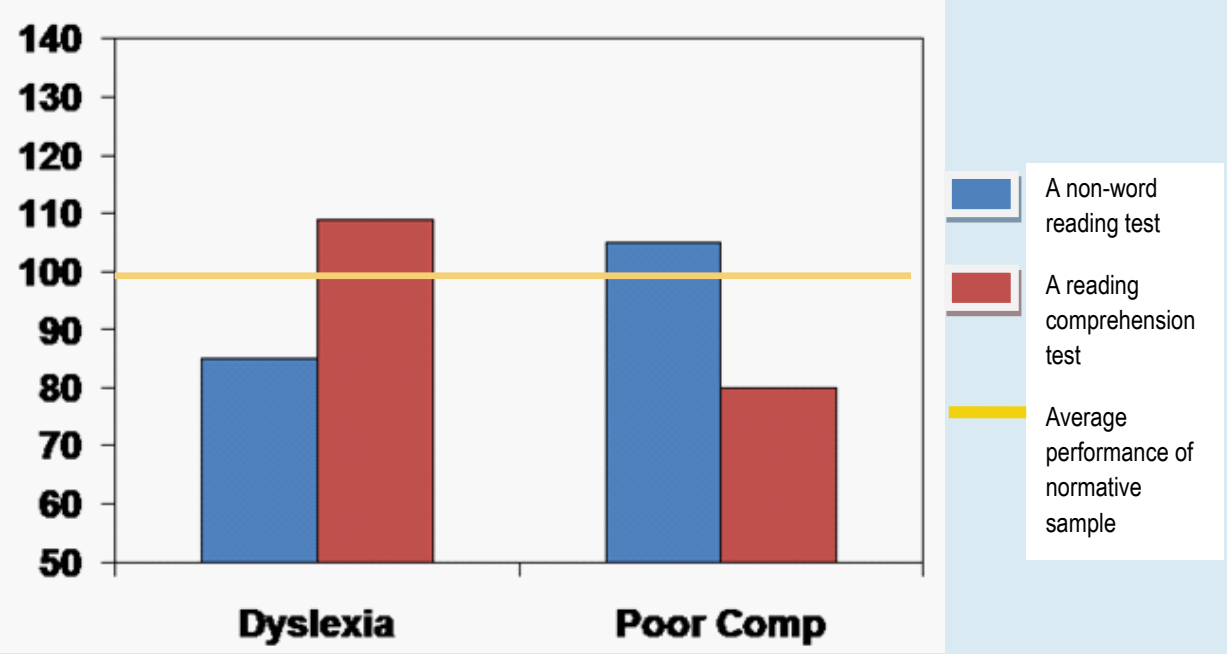
Although dyslexia was originally described by medical practitioners who focused on what they considered to be visual impairments, a landmark review pointed also to a variety of verbal deficits (Vellutino, 1979). In due course, and with evidence from several strands of research principally with alphabetic languages, the verbal deficit hypothesis evolved into the now dominant view that the core deficit in dyslexia is in the *phonological domain* and encompasses overlapping difficulties in phonological awareness, phoneme segmentation, phonological memory and phonological learning (Vellutino et al, 2004). Finally, though not yet fully understood, are deficits in *rapid automatized naming*, which requires the efficient retrieval of phonological codes (verbal codes like letter sounds, number and color names) from their visual forms (letters, digits or color swatches). Rapid automatized naming deficits have been found in semanto-phonetic Chinese scripts like Cantonese and Mandarin, the alphasyllabic scripts like Kannada and Korean and alphabetic scripts like Arabic, English, German and Greek.

An explanation of dyslexia that is entirely drawn from within the phonological domain is, however, insufficient to cover the range of deficits found among poor readers, particularly in the non-alphabetic writing systems. Ho et al (2002), for example, found that 50% of all poor readers were slow in rapid naming, 39% and 37% showed lowered orthographic processing (symbol awareness) and visual processing respectively, and 15% were poor in phonological processing. In a similar multi-factorial explanation for reading difficulties for Kannada, a language of South India, Nag and Snowling (2010) found that all poor readers were poor in symbol knowledge (in this case *akshara* knowledge), 62% were slow in rapid automatized naming, 60% were poor in phonological processing, 14% in visual processing and 62% in oral language. Findings from surveys such as these strongly endorse a multiple-deficit view of reading difficulties (Pennington, 2006). It is clear from these and several other cross-linguistic studies that explanations of poor reading, reading difficulties and dyslexia have to take into account domains of oral language, attention and visual processing and orthographic knowledge.

Two distinct forms of reading difficulty. In dyslexia the clinical picture is characterized by *compromised decoding skills while comprehension skills are intact* (either appropriate or above expectation for the child's age, grade or general abilities). There is however a second group of struggling readers who are poor in reading comprehension. While their decoding skills are appropriate for age, grade and general ability, they lag behind in comprehension skills. Figure C.3.6 below shows the difference in the attainment profiles of the two groups. There is converging evidence from several cross-linguistic studies that such discrete profiles are often seen among poor readers. This suggests a double dissociation between phonological skills for reading (decoding) and semantic skills for reading (comprehension).

A dimensional view of dyslexia. Figure C.3.6 presents reading difficulties as a modular phenomenon. There are however several challenges to such a neat, categorical view of dyslexia and literacy difficulties. The field of behavioral genetics has shown that genes have rather general effects and hence are unlikely to produce such neat dissociations with any frequency. Furthermore, single-deficit accounts fail to explain why some children succumb to reading impairments while others, with similarly affected processes, do not. Moreover, literacy difficulties show continuities with language impairments and co-morbidities are common. It is against this background, that the proposal of a dimensional view of developmental disorders has been made (see Hulme & Snowling, 2009 for a review). Developing this line of argument, a recent review in the UK concluded that dyslexia is a dimensional disorder with no clear cut-offs (Rose, 2009). Co-occurring difficulties include problems with language, motor co-ordination, mental calculation, concentration and personal organization, though it must be noted that none of these are, by themselves, markers of dyslexia.

Figure C.3.6 Two distinct attainments profiles: Children with dyslexia and poor comprehenders (Poor Comp).



A corollary of this view is that whether or not a child develops dyslexia depends both on the number of risk factors a child carries and their severity. Thus, mild phonological deficits may be easily compensated. However, more severe phonological deficits will impact on phonological decoding skills and spelling accuracy. More information for a multi-factorial understanding of the dimensions and risk factors in dyslexia comes from surveys. In Chinese, Ho et al (2002) found that more than 50% of poor readers had cognitive deficits in three or four domains while less than 25% of poor readers had difficulty in just one domain. Similarly, for Kannada, Nag and Snowling (2011) found that 13.8% of all poor readers had deficits in the five domains examined in the survey: oral language and speed of processing, and the orthographic, phonological and visual processing domains.

Developmental Trajectory. It has been known for many years that dyslexia runs in families and recent studies suggest there is about a 40% risk of dyslexia in first degree relatives. Although debated, there appears to be a greater likelihood of a boy being affected than a girl, perhaps because dyslexia is associated with developmental language problems which are more common in males. Although dyslexia is most usually diagnosed in middle childhood it is clear from longitudinal studies that its effects are evident as early as age three and persist through adolescence into adulthood. Table C.3.4 shows the risk factors for dyslexia at different stages of development.

Children with reading comprehension impairment

These children (sometimes referred to as *poor comprehenders*) have a pattern of reading difficulty that contrasts sharply with dyslexia. They can read words and

Table C.3.4 Risk factors and behavioral symptoms indicative of dyslexia at different developmental phases.

STAGE OF DEVELOPMENT	RISK FACTORS FOR DYSLEXIA
Birth	• Affected family member
Preschool	• Late talker • Speech difficulties • Slow to learn colors and letters
School entry	• Poor knowledge of letters • Poor rhyming or phoneme skills
Middle school	• Expressive language difficulties • Small sight vocabulary • Problems reading novel words • Spelling difficult to decipher • Poor written expression • Verbal working memory impairments
Secondary school and beyond	• Low level of reading fluency • Spelling problems • Written work below expectation based on verbal performance • Inattention • Poorly developed study skills • Often academic self-esteem is low

spell words accurately but have problems understanding the meaning of what they read. The poor comprehender's profile can be seen on its own or in combination with other disorders, for example, autism, when the term "hyperlexia" is sometimes used. As a group, poor comprehenders have been much less studied than children with dyslexia and the condition is not well recognized by teachers even though, in alphabetic contexts, studies suggest that between 6% and 10% of primary school pupils appear to be affected (see Hulme & Snowling, 2010 for a review). Reading comprehension impairment may therefore be considered a "hidden" disability associated with underachievement.

Given that the specific problems experienced by poor comprehenders are in reading for meaning, it is not surprising to find that their language skills are weak in relation to non-verbal intelligence. In contrast to dyslexia, they show normal levels of phonological awareness, rapid automatized naming and phonological learning but they have difficulties with semantic processing and in grammatical skills. They also show a range of difficulties in higher-level text processing, such as problems with making inferences, especially across large sections of text where verbal working memory is involved, knowledge of story structure and comprehension monitoring. The findings of a small number of prospective longitudinal studies of poor comprehenders suggest that their cognitive profile is stable over time and the skills which they bring to the task of reading include well developed phonological skills coupled with vocabulary impairments.

In the proposed DSM-5, reading comprehension difficulties are simply listed as a symptom of language impairment, rather than as a disorder per se, a decision which has caused consternation.

Turning to *bilingual and multilingual children*, we now know that some aspects of the broader oral language develop faster than others in the languages learnt later – sometimes referred to as *profile effects* (Oller et al, 2007). In Spanish-English and Turkish-English bilinguals for example, English vocabulary and the complex grammar such as seen in passive sentences are slower to develop than simple grammar (Bodman et al, 2010; Chondrogianni & Marinis, 2011; Oller et al, 2007). It follows that many children who are learning to read in a non-native language will be at risk of reading comprehension impairment associated with their limited command of the language of instruction. Similar trends were also seen in a recent survey in the UK for the standardization of the *York Assessment of Reading and Comprehension.* Secondary school pupils who had English as an additional language did as well in word-level reading as their monolingual English peers but had significantly poorer reading comprehension. Broadly similar profile effects have been reported among learners of other languages.



Second language

The initial phases of learning additional languages can be slow, leaving many clinicians confused about when to assume that the child will "catch up" and when to assess for dyslexia. For an online resource on issues related to second language learners and the diagnosis of literacy difficulties, click on the picture above.

AETIOLOGY

Dyslexia

It is now well established that reading and phonological skills are *highly heritable* and hence dyslexia runs in families (Pennington & Olson, 2005). A recent behavior-genetic analysis of Chinese-speaking children suggests this is likely to be the case across languages (Chow et al, 2011). Importantly, however, some of the shared genetic variance between twins is due to gene-environment interaction. Thus, the home literacy background provided by more literate parents may foster reading skills, and better readers may themselves actively seek out more literary experiences; it can be expected that such gene-environment interactions will play out differently in low and middle income countries.

Studies of the molecular basis of genetic influences on reading have used a variety of methods. To date, the strongest evidence for linkage with dyslexia (in terms of number of replications) is a site on the short arm of chromosome 6, and currently molecular biologists are having some success in identifying candidate genes. It is important to remember, however, that genetic influences are probabilistic; disorders like dyslexia depend on the combined effect of many genes, as well as on environmental influences.

It has been reported that there is a wide range of *structural and functional brain differences* between people with dyslexia and controls and an exciting line of research is exploring whether candidate susceptibility genes for dyslexia are also responsible for subtle cortical abnormalities that are related to neuronal migration and axon growth. The use of neuroimaging to identify which brain systems might be impaired in dyslexia holds great promise, although there are still methodological issues to resolve. For example, if one group suffers from a reading disorder and the other group does not, their performance on reading tasks will differ and so will their reading experience. These methodological problems will be compounded when one considers people who are learning to read in a language that differs from the home language, and people who are bi- or multi-scriptal.

Notwithstanding these concerns, a recent meta-analysis (Richlan et al, 2011) reported underactivation in inferior parietal, superior temporal, middle and inferior temporal and fusiform regions of the left hemisphere in people with dyslexia during reading or reading-related tasks. In addition, there were left frontal abnormalities in the inferior frontal gyrus accompanied by overactivation in the primary motor cortex and the anterior insula. The studies reviewed were from several European languages, the assumption being that these patterns are universal across alphabetic writing systems. At the time of writing, the evidence pertaining to brain activation in dyslexia in non-alphabetic languages is in need of replication. More generally, the causal status of brain differences in dyslexia is debatable; brain development shows considerable plasticity and both its structure and function are shaped by use.



The social and environmental context is a complex, multi-dimensional construct. However, researchers reduce measurement of this construct to a manageable set of measures, common proxies being mother's educational level, enrolment in welfare schemes such as school lunches, and location of schooling, such as the school district and government vs. private ownership of the school the child attends. A good starting point when attempting to understand reading disorders in low and medium income countries is to develop a picture of the social and environmental context. Click the picture above to see a description of the multiple dimensions of social and environmental realities of primary school children in the Southern district of Chamarajanagara in India.

Reading Comprehension Impairment

Much less is known about the etiology of reading comprehension impairment. The gender ratio appears to be more equal than in dyslexia but epidemiological data are sparse. It seems probable, given its association with language impairment, that genetic influences on reading comprehension impairment will be substantial. Preliminary data from behavior genetics suggest this is indeed the case but findings are in need of replication.

Social and environmental influences

Aside from biological and cognitive factors, it is important not to overlook the critical role of the environment in shaping a child's literacy development. Evidence indicates that reading disorders show a strong social gradient and surveys suggest that poor readers often come from large families, where later-born children may face delays in language development. Direct reading instruction in the home is also important, as different styles of home literacy are associated with individual differences in the pre-reading skills which children bring to school (Senechal & LeFevre, 2002). In turn, schooling can make a substantial difference to reading

achievement (NAPE 1999- 2008). In addition to these factors, being a poor reader affects the motivation to read. From very early in development, children differ in their interest in books, and children at risk of dyslexia may well be among those who are more difficult to engage.

One variable that can have a significant impact on the behavioral manifestations of a reading disorder is reading practice which, in turn, depends on "print exposure". Indeed, the effects of low exposure are cumulative, causing differences in reading competence to become magnified over time. While poor comprehenders can read fluently, it is unlikely they will read for pleasure. It follows that low levels of motivation for reading may affect these children as much as children with dyslexia and there will be a wide range of sequelae affecting classroom performance and achievement in school.

In summary, as might be expected for a complex skill such as reading, the etiology of reading difficulties and reading disorders is varied and depends on both genetic and environmental factors. Some children carry a genetic risk of dyslexia but whether or not they are classified as dyslexic depends upon the particular language and school context in which they learn and the other skills (or deficits) they bring to the task of reading. A dimensional view of literacy difficulties moves us to think of the causes of disorders as not just multi-factorial but also as occurring due to the accumulation of risk and protective factors that shape (moderate) its manifestation.

ASSESSMENT

Research from multiple languages has given us insights into the components of literacy and associated cognitive domains that need to be assessed to gain insights into a child's literacy learning difficulties. This section lists these domains and gives examples of tasks that have been shown to be useful for assessment. Where possible, sample items are included. This section does not suggest specific tests. This is because literacy and language tests are useful only if they assess skills and knowledge that are known to be specifically associated with particular writing systems and languages. Moreover, tests are valuable only if they have been locally standardized.

A framework is described in the box below that draws upon a multi-factorial view of literacy development, a dimensional view of learning difficulties and the

A broad framework for assessment

1. Literacy learning occurs within the larger context of language and its functions. Assessment of literacy learning difficulties must cover the sub-skills of language development
2. Literacy learning has multiple foundations. Assessment must be across multiple cognitive domains
3. Criteria for literacy difficulties are moderated by local context. Assessment results must be interpreted in comparison to only those who have closely similar linguistic, socio-economic and teaching histories
4. Dyslexia and learning difficulties are dimensional constructs shaped by multiple factors. Assessment must not only comment on the current clinical picture but also the 'risk' and 'protective' factors concurrently documented.

acknowledgement that the cut-off for diagnosis is externally negotiated based on the local context. Apart from these theoretical underpinnings, it is also important to recall two trends in diagnosis: the use of discrepancy criteria is increasingly falling out of favor and the use of a response to intervention approach is particularly relevant when children have had low opportunity for quality instruction.

A comprehensive assessment of literacy needs to document attainments in component skills such as:

- Letter knowledge
- Reading accuracy
- Reading speed
- Reading comprehension
- Spelling accuracy
- Rate of writing, and
- Quality of written expression.

On the other hand, an assessment of the supporting foundations for literacy needs to cover both language and cognitive domains. The language domains of interest are the broader skills associated with semantics, morphology, syntax and pragmatics as well as the more basic skills associated with phonological processing. Other domains of interest are general abilities and non-verbal processing, visual processing and speed of processing. There is increasing evidence that learning difficulties co-exist with other difficulties (comorbidities). Should there be any indication of additional areas of difficulty, these too need assessment.



Click on the picture to access a Special Issue of the Journal of Pediatric Psychology on ADHD, its co-morbidities and links to school underachievement (open access).

A final point has to do with sources of information about these domains. A prudent approach would be to *collate information from multiple sources* rather than depending on a single source or test. Table C.3.5 gives the domains that must be assessed and Tables C.3.6 to C.3.8 show the tasks that can be used.

Ideas for assessment of general cognitive and perceptual skills

General abilities

Culture fair tests are difficult to find. The test with the most widespread use currently is the Raven's Progressive Matrices.

Speed of processing

This can be done with a collection of tests that time children's performance, such as visual search or coding from the Wechsler tests. More specific tests linked to literacy performance include the rapid automatized naming task and timed tasks of phonological manipulation (examples in Table C.3.7).

Visual processing

The use of visual processing tasks in literacy assessment is gaining interest for languages with extensive, visuo-spatially complex symbol sets. There are several ways in which visual processing has been assessed. One set of tasks targets visual short term memory, where children have to recall just shown visuals of different orientations and degree of detail. Another set of tests assesses visual sequential memory where strings of visuals are shown and children have to recall the target string from a set of distracter sequences.

Table C.3.5 Areas of assessment that are of diagnostic importance

LITERACY SKILLS	PHONOLOGICAL PROCESSING	BROADER ORAL LANGUAGE	OTHER AREAS	POTENTIAL CO-MORBIDITIES
• Symbol knowledge • Reading accuracy • Reading speed • Spelling • Reading comprehension • Expressive writing - quality and rate	• Phonological awareness • Syllable processing • Phoneme processing • Verbal short term memory • Rapid automatized naming	• Vocabulary • Grammar knowledge • Knowledge of inflections	• General cognitive abilities • Speed of processing • Visual processing	• Attention deficits • Speech sound disorders • Numeracy difficulties • Motor coordination difficulties • Anxiety symptoms

Table C.3.6 Sample tasks for assessment of literacy skills.

Symbol Knowledge: assessed by giving a list of the symbol set of the writing system.	
	• For contained orthographies all symbols are shown. • For extensive orthographies, symbols are chosen according to some agreed criteria. For the akshara languages for example, the list may be sets of Ca, CV and CCV symbols.
Reading and Spelling accuracy: assessed using both lists and sentences.	
	• Word can be graded for frequency, regularity and length of words. School textbooks can sometimes be a good source for constructing these tests. • If words in the language require oral language skills for accurate decoding (see examples in pgs 12-13), consider adding such words as a subset in the list. • Non-word lists can be developed by changing one or more symbol units in words.
Reading speed: typically assessed as number of words correctly read per minute.	
Reading comprehension: assessed using single sentences and longer passages.	
	• Both factual and inferential questions are necessary. • Asking to give a title to a passage is a useful way to capture comprehension. • Using multiple choice questions is a useful way to capture comprehension if children are reticent or not very fluent in the language (e.g., with second language learners).
Expressive writing: assessed using narrative skills on a prescribed topic or a self-chosen topic.	
	• Rate of writing – number of words per minute. • At the word level, writing may be assessed for spelling, use of particular grammatical structures like adjectives, connectors and determiners and use of dialect words. • For the narrative, assessment parameters include sequencing, style and usage.

Table C.3.7 Sample tasks for assessment of phonological processing

Phonological awareness: assessed using segmentation and blending tasks.

Sample: Break up 'lomputer' into small sounds. Response expected from child: 'lom-pu-ter'

Sample: Join the following sounds: 'gu – ha – na'. Response expected from child: 'guhana'

Phonological processing: assessed by asking child to manipulate a target sound. Sample of syllable and phoneme processing tasks using non-words:

Type of Task	Arabic	Bengali	Chinese	English
*Deletion of initial syllable**				
Target item	*wahid* - /wa/	*baro* - /ba/	*t*úsh*ū*- /tú/	*fifty* - /fif/
Expected response	*hid*	*ro*	*sh*ū	*ty*
*Deletion of initial phoneme**				
Target item	*wahid* - /w/	*baro* - /b/	*t*úsh*ū*- /t/	*fifty*- /f/
Expected response	*ahid*	*aro*	ú*sh*ū	*ifty*
*Deletion of final phoneme**				
Target item	*wahid* - /d/	*baro* - /o/	*t*úsh*ū*- /ū/	*fifty* - /y/
Expected response	*wahi*	*bar*	*t*úsh	*fift*

*may also be administered as a timed task for additional information about speed of processing

Verbal short term memory: assessed by asking child to repeat 2 to 5 or 6 just heard items

- Non-word repetition using syllable strings (e.g., *supila, mantockvip*, *kavasinuta*).
- Digit span using numbers (e.g., *2-9, 2-5-8, 4-6-9-2*).
- Word span using early acquired words (e.g., *pen, leaf, cup, tin*).
- If using digits and words, items should be similar in length (e.g., all bi-syllabic).

Rapid automatized naming: assessed by asking children to read out quickly a neatly laid out set of digits, symbols or colour swatches.

- If using digits and colours, items should be similar in length (e.g. all bi-syllabic).

Attention

Many children with ADHD read well, though some experience problems of reading comprehension owing to its working memory and executive demands. However, there is a strong tendency for dyslexia to co-occur with symptoms of inattention and recent genetic data suggest a common genetic basis. It follows that it is important to make an assessment of a child's ability to control and sustain attention. Ideally, information should be sought from parents and teachers and in this regard rating scales are popular. The Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) includes 5 questions pertaining to attention and can provide a screen for "hyperactivity" and poor attention. It is also useful to supplement these data with behavioral observation in the classroom.

Developmental coordination disorder

A developmental disorder in which children fail to develop normal motor coordination in the absence of general learning difficulties. The disorder can affect both fine and gross motor skills, and is present despite the individuals having had similar opportunity to gain motor skills as their peers.

Motor coordination

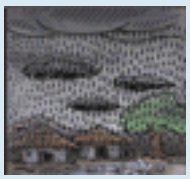
Developmental coordination disorder (also called *dyspraxia*) is one of the most common co-morbid conditions of childhood. Its nature and developmental

Table C.3.8 Sample tasks for assessment of broader oral language skills

Vocabulary: assessed by asking for picture names or definitions **(expressive vocabulary);** vocabulary knowledge can also be assessed using picture-word matching (**receptive vocabulary**)

- Word lists must be graded for age of acquisition, concrete and abstract words, and frequency.
- A scheme for scoring child's response: errors (Sc = 0), passive use of word in idiomatic language (Sc = 1), use of word in sentence form (Sc = 2), definition, equivalent word from another language (Sc = 3)
- If using pictures, trial for cultural appropriateness and clarity of illustrations. See example below, target item is 'rainy'.



Grammar knowledge: assessed using a variety of tasks, three are listed here.

- Sentence Repetition task: children are asked to repeat a just heard sentence (e.g., Item: '*the cats ran to the milk store'* Child's response: '*Cat run to milkshop')*
- Grammaticality Judgement task: give a mix of grammatically correct and incorrect sentences and ask child to identify which one is in error.
- Pointing to pictures (receptive task, useful for reticent children, second language users and children with working memory difficulties): have a set of four pictures broadly linked to a sentence. Call out sentence and ask child to point to the most appropriate picture.

Knowledge of Inflections: assessed by focusing on inflections in stimuli given to the child

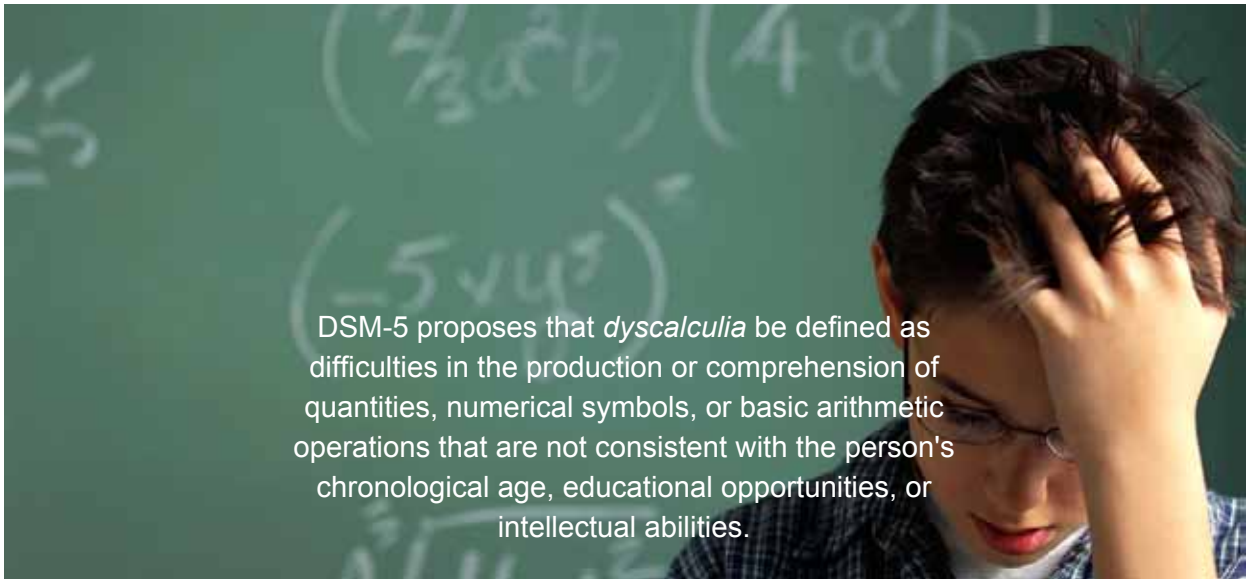
- The sentence repetition task can be used to pick out omissions, substitutions or additions of inflections (e.g. the child drops plural *–s* in the 'cat' item given above)

Sentence stubs can be used for prompting inflected words. (e.g. to elicit past tense –ed inflections: '*I like to paint. Yesterday I _____ (painted)*'.

course together with procedures for assessment and treatment are described in this document. The Dyspraxia Foundation also has a useful website for professionals and families. It is possible to use the information in these two resources to develop a checklist which will be useful in the community being served (be it pre-school, primary or secondary level). In terms of behavioral assessment for a suspected co-morbidity with specific learning difficulties, it is important to make an assessment of pencil control, quality of writing and copying skills. For the older child, producing complex diagrams (e.g., in science) and using scissors and other tools (e.g., for project work in middle school, in vocational courses that are oriented to fine motor skills such as carpentry and in design & technology courses) may pose a problem.

Number skills

DSM-5 proposes that *dyscalculia* be defined as *difficulties in production or comprehension of quantities, numerical symbols, or basic arithmetic operations that are not consistent with the person's chronological age, educational opportunities, or intellectual abilities*. When numeracy is an issue for a child, it is important to know if their difficulties are associated with number facts and their manipulation



(arithmetic) or with more abstract mathematical thinking. Many children with dyslexia struggle to learn number facts, especially multiplication tables, but may be good mathematicians. In contrast, the poor comprehender profile has been reported to be associated with poor mathematics in the face of well-developed arithmetic skills. It follows that both aspects of numeracy should be assessed. DSM-5 advocates that multiple sources of information be used to assess numerical, arithmetic, and arithmetic-related abilities. Where standardized tests are not available, it is possible to devise short age-appropriate tasks to tap basic arithmetic facts, simple addition and subtraction and verbally posed mathematical problems for solution. The website "About Dyscalculia" provides ideas for observations teachers can make in the classroom.

Anxiety and coping

Many children with specific learning difficulties experience anxiety in the classroom and, for some, this may contribute to a more general anxiety disorder. Similarly, self-esteem is lowered as a consequence of literacy problems since these can affect performance in most areas of the curriculum. The SDQ (Goodman, 1997) is a useful tool for understanding children's emotional and behavioral difficulties. This is a 25 item questionnaire covering emotional behavioral problems, conduct problems, hyperactivity/inattention, issues with relationships especially with peers and the strength of positive social behaviors. There are translations of this questionnaire in several languages, and importantly, SDQ is an open access tool (see also Chapter A.5).

Some practical questions

When a child is taken for assessment, some key requirements are the availability of skilled professionals, reliable testing tools and quality support services; in many middle and low income countries, access to all three of these basic requirements is either patchy or minimal. This is problematic because a poor quality assessment has the potential to mislead or, worse, cause harm to the child. The most worrisome contexts are where children live in exceptionally deprived circumstances, school systems do not recognize the learning difficulties, parents and community elders are unaware about the disorder and provisions and

Table C.3.9 Five questions to ensure ethical practice in the assessment of school underachievement

Is there a collective understanding of the:

- Authorized person who can diagnose?
- Professional protocols for assessment and diagnosis?
- Classification system and/or diagnostic manual to be followed?
- Reliability and validity of the tools being used?
- Follow-up support that will be offered?

hence cannot advocate for the child, professional training programs do not give up-to-date details about literacy difficulties and their assessment and there are no standardized tests. Table C.3.9 shows a set of questions that can be asked in such situations. Articulating answers for these questions can help set the agenda for developing an assessment system for screening and identification of specific learning difficulties in communities where such a practice is not yet mature.

The move is towards resource intensive assessment devices. A gold standard for assessment is an individually administered test that has sound psychometric properties. This is often an expensive proposition, requiring not just theoretical expertise but also large numbers of personnel to collect and analyze the standardization data. Many middle and low income countries are nowhere near developing such tests.

A first step could however be to *develop informal graded tests.* These tests are based on locally sourced materials which are not expensive to collate (e.g., textbooks, recordings of children's speech and local stories). The types of tests could be around the tasks suggested in Tables C.3.5 to C.3.8. These informal tests can begin to reveal children's profiles of strengths and difficulties and allow for the first level of identification. More importantly, these tests can give a wealth of information for developing focused interventions.

A second step would be to *identify who are the most vulnerable.* This can be done through collecting local data and using an arbitrary cut-off. A useful cut-off for identifying the most vulnerable is to pick all those children whose scores fall below 1.5 standard deviations of the mean score on a test. An even more stringent cut-off may be preferable in unstable contexts (e.g., frequent school closure, recently changed language of instruction, a recent traumatic event in the region like a war or natural disaster). The local data can be from a selection of schools and the main expense here is the mass production of the tests and time needed to prepare, administer, score and identify the mean scores and standard deviations for each test.

A logical next step would be to *develop standardized tools*. Such an enterprise should follow from a theoretical model of how literacy is acquired in the language of interest, and a good grasp of the sample characteristics of the region. In contexts where standardized tests have been developed, it is useful to remember that norms change over time and hence, tests should be reviewed *periodically for relevance.*

INTERVENTION

A good starting point for developing an intervention is an understanding of the causes of a reading disorder. Indeed targeting impaired processes provides the motivation for the design and content of an intervention.

For the alphabetic languages, a number of meta-analyses have guided the development of good practice for the teaching of reading, notably that of the US National Reading Panel and by the National Early Literacy Panel. In turn, there are now a growing number of evidence based interventions for dyslexia; a useful website from the UK is Interventions for Literacy, with intervention ideas for children struggling to read in English, both when this is their home language (English as first language) or a non-dominant language (English as second language).

For lower and middle income countries a good understanding of the principles of interventions and their suitability for different children is the first step to indigenous programs. Snowling and Hulme (2010) reviewed the ingredients of evidence-based interventions for language and literacy difficulties, and this can be a good starting point for developing local interventions. Principally it is good practice to ensure that interventions:

- Are systematic, well-structured and multi-sensory,
- Incorporate direct teaching-learning,
- Incorporate a good amount of time for consolidation,
- With frequent revision, to take account of the likely limited attention and learning difficulties of the child.

For dyslexia in the alphabetic languages, effective interventions should include training in letter-sounds, phoneme awareness, linking letter and phonemes through writing and reading from texts at the appropriate level to reinforce emerging skills. In contrast, poor comprehenders require a different "diet" attuned to their needs and can benefit from training in oral language skills particularly vocabulary training, the development of inferencing skills and work on story structure and narrative. Of course it is important to bear in mind that many children will have problems with decoding and comprehension, in which case a mixed approach is needed.



Unfortunately, the field of dyslexia is plagued with advertised "cures" which have no evidence base. It is therefore important for professionals to critically review the content of programs to ensure their suitability. Click on the picture to access a video by Professor Dorothy Bishop which provides good advice in this regard.

Websites with ideas for intervention

- Preferably, intervention should be delivered early, focusing on building the foundations for literacy development in the early childhood years. This Nuffield Foundation website gives ideas for intervention in a pre-school setting, but can also be adapted to informal groups in the community and within the home
- Interventions for children in primary school can be either in a group setting or one-to-one. The website Reading for Meaning gives ideas that can be quickly adapted to different languages and writing systems
- Involving parents in supporting their children's literacy development at home is good practice. This DysTalk video provides ideas as to what might help both in pre-school and after school entry. Although the video focuses on alphabetic contexts, the principles are useful for non-alphabetic writing systems also. The key assumption is that parents have a level of literacy and financial resources to try out these home-based ideas
- These documents from The Promise Foundation give examples of low cost interventions in pre-schools, primary schools and the community: Handbook on Prevention of Child Labour for Anganwadi Workers and Handbook on Prevention of Child Labour for Village Community Workers.

Role of visuo-motor training for visually complex characters

Some writing systems have more detailed characters than others and hence writing them requires very well-developed visuo-spatial and motor skills. It has been suggested that repeated writing of orthographic symbols, for example kanji for children in Japan (Wydell, 2003) and akshara for children in southern India (Nag, 2011) is good practice. Children in these languages may also benefit from practice of motor sequences for writing a symbol/ word: in Japan called KUSHO – 'writing in the air', in India, writing in sand or traditionally in plates of grains. These techniques find their parallel in Western cultures in the *Fernald method* of teaching which involves tracing letters, which experimental studies have shown to be effective.

Summary

- Dyslexia and comprehension impairment are dimensional constructs similar to obesity, hypertension and many other disorders. In other words, the presence of literacy difficulties is along a continuum of severity and the most severe among them qualify for a diagnosis as formulated by the diagnostic manuals.
- Prevalence across countries range from 4% to 18% depending on the definitions used and the cut-off set. Epidemiological data are, however, extremely sensitive to location and definition; in places where there is no local data available a useful first step is to gather prevalence data. This will help to clarify the frequency of the difficulty, its distribution and what is the nature of the services that need to be planned.
- Spoken language is a foundation for reading and literacy. Language skills may also be an important compensatory resource for children with poor phonology (dyslexia). Interventions that target broader oral language in early childhood and primary school years can strengthen compensatory resources.

SCHOOL UNDER-ACHIEVEMENT SECONDARY TO OTHER DISORDERS

Childhood psychiatric disorder

An epidemiological survey of 1403 children between the ages of 8 and 12 in the Southern Indian district of Calicut (Kerala State) showed a prevalence of childhood psychiatric disorders of 9.4%. There were strong associations with socio-economic parameters but, more importantly, with both general school underachievement and specific difficulties with reading and vocabulary (Hackett et al, 1999). For the city of Bangalore, prevalence was higher: 13 % for psychiatric disorders among 4 to 16 year olds; up to 10% showed scholastic difficulties and up to 2% showed co-occurring psychiatric disorder and school underachievement (Srinath et al, 2005). Studies in other countries have also shown an association between literacy difficulties and childhood psychiatric problems. One reason why academic underachievement may co-occur with psychiatric disorder is because of the disorder interfering with school attendance. Other reasons could be symptoms of the disorder disrupting concentration during lessons, study time and exams. Some of the main reasons for dropping school grades are transient adjustments and

post-traumatic stress disorders. These may follow life experiences such as abuse, the loss of a parent or events such as war or natural disaster.

Neurodevelopmental disorders

Neurodevelopmental disorders (formerly known as developmental disabilities and mental retardation) are a related group of conditions associated with learning disabilities and school underachievement (see also Chapter C.1). The prevalence of learning and developmental disabilities in high income countries is between 10% and 20 % while in low and middle income countries prevalence may be higher (Durkin et al, 2005). The trends in increasing prevalence rates in developmental and associated learning disorders in high, medium and low income countries may have different origins. In high income countries, there is a discernible growth in recognition of developmental disorders and increased awareness in the general public, a notable example being the autism spectrum disorders. For middle and low income countries, two different social health care processes have been unfolding: on the one hand, there has been a definite reduction in child mortality but, on the other, there are multiple disadvantages experienced by children. As a consequence, more children are at risk for developmental disorders generally, and for learning difficulties specifically. Given below is an illustrative list of neurodevelopmental sources for school underachievement:

- *Genetic:* chromosomal disorders such as Down's syndrome, segmental autosomal syndromes such as Prader-Willi syndrome, and autosomal dominant neurocutaneous syndromes, such as neurofibromatosis
- *Nutritional:* such as iodine deficiency and vitamin A deficiency
- *Prenatal or perinatal infection*s such as toxoplasmosis, rubella, group B streptococcus and HIV
- *Postnatal or childhood infections* such as encephalitis, meningitis, cerebral malaria, polio and otitis media
- *Toxic exposure in the prenatal period* to alcohol, lead and mercury, and to drugs taken by mother such as antimicrobials (e.g., sulfonamides, isoniazid, ribavirin), anticonvulsants (such as phenytoin, carbamazepine), and other (such as thalidomide). Lead and mercury exposure continues to be dangerous in the post-natal and childhood period
- *Brain injuries* caused by premature birth and birth asphyxia
- *Other forms of traumatic brain injuries* caused by accidents, child abuse and neglect
- *Chronic disadvantage* from poverty, economic backwardness, severe malnutrition, continuous social deprivation and absence of cognitive stimulation.

Sensory impairment

Sensory impairments are one of the most obvious causes of educational underachievement. Although problems of vision or hearing are easy to notice when severe, like learning difficulties, they manifest along a continuum of severity and subtle impairments can slip recognition. For example, about 10% of all primary school children in low income communities have eyesight problems (Bundy et al, 2003), and many among them go undetected. In such undiagnosed cases, children

DSM-5

Click here to access the whole range of neurodevelopmental disorders proposed for DSM-5

may be underachieving at school because the primary difficulty with vision has escaped notice. Therefore, at a systemic level, the urgent issue is to inform parents, teachers and children about sensory difficulties (watch *Nanna Kannu* (My Eyes) to see an example of a sensitization program targeting children in Southern India).



Nanna Kannu (My Eyes), Kannada with English subtitles (5:00). Click on the picture to view a video clip to help children talk about their vision difficulties (from Southern India).

Vision

A simple fact is that properly fitted eyeglasses (spectacles) can in most cases correct poor eyesight. Eyeglasses also indirectly help in school achievement. One large-scale study of eyeglasses intervention documented this knock-on effect on school performance, showing that children who were given glasses "were less likely to fail a class" (Hannum & Zhang, 2008). However, access to intervention can be a challenge with very few children actually getting spectacles in some exceptionally poor or marginalized communities. For these children, vision problems go undetected because screening programs do not cover their communities; even if the vision difficulty is detected, the benefits of treatment may be lost because eyeglasses are simply unaffordable. The accumulated impact of uncorrected vision on school achievement for such children is substantial.

Moreover difficulties with vision may be accompanied by subtle cognitive impairments. Children with *convergence insufficiency* for example experience blurred vision, double images, headaches and eye fatigue when reading and writing (see case vignette).

Convergence insufficiency

An inability to focus both eyes simultaneously on a single point at a close distance, over a sustained period of time. Typically, one eye will turn outward when focusing on a word or object from closer than a certain distance.

Hearing

Hearing problems, like visual impairments, have both direct and indirect effects on school attainment. If children are unable to hear what their teacher says and is in too big a class for lip-reading to be useful, then they will be left behind in all areas of the curriculum. More subtle impairments will affect attention to auditory information and the development of literacy skills. While in high-income countries (e.g., Norway, UK) many children with congenital hearing impairments are now fitted with bilateral cochlear implants, which significantly improve their hearing and consequent language development, neither screening nor implantation programs are widespread in low and middle income countries. Less severe problems, including conductive hearing loss, may also go unattended.

As discussed above, phonological skills are a foundational skill for word decoding. It can be inferred that children who are hearing-impaired will be at high risk of reading problems. However, being hearing impaired does not automatically imply that children will be limited in their ability to reflect on the sounds of the language (Leybaert, 2005). Instead, individual differences in phonological processing depend upon the availability of speech skills and communication experiences. Early childhood experiences can either have a high emphasis on auditory input, amplification, speech reading and cueing (*oral-aural mode*) making optimal use of the residual hearing available to the child, or in the use of gestures, signing and finger spelling in conjunction with speech and audition (*total-communication mode*). It appears that phonological skills are slow to develop among children exposed to the *total-communication mode* when compared to children exposed to the *oral-aural mode*. These differences are independent of the type of writing system the child is learning to read – e.g., the alphasyllabic orthographies (Vasanta, 2007), the alphabetic scripts (Nielsen & Luetke-Stahlman,

Penn Population Aging Research Center

Poverty, vision difficulties and learning

Click on the picture to access findings from a survey in rural China. Similar trends have been reported in several other low income communities.

Case Vignette: Vision difficulties and school under-achievement

NT began avoiding books in pre-school. He particularly seemed to avoid reading under bright lights ("I really like working in the dark… mostly I don't like tube light"). It was sometime before a specialist recognized that NT had convergence insufficiency – a disorder of near vision where the two eyes have a strong tendency to drift outwards rather than to come together and work as a team. If both eyes do not aim at the same spot, many activities become difficult – including reading and writing.

NT began exercises to help both eyes cooperate; by grade 5 the convergence difficulties had begun to improve. NT reported "I am no longer seeing double" when reading "very small words"'. However, subtle difficulties with school work remained. The first assessment for school underachievement showed NT was reading more than three years below his grade level. Simultaneously he was showing significant anxiety. The challenge at this stage was to identify if school under-achievement was stemming from the vision difficulties, the severe anxiety, or an independently occurring dyslexia or language impairment which had gone undetected. The source of NT's reading difficulties became clearer over time. Two years later, with anxiety substantially under control, his delay in literacy attainment continued. When reading he showed low accuracy, particularly for unfamiliar words ("phonograph" red as "photography"). However, on phonological tasks his performance was above average for phoneme segmentation, deletion and substitution. This (among other tests) confirmed that literacy difficulties were not because of poor phonological-decoding skills, and thus ruled out dyslexia. In addition, his grasp of grammatical structures as well as vocabulary was ahead of his age and grade, ruling out difficulties subsequent to language impairment. With the contribution of anxiety controlled for, the assessment confirmed the presence of learning difficulties secondary to vision difficulties.

As is the case with many learning difficulties, the domains of difficulty persisted into high school. At age 16, NT's reading accuracy for low frequency words was low, with a reading delay of 2 years. Further, he read approximately 105 words per minute and, when tired, less than 70. This reading speed is exceptionally slow: by 13 to 15 years of age, a range of 170 to 200 words per minute is expected. NT's cognitive attainments were also uneven. On a standardized test (WAIS II), NT was exceptional in verbal comprehension (93rd percentile), average in working memory (55th percentile) but borderline in processing speed (just 4% of children were below his score). The processing speed tasks in WIAS II are similar to passage reading because both need continuous visual tracking and thus a convergence of both eyes. Clearly, NT was still poor in this skill. NT needed extra support to help him face exams in high school (grades 8 to 12). He received a comprehensive report which was then used to win for him extra time during exams. The table below summarizes how his scores improved with 70% extra time.

Task	15 min timed test	With extended time
English language questions	• Completed 50% of test • Performance at 57%.	• Needed 10 minutes extra • Performance now at 70%.
Analytical-logical questions	• Completed 50% of test • Performance at 43%.	• Needed 12 minutes extra • Performance now at 90%.

NT will continue needing help beyond school, whether he attends university or other further education institution. Educational courses have critical activities in which a student must show competence. NT would do well to choose a higher education course – ideally one which draws upon his interests and aptitudes but is not particularly dependent on visual tracking and high quality convergence. He will also need to plan his study time in such a way that he is not reading (or performing other eye coordination activities) for a long time because this will compound his eye fatigue and slow him down. Finally, he would benefit from extra time for exams, especially when a lot of writing is required.

2002). It follows then that the nature of the sensory deficit and the methods of management of the primary sensory impairment can have long term implications on literacy acquisition, and school underachievement.

Summary

- Not all children who present with poor school attainment will have primary learning difficulties. Differential diagnosis is important since learning difficulties may be a symptom of another psychiatric disorder or of a sensory impairment.
- In some countries, school systems have arrangements in place which make allowances for children's learning difficulties and additional needs. These may include extra time during formal assessments, the use of scribes, ability to drop a second and third language in school and to study a simpler course.
- These concessions in the curriculum and for school examinations are meant to ensure that scholastic achievement of children with special educational needs are as close to their true potential as possible.
- Often these provisions are made available to some or all of the following areas of difficulty: sensory impairments, developmental disorders, emotional and behavioral disorders and neurological difficulties.
- These provisions are, however, rarely made available to children with transient adjustment difficulties, victims of natural disasters, or other traumatic situations such as war and civic strife.

CONCLUDING COMMENTS

Classification

- Categories of developmental disorder are underpinned by dimensions and associated "risk factors"
- Dyslexia is a dimensional impairment even though it is often discussed as a diagnostic "entity" with clear-cut boundaries
- Dimensional impairments interact during development to produce heterogeneity within and between disorders
- The reliability of cross-sectional indicators may be less than of longitudinal indicators. It is better to recruit all low performing children into adapted interventions and then to monitor their response to the intervention. Those not catching up to grade level in spite of individualized support would be the ones most reliably diagnosed as with SLD
- Language-based measures, more than intelligence and general processing measures, are better predictors of later literacy difficulties
- There is a need for context-specific assessment tools that are not merely a translation from tools developed elsewhere. Indeed, blind translation of screening tools can seriously mislead diagnosis.

- Language and phonological skills may be taken as the foundation skills for literacy development. When skill and sub-skills in either one of these domains are selectively impaired "compensation" is possible. But the more severe the impairment and the greater the number of sub-skills that are impaired, the more severe will be the literacy difficulty. The profile of difficulty will either be one of dyslexia or a reading comprehension difficulty or a mix of both
- Two aspects of current child development research – resilience and social ecology – have influenced current understanding of what may be the best practices for children in need. Both of these socio-emotional constructs remain crucial in any evaluation and intervention process that have been set up for children with school underachievement and specific learning difficulties.

Instruction

- Quality of instruction in mainstream classrooms decides how many children will fall behind. Thus, with poor quality instruction many more children will fall below a cut-off of attainments
- For many children showing early difficulties, supplementary input and adapted programs can help resolve difficulties. For older children and later emerging difficulties, remedial programs can help
- Quality of instruction in remedial programs also decides how many children will respond to intervention. With poor quality remediation, the preventative role of interventions will be minimal
- Some patterns are visible in the occurrence of co-morbidities between literacy difficulties and other disorders. It is essential to more fully understand these co-occurring difficulties and their implication for instructional programs
- When interventions to promote reading or language are based on a theoretically valid framework this can be effective
- Targeted interventions need to focus on the dimensions that underpin literacy difficulties (broader oral language and phonology).



One language is never enough

To see this sentence written in many of the scripts of the world click on the picture.

What to invest in?

- *A preventative approach rather than a curative approach*. Hence, prioritize quality-first teaching for all, early identification of children whose development is delayed, interventions for children showing mild difficulties which may increase if left unattended and interventions that address the multiple foundations for learning
- *Screening tools*. For literacy difficulties, measures related to language and reading; for math, measures related to reading and number skills
- *Formats for determining risk status*. This is an arbitrary cut-off and may, for example, be any child below the 50% mark for the grade. If there are several children with low attainments, choose a whole class and mainstream an

intensive program

- *An intensive whole class program*. This is not just for the nurturance needed for all children but also because classification is easier if we know that children have received quality intervention and in spite of that they are still struggling
- *Decide on which group will be prioritized for support*. For example, focus could be on children who are on the borderline of underachievement and who will respond to intervention and quickly move out of the "at risk" status. Alternatively, priority could be given to those who are substantially behind and who appear to have long term reading difficulties
- *Format for determining diagnosis*. Mix response to intervention approaches with approaches that depend on discrepancy criteria for diagnosis. Thus if the child remains below grade and age level despite intervention and if the child's cognitive profile is below his peers, then confirm diagnosis of a general learning difficulty (having discounted emotional or behavioral problems)
- *Develop a nuanced picture of the social and environmental context*. This is important, particularly to understand the role of local social deprivation and its impact on attainment in literacy and language.



William-Adolphe Bouguereau (1825-1905) *La leçon difficile* (The Difficult Lesson) Wikimedia Commons

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Paul Mlangasi, a blind teacher, explains a passage in Braille to a young boy at the Wilson Carlile school for blind children at Buigiri, near Dodoma, Central Province, Tanzania. The National Archives UK.



ENURESIS

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Conflict of interest: none disclosed

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Suggested citation: von Gontard A. Enuresis. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Enuresis constitutes a very common group of disorders in childhood that occur world-wide at approximately the same rate. 10% of all 7-year-olds, wet the bed at night and 2% to 3% during the day. Despite a high remission rate, still 1% to 2% of all adolescents are affected by nocturnal enuresis and less than 1% by daytime wetting. The vast majority of elimination disorders are functional, i.e., not due to neurological, structural or medical causes (von Gontard & Neveus, 2006).

Enuresis is associated with emotional distress in both children and parents, which is reversible once children become dry. Achieving continence is therefore the main goal of treatment and will lead to an improvement of self-worth and self-confidence (Longstaffe et al, 2000). On the other hand, 20%-40% of all children with enuresis have additional, comorbid psychological disorders, not only externalising conditions such as attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD) but also internalising disorders such as depression. These comorbid conditions require separate assessment and treatment – in addition to the symptom-oriented treatment of the child's elimination disorder.

Most types of enuresis can be treated effectively with counselling and cognitive-behavioural approaches but some may require additional medication. These therapies can in most cases be provided in primary care outpatient settings – provided that they are based on a correct diagnosis and that child and parents are given adequate professional care with sufficient time. The aim of this chapter is to provide a practical approach to the assessment and treatment of children with enuresis that can be implemented in different settings even in those with limited resources.

DEFINITION AND CLASSIFICATION

Enuresis is defined by both ICD-10 (World Health Organisation, 2008) and DSM-IV-TR (American Psychiatric Association, 2000) as involuntary (or even intentional) wetting in children 5 years of age or older after organic causes have been ruled out. The wetting must have persisted for at least three months to be considered a disorder. According to ICD-10, enuresis is diagnosed if wetting occurs two times a month in children under 7 years of age and once a month in children 7 years and older. The criteria according to DSM-IV is less precise: the voiding must occur at least twice per week or else must cause clinically significant distress or impairment in social, academic (occupational) or other important areas of functioning. Both ICD-10 and DSM-IV-TR describe nocturnal, diurnal or combined enuresis – no other subtypes are included. Also, ICD-10 excludes a diagnosis of enuresis if other psychiatric disorders are present. Both ICD-10 and DSM-IV-TR are outdated and do not reflect newer research findings in this field. Unfortunately, the proposed DSM-5 criteria are not very useful and may even constitute a step back from DSM-IV. The Children's Continence Society (ICCS) (Neveus et al., 2006) has proposed newer, more practical suggestions, which are being revised in 2012. The aim is to provide simple, descriptive clinical terms that can be used in all settings world-wide.

According to the ICCS criteria, *enuresis* denotes an intermittent (i.e., not continuous) wetting during sleep in children after their fifth birthday. The term *nocturnal* can be added for clarity (i.e., enuresis and nocturnal enuresis are

Table C.4.1 Definitions according to the Children's Continence Society

Symptom	Disorder
• Intermittent wetting during sleep • Age 5 or more	Enuresis or nocturnal enuresis
• Daytime wetting • Age 5 or more	Urinary incontinence or daytime urinary incontinence (not "diurnal enuresis"). In most cases functional.

synonyms). Daytime wetting is termed *urinary incontinence*, which can be organic (structural, neurogenic or due to other physical causes) or functional. As the vast majority of cases are functional, most children with daytime wetting would be considered to have some form of functional urinary incontinence. According to these criteria, the term *diurnal enuresis* is obsolete and should be avoided. If children wet during sleep and during the day, they would receive two diagnoses: enuresis *and* urinary incontinence.

The classification of enuresis is simple. Only two aspects need to be considered: the longest dry period and if lower urinary tract symptoms are present:

- *Primary enuresis* means that the child has been dry for less than 6 months (or not at all)
- *Secondary enuresis* means that a relapse after a dry period of at least 6 months has occurred.

The dry period can occur at any age; also, it does not matter if it came about spontaneously or was achieved by treatment. This distinction is important because children with *secondary enuresis* have experienced stressful life-events (such as separation of parents, birth of siblings, etc.) more often and have higher rates of comorbid psychiatric disorders (Järvelin et al, 1990; von Gontard et al, 2011b). These issues have to be considered in assessment and treatment, otherwise the treatment of primary and secondary enuresis is exactly the same.

The presence of lower urinary tract symptoms is more important as it carries implications for treatment. Children who wet during sleep and do not have daytime symptoms suggesting disturbances of bladder function are suffering from *monosymptomatic* enuresis. In other words, they wet at night but bladder storage and emptying is completely normal (i.e., children go to the toilet 5-7 times during the day, do not postpone micturition with the use of holding manoeuvres, do not experience urge symptoms and can empty their bladders without problems). In these cases, treatment can focus on the wetting episodes during sleep without further preliminary procedures.

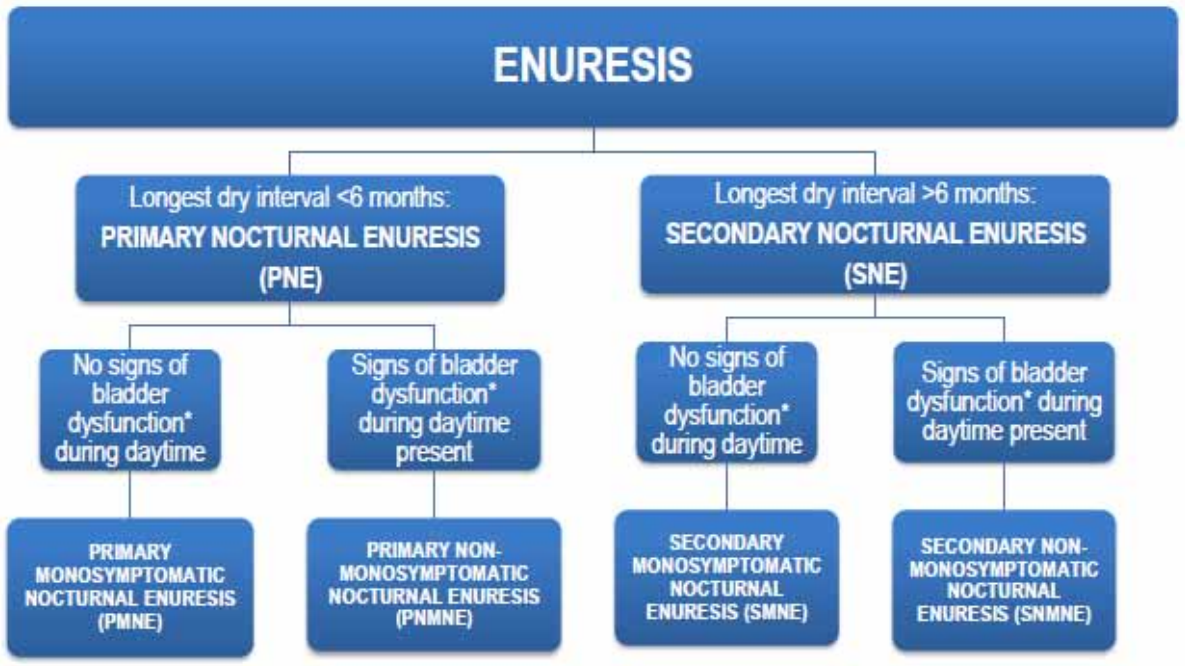
Children who have lower urinary tract symptoms and may have gastrointestinal symptoms, such as constipation and soiling, have *non-monosymptomatic* enuresis. In non-monosymptomatic nocturnal enuresis, daytime symptoms have to be treated first before addressing the night-time wetting. The terms monosymptomatic and non-monosymptomatic are based entirely on history and verified by voiding diaries, i.e., are based on clinical assessment only (von Gontard & Neveus, 2006).



James Joyce wet his bed. The first page of Joyce's *Portrait of the Artist as a Young Man* contains the following: "when you first wet the bed it is warm and then it gets cold. His mother put on the oilsheet. That had the queer smell" (Gill, 1995).

Portrait by Robert Amos
www.robertamos.com

Figure C.4.1 Classification of nocturnal enuresis according to the Children's Continence Society



*Daytime incontinence, increased/decreased day-time voiding frequency, urgency, voiding postponement, holding manoeuvres, intermittent urine stream, interrupted flow, constipation, encopresis, etc.

The classification of daytime urinary incontinence is more complex. Most types are functional – organic urinary incontinence is rare and can be due to structural, neurogenic or other medical causes. The three main syndromes of functional urinary incontinence are:

- Urge incontinence
- Voiding postponement, and
- Dysfunctional voiding.

Rare types include: stress incontinence, giggle incontinence, detrusor underactivity and others. Each one of these types of urinary incontinence has typical symptoms.

Urge:
The strong, sudden need to urinate.

Urge incontinence or overactive bladder is characterised by urge symptoms, increased micturition frequency and small voided volumes. By contrast, low micturition frequency and postponement of micturition is typical in *voiding postponement*. In both cases children employ holding manoeuvres to avoid wetting.

Dysfunctional voiding is a disorder of the emptying phase: instead of relaxing the sphincter muscle, it is contracted paradoxically. Straining and an interrupted urine stream are indicative of this disorder.

Stress incontinence is rare in children – in contrast to adults. Wetting during coughing, sneezing (i.e., any increase of intra-abdominal pressure) and small volumes are typical. *Giggle incontinence* is characterised by wetting during laughing, large volumes with apparently complete emptying. *Detrusor underactivity*, a decompensation of the detrusor muscle, is marked by an interrupted stream; consequently, emptying the bladder is possible only by straining.

Table C.4.2 Classification of daytime wetting (functional urinary incontinence) and key distinguishing symptoms

Type	Key symptoms
Urge incontinence (overactive bladder)	• Urge • Frequency more than 7 times per day • Small volume voided
Voiding postponement	• Infrequent micturition (< 5 times per day) • Postponement
Dysfunctional voiding	• Straining to initiate and during micturition • Interrupted stream of urine
Stress incontinence	• Wetting during coughing, sneezing • Small volumes
Giggle incontinence	• Wetting during laughing • Large volumes with apparently complete emptying
Detrusor underactivity	• Interrupted stream • Emptying of bladder possible only by straining

As daytime urinary incontinence (and non-monosymptomatic enuresis) can be identified by altered rates of micturition frequency and volume, it is helpful to know the normal values (these are only an approximation), which are shown in Table C.4.2. Normally, children void 5 to 7 times a day. The normal voided volume in millilitres can be calculated by adding one to the age of the child and multiplying by 30. For example a normal amount of micturition in an 8 year old child would be: 8 + 1 = 9; 9 x 30 = 270 ml.

Approximate normal values in childhood

Micturition frequency

- 5-7 times per day

Voided volumes

- (age + one) multiplied by 30ml

The aim of treatment is to achieve long-term continued and complete dryness, not just a reduction of symptoms. Regrettably, this is not achieved in all cases; for some children and families, however, a reduction in the frequency of episodes can provide relief and has been shown to improve self-esteem (Longstaffe et al, 2000).

EPIDEMIOLOGY

Enuresis is 2-3 times more common than daytime urinary incontinence; it is 1.5 to 2 times more common in boys than girls. Prevalence of night wetting decreases with increasing age: 20% in 4 year olds, 10% in 7 year olds, 1%-2% in adolescents, and 0.3%-1.7% among adults (von Gontard & Neveus, 2006). Prevalence depend on how enuresis is defined, especially on the number of wet nights required. In a large population study of 8151 children aged 7½ years, 15.5% had nocturnal enuresis (boys 20.2%, girls 10.5%). Frequent enuresis, defined by two or more wet nights per week, affected only 2.6% of them (boys 3.6%, girls 1.6%) (Butler et al, 2005). Primary is more common than secondary enuresis, with comparable rates at the age of 7 years (Fergusson et al, 1986). Monosymptomatic enuresis is twice (68.5%) as common as non-monosymptomatic enuresis (31.5%) (Butler et al, 2006).

Daytime urinary incontinence is 1.5 times more common in girls than boys (Bower et al, 1996; Hellström et al, 1990); 2%-3% of 7 year olds and less than 1% of adolescents wet during the day (Hellström et al, 1990; Largo et al, 1978). In a UK population study of 13,973 children, the rates of infrequent (less than 2 times per week) and frequent (more than 2 times per week) were respectively: 13.6% and 1.9% at the age of 4½; 7.8% and 1.5% at 5½; 9.7% and 1.0% at 6½; 6.9% and 1.0% at 7½; 4.4% and 0.5% at 9½ years (Swithinbank et al, 2010). Different trajectories can be identified:

- Children with chronic, persistent incontinence over many years
- Children with relapses and
- A group with a continuous spontaneous remission rate (Heron et al, 2008).

Urge incontinence is the most common, affecting 4% of 7-year olds, especially girls (Hellström et al, 1990). Voiding postponement is the second most common type based on clinical studies. Population-based rates for the other types are lacking.



Click on the picture to hear two children share their experience of bedwetting.

The prevalence of nocturnal enuresis is comparable world-wide:

- 4.3% of Chinese children and adolescents aged 6-16 years (Liu et al, 2000)
- 8% of children aged 6-11 years in Taiwan (Chang et al, 2011)
- 14.9% of children aged 5-7 years in Turkey (Erdogan et al, 2007)
- 15% of children and adolescents in Saudi Arabia (Kalo & Bella, 1996)
- 17.4% of 7 years olds in Sudan (Rahim & Cederblad, 1986)
- 20.8% of children and adolescents aged 6-15 years in Ethiopia, including daytime incontinence (Desta et al, 2007).

Variation in rates is probably due to different definitions, modes of assessment and possible underreporting due to social desirability, particularly in the Chinese and Taiwanese studies.

Only a few studies have reported daytime urinary incontinence. For example, 16.6% of Korean children aged 5-13 years had overactive bladder, 4.5% daytime incontinence and 6.4% enuresis (Chung et al, 2009).

CLINICAL PRESENTATIONS

Typical symptoms of *monosymptomatic enuresis* are: deep sleep and difficult arousal (Wolfish et al, 1997), increased urine volume at night (polyuria) with large wetted volumes. The typical presentation is a child who is extremely difficult to wake and who wets the bed with large amounts of urine. In contrast, bladder function during the day is completely normal.

Children with a *non-monosymptomatic enuresis* have the same symptoms but, in addition, have signs similar to those with daytime urinary incontinence (except wetting). This means that some go to the toilet infrequently and postpone micturition with holding manoeuvres, others have signs of urgency and frequency, while others have to strain and the urine stream is interrupted. Also, urinary tract infections (UTI's), constipation and encopresis are possible.

Children with *secondary enuresis* have higher rates of comorbid behavioural and emotional disorders (von Gontard et al, 1999). A relapse can be precipitated by stressful life-events such as separation or divorce of parents (Järvelin et al, 1990). Otherwise, they do not differ from those with primary enuresis.

Children with *urge incontinence* are characterised by:

- High micturition frequency (more than 7 times per day with short intervals in between)
- Urge symptoms, sometimes with sudden, intensive urge
- Incontinence with small micturition volumes, increasing with tiredness, e.g., during the afternoon
- Holding manoeuvres such as contracting pelvic floor muscles, pressing thighs together, holding abdomen, jumping from one leg to the next, sitting on heel, squatting with the heel pressed against the perineum (curtsey sign)
- Vulvovaginitis, perigenital dermatitis
- Urinary tract infections

Typical signs of voiding postponement are:

- Low micturition frequency (less than 5 times per day)
- Postponement of micturition in certain situations (school, play, reading, television). With increasing postponement and fullness of bladder, holding manoeuvres are instituted (as in urge incontinence) until wetting cannot be avoided.
- Constipation and encopresis are common.

Voiding postponement is characterised by:

- Repeated straining at the beginning and during micturition
- Intermittent and fractioned urine flow
- Incomplete bladder emptying with residual urine and UTI's
- Stool retention, constipation and encopresis
- Vesico-ureteral reflux.

Clinical symptoms of *stress incontinence* are wetting during situations that result in increased intra-abdominal pressure (coughing, sneezing, play and sports). *Giggle incontinence* is associated with cataplexy, i.e., motor contractions can be visible. The incontinence is initiated by laughing and often cannot be stopped until the bladder is empty. Children with *underactive bladder* have infrequent micturitions (less than 5 times per day), a large bladder with incomplete emptying and large residual volumes.

ETIOLOGY AND RISK FACTORS

Genetic and neurobiological factors interact with environmental influences in the pathogenesis of elimination disorders. While some have a marked genetic component (monosymptomatic enuresis and urge incontninence), in others both genetic and environmental factors are involved (secondary enuresis), while some are mostly environmentally determined (voiding postponement).

Enuresis

Enuresis is a genetically determined maturational disorder of the central nervous system (von Gontard et al, 2001; 2011a); 70% to 80% of all children with enuresis have affected relatives. The concordance rates are higher among mono- than di-zygotic twins (Bakwin, 1973). The recurrence risk for a child to be affected by enuresis is 40 % if one parent and 70 % if both parents had been enuretic (Bakwin 1973). Most cases are consistent with with an autosomal dominant mode

The fundamental idea that children willfully control their thought processes during sleep and the proposition that such cognitive control accounts for bedwetting are simply not plausible. If such propositions were true, then why do we have a history of 3,500 years of parents and professionals talking to children about stopping bedwetting with little or no results? The one treatment that we know to work reliably, the urine alarm, does not require cognitive control and most likely works via a process of active avoidance conditioning […] It is disturbing enough to think that talking therapy for enuresis may make a comeback, but it is even more disturbing to consider […] that the most effective treatment known for children's bedwetting is rarely promulgated by our current health care system (Houts, 2000).

of inheritance; only one third of cases are sporadic (von Gontard et al, 2001). Several loci on chromosomes 12, 13 and 22 have been identified in linkage studies – irrespective of the type of enuresis (von Gontard et al, 2001). Candidate genes have not been identified yet. A genetic predisposition for enuresis remains life-long and can be reactivated by risk factors, even in adulthood (Hublin et al, 1998).

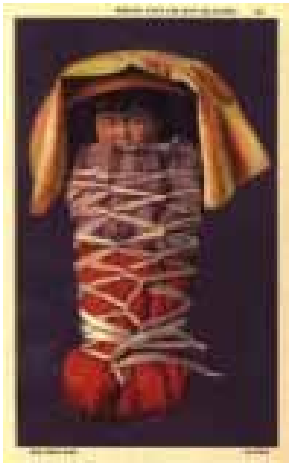
Children with enuresis have more neurological "soft signs" and need longer to complete motor tasks (von Gontard et al, 2006). In contrast, sleep architecture is not affected. Enuresis occurs in non-REM sleep phases, i.e. it is not associated with dreaming (enuresis during REM sleep is the exception). Enuresis occurs predominantly in the first third of the night – some children even wet the bed 10 minutes after falling asleep. The mean latency is 3 hours (Neveus et al, 1999). This explains why some children with enuresis wet even during daytime naps.

The main mechanisms responsible for the development of enuresis include:

- Increased urine volume (polyuria) affects some, but not all children. This is associated with a circadian variation (but not lack) of the antidiuretic hormone (Rittig et al, 1989).
- Impaired arousal is another important factor (Wolfish et al, 1997). In standardised waking schedules with sounds of up to 120 decibels, only 9% of children with enuresis can be woken up – significantly fewer than controls. This means that children with enuresis do not wake up when their bladder is full.
- Finally, children have an inhibition deficit of the pontine micturition centre of the brainstem. When the bladder is full during sleep, they are not able to sufficiently suppress emptying (Koff, 1996).

In addition to local bladder dysfunction, the same factors are responsible for the development of *non-monosymptomatic enuresis*.

Psychosocial factors modulate genetic and neurobiological risks in different ways. The time of initiation and intensity of toilet training, for example, has no effect on the development of enuresis (Largo et al, 1978; 1996). Psychosocial factors play a minor role in primary enuresis, as the rate of psychological disorders and risk factors is not increased (Fergusson et al, 1986; Feehan et al, 1990). Children with secondary enuresis, however, have both higher rates of emotional and behavioural disorders as well as stressful life events prior to the relapse (Järvelin et al, 1990; Feehan et al, 1990). The age of school entry (5-6 years) is the most common age for relapse while parental separation or divorce is the most important life event (Järvelin et al, 1990).



In West Africa, children who wet the bed were "treated" by attaching a large frog to their waist, and this apparently frightened them into being dry. Among the Navaho tribe, one preferred treatment was a ritual that required enuretic children to stand naked over a burning bird's nest, and this was believed to produce a cure of bedwetting because birds did not soil their nests (Houts, 2000).

Urinary incontinence

Genetic factors play a role in daytime urinary incontinence as well. In a population-based study of 8230 children, the odds ratio for daytime incontinence increased by 3.28 if the mother and by 10.1 if the father was affected (von Gontard et al, 2011a). Linkage studies demonstrate a positive linkage to chromosome 17 (Eiberg et al, 2001). Urge incontinence is caused by spontaneous contractions of the detrusor during the filling phase of the bladder, which are not sufficiently inhibited by the central nervous system (Franco, 2007). Genetic factors also play a major role in giggle incontinence but not in the other types of incontinence.

Daytime continence is not influenced by early or intensive toilet training in general (Largo et al, 1996; 1978). However, psychosocial factors do play a major role in daytime incontinence (see section on comorbidity). Voiding postponement can be due to an acquired habit or as one of many oppositional symptoms as part of ODD (Kuhn et al., 2008).

COMORBIDITY

Enuresis

Overall, psychological disorders are 2 to 5 times more frequent in children with elimination disorders. In summary, 20%-30% of children with enuresis, 20%-40% of those with urinary incontinence, and 30-50% with encopresis have clinically relevant comorbid disorders (von Gontard et al, 2011b). Comorbidity rates are highest in children with secondary enuresis – up to 40% in population-based and 75% in clinic-based studies (Feehan et al, 1990; von Gontard et al, 1999). Children with non-monosymptomatic enuresis have more comorbid disorders than those with monosymptomatic enuresis (Butler et al, 2006).

ADHD is he most common comorbid disorder in enuresis. In a population study of 1379 children aged 6 years, 9.4% had clinically relevant ADHD symptoms compared to 3.4% of non-wetting children (von Gontard et al, 2011c). The rate of ADHD in enuretic children presented to a paediatric hospital was 28.3%, compared to 10.3% in a non-selected sample (Baeyens et al, 2006). Enuresis persisted longer in children with ADHD – 2 years later, 65% were still enuretic compared to 37% of controls (Baeyens et al, 2005). Enuresis in combination with ADHD is more difficult to treat due to non-compliance. With alarm treatment, 43% of those with comorbid ADHD were dry (versus 69% of those with enuresis alone) at 6 months and only 19% (versus 66%) at 12 months. The rate of non-compliance was 38% if both enuresis and ADHD co-existed (Crimmins et al, 2003).

Externalising disorders predominate but internalising conditions can also occur. In a British population-based study of 8242 children at the age of 7½ years, those with enuresis also suffered from separation anxiety (8.0%), social anxiety (70%), specific phobia (14.1%), generalised anxiety (10.5%), depression (14.2%), ODD (8.8%), conduct disorders (8.5%) and ADHD (17.6%) (Joinson et al, 2007).

Children with enuresis are not only afflicted with more comorbid disorders, they are also more distressed and show more subclinical symptoms, which often improve upon attaining dryness. Self-esteem can be affected and can improve under treatment – irrespective of treatment success (Longstaffe et al, 2000). Also, quality of life can be reduced by the enuresis (Bachmann et al, 2009). Both children and parents can be distressed by the enuresis.

Daytime urinary incontinence

Comorbidity rates among children with daytime urinary incontinence (30%-40%) are slightly higher than in children with enuresis (20%-40%) (von Gontard et al, 2011b). In a population-based study of 8242 children aged 7 ½ years, externalising disorders were prominent with significantly increased rates of ADHD (24.8%), ODD (10.9%) and conduct disorders (11.8%) (Joinson et al, 2006). In another population study, 36.7% of children with urinary incontinence had ADHD symptoms, in comparison to 3.4% of dry children (von Gontard

et al, 2011c). Adherence to treatment is lower in cases of urinary incontinence and ADHD: only 68% became dry, compared to 91% of controls with urinary incontinence without ADHD (Crimmins et al, 2003).

Children with urge incontinence have lower rates of comorbid disorders than those with voiding postponement (36% vs. 59%) but higher than controls (9%) (Kuhn et al, 2009). Children with urge incontinence predominantly have internalising disorders while the most typical disorder in voiding postponement is ODD (Kuhn et al, 2009). It would appear that comorbid disorders are a consequence of wetting in urge incontinence while ODD seems to be the underlying problem in voiding postponement. Much less is known about comorbidity in the other types of incontinence.

DIAGNOSIS

Assessment and a careful diagnosis are the bases for successful treatment – each subtype of enuresis and urinary incontinence responds best to its specific treatment. Assessment also means building a relationship with the child and parents that will become the foundation for the entire course of therapy. It is therefore advisable to take plenty of time for the first consultation with child and parents. More details on the diagnosis and treatment of all elimination disorders can be found in von Gontard and Neveus (2006), which is still the most comprehensive textbook on the topic, with both background information and practical procedures.

Assessment in enuresis and urinary incontinence

- History
- 48-hour frequency/ volume chart
- Questionnaires
- Paediatric physical examination
- Urinalysis
- Child psychiatric screening or assessment
- Sonography (if available).

Only if indicated

- Urine bacteriology
- Uroflowmetry and pelvic-floor EMG
- Other diagnostic procedures: radiological examinations, invasive urodynamics, cystoscopy, etc.

Most of the diagnostic process is based on simple, good clinical practice that can be delivered in most primary care settings. The most important step is a good and thorough history. The history will lead the clinician towards possible diagnoses which need to be followed up and enable the exclusion of many other conditions. An example of a detailed history with pertinent questions can be found in Appendix C.4.1.

Frequency-volume chart

The second most important step is a 48-hour frequency-volume chart. Parents are asked to observe, record and measure over 48 hours when and how much their child voids and drinks, as well as associated symptoms such as incontinence, holding manoeuvres, etc. Parents can be given a simple plastic measuring cup (which they will return at the next visit and that can be used many more times). This chart gives essential information for the diagnosis. In urge incontinence, for example, a micturition frequency of over 7 and small volumes (of 20-60ml) are typical; in voiding postponement, some children void only 2 or 3 times a day with large volumes of 400ml or more. Also, drinking habits can be assessed: most children with elimination disorders do not drink enough fluids (some only 400-600ml), while polydipsia is extremely rare. Most parents are not aware of their child's voiding and drinking habits and will not be able to provide this information when asked. An example of a chart is presented in Appendix C.4.2.

Questionnaires

Specific enuresis questionnaires are helpful to confirm and augment the information children and parents provide (see Appendix C.4.3). The 48-hour volume/frequency chart, however, is far more important than a questionnaire.

Physical examination

Each child should be examined physically at least once at the beginning of treatment. It is essential that organic causes of incontinence are ruled out. A full paediatric and neuorological exam is recommended. Children with daytime incontinence may require several examinations in the course of treatment, especially if UTI's and other complications occur. For most children with enuresis, especially with monosymptomatic enuresis, one exam will suffice.

Investigations

At least one urinalysis (with a urine stick) is recommended to be sure that no signs of bacteriuria and manifest UTI are present. This is especially important in daytime urinary incontinence; it is usually negative in children with monosymptomatic enuresis.

If available, sonography is a very useful, non-invasive tool. In addition to the detecting structural anomalies of the urinary tract, sonography can give valuable information regarding three functional changes:

- A thickened bladder wall (> 2.5mm) can be indicative of a hypertrophy of the bladder wall as a sign of bladder dysfunction or it can be due to UTI's
- Residual urine (>20ml) can be indicative of incomplete bladder emptying; and finally,
- An enlarged rectal diameter of more than 25mm can be a sign of stool retention and constipation.



Click on the picture to hear two mothers share their experience of bedwetting

However, even in Europe, sonography is not easily available in many countries and thus not routinely performed in children with enuresis and urinary incontinence. In complicated cases with recurrent UTI's it is definitely indicated.

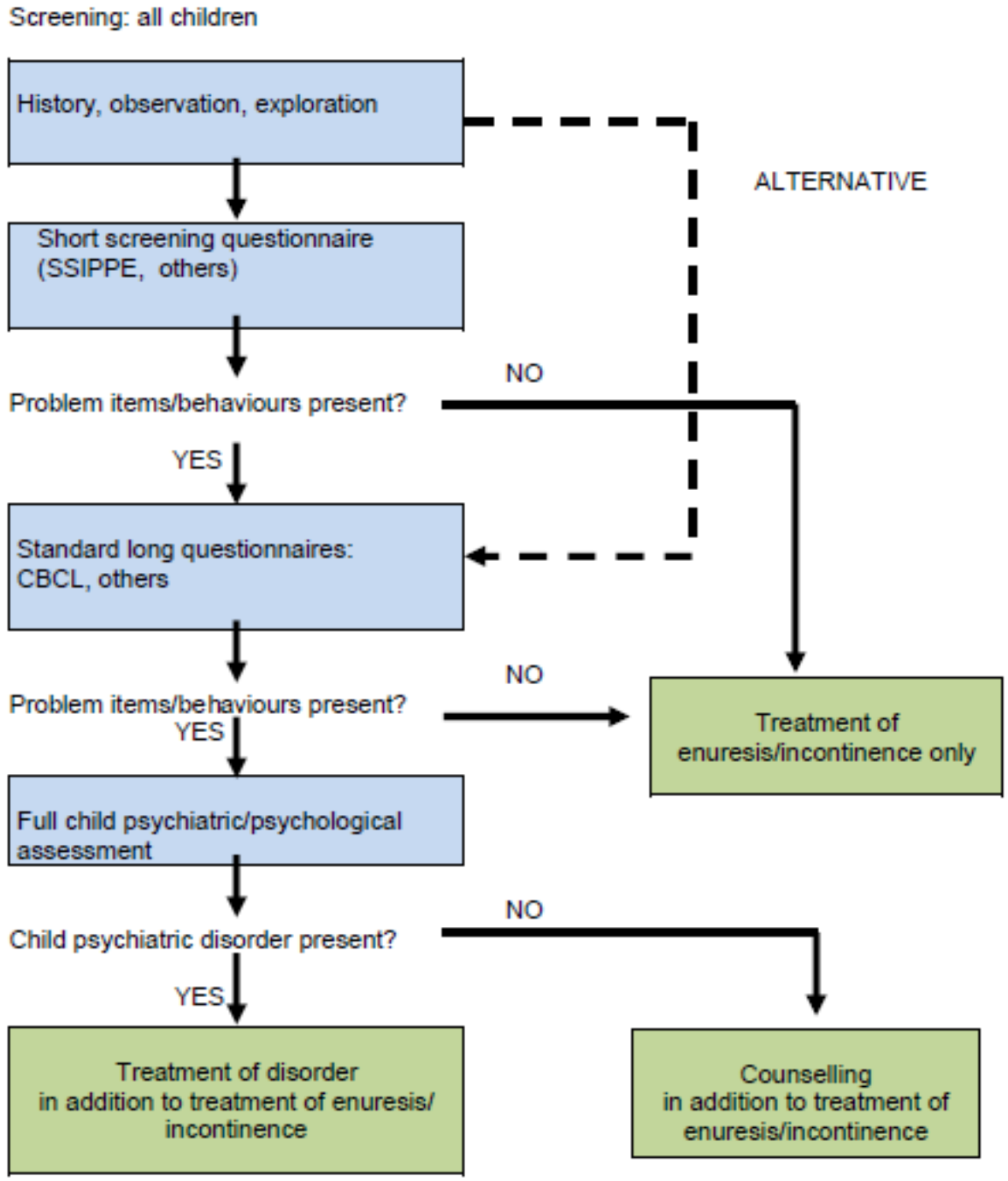
All other procedures are not routinely indicated. Uroflowmetry alone or combined with pelvic floor EMG is required for the diagnosis of dysfunctional voiding (Chase et al, 2011). So-called staccato (changes in flow rates) or fractioned (complete interruption of flow) are typical, combined with contractions of the pelvic floor. If not available, good clinical practice would be to listen and observe a child during the emptying of the bladder: one can hear and observe the straining as well as the waxing and waning of the urine stream.

All other, especially invasive, procedures should not be performed in children with enuresis or functional urinary incontinence unless they are absolutely indicated medically. Radiological and further urological investigations should be avoided as they are in most cases not necessary and can harm the child.

Psychiatric assessment

In a child psychiatric setting, a routine assessment regarding comorbid emotional and behavioural disorders is recommended. In all other settings (paediatric, urologic etc.) at least a screening with a validated and standardised parental questionnaire is recommended because of the high frequency of comorbid disorders (von Gontard et al, 2011b). This can be done in one or two stages, either by using a short screening questionnaire, such as the SSIPPE (Van Hoecke et al, 2007), first and a long questionnaire next, or by using a long questionnaire such as the CBCL (Achenbach, 1991). If many problem items are endorsed, a full assessment by a child psychologist or psychiatrist should follow. If comorbid disorders are present, they should be treated (see Figure C.4.1).

Figure C.4.1 Flow chart for assessment of psychological symptoms (subclinical) or disorders (clinical): specific treatment for enuresis/incontinence is the same for all children; those with symptoms require counselling, those with disorders need treatment (from von Gontard et al, 2011b)



Differential diagnosis

Somatic causes of urinary incontinence must be excluded. These include structural anomalies (such as epispadias, hypospadias, urethral valves, and other malformations of the urinary tract), neurologic conditions (such as spina bifida occulta, tethered-cord-syndrome, etc.) and other paediatric diseases (such as diabetes insipidus, diabetes mellitus). Comorbid emotional and behavioural disorders should be assessed in addition to the type of elimination disorder.

TREATMENT

Again, treatment of enuresis and urinary incontinence is based on simple, effective steps that can be delivered in many primary care settings. However, it is time-consuming as most interventions require cooperation of the child and parents. More detailed information is provided in von Gontard and Neveus (2006).

Enuresis

Several meta-analyses have shown conclusively that, overall, non-pharmacological interventions are more effective than medication, which also has its place if indicated (Houts et al, 1994; Lister-Sharp et al, 1997). The classic meta-analysis of Houts et al (1994) shows this quite clearly (Figure C.4.2).

General principles

Certain general principles should be followed for treatment:

- A child should be at least 5 years of age (the age required to diagnose enuresis and urinary incontinence), younger children do not require treatment
- Treatment should always be symptom-orientated, aimed at achieving continence (i.e., complete dryness). Primary psychotherapy for enuresis is not effective and not indicated. Comorbid disorders should be treated separately according to evidence-based recommendations
- When there are several concurrent disorders, encopresis and constipation should be treated first because some children will stop wetting once these problems have been dealt with
- Daytime incontinence should be treated first, as many children will stop wetting at night once the daytime problems have been treated
- In non-monosymptomatic enuresis, all daytime bladder problems should be tackled first (according to the principles of urinary incontinence) before starting the specific treatment of enuresis
- Primary and secondary enuresis are treated in the same way

The initial treatment steps are simple, non-specific aspects of "good practice":

- Counselling, support and provision of information
- Enhancing motivation and alleviating guilt feelings
- Educating about drinking and toileting habits: drinking more fluids during the day, taking time while on the toilet, sitting in a relaxed way, refraining from holding manoeuvres, etc.
- Discontinuing all ineffective measures such as punishing the child, fluid restrictions, waking and lifting, ineffective medication, other alternative medicine treatments

Recommendations to rate treatment outcome according to the Children's Continence Society (Neveus et al, 2006):

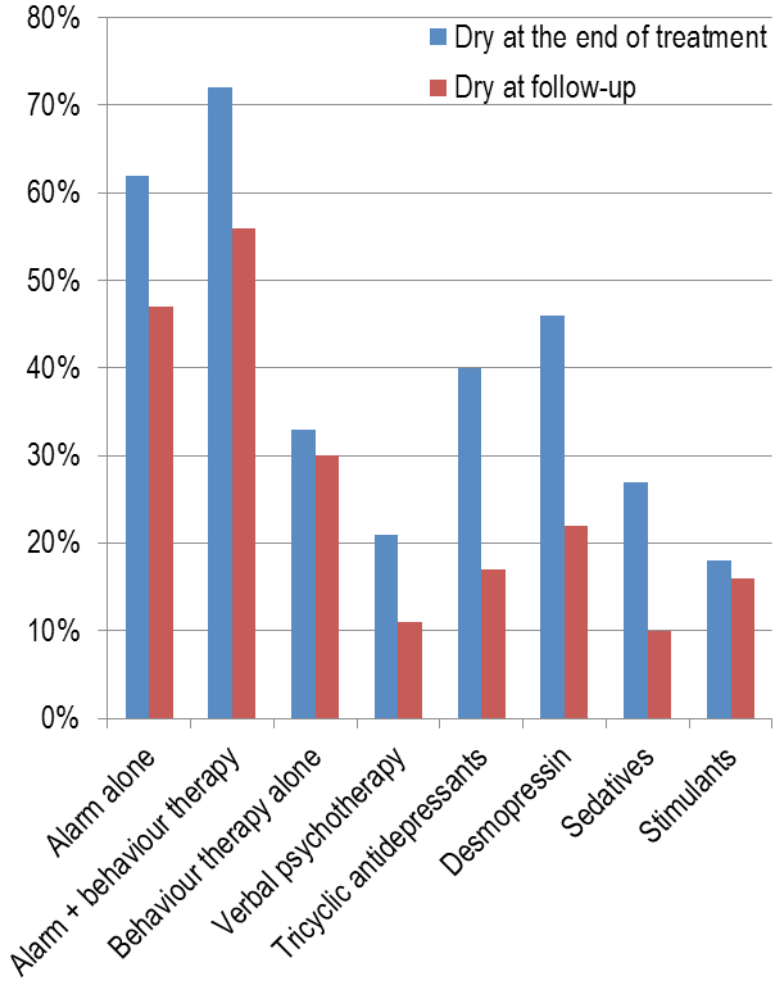
Initial outcome

- Non-response: 0 to 49% reduction
- Partial response: 50 to 89% reduction
- Response: >90% reduction
- Full response: 100% or less than 1 accident per month.

Long-term outcome

- Relapse: more than one episode per month
- Continued success: no relapse in 6 months after treatment
- Complete success: no relapse in two years after treatment

Figure C.4.2 Effectiveness of different treatment forms for nocturnal enuresis (% dry at the end of treatment and at follow-up) (Houts et al, 1994).



- A baseline period is then recommended with a simple observation and recording of wet and dry nights over a period of 4 weeks. Children are asked to draw a symbol for wet and dry nights (clouds and suns, stars, etc.) in a chart and bring it to the next consultation. An example of chart is depicted in Appendix C.4.4.

These simple measures will achieve dryness in 15-20% of cases without further intervention and are supported by evidence (Cochrane review of Glazener and Evans, 2004). If these simple interventions do not suffice, specific treatment is required.

Two main interventions are available: alarm treatment and pharmacotherapy. As alarm treatment is more effective and has the best long-term results, this should be the first line treatment if child and parent are motivated. As shown in Figure C.4.2, 62% of children are dry at the end of treatment and 47% at follow-up. Houts et al (1994) conclude that "urine alarm treatments should not only be considered the treatment of choice, but the evidence from this review suggests that cure rather than management is a realistic goal for the majority of children

suffering from nocturnal enuresis." A Cochrane review of 22 RCT's involving 1125 children concluded: "Alarm interventions are an effective treatment for nocturnal enuresis. Desmopressin and tricyclics appeared as effective while on treatment, but this effect was not sustained after treatment stopped and alarms may be more effective in the long run" (Glazener et al, 2005).

If alarm treatment cannot be implemented adequately, medication (desmopressin) is the second line treatment. If either method fails, a switch to the other treatment is recommended (Neveus et al, 2010) and was shown to be effective (Kwak et al, 2010).

Alarm treatment

An alarm consists of a pad or a metal sensor, which is connected to a bell by a wire. Once the sensor becomes wet, an electric circuit is closed and the alarm is set off. Alarms are very simple devices; they can be cleaned and used by different children many times over. Sterilisation is not required, as urine is per se a sterile fluid (unless UTI's are present), cleaning with a surface disinfectant is enough.

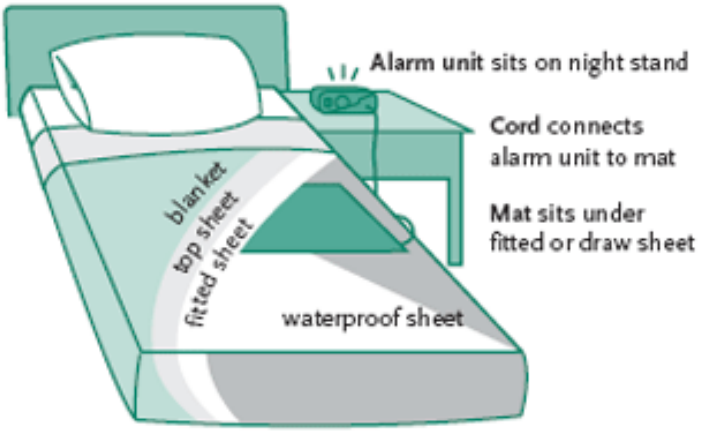
Two different types of alarms exist, body worn and bedside. In body worn alarms, the bell is attached to the night dress while the sensor is attached to the underpants. If desired, body worn alarms can be used with diapers. In bedside alarms, a metal foil or a cloth pad (with integrated wires) is placed under the top sheet of the bed and connected to an alarm next to the bed. Both alarms are equally effective. Therefore, children should decide which alarm they prefer.

The alarm should not just be prescribed but its functions demonstrated and shown directly during the consultation. Children should feel responsible for their treatment. Some instructions are extremely important and should be gone through in detail with parents and child:

1. Children are asked to go to the toilet before going to bed
2. The alarm is attached and switched on
3. In case of a dry night, nothing happens and the child can turn off the alarm the next morning. In case of wetting, the alarm is triggered and the child should wake up completely, either by themselves or with parental help
4. The child is asked to go to the toilet and urinate
5. The night dress and the bedding are changed and the alarm is reset.
6. The child should be actively involved in this process. If the child wets a second time during the night, the whole routine is repeated.
7. Parents are asked to record all relevant data in a chart (see Appendix C.4.5).

To be successful, the alarm must be used every night for a maximum of 16 weeks. Some children become dry in only a few weeks, most will require 8 to 10 weeks and some a little longer. After 14 consecutive dry nights, use of the alarm is discontinued and the child is considered to be dry. Parents are advised to restart alarm treatment if a relapse (two wet nights per week) happens, this occurs in up to 30% of cases.

The alarm treatment relies on operant conditioning and should be enhanced with other measures including positive reinforcement with praise and other rewards, as well as aversive consequences such as getting up, going to the



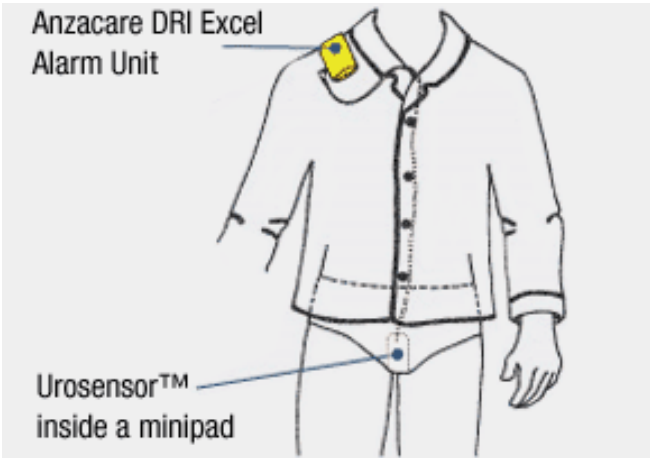


Figure C4.3 Two models of bed-wetting alarms

toilet and remaking the bed (Butler, 1994). Dryness can be achieved by two basic mechanisms: either children learn to wake up and go to the toilet (one third) or they sleep through the night without wetting (two thirds).

Usually, simple alarm treatment is sufficient. It can, however, be reinforced by additional means. A simple addition to the alarm is the so called "arousal training" by van Londen et al (1993). In arousal training the alarm is set up before sleep, the alarm is triggered, children are instructed to turn off the alarm within three minutes, go to the toilet and reset the alarm. If this is achieved correctly children are rewarded with two tokens, such as stickers. If this is not achieved, one token has to be returned. In younger children, we found it advisable to modify this training: children receive one token if they are successful but do not have to pay back a token, which would be too frustrating for them. Arousal training has been shown to be more successful than alarm alone. A well-known training program is "dry bed training" by Azrin et al (1974). This is a complicated, difficult to perform program which starts with an intensive night (in which the child is awaken once every hour until 1 am) followed by maintenance treatment. Meta-analyses have shown that "dry bed training" is no more effective than alarm treatment alone (Lister-Sharp et al, 1977). Therefore, it is not recommended.

The combination of alarm treatment and desmopressin cannot be recommended due to conflicting results. However, if a child has urge symptoms (i.e., a non-monosymptomatic enuresis) a combination of anticholinergic

medication (for example 2.5mg to 5mg Oxybutinin or Propiverin at night) is helpful, otherwise the alarm may go off several times per night and the outcome will be less favourable.

Medication

Indications for medication are:

- Unwillingness to undertake alarm treatment
- Lack of motivation in the children
- Family overwhelmed by demands such as a work situation, cramped housing, infants to care for, i.e., cooperation with alarm treatment is not possible
- Short-term dryness is required, e.g., for school outings.

There are two groups of medication with a clear antienuretic effect: desmopressin and tricyclic antidepressants (TCAs). Although both are effective, desmopressin has less side-effects and is therefore the preferred substance.

Desmopressin (1-deamino-8-D-arginine vasopressin, abbreviated DDAVP) is a synthetic analogue of the antidiuretic hormone (ADH). A reduction of wet nights or even dryness can be achieved in 70% of cases: 30% of children are full responders, 40% partial responders, and 30% non-responders (Neveus et al, 2010). After discontinuing medication most children relapse, so that desmopressin has a low curative potential (Neveus et al, 2010). According to van Kerrebroeck (2002), only 18%-38% of children remain dry 6 months after medication is withdrawn. Compared with the alarm, desmopressin has a distinctly lower curative effect in the long run.

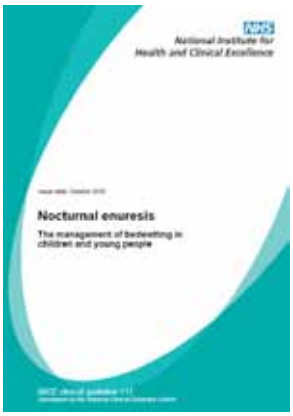
Desmopressin is taken in tablet form in the evenings only. The oral dosage is 0.2mg to 0.4mg. It is advisable to titrate the required dosis over 4 weeks, as shown in the chart in Appendix C.4.6. One starts with the low dosage of 0.2mg in the evening for two weeks. If the child is dry or a marked reduction of wet nights is documented one stays with this dosage. Otherwise, medication is increased

40 years of being treated for nocturnal enuresis

In the course of forty years I have consulted a wide range of experts in the hope of finding a solution to my nocturnal enuresis [...] Most of the GPs [family doctors] advised curtailment of drinking and methods of awakening in the night. The urologists performed various technical studies that showed no abnormalities. Alarm systems usually gave relief for a short period. Consultations with a naturopath and a homeopath yielded no benefits, and consequent disappointment resulted in new mental strain... I consulted a psychologist who, although unable to find anything abnormal in my personality, advised Pavlov's method of adaptation: immediately after waking with a wet bed, I was to take a cold shower as punishment for the “bad” behaviour. A urologist prescribed imipramine, despite its severe side effects including excessive sweating, dizziness, and a dry mouth. The psychiatrist used sandpit therapy to trace traumatic experiences in childhood: recognition and acceptance of precipitating experiences might, it was hoped, remove the cause of my enuresis. Two years of weekly sessions of 45 minutes had a major influence in my personality. Sandpit therapy, with its focus on the ego, changed me from a sociable to a self-centred individual. Again, the bedwetting was unaffected [...] Finally, after nearly four decades and many years of disappointing experiences I consulted Professor Janknegt, who suggested desmopressin (DDAVP)—an analogue of antidiuretic hormone. Used as a nasal spray once a night this brought immediate relief. Discontinuation of the spray immediately results in bedwetting. So far, there have been no side-effects […] Over the years, the intrinsic difficulties of nocturnal enuresis have been compounded by the effects of unsuccessful treatments.

De Graaf MJ. Lancet 1992, 340:957-958.

to 0.4mg in the evening. If children do not become dry with 0.4mg, they are considered to be non-responders and desmopressin is discontinued. Otherwise, one can continue with the required dosage for a maximum of 12 weeks, after which desmopressin should be stopped to check if the child can remain dry without medication. If a relapse occurs, desmopressin can be given for another 12 weeks and this regime can be continued for as long as indicated. Adverse effects are rare and not pronounced, like head and stomach aches, lack of appetite, etc. The most dramatic, though rare side effect is hyponatremia and water intoxication, which may require intensive care. Therefore it is important not to overdose and not to drink a large amount of fluids after taking the medication. Laboratory blood tests are not necessary.



Click on the picture to access the NICE guideline for the management of enuresis

Tricyclic antidepressants such as imipramine have a proven anti-enuretic effect and similar relapse rates as desmopressin. Due to cardiac arrhythmias even with therapeutic doses, a detailed family history, ECG before and during treatment and blood tests are recommended. A low dose of 10mg to 25mg in the evening (1mg per kg of body weight per day or less) is often sufficient. If higher doses are necessary, imipramine should be give 3 times a day and the medication slowly increased to a maximum of 3mg per kg of body weight per day. Due to side effects (and toxic effects in case overdosage), imipramine has become a third line treatment for severe therapy-resistant cases.

Urinary incontinence

The same basic principles as in the treatment of enuresis should be followed, e.g., provision of information, counselling, supporting and motivating both child and parent is essential.

The main focus in the treatment of *urge incontinence* is a symptom-oriented cognitive-behavioural approach aimed at a conscious control of the urge without the use of the pelvic floor muscles, i.e., holding manoeuvres (Vijverberg et al, 1997). Children are instructed to note when they feel an urge and go to the toilet right away without using holding manoeuvres. They are asked to document in a chart if their pants were dry (with the symbol of a flag, for example) or if they were wet (with the symbol of a cloud, for example). This means, that children should be allowed to go to the toilet in any situation, especially in kindergarten and school. If adhered to, the number of voidings is typically reduced first, followed by a reduction in the number of wet episodes.

This simple approach is sufficient for 1/3 of children; the other 2/3 will require additional medication. Monitoring – observing and documenting (i.e., the cognitive-behavioural component) – should continue throughout the therapy. Anticholinergic medication is indicated. Oxybutine is a well-known preparation available as generic drug in most countries. It should be introduced slowly to avoid side-effects up to an initial dosage of 0.3mg per kg of body weight per day in 3 doses (maximum daily dosage: 15mg). If not effective, it can be increased to 0.6mg per kg of body weight per day (maximum 15mg/day). Side-effects are dose-dependent and reversible. They include typical anticholinergic effects such as flushing, blurred vision, tachycardia, hyperactivity, dryness of the mouth, residual urine and constipation.

An alternative is propiverin, which unfortunately is not available in many countries. The dosage is a maximum of 0.8mg of body weight per day in two doses (with a total maximum of 15mg/day). Side effects are similar but possibly at a lower rate. If one of these two standard medications is not effective or is accompanied by too many side effects, a switch-over to the other medication is recommended. Other anticholinergic medications such as tolterodine, solifenacine and others are used in adults but are not recommended for standard treatment in children.

A symptom-oriented approach is indicated in all cases of *voiding postponement*. The first step is provision of information and psycho-education. Often, the association of voiding postponement, retention of urine and incontinence are not known to parents and children. Children and parents are instructed to increase the frequency of micturition. The goal is to go to the toilet seven times a day at regular intervals. Children should sit on the toilet in a relaxed way and take plenty of time. Micturitions in the toilet as well as wetting episodes are noted in a chart. Often this requires parents to send their child to the toilet. To increase motivation, a simple token system with positive reinforcements can be added. In older children, digital wrist alarm watches (or cell phones) can be of help. Intervals of 1½ to 3 hours are set to remind the child to go to the toilet. However, these approaches are often not sufficient because of the high behavioural comorbidity, especially with ODD, which requires additional treatment.



Click on the picture to access the website of the International Children's Continence Society (ICCS). Families and professionals can find in the website a variety of useful information and resources.

Treatment of *dysfunctional voiding* includes increasing motivation, cognitive-behavioural elements, relaxation and general drinking and toileting advice (Chase et al, 2010). If necessary, voiding frequency and oral fluids can be increased. Toilet re-training is initiated. It is recommended that children take a lot of time, sit in a relaxed manner on the toilet seat, spread their legs apart and have contact with the floor either directly or with a little foot stool. The children are asked to relax completely, initiate micturition without straining and simply let the urine flow until they have the feeling that the bladder is empty. The most specific and effective treatment is biofeedback – either with uroflowmetry or pelvic-floor EMG (Chase et al, 2010). Signals of the urine stream or pelvic floor contractions are presented to the child in real time either visually or acoustically. Many child-friendly programmes and animations are available. EMG-feedback can be performed at home under instruction; otherwise, biofeedback is limited to specialised outpatient departments and beyond the scope of most primary care services. Coordination and continence can be achieved in a few sessions in most children. Medication is not indicated (Chase et al, 2010).

Giggle incontinence is treated with a classical conditioning paradigm (Elzinga-Plomp et al, 1995) or with high-dose methylphenidate (due to the overlap with cataplexy and narcolepsy) (Sher & Reinberg, 1996). Stress incontinence is treated by physiotherapy or imipramine. Children with underactive bladder require an intensive training and often intermittent catheterisation. All of these rare disorders do require specialised treatment (see von Gontard & Neveus, 2006).

In therapy-resistant cases, structured group therapies have been successful (Equit et al, 2012). These combine counselling, provision of information, relaxation techniques, cognitive-behavioural, play and group therapy approaches.

COURSE

Enuresis has excellent long-term outcome with a high spontaneous remission rate – 13% per year – and effective treatments are available; 60% to 80% become dry with alarm treatment and 50% remain so on the long-term (Houts et al, 1994). Still, a small group of children have chronic enuresis with 1%-2% of adolescents affected. Nocturia (waking up at night and voiding) can be a residual symptom. The prevalence of enuresis overall is 1.7% in adults, with an 8-fold risk for enuresis if they had wetted as children (Hublin et al, 1998).

Studies of the long-term outcome of daytime incontinence are lacking. Urge incontinence seems to have the best prognosis, while voiding postponement, especially combined with ODD is difficult to treat. Daytime incontinence increases in adulthood with age, especially in women, although these are not necessarily a consequence of childhood incontinence.

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It is not known when enuresis became a medical problem, but it has been recognized as a disturbance of childhood necessitating medical treatment since the time of the Papyrus Ebers' which is dated 1550 BC. Juniper berries were the recommended treatment (Glicklich, 1951).

Appendix C.4.1

CLINICAL HISTORY

OF WETTING PROBLEMS AND POSSIBLE COMORBID DISORDERS

(von Gontard, 2001; von Gontard & Neveus, 2006, with permission)

PRESENTING SYMPTOMS

General introduction: Do you know why you and your parents are here today?

Time of wetting: Is it because you wet the bed or because your pants are wet during the day?

Start with the most important symptom, i.e., night or daytime problems

NOCTURNAL WETTING

Frequency of wetting: Do you wet the bed every night or are there dry nights? How many nights per week is your bed wet (or dry)?

Amount of wetting: Is the bed damp or completely wet?

Depth of sleep: How deep does your child sleep? Is it easy or difficult to wake him/her? What do you have to do to get you child awake? Does your child sometimes wake up at night to go to the toilet (nocturia)?

Dry intervals: What is the longest period of time that your child has been completely dry (days, weeks, months)? How old was your child then? Did anything happen around the time of the relapse that might have had an impact for your child to start wetting again?

Impact and distress: How is it for you when your bed is wet? Are you sad? Annoyed? Angry? Ashamed? Or do you feel it does not matter? Do you want to get dry? Are you willing to do something about it and put some effort into the therapy?

Social consequences: Have you been teased by somebody else about the wetting? Have you avoided sleeping over with friends or join in on outings with your school class because of that?

DAYTIME WETTING AND MICTURITION PROBLEMS DURING THE DAY

Frequency of wetting: Are your pants wet every day or do you also have dry days? How many days per week are your trousers wet? Does it happen that you wet during the day not once, but several times? How many times does it usually occur?

Amount of wetting: Are the pants damp or really wet? Can the wet spot be seen through the clothing?

Timing during the day: Do you usually wet during the morning, in the afternoon or on the evening?

Frequency of micturition: How often does your child go to the toilet during the day (3, 5, 10 or 20 times? (Normal range is 5 to 7 times per day).

Voiding postponement: Have you ever noticed that your child does not go to the toilet right away, but puts off the voiding for as long as possible? In which situations does this happen most often (for example: in school, coming home from school, while playing, while watching TV or during other activities)?

Holding manoeuvres: How do you notice that your child needs to go to the toilet? Does it seem to be absent-minded? What exactly does your child do to delay voiding? Have you ever noticed that he/she crosses their legs, jumps from one leg to the other, holds its tummy or genitals, squats or sits on its heels?

Urge symptoms Does it happen that your child feels a sudden and strong urge to go to the toilet (even though it goes to the toilet often)? For example, how long can you drive the car or go shopping, before your child has to go to the toilet? Do you have enough time to wait for the next rest room or do you have to stop right away to let your child void?

Dry intervals during the day: When did your child get dry during the day? Is your child still wetting during the day? What was the longest time period your child has ever been dry (days, weeks, months)? How old was your child then? Were important things happening at the time of the relapse that might have had an effect on your child to start wetting again?

Problems with micturition: Does your child have to strain at the beginning of micturition or does the urine come spontaneously? Is there one continuous stream when voiding or is the voiding interrupted? If it is interrupted, how many times? Does your child need to strain to get it going again?

Urinary tract infections: Does your child complain about pain during voiding? Does your child have to go the toilet more often than usual? How many urinary tract infections has your child had so far? When did the first infection occur? Has your child had infections with fever and pain in the kidney areas? Have the infections been treated with antibiotics? Has your child had long-term prophylaxis with antibiotics? Is taking medication at the moment? Has your child had skin infections in the genital area (dermatitis)?

Medical complications: Have there been other medical complications such as refluxes, operations, etc?

Eating and drinking habits: Please describe the eating habits of your child. Prefers biscuits, white bread other low fibre food? How much and what does your child drink each the day?

Attributions: What do you think is the cause of your child's wetting problem? Do you have any idea about how it happened? Have you ever felt guilty about it? Have you ever blamed yourself for it? Have you ever been blamed by others? Do you think your child is doing it on purpose? Who is distressed the most about the wetting: you or your child? What do you think should change? What are your expectations? Are you and your child willing to cooperate actively with treatment?

TREATMENT TRIALS

Previous therapy: What have you tried so far to get your child dry? (Ineffective forms of treatment) Fluid restriction, waking, holding, punishment, other measures? (Effective forms of treatment) Charts and calendars, rewards, alarm treatment, medication? Which medications(Minirin, Imipramine, others)? How were the treatment trials conducted, please describe for how long with what effects? Whom have you consulted for your child's wetting problem:

paediatrician, urologist, psychologist, psychiatrist, child guidance centres, etc.? Which investigations have been performed so far?

ENCOPRESIS

Soiling: Does your child sometimes soil his underwear? How many times per week does it happen? Are they large amounts or stool smearing? Does it happen only during the day or also at night? How does your child react when it soils? How old was your child when he became clean (stools in the toilet and not in the diapers)? Have there been any relapses in the past?

Toilet habits: How often does your child have bowel movements per week? Does it ever happen that it does not have bowel movements for several days in a row? Is your child constipated regularly? Is defecating painful? Has there been blood on the stools? What have you done about it so far?

THE CHILD PSYCHIATRIC HISTORY

The child psychiatric history is divided into the presenting symptom(s), personal and developmental history and the family history (see Chapter A.5). In most cases, parents and child are interviewed together – in this way differing views can be assessed easily. In some cases, it is best to interview parents alone (i.e., marital conflicts, abuse, etc.). In others, it can be useful to see and talk to the child alone, particularly older children. Some children are more open to talk about their problems when parents are not present.

PRESENTING SYMPTOMS

At the end of the wetting history, it is useful to ask an open question regarding other problem areas.

Other behavioural problems: Are there other areas in your child's behaviour that you are worried about? Please describe them in detail.

As in the history of the wetting problem, each presenting symptom should be dealt with in turn. The following points are worth considering.

Presenting symptoms: Please describe the problem in your own words in as much detailed as possible. How often does it occur? In which situations (at home, at school, with friends)? How does your child react? How do you react? When did it begin? How has it developed so far? Has it remained the same, got worse or diminished in intensity or frequency? What have you done about it so far? Has the child been seen or treated for the problem? Where, by whom and with which effect? What are your main worries? What would you like to change? How do you think this could change? What do you expect from this consultation?

It is also useful to ask a few general questions about possible problem domains that often occur in children and that might be missed by open questions. If parents answer positively, each of the problems need to be explored in detail.

OTHER PROBLEM AREAS

Externalising problems: Is your child restless, constantly fidgeting or too active? Is easily distracted? For how long can concentrate? Are there certain situations in which he finds it especially difficult to concentrate, for example at school? Does your child seem to act impulsively, without thinking? Is sometimes aggressive verbally, towards objects or people? How does your child respond to rules? Does he obey your rules? Is he oppositional? How does it react to your setting limits and saying no? Are there particular problem areas: homework, coming home too late, lying, stealing…?

Internalising problems: Is your child sad, unhappy or withdrawn? Has your child lost interest in play, seeing other children? Does she find it difficult to get an activity going? Does your child worry a lot? Are there problems with sleeping or eating? Is she afraid of certain objects, situations or animals (phobias)? Afraid of strangers, groups of children (social anxiety)? When you go away (separation anxiety)? Without apparent reason (generalised anxiety)? Has your child developed any peculiar habits, rituals or interests? Does she tend to repeat things in the same way?

PERSONAL AND DEVELOPMENTAL HISTORY

Pregnancy: Was the pregnancy planned (desired) or unexpected? What were your feelings during pregnancy? Were there medical complications? Did anything happen that you found stressful?

Birth: Was delivery at the expected date, too early, too late? Was it a spontaneous birth? Were there complications during or after birth? What was the birth weight of your child?

Infancy: Was your child breast-fed? For how long? If not, what were the reasons? Was your child a quiet, content or active baby (temperament)? Were there problems with feeding, weight gain, sleeping, excessive crying?

Motor development: When did your child start sitting, standing, walking freely?

Speech and language: When did your child say its first words (and which were they)? When did your child say its first two-word sentences? Were there any problems with articulation, the way sentences were formed (expressive language) or with understanding (receptive language)?

Kindergarten: When did your child enter kindergarten? Did he show problems staying there, i.e. about being away from you? Were there problems with other children or with teachers? If yes, please describe.

School: When did your child enter school? Which grade is he doing now? What type of school? Did he have to repeat a grade? Does he like to go to school? Please describe. What are his favourite subjects? What are the grades in the different subjects? Does your child have special problems with teachers? With other children? Please describe.

Leisure time: What does your child do during free time? What are his favourite games and type of play (role playing, construction games, activity games, computer games, etc.)? Are there planned activities? What are his interests and hobbies? Does he practice sports? Does your child have friends (how many and how close)? Does he spend his free time alone or with friends? What role does your child play in groups with other children of the same age?

Illnesses: What illnesses, operations, hospital treatment, accidents, and allergies has your child had so far?

FAMILY HISTORY

Parents:	Age, occupation (educational achievemnt), illnesses. Marital relationship? Did you wet the bed as a child? How would you describe your relationship to your child?
Siblings:	Age. Biological siblings? School-grade, illnesses and wetting problems. How do your children relate to each other? Are there especially close bonds or rivalries?
Other relatives:	Did other relatives wet the bed as children? Other illnesses, especially psychiatric or kidney?

Regarding the problems of enuresis and urinary incontinence (as well as nocturia and micturition problems such as urge) we have made it a routine to draw a complete pedigree over three generations. Often, other relatives will be missed unless one asks directly and explicitly if they have wetted in the past (or currently).

It is usually best to end the history by asking one open question, such as "is there anything else we may have missed or that you think it may be important?"

Appendix C.4.2

FREQUENCY/ VOLUME CHART

(von Gontard & Neveus, 2006, with permission)

Instructions:

Dear parents,

To assess and treat the wetting problem of your child in the best possible way, we would be very thankful for your help and your observations.

Please fill out this chart on a day without school or kindergarten (weekend or holiday). You must note every time that your child goes to the toilet or wets him or herself. This should start on one morning and continue through to the next morning (24 hours). If possible, **please fill out two charts on two consecutive days**, this is even more useful.

Please talk to your child about it beforehand. You should not send your child to the toilet. Instead, he/she should tell you when he/she wants to go to the toilet and should urinate into a measuring cup. Please measure the amount of urine, record it and the time of day in the chart. You can discard the urine afterwards.

If your child needs to strain to start urinating of if the stream of urine is interrupted (e.g., stops and starts) please note this in the appropriate column in the chart (3rd from the left).

If your child wets his/her clothes, again please note the time and if they were wet (large amount of urine) or just damp (small amount).

If your child feels a sudden urge to go to the toilet, please note this with the time in the next column.

If you observe that your child crosses his/her legs, squats or tries to hold back the urine in any other way, please note this (with the time) in the column headed "Urge".

Finally, please measure and note the amount of ALL fluids your child drinks during the day (with times).

Thank you very much for your help!

48-HOUR-FREQUENCY/VOLUME CHART

Name_____ Date of birth_____

Date_____

Time of day	Urine volume (ml)	Straining/ interrupted stream	Wetting: damp/wet?	Urge	Comments/ observations	Drinking fluids (ml)

Appendix C.4.3

PARENT QUESTIONNAIRE
ENURESIS/URINARY INCONTINENCE

(Beetz, von Gontard, Lettgen, 1994; translated and adapted by von Gontard, 2003)

Name:_____ Date of birth:_____

Date:_____

DAYTIME WETTING	**YES**	**NO**
Does your child wet his/her clothes during the day?	[ ]	[ ]
Has your child ever been dry during the day?	[ ]	[ ]

If yes, for how long? _____ (weeks/months/ years)

And at which age? _____ (years)

On how many days a week does your child wet during daytime? _____(days per week)

How many times a day does your child wet?_____(times per day)

Is the clothing usually damp?	[ ]	[ ]
Is the clothing usually wet?	[ ]	[ ]
Does urine dribble constantly?	]	[ ]
Does your child wet his/her clothes immediately after having gone to the toilet?	[ ]	[ ]
Does your child notice when he/she wets?	[ ]	[ ]

NIGHTTIME WETTING	**YES**	**NO**
Does your child wet the bed (or diapers) during the night?	[ ]	[ ]
Has your child ever been dry during the night?	[ ]	[ ]

If yes, for how long? _____ (weeks/months/ years)

And at which age? _____ (years)

On how many nights a week does your child wet? _____(nights per week)

Is the bed usually damp?	[ ]	[ ]
Is the bed usually wet?	[ ]	[ ]
Does your child wake up to go to the toilet?	[ ]	[ ]
Does your child wake up after wetting the bed?	[ ]	[ ]
Is your child a deep sleeper, i.e. difficult to wake up?	[ ]	[ ]
Has any other member of your family wetted (day or night)?	[ ]	[ ]

If yes, who? _____

TOILET HABITS	**YES**	**NO**
How many times a day does your child void(on average)?_____(times/day)		
How long can your child manage without going to the toilet (during shopping, car trips, etc.)? _____(hours)		
Does your child go to the toilet him/herself if he/she needs to?	[ ]	[ ]
Do you have to send your child to the toilet?	[ ]	[ ]
If your child wants to pee, does he/she have to strain at the beginning or during voiding?	[ ]	[ ]
When your child voids, is the stream interrupted?	[ ]	[ ]
Does your child hurry and not take enough time for voiding?	[ ]	[ ]

OBSERVABLE REACTIONS	**YES**	**NO**
Does your child feel a sudden urge to go to the toilet?	[ ]	[ ]
When your child needs to void, does he/she have to rush to the toilet immediately?	[ ]	[ ]
Does your child cross his/her legs, squat, sit on a heel, etc. to prevent wetting?	[ ]	[ ]
Does your child postpone going to the toilet as long as possible?	[ ]	[ ]

If, yes, in which situations (school, play, TV, etc.), please specify _____

URINARY TRACT INFECTIONS	**YES**	**NO**
Has your child ever had a urinary tract infection?	[ ]	[ ]
If yes, how many _____(times)		
Has your child had urinary tract infections with fever?	[ ]	[ ]
Has your child been treated for an illness of the urinary tract?	[ ]	[ ]

If yes, please specify _____

STOOL HABITS	**YES**	**NO**
Does your child have daily bowel movements?	[ ]	[ ]
If not, how many times/ week?_____(times/week)		
Is your child regularly constipated?	[ ]	[ ]
Does your child soil his/her underwear (during the day)?	[ ]	[ ]
Does your child soil during sleep?	[ ]	[ ]
If yes, small amounts (smear)	[ ]	[ ]
Or large amounts (stool)	[ ]	[ ]
How often does your child soil?_____(times/week)_____(times/month)		
Has your child previously had complete bowel control?	[ ]	[ ]
If yes, at what age _____(years)		

And for how long _____(months/years)

Does soiling occur in special situations?	[ ]	[ ]

If yes, please specify_____

BEHAVIOUR: WETTING	**YES**	**NO**
Is your child distressed by the wetting?	[ ]	[ ]
Are you distressed because of your child's wetting?	[ ]	[ ]
Has your child been teased because of the wetting?	[ ]	[ ]
Are there things your child did not do (school outings, sleeping over with friends) because of the wetting?	[ ]	[ ]
Does your child wet more often in stressful times?	[ ]	[ ]
Is your child cooperative and motivated for treatment?	[ ]	[ ]
If your child had been dry before, do you see any event that might be associated with the relapse?	[ ]	[ ]

If yes, please specify _____

What in your opinion is the reason for the wetting?

Please specify_____

BEHAVIOUR: GENERNAL	**YES**	**NO**
Does your child have difficulties obeying rules?	[ ]	[ ]
Is your child restless, on the go, easily distracted?	[ ]	[ ]
Does your child have difficulty concentrating?	[ ]	[ ]
Is your child sometimes anxious?	[ ]	[ ]
Is your child sometimes sad, unhappy, withdrawn?	[ ]	[ ]
Does your child have problems in school?	[ ]	[ ]

If yes, please specify _____

Does your child have problems in other areas?	[ ]	[ ]

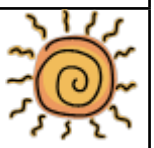
If yes, please specify_____

Appendix C.4.4

EXAMPLE OF NOCTURNAL ENURESIS BASELINE CHART

(Dry night recorded as 'sun', wet one as 'cloud'– or any other symbol chosen by the child)

This chart belongs to:_____

WEEK	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1.							
2.							
3.							
4.							

Appendix C.4.5

EXAMPLE OF A CHART TO MONITOR ALARM TREATMENT

(modified from Butler 1988)

IF DRY			IF WET					
Date	Dry	Got up and went to toilet without alarm	Time of alarm	Child awoke by him/herself		Amount of urine in bed (diaper) L=large M=medium S=small	Passed urine in toilet	
				Yes	No		Yes	No
Monday 10th	✓	✓						
Tuesday 11th			11.30	yes		M		✓
Wed 12th								

Appendix C.4.6

TITRATION CHART FOR ORAL DESMOPRESSIN

(von Gontard & Neveus, 2006)

1st and 2nd weeks: Desmopressin tablets: 0.2 mg (200µg) in the evening (one tablet)

Date	Dry	Amount of urine		Remarks
		Reduced	Same as before	
Monday 16	No	Yes		Did not want to go to school
Tuesday 17	Yes			Very happy

3rd and 4th weeks: Desmopressin tablets: 0.4mg (400µg) in the evening (two tablets)*
*If dry or marked reduction of wet nights → continue with this dose (0.2mg: one tablet)
*If not effective (no reduction of wet nights) → increase to 0.4mg (two tablets).

Date	Dry	Amount of urine		Remarks
		Reduced	Same as before	

*If dry or marked reduction of wet nights → continue with this dosis (0.4mg: two tablets)
*If not effective → discontinue (desmopressin non-responder)

ENCOPRESIS

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Conflict of interest: none disclosed

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Suggested citation: von Gontard A. Encopresis. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Encopresis (or fecal incontinence) is a disorder which affects children worldwide. It is even more stigmatized than enuresis and urinary incontinence and is associated with high levels of distress for both children and parents. Also, the rate of comorbid emotional disorders is higher, affecting 30%-50% of all children with encopresis (von Gontard et al, 2011).

Two major forms of encopresis can be differentiated: encopresis *with* and *without* constipation. The specific differentiation into these two subtypes is of utmost importance as they differ according to pathophysiology, clinical features and, especially, treatment (i.e., the former does not respond to laxatives, while in the latter they are essential in treatment). The aim of this chapter is to give an overview and practical approaches to assessment and treatment of these two subtypes of encopresis.

DEFINITION AND CLASSIFICATION

According to ICD-10 (World Health Organization, WHO, 2008) and DSM-IV-TR (American Psychiatric Association, APA, 2000), encopresis is defined as both voluntary and involuntary passage of feces in inappropriate places in a child aged four years or older, after organic causes have been ruled out. Despite major similarities between the two systems, they differ regarding essential points, especially the definition of subtypes. In ICD-10, one episode per month for at least three months is needed. ICD-10 does not define subtypes nor differentiate clearly between encopresis with and without constipation. The duration required for diagnosis in DSM-IV-TR (2000) is the same but it distinguishes between encopresis with and without constipation.

Table C.5.1 Rome-III diagnostic criteria for functional constipation and non-retentive stool incontinence (Rasquin et al, 2006)

Functional constipation*
Must include two or more of the following in a child with a developmental age of at least four years with insufficient criteria for diagnosis of irritable bowel syndrome: • Two or fewer defecations in the toilet per week • At least one episode of fecal incontinence per week • History of retentive posturing or excessive volitional stool retention • History of painful and hard bowel movements • Presence of a large fecal mass in the rectum • History of large diameter stools that may obstruct the toilet. * Criteria must be fulfilled at least once per week for at least two months
Non-retentive fecal incontinence*
Must include all of the following in a child with a developmental age at least four years: • Defecation into places inappropriate to the social context at least once per month • No evidence of an inflammatory, anatomic, metabolic, or neoplastic process that explains the subjects symptoms • No evidence of fecal retention * Criteria must be fulfilled for at least two months

Based on current research and validation studies, the most precise taxonomy was proposed by pediatric gastroenterologists in their Rome-III classification for functional disorders of the gastrointestinal tract (Table C.5.1) (Rasquin et al, 2006). The first difference is that the neutral term of *fecal incontinence* was chosen instead of encopresis. This means, that fecal incontinence and encopresis can be used as synonyms (as in this chapter). The second change is that constipation was defined as the main disorder that can – but does not necessarily have to – be associated with soiling. Constipation is, in fact, more common than encopresis: many constipated children do not soil. The main symptoms of *functional constipation* can be seen in Table C.5.1. The definition of constipation cannot be based on a low defecation frequency on the toilet alone: some children pass stools every day but still retain fecal masses in the rectum and colon. Therefore, additional clinical signs and symptoms are needed and these are listed explicitly in the Rome-III criteria. The authors chose a shorter duration – two months – to encourage early treatment and to avoid chronification. Two symptoms must be present: a low defecation frequency; soiling; holding maneuvers; painful, hardened stool; and large fecal masses.

For encopresis without constipation, the neutral term of *non-retentive fecal incontinence* was suggested. The etiology of this subtype is not known and much less research has been generated for this disorder than for constipation (Bongers et al, 2007). Except for a shorter duration of two months, the criteria are similar to those of DSM-IV.

EPIDEMIOLOGY

Encopresis is a common disorder affecting 1% to 3% of children older than four years (the definitional age). Three different trajectories can be defined (Heron et al, 2008):

- Children with chronic encopresis over many years
- Those with relapses, and
- A group with a tendency to remit spontaneously.

In a Dutch study, 4.1 % of 5-6 year olds and 1.6 % of 11-12 year olds were affected (van der Wal et al., 2005). Prevalence depends on the definition used; for example, 5.4 % of 7-year old children soiled, but only 1.4 % once or more per week (Joinson et al, 2006). Encopresis can persist into adolescence and even young adulthood. Without constipation (i.e., non-retentive fecal incontinence), 49% of children soiled at the age of 12 years, and 15% at 18 years in a long-term follow up (Bongers et al, 2007). The prognosis of constipation is less favorable: only 80 % had a good outcome by the age of 16 years, and 75% to 80% at 16-27 years (Bongers et al, 2010).

Three to four times more boys are affected by encopresis than girls (Bellman, 1966). Encopresis occurs almost always during the day (Bellman, 1966). Nocturnal encopresis is more often associated with organic causes and requires a more detailed somatic assessment.

Most children from the age of four years onwards have one bowel movement a day – with great individual variability (Bloom et al, 1993). Chronic constipation is a more common disorder than encopresis. According to a large meta-analysis, the median prevalence was 9% world-wide with different definitions used (van

den Berg et al, 2006). This meta-analysis included studies from countries such as Italy, US, Hong Kong, Japan, Finland, Turkey, Brazil, Saudi Arabia, among others.

CLINICAL SIGNS AND SYMPTOMS

As the differentiation of the two subtypes – constipation and non-retentive fecal incontinence – is decisive for treatment, it is important to know the basic signs and symptoms of each. Based on the research of Benninga et al (1994; 2004), as well as others, the main differences between the subtypes are shown in Table C.5.2.

Children with encopresis with constipation (or functional constipation) have a reduced number of bowel movements with large stools of altered consistency (too soft or too hard). They often experience pain during defecation. Abdominal pain and reduced appetite are typical. The colon transit time is increased, abdominal and rectal masses are palpable. In sonography, the rectal diameter is increased (> 25 mm). Often, daytime urinary incontinence and even enuresis co-exists. Additional emotional and behavioral disorders are found in 30%-50% of them and, finally, laxative therapy is helpful.

Children with encopresis without constipation (non-retentive fecal incontinence) do not have many of these symptoms. They have daily bowel movements of normal size and consistency. Pain is not frequent and appetite is

Table C.5.2 Differences between encopresis with constipation and non-retentive fecal incontinence

	Encopresis with constipation	Non-retentive fecal incontinence
Bowel movements	Seldom	Daily
Large amounts of stools	Yes	No
Normal stools (consistency)	One half	Nearly all
Pain during defecation	One half	Seldom
Abdominal pain	Often	Seldom
Appetite	Reduced	Good
Colon transit time	Long	Normal
Palpable abdominal mass	Often	None
Palpable rectal mass	Often	Never
Rectal diameter (sonography)	Increased	Normal
Daytime urinary incontinence	One tenth	Seldom
Nocturnal enuresis	One third	Tenth
Comorbidity with behavioral and emotional disorders	30%-50%	30%-50%
Laxative therapy	Helpful	Not helpful, even worsening

good. Colon transit time is normal and no stool masses can be palpated. Enuresis and urinary incontinence are less common, while comorbidity with psychological disturbances is similar (30%-50%). Finally, laxatives have no effect – can even worsen the soiling.

ETIOLOGY

Fecal continence is achieved following night-time and daytime urinary continence (Largo et al, 1978; 1996). Early toilet training can lead to early fecal continence in infancy and toddlerhood but has no influence on the development of encopresis at the age of 4 years. Encopresis can be preceded by delayed development and difficult temperament in the child, as well as maternal depression and anxiety (Joinson et al, 2008).

Functional constipation

Genetic factors do play a role in constipation but less so in encopresis. The concordance rate for constipation for monozygotic twins is 70%, for dizygotic twins 18%. The risk of occurrence is 26% if one parent is affected, 46% if both parents, 40% if father, and 19% if mother is affected (Bakwin & Davidson, 1971).

Functional constipation often develops after an acute constipation, which affects 16%-22% of young children. This can be triggered by a wide variety of psychological factors such as stressful life events, losses, family conflict, as well as somatic factors such as anal fissures, changes of diet, intensive toilet training and medication (Cox et al, 1998). Irrespective of the initial triggers, a sequence of chronic stool retention can follow. Acute constipation causes painful defecation and avoidance of defecation, inducing a paradoxical contraction of the external anal sphincter, which becomes habitual. Avoidance of bowel movements leads to accumulation of fecal material in the rectum and colon. Transit times are increased, peristalsis and sensation are decreased. Fluid withdrawal leads to large, hard fecal masses and a megacolon. Encopresis occurs because of interference of these masses with rectal function and by fresh stools bypassing the hard fecal masses.

Non-retentive fecal incontinence

In contrast to the clear model of functional constipation, the etiology of non-retentive fecal incontinence is not known (Bongers et al, 2007). It cannot be caused by psychological factors alone, as the comorbidity rate of both types of encopresis is the similar: 30%-50% of cases (Benninga et al, 1994; 2004; von Gontard et al, 2011).

COMORBIDITY

Overall, 30-50% of all children with encopresis have a comorbid emotional or behavioral disorder. This means, that three to five times more children with encopresis have additional disturbances in comparison to non-soiling children.

In a large population-based study of children aged 7½ years, children with encopresis had significantly increased rates of separation anxiety (4.3%), specific phobias (4.3%), generalized anxiety (3.4%), ADHD (9.2%) and oppositional defiant disorder (11.9%) (Joinson et al, 2006). In other words, children with fecal incontinence show a heterogeneous pattern of both internalizing and externalizing disorder comorbidity. Regarding subtype, encopretic children with constipation

Table C.5.3 Standard and extended assessment of encopresis

Standard assessment (sufficient for most cases)

- History
- Questionnaires and scales
- Physical examination
- Sonography (not in all centers)
- Screening for behavioral disorders or full child psychiatric assessment

Extended assessment (only if indicated)

- Stool bacteriology
- Radiology:
  - Plain abdominal x-ray
  - Colon contrast X-ray
  - MRI of colon
- Manometry
- Endoscopy and biopsy

have similar rates of behavioral scores in the clinical range as children without constipation (Benninga et al, 1994; 2004). In other words, they cannot be differentiated according to the behavioral comorbidity.

DIAGNOSIS

The assessment of children with encopresis should be as non-invasive as possible, and should always include parents or other caregivers. For most children, a basic evaluation that can be conducted in many primary care settings is sufficient (Table C.5.3).

The history is the most important aspect of assessment. If conducted correctly and empathically, the most relevant information will be gathered through the history. It is worthwhile to take enough time during the initial consultation. Useful questions for a detailed history can be found in Appendix C.5.1.

Questionnaires can be a useful and time-saving procedure to gain information and to check if the information obtained through history is complete. A short questionnaire is shown in Appendix C.5.2.

A very useful chart is the Bristol Stool Chart. Seven types of stool forms are depicted ranging from “separate hard lumps, like nuts (hard to pass)” (type 1) to “watery, no solid pieces, entirely liquid” (type 7). The scale enables parents and children to identify the predominant type of stool easily and without lengthy descriptions. The course of treatment can also be monitored using this scale.

Each child should have a physical examination. Both a general pediatric and a neurological examination are recommended. The perianal and perigenital areas should be inspected. Spine, reflex differences and asymmetries of buttocks should be noted. A rectal examination should be performed at least once. If sonography is available, this can replace the rectal exam if no organic form or fecal incontinence is suspected.

If available, sonography of abdomen, kidneys, bladder and retrovesical region is helpful. The most important finding is an enlarged rectal diameter of >25-30 mm in children with constipation (Joensson et al, 2008). In these cases, a rectal examination can be avoided. If sonography is not possible, a standard rectal exam should be performed and rectal masses can be palpated.

Due to the high comorbidity rate, a child psychiatric assessment is recommended in child psychiatric settings. In other settings, screening with validated questionnaires (such as the Child Behavior Checklist; Achenbach, 1991) is recommended. If scores are in the clinical range, further assessment or child psychiatric referral is recommended (von Gontard et al, 2011).

All other examinations are not routinely indicated – only if an organic type of fecal incontinence is suspected. It is important to avoid unnecessary and invasive investigations. Further details regarding assessment can be found in von Gontard and Neveus (2006).

Differential diagnosis

Somatic causes are present in 5% of children with chronic constipation and must be ruled out. These include anatomic causes such as anal fissures, abscesses, skin tags, dermatitis, anal stenosis and other ano-rectal malformations. Metabolic and endocrine causes include cystic fibrosis, celiac disease, cow milk intolerance/ allergy, diabetes mellitus and hypothyroidism. Neurological causes include cerebral palsy, spina bifida and myelomeningocele. Constipation can also be caused by various drugs (von Gontard and Neveus, 2006).

The most important differential diagnosis is Hirschsprung's disease, which affects 1:5000 infants and is an intrinsic neuromuscular disease of the gastrointestinal tract characterized by aganglionosis. Symptoms begin in the neonatal period with vomiting, abdominal distension, and food refusal. Older children can have small caliber stools, while soiling is a rare symptom. Most cases (80%) are diagnosed by the age of 4 years (Felt et al, 1999).

Organic causes in non-retentive fecal incontinence are much less frequent affecting a maximum of 1% of children. The most important are infectious diarrhea, neurological conditions such as *spina bifida occulta* and postoperative residual symptoms.

TREATMENT

Following assessment, children and parents are given detailed information on the subtype of encopresis (psychoeducation). As in the treatment of enuresis, unspecific factors such as enhancing motivation and building a good therapeutic relationship are helpful. Feelings of guilt, dysfunctional parental attributions ("my child is doing this on purpose") and frustration can be verbalized. Ineffective parental interventions such as punishment or non-indicated medication can be discussed with parents. If the child's food intake is restricted to low fiber foods, a change in the child's diet can be useful. Also, the amount of fluids should be increased, as many children do not drink enough during the day.

Toilet training

A baseline period with observation and recording is not necessary. Instead, toilet training is initiated right from the start. This training is indicated for both

types of encopresis. Children are asked to sit on the toilet three times a day, after mealtimes. This time is especially useful as the postprandial defecation reflexes are then most active. Children are asked to sit on the toilet five to ten minutes in a relaxed way, for this, it is important that their feet touch the floor. Otherwise a little foot-stool should be provided. These toilet sessions should be experienced in a positive way: children are allowed to read comics, books, play with computers or cell phones, draw pictures, etc. They do are not expected to pass urine or stools every time. These toilet sessions are documented in a chart as depicted in Appendix C.5.3. If necessary, the co-operation of the child can be enhanced positively by a simple token system with small rewards. All criticism or punishment should be avoided.

Laxatives

In *non-retentive fecal incontinence*, this toilet training is the main aspect of treatment. Laxatives are not indicated. In children with *constipation*, toilet training is combined with laxatives: first *disimpaction*, then maintenance treatment.

Disimpaction is necessary to evacuate fecal masses at the beginning of treatment. This can be performed rectally or orally. In rectal disimpaction, enemas are applied. The most widely used and recommended are enemas containing phosphates such as sodium hydrogen phosphate and sodium monohydrogen phosphate. Recommended doses are 30ml/10kg of bodyweight or half an enema for pre-school children, ¾ to one enema in school children. Often, these have to be repeated several times. An alternative is oral disimpaction with polyethylenglykol (PEG; macrogol). Large doses of up to 1.5g/kg body weight per day are given. Sufficient oral fluids are required for this osmotic laxative to be effective.

Once large stool masses have been passed, a lower maintenance dose should be given. Through these procedures success is achieved in 80% of children with rectal and 68% with oral disimpaction, both leading to a normalization of colon transit times (Bekkali et al, 2009).

Maintenance treatment

After successful disimpaction, a long-term maintenance treatment over a minimum of six months to two years should follow to avoid re-accumulation of stool masses (Felt et al, 1999). In addition to toilet training three times a day after mealtimes, oral laxatives are given. The standard and most effective laxative is polyethylglykol (PEG; macrogol), a long, linear polymer that binds water (Candy & Belsey, 2009; Pijpers et al, 2009). Side effects such as abdominal pain are rare. The initial dose is 0.4g/kg bodyweight per day in two doses. If stools are too hard, the dose is increased, if too soft, reduced. The therapeutic range varies from 0.2g/kg to 1.4g/kg bodyweight per day (Nurko et al, 2008). Lactulose, a disaccharide, is less effective and has more side effects. The dosage of liquid lactulose ranges from 1ml/kg to 3ml/kg bodyweight per day in one to three doses.

If comorbid emotional and behavioral disorders are present, these need to be treated separately. Untreated comorbid disorders will reduce adherence and compliance and outcome of encopresis treatment will not be optimal.

COURSE AND OUTCOME

The untreated long-term course of both types of encopresis is not favorable. Constipation and non-retentive fecal incontinence can persist into adolescence and even young adulthood (see epidemiology). Therefore, encopresis needs to be treated actively and patients should be seen at regular intervals. In case of constipation, laxatives should be given for long enough; two years or longer in some children.

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Appendix C.5.1

TAKING A CLINICAL HISTORY OF ENCOPRESIS AND CONSTIPATION: EXAMPLES OF QUESTIONS*

Presentation

- Do you know why you are here?
- Is it because you soil your pants?
- Do you want to talk about it?

Frequency of encopresis

- Does your child soil during the day?
- How often does he** soil during the day (days per week; days per month)?
- How often does he soil each day (times per day)?
- At what time of day does he usually soil (morning, noon, in the afternoons, evenings)?
- Does your child soil during the night?
- How often does he soil during the night?

Symptoms

- If your child soils, how large are the stools (only smearing; smearing and stool masses; only stool masses)?
- What is the consistency of his stools (hard, soft, watery – show the Bristol Stool Chart)?
- In which situations does he soil?
- Does he soil in stressful situations?
- Can he postpone defecating if no toilet is available, e.g. while driving? If yes, for how long?

Relapses

- Has your child ever had a period in its life without soiling?
- If yes, what was the longest period?
- At what age did this occur?
- Was there a reason for the relapse (no, constipation, diarrhea, pain while defecating, going to kindergarten, going to school, birth of a sibling, separation of parents, other life events)?

Toileting behavior

- Does he wear a diaper?
- If yes, when (during the day, at night only, both day and night)?
- How many days per week does he pass stools into the toilet?
- How many times per day does he defecate?
- How large are the stools in the toilet?
- Do you have to send him to the toilet? If yes, is this effective?
- Does he enough time when going to the toilet? If yes, how long?
- Does he play or read while sitting on the toilet?

Associated symptoms

- Does your child go to the toilet regularly, at certain times of the day? If yes, when?
- Does he have difficulty passing stools?
- Does he have to strain?
- Is defecation painful?
- What is the consistency of the stools in the toilet (hard, soft, watery, with different consistencies, with blood – show Bristol Stool Chart)?
- Does he complain of stomach or abdominal pain? If yes, how often?
- How strong is this pain?
- When does he experience stomach pains? Before or after meals?
- Is pain relieved after going to the toilet?
- Does he pass wind?

Perceptions and reactions after soiling

- Does your child notice when he has soiled?
- Do you notice when he has soiled?
- How do you notice it?
- Does he tell you when he has soiled?
- If no, does he try to conceal it? Does he hide his underpants?
- How does he react when he has soiled (indifferent, no reaction, sad, anxious, disappointed, ashamed, desperate, angry or other reactions)?
- Who removes the stools from the clothing (or the bed)?
- Is he upset about the soiling? If yes, how much?
- If yes, how does this distress show?
- Is he motivated for treatment?

Reaction of parents and others in the child's environment

- How do you react when your child has soiled?
- Are you distressed by his soiling? If yes, how much?
- Have you punished him because of the soiling?
- Do you think he soils on purpose?
- Who knows that he soils?
- Has he been rejected by peers because of the soiling? If yes, how?
- How often does this occur?
- Has he been unable to take part in activities because of the soiling? If yes, which activities (school outings, swimming, others)?
- Does he engage in sports? If yes, what sports?

Eating and drinking habits

- How much fluid does your child drink per day?
- Does he prefer to eat low fiber foods? If yes, which ones?
- Does your child prefer to eat other specific types of foods? If yes, which ones?

Previous treatment

- Has your child taken laxatives? If yes, which ones? For how long?
- Has he been examined because of the soiling? If yes, where and when?
- Has he been treated because of his soiling? If yes, where and when?
- What have you personally done to treat the soiling?

Family history

- Has anyone else in your family soiled?
- Have members of your family been affected by constipation? Nighttime or daytime wetting?
- Has anyone had illnesses of the kidney, stomach or bowels?

* von Gontard & Neveus, 2006; von Gontard, 2010.

**He or she as appropriate

Appendix C.5.2

ENCOPRESIS QUESTIONNAIRE – SCREENING VERSION*

Questions	Answers	
Frequency of encopresis		
Does your child soil during the day?	☐	yes
	☐	no
How often does your child soil during the day?	_____	days per week
	_____	days per month
How often does your child soil per day?	_____	times per day
Does your child soil during the night?	☐	yes
	☐	no
How often does your child soil during the night?	_____	nights per week
	_____	nights per month
Encopresis symptoms		
If your child soils, how large are the stool masses?	☐	only smearing
	☐	smearing and stool masses
	☐	only stool masses
What is the consistency of your child's stool?	☐	hard
	☐	soft
	☐	watery
Relapses		
Has your child ever had a period in its life without soiling?	☐	yes
	☐	no
If yes, at what age did this occur? - from age of	_____	years; months
- to age of	_____	years; months
Toileting behavior		
On how many days per week does your child pass stools into the toilet?	_____	days per week
How many times per day does your child defecate?	_____	times per day
How large are the stool masses in the toilet?	☐	small
	☐	medium
	☐	large

What is the consistency of your child's stool in the toilet?	☐	hard
	☐	soft
	☐	watery
	☐	with blood
Is defecation painful for your child?	☐	yes
	☐	no
Does your child have stomach or abdominal pains?	☐	yes
	☐	no
Perceptions and reactions after soiling		
Does your child suffer emotionally due to the soiling?	☐	yes
	☐	no
Is your child motivated for treatment?	☐	yes
Have you punished your child because of its soiling?	☐	yes
	☐	no
Wetting		
How often does your child go to the toilet to urinate?	_____	Times per day
Does your child wet during the day?	☐	yes
	☐	no
If yes, how often?	_____	Days per week
Does your child wet at night?	☐	yes
	☐	no
If yes, how often?	_____	Days per week
How much fluid does your child drink per day?	_____	Litres per day

*von Gontard and Neveus, 2006 ; von Gontard, 2010.

Appendix C.5.3

DOCUMENTING TOILET TRAINING (ENCOPRESIS CHART)*

Date		Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning								
Sent to toilet (→) **Went alone (!)**								
Pants:	dry (D) Wet (W) Stools, small (S) Stools, large (L)							
Toilet:	Urine (U) Stools (S)							
Midday								
Sent to toilet (→) **Went alone (!)**								
Pants:	Dry (D) Wet (W) Stools, small (S) Stools, large (L)							
Toilet:	Urine (U) Stools (S)							
Evening								
Sent to toilet (→) **Went alone (!)**								
Pants:	Dry (D) Wet (W) Stools, small (S) Stools, large (L)							
Toilet:	Urine (U) Stools (S)							

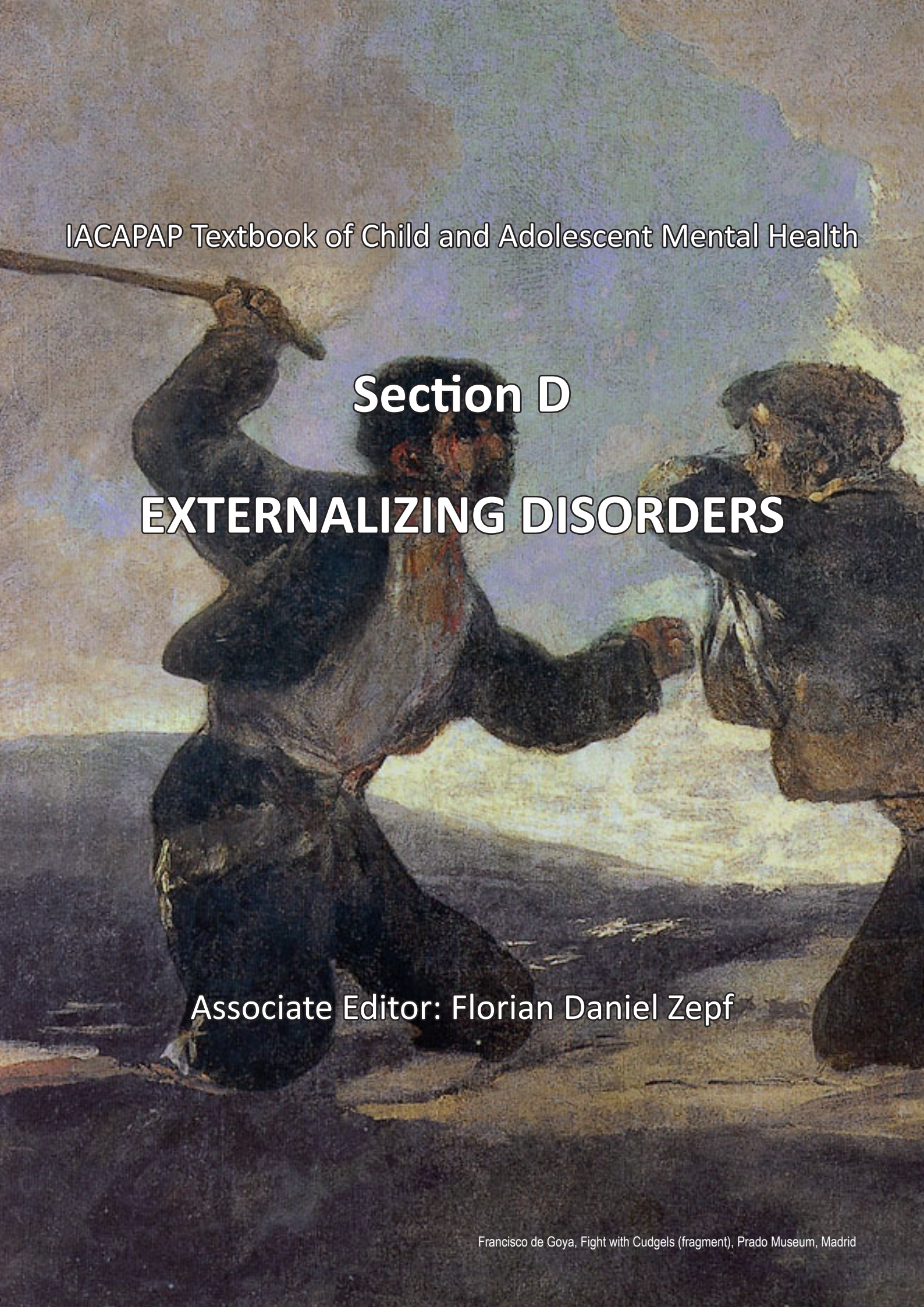
*von Gontard and Neveus, 2006; von Gontard, 2010.

IACAPAP Textbook of Child and Adolescent Mental Health

Section D

EXTERNALIZING DISORDERS

Associate Editor: Florian Daniel Zepf



Francisco de Goya, Fight with Cudgels (fragment), Prado Museum, Madrid

ATTENTION DEFICIT HYPERACTIVITY DISORDER

Tais S Moriyama, Aline J M Cho, Rachel E Verin, Joaquín Fuentes & Guilherme V Polanczyk



Tree climbing
(Vauvau, 2009)

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Conflict of interest: none reported

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Suggested citation: Moriyama TS, Cho AJM, Verin RE, Fuentes J, Polanczyk GW. Attention deficit hyperactivity disorder In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

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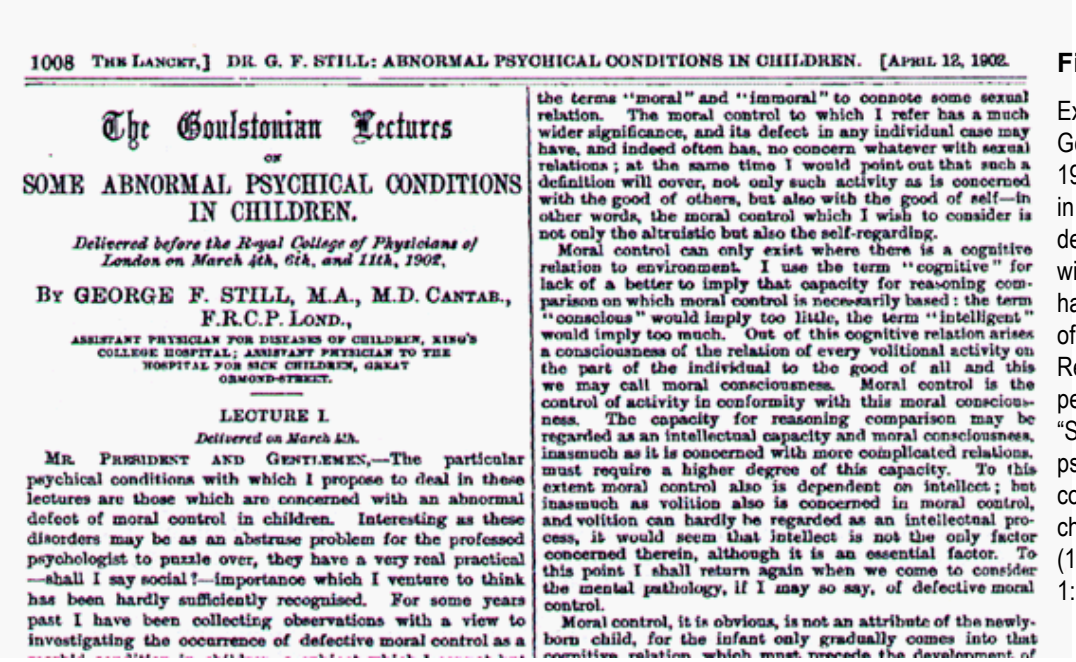
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Although attention difficulties, impulsivity and hyperactivity are common in the general population and may represent transitory or normative developmental patterns, certain individuals have a typical course and combination of symptoms associated with functional impairment, with well-known risk factors, abnormal neuropsychological functioning and neurobiological correlates. These individuals are affected by attention-deficit/hyperactivity disorder (ADHD), one of the most common mental disorders among children and adolescents, with approximately 5% of children under 18 years affected worldwide (Polanczyk et al, 2007). This chapter describes how to identify and treat such individuals.

HISTORICAL NOTE

ADHD has long been described in the medical literature. Heinrich Hoffmann (1809-1894), a German psychiatrist, was the first to describe children whose behavior was marked by impulsivity and hyperactivity. He named this behavioral problem "impulsive insanity" or "defective inhibition". In 1902 the pediatrician George Still published in *The Lancet* a description of children with motor agitation, attention problems, difficulty in controlling impulses and need for immediate reward (Still, 1902; Figure D.1.1). In his description he attributed the behavioral characteristics to the fact that these children had "no consideration for others" and called the disorder "deficit of moral control". This historical misconception is emblematic of the stigma associated with ADHD symptoms: affected children are commonly misinterpreted as having control over their behavior and being responsible for their symptoms. In the following decades the syndrome was associated with brain lesions and the disorder was named *minimal brain damage* (Hohman, 1922, Kahn & Cohen, 1934). This label brought to the disorder the status of a biological rather than a moral problem but carried the incorrect assumption that ADHD was the result of a brain injury. Later it was recognized that not all children had physical observable lesions and thus it was renamed *minimal brain dysfunction* (Clements & Peters, 1962). In 1934 Kramer-Pollnow described a syndrome he referred to as *hyperkinetische Erkrankung*



1008 THE LANCET,] DR. G. F. STILL: ABNORMAL PSYCHICAL CONDITIONS IN CHILDREN. [APRIL 12, 1902.

The Goulstonian Lectures
ON
SOME ABNORMAL PSYCHICAL CONDITIONS IN CHILDREN.

Delivered before the Royal College of Physicians of London on March 4th, 6th, and 11th, 1902,

BY GEORGE F. STILL, M.A., M.D. CANTAB., F.R.C.P. LOND.,
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LECTURE I.

Delivered on March 4th.

MR. PRESIDENT AND GENTLEMEN,—The particular psychical conditions with which I propose to deal in these lectures are those which are concerned with an abnormal defect of moral control in children. Interesting as these disorders may be as an abstruse problem for the professed psychologist to puzzle over, they have a very real practical—shall I say social?—importance which I venture to think has been hardly sufficiently recognised. For some years past I have been collecting observations with a view to investigating the occurrence of defective moral control as a

the terms "moral" and "immoral" to connote some sexual relation. The moral control to which I refer has a much wider significance, and its defect in any individual case may have, and indeed often has, no concern whatever with sexual relations; at the same time I would point out that such a definition will cover, not only such activity as is concerned with the good of others, but also with the good of self—in other words, the moral control which I wish to consider is not only the altruistic but also the self-regarding.

Moral control can only exist where there is a cognitive relation to environment. I use the term "cognitive" for lack of a better to imply that capacity for reasoning comparison on which moral control is necessarily based: the term "conscious" would imply too little, the term "intelligent" would imply too much. Out of this cognitive relation arises a consciousness of the relation of every volitional activity on the part of the individual to the good of all and this we may call moral consciousness. Moral control is the control of activity in conformity with this moral consciousness. The capacity for reasoning comparison may be regarded as an intellectual capacity and moral consciousness, inasmuch as it is concerned with more complicated relations, must require a higher degree of this capacity. To this extent moral control also is dependent on intellect; but inasmuch as volition also is concerned in moral control, and volition can hardly be regarded as an intellectual process, it would seem that intellect is not the only factor concerned therein, although it is an essential factor. To this point I shall return again when we come to consider the mental pathology, if I may so say, of defective moral control.

Moral control, it is obvious, is not an attribute of the newly-born child, for the infant only gradually comes into that

Figure D.1.1

Excerpt from George Still's 1902 paper in which he describes children with ADHD as having a "deficit of moral control". Reprinted with permission from "Some abnormal psychical conditions in children. Still G (1902). Lancet, 1:1008-1012.



Figure D.1.2

Der Struwwelpeter, an illustrated book portraying children misbehaving ("Impulsive Insanity/Defective Inhibition") by Heinrich Hoffman (1854).

(hyperkinetic disease) characterized by restlessness and distractibility (Sharkey & Fritzgerald, 2007). In 1937 the first effective treatment for ADHD was described by Bradley who reported that benzedrine could decrease hyperactivity and improve attention and academic performance (Bradley, 1937).

Hyperactivity was the symptom used to name the disorder when first included in the World Health Organization's International Classification of Diseases, 9th edition (ICD-9) as "hyperkinetic syndrome of childhood" (subsequently called "hyperkinetic disorder" in ICD-10) and in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders second edition (DSM-2) ("hyperkinetic reaction of childhood"). It is only since 1980 that inattention was also emphasized and the disorder was reconceptualized as "attention-deficit disorder with or without hyperactivity" (DSM-III) and subsequently "attention-deficit hyperactivity disorder" (DSM-III-R and DSM-IV).

EPIDEMIOLOGY

Prevalence estimates of ADHD vary depending on the criteria used. A recent systematic review pooled data from 102 studies from all over the world and computed a rate of 5% for individuals bellow 18 years of age, 6% for school age children and 3% among adolescents (Polanczyk et al, 2007). Although estimates were heterogeneous, there was no clear evidence of variation across cultures.

Pooled data confirmed a higher prevalence among males than females, a widely acknowledged clinical observation.

ETIOLOGY AND RISK FACTORS

ADHD is a familial disorder with a strong genetic component. Its heritability (the proportion of variance attributed to additive genetic factors) has been estimated as 76% (Faraone et al, 2005), one of the highest among the mental disorders. Nevertheless, genetic factors alone do not explain the disorder's occurrence. The etiology of ADHD is considered to be multifactorial, that is, multiple environmental, genetic and biological factors play a role in increasing the risk for the disorder.

A number of candidate genes have been associated with ADHD, particularly genes related to catecholaminergic systems, but each gene seems to be responsible for only a small increase in the risk of developing the disorder (Faraone et al, 2005). Furthermore, studies that scan the whole genome without an *a priori* hypothesis, the so called *genome-wide association studies,* did not add new polymorphisms to the current knowledge (Neale et al, 2010). This apparent contradiction between a high heritability and negative results from genome-wide association studies has encouraged research for alternative etiological hypotheses. One possibility is that the disorder emerges from the interaction between genetic and environmental factors (Nigg et al, 2010). In fact, gene-environment interactions have been reported for the interaction between intra-utero tobacco exposure and variations of DAT1 and DAT4 genes (Nigg et al, 2010).

A number of environmental risk factors have been tested for their association with ADHD (Banerjee et al, 2007). Prematurity seems to be the factor most consistently associated with ADHD (Bhutta et al, 2002). Limited evidence also points to intra-utero exposure to tobacco (Langley et al, 2005; Linnet et al, 2003) and low birth weight (Hack et al, 2004; Mick et al, 2002) as possible risk factors. More studies are needed to assess the impact of intra-utero exposure to alcohol and drugs, maternal psychological problems during pregnancy, perinatal and pre-natal complications, traumatic brain injury, duration of breastfeeding, early deprivation and familial and psychosocial factors as well as intrauterine exposure to caffeine (Linnet et al, 2003) and birth in specific seasons of the year (Atladottir et al, 2007). It is also prudent to remember that no conclusive data exist linking ADHD to food additives, environmental toxins and computer games.

The main risk factors already identified are:

- Genes (DAT1, DRD4, DRD5, 5HTT, HTR1 B, SNAP25)
- Prematurity
- Intra-uterus exposure to tobacco
- Low birth weight

A number of causal agents, both genetic and environmental, can contribute to the development of ADHD. However, each individual risk factor explains only a small proportion of the risk of developing the disorder. None of the risk factors identified are necessary for the development of ADHD, they are non-specific and related to other mental disorders and neurodevelopmental abnormalities as well.

Neurobiology of ADHD

A growing body of evidence has associated ADHD with specific neurobiological deficits. It is important to note however that the neuroanatomical deficits implicated in ADHD cannot be interpreted as *brain damage*; they represent slight differences in mean values when samples of patients with ADHD are compared to controls. Furthermore none of the deficits identified so far are crucial for the development of the disorder, they cannot be linked to ADHD in a causal way and cannot yet be used for diagnostic purposes.

Convincing data exist supporting a frontal-striatal dysfunction in ADHD (Castellanos et al, 2006). According to these data, individuals with ADHD would have deficits in executive functions and inhibitory control that are anatomically associated with thalamo-cortico-striatal circuits. Activity in these

What is the Internet doing to our brains?

In recent years concerns have emerged about the potential harm of Internet use and computer games by children. Click on the picture to view a talk by Professor Paul Howard Jones discussing this issue (26:30).



circuits is mediated by GABA and modulated by catecholamines (dopamine and norepinephrine) (Kieling et al, 2008). In fact the evidence points to a catecholaminergic dysregulation associated with the disorder (Kieling et al, 2008; Taylor & Sonuga-Barke, 2008; Swanson et al, 2007):

- ADHD symptoms are alleviated by dopaminergic and noradrenergic agonists such as methylphenidate, amphetamine and atomoxetine
- A number of genes associated with cathecolaminergic systems increase the risk for the disorder
- In animal models it is possible to mimic ADHD symptoms by decreasing cathecolaminergic function
- Noradrenaline and dopamine are key neurotransmitters in brain regions associated with ADHD.

A large and well-conducted prospective study has shown that ADHD children show an overall delay in cortical maturation (measured by cortical thickness) when compared to controls (see Figure D.1.3). The delay was more prominent in areas related to attention, particularly the lateral pre-frontal cortex (Shaw et al, 2007).

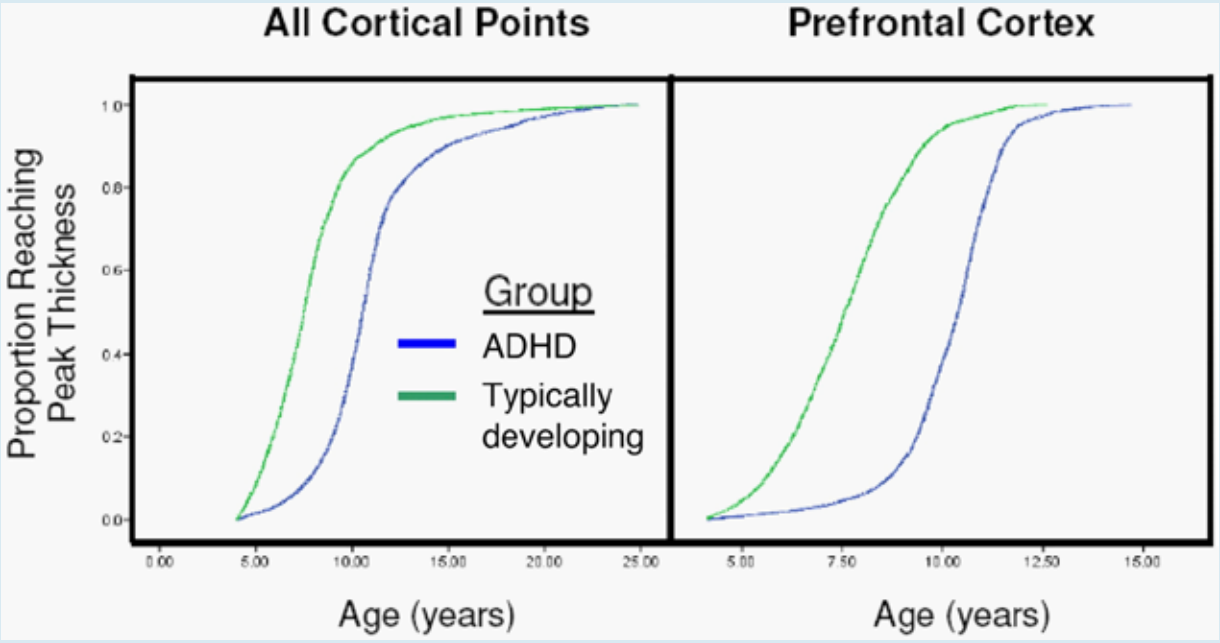


Click on the picture to hear Russell Barkley PhD describe his understanding of executive functions and their relevance for ADHD

CLINICAL PRESENTATION

ADHD is characterized by symptoms of *inattention*, *hyperactivity* and/or *impulsivity*. By definition, onset of symptoms must be early in childhood and differ from what is expected in normal development.

Figure D.1.3 Kaplan–Meier curves illustrating the proportion of cortical points that had attained peak thickness at each age for all cerebral cortical points (Left) and the prefrontal cortex (Right).



Shaw P et al. PNAS 2007;104:19649-19654 ©2007 by National Academy of Sciences; reproduced with permission.

Inattention refers to a behavioral pattern in which the individual has difficulty initiating, remaining engaged in and completing a task. Inattentive children struggle to organize tasks and activities, to listen when spoken to, to plan or execute actions. Inattention also includes distractibility, forgetfulness, frequent loss or difficulty keeping track of objects. In adolescents and adults it is common to observe distorted time perception; patients commonly underestimate time in relation to tasks to be executed and tend to procrastinate.

Hyperactivity is characterized by:

- Excessive physical activity
- Constant feelings of restlessness, making patients incapable of remaining still even in situations in which that is expected
- Non-goal-directed motor activity; that is, activity is purposeless and affects the environment in a negative way (frequently standing up and walking purposelessly when they should remain seated, or move the hands and manipulate small objects when they are expected to remain still)
- Frequent fidgeting or squirming in their seat
- Inability to play quietly
- Talking too much, running around or climbing when it is inappropriate.

Impulsivity refers to difficulty in delaying an action or response even when it is known that this action will have negative consequences. Impulsiveness is associated with the need for immediate over delayed gratification, even when the postponement would lead to better results. Impulsive behaviors manifest themselves as difficulty waiting one's turn to speak, in games and play activities or crossing the street. It can manifest also as a tendency to act without thinking. For example, giving immediate answers irrespective of their accuracy, giving answers not related to the question, or blurting out answers before the question is finished.

Parents may hesitate in accepting an ADHD diagnosis based on the perception that the child is able to remain focused when performing specific tasks such as playing videogames, watching television or in certain situations. It is important to highlight that motivation, the relevance and attractiveness of the task for the child, and the environment largely influence the manifestation of symptoms.

Differences in presentation according to age

Clinical presentation varies according to developmental stage. Table D.1.1 lists the most common symptoms according to age. Evaluation of hyperactivity, inattention, and impulsiveness among *preschoolers* is particularly difficult since these behaviors are normal in this age group; they can be considered abnormal only when they are very severe, pervasive and cause significant impairment of functioning (Byrne et al, 2000). In the school years children with ADHD will frequently draw attention to themselves for their poor school performance and attention problems; they are identified more easily than in preschoolers. Hyperactivity tends to decrease during adolescence or to change into subjective feelings of inner restlessness.

Underestimation of time by ADHD patients

Experiments have shown that individuals with ADHD underestimate the time needed to complete a task. In these experiments, individuals with ADHD and controls were instructed to perform a task (for example sorting books alphabetically and by year of publication); before doing so they were asked how long they believed it would take them to complete the task. Afterwards, time spent to complete the task was recorded and the time actually needed to do the task was compared with the time estimated. Compared to controls, individuals with ADHD underestimated the time needed to complete the task.



For educational videos and other materials, click on the picture to access the American Academy of Child and Adolescent Psychiatry Resource Center on ADHD

Table D.1.1 Changes in ADHD symptoms from childhood to adulthood

	Preschool years	Primary school years	Adolescence	Adulthood
Inattention	• Short play sequences (<3 min) • Leaving activities incomplete • Not listening	• Brief activities (<10 min) • Premature changes of activity • Forgetful; disorganized; distracted environment	• Less persistence than peers (<30 min) • Lack of focus on the details of a task • Poor planning ahead	• Details not completed • Appointments forgotten • Lack of foresight
Overactivity	• "Whirlwind"	• Restless when calm expected	• Fidgety	• Subjective feelings of restlessness
Impulsivity	• Does not listen • No sense of danger (hard to distinguish from oppositionality)	• Acting out of turn; interrupting other children and blurting out answers • Thoughtless rule-breaking • Intrusions on peers; accidents	• Poor self-control • Reckless risk-taking	• Motor and other accidents • Premature and unwise decision-making • Impatience

Source: Taylor E, Sonuga-Barke E (2008), "Disorders of attention and activity" In Rutter M et al (eds), Rutter's Child and Adolescent Psychiatry, p. 522. ©Blackwell Publishing Limited, with permission.

ADHD in DSM-5

Reviews of the DSM and ICD classifications are in progress. Proposals for DSM-5 are not yet finalized. Proposed options include:

1. Classifying ADHD under the heading "neurodevelopmental disorders" (together with intellectual disability, communication disorders and autism spectrum disorders, among others), instead of under the current heading of "attention deficit and disruptive behavior disorders."

2. Overall structure. Proposed options are:
   - Keeping the same structure as in DSM-IV (three subtypes: combined, predominantly hyperactive, and predominantly inattentive)
   - Keeping the existing structure but without subtypes
   - Replacing the existing structure with one diagnosis only: "combined ADHD".

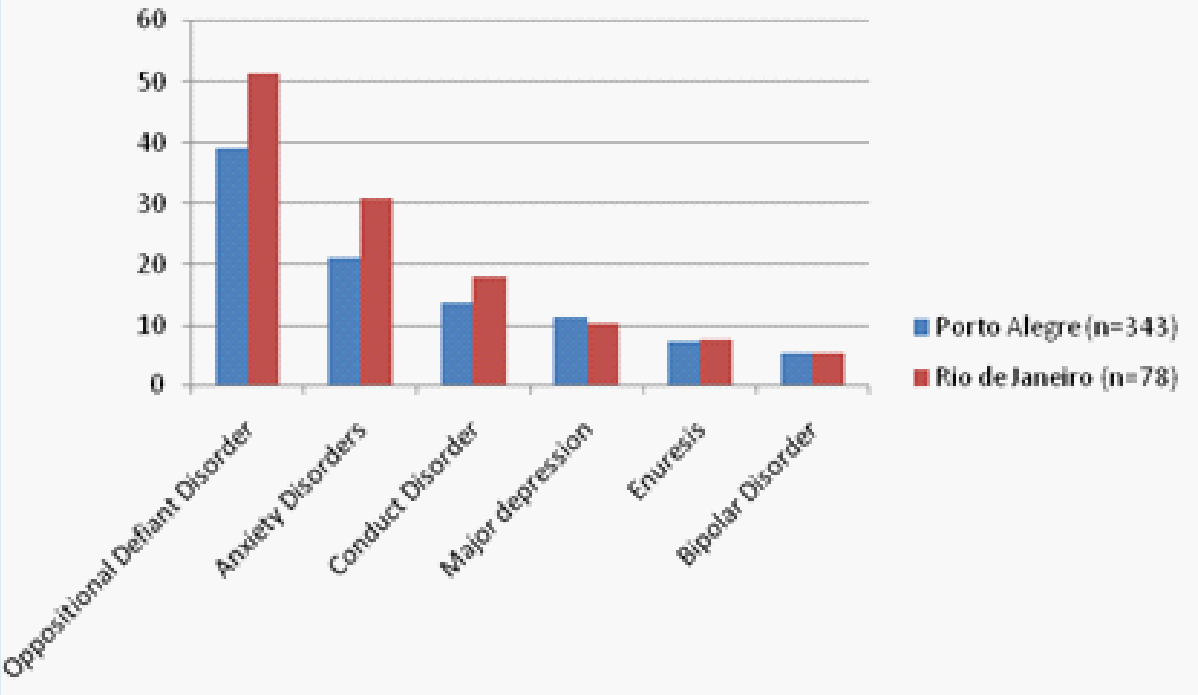
3. Predominantly inattentive ADHD.

   Apart from no change, options considered include:
   - Redefining a "restrictive predominantly inattentive" subtype
   - Creating a new diagnosis of "attention-deficit disorder".

4. Number, content, and distribution of criteria. The options considered include:
   - No change
   - Increasing the total number of symptoms by adding four new impulsivity criteria (often acts without thinking; is often impatient; often rushes through activities or tasks, is fast paced; often has difficulty resisting immediate temptations or appealing opportunities, while disregarding negative consequences).

5. Age of onset of symptoms. The options considered are no change or increasing the age of onset of symptoms to be present "on or before age 12" (instead of the current "before age 7")

Figure D.1.4 Comorbid disorders in community samples of individuals with ADHD in two Brazilian cities



Adapted with permission from Souza et al (2004), "Attention-deficit/hyperactivity disorder and comorbidity in Brazil." European Child & Adolescent Psychiatry, 13:245.

Comorbidity

Children with ADHD often suffer from other psychiatric conditions; systematic screening for the presence of other mental disorders is essential. Figure D.1.4 shows the prevalence of comorbid disorders in two Brazilian cohorts of children with ADHD; oppositional defiant disorder, anxiety disorders, conduct disorders and depression are among the most frequent (Souza et al, 2004).

Detection

Much concern has emerged in recent years about over-diagnosis of ADHD in developed countries (Sciutto & Eisenberg, 2007). However, in less advantaged environments ADHD goes frequently unrecognized and untreated. In a systematic review of community studies conducted in Latin American and Carribbean countries, treatment rates among children with ADHD ranged from none to 7% (Polanczyk et al, 2008). In developing and underdeveloped nations, where access to medical care and information is limited, ADHD is usually not detected and parents and families cope with symptoms as well as they can, for example, by avoiding places or situations where they know symptoms will be especially disruptive (like restaurants or shops). Often teachers are the ones that refer children for treatment. In adolescents and adults, comorbidity is often the factor that leads people to seek treatment. Patients may be referred due to problems such as substance misuse, depression or difficulties in inter-personal relationships.

Individuals affected by ADHD and their families commonly misinterpret symptoms as "part of their personality" or their "way of being." In these circumstances, parents are unlikely to seek medical attention unless the behavior is associated with impaired functioning noticed by others, like academic failure; in this case, teachers are the ones who suggest parents to seek treatment.

Table D.1.2 Comparison between ICD-10 and DSM-IV diagnostic criteria for ADHD

	DSM-IV	ICD-10
Number of symptoms needed for the diagnosis	• 6 or more out of 9 symptoms of inattention OR • 6 or more out of 9 symptoms of hyperactivity/impulsivity	• 6 or more out of 9 symptoms of inattention AND • 3 or more out of 5 symptoms of hyperactivity AND • At least 1 out of 4 symptoms of impulsivity
Age of symptom onset	Before 7 years of age	Before 7 years of age
Minimal duration of symptoms	6 months	6 months
Pervasiveness	Symptoms present in two or more settings (e.g., school, work, home)	Symptoms at school are only needed if applicable for the age and developmental level of the child. Fewer symptoms are required to appear at school (2 out of 4 symptoms of inattention and 3 out of 5 symptoms of hyperactivity)
Sources of information required	Not mentioned	Report of parent or teacher (when appropriate) AND direct observation of symptoms OR significant impairment of performance on psychometric tests of attention.
Exclusion of the diagnosis if	Symptoms occur exclusively during the course of pervasive developmental disorder, schizophrenia or other psychotic disorder, and are not better accounted for by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder or a personality disorder)	Criteria are met for pervasive developmental disorder, mania, depressive or anxiety disorder or IQ < 50
Possible diagnoses	• Attention deficit hyperactivity disorder predominantly inattentive type • Attention deficit hyperactivity disorder predominantly hyperactive-impulsive type • Attention deficit hyperactivity disorder combined type	• Disturbance of activity and attention (the general criteria for hyperkinetic disorder must be met, but not those for conduct disorder) • Hyperkinetic conduct disorder (when criteria for conduct disorder are also met) • Other hyperkinetic disorders • Hyperkinetic disorder, unspecified

DIAGNOSIS

The diagnosis of ADHD is exclusively made on clinical grounds and can follow either DSM-IV (American Psychiatric Association, 1994) or ICD-10 (World Health Organization, 1993) criteria. The child's developmental stage must be considered in clinical evaluation as well as symptom pervasiveness (occurrence in more than one environment, like home and school) and clear evidence of clinically significant impairment in social, academic, or occupational functioning. In younger children it is essential to assess the family environment; where there is chaotic or inconsistent parenting, abuse or neglect, children often respond



Click on the picture to view Russell Barkley PhD arguing that the core problem in ADHD is not inattention but a disorder of self-regulation

behaving in ways very similar to those of ADHD. Ignoring this can easily lead to misdiagnosis.

Symptoms listed in the two classification systems are equivalent. However, to fulfill ICD-10 criteria, symptoms must be present in all three dimensions (attention, hyperactivity and impulsivity) while DSM-IV includes hyperactivity and impulsivity symptoms in the same dimension and states that individuals may present symptoms in only one (out of two) dimension. DSM-IV requires at least 6 out of 9 symptoms of inattention or at least 6 out of 9 symptoms of hyperactivity/impulsivity for the diagnosis of ADHD. In both classifications symptoms need to persist for at least 6 months to a degree that is maladaptive and inconsistent with the developmental stage.

According to DSM-IV, there are three possible subtypes based on the presence or absence of specific symptoms in the past 6 months:

- *Combined* (if criteria for inattention and hyperactivity/impulsivity are met)
- *Predominantly inattentive* (if criteria for attention deficit are met but criteria for hyperactivity/impulsivity are not met)
- *Predominantly hyperactive-impulsive* (if criteria for hyperactivity/impulsivity are met but criteria for inattention are not met).

The predominantly inattentive subtype is more frequent among girls and less common in clinic settings because children are less often referred for treatment due to inattention than hyperactivity. This subtype is commonly associated with poor academic performance, cognitive deficits and delayed development. Predominantly inattentive patients are commonly described as disorganized, quiet, dreamers, and as "staring off into space". The predominantly hyperactive-impulsive subtype is less common both in clinic and community settings. The combined subtype is the most commonly diagnosed subtype in clinic settings. Although all subtypes of ADHD are associated with oppositional defiant behaviors this association is stronger for the combined subtype, making treatment more challenging. Furthermore, the combined subtype is associated with higher functional impairment than the other two types.

Informant

Irrespective of the pervasiveness criterion (presence of symptoms in at least two different settings), it is necessary to have more than one source of information, usually parents *and* teachers. This is because informants (either parents or teachers) observe the child in different contexts, which may influence the occurrence of symptoms, and informants are susceptible to a variety of biases. Parents have a longitudinal view and can give valuable information on their child's neurodevelopmental trajectory. However, they tend to have more difficulties admitting their children's problems. Teachers, on the other hand, are in constant contact with a large number of children of the same age, which allow them to easily identify deviant behaviors, and are aware of objective measures of children's academic performance, which make them more able to detect academic deficits.

Apart from obtaining information from parents and teachers, clinicians should also examine the child, even though symptoms are often absent during the assessment interview. It would be unrealistic to expect observing a child

Controversies about the classification of ADHD

Questions have emerged regarding the classification of ADHD (Rohde, 2008). One relates to the validity and utility of differentiating ADHD into subtypes: subtypes are unstable over time, familial liability seems unspecific, and all subtypes respond to the same drug treatments (Lahey & Willcutt, 2010). Another refers to the need to include functional impairment as a diagnostic criterion because many children with ADHD will have reduced or no impairment because of compensatory skills or extra effort. On the other hand, not including functional impairment as a criterion may lead to over-diagnosis and treatment of children who do not have deficits. A third question relates to the age of onset criterion, that symptoms and associated impairment must emerge before age 7. This is not supported by empirical evidence (Rohde et al, 2000; Polanczyk et al, 2010). In this regard, clinicians should bear in mind that patients must be evaluated individually when considering the need for treatment.

demolishing or running amok in the doctor's office to make a diagnosis of ADHD. Furthermore, examining the child is important in order to exclude other diagnoses. Adolescents should be asked to report symptoms they experienced during childhood. Adolescents often deny symptoms in the past, interpreting such symptoms as normal behaviors or minimizing their impact. Parents' information and school reports may help to determine age of onset of symptoms.

The clinical interview with parents is also important to gather detailed information on peer and family relationships, medical history and investigation for other mental disorders that can co-exist with ADHD. It is important to ascertain whether there is inconsistent or chaotic parenting, abuse or neglect which may lead children to behave similarly to children with ADHD.

Although there is significant overlap between DSM-IV and ICD-10 diagnostic criteria, the latter is more restrictive. ICD-10 hyperkinetic disorder is similar to DSM IV combined subtype, a more severe variant of the condition than the predominantly inattentive and predominantly hyperactive-impulsive types (Lee et al, 2008).

Additional investigations

As already mentioned, the diagnosis of ADHD is clinically-based and no additional tests are necessary unless the clinician suspects the presence of other conditions (American Academy of Pediatrics, 2011). The use of rating scales is helpful in quantifying the presence and severity of specific symptoms and monitoring treatment response. Scales can be completed by parents and teachers and are easy to use; in rare cases in which an underlying physical disorder may be suspected, a specialist opinion may be useful, for example, brief or nighttime seizures can occasionally cause attention problems and restlessness that can be misinterpreted as ADHD; in cases where epilepsy is suspected, a neurological evaluation and EEG is required. The use of EEG for the diagnosis of ADHD, although popular in some countries, is not necessary and there are serious doubts about its validity. Likewise, there is usually no need for imaging studies except when a neurological disorder is suspected.

The majority of neuropsychological tests are copyrigh and expensive, which restricts their use, although specific tests can be of help. Intelligence tests

Figure D.1.3 The STROOP test



The strop test is used to measure attention. It takes advantage of our ability to read words more quickly and automatically than naming colors. The cognitive mechanism involved in this task is called directed attention: one has to manage one's attention, inhibit or stop one response in order to say or do something else. It is one of the tests that, despite not being diagnostic, provides data about attentional ability.

Table D.1.4 Selected Scales for ADHD freely available for clinical use

SCALE (age range)	RATER	COMMENTS
SNAP IV (5–11 years) Swanson et al (2001)	• Self • Parent • Teacher	There are several versions: • 90-item (full version); rates several dimensions of behavior apart from ADHD and includes SKAMP (to measure severity of impairment at school); it takes about 30 minutes to administer • 31-item version (includes rating of ADHD and oppositional defiant disorder); it takes 10 minutes to administer
SWAN (5–11 years) Swanson et al (2001)	• Self • Parent • Teacher	• 26 items
SDQ Strengths and Difficulties Questionnaire (Goodman et al, 2000)	• Self • Parent • Teacher	• Measures overall psychopathology, but a subscale can be used to screen ADHD risk • Reasonably sensible when screening "possible" ADHD illness • Available in several languages

(e.g., Wechsler) can be useful in clarifying intellectual deficits or IQ level and its implications. The Continuous Performance Test (CPT-II), Wisconsin Cart-Sorting test, STROOP test, and "Go/no go" tests are useful for research.

Rating scales

While diagnosis cannot be made on the basis of rating scale data alone, using rating scales is good clinical practice for screening purposes, to measure symptom severity and to monitor response to treatment and outcome. There are numerous rating scales that can be either specific for ADHD or for general psychopathology, most have a child, parent and teacher versions. The table below lists some of the rating scales available in the public domain.

COURSE

Growing evidence indicates that ADHD is a chronic disorder and that symptoms often persist into adult life, although disagreement exists about the extent of this; estimates vary across studies – most of the variation may be due to methodological differences such as definition of persistency (presence of symptoms or the full syndrome) and age when individuals are evaluated (Mannuzza et al, 2003). A recent review found a persistency of 15% for young-adults when presence of the full syndrome is considered, and 40-60% when cases in partial remission are included (Faraone et al, 2006).

Persistence of symptoms seems to be associated with severity. Patients with more severe symptoms and combined type ADHD are at higher risk for persistence (Kessler et al, 2005). Durability of symptoms is also associated with negative outcomes such as lower academic achievement (Mannuzza et al, 1997), marital problems and marriage dissatisfaction, divorce, difficulty dealing with offspring (Barkley & Fischer, 2010), lower job performance, unemployment, maintaining job positions below the individual's potential (Stein, 2008; Mannuzza et al, 1997),

involvement in traffic accidents (Barkley & Cox, 2007) and increased risk for other psychiatric disorders (Mannuzza et al, 1998).

TREATMENT

ADHD interferes with multiple areas of functioning, such as behavior at home, in social situations, school performance; treatment should seek to improve functioning in all these areas. Multimodal interventions with different treatment targets are theoretically optimal, although few studies have directly compared multimodal treatment with pharmacotherapy alone (Abikoff et al, 2004). Many targets for intervention can be enumerated: ADHD symptoms, cognitive deficits and associated behaviors, academic performance, comorbid conditions, parental psychopathology, family and school-based problems. Following assessment, clinicians should decide about targets for intervention and formulate a treatment plan integrating the different modalities needed to achieve all the treatment goals. Treatment plans should be individually tailored to each patient and constantly reviewed and updated according to emerging needs and previous response. A close monitoring of treatment response is required and should include data from different sources, including parents', patients' and teachers' reports of perceived changes following interventions (Pliszka, 2007).

The literature is consistent on the effectiveness of stimulant medications and behavioral interventions in the management of the core symptoms of ADHD (American Academy of Pediatrics, 2011). Pharmacotherapy is effective for most children. Behavioral interventions are also valuable as primary treatment or as an adjunct treatment for many children, depending on the nature of coexisting conditions, outcomes targeted and family circumstances (American Academy of Pediatrics, 2011). Treatment plans should include at least one of these two treatment modalities (see Table D.1.5).



Click on the picture to access the excellent guideline on ADHD treatment by the National Institute for Health and Clinical Excellence (NICE)

The decision to use non-pharmacological versus pharmacological intervention should be based on patient's age, profile of symptoms and disease severity, individual risk for side effects, treatment adherence issues, comorbid disorders, parents' and child's preference, cost, access to medication, and availability of trained therapists.

Education

Clinicians should give adequate information to patients and their families using a language they can understand. The main aims of psychoeducation are to:

- Ensure that patients and their family understand what ADHD is
- Enhance treatment adherence by involving patients and parents in the treatment plan and making sure that they understand the benefits and risks, such as side effects of medication
- Identify barriers to treatment.

Education may also involve school staff; whenever possible clinicians should contact and educate schoolteachers.

Behavior therapy

The effect size of behavioral interventions on ADHD symptoms is smaller than that of stimulant medications (Fabiano et al, 2009). Many guidelines for

behavior therapy in ADHD are available (Bauermeister et al, 2006). In general terms, the therapist identifies problem behaviors and collects detailed data on the circumstances that precede and follow such behaviors. Usually behaviors become ingrained when reinforced. After the identification of reinforcing consequences a detailed plan on how to deal with problematic situations is drawn up and a different set of techniques to stop reinforcing unwanted behaviors or extinguish them is implemented (Antshel & Barkley, 2008). Behavior therapy for ADHD almost always involves parents and teachers as well as the child.

Parent training

Parents can be trained to constructively deal with their child behavior by teaching them how to reinforce desirable behaviors and extinguish misbehavior. For example, how to set and communicate sensible, appropriate and achievable rules and what to do when the child adheres to the rules or breaks them. The strength of evidence for parent behavior training as the first-line intervention for improved behavior among preschoolers at risk for ADHD is high, while the strength of evidence for methylphenidate is low (Charach et al, 2011).

Pharmacotherapy

Many medications have been shown to be effective and safe for children with ADHD. Medications can be divided into stimulants and non-stimulants.

Stimulant medications

Stimulant medications (see Table D.1.3) have been used for decades in the treatment of ADHD and are licensed for this purpose in many countries. The efficacy and safety of these drugs have been extensively examined in numerous clinical trials as well as in systematic reviews and meta-analyses (Swanson et al, 2007; Biederman & Spencer, 2008; Adler, 2007; Adler, 2008; Faraone & Buitelaar, 2010; Faraone & Glatt, 2010). Trials consistently show that stimulants are more effective than placebo, with effect-sizes varying from 0.8 to 1.1 and a positive early clinical response in approximately 70% of cases. Most commonly used stimulant medications include methylphenidate, dexmethilphenidate, dextroamphetamine and mixed amphetamine salts. Other agents such as methamphetamine are available in certain countries. Medications are available in different presentations, including short-acting, long-acting and sustained-release. The main advantage of long-acting and sustained-release preparations is that one dose in the morning may sustain effect during the whole day, increasing adherence. However, they are more expensive, which limits their use. No conclusive evidence exists favoring any of the stimulants over others in terms of efficacy and side effect profile.

Stimulant dosage is not weight dependent. Clinicians should begin with a low dose and titrate upward to achieve optimal response (see Table D.1.3). The best dose is the one that leads to maximum benefit with minimal side effects. Although controlled studies that compare different dosing schedules are lacking, some clinicians believe that interrupting medication during weekends and holidays may compromise its efficacy.

Methylphenidate is available in immediate release and sustained release preparations. Immediate release methylphenidate reaches plasma peak levels in 1 to 3 hours after ingestion. Effects last approximately 4 hours; thus a two- or three-times-a-day schedule is necessary for symptom coverage. Methylphenidate SODAS® is a long-acting formulation in which half the amount is immediately released and the other half is released after 4 hours. Methylphenidate OROS® releases about one quarter of the amount immediately and the rest during the next 9 hours. The two later preparations only require a once-a-day dosage schedule.

There are different amphetamine preparations for ADHD but availability varies between countries. Brand names, dosing and duration of behavioral effect for each of this drugs can be found in Table D.1.3. Lisdexamphetamine has been recently approved for the treatment of children and adults with ADHD in the US,

Table D.1.3 Stimulant drugs available to treat ADHD

Drug	Duration type	Brand name*	Dosage schedule	Approximate duration of action (hours)	Typical starting dose (mg)	Maximum daily dose mg
Methylphenidate	Short-acting	Ritalin Metadate Methylin	BID to TID	3-5	5	60
		Focalin	BID to TID		2.5	20
	Intermediate-acting	Ritalin SR Metadate ER Methylin ER	QD to BID	3-8	10	60
	Extended release	Metadate CD Ritalin LA	QD	8-10	10	60
		Concerta	QD	12	18	72
		Focalin SR	QD	12	5	30
		Daytrana	Patch worn for up to 9 hours		10	30
Amphetamines	Short-acting	Dexedrine Dextrostat	BID to TID	4	5	30
		Adderall	QD to BID	4	5	40
	Intermediate-acting	Dexedrine spansule	QD to BID	10	5	40
	Extended release	Adderal-XR	QD	10	10	30
		Vyvanse	QD	13	30	70

QD: once a day; BID: twice a day; TID: three times a day.
*All may not be available in some countries and brand names may be different.

Canada and Brazil. Lisdexamphetamine is an inactive component (prodrug) that is gradually converted into an active form of dextro-amphetamine in the body. Due to its gradual conversion, effect of Lisdexamphetamine is prolonged – up to 13 hours – thus not needing repeated doses during the day. Another common form of amphetamine approved in some countries for the treatment of ADHD is a preparation of mixed amphetamine salts. It is intermediate-acting and can be taken once or twice a day (see Table D.1.3).

Non-stimulant medications

Non-stimulant medications are considered second line treatments in case of intolerance, contra-indications or treatment failure. Evidence of effectiveness of these drugs, although not as strong as for stimulants, is good for atomoxetine, extended-release guanfacine, and extended-release clonidine (in that order) (American Academy of Pediatrics, 2011):

- ***Atomoxetine*** is a selective noradrenaline reuptake inhibitor (SNRI) that appears to cause a secondary increase in dopamine levels. The estimated effect size of atomoxetine for the treatment of ADHD

Long term efficacy of stimulant medication

Although evidence of the short-term effecticacy of stimulants is very robust, there are very few data on the longer-term effectiveness of these medications. One of the few long-term trials is the NIMH Collaborative Multisite Multimodal Treatment Study of Children with Attention-Deficit/Hyperactivity Disorder (MTA). In this study, 579 children with a mean age of 8 years diagnosed with DSM-IV ADHD combined type were randomly assigned to 14 months of systematic medication management, multicomponent behavior therapy, a combination of both, or usual community care. After 14 months, the MTA became an uncontrolled naturalistic study: children were allowed any treatment and followed up even if treatment was abandoned.

Initial results, at the end of the randomized treatment phase (14 months), showed that all groups had improved over baseline. However, methylphenidate proved to be superior to behavioral treatment and to routine community care. Further, the combined treatment did not produce greater benefits than medication alone for core ADHD symptoms.

By the next follow-up, 3 years after enrolment (when participants were about 12 years of age) there were no significant group differences. This result was confirmed in the next two follow-up assessments at 6 and 8 years (when participants were about 17 years old). While differences between the groups had disappeared, the initial improvement was maintained. However, these adolescents still showed significantly more symptoms and impairment than a community control group. Participants still taking medication by 6 and 8 years performed no better than their non-medicated counterparts despite a 41% increase in the average total daily dose (Abikoff et al, 2004; Molina et al, 2009).

The sobering results of the MTA suggest that maintaining a good treatment response probably requires a sustained effort that takes into account long-term academic and behavioral problems commonly associated with ADHD and adapts to the demands of adolescence. Medication may continue to be helpful for some teenagers, but their needs should be re-evaluated periodically. A child's initial clinical presentation, including symptom severity, behavior problems, social skills and family resources, may predict how they will function as teens more so than the type of treatment they receive.



Click on the picture to view James Swanson's talk at the Karolinska Institute about the MTA study and its long-term results (15:00)

(approximately 0.8) is higher than that of other non-stimulant drugs but smaller than for stimulants (Hazell et al, 2011). Atomoxetine can reduce anxiety symptoms in adults and children and is an option for the treatment of ADHD with comorbid anxiety disorders. It is also preferable for patients with a history of substance misuse (or if there are other household members who use drugs because of the risk of diversion). Compared to stimulants, atomoxetine has a slower onset of action but can be taken once daily. Starting dose is 0.5mg/kg/day that can be increased up to 1.2mg/kg/day. The most frequent adverse events are transitory gastrointestinal symptoms, reduced appetite, sleep problems, increased heart rate and blood pressure. Severe but very rare side effects include hepatotoxicity, with increase in hepatic enzymes, bilirubin and jaundice; emergent suicidal behaviors (both suicidal ideation and attempts) have also been reported.

- ***Clonidine*** and ***guanfacine*** are alpha-2 agonists with demonstrated efficacy in the treatment of ADHD. Guanfacine is more selective than clonidine causing fewer adverse effects such as somnolence. These medications can also be used for patients with comorbid tic disorders or Tourette's syndrome, in which its efficacy seems to be higher. There are now long-acting formulations for both clonidine and guanfacine available.

- ***Modafinil*** is a non-stimulant medication used for the treatment of narcolepsy that has been tested for ADHD; its efficacy has been demonstrated in randomized clinical trials.
- ***Tricyclic antidepressants*** such as imipramine, have also been shown to reduce ADHD symptoms. Nevertheless tricyclic antidepressants are associated with significant side effects, are less effective than stimulant medications and should be used only after failure to respond to two or three stimulants and atomoxetine (AAP, 2011). Tricyclic antidepressants can interfere with cardiac conduction and can cause sudden death; it is important that patients are monitored with electrocardiogram before and during treatment.
- ***Bupropion*** is considered a third line treatment for ADHD; it can be tried in case of failure of stimulants, atomoxetine and alpha-2 agonists. Bupropion lowers seizure threshold in a dose dependent fashion.

Side effects

Side effects must always be discussed in detail with the patient and parents before prescribing medication. The most common side effects associated with psychostimulants are insomnia, headache, irritability, agitation, nervousness, tremor, loss of appetite, nausea and weight loss. These unwanted effects tend to be mild, dose dependent and transitory. Stimulants can exacerbate tics, psychotic and manic symptoms, and seizures in children at risk for such conditions. Although these disorders are not an absolute contra-indications for stimulants, clinicians should consider alternative treatments such as behavior therapy or atomoxetine (in the case of tics, psychotic symptoms and anxiety) and use stimulants only if the potential benefit is greater than the potential harm. For more information on how to monitor and manage side effects see Table D.1.4.

Controversies have emerged in relation to the safety of stimulants in children with ADHD. The main concerns relate to their effect on growth, the cardiovascular system and risk for abuse or diversion.

Sudden death

There is a theoretical potential for all stimulants to increase the risk of sudden cardiac death and stroke. It is not clear whether this risk is dependent on the stimulant used, the individual's participation in strenuous exercise, or possible underlying cardiac risk factors. Methylphenidate has been associated with sudden cardiac death in individuals with structural cardiac abnormalities but there is no evidence that the frequency of heart attack is higher among those using methylphenidate than in the general population (Elia and Vetter, 2010; Stiefel and Besag, 2010). Several large studies and meta-analyses have shown no evidence that current use of an ADHD drug is associated with an increased risk of serious cardiovascular events. Although the risk cannot be ruled out altogether, the absolute magnitude of such an increased risk is very low (Cooper et al, 2011).

Growth retardation

Stimulants may stunt children's growth and may reduce final adult height. There is no doubt that stimulants reduce growth slightly and this needs to be

Table D.1.4 Monitoring and managing medication side effects

Side effect	May occur with:	Monitoring	Management
Loss of appetite or weight loss	• Methylphenidate • Atomoxetine • Amphetamines	• Measure weight before treatment and then every 3-6 months • Plot on a growth chart	• Avoid taking the medication before meals • Give patient and parents dietary advice or refer for dietary advice
Growth retardation	• Methylphenidate • Atomoxetine • Amphetamines	• Measure height before treatment and then every 3-6 months • Plot on a growth chart	• Consider stopping medication during weekends and school holidays • Consider dosage reduction or stop medication if there is clear evidence of growth suppression
Insomnia	• Methylphenidate • Amphetamines	• Gather information about sleep patterns before and after starting treatment	• Consider changing the dose schedule avoiding medication in the afternoon • Reduce dose • Change to atomoxetine
Hepatotoxicity	• Atomoxetine	• Inform parents about risk of liver damage • Monitor ALT and AST levels before and after starting treatment	• Stop atomoxetineimmediately if jaundice or laboratory evidence of liver damage emerges • Change to another medication but do not resume atomoxetine
Abnormal blood pressure or cardiac function	• Methylphenidate • Atomoxetine • Amphetamines	• Before starting medication, collect detailed information about: – Personal and family history of cardiovascular events (particularly sudden cardiac death) – Physical findings suggestive of Marfan's syndrome or long Q-T syndrome • At follow up appointments Monitor heart rate, blood pressure and the presence of abnormal murmurs	• In case of suspected cardiovascular abnormality refer patient to a cardiologist before commencing medication • In case of blood pressure higher than the 95th percentile (or any clinically relevant increase) or arrhythmia/tachycardia, stop the medication and refer to a cardiologist
Seizures	• Methylphenidate • Atomoxetine	• Warn parents about risk of seizures	• Stop medication. • Consider using dexamphetamine.
Tics	• Methylphenidate • Amphetamines	• Monitor the presence of tics before and after starting treatment	• Reduce/stop the stimulant if tics get worse • Discuss with parents and patient the benefits and risks of continuing stimulant treatment • Consider atomoxetine
Anxiety symptoms	• Methylphenidate • Amphetamines	• Investigate presence of anxiety symptoms before and after starting treatment	• Titrate the dose more slowly • In case of worsening or emerging anxiety symptoms consider concomitant treatment of anxiety • Change to atomoxetine

Table D.1.4 (continuation)

Side effect	May occur with	Monitoring	Management
Psychotic symptoms	• Methylphenidate • Amphetamines	• Monitor psychotic symptoms before and after starting treatment	• In case of high risk for, or emerging psychotic symptoms stop stimulants • Consider atomoxetine • If symptoms persist after stopping stimulants treat psychotic symptoms.
Aggressive or hostile behavior and suicidal thinking	• Atomoxetine	• Ask patients about suicidal or aggressive ideation or impulses	• Warn parents about risk for such behaviors before starting treatment • Discuss with parents how to keep their child safe from self-harm • If symptoms persists after one month consider changing to another medication
Drug misuse or diversion	• Methylphenidate • Amphetamines	• Monitor the number of pills prescribed and gather information about behaviors that may suggest abuse/ diversion • Do family members abuse substances?	• Ask parents to monitor or supervise taking the medication • In case of high risk for abuse, suspected abuse or diversion, atomoxetine should be prescribed

discussed with parents and patients. Therefore children's growth ought to be monitored regularly while on stimulants. Growth resumes once stimulants are stopped, stopping the drug suring summer hollidays may minimize the risk of growth retardation when this is a concern. Other options include reducing the dose, stopping or switching to atomoxetine (Pliszka, 2007).

Abuse and diversion

All stimulant medications have potential for abuse. Abuse and diversion (e.g., selling the medication, giving it to friends or relatives, having it stolen), although rare, has increased in recent years in some countries where stimulants are widely prescribed. Abusers often report using stimulants to increase academic performance but recreational use also occurs. Misuse is more common among those with comorbid conduct or substance use disorders. Household members or college students who abuse substances may also steal the medication from patients if not appropriately protected. Although long-acting stimulants may be less likely to be misused or diverted, atomoxetine should be prescribed in these cases (Faraone & Wilens, 2007).

New therapeutic approaches

New therapeutic approaches are emerging. Neurofeedback, a type of biofeedback that uses electroencephalographic signals to promote self-training of brain activity, has shown some positive initial results (Arns et al, 2009). Another intervention under study is cognitive training (Halperin & Healey, 2011). Cognitive training seeks to improve working memory and executive functions

through a variety of means including computer applications. Omega-3 fatty acid supplementation is also receiving considerable attention; some studies suggest that it improves ADHD symptoms (Bloch & Qawasmi, 2011).

To date there is no enough evidence to support the following interventions for the treatment of ADHD:

- Acupuncture (Li et al, 2011)
- Meditation (Krisanaprakornkit et al, 2010)
- Homeopathy (Coulter & Dean, 2007)
- Physical exercise (Gapin et al, 2011)
- Chiropractic care (Karpouzis et al, 2010)
- *Hypericum perforatum* (St John's wort)(Weber et al, 2008)
- Music therapy (Rickson, 2006)
- Bach flower remedies (Pintov et al, 2005), and
- Elimination diets (Pelsser et al, 2011).

Table D.1.5 Summary of recommendations for treatment

Severity	4–5 years of age	6–11 years of age	12–18 years of age
Mild to moderate	• Psychoeducation • Parent training programs • Teacher-administered behavior therapy • If no improvement and symptoms are severe, consider methylphenidate.	• Parent training programs and CBT • If no access to CBT and in severe cases with uncomplicated ADHD: stimulants or atomoxetine • If no response: add stimulants or atomoxetine (first line medications) • If no adequate response or significant side effects: switch to another first line medication (e.g., from methylphenidate to dexamphetamine or to atomoxetine) • If no response and significant comorbidity: try second line medications	• Stimulants or atomoxetine • If no response: add CBT • If no adequate response or significant side effects: switch to another first line medication (e.g., from methylphenidate to dexamphetamine or to atomoxetine) • If no response and significant comorbidity: try second line medications
Severe		• Stimulants or atomoxetine, if possible combined with CBT • If no adequate response or significant side effects: switch to another first line medication (e.g., from methylphenidate to dexamphetamine or to atomoxetine) • If no response and significant comorbidity: try second line medications	• Stimulants or atomoxetine, if possible combined with CBT • If no adequate response or significant side effects: switch to another first line medication (e.g., from methylphenidate to dexamphetamine or to atomoxetine) • If no response and significant comorbidity: try second line medications

First line medications: stimulants, atomoxetine
Second line medications: extended release guanfacine,
Third line medications: extended release clonidine, tricyclic antidepressants, brupopion

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OPPOSITIONAL DEFIANT DISORDER

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Acknowledgments: The authors are grateful Professor Stephen Scott for his helpful comments. Dr Stringaris gratefully acknowledges the support of the Wellcome Trust.

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Suggested citation: Quy K, Stringaris A. Oppositional defiant disorder. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Disruptive behaviour disorders are common and are associated with substantial impairment for both children and their families, and with a range of poorer adjustment outcomes in later development (Ford et al, 2003; Burke et al, 2005; Copeland et al, 2009; Kim-Cohen et al, 2003; Costello et al, 2003). Disruptive behaviour problems are also associated with increased cost to society: it is estimated that the costs arising for individuals with antisocial behaviours in childhood are at least 10 times higher than in non-antisocial individuals by the time they reach 28 years (Scott et al, 2001a).

The two main classification systems, the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV; APA, 1994, 2000) and the International Classification of Diseases, 10th Revision (ICD-10; WHO, 1993) specify oppositional defiant disorder (ODD) as a persistent pattern of defiant, disobedient and antagonistic behaviour toward adults. This disorder is defined by the absence of the more serious acts of aggression or antisocial behaviour associated with conduct disorder.

DIAGNOSIS

The DSM-IV criteria for ODD require four or more symptoms to be present for *at least six months*. Symptoms must occur at a level greater than in individuals of comparable age or developmental stage and must cause 'significant' impairment. A diagnosis of ODD must exclude conduct disorder. Key features of ODD highlighted by ICD-10 guidelines include a persistent pattern of provocative, hostile and non-compliant behaviour, characterised by low temper threshold.

DSM-IV ODD symptoms

- Is often angry and resentful
- Often argues with adults
- Is often touchy or easily annoyed by others
- Often loses temper
- Often deliberately annoys or irritates others
- Often blames others for his or her mistakes or misbehaviour
- Often actively defies or refuses to comply with adult requests or rules
- Is often spiteful and vindictive

EPIDEMIOLOGY

ODD is a relatively common childhood disorder with an estimated prevalence of 2% to 10% (Maughan et al, 2004; Costello et al, 2003). Prevalence estimates may, however, vary depending on factors such as informant source (e.g., parent vs. child) type of report (e.g., concurrent vs. retrospective) and whether or not children meeting criteria for conduct disorder are included. ODD is significantly more common in boys than girls. Symptoms are relatively stable between the ages of five and ten, but are thought to decline after that point. ODD is diagnosed more rarely in older children, partly in order to avoid labelling normative discord between children and their parents during adolescence. Table D.2.1 summarises prevalence rates from a number of large studies.

Cross-cultural differences in prevalence

Data drawn from World Health Organisation and World Mental Health surveys indicate that estimates of the prevalence of ODD vary widely across countries. For example, data from a large-scale international survey published by Kessler et al (2007) demonstrated marked variation in the lifetime prevalence of impulse control disorders (comprising intermittent explosive disorder, oppositional defiant disorder, conduct disorder, and attention-deficit/ hyperactivity disorder).

Relationship between ODD and conduct disorder

The extent to which ODD and conduct disorder should be considered as separate or as a single disorder is the subject of some debate. This is reflected in existing classification systems: in DSM-IV the diagnosis of conduct disorder

Table D.2.1 Estimates of the prevalence ODD

	Age range	Boys (%)	Girls (%)
British Child and Adolescent Mental Health Survey (Meltzer et al, 2000; Ford et al, 2003)	5-10 years	4.8	2.1
	11-15 years	2.8	1.3
The Great Smoky Mountains Study (Costello et al, 2003) – three-month prevalence	9-16 years	3.1	2.1
The Bergen Child Study (Munkvold et al, 2009)	7-9 years	2.0	0.9

can include all of the features of ODD and it is treated as a precursor to conduct disorder. In ICD-10, ODD is thought to only be a milder form of conduct disorder, so the two are considered as a unique category, as they sometimes are in empirical research studies (Kim-Cohen et al, 2003). However, while ODD and conduct disorder have been found to have high levels of comorbidity, the majority of children diagnosed with ODD do not go on to develop conduct disorder (Rowe et al, 2002), and the two disorders are distinguishable by a range of different correlates (Dick et al, 2005; Nock et al, 2007).

Relationship between ODD and other disorders (co-morbidity and heterotypic continuity)

ODD is characteristically comorbid, in that it occurs together with or before a wide range of other disorders (Costello et al, 2003) including anxiety and depressive disorders (girls), conduct disorder and substance use disorders. Children with ADHD often go on to develop ODD. The wide range of associations between ODD and other disorders is depicted in Figure D.2.2.

ODD has consistently been found to predict later depression (Copeland et al, 2009; Burke et al, 2010; Burke et al, 2005) and anxiety (Maughan et al, 2004). Most strikingly, Copeland et al (2009) found that childhood oppositional defiant disorder predicted young adult depression; young adult depression and

Figure D.2.1 Lifetime prevalence of impulse control disorders (Kessler et al, 2007)

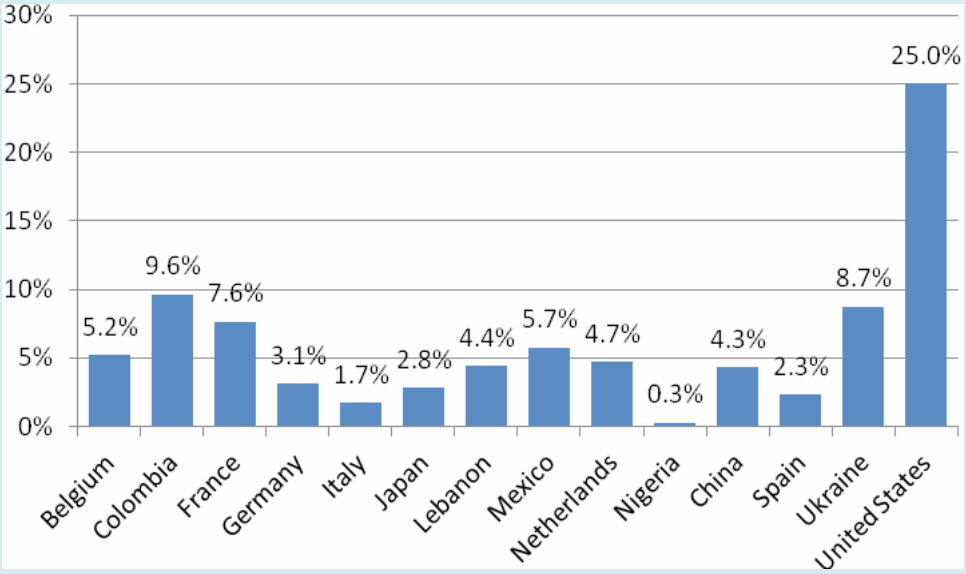
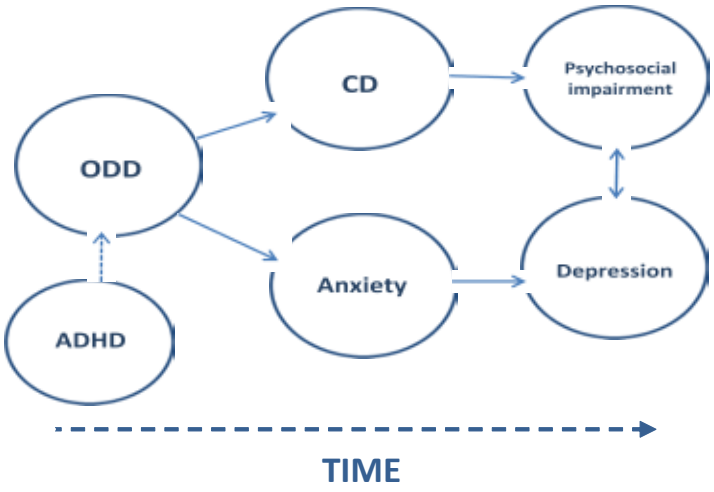


Figure D.2.2: The relationship between ODD and other disorders (modified from Burke et al, 2005)



ODD: oppositional defiant disorder; CD: conduct disorder; ADHD: attention deficit/hyperactivity disorder (common precursor to ODD)

anxiety disorders were often preceded by adolescent ODD, but not CD. The relationship between ODD and emotional problems is particularly puzzling – it has been suggested that it may be the affective aspects of ODD that predict emotional disorders such as anxiety and depression (Burke et al, 2005; Stringaris & Goodman, 2009b)

In an attempt to explain the heterogeneity of the associations between childhood ODD and adult disorders, Stringaris and Goodman (2009a, 2009b) proposed that the DSM-IV ODD criteria consist of three *a priori* specified dimensions described as "irritability," "headstrong and "hurtful" behaviour. Others (Rowe et al, 2010) have identified only two dimensions – irritability and headstrong, while others have suggested slightly different partition of symptoms (Burke et al, 2010). The findings suggest that "irritable" mood is more strongly predictive of later emotional disorder (Stringaris et al, 2009), while "headstrong" and "hurtful" behaviours are more predictive of conduct problems. The clinical utility of these distinctions has yet to be established (Rowe et al, 2010; Burke et al, 2010; Aebi et al, 2010).

AETIOLOGY AND RISK FACTORS

While no single cause of ODD has been identified, a number of risk factors and markers have been found to be associated with oppositional behaviour.

Genetics

Genetic effects contribute significantly to the development of ODD symptoms with heritability estimates exceeding 50%, with genetic factors accounting more than 70% of the variability in individual measures based on parent reports (Eaves et al, 1997). While some have suggested that ODD shares substantial genetic overlap with conduct disorder (Eaves et al, 2000), other studies have indicated unique effects for each (Rowe et al, 2008, Dick et al, 2005). In

addition, it seems that genetic effects underlie the association between ODD and ADHD (Hewitt et al, 1997) as well as between ODD and depressive disorder (Rowe et al, 2008). In a twin study of adolescents, self-reported irritability symptoms of ODD shared genetic effects with depressive symptoms, whereas "headstrong/hurtful" symptoms of ODD shared genetic risk with delinquent symptoms (Stringaris et al, 2012).

Gene-environment interplay

The notion that the effects of exposure to an environmental factor (e.g. childhood maltreatment) on a child's behaviour is conditional upon that child's genetic make-up has face validity and biological plausibility (Rutter, 2006). In one of the pioneering studies in the field (Caspi et al, 2002), a functional polymorphism in the promoter region of the gene that codes for the neurotransmitter-metabolizing enzyme monoamine oxidase A (MAO-A) was found to moderate the effect of child maltreatment on future conduct and antisocial problems, although several later studies did not find such an interaction. Maltreated children with a genotype that leads to low levels of MAOA activity more often displayed conduct disorder and antisocial behaviours at follow up, than children with a high-activity MAOA genotype (Caspi et al, 2002). This will be discussed further in the chapter on conduct disorder (Chapter D.3).

Age of onset

The age of onset of antisocial symptoms (Moffitt, 1993) seems to be a good predictor of later outcome. Moffitt (1993) distinguishes between children whose symptoms first emerge in childhood and persist into adolescence (childhood onset persistent) compared to those whose symptoms first occurr in adolescence. Individuals in the childhood onset persistent group have been found to have poorer adult outcomes when compared with non-disordered and adolescent-onset peers (Moffitt, 2003; Moffitt, 2006; Moffitt et al, 2002; Odgers et al, 2007; Farrington et al, 2006). Age of onset as a predictor of later outcomes is discussed further in Chapter D.3.

Temperament

Temperamental factors in toddlerhood, such as irritability, impulsivity, and intensity of reactions to negative stimuli, may contribute to the development of a pattern of oppositional and defiant behaviour. It is possible that ODD is arrived at through different temperamental routes that could serve to explain its comorbidity. Stringaris et al (2010) showed that the comorbidity between ODD and internalizing disorders was more strongly associated with early temperamental emotionality, whereas the comorbidity between ODD and ADDH was better predicted by temperamental over activity.

Peer influences

Children who display oppositional behaviour are more inclined to experience disrupted or problematic peer relationships. Such children are commonly rejected by non-deviant peers, and tend instead to associate with other children who exhibit problem behaviour. It would appear likely that the relationship between peer rejection and childhood ODD symptoms is a bi-directional one, as is nicely illustrated in a series of studies about bullying (summarised in Arseneault et al, 2010).

Callous and unemotional traits

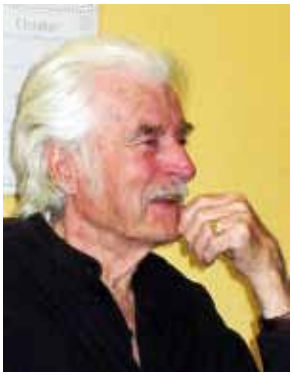
The concept of psychopathy has been extended to young people in recent years (Frick et al, 1994) with a focus on callous and unemotional traits. While not all children diagnosed with conduct disorder have callous and unemotional traits (Frick et al, 2000), the presence of such traits appears to distinguish a subgroup of children with more serious conduct problems. Callous and unemotional traits seem to be highly heritable (Viding et al, 2005) and characterised by poor recognition of emotion (particularly fear) in facial expression (Blair et al, 2006; Dadds et al, 2006). The importance of callous and unemotional traits is discussed further in Chapter D.3.

Neighbourhoods

The broader environment surrounding the child may also be a risk factor. Disruptive behaviour has consistently been associated with social and economic disadvantage and neighbourhood violence (Guerra et al, 1995; Rowe et al, 2002).

Family factors

The importance of the interplay between genes and family-level environmental factors has become increasingly clear in the aetiology of children's disruptive behaviour problems (Moffitt, 2005). Evidence from adoption studies (O'Connor et al, 1998; Ge et al, 1996) shows that children at high genetic risk for antisocial behaviour were more likely to receive negative parenting from the adoptive parents than were children with low genetic risk for antisocial behaviour. Conversely, it is known from studies using a monozygotic twin design that family-level effects contribute to children's risk for externalising problems over and above children genetic effects (Jaffee et al, 2003; Caspi et al, 2004). In other words, parental behaviour towards children can be a true environmental risk.



Gerald R Patterson, founder of the Oregon Social Learning Centre, described the so called "coercive family processes" and their role in the development and maintenance of behaviour problems.

Models of family influences

Patterson (1982) proposed a model about how parental behaviour may exacerbate children's negative behaviour and result in what he designated as "coercive family processes". His work has shown that parents of children with disruptive behaviour problems are more likely to be inconsistent in how they apply rules, and give commands that are either unclear or the result of their own current emotional state rather than contingent upon the child's behaviour. A typical mutually coercive process would arise when a parent responds in an unduly harsh way to a child's mildly disruptive behaviour, upon which the child may further escalate its oppositional behaviour. This in turn leads to yet harsher responses by the parent with further escalation. The result is that the parent may in the end give in, reinforcing the child's negative behaviours. This paradoxical "reward" of a child's negative behaviour may both increase and maintain oppositional behaviours and is the specific target of therapeutic interventions (see below).

ASSESSMENT

Measurement instruments

It is feasible to assess oppositional problems in children as young as 5 years of age (Kim-Cohen et al, 2005). A wide range of instruments is available to measure ODD symptoms and to assist in the diagnostic process and monitoring. Clinicians should always bear in mind that diagnosis is based on their judgment

Table D.2.2 Assessment tools commonly used to identify ODD (symptoms or the disorder).

Type	Name	Availability
Questionnaires	• The Eyberg Child Behavior Inventory (ECBI: Eyberg & Ross, 1978; Eyberg & Robinson, 1983)	Can be purchased from PAR
	• The Child Behaviour Checklist (Achenbach & Edelbrock, 1983)	Can be purchased from ASEBA
	• The Behaviour Assessment for Children (BASC-2: Reynolds & Kamphaus, 2004)	Can be purchased from Pearson
	• Conners Child Behaviour Checklist (Conners & Barkley, 1985)	Can be purchased from MHS
	• Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997)	Available free of charge from SDQ website subject to conditions.
Semi-structured interviews	• The Child and Adolescent Psychiatric Assessment (Angold & Costello, 2000)	Available free of charge fom Duke University, subject to copyright approval from the author.
Structured interviews	The Development and Well-Being Assessment (DAWBA: Goodman et al, 2000) combines questionnaires and interviews (with both structured and semi structured elements)	Available free of charge from the DAWBA website, for non-commercial purposes.
	• The Diagnostic Interview Schedule for Children (DISC: Shaffer et al, 1993; Schwab-Stone et al, 1993; Shaffer et al, 2000; Shaffer et al, 2004)	Available by emailing disc@worldnet.att.net (administration charge for paper copies)
Observational instruments	• The Disruptive Behaviour Diagnostic Observation Schedule (Wakschlag et al, 2008b, Wakschlag et al, 2008a)	

and integration of the information gathered by interviews, clinical examination, scales and other means (summarised in Table D.2.2).

Useful principles for assessing children with ODD include: a) try to obtain information from as many different sources (parent, child, teacher) as possible; b) assess comorbid psychiatric problems, particularly ADHD; c) assess other risk factors at family, school and neighbourhood level. Children with disruptive behaviour problems often come from deprived backgrounds. It is important to identify factors (such as bullying or peer deviance) that maintain or increase oppositional behaviours. The same applies to performance at school: a child with reading difficulties or hyperactivity may be more likely to manifest oppositional behaviours at school.

Differential diagnosis

Oppositionality can be seen in many childhood conditions. It is important for the clinician to recognise those cases where other disorders may have given rise to it. For example, it is not uncommon for children who develop a specific phobia or other anxiety disorders (such as OCD) to become oppositional and uncooperative, particularly in situations in which they expect to be exposed to the feared situation. Clinicians treating children with OCD whose rituals are disrupted know this phenomenon all too well. In these cases, assigning a diagnosis

Jack is 7 years of age. His mother reported that he was "very difficult" and that he had "always" been like that. He would lose his temper over seemingly trivial matters, such as losing at a video game he played with his best friend: "he gets red in the face and starts huffing, shouts and cries". Also he was often grumpy for no apparent reason. His mother described that when he did not want to do something "he simply won't". He often refused to go to bed; "we have massive rows in the evenings because of this". Jack sometimes got so angry that he broke his own toys or threw them around.

Jack has had no contact with his father since the age of six months. His mother said that Jack's father was an "angry and aggressive man", who often shouted and lost his temper.

His teacher said that Jack was argumentative and refused to do as he was asked in class and constantly annoyed the other children by throwing bits of paper at them and taking their pencils or toys. The other children in the class didn't like to play with Jack and this made him angry. Recently, some of the older children had been mocking him and pushing him around in the playground. He often came home looking sad and grumpy.

Jack's mother said that she was "at the end of her tether" and that "You can't reason with him, you can't shout at him, it just doesn't help – no matter what I do it just doesn't work".

Jack and his mother were seen at their local child and adolescent mental health service. On the basis of his symptoms and level of impairment, Jack was given a diagnosis of ODD and his mother was offered to take part in a parent management course.

Within only a few weeks of attending the course she found this very helpful in dealing with Jack's behaviours. At the end of the intervention, Jack no longer displayed significant symptoms of ODD. His tantrums had become very rare and he was, overall, much less defiant. He and his mother were more able to enjoy activities and play together. Jack's mother reports that she now finds it easier to identify Jack's good behaviours and praise them accordingly.

of oppositional defiant disorder and failing to recognise and address the underlying anxiety disorder is counterproductive. The same applies to children with ADHD who often develop oppositionality. Indeed, oppositionality might be the main reason for the referral of such children. It is crucial for the clinician to be able to look for ADHD as a possible underlying issue of the disturbance, even when the parents' chief worry is their child's oppositionality. This has important treatment implications (see below). Similar situations can arise in children with autism, who can become particularly oppositional in the face of change of routine or due to sensory sensitivities. Here too, clinicians will want to recognise possible underlying problems and ensure that these are adequately treated.

TREATMENT

Some general principles apply to the treatment of oppositional problems as with other psychiatric disorder. Comorbidities should be identified as they are likely to require treatment in their own right. This is particularly true for ADHD and to a large extent also for childhood depression and anxiety. Other treatable or modifiable risks (e.g., ongoing bullying or failure at school due to learning difficulties) should always be assessed and addressed as part of the treatment package offered to the family.

A number of treatments are available to clinicians, depending on the needs of the individual child and family. For example, behaviour occurring predominantly in either the home or school context may be best managed using a treatment designed to address context-specific issues. More pervasive problems may call for more intensive individual work (Moffitt & Scott, 2008).

Parent management training

Parent management training-based on principles of social learning theory is a key feature of treatment in ODD. Problematic parent-child interaction patterns

have been implicated in the development and maintenance of oppositional behaviour and principles of social learning, particular in relation to operant conditioning (the role of reinforcement / consequences in altering behaviour), have been found to be useful in modifying behaviour in both parents and children (Feldman & Kazdin, 1995). Parent management training teaches parents to identify prosocial and problem behaviour and apply punishment and reinforcement techniques designed to increase the frequency of desired behaviours and decrease the frequency of undesired ones.

Examples of parenting programmes

Several programmes based on social learning theory have been found to be effective in addressing early onset antisocial behaviour, namely:

- *The Incredible Years (Webster-Stratton, 1981)*

  One of the best validated is Webster-Stratton's "Incredible Years", a behaviourally-based training programme designed for use with parents (Webster-Stratton & Hammond, 1997; Webster-Stratton, 1982; Webster-Stratton, 1981), teachers and children (Webster-Stratton & Hammond, 1997). Scott and colleagues (2001b) carried out a multi-centre controlled trial of the group parenting version in a sample of 141 (intervention group, n=90; waiting list control group, n=51) children aged 3 to 8 years who were referred for antisocial behaviour to their local multidisciplinary child and adolescent mental health service. They used the videotape-based "Basic" programme (Webster-Stratton & Hancock, 1998). This comprised 13-16 2-hour weekly sessions in which parents were shown video segments with scenes showing *right* and *wrong* ways to manage children. The programme covered play, praise and rewards, limit-setting, and handling misbehaviour. After watching the videos, parents were encouraged to discuss their own children's behaviour and rehearsed different approaches to handling it. Parents were also given weekly activities to try at home (homework) and progress was supported by telephone contact. Programme costs were comparable with the cost of individual treatment. Substantial and statistically significant decreases in antisocial behaviour compared with controls were found in parents' ratings of children's conduct problems as well as hyperactivity; parent reports of total number of problems per day; conduct problems and total deviance as measured by the Strengths and Difficulties Questionnaire (Goodman, 1997); externalising and total problem scores as assessed by the Child Behaviour Checklist (Achenbach & Edelbrock, 1983); parent defined problems (the three problems parents identified as the ones they most wanted to see improved); and ICD10 diagnosis of oppositional defiant disorder. Parent behaviour was also measured and significant decreases were found in observations of parents' inappropriate commands. Two further programmes have also been developed: the "Advance" programme, designed to manage parental relationships and the "Partners" programme, designed to support children's academic learning and build up parent-teacher relationships. Integrating the three programmes has been found to achieve the most substantial improvements in behaviour.

- *The Triple P—Positive Parenting Programme*

  Triple P is an evidence based parenting and family support programme



A group of parents graduate from a parenting program in South Africa. Source: Beautifulgate.

designed to prevent and manage behaviour problems in preadolescent children by enhancing parenting skills and improving parent-child relationships. The programme comprises multiple levels: universal intervention designed to provide information on parenting issues for interested parents; provision of advice for specific problem behaviours; brief programmes to provide advice and training parents dealing with minor behaviour problems; and more intensive programmes comprising training in mood management strategies, coping skills and partner support skills designed to address more persistent and pervasive behaviour problems. Triple P has been validated in a number of studies with a range of family types and cultural backgrounds (Graaf et al, 1998, Bor et al, 2002).

Alternative approaches

Strategies have also been put forward to treat behaviour problems in families where such programmes have been unsuccessful. Scott and Dadds (2009) suggest a number of alternative ways of approaching intervention which may provide a framework to address factors which may limit the efficacy parent training programmes. They recommend taking account of attachment security and the parent-child relationship in considering intervention strategies, in order to allow for the impact which disrupted attachment may have on the meaning of expected reinforcers or punishments. In addition, they emphasise the importance of wider social contexts which may impact on the child, such as parent relationships, siblings, extended families and neighbourhoods. Finally, they encourage clinicians to consider beliefs held by parents about the child (or aspects of parenting) which may be interfering with treatment.

School-based interventions

1. Teachers may also be provided with additional tools to promote improvements in classroom behaviour. Social learning theory is also key in this approach. Moffitt and Scott (2008) identify four primary domains of functioning to be addressed:Promoting compliance and adherence to classroom rules and acceptable behaviours
2. Supporting the development of problem solving skills
3. Preventing problem behaviour
4. Avoiding the escalation of oppositional behaviour

Goals in managing ODD (from Fraser & Wray, 2008)

For parents
- Improve positive parenting skills
- Enhance skills in problem solving, conflict resolution and communication

For the child
- Development of effective communication, problem-solving and anger management skills

For the family
- Family counselling and support to deal with the stresses in their relationships and the home environment

In the classroom
- Encourage the teacher or school counsellor to provide social skills sessions to improve peer relationship.

Individual therapy – anger management

Existing evidence indicates that CBT-based anger management training may be particularly helpful in treating anger (Beck & Fernandez, 1998; Lochman et al, 2011). This training uses a coping skills approach involving stress inoculation interventions comprising three elements: cognitive preparation, skill acquisition, and application training (Meichenbaum, 1996). In the first phase, cognitive preparation, the trainer works to establish a relationship with the patient. The patient is coached to reconceptualise stressors as potentially modifiable problems which can be managed using coping strategies. In the second phase, skill acquisition, the patient is taught specific coping strategies, such as emotional self-regulation, acceptance, problem-solving, and attention diversion procedures; systems which may be applied to particular problems experienced by the patient and their family. In the final phase, the patient is taught to apply these strategies in practice. Stressors are gradually introduced (using for example role playing techniques), until the patient can employ coping skills in real-life situations.

Medication

There is no evidence that medication is effective for the treatment of ODD. In children with ADHD, treatment with stimulants is known to improve conduct and oppositional symptoms (NICE, 2008); however, there is not much evidence to support use of stimulants to treat oppositional problems in children without ADHD. A trial in children with ADHD (Blader et al, 2009) showed that sodium valproate may be useful for those children whose aggression did not respond to stimulants. However, these were hospitalized children and the results may not apply to the children commonly seen in outpatient samples. A trial of Lithium in children with severe irritability has shown no effects (Dickstein et al, 2009). It is far from clear that the effects of risperidone on the difficult behaviours of children with autism (McCracken et al, 2002) or developmental disability can be extrapolated to typically developing children. Serotonin reuptake inhibitors are sometimes used for the treatment of anger in adult populations but evidence for its effectiveness in youth is lacking. The dramatic increase in diagnosis of bipolar disorder, particularly in the US (Blader & Carlson, 2007; Moreno et al, 2007) over the last 10-15 years has been associated with an increase in the prescription of anti-psychotic drugs for children (Olfson et al, 2006). It has been argued that cases with symptoms typical of ODD, such as irritability, have been misdiagnosed as suffering from bipolar disorder. There is no good evidence to support such expansion of the diagnostic boundaries of bipolar disorder (Leibenluft, 2011; Stringaris, 2011) and, on current evidence, anti-manic drugs should not be given to children with ODD alone (for a more detailed discussion of this issue see Chapter E.3). Judicious use of sedating agents in emergency settings or dopamine antagonists (e.g., risperidone) used short term for specific symptom control may be considered on a case-to-case basis. Clinicians using such medications will want to have informed parents and child fully about the reasons for their use (instead of alternatives) as well as of the potential side effects. Clear treatment goals (i.e., reduction/change in particular behaviours or rating scale-scores) should be agreed at the outset within the clinical team and with the patients and carers. The effects (and unwanted effects) of the treatment should be carefully and regularly reviewed.

There is no evidence that medication is effective for the treatment of ODD. In children with ADHD, treatment with stimulants is known to improve conduct and oppositional symptoms; however, there is not much evidence to support use of stimulants to treat oppositional problems in children without ADHD.

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CONDUCT DISORDERS

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Conflict of interest: none reported.

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Suggested citation: Scott S. Conduct disorders. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

This section follows on from Chapter D.2, oppositional defiant disorder, by focusing on conduct disorder, which tends to occur in older children and teenagers.

CLASSIFICATION

ICD-10

ICD-10 has a category for conduct disorders, F91. The *clinical descriptions and diagnostic guidelines* state:

> "Examples of the behaviours on which the diagnosis is based include the following: excessive levels of fighting or bullying; cruelty to animals or other people; severe destructiveness to property; firesetting; stealing; repeated lying; truancy from school and running away from home; unusually frequent and severe temper tantrums; defiant provocative behaviour; and persistent severe disobedience. Any one of these categories, if marked, is sufficient for the diagnosis, but isolated dissocial acts are not." (p267)

An enduring pattern of behaviour should be present, but no time frame is given and there is no impairment or impact criterion stated.

The ICD-10 *diagnostic criteria for research* differ, requiring symptoms to have been present for at least 6 months, and the introductory rubric indicates that impact upon others (in terms of violation of their basic rights), but not impairment of the child, can contribute to the diagnosis. The research criteria take a menu-driven approach whereby a certain number of symptoms have to be present. 15 behaviours are listed to consider for the diagnosis of *conduct disorder*, which usually but not exclusively apply to older children and teenagers. They can be grouped into four classes:

- *Aggression to people and animals*
  - Often lies or breaks promises to obtain goods or favours or to avoid obligations
  - Frequently initiates physical fights (this does not include fights with siblings)
  - Has used a weapon that can cause serious physical harm to others (e.g., bat, brick, broken bottle, knife, gun)
  - Often stays out after dark despite parenting prohibition (beginning before 13 years of age)
  - Exhibits physical cruelty to other people (e.g., ties up, cuts or burns a victim)
  - Exhibits physical cruelty to animals.
- *Destruction of property*
  - Deliberately destroys the property of others (other than by fire-setting)
  - Deliberately sets fires with a risk or intention of causing serious damage).
- *Deceitfulness or theft*
  - Steals objects of non-trivial value without confronting the victim, either within the home or outside (e.g. shoplifting, burglary, forgery).

- *Serious violations of rules*
  - Is frequently truant from school, beginning before 13 years of age
  - Has run away from parental or parental surrogate home at least twice or has run away once for more than a single night (this does not include leaving to avoid physical or sexual abuse)
  - Commits a crime involving confrontation with the victim (including purse-snatching, extortion, mugging)
  - Forces another person into sexual activity
  - Frequently bullies others (e.g., deliberate infliction of pain or hurt, including persistent
  - Intimidation, tormenting, or molestation)
  - Breaks into someone else's house, building or car.

To make a diagnosis, three symptoms from this list have to be present, one for at least six months. There is no impairment criterion. There are three subtypes: *conduct disorder confined to the family context* (F91.0), *unsocialised conduct disorder* (F91.1, where the young person has no friends and is rejected by peers), and *socialised conduct disorder* (F91.2, where peer relationships are normal). It is recommended that age of onset be specified, with *childhood onset type* manifesting before age 10, and *adolescent onset type* after. Severity should be categorised as *mild, moderate,* or *severe* according to number of symptoms *or* impact on others, e.g., causing severe physical injury; vandalism; theft.

Where there are sufficient symptoms of a comorbid disorder to meet diagnostic criteria, the ICD-10 system discourages the application of a second diagnosis, and instead offers single, combined categories. There are two major kinds: mixed disorders of conduct and emotions, of which *depressive conduct disorder* (F92.0) is the best researched; and *hyperkinetic conduct disorder* (F90.1). There is modest evidence to suggest these combined conditions may differ somewhat from their constituent elements.

DSM-IV

The DSM IV-R system follows the ICD-10 research criteria very closely and does not have separate clinical guidelines. The same 15 behaviours are given for the diagnosis of conduct disorder (312.8), with almost identical wording. As for ICD-10, 3 symptoms need to be present for diagnosis. Severity, and childhood or adolescent onset are specified in the same way. However, unlike ICD-10, there is no division into socialised/unsocialised, or family context only types, and there *is* a requirement for the behaviour to cause clinically significant impairment in social, academic, or social functioning. Comorbidity in DSM IV-R is handled by giving as many separate diagnoses as necessary, rather than by having single, combined categories.

Differential diagnosis

Making a diagnosis of conduct disorder is usually straightforward but comorbid conditions are often missed. The differential diagnosis may include:

Hyperkinetic syndrome/attention deficit hyperactivity disorder

These are the names given by ICD-10 and DSM IV-R respectively for

similar conditions, except that the former is more severe. For convenience the term *hyperactivity* will be used here. It is characterised by impulsivity, inattention, and motor overactivity. Any of these three sets of symptoms can be misconstrued as antisocial, particularly impulsivity, which can also be present in conduct disorder. However, none of the symptoms of conduct disorder are a part of hyperactivity so, excluding conduct disorder should not be difficult. A frequently made error however, is to miss comorbid hyperactivity when conduct disorder is definitely present. Standardised questionnaires are very helpful here, such as the Strengths and Difficulties Questionnaire, which is brief, and just as effective at detecting hyperactivity as much longer alternatives.

Adjustment reaction to an external stressor

This can be diagnosed when onset occurs soon after exposure to an identifiable psychosocial stressor such as divorce, bereavement, trauma, abuse or adoption. The onset should be within one month for ICD-10, and three months for DSM IV-R, and symptoms should not persist for more than six months after the cessation of the stress or its sequelae.

Mood disorders

Depression can present with irritability and oppositional symptoms but, unlike typical conduct disorder, mood is usually clearly low and there are vegetative features; also more severe conduct problems are absent. Early manic depressive disorder can be harder to distinguish, as there is often considerable defiance and irritability combined with disregard for rules, and behaviour which violates the rights of others. Low self-esteem is the norm in conduct disorder, as is a lack of friends or constructive pastimes. Therefore it is easy to overlook more pronounced depressive symptoms. Systematic surveys reveal that around a third of children with conduct disorder have depressive or other emotional symptoms severe enough to warrant a diagnosis.

Autistic spectrum disorders

These are often accompanied by marked tantrums or destructiveness, which may be the reason for seeking a referral. Enquiring about other symptoms of autistic spectrum disorders should reveal their presence.

Dissocial/antisocial personality disorder

In ICD-10 it is suggested a person should be 17 or older before dissocial personality is considered. Since at age 18 most diagnoses specific to childhood and adolescence no longer apply, in practice there is seldom difficulty. In DSM IV-R conduct disorder can be diagnosed over 18, so there is potential overlap. A difference in emphasis is the severity and pervasiveness of the symptoms of those with personality disorder, whereby all the individual's relationships are affected by the behaviour pattern, and the individual's beliefs about his antisocial behaviour are characterised by callousness and lack of remorse. Coexistent with conduct disorder there may be the personality *trait* of *psychopathy*. The characteristics of the psychopath include grandiosity, callousness, deceitfulness, shallow affect and lack of remorse. These traits, as assessed by the Hare Psychopathy Checklist, have

Can the "fledgling psychopath" be identified in childhood, as a high priority target for prevention? Callous unemotional traits such as lack of guilt, absence of empathy, and shallow, constricted emotions can be observed in children.

been shown to predict which individuals will engage in the most serious and violent crime careers. Can the "fledgling psychopath" be identified in childhood, as a high priority target for prevention? Callous unemotional traits such as lack of guilt, absence of empathy, and shallow, constricted emotions can be observed in children. A number of reliable instruments are now available for the clinical assessment and diagnosis of psychopathic traits in juvenile patients (Salekin & Lynam, 2010).

Subcultural deviance

Some youths are antisocial and commit crimes but are not particularly aggressive or defiant. They are well adjusted within a deviant peer culture that approves of recreational drug use, shoplifting, etc. In some localities a third or more teenage males fit this description and would meet ICD-10 diagnostic guidelines for socialised conduct disorder. Some clinicians are unhappy to label such a large proportion of the population with a psychiatric disorder. Using DSM IV-R criteria would preclude the diagnosis for most youths like this due to the requirement for significant impairment.

Multiaxial assessment

ICD-10 recommends that multiaxial assessment be carried out for children and adolescents, while DSM IV-R suggests it for all ages. In both systems, axis one is used for psychiatric disorders, which have been discussed above. The last three axes in both systems cover general medical conditions, psychosocial problems, and level of social functioning respectively; these topics will be alluded to below under aetiology. In the middle are two axes in ICD-10, which cover specific (*Axis two*) and general (*Axis three*) learning disabilities respectively; and one in DSM IV-R (*Axis two*) which covers personality disorders *and* general learning disabilities.



Conduct disordered children often become involved in physical fights.

Photo: Tony Fischer

Both *specific and general learning disabilities* are essential to assess in individuals with conduct problems. Fully a third of children with conduct disorder also have specific reading retardation, defined as having a reading level two standard deviations below that predicted by the person's IQ (see also Chapter C.3). While this may in part be due to lack of adequate schooling, there is good evidence that the cognitive deficits often precede the behavioural problems. General learning disability (mental retardation) is often missed in children with conduct disorder unless IQ testing is carried out. The rate of conduct disorder rise several-fold as IQ gets below 70.

EPIDEMIOLOGY

Between 2% and 8% of children and adolescents have conduct disorders. With respect to historical period, A modest rise in diagnosable conduct disorder over the second half of the twentieth century has also been observed comparing assessments of three successive birth cohorts in Britain. There is a marked social class gradient. With respect to ethnicity, youth self-reports of antisocial behaviours and crime victim survey reports of perpetrators' ethnicity show an excess of offenders of black African ancestry. Importantly, Hispanic Americans in the USA and British Asians in the UK do not tend to show an excess of offending compared to their white counterparts, indeed the latter have lower rates than the native white population.



Click on the picture to access the UK Independent Commission on Youth Crime and Antisocial Behaviour' 2010 report *Time for a fresh Start*.

Gender

The sex ratio is approximately 4 to10 males for each female overall, with males further exceeding females in the frequency and severity of behaviours. On balance, research suggests that the causes of conduct problems are the same for both sexes, but males have more conduct disorder because they experience more of its individual-level risk factors (e.g., hyperactivity, neuro-developmental delays). However, recent years have seen concern among clinicians about increasingly treating antisocial behaviour among girls.

Developmental subtypes

Life-course persistent versus adolescence-limited

There has been considerable attention paid to the distinction between aggressive and disruptive behaviors that are first seen in early childhood versus those that start in adolescence (Moffitt, 1993a; Patterson & Yoerger, 1993), and these two subtypes are encoded in the DSM-IV diagnostic system for conduct disorder. Early onset is a strong predictor of persistence through childhood – and early onset delinquency is more likely to persist into adult life. Findings from the longitudinal Dunedin study, following a 1972-73 birth cohort, have shown that those with early onset differ from those with later onset in that they have lower IQ, more attentional and impulsivity problems, poorer scores on neuropsychological tests, greater peer difficulties and are more likely to come from adverse family circumstances (Moffitt et al, 2001). Those with later onset, by contrast are thought to become delinquent predominantly as a result of social influences such as association with other delinquent youths, or seeking social status through delinquent behaviors. Moffitt (1993a) termed the early-onset group "life

course persistent", and the later-onset group "adolescence-limited" thus linking developmental course to the differences in underlying deficits. The distinction between the two groups has been broadly supported in longitudinal studies of several cohorts from a dozen countries (Moffitt, 2006). Findings from the follow up of the Dunedin cohort support relatively poorer adult outcomes for the early-onset group in the domains of violence, mental health, substance abuse, work and family life (Moffitt et al, 2002). Follow-up to age 32 revealed that the early-onset life course persistent group had compromised physical health relative to other cohort men, as shown by increased injuries, primary-care physician and hospital visits, and clinical tests of sexually transmitted infections, systemic inflammation, periodontal disease, decayed teeth, and chronic bronchitis.

However the 'adolescence-limited' group were not without adult difficulties (Moffitt et al, 2002). As adults they still engaged in self-reported offending, and also had problems with alcohol and drugs. The Cambridge Study in Delinquent Development, a longitudinal study of 411 London males from age 8 to 46, also found that those with antisocial behaviors starting in adolescence were likely to continue to commit undetected crimes in adult life, although their work performance and close relationships were not impaired (McGee & Farrington, 2010). Thus, the age-of-onset subtype distinction has strong predictive validity, but adolescent-onset anti-social behaviors may have more long-lasting consequences than previously supposed and thus both, childhood-onset and adolescent-onset conduct problems, warrant clinical attention.



Lee N Robins (1922-2009) made a significant contribution to the understanding of the natural history of conduct disorder in her seminal book *Deviant Children Grown Up*.

Childhood-limited conduct problems

Robins (1966) first pointed out that one half of conduct-problem children do not grow up to have antisocial personalities. Longitudinal studies aiming to document the continuity of antisocial behavior from childhood to adolescence to adulthood have repeatedly revealed the existence of an exceptional group of children who lack such continuity. These are often termed "childhood-limited" conduct problems (Moffitt, 2006). Some studies define this childhood-limited group broadly (as a large group of children having any elevated disruptive behavior), and these draw our attention to the ubiquity of temporary conduct problems in the healthy population of children, and show that so long as mild conduct problems do not persist they need not portend poor prognosis (Tremblay, 2003). In contrast, other studies define this childhood-limited group more narrowly (as a small group of children exhibiting extreme, pervasive, and persistent antisocial behavior problems only during childhood). These studies report that such childhood-limited antisocial boys develop into adult men who are depressed, anxious, socially isolated, and have low-paid jobs (Farrington et al, 1988; Moffitt et al, 2002). Thus, boys whose conduct problems are severe and persistent enough to warrant a clinical diagnosis may not later develop antisocial personality, but they will suffer other forms of maladjustment as adults. Thus, all conduct-disorder children warrant clinical attention.

When a young child presents for assessment, the clinician's task is to make a differential diagnosis between childhood-onset CD that will be only childhood-limited, versus childhood-onset CD that will in future have a life-course persistent course and pathological prognosis. DSM-IV's age of onset distinction cannot help with this task because all child patients, by definition, have childhood onset.

Researchers have tried to distinguish life-course persistent versus childhood-limited trajectory groups by using childhood risk factors, without much success (Moffitt, 2006). However, initial evidence indicates that comorbid ADHD, as well as family psychiatric history, characterize the persistent subtype, but not the childhood-limited subtype.

AETIOLOGY

Individual-level characteristics

Genotypes

The search for specific genetic polymorphisms associated with conduct problems is a very new scientific initiative and little has yet been accomplished. One genome-wide linkage study has identified chromosomal regions that are good bets for harbouring conduct problem-related polymorphisms, but the polymorphisms have not been specified and the regions have not been replicated (Stallings et al, 2005). The most-studied candidate gene in relation to conduct problems is the MAOA promoter polymorphism. The gene encodes the MAOA enzyme, which metabolizes neurotransmitters linked to aggressive behavior by previous research in mice, and among men in a Dutch family pedigree. Thus, MAOA was selected as the candidate gene to test a hypothesis that genetic vulnerability might moderate the effect of child maltreatment on later conduct problems in the cycle of violence (Caspi et al, 2002). Maltreatment history and genotype interacted to predict four different measures of antisocial outcome: diagnosed adolescent conduct disorder, a personality assessment of aggression, symptoms of adult antisocial personality disorder reported by informants who knew the study member well, and adult court conviction for violent crime. Replication of this study was of utmost importance because reports of associations between measured genes and disorders are notorious for their poor replication record. Positive and negative replication studies have appeared and a meta-analysis of these studies showed the association between MAOA genotype and conduct problems is modest but statistically significant (Kim-Cohen et al, 2006). Findings of specific genetic polymorphisms associated with antisocial behavior will probably not be applied for genetic diagnosis purposes because of the inherent complexity of gene-behavior connections. Rather, gene-environment research will benefit efforts to understand how brain mechanisms connect external risk factors and genomic variation to the conduct disorders (Meyer-Lindenberg et al. 2006).

Perinatal complications

Birth complications might be a contributory factor to neuropsychological deficits that are associated with conduct problems (Moffitt, 1993). The evidence regarding this was mixed but recent reports from large-scale general population studies have found associations between life-course persistent type conduct problems and perinatal complications, minor physical anomalies, and low birth weight (Brennan et al, 2003). Most studies support a biosocial model in which obstetric complications might confer vulnerability to other co-ocurring risks such as hostile or inconsistent parenting (Arseneault et al, 2002; Kratzer & Hodgins, 1999; Tibbetts & Piquero, 1999; Raine et al, 1997). Studies have further indicated that smoking in pregnancy increases the risk of conduct problems in the offspring (Brennan et al, 2003), but a causal link between smoking and conduct problems has not been established (Fergusson, 1999).

Temperament

Individual differences in infancy that might contribute to subsequent risk of psychopathology were conceptualised by Thomas and Chess in terms of "temperament", which they viewed as inherited and not significantly influenced by experience (Thomas et al, 1968). Several prospective studies have shown associations between temperament and conduct problems (Keenan & Shaw, 2003), and also predicted antisocial personality disorder and criminal offending into adulthood (Caspi et al, 1996). Temperament as originally conceived, should be strongly heritable and experience-free. However measures of temperament are only moderately heritable and a child's engagement with the social world from birth means that temperament measures inevitably assess the outcome of social processes. It may be that the contributions of temperament will be seen most consistently in combination with environmental risk factors (Nigg, 2006).

Neurotransmitters



To access the US Surgeon Generals' thorough report on youth violence, click on the picture.

Neurotransmitters have been linked to antisocial behavior in adult samples and in non-human animal models (Nelson, 2006). It would be a major advance if it were possible to link neurotransmitter levels and activity to conduct problems in children. However, in general, the findings with children have not been consistent (Hill, 2002). For example, in the Pittsburgh Youth cohort, boys with longstanding conduct problems showed downward changes in urinary epinephrine level following a stressful challenge task, whereas prosocial boys showed upward epinephrine responses to the challenge (McBurnett et al. 2005). However other studies have failed to find an association between conduct disorder and measures of noradrenaline in children (Hill, 2002). Some limited evidence supports the view that, as in adults, serotonin is linked with aggression in children, but findings for indices of serotonin function in children are also markedly inconsistent (Pine et al, 1997). It should be borne in mind that neurotransmitters in the brain are only indirectly measured – most measures of neurotransmitter levels are crude indicators of activity – and little is known about neurotransmitters in the juvenile brain.

Verbal deficits

Children with conduct problems have been shown consistently to have increased rates of deficits in language-based verbal skills (Lynam & Henry, 2001; Nigg et al, 2003). Conduct disordered children, delinquent adolescents, and adult antisocial individuals show poor performance on standardised tests of verbal ability and in tests of IQ, with poor verbal and performance scores. These associations hold after controlling for potential confounds such as race, socioeconomic status, academic attainment, and test motivation (Lynamet al, 1993). Longitudinal studies show that persistence in antisocial behavior over periods of years is predicted by low verbal IQ in childhood (Farrington & Hawkins, 1991; Lahey et al, 1995; Lynam & Henry, 2001). Deficits in verbal capacities are found also with oppositional defiant disorder among preschool-aged clinic-referred boys (Speltz et al, 1999). Several possible ways in which poor verbal ability might influence behavior can be drawn from Luria's theory of the role of verbal memory and verbal abstract reasoning in the development of self-control (Luria, 1961). The abilities to recall oral instructions and to use language to think through the consequences of actions contribute to the effective control of actions. Children who cannot reason

or assert themselves verbally may attempt to gain control of social exchanges using aggression (Dodge, 1993). It is likely that there are also indirect effects in which low verbal IQ contributes to academic difficulties, which in turn mean that the child's experience of school becomes unrewarding rather than a source of self-esteem and support.

Executive dysfunction

Children and adolescents with conduct problems have been shown consistently to have poor tested executive functions (Ishikawa & Raine, 2003; Lynam & Henry, 2001; Moffitt 1993b; Nigg & Huang-Pollock, 2003; Hobson et al, 2011). Executive functions comprise those abilities implicated in successfully achieving goals through appropriate, effective actions. Specific skills include learning and applying contingency rules, abstract reasoning, problem solving, self-monitoring, sustained attention and concentration, relating previous actions to future goals, and inhibiting inappropriate responses. These mental functions are largely, although not exclusively, associated with the frontal lobes (Pennington & Ozonoff, 1996). Important data was generated from a Montreal cohort studied from the age of six years (Séguin et al, 1999). The study used executive function tests, which have been shown to be associated with different anatomical structures in the brain, on the basis of lesion and functional imaging studies. Chronic aggression was associated with lower scores on tests tapping executive functions of the frontal brain region, and the findings held after controlling for general memory, IQ, and ADHD. Although most studies of executive deficits involve adolescents, such deficits have also been linked with disruptive behaviors in preschool children (Hughes et al, 1998; Speltz et al, 1999).

Executive functions

The term "executive functions" is used to describe cognitive processes that activate, organize, integrate and manage other functions such as planning, problem solving, verbal reasoning, inhibition, mental flexibility and multi-tasking.

Information processing & social cognition

Dodge (1993) proposed the leading information-processing model for the genesis of aggressive behaviours within social interactions. The model hypothesises that children who are prone to aggression focus on threatening aspects of others' actions, interpret hostile intent in the neutral actions of others, and are more likely to select and to favour aggressive solution to social challenges. Several studies have demonstrated that aggressive children make such errors of social cognition. An extensive review of the many studies of social cognitions among conduct-problem children has been presented elsewhere. Dodge (1993) hypothesised that the tendencies to encode hostile aspects of situation and to attribute hostile intent to ambiguous social cues and to access and favour aggressive responses to social challenges are the result of repeated exposure to physical maltreatment. This prediction was tested prospectively (Dodge et al,1995). Physical abuse documented in kindergarten was strongly associated with conduct problems in primary school; 28% of the abused group developed conduct problems compared with 6% of the non-abused. Encoding errors, hostile attributions, and biases toward accessing and favouring aggressive responses were each associated with conduct problem outcome and with having experienced physical abuse. Encoding errors and accessing aggressive responses mediated the link between physical abuse and conduct problems, but hostile attributions and positive evaluation of aggressive responses did not. This prospective study thus provided some support for the social cognition model.



Adolescents with conduct disorder are responsible for a large part of the crime in most communities.

Risks within the family

Genetic liability

There is now solid evidence from twin and adoption studies that conduct problems assessed both dimensionally and categorically are substantially heritable (Moffitt, 2005a; Rhee & Waldman, 2002). However, knowing that conduct problems are under some genetic influence is less useful clinically than knowing that this genetic influence appears to be reduced, or enhanced, depending on interaction with circumstances in the child's environment. Several genetically sensitive studies have allowed interactions between family genetic liability and rearing environment to be examined. Adoption studies have reported an interaction between antisocial behavior in the biological parent and adverse conditions in the adoptive home that predicted the adopted child's antisocial outcome (Bohman 1996; Cadoret et al, 1995). The genetic risk was modified by the rearing environment. A twin study also yielded evidence that family genetic liability and environmental risks interact (Jaffee et al, 2005). In this study, the experience of maltreatment was associated with an increase of 24% in the probability of diagnosable conduct disorder among children at high genetic risk, but an increase of only 2% among children at low genetic risk. Thus, awareness of a familial liability toward psychopathology increases the urgency to intervene to improve a child's social environment.

Low income

There is an association between severe poverty and early-childhood conduct problems (Murray & Farrington, 2010). Early theories proposed direct effects of poverty related to strains arising from the gap between aspirations and realities and from lacking opportunity to acquire social status and prestige. Subsequent research has indicated that the association between low income and childhood conduct problems is indirect, mediated via family processes such as marital discord and parenting deficits (Maughan, 2001). As one example of this research, the Iowa longitudinal study of 378 rural families found that family economic stress was associated with adolescent conduct problems, but this was mediated via parental depression, marital conflict and parental hostility (Conger et al, 994). Another study took advantage of a naturally occurring experiment (Costello et al, 2003). Native American families in North Carolina, formerly living below the poverty line,

benefited from increased income from newly opened casinos. In many families, the children's behavior problems decreased markedly as a result. However, the effect of increased income was mediated through better parent-child relationships. This mediation is not limited to poverty in recent times. The Glueck's study of delinquency from the historical period of economic depression also found that harsh discipline, low supervision, and weak parent-child attachments accounted for the effects of poverty on children's antisocial behaviors in the 1930's (Sampson & Laub, 1984).

Parent-child attachment

Early studies of low-risk samples, using the secure-insecure attachment classification, failed to find robust associations with externalising problems, but subsequent studies of higher-risk samples using the disorganised classification report that disorganised attachment can predict conduct problems (Van Ijzendorn et al, 1999). Disorganisation is identified in Ainsworth's Strange Situation Test if the child shows bizarre or contradictory behaviors with the caregiver when reunited after separation (Main & Solomon, 1986). However, low rates of infants with disorganized attachment in study samples mean that findings should be viewed with caution. Although it seems obvious that poor parent-child relations in general predict conduct problems, it has yet to be established whether attachment difficulties, as measured by observational paradigms, have an independent causal role in the development of behavior problems. Attachment classifications could be markers for other relevant family risks. However, Futh et al (2008) used a doll play task with six-year-olds showing an independent association between insecure attachment and conduct problems and Scott et al (2011) found that in adolescents insecure attachment (measured using the Child Attachment Interview) predicted conduct problems even after taking into account current parenting quality, suggesting it may have at least a maintaining role.

Discipline and parenting

Parents of conduct disordered children are more inconsistent in their use of rules, issue more and more unclear commands, are more likely to respond to their children on the basis of their own mood rather than the characteristics of the child's behavior, are less likely to monitor their children's whereabouts, and are less responsive to their children's prosocial behavior. Patterson proposed a specific mechanism for the promotion of oppositional and aggressive behaviors in children. A parent responds to mild oppositional behavior by a child with a prohibition, to which the child responds by escalating his behavior and mutual escalation continues until the parent backs off, thus negatively reinforcing the child's behavior. The parent's inconsistent behavior increases the likelihood of the child showing further oppositional or aggressive behavior. In addition to specific tests of Patterson's reinforcement model (Gardner, 1989; Snyder & Patterson, 1995) there is ample evidence that conduct problems are associated with hostile, critical, punitive and coercive parenting (Rutter et al, 1998); conduct disordered children elicit more negative reactions from all groups of parents than non- conduct disorder children.

"All in all, the most marked difference between the disciplinary practices of the parents of the delinquents and those of the non-delinquents is found in the considerably greater extent to which the former resorted to physical punishment and the lesser extent to which they reasoned with the boys about their misconduct." (Glueck & Glueck, 1950)

The fact that children's behaviors can evoke negative parenting does not mean that negative parenting has no impact on children's behavior. One study reported that negative maternal control at age four was significantly associated

with conduct problems at age nine, after controlling for children's initial behavior problems at age four (Campbell et al, 1996). The E-Risk longitudinal twin study of British families examined the effects of fathers' parenting on young children's aggression (Jaffee et al, 2003). As expected, a prosocial father's *absence* predicted more aggression by his children. But in contrast, an antisocial father's *presence* predicted more aggression by his children, and his harmful effect was exacerbated the more time each week he spent taking care of the children. In another report, the E-risk study evaluated the hypothesis that because depressed mothers provide inept parenting, maternal depression promotes children's aggression (Kim-Cohen et al, 2005). Children of depressed mothers often develop conduct problems, but it has not been clear that this correlation represents environmental transmission. Although the connection between mothers' depression and children's conduct problems decreased somewhat after stringent control for familial liability to psychopathology, it remained statistically significant. Further, depressed women might exaggerate their ratings of their children's problem behaviors, but the pattern of findings remained the same when teachers rated the children's behavior. A temporal analysis showed that if E-risk mothers experienced depression only before their children's birth, the children were not unusually aggressive. In contrast, only if mothers suffered depression while rearing their children were the children likely to develop aggression. Finally, the possibility that the association was spurious because children's aggression provoked their mothers' depression was ruled out by documenting that children exposed to an episode of maternal depression between ages five and seven became even more aggressive by age seven than they had been at age five. Taken together these and other findings provide good evidence for the role of discipline in conduct problems (Moffitt, 2005b).



Click on the picture to access the University of Colorado *Blueprints for Violence Prevention*.

Exposure to adult marital conflict and domestic violence

It is likely that family processes other than parenting skills and quality of parent-child attachment relationships have a role. Many studies have shown that children exposed to domestic violence between adults are subsequently more likely to themselves become aggressive (Moffitt & Caspi, 1998). Davies and Cummings (1994) proposed that marital conflict influences children's behavior because of its effect on their regulation of emotion. For example, a child may respond to frightening emotions arising from marital conflict by down-regulating his own emotions through denial of the situation. This in turn may lead to inaccurate appraisal of other social situations and ineffective problem solving. Repeated exposure to family conflict is thought to lower childrens' thresholds for psychological dysregulation, resulting in greater behavioral reactivity to stress (Cummings & Davies, 2002). Children's aggression may also be increased by marital discord because children are likely to imitate aggressive behavior modelled by their parents (Bandura, 1977). Through parental aggression children may learn that aggression is a normative part of family relationships, that it is an effective way of controlling others, and that aggression is sanctioned, not punished (Osofsky, 1995).

Maltreatment

Physical punishment is widely used, and parents of children with conduct problems frequently resort to it out of desperation. Links with conduct problems are not however straightforward. One study found that physical punishment was clearly associated with behavior problems in white American children, but not in African-American ones (Deater-Deckard et al, 1996). Furthermore, the risk for



Birching (19th century Russia). Kaluga Art Museum.

conduct problems does not apply equally to all forms of physical punishment. The E-risk longitudinal twin study was able to compare the effects of corporal punishment (smacking, spanking) versus injurious physical maltreatment using twin-specific reports of both experiences (Jaffee et al, 2004). Results showed that children's genetic endowment accounted for virtually all of the association between their corporal punishment and their conduct problems. This indicated *a child effect* – in which children's bad conduct provokes their parents to use more corporal punishment, rather than the reverse. Findings about injurious physical maltreatment were the opposite. There was no child effect provoking maltreatment and, moreover, significant effects of maltreatment on child aggression remained after controlling for any genetic transmission of liability to aggression from antisocial parents.

Overall, associations between physical abuse and conduct problems are well established (Hill, 2002). In the Christchurch cohort, child sexual abuse predicted conduct problems after controlling for other childhood adversities (Ferguson et al, 1996). In a large prospective study of court-substantiated cases of abuse and neglect, 26% of abused and neglected adolescents were antisocial, contrasted with 17% in a well-matched comparison group, implying a modest but long-lasting effect of abuse and neglect (Widom, 1997). Investigating the relationship of child maltreatment to psychopathology is particularly difficult for ethical reasons. Little is known about the possible mechanisms linking maltreatment to conduct problems, although threats to security of attachment, difficulties in affect regulation, distortions of information processing and self-concept reviewed elsewhere in this chapter are likely to be relevant.

Risks outside the family

Neighbourhood

It has long been assumed that bad neighbourhoods have the effect of encouraging children to develop conduct problems. Parents strive to secure the best neighbourhood and school for their child that they can afford. Although it is obvious that some local areas have higher crime rates than others, it has been difficult to document any direct link between neighbourhood characteristics and child behavior for a number of reasons. For example, neighbourhood characteristics were conceptualized in overly simple structural-demographic terms, such as percentage of non-white residents or percentage of single-parent households. Moreover, research designs could not rule out the alternative possibility that families whose members are antisocial tend to selectively move into bad neighbourhoods. A new generation of neighbourhood research is addressing these challenges (Beyers et al, 2003; Caspi et al, 2000; Sampson et al, 1997). New research suggests that the neighbourhood factors that are important go beyond structural-demographic characteristics. Neighbourhood-level social processes such as "collective efficacy" and "social control," do influence young children's conduct problems, probably by supporting or failing to support parents in their efforts to rear children.

Peers

Children with conduct problems have poorer peer relationships than non-disordered children in that they tend to associate with children with similar antisocial behaviors, they have discordant interactions with other children, and experience rejection by non-deviant peers (Vitaro et al, 2001). Three principal explanations have been tested and evidence found for all three. Either children's antisocial behaviors lead them to have peer problems or deviant peer relationships lead to antisocial behaviours or some common factor leads to both.

Regarding the possibility that conduct problems lead to peer difficulties, there is ample evidence that children with established conduct problems are more likely to have more conflict with peers and to be rejected by non-deviant peers (Coie, 2004). This peer rejection has been shown to contribute to declines in academic achievement and increases in aggression across the first year of primary schooling (Coie, 2004). One consequence of rejection by healthy peers is that, from as young as five years of age, aggressive-antisocial children are obliged to associate with other deviant children (Farver, 1996; Fergusson et al, 1999).

In light of the limited evidence that peer difficulties prompt the onset of childhood conduct problems and the rather more substantial evidence that children's peer difficulties are a consequence of their conduct problems, is there any reason to think that peer processes influence the long-term course of conduct problems? Regarding the possibility that peers lead to conduct problems, this has been shown to come about in several ways. Youth who are aggressive are attracted to each other and deviant youth reinforce each others' antisocial behaviors and attitudes (Boivin & Vitaro, 1995). Evidence that peer influences do increase antisocial behaviors applies primarily to the adolescent developmental stage (Warr, 2002). Strong evidence comes from treatment experiments: in two controlled clinical trials, boys treated in groups did worse than untreated controls; treatment was followed by increased adolescent problem behaviors and poorer outcomes (Dishion et al, 1999). After group-level treatment brought the boys together they

mutually reinforced each other's antisocial activities, a finding which argues for individual treatment approaches. A natural-experiment study tracked change in antisocial behavior among boys who joined a gang to reveal that joining a gang increased each adolescent's individual offending over his pre-gang baseline, whereas leaving the gang decreased each individual's personal offending rate (Thornberry et al, 1993). Overall, we must consider the dynamic and reciprocal manner in which children's conduct problems influence who their friends are and in which those friends later promote the young person's conduct problems (Vitaro et al, 2001).

From risk predictor to evidence for causation

Associations have been documented above between conduct problems and a wide range of risk factors. A variable is called a *risk factor* if it has a documented predictive relation with antisocial outcomes, whether or not the association is causal. The causal status of most of these risk factors is unknown; we know what statistically predicts conduct-problem outcomes but not how or why (Kraemer, 2003). Establishing a causal role for a risk factor is by no means straightforward, particularly as it is unethical to experimentally expose healthy children to risk factors to observe whether those factors can generate new conduct problems. There is no one solution to the problem, although the use of genetically sensitive designs and the study of within-individual change in natural experiments and treatment studies have considerable methodological advantages for suggesting causal influences on conduct problems (Moffitt, 2005b; Rutter, 2000; Rutter et al, 2006). This chapter has emphasized risk factors that have research evidence to support a causal role in conduct problems. For example, above we have cited research that supports causation by depressed mothers' poor discipline (Kim-Cohen et al, 2005), child maltreatment (Dodge et al, 1995; Jaffee et al, 2004), family poverty (Costello et al, 2003), familial genetic liability (Moffitt, 2005a), and affiliating with delinquent peers (Dishion et al, 1999; Thornberry et al, 1993). These studies' designs either took advantage of natural experiments or otherwise were able to rule out alternative explanations to causation (Moffitt, 2005b). Other risk factors described here have not been decisively tested for causation yet but they do have evidence that they are robust predictors of conduct problems across many studies carried out in different contexts (e.g., perinatal complications, temperament, verbal and executive deficits, slow heart rate, social cognitions, exposure to parental conflict). Still other risk factors benefit from strong causal theory, warranting inclusion in this chapter, but the evidence base to show reliable association with conduct problems is not yet

TABLE D.3.1 Factors predicting poor outcome

Onset	Early onset of severe problems, before age 8
Phenomenology	Antisocial acts which are severe, frequent, and varied
Comorbidity	Hyperactivity and attention problems
Intelligence	Lower IQ
Family History	Parental criminality; parental alcoholism
Parenting	Harsh, inconsistent parenting with high criticism, low warmth, low involvement and low supervision.
Wider environment	Low income family in poor neighbourhood with ineffective schools.

strong (e.g., attachment, neurotransmitters, MAOA genotype, smoking during pregnancy, neighbourhood context).

COURSE AND PROGNOSIS

Of those with early onset conduct disorder (before eight years of age) about half persist with serious problems into adulthood. Of those with adolescent onset, the great majority (over 85%) desist in their antisocial behaviour by their early twenties. Factors which predict poor outcome are shown in Table D.3.1.

To detect protective factors, children who do well despite adverse risk factors have been studied. These so-called *resilient* children, however, have been shown to have lower levels of risk factors, for example a boy with antisocial behaviour and low IQ living in a rough neighbourhood but living with supportive, concerned parents. Protective factors are mostly the opposite end of the spectrum of the same risk factor, thus good parenting and high IQ are protective. Nonetheless there are factors which are associated with resilience independent of known adverse influences. These include a good relationship with at least one adult, who does not necessarily have to be the parent; a sense of pride and self-esteem; and skills or competencies.

Adult outcome

Studies of groups of children with early onset conduct disorder indicate a wide range of problems not only confined to antisocial acts, as shown in Table D.3.2.

What is clear is that not only are there substantially increased rates of antisocial acts in adulthood but that the general psychosocial functioning of children with conduct disorder grown up is strikingly poor. For most of the characteristics shown in Table D.3.2, the increase compared to controls is at least double for community cases who were never referred, and three to four times for referred children.

Table D.3.2 Adult outcome

Antisocial Behaviour	More violent and non-violent crimes, e.g. mugging, grievous bodily harm; theft, car crimes, fraud.
Psychiatric problems	Increased rates of antisocial personality, alcohol and drug abuse, anxiety, depression and somatic complaints, episodes of deliberate self-harm and completed suicide, time in psychiatric hospitals
Education and Training	Poorer examination results, more truancy and early school leaving, fewer vocational qualifications
Work	More unemployment, jobs held for shorter time, jobs low status and income, increased claiming of benefits and welfare
Social network	Few if any significant friends, low involvement with relatives, neighbours, clubs and organisations
Intimate relationships	Increased rate of short lived, violent cohabiting relationships; partners often also antisocial
Children	Increased rates of child abuse, conduct problems in offspring, children taken into care
Health	More medical problems, earlier death

Pathways

The path from childhood conduct disorder to poor adult outcome is neither inevitable nor linear. Different sets of influences impinge on the individual growing up and shape the life course. Many of these can accentuate problems. Thus a toddler with an irritable temperament and short attention span may not learn good social skills if he is raised in a family lacking them and where he can only get his way by behaving antisocially and grasping for what he needs. At school he may fall in with a deviant crowd of peers, where violence and other antisocial acts are talked up and give him a sense of esteem. His generally poor academic ability and difficult behaviour in class may lead him to truant increasingly, which in turn makes him fall further behind. He may then leave school with no qualifications, fail to find a job and resort to drugs. To fund his drug habit he may turn to crime and, once convicted, find it even harder to get a job. From this example, it can be seen that adverse experiences do not only arise passively and independently of the young person's behaviour; rather, the behaviour predisposes them to end up in increasingly risky and damaging environments. Consequently, the number of adverse life events experienced is greatly increased. The path from early hyperactivity into later conduct disorder is also not inevitable. In the presence of a warm supportive family atmosphere it is far less likely than if the parents are highly critical and hostile.

Other influences can however steer the individual away from and antisocial path. For example, the fascinating follow-up of delinquent boys to age 70 by Laub and Sampson showed that the following led to desistence: being separated from a deviant peer group; marrying to a non-deviant partner; moving away from a poor neighbourhood; military service which imparted skills.

PRINCIPLES OF TREATMENT

1. **Engage the family**

   Any family coming to a mental health service is likely to have some fears about being judged as bad and possibly mad. Families of conduct problem children are more likely to be disadvantaged and disorganised, to have had arguments with official agencies such as schools and welfare officers and to be suspicious of officialdom. Dropout rates in treatment for conduct problem families are high – often up to 60% (Kazdin, 1996). Practical measures, such as assisting with transportation, providing childcare and holding sessions in the evening or at other times to suit the family are all likely to facilitate retention. Forming a good alliance with the family is especially important, and Prinz and Miller (1994) showed that adding engagement strategies during the assessment, such as showing parents that the therapist clearly understood their viewpoint, led to increased attendance at treatment sessions. Once engaged, the quality of the therapist's alliance with the family affects treatment success, accounting for 15% of the variance in outcome in the meta-analysis by Shirk and Carver (2003).

2. **Select which treatment type to use and who should deliver it**

   If possible, interventions need to address each context specifically, rather than assuming that successful treatment in one area will generalise to another. Thus improvements in the home arising from a successful parent

training programme will not necessarily lead to less antisocial behaviour at school (Scott, 2008). If classroom behaviour is a problem and a school visit shows that the teacher is not using effective methods, then advice to the teacher and other school staff can be very effective. Where there are pervasive problems including fights with peers, then individual work on anger management and social skills should be added. Medication is controversial and generally best avoided; possible indications are discussed below. Generally speaking, due to the strong evidence for its effectiveness, the first line of treatment should be parent training.

Most countries have insufficient resources to treat all antisocial behaviour in childhood, so a decision will need to be made as to whether other agencies can be involved. Thus a number of voluntary sector bodies now provide parent training and schools may also be able to set up suitable behavioural programmes.

3. **Develop strengths**

Identifying the strengths of the young person and the family is crucial. This helps engagement and increases the chances of effective treatment. Encouragement of abilities helps the child spend more time behaving constructively rather than destructively – e.g., more time spent playing football is less time spent hanging round the streets looking for trouble. Encouragement of prosocial activities – for example to complete a good drawing or to play a musical instrument well – also increases achievements and self-esteem and hope for the future.



Click on the picture to access the US Federal Government's site National Youth Violence Prevention Resource Center which has recent research findings and provides online training for prevention.

4. **Treat comorbid conditions**

Child antisocial behaviour often affects others so strongly that comorbid conditions can easily be missed. Yet, comorbidity is the rule rather than the exception in clinical referrals. Common accompaniments are depression and ADHD; a number will have PTSD, for example in the context of violence inflicted on themselves by a father, or witnessing beatings received by their mother from a partner.

5. **Promote social and scholastic learning**

Treatment involves more than the reduction of antisocial behaviour – thus stopping tantrums and aggressive outbursts, while helpful, will not lead to good functioning if the child lacks the skills to make friends or to negotiate: positive behaviours need to be taught too. Specific learning disabilities such as reading retardation, which is particularly common in these children, need treatment, as do more general difficulties such as planning homework.

6. **Use guidelines**

The American Academy of Child and Adolescent Psychiatry has published sensible practice parameters for the assessment and treatment of conduct disorder (AACAP 1997); the UK National Institute for Health and Clinical Excellence (NICE) has published a "technology appraisal" of the clinical and cost effectiveness of parent-training programmes (2006) and is due to publish in 2013 a guideline on assessment and treatment of conduct disorders.

7. **Treat the child in their natural environment**

Most of the interventions described below are intended for outpatient or community settings. Psychiatric hospitalization is very rarely necessary; there no evidence that inpatient treatment leads to gains that are maintained after the child is returned to their family.

Specific interventions

Family based

The best known in the context of delinquency is Functional Family Therapy (FFT), brought into being in 1969 by James Alexander and colleagues (Alexander et al, 2000). It is designed to be practicable and relatively inexpensive; 8-12 one hour sessions are given in the family home to overcome attendance problems common in this client group. For more intractable cases, 26-30 hours are offered, usually over three months. The target age range is 11-18. There are four phases to treatment. The first two are the *engagement* and *motivation* phases. Here the therapist works hard to enhance the perception that change is possible and to minimise perceptions that might signify insensitivity or inappropriateness (e.g., poor programme image, difficult to access, insensitive referral). The aim is to keep the family in treatment, and then to move on to find what precisely the family wants. Techniques include *reframing*, whereby positive attributes are enhanced (e.g., a youth who offends a lot but doesn't get caught is labeled as bright) and the emotional motivation is brought out (e.g., a mother who continually nags may be labelled as caring, upset and hurt).



Click on the picture to view *Preventing Violence and Related Health-Risking Behaviors in Adolescents,* a NIH Sate of the Science Consensus Report.

Families are encouraged to see themselves as doing the best they can under the circumstances. *Problem-solving* and *behaviour change* are not commenced until motivation is enhanced, negativity decreased, and a positive alliance established. Explicit attempts are made to reduce negative spirals in family interactions by interrupting and diverting the flow of negative, blaming speeches. Reframes do not belittle the impact of the negative behaviour, but each family member should feel at the end of these two initial stages that:

- They are not inherently bad, it is the way they have done things that hasn't worked
- Even though they have made mistakes, the therapist *sided* with them as much as with everybody else
- Even though they experience the problems differently, each family member must contribute to the solution
- Even though they may have a lot to change, the therapist will work hard to protect them and everyone else in the family
- They want to come back to the next session because it finally seems that things might get better.

The third phase of FFT targets *behaviour change*. There are two main elements to this, communication training and parent training. The success of this stage is dependent on the first two having been achieved and is not commenced unless they have been (this differs from some programmes where a predetermined number of sessions is allocated to each topic irrespective of the rate of family progress). This stage is applied flexibly according to family needs. Thus if there are two parents who continually argue and this is impinging on the adolescent, the

"marital subsystem" will be addressed, using standard techniques, These include:

1. Using the first person voice rather than the second (instead of "you are a lazy slob", "I find it upsets me when you leave your socks on the floor")
2. Being direct (instead of complaining to partner "he never…", say it directly to the youth)
3. Brevity instead of long speeches
4. Behavioural specificity about what is desired
5. Offering alternatives to the young person, and
6. Active listening.

Parent training techniques are similar to those found in standard approaches and include praise, rewards (called contracting in FFT – e.g., if you come home by 6pm each night, I will take you to the cinema on Saturday), limit setting, consequences and response-cost (e.g., losing TV time for swearing).

The fourth and final phase of FFT is *generalisation*. Here the goal is to get the improvements made in a few specific situations to generalise to other similar family situations, to help the youth and family negotiate positively with community agencies such as school, and help them get the resources they need. Sometimes this latter goal may require the therapist to be a case manager for the family. Therefore, to do this requires that the therapist knows the community agencies and how the system works.

Effectiveness

The effectiveness of FFT is well established, there have been over 10 replication studies (Alexander et al, 2000), of which over half have been independent of the developers, and four are underway in Sweden. The trials published to date all have been positive, with typical recidivism rates being 20% to 30% lower than in controls.

Multiple component interventions

Multisystemic Therapy

The example of Multisystemic Therapy (MST) will be taken as it is one of the best treatments of this kind. MST was developed by Henggeler and colleagues in the US (Huey et al, 2000). There are nine treatment principles:

1. An assessment should be made to determine the fit between the problems and the wider environment: difficulties are understood as a reaction to a specific context, not seen as necessarily intrinsic deficits
2. Therapeutic contacts emphasize the positive and use systemic strengths as levers for change. Already the assessment will have identified strengths (such as being good at sports, getting on well with grandmother, the presence of prosocial peers in grandmother's neighbourhood). The implementation of this principle means that each contact should acknowledge and work on these.
3. Interventions are designed to promote responsible behaviour and decrease irresponsible behaviour.
4. Interventions are focused in the present, are action oriented, and have specific, well-defined goals. The approach is what can be done in the

here and now, in contrast to some therapies that emphasise the need to understand the family and the youth's past.

5. Interventions target sequences of behaviour in multiple systems that maintain problems.
6. Interventions are developmentally appropriate. They should fit the life stage and personal level of the family members.
7. Interventions require daily or weekly effort by family members. This enables frequent practice of new skills and frequent positive feedback for efforts made. Non-adherence to treatment agreements rapidly becomes apparent.
8. The effectiveness of the intervention is evaluated continuously from multiple perspectives with the intervention team assuming responsibility for overcoming barriers to successful outcomes.
9. Interventions are designed to promote treatment generalization by empowering parents to address the youth's needs across multiple contexts.

The way the therapy is delivered is closely controlled. Due to the weekly monitoring of progress; if there are barriers to improvement, these should be rapidly addressed and the hypotheses of what is going on in the family and systems around the youth should be revised in the light of progress. Clinicians only take on 4-6 cases since the work is intensive. There is close attention to quality control by weekly supervision along prescribed lines and parents and youths themselves fill in weekly questionnaires on whether they have been receiving therapy as planned. Therapy is given for three months and then stopped.

Effectiveness

The first raft of outcome studies by the programme developers was positive. Thus the meta-analysis of papers up to and including 2002 by authors that include one of the programme developers, Charles Borduin, found that in 7 outcome studies comparing MST to treatment as usual or an alternative with 708 youths by 35 therapists, the mean overall effective size across several domains was 0.55 (Curtis et al, 2004). Outcome domains ranged from offending (arrests, days in prison, self-reported criminality, self reported drug-use) where the mean effect size (ES) was 0.50, peer relations (ES: 0.11), family relations (self-reported ES: 0.57, observed ES: 0.76), and individual youth and parent psychopathology symptoms (ES: 0.28). However, the three studies using the developers own graduate students as therapists achieved noticeably larger effect sizes (mean 0.81) than when the developers were supervising local community therapists, where the effect size mean was down to 0.26.

Long-term follow-up 14 years later (when participants' mean age was 29 years) by the developers of one of the first trials (with 176 cases allocated to MST or usual individual therapy), gave recidivism rates of 50% vs 81% respectively. However, in the process of evaluation, the next test of any therapy is its effectiveness when carried out by teams who have no financial or employment ties with the developers (although they may pay the developers for materials and supervision) and with an independent evaluation team (Littell, 2005). The only independent evaluation was also the only one to use proper intention to treat analyses (rather than exclude treatment refusers etc.) in a large sample (n=409) in Ontario, Canada. It found that MST resulted in no improvement compared



with treatment as usual on any outcome, either immediately or by the three year follow up (Lescheid & Cunningham, 2002). A smaller (n=75) independent study in Norway (Ogden & Hagen, 2006) was more positive, founding ESs of 0.26 for self-reported delinquency, 0.50 for parent-rated, and 0.68 for teacher-rated, though here there was 40% missing data.

Interventions that do not work

Harsh, military style shock incarceration, so-called "boot camps", are still popular for young offenders in the US and were promoted by the Office of Juvenile Justice and Delinquency Prevention in 1992 when 3 pilot programmes were set up. However, several reviews have concluded they are ineffective (Tyler et al, 2001; Stinchcomb, 2005; Benda, 2005; Cullen et al, 2005). A randomized control trial by the California Youth Authority that included long-term arrest data found no difference between boot camp and standard custody and parole (Bottcher & Ezell, 2005). In contrast, a meta-analysis of 28 studies of wilderness programmes found an overall effect size of 0.18, with recidivism rates of 29% vs 37% for controls (Wilson & Lipsey 2000). Programmes with intense physical activity and a distinct therapeutic component were the most effective. Another approach is to seek to frighten young delinquents with visits to prisons in an attempt to deter them, for example in the "Scared Straight" programme. However, a meta-analysis of nine controlled trials found that the intervention is on average more harmful than doing nothing; it led to worse outcomes in the participants (Petrosino et al, 2003).

Medication

At present, there are no pharmacological interventions approved specifically for conduct disorder. Nonetheless, in the US, medications are used relatively frequently and increasingly in this population (Steiner et al, 2003; Turgay, 2004). Primary care physicians are often placed in the position of managing such medications. Concerns have been raised because primary care clinicians often lack training in developmental psychopathology and adequate time for thorough assessment and monitoring (Vitiello, 2001). In the UK medication would not

At present, there are no pharmacological interventions approved specifically for conduct disorder.

generally be supported as good practice because, as discussed below, well-replicated trials of effectiveness are limited, particularly for children without ADHD.

The best-studied pharmacological interventions for youth with conduct problems are psychostimulants (methylphenidate and dexamfetamine), as used with children with co-morbid ADHD and conduct disorder. In these circumstances, there is evidence that reduction in hyperactivity/impulsivity will also result in reduced conduct problems (Connor et al, 2002; Gerardin et al, 2002). There is insufficient reliable evidence to decide whether stimulants reduce aggression in the absence of ADHD; one study by Klein et al (1997) found that improvements in conduct disorder symptoms were independent of ADHD symptom reduction, but this needs replication.

Other pharmacological approaches for antisocial behaviour targeted reactive aggression and over-arousal, primarily in highly aggressive and psychiatrically hospitalised youth. Medications used in these conditions include those purported to target affect dysregulation (e.g., buspirone, clonidine) and mood stabilizers (e.g., lithium, carbamazepine). While Campbell et al found that lithium reduced aggression and hostility in psychiatrically hospitalized youth (Campbell et al, 1995; Malone et al, 2000), others failed to show effectiveness in outpatient samples (e.g., Klein, 1991) and in studies of shorter treatment intervals (i.e., 2-weeks or less) (Rifkin et al, 1997). Carbamazepine failed to outperform placebo in a double-blind placebo controlled study (Cueva et al, 1996). In children with aggression and hyperactivity, Hazell and Stuart (2003) in a placebo controlled, randomized trial of stimulants plus placebo versus stimulants plus clonidine found the latter was more effective. However, it should be noted that polypharmacy carries the risk of increased side effects (Impicciatore et al, 2001).

In the last few years, the use of antipsychotics such as risperidone, and other drugs such as clonidine in outpatient settings has been increasing. However, there is only modest evidence for their effectiveness in conduct disorder in normal IQ children without ADHD. The review by Pappadopoulos et al (2006) found that ESs were larger where ADHD or intellectual disability were present. Findling et al (2000), in a small (n=10 per group), double blind, placebo-controlled study, found significant short-term reduction in aggression. The Risperidone Disruptive Behaviour Study Group used a placebo-controlled, double blind design to examine the effects of risperidone in 110 children with subaverage IQ and conduct problems. Results suggest that risperidone resulted in significant improvements in behaviour versus placebo (Aman et al, 2002; Snyder et al, 2002) but it remains unclear whether the same findings would apply to children with normal IQ. Newer antipsychotics, while not especially sedating, have substantial side-effects, for example risperidone typically leads to considerable weight gain and the prevalence of long-term movement disorders in the long-term is unknown (Reyes et al, 2006). When antipsychotics might be contemplated? Clinical experience suggests they can lead to dramatic reductions in aggression in some cases, especially where there is poor emotional regulation characterized by prolonged rages. Prescribing antipsychotics for relatively short periods (for example, up to 4 months) in low doses (e.g., no more than 1 mg to 1.5 mg of risperidone per day) can help families cope. During this time it is crucial to introduce more effective psychological management. However, antipsychotics are not recommended in anything other than unusual circumstances.

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DISRUPTIVE MOOD DYSREGULATION DISORDER

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Conflict of interest: unrestricted award by the American Psychiatric Association, the American Psychiatric Institute for Research and Education and Astra Zeneca. Research support from *Bundesministerium für Wirtschaft und Technologie*, the *Deutsche Gesellschaft für Sozialpädiatrie und Jugendmedizin*, and the Paul and Ursula Klein Foundation. Recipient of a travel-stipend donated by the GlaxoSmithKline Foundation, an unrestricted educational grant, speaker honoraria and travel support by Shire pharmaceuticals and support from the Raine Foundation for Medical Research.



Detail of Children's Games (1560), Pieter Brueghel the Elder, *Kunsthistorisches Museum*, Vienna

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Suggested citation: Zepf FD, Holtmann M. Disruptive mood dysregulation disorder. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions, 2012.

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Conflict of interest: served in an advisory or consultancy role for Shire, Lilly, Novartis, and Bristol-Myers Squibb, and received conference attendance support or was paid for public speaking by AstraZeneca, Janssen-Cilag, Lilly, Neuroconn, Medice, Novartis and Shire.

Acknowledgements: the authors would like to thank Ellen Leibenluft and Joseph M Rey for their valuable comments.

When parents and caregivers refer their children because of increased energy levels and rapid mood changes clinicians are confronted with the task of ruling out a manic or hypomanic episode (see also Chapter E.2). The diagnosis of juvenile mania, the *sine qua non* of bipolar illness, is often complicated in children because of its rather unspecific symptoms (e.g., episodes of anger, elation and irritability, often accompanied by aggressive behavior).

Kraepelin's 100-years-old legacy, the unambiguous distinction between *dementia praecox* (schizophrenia) and manic depressive illness (bipolar disorder), has been questioned increasingly (Lichtenstein et al, 2009). Not only the distinction between schizophrenia and bipolar disorder but also the construct of bipolar disorder itself are coming under attack (Parker, 2009). Against this shifting background, considerable controversy has arisen during the last 20 years about the prevalence and characteristics of bipolar disorder in the young.

The traditional view is that bipolar disorder can occur in pre-pubertal children – but rarely – becoming increasingly prevalent during adolescence, and that symptoms in the young are largely the same as in adults. A contrasting stance asserts that bipolar disorder is not uncommon in children, even among toddlers and preschoolers, and that symptoms are quite different from those observed in adults. According to the latter view, the episodic nature of bipolar disorder is often absent in young patients; mood changes – even within the hour – are much more common than in adults and aggressiveness, irritability, sleep disturbance and increased energy are the symptoms observed more often in children with bipolar disorder that in adults with the illness (Danielyan et al, 2007). Proponents of this view also maintain that bipolar disorder is often misdiagnosed as, or co-morbid with attention deficit hyperactivity disorder (ADHD) (Biederman et al, 1998). Indeed, ADHD does show a significant symptom overlap with bipolar disorder in children and adolescents as can be seen in Figure E.3.1 (Zepf, 2009).

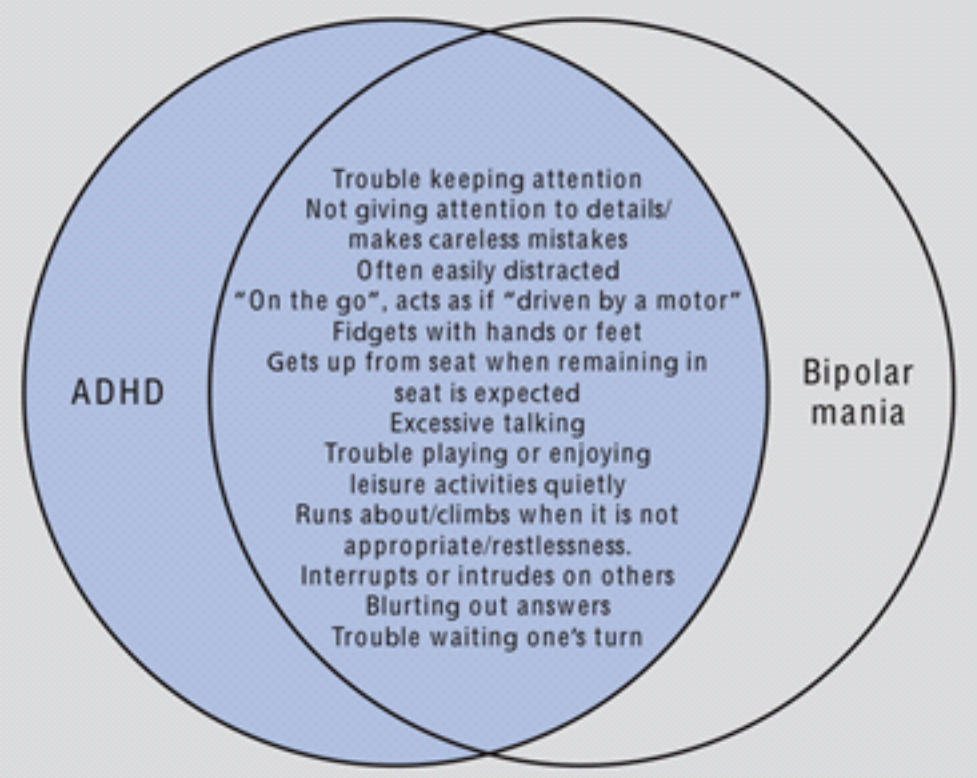
The pediatric bipolar disorder controversy

Clinical diagnoses of bipolar disorder have increased dramatically in children in the last 20 years, especially in the US, accompanied by an explosion in publications – more articles were published on pediatric bipolar disorder in January 2008 than in the decade from 1986 to 1996 (Leibenluft, 2008). For example, in the US between 1993 and 2003 the number of adults diagnosed with bipolar disorder doubled, but increased *40 times* in people younger than 20 years (Blader & Carlson, 2007; Moreno et al, 2007). This means that clinicians are either better able to detect the illness or that many have adopted a controversial widening of the construct – if an epidemic of bipolar disorder is excluded.

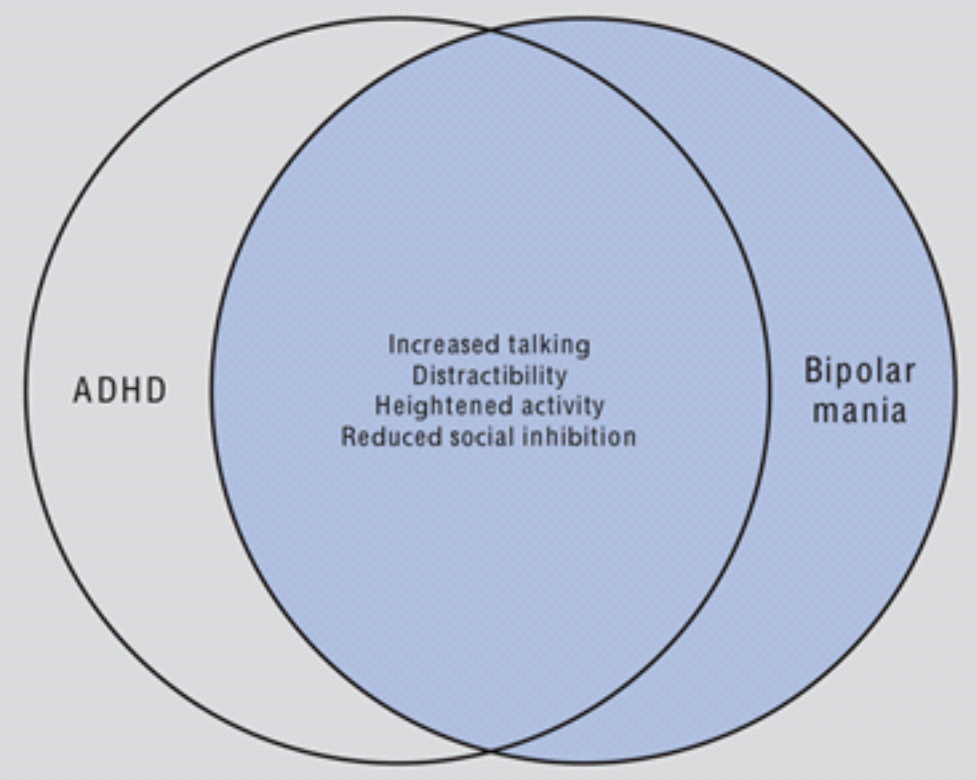
Although an uncommon diagnosis in many countries apart from the US, a growing body of research shows that some pre-pubertal children show symptoms consistent with DSM-IV criteria for bipolar disorder, demonstrate continuity with adult bipolar disorder and have poor outcomes. The controversy refers to the view that bipolar disorder may present differently in children than in adults – this type of dispute is not new; a similar process occurred in relation to depression half a century ago, and was settled by acknowledging that adult diagnostic criteria were applicable with minor modifications to children. Differences refer to the definition of episode and mood abnormality.

Figure E.3.1: Diagnostic overlap in manic episodes and ADHD

DSM-IV symptoms of ADHD that can also be observed in a manic episode



DSM-IV symptoms of a manic episode that can also be observed in ADHD



Zepf, 2009, adapted with permission from Wingo & Ghaemi, ©2007, Physicians Postgraduate Press and Kent & Craddock, Journal of Affective Disorders, 73:211-221,©2003, with permission from Elsevier.

Episode

According to DSM-IV, an *episode* is characterized by a *distinct period* of mood change distinguishable from baseline, lasting at least one week for mania or four days for hypomania. These discrete episodes are separated by periods of euthymia or sub-syndromal symptoms. Several research groups have contended that this criterion fails to detect a proportion of children with bipolar disorder because such children have episodes shorter than four days or have symptoms that are chronic (i.e., non-episodic).

Mood abnormality

Some clinicians and researchers believe that the typical symptoms of a manic episode (abnormal, persistently elevated, expansive, or irritable mood and increased activity or energy) are often absent in children. An important question is whether or not children with bipolar disorder, like adults with the illness, have episodes and, if severe, non-episodic irritability is a developmental presentation of pediatric mania (while euphoria would be most characteristic of adult mania).

It could be concluded that there is a group of severely impaired children who show symptoms that overlap with bipolar disorder (and in many cases with ADHD) but who do not meet strict criteria for either diagnosis – this could potentially be a new, different disorder. The present chapter focuses on children with these emotional and behavioral problems, which are different from those typical of hypomania or mania. These children are characterized by *chronic unstable mood* and *heightened irritability*. A term frequently used to describe this phenotype has been *severe mood dysregulation* (SMD), largely equivalent to "disruptive mood dysregulation disorder" proposed for DSM-5.

The concept of SMD has been proposed by Leibenluft et al in 2003. Research findings providing neurobiological support for this phenotype have been published only within the last nine years. Because of this, only preliminary information can be given on epidemiological aspects and prevalence as well as evidence-based treatment strategies and pathways to care.

SEVERE MOOD DYSREGULATION (SMD)

SMD encompasses symptoms of hyper-arousal (as observed in manic episodes, but also sometimes in ADHD) accompanied by severe chronic and, above all, *non-episodic* irritability. Whereas some researchers argue that children and adolescents with bipolar disorder present with a rather narrow behavioral phenotype, which resembles bipolar disorder in adults, with clear episodes of depressed mood and of mania or hypomania, patients with SMD do not show well defined episodes. However, bipolar disorder in children and adolescents and SMD show comparable levels of impairment. Evidence suggests that SMD increases the risk of early adulthood depressive disorders (Brotman et al, 2006) and anxiety disorders (Stringaris et al, 2009) but not for bipolar disorder, which is less frequently observed in families of children with SMD than in families of children with bipolar disorder in both community and clinical populations (Brotman et al, 2007; Leibenluft, 2011).

Who are the children with severe mood dysregulation?

"These explosive children are not new. A closer look at the traditional diagnoses that apply to this group of youth gives us further insight. Although there is no significant difference in the rates of ADHD between children with narrow phenotype bipolar disorder and those with severe mood dysregulation (60.6% and 86.7%, respectively), more than twice the number of children with severe mood dysregulation have oppositional defiant disorder (39.4% versus 83.3%) […] If we recast children with severe mood dysregulation as children with prominent combined ADHD and oppositional defiant disorder, we find we have considerable knowledge about them already. For instance, follow-up studies do not report inordinate rates of narrow phenotype bipolar disorder in children with ADHD plus oppositional defiant disorder. However, conduct disorder (CD) and later antisocial behavior/criminality and substance abuse are the unfortunate legacies of combined ADHD and oppositional defiant disorder" (Carlson, 2007).

Prevalence

An epidemiologic study found a lifetime prevalence of 3.3% for a retrospectively assigned proxy diagnosis of SMD in children 9 to 19 years of age (Brotman et al, 2006), and SMD was associated with depressive and anxiety symptoms in later adulthood (Brotman et al, 2006; Stringaris et al, 2009); no further research is available so far apart from studies on a psychometric profile in the Child Behavior Checklist (CBCL; Achenbach, 1991) that can characterize such mood problems (see below). Overall, these preliminary data suggest that SMD is relatively common in childhood.



Click on the picture to view a brief video interview with Ellen Leibenluft MD on bipolar disorder in childhood summarizing the relationship between chronic irritability and chronic mood dysregulation problems, and how these problems differ from bipolar disorder in children

Neurobiology

The work conducted so far suggests that children and adolescents with SMD and bipolar disorder differ from healthy controls and patients with anxiety or depressive disorder in facial expression recognition tasks, but patients with SMD and bipolar disorder do not differ from each other in these tasks although both groups seem to get more frustrated than controls on a rigged task (Guyer et al, 2007). Behavioral and psycho-physiological performance differ between SMD and bipolar patients, with children with SMD showing a diminished N1 event-related potential amplitude when compared to controls and children with bipolar disorder, and patients with bipolar disorder showing a decreased parietal P3 (Rich et al, 2007).

Children with ADHD show increased activation of the left amygdala, a region of the brain that is particularly important for emotion, when compared to controls and patients with SMD and bipolar disorder when rating the subjective fear of faces with neutral expressions, while participants with SMD show an underactivation (Brotman et al, 2010). In regard to altered reward and punishment processing, a feature that is relevant for a variety of neuropsychiatric conditions, preliminary research suggests that youths with SMD (and also individuals with bipolar disorder) do not differ from healthy people, in contrast to individuals with psychopathy (Rau et al, 2008).

With respect to motor inhibition, a feature that is relevant for heightened activity in patients, neural recruitment during failed motor inhibition differentiates children with SMD and bipolar disorder from each other (Deveney et al, 2012a). One study on emotional prosody labeling deficits (as indexed by the inability to identify nonverbal emotional cues) indicated that such impairments were larger in people diagnosed with SMD than in controls (Deveney et al, 2012b). It can be concluded at this stage that underlying brain mechanisms of several processes that are related to the symptomatology of SMD are different between patients with SMD, bipolar disorder and healthy people. This section will be updated reguarly when more data become available.

Clinical presentation and diagnostic criteria

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is currently undergoing a major revision, with SMD being discussed as a possible new diagnostic category. The label currently proposed for the new condition is "disruptive mood dysregulation disorder", grouped under the depressive disorders. Table E.3.1 summarizes the proposed diagnostic criteria for disruptive mood dysregulation disorder for DSM-5 as they stood at the time of writing.

Table E.3.1 Summary of diagnostic criteria for disruptive mood dysregulation disorder proposed for DSM-5.

A	Severe recurrent temper outbursts in response to common stressors, which are: • Manifest verbally or behaviorally, such as in the form of verbal rages, or physical aggression towards people or property. • Grossly out of proportion in intensity or duration to the situation or provocation. • Inconsistent with the child's developmental level.
B	Temper outbursts occur, on average, three or more times per week.
C	Mood between temper outbursts is persistently negative (irritable, angry, and/or sad) nearly every day
D	Criteria A-C have been present for at least 12 months and symptoms have been absent for less than 3 months at a time
E	Symptoms in at least two settings (at home, at school, or with peers) and must be severe at least in one setting.
F	Aged 6 years or older
G	Onset before 10 years of age
H & I	Does not meet criteria for another mental disorder (e.g., bipolar, major depression, psychosis) but it can coexist with oppositional defiant disorder, ADHD, conduct disorder or substance use disorder.

As at November 6th 2011 (Source: APA)

Diagnostic criteria for research on SMD have been used to characterize young people with this type of problem, which are summarized in Table E.3.2. It is of note that age of onset differs between the two: before 10 years of age for disruptive mood dysregulation disorder and before 12 for SMD. Moreover, a diagnosis of SMD requires symptoms of hyperarousal, whereas disruptive mood dysregulation disorder does not, with the rationale that clinicians can also assign a concurrent diagnosis of ADHD if warranted.

Child Behavior Checklist dysregulation profile (CBCL-DP)

An additional line of research has used the CBCL (Achenbach, 1991) to capture a phenotype showing broad overlap with the clinical presentation of SMD. A profile has been identified that captures the mixed phenotype of severe behavioral and affective dysregulation, including irritability, aggression, "affective storms", hyperarousal and mood instability. This profile is characterized by simultaneous extreme values on the syndrome scales "anxious/depressed", "attention problems", and "aggressive behavior". This profile was initially coined the CBCL-pediatric bipolar disorder phenotype because it is commonly seen in children with bipolar disorder (Biederman et al, 1995). However, the specificity of the association with bipolar disorder has recently come into question (Diler et al, 2009; Holtmann et al, 2008; Volk & Todd, 2007). Therefore, Althoff et al (2008) suggested to change the name to the "CBCL-dysregulation profile" (CBCL-DP), a proposal which is adopted in this chapter. About 1-2% of youth in epidemiological samples (Volk & Todd, 2007; Holtmann et al, 2007; Hudziak et al, 2005), 6-7% in child psychiatric clinical samples and 13-20% of children with ADHD meet criteria for this behavioral phenotype (Holtmann et al, 2008).

The CBCL-DP may be a valuable tool to identify patients with severe mood problems. High scores may indicate persisting problems and poor outcomes, such

Table E.3.2 Research diagnostic criteria for severe mood dysregulation (adapted from Leibenluft, 2011; Leibenluft et al, 2003)

Inclusion criteria	Exclusion criteria
1. Age 7–17 years, with onset of the syndrome before age 12	Exhibits any of these cardinal manic symptoms: • Elevated or expansive mood • Grandiosity or inflated self-esteem • Episodically decreased need for sleep
2. Abnormal mood (specifically, anger or sadness), present at least half of the day most days, and of sufficient severity to be noticeable by people in the child's environment (e.g., parents, teachers, peers)	Symptoms occur in distinct periods lasting more than one day
3. Hyper-arousal (defined by at least three of the following: insomnia, agitation, distractibility, racing thoughts or flight of ideas, pressured speech, and intrusiveness)	Meets criteria for schizophrenia, schizoaffective disorder, pervasive developmental disorder, or posttraumatic stress disorder
4. Compared to peers, the child exhibits markedly increased reactivity to negative emotional stimuli that is manifest verbally or behaviorally. For example, the child responds to frustration with extended temper tantrums (inappropriate for age or precipitating event), verbal rages or aggression toward people or property. Such events occur, on average, at least three times a week.	Meets criteria for substance abuse disorder in the past 3 months
5. The symptoms in 2, 3 and 4 are currently present and have been present for at least 12 months without any symptom-free periods exceeding 2 months.	IQ < 70
6. The symptoms are severely impairing in at least one setting (home, school or with peers) and are at least mildly impairing in a second setting.	Symptoms are due to the direct physiological effects of a drug of abuse, or to a general medical or neurological condition

as substance use, suicidality, and functional impairment (Holtmann et al, 2011; Jucksch et al, 2011).

Comorbidity

It is essential for clinicians to be able to make a differential diagnosis between SMD and bipolar disorder. Importantly, bipolar disorder should not be diagnosed in the absence of episodes characterized by a distinct change in mood and concurrent changes in behavior and cognition (Baroni et al, 2009). Regarding the differential diagnosis of ADHD and mania, symptoms such as distractibility, agitation, etc. should only be considered to be symptoms of mania if these symptoms are clearly worse than the patient's baseline symptomatology and occur in tandem with mood changes and other symptoms of mania (see Table E.3.1). In youths with bipolar disorder, co-morbid ADHD should be only diagnosed based on observations made while the patient is euthymic (Baroni et al, 2009).

TREATMENT

Only very few studies addressed specific treatment approaches for SMD. One study in hospitalized patients with SMD investigated the effect of lithium. Because in this study a significant proportion of participants with SMD experienced clinical improvement during an initial two-week, single-blind, placebo run-in

M was 7.5 years of age when his parents became increasingly aware and worried because of his frequent temper outbursts, which seemed to happen without a noticeable or minor trigger, such as after arguing with his older sister over which TV channel they would watch. These outbursts had increased in intensity and frequency over time, with verbal and physical aggression towards his classmates as well as objects. Between these outbursts M mostly showed a negative mood. He once mentioned to his friends and parents that he was thinking about what would happen if he was no longer alive. His peers wondered why M was always so cranky and irritable; minor provocations leading to aggressive reactions far out of proportion. The mentioned outbursts happened on average 3-4 times per week; initially, however, frequency was lower. Outbursts led to frequent fights at school, and soon teachers contacted the parents to come and discuss M's behavioral problems. Before the current presentation M had been taken to a community health center because teachers had raised the possibility that M was suffering from ADHD. However, the diagnostic process was lengthy as M frequently refused to participate in an evaluation and only rarely showed up for clinical appointments.

A diagnosis of severe mood dysregulation disorder was made. A diagnosis of major depression as well as conduct disorder were ruled out based on self-, parent and teacher reports obtained through interviews and/or additional diagnostic questionnaires. Treatment with risperidone was initiated based upon clinical experience because of the frequent temper outbursts. In addition, M received behavioral psychotherapy with a local psychologist in order to identify potential triggers and stressors leading to temper outbursts and negative mood, and to develop strategies to cope with stressful situations that could easily impact M's mood. Further, M and his parents had several meetings with teachers and community health workers to plan strategies for prevention and constructive management of his temper outbursts (such as time-out strategies, understanding and avoiding triggers for aggression and management/coping strategies for stressful situations), frequency and intensity of M's outbursts gradually decreased from the initiation of treatment; he became more cooperative and willing to participate in further treatment and assessment, which lead to the diagnosis of ADHD (based on clinical observations, self-, -parent and teacher-reports as well as cognitive and neuropsychological testing). Subsequently, treatment with methylphenidate was initiated leading to a further improvement of his scholastic performance and, with only a short latency, to a further improvement of his outbursts. M currently only receives treatment with methylphenidate as treatment with risperidone was discontinued after approximately six months in which he was able to significantly reduce his temper outbursts and aggressive problems. However, treatment for ADHD symptoms needed to be continued, but his mood dysregulation problems improved significantly.

period after stopping treatment with other medications, no valid conclusions could be drawn (Dickstein et al, 2009). In addition, there were no significant differences between the randomized groups regarding clinical outcome.

Given the high comorbidity with ADHD, there has been a focus on stimulants as a possible treatment approach (Waxmonsky et al, 2008). Significant improvements have been reported following stimulant medication, indicating a decrease of ADHD, ODD, and mood symptoms. A combination treatment including varying intensities of behavior modification therapy and stimulant medication (methylphenidate) was developed for subjects with ADHD and SMD. Results showed that methylphenidate and behavior modification therapy were effective and acceptable treatments for children presenting with both disorders. The authors, however, stated that SMD subjects were more likely to remain significantly impaired than non-SMD subjects after an intervention period of 3 weeks. In another treatment trial, Waxmonsky et al (2012) developed a novel group-based therapy. Children with ADHD and SMD were randomized to either psychosocial community treatment or group therapy for 11 weeks while maintained in an optimal dose of stimulant medication prior to randomisation. The group therapy program consisted of concurrent 90-minute sessions for parent and children. With this treatment, children showed a significant decline in levels

of suicidal ideation whereas parents showed more positive parenting behaviors.

In the absence of sound empirical evidence, medications that may improve symptoms such as irritability and depressed mood may be valuable – all used "off label". In this line, antidepressants (e.g., SSRIs) as well as mood stabilizers (e.g., lithium, valproic acid) may be considered. Second generation antipsychotics such as risperidone, aripiprazole, olanzapine and ziprasidone, have also been suggested to be beneficial. However, prescribing practices have been under scrutiny due to the marked increase of on-label and off-label use, and concerns regarding medication safety. Antipsychotic medication may cause adverse effects such as sedation, cognitive impairment, extrapyramidal symptoms, weight gain and metabolic changes. Therefore, discussion with parents and patients as well as a careful monitoring of potential side effects by an experienced clinician are warranted when prescribing these medications.

Apart from medication, educational aspects are highly relevant. In particular, clinicians, teachers and parents need to work closely together to address and meet these patients' special needs (e.g., classroom support, more time to complete school tests, etc.). This also refers to the adverse effects of medication; teachers should be made aware of them. Patients and families should also receive education about the disorder, co-morbid symptoms and related impairments as well as strategies for intervention and coping. Finally, changes in lifestyle can be addressed together with the help of allied health professionals. Such changes could include, for example, strategies for coping with crises and identifying potential stressors and triggers for such situations. A plan to manage emergencies (e.g., suicidal behaviour, extreme loss of control) needs to be put in place also. Moreover, parenting programs and family therapy need to be considered as many of these children come from problematic families with poor parenting and communication skills, or whose parents suffer from psychiatric disorders themselves. In that case a referral to a psychiatrist should be considered.

Key practitioner messages (Baroni et al, 2009)

- The diagnosis of bipolar disorder in youth […] should only be made in the presence of identifiable manic or hypomanic episodes.
- In DSM-IV, ICD-10, and NICE Guidelines, manic episodes must last for 7 days or more and include a distinct change from baseline mood with concurrent alterations in behavior.
- DSM-IV and ICD-10 support a diagnosis of hypomania in children if episodes last at least four days.
- There is no single optimum diagnosis for youth with severe, non-episodic irritability. Current evidence suggests that such irritability may be a variant of depression.
- Youth with severe, non-episodic irritability differ from those with bipolar disorder in longitudinal course, family history, and performance on many, although not all, tasks linked to pathophysiology.

OUTCOME

Not surprisingly, there is limited evidence on the long term outcome of patients with SMD. One study involving a 2-year follow-up of youths with SMD showed that they had lower rates of manic, hypomanic or mixed episodes than patients with bipolar disorder (Stringaris et al, 2010). There is also evidence that patients with SMD have an increased risk for depressive and anxiety disorders in later adulthood (Brotman et al, 2006; Stringaris et al, 2009). Long term follow-up of children captured by the CBCL-DP phenotype suggest that young adults with a positive CBCL-DP in childhood are at increased risk for substance use, conduct and mood disorders, suicidal ideation and suicide attempts. In addition, they showed a marked impairment in overall functioning (Althoff et al, 2010; Holtmann et al, 2011).

CONCLUSIONS

SMD represents a potentially new diagnostic entity based on recent clinical observations and research evidence. Irrespective of whether SMD is accepted as a new disorder, it remains to be conclusively demonstrated whether children with these symptoms suffer from a new condition or from severe forms of widely known

psychiatric disorders (in particular bipolar disorder, conduct disorder, oppositional defiant disorder, ADHD) or their combination (Carlson, 2007). It would appear that many of the children diagnosed with bipolar illness, particularly in the US, might have suffered in fact from a combination of ADHD *and* oppositional defiant disorder or conduct disorder. Experienced clinicians know that many of these children come from very disturbed families in which abuse, neglect and separation from attachment figures is often the norm. However, this is sometimes ignored in taxonomic and research studies. This adds another layer of complexity, in particular because it becomes very difficult to establish which of the child's behaviors are due to a "biological" disorder and which ones are the result of, or response to family dysfunction.

According to the guidelines of the British National Institute for Health and Clinical Excellence (NICE,) as well as of the American Academy of Child and Adolescent Psychiatry (AACAP, 2007) summarized in a recent overview for clinical practitioners (Baroni et al, 2009), the diagnosis of bipolar disorder in children should only be applied if the patient presents with a history of manic or hypomanic episodes in line with relevant diagnostic criteria (e.g., as regards the duration and frequency of such episodes).

Current treatment approaches to SMD comprise psychopharmacology (although there is limited evidence available), parenting programs, family support, psychotherapy, and psychoeducation. Research is currently underway that will hopefully ascertain which interventions are effective.

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SUICIDE AND SELF-HARMING BEHAVIOUR

Thomas Jans, Yesim Taneli & Andreas Warnke



On April 8, 1986, 18-year-old Yukiko Okada jumped to her death from a seven-story building. The reason for the suicide is still unknown. Her death was followed by many copycat suicides in Japan (referred to at the time as the "Yukiko Syndrome"). Okada, a singer, was adored by millions of fans in Japan.

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Suggested citation: Jans T, Taneli Y, Warnke A. Suicide and self-harming behaviour. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

In many countries suicide is one of the leading causes of death among children and adolescents. Identifying young people at risk and offering effective treatment is a major concern of mental health policies. This chapter includes a review of suicidality in children and adolescents. Non-suicidal self-injury will also be addressed, but the major focus will be on attempted and completed suicide. The review refers to epidemiology, risk factors and etiological features, clinical presentation, assessment, treatment and prevention. Because clinical issues are emphasized this review does not include an overview of the neuropsychobiology of suicidality.

The term "non-suicidal self-injury" does not include self-mutilation or other actions causing bodily symptoms with the pure intent of eliciting medical care or advice (Munchhausen syndrome) or malingering (to achieve some benefit).

Table E.4.1 Coding of non-suicidal self-injury, suicide attempts and suicide as an "external cause of morbidity and mortality" according to ICD-10 (X60–X84)*

X6..	Intentional self-poisoning by and exposure to:
X60.	Non-opioid analgesics, antipyretics and antirheumatics
X61.	Antiepileptic, sedative-hypnotic, antiparkinsonism and psychotropic drugs not elsewhere classified
X62.	Narcotics and psychodysleptics [hallucinogens] not elsewhere classified
X63.	Other drugs acting on the autonomic nervous system
X64.	Other and unspecified drugs, medicaments and biological substances
X65.	Alcohol
X66.	Organic solvents and halogenated hydrocarbons and their vapours
X67.	Other gases and vapours
X68.	Pesticides
X69.	Other and unspecified chemicals and noxious substances
X7../X8..	**Intentional self-harm by:**
X70.	Hanging, strangulation and suffocation
X71.	Drowning and submersion
X72.	Handgun discharge
X73.	By rifle, shotgun and larger firearm discharge
X74.	Other and unspecified firearm discharge
X75.	Explosive material
X76.	Smoke, fire and flames
X77.	Steam, hot vapours and hot objects
X78.	Sharp object
X79.	Blunt object
X80.	Jumping from a high place
X81.	Jumping or lying before moving object
X82.	Crashing of motor vehicle
X83.	Other specified means
X84.	Unspecified means

*World Health Organisation, 1996.

Definitions

- *Suicidality* refers to the cognitions and activities of persons seeking their own death, including thoughts, actions or omissions
- *Suicide* (from the Latin *sui caedere*, to kill oneself) means the act of a person intentionally causing his or her own death
- *Suicide attempt* denotes non-fatal acts or preparations intended to result in death. The suicidal act may have been abandoned, interrupted or was unsuccessful
- *Parasuicide* refers to a non-habitual, potentially life-threatening self-harming behaviour which is performed without the intention to kill oneself. Because the behaviour is non-suicidal, some authors prefer the terms "deliberate self-injury", "deliberate self-harm" or "non-suicidal self-injury" (NSSI) (in this chapter the term non-suicidal self-injury is used).

Because of the indirect nature of the self-harm consequences, unprotected intercourse, high-risk behaviors (e.g., extreme forms of downhill riding, illegal car racing) or intoxication by psychoactive substances are not included even if an intention to self-destruct may be present. For descriptive purposes, non-lethal suicide attempts and non-suicidal self-injury are classified using the same codes.

The mere listing of codes in Table E.4.1 does not indicate how frequent these different methods of self-harm are in children and adolescents. Methods commonly used are presented in the box. These methods comprise non-lethal self-harming behaviors – like pinching, scratching or biting – as well as highly lethal methods, which are mostly associated with clear suicidal intent (e.g., use of firearms, jumping from high places). However, from a clinical point of view, it is crucial to differentiate between suicide attempts and non-suicidal self-injury (see Table E.4.2).

Frequently used methods of self-harm

(Non-lethal suicide attempts and non-suicidal self-injury) (Greydanus et al, 2009)

- Drug overdose
- Poisoning
- Cutting
- Other forms of self-mutilation
  - Self-hitting
  - Pinching
  - Scratching
  - Biting
  - Burning
- Shooting oneself
- Hanging
- Jumping from high places
- Jumping into wells

Intent

The key difference between deliberate self-injury and suicide attempt is in the *intent* to end one's life. For example, a 14 year old girl takes a small overdose of paracetamol intending to kill herself, although she does not succeed (*suicide attempt*). Another 14 year old girl takes a large overdose of paracetamol because she is angry and upset. She did not want to kill herself (*non-suicidal self-injury*). Further, some non-suicidal self-harming acts may actually result in death – by ignorance or miscalculation (the latter 14 year old was not aware of the toxic effects of paracetamol and actually died as a result). It has to be kept in mind that both forms of self-harm may overlap: individuals with suicide attempts may also show non-suicidal self-injuring behavior and vice versa.

Regrettably, evaluating intent is often difficult in clinical practice. This has been a major barrier in researching this topic. The Columbia Classification Algorithm for Suicide Assessment (C-CASA) – a standardized suicide rating system developed for the evaluation of suicidality in antidepressant trials – has been shown to be reliable, transportable, and the FDA has mandated that it should be used in psychotropic and other drug trials (Posner et al, 2007). Although this is a research instrument, it may also be useful in clinical practice, at least by standardizing the terminology. C-CASA definitions and selected training examples are shown in table E.4.3.

Table E.4.2 Differences between suicide attempt and non-suicidal self-injury

Suicide attempt	Non-suicidal self-injury ("parasuicide")
• Intending to end one's life	• No suicidal intent
• May be impulsive, but in most of the cases there is a chronic feeling of hopelessness or loneliness	• Emotional state is acute anger, despair or intolerable distress
• More severe and life-threatening forms of self-destructive behaviours are typical (e.g., self-poisoning, hanging, jumping, use of firearms)	• Less severe and mostly not life-threatening forms of self-destructive behaviours are typical (e.g., skin lesions by biting, cutting, burning or freezing)
	• Typically, the person is aware that the behaviour may cause serious injury, but is not life-threatening
• There is a clear risk that suicide attempts are repeated, but to a lesser frequency than non-suicidal self-injuries	• Recurrent self-injury is common

Table E.4.3 Columbia Classification Algorithm for Suicide Assessment (C-CASA): definitions and training examples*

Classification/ Category	Definition	Example
Suicidal events		
Completed suicide	A self-injurious behavior that resulted in fatality and was associated with at least some intent to die as a result of the act.	After a long argument with his girlfriend, which resulted in the end of their relationship, the patient collected a rope and rode his bike to an isolated area where he fatally hanged himself. A suicide note was later found.
Suicide attempt	A potentially self-injurious behavior, associated with at least some intent to die, as a result of the act. Evidence that the individual intended to kill him/herself, at least to some degree, can be explicit or inferred from the behavior or circumstance. A suicide attempt may or may not result in actual injury.	After a fight with her friends at school, in which they discontinued speaking with her, the patient ingested approximately 16 aspirin and eight other pills of different types on the school grounds. She said that she deserved to die, which was why she swallowed the pills.
Preparatory acts toward imminent suicidal behavior	The individual takes steps to injure him- or herself, but is stopped by self or others from starting the self-injurious act before the potential for harm has begun.	The patient had run away from home overnight because his father had gone to school and retrieved a recent "bad" report card. He was fearful of his father's reaction. Upon his return home, a 5- to 6-hour argument with his parents ensued, and he took a vegetable (broad, sharp) knife and went to his room. He reported putting the knife to his wrist but never puncturing the skin.
Suicidal ideation	Passive thoughts about wanting to be dead or active thoughts about killing oneself, not accompanied by preparatory behavior.	Active thoughts: The patient reported to the doctor that he was thinking about hanging himself in the closet. He was taken to the hospital and admitted.
Non-suicidal events		
Self-injurious behaviour, no suicidal intent	Self-injurious behavior associated with no intent to die. The behavior is intended purely for other reasons, either to relieve distress (often referred to as "self-mutilation," e.g., superficial cuts or scratches, hitting/banging, or burns) or to effect change in others or the environment.	The patient was feeling ignored. She went into the family kitchen where her mother and sister were talking. She took a knife out of the drawer and made a cut on her arm. She denied that she wanted to die at all ("not even a little"), but she just wanted them to pay attention to her.
Other, no deliberate self-harm	No evidence of any suicidality or deliberate self-injurious behavior associated with the event. The event is characterized as an accidental injury, psychiatric or behavioral symptoms only, or medical symptoms or procedure only.	The patient had a cut on the neck from shaving.
Indeterminate or potentially suicidal events		
Self-injurious behaviour, suicidal intent unknown	Self-injurious behavior where associated intent to die is unknown and cannot be inferred. The injury or potential for injury is clear, but why the individual engaged in that behavior is unclear.	The patient cut her wrists after an argument with her boyfriend (no further information).
Not enough information	Insufficient information to determine whether the event involved deliberate suicidal behaviour or ideation. There is reason to suspect the possibility of suicidality but not enough to be confident that the event was not something other, such as an accident or psychiatric symptom. An injury sustained on a place on the body consistent with deliberate self-harm or suicidal behavior (e.g., wrists), without any information as to how the injury was received, would warrant placement in this category.	A child who "stabbed himself in [the] neck with a pencil." The event may have been deliberate as opposed to accidental, as suggested by "stabbed," but not enough information was provided to determine whether the event was deliberate.

*Posner et al (2007); only one of several C-CASA examples is cited.

EPIDEMIOLOGY

According to World Health Organization statistics about one million people worldwide die from suicide every year (mean mortality rate: 16 per 100.000), that is, one death every 40 seconds. In some countries suicide is the second leading cause of death in the 10 to 24 years age group. For example, in Germany only accidents – mainly fatal traffic injuries – are a more frequent cause of death in adolescents aged between 15 to 19 years (Elsässer, 2010). The relative weight of suicide as a cause of death varies between countries and regions according to the impact of a variety of factors (see Table E.4.4). Nevertheless, suicide remains an important cause of death among adolescents and young adults worldwide.

As an example of nation-specific variations in suicide rates, European data are presented in Figure E.4.1. The mean rate of suicide among 15 to 19 year olds for 27 European countries in 2009 was 4.9 per 100.000 (males: 7.4; females: 2.3). Suicide rates varied widely from 1.0 (Greece) to 20.2 (Lithuania).

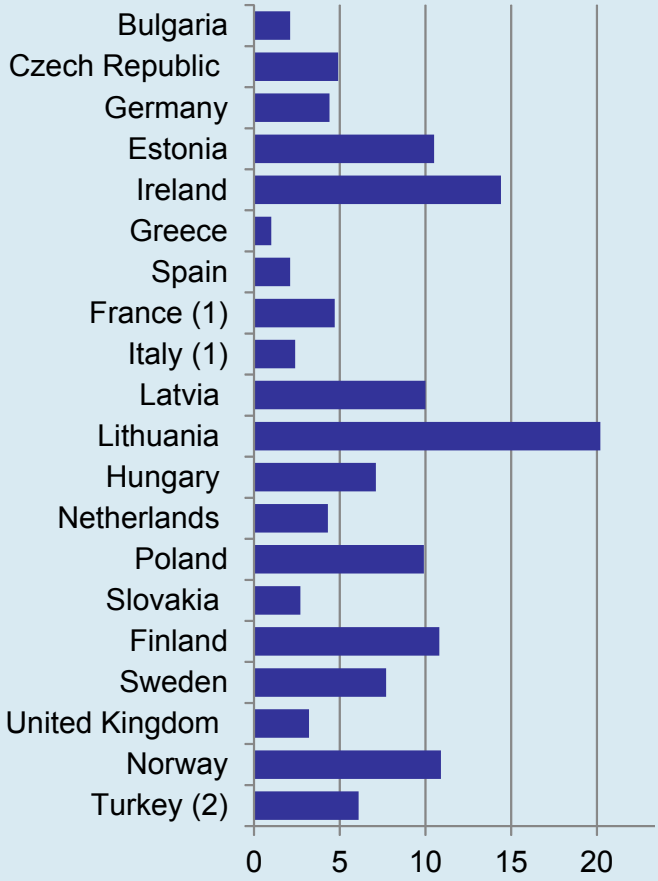
Because of unreliable allocation – e.g., inaccurate ascertainment, religious or cultural attitudes about suicide – reported suicide rates are likely to underestimate the problem. Moreover, these figures do not include suicide attempts, which occur 10 to 20 times more frequently than completed suicides. Serious suicide attempts are estimated to occur in about 3% of adolescents in Western societies. Keeping these variations in mind, general statements on the epidemiology of suicide may be invalid for specific populations, regions and time periods.

Table E.4.4 Main causes of death in adolescents and young adults in decreasing order of frequency*

Africa:	**Southeast Asia:**	**South America/Caribbean:**
1. AIDS	1. Unintended Injuries	1. Homicide/War
2. Other infections	2. Other Infections	2. Unintended Injuries
3. Homicide/War	3. AIDS	3. Suicide
4. Unintended Injuries	4. Suicide	4. Other Infections
5. Suicide	5. Homicide/War	5. AIDS
Western Pacific:[1]	**Europe:**	**Eastern Mediterranean:**[2]
1. Unintended Injuries	1. Unintended Injuries	1. Unintended Injuries
2. Suicide	2. Suicide	2. Other Infections
3. Other Infections	3. Homicide/War	3. Homicide/War
4. Homicide/War	4. Other Infections	4. AIDS
5. AIDS	5. AIDS	5. Suicide
North America:		
1. Unintended Injuries		
2. Suicide		
3. Homicide	[1]Australia, New Zealand, China, Japan, Korea, Malaysia, Micronesia, Philippines, Singapore, Vietnam, and others in this area	
4. Cancer		
5. Other Infections	[2]Afghanistan, Egypt, Iraq, Jordan, Saudi Arabia, Israel, and other Middle East Countries	
6. AIDS		

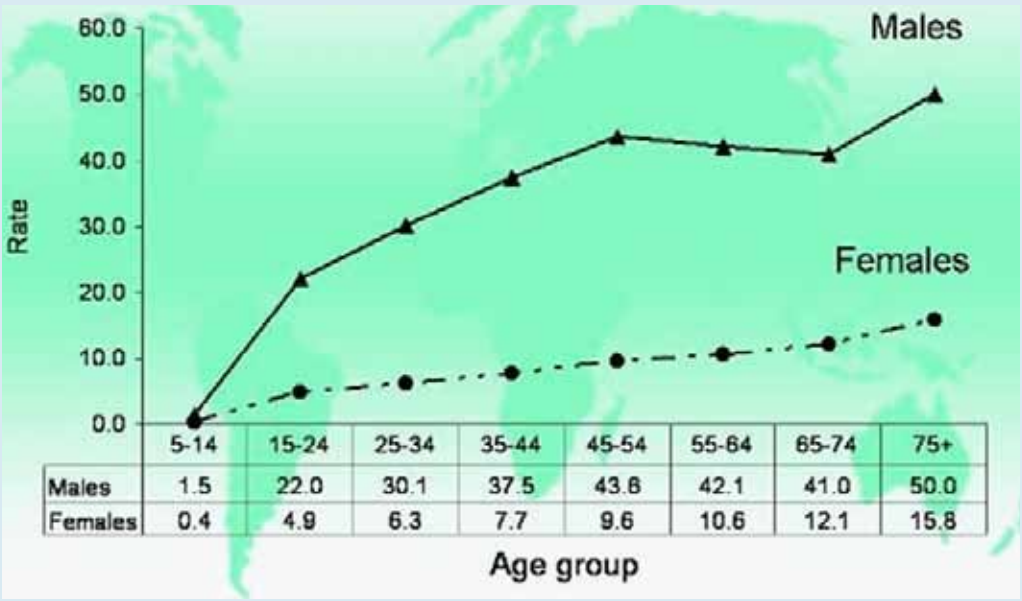
*Adapted from Greydanus et al (2009).

Figure E.4.1 Suicide death rate in Europe (selected countries): Adolescents aged 15 to 19 years (death rate per 100.000 persons)



(1) Italy, France: data from 2008
(2) Turkey: data from 2010; source: TurkStat; Suicide Statistics 2010
Data from 2009; source: Eurostat.

Figure E.4.2 Suicide rates (per 100.000) by gender and age.



	5-14	15-24	25-34	35-44	45-54	55-64	65-74	75+
Males	1.5	22.0	30.1	37.5	43.6	42.1	41.0	50.0
Females	0.4	4.9	6.3	7.7	9.6	10.6	12.1	15.8

Data from 2000; Source: WHO

Qualifications need to be made with respect to:

- Age
- Gender
- Specific regions and countries
- Ethnicity, and
- Secular trends.



Click on the picture to access WHO suicide statistics.

Age

Globally, during the last few decades suicide rates have been highest in the elderly (see Figure E.4.2). However, according to World Health Organization's Suicide Prevention Program (SUPRE) website, in some countries suicide rates among young people have increased so much that adolescents and young adults represent the group at highest risk for suicide. This refers to a third of all countries and holds for more and less industrialized nations. Therefore, clearly elevated suicide rates in the elderly seem not to be present worldwide. High suicide rates among adolescents and young adults can be seen, for example, in New Zealand and Japan. In pre-pubertal children completed suicide is very rare. Children become able to understand the concept of suicide from the age of 8 years and become capable of carrying it out, leading to increasing rates of completed suicide in pubertal children and young adolescents. Relatively low suicide rates in children may be accounted for by the age-dependent absence of, or lower exposure to major risk factors (e.g., mental illness, substance-related disorders) or the protection offered by a close relationship with the family.

Gender

Overall, rates of completed suicide are higher in males than in females. This holds true for all age groups, with a male to female ratio of about 4:1 in adolescents and young adults. However, gender ratios vary between countries. There are regions in which the gender distribution of completed suicides is similar (e.g., China). In Turkey, male to female ratios of 0.6:1 for ages up to 14 years and 1.1:1 for ages 15-19 years have been reported (TurkStat; Suicide Statistics 2010, www.tuik.gov.tr, 2011; Turkey's Statistical Yearbook 2009, www.tuik.gov.tr, 2010). Suicide among young girls is alarmingly high in the west coastal region of India (Kanchan et al, 2009). Reasons for the relatively high suicide rates among young females in some countries in Asia may partly be due to the easy access and use of pesticides, particularly lethal, and the limited access to emergency medical services (by contrast, in Western European countries the use of the less lethal analgesics is far more prevalent in suicidal females).

Globally higher rates of completed suicide in males are associated with more violent means (e.g., guns, hanging) and the pattern of risk factors in males (e.g., impulsive aggression, alcohol misuse). However, with respect to gender ratio the opposite is true for suicide attempts, which are far more common in females than in males (sometimes referred to as the "gender paradox").

Specific regions and countries

Regional variations in suicide rates reflect varying environmental and social risk factors. Reported suicide rates vary widely between countries; even within quite homogenous states there are regional differences (e.g., relatively high rates in Saxony in Germany). The highest rates worldwide are reported for Eastern

European Countries, among them countries with a traditionally high suicide rate since the end of the 19th century (e.g., Estonia). Relatively low rates are reported for the Gulf States.

Besides differences in the recording of suicides, variations suggest country-specific patterns of risk and protective factors (e.g., socio-economic disadvantage, rapid cultural change), geography and climate (e.g., light exposure and depression), access to lethal means (e.g., poisons or firearms), use of alcohol and drugs, ethnicity, and religious beliefs.

Low suicide rates in the Gulf States may reflect religious norms and low alcohol use. In general, a gradient has been described whereupon agnostics show the highest suicide rates, Muslims have the lowest, while Christians, Buddhists and Hindus are in the middle (Bertolote & Fleischman, 2009).

Suicide rates are high among minority groups, particularly those who have undergone rapid social change, acculturation or have become disenfranchised as a result of colonization (e.g., American Indians, Australian aborigines, Inuit). For a comprehensive review the reader may refer to Colucci and Martin (2007).

Secular trends

An increase in the rate and absolute number of suicides has been described in the last decades (Bertolote & Fleischman, 2009). However, this effect is not consistent. For example, across OECD countries (the Organization for Economic Co-operation and Development comprises 32 industrialized nations) there has been a slight decline in suicide rates overall. Some countries with traditionally high rates (e.g., Hungary) have shown a sharp decline while others with low rates (e.g., Korea, Japan) have shown a sharp increase. The reasons for these changes are not well understood but may include rapid social or economic changes (e.g., unemployment). However, major burdens for a population may also have the opposite effect. For example, in Germany suicide rates decreased considerably in the years following the 1st and 2nd world wars. For a circumscribed period, the urge of a society to concentrate on the basic needs of daily life may partly protect from suicide.



Time trends appear not to be stable. For example, in many Western countries a reduction in youth suicide rates was observed in the last two decades. This decline may be explained by the more prevalent and effective treatment of psychiatric disorders (e.g. pharmacological treatment of depression). However, following a decade of steady decline, a relative increase in youth suicide was observed in the US in 2004 and 2005 (Bridge et al, 2008). Among the factors speculatively blamed for this increase were the influence of online social networks, increase in suicide among young US military, and higher rates of untreated depression following FDA warnings on suicidality associated with the use of antidepressants.



Recent US data on suicidal behavior among 9th to 12th grade students are available from the Youth Risk Behavior Survey (YRBS), Centers for Disease Control.

Suicidal thoughts and suicide-attempts

In 2009, 9th to 12th grade US students reported in the previous 12 months to have:

- Seriously considered attempting suicide (13.8%)
- Made a suicide plan (10.9%)
- Attempted suicide one or more times (6.3%,)
- Attempted suicide resulting in injury, poisoning, or an overdose that had to be treated by a doctor or nurse (1.9%).

Changes from 1991 to 2009 point to an overall decrease in suicidal thoughts and behavior in US youth. The Youth Risk Behavior Survey data illustrate that suicidal ideation is very common among adolescents and that a significant percentage is carrying out serious suicide attempts. Fortunately, rates for completed suicide are comparatively low (US data for 2006: 4.16 per 100.000 among 10-19 year olds; Cash & Bridge 2009). However, data indicate a progression in the development of acute suicidality from suicidal ideation, to planning and to a suicide attempt. Thus, suicidal thoughts always have to be considered a significant warning sign requiring professional advice. With respect to suicidal ideation and suicide attempts, there is a female preponderance in most countries (more than twice as common among females).

There are differences between countries and regions in rates of suicidal ideation and suicide attempts, similar to what happens with suicide. For example, in South-West Nigeria about 20% of youths aged 10-17 years reported suicidal thoughts and about 12% reported a suicide attempt – rather high (Omigbodun et al, 2008). However, risk factors for suicidality in that study were comparable to those reported in the international literature (e.g., disrupted family environment, financial disadvantage, experiencing abuse or violence, substance use) with the exception of a similar prevalence in males and females.

Means of suicide

In North America, firearms are the most frequent way for young people to commit suicide, followed by hanging, suffocation and self-poisoning (Branco et al, 2010). In Western Europe, by contrast, firearms play a minor role; jumping from high places or before a train is the main method. Poisoning by pesticides is prevalent in agricultural regions in low and middle-income countries such as China and India. In Turkey, in 2010 the five most common methods of suicide among 15-19 year olds were in decreasing frequency: hanging, firearms, chemicals, jumping

from a high place, and jumping into water (TurkStat; Suicide Statistics 2010, www.tuik.gov.tr, 2011). Carbon monoxide poisoning is becoming widespread in some Western Pacific countries (e.g., Taiwan). In Western Europe and North America, over-the-counter pharmaceuticals (mainly analgesics) and psychotropic drugs are common.

Risk factors

Major risk factors for suicide in adolescence are summarized in Table E.4.5. As stated, there is a lack of research on suicide in preadolescents. No specific pattern of risk factors for this age group has been found yet (Kloos et al. 2007). In preadolescents, family-related stressors may play a more significant role than in adolescents, while age-dependent psychopathology (e.g., alcohol use, bipolar disorder, psychosis) may have less influence.

The effects of age and gender have already been described. However, it should be kept in mind that statistical risk refers to averages in a community and has limited relevance for the assessment and treatment of individual patients. For example, a female adolescent is statistically at lower risk for completed suicide after a suicide attempt than a male counterpart. However, *assessment and treatment are not gender-specific!*

Prior suicide attempts

A prior suicide attempt is one of the most important predictors of further attempts and of completed suicide (Spirito & Esposito-Smythers, 2006):

- About 30% of completed suicides have a history of suicide attempts
- After a suicide attempt the risk of a further attempt is 20 times higher than in individuals without a history of attempted suicide
- The risk of a serious suicide attempt is strongly associated with the number of previous suicide attempts.

Table E.4.5 Major risk factors for suicide among adolescents*

- Previous suicide attempt
- Psychopathology
  - Especially major depressive disorder, bipolar disorder, conduct disorder, and substance use disorders
  - Psychiatric co-morbidity, especially the combination of mood, disruptive, and substance use disorders
  - Dysfunctional personality traits (especially antisocial, borderline, histrionic, and narcissistic traits)
  - Feelings of hopelessness and worthlessness
  - Impulsive aggression: the tendency to react to frustration or provocation with hostility or aggression
- Family factors
  - A family history of depression or suicide
  - Loss of a parent through death or divorce
  - Family discord
- Physical and sexual abuse
- Lack of a support network, poor relationships with peers and feelings of social isolation
- "Coming out" or dealing with homosexual feelings in an unsupportive family, community or school environment
- Availability of lethal means
- Having been exposed to suicide (e.g., suicide or suicide attempt in family members or friends; media reporting)

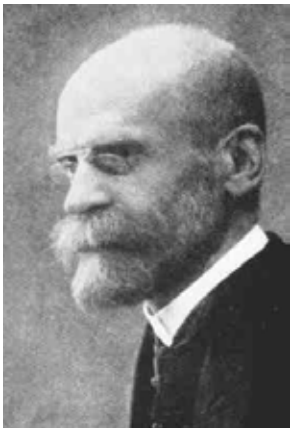
*Adapted from Cash and Bridge (2009).

Psychiatric disorder

Psychopathology is another major risk factor for suicide in children and adolescents. Psychiatric disorders are present in 80% to 90% of suicides. *Mood*, *anxiety*, *conduct* and *substance use disorders* are the most important conditions. Besides co-morbidity the *severity of impairment* caused by psychiatric symptoms as well as the *total symptom load* is of importance. The severity of symptom-related impairment explained most of the risk for suicidality associated with current psychiatric disorders in the Great Smoky Mountains Study (Foley et al, 2006). A single symptom, sleep problems has been associated with suicidality (Wong et al, 2011). Problems sleeping in early adolescence were associated with suicidality and self-harm in late adolescence, even when other risk factors – depression included – were statistically controlled for.

Apart from the presence of manifest psychiatric disorders, *health risk behaviors* (disruptive, sexual and substance use behaviors) are associated with higher suicidal risk in young adolescents (Afifi et al, 2008). Feelings of *hopelessness and worthlessness* as well as *impulsive aggression* are also linked with suicidality. Although these states often occur within the context of depression or conduct disorder, they may also be significant in individuals without a psychiatric disorder. This also refers to the disinhibiting effects of *acute intoxication* which may account for suicidal acts in individuals without manifest substance dependence.

Suicidal behavior can also occur in youngsters without current psychiatric disorder. In the Great Smoky Mountains Study, youth suicide in the absence of a psychiatric disorder was related to prior suicidal behavior, legal and disciplinary problems and psychiatric disorders in the family.



Émile Durkheim (1858-917), French sociologist, sought to explain suicide as a social phenomenon.

Family environment

Parental psychopathology and *suicidal behavior in the family* is associated with higher suicidal risk in the offspring. The liability to suicide in families may be independent of a family history of psychiatric illness. Children of parents with mood disorders show more suicide attempts when there is a history of parental suicidality as compared to the offspring of parents without suicide attempts. Family psychopathology – especially suicide attempts in mothers and substance misuse in both parents – and family discord predict higher suicidality in adolescence even when psychiatric morbidity is controlled for (Pfeffer et al, 1998).

Adversity

In the Great Smoky Mountains Study, poverty was associated with suicidal behavior irrespective of the psychiatric profile or the severity of psychopathology. Stability of the psychosocial network is also relevant. In a Danish study, frequent changes of residence were associated with an increased risk of attempted and completed suicide in children and adolescents (Qin et al, 2009). Greater childhood adversity – exemplified among others by physical or sexual abuse and witnessing domestic violence – was found to be associated with higher psychiatric morbidity, suicidal ideation and suicide attempts in adulthood (Afifi et al, 2008). The severity of sexual abuse correlated with the risk of suicide attempts in a Canadian sample (Brezo et al, 2008). This is observed even in preadolescents. In a study of maltreated 8-year-old children, 10% reported suicidal ideation (Thompson et al, 2005).

Modeling suicidal behavior – The "Werther effect"

There has been much discussion about the influence of media depictions of suicidal acts on the frequency of suicide. A classic example is what happened in Germany after the publication of Goethe's popular book "The Sorrows of Young Werther" in 1774. Publication was followed by a number of suicides of young people. This was attributed to the vivid description of the young protagonist romantically killing himself after being rejected by the woman he loved. The book was subsequently banned in most of Europe.

Suicide clustering following media reporting and fictional presentation of suicide on television does occur ("Werther-effect"). According to a German naturalistic study (Schmidtke & Hafner, 1988), broadcast of a soap opera showing the railway suicide of a 19 year-old male resulted in an increase (175%) in railway suicides among 15 to 19 year-old males. Factors associated with imitation are: time (suicides peak in the first few days after publication), amount and prominence of media coverage, similarity between victim and teenager, celebrity status of the victim, specific description of the suicide (method, time, place), romanticized and sensationalized reporting, suggestions that there is an epidemic, and simplifying the reasons for suicide (World Health Organization, 2008).



Suicide attempts and suicides among peers (Hazell & Lewin, 1993) also increase the risk. Different pathways can lead to a clustering of suicides. Apart from posttraumatic stress symptoms, bereavement and assortative friendships with vulnerable peers, mere imitation is a significant factor.

Stressors

Bullying is associated with suicidal attempts and self-harming behavior. In a Finnish study, frequent victimization among girls was associated with later suicide attempts and completed suicide even after controlling for psychopathology. Bullying and victimization was also associated with suicidality in boys, but not after controlling for depressive and disruptive symptoms (Klomek et al, 2009).

Other relevant stressors include *legal or disciplinary crisis*, *incarceration* and *school difficulties*. Highly competitive placement examinations for high schools may contribute to suicide. For example, in 2010 in Turkey, 13 young people aged up to 19 years committed suicide which was hypothesized to be associated with recent academic failure (TurkStat; Suicide Statistics, 2010, www.tuik.gov.tr, 2011).

Sexuality

There is good evidence that gay, lesbian, and bisexual young people are at increased risk of suicidal behavior (Fergusson et al, 1999; Russell & Joyner, 2001). This may be more so when "coming out" or when families are not supportive (Ryan et al, 2009).

Internet and social networks

A broad spectrum of suicide websites is available on the Internet. There are helpful "anti-suicide" websites mostly maintained by self-help groups, government or international organizations. On the other hand, there are sites clearly celebrating suicide, giving advice on lethal means, offering chat groups in which users can announce their intention to suicide or fix a date for a joint suicide. Some of these websites are linked to specific subcultures (e.g., Emo). In relation to German language sites, there are currently about 100 suicide forums, 40 of them with information judged to be harmful to minors.

SUICIDAL BEHAVIOUR

Clinical course

Stages of suicidal behavior

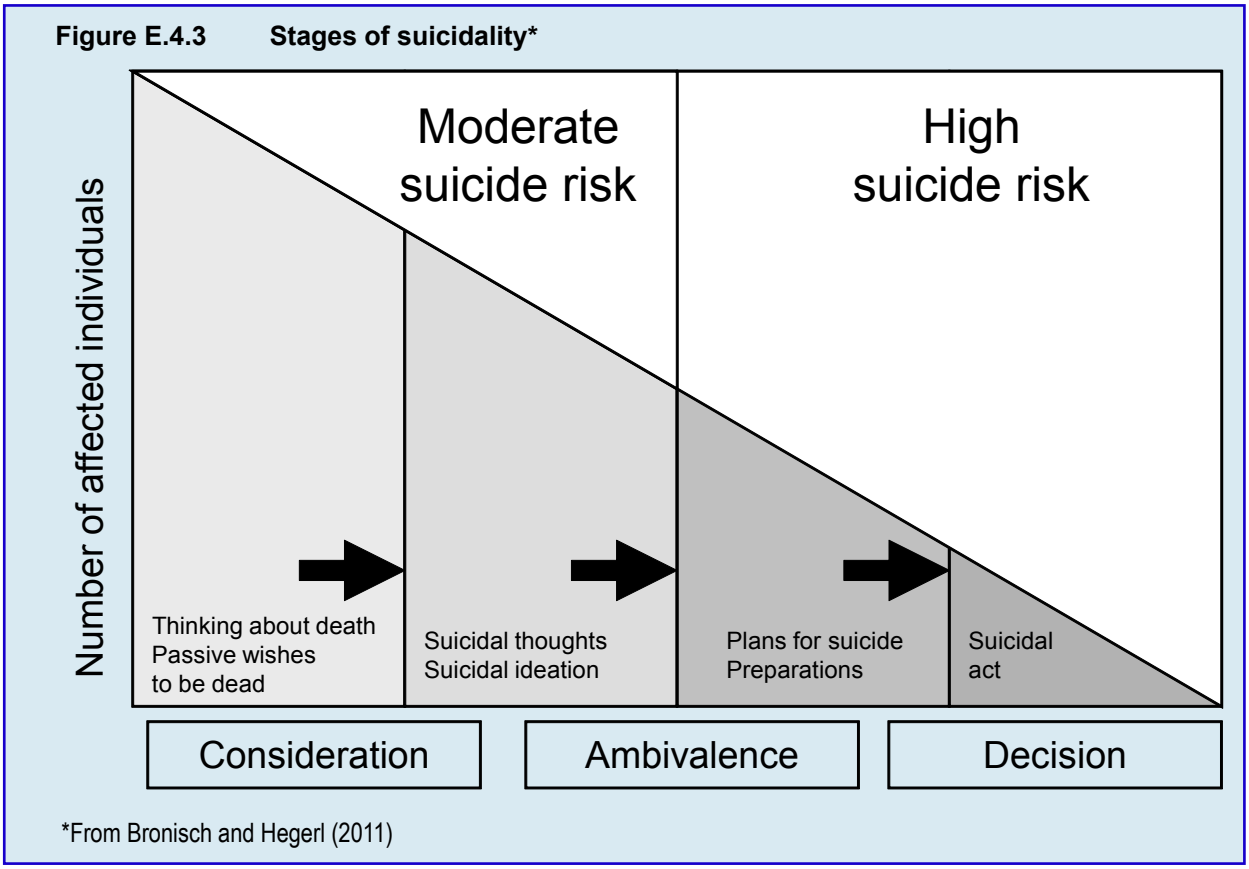
Suicidality can be conceptualized as a continuum with thoughts about death at the one end and serious suicidal acts at the other (Figure E.4.3; Bronisch & Hegerl, 2011). Acute suicidality often develops in a stepwise fashion with increasing and more specific ideation and planning overcoming ambivalence and the individual becoming more and more determined.

As suicidal ideation becomes more specific, a characteristic "pre-suicidal syndrome" (Ringel in 1959; Ringel, 1976) may develop. According to Warnke (2008) it is characterized by:

- Feelings of hopelessness, self-blame, of being alone and misunderstood
- Negative ruminations, self-pity
- Inactivity and social withdrawal
- Inhibited aggression turned toward the self (auto-aggression)
- Suicidal fantasies and planning
- Dysphoria
- Somatic symptoms, sleep problems, fatigue, and loss of appetite.

Once the decision to commit suicide is made, the suicidal person may be less agitated and appears more stable, leading clinicians to underestimate the suicide risk. Presence of the pre-suicidal syndrome should be a warning sign. However, this may be less so in children and adolescents in whom impulsive suicide is more

Figure E.4.3 Stages of suicidality*



*From Bronisch and Hegerl (2011)

common than in adults. Therefore, it has to be kept in mind that suicide attempts may occur during any of the stages depicted in Figure E.4.3.

Suicide usually occurs in a crisis and is rarely happens in the absence of other important factors. For this crisis to take place it usually requires a predisposition, a trigger, a facilitator and availability of a method to carry it through. Being aware of this allows possible interventions to decrease the risk at various stages of the crisis.

- *Predisposition.* As already discussed, youth who attempt suicide have a predisposition to do so, in many cases because of a mental health problem, often depression.
- *Trigger.* Most suicides or suicide attempts take place after something happened that made adolescents feel unhappy, afraid or angry. Conflicts with other people (parents, friends, school, police) are frequent triggers. Examples are disciplinary crises (when teenagers are found to have done something wrong such as stealing and are awaiting punishment), a public humiliation, the threat of separation from a girlfriend or boyfriend, and disclosure of sexual abuse. These are usually perceived as more catastrophic by the teenager than by other people.
- *Facilitator.* The strong emotions produced by crises are more likely to lead to suicide if the young person's judgment is impaired by alcohol or drugs. Other facilitators include identification with someone well known or admired who committed suicide, suicides among family members or friends, or if the teenager lacks firm religious beliefs that forbid suicide.
- *Opportunity.* Finally, adolescents need to have access to the means of committing suicide in an acceptable way for them. Although it may appear strange, people often have a clear idea about the way they would like to kill themselves.



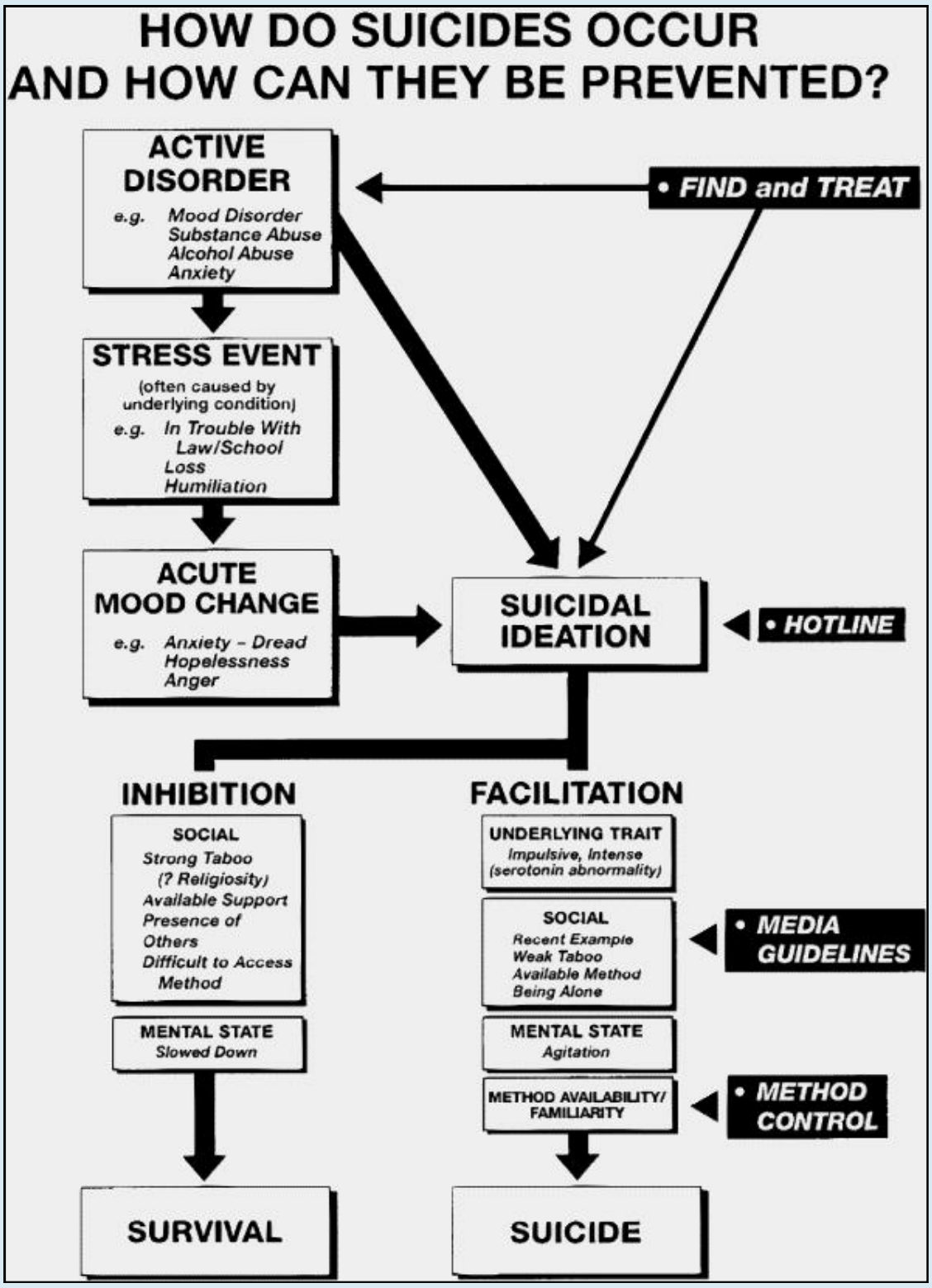
Click on the picture to hear a powerful anti-suicide message ("If you're contemplating suicide, this is for you...") by the gifted rapper Angel Haze. Warning: coarse language. (04:12)

As an example, features of the development of suicidality which are relevant for suicide prevention are shown in figure E.4.4 (American Academy of Child and Adolescent Psychiatry, AACAP, 2001).

Course

In most studies on the natural history of self-harming behavior no distinction is made between non-suicidal self-injury and suicide attempts. This is partly due to research relying on data gathered in non-psychiatric routine clinical care (without thorough examination with respect to suicidal intent). Moreover, in a significant proportion of patients non-suicidal and suicidal self-harm co-occur. As stated above, the risk for completed suicide is considerably increased in individuals with a previous suicide attempt: 0.5% to 2% at one year, above 5% at nine years (Owens, 2002). Repetition rates are high (e.g., 16% at 1 year, 21% at 1 to 4 years and 23% at over 4 years; Owens, 2002). In a large British sample of children and adolescents aged less than 15 years who presented to general hospitals because of deliberate self-harm, long-term follow-up (11 years) pointed to death by suicide in 1% of the patients (Hawton & Harris, 2008). This reflects a relatively low individual risk of completed suicide in self-harming patients even in the long term. On the other hand, the data suggest that people who self-harm have suicide risk 100 times higher than in the general population.

Figure E.4.4 Model of the development of suicidality with types of targeted preventive interventions



Reproduced with permission from Practice parameter for the assessment and treatment of children and adolescents with suicidal behavior. Journal of the American Academy of Child & Adolescent Psychiatry. 40 (sup):24S-51S. ©2001 American Academy of Child and Adolescent Psychiatry.

ASSESSMENT

There are questionnaires available to screen for suicide risk in children and adolescents but they will not be discussed here in detail because most are only available in English and data on their psychometric properties and specific translations may not be available (the interested reader may refer to AACAP, 2001).

Because of its large distribution, owing to its translation into more than 100 languages, the Columbia–Suicide Severity Rating Scale (C-SSRS; Posner et al, 2011) is described. The C-SSRS was designed to distinguish between suicidal ideation and suicidal behavior measuring four constructs:

1) Severity of ideation (wish to be dead, nonspecific active suicidal thoughts, suicidal thoughts including methods, suicidal intent, and suicidal intent with a plan)
2) Intensity of ideation (frequency, duration, controllability, deterrents, and reason for ideation)
3) Behavior (actual, aborted and interrupted attempts; preparatory behavior; and non-suicidal self-injurious behavior)
4) Lethality.



Click on the picture to access the Columbia-Suicide Severity Rating Scale (C-SSRS) training program.

Different forms of this scale have been developed, including versions for children. Forms are available on the C-SSRS website. Psychometric properties appear to be good (Posner et al, 2011), and administration time is only a few minutes. A training program is available on the website, which is required for clinical trials and strongly recommended for clinical practice before administering the C-SSRS.

Rating scales can be helpful for screening purposes – e.g., in prevention projects to detect individuals at risk. However, a clinical assessment by a trained professional is required to assess suicide risk. This assessment should comprise a physical and psychiatric examination including a comprehensive history (with information from patient, parents and significant others) to obtain information about acute psychosocial stressors, psychiatric diagnoses, current mental status and circumstances of prior suicide attempts.

Suicidality should be addressed directly and openly in a supportive atmosphere. There is no risk to cause suicidality by talking about it; there is a risk of ignoring suicidality if the topic is avoided. Assessment should be stepwise, from general to specific questions. Examples of questions to be asked when screening for suicidality are given in table E.4.6. Further assessment may be skipped if acute suicide risk can be ruled out. On the other hand, exploration will be more detailed if risk factors for suicide become apparent.

A sophisticated exploration will comprehensively cover all known suicide risk factors; these are summarized in tables E.4.7 to E.4.9 (Warnke, 2008), comprising:

- Current individual factors (mental state examination)
- Individual factors in the past (patient's history) and in the family (family history)
- Specific characteristics of prior suicide attempts.

Table E.4.6 Examples of questions to screen for suicide risk (DGPPN, 2009)

- "Have you been thinking that you don't want to live anymore or that life is not worth living?"
- "Does this happen often?"
- "Do you think about it unintentionally? That is: Have you been bothered by unwanted suicidal thoughts?"
- "Have you been able to push these thoughts aside?"
- "Do you have specific ideas about how you would do it?"
- "Did you make any plans or preparations?"
- "Is there anything that prevents you from doing it?"
- "Did you talk to anyone about your suicidal ideas?"
- "Did you ever try to kill yourself?"
- "Has anyone in your family or among your friends or acquaintances committed suicide?"

Table E.4.7 Indicators of acute suicide risk - current individual factors (mental state examination)

Suicidal ideation:

- No disassociation from suicidality even after a long conversation
- Pressing suicidal thoughts, emerging spontaneously
- Precise suicide plan (method, place, time, or other specifications)
- Preparation for suicide, especially in the case of a violent method; preparations to say goodbye
- Altruistic (pseudo-altruistic) ideas of suicide; ideas of self-sacrifice

Symptoms and co-morbidities:

- Marked hopelessness (missing perspectives for the future; low academic achievement; failing on the job; the conflict leading to suicidal ideation remains unsolved)
- Recent social withdrawal
- High agitation, irritability, aggression, emotional instability or panic
- Intoxication (alcohol, drugs)
- Symptoms of acute psychosis
- Impaired impulse control and disinhibition (e.g., in the case of alcohol intoxication, acute delirium or mania)
- Symptoms of severe depression
- Prominent symptoms of personality disorder or conduct disorder, most notably in combination with alcohol abuse

Other important factors:

- A stable rapport cannot be established
- Patient making the effort to be admitted to inpatient-treatment
- Time of examination within a one-year period after the last suicide attempt

The co-occurence of various risk factors should be taken into account. This is exemplified in the following case vignettes:

- A 14 year-old girl was unsure about her sexual orientation; she had romantic feelings towards a female classmate who had harshly rejected her recently. The girl performed poorly academically and had become increasingly depressed three months prior to examination. Psychiatric assessment was prompted by her posting a suicide note in a chat room. Her parents reported that her uncle had died by suicide two years earlier.
- A 16 year-old was referred for psychiatric assessment by the emergency unit where self-inflicted skin cuts on his wrists had been treated; he was also inebriated. The young man had been stigmatized by a congenital haemangioma on his left cheek. He had been brought up by his single mother on her own, she had become pregnant with him at the age of 17; she had not had a stable relationship. The boy had talked about recent suicide attempts with his classmates.

Table E.4.8 Indicators of acute suicide risk - individual factors in the past (patient history) and in the family (family history)

Patient history

- Previous suicide attempts
- Suicides in the surroundings

Social stresses

- Loss of a loved one - most notably a parent - by suicide, natural or accidental death, separation, divorce or long-standing absence
- End of a close relationship (romantic or friendship)
- Missing social contacts and poor integration in the peer group leading to feelings of being lonely and rejected, most notably in the case of migration or relocation

Symptoms and co-morbidities

- Aggressive behaviour and delinquency
- Psychiatric disorders, most notably depression and substance misuse/dependency
- Children: poor discipline, school absenteeism

Other important factors

- No religious or similar attachments
- Seemingly unsolvable conflicts due to unwanted pregnancy
- Conflicts due to homosexuality

Family history

- Suicides and suicide attempts in family members
- Paternal psychopathology
- A family history of violence, misuse and substance abuse
- Unstable family relations and unresolved conflicts in the family, missing social support by family members



Access to lethal means increases suicide risk.

Table E.4.9 Indicators of acute suicide risk - characteristics of prior suicide attempt

- Suicide attempts or suicidal thoughts referring to a "hard method" (e.g., hanging, shooting, jumping from a high place, jumping or lying before moving vehicle)
- The suicide attempt is well-thought-out with a clear planning
- Low chance of help and intervention (specific arrangements were made to prevent being found, e.g., suicide attempt in isolation, far from others, time of suicide chosen to prevent being found, not alerting others after the suicidal act)
- Others have been informed of the suicide intention, a suicide note was written
- A clear wish to die is expressed without relief about being still alive

Table E.4.10 Specific issues in the assessment of pre-pubertal children – example of questions*

Interviewing children whose grasp of the concepts of time, causality and death may be limited:

- "Do you think about killing yourself more than once or twice a day?"
- "Have you tried to kill yourself since last summer/since school began?"
- "What do you think would happen when you tried to jump out of the window?"
- "What would happen if you died; what would that be like?"

Interviewing parents about suicidal ideation and behavior in their children

- "What exactly happened (step by step) on the day your child spoke of wanting or tried to hurt himself?"
- "How did you find out that your child was thinking about or trying to hurt himself?"
- "What were you doing when your child was thinking about or trying to hurt himself?"
- "What happened after your child thought about or tried to hurt himself?"

*Jacobsen et al (1994)



Click on the picture to view the NICE guideline "Self-harm: The Short-Term Physical and Psychological Management and Secondary Prevention of Self-Harm in Primary and Secondary Care"

Table E.4.10 gives examples of the kind of issues that need to be explored when evaluating suicide risk in prepubertal children. Apart from the topics already mentioned, specific aspects refer to the difficulties interviewing children whose comprehension of time, causality and death may be inadequate.

RISK ASSESSMENT

Click here to access the NICE guideline "Self-harm: Longer-Term Management"

Acute suicide risk is low if:

- There is no major psychiatric disorder present requiring treatment
- The patient is able to form an adequate therapeutic alliance with the clinician
- The suicide attempter did not intend to die
- The patient clearly and believably states that a re-attempt will not take place
- The patient is hopeful about the future and has concrete goals with respect to his engagement in everyday activities
- Stable social and family support is available
- No significant life stressors are present.

Table E.4.11 Suicide risk assessment*

	High risk	Medium risk	Low risk
'At risk' mental state • Depressed • Psychotic • Hopelessness, despair • Guilt, shame, anger, agitation • Impulsivity	Examples: • Severe depression • Command hallucinations or delusions about dying • Preoccupied with hopelessness, despair, feelings of worthlessness • Severe anger, hostility.	Examples: • Moderate depression • Some sadness • Some symptoms of psychosis • Some feelings of hopelessness • Moderate anger, hostility.	Examples: • Nil or mild depression, • sadness • No psychotic symptoms • Feels hopeful about the future • None/mild anger, hostility.
Suicide attempt or suicidal thoughts • Intentionality • Lethality • Access to means • Previous suicide attempts	Examples: • Continual/specific thoughts • Evidence of clear intention • An attempt with high lethality (ever).	Examples: • Frequent thoughts • Multiple attempts of low lethality • Repeated threats.	Examples: • Nil or vague thoughts • No recent attempt or one recent attempt of low lethality and low intentionality.
Substance disorder (current misuse of alcohol and other drugs)	• Current substance intoxication, abuse or dependence.	• Risk of substance intoxication, abuse or dependence.	• Nil or infrequent use of substances.
Corroborative history • Family, carers • Medical records • Other service providers and sources	• Unable to access information, unable to verify information, or there is a conflicting account of events to that of those of the person at risk.	• Access to some information • Doubts about plausibility of person's account of events.	• Able to access or verify information and account of events of person at risk (logic, plausibility).
Strengths and supports (coping & connectedness) • Expressed communication • Availability of supports • Willingness and capacity of support persons	Examples: • Patient is refusing help • Lack of supportive relationships or hostile relationships • Relatives or friends not available, unwilling or unable to help • Parental mental illness • Violence or substance misuse in the family.	Examples: • Patient is ambivalent • Moderate connectedness • Few relationships, may be available but unwilling or unable to help consistently • Moderate mental symptoms in family members • Some instability or dysfunctional parenting.	Examples: • Patient is accepting help • Therapeutic alliance forming • Highly connected, good relationships and supports • Relationships willing and able to help consistently • Supporting family environment.
Reflective practice • Level & quality of engagement • Changeability of risk level • Assessment confidence in risk level	• Low assessment confidence or high changeability or no rapport • Poor engagement		• High assessment confidence and low changeability • Good rapport, engagement.

No (foreseeable) risk: Following comprehensive suicide risk assessment, there is no evidence of current risk to the person. No thoughts of suicide or history of attempts, has a good social support network.

*Modified from NSW Department of Health (2004, p20)

Table E.4.12 Acute management of suicidal behaviour*

High risk or high changeability or low assessment confidence: Re-assess within 24 hours
• Ensure the patient is in an appropriately safe and secure environment • Organise re-assessment within 24 hours • Organise ongoing management and close monitoring • Make contingency plans for rapid re-assessment if distress or symptoms escalate.
Medium risk (significant but moderate risk): Re-assess within one week
• Organise re-assessment within one week • Make contingency plans for rapid re-assessment if distress or symptoms escalate
Low risk (definite but low suicide risk): Re-assess within one month
• Organise re-assessment within one month (timeframe for review should be determined based on clinical judgment) • Reassess within one week after discharge from an in-patient unit • Provide written information on 24-hour access to suitable clinical care

*NSW Department of Health (2004a, p21).

Often suicide risk cannot be excluded definitively and an estimation of the level of risk is needed. Table E.4.11 presents a summary of factors that need to be considered for categorizing patients as being at high, medium, low or no foreseeable risk of suicide (NSW Department of Health, 2004a).

Special attention has to be paid to the *changeability of risk* (e.g., suicide risk is not static, it varies due to changes in mental state, relationships or stressors) and to the *confidence* on the assessment. Low assessment confidence can be attributed to (1) factors within the person (e.g., mental illness, the patient is intoxicated); (2) factors within the social environment (e.g., a divorce with a custody battle causing one parent to remain silent about problems), or (3) factors within the assessment procedure (e.g., incomplete assessment, the patient refuses to give information) (NSW Department of Health, 2004a).

MANAGEMENT OF SUICIDAL BEHAVIOR

Optimal treatment of children and adolescents with suicidal behavior requires a continuum of services including emergency intervention, outpatient, home-based, day and inpatient treatment (Steele & Doey, 2007). In practice, however, this is often not possible due to lack of resources.

The first step in managing suicidality is to make sure that the child or adolescent at risk is safe and receives support. The management strategy depends on the level and changeability of risk and assessment confidence (see Table E.4.12).

At the emergency department, young persons who have made a suicide attempt should be assessed by an experienced mental health professional, including interview with parents or relatives and a thorough risk assessment. Staff should be trained to provide care for suicidal youths, who are often disliked by emergency room staff. Suicidal youth need to be treated with the same attention and respect as any other patient, avoiding either blaming them for endangering their life or making well-meant attempts to cheer them up while dismissing the severity of their predicament. Before discharge, it is essential to have prepared a plan to deal

with the crisis, making sure that supporting contact (e.g., telephone) is available 24 hours a day. "To-do-steps" of the contingency plan will depend on the intensity of the emotional crisis and should be worked out in cooperation with the patient and caregivers (NSW Department of Health 2004a). Before discharging a suicidal patient from an emergency unit or crisis centre it is always necessary to (AACAP, 2001):

- Counsel patient and family about the disinhibiting effects of drugs or alcohol
- Check that firearms and lethal medications and substances can be effectively secured or removed
- Check that there is a supportive person at home
- Check that a follow-up appointment has been scheduled (see Table E.4.12).

A 14 year old boy (Michael) was meandering on the railway tracks when he was removed by railway workers. The police were called and initiated a referral to child psychiatry service. During assessment Michael admitted that he had repeatedly falsified school report cards to hide his poor grades. A meeting between his parents and his teacher was to take place soon and the truth would inevitably be unearthed. Michael was afraid of his parents' reaction and had no idea about how to deal with this situation. He thought that getting injured or killed on the tracks was the only way to avoid the confrontation with his parents. Besides his poor achievement at school no other major risk factors for suicide could be determined. He was able to discuss his wrongdoings with his parents who accepted his apologies. Since there were no symptoms of other mental disorders and he did not intend harming himself any longer, he was discharged from the child psychiatric unit one day after admission. An appointment with the child psychiatrist had been scheduled for three days after discharge. Michael and his parents agreed that involving the school should also be part of the management plan. Poor grades and the impending meeting with the schoolmaster were still a significant worry for him.

The contingency plan worked out with Michael and his parents was as follows:

1. ***For Michael***: *If I'm feeling desperate and have a strong urge to harm myself, I will openly talk to my parents. We will contact <name of the mental health professional>. <name of the mental health professional> will offer an appointment on the same or the following day.*

2. ***For Michael***: *If my parents are not present at that time, I will address a person I trust <names of persons>. If no such person is available, I will contact <name of the mental health professional> myself.*

3. ***For Michael and his parents***: *If <name of the mental health professional> cannot be contacted, we will phone <emergency number of the child psychiatric unit> and request an immediate appointment. The <child psychiatric unit> will offer this appointment within a few hours.*

4. ***For Michael's parents***: *If Michael feels as described above, one of us will stay with him until the appointment takes place. If this cannot be ensured, we will call for an immediate emergency appointment as specified above.*

5. *If, for some reason, <name of the mental health professional> cannot offer an appointment, an appointment will be organised with a colleague instead.*

Contingency planning (NSW Department of Health, 2004a, p23).

Contingency planning requires the clinician and the person at risk and their family to anticipate likely escalations of risk such as:

- Deterioration of family relationships
- Increase in symptoms (depression, insomnia, hallucinations, suicidal feelings)
- Temporary unavailability of the clinician or acute care team.

Contingency planning may be framed, communicated and documented in the following manner:

- If the patient <e.g., has a worsening of suicidal thoughts>, then the patient will <actions to be performed, e.g., phone doctor NN, speak with parents about it>
- The family will <actions to be performed by the family, e.g., ensure the patient is not left alone, phone doctor NN, give prescribed medication>
- The service will <actions to be performed by the service, e.g., organise an urgent review, do a home visit>

In addition, a no-suicide contract may be helpful (formulated as a commitment by the patient and not as an insurance for the mental health professional since there is no empirical evidence that no-suicide contracts are actually effective). A no-suicide contract usually includes (1) confirmation that the patient is not to endanger his life during a defined short period (e.g., the next day, until the next session with the therapist); (2) a commitment by the patient to adhere to the therapy; (3) a commitment by the patient to comply with the contingency plan.

The management of suicidality in youth requires clear communication with the young person and family. This also holds for contact with the school, which should always be attempted after obtaining permission from the young person and family.

Important messages to the suicidal youth, his parents and teachers

It is essential that clinicians inspire confidence and give the impression that they are familiar with this type of problem and in control, avoiding fuelling unnecessary drama but calming, reassuring and soothing everyone involved. However, one needs to be careful about not deceiving patients or promising things that one cannot deliver.

Messages to the suicidal youth:

- My main concern is your safety and I will try to ensure that the best way I can
- Your treatment will be kept confidential unless you give permission to discuss it with other professionals or unless there is immediate risk to your or other people's life
- Many young people think about death or suicide and some try to kill themselves at one time or another
- Almost every decision you make can be changed. However, death is final and irrevocable. It's worth taking enough time to balance the pros and cons
- We would like to know more about you. Together we may get to understand the circumstances that placed you in this crisis
- Every suicidal youth I have met had reasons for their self-destructive ideas but in most cases reasons changed over time
- I am sure that together we can find a way out of your predicament – even if this seems out of reach for you right now
- As a first step we will try to formulate a contingency plan with you and your parents.

Messages to parents and caregivers:

- Suicidal thoughts and attempts are not uncommon in young people. In most of cases, this is an acute crisis that is overcome within a short period of time. We are familiar with managing suicidal crises and will frankly discuss every step with you
- Like with every medical treatment we are bound by confidentiality. In the course of treatment it may be useful to establish contact with other professionals (e.g., teachers, psychologists). However, contact will only be established with your child's consent or if there is immediate risk to your child's life

- The first priority is to ensure your child's safety. Close supervision is needed until we can estimate the suicide risk. Depending on the estimated risk, we will decide after consultation with you and your child on further treatment options
- As a first step we will formulate a contingency plan for you, your child and us
- Dealing with suicidal behavior is only effective if there is a close cooperation between you, your child and treatment team.

Parents should receive specific information on the setting and therapeutic options for the treatment of their child. They should have the opportunity to express their opinions and feelings. Unscheduled contact (by phone or face to face) should be offered to deal with suicidal behaviour, or if they have worrying questions or complaints about the management.

Messages to teachers and school staff:

- When the suicidal youth return to school, a thorough risk estimation will have been made which will have concluded they are stable enough to engage in daily school activities
- A contingency plan to deal with potential issues will have been worked out. This includes specific advice about what school staff can do and who to contact in case of concern about the student
- Because school is an important part of a young person's life, teachers and other school staff can be of assistance in helping students settle after a suicidal crisis. Specific strategies will be discussed with school staff, the family and health professionals
- Teachers should regularly talk to the student and parents to keep track of his progress
- Suicidality is a dynamic rather than a static phenomenon. Hence, students may experience a crisis again. Teachers should feel free to talk openly to the young persons if they have concerns that they may be deteriorating. Avoid arguing or giving hasty advice but speak with the treating clinician instead
- General strategies in case of a suicidal crisis may include:
  - Do not leave the suicidal student alone, even for a short time; escort the student away from other students to a safe place
  - Ask whether they are in possession of potentially dangerous objects or medications. If students have dangerous items, try to persuade them to give them to you but do not engage in a physical struggle
  - If a student keeps dangerous items, clearly makes suicidal statements or is agitated, call an ambulance, the police and the student's parents
  - If students are cooperative, contact the parents and ask them to pick up their child
  - Tell students and their parents that you would like to contact the patient's treating mental health service to inform them of the situation
- School staff should document all actions taken.



Click on the picture to view eighth grader Jonah Mowry share his story of years of bullying and self-injury, and fears for the future (04:36)

Hospital admission or not

Not all persons at risk of suicide can or should be admitted to hospital. Hospitalization may have little benefit and even increase risk for some people.

Many issues are involved in the decision to hospitalize – availability of resources, hospital beds, informal support networks and cultural traditions may all play a role – and there are no hard and fast rules but such a decision should be made on clinical grounds and involving the patient and family. If in doubt, one should consult with a colleague. In general, hospitalization may be needed if:

- Suicide risk is high, particularly if no alternative ways of ensuring the patient's safety are available
- There has been a recent suicide attempt requiring intensive medical care
- It is not possible to reliably estimate suicide risk.

If hospitalization is required, treatment should ideally take place in a secure child psychiatry ward. If this is not possible – e.g., surgical or medical care is needed – close supervision of the patient has to be assured. When acute suicidality occurs together with high agitation, short-term medication may be considered (e.g., benzodiazepines, neuroleptics). Inpatient treatment can be life-saving, provides relief from acute stressors and overwhelming demands and may enable patients to gradually regain control of their lives as well as to start treatment of concurrent psychiatric illnesses.

Inpatient units treating suicidal patients should establish protocols to maximize safety. This includes routine search on admission and further searches when there are grounds for suspicion. Special attention has to be paid to the physical surroundings (e.g., hanging points, blind spots, exits, design of windows, storage of poisonous substances). An "Access to Means of Suicide and Deliberate Self-harm Facility Checklist" can be found in NSW Mental Health Service (2004b).

General principles for the management of suicidality

Management should be individually tailored to target the risks factors for a specific patient. Interventions should not be restricted to specific psychopharmacological or psychotherapeutic interventions but involve a comprehensive treatment plan including other strategies to achieve relief from acute stressors. This will largely depend on the services available. In low income countries this comprehensive management may be unrealistic. However, in most places, informal supports can be marshaled to ensure patients safety by enlisting the support of the extended family, community elders and religious figures. These principles may include:

- Strategies to improve adherence to treatment (e.g., offering short interventions that are acceptable to the youth; sometimes focusing on support is more effective than insight-oriented psychotherapy)
- Active involvement of the patient and parents in the planning and implementation of interventions
- Protecting the patient if major adversities threatening the patient's mental and physical health are present
- Offering support to the family (e.g., in case of marital conflict, problems arising from divorce, parental mental illness, poor parenting practices, parental substance misuse)
- Enlisting support from child welfare agencies if indicated
- Organizing for relief from excessive demands (e.g., school demands exceeding patients' current capacity)
- Treating underlying psychiatric disorders

- Regular monitoring for recurrence of suicidal behavior
- An emergency plan for acute suicidal crises
- Offering flexible treatment sessions, time and frequency adapted to the patient's needs
- Establishing an effective communication between all the professionals involved (social worker, psychotherapist, child psychiatrist, pediatrician).

Psychosocial interventions

These have been reviewed by Daniel and Goldston (2009) and comprise:

- *Interventions to foster help-seeking behavior and to improve follow-up*, are important because of the low treatment compliance that has repeatedly been described for youths who attempted suicide: motivating youths and parents by providing psychoeducation during the attendance to the emergency department. Moreover, compliance is fostered by actively contacting the families immediately after discharge from the emergency department. The effectiveness of SMS messaging and other approaches using new media are also being examined
- *Organizing support for the suicidal youth*, e.g., by social workers assisting the youth's aftercare. Other approaches involve identifying and coaching support persons in the patient's environment (parents, extended family members, individuals at school or the religious community).
- *Strategies to improve parent-child relationships*. These include improving problem solving within the family, parenting and communication skills.
- *Cognitive behavior therapy (CBT)*
- *Multisystemic therapy (MST)*
- *Dialectic behavioral therapy (DBT)* (see Chapter H.4). Originally developed for the treatment of borderline personality disorder, DBT involves training in mindfulness, interpersonal skills, emotion regulation and stress tolerance and it has been adapted for adolescents with suicidal behavior.

Empirical data on the effectiveness of interventions are sparse and, currently, no intervention can be recommended over another (Daniel & Goldston, 2009; Robinson et al, 2011). In respect to engagement in therapy, specific psychological treatments seem not to be superior to treatment as usual (Ougrin & Latif, 2011). A review by Crawford et al (2007) on the efficacy of psychosocial interventions following self-harm (mainly in adults) concluded that there is no evidence they reduce the likelihood of subsequent suicide.

Psychopharmacological treatment

There are no specific medications for suicidality. However, medication may be needed to treat underlying psychiatric disorders. Risk of suicidality with SSRI use has been extensively discussed (see Chapters A.8 and E.1). The implication is that depressed adolescents treated with medication, and their families, need to know about this risk, and what to do if suicidal behavior emerges. They require careful follow up.

Problems and risks in treatment

Pitfalls and lapses in the management of suicidal youth may occur if:

- There is not enough cooperation or communication between the agencies and people involved
- Collateral information is not obtained
- Comorbid conditions are not treated
- Demands and stressors are overlooked
- Suicidal behavior is labeled as manipulative or not serious
- Minimization ("flight to health") by the patient is uncritically accepted (e.g., "I am OK", "There is nothing wrong with me")
- There is too much focus on therapy, overburdening the patient
- Confrontation strategies are too hard
- There is not enough validation of the patient's predicament
- There is too much use of clichés
- Termination of treatment or non-adherence is accepted without scrutiny
- Signs of suicide risk are overlooked
- Suicidality is not monitored during the course of treatment
- Dependence on the therapist is overlooked at the end of treatment
- Therapists neglect their own supervision.

PREVENTION

The World Health Organization suicide prevention (SUPRE) program emphasizes reducing mortality, morbidity and other consequences of suicidal behaviors by:

- Minimizing access to means of suicide (e.g., toxic substances, firearms)
- Early detection and treatment of mental disorders, and
- Responsible media reporting of suicide.

Risk factors are universal but their nature and relative importance differ from region to region. The WHO is running suicide prevention programs taking culture-specific issues into account (http://www.who.int/mental_health/prevention/suicide). For example, enhancing early recognition and treatment of mental disorders may be more important in low- than high-income countries; controlling access to firearms is more important in North America than in Western Europe where building physical barriers (e.g., in bridges, railways) to make jumping difficult is more relevant. Restricting access to pesticides and education about their effects are especially important in the countryside in low- and middle-income countries. Reducing harmful alcohol consumption is a major concern in Western and Eastern Europe but of minor importance in the Middle East. Programs addressing the disadvantage of minority indigenous peoples are also necessary (e.g., Aborigines in Australia, Maori in New Zealand, Indians in the US, and Inuit in Canada and Greenland).

Recommendations for schools and media professionals are summarized in Tables E.4.13 and E.4.14. For an overview of preventive strategies please see figure E.4.4.



The World Health Organization has useful guides for suicide prevention targeting:

- Physicians
- Teachers and school staff
- Media professionals

Empirical evidence for the effectiveness of suicide-preventive interventions in reducing suicidal behavior is poor (Wasserman et al, 2010). According to AACAP (2001) the following strategies have been investigated in interventional studies:

- Direct case-finding among students or among the patients of primary practitioners by screening for conditions that place teenagers at risk for suicide (effective and recommended)
- Media counseling to minimize imitative suicide (inconsistent data on effectiveness but recommended)
- Training professionals to improve recognition and treatment of mood disorders (possibly effective, recommended)
- Crisis hotlines (inconsistent data on effectiveness but recommended)
- Control of method of suicide, e.g., firearms (effective and recommended – however, a long-lasting general effect is doubtful)
- Indirect case-finding by educating the public, e.g., teachers, parents, peers, to identify warning signs (not effective – it may increase suicides – not recommended).

Table E.4.13 Preventing suicide: recommendations for teachers and school staff (WHO, 2000; p16)

Suicide is not an incomprehensible bolt from the blue: suicidal students give people around them enough warnings and scope to intervene. In suicide prevention work, teachers and other school staff face a challenge of great strategic importance, in which it is fundamental to:

- Identify students with personality disturbances and offer them psychological support
- Forge closer bonds with young people by talking to them and trying to understand and help
- Alleviate mental distress
- Be observant of and trained in the early recognition of suicidal communication whether through verbal statements and/or behavioral changes
- Help less skillful students with their school work, to be observant of truancy
- De-stigmatize mental illness and help to eliminate misuse of alcohol and drugs, to refer students for treatment of psychiatric disorders and alcohol and drug abuse
- Restrict students' access to means of suicide - toxic and lethal drugs, pesticides, firearms and other weapons, etc.
- Give teachers and other school personnel on-the-spot access to means of alleviating their stress at work.

Table E.4.14 Preventing suicide: recommendations for media professionals (WHO, 2008; p3)

- Take the opportunity to educate the public about suicide
- Avoid language which sensationalizes or normalizes suicide, or presents it as a solution to problems
- Avoid prominent placement and undue repetition of stories about suicide
- Avoid explicit description of the method used in a completed or attempted suicide
- Avoid providing detailed information about the site of a completed or attempted suicide
- Word headlines carefully
- Exercise caution in using photographs or video footage
- Take particular care in reporting celebrity suicides
- Recognize that media professionals themselves may be affected by stories about suicide
- Show due consideration for people bereaved by suicide
- Provide information about where to seek help

In Europe a large multinational randomized controlled trial (the SEYLE project; "Saving and Empowering Young Lives in Europe") is currently underway (Wasserman et al, 2010; http://www.seyle.eu/). SEYLE will investigate three preventive programs: (1) empowering students by increasing their self-efficacy, (2) empowering mental health professional in identifying subjects at risk, and (3) empowering teachers and parents in at-risk case finding and referring to mental health facilities.

NON-SUICIDAL SELF-INJURY

This section deals with non-suicidal self-injury (NSSI) in emotionally unstable patients acting out their inner distress. However, self-harming behavior may also occur in other psychiatric conditions such as in psychosis, mental retardation, pervasive development disorders, and severe deprivation. For management of self-harm in these disorders please refer to the respective chapter in this textbook.

Non-suicidal self-injury mainly involve skin lesions (e.g., cutting or carving the skin; picking at a wound; scraping, erasing or picking the skin until it bleeds; self-biting; inserting objects under the skin; self-tattooing; burning or freezing the skin; pulling hair out; self-hitting). Swallowing sharp or non-edible objects and non-suicidal self-poisoning also occur. Refusal to take prescribed medication in the case of severe illness or risky behaviors as a symptom of a specific psychiatric disorder are usually not subsumed under the concept of NSSI (e.g., refusing to eat in the case of anorexia nervosa, self-mutilation in the context of psychosis, auto-aggressive behavior in mental retardation). The relationship between culturally sanctioned self-mutilation (e.g., in the Goth scene in some Western societies, initiation rituals) and NSSI is not well understood.

Epidemiology

Non-suicidal deliberate self-injury is very frequent in high income countries. Rates of 26% to 37% have been reported for US community-based samples of middle to upper class youths (9th to 12th graders) (Yates et al, 2008). However, prevalence varies between samples and regions. In a community-based Canadian sample, 17% of youths reported that they had harmed themselves at least once (Nixon et al, 2008). Rates between 6% and 10% have been described for Irish, Australian and Japanese samples (Greydanus & Shek, 2009). A review of community-based studies described prevalences ranging between 13% and 23% (Jacobson & Gould, 2007). Prevalence is higher in late adolescence than early adolescence or childhood. The peak age of onset is early adolescence, between 12 and 14 years of age.

Risk factors

NSSI in adolescents is associated with high psychiatric morbidity, especially mood disorders, substance use disorders, and externalizing disorders (Nitkowski & Petermann, 2011). However, data on psychiatric morbidity in self-injuring individuals are limited because they mainly refer to clinical samples. In a community-based study, only suicidal ideation, major depression and undesirable life events predicted non-suicidal self-injury (Garrison et al, 1993).

Besides psychopathology, other risk factors associated with NSSI are a history of sexual or physical abuse, negative life events, and symptoms often linked with psychiatric morbidity (depression, dissociation, anxiety, alexithymia, hostility,

poor self-esteem, antisocial behavior, smoking, emotional reactivity, deficits in emotion regulation) (Jacobson & Gould, 2007). Stressful life events often involve interpersonal conflict, losses, family discord, difficulties with friends, problems in romantic relationships and school problems (de Kloet et al, 2011).

Jacobson et al (2008) in a chart review compared four groups of adolescent outpatients: (1) no NSSI, (2) NSSI alone, (3) suicide attempt, and (4) suicide attempt plus NSSI. They found that NSSI patients had similar rates of suicidal ideation as those without deliberate self-harm, supporting the validity of the distinction between suicide attempts and NSSI. Other results point to the following additional conclusions (Jacobson & Gould, 2007):

- Depression seems not to be a specific risk factor for NSSI (as compared to suicide attempt)
- The co-occurrence of NSSI and suicide attempts points to a more severe psychopathology
- All risk factors empirically found for NSSI are not specific and are also risk factors for suicidal behavior
- Suicidal behavior and NSSI are related: engaging in one behavior increases the likelihood of engaging in the other (Lofthouse & Yager-Schweller, 2009).

Table E.4.15 summarizes the different psychological functions that may be fulfilled by NSSI. According to a review by Klonsky (2007) all these models are at least moderately supported by empirical evidence. A framework to analyze NSSI behavior is provided by operant learning theory and summarized in Table E.4.16 (Nock & Prinstein, 2004). Self-injuring behavior has positive and negative reinforcement aspects and meets both intrapersonal and interpersonal (social) functions.

Clinical course

Most NSSI in adolescents resolves spontaneously by the time they become young adults. A series of surveys that followed 1800 adolescents over from the age of 14-15 years found that about one in ten had self-harmed (Moran et al, 2011). Self-harm was more frequent in girls and the most common method was cutting or burning. However, self-harm declined significantly by the age of 17, with nine

Table E.4.15 Hypothesized functions of non-suicidal self-injury and support by empirical evidence.*

Function	Description	Evidence
Affect-regulation	To diminish acute negative affect or aversive affective arousal	Strong
Anti-dissociation	To end feelings of depersonalization or other dissociative states	Modest
Anti-suicide	To replace, compromise with, or avoid suicide attempts	Modest
Interpersonal boundaries	To assert one's autonomy or a distinction between self and others	Modest
Interpersonal-influence	To seek help from or manipulate others	Modest
Self-punishment	To punish oneself or express anger towards oneself	Strong
Sensation-seeking	To generate excitement	Modest

*Klonsky (2007)

Table E.4.16 Functional analysis of the consequences of non-suicidal self-injury*

	Intrapersonal	Interpersonal
Positive reinforcement	· To punish oneself · To feel relaxed	· To get attention or help from significant others · To make others angry, punish them or to exert control
Negative reinforcement	· To distract from negative thoughts and feelings (affect-regulation) · To feel something, even if it is pain (anti-dissociation) · Injuries may prevent from engaging in serious self-harm (anti-suicide)	· To avoid doing something unpleasant (this should be differentiated from malingering)

*Nock and Prinstein (2004)

out of ten of those who initially reported self-harm reporting not self-harming in young adulthood. Self-harm was more likely to persist in females and it was associated with depression and anxiety, antisocial behavior, high risk alcohol use, cannabis use, and cigarette smoking.

Assessment

Every child or adolescent who has self-harmed should be assessed for risk of repetition and suicide risk. According to the NICE guideline (2011), assessment should take into account :

- Methods and frequency of current and past self-harm
- Current and past suicidal intent
- Depressive symptoms and their relationship to self-harm
- Psychiatric illness and its relationship to self-harm
- The personal and social context and any other specific factors preceding self-harm, such as specific unpleasant affective states or emotions and changes in relationships
- Specific risk factors and protective factors (social, psychological, pharmacological and motivational) that may increase or decrease the risks associated with self-harm
- Coping strategies that the person has used to either successfully limit or avert self-harm or to contain the impact of personal, social or other factors preceding episodes of self-harm
- Significant relationships that may either be supportive or represent a threat (such as abuse or neglect) and may lead to changes in the level of risk
- Immediate and longer-term risks.

Parents and other important caregivers should be included in the assessment. Individual assessment is essential and should take into account the psychological needs met by the self-harm described in Table E.4.15; in each individual patient one or more of them may predominate. The use of risk assessment tools and scales to predict future suicide or repetition of self-harm is not recommended by the NICE guideline.



A 16 year-old girl was called by her boyfriend who cancelled their date scheduled for that evening because his soccer (football) mates were having a meeting he preferred to go to (antecedent). She agreed during the phone call but afterwards she felt hurt and negative thoughts proliferated ("he doesn't love me", "I will lose him", "I am not attractive to him or to anybody else"). The girl felt increasingly desperate, angry with herself; urges to harm herself began to emerge. Finally, she began cutting her arms superficially with a razor, watching the blood seeping from the wounds (cognitive, emotional and behavioral reactions). While watching her arms bleed she felt relieved (reinforcing consequence). When her boyfriend found out what had happened, he apologized and comforted her (reinforcing consequence) and promised never to do anything similar again (reinforcing consequence). Together with her therapist, she explored alternative ways of coping with this situation: planning dates more carefully; voicing her disappointment and her wishes instead of silently accepting; examining alternative interpretations of her boyfriend's behavior instead of devaluating herself; finding alternative activities for the evening; considering the long-term consequences of self-harm (e.g., scarring); rewarding herself for alternative behaviors.

Treatment

For detailed information please refer to NICE clinical guideline ("The short-term physical and psychological management and secondary prevention of self-harm in primary and secondary care" (NICE, 2004). This guideline includes both the management of NSSI and suicide attempts.

Hospitalization is needed if:

- NSSI co-occurs with high suicide risk
- NSSI coexists with severe co-morbid disorders requiring inpatient treatment
- NSSI severely endangers the physical health or social functioning of the patient (e.g., repeated surgery is needed, self-harming behavior at school)
- Outpatient treatment has not been successful,
- A reliable assessment is not possible in an outpatient setting.

Patients severely harming themselves may need the same close supervision as patients with high or moderate suicide risk. Following the NICE (2011) guideline, long-term treatment of self-harm involves *psychoeducation* of patients and their families. Treatment goals may include:

- Preventing escalation of self-harm
- Reducing harm arising from self-harm
- Reducing or stopping self-harm
- Reducing or stopping other risk-related behavior
- Improving social or occupational functioning
- Improving quality of life
- Improving any associated mental health condition.

A risk management plan should be developed covering strategies to deal with the risks identified (psychological, pharmacological, social and relational). This plan should include self-management strategies and ways of accessing services and receiving support during a crisis when self-management strategies fail.

The NICE guideline also recommends considering *short-term psychological interventions* that specifically target the self-harm. Interventions could include cognitive-behavioral, psychodynamic or problem-solving elements – therapists

should be specifically trained in the treatment they use in the management of self-harm. Strategies may involve interventions already described earlier in the section on management of suicidal behavior. Individual treatment should be based on a functional analysis of the self-harming behavior that takes into account (1) antecedents, (2) type of self-harming behavior and associated cognitions, emotions and sensations, and (3) the consequences of self-harm, mainly in terms of the psychological needs met by NSSI, described in Table E.4.15.

Alternative behaviors that can be helpful instead of self-injuring comprise:

- *Low urge to self-harm: distracting activities* such as playing with a pet, listening to music and singing, reading, writing, painting, calling a friend, counting breaths, taking a warm bath, taking a walk to be near other people, using meditation or relaxation techniques, listening to a comedy tape or video, repeating 5 things one sees, smells, touches, tastes in the present surroundings.
- *Medium urge to self-harm: highly activating behavior, high sensory or low painful non-harming stimulation*, such as eating a lemon, snapping a rubber band on the wrist, running, biking, sit-ups, hitting pillows, dancing, using a red felt tip pen to mark regions on the skin where cutting usually occurs, squeezing a stress ball, making some noise, screaming into a pillow, tearing up paper (old phonebooks, newspapers).
- *High urge to self-harm: moderate painful non-harming stimulation*, e.g. chewing jalapeño pepper, taking a very cold shower, placing hands in freezing cold water, walking with dried peas in the shoes, rubbing ice across the skin where cutting usually occurs.

In severe cases, advice on *damage limitation* techniques should be given (using a clean and sharp blade, avoiding cutting areas near major veins and arteries, not sharing instruments used for self-harm; ensuring tetanus protection; having access to first aid and a basic knowledge of medical care; avoiding alcohol/drug use in association with self-harm).

Despite encouraging results from pilot studies, empirical evidence for the efficacy of psychosocial interventions, including dialectic behavior therapy, in the treatment of self-injuring behavior in adolescents still is inadequate (Wilkinson & Goodyer, 2011). There is also no evidence supporting the use of medication to reduce self-harm, although medication may be indicated to treat comorbid disorders.

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Ruslana Sergeyevna Korshunova (1987-2008), a very successful Kazakh model, jumped to her death from the ninth-floor balcony of her Manhattan apartment.

IACAPAP Textbook of Child and Adolescent Mental Health

Section F

ANXIETY DISORDERS

Associate Editors: Ana Figueroa & Cesar Soutullo

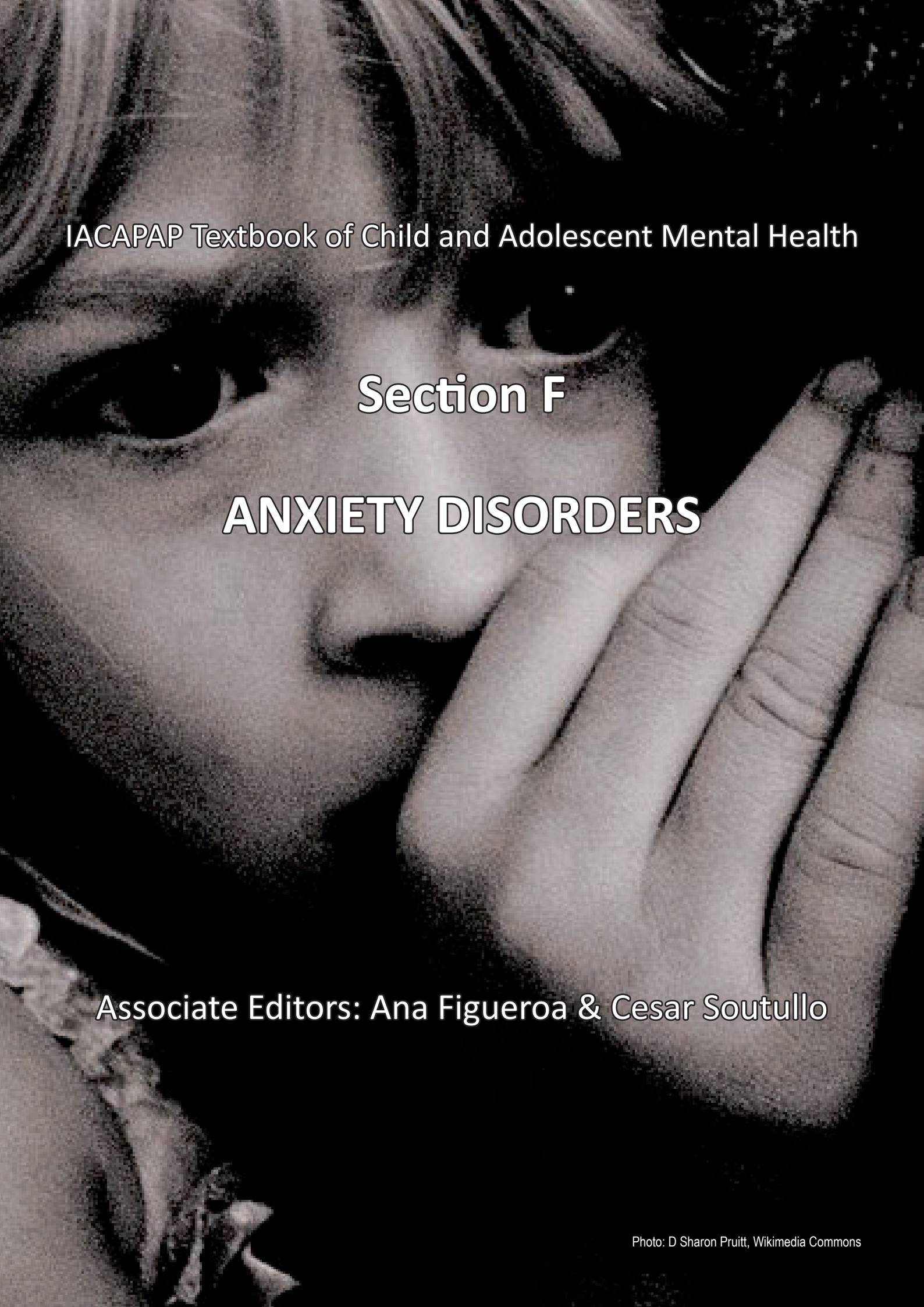


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ANXIETY DISORDERS IN CHILDREN AND ADOLESCENTS

NATURE, DEVELOPMENT, TREATMENT AND PREVENTION

Ronald M Rapee



Monsters, Inc® Pixar

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Conflict of interest: receiving royalties from the book, *Helping your Anxious Child: A Step by Step Guide for Parents*. Proceeds from sales of the *Cool Kids* program go to the Centre for Emotional Health at Macquarie University to assist research and treatment for anxious children – no individual receives any income from these materials.

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Suggested citation: Rapee RM. Anxiety disorders in children and adolescents: Nature, development, treatment and prevention. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

It was not very many years ago that anxiety disorders in children were thought to be relatively rare and low impact conditions. As a result our empirical knowledge about child anxiety is less extensive than it is for the adult conditions. Nevertheless, the past 15 to 20 years have seen a dramatic increase in the number of studies examining child anxiety and we are now building a good understanding of the nature, development and treatment of these disorders. Even more recently interest has started to focus on possible prevention of anxiety and, given the overlap between anxiety and depression as well as the continuity from childhood into adulthood, this work has far-reaching implications for prevention of internalising difficulties right across the lifespan.

Compared with research in the adult realm that tends to split disorders very specifically, within the child and adolescent fields, there is a more common tendency to examine anxiety relatively broadly and in many cases to examine internalising disorders as a whole. Therefore, in the current chapter, I will talk about anxiety disorders in most cases very broadly and consider factors relevant to all the anxiety disorders as a group. This is especially the case for treatment, where most empirically supported psychological packages have tended to include children across the range of anxiety disorders. However, given that other chapters in this book focus on obsessive compulsive disorder, post-traumatic reactions and separation anxiety, I will focus, where possible, more directly on the remaining disorders, generalised anxiety, social anxiety and specific phobias. To reduce repetition, I will generally use the terms child anxiety or childhood anxiety to refer to anxiety in both children and adolescents, unless specific age distinctions are necessary.

Internalising disorders

As opposed to "externalising" or "undercontrolled" disorders" (such as conduct disorder) in which children tend to externalize or act out inner conflict or emotions (e.g., through aggression) – internalizing disorders reflect problems within the self, such as fears, worrying and unhappiness, traditionally subsumed under the rubric of "neuroses", "overcontrolled" or "overinhibited" problems. Children with internalising disorders tend to deal with problems and emotional conflict internally rather than acting them out. Internalizing disorders usually cause more distress to the child than to those around them, the opposite of what happens with externalizing disorders.

DESCRIPTION AND DIAGNOSIS

The core feature of anxiety disorders is *avoidance*. In most cases this includes overt avoidance of specific situations, places, or stimuli, but it may also involve more subtle forms of avoidance such as hesitancy, uncertainty, withdrawal, or ritualised actions. These behaviours are relatively consistent across disorders and the key difference between specific disorders is the trigger for this avoidance. The avoidance is generally accompanied by affective components of fearfulness, distress or shyness. Some children, however, especially younger ones, may have difficulty verbalising these emotions. Anxiousness occurs due to an expectation that some dangerous or negative event is about to occur - in other words an expectation of threat. Therefore, in identifying the anxious child, it is crucial to determine that the avoidance occurs due to an expectation of some sort of threat. For example, two children may say that they do not want to go to school. In one case this appears to be due to the fact that they are having more fun going to the shops with their friends, while in the second case it appears to be due to a belief that other children are making fun of the child. Even though both may superficially seem to be avoiding school, the former case would not reflect anxiety since the behaviour is not motivated by a perceived threat. All of the anxiety disorders will involve an *anticipation of threat*, which may take the form of worry, rumination, anxious anticipation, or negative thoughts. The key differences between disorders lie in the content of these beliefs as will be described below. In addition to the described beliefs, behaviours, and emotions, anxious children will often report a range of associated *physical complaints reflecting heightened arousal*; however, these are rarely specific to a given disorder and hence are rarely diagnostic. Physical symptoms that

Table F.1.1 Core and associated features of the various anxiety disorders.

DISORDER	CORE FEATURES	ASSOCIATED FEATURES
Separation anxiety disorder	Fear or concern that something bad will happen to the child or attachment figure (commonly a parent) when they are separated. As a result of this belief, the child avoids separation from the attachment figure.	• Dreams or nightmares about separation • Refusal to face situations that involve separation, including sleeping away from home, going to school, visiting friends or relatives, staying at home alone or with child minders • Worry about the consequences of separation including fears of being kidnapped or injured or of the attachment figure being hurt, or killed while apart • Physical symptoms when separation is anticipated including, vomiting, diarrhoea, and stomach aches
Generalised anxiety disorder	A tendency to worry about a wide range of negative possibilities, that something bad will happen	• Repeated and extensive worry about several areas such as family finances, friendships, schoolwork, sports performance, self and family health, and minor, daily issues. • Tendency to repeatedly seek reassurance from parents or others about fears. • Avoidance of novelty, negative news, uncertain situations, and making mistakes. • Physical symptoms, sleeplessness and irritability when worried.
Social phobia	Fear and avoidance of social interactions or social performance due to a belief that others will negatively evaluate the child	• Avoidance of a range of social activities or situations including, speaking or performing in front of others, meeting new children, talking to authority figures such as teachers, being the centre of attention in any way, and for teenagers, fears of dating • Worries about negative evaluation from others including that others will think they are unattractive, stupid, unpleasant, overly confident, or odd • A limited number of friends and difficulty making new friends • High levels of self-consciousness or self-focussed attention
Specific phobias	The core feature of specific phobias involves fear and avoidance in response to a range of specific cues, situations, or objects. There is a common belief that the object or situation will lead to personal harm	Some common fears in children include: • Animals such as dogs or birds • Insects or spiders • The dark • Loud noises and especially storms • Clowns, masks, or unusual looking people • Blood, illness, injections
Panic Disorder and agoraphobia*		
Panic Disorder	Experience and fear of unexpected panic attacks, commonly involving several somatic symptoms and fears of dying or going crazy.	• Several somatic symptoms that usually peak relatively quickly and last for a specific period • Symptoms commonly include palpitations, breathlessness, dizziness, trembling, and chest pain • At least some attacks occur unexpectedly or "out of the blue"
Agoraphobia	Agoraphobia involves an additional fear and avoidance of several "agoraphobic" situations, commonly due to a fear of experiencing a panic attack in those situations.	• Avoidance of situations due to fear of symptoms or their consequences • Common agoraphobic situations include places from which quick escape is difficult such as public transport, enclosed spaces, cinemas, hairdressers, or heavy traffic. • There is a common reliance on specific safety cues, commonly a safe attachment figure.

* Both panic disorder and agoraphobia have their mean age of onset in early adulthood and hence are rare in childhood. Only occasional cases occur prior to 15 years and small numbers will begin to present from 15 to 18 years.

are common among anxious children include: headaches, stomach aches, nausea, vomiting, diarrhoea, and muscle tension. In addition, it is common for many anxious children, especially those that worry considerably, to have difficulty with sleep.

As mentioned, the key differences between specific anxiety disorders involve the particular triggers for the anxiousness, the situations that are avoided, and the content of the beliefs, as shown in Table F.1.1. Separation anxiety and school refusal are described in detail in Chapter F.2.

Other anxiety disorders

As mentioned previously, other anxiety disorders are covered in their own chapters and hence will be addressed only briefly here. Children with *obsessive compulsive disorder* (OCD) report repetitive and intrusive thoughts, images or urges, often accompanied by repeated characteristic actions or behaviours with the goal of reducing anxiety. The mental components commonly focus on some expected threat or danger (hence it is an anxiety disorder), although some forms of OCD may fail to report threat expectations and may focus more on a sense of disgust and a belief that certain actions simply "feel right". When a threat expectation does exist, the corresponding rituals are generally aimed at preventing or undoing the expected danger. In children, the picture is complicated by the fact that many children, especially younger ones, are unable to clearly report on their beliefs and motivations. Among children, the most common rituals involve washing and fears of contamination, and checking or ordering and fears of catastrophe if certain actions are not adequately performed.

Post traumatic stress disorder involves a constellation of symptoms of heightened arousal (e.g., jumpiness), intrusions (e.g., distress on reminders of the trauma), detachment (e.g., trouble remembering aspects of the trauma, numbness and flatness), and avoidance that occur following a severe (life threatening) event. Although, sadly, many children in our world experience life threatening events, post traumatic stress disorder is relatively infrequent in childhood (Rapee et al, 2009). Some authors have argued that this is because the criteria are not sensitive to the presentation among children, while others suggest that it may reflect the reduced sense of past and future in children's cognitive development. Post traumatic stress disorder is discussed in detail in Chapter F.4.

School refusal

Although school refusal is not a formal diagnosis in either the DSM or ICD, a brief mention is warranted here due to its common discussion in various circles. There is little doubt that many children do not wish to attend school and in a small percentage of cases they may not attend for lengthy periods. This is often referred to as school refusal. School refusal is not an anxiety disorder and may be motivated by many factors aside from anxiety, but when it occurs, anxiety is a common underlying element. However, anxiety alone is not a sufficient explanation. School refusal involves both a motivation from the child to not attend school (sometimes due to anxiety) combined with a social and usually parental acquiescence to this demand. Naturally, this latter component will vary between societies depending on the laws for school attendance, social norms, and parental needs (such as extreme poverty). However, where laws and norms provide

Social anxiety

It should be noted that socially anxious children are not necessarily poor in social skills. They are commonly ignored or neglected rather than rejected. However, as a result of their anxiety, they may sometimes act in a socially awkward manner and may perform poorly in social situations. For example they may not speak very much or may talk very quietly, they may show poor eye contact, or they may talk in a hesitant and uncertain manner.

an expectation for school attendance (such as in most Western countries), school refusal commonly involves some difficulty within the family or at least one parent. For example, in some cases school nonattendance is partly encouraged by a parent who may wish the child to help with their own needs (e.g., a physical or mental disability) or the parent / child relationship may become pathological due to severe marital difficulties, and so on. In other words, chronic school refusal may reflect a variety of anxiety (or other) difficulties within the child (e.g., fear of the school work, separation anxiety, social fears, bullying, etc) combined with parental or family difficulties and in some cases with social support for nonattendance (see Chapter F.2 for further discussion).

Comorbidity

As mentioned earlier, it is common for discussions of childhood anxiety to focus broadly across anxiety (and sometimes related disorders) rather than focussing on only a single disorder. One of the main reasons for this is the strong overlap between anxiety disorders and between anxiety and other internalising disorders, especially depression. Clinically anxious children rarely meet criteria for only one disorder. Within treatment-seeking populations, around 80% to 90% meet criteria for more than one mental disorder. The majority, up to 75%, meet criteria for more than one anxiety disorder. A further 10% to 30% also meet criteria for an additional mood disorder. Age differences are apparent here – around 30% of treatment-seeking adolescents meet criteria for an additional mood disorder while only around 10% to15% of younger anxious children do so. About 25% of younger treatment-seeking anxious children will also meet criteria for an additional behavioural disorder. Similar figures are found in population-based samples, although the proportion of children with a single anxiety disorder is slightly higher. Nevertheless, even in population based samples, children with anxiety disorders are markedly more likely to have additional anxiety, mood, and behavioural disorders. Interestingly, anxious children do not appear to be at greater risk for substance abuse, most likely reflecting the fact that these children generally obey rules and do not take risks. The overlap between anxiety disorders and alcohol abuse does not appear until late adolescence or early adulthood (Costello et al, 2003).

EPIDEMIOLOGY

Prevalence

Prevalence estimates of child anxiety have been somewhat variable across countries and studies due to many factors including variations in criteria, assessment instruments and sampling. Overall, around 5% of children and adolescents meet criteria for an anxiety disorder during a given period of time in Western populations (Rapee et al, 2009). There is little data available from other cultures, but one study from Puerto Rico has shown similar rates (Canino et al, 2004). In most studies prevalence is highest for specific phobias and moderate for separation anxiety, generalised anxiety and social phobia. Considerably lower rates are reported for obsessive compulsive disorder and the lowest rates are reported for post traumatic stress disorder.

Gender distribution

Anxiety disorders are more common in females than males in the general

population. Most population studies estimate around 1.5-2 times as many females compared to males for most anxiety disorders. There is some evidence that this gender difference appears very early – as young as 5 years of age. In contrast, distributions within treatment-seeking samples in Western societies are more equal and even include slightly more males.

Age of onset

Anxiety disorders are among some of the earliest disorders to appear and most commonly begin by middle childhood to mid adolescence. As will be discussed later, it is common for anxiety disorders to appear within a context of temperamental inhibition (see below) and fearfulness. Hence it is often difficult to determine exactly when the actual anxiety disorder first begins and, to some extent, anxious children can often be said to be anxious from birth. However, estimates of average age of onset (these are averages, disorder can start earlier in individual cases) for the different disorders are as follows:

- Animal phobias – early childhood (around 6-7 years)
- Separation anxiety disorder – early to mid-childhood (around 7-8 years)
- Generalised anxiety disorder – late childhood (around 10-12 years)
- Social anxiety disorder – early adolescence (around 11-13 years)
- Obsessive compulsive disorder – mid adolescence (around 13-15 years)
- Panic disorder – early adulthood (around 22-24 years)

Course

Anxiety disorders are among the most stable forms of psychopathology and show relatively little spontaneous remission. Anxious children are also at increased risk of developing other disorders during adolescence and into adulthood. Longitudinal research has shown that anxious children are at significantly greater risk for anxiety and mood disorders in adolescence and for anxiety, mood, and substance use disorders as well as suicide in adulthood (Last et al, 1997; Pine et al, 1998).

Other demographic features

Interestingly, anxiety in childhood is characterised by very few demographic risk factors. There is some evidence that low socioeconomic status might provide some risk for anxiety but the data are mixed and the degree of risk is small. Similarly, some research has hinted that socially anxious children in particular are more likely to be first born but other research has failed to support this finding. Most other demographic characteristics fail to predict anxiety. Hence anxious children are not characterised by family size, parental marital status, educational attainment or intelligence (Rapee et al, 2009).

ASSESSMENT

Clinical evaluation generally includes a combination of questionnaires, diagnostic interview and behavioural observation. However, in most clinical settings, a diagnostic interview and a small number of questionnaires will be most

appropriate.

Diagnostic interview

Several structured diagnostic interviews exist to assist in determining either DSM or ICD criteria for childhood disorders including anxiety. Most interviews include a large number of questions aimed to tap each of the relevant diagnostic criteria and generally differ in their degree of structure. Some widely used instruments include:

- *Kiddie Schedule for Affective Disorders and Schizophrenia* (K-SADS)
- *Development and Wellbeing Assessment* (DAWBA)
- *Diagnostic Interview Schedule for Children* (DISC)

If the interest is in anxiety more specifically, then the *Anxiety Disorders Interview Schedule for Children* (ADIS-C) (Silverman & Albano, 1996) has a primary focus on these disorders. For very young children, the *Preschool Age Psychiatric Assessment* (PAPA) is a useful instrument (Egger et al, 2006). Most structured interviews involve separate interviews with the parents and the child (at least once the child is 8 years old or so) and the clinician is then faced with the task of combining the information in some way.

Like most disorders of childhood, information from parents and children about anxiety disorders commonly contains several discordant aspects. Clinical judgement and experience needs to be applied to determine which information is more heavily weighted and how best to combine the information (see Chapter A.3 for a detailed discussion of this issue). Anxious children are often thought to "fake good" (Kendall & Chansky, 1991) – in other words, to deny feeling anxious or to provide answers that they think are socially acceptable. However, many parents are also anxious (discussed below) and in some cases will exaggerate the child's difficulties due to their own distress. Hence, the interviewer needs to obtain sufficient detail to allow a judgement about which is the most accurate report and which aspects of the information may be inaccurate for various reasons.

Clinically, distinguishing between specific disorders can be difficult. As described above, it is important to determine the basic motivation behind particular behaviours in order to identify the relevant diagnosis. For example, young children who have a tantrum when their parents plan to go out may be doing so due to the attention and subsequent rewards they receive, or to fear of being separated. Clinically, once all behaviours, motivations, and diagnostic criteria have been assessed and it has been determined that a child meets criteria for two (or more) clearly distinct disorders, it is generally useful to determine which of the disorders is *primary* or *principal*. Most authors conceptualise the *principal disorder* as the one that produces the greatest impact and interference in the child's life. Hence this disorder is usually the first focus in therapy. Most empirical evaluations of treatments for child anxiety are based on children who meet criteria for anxiety disorders as their principal disorder. In some cases however, it may be more important to determine which disorder appears to be the *underlying* or *causal* problem. For example, a child suffering depression, loneliness and victimisation because of their social anxiety may respond best if the social anxiety is treated first, regardless of whether it is the primary condition. In some cases, a particular

problem may be expected to interfere with treatment response and may therefore require initial attention, even if it is not the principal disorder. For example, a child whose anxiety appears to be most interfering but whose additional depression results in low motivation may need treatment addressed to the depression and motivation before they will be able to engage in treatment for the anxiety.

Questionnaire assessment of child anxiety

The severity of anxiety or extent of anxiety symptomatology can be measured using several well developed questionnaires. Most of these measures have demonstrated good psychometric properties from around age 8 or 9 years and can be used up to middle or late adolescence. From middle adolescence, adult measures of anxiety are usually suitable. Very few measures have been developed for younger children.



Click on the picture to view the Centre for Emotional Health's website from where the CATS, SAS-TR, and CALIS, as well as the PASR can be downloaded free of charge. Some of these scales are available in languages other than English.

A few questionnaires contain several subscales that each tap diagnostic-like constructs such as separation anxiety, social anxiety or generalised anxiety. Most of these questionnaires have parallel versions for the parent and child. These include:

- *Spence Children's Anxiety Scale* (SCAS) (free of charge)
- *Screen for Anxiety and Related Disorders* (SCARED)
- *Multidimensional Anxiety Scale for Children* (MASC)

A similar measure has recently been developed for preschool-aged children, to be completed by their parents only – the *Preschool Anxiety Scale, Revised* (PAS-R) (free of charge and available in several languages).

Several older measures aim to assess the overall degree of anxiousness more broadly. These include:

- *Revised Children's Manifest Anxiety Scale* (RCMAS)
- *State Trait Anxiety Inventory for Children* (STAIC)
- *Beck Anxiety Inventory for Youth*

A similar measure assessing internalising symptomatology completed by parents has also been developed for children at preschool age – *Children's Moods, Fears and Worries* (Bayer et al, 2006).

In some circumstances, more specific and detailed assessment of a particular form of anxiety may be required. In these cases, a few measures tap into specific aspects of anxiety including:

- *Fear Survey Schedule for Children Revised* (FSSCR)
- *Social Phobia and Anxiety Inventory for Children* (SPAIC)
- *Social Anxiety Scale for Children - Revised* (SASC-R)
- *Children's Anxiety Sensitivity Index* (CASI) (Silverman et al, 1991)

Finally, a few measures from our own centre may be of value since they tap relevant aspects related to anxiety disorders. The *Children's Automatic Thoughts Scale (*CATS) is designed to assess specific beliefs experienced by children and adolescents with a variety of disorders. Two of the subscales are especially relevant to anxiety: beliefs related to social threat and physical threat. The remaining subscales assess beliefs related to personal failure and hostility. The *School Anxiety*

Scale - Teacher Report (SAS-TR) provides a measure of children's anxiety that can be completed by the classroom teacher. This measure therefore provides an additional source of information that can flesh out a broader clinical picture of the anxious child. Finally, the *Children's Anxiety Life Interference Scale* (CALIS) provides two parallel measures (one reported by the child and the other by his/her parents) that assess the extent to which the child's anxiety impacts on the child's and family's life.

RISK AND MAINTAINING FACTORS

Family transmission

Anxiety runs in families. First degree relatives of people with anxiety disorders are at significantly increased risk to also have anxiety as well as mood disorders. The same is true more specifically for anxiety in children and adolescents. Anxious children are considerably more likely to have parents with anxiety disorders and adults with anxiety disorders are more likely to have anxious children (Rapee et al, 2009). A similar relationship occurs more generally for temperament that is related to anxiety (see below). Adults with anxiety disorders are more likely to have children who are highly inhibited and inhibited children are more likely to have parents with anxiety and mood disorders (Rosenbaum et al, 1993).

One important finding is that family transmission of anxiety seems to show some specificity. In other words, several studies have shown that people with a particular anxiety disorder (e.g., social phobia) are more likely to have first degree relatives with that same disorder (social phobia) than with other anxiety disorders. This is different from research on genetic factors that has not shown specificity (see below). Of course family transmission can reflect both genetic and environmental influences, so it is tempting to speculate that genetic transmission confers a broad, general risk, while family environment may shape that risk into specific manifestations.



Jerome Kagan, professor of psychology at Harvard University, is one of the scholars who contributed to developing the concept of temperament, which he defined as stable behavioural and emotional reactions that appear early in life. He described two types of temperament: inhibited and uninhibited. The former applies to children who are shy, timid, socially withdrawn and fearful, while the latter refers to children who are outgoing, sociable and daring.

Genetic factors

There is little doubt that anxiety disorders are heritable. Best estimates suggest that around 40% of the variance in anxiety symptoms and in diagnoses of anxiety disorder is mediated by genetic factors. This estimate is even higher if one looks at stability of anxiety over time. Slightly less research, but with similar findings, has been done on anxiety specifically during the childhood years. Twin studies of anxiety in children indicate that around 30% to 40% of the variance in symptoms and disorders can be attributed to heritability (Gregory & Eley, 2007). There is some evidence (albeit with limitations) that heritability estimates for temperamental risk for anxiety (e.g., inhibition) is slightly higher (Rapee & Coplan, 2010). As mentioned above, genetic risk across anxiety disorders appears to be largely general and seems to primarily load on a very broad factor such as general neuroticism (Gregory & Eley, 2007).

Work on specific genes underlying anxiety disorders is less extensive and, to date, no evidence exists linking any individual gene specifically to anxiety. Many candidates have been explored; the most widely studied being the promoter region of the serotonin transporter gene (5HTTLPR). However, polymorphisms on this gene have been associated with different disorders and it is unlikely that it would

play a specific role in anxiety. In fact, one theory states that having two short alleles on the 5HTT gene may increase an individual's overall responsiveness to environmental events (both positive and negative) (Belsky et al, 2009).

Temperamental factors

Temperamental risk for anxiety is probably the best studied and most clearly established risk factor (Fox et al, 2005; Rapee et al, 2009). A variety of similar temperaments have been associated with child anxiety including: behavioural inhibition, withdrawal, shyness and fearfulness. I will refer to these various temperaments in this section under the general term *inhibition*. Extensive research has shown that very young children who are identified as high on inhibition are at greater risk for later anxiety disorders. As described above, research has also linked inhibition with anxiety disorders in first degree relatives. The most common assessment of inhibition occurs in children from around 2-5 years of age. This may be done via questionnaires or direct observation. Common features of inhibition include:

It seems that fear of strangers can be increased through an interaction between the infant's temperament and the mother's overt indicators of fear.

- Withdrawal in the face of novelty
- Slowness to warm up to strangers or peers
- Lack of smiling
- Close proximity to an attachment figure
- Lack of talk
- Limited eye contact or "coy" eye gaze
- Unwillingness to explore new situations.

Children who show these characteristics during preschool age are 2-4 times more likely to meet criteria for anxiety disorders by middle childhood and this increased risk has been shown to continue at least into adolescence (Fox et al, 2005). Some evidence has also indicated that infants (aged 3-6 months) who show high levels of arousal and emotionality are at greater risk to show high inhibition by 2-5 years. Therefore, it seems to be possible to identify increased risk for anxiety from a few months of age (Kagan & Snidman, 1991).

Theoretically the main complication with this research is the extensive overlap between the constructs of inhibition and anxiety disorders. Thus one could argue that inhibition is simply a less clear version or an early manifestation of an anxiety disorder. There is some evidence that inhibition and disorder have some unique features and thereby represent distinct constructs, but the issue is far from settled (Rapee & Coplan, 2010).

Parent and family factors

Given the evidence for the transmission of anxiety within families described above, it has commonly been assumed that parents and the family environment must contribute to the development of anxiety disorders. However, evidence has been difficult to obtain and data have not been entirely consistent. The most extensive research has focussed on parenting and parent-child interactions.

There is now little doubt that the parenting of anxious children is characterised by *overprotection*, *intrusiveness* and, to a lesser extent, *negativity* (McLeod et al, 2007). Whether this relationship is causal is much harder to determine and, to date, there has been very little examination of this issue. Theories

argue that the parent-child relationship is likely to reflect cyclical interactions. That is, inhibited children are likely to elicit overprotection from their parents and, in turn, overprotective parenting is likely to lead to further anxiety (Hudson & Rapee, 2004; Rubin et al, 2009). Few longitudinal studies have addressed this relationship, but at least some evidence is consistent with this theory (Edwards et al, 2010). There is also some evidence that an interaction between the serotonin transporter gene and parenting predicts later anxiety in young children (Fox et al, 2005).

It has often been assumed that anxious parents increase risk for anxiety in their children by modelling their own fears and coping strategies. This theory, however, has received very little examination. The main research has come from laboratory studies with very young children. Research has shown that children aged around 6-18 months can learn to fear and avoid a novel stimulus by observing their mothers acting in a fearful manner. More importantly, socially anxious mothers have been shown to transmit a fear of strangers to their infants in this way, and the extent of fear that the infant develops depends partly on the pre-existing level of inhibited temperament that the infant displays (de Rosnay et al, 2006). Thus it seems that fear of strangers can be increased through an interaction between the infant's temperament and the mother's overt indications of fear. Among older children it has been shown that verbally transmitted information about danger can increase fear of particular cues. For example, when children are presented with information about a novel cue that suggests the cue might be dangerous, they show increases in fear, physiological arousal, threat beliefs, and avoidance of the cue that can last for several months (Field, 2006).

Finally, a key question is whether disturbed family environments play a role in the development of child anxiety. There has been a wealth of longitudinal research examining the long term impact of family distress and violence, parent divorce or separation, and sexual and physical abuse, although little of this work has focussed clearly on anxiety disorders. Overall, it appears that sexual abuse – and to a lesser extent physical abuse and family violence – can increase anxiousness in children. However, this increase is likely to be temporary and it is not clear whether these factors contribute significantly to the development of longer-term anxiety disorders. More importantly, it is clear that these factors are relatively non-specific and increase risk for a wide variety of child psychopathology, probably least of all anxiety disorders (Rapee, in press).

Life events

Although there has been a large body of research examining the role of negative life events in the onset of adult anxiety disorders (mostly agoraphobia), there has been very little work looking at life events in childhood anxiety. This may be because child anxiety often develops in a background of inhibited temperament and a clear and sudden onset to the disorder is relatively rare. What research has been conducted suggests that anxious children do report a greater number and impact of negative life events than do children without anxiety disorders. While it is possible that this difference reflects cognitive and reporting biases, at least some work has demonstrated this difference using interviews with parents and identifying corroborating evidence (Allen et al, 2008). Nevertheless, demonstrating that anxious children have more negative life events than non-anxious children



Click on the picture to hear Eli R Lebowitz PhD talk about CBT for childhood anxiety disorders (13:14 minutes)

does not mean that these events necessarily cause or trigger their anxiety. Indeed the data suggest that the greatest difference is found on so-called "dependent" life events. Dependent events are ones that might be the result of the child's behaviour (e.g., doing badly in a test might be a result of the child not studying). Thus it is very possible that child anxiety leads to more negative life events, perhaps due to the worry and avoidance associated with the anxiety. Of course it is also possible that this increased stress, in turn, helps to maintain and even increase the anxiety.

One specific form of life event that has received particular attention is *bullying and teasing*. There is considerable evidence that anxious children are more likely to be teased and bullied than non-anxious children and that they are often neglected or even rejected by their peers (Grills & Ollendick, 2002). Once again the direction of causation is unknown but it is very likely that anxious children elicit teasing from others due to their behaviours; in turn, it is likely that teasing will further enhance their anxiety.

Results indicate that 50% to 60% of children are considered diagnosis-free at the end of treatment (skills-based or CBT programs) and this figure typically increases to 70%-80% up to 12 months following the end of treatment

Cognitive biases

Anxious children report heightened threat beliefs and expectations. To some extent this is a reflection of the diagnosis, but it is also argued to represent a core maintaining feature. Although there is considerable overlap, to some extent the threat expectancies are specific. That is, socially phobic children are more likely to have increased expectancies for social threat (e.g., “other kids won't like me”), children with separation anxiety will have increased expectancies for physical threat (e.g., “my parents will get hurt”), and so on. Evidence suggests that these threat beliefs are greater among anxious children than among children with other psychopathology and that they decrease with successful treatment (Schniering & Lyneham, 2007). Whether they are causally related to the onset of anxiety or simply reflect the anxiousness is not clear.

More recent research has also begun to focus extensively on the ways in which anxious children process threatening information (Hadwin et al, 2006). As has been shown in adults, anxious children have both a bias in attention toward threat and a bias to interpret ambiguous information in a threat-consistent manner. Some research has shown that these biases decrease with successful treatment.

TREATMENT

Psychopharmacology

Pharmacological management of anxiety in children has typically focussed on the use of selective serotonin reuptake inhibitors (SSRIs). Some earlier research utilising tricyclic antidepressants focussed on OCD and is covered in Chapter F.3. Several studies have demonstrated significant efficacy of SSRIs such as fluoxetine, sertraline, and paroxetine in the management of broad-based anxiety disorders, although most studies have primarily focussed on treatment of OCD (Ipser et al, 2009). Little difference has been shown between specific agents, although paroxetine is not recommended in this age group. Treatment has generally lasted 10-15 weeks. Outcome results indicate that 50% to 60% of children are considered treatment responders at the end of treatment compared with around 30% of those on placebo. Unfortunately, the longer term maintenance of gains has rarely been investigated, but there is some hint in the literature that medication effects may

level off after around 8 weeks (Ipser et al, 2009). Adverse medication events are relatively infrequent but do occur significantly and up to 7% of anxious children on SSRIs discontinue due to side effects. Suicidality needs to be monitored in all young people taking an SSRI (for more details on pharmacological treatment see Chapter A.8 and Table A.8.1).

Skills-based programs

Most evidence-based psychological treatment for childhood anxiety falls under the broad category of cognitive-behavioural or skills-based treatment. The fundamental basis is teaching the child (and sometimes the parents) specific skills to help manage the child's anxiety. Most treatments comprise comprehensive packages or combinations of techniques. Specific treatment techniques include:

- Psychoeducation
- Relaxation
- *In vivo* or imaginal exposure
- Contingency management
- Parent training
- Cognitive restructuring
- Social skills and assertiveness training

Treatment programs typically last 8-15 weeks of around 1-2 hours per session and have been delivered in either group format or individually. Results indicate that 50% to 60% of children are considered diagnosis-free at the end of treatment and this figure typically increases to 70%-80% up to 12 months following the end of treatment (James et al, 2006). A few studies have indicated maintenance of treatment gains up to 6-8 years following treatment (e.g., Kendall et al, 2004).

A number of studies have tried to identify factors that may influence treatment efficacy. There is little evidence that outcome is different when treatment

Table F.1.2 Sessions and components of the *Cool Kids* program.

Session	Coverage - Child	Coverage - Parents
1	Psychoeducation	Psychoeducation and treatment rationale
2	Cognitive restructuring	Cognitive restructuring for both parent and child
3	Cognitive restructuring practice	Cognitive restructuring practice Child management skills
4	In vivo exposure and development of hierarchies	In vivo exposure and development of hierarchies
5	Dealing with difficulties in exposure	Dealing with difficulties in exposure
6	Practice exposure and cognitive restructuring	Practice exposure, cognitive restructuring and child management
7	Introduce assertiveness and social skills	Ways to increase assertiveness and social skills
8	Teasing and bullying	Teasing and bullying
9	Practice and review	Practice and review
10	Practice, review and relapse prevention	Practice, review and relapse prevention

Table F.1.3 Treating childhood anxiety disorders in practice

- *First line treatment*: Low-intensity treatment – including use of books (bibliotherapy), CD's or internet programs (e-therapy). May not be recommended in cases of highly urgent need (e.g., chronic school refusal) or high risk (e.g., suicidal ideation), or in cases of especially poor parent-child relationships
- *If unwilling to attempt low intensity* – then low-intensity is not recommended – *or patient does not improve* with low-intensity treatment, suggest traditional CBT or skills-based treatment with a qualified practitioner in all cases, with the exception of patients who refuse skills-based treatment or CBT is not available
- *If a patient does not improve* after a treatment program delivered by a skilful clinician for long enough (12-20 weeks), refuses skills-based treatment or CBT is not available, consider medication
- When patients are treated with *medication* – alone or in combination with CBT (multimodal treatment) – keep in mind that:
  - No medication is approved by the US Food and Drug Administration (FDA) for any anxiety disorder in patients younger than 6 years of age (see Table A.8.1). Overall, avoid medication in younger children (i.e., younger than 10 years of age).
  - While there is some evidence of effectiveness for some SSRIs for several anxiety disorders (e.g., OCD, social phobia, generalised anxiety) (see Table A.8.1), they are formally approved by the FDA in the US only for the treatment of OCD (that is, they are used "off label" for anxiety disorders other than OCD). This may not be the case in other countries.
  - Avoid using benzodiazepines. While benzodiazepines reduce anxiety in the short term, there is no evidence they are effective treating the disorder. They have more side effects in young people and potential for dependence.
  - Monitor side effects, particularly suicidality.
  - Review regularly, initially weekly, later on monthly.
  - Monitor response using an appropriate rating scale and switch to another SSRI if there is no improvement or, if not already tried, add CBT.



Click on the picture to hear Professor Rapee talk about anxiety disorders (06:08)

is delivered in either a group or individual format. A more important issue that has received some attention is the extent to which it is necessary to include parents and to teach them specific skills in treatment. Evidence on this issue has been mixed but generally indicates some, although small, benefits of including parents as active participants in the treatment (Creswell & Cartwright-Hatton, 2007). However, studies that have addressed this issue have rarely taken the age of the child into account. As might be expected, the hints in the literature suggest that including parents in treatment is likely to be relatively important in the treatment of younger children, but shows little benefit in the treatment of adolescents (Barrett et al, 1996).

Another relevant question is the influence of comorbid diagnoses on treatment effects. Surprisingly, the majority of research to date has failed to show that treatment response is worse for anxious children with comorbid disorders. In other words, anxious children seem to respond equally well to skills-based treatment packages even if they have additional difficulties with anxiety, depression, or externalising problems (Ollendick et al, 2008). Having said that, there is mixed evidence for depression; a few studies have suggested that comorbid depression may reduce treatment response (Rapee et al, 2009). A recent study from our own clinic

has shed a little more light on this issue. Based on our data, it appears that having a comorbid disorder does not influence the degree of change across treatment but does influence the endpoint. Because children with comorbid disorders (especially comorbid externalising disorders and depression) typically have more severe anxiety to begin with, the point they reach at the end of treatment is generally not as good as children without comorbid disorders, although the degree of change across treatment is very similar. Some recent research has also begun to show that children with high functioning autism and comorbid anxiety also respond very well to treatment of their anxiety (Moree & Davis, 2010).

Few other predictors of treatment response have been found. There have been hints that parent psychopathology, both parent anxiety and depression, predicts worse outcome, but some studies have failed to show this effect. Other factors such as marital status, parent education, and family size appear to have little effect. One very recent study showed that genetic status might predict treatment response. Children with short alleles on the 5HTTLPR gene showed a better response to treatment at follow-up than did children with two long alleles (Eley et al, in press). Naturally, this very interesting finding needs replication.

A program example: *Cool Kids*

There are several skills-based treatment packages for the management of anxiety disorders in young people and most contain very similar components. To provide an example, I will describe our own program, *Cool Kids. Cool Kids* is a manualised treatment program for anxious young people aged 7-17 years. There is a detailed set of guidelines for therapists that is supported by workbooks for the parent and the young person. Different workbooks and a slightly different structure are used for younger (7-12) and older (13-17) children. There are also modified versions for use with children with autism, for adolescents with comorbid depression, and for families who are unable to attend a clinic for face-to-face treatment.

Treatment using *Cool Kids* generally comprises 10 sessions over 12 weeks. Parents are an integral component and are seen at all sessions when treatment is with children but have a slightly reduced involvement when treatment is with adolescents. The program can be delivered in either group or individual format. Sessions typically last 60 minutes when delivered individually and 120 minutes when delivered as a group. There are separate components covered with children and parents. The sessions and components of *Cool Kids* are shown in Table F.1.2.

Overall efficacy for *Cool Kids* is good and, as described above, there are few negative predictors. We generally include any child with an anxiety disorder as their principal (most interfering) disorder, including children with OCD, and we rarely exclude children due to comorbidity. Our data indicate few differences in outcome. In fact the only group who seems to respond slightly worse to treatment is young people with social phobia. Therapists with training in clinical psychology, experience in working with young people, and skills in the delivery of cognitive behavioural treatments are able to run the program; training workshops are regularly conducted through our centre. At present, manuals have been translated into several languages including Spanish, Korean, Chinese, Turkish, and some Scandinavian languages.

PREVENTION AND EARLY INTERVENTION

Given the growing knowledge of risk factors for the development of child anxiety, interest has begun to rise into the possibility of very early intervention and prevention. In addition, growing recognition of the public health implications of psychopathology has increased the realisation that a large proportion of children who are high in anxiousness but do not meet criteria for an actual disorder may nevertheless be suffering and endure restrictions on their lives. As a result, recent work has begun to evaluate programs for prevention and early intervention of anxiety (Lyneham & Rapee, in press). These programs have covered all levels of intervention: universal, selective and indicated.

Several large trials have demonstrated the efficacy of anxiety management programs applied universally across sub-populations obtained via schools. These programs typically cover similar skills to those found in clinical packages including education, relaxation, cognitive restructuring, and *in-vivo* exposure; often they include additional skills such as communication and problem-solving. Therefore, they may be better thought of as *broad emotional health programs* that aim to teach young people ways of managing all distressing emotions. Results have been slightly inconsistent, but have mostly indicated reductions in anxiety, usually with small effect sizes (Bayer et al, 2009). Given that these are universal programs and are not targeting high risk groups, large effects are not expected and even small effects across an entire population are meaningful.

Selective anxiety programs refer to those that target children who report moderate to high symptoms of anxiety but do not necessarily meet criteria for a disorder. The presumption is that these children are at increased risk to develop disorders in the future and hence teaching them anxiety management skills provides a clear method of prevention. However, even if they do not go on to develop anxiety disorders, the low to moderate distress and life interference experienced by these children makes them a valid target for skills training, especially given that very few have sought professional help. As with universal programs, the majority of these interventions have used school-based populations. There are many methods of selecting children with high levels of anxiety, but most trials so far have used a combination of student self report and teacher report. Once again, the content of these programs is very similar (or identical) to that of clinical treatment programs. Results have mostly indicated significant reductions in anxiety following intervention, generally with moderate effect sizes (Mifsud & Rapee, 2005). Some research has shown continued benefits up to two years following intervention (Dadds et al, 1999).

Finally, a few studies have begun to investigate *indicated* programs for the prevention of anxiety – i.e., programs aimed at children scoring high on anxiety risk factors. Targeted children have most commonly been selected on the basis of high levels of temperamental inhibition, but high parent anxiety has also been used to identify relevant children. In the only longer term study to date, we developed a modified version of *Cool Kids* called *Cool Little Kids*. The program is aimed at parents of inhibited preschool-aged children and comprises 6 group sessions. Components are mostly aimed at reducing parent overprotection and encouraging in-vivo exposure for the children. By age 7, children whose parents attended the program showed significantly lower levels of anxiety symptoms and fewer anxiety

diagnoses compared to children whose parents received no training (Rapee et al, 2010).

CONCLUSION

The past two decades have seen a tremendous expansion in our knowledge of the development and management of childhood anxiety disorders. Many key issues remain to be evaluated and we still have a long way to go but we are currently at a point where anxious children are recognised and can be thoroughly assessed. We have treatments that work for the majority of patients and programs are beginning to prevent the development of anxiety. Several promising areas of research are just starting to grow and will hopefully provide further advances in the coming years. These include:

- Better understanding of risk factors for anxiety through longitudinal research
- Closer evaluation of gene-environment interactions in the development of anxiety
- More understanding of peer interactions in anxiety and their influence on its development
- Better methods of disseminating treatments, for example through internet and distance (tele-health) programs
- Evaluation of novel improvements to treatment such as the use of memory consolidation agents or cognitive bias modification.

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SEPARATION ANXIETY

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Children going to school in Ndola, Zambia
Photo: Jack Gin

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Conflict of interest: research funding from: Eli Lilly. CME: Eli Lilly, Janssen, Shire. Speaker: Eli Lilly, Janssen, Shire, Spanish National Health Service

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Conflict of interest: research funding from Abbott, Alicia Koplowitz Foundation, Bristol-Myers Squibb, Eli Lilly, Gobierno de Navarra, Carlos III Institute (FIS), Redes

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Suggested citation: Figueroa A, Soutullo C, Ono Y, Saito K. Separation anxiety. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Anxiety disorders are probably the most common psychopathology in youth, with prevalence estimates ranging from 5% to 25% worldwide, but a much lower percentage receive treatment (Boyd et al, 2000; Costello et al, 2003). Separation anxiety disorder (SAD) accounts for approximately half of the referrals among all anxiety disorders (Cartwright-Hatton et al, 2006). Most pediatric anxiety disorders have the same diagnostic criteria as those in adults except SAD, currently classified in DSM and ICD as one of the disorders usually diagnosed in infancy, childhood, or adolescence (Krain et al, 2007).

SAD is characterized by an abnormal reactivity to real or imagined separation from attachment figures that significantly interferes with daily activities and developmental tasks. To meet DSM-IV-R diagnostic criteria, the anxiety must be beyond what is expected for the child's developmental level, last longer than four weeks, begin before age 18 and cause significant distress or impairment (American Psychiatric Association, 2000).

SAD can cause marked distress and impairment, can lead to several negative psychosocial outcomes, and is predictive of adult psychiatric disorders, especially panic disorder. In spite of this, the disorder has seldom been studied, and children are not usually clinically assessed until SAD results in school refusal or marked somatic symptoms. Available effective treatments include psychotherapy and medications.

CLINICAL PRESENTATION

SAD has a heterogeneous clinical presentation. The cardinal symptom is a significant or developmentally inappropriate *distress*, or excessive and unrealistic fears, upon *separation* from attachment figures (usually parents) or the home (American Psychiatric Association, 2000). There are three key characteristics of separation anxiety disorder:

- Excessive and persistent fears or worries before and at the time of separation.
- Behavioral and somatic symptoms before, during and after the separation, and
- Persistent avoidance or attempts to escape the separation situation.

The child *worries* that something may happen to his parents (e.g., that they will disappear, get lost or forget about him) or that the child will get lost, kidnapped or killed if he is not near his parents. *Behavioral symptoms* include crying, clinging, complaining upon separation, and searching or calling for the parent after their departure. *Physical symptoms* are similar to those in a panic attack or somatization disorder, such as:

- Headaches
- Abdominal pain
- Fainting spells, lightheadedness, dizziness
- Nightmares, sleep difficulties
- Nausea, vomiting
- Cramps, muscle aches
- Palpitations, chest pain.

Temáticas de Investigación Cooperativa, Pfizer, PIUNA, Stanley Medical Research Institute-NAMI, and Solvay. Consultant: Alicia Koplowitz Foundation, Bristol-Myers Squibb/Otsuka, Editorial Médica Panamericana, Eli Lilly, Juste, European Interdisciplinary Network ADHD Quality Assurance, Janssen, Pfizer, and Shire. Speaker: AstraZeneca, Eli Lilly, GlaxoSmithKline, Janssen, Novartis, SEP-SEPB, Shire and Solvay.

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Due to these physical symptoms, SAD is a frequent cause of school absenteeism and multiple visits to the family doctor or pediatrician to rule out a medical problem. Symptoms only appear on school days and usually disappear as soon as the parents decide the child will stay at home.

Clinical presentation differs according to the patient´s age**.** Young children describe having nightmares about separation themes more often than older children. Also, compared to adolescents, children show more often extreme distress upon separation. They frequently display oppositional behaviors such as temper tantrums in separation situation. Adolescents with SAD have physical complaints more often on school days. Situations in which separation anxiety symptoms can appear are when the child:

- Is left at daycare
- Enters school
- Gets on the school bus
- Is asked to go to bed
- Is left at home with baby sitters
- Begins summer camp
- Moves households
- Stays overnight with friends or relatives
- Confronts parental separation or divorce.



Click on the picture to view a short video on separation anxiety.

Separation anxiety symptoms appear more frequently in situations such as a change of school, starting a new school term (after summer vacation, or when starting high school), changing friends, experiencing adverse events such as being bullied, or suffering a medical illness.

The boundaries for clinical significance of symptoms vary depending on cultural factors. Different cultures have different expectations about autonomy, level of supervision, sleeping practices, housing characteristics (e.g., availability of rooms, size of the house), and the role of parents in child care (e.g., taking care of the child themselves or leaving the child in daycare) (Hanna et al, 2006).

Marina is a nine year old girl who lives in a large city with her parents and her four year old brother. She is doing 4th grade at a private school. Since she started kindergarten at the age of two, her teachers noted she was shy and would only start relating to her class mates by the end of the school year. During the first months of the school year she spent as much time as possible with her tutor, even avoiding contact with the rest of the teachers. Transition to pre-school had been difficult but she managed to make some friends by the last trimester. After that, although she appeared distressed at the beginning of each school year, she managed to relate normally to her classmates.

At the age of nine, Marina had the flu, which made her stay in bed for two weeks. When she got better and was allowed to attend school, she cried impatiently clinging to her mother while begging her not to go. After a few days she managed to return to school without excessive crying. However, in the middle of the morning she began complaining of abdominal pain and had to return home. Her pediatrician found no evidence of abdominal pathology. Another day she felt very tired at school, dizzy and with headaches. Again, the pediatrician found no evidence of pathology that would explain her symptoms, but her parents were worried about Marina's problems and went to see a different doctor who conducted more tests that were all negative. She never experienced these physical problems on weekends but when Sunday night arrived she became anxious about presenting the same symptoms at school again on Monday.

Comment: this clinical vignette highlights the symptoms of social anxiety that often precede SAD, the viral infection that triggers the onset of SAD, the problems with separation and the non-explained medical symptoms upon separation.

DIAGNOSTIC CRITERIA

Diagnostic criteria for SAD include:

- Presence of at least 3 out of the 8 possible anxiety symptoms that appear during separation situations (e.g., separation from home or from major attachment figures; fear of losing or possible harm befalling to major attachment figures; reluctance or refusal to go to school, or be alone or without major attachment figures, etc.)
- Symptoms must be present during at least four weeks, and must start before the age of 18.
- Symptoms cause at least moderate impairment and are not better explained by another psychiatric disorder.

The main modification proposed for DSM-V is that SAD be moved from the category of "disorders usually present in infancy, childhood or adolescent" to the general category of "anxiety disorders" along with the rest of anxiety disorders that are diagnosed in children and adults.

In ICD-10, SAD is called "separation anxiety of childhood". It is included in the section of "emotional disorders with onset specific to childhood" that includes phobic anxiety disorder of childhood and social anxiety disorder of childhood, among others.

EPIDEMIOLOGY

Few epidemiological studies have been published and most have methodological limitations and biases, so data is scarce. SAD has an early age of onset, the peak onset is between 7 and 9 years of age (Costello & Angold, 1995). Prevalence is 3%-5% in children and adolescents, and it decreases with increasing age (Costello & Angold, 1995). In the recently published national comorbidity survey study, Kessler et al (2011) found that anxiety disorders were the most common disorders in all time frames (followed by behavior, mood, and substance use disorders), and that SAD was the most common anxiety disorder in children but the seventh most common lifetime disorder because it often resolves before adolescence. Sub-threshold SAD is much more common. One study estimated that 50% of 8-year-olds suffered SAD symptoms that did not cause significant impairment. Some investigators suggest SAD in the US may be slightly more common in females, African-Americans and families with low socioeconomic status.

Age of onset and course

Anxiety symptoms upon separation from parents or major attachment figures are developmentally normal in children (see Chapter A.2). Distress about separation from attachment figures in infants is one of the most strongly preserved evolutionary behaviors (Shear et al, 2006). Separation anxiety symptoms usually peak between nine and 13 months of age, decrease usually after two years of age, with increasing levels of autonomy by the age of three. Separation anxiety symptoms may increase again by age four to five, usually when the child starts school (Costello et al, 2005; Mattis & Pincus, 2004; Krain et al, 2007). The presence of an anxiety disorder in one of the parents facilitates the persistence of normal separation anxiety (via genetic transmission and because anxious parents

may reduce exposure to separations, decreasing the chance of improvement). Because separation anxiety symptoms are developmentally normative before the age of five, a clinical diagnosis of SAD is rarely justified before then.

Longitudinal studies show that child SAD may be a risk factor for other anxiety disorders; it specifically increases the risk for panic disorder and agoraphobia in adults, mainly due to their similar clinical presentation (Biederman et al, 2005). This is supported by physiological studies, which show an increased sensitivity to carbon dioxide exposure in children with SAD as well as in patients with panic disorder (Pine et al, 2000). Other investigators suggest SAD increases vulnerability for a broad range of anxiety and mood disorders.

Approximately one-third of childhood cases of SAD persist into adulthood if untreated. A child with SAD may significantly limit his peer interactions, which could lead to impairment in social functioning or isolation during adulthood (e.g., remaining single or experiencing marital conflict) (Shear et al, 2006). According to the Child/Adolescent Anxiety Multimodal Study (CAMS; see treatment section below) predictors of remission are: younger age, nonminority status, lower baseline anxiety severity, absence of other internalizing disorders (e.g., anxiety, depression), and absence of social phobia.

The DSM-IV describes SAD as a childhood disorder that seldom persists into adulthood. However, several studies have found that the prevalence of *adult* SAD is around 6%, even higher than childhood SAD. According to one study, more than 70% of adult cases of SAD started in adulthood; so it might be a much more common condition than previously recognized (Shear et al., 2006).

- Prevalence of SAD is approximately 5% in children, decreasing in adolescence. Prevalence of adult SAD is around 6%
- SAD is the most common anxiety disorder in the pediatric population.
- Around 50% of eight year olds suffered separation anxiety symptoms that did not cause significant impairment
- Peak onset is between seven and nine years of age
- Because separation anxiety is developmentally normative before the age of five, a diagnosis of SAD is rarely justified before then
- SAD is a risk factor for other anxiety and psychiatric disorders.
- Approximately one-third of childhood cases of SAD persist into adulthood if left untreated.

ETIOLOGY

The etiology of SAD is complex and partly unknown. Studies demonstrate that both biological and environmental factors play a role, environmental factors might have a stronger influence in SAD than in other childhood anxiety disorders. Most proposed etiological factors are associated with anxiety disorders in general rather than SAD specifically. There is broad agreement that an interaction between different factors, biological and environmental, increases the risk for anxiety disorders. For example, the interaction of a mother with low anxiety tolerance and a child with behavioral inhibition is likely to result in anxiety in the child.

Biological factors

Genetic

SAD heritability varies from very low to moderate according to different studies. A large scale twin study suggested a significant genetic influence for SAD, accounting for a heritability of around 73% (Bolton et al, 2006). Most studies suggest anxiety disorders run in families (Pine, 1999), and that a person can inherit vulnerability for any anxiety disorder rather than for a specific anxiety disorder. Children with anxious parents are five times more likely to present an anxiety disorder. Some researchers have reported an association between panic disorder in parents and SAD in offspring (Biederman et al, 2004) though this has not been confirmed.

Psychological

Psychobiological processes such as fear conditioning are the underpinnings of anxiety disorders. These are the product of genes and environment on the functioning of brain regions involved in fear and reward circuits (amygdala, orbitofrontal cortex, and anterior cingulate cortex).

Dysfunction of some brain areas

The amygdala is one of the main areas implicated in anxiety (Beesdo et al, 2009).

Environmental

Many of the environmental risk factors are derived from cross-sectional epidemiological studies (that can not demonstrate a cause-effect relationship) (Pine & Klein, 2008).

Related to the child´s family

- Low parental warmth
- Parenting behaviors that discourage child autonomy (see Ginsburg et al, 2004, for a review). Overprotective and over-involved parents appear to be a specific risk factor for SAD.
- Insecure attachment, above all with the mother. An anxious-resistant attachment is associated with anxiety disorders (Warren et al, 1997). Children of anxious mothers often exhibit anxiety about separation (Beidel et al, 1997; Biederman et al, 2001), not only because children's fears about their own security, but also about their mother´s safety during separation
- Severe parental discord
- Separation or divorce
- Physical illness in a parent
- Mental disorder in a parent, such as panic disorder and major depression
- Father who is egocentric, immature, instable or with antisocial behaviors.

Early experiences

- Stressful life events are broadly associated with pediatric psychopathology in general
- Being involved in a major disaster or crime
- Exposure to family violence
- Parent losing a job
- Birth of a sibling

Child's temperament and characteristics

- Behavioral Inhibition reflects a consistent tendency to display fear and withdrawal in unfamiliar situations which the child tries to avoid. Behaviorally inhibited children are introverted, easily embarrassed or socially avoidant. It is usually evident by age two. These children are more likely than non-inhibited ones to exhibit significant levels of anxiety of various kinds, including SAD (Kagan et al, 1988; Biederman et al, 1993; Anthony et al, 2002)

- Low tolerance for humiliation
- Fear of failure
- Depression
- Gender. Females have higher rates of almost all anxiety disorders.

Related to the school

- Being bullied
- Failure to perform at the expected level in exams, sports or other academic activities.

COMORBIDITY

Childhood anxiety disorders are frequently comorbid with each other and with other forms of psychopathology. Thus it is common that children with SAD also present with other anxiety disorders or other conditions such as depression or disruptive behavior disorders (Krain et al, 2007). Compared to children with generalized anxiety and social phobia, children with SAD more frequently show other anxiety disorders, increasing the overall severity (Kendall et al, 2001); suffer comorbid specific phobias more often (Verduin et al, 2003); and are more likely to avoid school, resulting in school refusal (*futoko* in Japan).

Children with SAD more frequently present alos with:

- Major depression (Angold et al, 1999)
- Bipolar disorder (Wagner, 2006), and
- Attention-deficit hyperactivity disorder. Girls with the inattentive subtype of ADHD may have higher rates of comorbid SAD (Levy et al, 2005).

DIAGNOSIS

In DSM-IV and ICD-10, SAD is the only anxiety disorder classified in the section of "disorders usually diagnosed in infancy, childhood, or adolescence", and not included with the other anxiety disorders (although this is likely to change in DSM-5).

Diagnostic evaluation

School refusal and excessive somatic complaints in the context of actual or anticipated separations are the most common reasons for parents to seek treatment for SAD (Krain et al, 2007).

The diagnostic assessment of SAD requires a multi-informant, multi-method approach involving the child, parents and, if appropriate, school teachers or other significant caregivers (see Chapter A.5). The final diagnosis will be based on information from all these sources. While the gold standard is a structured or a semi-structured clinical interview where children and their parents are interviewed separately, structured interviews are often impractical in everyday clinical work.

Several semi-structured diagnostic interviews are available:

- The *Anxiety Disorder Interview Schedule for DSM-IV Child and Parent Version* (ADIS-IV-C/P; Silverman & Albano, 1996). The ADIS is designed for youth aged six to 17 years of age; it assesses DSM-

IV anxiety, mood, externalizing, tic, substance use and pervasive developmental disorders.

- The *Kiddie Schedule of Affective Disorders and Schizophrenia for School age children, Present and Lifetime version* (K-SADS-PL) is used for patients six-18 years of age to asses all Axis I diagnosis, except pervasive developmental disorders.

The majority of childhood anxiety assessment measures are developed for and validated with school-aged children, leaving disorders of early childhood relatively unexplored. *The Preschool Age Psychiatric Assessment* (PAPA), is a structured parent interview used to diagnose psychiatric disorders in children aged two to five.

During the interviews, clinicians should assess the three key groups of anxiety symptoms:

- Behaviors
- Thoughts
- Physical symptoms.

The clinician should explicitly ask about their presence currently and in the past, timing, frequency, how they interfere with daily functioning, and what function they may be serving. It is also important to gather information about early SAD symptoms their development over time, and assess their possible association with major life transitions or stressors. Anxious children tend to report more physical symptoms, while parents usually emphasize the avoidant behaviors. If possible, it is helpful for the clinician to actually see the patient in a anxiety provoking situation (i.e., entering school). Often children show intense SAD symptoms in the doctor´s office when they are required to separate from his parents.



Click on the picture to watch the video "Understanding separation anxiety"

As with any other psychiatric disorders, evaluation should include past psychiatric history, family psychiatric history, medical history and developmental history (see Chapter A.5).

Somatic symptoms generally have no physical origin. However, a careful physical examination with appropriate blood work is recommended to rule out physical causes, including anemia, streptococcal infection (search for anti-streptococcal antibodies), hyperthyroidism, hypothyroidism (ask for T3, T4, and TSH), mitral valve prolapse, asthma, gastrointestinal infection, inflammation, bleeding, or ulceration. Also, urine screening for drugs in adolescents is advisable. In some cases a clinician can suspect the presence of diabetes mellitus. Rarer conditions that could mimic SAD symptoms are: babesiosis, Lyme disease, and rickettsial infection. This is important in patients with a history of fever, rash, or sore throat with incomplete or no treatment with antibiotics, and a history of acute change in personality or anxiety or obsessive symptoms. Blood levels of lead and mercury can be measured to rule out heavy metal poisoning (especially in patients with abdominal pain). If other information suggests brain tumor or seizure disorder, the clinician should perform appropriate imaging studies.

As previously mentioned, to meet DSM-IV criteria for SAD, anxiety symptoms must be beyond what is expected for the child's developmental level, last longer than four weeks, begin before age 18, and cause significant distress or impairment (APA, 2000). Anxiety has to be exclusively related to separation

from home or attachment figures, and the patient must have at least three of the following:

- Recurrent excessive distress in separation situations
- Persistent and excessive worry about losing, or about possible harm befalling major attachment figures (e.g., health, accidents, death)
- Persistent and excessive worry that an untoward event will lead to separation from a major attachment figure (e.g., getting lost or being kidnapped)
- Persistent reluctance or refusal to go to school, work, or elsewhere because of fear of separation
- Persistent and excessive fear about or reluctance to be alone or without major attachment figures
- Persistent reluctance or refusal to go to sleep without being near a major attachment figure or to sleep away from home
- Repeated nightmares involving the theme of separation
- Repeated complaints of physical symptoms (such as headaches, stomachaches, nausea, or vomiting) when separation from major attachment figures occurs or is anticipated.

The current diagnostic criteria have been criticized because examples are restricted to untoward events happening to the child, but fail to capture untoward events to attachment figures that may lead to loss, such as worries about death and dying; the need for more studies to test the cut off of four weeks, which is arbitrary.

Rating Scales

Rating scales used in clinical practice or in research are completed by the patient, parents and or teachers; they provide valuable information to confirm the diagnosis, quantify the severity of symptoms and monitor treatment response. However, they should never be used as *diagnostic instruments* (see Chapter A.5).

Anxiety symptoms in children can be assessed by general psychopathology rating scales such as the *ASEBA* instruments (Achenbach, 2009) or specific scales such as the *State-Trait Anxiety Inventory for Children* (STAIC; Spielberger, 1973). The latter is probably more helpful to evaluate separation anxiety symptoms in children of all ages. All of the scales mentioned below have shown reasonably good validity and reliability.

Other widely used rating scales for anxiety symptoms in children and adolescents include the *Fear Survey Schedule for Children-Revised* (FSSC-R; Ollendick, 1983), the *Revised Child Manifest Anxiety Scale* (RCMAS; Reynolds, 1980), the *Stait-Trait Anxiety Inventory for Children* (STAIC; Papay & Spielberger, 1986), and the *Social Phobia and Anxiety Inventory for Children* (SPAI-C; Beidel et al, 2000).

Differential diagnosis

Anxiety symptoms can be the manifestation of:

- Normal developmental anxiety (e.g., normal fears during the first few days of school), in this case symptoms would be self-limiting
- Medical illness (e.g., hyperthyroidism, Cushing syndrome, brain tumor). Symptoms would not be restricted to situations involving

Table F.2.1 Scales* to rate separation anxiety symptoms

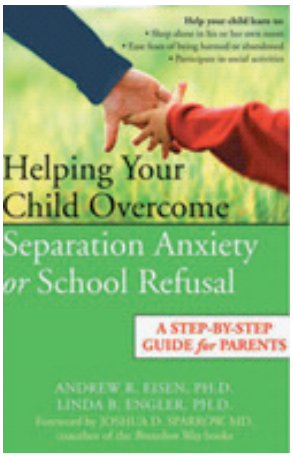
Scale	Rater	Patient´s age	Recommended for screening	SAD subscale	Comments
SCAS (Spence, 1997)	Child, (Parent version)	8-12	✓	✓	• 44 items, uses a 4-point scale • 6 subscales: separation anxiety, panic/agoraphobia, social anxiety, generalized anxiety, obsessions/compulsions, and fear of physical injury • Preschool scale for 2.5-6.5 years of age • Available in 16 languages
SAAS-C/P (Eisen & Schaefer, 2007)	Child, Parent			✓	• 34 items, some specific of SAD • 4 dimensions: fear of being alone, fear of abandonment, fear of physical illness, and worry about calamitous events. • Also contains a "frequency of calamitous events subscale" and "safety signals index".
SCARED-R (Muris et al, 1998)	Child (parent version)	7-18	✓✓✓	✓	• Total of 66 items including all DSM-IV anxiety disorders, 8-items specifically assess SAD. • Available in 8 languages
PARS (Research Units on Pediatric Psychopharmacology Anxiety Study Group, 2002)	Clinician				• Requires interviews with parents and child
RCADS (Chorpita et al, 2000)	Child, Parent	6-18		✓	• 47 items, self-report questionnaire. • Includes all anxiety disorders and major depression • It yields a total anxiety score and a total internalizing score. There is also a parent version. • Available in 5 languages.
The Preschool Anxiety Scale (Spence et al, 2001)	Parent	2-6			• Parent self-report. • A preschool version of the SCAS.

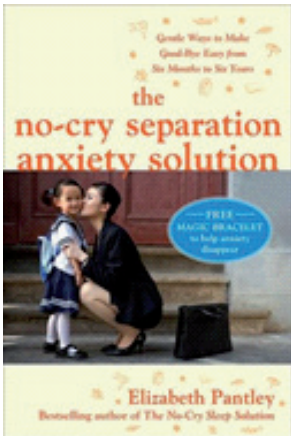
*Non-proprietary: free for clinical use.

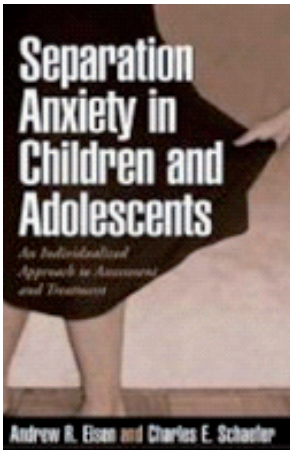
separation from attachment figures and the child would present other medical signs, such as vision or coordination impairment in the case of brain tumors

- Anxiety disorders different from SAD, such as generalized anxiety or social phobia (worries about "everything" or social situations, respectively, not fear about separation specifically), and the presence of an attachment figure does not alleviate symptoms (see Chapter F.1)
- Other psychiatric disorders such as depression
- In adolescents, alcohol and substance use such as cannabis, cocaine or caffeine. Symptoms would occur when under the effect of the substance or upon withdrawal
- Adverse environmental circumstances such as inappropriate academic placement, fear of violence at school (e.g., gang-related violence), being bullied, grief reaction. Symptoms would typically start acutely and worsen when exposed to these situations.
- Truancy. The adolescent would deliberately not attend school.

Clinicians may recommend books or websites to obtain more information, for example:







TREATMENT

There are multiple treatment options for children and adolescents suffering from SAD. The clinician should select the most appropriate therapeutic option for each specific patient after considering factors related to the disorder (severity, duration, dysfunction due to symptoms), the patient and his family (chronological and developmental age, insight, treatment preferences, family motivation and availability, financial resources), and the clinician (availability, skills and experience). Most data about effectiveness of treatment refer to non-pharmacological treatments: psychoeducation, behavioral management and different forms of cognitive behavioral therapy. Thus, these should be the clinician´s first choice.

Psychoeducation

In all cases, it is essential to build a good therapeutic alliance between the patient (and family) and the clinician. This is best developed in the context of psychoeducation**,** which is also fundamental in all treatment processes. Educating the family and the child (according to their developmental age), increases insight and motivation. Understanding the nature of anxiety and how it is experienced by the child will help parents and teachers sympathize with a child's struggles.

Psychoeducation should always cover:

- Anxiety as a normal emotion, at all developmental stages
- Factors that may cause, trigger or maintain anxiety symptoms
- The natural course of SAD
- Treatment alternatives, including their advantages and disadvantages
- Prognosis

There is a multitude of books and much (good and bad) information in the Internet about anxiety disorders. Some of the most useful can be found in side boxes.

Behavioral management

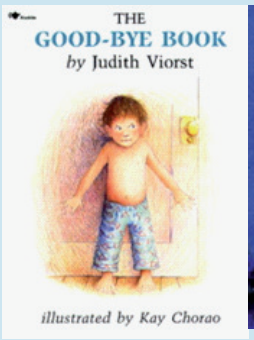
Behavioral management is indicated in all cases. It consists of informing family members and significant caregivers, how to manage mild symptoms and maladaptive attitudes such as avoidant behaviors or cognitive biases. It may be the only treatment required in cases of mild separation anxiety (which generally occur during pre-school). This should be combined with other therapies if there is no improvement or symptoms are moderately severe, or cause moderate dysfunction or distress. The main objective of behavioral management is to provide the child a flexible and supportive environment to overcome his separation anxiety symptoms.

The clinician may recommend parents to:

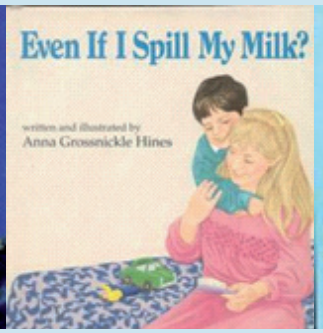
- Listen to the child's feelings empathically
- Keep calm when the child becomes anxious (to model the child's behavior)
- Remind the child that he had survived similar anxious situations before
- Teach simple relaxation techniques such as deep breathing, counting to 10, or visualizing a relaxing scene. Learning how to relax gives the child a sense of control over his body
- Plan transitions, such as getting to school in the morning or preparing for bed at night
- Help the child prepare a list of possible strategies in case anxiety appears in "difficult" situations
- Support the child's prompt return to school (long absences make return to school more difficult)

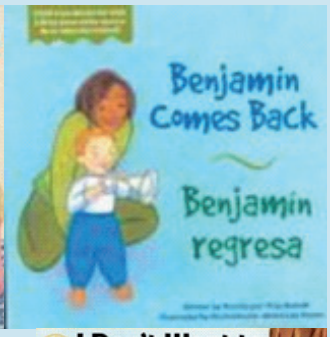
Interventions at home

A parent may read a specialized book with the anxious child, while reassuring that it is fine for the child to feel that way and that nothing will happen. There are many books for this purpose, such as "The good-bye book" by Judith Viorst; "The Kissing Hand" by Audrey Penn; "Even if I Spill My Milk" by Anna Grossnickle Hines; "Benjamin Comes Back" by Amy Brandt; "When Mama comes home" by Eileen Spinelli; "The invisible string" by Patrice Karst.

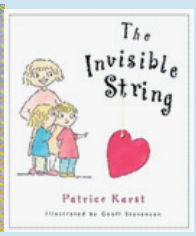




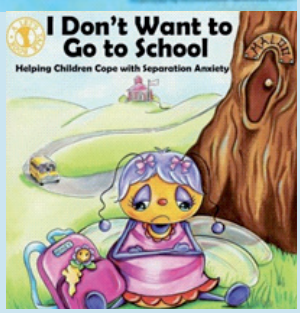








When symptoms of separation anxiety result in the child rejecting school, a parent can share books that specifically discuss this such as: "I don´t Want to Go to School" by Nancy Pando.



- Encourage the child's participation in activities outside the home, without attachment figures (promote *exposure*). Do not let him stay at home to avoid distress (do not allow *avoidance*)
- Praise the child's efforts (not only his results) to address symptoms (reinforce repeatedly during his way to success)
- Assure the child/adolescent that somatic symptoms are indicators of a problem that requires attention, just not a physical problem.

Interventions at school

The clinician can recommend teachers to:

- Initiate a plan to promote the child´s return to school as soon as possible
- Maintain frequent meetings with parents to facilitate collaboration in strategies to help the child normalize schooling
- Assess the cause of the child's school refusal and address it (e.g., problems with friends, fear of a teacher)
- Supervise the child´s arrival to school, preferably the same person every time
- Allow an attachment figure to initially accompany the child
- Allow a shorter school day and lengthen it gradually
- Identify a safe place where the child can go to reduce anxiety during stressful periods
- Identify a safe adult to whom the child can ask for comfort at all times, most of all during stressful periods
- Promote practicing relaxation techniques developed at home
- Provide alternative activities to distract the child from physical symptoms
- Encourage small group interactions. This can start with only one classmate. With time, the child will increase his competency and the group may be enlarged progressively. Provide assistance with these peer interactions.
- Reward a child's efforts
- Allow extra time for transitioning to different activities.

Cognitive Behavior Therapy (CBT)

Several randomized controlled studies have shown the short and long term effectiveness of CBT in ameliorating childhood anxiety disorders, including SAD. CBT is currently the treatment with the most evidence supporting its efficacy (Barrett et al, 1996; Kendall et al, 1997). Thus, CBT has become the initial treatment of choice. The exception is when anxiety symptoms are too severe to allow working with the child in therapy. In that case, medication or both treatments concurrently would be indicated.

There are several manualized CBT programs, mostly based on classical and operant principles and social learning. The duration of CBT depends on the severity, treatment design and patient´s response.

The targets of CBT are to:

- Gain insight about the presence and the origin of anxiety symptoms
- Control worries

- Reduce arousal
- Confront the feared situations.

To achieve those objectives, CBT usually includes the following:

- Psychoeducation
- Cognitive restructuring (reducing negative self-talk and addressing negative thoughts, among other strategies)
- Improving problem solving skills
- Relaxation training (to address physical symptoms)
- Modeling
- Contingency management
- Exposure and response prevention.

Exposure and response prevention are the key element of CBT for anxiety disorders, which is included in all programs in different forms. First the child is helped to list the top anxiety-provoking situations. This serves as an initial description of the symptoms, and will be used later as a measure of treatment progress. The child rates each situation for *level of fear* and *degree of avoidance*, on a 0 (not at all) to 10 (extreme) Likert scale (specifically designed for the child's developmental stage or cognitive level such as a "fear thermometer"). Some programs only grade the level of fear/anxiety, but the inclusion of an *avoidance rating* may help in designing exposure experiences. Therapist and parents may assist in performing the rating.

As explained, there are many CBT programs. Here, we mention two of them: *The Coping Cat* and the *Friends* programs.

The Coping Cat program

The Coping Cat (Kendall , 2000) is a manualized, proprietary intervention for youth with anxiety disorders, including SAD. The program incorporates cognitive restructuring and relaxation training followed by gradual exposure to anxiety-provoking situations applying learned coping skills. It has been shown to be effective in SAD (and also in generalized anxiety and social phobia). Randomized clinical trials have achieved remission rates as high as 66% (Kendall et al, 1997). Follow-up assessments at three and 7.5 years showed that treatment gains were maintained over time (Kendall & Southam-Gerow, 1996; Kendall et al, 2004).

The "Friends" program

The *Friends* program is a 10-session CBT intervention delivered in a group format for children with anxiety disorders, with two levels: treatment and universal preventive intervention. FRIENDS is the acronym for: F—Feeling worried?; R—Relax and feel good; I—Inner thoughts; E—Explore plans, N—Nice work so reward yourself; D—Don't forget to practice; and S—Stay calm, you know how to cope now. The program has all the essentials of CBT programs including cognitive restructuring for parents. Also, parents are encouraged to practice the skills daily and are given positive reinforcement for doing so. The program encourages families to develop supportive social networks, and children to develop friendships among group members by talking about difficult situations and learning from peers' experiences. It also incorporates some elements of interpersonal therapy. Shortt et al (2001) conducted a RCT applying the Friends program in children 6-10 years

old, with SAD, generalized anxiety or social phobia, obtaining remission rates of 69%. Therapeutic gains were maintained one year later.

Camp-like CBT

Camp-like CBT is an intensive intervention for school-age girls with SAD delivered in the context of a one-week camp-like setting. A potential benefit of a camp-based group approach for SAD is the incorporation of children's social context into treatment (away from parents), thus allowing a more naturalistic exposure regarding typical separation situations, such as group field trips, activities and sleepovers. The program also includes parents, whom clinicians educate on the management of SAD symptoms. A RCT suggested significant reductions in SAD severity and treatment gains (Ehrenreich et al, 2008).

The role of the family in CBT

Family involvement is essential because parents often play a role in the maintenance of children's separation fears and should support the treatment plan by consistently applying the behavioral management at home. Some programs, also CBT based, emphasize family involvement, such as *Parent-Child Interaction Therapy* (PCIT).

Parent-Child Interaction Therapy (Brinkmeyer & Eyberg, 2003) has been adapted for children aged four to eight with SAD (Choate et al, 2005; Pincus et al, 2005) but requires considerable resources often not available in many services, even in high income countries. PCIT has three stages:

- Child-directed interaction: teaches parents to be warm and praiseful, to promote the child's feeling of security in order to facilitate separation from the parent
- Bravery-directed interaction: the therapist works with both the parents and the child to develop a list of situations the child is fearful of or currently avoiding, in order of severity. The family creates a reward list to reinforce the child's efforts.
- Parent-directed interaction: parents learn how to manage the child´s misbehavior based on operant principles of behavior change (such as consistent positive and negative consequences). Also, parents learn not to reinforce the child´s anxious behaviors, for example not giving the child more attention when he skips class (Eisen et al, 1998).

During all three stages, parents are actively coached on how to apply the skills. Coaching may take place through a one-way mirror, using walkie-talkies or an ear-piece microphone. Mastery is measured by the number of times the parents use a specific skill. Preliminary analyses in as yet unpublished controlled trial to assess the efficacy of PCIT in children with SAD suggest a clinically significant improvement, with continued improvement over time.

CBT for pre-schoolers

Most CBT programs are designed for children aged six years or older. Hirshfeld-Becker et al (2010) examined the efficacy of a developmentally appropriate parent-child CBT program for anxiety disorders in children aged four to seven. The response rate was 69% (versus 32% in controls) and gains were maintained at one year follow-up.

Also available for preschoolers is the *CALM* program (Comer et al, 2012), a form of parent-child interaction therapy, for children aged three to eight with SAD, social anxiety disorder, generalized anxiety, or specific phobias. A controlled trial has shown promising results of live parent coaching in this population (Comer et al, 2012).

Pharmacological treatment

Medication should always be used *in addition* to behavioral or psychotherapeutic intervention. Medication is not generally recommended as a first line treatment for SAD. However, it is a useful strategy when CBT achieves no response or partial response, or when the child is significantly impaired. No medication has been specifically approved for SAD. However, various medications have been investigated for childhood anxiety disorders, such as selective serotonin reuptake inhibitors (SSRIs), tryciclic antidepressants (TCAs), benzodiazepines, buspirone, serotonin and noradrenaline reuptake inhibitors (SNRI), propanolol, clonidine, atypical antipsychotics, antihistamines and melatonin. All medications should be started, stopped or adjusted under the supervision of a trained clinician.

SSRIs

There are numerous RCTs assessing the efficacy of SSRIs in children and adolescents with SAD, generalized anxiety and social phobia (Reinblatt & Riddle, 2007). In those studies SSRIs have proved to be effective and have a favorable adverse effect profile. Thus, they are considered the first choice medication in anxiety disorders, including SAD (Reinblatt & Riddle, 2007). In fact, SSRIs may be more effective in anxiety disorders than in major depression (Bridge et al, 2007). In spite of the clinical evidence, no SSRI has been approved by the US Food and Drug Administration (FDA) for the treatment of anxiety disorders in children and adolescents. Thus, when clinicians prescribe an SSRI to a patient under 18 years old with SAD, they are doing so "off-label" in the US – the situation may be different in other countries (several SSRIs are approved for the treatment of obsessive compulsive disorder, see Table F.2.2). In June 2003 the FDA recommended that paroxetine not be used in children and adolescents with depression. The other SSRIs appear to be of similar effectiveness.

Different controlled trials have investigated different SSRIs: fluvoxamine (e.g., Research Units on Pediatric Psychopharmacology Anxiety Study Group, 2001); fluoxetine (e.g., Birmaher et al, 2003); sertraline (e.g., Walkup et al, 2008). However, there are no studies assessing the long term effectiveness in pediatric populations with SAD.

Table F.2.2 US Food and Drug Administration approved SSRIs for children and adolescents

SSRI	Indication	Patient´s age
Escitalopram	Depression	12-17
Fluoxetine	Depression	8-17
Fluoxetine	OCD	7-17
Fluvoxamine	OCD	8-17
Sertraline	OCD	6-17

Table F.2.3 Summary of the characteristics of commonly used SSRIs

SSRI	Initial dose (mg/day)	Target dose (mg/day)	Comments
Citalopram	5	10-40	
Escitalopram	5	10-30	
Fluoxetine	5	10-80	• Long half life • Can decrease appetite and sexual function
Fluvoxamine	10	50-300	
Paroxetine	5	10-60	• Very short half life • Less effective in children (FDA discourages its use) • Frequent side effects
Sertraline	25	50-200	• Few interactions • Few side effects

The Child/Adolescent Anxiety Multimodal Study (CAMS), one of the most comprehensive trials of anxiety disorders in youngsters is a good example of the studies available. This multisite trial included 488 children and adolescents (ages 7-17 years) with SAD, generalized anxiety or social phobia. Patients were randomized to 12-week treatment in one of these four arms: (a) sertraline, (b) cognitive behavioral therapy (CBT), (c) a combination of sertraline and CBT, and (d) clinical management with pill placebo. After 12 weeks of treatment all active therapies were superior to placebo. Remission rates (that is, achieving a nearly symptom-free state) were highest for the combined group (46% to 68%), followed by sertraline (34% to 46%), followed by CBT (20% to 46%), and lastly for placebo (15% to 27%). Rates of response (i.e., a clinically significant improvement) were significantly higher than rates of remission. The main conclusion was that CBT alone and sertraline alone were effective short term treatments but there was a clear advantage in combining both (Walkup et al, 2008).

Practical issues about prescribing SSRIs in children and adolescents

Prescribers should start with a low dose and titrate it weekly, monitoring clinical response and side effects. To achieve maximum benefit children may need as high a dose as adults. Table F2.3 presents initial and target doses. SSRIs can be administered daily in the morning. Evening dosing is possible if treatment does not disrupt sleep. SSRIs usually begin to be effective in two to four weeks. Up to 12 weeks may be required to determine whether the medication is effective for a specific patient. It can take up to 16 weeks to achieve significant clinical improvement. However, if a patient does not show any benefit by week eight, a different SSRI should be tried. Even when patients improve they frequently remain symptomatic. In that case, the clinician should assess the need to increase the dose if the patient tolerates it well. Most studies report additional benefit accruing over 6-12 months (Connolly et al, 2007). Thus, it is recommend continuing treatment at least for one year after achieving full remission. However, there is no specific evidence supporting this recommendation. Advantages of maintaining

pharmacotherapy include:

- Helping the child consolidate behavioral gains
- Increasing the synergistic effect of combination therapy (SSRI + CBT)
- Reducing the probability of relapse.

Deciding when to stop treatment may be difficult. It is not advisable to discontinue medication at the start of a new school year, while at camp, during final exams, or even during vacations. A discontinuation trial is advisable when the patient can be monitored closely and is in a stable environment at school and at home, that is, not in a novel situation. As with all medications, dose should be tapered progressively, avoiding abrupt discontinuation to prevent withdrawal effects. It is also important not to mistake withdrawal symptoms for a recurrence of the illness. If symptoms return, medication should be restarted back to the dose that resulted in remission.

Patients usually tolerate SSRIs well. Common side effects include: drowsiness, abdominal pain/discomfort, headaches, and feelings of restlessness. Apathy can be

Table F.2.4 Second line medications* for anxiety disorders in children and adolescents

Medication	Possible indication	Comments
SNRIs: (e.g., venlafaxine duloxetine)	• Refractory to SSRIs and CBT	• No compelling evidence of effectiveness in anxiety disorders • More side effects than SSRIs
TCAs: (e.g., imipramine, clomipramine)	• Refractory to SSRIs and CBT	• More side effects than SSRIs • Requires baseline and periodic ECG monitoring • Potentially lethal in overdose
Benzodiazepines: (e.g., clonazempam, clorazepate)	• Short term treatment of acute anxiety (rapid solution needed)	• Potential abuse and dependence • Risk of paradoxical reaction in children
Buspirone	• Refractory to SSRIs and CBT	• Effectiveness not demonstrated in children
Propranolol	• Intense autonomic response	• Should not be used by asthmatics or with antihypertensive agents
Clonidine	• Intense autonomic response • Comorbid PTSD or acute stress reactions	• More side effects than SSRIs • Potentially lethal in overdose • Requires baseline and periodic ECG and blood pressure monitoring
Antihistamines	• Insomnia	• Can provoke somnolence, increased appetite
Melatonin	• Insomnia	• Unknown long term side effects

*None of these medications are FDA approved for the treatment of anxiety disorders in children.

a late-onset side effect and it is less known because it is infrequent. Clinicians often misinterpret it as a symptom. Side effects, when present, are generally mild and usually dissipate after the first days or weeks of treatment. If these are marked or persistent the clinician should lower the dose. If they persist, the clinician should discontinue the medication and try another SSRI. There are anecdotal cases of new-onset easy bleeding or bruising. In most cases coagulation tests and bleeding times are either delayed or normal. Rarely, a patient may suffer a (hypo)manic switch or episode, characterized by changes in mood (elevated, euphoric or irritable) or behavior (grandiosity, fast speech, higher level of energy and activity), and possible psychotic symptoms (See Chapter E.2). Should this occur the medication must be discontinued and the clinician should assess a diagnosis of bipolar disorder. As is the case with depression, suicide risk should be monitored closely, particularly early during treatment. There is no need to routinely run laboratory testing or ECG at baseline or during follow-up, if the patient is asymptomatic.

Second line medications for SAD

Some patients do not tolerate SSRIs or do not show (sufficient) clinical response with them. In those cases, a clinician can indicate second line medications. These are listed in Table F.2.4.

SPECIFIC CROSS-CULTURAL SYNDROMES RELATED TO SEPARATION ANXIETY DISORDER

tokokyohi (school refusal) and ***futoko*** (school non-attendance)

Broadwin introduced the concept of "school refusal" in 1932, although he used the term "truancy". Until then, truancy referred to school non-attendance associated with antisocial behavior, Broadwin being the first to use the term to describe non-delinquent school absenteeism. In 1941 Johnson used the term "school phobia" to refer to long-term school absenteeism attributed to separation anxiety. Subsequently, experts described other causes for long term school absenteeism different from SAD. In 1948 Warren described this situation as "refusal to go to school"; since then, it was commonly designated "school refusal" (Hersov, 1960). In Japan, the concept of school phobia was introduced in the latter half of the 1950s. In the 1960s it was called "school refusal" (*toko kyohi* in Japanese). In the 1990s, experts used the term school non-attendance (*futoko* in Japanese). However both concepts are very similar and *toko kyohi* and *futoko* virtually describe the same symptoms, so we will use the term "school refusal" to refer to both, unless otherwise specified.

Berg (1980) defined "school refusal" as:

1. Severe difficulty attending school usually amounting to prolonged absenteeism.
2. Severe emotional distress when going to school, or anticipating the idea of going. Symptoms include excessive fearfulness, temper tantrums, feelings of misery, and physical complaints without an objective organic cause.
3. Staying at home in school hours, with parental knowledge.
4. Absence of significant anti-social behavior such as stealing, lying, running away, and destroying property.



Japanese school children with backpacks, Fukuoka, Japan

Photo: Blog of Andy HoboTraveler.com

Characteristics 2, 3 and 4 clearly distinguished the novel concept of "school refusal" from "truancy" and considered it a distinct disorder. Atkinson and Quarrington (1985) argued that School refusal should not be considered a mental disorder but a symptom or a socio-psychological phenomenon. Therefore they proposed that school refusal should be understood as *"long-term absenteeism characterized by the presence of fear, rejection, or anger vis-à-vis participation in school, combined with a strong sense of guilt concerning absenteeism itself, and concomitant conflict with life withdrawn into the home"* (Atkinson & Quarrington, 1985).

Unlike SAD, school refusal is not a DSM diagnosis. In the past school refusal was often used interchangeably with *school phobia*. We know now that not all children who refuse to go to school suffer from SAD. However, in young children the most frequent cause of school refusal is SAD, and should always be ruled-out. In 10 to 15 year olds, school refusal is generally due to generalized anxiety or social phobia (for a description of these disorders see Chapter F.1). In adolescents with school refusal an underlying panic disorder may be present, but also depression, obsessive-compulsive disorder, or somatoform disorder. Other reasons for adolescents refusing to go to school are violence in the home and excessive use of internet combined with social phobia / withdrawal (*hikikomori*). Unlike younger children, during early adolescence SAD is less often the cause

and school refusal often leads to long-term absenteeism. However, it is possible that school refusal is not accompanied by any psychiatric disorder; the etiology of school refusal can be very heterogeneous (Egger et al, 2003). Kearney and Albano (2004) conducted a study with 143 youth aged 5-17 with primary school refusal. Up to 22% had SAD, the most frequent psychiatric diagnosis, but 33% did not have any psychiatric diagnosis.

Recent reviews suggest a prevalence of school refusal between 1% and 5% in non-clinic referred and clinic-referred children, respectively. Peak onset occurs when at 5 to 6 and 10 to 11 years of age, coinciding with the transition to kindergarten and middle school respectively. Other high risk times for the onset of school refusal are moving to a different community or to a new school and after major social events or holidays.

Approximately 25% of cases of school refusal remit spontaneously or are successfully dealt with exclusively by parents. In adolescents, referral can be delayed because somatic complaints may not coincide exactly with separation situations (unlike in younger children), thus hindering diagnosis.

Longitudinal studies indicate that school refusal can lead to serious short-term problems such as academic decline, alienation from peers and family conflict (Kearney & Bensaheb, 2006) and long term consequences such as increased risk of psychiatric disorders and social and employment difficulties. Saito (2000) reported the results of a 10 year follow-up of 106 students who had been hospitalized for treatment of school refusal after graduating from a junior high school. By their mid-twenties, 73% were socially well adjusted while 27% were not. Further, half of the latter also showed social withdrawal (*hikikomori*).

KEY POINTS

- SAD is the most common childhood anxiety disorder, with a prevalence of around 5% in children, and it is associated with high levels of impairment.
- The key symptom of SAD is inappropriate distress or excessive and unrealistic fear upon separation from attachment figures or the home
- SAD is the most frequent cause of school refusal in young children, while generalized anxiety and social phobia are more often the cause in older youth
- Etiology of SAD includes biological and environmental factors
- Frequently children with SAD also suffer from other anxiety disorders or other psychiatric disorders such as depression or disruptive behavior disorders
- There are multiple, effective treatment options available.
- Psychoeducation and behavioral management should always be the starting point.
- CBT is the initial treatment of choice when children do not improve with psychoeducation and behavioral management
- Medication is indicated when CBT achieves no response or partial response, or when the child is significantly impaired. Medication and CBT should always be used in addition to psychoeducation and behavioral management
- The most effective treatment is the combination of CBT and medication
- Currently, no medication is approved by the FDA for children and adolescents with SAD (this may not be the case in other countries). However, clinicians often use SSRIs, which have been shown to effective and well tolerated
- If left untreated, SAD is associated with elevated risk for other internalizing disorders as well as impairments in educational attainment and social functioning.

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OBSESSIVE COMPULSIVE DISORDER IN CHILDREN AND ADOLESCENTS

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Suggested citation: Alvarenga PG, Mastrorosa RS , Rosário MC. Obsessive compulsive disorder in children and adolescents. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Obsessive-Compulsive Disorder (OCD) is a common neuropsychiatric disorder characterized by the presence of obsessions and/or compulsions that are time consuming and cause distress or interference in the patient's life (American Psychiatric Association, 2000). OCD affects all age groups independent of race, socioeconomic status or religion. Moreover, OCD has been estimated to cost approximately 8 billion dollars per year in the US (Hollander et al, 1998). Despite being frequent and disabling some studies suggest that almost 60% of OCD patients wait too long to seek treatment or do not receive treatment due to a lack of health professionals trained to identify OCD (Dell'Oso et al, 2007).

Pediatric OCD may resemble adult OCD but often presents particular clinical features. Recent studies support the idea that OCD is clinically and etiologically heterogeneous and that early-onset OCD may represent a unique subgroup (Miguel et al, 2005; Leckman et al, 2009). Furthermore, in 50% to 80% of OCD cases symptoms start before 18 years of age, which highlights the importance of understanding OCD as a developmental disorder (Kessler et al, 2005). The objective of this chapter is to present the more relevant issues on the evaluation and management of children and adolescents with OCD.



Jean Dominique Esquirol, a French psychiatrist, was the first to describe in 1838 a medical disorder quite similar to contemporary OCD

HISTORICAL OVERVIEW

Obsessive-compulsive symptoms have been identified since the 17th century. At that time, obsessions and compulsions were described as manifestations of religious melancholy and sufferers were considered to be "possessed" by outside forces. By the first half of the 19th century, OCD shifted into the scientific field. Jean Dominique Esquirol, a French psychiatrist, was the first to describe in 1838 a medical disorder quite similar to contemporary OCD and classified it as a "monomania" (a kind of partial delusion). At the end of the 19th century, OCD was classified as *neurasthenia*. As the 20th century began, both Sigmund Freud and Pierre Janet, a French psychologist, isolated OCD from neurasthenia. In 1903 Pierre Janet proposed that obsessional patients possessed an abnormal personality (called "psychastenia"), with features such as anxiety, excessive worrying and doubting, and described the successful treatment of compulsions and rituals with techniques that are similar to the ones used currently in behavioral therapy. Janet reported the case of a five-year old "psychastenic" boy with intrusive and repetitive thoughts. This is considered to be the first clinical description of pediatric OCD (for a review, see Alvarenga et al, 2007).

Currently, both the Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2000) and the International Classification of Diseases (ICD; World Health Organization, 1992) use the same diagnostic criteria for children, adolescents and adults, except that children are not required to have "insight". A revision of these classifications is taking place.

Impact of obsessive compulsive disorder

- OCD is a common neuropsychiatric disorder
- Causes substantial suffering and disability
- Costs approximately 8 billion dollars per year in the US
- Onset in 50% to 80% of cases is before 18 years of age
- Almost 60% of patients remain with symptoms.

EPIDEMIOLOGY

Lifetime prevalence of OCD is 1% to 3% making it one of the most prevalent neuropsychiatric disorders. OCD symptoms start before puberty in approximately one third to one-half of sufferers (Kessler et al, 2005). For instance, a study comprising 330 adult patients with OCD found that 49% presented their first symptoms before 11 years of age and 23% between 11 and 18 (de Mathis et al, 2009). In children and adolescents, OCD was considered to be rare until a study published in 1988 estimated a *one year* prevalence of 0.7% in the US (Flament et al, 1988). The more recent British child mental health survey reported a *point* prevalence of 0.25% among 5- to 15-year-olds; remarkably, most of the cases had never looked for treatment – similar to the results of adult epidemiological studies (Heyman et al, 2003).

The incidence of OCD has two peaks with different gender distributions; the first peak is in childhood, with symptoms mostly arising between 7 and 12 years of age and a male preponderance. The second peak occurs in early adulthood, at a mean age of 21 years and with a slight female majority (Geller et al, 1998).



The Oxford Don, Robert Burton, reported a case in his compendium, the Anatomy of Melancholy (1621): "If he be in a silent auditory, as at a sermon, he is afraid he shall speak aloud and unaware, something indecent, unfit to be said."

CLINICAL FEATURES

OCD is characterized by the presence of obsessions or compulsions that are time consuming (at least one hour per day), cause subjective distress or interfere with the patient's or the family's life. *Obsessions* are intrusive, unwanted ideas, images, fears, thoughts or worries that are experienced as uncomfortable, unpleasant, distressing or anxiety provoking. *Compulsions* are repetitive behaviors or mental acts performed to ignore, reduce or eliminate the anxiety or distress caused by the obsessive thoughts. Compulsions are usually executed according to certain rules the patient feels driven to follow (American Psychiatric Association, 2000). Obsessive compulsive symptoms vary considerably not only from patient to patient but also in the same patient over time. Despite this variation, some symptoms are more frequent than others and are described in Table F.3.1.

Even though there are many similarities in the clinical presentation across the lifespan, children and adolescents with OCD also show specific features. For instance, the younger the patient the higher is the probability of having compulsions without obsessions (Rosario-Campos et al, 2001). Children are also less likely to recognize their symptoms as ego dystonic, making them less willing to resist the urge to perform a compulsive behavior. Therefore, DSM-IV does not require children to have insight to qualify for the diagnosis. Children may also present *tic-like compulsions*, which may be confused with complex tics, mainly if the compulsions are simple rituals of touching (Rosario-Campos et al, 2005). In these cases, compulsions may be preceded or accompanied not only by obsessions but also by various types of sensory phenomena.

Sensory phenomena is a term used to define uncomfortable or disturbing sensations, perceptions, feelings or urges that either precede or accompany repetitive behaviors such as compulsions or tics. OCD patients might feel driven to repeat compulsions until they experience a sense of relief from these uncomfortable sensations. Sensory phenomena can be divided into physical and mental. Examples include sensations in the skin, "just-right" perceptions, and feelings of incompleteness (Rosario et al, 2008; 2009). For instance, people can "feel" an oily sensation on their hands and wash them repeatedly for this reason. Another person may feel "uncomfortable" with the way some objects are arranged on a shelf and may feel an urge to arrange them many times, until they look "just right". Evaluation of the presence and severity of sensory phenomena is relevant because some studies have reported that patients with early-onset and tic-related OCD show more sensory phenomena and some report that these sensory phenomena cause even more distress than the compulsions.

Age at onset

So far, there is no consensus on how best to define age of onset; some authors define it as the age when symptoms began (Rosário-Campos et al, 2001) while others define it as the age when symptoms started to interfere with normal functioning (Tükel et al, 2005). Also, there is no agreement about the best cut-off age for the early-onset subtype; cut-offs at age 10, 14 or 18 years have been proposed (Rosario-Campos et al, 2001). A study of comorbidity in 330 OCD patients shed some light on this question; the authors reported that including age at onset in the analyses as a continuous variable was most informative and that 10 and 17 years were appropriate cut-offs for early and late onset subgroups respectively (de Mathis et al, 2008).

Age at onset is important because there is emerging evidence that early-onset OCD may represent a distinct subtype of the disorder. Previous research has shown that adults who report an early onset display greater severity and persistence of symptoms and may be less responsive to treatment. Moreover, early-onset has been associated with fewer obsessions, more tic-like compulsions, more sensory phenomena, and a higher rate of comorbid tic disorders (Rosario-Campos et al, 2001; de Mathis et al, 2009).

Obsessive-compulsive symptom dimensions

Even though subdividing patients according to age of onset has proven to be useful in identifying more homogenous subgroups, a dimensional approach has proven to be of even greater value. Factor-analytic studies have reduced OCD symptoms to a few consistent and clinically meaningful dimensions: contamination/cleaning, obsessions/checking, symmetry/ordering, and hoarding (Mataix-Cols et al, 2005).

These symptom dimensions, which are similar in all age groups (Bloch et al, 2008), can be understood as overlapping clinical features that may be continuous with "normal" worries first evident in childhood (Leckman et al, 2009), are temporally stable, and correlate with various genetic, neuroimaging and treatment response variables (Mataix-Cols et al, 2005).

For instance, some studies have reported that early-onset OCD patients show higher severity in the following symptom dimensions: aggressive obsessions and related compulsions; sexual and religious obsessions and related compulsions; and symmetry, ordering and arranging obsessions and compulsions (Rosário-Campos et al, 2005; Leckman et al, 2009).

Comorbidity

Similar to adults with OCD, 60% to 80% of affected children and adolescents have one or more comorbid psychiatric disorders. Some of the most common are tic disorders, attention deficit hyperactivity disorder (ADHD), other anxiety disorders, mood and eating disorders (Geller, 2006).

The association between OCD and tic disorders is the most striking. OCD children have reported rates of tics ranging from 20% to 59%, compared to 9% and 6% in adolescents and adults, respectively. Similarly, 48% of early-onset adult OCD patients have tics or Tourette's syndrome, compared to 10% of those with a late-onset (Rosario-Campos et al, 2001). The impact of this association has led some to describe a "tic-related OCD" subgroup, characterized by a higher risk of transmission of both subclinical OCD and tics among first-degree relatives of OCD probands; higher male frequency; earlier age at onset; and a differential treatment response (Rosario et al, 2008).

Moreover, there is a group of disorders that seems to represent a clinical continuum (i.e., intrusive thoughts, anxiety and repetitive behaviors) and to share genetic and physiopathologic mechanisms with OCD. These disorders have been named obsessive-compulsive spectrum disorders and include OCD, body dysmorphic disorder, tic disorders, trichotillomania, and impulse control disorders (Bienvenu et al, 2012).

Course and outcome

The course of OCD is heterogeneous. The onset of symptoms can be abrupt or insidious, and content varies considerably from patient to patient. It is also frequent for symptoms to change over time, even though they often maintain a certain thematic consistency (Miguel et al, 2005).

Table F.3.1 Common obsessions and compulsions

OBSESSIONS	COMPUSIONS OR RITUALS
Injury, violence, aggression or natural disaster: • Recurrent, anxious thoughts or images that they may hurt themselves or other people (for example, when in contact with sharp objects or next to a window) • Fear of obeying aggressive impulses • Fear of not performing certain rituals (usually checking or avoidance) and as a consequence something bad may befall to people who are dear and the consequent responsibility for that.	Checking or avoidancedue to Injury, violence, aggression or natural d isaster obsessions: • Repeatedly checking doors, locks, stove, windows • Checking whether they injured themselves or other people • Verifying whether something bad did happen • Checking or taking other measures to prevent or avoid harm coming to them or others • Need to repeat routine activities to prevent bad consequences.
Sexual and Religious: • “Forbidden” or “improper” sexual thoughts, images, or impulses • Extreme concern about sinning or doing something morally wrong, saying or doing something religiously not acceptable	Checking or avoidance due to sexual, religious, or morality obsessions: • Making sure that they have not done anything wrong of a sexual/ religious nature • Avoiding certain actions, people, places or objects to prevent sexual or religious obsessions and compulsions from occurring • Need to repeat activities to prevent bad consequences • Need to generate "good" thoughts to compensate for or override "bad" thoughts • Silently counting, repeating phrases or praying
Worries or preoccupations or a need for symmetry, order and arranging: • Need for things to be symmetrical or balanced • Need for things to be perfect, exact or “just-right”	Repetition, order, arranging • Arranging objects many times until they are symmetrically aligned or matched • Counting objects like ceiling or floor tiles, books in a bookcase, nails in a wall, or even grains of sand on the beach • Straightening paper and pens on a desktop or books in a bookcase • Touching or doing something on the right side followed by the compulsion to touch or do the same thing on the left side
Contamination; obsessed about getting ill or injured as a result of: • Dirt or germs • Bodily waste or fluids (like vomit, urine, feces or saliva) • Environmental contaminants (like asbestos, radiation, or toxic waste) • Insects or animals • Sticky substances or residues • Household items or other inanimate objects	Checking, avoidance or repetition, excessive or ritualized: • Cleaning or washing of body parts or objects • Showers, baths, and other bathroom routines, which need to be done in a certain order • Excessive use of toilet tissue • Compulsion to perform the whole process again if the sequence of washing or cleaning is interrupted • Avoidance of touching objects, animals or people because they may be dirty or contaminated
Collecting and hoarding: • Fear of getting rid of unimportant objects believing they will be needed in the future • Inability to decide throwing things away	Hoarding or collecting: • Rooms filled with old newspapers, notes, cans, paper towels, wrappers or empty bottles • Picking up objects or trash from the street or from garbage cans.

Similar to what happens in adults, a long time may elapse until the diagnosis is made and treatment started. Studies have reported an average of 2.5 years from the onset of symptoms to diagnosis in the US (Geller et al, 2006) and even longer in Germany (Walitza et al, 2011). One of the reasons for this delay is secrecy. Patients often feel ashamed or guilty about their symptoms or behaviors and conceal them until they interfere with their daily functioning. Mild or moderate cases may only be diagnosed through indirect signs like an increase in the time needed to complete school tasks, isolation, or severely chapped skin as a result of washing compulsions (Rosario et al, 2008). In other cases, symptoms may resemble normal childhood routines. In fact, some repetitive behaviors may be normal in some developmental stages. Young children engage in a significant amount of ritualistic, repetitive, and compulsive-like activities that appear to be part of their normal behavioral repertoire; they often have a rigid routine at bedtime, mealtimes and at school. Various aspects of children's ritualistic and compulsive-like behaviors have been associated with children's fears and phobias. Therefore, OCD could be conceptualized as a pathological condition with continuity with normal behaviors during different developmental periods (Evans et al, 2002).

A 9-year longitudinal study assessing 145 children and adolescents with OCD revealed that the most common diagnoses at follow-up were generalized anxiety disorder (25%), followed by depressive disorders (16%) and a tic disorders (16%). Approximately two-thirds rated themselves as very much or much improved in relation to their OCD. Almost half (49%) of the participants reported that they needed further treatment. The largest predictor of persistence of OCD at follow-up in this sample was duration of the illness. Severity at baseline did not predict persistence. The impact of OCD on functional impairment and quality of life was mild to moderate (Micali et al, 2010). These findings suggest that pediatric OCD is a chronic or relapsing/remitting disorder that has long-term treatment implications. Other studies have shown that some children become subclinical over time (Stewart et al, 2004) and that children have a very favorable outcome when treated early (AACAP, 2012).



Click on the picture to view a general description of CBT (06:07)

Clinical assessment

Considering the secrecy surrounding OCD symptoms, it is important for family members to pay attention to early signs of ritualistic behaviors becoming troublesome. Table F.3.2 lists some questions that may help screening for OCD.

Table F.3.2 Screening questions to help in the identification of obsessive compulsive symptoms

Has your child ever shown:
• Concerns about catching a disease after touching something or unduly worrying about dirt, leading to repetitive hand washing?
• A preoccupation with ordering or arranging things so much so that it interferes with normal life of schooling?
• A need for things to look, feel or sound “just right”?
• Excessive worries, fears or concerns with aggressive, sexual or religious thoughts?
• An excessive need to collect or hoard objects?

Table F.3.3 Scales used in the evaluation of OCD patients

	CY-BOCS	DYBOCS	YGTSS	USP-SPS	FAS
Author (Year)	Scahill et al (1997)	Rosario-Campos et al (2006)	Leckman et al (1989)	Rosario et al (2008)	Calvocoressi et al (1999)
Aims	Assess presence and severity of obsessions and compulsions	Assess presence and severity of OCD symptom dimensions	Assess presence and severity of tics	Assess presence and severity of sensory phenomena	Assess levels of family accommodation
Administration time	15 minutes (excluding time to go over symptom checklist)	10 minutes for each dimension or 15 minutes for overall severity (excluding time to go over symptom checklist)	20 minutes (excluding time to go over symptom checklist)	20 minutes (excluding time to go over symptom checklist)	20 minutes (excluding time to go over symptom checklist)
Self-report	No	No	No	No	No
Valid and reliable	Yes	Yes	Yes	Yes	Yes
Clinically useful	Yes	Yes	Yes	Yes	Yes
Useful for research	Yes	Yes	Yes	Yes	Yes
Available in languages other than English	Yes	Yes	Yes	Yes	Yes

CYBOCS: Children´s Yale-Brown Obsessive-Compulsive Scale; DYBOCS: Dimensional Yale-Brown Obsessive-Compulsive Scale; USP-SPS: University of São Paulo Sensory Phenomena Scale; YGTSS: Yale Global Tic Severity Scale; FAS: Family Accommodation Scale.

When OCD is suspected, a comprehensive clinical evaluation – including detailed interviews with parents and, if possible teachers – is required in order to assess the compulsions, obsessions and sensory phenomena. In younger children, OCD features might appear subtly during play activities or drawing. It is vital to differentiate between obsessive compulsive symptoms and normal childhood ritualistic behavior, typical of specific developmental phases, such as mealtime or bedtime rituals. In this regard, detailed information about degree of distress, impairment and time consumed performing rituals should provide enough data to decide whether or not treatment is warranted. Moreover, it is also important to assess insight and the family's perception of the symptoms, as well as how family members deal with the patient.

Rating scales are useful to obtain detailed information regarding OCD symptoms, tics, and other aspects relevant to the diagnosis. Scales are also used to assess severity at baseline and to evaluate improvement in a more objective way during follow up treatment. Some of these instruments are listed on Table F.3.3, which are in the public domain and can be obtained from the authors upon request.

ETIOLOGICAL FACTORS

Factors that increase the risk of OCD are summarized in Table F.3.4 .

Genetic

Contrary to what was believed for many years – that OCD was essentially an environmentally caused illness – twin, family, segregation and linkage studies have shown that OCD runs in families and this is largely accounted for by genetic factors, with heritability in the range of 45% to 65% (van Grootheest et al, 2005). Genetic-family studies have shown that the earlier the onset of OCD symptoms in the probands the higher the risk for first-degree family members to have obsessive compulsive symptoms, OCD, tics or Tourette's disorder (Rosario-Campos et al, 2005). Conversely, twin studies have shown that concordance rates for monozygotic twins are significantly higher than for dizygotic twins. Considering that concordance rates are not 100%, genetic studies also demonstrate that non-genetic factors are also important in the etiology of OCD.

Genetic linkage studies have identified regions of the genome likely to contain susceptibility loci for OCD on chromosomes 1q, 3q, 6q, 7p, 9p, 10p, and 15q. Many candidate gene studies have been conducted, mostly focusing on serotonergic, glutamatergic and dopaminergic genes although without conclusive findings so far. Among all the polymorphisms that have been studied, some relevant findings involve glutamatergic expression and have been correlated with repetitive behaviors in humans and rodents (Miguel et al, 20005; AACAP, 2012).

Non-genetic

In predisposed subjects, environmental factors, such as emotional stress and traumatic brain injury may trigger OCD. Excessive weight gain during gestation; prolonged labor; preterm birth; and jaundice have been associated with the expression of OCD later in life (Vasconcelos et al, 2007).

Family accommodation

- Parents (and other relatives) facilitate or participate in children obsessive-compulsive symptoms
- Family accommodation reinforces symptoms and is associated with poor outcome
- Examples of family accommodation include among others parents answering doubting questions repetitively; not interrupting or limiting time-consuming washing tasks; helping children in ordering or hoarding rituals.

Table F.3.4 Factors that increase the risk of OCD

Genetic	• Family members with obsessive compulsive symptoms, OCD or tics • Promising candidate genes: SLC1A1 and SAPAP
Family	• Family history of OCD or OCD spectrum disorders (e.g., tic disorders, tricotillomania, body dysmorphic disorder) • High familial accommodation to obsessive-compulsive symptoms
Individual	• Presence of obsessive-compulsive symptoms and subclinical OCD • Neuropsychological abnormalities (global cognitive deficits, mental inflexibility, visual spatial deficits, impaired motor skills) • Comorbid psychiatric disorders (e.g., Tourette's syndrome)
Environmental	• Prenatal, perinatal and postnatal factors, e.g., excessive weight gain during gestation; prolonged labor; preterm birth; jaundice emotional stress, traumatic brain injury, exposure to substances (alcohol, cocaine, stimulants, and hormones) in early pregnancy • Streptococcal infections and rheumatic fever

Group A β-hemolytic streptococcal (GABHS) infection

The association between GABHS infection and rheumatic fever (a systemic autoimmune disease triggered by GABHS infection) and the onset or worsening of OCD or tics has received considerable attention during the last two decades. It is hypothesized that a GABHS infection in a susceptible host initiates the production of autoantibodies that cross-react with the cellular components of the basal ganglia (Mercadante et al, 2005). This hypothesis, which applies only to a small proportion of children who develop OCD, is supported by neuroimaging and immunological findings. OCD and other neuropsychiatric disorders are more common than expected in first degree relatives of rheumatic fever probands (Hounie et al, 2007).



Freud believed that OCD was the patient's maladaptive response to conflicts between unacceptable, unconscious sexual or aggressive id impulses and the demands of conscience and reality, regressing to concerns about control and to modes of thinking characteristic of the anal-sadistic stage of psychosexual development: ambivalence, which produced doubting, magical thinking, and superstitious compulsive acts.

Familial factors

Another important non genetic factor is the family. Younger children are more prone to involve relatives in their rituals, leading to higher levels of family accommodation. While some try to stop the child from performing the rituals, others "accommodate" or even reinforce the symptoms (Amir et al, 2000; McKay et al, 2006).

Neurobiological substrates

It has been hypothesized that there is a dysregulation of fronto-cortico-striato-thalamic circuits in OCD patients. Functional neuroimaging studies have shown that the orbitofrontal cortex, anterior cingulate and striatum are hyper activated in OCD patients and that this activation decreases after treatment (Friedlander et al, 2006**;** Rotge et al, 2008).

Neuropsychological tests have found deficits in mental flexibility and motor skills, visuospatial abilities, and some forms of executive functioning in individuals with obsessive compulsive symptoms and OCD (Mataix-Cols et al, 2008). Some of these deficits have also been found in first-degree relatives of OCD patients (Chamberlain et al, 2005). It has been suggested that some neuropsychological changes observed in childhood, such as deficits in visuospatial abilities, may be an early indication of risk for the development of OCD in adulthood (Grisham et al, 2009).

The serotonergic system seems to be involved in the pathophysiology of OCD – many trials have demonstrated a decrease in symptoms with the use of serotonergic drugs (Bloch et al, 2006). Peripheral serotonergic alterations are frequently observed in adolescents and adults with OCD (Delorme et al, 2005). Beyond the monoamine systems, some researchers suggest that oxytocin may also play a role (Leckman & Herman, 2002).

TREATMENT

Before starting treatment it is extremely important to take into consideration some relevant issues such as the correct identification of the most troublesome OCD symptoms, how long the patient has had the illness, impact on the patient's life and difficulties working with the family (Table F.3.5). A thorough assessment, involving both the patient, family members and school, is extremely important. Another important issue is an accurate assessment of comorbid conditions that usually accompany OCD. Comorbid conditions, if not evaluated or detected, can complicate treatment (Rosario et al, 2008).

Similar to the treatment recommendations for adults, treatment of OCD in children and adolescents relies on cognitive behavioral therapy (CBT), medication and psychoeducation. Both selective serotonin reuptake inhibitors (SSRIs) and CBT have been systematically studied and empirically shown to be useful in the treatment of children and adolescents with OCD.

OCD treatment guidelines

NICE: Obsessive compulsive disorder (OCD) and body dysmorphic disorder (BDD) (CG31) (November 2005)

AACAP: Practice parameter for the assessment and treatment of children and adolescents with obsessive compulsive disorder (January 2012)

Table F.3.5 Issues that need to be clarified during assessment and before treatment

Age of onset	• Age when symptoms were first noticed by the patient or family
Degree of suffering, impairment and time consumed performing rituals	• Important to distinguish OCD from transient obsessive or compulsive behaviors seen in the course of normal development. • Rating scales might aid in this task.
Insight	• Poor insight is common in pediatric patients
Presence of sensory phenomena	• Mental or physical premonitory urges often occur instead of obsessions.
Family attitude towards the illness	• Excessive criticism or high levels of accommodation of symptoms are associated with poorer outcome
Are there comorbid disorders?	• Evaluate for the presence of comorbid conditions (e.g., anxiety disorders, mood disorders, tic disorders, ADHD, alcohol and other substance use disorders).
History of psychiatric disorder in the family	• Are family members affected with OCD or other psychiatric disorders?

CBT manuals and self-help books available for therapists and families interested in these techniques (AACAP, 2012):

- *Talking Back to OCD: The Program that Helps Kids and Teens Say "No Way" and Parents Say "Way to Go"* by John March
- *Obsessive Compulsive Disorders: A Complete Guide to Getting Well and Staying Well* by Fred Penzell
- *Freeing Your Child from Obsessive Compulsive Disorder* by Tamar Chansky
- *What to do When your Child has Obsessive Compulsive Disorder: Strategies and Solutions*, by Aureen Pinto Wagner

Non-pharmacological treatment

CBT is the only psychological therapy shown to be effective in the treatment of childhood OCD (Rosario et al, 2008). Treatment of pediatric OCD should preferably start with CBT for mild to moderate cases, or a combination of CBT and pharmacotherapy for more severe cases, or when CBT is not available (Abramowitz et al, 2005; O´Connor et al, 2006; Walsh & McDougle, 2011).

The CBT theory of OCD integrates behavioral theory with a cognitive framework and has shown significant efficacy especially when in combination with exposure, response prevention, and cognitive restructuring. A meta-analysis has shown mean effect sizes of CBT up to 1.45 (confidence interval 0.68-2.22) despite the heterogeneity of the sample (Watson & Rees, 2008). Cognitive restructuring helps patients realize the influence of thoughts and beliefs on behavior (rituals and avoidance), the functional relationship between obsessions and rituals, and strategies to neutralize them while causing relief. The behavioral model uses exposure and response prevention techniques based on the relationship between obsessions and compulsions, with the purpose of weakening the association and the distress caused by them. It exposes the sufferers to the objects, people or situations they fear, and prevents them from performing the compulsion, in order to gradually reduce the anxiety level (Abramowitz et al, 2005). Cognitive and behavioral techniques complement each other and the power of one lies in its correct combination with the other (Barret et al, 2008; Williams et al, 2010).

Practical aspects in delivering CBT

Most CBT treatment manuals for OCD recommend twelve to twenty-five sessions. The manuals usually suggest that therapists use the first one or two sessions to collect detailed information about the patient's symptoms, how the patient and the family deal with them, family environment, school performance and other relevant issues on the patient's functioning. As much *psychoeducation* as possible is also to be provided; this will involve detailed information about all



Click on the picture to view a description of the UCLA OCD program (03:50)

aspects of the illness, including possible clinical symptoms, impact of comorbidity, treatment options, duration of illness and duration of treatment, the risks of family accommodation and how best to deal with a family member with OCD. Usually, a 50 minute CBT session includes a review of the goals, review of the previous week, provision of new information, therapist-assisted practice, homework for the coming week, and monitoring (Steketee, 1999).

The success of CBT depends on understanding the illness, the basis for the therapeutic activities and the cognitive processes implicated in the maintenance of the disorder. Clinical trials have shown that CBT has better outcomes when the people closest to the patient (parents, family members and teachers) are involved in treatment (Piacentini & Langley, 2004; Freeman et al, 2008). Family members may respond to the patient's symptoms by facilitating avoidance, assisting on ritualistic behaviors, or inadvertently participating in rituals (Calvocoressi et al, 1999; Barret et al, 2004; Freeman et al, 2008) described by some as *family accommodation* (Calvocoressi et al, 1999). High levels of family accommodation have been associated with symptom maintenance and poor outcome (Calvocoressi et al, 1999; Amir et al, 2000). Thus, parents must be included in the treatment (Freeman et al, 2008); in fact, parents often become co-therapists and administer treatment at home.

Pharmacological treatment

For greatest efficacy, the combination of CBT with medication has been suggested as the treatment of choice for moderate and severe OCD (AACAP, 2012). The Pediatric OCD Treatment Study (POTS), a 5-year, 3-site outcome study designed to compare placebo, sertraline, CBT, and combined CBT with sertraline, concluded that the combined treatment (CBT+sertraline) was more effective than CBT or sertraline alone. The effect sizes for the combined treatment, CBT alone and sertraline alone were 1.4, 0.97and 0.67, respectively (Pediatric OCD Treatment Study, 2004). Remission rates for SSRIs alone are less than one third (Pediatric OCD Treatment Study, 2004; Franklin et al, 2011).

Selective serotonin reuptake inhibitors (SSRIs) are the first-line medication for OCD in children, adolescents and adults (AACAP, 2012). *Clomipramine*, a serotoninergic tricyclic agent, was the first medication proven to be effective in the treatment of OCD. Despite its efficacy (effect size: 0.85, confidence interval 0.32–1.39) (Watson & Rees, 2008), side effects – gastrointestinal, autonomic,

Table F.3.6 Medications effective for the treatment of pediatric obsessive-compulsive disorder (adapted from Rosario et al, 2008).

Medication	FDA approved for OCD in children	Minimum age (FDA)	Starting dose (mg/day)	Maximum dose (mg/day)
Clomipramine	Yes	5	12.5 to 25	300
Fluoxetine	Yes	8	2,5 to10	80
Sertraline	Yes	6	12,5 to 25	200
Fluvoxamine	Yes	8	12,5 to 50	300
Paroxetine	Yes	8	2,5 to 10	60
Citalopram	No	N/A	2,5 to 10	60
Escitalopram	No	N/A	2,5 to10	30

N/A: not applicable.

hepatic and, particularly, cardiac conduction problems – limit the clinical use of clomipramine, especially in children and adolescents. For instance, prescribing clomipramine requires electrocardiographic evaluation at baseline and follow up (Mancuso et al, 2010; AACAP, 2012).

Well-designed clinical trials have demonstrated the efficacy and safety of the SSRIs fluoxetine, sertraline and fluvoxamine (alone or combined with CBT) in children and adolescents with OCD. Other SSRIs such as paroxetine, citalopram and escitalopram have also demonstrated efficacy in children and adolescents with OCD, even though the FDA has not yet approved pediatric use (Rosario et al, 2008; AACAP, 2012). A meta-analysis of all published randomized controlled trials in children and adolescents with OCD found an effect size of 0.46 (95% CI 0.37– 0.55) and showed a statistically significant difference between drug and placebo (Geller et al, 2003).

Treatment should start with a low dose to reduce the risk of adverse effects. An adequate trial should use the medication for at 10 to 16 weeks at adequate doses (Table F.3.6). The optimal duration of treatment for children with OCD is unknown. Most experts suggest that treatment should continue for at least 12 months after symptom resolution or stabilization, followed by a very gradual cessation (Rosario et al, 2008; Mancuso et al, 2010).

Non-responders

Despite the effectiveness of SSRIs, about half of the patients do not respond or have significant residual symptoms, even with adequate duration of treatment and maximum recommended or tolerated dosages. For these patients, some strategies have been suggested and are described below. Unfortunately, there are no systematic studies that compare switching medications with adding an augmenting agent to the initial medication (AACAP, 2012).



Click on the picture to hear Eli R Lebowitz PhD talk about "creating effective exposures" in the treatment of childhood anxiety disorders (14:21)

- The first strategy is to *change to another SSRI*.
- In adults with partial response to SSRI, *antipsychotics* (Bloch et al, 2006) and *clomipramine* (Figueroa et al, 1998) have been used as augmentation agents. Further investigation of these pharmacological interventions in children is necessary. Antipsychotics may be indicated in the presence of tic disorders or poor insight (Bloch et al, 2006). Clinical trials suggest that haloperidol (Mancuso et al, 2010), risperidone (Thomsen, 2004) and quetiapine (Cohen et al, 2003) can be effective. Olanzapine should be avoided in children due to limited safety and the risk for metabolic syndrome (Rosario et al, 2008). Concerns about neuroleptic augmentation include potential side effects such as sedation, dysphoria, weight gain, and extrapyramidal symptoms. Novel augmentation clinical trials have been reported for stimulants, gabapentin, sumatriptan, pindolol, inositol, opiates, St. John's wort, *N*-acetyl cysteine, memantine and riluzole, but further evidence is required before recommending their routine use (AACAP, 2012).
- Another strategy is to ascertain the presence of *comorbid disorders* (such as ADHD, tics, depression or conduct disorder). The presence of comorbid disorders has been associated with more severe symptoms and higher parental stress, and may have a worse response to treatment (Grados et al, 2008; Storch et al, 2008). In the presence of such conditions clinicians should consider treating them in parallel (AACAP, 2012)
- *Combining medication with CBT* should always be considered. Franklin et al (2011) investigated whether CBT would augment antidepressant treatment in children who had responded only partially to medication. The study involved 124 participants with OCD aged 7 to 17 years randomized to medication alone

The mother brought J, 9 years of age, because his teacher was concerned about his spending too much time doing exercises due to his concern that they had to be perfect. Also, J was leaving the classroom to wash his hands very often. His mother had also noticed the same at home.

J's was born after a lengthy delivery and showed moderated jaundice. J's father had been diagnosed with Tourette's syndrome during childhood, but had been free from symptoms for many years.

During the assessment interview J said he felt "itching" in his hands, which forced him to wash them repeatedly. He also said it took him a long time to do his homework because he needed to write and re-write everything until he felt that his handwriting was just right. J did not complain about his symptoms and did not avoid washing his hands although he spent about 2 hours a day doing it. He did not describe obsessive thoughts. When asked why he had to wash his hands or re-write things he said that he just had to do it. J does not have tics, in the past or currently.

Scores on the CYBOCS were 17 (zero for obsessions; 17 for compulsions). On the DYBOCS symptom dimensions, scores were zero for aggression, zero for sexual/religion, zero for hoarding, 12 for symmetry/ordering and 10 for contamination/cleaning. The total severity score was 12 and impairment 10, with a global DYBOCS severity score of 22 (moderate).

J and his family were referred to a twice a week CBT program, with sessions lasting 60 minutes. The therapist noticed that parents were extremely worried about J's future and whether or not he would succeed in school. After 12 sessions (six weeks) J showed some improvement in symptoms but parents remained very anxious. For instance, even though J was spending less time doing his homework, his mother decided to help him daily and was practically doing the homework for him. The therapist decided to continue with CBT but only once a week and parents started to participate in the sessions. After 16 weeks (22 sessions), the CYBOCS score had decreased to 8 and the global DYBOCS score to 11, which meant symptoms remission. Parents were also confident on J's school abilities.

Comment

This vignette illustrates a patient with OCD of moderate severity in symmetry/ordering and washing/contamination symptom dimensions. Symptoms were time consuming and compromised school performance. J had little insight about his symptoms. Even though J did not report obsessions, he showed sensory phenomena, both physical ("itching") and mental (perfectionism and "just right" feelings). Family history of Tourette's syndrome, birth trauma and jaundice increased vulnerability to OCD. Parents were very anxious and had a high score on the family accommodation scale.

Considering that symptoms were moderate and there were no comorbid disorders, the initial treatment recommendation was CBT. Fortunately, J. had access to professionals trained in CBT and the family agreed to this plan of action. Because OCD waxes and wanes and is potentially chronic, less intense maintenance CBT is advisable.

(SSRI), *medication plus conventional CBT* (apart from medication management visits a CBT protocol was administered by a psychologist consisting of 14 one-hour sessions over 12 weeks involving psychoeducation, cognitive training, hierarchies of feared situations from least to most anxiety provoking to guide exposure treatment, exposure and response prevention) or *medication plus instruction in CBT* (a pharmacotherapist assigned to manage medication also provided instruction in CBT procedures that were administered according to protocol – 7 sessions over 12 weeks – with an average duration of 45 minutes; instructions included psychoeducation, establishing a simple symptom severity hierarchy, exposure and response prevention targets, and assigning homework). Two brief telephone check-ins were also conducted to provide guidance about CBT implementation at home. After 12 weeks of treatment 68.6% in the *medication plus conventional CBT* group were considered responders compared with 34.0% in the *medication plus instruction in CBT* group, and 30.0% in the medication alone group. That is, 14 CBT sessions delivered by a trained expert added to medication doubled the response rate while a less intense CBT treatment by a non-expert did not increased effectiveness over medication alone (Pediatric OCD Treatment Study, 2004; Franklin et al, 2011)

Beyond the search for new treatment strategies, identification of people *at-risk* of developing OCD is required in order to develop preventive strategies. Several genetic, familial, individual and environmental risk factors have been described (Table F.3.4). Apart from general measures to enhance mental health, currently there are no prevention programs of demonstrated effectiveness.

Table F.3.7 Summary of recommendations for the treatment of OCD

TYPE	RECOMMENDED TREATMENT
Mild (CYBOCS score: 16-19*)	• CBT alone (single or group, minimum 10 sessions)
Moderate (CYBOCS score: 20-29*)	• CBT alone or combined with an SSRI (minimum 10-week trial)
Severe (CYBOCS score: 30-40*)	• CBT+SSRI (minimum 10-week trial)
Remission (CYBOCS total score less than 10)	• Maintenance CBT (booster sessions for a minimum of 12 months) • Maintenance of SSRI at an optimal dose for a minimum of 12 months
Partial response (35% to 50% decrease in CYBOCS score after achieving the optimal tolerated dose of SSRI for a minimum of 10 weeks)	• Switch to another SSRI • Augment with CBT (if not administered already) • Augment with atypical antipsychotic (E.g. risperidone, quetiapine, aripiprazole or haloperidol) • Augment with clomipramine (ECG monitoring)
Non-response (less than 35% symptom remission)	• Review diagnosis, comorbidities, compliance and family accommodation • Switch to another SSRI • Augment with CBT (if not administered already) • Augment with atypical antipsychotic (e.g., risperidone, quetiapine, aripiprazole or haloperidol) • Augment with clomipramine (ECG monitoring) • Treat comorbid disorders concurrently

* March & Mulle (1998) severity criteria. CBT: cognitive behavior treatment provided by a competent clinician trained in this form of treatment in sessions lasting at least 60 minutes; CYBOCS: Children's Yale-Brown Obsessive Compulsive Scale scores, SSRI: selective serotonin reuptake inhibitor.

SUPPORT GROUPS AND ASSOCIATIONS

When people are told they have a family member with OCD, they usually benefit from support groups to deal with it, particularly when the sufferer is a child or adolescent. Participating in a support group is helpful in handling the stress of raising a child with OCD. Support groups, that often have mental health professionals as advisers, meet regularly and seek to educate about the disorder, help people to recognize symptoms, reduce family accommodation, and find the right treatment. Getting together with people who face the same problems gives an opportunity to exchange experiences, discuss how others handle the symptoms and learn more about the disorder. Support groups can also be helpful for the patients, although less so in the case of children. A list of patient and family associations in several countries can be found at http://www.geonius.com/ocd/organizations.html

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IACAPAP Textbook of Child and Adolescent Mental Health

Section G

SUBSTANCE USE DISORDERS



Photo: kallerna , Wikimedia Commons

ALCOHOL MISUSE

Joseph M Rey



The Triumph of Bacchus or *The Drunks* (c.1629). Diego Velázquez, *Museo del Prado*, Madrid.

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Conflict of interest: none reported.

Acknowledgements: Drs Jennifer Bergen and Yvonne Bonomo (Australia) commented on earlier drafts.

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Suggested citation: Rey JM. Alcohol misuse. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Ethanol (ethyl alcohol), a natural product of the fermentation of foodstuffs rich in carbohydrates, has been part of human culture from the dawn of civilization, prized for its relaxing properties and facilitation of social intercourse; it may have also had survival value. Alcoholic beverages are legally available in most countries (exceptions are: Afghanistan, Brunei, Iran, Kuwait, Libya, Saudi Arabia, Sudan and Yemen). The majority of people use alcohol in a responsible manner most of the time. Yet, excessive consumption has large damaging social and health consequences. This chapter deals with the harmful effects of ethanol consumption in young people, henceforth referred to as *alcohol*. The terms *alcohol use disorder* (AUD), *alcohol dependence*, and *alcoholism* will be used interchangeably.

Alcoholic beverages can be classified as *fermented* and *distilled*. Fermented beverages are the product of fermentation of sugary foods. For example, beers are made from cereals, wines from grape juice and sake from rice; there are many other fermented beverages around the world from other foodstuffs. Distilled drinks (*spirits*) are produced by concentrating the ethanol in fermented products. For example, whiskeys are distilled from fermented cereals, brandies from fruit juices and rum from molasses. Vodka can be distilled from any fermented food – mostly grain or potatoes. Vodka and similar spirits are distilled so thoroughly that no taste from their particular starting foodstuff remains (Wikipedia).

The ethanol content of a drink is typically measured as millilitres of alcohol per 100 millilitres of the beverage expressed as a per cent – alcohol by volume (ABV). For example, a beer with 6% alcohol contains 6mL of alcohol per 100mL. Fermented beverages have a maximum of 18%; the alcohol content of spirits is much higher (e.g., 40%-50% for whiskey and vodka).

"A secure supply of alcohol appears to have been part of the human community's basic requirements much earlier than was long believed. As early as around 9,000 years ago, long before the invention of the wheel, inhabitants of the Neolithic village of Jiahu in China were brewing a type of mead with an alcohol content of 10%" (Thadeusz, 2009).

BURDEN OF ALCOHOL USE

Worldwide, alcohol is one of the main risk factors for incident disability-adjusted life-years (DALYs) in 10–24-year-olds, representing 7% of all DALYs (compared with 4% for unsafe sex, 3% for iron deficiency and 2% for illicit drug use) (Gore et al, 2011). Overall, about 4% of deaths worldwide are attributable to alcohol. Males (with a 6% mortality rate attributable to alcohol), poorer people and lower-income countries suffer a relatively greater burden than wealthier ones. Impact, in particular fatal injuries, is greater in the young of both sexes.

Per head consumption

Alcohol consumption and problems related to alcohol vary widely around the globe. Worldwide consumption in 2005 was equal to 6 L of pure alcohol per person aged 15 years or older. A large portion of this consumption – 29% (approximately 2 L per person) – was homemade, illegally produced or sold outside normal government controls. Eastern European countries have the highest consumption, riskiest patterns of drinking, and alcohol-related deaths and disabilities. One in every five deaths is due to harmful drinking in the Commonwealth of Independent States (CIS) (Azerbaijan, Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Turkmenistan, Uzbekistan and Ukraine). About 12% of drinkers show heavy episodic drinking. The proportion of people drinking alcohol to intoxication is lowest in western European countries and highest in CIS countries. Outside the CIS, risky patterns of drinking and rates of disease and disability attributable to alcohol are also high in Mexico and in most South American countries. Abstention rates are low in high-income, high consumption countries (e.g., Europe, North America), and high in North African and South Asian countries with large Muslim population, female abstention rates being very high in these regions (WHO, 2011). Click on the picture to access the WHO's *Global Status Report on Alcohol and Health 2011*.

"Across England, half a million children between the ages of 11 and 15 will have been drunk in the past four weeks, and young people under 18 will have consumed the equivalent of 2 million bottles of wine in the past week alone […] since 1990 the amount of alcohol consumed by 11 to 15 year olds who drink has doubled" (Donaldson, 2009). Click on the figure to access this document.



Alcohol is a causal factor in 60 types of diseases and injuries and a component cause in 200 others (WHO, 2011), including:

- Accidents, injuries and harm to both drinkers and the people around them (family, friends, bystanders)
- Reduced school, college and work performance, absenteeism
- Family disharmony, violence, abuse
- Suicide, homicide, crime
- Injury and death from motor vehicle and work accidents
- Risky sexual behaviour, sexually transmitted diseases, HIV infection
- Teratogenesis, with a range of negative outcomes to the foetus including low birth weight, cognitive deficits, and foetal alcohol spectrum disorders
- Neurotoxicity and inhibition of brain maturation, especially frontal lobe development
- Acquired brain damage in later years
- Cancer (oesophagus, liver, bowel, breast etc.) and other diseases (e.g., cirrhosis of the liver).

Alcohol-attributable costs amount to more than 1% of GDP in most nations, the United States of America (US) having the largest (2.7%) of the high-income countries and South Korea the highest (3.3%) among middle-income nations. The total annual cost of alcohol use to the US economy was estimated in 1998 to be $184 billion, and £20 billion in the United Kingdom (UK) in 2001 (Saunders et al. 2011).

Wet and _dry_ patterns of drinking

A *wet* pattern of drinking is characterised by frequent consumption of small amounts of alcohol, mostly wine, at meal times or family celebrations; it is common in Southern European countries.

A *dry* pattern is typified by irregular heavy drinking, often to intoxication, at less family-oriented social events. This pattern is more common in Central and Northern European countries.

There is an overlap between wet and wine-drinking countries, dry and beer- and spirit-drinking societies. However, this distinction is weakening, particularly among the young.

EPIDEMIOLOGY

There is wide variation in adolescents' drinking and attitudes to alcohol around the world, which are influenced by family, peers, schools, religious beliefs, and national and cultural mores. Drinking alcohol has become in many cultures a rite of passage into adulthood. In these cultures, drinking is but one aspect of teenage risk-taking behaviour (e.g., smoking, risky sex, illicit drug use) associated with rebelliousness and challenging of rules.

In recent decades there has been a worldwide increase in alcohol consumption due to:

- Industrialization of the developing world
- Globalization
- Growing wealth
- Increased availability of high alcohol pre-prepared drinks (e.g., alcopops)
- Lower relative prices of alcoholic beverages
- Increased publicity and marketing

Young men drink more than women but there is growing evidence that women are increasingly following men's patterns of consumption. This may be due to women becoming emancipated from traditional female roles and increasingly equal to men in terms of their aspirations and achievements.

"I drank an 'Irish car bomb' and a beer and two shots of Smirnoff vodka. I was perfectly fine. Then it hit me all at once (I think I drank too fast). I was told the following day that I tried to kiss people at the party including a girl, her sister and another boy (I'm a girl by the way). I woke to thorns in my feet, dirt in my shoes, my cell phone was in the woods, my keys in another person's custody, and my car rearranged. I woke not having to pee, so I hope I didn't just decide to pee in front of everybody. Oh god, I think I would die of shame!" (Anonymous).

THE PATHOPHYSIOLOGY OF ALCOHOL USE

Alcohol is rapidly absorbed and distributed throughout the body. Alcohol is a brain depressant causing disinhibition, impaired memory and decision making, and incoordination. With further doses this may progress to stupor, coma and death from respiratory depression. Other biological effects of alcohol include nausea, vomiting (with the risk of aspiration of vomit leading to asphyxiation), *hangover*, amnesic episodes (*blackouts*), and diseases such as acute gastritis. The

Table G.1.1. Alcohol intoxication: symptoms observed at various blood alcohol concentrations (BAC)

BAC range* (g/100 mL of blood) and [alcohol consumed − approximate standard drinks**]	Observable effects
0.01-0.05 [1-3]	Normal behaviour on observation, subjective feelings of relaxation, talkative, more confident.
0.05-0.08 [3-5]	**Euphoria**: increased self-confidence, talkativeness, disinhibition, loss of concentration, impaired psychomotor coordination.
0.09-0.15 [5-9]	**Excitement**: Slurring of speech, unsteady balance, emotional instability, loss of judgement.
0.16-0.25 [9-16]	**Confusion**: disorientation, confusion, nausea, vomiting, memory impairment, staggering gait, apathy, incoordination, loss of bladder control.
Above 0.25 [>16]	**Stupor, coma**: unconsciousness, breathing is suppressed, gag and cough reflexes diminished and possibly paralyzed, breathing slows, becomes increasingly irregular and may cease completely (death may occur at BAC above 0.45).

*This is a rough guide; BAC varies according to gender, weight and age; with regular alcohol consumption tolerance to alcohol and neuro-adaptation develops over time. Therefore this should not be taken as a guide to consumption. **In the previous 3 hours.

effects of various blood alcohol concentrations (BAC) are summarised in Table G.1.1.

Blackouts. Alcohol interferes with the formation of new memories. A common by-product of inebriation is memory loss for events that occurred while the person was intoxicated — blackout, a form of anterograde amnesia. Blackouts do not involve loss of consciousness, just loss of memory. The typical blackout lasts 2 to 6 hours, corresponding to the peak BAC. Blackouts are more likely when people drink large amounts of alcohol in a short time (i.e., with a rapid rise in BAC).

Hangovers develop when BAC returns from a high level to zero and may last longer than 24 hours. They are characterised by symptoms such as misery, drowsiness, concentration problems, dry mouth, dizziness, gastro-intestinal complaints, sweating, nausea, hyper-excitability, and anxiety. It is not known why symptoms can persist after alcohol and its metabolites have been eliminated from the body. Surprisingly, the causes of alcohol hangover are not known. A multitude of physiological changes take place after excessive drinking (e.g., dehydration, endocrine changes, metabolic acidosis) and all may contribute to hangover. It has also been hypothesized more recently that hangovers may be related to immune system activation or neurotransmitter imbalance. Adolescents seem to be less prone to experiencing hangovers.

Metabolism

A person's BAC will generally increase by 10-20 mg/100 ml for each 10g of alcohol consumed (about one standard drink) although it varies according to gender, weight, age, individual characteristics and previous drinking history (e.g., tolerance to alcohol). Alcohol is chiefly metabolized in the liver by oxidation to

Monitoring the Future and *ESPAD*

The *Monitoring the Future* project began in 1975 to survey substance use behaviours, attitudes and values of US secondary school students, college students and young adults. About 50,000 8th, 10th and 12th grade students are surveyed each year. Data and reports are available at the website.



The *European School Survey Project on Alcohol and Other Drugs* (ESPAD) began in 1995 and currently surveys more than 100,000 school students aged 16 years from 35 European countries. The 2007 survey is the last reported (Hibell et al., 2009).

Click on the respective picture to acess the *Monitoring the Future* and ESPAD websites.





Watch video by clicking on the picture

acetaldehyde via the enzymes alcohol dehydrogenase and aldehyde dehydrogenase. Acetaldehyde undergoes further conversions to form carbon dioxide and water. The metabolic breakdown of alcohol takes place at a constant rate of 7 g to 10 g per hour; this speed is not influenced by the amount of alcohol consumed.

Alcohol and the Developing Brain

The developing brain is likely to be exposed to alcohol during the foetal period via maternal drinking and during the rapid brain transformations of adolescence through the initiation of alcohol use (Spear, 2011). Alcohol during pregnancy is teratogenic; about 1% of all births in western countries are estimated to exhibit alcohol-induced deficits, collectively known as *foetal alcohol spectrum disorders* (FASD). A small group of these children show the *foetal alcohol syndrome* (FAS). FASD is likely when pregnant women binge-drink or repeatedly use alcohol. Timing is critical; the typical facial features of FAS are the result of exposure to alcohol during the third week – before women realize they are pregnant (see Chapter B.1).

Studies in humans and in laboratory animals suggest that the effects of alcohol on the adolescent brain may be slightly different from those in adults. For example, adolescents appear to be more resistant than adults to the intoxicating and aversive effects of alcohol (e.g., nausea, vomiting, anxiety, slurred speech) often cues to stop drinking – but more sensitive to the social facilitation effects. These differences may result in a relatively higher tolerance and intake of alcohol during adolescence (Spear, 2011).

Gary Reinbach, a 22 year old Englishman from Dagenham, Essex, died in hospital after he was refused a liver transplant because he could not prove he had not drank alcohol for at least six months — one of the requirements for liver transplant in the UK. Mr Reinbach had been admitted to hospital 10 weeks earlier with cirrhosis of the liver. His family said he had started drinking at 11 years of age and drank heavily after the age of 13 (Rouse, 2009).

Early Onset of Drinking

The earlier the onset of alcohol use the more likely the adverse outcomes. Onset of drinking before 14 years of age is an indicator of high risk for future

Table G.1.2. Factors that increase the risk of alcohol use disorders.

Factor	Comments
Genetic	• Adoption, twin and extended family studies show moderate to strong genetic components to the liability to use alcohol and to develop AUDs • The genetic causation of early onset drinking and subsequent dependence is less clear • Genetic factors leading to alcohol use, drug use, and behavioural disorders may overlap.
Individual	• Psychiatric disorder such as ADHD, conduct disorder, anxiety • Poor school performance.
Family	• Parental or sibling use of alcohol or drugs • Permissive parental attitudes to drinking • Poor parental supervision.
Social	• Having friends who use alcohol, tobacco or other substances • Easy availability (e.g., cheap alcohol) • Less strict laws about minimum drinking age, marketing and publicity • Culture of the country or social group (e.g., military settings, college, fraternity) • Being an indigenous minority group (e.g., American Indian, Canadian Inuit, Aboriginal Australian).



Alcohol use significantly increases the risk of suicide. To watch video click on the picture.

Figure G.1.1 Australian standard drinks. Source: Australian Government, NHMRC.



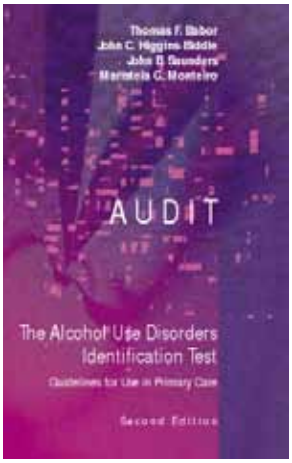
Standard drink

Within a given country, a standard drink is a drink that contains a specific amount of pure alcohol. One standard drink always contains the same amount of alcohol regardless of container size or type of alcoholic beverage (see Figure G.1.1).

Although the standard drink is used to quantify alcohol intake, there is no international agreement (standard) on what constitutes a standard drink, varying substantially from country to country — from 6 g of alcohol in Austria to 19 g in Japan (1.2 mL of ethanol equals 1 g). For example, a standard drink is 8 g of alcohol in the UK, 10 g in Australia, 12 g in France, and 14 g in Canada and the US. As a result, 500 mL of beer with an ABV of 5% represents 1 standard drink in Japan, 1.4 in the US, 1.6 in Denmark, Finland and France, 2.0 in Australia, Ireland and Poland, and 3.2 in Austria. This is confusing.

Table G.1.3. Issues that need to be clarified during assessment.

Age at initiation		The age at which more than a sip of alcohol was consumed
Frequency of consumption		Daily, weekly, irregularly?
Amount and type		Ask about the last drinking occasion and to recall the number of each type of drink consumed according to brand and in the adolescent's words ("I drank an 'Irish car bomb' [cocktail of Guinness stout, Bailey's Irish cream, and Jameson Irish whiskey] and a beer and two shots of Smirnoff vodka") – it is often easier for adolescents to remember this than the type of alcohol (beer, wine or spirits)
Pattern		Drinking patterns change over time, thus it is useful to ask about (1) recent drinking (e.g., past week or last drinking occasion) and (2) the heaviest drinking period
Context		– *Are there particular triggers for use, such as boredom, sadness, anger, anxiety?* – *Do you drink alone, with friends or both?* – *What are your friends' attitudes to alcohol?* – *What benefits do you get out of drinking?* – *Is alcohol available at home?* – *What do your parents think about drinking?* – *How do you pay for it?* – *Do you use other drugs?*
Alcohol-related consequences	***Intoxication***	– *Have you ever been drunk? If so, how many times?* – *Some young people deliberately plan to get drunk…do you?* – *Have you ever had blackouts (when you cannot remember the next day what happened the night before)?* – *Have you been involved in fights when under the influence of alcohol?* – *Have you been caught drink-driving?*
	Hangover	– *Have you ever had a hangover?* – *Does a hangover happen often when you drink?*
	Accidents	– *Have you been involved in a car accident after drinking?*
	Risk-taking	– *Have you had unprotected sex or sexual intercourse after having been drinking?* – *Did you regret that later?* – *Have you ever driven a car while intoxicated?*
Impairment		Whether alcohol use causes impairment in other areas of psychosocial functioning



Click on the picture to access *AUDIT, the Alcohol Use Disorders Identification Test: Guidelines for Use in Primary Care*

A two-question screen

Newton and colleagues (2011) recommend two questions to screen for possible alcohol misuse in emergency departments. Youth who answer yes to at least one of these questions have an eightfold risk of having an AUD and should be referred for assessment:

- *In the past year, have you sometimes been under the influence of alcohol in situations where you could have caused an accident or gotten hurt?*
- *Have there often been times when you had a lot more to drink than you intended to have?*

AUD and is associated with a more rapid progression to and longer duration of alcoholism and greater difficulty achieving abstinence (Skidmore et al, 2011).

Conduct disorder, anxiety, depression, ADHD, shyness, being abused, family conflict, poor parenting, inadequate monitoring, poverty, parental modelling of drinking, and peer influences have all been noted in the research literature as risk factors for early-onset drinking (Skidmore et al, 2011).

ETIOLOGY

The aetiology of AUDs is multifactorial. Some of the best known aetiological factors are summarized in Table G.1.2.

CLINICAL ASSESSMENT

Building rapport with the adolescent is the key aspect of a successful assessment. Many clinicians find that a non-judgemental approach using motivational interviewing techniques achieves the best results. Optimally, assessment requires information from multiple sources and is usually conducted as part of a wider substance use evaluation – several substances are often involved. School reports can be helpful by highlighting inconsistencies, repeated absences and other relevant behaviours. Issues that need to be clarified during assessment are summarised in Table G.1.3.

Confidentiality

Like in most psychiatric assessments of young persons, confidentiality and its limits are best dealt with at the beginning of the clinical interview. Check that the young person understands what is meant by confidentiality. The concept of adolescence varies between cultures with regard to the adolescent's independence and capacity to make decisions, and the role of the family. As a result, laws and expectations about confidentiality differ making it difficult to give unambiguous guidance that can be universally applied. Nonetheless professionals need to keep in mind that confidentiality, particularly if children are older than 14 years, is a key issue when assessing alcohol use: if adolescents are unsure about the confidentiality of their disclosures they are less likely to give accurate information. Parents also need to be made aware that respecting confidentiality is standard practice in adolescent health care (see Chapter A.1). It is often helpful to explain to parents that the purpose of confidentiality is not to exclude them but to facilitate the young person's personal development (Bonomo, 2011).

Validity of self-reports

Much of the information described in research studies has been obtained from the adolescents themselves (e.g., using self-report questionnaires) but there is some concern about its validity. Overall, information given by adolescents is more valid than that obtained from other sources. Parents often do not know the extent of their children's alcohol (or substance) use and tend to under-report these problems. Computer-assisted questionnaires may improve validity

Screening

Except in countries in which alcohol consumption is not allowed and this is enforced, clinicians need to assume that most adolescents presenting with mental health problems consume alcohol unless there is evidence to the contrary. Therefore, they should be screened for alcohol use.

Adolescents' alcohol (or drug) consumption is a sensitive topic which ought to be tackled similarly to suicide risk assessment. For example, questioning from the general to the specific and, when appropriate, using a *third person* approach (*Do students at your school drink alcohol? What about your friends…? Do you ever drink?* Alternatively: *Does your family drink alcohol during meals? Do you also drink?*). Once it is established that the teenager drinks, the age of onset of drinking, pattern of alcohol consumption and alcohol-related consequences need to be clarified. Careful questioning about the frequency, amount, types of alcohol consumed and circumstances associated with drinking is essential; this can be established

conversationally or using questionnaires or rating scales. Such a discussion will also provide opportunities for education, for example to explain non-judgementally what a standard drink is, the effects of different levels of alcohol in the blood and other relevant matters. Using standard drinks allows a quantification of consumption (g/day).

The assessment interview

The clinical interview of adolescents with a suspected alcohol problem should broadly follow the structure of a psychiatric assessment (see Chapter A.5) rather than focussing exclusively on alcohol use, and adjusting the interview style to the developmental stage and age of the adolescent. Psychiatric disorders (ADHD, conduct disorder, depression etc.) are often present in adolescents who misuse alcohol.

Enough information should be collected to answer the following questions (Goldstein 2010):

- What factors predispose the adolescent to use alcohol?
- What precipitates alcohol use and what were the triggers for this episode?
- Are there perpetuating factors that make it difficult for the adolescent to abstain?
- Does a family member (parent, sibling) misuse alcohol? What about peers?
- Are there protective factors that can be used in treatment?

Instruments

Among the many screening instruments one of the most widely used is the WHO's *Alcohol Use Disorders Identification Test (AUDIT*). The AUDIT was developed to screen for excessive drinking and to assist in brief assessment and management. Using AUDIT scores, four levels of risk have been defined (Babor et al, 2001):

- *Low-risk drinking or abstinence* (score lower than 8): no intervention required.
- *Alcohol use in excess of low-risk recommendations* (score 8 to 15): provide brief intervention using education and advice
- *Harmful or hazardous drinking* (score 16 to 19): combination of education, advice, brief counselling and continued monitoring, with further diagnostic evaluation or specific treatment if there is no improvement
- *High risk or dependence* (score above 19): these individuals require specific diagnostic evaluation and possible treatment for alcohol dependence.

Many measures have been published: questionnaire- or interview-based, short or comprehensive. They often assess not only alcohol but also other substance use (Teeson et al, 2011). Reliability and validity of these instruments when applied to adolescents is not well known.

Biomarkers

A biomarker is a biological characteristic that can be used to measure the progress of a disease (in this case AUD) or the effects of treatment. There are two main types of biomarkers: state and trait. *State biomarkers* provide information about drinking activity while *trait biomarkers* give indications of a person's genetic predisposition to alcoholism (Peterson 2004/2005)

Biomarkers contribute to diagnosis (for example, elevated gamma-glutamyltransferase [GGT] without obvious explanation would raise suspicions),

Biomarkers

Of recent alcohol use:

- BAC (usually measured with a breathalyser)

Of chronic alcohol use (e.g., 5 or more drinks per day, most days of the week). All have relatively low sensitivity and specificity and should be interpreted with caution:

- Increase in GGT
- Increase in aspartate aminotransferace (AST)
- Increase in alanine aminotransferace (ALT)
- Increase in mean corpuscular volume (MCV)

Binge drinking and extreme drinking

The traditional view of an alcoholic binge was an extended period of consumption to the point of being incapable of performing the usual activities or until losing consciousness. However, the definition of a binge is contentious. It has been redefined in the research literature as the consumption in a drinking session of five standard drinks for men and four standard drinks for women (on the grounds that this could lead to a significantly increased risk of harm). Please note the provisos highlighted in the standard drink section.

Extreme drinking is a growing phenomenon among young people in many countries. It is exemplified by prolonged, excessive drinking over a short period with the aim of getting drunk. While in the past being inebriated was frowned upon, disapproval has lessened in the current youth culture.

Table G.1.4. Diagnosing alcohol use disorder and alcohol withdrawal.

Alcohol use disorder	Alcohol withdrawal
• Continued use of alcohol in spite of it causing: • impairment of functioning • risk to themselves or others (e.g., driving under the influence) • social or interpersonal problems • physical health problems • Tolerance • Withdrawal symptoms • Craving • Desire or unsuccessful efforts to reduce alcohol use • Spending much time in activities to obtain, consume or recover from the effects of alcohol	• Autonomic hyperactivity (e.g., sweating, pulse rate greater than 100) • Increased hand tremor • Insomnia • Nausea or vomiting • Transient visual, tactile, or auditory hallucinations • Psychomotor agitation • Anxiety • Grand mal seizures
Make a diagnosis if two or more symptoms are present. If more than four symptoms, the problem is severe.	Make a diagnosis if two (or more) of these symptoms develop within hours or a few days of ceasing or reducing heavy or prolonged alcohol intake

to evaluate harm (e.g., liver damage) and to monitor abstinence but should always be interpreted with caution and taken in context clinically. There are no clinically useful trait biomarkers available yet.

DIAGNOSIS

Alcohol intoxication, *AUD* (also known as *alcohol dependence*, *addiction*, or *alcoholism*) and *alcohol withdrawal* are the clinical diagnoses relevant to adolescent alcohol misuse. The traditional classifications distinguish between alcohol *abuse* and alcohol *dependence*. However, research has failed to provide convincing evidence of the validity and clinical usefulness of this distinction. The recent trend (e.g., DSM-V) is for a single diagnosis of AUD with several levels of severity.

Alcohol intoxication

Intoxication is the most common alcohol-related problem found in adolescents – when severe, also called *alcohol poisoning*. A diagnosis of intoxication can be made *after excluding other causes* (such as haed injury or encephalitis) if individuals display at least one sign of intoxication (e.g., slurred speech,

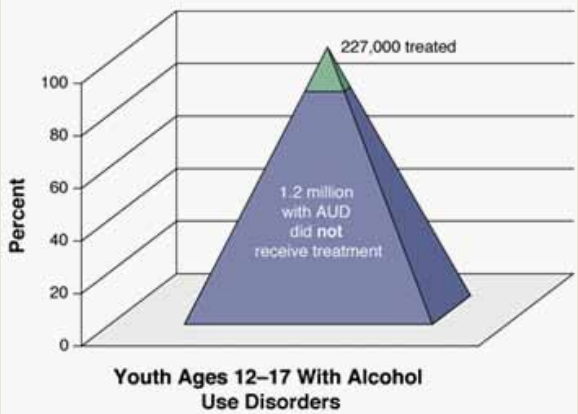


Figure G.1.2 In the US in 2002, only 16% of the 1.4 million youth aged 12 to 17 estimated to have alcohol use disorders reported receiving any type of service for these problems.
Source: National Institute on Alcohol Abuse and Alcoholism (NIAAA)

A 17-year-old German man was taken to emergency because of vomiting and dizziness after having run two 100 m races at school. He was hyperventilating, slightly tachycardic and tired but could be awaken. He subsequently revealed having drunk 3 L of an energy drink and 1 L of vodka (equivalent to 4600 mg of taurine, 780 mg of caffeine and 380 g of alcohol). Combining energy drinks with alcohol is becoming increasingly popular among youth. The combination, particularly in large amounts, poses considerable risk. (Schöffl et al, 2011).

incoordination, unsteady gait, nystagmus, attention or memory impairment, stupor, coma) after ingesting alcohol and are significantly impaired in their functioning as a result. When compared with adults, adolescents are much more likely to use alcohol episodically and heavily (binges), making drinking more dangerous. Rapid drinking of large amounts, often related to a bet or dare, is particularly hazardous.

Alcohol use disorder (AUD)

Repeated excessive consumption of alcohol leads over time to AUD – alcohol dependence (addiction) or alcoholism. AUD is a clinical syndrome in which alcohol is consumed irrespective of the person's circumstances and despite its harmful consequences. The person's life becomes increasing focused on obtaining alcohol (*craving*), consuming it, experiencing and recovering from its effects, and tends to be self-perpetuating (Saunders, 2011). The traditional symptoms of dependence are *tolerance* (need to consume increasing amounts) and *withdrawal* (physical symptoms upon cessation of consumption). Diagnostic criteria for AUD are summarised in Table G.1.4.

Alcohol withdrawal

The diagnosis of alcohol withdrawal is summarized in Table G.1.4. Withdrawal symptoms reflect an overactivity of the autonomic nervous system and typically appear between 6 and 48 hours after ceasing consumption. They rarely last longer than 48 hours. Withdrawal symptoms are infrequent in adolescents.

Although young persons may have stopped consuming alcohol some time before their presentation to the emergency department, BAC may continue to rise through the initial medical assessment, resuscitation, and treatment phases.

TREATMENT

Only a very small minority of people with AUDs receive treatment – about 10% in the US, with the initial treatment episode typically occurring 8-10 years after the onset of the disorder (see Figure G.1.2). Most individuals who develop AUD started drinking during their adolescent years. Thus, the focus in this age group should be prevention and early intervention – i.e., delaying the onset of drinking, reducing the amount of alcohol consumed, reducing binge drinking, minimising the risks, and detecting misuse early. If alcohol misuse is left untreated it often progresses to alcoholism.

ALCOHOL INTOXICATION

Alcohol intoxication is a common occurrence among adolescents, typically identified and handled informally by peers, teachers, relatives, or police; only a small proportion comes to the attention of health practitioners. Nevertheless, severe intoxication (alcohol poisoning) is an acute illness that requires immediate attention, particularly if ingestion of other substances has occurred also. An adolescent that initially appears mildly intoxicated may easily go unnoticed to become unresponsive and risk dying. Severely intoxicated adolescents can become hypothermic, develop arrhythmias, compromised heart function and breathing. Lack of gag or cough reflexes can lead to acute respiratory obstruction should the youth vomit (Vaca and Sayegh, 2011).

The key aspect of management is aggressive respiratory and cardiovascular supportive care. If the patient is intoxicated but awake and with a secure airway, a physical examination should be performed to exclude traumatic injuries (e.g., head injury) that may mimic the symptoms of intoxication or co-exist with it. Once intoxication is treated it is essential to follow up the adolescent and deliver a short intervention or treatment if necessary.

ALCOHOL WITHDAWAL

Once it is found that no significant comorbid physical illnesses are present, adolescents who show alcohol withdrawal symptoms can – and should – be treated on an ambulatory basis, if at all possible involving the family. *Supportive care* (reassurance and encouragement in a peaceful environment without criticism and with limited interpersonal interactions, plenty of fluids and good nutrition, and administration of thiamine and multivitamins) is enough to manage withdrawal in the majority of cases in which symptoms are not severe.

In severe cases, particularly if the risk of seizures is high (e.g., history of previous seizures, abnormal electrolytes, concomitant benzodiazepine abuse), the current treatment of choice is benzodiazepines, usually diazepam, following similar protocols to those in adults. This can be done either on a *fixed schedule* (doses are given at specified amounts and intervals) or, preferably, following a *symptom-triggered regime* (benzodiazepines are administered if the score in an alcohol withdrawal rating scale is above a specified cut-off). If there is severe agitation or hallucinations, the addition of haloperidol to diazepam may be helpful. Following successful withdrawal, it is essential to offer treatment for their alcoholism.

ALCOHOL USE DISORDER (AUD)

Alcoholic adolescents present specific challenges for therapists: they rarely seek treatment for alcohol misuse on their own accord but are brought by parents, or compelled by the school or the courts. In some countries, adolescents who violate alcohol policies (e.g., driving under the influence of alcohol, intoxication at school) are often ordered by the court or school authorities to undergo treatment. These individuals, often referred to as *mandated patients*, are at high risk for alcohol-related harm. There is evidence that mandated young people benefit from interventions as much as non-mandated individuals. Whether improvement is due to the intervention or to having been caught is unclear although both may play a role.

Teenagers are difficult to engage, usually don't want to stop drinking and don't see anything wrong with it. Building rapport, getting them to understand the risks of alcohol misuse and building motivation to change are essential first steps. Rather than a therapy, *motivational interviewing* is a widely accepted technique that can be used across most of the treatments mentioned to foster rapport and understanding of the risks of alcohol misuse; it seeks to enhance motivation to change by providing education and feedback and by exploring and resolving ambivalence. Family involvement in treatment results in better outcomes.

One of the advantages of treating AUDs is that one is able to objectively monitor consumption, i.e., abstinence. According to some treatment guidelines this "should be a routine part of the formal evaluation and ongoing assessment of substance use both during and after treatment" (Bukstein et al, 2005). Rather than having to rely on adolescents' reports, the advent of affordable breathalysers that can be used at home makes monitoring easier but their usefulness is limited to a few hours after alcohol is consumed and the adolescent should agree to the monitoring.

Goals of treatment vary according to country, therapy, therapist and patient. In some countries (e.g., US) treatment mostly seeks to achieve abstinence; other countries (e.g., some European countries) favour a *harm minimization* or *harm reduction* approach. Abstinence is the only effective option for many patients; however some who do not accept abstinence can achieve sensible drinking. The goal in AA is abstinence; the aim of other treatments can be abstinence or responsible use. Tailoring the treatment to the specific needs, personality and beliefs of the individual adolescent increases the likelihood of success.

Mandated patients

Individuals who have violated alcohol policies or laws and are ordered by the appropriate authority or court to undergo treatment for their alcohol misuse.

Stages of change

The stages of change model allows clinicians to understand the process whereby people move through different phases of readiness to change. These are:

- *Pre-contemplation*: not acknowledging that there is a problem that needs to be changed
- *Contemplation:* acknowledging that there is a problem but not yet wanting to make a change
- *Preparation/ determination:* getting ready to change – i.e., accepting treatment
- *Action*: changing behaviour – i.e., undergoing treatment
- *Maintenance*: maintaining the behaviour change – i.e., continuing with treatment/abstinence
- *Relapse*: return to former behaviours and abandoning the changes achieved

Responsible alcohol use

Drinking in a way that is unlikely to cause significant risk of harm to the individual or to others.

Table G.1.5. Summary of psychosocial treatments for alcohol use disorders and their effectiveness.

Treatment	Description	Evidence
Motivational enhancement therapy	Assumes that responsibility and capacity for change lie within the patient. The therapist provides individualized feedback about the effects of the patient's drinking. Working closely together, therapist and patient explore the benefits of abstinence, review treatment options, and design a plan to implement treatment goals.	The motivational interviewing technique — a key component of motivational enhancement therapy — was shown in adults to overcome patients' reluctance to enter treatment more effectively than did other conventional approaches.
Brief interventions	Up to 4 sessions, typically follows CBT principles and incorporates education, motivational interviewing, and individualised feedback. Often delivered opportunistically (e.g., following an alcohol-related motor vehicle crash).	Lump together a variety of interventions. Good evidence of effectiveness in adults, particularly in milder cases, but limited evidence in adolescents. There is concern about maintenance of gains over time.
Internet & cellular phone-based interventions	Much research interest and activity in this area. Mostly used to deliver brief interventions or to complement other treatments (e.g., face-to face). The better ones include education and individualised feedback.	Evidence beginning to emerge that they can be effective as part of a multimodal approach and if individualised feedback is provided. Cellular phone reminders appear to be effective in quitting smoking.
Family therapy	Assumes that the adolescent's behaviour is shaped (caused or reinforced) by family interactions. Therapies follow a variety of models.	The most widely practised and studied set of treatments in this age group but evidence of effectiveness is still limited.
Multy-systemic therapy	Delivered in adolescents' social environment (family, school, neighbourhood…) it provides intensive support seven days a week, 24 hours a day, and the treatments required (family, individual, pharmacological). Costly and resource-intensive.	There is evidence of effectiveness in complex cases with significant comorbidity (e.g., delinquency, conduct problems).
Contingency management	It follows operant conditioning principles by rewarding initiating treatment and maintaining abstinence. A key aspect is the availability of an objective measure of abstinence such as a negative breath test.	An attractive approach that empowers parents. The few studies available are promising but definite evidence is still lacking.
Cognitive behaviour therapy (CBT)	Individually or in conjunction with family therapy	CBT combined with family therapy obtains better results than CBT alone
Alcoholics Anonyms (AA)	"A fellowship of men and women who share their experience, strength and hope with each other that they may solve their common problem and help others to recover from alcoholism". The only requirement for membership is a desire to stop drinking (i.e., the goal is abstinence). AA follows a 12-steps program. Few AA groups for adolescents. AA attendance is often encouraged in multimodal treatments.	Some evidence of effectiveness in adults but limited research available in adolescents.
Multi-modal treatments	Treatment in practice is often multimodal, for example including family therapy, contingency management and AA attendance.	Multimodal treatments usually more effective than their unimodal counterparts.

Contingency management

Following Stanger et al (2009), a program of this kind would involve: (1) assessment of the problem; (2) adolescent and parents formally agreeing to undertake the program under the supervision of the clinician; (3) a detailed schedule of incremental voucher-based monetary or other rewards for consecutive negative breathalyser readings (parents would be expected to purchase or borrow a personal breathalyser) for the length of the treatment (e.g., 3 months). Because poor parental support and participation in treatment can become a barrier, parents may be rewarded also for their participation.

Because adolescent drinking takes place mostly during unsupervised time outside school, the breathalyser is used twice weekly at the parent's discretion when the adolescent arrives home from situations in which drinking might have taken place. The first negative breathalyser reading is rewarded, for example, with a $2 voucher, with $2 increments for each consecutive negative breath test. There is also a $10 bonus for each three consecutive negative tests. Vouchers are reset back to their initial value if results are positive, from which they can escalate again after an agreed number of consecutive negative results (e.g., three).

Example: 1st negative test: $2; 2nd negative test: $4; 3rd negative test: $6 + $10 (bonus for three consecutive negative tests); 4th test positive: $0, reward schedule is reset; 5th test negative: $0; 6th test negative: $0; 7th test negative: $0; 8th test negative: $2; 9th test negative: $4 etc. Voucher earnings can be redeemed for goods selected by the adolescent (e.g., movie passes, hobby equipment, items of clothing) but not for cash.

Psychosocial treatments

Psychosocial treatments for AUD and their effectiveness are summarised in Table G.1.5. *Brief interventions* are popular because of their short duration (from a few minutes to a few sessions) and appropriate in adolescents – in whom alcohol use is often not severe or entrenched. Short interventions are recommended in primary care settings or hospital emergency departments for individuals whose presenting complaint is not primarily an alcohol problem, although it may be alcohol-related such as a car accident (*opportunistic intervention*).

Youth and AA



There is particular interest and growing research on electronic options for the delivery of treatment for AUD. Internet and cellular phone-based treatments have features highly valued by teenagers (convenience, privacy, minimise stigma, use a medium in which young people feel comfortable) and governments (cheaper than face-to-face or group treatments, can reach many people); the issue is whether they are effective. Although evidence is still limited, it would appear that programs that among other features provide individualised feedback are effective in reducing excessive drinking and alcohol-related problems. That is, individualised feedback is a key element in effective programs.

According to Deas and Clark (2011), *contingency management therapies*, which are based on operant conditioning principles, may be a useful intervention. Contingency management provides incentives for initiating treatment and maintaining abstinence with vouchers for monetary and other rewards (appropriate to the socioeconomic conditions of the country and family but attractive enough to generate significant motivation in most adolescents); optimally, it requires the active involvement of the family. A key ingredient is an easy to use, reliable and objective measure of abstinence such as a negative breathalyser result.

AA initially attracted severely impaired middle-aged and older individuals. More recently, AA has begun to attract increasing numbers of young people and has begun to publish youth-specific literature. Younger patients with SUD differ from adults in that they are often less motivated for treatment, less likely to seek abstinence, and have less severe alcohol use, which makes their engagement with 12-step programs more difficult. However, adolescents do attend AA and positive outcomes appear to be associated with attendance (Kelly & Yeterian, 2011).



Is naltrexone effective for alcoholism?

Click on picture to watch David Sack MD discuss this issue.

Pharmacological treatments

Psychosocial interventions are the mainstay of AUD treatment in young people. The persistence of long-term craving in alcoholics, even after prolonged abstinence, often triggers a relapse. Craving is thought to be maintained by neuronal changes in addicted individuals, these changes may be amenable to

Table G.1.6. Pharmacological agents used to treat AUD.

Medication (dose*)	Comments
Disulfiram (start with 125mg/day, gradually increase to a maximum of 500mg/day)	An alcohol-sensitizing drug that has been available for a long time and may be a deterrent for drinking in patients willing to take it. If patients drink alcohol, the drug produces an unpleasant reaction.
Naltrexone (start at 25 mg/day for two days and increase to 50 mg per day)	Helps to prevent relapse among abstinent alcohol dependent individuals who are simultaneously undergoing psychosocial therapy. Naltrexone is only effective if taken on a regular basis. There is an extended-release preparation available in some countries requiring one monthly injection (watch for reaction at the injection site). Conduct liver function tests before prescribing as naltrexone can impair liver function tests; if liver function results are more than five times normal limits, proceed cautiously. Opioids should not be consumed while taking naltrexone.
Acamprosate (666 mg three times daily)	In one study, more than twice as many alcohol dependent individuals receiving acamprosate remained abstinent up to 1 year compared with participants receiving psychosocial treatment alone. Side effects include diarrhoea, dizziness, flatulence, loss of appetite, nausea, and trouble sleeping.
Other	Other promising agents currently being researched include *topiramate*, *ondansetron*, *baclofen*, and the *SSRIs*.

*These are the recommended doses for adults.

pharmacological intervention and have become a focus of intense research. So far, there is very limited data on adolescents, results being extrapolated from adult populations with all the limitations this entails. For example, there is little information about optimal dosage in adolescents.

The first proviso in the pharmacological management is that medication is effective only if administered as part of a comprehensive, multimodal treatment package and once the patient has stopped drinking. The second is that many factors need to be taken into consideration when prescribing for adolescents, weighing the potential risks and benefits of medication in a developing brain against the hazards of continuous alcohol use. Finally, medication is indicated only in addicted individuals, typically those who show craving, tolerance or withdrawal symptoms.

Pharmacological agents used to treat AUD are summarised in Table G.1.6. *Disulfiram* has been around for a long time and can be helpful especially when there is supervised dosing and the person is motivated. It is an aversive treatment that produces an unpleasant reaction if the individual taking it consumes alcohol. Disulfiram blocks the enzyme acetaldehyde dehydrogenase resulting in high concentrations of acetaldehyde in the blood. The person experiences flushing of the face, headache, low blood pressure, palpitations, dizziness, nausea and vomiting. All the other medications listed seek to reduce craving. Medications are effective only if taken regularly, so that patients' adherence and cooperation are essential. For more information see Johnson (2011).

Click on the picture to access a variety of resources from the NIAAA's *Helping Patients Who Drink Too Much: A Clinician's Guide and Related Professional Support Resources* site (some are also available in Spanish).



PREVENTION

The amount of alcohol-related harm in a society and the proportion of people who consume hazardous levels of alcohol are closely related to the overall or per capita consumption. However, most alcohol-related harm takes place not in the heaviest drinkers but in those whose consumption is at lesser levels. Though the evidence in favour of *universal* preventative measures that reduce overall



A car crash on Jagtvej in Copenhagen, Denmark. Source: Wikimedia Commons

Drink driving

There is considerable evidence that drink-driving accidents and fatalities can be reduced by:

- Lowering the legal concentration of alcohol in the blood while driving
- Systematic random breath-testing (when police regularly stop drivers to check BAC through breath testing)
- For repeat drink drivers, mandatory treatment and the use of an ignition interlock (mechanical device that does not allow a car to be driven by a driver who is over the legal alcohol limit).

(Source: Anderson et al, 2009)

alcohol consumption is compelling, whether it is better to concentrate on universal interventions or to target specific groups at high risk of harm (*targeted prevention*) remains contentious. The two approaches can and should be combined. Legislative measures illustrate the former while preventive programs in schools illustrate the latter.

LEGISLATIVE MEASURES

Most societies seek to manage or prevent the harm resulting from alcohol use through a variety of policies that range from total prohibition to a range of restrictions. Legislative strategies include laws that regulate minimum drinking age, driving under the influence of alcohol (drink driving), price of alcoholic beverages, availability of alcohol (alcohol outlets, their concentration, days and hours of sale), and marketing and advertising.

Minimum drinking age laws

Minimum drinking age laws stipulate who can purchase or consume alcoholic beverages. The legal drinking age usually refers to the minimum age at which alcohol can be consumed in licensed premises (bars, restaurants), which may be the same or different from the minimum age at which alcohol can be purchased. These laws do not usually apply to consumption at home. The minimum drinking age in most countries is 18 years (21 in the US). A few countries do not have minimum drinking age laws (e.g., Albania, Armenia, Azerbaijan, Fiji, Ghana, Jamaica, Kyrgyzstan, Morocco, Togo, Tonga, Vietnam).

Drink driving laws

In 1936, Norway passed the world's first law making an offense to drive with more than a specified amount of alcohol in the blood. Nowadays almost all countries outlaw driving a motor vehicle with BAC above specified levels, which vary according to country (e.g., 0.08/100ml in the US, Canada and the

UK; 0.05/100ml in Australia, France and Germany; 0.04/100ml in Lithuania; 0.03/100ml in Russia; 0.02/100ml in China, Norway and Sweden; 0.0/100ml in Brazil, Iran and Saudi Arabia).

All the measures that reduce alcohol consumption contribute to a greater or lesser extent to reduce alcohol-related road traffic accidents, particularly in young people. The risk of being involved in a crash is greater for the young at all BAC levels. Among US drivers with a BAC level of 0.08% or higher involved in fatal crashes in 2008, more than one third were between 21 and 24 years of age.

Designated driver programs seek to reduce alcohol-related accidents by providing a safe transportation for those who have been drinking. It is still unclear whether they lead to a reduction in drink driving or AUDs

Pricing policies

Minimum pricing means that alcoholic beverages cannot be sold for less than a set amount per unit of alcohol contained. Young people who drink and those who drink harmful amounts tend to choose cheaper beverages when prices increase. Establishing a minimum price per unit of alcohol would limit the ability of these groups to trade down to cheaper products.

A rise in alcohol price leads to less alcohol consumption and less alcohol-related harm, and vice versa. Young drinkers are very sensitive to price increases. Price rises:

- Delay the age when young people start drinking
- Reduce the number of drinking bouts
- Reduce the amount of alcohol consumed on each occasion
- Slow progression towards drinking larger amounts.

Availability of alcohol

There is good evidence that legislation to control the number of alcohol outlets, their concentration, and days and hours of sale influence alcohol related problems.

Marketing and advertising

Marketing and advertising of alcoholic beverages has become increasingly sophisticated and is globally worth many billions of dollars annually. It often targets young people through linking alcohol brands to sports and cultural activities, sponsorships and product placement. Restrictions placed on alcohol marketing and advertising reduce this effect, and data suggest that children and young people should be protected as much as possible. Thus restrictions are placed on, for example, sport sponsorship, and bans on television advertising at times when children and young people are more likely to watch or during children's programs.

PREVENTON PROGRAMS

Exposure to alcohol during early adolescence is associated with poorer outcomes in adulthood. However, many of the adolescents who use alcohol early also have a history of other problems (e.g., behaviour problems), which raises the question of whether early exposure to alcohol leads by itself to poorer outcomes or whether this only happens in adolescents who are already at risk through their pre-existing difficulties. Research evidence shows that early consumption of alcohol

Supervised drinking

There is a widespread belief particularly in *wet* countries that allowing adolescents to drink under adult supervision at family gatherings is a way of teaching them responsible drinking. Research has shown this not to be the case: adult-supervised drinking results in higher levels of harmful alcohol use in adolescents (McMorris et al, 2011). The later adolescents start drinking alcohol the better. Certainly they should not start before the age of 15 years.

ESPAD (Hibell et al, 2009) reports that among 16 year old European students, binge drinking is most prevalent (60%) in Denmark and the Isle of Man. Malta, Portugal, Estonia, Latvia and the UK also display high rates (around 55%). On average, binge drinking is more frequent among boys than girls (47% versus 39%) but in Iceland and Norway more girls than boys report binge drinking. ESPAD shows a clear increase (9%) in binge drinking from 1995 to 2007, mostly due to increasing rates among girls.

In the US, binge drinking among 12th graders peaked in 1979 (at about the same time as overall illicit drug use). Subsequently, it remained steady for a few years before declining substantially (from 41% in 1983 to a low of 28% in 1992). In 2010, 28% reported having been drunk in the past 30 days. Disapproval of binge drinking has also increased (Johnston et al. 2011).

by itself leads to worse adult outcomes (Boden & Fergusson, 2011; Odgers et al, 2008). Thus, interventions that delay the age of onset of drinking, reduce the amount of alcohol consumed and risky drinking patterns (e.g., binge drinking), will lessen the harm of alcohol.

School-age alcohol use is widespread in most western countries. So, it is not surprising that governments and communities seek to prevent or reduce alcohol consumption among students. Also, schools are optimal settings for the delivery of alcohol prevention programs because: (a) most individuals begin using alcohol during their school years; (b) schools provide an efficient way of reaching almost all young people; and (c) schools can implement a broad range of educational and disciplinary measures (Rey & Saltz, 2011).

Prevention programs can be *specific* (i.e., focus on alcohol) or *generic* (deal with a variety of behaviours and substances such as tobacco, alcohol, cannabis etc.). According to a recent review (Foxcroft & Tsertsvadze, 2011), generic programs based on psychosocial or developmental approaches are more likely to report longer term benefits than other interventions. Thus generic programs should be preferred over alcohol-specific ones. Those with better evidence of effectiveness are currently the *Unplugged* program (Caria et al, 2011), and the *Good Behaviour Game*. All require training.

To be successful schools need to adopt a sophisticated approach to prevention that includes universal, selective and indicated approaches (see Chapter A.8). Prevention programs, apart from being tailored to the circumstances of the specific age group, need to:

- Increase knowledge of the harm alcohol use can cause, physically, mentally and socially (including legal consequences)
- Provide opportunities to explore attitudes to and perceptions of alcohol use
- Help students develop decision-making, assertiveness, coping and expressive skills
- Increase awareness of how the media, marketing, role models as well as the views of parents, peers and society can influence alcohol use
- Provide personalized feedback.

A *whole school* approach (i.e., involving staff, parents and pupils) to alcohol is likely to be the most successful. In addition, schools should offer parents information about where they can get help to develop their parenting skills.

Schools also need to have in place mechanisms to identify students who are drinking or drinking excessively, to offer them brief, individual, evidence-based interventions by appropriately trained personnel or referral to external services. Violations of school alcohol policies may result in attending mandatory education or treatment programs. Medical amnesty (*Good Samaritan*) policies may lessen the risk of harm in case of alcohol poisoning.

Good Samaritan laws seek to protect from liability individuals who help others who are injured or ill, to reduce bystanders' hesitation to assist. In this context, they are policies protecting students from disciplinary action regarding alcohol and drug use if they seek medical help (also known as *Medical Amnesty Policies*).

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CANNABIS USE AND MISUSE

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Conflict of interest: research funding from the National Institute on Drug Abuse and the National Institute on Alcohol and Alcoholism; consultation for GW Pharmaceuticals

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Suggested citation: Budney AJ, Stanger C. Cannabis use and misuse. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Cannabis is the generic term for the psychoactive substance derived from *Cannabis sativa,* a plant grown in many areas of the world and widely used to alter consciousness. Many know cannabis by other names: *marijuana, hashish, dagga, bhang, ganja, dagga, weed, pot* or *reefer*, to name just a few. Throughout this chapter, we will use "cannabis" to refer to all the various forms of the substance.

Cannabis, more so than any other substance of potential abuse, has generated tremendous controversy worldwide. Estimates of global use exceed 166 million people (UNODC, 2008), and policies related to its legal status and potential for medical use vary across and within countries. Many have questioned its addictive potential. That is, they have been skeptical about whether or not someone can really become dependent or addicted to cannabis. The seriousness of the medical and psychosocial consequences of cannabis has also been challenged. Some believe that its status as a "gateway" substance leading to use of even more harmful drugs makes cannabis dangerous. These questions also lead one to wonder whether there is a need for potent treatments to help people quit. Recent advances in our knowledge about cannabis and addiction provide clarity to some of these questions. This chapter makes available science-based information on cannabis and its potential





Click on the picture above to access the National Institute on Drug Abuse (US) website and the one below to access the National Cannabis Intervention and Prevention Center (Australia)

ncpic
national cannabis prevention and information centre



Advertisement in the Jan 1895 issue of the "Medical Advance Journal"

for harm, with the goal of providing an informed and thoughtful understanding and appreciation of cannabis and its potential impact on adolescents.

Cannabis throughout history

By some accounts, cannabis first appeared approximately four thousand years ago in the Chinese culture as a plant grown for use of its fiber to make clothing, paper, and rope (Abel, 1980). Over time, people from many cultures have used cannabis as a medicine for various maladies and for spiritual ceremonies related to its mind-altering effects. Cannabis' value as useful fiber, its potential for medicinal use, and its psychoactive effects and abuse potential have combined to generate debate and controversy across cultures for many centuries.

In the 19th century cannabis became part of the US Pharmacopeia (ca.1870) based on medical writings describing its potential medicinal applications. Societal concern related to cannabis misuse and its consequences, however, lead to government-sponsored studies, which concluded that cannabis was not "addictive" and had potential health benefits (e.g., Ohio State Medical Society, 1860 and the Indian Hemp Drug Commission, 1895). Increasing cannabis use was a source of public controversy in the US in the early-mid 1900's as some expressed an irrational fear that marijuana use by African Americans and Mexican Americans would prompt children of the white middle and upper class to use marijuana. International concerns also grew, as reports from the International Opium Conference and the League of Nations indicated that multiple countries felt the need to place controls on cannabis, while other countries resisted such efforts. In 1924, the International Opium Conference labeled cannabis a "narcotic" and called for strict controls.



In 1941, Britain declared cannabis illegal, and the United States legislated a Marijuana Transfer Tax and removed cannabis from the US Pharmacopeia. In 1944, the New York Academy of Sciences indicated that the public concerns about cannabis were exaggerated and that cannabis does not lead to addiction, yet its report described multiple negative aspects of cannabis use. In 1972, the US National Commission on Marihuana and Drug Abuse recommended that cannabis possession be decriminalized. In that decade a number of US states replaced prison terms with civil penalties or misdemeanor fines. Concurrently, the US banned medical research on cannabis, while the state of New Mexico passed a law allowing cannabis for medical use.

In 1999, the Institute of Medicine released a comprehensive report acknowledging the potential negative effects of cannabis including addiction, but also provided a clear statement regarding its potential for medical benefits. Legalization and decriminalization discussions continue to evolve internationally with still no consensus and a resultant wide range of national and regional policies.

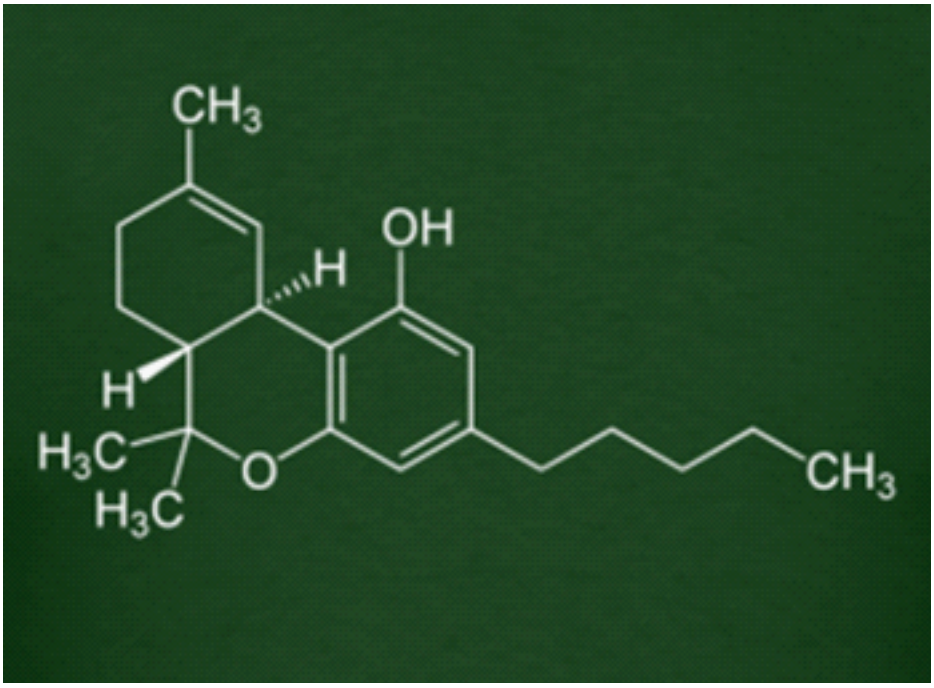
WHAT IS CANNABIS AND HOW DOES IT WORK?

Although cannabis contains many chemical substances, it is delta-9-tetrahydrocannabinol (THC) that has been identified as the primary compound that produces the "high" that occurs when smoking or ingesting the plant materials. It is likely that other compounds in cannabis also contribute and interact with THC to produce its myriad of physical and psychological effects. In particular, research has focused on better understanding the role of *cannabidiol*. Some evidence suggests that cannabidiol may moderate the effects of cannabis, reducing the potential anxiolytic and psychomimetic effects of THC, yet other studies have not observed such effects (Bhattacharyya et al, 2010; Karschner et al, 2011). Awareness and understanding of the compounds other than THC in cannabis has relevance to evaluating three pressing issues related to cannabis use:

- How the effects of cannabis use compare with the use of the pure THC that is sometimes administered in medical settings
- How the effects of synthetic THC-like compounds being consumed recreationally (e.g., K2, Spice, Kronic) compare with natural cannabis use, and
- How the other substances contribute to the impact on health when the smoke from cannabis is inhaled (e.g., carcinogens, tar).

How is cannabis prepared and consumed?

The cannabis plant is cultivated cannabis and then marketed in various forms. Most often, it is dried and divided either into mixtures that include the whole plant or only the unfertilized flowers of the female plant. The parts of the



Chemical structure of THC



Synthetic cannabinoids sprayed on plant materials: potent CB1 agonists with effects similar to cannabis, but less reliable and with more adverse effects.

plant have differing THC potency with whole plant mixtures being least potent (2%-5% THC content), and flower-only mixtures having much higher potency (up to 20%). The other common cannabis preparation is *hashish*, which comprises the cannabis plant resin, with a typically high potency of THC (10-15%). Hash oil preparations are even more potent; these consist of concentrated resin extract and may reach potencies up to 60%. Of note, the average cannabis available on the street for purchase has become increasingly potent over the past 20 years most likely due to increased expertise in hybridization and growing techniques.

The average cannabis available on the street for purchase has become increasingly potent over the past 20 years.

The most common method of administration of cannabis is smoking; the plant material is burned and the smoke is inhaled. Devices for smoking range from cigarettes (*joints*), pipes, water pipes (*bongs* or *hookahs*), and most recently hollowed out cigars that are usually called *blunts*. Smoking cannabis and tobacco simultaneously either via blunts, *spliffs* (joints that mix the substances together), or by chasing cannabis with tobacco has become more common recently, particularly among teens and young adults (Agrawal et al, 2011; 2012; Peters et al 2012)

Cannabis can also be "vaporized", which involves heating it to a temperature high enough to release psychoactive compounds for inhalation, but low enough that combustion does not occur. This route of administration is thought to be somewhat "safer" than traditional smoking methods.

Oral consumption of cannabis is also fairly common and usually involves dissolving it into food substances, frequently baked goods, although recently some places that dispense "medical marijuana" have begun to market other edible products that include doses of cannabis.

Do different administration methods have different effects?

Smoked and vaporized cannabis have similar bioavailability to THC, which results in a similar time course of intoxication effects. Onset of intoxication typically occurs within 1-2 minutes, reaches peak usually within 30 minutes, and can last for up to four hours. When consumed orally, bioavailability is lower, and thus intoxication is delayed with onset usually occurring after at least 30 minutes, peak effects resulting in approximately two hours, and effects lasting for more than six hours.



Cannabis paraphernalia

What are the general effects of cannabis use?

Cannabis ingestion has numerous, well-documented direct effects, most of which are dose dependent. The effects associated with the feeling of being "high" or "stoned" include euphoria, a sense of relaxation, increased giddiness or propensity for laughing, the sense that time seems to slow down, an increased appreciation for music and other art forms, and tendency to prefer nonverbal social activities or introspection. The less often discussed feelings of anxiety, paranoia, fear, or panic may also be experienced. These effects occur most often in less experienced users or following use of higher than usual doses. In rare cases, usually involving particularly high doses, users may experience hallucinations. These effects are not life threatening, dissipate with time, and may be reduced with comfort and reassurance.

Use of cannabis also produces several reliable physiological effects. The mouth becomes dry and appetite is stimulated (i.e., the onset of *munchies*) which typically results in an increase in the consumption of food and drink, particularly high calorie products. At low to moderate doses, cannabis typically has antiemetic effects (reduces nausea), but can induce nausea or vomiting at higher doses or among less experienced users. Cannabis use has a broad range of effects on cardiovascular function. Use is associated with increase in resting heart rate, slight increase in supine blood pressure, and increased orthostatic hypotension (dizziness or lightheadedness that results from a sudden drop in blood pressure after standing) (Jones, 2002). Also dilation of small blood vessels occurs, which results in redness of the eyes.

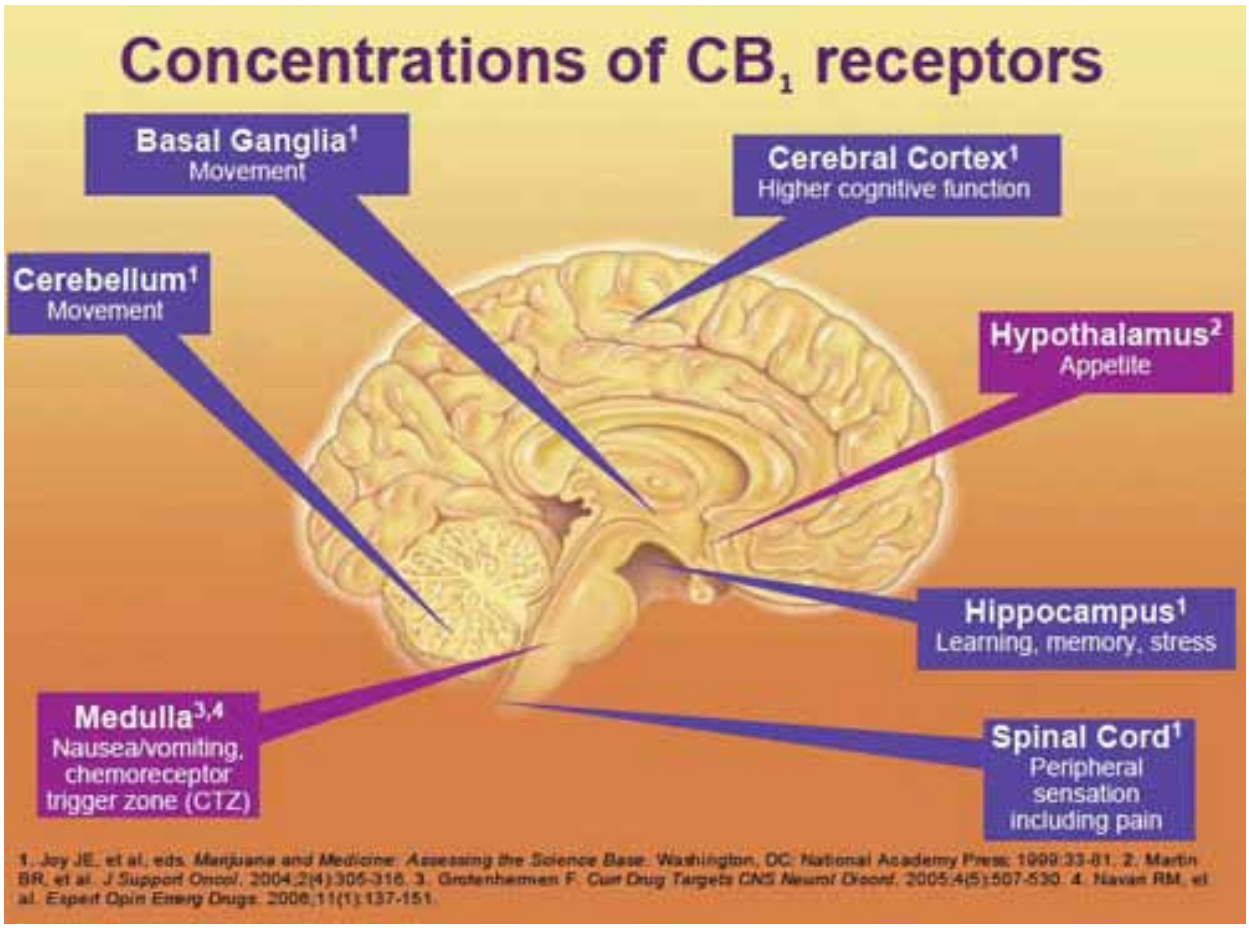
Cannabis can impair focused and divided attention, short term and episodic memory, some types of complex cognitive processing, and some aspects of motor ability (Vandrey & Mintzer, 2009). Many of these effects are not large, but are dose-

related and moderated by cannabis use history (tolerance). Generally, moderate doses of cannabis appear to have comparable effects to moderate doses of alcohol (BAC approximately 0.05%) on measures of motor ability, attention and episodic memory.

Sustained use of cannabis can impair attention, memory and complex cognitive abilities such as problem solving and mental flexibility (Kalant, 2004; Solowij et al., 2002). Neuroimaging studies indicate that long-term cannabis users have altered brain function in the prefrontal cortex, cerebellum, and hippocampus. Again, the functional significance of such impairments is difficult to assess and quantify. Most research suggests that much of the impairment associated with chronic cannabis use is likely reversed following extended periods of abstinence.

How does cannabis interact with the brain?

Cannabis exerts its effects primarily through an endogenous cannabinoid receptor system. Two receptor subtypes (CB1 and CB2) and five endogenous ligands have been identified. The psychoactive and reinforcing effects of cannabis are primarily mediated by activation of the CB1 receptor by the THC compound. This receptor is abundant throughout the central nervous system, but is expressed in the brain at the highest concentrations in the basal ganglia (reward, learning, motor control), cerebellum (sensorimotor coordination), hippocampus (memory), and cortex (planning, inhibition, higher-order cognition). Changes in brain activity following administration of THC are localized mostly in these areas, and neuroimaging studies indicate that these brain activity changes are THC dose- and time-dependent effects. The euphoric effects of cannabis are primarily related to



THC enhancing dopamine neuronal firing and synaptic dopamine levels in the reward pathway of the brain (Gardner, 2005), which not surprisingly is a hallmark neurobiological feature of most abused drugs.

Adolescent neuroimaging studies have indicated that chronic use of cannabis in adolescence leads to less efficient neural processing on tasks requiring executive function, and in particular, on tasks requiring higher level control of attention (Abdullaev et al, 2010). Similarly, frequent or recent cannabis use among teens, and onset of cannabis use prior to the age of 16 have been found to be associated with less efficient (overactive) cognitive processing on working memory tasks (Becker et al, 2010; Jager et al, 2010; Schweinsburg et al, 2010). Working memory is a cognitive system that holds information, permitting verbal and nonverbal activities such as reasoning and comprehension processing, which are important components involved in goal-oriented monitoring or manipulation of information that contributes to decision making (Becker & Morris, 1999). Adolescent cannabis users also have structural abnormalities including decreased cortical thickness (Lopez-Larson et al, 2011) and reduced cortical fractional anisotropy, suggestive of decreased myelination (Ashtari et al, 2009). These findings suggest that cannabis use alone or in combination with other substance use (e.g., alcohol) in adolescence may negatively influence normal neuro-developmental processes.

BEHAVIORAL, MEDICAL AND PSYCHIATRIC ADVERSE EFFECTS

Adolescents who report regular use compared to those who do not use cannabis are much more likely to (Tims et al, 2002):

- Use other substances and to develop substance use disorders
- Have poor academic performance and drop out of school
- Engage in delinquent behavior and get arrested
- Have other psychiatric problems and have more emergency room visits
- Engage in more risky behavior such as drugged driving, which increases risk of accidents, and sexual behavior that increases risk of unplanned pregnancy and of STDs.

In adults, regular cannabis use has also been linked to poor work history and less satisfactory relationships. Some research has raised concern that cannabis exposure to the fetus during pregnancy may impact learning and cognitive function during the school years (Fried et al, 2003). Cannabis has also been linked to increased respiratory problems (e.g., bronchitis), but has not clearly been associated with cancer risk, although smoking cannabis produces a high level of carcinogens (Tetrault et al, 2007).

Cannabis and schizophrenia

Although it is difficult to demonstrate that cannabis use is a causal factor in these adverse consequences, certainly it plays some contributing role. Of particular concern is whether cannabis use contributes to the development of severe mental illnesses such as schizophrenia (Sewell et al, 2009). A clear association between cannabis use and the development of psychotic disorders has been repeatedly demonstrated. Particular risk is associated with frequent use and early onset of use. Thus, this concern is of great importance during adolescence and young

adulthood. Evidence is not conclusive on whether or not these relationships are causal (e.g., whether cannabis use actually causes new cases of schizophrenia) or whether psychosis would have developed eventually without cannabis use (e.g., cannabis only bringing forward the onset of the illness). Cannabis is likely to trigger early onset of psychosis and perhaps the expression of psychosis among those with predisposing risk factors for psychosis. Moreover, among those with psychotic disorders, cannabis use clearly has a negative impact on its course and response to treatment, despite some evidence that it may enhance acute cognitive functioning in some persons with schizophrenia.

Is cannabis "addictive"?

Although agreement on how to best define "addiction" is sorely lacking, by most indicators, cannabis use can develop into cannabis addiction or diagnostically speaking, a cannabis use disorder. Laboratory, epidemiological, genetic, and clinical studies have demonstrated the biological plausibility, existence, prevalence and clinical importance of cannabis use disorders.

Neurobiology and genetics

As reviewed above, the neurobiology of how cannabis produces its effects and the concomitant endogenous cannabinoid system provide biological plausibility

Table G.2.1 Cannabis addiction is similar to other substance addictions

Biological plausibility
• Endogenous cannabinoid system • Cannabis activates dopamine reward pathways • Genetic determinants of cannabis use disorder
Clinically significant withdrawal syndrome
• Similar to tobacco withdrawal • Makes quitting difficult • Contributes to failed quit attempts
Phenomenology of cannabis use disorder
• Full range of abuse and dependence criteria • Multiple social, behavioral, and emotional associations • Moderately less severe syndrome than other substance use disorders
Prevalence
• Greater numbers of cannabis use disorders than of other illicit substance use disorders • Lower percentage of users develop a cannabis use disorder, but many more users of cannabis than of other illicit substances
Treatment
• Number of cannabis use disorder treatment admissions is comparable to that of cocaine and opioid use disorders • Treatment response similar to other substance use disorders

for cannabis addiction. That is, these neural systems and actions closely parallel those of most other drugs for which people can develop addictive problems. In addition, multiple studies have established that genetic influences contribute to the development of cannabis use disorders. Heritable factors – contributing between 30-80% of the total variance in risk of cannabis use disorder – have been reported and genetic linkage studies of cannabis use disorder and earlier stages of cannabis use (including frequency of use) further establish a genetic link to cannabis use problems (Agrawal & Lynskey, 2009). Three sources of genotypic risk (substance specific, substance non-specific and environmentally modifiable) have been identified. First, substance specific genes may impact vulnerability to the general addictive potential of cannabis. Second, specific genes may increase or decrease genetic vulnerability to externalizing behavior problems in general, including adolescent experimentation and misuse of psychoactive substances. Third, certain genes may impact an individual's reactivity to environmental variables such as stress, which may influence risk for substance misuse.

Cannabis withdrawal?

Drug withdrawal is a considered by many as a hallmark of addiction. Thus, one important part of the larger question of whether you can become addicted to cannabis is: does regular cannabis use result in the experience of withdrawal when one stops using? The past 10-15 years of research provide a clear answer to this question; a true, clinically significant cannabis withdrawal syndrome is experienced by many heavy users of cannabis (Budney & Hughes, 2006; Budney et al, 2004).

Cannabis withdrawal symptoms

- Irritability, anger, or aggression
- Nervousness or anxiety
- Sleep difficulty (e.g., insomnia, disturbing dreams)
- Decreased appetite or weight loss
- Restlessness
- Depressed mood
- Physical symptoms: stomach pain, shakiness/tremors, sweating, fever, chills, or headache
- Less common symptoms: fatigue, yawning, difficulty concentrating

The neurobiological basis for cannabis withdrawal was established with the discovery of the aforementioned endogenous cannabinoid system. Studies with nonhuman animals have shown that administration of a cannabinoid antagonist can precipitate withdrawal. Studies with humans have demonstrated that deprivation of THC in some users causes withdrawal symptoms, and that symptoms abate with re-administration of THC, clearly establishing the pharmacological specificity of cannabis withdrawal (e.g., Budney et al, 2007; Haney et al., 2004). Moreover, laboratory and clinical studies with adults and adolescents have provided support for the reliability, validity, and time course of a cannabis withdrawal syndrome (Budney et al, 2004; Chung et al, 2008; Levin et al, 2010; Milin et al, 2008; Vandrey et al, 2005). Most withdrawal effects appear within 24-48 hours of cessation, peak in 2-4 days, and return to baseline within 1-3 weeks. A substantial proportion (25%-95% across studies) of heavy marijuana users reports multiple withdrawal symptoms, with individuals seeking treatment for cannabis use disorders showing the highest rates of withdrawal.

Concern about the clinical significance or importance of this withdrawal syndrome was a primary reason for the omission of this condition from the DSM-IV. However, data now show that cannabis withdrawal is comparable in magnitude and severity to the well-established tobacco withdrawal syndrome (Budney et al, 2008; Vandrey et al, 2008); many adolescent and adult users report that withdrawal symptoms adversely impact their attempts to quit, and lead to the use of cannabis or other drugs to relieve withdrawal symptoms (Copersino et al, 2006); a substantial proportion of adults and adolescents in treatment for cannabis use disorder complain that these symptoms make cessation more difficult; and the severity of withdrawal appears to have predictive validity – adolescents with more



Photo: Tony Fischer

severe withdrawal have a higher probability of poor treatment outcome (Chung et al, 2008; Cornelius et al, 2008).

In summary, the cannabis withdrawal syndrome does not typically include major medical or psychiatric consequences and might be considered "mild" compared with heroin and alcohol withdrawal. However, the emotional and behavioral symptoms that are a hallmark of cannabis withdrawal impede cessation attempts, and as such should be assessed and addressed in clinical settings or when self-quitting.

EPIDEMIOLOGY OF CANNABIS USE DISORDER

As with other drugs, the majority of people who have tried cannabis do not develop a problem with addiction. However, the number of persons who at some time in their lives meet criteria for a cannabis use disorder as defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 2000) is more than double the number that meet such criteria for any other illicit drug (Anthony & Helzer, 1991; Anthony et al, 1994). This reflects the fact that many more people have ever used cannabis compared with having ever used other illicit drugs of abuse. In contrast, the percentage of persons who have ever used cannabis and who then develop dependence is lower (approximately 9% in the US) than with other illicit substances; for example, 15% of those who try cocaine and 24% of those who try heroin develop dependence. The 9% dependence rate among cannabis users may seem low but, given the large number of people who have used cannabis, this results in a substantial number of persons with cannabis use disorders. It is of some concern that the prevalence of cannabis use disorders has been increasing despite stable rates of use (Compton et al, 2004). Increased potency of cannabis available in the streets and earlier age of initiation of cannabis use may contribute to this trend. Early onset of cannabis use (or any substance of abuse) is particularly worrying as it is a strong predictor of

Figure G.2.1 Percent of US 12th grade students reporting marijuana and cigarette use in the past month, 1975 to 2011.



Source: Monitoring the Future study, University of Michigan

both substance use and mental health problems in young adulthood (Degenhardt et al, 2003; Fergusson et al, 2002; Gfroerer et al, 2002)

Severity

In most respects, the phenomenology of cannabis use disorders appears quite similar to that of other substance use disorders (Budney, 2006). Adults in treatment for a cannabis use disorder, on average, have been using cannabis daily for 10 years and made multiple unsuccessful attempts to quit (Budney, 2006; Copeland et al, 2001; Stephens et al, 2002). They experience the full range of symptoms of abuse or dependence. For example, they report continuing to use cannabis despite experiencing social, psychological and physical problems related to their use; they perceive themselves as unable to stop and most experience withdrawal symptoms when they stop abruptly. Moreover, they acknowledge relationship and family problems and guilt associated with using, financial difficulties, low energy and self-esteem, dissatisfaction with their productivity levels, sleep and memory problems, and low life satisfaction (Gruber et al, 2003; Stephens et al, 2002).

Though the phenomenology of cannabis use disorder is similar, there appear to be differences in severity (Budney, 2006; Budney et al, 1998). On average, individuals with cannabis dependence do not meet as many DSM dependence criteria as with alcohol, cocaine or opioid dependence. The withdrawal experience causes discomfort but is not associated with major health risks, and the associated health and psychosocial consequences, although substantial, are on average not as severe. Despite this milder dependence syndrome, quitting cannabis once problematic use has developed does not appear to be any easier than trying to quit other substances (see section on treatment below).

Treatment admissions

Paralleling the rise in cannabis use disorders, admissions to treatment services for primary cannabis use disorder have been dramatically increasing in

some countries (e.g., US, Australia) such that the percentages of those in treatment for cannabis use disorder is comparable to those in treatment for cocaine and heroin use disorders. This may be due to increased number of people developing cannabis use disorders, the growing recognition and acceptability of a need for treatment, and the availability of specific treatments. Moreover, the existence of such treatment programs may raise awareness of cannabis' addictive potential, which may result in more cannabis users contemplating the possibility that it might be a significant problem for them.

Among adolescents, cannabis is by far the most commonly acknowledged substance used among those entering treatment (Substance Abuse and Mental Health Services Administration, 2008). In the US, over 40% of treatment admissions for cannabis use disorder are persons under 20 years of age. Adolescents appear to be more vulnerable to the development of cannabis use disorders than adults, as indicated by more rapid development of cannabis use disorder from time of onset of use. There is a clear need for effective, easily accessible treatments specifically for cannabis use disorders and especially for adolescents.

Summary

Findings from a growing body of multidisciplinary research indicate that debate over whether or not cannabis use can lead to dependence or addiction should be considered obsolete. Cannabis misuse and addiction are relatively common and are associated with significant negative consequences. Moreover, cannabis-related problems reflect a significant public health issue that requires continued attention and action towards developing more effective treatment and prevention interventions.

GATEWAY EFFECT

Cannabis has been described as a "gateway" drug because its use usually precedes use of "harder" drugs such as cocaine and heroin, and frequent cannabis users have a much greater probability than nonusers of using heroin or cocaine in their lifetime. Such data, in addition to the high co-morbidity rates of cannabis use disorder and other substance use disorders, raise the question of whether cannabis use is causally related to use and misuse of other substances. Although cannabis use typically precedes other drug use, so do tobacco and alcohol. Recently, it has become more apparent that the timing of initiation of use of different substances varies geographically and by culture, indicating that drug availability and societal factors likely contribute to specific drug-onset trajectories. Hypotheses for cannabis as a gateway substance include:

- Neurobiological effects of cannabis use may increase sensitivity to the desirable effects of other substances
- Cannabis use increases opportunity for other substance use by placing the user in contact with those who use or sell other drugs
- Use of cannabis may impact cognitive functioning and decision making affecting choice of whether or not to use other drugs
- Common intrapersonal and environmental characteristics determine risk of substance use in general (e.g., conduct problems, neighborhood, neurobiology, parental factors).

Research demonstrates that genes, environmental factors and common pre-existing risk factors account for much – but not all – of the association between early initiation of cannabis use and future other substance use, suggesting that all these hypotheses have merit (Agrawal et al, 2007; Lynskey et al, 2006). However, each of these factors would also explain alternative sequences of the onset of drug use.

SCREENING, ASSESSMENT AND DIAGNOSIS

Assessment of cannabis use and cannabis use disorders is similar to that for other substance use disorders, with formal criteria for clinical diagnoses found in the DSM or the International Classification of Diseases (ICD). Structured or semi-structured diagnostic interviews (e.g., Structured Clinical Interview for DSM-IV [SCID]) are most appropriate for determining cannabis use disorder diagnoses. In addition, the Substance Dependence Severity Scale, a five-item scale designed to measure dependence severity, has been validated for assessing dependence in cannabis users (Miele et al, 2000).

A few cannabis specific instruments for screening for problematic cannabis use have been developed (Piontek et al, 2008). For example, The Cannabis Use Disorder Identification Test is a short screen for DSM-IV diagnosis of abuse or dependence (Annaheim et al, 2008). The Cannabis Problems Questionnaire has adult and adolescent versions that yield a severity score for cannabis-related problems (Copeland et al, 2005; Martin et al, 2006). The Marijuana Screening Inventory (Alexander & Leung, 2006) assesses patterns of use and identifies clinical cases.

Standard instruments that assess all types of substance use problems have a longer history and more data supporting their psychometric properties than cannabis-specific instruments. For adolescents, the CRAFFT is a 6-item questionnaire designed to screen for high-risk alcohol and other drug use (see Table G.2.2). It has excellent psychometric properties with adolescents, is self-administered, and can be used in a variety of health and educational settings (Knight et al, 2002). A positive CRAFFT screen suggests that further assessment of substance use disorders is warranted.

Two instruments that have been used primarily to measure change during treatment rather than as diagnostic or screening tools are the Marijuana Problem

Table G.2.2 Screening for adolescent substance use problems: the CRAFFT questionnaire

C	Have you ever ridden in a CAR driven by someone (including yourself) who was "high" or had been using alcohol or drugs?
R	Do you ever use alcohol or drugs to RELAX, feel better about yourself, or fit in?
A	Do you ever use alcohol or drugs while you are by yourself, or ALONE?
F	Do you ever FORGET things you did while using alcohol or drugs?
F	Do your family or FRIENDS ever tell you that you should cut down on your drinking or drug use?
T	Have you ever gotten into TROUBLE while you were using alcohol or drugs?



"*Millon Porros*" demonstration in Madrid in 2008 seeking legalization of cannabis use

Inventory and the Marijuana Withdrawal Checklist. The Marijuana Problem Inventory yields a severity score of specific cannabis-related consequences (Marijuana Treatment Project Research Group, 2004), and is a useful index of response to treatment. The Marijuana Withdrawal Checklist can be used to assess withdrawal symptom history but has more commonly been used in research studies to examine changes in withdrawal during the early stages of abstinence (Budney et al, 2003). Such information can be used to assess and manage treatment strategies related to concerns about withdrawal. Another withdrawal assessment tool, Cannabis Withdrawal Scale is under development and holds promise for use in clinical settings (Allsop et al, 2011).

Testing for cannabis use

Testing for evidence of recent cannabis use is a vitally important screening and treatment outcome tool for adolescents and adults, as many persons in such contexts may have good reason for not being truthful about their substance use. Multiple methods for reliable and valid urine testing for THC metabolites are available. Easy to use and inexpensive dipstick methods provide qualitative results (yes vs. no) in approximately 2-5 minutes. Other more sophisticated techniques (e.g., gas chromatography-mass spectrometry) are also available but require relatively expensive equipment or transport to a laboratory. Most importantly, for any of these tests, reliability and validity will be high only if specimen collection procedures ensure the integrity of the sample by:

- Observation of specimen provision
- Temperature check and testing for urine concentration level and contaminants
- Personnel with adequate training to accurately interpret the results (Cary, 2006).

Misconception and cynicism are common related to urine testing for cannabis. Clinical staff must develop expertise for collection and testing protocols, and interpretation of results.

Saliva and hair specimens can also be used. However, these technologies have limitations related to their window for detection of cannabis use. For example, current methods for saliva testing can detect only very recent use, while hair testing may detect fairly distant cannabis use and also has the potential for false positives caused by passive cannabis smoke. In summary, use of any biological screening methods requires comprehensive knowledge to facilitate reliable and valid testing and interpretation of results.

TREATMENT AND OUTCOME

People dependent on cannabis typically use the drug multiple times per day, may be ambivalent about its negative effects, acknowledge multiple perceived positive effects, and cost is relatively low; all these factors make quitting difficult. Treatment studies with adults and adolescents indicate that abstinence and relapse rates observed following treatment are highly similar to those observed with other substance use disorders (Budney, 2007; Waldron & Turner, 2008). Below we discuss treatment approaches for adolescents.

Most information on the efficacy of treatment for teens with cannabis use disorders comes from studies that have included youth who use various substances with the understanding that the majority have a primary cannabis use disorder. Multiple types of behavioral interventions have shown promise in randomized clinical trials including (Stanger & Budney, 2010; Waldron & Turner, 2008):

- Group and individual cognitive-behavioral therapy (CBT)
- CBT combined with motivational enhancement therapy
- Motivational enhancement therapy or CBT combined with contingency management, community reinforcement approach counseling, functional family therapy, multidimensional family therapy
- Multisystemic therapy
- Brief strategic family therapy
- Family support network, and
- Family behavior therapy.

The motivational enhancement therapy and CBT interventions that have been tested are similar in scope and duration to those used with adults. The family-focused interventions take advantage of social networks (parents, schools and other social agencies) that are somewhat unique to adolescents. These generally include efforts to address maladaptive family patterns that contribute to substance use (e.g., parent drug use, parent-child relationship problems, parent supervision), make use of resources in the school and criminal justice system, and address problems that might be associated with the teen's peer network. Although not clearly supported by the empirical literature (Dennis et al, 2004; Hendriks et al, 2011) some assert that these behaviorally-based, family approaches produce a more potent effect than those that do not include a family component.

That said, even with the most effective interventions tested to date, observed reductions in substance use have been modest and robust effects on abstinence rates have been difficult to demonstrate. In the largest clinical trial reported to date, 600 adolescents with cannabis use disorders received one of five treatments

(Dennis et al, 2004):

- Motivational enhancement therapy and CBT5 (2 individual and 3 group sessions)
- Motivational enhancement therapy and CBT12 (2 individual and 10 group sessions)
- Motivational enhancement therapy and CBT12 plus family support network
- Adolescent community reinforcement approach counseling, and
- Multidimensional family therapy.

Comparably significant decreases in drug use and symptoms of cannabis use disorder were observed with each treatment. Yet approximately two-thirds of the youth continued to experience significant substance-related symptoms. That is, many never achieved abstinence or substantial reductions in cannabis use, and many of those who were initially successful relapsed. Such modest outcomes are similar to those observed with earlier studies evaluating the aforementioned family-focused and individual/group therapies, indicating a strong need for continued development of more potent adolescent treatment models and interventions (Compton & Pringle, 2004).

Contingency management interventions

A recent evaluation of a novel contingency-management based intervention has shown some promise for enhancing treatment outcomes for teens with cannabis use disorders (also described in Chapter G.1). Contingency management interventions are based on extensive basic science and clinical research evidence showing that drug use and abuse are sensitive to systematically applied environmental consequences, i.e., reinforcement and punishment contingencies (Higgins et al, 2004). Contingency management approaches have become one of the most thoroughly researched and effective behavioral procedures to increase drug abstinence and other treatment targets across *adult* substance-dependence disorders (Higgins et al, 2008; Petry & Simic, 2002; Stitzer, 2006); however, such interventions have received only minimal attention in the adolescent substance use disorder treatment literature.

Contingency management may help address a number of important situational factors that affect treatment effectiveness. First, teens rarely seek treatment on their own accord, but rather are brought to treatment by their parents after being caught either using or getting in trouble because of use at home, school, or by the police. Accordingly, teens frequently do not perceive their cannabis use as a problem and motivation to quit using and remain abstinent is typically low. In contrast, parents usually consider their teens' cannabis use a problem and are motivated to take action. Contingency management for teen cannabis use, as described by Stanger and colleagues (Kamon, 2005; Stanger, 2009) addresses these issues via:

- An incentive program to motivate and reward teens to not use substances, which involves providing tangible incentives for documented abstinence from *all* substances

Table G.2.3 Adolescent Substance Abuse: Contingency Management Intervention*

Intervention components	Description
Motivational enhancement therapy/ cognitive behavior therapy (CBT)	Teens receive individual counseling including two sessions of motivational enhancement therapy followed by 10 sessions of CBT. Sessions address: • The positive and negative consequences of substance use • The teen's goals for the future and for treatment • Coping skills related to substance use (refusal skills, relapse prevention, coping with cravings) and • General life skills (problem solving, mood management, anger management).
Clinic based contingency management	• Teens earn incentives at each visit • Incentives for documented abstinence escalate with continuous abstinence • Substance use or failure to submit a specimen resets voucher values to the starting value, but are reset back to the maximum after three consecutive negative tests. Teens who remain abstinent throughout weeks 1–14 can earn vouchers worth $590.
Twice weekly urine drug testing	Objective testing for substance use is necessary to conduct the abstinence-based contingency management program, and is also necessary for valid evaluation of treatment progress. During treatment, teens submit twice weekly urine samples that are tested immediately in the clinic, with results shared with the teen, parents and clinical staff.
Substance monitoring contract	Parents create a contract specifying rewards the teen earns after each ½ week period of abstinence (documented by teen and parent report, urine drug testing, and parent administered breathalyzers—see Appendix G.2.1 for a model). Parents also specify consequences for substance use that last until the next period of documented abstinence.
Family management curriculum	This curriculum from the "adolescent transitions program" teaches parents basic principles and skills to decrease problem behaviors and increase prosocial behaviors (Dishion & Kavanagh, 2003).
Parent incentives	Parents receive incentives for: • Attending sessions • Attending urine drug testing appointments with the teen • Completing assignments to track teen behavior at home • Document parenting changes, and • Enforcing the substance monitoring contract Parents typically earn about $100 over the 14-week program.

* Stanger et al (2009).

- A behavioral parenting intervention that focuses on the development and implementation of an abstinence-based contract directing parents to provide tangible incentives for drug abstinence and to deliver negative consequences for evidence of continued use, and
- Incentives that motivate and reward parents for adhering to a parent training program and the abstinence contract.

These contingency management components are integrated with weekly individual motivational enhancement therapy/CBT counseling and twice weekly urine drug testing and alcohol breath testing (see Table G.2.3 and Appendix G.2.1).

Clinic-delivered incentive program

Teens receive incentives each time they provide urine specimens that test negative for cannabis and other drugs. In addition, to receive the incentive, parents must report that the teen has not used alcohol since the last scheduled urine test. Parents are provided with disposable breathalyzers and instructed on how to use them. Incentives have a monetary value that increases with each consecutive negative urine test and parent report. Cash is not provided, instead, gift cards/ certificates from various retailers are used.

Parent-delivered contingency management program.

Parents are expected to:

- Model appropriate behavior related to substance use
- Increase monitoring of their youth's behavior
- Learn to develop clear, consistent, and effective consequences for substance use, and
- Develop effective methods to motivate drug abstinence.

Therapists assist parents to develop a contract (see Appendix G.2.1), which includes specific positive and negative consequences that the parent will implement in response to urine and breath test results.

Objective testing

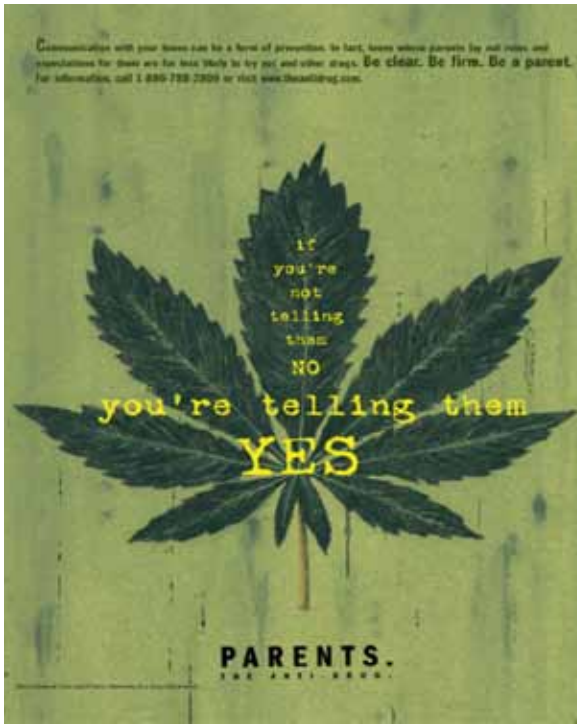
Objective testing for substance use is necessary to conduct the abstinence-based contingency management program and for valid evaluation of progress. Teens rarely show high motivation for abstinence and also typically face aversive consequences from parents, schools, or juvenile justice if they continue to use substances. Thus, they are motivated to give inaccurate self-reports and avoid or manipulate the objective testing procedures. Teens provide urine specimens prior to their counseling session under direct staff observation according to a twice weekly schedule throughout treatment. Specimens are immediately screened for cannabis, cocaine, opioids, benzodiazepines, amphetamines, and methamphetamine, and results are provided to teens, parents, and therapists within 10-15 minutes of providing the specimen if possible. Adulterant testing is conducted to assess for dilution and attempts to directly alter test results.

With cannabis, up to two weeks of abstinence (and sometimes longer) are needed to allow sufficient time for a valid negative test result (e.g., for THCCOOH: 50ng/ml cutoff). This time is highly variable and influenced by individual difference in physiology, amount and duration of cannabis use, and recent activity level. The contingency management program used in Stanger et al (2009) and in adult contingency management studies targeting cannabis use was delayed two weeks before implementing the incentives program. Teens are clearly informed and repeatedly reminded about the need to be abstinent for 1-2 weeks before urinalysis testing will result in a cannabis-negative finding. The other drugs tests performed typically take 3-7 days post use to test negative at their respective standard cutoff levels.

Results

This contingency management program combined with motivational enhancement therapy and CBT was compared with an intervention that included

motivational enhancement therapy, CBT, weekly educational parent sessions, and an attendance-based incentive program. Both treatments included twice weekly urine testing with results provided immediately to the parents and the teen. The contingency management group demonstrated greater rates of continuous abstinence during treatment than the comparison intervention, but this effect did not clearly extend to post-treatment assessments. Overall, rates of cannabis abstinence in both treatment conditions were relatively high compared with those reported in previous studies, suggesting that the comparison condition might also warrant further evaluation to determine its efficacy. The twice-weekly urine testing program provided in both treatment conditions, which systematically reported results to parents, was unique to this study and may be an active component in its own right.



Parent public service announcement

Maintaining treatment effects

An intervention for teens focused on maintaining treatment gains (reducing relapse), "assertive continuing care", warrants mention (Godley et al, 2007). With assertive continuing care, adolescents are assigned a case manager for 90 days after discharge from an inpatient treatment facility. The case manager makes weekly home visits with the goals of engaging the youth in other identified services, development of a new social support system involving pro-social activities, and generally reinforcing strategies to maintain abstinence. In a randomized trial comparing assertive continuing care to usual care, the assertive continuing care intervention was more effective in increasing adolescents' engagement and retention in care, and resulted in higher longer-term abstinence from cannabis.

Pharmacotherapy

Research exploring medications for cannabis use disorder has been stimulated by the increased recognition of the need for cannabis use disorder treatments, combined with new findings about cannabis withdrawal and better understanding of the endogenous cannabinoid system (Benyamina et al, 2008; Hart et al, 2005; Nordstrom & Levin, 2007; Vandrey & Haney, 2009). Unfortunately there is currently no strong evidence supporting any specific medication – thus there are no medications for cannabis use disorder approved by regulatory bodies. Among the many laboratory studies and a few clinical trials that have been published, only one study has assessed a medication for cannabis use disorder in adolescents or young adults. A small open label trial of N-acetylcysteine – a medication targeting glutamate – showed promise for reducing cannabis use in 18-21 year olds with cannabis use disorder (Gray et al, 2010). Preliminary reports from a controlled follow-up study appear to provide further support for the potential efficacy of this medication.

Medications research is targeting a number of different mechanisms. For example, *agonist* medications that have a similar mechanism of action as THC and can either substitute for cannabis or blunt the euphoric effects of cannabis if used

(in the case of relapse), or be used short-term to suppress withdrawal symptoms; CB1 receptor *antagonists* can reduce binding to the receptor and thereby reduce euphoric effects if cannabis were used or, possibly, prompt withdrawal symptoms in the case of inverse agonists. Although some promising data have emerged for one such antagonist, *rimonabant*, concerns regarding its safety (i.e., putatively causes depressive symptoms and suicidality) have stopped investigation and halted its use.

Another approach has been to test medications that might provide symptomatic relief of withdrawal or reduce desire or craving. To date, most studies have been unsuccessful in finding promising candidate medications using this approach. Two medications that improve sleep, lofexidine and zolpidem, have shown some promise for reducing withdrawal symptoms and in particular sleep difficulties that occur with abrupt cessation of cannabis.

Secondary prevention

"Check-up" interventions, originally developed to reach adult cannabis users who were ambivalent about stopping their use or who did not perceive their use to be a problem (Stephens et al, 2007), have recently been adapted for adolescents. An initial US study tested a check-up intervention with teens in grades 9-12 who had used cannabis at least 9 times in the past month (Walker et al, 2006). The check-up consisted of a computerized assessment and two 30-minute motivational enhancement sessions. Teens were recruited with posters and health education lectures and then were randomized to either the check-up intervention or a 3-month delayed treatment condition. Teens in both conditions significantly reduced their cannabis use, yet between-group differences were not observed. A second study with a similar sample of teens compared the same brief motivational enhancement intervention with an "educational feedback control" intervention and a delayed feedback control group (Walker et al, 2011). The two active treatments reduced cannabis use over 3 months with a greater reduction observed in the motivational enhancement condition. Both conditions showed reductions over 12 months with no between-group differences. Three additional studies further demonstrated that brief motivational enhancement-based interventions show promise for reducing cannabis use in adolescents outside a treatment setting (Martin & Copeland, 2008; McCambridge & Strang, 2004; Winters & Leitten, 2007). This body of research clearly shows that cannabis-using teens will engage in brief interventions that address cannabis use, and that these interventions can reduce use. Note that reduction and not abstinence is the most common outcome among teens exposed to these interventions.

In summary, a number of behavior- and family-based psychosocial interventions have been developed that are efficacious for treating cannabis use disorders in adolescents. Unfortunately, as with treatment in adults and for substance use disorders in general, the rates of abstinence are modest. Integrating contingency management-based programs is one way of enhancing response rates, but still many teens do not respond. Clearly, further development of effective treatments will be required to better prevent and meet the needs of those who experience problems related to cannabis use.

RISK FACTORS

In addition to the aforementioned genetic risk for the development of cannabis use disorder – or substance use disorders in general – environmental

factors contribute to the use and abuse of cannabis. Perhaps availability is of most importance. Because of high demand and ease of growing, cannabis is the most widely available illicit drug in the world. Legal policies regarding cannabis possession likely impact access and use rates. Although some argue that "legal use" – such as that in the Netherlands where use of cannabis by adults and regulated sale of small quantities is tolerated – does not increase rates of use and cannabis use disorder, this may be because cannabis is widely available and accessible even in countries where it is not tolerated. In the US, where it is illegal, cannabis is almost as easy for teens to obtain as alcohol or tobacco (Johnston et al, 2009).

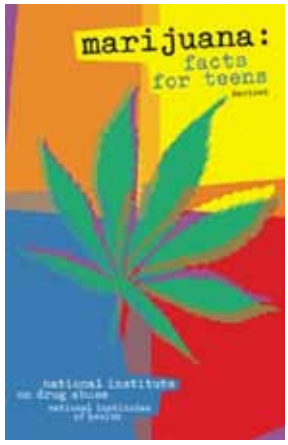
Other factors that strongly predict cannabis use and cannabis use disorders include (Brook et al, 2001; von Sydow et al, 2002):

- Delinquent behavior
- Chaotic home environment
- Low socio-economic status
- Other psychopathology
- Low perceived risk of harm
- Use of other substances
- Use by peers, and
- Use by family members.

Moreover, early initiation of use increases the probability of developing a cannabis use disorder, any substance use disorder, and other psychiatric disorders.



Click on the picture above to access NIDA's publication "Marijuana: Facts Parents Need to Know" and the picture below for "Marijuana: Facts for Teens". Both provide reliable information.



PREVENTION

Given the difficulty in successfully treating cannabis use disorders, prevention efforts become paramount for reducing the consequences associated with cannabis use and cannabis use disorders. Targets and strategies for prevention are similar to those for other types of substance use disorders and are focused on the risk factors mentioned. Educational campaigns, social policies, and media portrayals of cannabis that increase the perception that cannabis is potentially harmful and may lead to problems are likely to reduce the probability of use and delay initiation. Parenting education and training on effective family approaches to discuss and handle substance use in general and cannabis use in particular, are important targets (Stormshak et al, 2011). A number of websites (mentioned elsewhere in this chapter) offer excellent science-based information to guide this process. Similarly teen educational approaches that are balanced, science-based and rational, rather than based on "scare-tactics" are also available and likely to have positive impact. More broadly, particular school-based prevention programs can be helpful (Porath-Waller et al, 2010; Rohrbach et al, 2010). And last, enhanced general education programming and approaches for low socio-economic, high risk youth can be an effective method for reducing or delaying the onset of cannabis use (Tobler et al, 2011).

MEDICAL MARIJUANA AND LEGALIZATION

Controversy related to the potential for medicinal use of cannabis and its legalization has caused confusion and mistrust of the data about cannabis and its potential adverse consequences and benefits. These issues warrant discussion

because laws and regulations can strongly affect a teen's perception of the risk of harm associated with cannabis – and thereby the likelihood that they may try it or decide to use it regularly.

Medicinal use

In 1999, the Institute of Medicine acknowledged the importance of studying the risks and benefits of the use of cannabis and cannabinoids for specific medical conditions. Available data clearly *suggest* that the compounds in cannabis have potential beneficial effects for a number of medical conditions. This is not surprising as oral preparations of pure THC have been approved by regulatory bodies in multiple countries for AIDS wasting syndrome and for cancer patients receiving chemotherapy. The synthetic cannabinoid *nabilone* has been approved for use in cancer patients undergoing chemotherapy. An oro-mucosal spray extract, which contains THC and cannabidiol is approved for use in Canada and New Zealand to manage muscle spasticity in patients with multiple sclerosis and for neuropathic pain in cancer patients.



Vaporizer used to consume cannabis.

The important question, however, is whether *smoked* cannabis should be considered a "medicine" and be prescribed for specific ailments. Arguments for added benefit from smoked cannabis compared with oral or oral-mucosal modes of administration are related to the more rapid onset and absorption of THC that occurs from inhalation of the smoke, and the possible therapeutic contribution of constituents of cannabis other than THC (e.g., delta-8-THC and cannabidiol). Disadvantages include the adverse effects of smoke on the respiratory system and its potential carcinogenic impact, difficulty in determining therapeutic doses and reliably delivering such doses through smoke inhalation, increased probability for intoxication, and the potential to develop a cannabis use disorder with its associated social, cognitive, and behavioral consequences. Currently, the evidence for determining the efficacy and safety of specific doses of smoked cannabis for targeted medical indications does not approach that required by regulatory bodies to even consider approval.

Our rapidly increasing knowledge about the endocannabinoid system has increased optimism for the eventual use of cannabinoids (cannabis-like compounds) as medicines in areas such as treatment of pain, neuromuscular and neurodegenerative disorders, eating or appetite disorders, autoimmune diseases, and other psychiatric disorders (Budney & Lile, 2009). The target of such work is to produce alternative synthetic cannabinoid-based medications that reproduce the putative positive effects of smoked cannabis while reducing the aforementioned concerns. This path might approximate that of opioid medications, which have been developed and marketed for pain despite their abuse potential and substantial side effects, but have not included a smoked formulation for administration.

Discussion of legalization of cannabis can obviously influence how a teen may perceive the potential harm associated with cannabis use. Controversy regarding its legal status has grown since the early part of the 20th century. Pro-cannabis groups have been calling for decriminalization or legalization for many years, with most recent efforts directed at legalization for medical use. Arguments for legalization include:

- Alcohol use and abuse are more harmful and costly
- Regulated and taxed cannabis would provide fiscal benefits to society

and quality control for cannabis

- Addictive potential is relatively low
- Reduce crime related to dealing and prevent criminal status labels and future consequences for those who get arrested, and reduce the costs associated with prosecution
- Cannabis has medical benefits
- Criminalization impinges on personal freedom.

Counter arguments include:

- The psychosocial, health, and psychiatric consequences associated with cannabis misuse and related disorders are substantial
- Reduced cost combined with marketing/advertising would increase use and cannabis use disorders, particularly in vulnerable groups such as teens and those of low socioeconomic status
- Medical potential can be claimed for most substances that are abused and illegal
- Legalization would reduce the perceived harm and increase use, increased use will result in more driving under the influence of drugs and accidents.

Many of these points made by both pro- and anti-cannabis supporters have merit. Policymakers, who must decide how to manage cannabis in their respective cultures, are faced with a most difficult task of balancing multiple factors; most countries to date have sided with arguments related to the government protection of the public, including teens, from a potentially harmful substance.

CONCLUSION

Cannabis misuse, abuse, dependence and withdrawal are real and relatively common problems with significant associated consequences that reflect a clear public health problem, particularly for adolescents and young adults. In most respects, cannabis use and the development of cannabis use disorders approximate what is observed with most other substances of abuse. A reasonable perspective is to acknowledge that some level of cannabis use can and does result in harmful effects. Like all other substances, including alcohol, that have addictive potential, most individuals who initiate cannabis use do not experience significant consequences, but others misuse, abuse, or become dependent and experience adverse outcomes. Fortunately, recent research has provided a wealth of knowledge for guiding the assessment, diagnosis, and treatment of cannabis use disorders, as well as prevention efforts. Hopefully, science will continue to provide more information that will enhance the development, availability and effectiveness of clinical and prevention approaches.



Cannabis coffee shop in Amsterdam

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Appendix G.2.1

SUBSTANCE MONITORING CONTRACT

If <name of adolescent>'s urine drug screen is negative (no drugs detected or reported) and there were no positive or refused alcohol breath tests since the last drug screen, I will:

1. Praise the progress!
2. Ask how I can help them keep up the good work
3. Celebrate their progress by <list rewards>:

_____

_____

_____

If <name of adolescent>'s urine drug screen is positive (drugs detected or reported) and/or there were positive or refused alcohol breath tests since the last drug screen, and/or urine screen is refused, I will:

1. Remain calm!
2. Not give a lecture
3. Ask how I can help them
4. Express confidence that they can do better next time
5. Use the following consequence:

_____

Parent Signature	Date
Teen Signature	Date
Therapist Signature	Date

OTHER SUBSTANCE USE

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Suggested citation: Cheung W, Kit-sum Lam A, Hung S. Other substance use. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Epidemiological studies have shown that substance use is common among adolescents and age of first use is decreasing; a significant proportion of them subsequently develop a stereotypic pattern of use. It is well known that some psychoactive substances have particularly detrimental effects on mental health and cognitive functions, which increases the burden for child and adolescent mental health services. This chapter focuses mainly on the use of substances other than alcohol and cannabis: amphetamines, benzodiazepines, cocaine, codeine, opiates, "club" or "recreational" drugs (GHB, MDMA, Ketamine, and mephedrone), hallucinogens, and inhalants. The terms "substance" and "drug" are used interchangeably.



Click on the pictures to view several teenagers talking about their progression from experimentation of cannabis to abusing multiple substances to addiction (4:10 and 5:13)



EPIDEMIOLOGY

The prevalence of substance use in adolescents varies widely in different epidemiological studies. The Monitoring the Future (MTF) study is an annual large-scale survey of nationally representative samples of secondary school students in the US that has been conducted since 1975. In 2010, 16.8% of the participants had ever used an illicit substance other than marijuana, 11.8% had used in the past year, and 5.7% in the past 30 days (Johnston et al, 2011). Use of inhalants (glue, nail polish remover, gasoline, solvents, butane and propellants) is most common among younger adolescents. Among the 2010 respondents, 7.8% of 8th graders reported having used inhalants by the end of 6th grade but use tends to decline as adolescents grow older. Another important finding was that the proportion of 12th graders in 2010 who reported using prescription (psychotropic) drugs (e.g., amphetamines, sedatives, tranquillizers, and narcotics other than heroin) without medical supervision was 15%, up slightly from 14.4% in 2009.

A similar trend of decreasing use of inhalants with increasing age was also reported among Australian students; while 11% of 12-year-olds had used inhalants in the last month, only 4% of 17-year-olds had used recently (White & Smith, 2009). The survey also found that around 5% of students aged 13 and above had used tranquillizers in the last month and around 2% of students aged 15 and above had used amphetamines in the last month. Another annual survey (Fuller, 2011) to monitor smoking, drinking and drug use among secondary school pupils age 11 to 15 in England found that 18% of students had ever used drugs, 12% had consumed a drug in the last year and 7% in the last month; while 3.8% had sniffed inhalants in the last year, less than 2% had used other drugs. A survey conducted in three vocational schools (age 15-21) in Thailand in 1999 showed that 29% of students reported ever having used methamphetamine. The prevalence of methamphetamine-positive urine test was 10% while opiate-positive urine test was low (0.2%) (Griensven et al, 2001).

In Hong Kong, a survey of upper primary (aged 9-11) and secondary school (12-18) students has been conducted every four years. The 2008/09 survey (Narcotics Division of Security Bureau of Hong Kong, 2011) showed that the proportion of lifetime and 30-day drug-taking among secondary students was 4.3% and 1.5% respectively; the proportion among upper primary school students was estimated to be 1.6% and 0.5% respectively. Among drug-taking secondary school students, 15.6% first used drugs at the age of 10 or below. In contrast to their American or European counterparts, more secondary school students in

Hong Kong used Ketamine (49.4%) than cannabis (35.6%) and upper primary school students preferred cough medicines (37.5%) and paint thinners (30.7%).

NATURAL HISTORY OF SUBSTANCE ABUSE

A 19-year follow-up of a representative population cohort provides some insight about the natural history of drug use from adolescence to adulthood (Chen & Kandel, 1995). The major period of risk for initiation into the use of cigarettes, alcohol, and marijuana is mostly over by age 20. Most of the other drug use is both initiated and stopped before the late 20s. Both the prevalence of high frequency use and the quantities consumed during periods of heavy use of most of the substances (except cigarette smoking) decline in adulthood. The prevalence of prescribed psychotropics use does not show much change over time and usage rates are consistently higher for women than for men. For all drugs in general, however, initiation rates are higher for men while cessation rates are higher for women.

FACTORS INFLUENCING SUBSTANCE USE

Individual factors

Prenatal exposure to substances

- Evidence reveals an elevation of risk for alcohol, cannabis, and cocaine use during adolescence or early adulthood in people prenatally exposed to these substances (Baer et al, 2003; Day 2006; Delaney-Black et al, 2011)
- Risks are not only mediated through a propensity for conduct disorder or other developmental problems but also probably directly related to the influence on intrauterine neural development.

Mark

Mark was a skinny teenager brought in by his school social worker for his irritable mood and aggressive behaviors in the last year. Mark appeared indifferent; he attended only as a favor to the social worker who had been caring for him, even though he did not attend school often.

Mark had a rough childhood. His mother was a teenager when Mark and his elder brother were born. Mark's father left the family shortly after. The two boys stayed with their grandmother until she was killed in a traffic accident seven years later. Childcare arrangements then became disorganized. As an active, curious and impulsive boy, Mark had needed extra attention since he was a toddler. His mother frequently resorted to spanking despite being aware that it did not work with him. Mark was sad after the death of his grandmother; he felt he had no one to talk to when his elder brother became increasingly volatile. In the last few years, he witnessed his older brother snorting ketamine a few times. At home, Mark particularly disliked the men who stayed over with his mother. He was annoyed by the noises they made late at night. Mark was not happy at school either; lessons were boring and sitting in the classroom was a torture, homework was a grueling task every day. He was the class clown; otherwise recesses and physical education were the only fun time for him. Mark often got into trouble with teachers; he felt they unfairly picked on him for trivial matters. In general, teachers commented that he was a clever but naughty, chatty and underachieving student. He was at the bottom in all school examinations except for the first year of elementary school. In fourth grade, he was considered to suffer from dyslexia. However, neither the special educational arrangements set up nor repeating a grade helped him to improve. Regarded by most as a failing student, Mark was not liked by his classmates; nevertheless, he had a few friends outside school.

During the final year of elementary school, Mark became attached to several older teenagers in his neighborhood. He skipped school to hang out with them, staying out late smoking and drinking; this became worse once he started secondary school. Confrontations and scrutiny from teachers resulted in defiance and pushed Mark further away from school. Mark was introduced to snorting ketamine two years ago. He did not like using ketamine but found it hard to refuse friends' offers. He also tried other illicit drugs; "ice" was Mark's favorite – it made him feeling super alert and focused. He noticed he needed larger amounts to get "high" and often needed sleeping pills to tide him over the insomnia and the vivid unpleasant dreams. Lately, his girlfriend complained about him being oversensitive and irritable.

Genetics

- Although most studies focus on alcohol, evidence from family, twin and adoption studies demonstrate the important role of genetics on substance use disorder (Rhee et al, 2003)
- Recent studies shed light on the role of gene polymorphism on individual difference in the response to substance use; a low repeat MAOA allele may exacerbate the deleterious effects of cocaine in the brain (Alia-Klein et al, 2011)

Developmental

- Adolescence is a period of experimentation and risk taking.
- Adolescents feel the need to identify with peers to avoid being rejected by the group.
- Stress from the change in roles and expectations at school or at home
- Using drugs to "escape" and relieve anxiety and unhappiness.

Family factors

- Ineffective, coercive or hostile parenting, abuse, neglect, and poor supervision increase the risk of both conduct disorder and substance misuse (Fergusson & Woodward, 2000; Armstrong & Costello, 2002).
- Parents who use drugs (Haggerty et al, 2007).

Social factors

- Access to substances (e.g., from peers or neighborhood)
- Availability
- Economic deprivation, homelessness
- Exclusion from school and truancy
- Delinquency.



Click on the picture to access Drugscope (UK), an independent center of expertise on drugs that seeks to inform policy development and reduce drug-related risk.

Amanda

Amanda was a quiet, sensitive and perfectionistic 15-year-old girl. Her family had moved frequently from country to country in the last decade as her father held different positions in a multinational corporation. They had moved to Hong Kong six months ago. The school counsellor suggested that Amanda should see a psychiatrist after she was found cutting herself in a school toilet.

Although this was the first time she had slashed herself, Amanda had struggled quietly with every family move. In the past, talking to her mother helped to relieve those feelings but in the last two years she did not want to bother her mother who always looked tired and preoccupied. Amanda worried about her mother who always stayed up late unless she had a few sleeping pills or a few drinks, wondering whether that was related to the frequent arguments with her father.

Leaving the country where she had stayed for three years and where she had made some good friends was very painful for Amanda. She hated listening to her father saying again and again that things would be alright. She was frustrated that he treated her as a small child. Despite trying to study, Amanda could not help ruminating over the family moves, crying herself to sleep for weeks after the move. Waking up not refreshed, she could hardly focus in class. She seldom talked, her new classmates didn't look friendly and her old friends were often offline when she looked for them. Amanda felt nobody could understand her. School became increasingly burdensome; she did not have the energy to finish assignments let alone picking up her guitar, which she previously enjoyed. On weekends, she'd rather stay home munching. She felt unhappy and disappointed with her deteriorating school performance and feared that her predicament had no end. Amanda began stealing sleeping pills from her mother, which made her feel groggy but also relaxed. She soon realized that a few of those pills plus a few hours of privacy made her bedroom a haven, her mind free from all the troubles. She then began taking these pills even during the day. However, outside her bedroom, her situation did not improve, things actually got worse. On the morning in which she received the term results, Amanda felt absolutely defeated having failed two subjects. She locked herself in a toilet, wept and cut herself.

Table G.3.1 Characteristics of commonly misused substances

Substance	Physical form	Preferred mode of consumption	Detection time (Urine)[1]
Benzodiazepines	Tablet	Ingested or injected	3 days
Cocaine	Base (less water insoluble)	Smoked	24 – 96 hrs
	Salt (highly water soluble)	Snorted or injected	
Codeine	Liquid, capsule, tablet	Ingested	24 – 72 hrs
Morphine	Capsule, tablets, liquid	Ingested, injected	24 – 72 hrs
Dextromethorphan	Tablet, syrup	Ingested	(3-5 days)
GHB (γ-hydroxybutyrate)	Liquid or white powder	Ingested	5 – 12 hrs
Heroin	Powder	Smoked, inhaled, injected	24 – 72 hrs
Ketamine	Crystalline powder or liquid	Snorted, ingested, injected	24 – 72 hrs
MDMA (ecstasy)	Tablet	Ingested	24 – 72 hrs
Mephedrone	Powder or capsule	Snorted, ingested	24 – 96 hrs
Methamphetamine	Crystal (”ice”), powder	Inhaled from water pipe, smoked, injected	24 – 72 hrs
Volatile alkyl nitrites (popper)	Volatile liquid in ampules	Inhaled	24 – 48 hrs
Organic Solvent	Gases or clear liquid	Sniffed, inhaled	24 – 72 hrs
PCP (phencyclidine)	Powder, tablet, liquid	Ingested, smoked, injected	14 – 30 days
LSD (Lysergic acid diethylamide)	Tablet, capsule, liquid, licked off paper, injected	Ingested, inhaled, snorted, smoked	1.5 – 5 days
Zopiclone	Tablet	Ingested	24 – 72 hrs

[1] The duration of detection is variable and depends on the route, dosage, duration and pattern of administration, individual metabolism and laboratory essay cutoff.

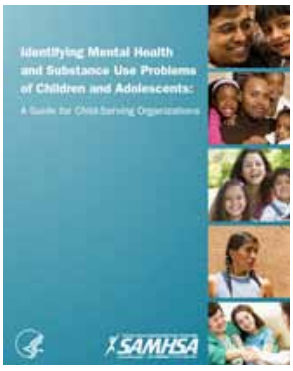


Click on the pictures to view “Facts about Drug Addiction” a clip that explains how drugs work (2:00)

SCREENING

There are several well validated screening tools to evaluate whether a youth may or may not have a drug problem; the results help to determine whether further assessment is needed:

- *CRAFFT* (see Appendix G.3.1) is a 6-item self-report tool that screens for use of both alcohol and drugs in adolescents. In one study, a cut-off score of 2 or more "yes" answers has a sensitivity of 92.3% and specificity of 82.1% (Knight et al, 1999). It appears to be a valid means of screening adolescents for substance-related disorders in adolescent clinics and in multi-ethnic adolescent populations (Knight et al, 2002; Subramaniam et al, 2010).
- *The Drug Abuse Screening Test for Adolescents (DAST-A)* is a 27-item self-report instrument that directly queries adolescents about adverse consequences experienced as a result of drug use. DAST-A scores greater than 6 yielded sensitivity, specificity, and positive predictive power of 79%, 85%, and 82%, respectively (Martino et al, 2000). DAST-A has good reliability and validity for screening psychiatrically ill adolescent inpatients for substance abuse problems.
- *The Assessment of Substance Misuse in Adolescence (ASMA)* is an 8-item questionnaire for adolescents not known to treatment services. Two cut-off scores have been suggested: a rating of "at risk" (score greater than 8) detected weekly or daily drug use with 85% sensitivity and 95% specificity; a rating of "problem drug use" (score greater than 12) detected daily drug use with 36% sensitivity and 99% specificity (Willner, 2000).



Click on the picture to access the monograph "Identifying Mental Health and Substance Use Problems of Children and Adolescents: A Guide for Child-Serving Organizations"

CLINICAL ASSESSMENT

Good assessment is a key aspect of the management of substance use disorders. Apart from information collection, it offers an opportunity to engage, educate and motivate the young person for change, even in the first encounter. Gaining an understanding of how patients conduct their lives, their aspirations and unmet needs, together with the pattern and impact of drug use are important in formulating the management plan.

General issues

- Be vigilant; look for signs of drug use
- Develop good rapport by maintaining an empathic and non-judgmental attitude to encourage disclosure of the drug misuse problems
- The goals and process of assessment must be made clear to the young people and their parents
- Be familiar with the local laws governing confidentiality about substance abuse and explain them to patient and parents
- Parents' involvement should be encouraged
- Because of the relatively short history and the developmental context (e.g., living with family) substance use disorders may manifest in different ways in adolescents than in adults



Click on the picture to access the US National Institute of Drug Abuse (NIDA), one of the best sites for substance misuse: it is reliable and contains many useful resources. NIDA supports and conducts research across a range of disciplines.

Table G.3.2 Effects of commonly misused substances

Substance	Pharmacology	Acute effect	Withdrawal syndrome
Benzodiazepines	$GABA_a$ receptor agonist; increase postsynaptic Cl^- influx	Sedation, relaxation, euphoria, impaired concentration, disorientation, drowsiness, confusion, incoordination, tremor, amnesia	Insomnia, anxiety, tremor, tachycardia, hypertension, diaphoresis. Transient visual, tactile, or auditory hallucinations or illusions; headache. Seizures.
Cocaine	Presynaptic dopamine, norepinephrine, serotonin reuptake blockade; release (mild) Na channel blockade.	Euphoria, enhanced concentration, sense of power and alertness, talkativeness, reduced appetite, anxiety, restlessness, panic attacks, irritability, paranoia, delusions, hallucinations.	Fatigue, difficulty concentrating, craving, anhedonia, vivid unpleasant dreams, myalgia, psychomotor retardation-agitation, hyperphagia-anorexia, insomnia or hypersomnia.
Codeine	Opioid analogue, mu-opioid receptor agonist.	Cough suppressant, analgesia, euphoria, drowsiness, depression, constricted pupils.	Irritability, agitation, insomnia, lethargy, depressed mood, suicidal ideation, lacrimation, diarrhea.
Morphine	mu-opioid receptor agonist.	Euphoria, sense of well-being, drowsiness, respiratory depression, constricted pupils, analgesia, decreased awareness.	Irritability, agitation, anxiety, insomnia, tremor, chills, runny nose, dilated pupils, pilo-erection, bone pain, abdominal pain, loss of appetite, vomiting, diarrhea.
Dextromethorphan	Opioid analogue, NMDA receptor antagonist increasing the synthesis and release of serotonin, as well as inhibiting the reuptake of serotonin	Euphoria, dissociation and dream-like experiences, hallucinations, drowsiness, dizziness, slurred speech, vomiting, diarrhea, pruritus.	Insomnia, nausea, hyperhidrosis, depression, difficulties with thinking and memory.
GHB (gamma-hydroxybutyrate)	Activates $GABA_b$ receptor, and a distinct GHB receptor.	Euphoria, disinhibition, drowsiness, slurred speech, loss of motor control, enhanced empathy and sexual intimacy.	Insomnia, anxiety, agitation, delirium, hallucinations, muscular cramps, autonomic instability.
Heroin	mu-opioid receptor agonist	Euphoria, lethargy, sense of well-being, drowsiness, constricted pupils, hypoactive state.	Insomnia, anxiety, agitation, tremor, chills, runny nose, dilated pupils, increased heart rate and blood pressure, bone pain, cramps, abdominal pain, loss of appetite, vomiting, diarrhea.
Ketamine	NMDA receptor antagonism, enhancing glutamate release.	Analgesia, numbness, amnesia, dissociation, disorientation, hallucinations.	Fatigue, insomnia, irritability, depression.

GABA: gamma-aminobutyric acid; 5-HT: 5-hydroxytryptamine (serotonin); MDMA: 3,4-methylenedioxy-N-methylamphetamine; NMDA: N-Methyl-D-aspartic acid.

Table G.3.2 (continuation)

Substance	Pharmacology	Acute effect	Withdrawal syndrome
MDMA (ecstasy)	Post-synaptic serotonin receptors agonist.	Empathy-enhancing, heightened confidence & sense of well-being, mild depersonalization and derealization, jaw clenching, thirst, dry mouth, restlessness, impaired balance, poor concentration, reduced appetite, dizziness, bruxism, diaphoresis.	Depression, anxiety, impaired concentration.
Mephedrone	Stimulate the release and then inhibit the reuptake of monoamine neurotransmitters.	Euphoria, increased concentration, talkativeness, urge to move, empathy, jaw clenching, reduced appetite, insomnia, headache, nausea, palpitations, increased sex drive, excessive sweating and cold blue finger/toes.	Tiredness, insomnia, nasal congestion, impaired concentration, irritability, blackouts, depression, anxiety, unusual sweat odor, increased appetite and craving.
Methamphetamine	Low dose: dopamine and norepinephrine reuptake blockade. High dose: increases dopamine, norepinephrine and serotonin release.	Euphoria, enhanced wakefulness, anxiety, reduced appetite, increased physical activity, excitement, anger, hallucination and paranoid delusion, impaired judgment.	Fatigue, insomnia or hypersomnia, vivid unpleasant dreams, mood lability, anxiety, depression, irritability, violence, paranoid psychosis, suicidality, motor stereotypies.
Volatile alkyl nitrites (popper)	Potent vasodilator and relaxation of smooth muscles.	Heat sensation and excitement	Craving, tachycardia, diaphoresis.
Organic solvents	Unknown.	Excitation, disinhibition, drowsiness, light-headedness, agitation, anesthesia and poorly coordinated movements.	Headaches, nosebleeds, dry cough, anxiety attacks, poor appetite, tension, nausea and vomiting, chest pains, dizziness, depression, insomnia.
PCP (Phencyclidine)	NMDA receptor antagonist, enhancing glutamate release.	Agitation, euphoria, nystagmus, ataxia, slurred speech, confusion, delirium, psychosis.	Vocalizations, bruxism, diarrhea, oculomotor hyperactivity, tremor, pilo-erection, somnolence, seizures.
LSD (lysergic acid diethylamide)	5-HT_{2A} agonist.	Heightened sense, vivid hallucinations, synesthesia, derealization, panic reactions, autonomic hyperactivity (pupil dilation, pilo-erection, diaphoresis, tachycardia, hyper-reflexia, tremor), impaired coordination.	Not documented
Zopiclone	α1,2,3 and 5 of $GABA_A$ receptors agonist	Reduces sleep latency, increases the slow-wave sleep.	Similar to benzodiazepines.

GABA: gamma-aminobutyric acid; 5-HT: 5-hydroxytryptamine (serotonin); MDMA: 3,4-methylenedioxy-N-methylamphetamine; NMDA: N-Methyl-D-aspartic acid.

- Clarify the young person's understanding of symptoms
- Care for the general health needs and drug related problems, whether or not the patient is ready to stop using drugs

History

The following information needs to be obtained (see also Chapter A.5):

- Substances used (current and past), for each type:
  - Age at first use
  - Frequency
  - Duration
  - Minimum, maximum and usual quantity consumed
  - Route of administration
  - Substances taken in combination
- Binging, memory loss and overdose episodes
- Accidents and injuries related to substance use
- Previous attempts to stop using
- Withdrawal symptoms
- Presence of psychotic symptoms and their association with drug consumption
- Symptoms of psychological or physical dependence
- Immediate risk factors:
  - Overdoses, deliberate self-harm and attempted suicide
  - Injecting behavior
  - Multiple substance use
- Co-existing psychiatric problems (e.g., depression, conduct disorder, psychosis, ADHD)
- Substance use in risky contexts
  - Substance use in the presence of family members
  - Sexual exploitation or risky sexual behavior
  - Criminal behavior
- Physical problems
  - Infections (e.g., hepatitis B/C, HIV, venereal disease)
  - Urological problems related to ketamine use.



Click on the picture to access Street Drugs, a website with information specifically for students, parents, teachers, and health professionals. The site also has research reports, frequently asked questions and materials such as posters and interactive media.

It is necessary to also obtain information about patients' understanding of their substance use by enquiring about:

- Level of knowledge of substances and associated risks
- Where, how and with whom they take substances
- Who else among their friends and family uses drugs
- Whether, according to the patient, substances are being used to control mood, thoughts or behavior
- Their understanding about how substance use affects their lives
- Hopes and fears in relation to substance use and being drug free; previous experiences of being drug and alcohol free
- Family's views on substance abuse
- Available supports if changing substance use behavior

Becky

Becky was 16 when first admitted to the psychiatric unit of a general hospital after being brought by the police. According to the admission notes, she was "hysterical" and attempted to jump from the roof of a building after a fight with her boyfriend. Becky was quiet and settled after the second day of her admission remaining cooperative during the ten days of her hospital stay. Assessment revealed that Becky had quit school a year earlier and done nothing since then. She had a poor relationship with her family and they got used to her being absent for days at a time. For a week before the admission, Becky was upset about her boyfriend dating one of her close friends. She confronted them a few times but they never admitted it. She felt depressed, angry and betrayed but denied intending to kill herself. She described herself as unusually "out of control" when she threatened to jump from the roof. Physical examination and laboratory investigations, including urine toxicology screening, did not reveal abnormal findings; pregnancy test was negative. Becky was mostly quiet in the ward. Her mood improved gradually. No abnormal behaviors were observed throughout her admission. Becky was diagnosed with adjustment disorder.

She was expected to attend a clinic for follow up two weeks later but turned up one month later. In that visit, Becky disclosed that she had been hearing voices talking to her for many weeks until several days after her hospital admission. She concealed that because she believed she would be kept in hospital longer. She stressed again that she had not taken any illicit drugs but had been taking slimming pills for several weeks before the incident. When she stopped taking those the voices also stopped. Becky appeared calm and friendly in the following two clinic visits but the service subsequently lost contact with her. She reappeared in the clinic five months later disclosing she had been smoking "ice" with her friends for nearly a year. Throughout this period, she heard voices talking to her from time to time. She was uncertain whether her hallucinatory experiences were related to her drug use because sometimes those voices were exceptionally long lasting; she was 3-months-pregnant.

- Expectations of treatments and motivation – according to the stages-of-change model (Prochaska & DiClemente, 1992).

A good understanding of the psychosocial impact of substance use is also necessary for diagnosis and to plan treatment, this would include a thorough grasp of young people's lives:

- How they conduct their lives
- In what activities they engage
- Who has an influence on them
- How they perceive their lives
- What aspirations they have
- What are their unmet needs
- What are the consequences of their substance abuse for them
- What are their goals and aspirations.

DIAGNOSIS

Abuse

To establish a diagnosis of substance abuse in DSM-IV (American Psychiatric Association, 1994), there should be a pattern of recurrent use resulting in failure to fulfil major role obligations at home, work or school; legal problems; social or interpersonal problems; and physically hazardous situations within a 12-month period. The parallel category in ICD-10 (World Health Organization, 1992) is termed as "harmful use" and emphasizes actual damage caused to mental or physical health, but not to adverse social consequences for the substance user.

Dependence

Making a diagnosis of substance dependence according to DSM-IV requires meeting within a 12-month period three of seven criteria: tolerance, withdrawal symptoms, compulsive nature of use, failure to quit, amount of time spent seeking

drugs, giving up on other more appropriate activities, and use despite adverse consequences. Similar criteria are required according to ICD-10. For further discussion of the validity of the distinction between abuse and dependence see section on DSM-5 below.

Despite diagnostic criteria in both classification systems having been used for many years, there are still problems when applying them to adolescents. The criteria for tolerance, withdrawal and medical complications may not be applicable to adolescents because of the relatively short history of substance use.

Proposed changes for DSM-5

In the proposed changes for DSM-5, the overall section is to be labelled "addiction and related disorders," which would include gambling – a non-substance or behavioural addiction. A new category of "substance use disorder" is proposed, which would combine the two current diagnoses of "substance abuse" and "dependence" (on the basis that this historical distinction is not supported by empirical evidence), with severity rated according to the number of symptoms. The criterion "legal difficulties" is to be eliminated while "drug craving" is to be added. Tolerance and withdrawal symptoms are not to be counted towards the diagnosis when patients are involved in an appropriate medical treatment program for a problem such as pain, anxiety or depression unless they have other symptoms of aberrant behavior demonstrating compulsive drug seeking (O'Brien, 2011). The makers of DSM-5 hope this would clear misconceptions and avoid patients with other psychiatric disorders having their successful treatment discontinued to address their "dependence" (Heilig, 2011).



Click on the picture to access Erowid, a useful website with information about everything to do with drugs

Whether the proposed changes for DSM-5 are clinically useful in separating patients with patterns of substance use that would respond to brief psychological interventions from those needing more substantial treatment requires further exploration (Poznyak et al, 2011). Criticisms include that with no other alternative than acute intoxication, individuals who use psychoactive substances infrequently without major indications of dependence are unlikely to have their substance-related problems diagnosed in emergency rooms, hospital wards and out-patient clinics, thus unlikely to receive early intervention – proven effective with non-dependent substance users (Babor, 2011). Furthermore, by collapsing the diagnosis of abuse and dependence into a single disorder, it is possible to make a diagnosis of substance use disorder with as few as two psychosocial criteria and the subjective judgment of the clinician (Meyer, 2011). Despite some positive changes, the proposed DSM-5 criteria for substance use disorders do not go very far in improving their diagnosis in youth; targeted developmental adjustments, including clearer operational symptom definitions, are needed to ensure that DSM-5 validly identifies substance use disorders across all developmental periods (Winters et al, 2011).

Drug testing in adolescents

Current practice parameters (Bukstein et al, 2005) state that toxicology "should be a routine part of the formal evaluation and ongoing assessment of substance use both during and after treatment". Self-reports by drug using adolescents are often unreliable, especially in the community, school and legal settings. Denial, social desirability responses, concern over legal or other perceived consequences are likely to result in an under-reporting of drug use in this age

group. Drug testing could provide objective information to the treating clinician for screening, diagnosis and to monitor adherence to treatment and outcome.

In clinic settings, drug testing is practical and cost-effective using point-of-care immunoassay test kits on urine samples to detect the presence of substances of abuse. To confirm a positive result, gas chromatography and mass spectroscopy may be required in some circumstances (e.g., if legal penalties apply). The main limitation is that the period during which most substances can be detected range from 1-3 days and care must be taken to prevent tinkering with the sample (sample should be provided under direct supervision by same-sex staff; pH or specific weight of the sample helps to check whether there is dilution; measuring the temperature is also helpful to prevent tampering). Point-of-care immunoassay tests on saliva can also be performed; however, they are more expensive and detection period is shorter (6-12 hours). Hair testing detects drug use in the last 3 months (except for the previous 7 days). Samples are difficult to adulterate but perming, bleaching and straightening treatments may alter drug levels in hair samples; the test is expensive and cannot be done on-site. Sweat testing prospectively investigates substance use over 1-3 weeks. The patch collects traces of the substances and their metabolites left from evaporated sweat; it is also expensive although a little less than hair testing. Drug testing of blood samples is useful in avoiding tampering but is invasive and costly.



Click on the picture to view a high school student talking about his battle with drugs (10:05)

It is important to consider several factors before conducting a drug screen:

- Adolescents are expected to enter into a confidential relationship with the therapist if they are shown to be competent to give consent. Hence, it is a good practice to explain the needs and implications (both of positive or negative results) of the drug screen and obtain informed consent from the adolescent
- It is not advisable to request for a drug screen solely because of parental suspicion
- The therapist is encouraged to discuss with the adolescent the limits of



Sniffing solvents

confidentiality, who will be informed of the results of the drug screen and what the process will be.

It is important to bear in mind that substances such as amphetamines, cocaine, and opiates are not likely to be detectable in the urine after 1-4 days (see Table G.3.1). The availability of these laboratory tests does not obviate the need for careful screening via interview and self-report, but they are an important tool in the assessment and monitoring of substance use. Moreover, use of drug screens increases the reliability of the adolescent's self-reported substance use, which can have therapeutic value in itself. One approach to requesting a drug screen is to tell the adolescent that it is likely to be positive if they have used cannabis in the past month. If the adolescent endorses substance use, the clinician may not wish to obtain a drug screen. Another common clinical and research practice is to consider a refused drug screen as equivalent to a positive screen. (Goldstein, 2009)



Click on the picture to access information about club drugs provided by NIDA (US)

TREATMENT

After a comprehensive assessment, the young person and their parents should be involved in planning the treatment. Treatment goals will largely depend on the motivation and circumstances of each individual. It is useful to view the substance abuse as a symptom of a complex dysfunction in the young person, the family, school and social environment requiring an overall management plan, which should also address issues such as attachment, educational needs, physical and psychological health, lifestyle, peer relationships and psychological stress in a coordinated manner.

The level of care required will be determined by the intensity and complexity of the presenting problems and the needs of the patient. The management plan should be realistic, acceptable to the patient and the family, and feasible within the available resources. Adolescents whose frequency of drug use is low and drug-related problems mild, are best managed by their family physician. For those who abuse drugs frequently and have moderate to severe drug-related psychiatric comorbidities, they are best managed by a child and adolescent mental health team. Referral to a specialized addiction team is appropriate if the complex needs of the youngster cannot be met by the lower level of care.

Some interventions directly address the substance use and include: psycho-education, enhancement of motivation, harm reduction interventions and relapse prevention. Others target different aspects such as social skills, family relationships, mood, impulse control, mental and physical health.

Brief interventions

These are opportunistically offered in settings such as family clinic, social care settings and emergency departments to people with limited contact with drug services who use drugs but do not have a full blown drug use disorder. Information and advice about reducing the risks of drug misuse (e.g., exposure to blood-borne viruses) are to be provided to all of them during routine contacts or opportunistically. Sessions aimed at enhancing the motivation to change drug-use behavior can thus be arranged. During the session, therapists need to explore ambivalence about drug use and possible treatment. Increased rates of abstinence from heroin, cocaine, and amphetamine have been demonstrated with this minimal intervention (Bernstein et al, 2005; Baker et al, 2005).

Self-help groups

Narcotic Anonymous and Cocaine Anonymous are the best examples. They are based on the 12-step principles, which emphasize abstinence as the goal of treatment (see also Chapter G.1). While definite evidence of effectiveness is still lacking, weekly or more frequent 12-step participation seems to be associated with lower drug and alcohol consumption (Fiorentine, 1999). Possible mediating effects of social support and religious service attendance in maintaining long-term recovery among adolescents have also been postulated (Chi et al, 2009).

Motivational interviewing

Motivational interviewing is a technique that helps patients explore and resolve their ambivalence about drug taking. This is achieved through reflective listening, development of discrepancy, sidestepping resistance by responding with empathy and understanding, and supporting self-efficacy in order to commit and reach a decision to change (Miller & Rollnick, 1991).

The therapist is encouraged to adopt a non-judgmental stance and steer the patient to express concern and identify problems related to the substance abuse. Through empathetic listening and reflection of the patient's response in a modified form, the patient is encouraged to express the discrepancy between his personal ideal goals and the actual behaviors (e.g., desire to be a top hair-stylist but to continue drinking alcohol despite hand tremor). This helps to increase the motivation to change.

To reduce the resistance to change, the therapist should avoid confrontation and argument with patients (e.g., whether methamphetamine use enhances one's working performance or not). Instead the therapist should be able to understand the patient's frame of reference, filter and amplify the patient's encouraging thoughts, elicit statements from the patient that encourage change, match the stage of change of the patient, and express acceptance and affirmation of the patient's freedom of choice and self-direction (Rollnick & Miller, 1995).

Drug users who received motivational interviewing were more likely to reduce their drug use, comply more with treatment requirements, stay longer in treatment, have fewer post-treatment psychiatric problems, become abstinent more often and have fewer relapses (Baker et al, 2001; Daley et al, 1998; Macgowan & Engle, 2010; Saunders et al, 1995).

Relapse prevention

Relapse prevention combines behavioral skills training, cognitive training and lifestyle change (Marlatt & Gordon, 1985). The goal is to teach drug users to identify, anticipate and cope with the high risk situations that may lead to relapse. Patients are encouraged to set achievable behavioral goals to enhance their self-efficacy. Myths about the perceived effects of drugs on the patient should be clarified. Reframing the meaning of events leading to lapses helps to minimize the sense of failure, encourage the establishment of a lapse management plan and reduce the chances of relapse. In addition, patients are encouraged to increase their engagement in rewarding or stress-reducing activities in their daily routine to enhance the self-efficacy.

Review on 24 interventions focusing on substance use showed that relapse prevention has comparable effectiveness to other active treatments (Carroll, 1996), may reduce the intensity of relapse episodes if relapse occurs and has significantly better outcomes even for more impaired substance abusers (Carroll et al, 1991; Carroll et al, 1995). A recent extensive review found that self-help interventions based on a relapse prevention approach showed a significant overall effect in increasing long-term abstinence in smokers (Agboola et al, 2010). Another meta-analysis of 53 controlled trials of CBT primarily based on the a relapse prevention approach showed that 58% of individuals who received CBT had better outcomes than those in comparison conditions (Magill & Ray, 2009).

Contingency management

Contingency management is a type of reinforcement program to motivate drug users to abstain by rewarding them with cash or vouchers for shopping or privileges such as take-home methadone (see also Chapters G.1 and G.2). Abstinence is usually assessed through urine drug testing. The amount of the reward (e.g., the monetary value of the vouchers) usually increases with the increasing duration of continuous abstinence (e.g., number of consecutive drug-free urine tests). It has been found that contingency management is useful for non-responsive patients (Gossop, 2003).



Click on the picture to view a clip that can be recommended for parent education on teen drug use (3:39)

Family-based interventions

Family-based interventions have shown some success in decreasing substance use, reducing the risk for further substance involvement, better retention in treatment and bolstering protective factors in multiple domains of the adolescent's life.

Multi-dimensional family therapy aims to change adolescents' drug abusing lifestyle into a developmentally normative way of life, to improve functioning, to increase parents' commitment and improve their parenting skills and communication with the adolescent (Liddle, 2002). Multi-dimensional family therapy seeks to reduce risk factors and promote protective factors in the individual, family, peer and school domains, reduce the substance use and delinquency (Liddle et al, 2004; Rowe et al, 2003; Rowe 2010). A study found that multi-dimensional family therapy produced superior treatment outcomes in youth with more severe drug use and greater psychiatric co-morbidity when compared with individually focused cognitive-behavioral therapy (Henderson et al, 2010).

Pharmacological treatment

Pharmacotherapy for young people who regularly misuse substances can be used to reduce immediate harm from substance misuse, stabilize the young people and enable them to move to abstinence (Department of Health UK, 2007).

Pharmacological treatment is useful in:

- Treatment of drug withdrawal
  - During the process of detoxification
  - To eliminate or reduce the severity of withdrawal symptoms when the physically dependent user stops taking drugs

- Substitute treatment (also called maintenance or replacement therapy)
  - The prescription of a substance with similar pharmacological action to the drug of dependence, but with a lower degree of risk
  - To reduce the exposure to risk behaviors and stabilize health and social functioning before addressing the physical adaptation dimension of dependence
- Relapse prevention
  - To prevent relapse after detoxification.

Benzodiazepines dependence

Detoxification of patients who suffer from benzodiazepine dependence, rare in the young, should be carefully planned and closely monitored for presence of withdrawal symptoms like insomnia, restlessness, muscle spasm and seizures. Monitoring mental state and suicidal risk is also necessary. Inpatient detoxification is best considered for those whose compliance was poor in the past or who are at risk of developing severe withdrawal symptoms such as convulsions. A long acting benzodiazepine (e.g., diazepam) in a gradually reducing dose regimen is widely used in the detoxification process. Prescription of benzodiazepines as maintenance treatment is not recommended.

Stimulant dependence

Symptoms like craving, insomnia or hypersomnia, lethargy, agitation and depression, are reported when a regular user stops taking stimulants. However, no medication is effective for the treatment of amphetamine withdrawal (Shoptaw et al, 2009). The presence of depressed mood, irritability, violent and suicidal ideation during the withdrawal period requires close monitoring. Psychotic episodes related to stimulant use are usually short-lived and subside spontaneously after cessation of use. Substitute treatment (e.g., bupropion, dexamphetamine, methylphenidate, modafinil, mazindol, methamphetamine and selegiline) is not recommended (Castells et al, 2010; Department of Health UK, 2007).



Click on the picture to access a website about amphetamines created by Turning Point Alcohol and Drug Centre in Melbourne (Australia). It offers self-help information and treatment options for methamphetamine users and useful information for families and health professionals.

Opiate dependence

Opiate withdrawal can be very uncomfortable but is rarely life-threatening. Patients usually complain of musculoskeletal pain, insomnia, nausea or vomiting, gooseflesh, chills, sweating, running nose, yawning and watery eyes. Withdrawal symptoms can be relieved by:

- Gradually reducing the dose of methadone
- Buprenorphine
- Clonidine and lofexidine
- Symptomatic treatment
- Acupuncture.

When the patient is not ready for complete abstinence from opiates, methadone maintenance treatment can be suggested as substitution therapy (though this is not accepted or legal in some countries). Methadone maintenance helps to relieve withdrawal symptoms, eliminate craving and block the euphoric effects of illicit opioids. Methadone maintenance also helps to reduce the transmission of infections associated with intravenous injection such as hepatitis and HIV because it helps to reduce injecting, sharing needles and risky sexual behavior (e.g., multiple partners or exchange of sex for drugs or money) among

heroin dependent individuals (Gossop et al, 2002; Gowing et al, 2011; Sorensen & Copeland, 2000). It is the treatment of choice for pregnant adolescents who abuse heroin.

Despite abundant evidence about its usefulness in reducing the harm of opioid dependence, there is controversy about methadone maintenance in many countries. This is because methadone maintenance is regarded as a legally available opioid. In addition, it is also not uncommon to find that some patients receiving methadone maintenance also use heroin.

Buprenorphine is a partial opioid agonist-antagonist at least as effective as methadone as a substitution agent in reducing illicit opioid use and retaining patients in treatment (Johnson et al, 2000). When compared with methadone, buprenorphine is safe – lower risk of overdose – and is well tolerated. Fewer withdrawal symptoms are also reported during detoxification. A combination of buprenorphine and naloxone (Suboxone®) has replaced the previous buprenorphine preparation (Subutex®) to prevent the drug from being used intravenously. Suboxone® comes as sublingual tablet and film. Both of them are to be taken once daily. Suboxone® film, in contrast to sublingual tablet, has a better taste and takes shorter time to dissolve.



Click on the picture to access the Australian National Inhalants information Service that provides information about inhalant abuse.

Naltrexone is an oral long-acting opioid antagonist which blocks or reduces the effects of opioids including euphoria. Naltrexone is well tolerated at the usual dose, only becoming aversive by precipitating withdrawal symptoms in persons using opioids. It may play a role in preventing relapse to opioid use after withdrawal (Marsch et al, 2005), although it is used more often in the management of alcoholism. Opiate-containing medications (e.g., cough syrup, pain killers) should be avoided when a patient is on naltrexone. Because of the risk of hepatotoxicity, baseline tests and regular monitoring of liver function is recommended.

Inhalant abuse

There is no specific medication available for detoxification from inhalants. During acute intoxication, the patient should be assessed and treated symptomatically. Hydration and cardiorespiratory status should be monitored closely. A calm and supportive environment is necessary. Antiarrhythmic drugs or beta-blockers are sometime necessary to stabilize the myocardium; sympathomimetics or bronchodilators should be avoided. Comorbid psychiatric conditions should be treated accordingly (Williams et al, 2007; Baydala 2010).



Click on the picture to watch a clip from the fictional movie "Samson and Delilah" depicting petrol sniffing in aboriginal Australians and its effects. Samson and Delilah's world is small—an isolated community in the Central Australian desert. When tragedy strikes they turn their backs on home and embark on a journey of survival. Lost, unwanted and alone they discover that life isn't always fair, but love never judges (14:56)

PREVENTION

Substance use in adolescents is the result of the interplay between risk and protective factors in the individual, family, peer group, school and local social community. The objectives of prevention are to reduce or delay the initiation of drug use, to delay progression from experimentation to problematic use and to minimize complications.

Universal prevention

Universal prevention activities can be general-population-based and school-based. The content is mainly focused on information transfer, information about the latest drug scene, the possible complication and ways to handle this are conveyed to the general public through the media and talks to increase the public's awareness

of drug issues. Training on personal and social skills, advice on curriculum design to improve knowledge of drug-related issues and parenting skills can be provided through school-based activities. It has been shown that school-based programs aimed at improving social skills are effective in reducing drug use (Faggiano et al, 2005), but not so successful in reducing tobacco smoking and alcohol abuse (Thomas & Perera, 2006).

The European Drug Addiction Prevention trial is one of the large scale school-based programs which involved 170 schools (7079 pupils 12–14 years of age) in seven European countries. The program consisted of a 12-hour curriculum based on a comprehensive social influence approach with special emphasis on correcting the students' beliefs about drugs and drug use. It has been shown that there were persistent positive effects over 18 months for alcohol and cannabis use (Faggiano et al, 2010).

Targeted prevention

Targeted prevention focuses attention on those who are at higher risk of drug use. Vulnerable youth and their families are identified either by school teachers or by case workers for further skill-based training, e.g., impulse control and coping skills training for the youth and parenting skills training for the parents. For example, Project Towards No Drug Abuse (Project TND) is funded by the National Institute on Drug Abuse for adolescents aged 14 to 19 years attending both regular and alternative schools. Project TND aims to prevent tobacco, alcohol, and other drug use and to help students make healthy, informed choices. It is taught through twelve 40 to 50-minute lessons and focuses on the following areas:



Click on the picture to view a clip about whether parents should talk about their drug use with children (4:15)

1. Motivational factors:
    - Address students' attitudes, beliefs, expectations, and desires regarding drug use
    - Address student's cognitive misperceptions and myths around drug use.
2. Skills (social, self-control and coping skills):
    - Aim to provide students with healthier coping, communication and self-control skills so that they do not resort to substance use.
3. Decision-making:
    - How to make decisions
    - Make a commitment to not use drugs and to continue the conversations from Project TND with their peers.

Sussman and colleagues (2004) have shown that TND reduces substance use among adolescents both at short and long-term (1 year) follow-up. In addition, they also showed that TND was effective among regular high school youth and high-risk youth who attend alternative high schools. However, stigma and selection criteria for the "high risk" group may affect outcome.

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Appendix G.3.1

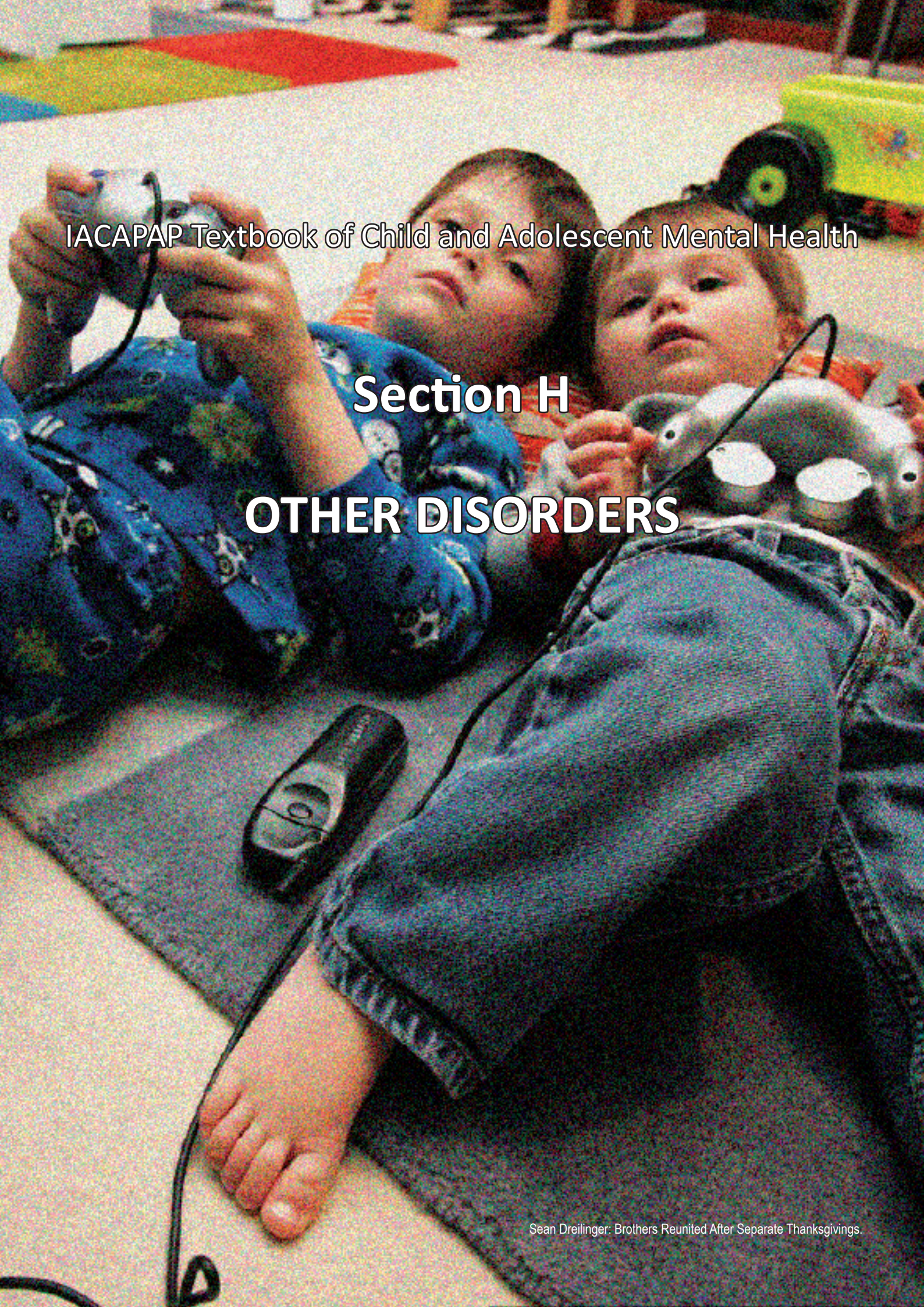
CRAFFT

C	Have you ever ridden in a **CAR** driven by someone (including yourself) who was "high" or had been using alcohol or drug?
R	Do you ever use alcohol or drug to **RELAX**, feel better about yourself or to fit in?
A	Do you ever use alcohol or drug while you are by yourself, **ALONE**?
F	Do you ever **FORGET** things you did while using alcohol or drugs?
F	Do your family or **FRIENDS** ever tell you that you should cut down on your drinking or drug use?
T	Have you ever gotten into **TROUBLE** while you were using alcohol or drugs?

Source: Knight JR, Sherritt L, Shrier LA et al (2002). Validity of the CRAFFT substance abuse screening test among adolescent clinic patients. Archives of Pediatrics and Adolescent Medicine, 156:607-614.

Section H

OTHER DISORDERS



Sean Dreilinger: Brothers Reunited After Separate Thanksgivings.

EATING DISORDERS

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Conflict of interest: none declared

Acknowledgement: art work was provided by patients in the EDGE Young People's group.

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Suggested citation: Morris J. Eating disorders. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

This chapter will focus on anorexia nervosa and to a lesser extent bulimia nervosa. These are two of the most common and severe psychiatric disorders of adolescence, characterized by the obsessive drive to lose weight. Other disorders of eating – often described as "feeding disorders" and seen more often in younger children – are considered here largely in terms of differential diagnosis. Some of these disorders share the psychological sequelae of weight loss and may evolve into secondary anorexia or bulimia if the obsession with thin body image develops. This is particularly likely in westernized cultures. Childhood obesity is not specifically addressed here, although a variety of psychological difficulties may be associated with its origins and consequences.

In what follows, the term "parent" is used to mean parents, guardians and careers, while "child" is used to mean both children and adolescents unless otherwise specified. Sometimes the child is referred to as "she" since the majority of sufferers are female, but both genders are included. We speak deliberately of "parents" rather than just "mothers", since family carers of both genders can provide important contributions to recovery. Sometimes the term "adults" is used, indicating that professionals – doctors, nurses and other therapists – are included in the comment.

Historical Background

Anorexia nervosa is a syndrome of obsessional fear of weight gain, manifest in a range of compulsive weight-losing behaviours. It has been recognised for many centuries, in all societies, even where cultural preference is for a well-fed appearance. It is believed that some of the medieval Christian female Saints, such as St Catherine of Sienna, suffered from anorexia nervosa, whilst Richard Morton famously described two cases in a paper of 1689. By the late 19th century there was competition between the English physician William Gull (1874) and the French Lasègue, both claiming to have been the first to describe the condition. While experts still disagree, it would appear that it was Lasègue (1873) who gave the condition its enduring name "anorexia" in his paper *De l'anorexie hysterique*.

Awareness of the condition was largely limited to the medical profession until the latter part of the 20th century, when German-American psychoanalyst Hilde Bruch published her popular work *The Golden Cage: the Enigma of Anorexia*

Feeding/eating problems in children and their key characteristics

- Failure to thrive: physical or social causes
- Selective eating: extreme faddiness
- Restrictive eating: child has small appetite and eats a normal range of food but in small amounts
- Functional dysphagia: fear of choking or vomiting—certain foods avoided
- Food refusal: refusal to eat rather than searching for thinness
- Pervasive refusal syndrome: not only food is refused but also refusal to drink, talk, walk and engage in any form of self-care. May be a consequence of severe trauma
- Food avoidance emotional disorder: mood disturbance with weight loss
- Obsessive compulsive disorder: eating rituals and other rituals
- Weight loss associated with psychostimulants (e.g., for ADHD)
- Weight gain associated with antipsychotic medication, which increases appetite
- Anorexia and bulimia nervosa

Nervosa in 1978. At the same time, clinicians were also becoming aware of a new "ominous variant of anorexia nervosa", or "bulimia nervosa" as Russell (1979) described the condition. In fact his classic paper describes the bulimic subtype of anorexia – a condition in which low weight is maintained by bingeing and purging as well as restricting food intake. However, the name bulimia nervosa was used as a label for the newly observed epidemic characterized by dysregulated eating in which increasing binges undermine the sufferer's attempts to lose weight.

Definitions

The so-called *eating* disorders are misnamed: disordered eating is only one of the symptoms. It may be more helpful to consider them as disorders of obsessive fear of weight gain, involving a range of different compulsions designed to avoid the dreaded consequence. The term *anorexia* which literally means "lack of hunger" is particularly unsuitable for an illness in which the sufferers are constantly obsessed by thoughts – and even dreams – of food, and tormented by calculating how to resist their extreme hunger in order to avoid weight gain.

Restriction of eating is obviously a prominent feature, but there are many other *compensatory* behaviors, such as over-exercising, various forms of purging and repeated checking and reassurance-seeking by weighing, measuring or mirror gazing, for instance. The precise definition is a matter of some controversy, since psychiatric diagnosis is evolving. The DSM (American Psychiatric Association, 2000) and ICD (World Health Organization, 1992) are gradually moving closer to describing syndromes that embody statistically valid symptom clusters, reflect growing genetic and neurological understanding, and predict responses to treatment. These considerations make it worthwhile, even in children and

Body Masss Index (BMI)

- Body mass index (BMI, Quatelet's index) is a commonly used index of adiposity that controls for the effects of height when assessing weight
- BMI = weight in kg divided by height (in meters) squared
- BMI is used in actuarial tables, since a BMI of 20 to 25 is associated with lower morbidity and mortality
- Children and adolescents are in a state of perpetual and irregular growth, so that BMI may be blind to a fall-off in expected height as well as weight.

Table H.1.1 Symptoms used for the diagnosis of anorexia and bulimia nervosa

Anorexia nervosa	Bulimia nervosa
Abnormal eating	
• Restricting food intake and weight loss to less than that minimally expected for age, sex and developmental stage (e.g., <85% of that expected, BMI <17,5 in fully grown adults)	• Recurrent episodes of binge eating • A sense of lack of control over eating during the binging episode
Fear of gaining weight	
• Persistent behaviour to avoid weight gain (e.g., dieting, exercising—restricting type—vomiting, purging, using laxatives—binge eating/purging type)	• Compensatory behaviour in order to prevent weight gain after binging (e.g., vomiting after binging, purging—purging type—alternating periods of fasting, excessive exercise—nonpurging type) • Weight is usually average or above average
Body shape distortion	
• Undue influence of one's body weight or shape on self-evaluation • Lack of recognition of the seriousness of the problem	
Amenorhea	
• Missing three or more consecutive periods in postmenarcheal females*	

*DSM-5 proposes not to include amenorhea as a diagnostic symptom; BMI: body mass index.

adolescents, to divide the disorders into anorexia nervosa and bulimia nervosa, acknowledging some overlap and acknowledging also that using weight or body mass index (BMI) to distinguish between the two may not be an accurate proxy for the nature of the core psychological disorder. Young people with bulimia nervosa, who by definition have a normal weight, share the drive for thinness. However, people who maintain low weight for long periods by restriction alone or with exercise may be genetically different from those who end up bingeing and purging (Kiezebrink at al, 2009).

Table H.1.2 Comparative symptoms in the eating and feeding disorders

Disorder	Weight	Body image concerns	Presence of bingeing	Purging	Comments
Famine induced starvation	Low	No	When food available	No	Starvation brings its own psychological consequences
Weight loss of physical illness	Low	No	Not usually	No, though vomiting and diarrhea may occur as part of the illness	
Anorexia nervosa, restrictive type (AN-R)	Low, and usually stable	Yes, marked, although occasionally thinness and starvation are valued for religious reasons	No	No, by definition. However, compulsive exercise is often part of the picture	Deliberate self-harm may be used to self-punish or if obligatory refeeding is imposed
Anorexia nervosa, binge purge subtype (AN- BN)	Low and fluctuating	Yes, as for AN-R	Yes, but usually smaller binges than in normal weight AN-BN	Yes, by self-induced vomiting, use of laxatives, compulsive exercising or over activity	See above
Bulimia nervosa	Normal	Yes	Yes, often massive	Yes	
Eating disorder in Psychosis	Low or normal	Sometimes. Explanations may be bizarre or delusional	Occasionally	Rarely	
Autistic spectrum disorders	Low, normal or overweight	Sometimes and may be eccentric	Occasionally	Occasionally	Exercise may become compulsive also
Emotional food avoidance	Usually low or falling	No	Not usually	Not usually	Patient may be too weak and display chronic fatigue
Obsessive compulsive disorder	Low, normal or overweight	Often (body dysmorphia)	Variable	Variable	All habits may become subject to obsessionality

AN-R: anorexia nervosa, restrictive type; AN-BN: anorexia nervosa, binge purge type.

Disorders of concern about body image are increasingly seen in pre-pubertal children of both genders. Nomenclature is misleading to non-specialists. On one hand there are so-called "feeding" disorders, where food is shunned for reasons other than its *fattening* capacity, occurring in the context of other physical and psychological disorders. On the other hand, the so-called "eating disorders" are characterized by a deliberate drive for thinness. Sometimes obsessive food avoidance without body image concern closely resembles anorexia nervosa.

EPIDEMIOLOGY, GENDER AND CULTURE

Anorexia nervosa

The average age of onset for anorexia nervosa is around 15 years. It is the commonest cause of weight loss in teenage girls and the commonest cause of inpatient admission to child and adolescent services. Eric Stice (2009) found that 12% of US high school girls developed a diagnosable eating disorder before the age of 20 but more than 90% recovered within a year, with or without treatment. A small minority (0.6%) met criteria for anorexia with another 0.6% developing partial or atypical anorexia. This is close to the incidence reported in a range of epidemiological studies.

Whilst more than 90% of anorexia sufferers are female when prevalence is measured across the life span, in the teenage years, there is a larger percentage of young boys than this figure suggests, and there is growing awareness that body image concerns may take a different form in boys. Some male sufferers describe striving for a muscular body rather than merely a thin one. Compulsive exercise rather than food restriction may be the earliest sign of the disorder in these cases. Some boys become addicted to exercise without body image concerns at first, although these often develop later.

Rationale for food avoidance varies across cultures, with religious explanations for fasting and self-denial prevalent in some, whilst Blake Woodside (2003) has described Indian patients who endorse gastro-intestinal symptoms as their reason for not eating. Interestingly, if these individuals are treated in groups with sufferers from 'Western' anorexia, they often develop fear of becoming fat and body image concerns that replace their earlier somatic concerns. Even in Western settings, some patients start out with 'somatic' or 'ascetic' preoccupations but go on to re-ascribe their behavior to the media-endorsed value of thinness.

Bulimia nervosa

The emergence of bulimia nervosa in the late 20th century corresponds with both media glorification of a thin body image, with increasing availability of palatable high calorie snack food, and the loss of ceremonious communal mealtimes. For many years after the identification of bulimia nervosa it was believed that the age of onset was later than for anorexia, with the disorder usually occurring for the first time in early adult life, particularly in students in their late teens or early 20s. More recently, Stice and colleagues (2009) have confirmed suspicions that in fact the age of onset of bulimia nervosa is much the same as that of anorexia nervosa – early to mid-teens. It is easier to conceal bulimia than anorexia, however, and the average medical presentation does not occur until the sufferer has been aware of the disorder for about six years.

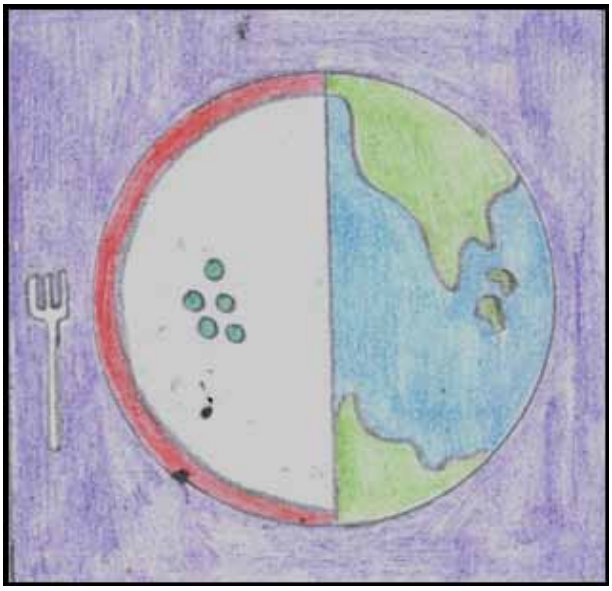
Are eating disorders becoming more common?

Anorexia nervosa is found in all historical periods and geographical areas. Reported increases often reflect increased awareness and availability of treatment services

Bulimia nervosa is largely a disease of affluence, reflecting both the increased availability of food and value of slimness

The Island of Fiji did not have television for many years. It experienced an increase in eating disorders after the introduction of TV, but largely of the bulimia type. Despite the increased prevalence of dieting, the average BMI of the population increased.

Up to 12% adolescent girls suffer at least transiently from bulimia nervosa (Stice et al, 2009). It is not yet know how many boys are affected, but increasing emphasis on boys' appearance may be contributing to an increase, and it is believed that boys in the gay community are more vulnerable to develop bulimia nervosa.



AETIOLOGY AND RISK FACTORS

Genetics

There is substantial evidence that complex genetic factors predispose to the development of the various eating disorders – not necessarily corresponding to accepted diagnostic categories. Family studies have demonstrated the aggregation of cases within families, whilst twin studies of both anorexia and bulimia indicate greater concordance for monozygotic than dizygotic twins. Scandinavian studies (Gillberg & Råstam, 1992) suggest an association between anorexia and autistic spectrum conditions such as Asperger's syndrome, particularly in male sufferers.

Where there is anorexia in a family member, it is often found that other relatives frequently show high perfectionistic and obsessive personality traits. It is not the case that the illnesses are straightforwardly inherited. Rather, individuals appear to inherit personality traits of perfectionism and high anxiety, and the cognitive tendency to perceive fine detail rather than the "bigger picture". Where there is bulimia, other relatives seem more likely to be vulnerable to depression and substance misuse. It has also been observed that eating disorders often complicate or are comorbid with borderline personality disorder.

Environmental factors

Families where at least one person has an eating disorder may contribute both genetically and environmentally. Since eating disorders occur in a familial environment of increased genetic risk, it becomes difficult to dissect the genetic and environmental contribution to the illness.

Work showing a high incidence of perinatal loss in families of teenagers with anorexia (Shoebridge & Gowers, 2000) suggests a causative role for pathological grief, but the study did not take into account the possibility that the mothers concerned were themselves of low weight and so more likely to miscarry. The same study found that girls with anorexia were less likely than controls to have spent a night away from home before age 12. This may reflect an empathic response to the personalities of the children concerned rather than be a cause of the disorder.

Other research reveals that having been born in spring in nations where there is a seasonal difference in climate increases the risk for anorexia nervosa (Eagles et al, 2001). It is still not known whether there are environmental factors involved or whether the observation reflects an increase in summer conceptions in underweight parents who are less fertile when cold weather places extra demands on their energy levels.

Triggers

Puberty and adolescence are undoubtedly major triggers. Young people simultaneously experience the challenge of living with a changing and growing body, new hormone-driven urges, the new cultural expectations, sexual, intellectual and social demands, and the need to process all these with a brain that is itself anatomically and chemically in a state of flux. However, it may be observed that these are non-specific triggers. In young people with different predisposing vulnerabilities, such triggers may precipitate different disorders, such as a depressive illness, obsessive compulsive disorder or substance misuse. In particular, the onset of both anorexia and bulimia nervosa may be triggered by identical precipitants and may even appear similar for some time. Bulimic teenagers may initially lose some weight before binges undo this, and some sufferers follow a fluctuating course, meeting different criteria at different times, and often attracting the diagnosis "eating disorder not otherwise specified". This unsatisfactory state of affairs makes it difficult to use current definitions and classifications to distinguish between disorders which may well have different genetic roots and perhaps respond to different treatments.

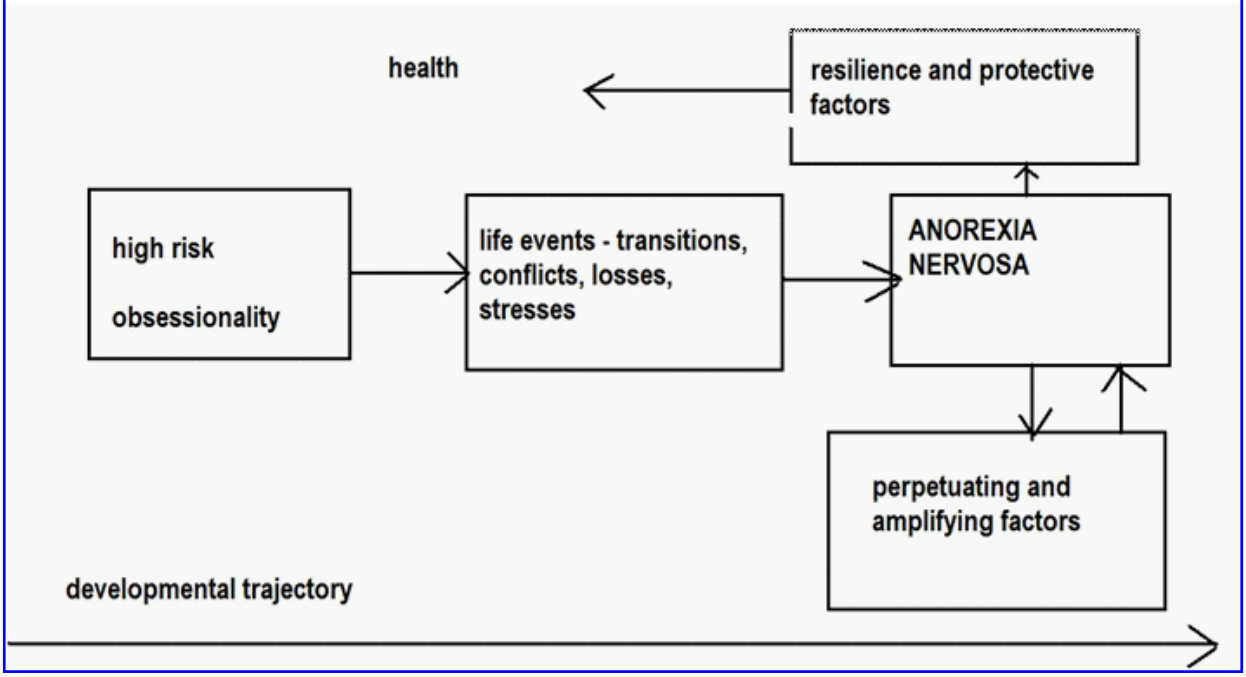
CLINICAL FEATURES AND DIAGNOSIS

Anorexia nervosa

Psychiatric classifications such as ICD-10 and DSM-IV define anorexia nervosa as:

- Restricted eating leading to deliberate weight loss, or failure to grow and increase in weight and height as expected according to age and gender with
- Fear of weight gain, and
- Disturbance of perception of body image, which translates any distress into a perception that their body is too fat.

Figure H.1.1 A model of the development of anorexia nervosa



For patients to meet the diagnostic criteria, there should be at least a loss of 15% of minimum normal weight or, according to ICD-10, a BMI below 17.5 in fully grown adults. Menstruation is typically absent (though women who take the contraceptive pill may have withdrawal bleeds). In males, low testosterone causes atrophied genitalia and absence of morning erections. In the *restrictive subtype*, low weight is achieved by starvation alone or with over-activity. The *binge-purge* subtype involves purging by means of vomiting, use of laxatives, diuretics or slimming pills to get rid of calories. It is widely agreed that these criteria exclude many who may fit into the spirit of the diagnosis. For example, a young woman with a BMI of 18 might cease menstruating if disproportionately muscled because of obsessive exercising. On the other hand, some eastern women who are delicately built, menstruate and become pregnant at a low BMI. Even in adult patients, strict adherence to formal criteria results in the majority of clinic patients falling into the *atypical* or *not otherwise specified* categories.

In children and teenagers it is even more important not to be hidebound by such diagnostic criteria. In particular, weight and height are moving targets in a growing body. A healthy 12 year old boy on the 50th centile for both weight and height will have a BMI of around 17.5 – which would qualify for a diagnosis of anorexia in an adult woman. On the other hand the teenage daughter of tall parents may have a BMI within the normal range but have severely restricted her intake so that her metabolic rate slows down; she fails to grow and experiences severe obsessive symptoms.

It is best practice to plot the weight and height of young patients on standard growth charts to compare progression and trends with what is expected. Information about parental height improves the perspective in which growth is assessed. The outward weight and height trajectory of a child is our best proxy for the healthy nutrition of the developing brain within. As already discussed, current definitions and classifications fail to discriminate between probable differences in genetic susceptibility, but adolescents whose eating disorder causes starvation must be re-fed to prevent physical and neurological stunting, regardless of precise aetiology.

Anorexia nervosa patients are usually protective of their habits, or so focused on losing weight they no longer notice or admit the physical and social consequences of starvation, so it is helpful to also hear from parents, siblings or other informants. It is useful to document the timeline of weight loss, the patient's highest and lowest weight, preferred weight, and menstruation. Clinicians need to know about current daily food intake, liquids consumed, including low calorie and caffeine-containing drinks, alcohol, drugs and medications. Is there self-induced vomiting, compulsive activity and exercise, use of laxatives, diet pills, herbal medicines, and deliberate exposure to the cold? These behaviors interfere with health and social functioning as well as prevent weight gain. Sufferers typically engage in a mixture of both body-checking behaviors (repeated weighing, measuring, mirror gazing, touching, prodding, pinching, trying on particular garments and comparison with others) and avoidance (such as not appearing in swimming costumes or without makeup, or being unable to take a bath because of looking down on their body). Social withdrawal and conflict are both common, and shy, obedient girls may become violent, foul-mouthed or self-harming if their eating disordered rules are

What is a binge?

The definition of a binge is:

- A quantity of food consumed at a single sitting, which is
- Considerably larger in amount than what would be reasonably consumed at a single meal

AND

- Different in character from what is consumed at mealtimes—for instance it consists of all one type of food, usually food the individual forbids themselves to eat deliberately, such as confectionary. It may not be properly prepared and the person rarely sits at a table to eat

AND

- There is a sense of loss of control over the consumption of the food

Sufferers may eventually give up trying to control binges and may even plan them. Some patients with anorexia describe any unplanned food consumption a as binge. There is generally purging behavior after a binge and sufferers may use the term binge to refer to the purging behavior itself.

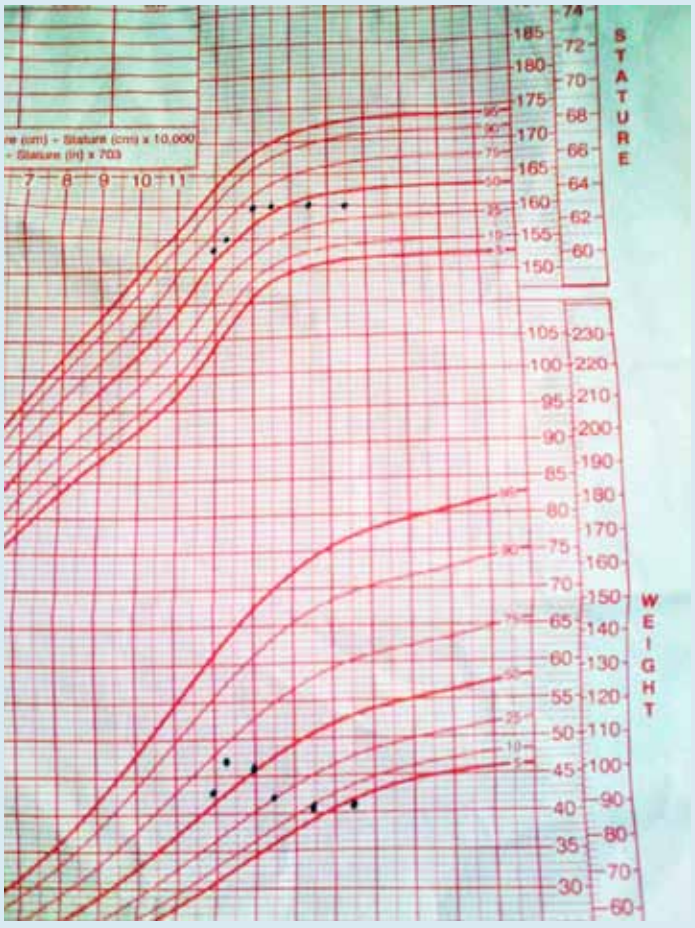
14 year old Sita presented to the adolescent mental health clinic after multiple gastro-intestinal investigations had failed to explain her weight loss, constipation and abdominal pain. She was assessed by a psychologist who raised the possibility of sexual abuse—this caused massive offence to Sita's parents. She had gradually stopped eating every food type that she associated with stomach pain and now existed on a very restricted range of bland foods, in diminishing quantities.

She was hospitalized in a pediatric ward where she declined almost everything on the menu and was eventually naso-gastrically fed (with her and her parents' consent) as a pragmatic measure to re-nourish her. She was also admitted to the day program for young people with psychological disorders—mostly girls with anorexia or depressive disorders.

Sita subsequently developed a marked pride in her emaciated body and concern about weight gain. She began to read the calorie labels on food items and to obsess about her clothes size. Her unhappy parents now complained that the clinic had caused their child to "catch anorexia".

challenged. Those with bulimic difficulties may become so desperately hungry that they steal or hoard food.

Surprisingly, very low weight can be missed when young patients dress and make up smartly. Family members who see the person daily may not notice insidious changes. It is helpful if there is a climate of awareness in schools and among primary care clinicians. We can make it a habit to routinely ask young patients about their eating habits. The SCOFF questionnaire (Morgan et al, 1999) is a validated, brief instrument to screen for eating disorders, similar in concept



Example of weight graph

At the end of primary school, this girl was amongst the tallest of her peers, though in healthy proportion in terms of weight for height. However, she developed anorexia nervosa and lost weight over a matter of months. From the onset of the illness she also stopped gaining height and was overtaken by her classmates.

SCOFF questionnaire (Morgan et al,1999)

- Do you make yourself **S**ick because you feel uncomfortably full?
- Do you worry you have lost **C**ontrol over how much you eat?
- Have you recently lost more than **O**ne stone (6kg) in weight over a 3 month period?
- Do you believe yourself to be **F**at when others say you are thin?
- Would you say that **F**ood dominates your life?

to the CAGE questionnaire for alcohol problems (see Box). It is important to actively seek the psychological symptoms of eating disorders rather than proceed simply by *excluding* physical diseases. In our concern not to overlook diabetes, thyrotoxicosis, cystic fibrosis, bowel diseases, malignancies or other causes of weight loss, young people are often over-investigated while the possibility of anorexia nervosa is neglected.

Bulimia nervosa

This diagnosis is usually made from the binge-purge behavior of a normal weight sufferer – the BITE questionnaire (see Appendix) is a useful way to assess the range and severity of symptoms. Menstrual irregularities, fertility problems, unexplained seizures, "funny turns", and chronic fatigue should alert us to possible eating disorder. Gastro-intestinal complaints can be both the consequence of and the excuse for an eating disorder (as in the case vignette of Sita). More psychological presentations include depression, anxiety, obsessional symptoms and relationship problems. Girls are of course at higher risk, but boys with unexplained weight loss should be also asked about diet, exercise and attitudes to their physique. Observation in a hospital or day clinic may reveal symptoms a patient does not tell clinicians.

Investigation of physical conditions and psychological symptoms

Eating and feeding disorders need a multi-disciplinary evaluation involving physical investigations, food diaries, growth charts, and psychiatric assessment. Family history and involvement are crucial; it is illuminating to observe a family meal, preferably in the home. Alternatively the family can be asked to bring a picnic meal to be eaten in the clinic.

It's essential to measure and weigh patients – extreme reluctance to be weighed is likely to be a symptom of excessive body image concern. This can help to explain that patients who co-operate with physical monitoring can be more safely managed as outpatients that those who are uncooperative and emaciation can only be estimated. Physicians sometimes decline to admit patients whose diagnosis is a psychiatric one, and may need to be supported by specialist mental health nurses, so that treatment for the physical sequelae of starvation are not undermined by the patient's psychopathological concerns.

Routine blood tests are helpful in excluding most of the common differential diagnoses of weight loss. Glucose is low in anorexia (except with comorbid, poorly controlled diabetes). The thyroid is often protectively and reversibly underactive in anorexia nervosa, with normal or slightly low TSH, whereas T4 will be high with suppressed TSH if weight loss is caused by thyrotoxicosis. Electrolytes may show low urea (reflecting protein intake), and low potassium (vomiting). Liver function tests may suggest comorbid drug or alcohol problems, though extreme

Useful questionnaires and rating scales

- The Eating Disorders Examination, self-report version (EDE-Q; Fairburn & Beglin, 1994). This instrument is freely available and one of the most widely used self-report questionnaires; suitable for adolescents but not for younger children.
- Eating Disorders Inventory-3 (Garner, 2004). Self-rated questionnaire covering 12 domains of eating cognitions, behaviours and social function; validated for younger patients and sensitive to change.
- The Children's Eating Attitudes Test (ChEAT; Maloney et al, 1988). Version of the adult EAT, also self-report questionnaire
- Morgan-Russell Average Outcome Scale (MRAOS; Morgan & Hayward, 1988). Interviewer-based measure of global outcome in anorexia nervosa (not copyright).
- Bulimic Investigatory Test (BITE; Freeman & Henderson, 1997). Self-report questionnaire validated for adult patients but also suitable for adolescents; highly sensitive to change in bulimic symptoms, so useful to track progress in treatment (not copyright).

starvation alone can cause liver damage. Anorexia often causes anemia, and if white cell count is *not* low this may reflect infection. Neutropenia is usual in starved patients – if significantly below one, the patient needs to be protected from exposure to infection. ECGs are helpful to monitor electrolyte and cardiac status. Annual bone density scans, if available, allow monitoring the risk of osteoporosis but do not change management.

Young women may become pregnant at an unhealthy low weight and vomiting makes oral contraception unreliable. It is wise always to consider pregnancy as a possibility in young women with weight change, vomiting and amenorrhea. If there is both an eating disorder *and* pregnancy, the patient needs to be monitored physically, nutritionally and psychologically with great care throughout the pregnancy and beyond, so that the mother-baby pair can build a healthy relationship and survive the eating disorder together. Eating disorders, even if sub-clinical, can impair fertility and increase the risk of damage to an unborn child. Both pregnancy and labor may be more difficult. Up-to-date information should be sought about the relative risks of medication versus untreated disorders during pregnancy and lactation. Mothers who have suffered from an eating disorder themselves may need support to learn the skills of healthy playful toddler feeding. It follows that it is always advisable to discuss issues related to conception in a sensitive and supportive manner.

Always assess mood and anxiety symptoms – this is a helpful way to find common ground with patients who reject physical concerns. Moreover the risk of self-harm and suicide is raised in anorexia nervosa.

Comorbidity

In addition to considering the following conditions as differential diagnoses, it is important to recognize their co-existence with eating disorders.

Psychological co-morbidity:

- Depression. This may occur secondary to starvation
- Anxiety and obsessionality. In some cases the eating disorder is one of a range of symptoms of extreme anxiety. Starvation also causes obsessive symptoms around food and body image (Keys, 1950)
- Autistic spectrum disorders
- Emerging borderline personality disorder
- Substance abuse. Opiates cause nausea and reduced appetite, young people may use all available money for drugs rather than food
- Chronic fatigue syndrome: it may be associated with eating disorders and is unlikely to respond to treatment unless all symptoms are tackled simultaneously.

Physical comorbidity:

- Insulin omission is a common practice in people with insulin-dependent diabetes, particularly girls, who use it as a way to lose weight. The result is that even if weight remains in the normal range and no other purging behaviors are present, lasting damage can be done to the body because of poor glycemic control. Mortality in people with comorbid diabetes and an eating disorder is many times the mortality for either condition separately

No to anorexia



"I thought this could be a chance to use my suffering to get a message across, and finally put an image on what thinness represents and the danger it leads to — which is death", said Isabelle Caro, a French actress and model who died of complications of anorexia nervosa on 17 November 2010 in Tokyo, Japan. She was 28 years old.

Caro had received a variety of unsuccessful treatments. She had suffered from anorexia since she was 13, and was hospitalized for the first time when she was 20. At her worst, in 2006, she went into a coma weighing just 25 kg (BMI = 9.2).

Caro used the last years of her life to campaign against the fashion industry using skinny models. The climax of this campaign was when she posed nude to be photographed for an anti-anorexia campaign for a clothing company. Images in newspapers and billboards under the headline "No Anorexia" were released during Milan's 2007 fashion week. At the time she had a BMI under 12. The fashion industry was under the spotlight about anorexia after a 21-year-old Brazilian model had died from the disorder. Caro's pictures caused a stir, sparking much debate. The campaign was initially approved by Italy's health department, but was subsequently banned by the advertising watchdog while France's authority told French companies not to use it. Some groups working with anorexia patients also believed that this campaign was not helpful.

Caro spoke often about anorexia, her efforts to overcome it, and the menace of eating disorders in the fashion industry. She was working to pass a law in the French parliament that would prohibit models from working if they were too thin.

"No to anorexia" campaigner dies. IACAPAP Bulletin, February 2011, p28.

- Cystic fibrosis is another condition where under-treatment of the disease results in weight loss, which may be welcomed by the young person, but at unrealized expense to overall health
- Gastrointestinal conditions, epilepsy and even cancer may predispose body-image conscious youth to neglect any treatment which increases body weight.

COURSE AND BURDEN

Anorexia nervosa is one of the most lethal psychiatric conditions, has a long course and not all patients recover; the average time to recovery (where it occurs) is six to seven years (Strober et al, 1997). As a result, patients with anorexia are a substantial burden on psychiatric services and on their families, with morbidity in carers on a par with that experienced by those caring for patients with schizophrenia (Whitney, 2007). Whilst symptoms of bulimia nervosa may remit spontaneously in the young, there is still disagreement as to whether early diagnosis and intervention bring about better outcomes or whether they merely reflect the natural course of the disorder in teenagers.



Click on the picture to access the NICE guideline "Eating Disorders: Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders"

MANAGEMENT

Anorexia nervosa

In anorexia nervosa, clinicians are faced with the challenge of managing the acute physical risk being aware of how psychopathology increases that risk beyond that of the physical condition alone. Precipitous weight loss (>1kg/week, less in small children) is dangerous. Mortality is further increased by purging

or substance abuse. Such patients should be urgently discussed with specialists. Some need hospital admission – and involuntary treatment if necessary to save life. Particular danger signs in emaciated patients are weakness (climbing stairs, rising from a squat), chest pain, and cognitive slowing.

Physical indices of risk such as blood tests or weight measurements fail to take account of the behavioral risk, which would be absent in patients with similar results from other illness, as the latter can be expected to co-operate with advice and treatment rather than opposing and undermining it. Thus general medical wards need extra support in nursing children and young people with eating disorders in order to compassionately but firmly deal with their damaging behaviors.

There is particular urgency about refeeding underweight children; the smaller the child, the faster the dehydration and deterioration. Children's metabolism is faster than adults'. Physical growth and exposure to infections add further demands. Starvation at times of crucial physiological growth may cause long-term damage. For example, starvation in 10-14 year olds during the siege of Leningrad was associated with higher blood pressure, cholesterol levels and overall mortality in long term survivors. The Dutch famine of 1944 (Stein et al, 1975), showed similar consequences including second generation consequences of starvation, such as obesity in the offspring of starved pregnant women. There may be permanent stunting of height in those starved during puberty and effects on a still developing brain. The brain, particularly the frontal lobes, continues developing during adolescence, with both profusion and pruning of neural connections (Giedd, 2008), reflected in growing social skills and capacity for abstract thought, but patients with severe anorexia nervosa continue to function in a concrete, childlike way despite academic success and superficial maturity.

Cognitive function is impaired by short-term starvation and by vomiting – with enormous individual variation. Considerable recovery occurs with re-nutrition, allowing better engagement in psychological therapies. Social and psychological development can be compromised by illness and by hospitalization. Happily, there is evidence that a well-supported family can be a substitute for inpatient care and can maintain progress in those discharged from hospital.

Families become understandably frightened, helpless and angry when children starve themselves, and high levels of arousal make eating even harder. Family education needs to avoid blame but welcome responsibility, acknowledge the seriousness and difficulty of the situation, and teach firmness with calm. It's helpful if carers can understand the child's fears but not let go of the conviction that the symptoms are unacceptable and damaging. Neither collusion nor bullying is as effective in facilitating healthy change as concerned firmness.

It is helpful to communicate with schools and other agencies involved. Teachers and youth leaders may not want to supervise meals, but they can set appropriate boundaries on exercise and activity and arrange privacy at mealtimes. School activity trips may not be safe for low weight children or ritualistic eaters.

Dietetic expertise is essential on inpatient wards but it is neither necessary nor sufficient for outpatients to have specialist dietetic input. The problem lies far less in terms of knowing what to eat – learning how to tolerate the absorption of sufficient calories is the struggle. Re-nutrition is central to treatment and

Refeeding syndrome

The refeeding syndrome is a potentially fatal shift in fluids and electrolytes that can occur in malnourished patients receiving too fast, imperfectly balanced, artificial or even oral feeding. It may encompass a mixture of biochemical, electrolyte, fluid balance and metabolic changes that may include—or lead to—hypophosphatemia, hypomagnesaemia, hypokalemia, gastric dilation, congestive cardiac failure, severe edema, confusion, coma, and death. The refeeding syndrome was a common cause of death in the early management of anorexia as well as other starved patients. However, there has been criticism that current guidelines on refeeding are over-cautious and lead to initial further weight loss with increased risk and longer stays in hospital.

Refeeding at home can be undertaken more safely by avoiding sudden changes to the diet and using high phosphate products such as milk as a major constituent of the diet.

recovery cannot occur without this. Restoration of weight against the patient's will can only lead to recovery if therapy – or life itself – can persuade the patient to voluntarily maintain a healthy weight. Supportive therapy is needed to support non-negotiable life-saving feeding, whilst motivational approaches take over as the patient improves. Families benefit from therapy not only to prevent burnout and depression, but because family work that has the characteristics of the Maudsley model (Crisp et al, 1991) has been demonstrated to be thus far the most effective long term treatment for the disorder. Well-meaning efforts to treat depression in an extremely low weight patient are likely to meet with limited success unless re-nutrition is in progress.

Motivational approaches

Sadly, it is not common for an intelligent child who is shown the physical dangers of starvation to be frightened into eating normally again. Indeed the child's indifference, in contrast with adults' increasingly fearful concern, may widen the gulf between them. The best approach is to gradually and repeatedly help children see the links between the symptoms they dislike – weariness, agitation, obsessionality, being preoccupied with food and its avoidance, sleep problems, feeling the cold, loss of friendships, inability to join in socially, falling sport or academic performance, "fussing" by parents – and the anorexic illness. It is useful as children progresses to help them notice how weight gain brings the corresponding benefits: more energy, clear headedness, resistance to cold, growing in height (it's generally "cool" to be tall), capacity to have fun with friends, and being well enough to join in games again.

We should acknowledge sympathetically, not angrily, the benefits which undoubtedly come with a serious eating disorder: its power to oblige people to care and placate, the relief from social and sexual demands, the sense that one's body is now controlled rather than terrifyingly unpredictable. Young patients need new techniques for coping with these aspects of life without having to starve themselves.

The principles of motivational interviewing have been adapted for use in the management of eating disorders from the Miller and Rollnick (2008) approach to substance misuse disorders. They are not intended to constitute a stand-alone treatment but to enable the development of a therapeutic relationship in otherwise unpromising circumstances (Geller, 2005). The clinician encourages the patients to explore the consequences of anorexic behavior as openly and scientifically as possible, so that patients are the ones to articulate the disadvantages as much as possible. When a therapist *tells* patients what to do, they resort automatically to an oppositional stance (even the best clinicians find this happening sometimes, but can recover by realizing that the pattern is happening.) There are a number of workbooks available to foster playful motivation techniques, such as writing "love letters" and "rejection letters" to anorexia.

Clinicians who explore ambivalence sensitively, seeking to understand both pros and cons of the eating disorder, are more likely to find themselves on the side of the patient *against* the disorder. Patients find it less daunting to give up their eating disorder if they can learn alternative coping skills.

Extract from a letter to anorexia

Dear Mr Anorexia,

I am writing this letter to dump you. Yes really! I have fallen out of love with you. It's not you, it's me.

I will never forget you. I did truly love you once and we had a good time for a bit, but you are just too high maintenance and it is wrecking my life.

My family never liked you but that made you just seem more cool. But then I found I was losing friends over you and they said my parents were right and you were wrong for me. You don't really care for me, I see that now – you want me to think about you all the time instead of looking after myself properly ...



Principles of the Mausdsley model of family therapy in anorexia nervosa

- The family is encouraged to take the illness very seriously
- Anorexia is *externalized*; that is, it is spoken of as an entity in itself ("the anorexia") and treated as a life-threatening illness rather than the child's choice
- Therapy is not focused on the causes of the illness and avoids blaming the family for their child's illness
- On the other hand responsibility for recovery is explicitly placed with the family in partnership with professionals
- The adults re-take control until the child can feed herself autonomously again. They are urged to use all their existing skills and to learn new ones where necessary to bring this about
- Only when adequate nutrition is successfully achieved and maintained there is an examination of developmental issues.

Medication

One useful metaphor in work with anorexia nervosa is that *food is the medicine*. This means that food has to be prescribed and taken at the times specified and in the amounts prescribed. It is the task of the nurses or parents to dispense the *medicine* in the right dose and ensure that the child takes it. It is the child's job to take the *medicine* and not get rid of it, even though they may not enjoy the taste or may be upset by the side-effects (weight gain). This is non-negotiable ; the choice for the young person is limited to how they take their medicine – orally as food, orally as commercially available supplement drinks (if available) or by a naso-gastric tube.

There is little evidence to support prescribing of psychoactive medication in the treatment of eating disorders, and in fact it is important to avoid drugs which may prolong the QTc interval and thus threaten the weakened heart (e.g., first generation antipsychotics, tricyclic antidepressants, some antihistamines and macrolide antibiotics). However, once weight is normal or at least improving, with a normal ECG, some patients may benefit from SSRIs at a high, anti-obsessional dose, such as 60mg fluoxetine or 200mg of sertraline, although evidence for this is so far anecdotal (Fairburn, 2009). Initial reports that fluoxetine might reduce relapse in weight-recovered anorexic patients failed to be replicated in later studies, unfortunately.

A growing body of evidence supports the prescription of relatively low doses (2.5-10mg) of olanzapine to reduce rumination and improve tolerance of weight gain in both adults and young people with anorexia nervosa and it is safe (Couturier & Lock, 2007; Bissada et al, 2008). It may be preferred to benzodiazepines in promoting relief from anxiety and, if necessary, tranquillization to allow insertion of nasogastric tubes.

Motivational talk

- Anticipate ambivalence
- Express empathy
- Roll with resistance
- Develop discrepancy
- Support self-efficacy

The non-negotiables

- Patients move – however slowly – towards the healthy weight range, not away from it
- Everyone has to learn to accept and co-operate with medical monitoring to stay safe and to develop trust and respect
- Doctors and parents have a legal and moral duty to save life and prevent irreversible damage – this is known as the "appeal to a higher power"

Bulimia nervosa

Bulima nervosa in young people appears to benefit from high dose antidepressants as in adults – typically fluoxetine 60mg daily (Couturier &

Lock, 2007). However, cognitive behavioral therapy (CBT), targeting bulimic symptoms, is the gold standard treatment for this disorder in adolescents as in adults (Pretorius et al, 2009). Where no trained therapists are available there are good results reported using self-help books, CDs or web-based programs, guided or directed by a professional if possible. The interpersonal therapy (IPT) model of Kerman and Weissman has also been successfully used in the treatment of bulimia in young adults, and is likely to be a reasonable alternative to CBT for adolescents (Fairburn et al, 1995).



It would appear reasonable to employ CBT and IPT for low weight as well as normal weight eating disorders, and indeed Fairburn's CBT-E – an enhanced version of CBT – has been recommended by the originator as suitable for all eating disorders in patients down to age 15 and down to a BMI of 15 (Fairburn, 2009); unfortunately, many young patients will not fall into this category. In addition, work in Christchurch (Mackintosh et al, 2005) has demonstrated that adults with anorexia nervosa actually did worse when treated with formal CBT or IPT than when treated with a non-specific supportive clinical management.

Models of service delivery for eating disorders

The key to safe and effective treatment of anorexia nervosa is the orchestration of a coordinated systemic response. This is harder than it sounds when the patients instinctively behave in a way which protects anorexic behavior and brings about maximum confusion and disruption to the therapeutic process. School can be a particularly difficult place for teenagers who need to be monitored – their return to school may not turn out to be a journey towards health and progress but a retreat from adult supervision, allowing anorexic behaviors to flourish. The competitive environment of school examinations often further drives anorexic and obsessive responses to stress, and adults often hesitate to interrupt public examinations to prioritize treatment.

Group therapy may appear on the face of it to be a more economical way to deliver treatment. However, anorexia nervosa patients tend to avoid groups or use them to compete with other sufferers. Mixed groups with anorexic and bulimic patients can cause particular problems. Families, though, may benefit considerably from the support offered by other struggling parents and there is growing evidence for the value of multi-family groups (Eisler, 2005).

When a bulimia nervosa patient is maintaining a normal weight and is able to access minimal medical monitoring, web-based and CD-ROM annualized treatments can provide a useful initial treatment. Schmidt's team (Pretorius et al, 2009) have modified these materials specifically for adolescents from the authors' own self-help book "*Getting Better Bit(e) by Bit(e)"* (Schmidt & Treasure, 1993).

Admit to hospital or manage at home?

Gowers et al (2007) found that where it was safe to manage anorexic patients on an outpatient basis, the outcome was significantly better, particularly if treatment was delivered by an outpatient clinic with specialist expertise in eating disorders. Even general outpatient child and adolescent psychiatrists brought about greater physical and psychosocial improvement than did inpatient treatment. However, this study excluded patients believed to be too unsafe to manage at home. Further, in many settings there is no outpatient clinic available, although outreach services and telemedicine are increasingly able to deliver home-based care.

COURSE AND PROGNOSIS

Sten Theander's (1985) early follow up studies found that a shocking 20% of anorexic patients died of causes related to the disorder. Even now, mortality in anorexia is ten times that in the general population and is among the top three or four causes of death in teenagers. Today's lower mortality figures partly reflect changes in diagnostic criteria – since the publication of DSM III-R in 1987 we require only 15% body weight to be lost (or a BMI below 17.5) before making the diagnosis, compared with 25% (BMI below 15) previously. As a result, the

population of people diagnosed with anorexia nervosa has expanded, whilst the number of people so starved by the disorder that they die remains fairly constant, so that when expressed as a percentage, it would appear superficially that the death rate is decreasing.

Treatment for fully established anorexia nervosa is slow and difficult: the average time to recovery is six to seven years though treatment is likely to be episodic rather than continuous over this period. Younger, intensively-treated patients often show a more rapid improvement, and it is likely that some cases will resolve even without treatment.

Improved management may also contribute to longer survival – it is now acknowledged that a tolerant, respectful relationship allows long-term physical monitoring and support to be offered. Early treatments for anorexia nervosa tended to involve strict behavioural regimes whereby patients started hospital admission on bed-rest and were allowed 'privileges' such as using a toilet rather than a bed-pan, or being allowed to receive visitors only in return for weight gain. Such regimes are no longer seen as either useful or acceptable, although sadly, the spirit of 'rewarding' or 'punishing' patients based on their weight, seems to persist in some centres. This may be an instinctive response to the nature of anorexia itself, which is to offer a sense of reward for weight lost or punishment for weight gained.

A significant minority of anorexic patients fails to fully recover but these patients may at least be enabled to live valuable and tolerable lives. It is not possible to identify which patients will fall into this category whilst they are still in their teens, and young people should not be regarded as *chronic* sufferers until many years of treatment have passed.

Starvation and malnutrition from all causes reduce fertility. The minimum weight needed for menstruation and fertility varies between individuals. Young people with anorexia and their families often fear that fertility is irredeemably damaged by the disorder, when in fact with restoration of adequate weight and healthy eating patterns, fertility returns given time. Patients in their thirties and forties, with longstanding primary amenorrhoea have been shown to be ovulating normally after weight recovery.

Sadly, though, the death rate from anorexia nervosa is still high. The excess mortality is partly as a result of the physical damage associated with the illness and partly because of suicide. Some deaths may result from ambivalently-taken overdoses that would not have killed individuals with a healthy weight. Likewise, the effects of substance abuse are greatly amplified at low weight. In cold countries, the majority of deaths occur in the winter months when hypothermia and infections (including tuberculosis) account for many fatalities. The starved heart is especially vulnerable when over-exercised in cold temperatures. In hot countries dehydration and enteric infections are important risks. Patients who have induced vomiting can harm the gastrointestinal system, predisposing them to fatal perforation.

Follow up

In childhood and adolescence and when anorexia acutely threatens life we are obliged to take action, but if patients do not recover despite intensive efforts and

Is it "just a phase"?

Experts disagree about the benefits of early intervention. Perhaps there are some spontaneous early recoveries, regardless of treatment. Chronicity is associated with poor prognosis

- Stice et al (2009) reported an eight-year prospective study of 495 female adolescents from age 12 to 20. There was a 12% prevalence of some form of eating disorder by age 20, but most resolved within months and more than 90% resolved within one year
- Steinhausen et al (1991) found that the longer the duration of an eating disorder the harder it is to recover
- Treasure and Russell (2011) claimed that early treatment is essential, pointing retrospectively to improved outcomes in younger patients with a relatively brief history of anorexia nervosa
- Meta-analytic studies (Schoemaker, 1997; Raes et al, 2001) found that early recognition and diagnosis did not guarantee earlier recovery.

are not at significant risk of death, the priority becomes to maintain useful contact and keep the door open for them to accept as much help as possible: medical monitoring, a listening ear and keeping hope – and patients – alive. Recent studies show that recovery is still possible even twenty years after the onset of anorexia. Because of the age group affected and the time span involved, patients' care often involves many transitions, for instance, moving from children's services to adult clinics, leaving the relatively protected environment of school, leaving home, perhaps to take on challenging university courses or to work away from home, and thus further changes in health service care.

Transitions are peak times for relapse and decompensating. People with anorexia tend to see their illness as a coping strategy and even as a cherished identity, so that professional energy is needed to either entice or, when necessary, coerce them into treatment. Unsurprisingly, many professionals experience anger and frustration at one time or another. However, young people and families where there is anorexia nervosa tend to be high-achieving, interesting people who have a great deal to contribute to society, and anorexia and bulimia are psychiatric disorders where complete and lasting recovery does occur.

PREVENTION

Prevention programs are typically conducted with groups of children or adolescents in school or clinic settings or with youth groups such as athletics clubs. Overall, the outcome of prevention programs has been mixed. Targeted programs show small to moderate effect sizes, whereas universal ones have been found to be largely ineffective. The most efficacious interventions focus on self-esteem, training individually or in groups (Stice et al, 2007). Some countries have considered policies to require a minimum BMI for fashion models and already some schools of dance require minimum as well as maximum BMI bands. It is too soon as yet to evaluate the preventative effects of such policies, but they give a sound message to the public.

Concern has been raised that anti-obesity campaigns may have the undesirable side-effect of promoting eating disorders in the vulnerable. It has been demonstrated, however, that thoughtfully delivered health promotion that examines healthy nutrition and exercise (rather than focussing on weight reduction) can actually protect against both obesity and body-image related eating disorders (Schwarz & Henderson, 2009).

BARRIERS TO THE IMPLEMENTATION OF CARE IN DEVELOPING COUNTRIES

Until recently, traditional and ceremonial eating practices and family influences offered developing countries relative protection against the development of eating disorders, together with an ideal setting in which to treat those who have succumbed to the illness. The structured regular eating patterns of specialist units and the ethos that patients eat what is put in front of them without quibbling and with respect to friends and kin eating alongside them is very close to the healthy traditional attitudes to eating that can keep humans healthy physically, psychologically and socially. The thin body image ideal has not been endorsed by non-Western cultures until lately and, even now, countries where AIDS is feared tend not to admire an emaciated body.

Websites

Most of the websites of larger professional or major charitable bodies are reliable and up to date. There are many excellent lay-run sites and also many dangerously misinformed and even "pro-anorexia" sites, often short-lived or outdated.

- The Centre for Eating and Dieting Disorders (Australia)
- The American-based but internationally represented Academy of Eating Disorders offers a useful information, including guidelines for medical management.
- The site of the Royal College of Paediatrics and Child Health has a section which makes WHO Growth Charts available (click Child Heath/Research Projects/Growth Charts)
- The Royal College of Psychiatrists' website has useful information both for professionals, carers and sufferers of all ages.
- "BEAT", formerly the UK Eating Disorders Association, offers information and help for lay people on all aspects of eating disorders.
- "Diabetics With Eating Disorders" (DWED) a website by and for diabetics with eating disorders.
- "Men get eating disorders too" by and for men and boys.
- "Something Fishy" is an English language website that provides links to sites in other languages.

It is a sad irony that whilst disordered and obsessive body image values have been widely transmitted by TV, the Internet and other media, it is more difficult for health services to keep up with the harm. The treatment of eating disorders in young people does not need to rely on sophisticated or expensive medications (although it does of course involve provision of food, which is not necessarily available throughout the world). Education and training in structured psychotherapies is equally – if not more – expensive. Bulimia nervosa can respond well to CBT delivered in self-help or guided self-help form, but there is evidence that in anorexia nervosa outcome relates more closely to the level of experience of the clinician than to any specific model of therapy (Dare et al, 2001). Anorexia nervosa, though devastating, is relatively rare and is often hidden not only by sufferers but also by ashamed families, so that general clinicians are unlikely to build up expertise, whilst specialist centres are too expensive and too far geographically to serve much of the world's population.

In the final analysis it is the family – or surrogate family – which will need to come to the rescue of the child from anorexia. The style of parenting required can seem counter-intuitive to western middle-class families and may also be counter-intuitive to families afflicted by the same obsessionality as the affected child. However, the Maudsley model of family therapy is both manualized and described in a lay paperback so that it is accessible to all English speaking literate families (Lock et al, 2001; Lock & Le Grange, 2005). Minuchin et al (1978) introduced family therapy for anorexia on the mistaken assumption that family behaviour is the cause of eating disorders. Modern research has demonstrated that families are the most likely source of recovery.

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TIC DISORDERS

Hannah Metzger, Sina Wanderer & Veit Roessner



Samuel Johnson, one of the most influential English literary figures, particularly because of his "Dictionary of the English Language" published in 1755, appears to have suffered from Tourette's disorder.

Portrait by Joshua Reynolds

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Suggested citation: Metzger H, Wanderer S, Veit Roessner V. Tic disorders. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Tics may range from a discrete, hardly noticeable flinching of the eye to a painful, socially incapacitating und subjectively shameful phenomena involving several muscle groups. Those afflicted by tics, as well as their family, may experience substantial suffering due to the symptoms, be it through bullying or to inappropriate response by caregivers resulting in a dysfunctional parent-child relationship. People in the extended environment may also react with irritation, for instance where vocal tics occur in inappropriate settings, such as the cinema or the classroom. On the other hand, some of the people afflicted successfully develop strategies to control their tics and learn to live and cope with them.

Classification usually follows the criteria of the International Classification of Diseases (ICD-10; World Health Organisation, 1996) or the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association,1994). Tic disorders are best classified among the neuropsychiatric disorders. Table H.2.1 shows the classification of tic disorders.

Whether a *transient* or a *chronic* tic disorder is present depends on the duration of symptoms: in the case of a transient tic disorder, symptoms last less than 12 months. Transient tic disorders mostly occur in school age children and usually do not require specific treatment.

Diagnosis of Gilles-de-la-Tourette syndrome (or simply Tourette syndrome or disorder) is warranted in cases where several motor tics and at least one vocal tic are present at the same time or have been present in the past. Motor and vocal tics do not have to be present at the same time but should have occurred almost every day over one year at least to warrant the diagnosis. The onset of Tourette syndrome is generally before the age of 18; it rarely occurs for the first time in adulthood.



Georges Albert Édouard Brutus Gilles de la Tourette (1857-1904), French neurologist, described the symptoms of the syndrome that bears his name in nine patients in 1884, which he termed “maladie des tics". Gilles de la Tourette had a colourful and eventful life. He was shot in the head in his consulting rooms by a paranoid young woman who had been a patient at the Salpêtrière Hospital claiming she had been hypnotised by him against her will causing her to lose her sanity. The trial sparked intense public debate over whether hypnosis could be used to induce criminal behavior in otherwise law-abiding citizens.

He died in a psychiatric hospital in Lausanne, Switzerland, where he had been interned probably because of a bipolar illness and syphilis.

EPIDEMIOLOGY

It is estimated that 4% to12 % of all children suffer from tics at some time during their development. Approximately 3%-4% are afflicted by a chronic tic disorder and 1% with Tourette’s syndrome (Rothenberger et al, 2007). Children and adolescents are 10 times more likely to suffer from tics than adults (Kerbeshian & Burd 1992). This may be due to the high spontaneous remission rate in younger patients. Boys are afflicted three to four times more often than girls (Freeman, 2007). A familial predisposition has been established (O’Rourke et al, 2011).

Table H.2.1 Classification of tic disorders according to ICD-10 and DSM-IV

ICD- 10		DSM - IV	
F95.0	Transient tic disorder	307.21	Transient tic disorder
F95.1	Chronic motor or vocal tic disorder	307.22	Chronic motor or vocal tic disorder
F95.2	Combined vocal and multiple motor tic disorder (Gilles-de-la-Tourette syndrome)	307.23	Tourette's disorder
F95.8	Other tic disorder	307.20	Tic disorder NOS (not otherwise specified)
F95.9	Unspecified		

Cultural differences

The prevalence of Tourette syndrome is about 1% worldwide (Robertson et al, 2009). However, Tourette syndrome is less likely to occur in some countries. Differences in prevalence across various countries seem partly to reflect the fact that not all follow the same classification system. China, for example, has reported slightly lower prevalence rates; rates appear to be lower among African Americans in the US and occurrence is extremely rare in Sub-Saharan black Africans. Possible reasons for these findings include the implementation of different diagnostic systems, other medical priorities with less likelihood to seek treatment, ethnic and epigenetic differences, genetic and allelic differences in different races and the presence of a mixture of races (Robertson, 2008). By contrast, a cross-cultural review by Staley et al (1997) concluded that demography, family history, clinical features, associated conditions, comorbidity and treatment outcome were basically the same across cultures.

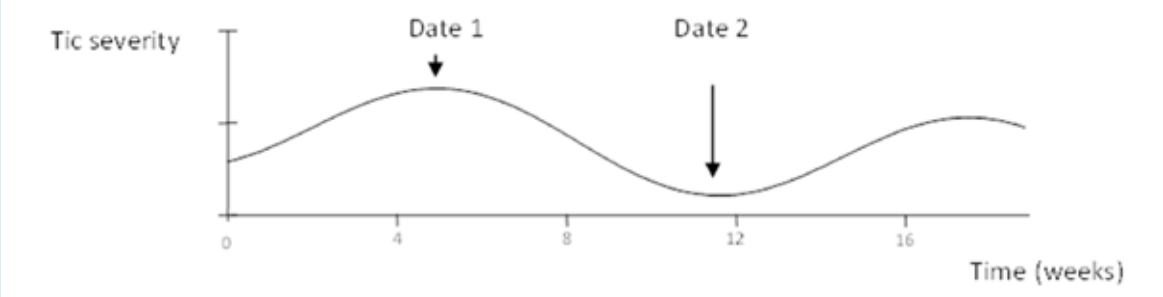
Tic
Sudden, rapid, recurrent, nonrhythmic motor movement or vocalization.

Age at onset and course

Tics generally occur for the first time between the ages of two and 15 years. However, the peak age of onset is between six and eight years. Typically, the first symptom is a simple motor tic in the face, such as eye blinking or grimacing. With time, they spread to shoulders, extremities and torso. Often vocal tics appear two to four years after the start of the motor tics (Leckman et al, 1998).

In most cases tics fluctuate in their location, complexity, type, intensity and frequency. This can be confusing and frustrating for parents of children afflicted by tics. Fluctuations often occur at irregular intervals, approximately every six to 12 weeks, without any apparent reason (Roessner et al, 2004). This changing course is one of the main distinguishing features when differentiating between Tourette syndrome and the abnormal movements found in conjunction with other illnesses, such as dystonia or chorea, which typically do not change or show less accentuated fluctuations.

Figure H.2.1 Evaluation of treatment efficacy in Tourette's syndrome in light of the natural waxing and waning



At date 1 (in which a reduction in tics naturally occurs) a therapeutic intervention is followed by a reduction in tics irrespective of the intervention's potential to increase or not to have an effect on tics. The reduction could be falsely attributed to the intervention when in fact was the result of the tics natural waxing and waning. A therapeutic intervention at date 2 could be followed by an increase in tics despite its potential to reduce tics. The effect of the therapeutic intervention might attenuate the natural waxing of the tics but is biased by the spontaneous increase. This means that a meaningful appraisal of treatment efficacy in Tourette's disorder can only be ascertained in most cases after a long observation period. Source: Roessner et al (2011). Reproduced with permission.

Usually there is a worsening of symptoms during adolescence. As children progresses into young adulthood, tics often go into remission (Sandor et al, 1990). As a result, children and adolescents are 10 times more likely to be affected than adults.

With increasing age, tic-afflicted patients also gain better control over their tics and are often able to suppress them for minutes or up to several hours. However, after a period of suppression, patients often feel compelled to exhibit their tics with heightened intensity (Banaschewski et al, 2003). For this reason some children may be able to suppress their tics over the course of the school day but, as soon as the child arrives at home, tics reappear with more intensity and the feelings of heightened tension generated by the suppression of tics will temporarily fade.

The severity of the tic disorder during childhood only has a limited predictive value concerning the illness in adulthood. A poor prognosis is usually associated with:

- Familial history
- Existence of vocal or complex tics
- Comorbid hyperkinetic disorder
- Obsessive-compulsive symptoms
- Aggressive behavior against self or others.



Click on the picture to view a video clip showing a variety of tics (3:13)

Spontaneous remission of chronic simple or multiple tics occurs in 50% to 70 % of cases and 3% to 40% for Tourette syndrome (Erenberg et al,1987).

ETIOLOGY AND RISK FACTORS

Although the cause of primary tic disorders has not been conclusively determined, it is widely assumed to be the result of an interaction of genetic, neurobiological and psychological factors as well as environmental influences. A dysregulation within cortico-striato-thalamo-cortical circuits with deviations within the dopaminergic and serotonergic systems is believed to be responsible for the occurrence of tics. It seems that overactivity of the dopaminergic system in the basal ganglia leads to deficient subcortical inhibition and impaired automatic control of movement, which then clinically presents itself as motor or vocal tics (Leckman et al 1997; Singer, 2011).

A familial predisposition is as a risk factor. Heritability has been estimated to be around 50 % (Singer & Walkup, 1991). Various prenatal, perinatal and postnatal factors are considered possible factors that increase the risk. They include premature birth, perinatal hypoxia, low birth weight as well as excessive nicotine and caffeine consumption by mother during pregnancy. On rare occasions tics may develop as secondary symptom of tumors, poisoning, infection, head trauma or vascular disease (Burd et al, 1999; Mathews et al, 2006) .

Medical imaging techniques have determined that, on a neuroanatomical level, patients with tics show a reduced volume of the basal ganglia as well as the corpus callosum, but heterogeneity of study samples in terms of several confounders (e.g., long-term use of medication, tic performance and suppression over years) prevents firm conclusions. Furthermore, deviation of glucose metabolism in the basal ganglia, prefrontal and the somatic sensorimotor cortex, insula and

temporal lobe has become apparent. Apart from dopaminergic overactivity, other neurotransmitters implicated include dysfunctions within the serotonergic and noradrenergic systems.

In terms of psychosocial factors, poor child rearing techniques have been ruled out as risk factor. However, environmental influences, first and foremost psychosocial stress, undoubtedly modulate tic severity. Experiences that cause fear, emotional trauma and social pressure generally result in an exacerbation of tics.

TICS

Tics are sudden, abrupt, fast movements comprising various muscle groups, with or without vocal utterances, which occur involuntarily. Tics are brief but repetitive – though not rhythmic – and usually appear in short bursts or even series. They may be classified according to the degree of complexity (simple, complex) as well as their quality (motor, vocal) (Rothenberger et al, 2007).

Motor tics range from simple, sudden movements such as eye blinking or grimacing, to complex behavioral patterns, for example crouching down or hopping. In extreme cases, complex motor tics may present themselves as obscene gestures (referred to as *copropraxia*; e.g., pulling trousers down) or even have an element of self-harm (e.g., hitting oneself in the head). In some cases the afflicted person is compelled to repeat or imitate a movement observed in another person (*echopraxia*).

Vocal or phonic tics are involuntary utterances of sounds, noises, sentences or words. A simple vocal tic may be a slight coughing, clearing of throat, wheezing, squeaking or loud shouting. More complex vocal tics involve syllables, words or sentences. *Coprolalia* is the utterance of obscene or aggressive words or sentences. Coprolalia occurs seldom, in less than 20% of persons affected by Tourette disorder (Rothenberger et al, 2007). In other cases sufferers feel compelled to repeat their own previously spoken words (*palilalia* – it is called *echolalia* if they repeat words previously spoken by someone else).

By the age of 10 or 11 years, children begin to report a premonitory urge. This can be any kind of sensation, typically a tickling, itching or prickling feeling, in the area of the muscle groups involved, announcing the imminent occurrence of a tic (Steinberg et al, 2010).

Table H.2.2 Common motor and vocal tics.

Motor Tics	Vocal Tics
• Eye blinking	• Coughing
• Rolling of eyes	• Throat clearing
• Grimacing	• Sniffing
• Shaking of head	• Whistling
• Twitching of shoulders	• Grunting
• Twitching of torso and pelvis	• Animal sounds
• Twitching of abdomen	• Uttering of syllables
• Movements of the hands and arms	• Uttering of words
• Movements of the feet and legs	• Shouting

DIAGNOSIS

A detailed medical history should be obtained from birth onwards. Additionally, standardized questionnaires may be used. The Child Behavior Checklist (Achenbach, 1991) can be employed to obtain information concerning possible comorbid disorders (see Chapter A.5). The Strengths and Difficulties Questionnaire (Goodman, 1997) can also be recommended for this purpose (see Chapter A.5). Tic-specific or semi-structured interviews include the *Yale Global Tic Severity Scale* (YGTSS) (Leckman et al, 1989) and the *Tourette's Syndrome Severity Scale* (TSSS) (Walkup et al, 1992). Parental or self-rating can be done using the *Yale Tourette Syndrome Symptom List-Revised* (TSSL-R) (Leckman et al, 1989).

A thorough physical and neurological examination should be conducted, including an EEG. The main purpose for this is to exclude other possible illnesses that could cause the symptoms. Usually no further tests, such as an MRI, are necessary unless there are pathological findings. ECG, thyroid function tests or other procedures (e.g., metabolic tests) are not necessary in the absence of abnormal findings.

Tests of cognitive ability are not necessary either unless there is indication of learning problems. Completing questionnaires provides a good opportunity to observe the patient in a challenging situation, even though patients are often able to suppress tics for a certain period so that the true extent of the symptoms may not be observed.

Differential diagnosis and comorbidity

Specific circumstances may cause variation of tic symptoms. Emotional states such as fear, joy or tension frequently lead to an increase. Distractions, an occupation requiring high concentration and consumption of cannabis or alcohol

Table H.2.3 Differential diagnoses of motor tics (Roessner & Wanderer 2010)

Aspect of tics	Disorder – differential diagnoses
Preoccupation with tic control	Attention problem
Tic repetition	Obsessive-compulsive phenomena
"Exaggerated" tic[1]	Psychogenic origin
Monotonous tic	Stereotypy
Eye rolling	Absence
Rapid shuffling steps	Akathisia, juvenile Parkinson, compulsion
Distortions and similar[2]	Dystonia/ Dyskinesia
Convulsive grimacing	Blepharospasm
"Jerky" tics	Chorea
"Shuddering" tics	Myoclonus
Tics during sleep	Restless legs, epilepsy, parasomnias

[1]This could be a movement or sound performed in an over-emphasized manner, therefore lacking the suddenness or uncontrollability of a typical tic.
[2]This would involve movements of a more coiling or writhing nature.

Table H.2.4 Psychiatric disorders often associated with tic disorders

Comorbid disorder	% of children with tic disorder affected
Attention deficit hyperactivity disorder (ADHD)	40 – 60
Obsessive-compulsive symptoms	40 - 70
Anxiety disorders	25 – 40
Depressive symptoms	Around 50
Sleeping disorders	12 – 44

may lead to a decrease. Tics hardly ever interfere with intentional movements such as cycling. It is possible for tics to appear during any of the sleep stages, albeit with reduced frequency, intensity and complexity. Due to the aforementioned characteristics, it is possible to differentiate tic symptoms from most other movement disorders (see table H.2.3).

Approximately 65 % of children and adolescents with chronic motor or vocal tic disorder have a comorbid condition (Conelea et al, in press). Around 90% of those with TS develop one or more psychiatric disorders (Freeman, 2007). The probability of having a comorbid disorder increases with the severity of tics, early onset and familial loading.

TREATMENT

Psychoeducation

Psychoeducation, involving the patient as well as relevant caregivers, should be provided at the beginning of treatment. Further, individual causal factors and options for treatment should be discussed. Referral to self-help groups is also useful. Treatment is usually delivered as an out-patient; inpatient treatment can be necessary in severe cases requiring more extensive investigations, when severe comorbid disorders are present or to monitor and achieve optimal drug treatment. Figure H.2.2 shows a decision tree (Roessner et al, 2011).

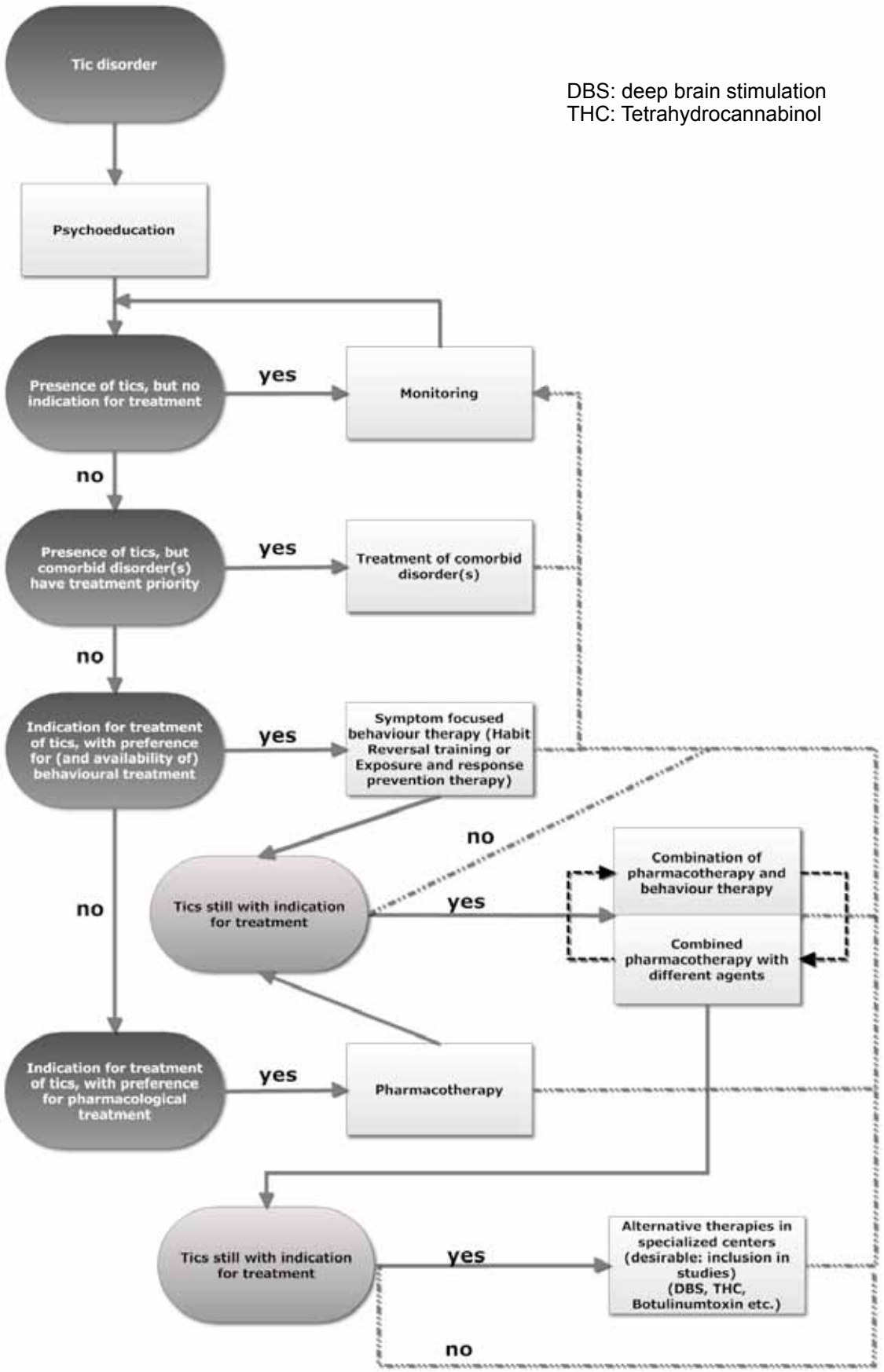
Psychoeducation involves providing detailed information to the relevant persons, in the case of young people this usually will involve parents and teachers. Information should be provided regarding the disorder, its course, investigations and options for treatment. Information which often is of use to teachers involves recommending allowing the child to sit exams on their own or to be permitted to leave the classroom for short periods – to lessen the urge to release the tics.

In cases of mild severity – taking into account the high rate of spontaneous remission – psychoeducation is all that is required. For this reason it makes sense to adopt a "wait-and-see" approach, keeping a watchful eye on recurrences or possible comorbid disorders (Wanderer et al, 2012).

Psychotherapy

Cognitive behavioral methods are the most effective psychotherapeutic intervention. This treatment should be administered by trained professionals well

Figure H.2.2 Decision tree for the treatment of tic disorders including Tourette syndrome (Roessner et al, 2011).



versed in the complexities of the disorder. It may involve the following (Verdellen et al, 2011):

- For well-motivated and insightful patients, *habit reversal training* has been shown to be effective. Training comprises a set of techniques intended to help patients become aware of impending tics and practicing a competing response to inhibit or interrupt the tic. These techniques include relaxation training, contingency management and generalization training. To heighten tic awareness, methods such as:
  - Response description (patients learn to describe the topography of their tics and develop a detailed, usually written, description of each tic)
  - Response detection (patients receive feedback concerning the occurrence of a tic, until they can detect the target behavior unassisted)
  - Early warning procedures (patients practice identifying the early signs of a tic, such as specific urges, sensations or thoughts) and
  - Situation awareness (patients describe people, places or situations in which the tics occur most commonly) are included in the training.
  - Competing response training involves the patient learning to purposefully initiate a tic for one to three minutes or until the urge to perform the tic has disappeared.
- *Exposure and response prevention* is based on the association of a premonitory urge followed by the vocal or motor tic, which results in the relief of the urge sensation. The aim is to break the association between the urge and the resultant tic, which – according to learning theory – has been strengthened over time. By confronting the patient with the premonitory urge over a longer period (exposure) and having them resist giving in to it (response prevention), the patients would learn to endure the urge without having to act out the tic (habituation). Patients are also encouraged to *self-monitor* symptoms by recording times and situations in which tics occur over certain periods to ascertain when and where tics are most frequent.
- *Massed (negative) practice* involves intentionally and repeatedly acting out the tic in an effortful and rapid way over a certain period with short rests in between. The long-term effectiveness of this seems limited but can help patients if they are about to enter situations which require tic-free appearance (i.e., going to the cinema).
- *Relaxation training* is assumed to help reduce tics because tic intensity often increases in times of stress and anxiety. Relaxation training includes progressive muscle relaxation, imagery, autogenic training or deep breathing and is mostly applied as one part of a multi-modal treatment plan. In terms of effectiveness, Peterson and Azrin (1992) found that tics were reduced by 32% with relaxation training, by 55% with habit reversal training and by 44% with self-monitoring techniques.

- *Contingency management*, again as a part of a multi-modal program, seeks to positively reinforce tic-free intervals (e.g., through tokens, praise or demonstration of affection) and to ignore tics. According to learning theory this should result in a lessening of the behavior (in this case, the occurrence of tics). Because this method is usually incorporated in multi-component treatment packages, it has been difficult to assess the value of this specific technique.
- Sometimes the presence of a tic disorder in a child may result in significant problems among family members. In such cases *family therapy* should be recommended.

Medication

There is good empirical evidence supporting the use of a variety of medications for Tourette syndrome (see below). However, medication for Tourette syndrome is often prescribed "off-label". For instance, the only drug approved for tics in Germany is haloperidol, which on current evidence is considered only a medication of third choice. Pharmacological treatment is recommended when tics result in significant subjective discomfort, such as muscular pain or physical injury, ongoing social problems (e.g., isolation or bullying), emotional problems, or significant functional impediment, typically in academic performance (Roessner et al, 2011). The aim is to achieve the best balance between maximum benefit and minimum side effects. It is not to be expected that tics will disappear completely with medication; at best, symptoms will be alleviated.

Before initiating pharmacological treatment, the following investigations should be carried out: blood and liver function tests, prolactin levels, ECG, EEG, as well as physical and neurological examinations (to establish a baseline, exclude cardiac contraindications, including long QT syndromes, other physical illnesses or potential contraindications for the use of medication). Additionally, it is important to assess whether the tic disorder or another comorbid disorder is causing the greatest impairment, in order to determine which of the disorders should be primarily treated. For instance, treating comorbid ADHD can result in improved ability to suppress the tics without having to specifically treat them – conversely, psychostimulant drugs may rarely worsen the tics.

Generally speaking, medication should start slowly, with effectiveness and tolerability being assessed at regular intervals. Once optimal dosage has been ascertained, medication should be taken regularly for at least one year before considering a discontinuation. At the very latest, medication should be reduced in late adolescence to ascertain whether continuation is necessary, taking into account the high rates of spontaneous remission. Table H.2.5 summarizes the European recommendations about medication for tic disorders.

- *Haloperidol* is the only medication officially approved for the treatment of tic disorders in Europe (from the age of three years). Haloperidol has strong antidopaminergic action and results in a reduction of tics in approximately 80 % of cases. However, adverse reactions such as extrapyramidal symptoms occur quite frequently, which makes haloperidol not the treatment of first choice.

Table H.2.5 Medications with some evidence of effectiveness for the treatment of Tourette's syndrome (Roessner et al, 2011)

Medication		Level of evidence	Starting dosage (mg)	Therapeutic range (mg)	Common adverse effects	Investigations at start and during follow up
Alpha-adrenergic agonists	Clonidine	A	0.05	0.1-0.3	• Orthostatic hypotension • Sedation, sleepiness	• Blood pressure • ECG
	Guanfacine	A	0.5-1.0	1.0-4.0		
First generation antipsychotics	Haloperidol	A	0.25-0.5	0.25-15.0	• EPS • Sedation • Increased appetite and weight	• Blood count • ECG • Weight • Transaminases • Neurologic status • Prolactine
	Pimozide	A	0.25-0.5	0.25-15.0		
Second generation antipsychotics	Aripirazole	C	2,50	2.5-30	• Sedation • Akathisia • EPS • Headache • Increased appetite, weight • Orthostatic hypotension	• Blood count • Blood pressure • Weight • ECG • Transaminases • Blood sugar and lipids
	Olanzapine	C	100-150	100-600		
	Quetapine	C	100-150	100-600		
	Risperidone	A	0.25	0.25-6.0		
	Ziprasidone	A	5.0-10.0	5.0-10.0		
Benzamides	Sulpiride	B	50-100 (2mg/kg)	2-10 mg/kg	• Problems with sleep • Agitation • Increased appetite	• Blood count • ECG • Weight, Transaminases
	Tiapride	B	50-100 (2mg/kg)	2-10 mg/kg	• Sedation • Increased appetite	• Prolactine • Electrolytes

EPS: extrapyramidal symptoms. Evidence level: A, >2 randomized controlled trials; B, 1 randomized controlled trial; C, anecdotal (case studies, open trials).

- *Tiapride* is a selective D2 receptor antagonist that shows virtually no antipsychotic action. It has a good side effect profile and is well tolerated with few extrapyramidal symptoms. The most frequent adverse reactions are drowsiness, moderate transient hyperprolactinemia and weight gain. There is no evidence of negative effects on children's cognitive performance. Tiapride is currently the first-choice medication for treatment of Tourette syndrome in Germany.
- *Risperidone* is a second generation antipsychotic agent with a high affinity for D2 and 5-HT2 receptors. Efficacy is similar to that of haloperidol but with a more favorable side effect profile (see Table H.2.5).
- *Aripiprazole* has shown promising effects specifically in patients who had not responded to, or had not tolerated well other medications. Aripiprazole has a high affinity for D2 receptors but, in contrast to other second generation antipsychotics, it is also a partial agonist of 5HT1A receptors and a potent antagonist at 5HT2A receptors. This profile has raised hopes that it may be better than the other drugs (Roessner, 2011). It also has the advantage that weight gain is low. Nausea and sedation are the most frequently reported adverse effects.

Although the best evidence from clinical trials is still that for the typical antipsychotics haloperidol and pimozide, European clinical practice has gradually substituted these substances with atypical antipsychotics, foremost risperidone. Availability of and experience with specific medications, however, also plays a role in the choice. In the German-speaking world, tiapride is regarded as the first choice drug in the treatment of tic disorders in children and adolescents (Rothenberger et al, 2007). Although evidence is comparatively limited, Roberston and Stern (2000) also recommend tiapride as well as sulpiride in their review of treatment for tic disorders, due to their balance of efficacy and tolerability. Aripiprazole has shown potential regarding efficacy in refractory cases. There is, however, a lack of placebo-controlled studies for this medication.

Treating Tourette syndrome comorbid with other disorders

When there are comorbid psychiatric disorders and Tourette syndrome, it should always be ascertained which of the presenting conditions is causing the greater impairment. Treating one disorder frequently has a positive effect on the other and may render further specific treatment unnecessary.

Attention deficit hyperactivity disorder (ADHD)

If ADHD is comorbid with a tic disorder, the former may be treated with psychostimulants, such as methylphenidate. There has been a longstanding argument about whether psychostimulants may cause, trigger or worsen tics in these cases and, therefore, whether they should be contraindicated in these circumstances. Recent studies have shown that in most cases psychostimulants do not lead to an exacerbation of tics (Pringsheim & Steeves, 2011). Treating patients with atomoxetine or clonidine has proven effective as long as the Tourette syndrome is only of mild to moderate severity (Roessner et al, 2011). These two medications mainly reduce ADHD symptoms only having a marginal effect on

tics. Should the aforementioned medication have little effect on tics, the addition of risperidone can be considered. Alternatively, ADHD symptoms may be treated with methylphenidate, which can be combined with risperidone if necessary.

Emotional disorders

In cases presenting with mild to moderate depressive or anxious symptoms comorbid with Tourette syndrome, pharmacological treatment solely with sulpiride can be considered. Sulpiride has positive effects on tics as well as the comorbid emotional problems with few extrapyramidal symptoms and vegetative adverse reactions (Roessner et al, 2011), with the exception of galactorrhea.

Another option for treating Tourette syndrome with comorbid depression or obsessive-compulsive disorder is using a selective serotonin reuptake-inhibitor (SSRI). Antipsychotic drugs can be prescribed in combination with SSRIs in cases of moderate to severe tic symptoms.

Alternative medicine treatments

Substantial anecdotal evidence exists concerning the benefits of physical activity (rhythmic sports, such as swimming) and recreational activities in general. Patients should be informed and encouraged accordingly. There is no evidence that diet, vitamins or mineral supplements as well as hypnosis are of benefit and should not be recommended.

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CHILDREN WITH ATYPICAL GENDER DEVELOPMENT

Louise Newman



Boy with Doll by Aleksandr Vladimirovich Makovsky (1869-1924)

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Conflict of interest: none declared

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Suggested citation: Newman L. Children with atypical gender development. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Gender dysphoria the sense of discomfort with one's biological sex and assigned gender role – may present in children from the age of 2 years. Some children may express unhappiness at their gender and often may express the desire to change sex. This can have a significant impact on child development in a broad way and also on family functioning. Families vary in their response to a child's cross-gendered preferences or gender questions with some showing acceptance and tolerance and others expressing anxiety and a desire to resolve the issue. There are scarce data available as to the prevalence of this condition in children and there is ongoing debate about the best clinical approach to it. The evidence base about treatment in children is limited and the ethical issues are complex. It is essential when seeing children with gender issues to try and understand the families' ideas and expectations around sex differences and appropriate gendered behaviour, and the way in which these ideas impact on their relationship with their child. The child with atypical gender development faces not only the dilemma of lack of congruence between body and psychological gender identification but also the anxiety that this issue often arouses in parents. Supporting children with gender variance involves family counselling, individual work with the child and attention to the school environment. The use of hormonal interventions around the time of puberty remains controversial but can relieve distress in some children with ongoing gender dysphoria and support psychological interventions.

CONCEPTS OF SEX AND GENDER

The anatomical sex of an infant and parents' own ideas and values about gender and behaviour are key aspects of early parenting. Parents have a range of views about gender which influence interaction with the infant and parenting expectations. Gender identity or sense of being male or female is the end result of biological and psychosocial factors. Theories of infant development have tended to focus on *sex differences* as opposed to *gender development*. More recently, interests have turned to understanding the complex interactions of biology and social experiences or culture that are involved in creating gender.

Concepts of sex and gender exemplify the tensions between biology and culture, and older and newer models of development. In older models, sex is usually seen as genetically influenced and innate, and results in psychological or social differences in males and females or gender roles. Contemporary theories point out that biology always interacts with environment. Biological sex differences are influenced by culture and language and differing social expectations of males and females. Cultural expectations also influence parenting and the earliest interactions with male and female infants.

Biological sex and infant development

The majority of neonates are designated either male or female at birth – or prenatally with the use of ultrasound technology. Biologically, sex has profound implications for infant development for complex reasons. First, there is increasing evidence of differences in male and female brain differentiation, although the extent to which this directly influences observable sex differences in behavior and psychological functioning is unclear. Second, caregivers have their own sets of beliefs and expectations about male and female infants, which influence

Definitions

Contemporary theories distinguish sex from gender

- *Sex* refers to anatomical and biological (genetic and hormonal) categories of male and female, but even biology is complex and subject to interpretation. In nature, there may well be more than two sexes or at least variability in male and female sexual characteristics
- *Gender* refers to a prevailing socio-cultural model and defines social expectations of masculinity and femininity. These expectations encompass socio-cultural models of personality, attitudes and behaviors that are seen as linked to each sex. Gender also refers to the social performance indicative of an internal sexual identity – the outward behaviours of masculinity or femininity as they are socially defined
- *Gender identity* is a complex mixture of biology, socialization, psychological identification and sexuality. It refers to the individual's sense of himself or herself as a biological, psychological and social male or female. There is ongoing discussion about the neurobiological basis for gender-identity
- *Gender role* refers to the behaviors, attitudes and personality traits designated socio-culturally as masculine or feminine. Gender role is incorporated in the self as a set of behaviors, attitudes and personality traits designated socio-culturally as masculine or feminine. In children, this is measured by such variables as a preference to associate with same-sex peers, fantasy and play roles and type of play. There is an ongoing controversy over the influence of biological variables such as prenatal sex hormones on observable gender-role behavior
- *Sexual orientation* is defined by response to sexual stimuli while sexual identity refers to the definition of oneself in terms of sexual preference. Sexual orientation emerges after puberty but is not necessarily congruent with sexual identity. For example, it is possible for a male to be primarily aroused by homosexual stimuli but to have a gender identity of himself as heterosexual.

their perceptions of and interactions with their infants. Finally, different social and cultural groups have complex and variable expectations and definitions of masculinity and femininity, which define appropriate behaviors, personality attributes and social roles. These definitions change over time. For example, in Western culture there has been a significant change in gender roles with less clear boundaries between male and female roles. Infants develop a sense of gender identity or a self- definition as male or female in the first 2-3 years of life, and this is influenced by biological, psychological and socio-cultural factors. There are ongoing debates over the relative importance of these factors in producing observable differences between males and females but it is clear that differences are evident in infancy.

Disorders of sex development

Deviations in the normal steps of sexual differentiation can result in so-called disorders of sex development with disruption of internal or external sexual structures. There are a variety of conditions, some with unusual external genitalia and others with poorly developed internal sexual structures. Some neonates have *ambiguous genitalia,* most commonly masculinization of the external genitals of a female infant due to exposure to male hormones in utero where an excess of androgen is produced by the adrenal gland (i.e., congenital adrenal hyperplasia). Other conditions include ovo-testicular disorders of sex development and complete androgen insensitivity syndrome – a condition where a 46,XY infant has female external genitalia. The clinical question in relation to disorders of sex development

is how to decide to what sex the infant should be assigned. Money and Ehrhardt (1968) studied the rearing of children with disorders of sex development in the 1950s and concluded the sex of rearing – upbringing – was the most important factor in producing a "successful" outcome as male or female. They also stated that attempting to change gender after the age of 2.5 years was *not* likely to be successful. More recently this has been challenged by the concept of "brain set" and the biological factors underlying gender identity.

Significance of cultural variations

The significance of these cultural variations is that they raise the possibility of alternative models of the relation between sex and gender and suggest that there is no fixed relation between the body, psychological identification and the social manifestations of gender. It has also been argued that cultural context determines whether gender variation is seen as a *disorder* needing treatment or an understood and tolerated variation. For the clinician it is important that adoption of a Western model and formulation of gender identity and development does not preclude an understanding of possible alternative frameworks, and a particular normative model of gender development is not rigidly imposed on children and families seeking to understand gender variation.

It is clear that, whether or not gender variability is seen as a mental disorder, it is strongly influenced by cultural expectations of gender behavior. What is seen in one culture as problematic may not be seen in the same way by another culture. The important consideration is whether concerns about gender behavior have an effect on the infant's social relationships and functioning.

Mary

Mary, aged 2 years, was born with multiple pelvic abnormalities, including an imperforate anus, ambiguous external genitalia with penile agenesis, and urinary system abnormalities. Examination of chromosomes showed the infant to be 46,XY and an ultrasound examination showed internal undescended testes. Mary needed emergency surgery to the urinary system and bowel and was raised as female having later genital surgery. At the age of two, Mary is a secure child with female appearance who enjoys "female-type play" but also "rough and tumble" activities. While there is some evidence that male and female brains develop differently in utero, socialization is a very important influence on gender identity.

CLINICAL PRESENTATIONS

No reliable data exist for estimating the incidence of gender dysphoria and gender-identity disorder (GID) in the general population. In developed, western countries, boys are referred for treatment more often than girls (ratio of 5:1) but it is not clear if this is the result of greater tolerance of gender variant behaviours in young girls, and a corresponding social anxiety about so-called effeminate boys. Longitudinal studies suggest that not all childhood gender dysphoria is associated with a trans-sexual outcome (Zucker, 1995), and there are ongoing discussions about the relationship of childhood gender dysphoria and adolescent and adult-type cross-gender identification and trans-sexuality. It is possible that there are several developmental pathways to cross-gendered identification in children and that this is not a unitary condition. As discussed below, neurobiological theories tend to see gender as an outcome of brain functioning, whilst psychological theories have focused on early development of identity within the context of attachment relationships and see gender issues arising in this context.

Regardless of etiology, children with gender dysphoria present with a range of cross-gendered fantasies and behaviors and show preference for games, activities and clothes usually assigned to the opposite sex. Young boys around 2-3 years of age may be interested in persistent cross-dressing and are very attentive to details of female fashion, behaviors and mannerisms. Some of these little boys may show clear preference for playing with girls and prefer dolls and home themes in play. They identify with female characters in stories and films and prefer characters such as Cinderella or Snow White. They show little interest in boy-type activities or

typical rough-and-tumble play. That type of play is usually persistent and difficult to discourage. Older boys may make more direct statements regarding their desire to be a girl or experience of "really being" a girl in a boy's body. The majority of these boys are aware of their anatomical sex but feel it is incorrect or a mistake and some develop marked aversion to their genitals and attempt to hide them.

In girls with GID the presenting issues are very similar, with young girls identifying with male activities and behaviors and often expressing the belief that they will grow a penis in the future. At school they prefer to play with boys and may insist on going to the boy's bathroom and wear boys' or gender-neutral clothes. They experience distress if they are made to wear girls' clothes or join in girls' activities such as games.

Clearly these experiences can be confusing and distressing for the child who immediately has a sense of being different from their peers. Young children might express their confusion openly but in the face of teasing or bullying have a sense of a secret that could be potentially dangerous. Whist some children confide in parents and family, families themselves are often confronted and confused by their child's issues and may also experience anxiety about how the extended family and community will respond.

DIAGNOSIS

The diagnosis of GID remains controversial although both DSM-IV and ICD-10 include this diagnosis. The DSM-IV criteria refer to a strong identification

Table H.4.1 Diagnostic criteria for gender identity disorder

A.	Persistent cross-gender identification (not merely a desire for any perceived cultural advantages of being the other sex). In children, the disturbance is manifested by 4 (or more) of the following:
	1. Repeatedly stated desire to be, or insistence that he or she is, the other sex 2. In boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine, clothing 3. Strong and persistent preferences for cross-sex roles in make-believe play or expressed phantasies of being the other sex 4. Intense desire to participate in the stereotypical games and pastimes of the other sex 5. Strong preference for playmates of the other sex
	In adolescents and adults, the disturbance is manifested by symptoms such as a stated desire to be the other sex, frequent passing as the other sex, desire to live or be treated as the other sex, or the conviction that he or she has the typical feelings and reactions of the other sex
B.	Discomfort with his or her sex or the inappropriateness of the gender role of that sex
	In children, the disturbance is manifested by any of the following: • In boys, assertion that his genitals are disgusting or will disappear, assertion that it would be better not to have a penis, or aversion toward rough-and-tumble play and rejection of male stereotypical toys, games, and activities • In girls, rejection of urinating in a sitting position, assertion that she has or will grow a penis, assertion that she does not want to grow breasts or menstruate, or marked aversion toward normative feminine clothing
	In adolescents and adults, the disturbance is manifested by symptoms such as pre-occupation with getting rid of primary and secondary sex characteristics (e.g., request for hormones, surgery, or other procedures to physically alter sexual characteristics to simulate the other sex) or belief that he or she was born the wrong sex
C.	The disturbance is not concurrent with a physical disorder of sex development condition

with and preference for the gender role characteristics of the other sex (Table H.4.1) while ICD-10 has separate criteria for girls and for boys. The revision of DSM-IV currently underway proposes to change the name from "gender identity disorder" to "gender incongruence" because the latter is seen as a descriptive term that better reflects the incongruence between what identity one experiences or expresses and how one is expected to live based on one's assigned gender. The revision also proposes to emphasize "gender incongruence" in contrast to cross-gender identification per se in the diagnostic criteria.

Differential diagnosis

In young children around 2.5—3.5 years of age gender becomes part of self-definition and the social world. The child can label self and peers according to gender by around 28 months (Fagot, 1995) and this is related to the development of same-sex play preference. In typical development, gender becomes integral to a positive self-concept. Prior to this it is common for young children to express the wish to be *all sexes* and have the characteristics of both genders. A small boy for example may wish to give birth or grow breasts and still remain a boy, and a girl may wish to grow a penis. The wish to be both genders is generally given up but may be accompanied by anger and envy. This should not be seen as a GID where the wish is to be the opposite sex and there may be aversion to the assigned sex.



Click on the picture to access Mermaids, UK site that provides information and support for children and teenagers with gender identity issues

It is also important to look at the context of development of cross-gender interests and wishes, as transient wishes may occur in the context of anxiety, particularly as this relates to the mother as primary attachment figure. In some cases the child may be anxious about the availability of the mother and seek comfort in adopting a female role, in other cases the child may be anxious about the mother's acceptance of their gender. This may occur for example if the mother has experienced trauma or assault by a male figure. These dynamics can impact on the child's experience of gender and may represent unresolved issues relating to gender and sexuality in the mind of the parent. It is significant that studies find an association between GID and maternal depression and anxiety in the child's first three years of life (Zucker, 1995).

Assessment of the child and family should also examine the family's and cultural understanding of gender behavior and attitudes towards gender non-conformity. Some families react with anxiety if a boy shows typically female interests and this may relate to an underlying anxiety about potential homosexuality. There is cultural variation in tolerance for cross-gender behavior which influences both family response and presentation for treatment (Newman, 2002).

Theories of atypical gender development

It is likely that there are several developmental pathways to GID in childhood and that not all childhood GlD is related to trans-sexuality in adulthood. Both psychological and biological models of the condition have been proposed and these may well be describing somewhat different conditions. Biological theories have focused on processes of brain sexual differentiation as male or female and the influence of pre- and peri-natal sex hormone exposure. It is proposed that there can be a discrepancy between genital differentiation and brain sex differentiation underlying trans-sexuality, presumably resulting in early-onset cross-gender identification.

Other models have examined sexually dimorphic brain nuclei in the hypothalamus which are hypothesized to influence gender identity and sexual orientation. Small studies of the brain of male-to-female transsexuals have reported small volumes within the range of typical females (Zhou et al, 1995) and the opposite was found in a female-to-male case. These findings, whilst interesting, do not amount to a direct endorsement of possible mechanisms for this difference.

Current psychological theories look at vulnerabilities for the development of GlD along with factors in parenting and attachment that may shape the development of gender dysphoria. Coates and Person (1985) describe GID boys as having temperamental anxiety and vulnerability to separation as well as frequent trauma in the relationship with the mother in early childhood, including maternal depression and family disruption or conflict. They propose that the child experiences separation anxiety and identifies with the mother to avoid losing her. Zucker (1995) also argues that children with GlD may be predisposed to anxiety and that this is exacerbated in the context of an insecure attachment relationship. They note that some families may reinforce cross-gender behavior and interests, and those particular aspects of the parents' gender issues influence their response to the child. For example, mothers with issues related to masculinity and perception of male aggression may be less rewarding of typical male behaviors. Fathers in some families have been described as distant and not providing positive male role models for boys with GID.

Several studies have found significant rates of psychological disorder in parents of children with GlD including personality disorder, maternal post-natal depression and indications of maternal emotional unavailability (Marantz & Coates, 1991). These, however, are very general factors associated with a range of attachment problems and mental health or developmental outcomes and cannot be seen as providing a specific model of the development of GID.

ASSESSMENT ISSUES

Increasingly, there have been challenges to both the notion of a purely socio-cultural construction of gender identity and to the idea that a binary biological sex determines psychological aspects of gender. This increasing complexity points to the need for a bio-psychosocial understanding that can take into account interactions between biological and psychosocial factors in mediating gender identity.

In clinical practice, when assessing children with gender dysphoria and their families, these debates are frequently a focus of discussion. Parents are often focused on supporting their child and react in a protective way. Some parents support a biological model of etiology and find exploration of other factors difficult. Initially, it is important to explore the families' particular understanding of gender and gender variance and how this may be influenced by cultural belief systems. Table H.4.2 lists issues in cross-cultural assessment of GlD.In clinical practice, when assessing children with gender dysphoria and their families, these debates are frequently a focus of discussion. Parents are often focused on supporting their child and react in a protective way. Some parents support a biological model of etiology and find exploration of other factors difficult. Initially, it is important to explore the families' particular understanding of gender and gender variance and how this may be influenced by cultural belief systems. Table H.4.2 lists issues in cross-cultural assessment of GlD.

Table H.4.2 Issues in cross-cultural assessment of gender identity disorder

- How does this culture understand the differences between male and female?
- What account is given of the development of male and female individuals? Are differences and roles "innate" or "learned"?
- Are all individuals male or female, or are alternative positions possible?
- What does the religious/spiritual context say about gender roles and positions? Are there taboos against the violation of gender roles and gender change?
- Does the culture separate questions of sexual orientation from gender, or is gender variation seen as signifying potential homosexuality?
- What are the cultural attitudes towards homosexuality and gender variation?
- Does the culture have an assigned place for gender-variant individuals?
- What attitudes exist about sex-modifying procedures and the involvement of medical/surgical systems in interventions aimed at gender change?

Michael

Michael is a 3-year-old boy referred by his preschool for assessment as he has clear cross-gender identification and behaviors. Michael's family is from Thailand; they have been residing in Australia for 12 months. The parents are non-English-speaking Buddhists and describe a belief system ascribing positive value to gender transition and an acceptance that some children are born as a "third gender". Michael's parents are aware that he is being teased at preschool and is having difficulties with his peers. There are adult transsexuals in the extended family. Michael is not discouraged from cross-gendered behavior and the school has found it difficult to discuss these issues with Michael's parents

Cross-cultural assessment

A major aspect in the assessment of gender dysphoria in multicultural contexts is how best to establish the particular model of sex-gender and gender deviance held by the child and family. Planning appropriate intervention can only occur when it is seen how the family understands gender variation and how it will be managed within the cultural framework of the family. It is also important that the child be supported in his overall social context and in managing what may be a cultural "gap" between the family and mainstream social values. The examples in the boxes illustrate some of the complexities of cross-cultural assessment of GID.

Several issues and dilemmas are raised in Michael's case:

- Should Michael's family be encouraged to view Michael's development as disturbed and his cross-gender identification as pathological, even though they currently do not see it as such?
- Should the school environment be one that discourages Michael from expressing his cross-gendered interests even though he can express these at home?
- Is it possible to *change* Michael's family's understanding of gender identity and is it ethical to attempt to do this?

In practice, a key issue is working with Michael's stated difficulties with his peers and academic performance. Regardless of his family's acceptance of him, Michael is attempting to adapt to a peer group and community in which his experience is unusual and his position as cross-gendered may have negative effects on his ongoing development.

Sam

Sam is a 4-year-old boy from an Arabic family who presents with concerns that he is effeminate and "homosexual". Sam has some cross-gender interests but does not meet diagnostic criteria for GID. The family culture is one of significant homophobia and rigid models of gender-role behaviour. Sam's father is seeking genetic and hormonal investigation of Sam believing that he has a biological disorder. He has been physically punishing Sam for his behavior.

In the case of Sam, he is exhibiting gender-aberrant behavior as defined by his family's cultural understanding of appropriate male behavior. The immediate clinical concern is the degree of hostility directed towards Sam and the difficulty of engaging Sam's father. It may be necessary to involve culturally representative clinicians (if available) and to encourage involvement of all family members in initial negotiations in relation to an intervention framework. It is important to acknowledge and respect the family's concerns about Sam's development, and to contain immediate anxiety by offering appropriate support and to be cautious in "challenging" the family's understanding of Sam's *disorder* as biological in origin.

As these examples illustrate, the cultural context influences both the presentation and understanding of gender dysphoria and gender-aberrant behavior. Non-normative gender-role behavior may in one context be seen as unproblematic variation (Michael's case), while in another it may be defined as a disorder (Sam). Different cultures will formulate concepts of *gender disorder* according to varying models of sex-gender and the development of gender identity. They will also vary in their understanding of the stability or fluidity of gender identity and degrees of accommodation of gender transition. In some contexts it will be possible to adopt alternative or additional gender positions.

Child assessment

Assessment of a child with gender issues needs to distinguish between cross-gendered behaviors (toy, play preference and peer activities) and identification (identity statements, role and fantasy play) and establish the degree of dysphoria or distress. Not all children express aversion towards their own bodies or a clear desire to change their body, and some children will be reluctant to disclose these feelings.

A comprehensive assessment involves exploration of parents' understanding and functioning, child's gender identity and overall child development. Several instruments are available including the Gender Identity Interview (Zucker, 1995) and the Gender Male Questionnaire (Igntema & Cohen-Lettens, unpublished). For young children, instruments focus on the ability to identify male and female and the capacity to understand the stability of gender. The Draw-a-Person test can provide important qualitative information regarding the child's gender concepts (Rekers et al, 1990).



Click on the picture to access True Colours, an Australian site for young people who experience transsexualism

INTERVENTION ISSUES

Treatment approaches for children with gender dysphoria or GID vary according to the theoretical understanding of the condition and findings on assessment. Coates (2006), for example, states that there are likely to be multiple pathways to childhood GID and that not all have been adequately described in the literature. Treatment needs to be adapted to the needs of the particular child and family.

Approaches to intervention range from behavioral strategies aiming to reduce the expression of cross-gendered behavior, to psychoanalytic approaches which seek to explore the psychological function and meaning of cross-gender identification. Broader psychosocial interventions include family psychoeducation and support and school-based interventions. There is ongoing debate about the purpose of treatment (and what is being treated), but also a recognition of *gender difference* as having major developmental impact and of the importance of early intervention.

Behavioral approaches in the 1970s and 1980s saw GID as a result of inappropriate learning experiences and aimed to reinforce gender behaviors and skills. Cross-gender behaviors are discouraged and the family is trained in the application of reinforcement of gender-typical behavior such as appropriate walking and athletic skills in boys. The relationship with the same-sex parent is encouraged to provide a role model. There are clearly several questions raised by this type of approach: the ethics of attempting to behaviorally control psychological identification; the potential for negative impact on self- esteem; and the rather

narrow focus on external behavior, which does not look at broader developmental issues.

More recent approaches combine behavioral strategies with a psychodynamic understanding and work with the family to support the child's overall development. Meyer-Bahlburg (1985) describes working with parents to support the father-son relationship, promote gender-neutral interests and activities and support the child's peer relationships. Freedman et al (2011) focus less on changing the child's gender identity than on addressing developmental issues and family functioning. This way includes, for example, addressing anxiety about separation, insecure attachment and depressive symptoms commonly found in boys with GID (Coates & Person, 1985; Zucker, 1995).

Puberty-blocking hormones

The use of puberty-blockers (Gonadotrophin Releasing Hormone analogues, GnRH) allows reversible suppression of "puberty hormones" and the associated physical changes of puberty. The rationale for their use is largely psychological, based on observations of the distress and depression that may accompany body change in transgendered adolescents. Suppression of puberty can reduce immediate anxiety and distress and supports ongoing psychological intervention and counseling.

The US Endocrine Society Clinical Practice Guideline (2009) recommends use of GnRH analogues no later than Tanner stages 2-3 to suppress puberty in adolescents with a clear diagnosis of GID and introduction of cross-gender hormone treatment at 16 years of age.

Geddes (2008) points out that some children will not continue to have transgender feelings or cross- gender identification into adulthood although the proportion that reverts to their original sex is unclear. Few trials have explored the long-term effects of delaying puberty in this age group and there are also concerns about the capacity to make informed decisions about this issue at 12 or 15 years of age.



Click on the picture to access the site of the Gender Identity Research and Education Society (GIRES)

Debate is ongoing about the most appropriate treatment strategy for GID, particularly about the use of early hormonal treatment. The guidelines of the British Royal College of Psychiatrists (1998) support the use of (reversible) self-steroid inhibitors where indicated with the aim of reducing distress and increasing the ability to conduct psychiatric treatment. Others have cautioned against the use of puberty blockers on the grounds that these treatments will impact on emerging sexual identity which may be involved in a significant number of adolescents struggling with ego-dystonic homosexuality (Korte et al, 2008). It is also relevant that the course of GID in children is variable and plastic and that progression to trans-sexual development cannot be easily predicted in individual cases.

For younger children, work with families may support parents and provide important strategies for helping the child with gender variance problems manage ongoing developmental challenges and the broader social environment. Group approaches to parental support may be effective in reducing perceived isolation. Freedman et al (2011) note the importance of treating the cycle of secrecy around gender questions and enabling the child and family to tolerate uncertainty in gender-identity development.

Clinical management of children with gender issues often involves integrated psychological, social and biological interventions. In the current state of knowledge physical interventions are used cautiously and following comprehensive assessment. Providing parents and families with a clear, planned and staged model of treatment is important and may help them deal with and ameliorate the child's distress.

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BORDERLINE PERSONALITY DISORDER

Lionel Cailhol, Ludovic Gicquel & Jean-Philippe Raynaud



Workshop of Peter Paul Rubens (about 1640), The Death of Dido, Getty Museum.

After piling a wooden effigy of her deceased husband in their matrimonial bed atop her own funeral pyre, Dido, the queen of Carthage, stabs herself with her lover Aeneas's sword. Virgil tells the story of her grief-stricken reaction to her abandonment by Aeneas.

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Suggested citation: Cailhol L, Gicquel L, Raynaud J-P. Borderline personality disorder. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Borderline personality disorder (BPD) is characterised by a pervasive and persistent pattern of instability and impulsivity. BPD has enjoyed much research attention for several decades both in terms of understanding it and tackling it. Whilst the label of BPD is frequently used in clinic settings dealing with teenagers its use in the young remains controversial. Nevertheless, many believe that a set of converging arguments makes use legitimate in this age group (Miller et al, 2008).

From a didactic perspective, this chapter uses the concept of BPD as defined in DSM-IV. However, readers need to be aware of the risks of this reductionism in relation to other conceptualizations of the condition. In this chapter we highlight the high frequency of the disorder in adult and adolescent populations and its psycho-social consequences. A large section is dedicated to diagnosis and differential diagnosis. The chapter finishes with a description of useful treatment strategies.

"Borderline patients have long been to psychiatry what psychiatry has been to medicine − a subject of public health significance that is under-recognized, undertreated, underfunded and stigmatized by the larger discipline. As with psychiatry and medicine, this is changing. New knowledge, new attitudes, and new resources promise new hope for persons with borderline personality" (Kernberg & Michels, 2009)

EPIDEMIOLOGY

Prevalence

Prevalence of BPD is estimated to be between 0.7% and 1.8% (Swartz et al, 1990; Torgersen, 2001). A recent general population study involving about 35,000 participants found lifetime prevalence for BPD of 5.9% using the Alcohol Use Disorder and Associated Disabilities Interview Schedule-DSM-IV version (Grant et al, 1995). Within clinical populations, US data show a prevalence of 6.4% in general medical samples (Gross et al, 2002), and from 10% to 23% in out-patients suffering from mental health problems (Korzekwa et al, 2008; Swartz et al, 1990), and 20% among psychiatric inpatients.

Data are scarce for children and adolescents and samples are much smaller. A French study found a high prevalence of BPD in adolescents (10% in boys and 18% in girls) as measured by the DIB-R (Diagnostic Interview for Borderlines – Revised) adapted for adolescents (Chabrol et al, 2001a). A Chinese study reported a more modest prevalence of 2% (Leung & Leung, 2009).

Gender and culture

Currently, prevalence in the general population is considered to be similar for both genders (Leichsenring et al, 2011). In clinical samples, females represent three quarters of all patients. Some experts hypothesize this may be due to men's difficulty accessing care, particularly psychotherapy (Goodman et al, 2010). This effect can also be seen in adolescents (Cailhol et al, in press). This is not a problem specific to BPD but found in other mental disorders also (O'Loughlin et al, 2011).

The concept of BPD originated in Western taxonomies (European and then North American). However, even in its definition, it runs into cultural difficulties. For example, the threshold for emotional lability may be different in Latin and Nordic countries and dissociative symptoms are not interpreted in the same way from one continent to the next. So, thresholds set by clinicians for each of the criteria may differ depending on their and their patients' culture. To our knowledge, the symptomatic expression of BDP in adolescence according to culture has barely been explored.

Through the International Classification of Diseases (ICD), the World Health Organisation (WHO) has promoted the use of this diagnosis throughout the world, in addition to validating an international tool for its diagnosis (Loranger et al, 1994). Nevertheless, the North American model (Diagnostic and Statistical Manual of Mental Disorders, DSM) dominates in research publications (Maffei, 2006). Scientists from different regions of the world continue to use the DSM diagnostic criteria as shown by recent publications, which highlights the issue of diagnosis according to culture (Rossier & Rigozzi, 2008; Wong et al, 2010). Migration does not seem to increase the risk of BPD (Pascual et al, 2008).



The concept of BPD has become part of cultural representations of Western populations: it has emerged in Facebook® and in artistic works (i.e., the book "Borderline" by Marie-Sissi Labrèche, or the film "Girl Interrupted" directed by James Mangold − based on Susanna Kaysen's account of her 18-month stay in a mental hospital).

Burden of illness

It is estimated that BPD costs up to 17,000€ a year per patient in direct and indirect costs in the Netherlands (van Asselt et al, 2007). This includes treatment, particularly hospitalisation, sick leave and loss of productivity. If prevalence in the general population is considered, costs would be substantial. Nevertheless, this European data cannot be extrapolated to the rest of the world as it reflects the medical-economic context in Western countries.

The consequences of BPD for the people around the sufferer depend on their vulnerability to the behaviour and demands of BPD individuals. Families of adolescents in particular need to tackle their child's demands for autonomy whilst protecting the youth and learn to manage worries related to risk-taking behaviour. This can cause considerable stress (Fruzzetti et al, 2005; Gerull et al, 2008; Hoffman et al, 2005).

Apart from physical complications ensuing from self-harming behaviours, BPD patients are exposed to risks due to their impulsivity – resulting in accidents, substance misuse and sexually transmitted diseases among others (Sansone et al, 1996; 2000a; 2000b; 2001). Finally, instability in emotional and inter-personal relationships leads to communication problems between parents and children (Guedeney et al, 2008; Hobson et al, 2005, 2009; Newman et al, 2007). Observational studies of mothers with BPD concerning attitudes towards their infants and young children show less availability, poorer organisation of behaviours and mood and lower expectations of positive interactions. These mothers are described more often as overprotective/intrusive and as less demonstrative/sensitive (Abela et al, 2005; McClellan & Hamilton, 2006; Newman et al, 2007). Their children experience higher rates of parental separation and loss of employment compared to those whose mothers suffer from depression or from other personality disorders.

The psychological development of children with BPD mothers is affected and they tend to withdraw from their surroundings (Abela et al, 2005; McClellan & Hamilton, 2006). These children are less attentive, interested or eager to interact with their mothers and demonstrate a more disorganised attachment in the Strange Situation Test (Abela et al, 2005). Children of mothers with BPD show high rates of suicidal thoughts (25%); the risk of children suffering from depression is seven times higher if the mother has a double diagnosis of depression and BPD (Bradley et al, 2005).

AGE OF ONSET AND COURSE

DSM-IV recommends that a diagnosis of BPD should not be made before the age of 18 years. In practice diagnosis is made earlier when symptoms are clear and persistent.

Follow up studies show that remission is common – 74% after 6 years; 88% after 10 years (Zanarini et al, 2003a, 2006) – questioning the notion that this is a chronic, unremitting condition. There appear to be two clusters of symptoms, one (characterised by anger, feelings of abandonment) tends to be stable or persistent while the other (characterised by self-harm and suicide attempts) is unstable or less persistent. It should be clarified that in most cases remission actually means a reduction in the number of symptoms below the diagnostic threshold and not necessarily the complete resolution of the disorder (Shea et al, 2002).

The risk of death by suicide in BPD patients is estimated at between 4% and 10%, one of the highest of any psychiatric illness. Suicide risk is higher in the event of co-occurrence with a mood disorder or substance abuse and with increasing number of suicide attempts (Paris, 2002). Suicide seems to occur late in the course of the disorder, around 30-37 years of age, and rarely during treatment (Paris, 2002).

These individuals' functioning is significantly impaired (e.g., Global Assessment of Functioning scale scores around 50), with frequent job losses, unstable relationships and history of rape (Zittel Conklin & Westen, 2005). Functioning is more impaired than in other Axis II disorders and in depression (Skodol et al, 2002; Zanarini et al, 2005).



Click on the picture to view Emily's history (10:43)

Like in adults, remission is high when diagnosis is made during adolescence (Biskin et al, 2011); the peak frequency of BPD symptoms appears to be at 14 years of age (Chabrol et al, 2001b). However, in spite of the high remission rate, the presence of BPD in adolescence is far from harmless. Apart from the already mentioned complications inherent to the disorder, diagnosis increases the risk of other negative outcomes, for example, 80% of teenagers with BPD will suffer from a personality disorder in adulthood, even though BPD will occur in only 16% of them (Deschamps & Vreugdenhil, 2008).

CAUSES AND RISK FACTORS

The cause of BPD is unknown. However, several explanatory hypotheses can be found in the medical literature. The most widely accepted theories are psychogenic, mostly following psychoanalytic thinking. One of the initial explanations was based on the *object-relations theory* championed by Otto Kernberg (Clarkin et al, 2006). More recently, John Bowlby's *attachment theory* has provided further insights on the possible mechanisms underlining BPD (Bateman, 2004) while another view emphasizes the importance of *emotional dysregulation* (Linehan, 1993). Finally, *cognitive theories* highlight dysfunctional thinking patterns learnt in childhood, which are maintained in adulthood (Young, 1999). All these theories stress the importance of individuals' emotional development, scarred by trauma and emotional deficits, subsequent to a failure to adapt the environment to a child's needs.

At an epidemiological level, retrospective research has shown a significant prevalence of childhood trauma, sexual abuse, prolonged separations and neglect among patients with BPD (Zanarini et al, 1997). These experiences cannot be construed as direct causes of BPD. Although childhood trauma is high in this



She was born in 1926 and died in 1962 in tragic circumstances. She was an American actress that became a major sex symbol. She grew up with a mentally unstable mother who was financially unable to care for her. She was two years below the legal age when she married her first husband. She took numerous overdoses and had many passionate relationships. She underwent several psychological treatments and psychiatric hospitalizations.

population, it is not present in all cases and, when it does exist, it not always causes a BPD. Nevertheless, the high occurrence of early trauma has been used to support an alternative model of the disorder – as a traumatic disorder resulting from chronic childhood trauma (Golier et al, 2003). Figure H.4.1 illustrates the correlations between childhood abuse and post-traumatic stress disorder (PTSD) or BPD in adulthood. Without completely explaining the disorder, repeated childhood trauma seems to be a frequent element in BPD populations and among patients with PTSD. It should be highlighted also that about half the patients with BPD also meet criteria for PTSD.

Early maternal separation is associated with both BPD and the persistence of BPD symptoms over time (Crawford et al, 2009). Finally, BPD also has a genetic component; heritability is estimated at 47 % (Livesley, 1998). As in almost all psychiatric disorders, inheritance in BPD is polygenic. Further, interaction between genes and environment, as described in the preceding paragraphs, makes it difficult to interpret these data (Steele & Siever, 2010).

DIAGNOSIS

Clinical symptoms

In an effort to improve diagnostic reliability, DSM-III (American Psychiatric Association, 1981) introduced a multi-axial system, placed personality disorders on Axis II – alongside mental retardation – and described BPD as a separate diagnosis. According to DSM-IV (American Psychiatric Association, 1994), the main characteristics of BPD are instability and impulsivity, as described Table H.4.1. The International Classification of Diseases, 10th edition (ICD-10)

Table H.4.1 Criteria and dimensions of borderline personality disorder

	DSM-IV-TR CRITERIA	DIMENSION
6 -	Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).	Emotional
7 -	Chronic feelings of emptiness	
8 -	Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)	
3 -	Identity disturbance: markedly and persistently unstable self-image or sense of self.	Cognitive
9 -	Transient, stress-related paranoid ideation or severe dissociative symptoms	
4 -	Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). Note: Do not include suicidal or self-mutilating behaviour covered in Criterion 5.	Impulsive
5 -	Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour	
1 -	Frantic efforts to avoid real or imagined abandonment. Note: Does not include suicidal or self-mutilating behaviour covered in Criterion 5.	Interpersonal
2 -	A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.	

(*Organisation Mondiale de la Santé*, 2000), places BPD within the "emotionally labile personalities" that include an impulsive sub-type (Table H.4.2). Both classifications require the behaviour pattern to be pervasive, to begin in adolescence or early adulthood and to cause significant impairment in functioning.

Both classifications, DSM and ICD, are currently being revised. The preliminary version proposes to retain BPD in DSM 5, while some other personality disorders are proposed for removal; this is discussed below in more detail.

Subtypes

DSM-IV does not distinguish subtypes within BPD. Subtypes may be defined by the comorbidities. Nevertheless, some researchers propose two subtypes: dependent and impulsive. The former would be characterised by ambivalent, unstable relationships; the latter by a pattern of impulsive acts in multiple areas, including breaking the law. ICD-10, on the contrary, describes an impulsive and a borderline subtype (see Table H.4.2).



Multiple cuts are common in people with BPD

Table H.4. 2 ICD-10 criteria for emotionally labile personality

F60.3 Emotionally unstable (borderline) personality disorder

A personality disorder in which there is a marked tendency to act impulsively without consideration of the consequences, together with affective instability. The ability to plan ahead may be minimal, and outbursts of intense anger may often lead to violence or "behavioural explosions"; these are easily precipitated when impulsive acts are criticized or thwarted by others. Two variants of this personality disorder are specified, and both share this general theme of impulsiveness and lack of self-control.

Impulsive type:

The predominant characteristics are emotional instability and lack of impulse control. Outbursts of violence or threatening behaviour are common, particularly in response to criticism by others.

Borderline type:

Several of the characteristics of emotional instability are present; in addition, the patient's own self-image, aims, and internal preferences (including sexual) are often unclear or disturbed. There are usually chronic feelings of emptiness. A liability to become involved in intense and unstable relationships may cause repeated emotional crises and may be associated with excessive efforts to avoid abandonment and a series of suicidal threats or acts of self-harm (although these may occur without obvious precipitants).

Presenting symptoms

It is rare for patients to go to see their doctor complaining of BPD, even though publicity about the disorder in the media and Internet has started to make people more aware of this illness. Presentations are often prompted by another psychiatric problem (i.e., substance misuse, mood swings), problematic behaviour (i.e., abnormal eating, self-harm), or relationship problems. While self-harm decreases over time, it is a particularly useful identifying symptom in adolescence.

From a categorical to a dimensional concept of BPD

If we were to follow the DSM criteria to the letter, BPD would only be diagnosed in adults (Gicquel et al, 2011). However, some clinicians consider that this diagnosis can be made in adolescents with the proviso of accepting a lower predictive value than for adults (Bondurant et al, 2004). Aware of the shortcomings of current taxonomies, there has been a trend towards a dimensional conceptualization of the disorder. Table H.4.1 shows the diagnostic criteria and the four dimensions that have emerged from these criteria.

Although still in gestation, the fifth edition of the DSM will probably include a dimensional approach alongside the categorical one currently in use. To make a diagnosis of BPD it would be required (see Table H.4.3):

(1) Significant impairments in *self* (identity or self-direction; this means how patients view themselves as well as how they identify and pursue goals in life) and *interpersonal* functioning (empathy or intimacy; meaning that an individual is able to understand other people's perspectives and form close relationships)
(2) One or more pathological personality trait domains or trait facets
(3) That are relatively stable across time situations
(4) That symptoms are not better understood as normative for the individual's developmental stage or socio-cultural environment; and

Table H.4.3: Summary of proposed diagnostic criteria for DSM-5 for borderline personality disorder (as at December 2011; source: DSM 5 Work Group)

1. A person must show significant impairment in two areas of personality functioning (from mild to extreme):
   - *Self* (identity, self-direction)
   - *Interpersonal* (empathy, intimacy)
2. Abnormal personality traits in at least one of these three areas:
   - *Negative affectivity:*
     - Unstable emotional experiences and frequent mood changes that are easily aroused, intense, or out of proportion to events and circumstances
     - Intense feelings of tension or panic, often in reaction to interpersonal stresses; feeling fearful, apprehensive, or threatened by uncertainty; fears of falling apart or losing control
     - Fears of rejection by – or separation from – significant others, associated with fears of excessive dependency and complete loss of autonomy
     - Frequently feeling down, miserable or hopeless and difficulty recovering from these moods; pessimism about the future; shame; feelings of inferiority; suicidal behaviour
   - *Disinhibition:*
     - Impulsivity: Acting on the spur of the moment; difficulty establishing or following plans; self-harming behaviour under emotional distress
     - Risk taking: Engaging in dangerous, risky, and potentially self-damaging activities
   - *Antagonism:* Persistent or frequent angry feelings in response to minor slights and insults
3. Impairment and personality traits are relatively stable across time and situations
4. Impairment is notconsistent with developmental stage or socio-cultural environment
5. Symptoms are not due to substance use or a general medical condition.

(5) Symptoms are not due to substance use or a general medical condition (e.g., severe head trauma).

Within this framework, personality disorders would lie at the extreme end of personality traits ranging from normal to pathological. Research by Zanarini et al (2007) highlights the stability of the disorder, the average duration of symptoms and the potential for remission and recovery, this is summarised in Table H.4.4.

It remains to be seen whether some adolescents experience “borderline moments” and whether others show marginal functioning or organisation. It is a fact that not all marginal adolescents develop BPD. This raises the question of the future of adolescents with marginal functioning. In this line, Bornovalova et al (2009) highlight the risk of diagnostic "labelling" of personality disorders in adolescents, a population undergoing many different developmental changes.

Comorbidity

An international French-speaking study in adolescents led by the European Research Network on BPD (EURNET-BPD) found that BPD is very often comorbid with Axis I disorders: depression (71%), anorexia (40%), bulimia (33%), alcohol abuse (24%) and substance abuse (8%). In particular, comorbid ADHD may be an indicator of severity (Speranza et al, 2011). These data are similar to that reported for adults (Zanarini et al, 1998a). Data from the EURNET-

Table H.4.4 Evolution of borderline personality disorder symptoms over time.

SYMPTOMS	AVERAGE DURATION	
• Para-psychotic manifestations • Risky sexual behaviour • Regression linked to treatment • Counter-transference problems, "special" treatment relations	0 – 2 years	Acute symptoms
• Abuse, dependence on psychoactive substances • Self-harm • Repeated suicide attempts • Demandingness • Severe identity disorder	2 – 4 years	Acute symptoms
• Stormy relationships • Manipulation, sadism, devaluation • Emotional instability • Unusual perceptual experiences, strange thoughts • Feelings of abandonment, annihilation, collapse • Non hallucinatory paranoid experiences	4 – 6 years	Temperamental symptoms
• Major depressive episode, chronic depression • Chronic feelings of despair, guilt • Chronic anxiety • Overall impulsivity • Cannot bear to be alone • Conflict around dependence on care • Dependency, masochism	6 – 8 years	Temperamental symptoms
• Chronic anger, frequent bouts of anger • Chronic feeling of solitude, emptiness	8 – 10 years	Temperamental symptoms

BPD group found that the highest Axis II comorbidity was for antisocial (22%) and avoidant personality disorders (21%), also similar to those found in adults (Zanarini et al, 1998b); there are gender differences in both adolescents and adults with a predominance of comorbid antisocial personality among boys.

Psychometric evaluation

Many instruments exist to evaluate personality disorders in adults. These are the most widely used:

- SIDP-IV (Structured Interview for the Diagnosis of DSM-IV Personality Disorders) (Stangl et al, 1985). The DSM-IV version is widely used internationally (Pföhl et al, 1995) and has been used for adolescents (Chabrol et al, 2002)
- SCID-II (Structured Clinical Interview for DSM-IV) (First et al, 1997), complimenting SCID-I, which is used to diagnose Axis I disorders
- The IPDE (International Personality Disorders Examination; (Loranger et al, 1994) is a semi-structured interview that generates personality disorder diagnoses according to both ICD-10 and DSM-IV

- DIB-R (Diagnostic Interview for Borderline-Revised; Zanarini et al, 1990) is a semi-structured interview with 129 items. Although it does not diagnose DSM-IV BPD, it has satisfactory convergent validity with DSM-IV
- CAPA (Child and Adolescent Psychiatric Assessment) may also be relevant for BPD diagnosis (Renou et al, 2004).
- There are also self-report questionnaires that can be useful as screening instruments, such as the MSI-BPD (McLean Screening Instrument for BPD) and the PDQ-4+ (Personality Diagnostic Questionnaire) (Zanarini et al, 2003b, Hyler et al, 1989).

TREATMENT

Two treatment guidelines for BPD are available, one by the American Psychiatric Association (2001) and another by the National Institute for Health and Clinical Excellence (NICE, 2009). Both have few recommendations specifically for adolescents.



Click on the picture to access the NICE guideline

Aims

Setting a treatment plan and treatment goals is the first step in management, which will be influenced by the patient's instability. In practice, this will entail monitoring the patient's progress, working from a crisis management approach to deal with crisis and to manage harmful behaviour, progressing towards long term work on the personality aspects. At each stage a therapeutic contract is set up after needs and reasons for change are determined. Individualised aims would follow a hierarchy that needs to be explained to the adolescent. For example, reducing the risk of death would take precedence over treating symptoms or improving quality of life. Furthermore, adult caregivers need to be involved and assist in management (e.g., by removing toxic substances).

Care framework

Treatment of adolescents with BPD *should usually be delivered as outpatient*. A sequential and eclectic approach offers a pragmatic solution to the clinical diversity and the natural evolution of the disorder (Gunderson, 2001). Determining the care framework thereby involves different aspects:

- Risk evaluation
- Mental state
- Level of psychosocial functioning
- Aims and motivation of the patient
- Social environment
- Comorbidity and
- Predominant symptoms.

Outpatient treatment can be delivered by an individual clinician, as a partnership between a treating psychiatrist and a psychotherapist, or in a day hospital setting, if available. It is helpful – as general rule – if psychotherapy and medication prescription are provided by different clinicians. Finally, the school can also play a role in the management of adolescents with BPD by offering stability and a place where they can build their identity and relationships, essential ingredients for these patients' improvement.

In practice, *inpatient treatment* can be considered for cases with severe comorbidity (e.g., addictions, severe depression) and when crisis management or day hospitalisation are unable to contain the patient. The risk of short term management of suicidality by admission to hospital, is that the patient regresses. Further, there is no effectiveness data.

Biological treatments

According to the National Institute for Health and Clinical Excellence (NICE) (2009) guidance, drug treatment should not be used specifically for borderline personality disorder or for the individual symptoms or behaviour associated with the condition (for example, repeated self-harm, marked emotional instability, risk-taking behaviour and transient psychotic symptoms). However, comorbid disorders may require medication treatment. In addition, side effect profiles, compliance and the risk of incorrect usage limit the usefulness of medication. Finally, to our knowledge, no drug has been approved for BPD treatment, for adults or adolescents. These precautions highlight the limited role of psychotropic drugs in the overall care of BPD.

Apart from expert opinion, several meta-analyses provide guidance (Binks et al, 2006a; Ingenhoven & Duivenvoorden, 2011; Mercer, 2007; Nose et al, 2006; Rinne & Ingenhoven, 2007; Stoffers et al, 2010). The substances studied include neuroleptics, antidepressants, omega-3 fatty acids and anticonvulsants. However, the short duration of the trials, the low number of studies, the high number of subjects lost to follow up, the absence of comparative studies, and restrictive inclusion criteria in most of the controlled trials limit the interpretation of the results.

As far as benzodiazepines are concerned, they can be used in one-off situations but have considerable risk for addiction or disinhibiting these patients (American Psychiatric Association, 2001). In general, sedatives should not be prescribed for more than a week to deal with a crisis (National Institute for Health and Clinical Excellence, 2009). This explains the need for intensive monitoring and regular treatment review to identify unhelpful medications and their cautious and gradual removal. Antipsychotic drugs, in particular, should not be used for medium- or long-term treatment (National Institute for Health and Clinical Excellence, 2009). However, in the short-term, antipsychotics can have beneficial effects on cognitive-perceptual symptoms, anger, and mood lability (Ingenhoven & Duivenvoorden, 2011).

Psychotherapy

Psychotherapies used to treat BPD share many aspects. For example, most highlight the importance of drawing a care contract at the start of therapy, including ways of dealing with risk situations, particularly suicidal crises, and contact between sessions (e.g., telephone), which must be agreed upon.

When considering psychological treatment for a person with BPD, clinicians should take into account (National Institute for Health and Clinical Excellence, 2009):

- Patients' choice and preference
- Degree of impairment and severity
- Patients' willingness to engage with therapy and their motivation to change

Tips for treatment

Support. Given the high demands these patients place on clinicians, working in a team makes it easier to manage them. If a team is not available, regular supervision or access to colleagues for advice is highly recommended.

Continuity. Continuity of care over time is essential since treatment usually lasts years rather than weeks or months. Building a therapeutic relationship requires reliability from the professionals providing care.

Clear framework. Both clinician and patients must have a clear understanding of their work, its limits and how they will go about it.

Responsibility. While patients' behaviour and even diagnosis encourage systems (family, therapists, institutions) to take responsibility away from patients, it is useful to remember that increasing their emotional control involves gradually accepting more responsibility.

- Patients' ability to remain within the boundaries of a therapeutic relationship
- The availability of personal and professional support.

A variety of psychotherapy approaches have been used for BPD, including individual, group, and crisis treatments. There is no evidence to suggest that one specific form of psychotherapy is more effective than another (Binks et al, 2006b; Leichsenring & Leibing, 2003; Leichsenring et al, 2011).

Dialectical Behavior Therapy (DBT) – developed by Linehan from 1991 onwards – involves an integrative approach (behavioural, cognitive and mindfulness) grounded on a bio-psycho-social understanding of the disorder, where emotional regulation is considered the main problem (see Box). Only the first part of the treatment – dealing with the management of self-harming behaviours – has been validated.

Schema Focused Therapy (SFT) seeks to extend CBT principles to the treatment of personality disorders by placing greater emphasis on the therapeutic relationship, affect and mood states, lifelong coping styles (e.g., avoidance and overcompensation), entrenched core themes (i.e., maladaptive schemas, which develop when specific, core childhood needs are not met), and more discussion of childhood experiences and developmental processes. One study found that after three years of treatment SFT was more effective than a psychodynamically-based transference-focused psychotherapy for participants with BPD (Giesen-Bloo et al, 2006).

Dialectic behaviour therapy (DBT)

DBT was developed specifically for individuals with self-harm behaviours, such as self-cutting, suicidal thoughts and suicide attempts. Many patients with these behaviours have BPD. A key assumption in DBT is that self-destructive behaviours are learned coping techniques to manage unbearably intense and negative emotions. An invalidating environment is also a major contributing factor. An invalidating environment refers to the failure to treat a person in an attentive, respectful and understanding manner. Invalidating environments range from a poor fit between child and parents (e.g., a shy child growing up in a family of extroverts who tease her about her shyness) to extremes of physical or emotional abuse.

DBT provides patients with individual therapy, a skills group and phone coaching. Individual therapy entails once weekly individual sessions. Patients must also attend a two-hour weekly skills group for at least one year and are asked to call their individual therapists for skills coaching prior to hurting themselves. The therapist then walks them through alternatives to self-harming.

The three fundamentals of DBT are CBT, acceptance and dialectics. Learning new behaviours is critical in DBT and is a focus in every individual session, skills group or phone call (for coaching). There are several levels and types of acceptance (validation), from being respectful to what patients are saying, feeling, and doing to treating the patient as an equal (i.e., as opposed to being treated like a fragile mental patient). "Dialectics" assumes that everything is connected to everything else, change is constant and inevitable, and that opposites can be integrated.

Mentalization Based Treatment (MBT) is a psychodynamic therapy developed by Bateman and Fonagy (1999, 2004). "Mentalization" in this model means the ability to differentiate and separate out one's own thoughts and feelings from those of other people around. The various aspects of mentalization are emphasized in MBT, are reinforced and practiced within a supportive psychotherapy setting. Because the approach is psychodynamic, therapy tends to be less directive than CBT-based treatments.



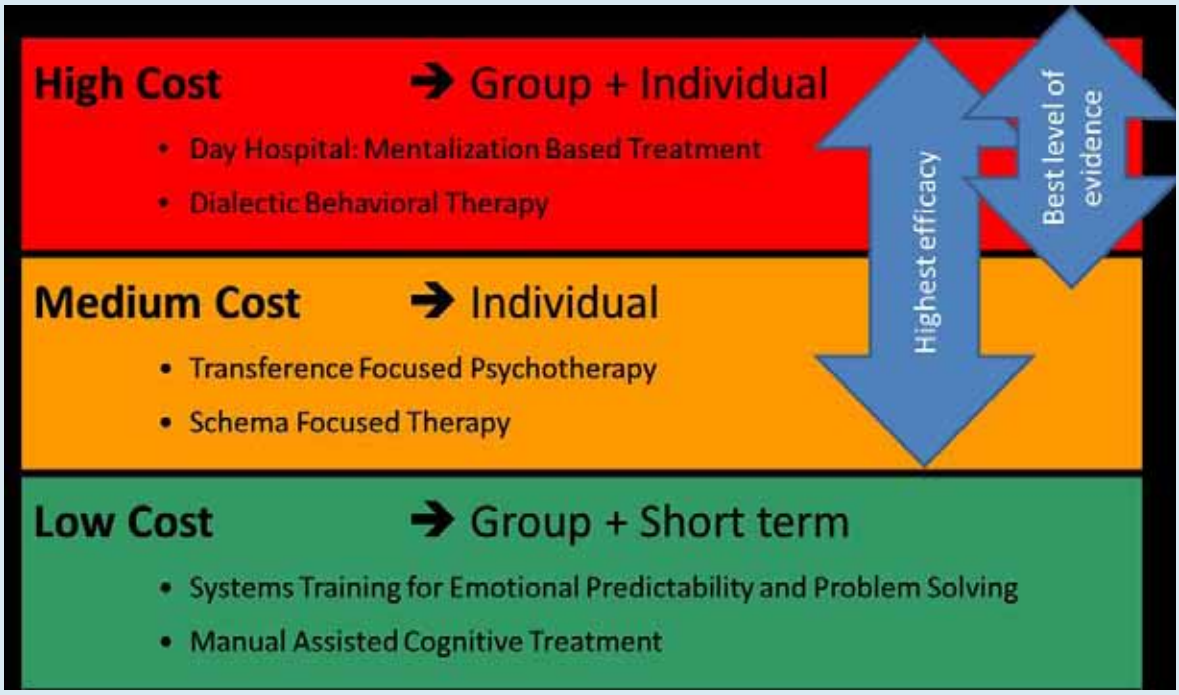
Click on the picture to access a New York Times article on Marcia Linehan's struggle with her BPD and the birth of Dialectical Behavior Therapy

Transference Focused Psychotherapy (TFP) is another psychodynamic approach. TFP Assumes there is a psychological structure that underlies the specific symptoms of BPD. In such a psychological organization, thoughts and feelings about self and others are split into dichotomous experiences of good or bad, black or white, all or nothing. Since these either/or states determine the nature of the patient's perceptions, *splitting* leads to chaotic interpersonal relations, impulsive self-destructive behaviours, and other symptoms of BPD. Splitting is a primitive defence mechanism in which the person externalizes internal conflicts by seeking to draw others around them into taking sides or being "good" or "bad". Treatment – consisting of twice weekly individual psychotherapy sessions – focus on transference because it is believed that patients live out their predominant object relations dyads in the transference (Clarkin et al, 2007).

In adolescents, *Cognitive Analytic Therapy* (CAT; Ryle, 2004, Ryle & Beard, 1993) demonstrated similar efficacy to a "manualised good clinical care" treatment (Chanen et al, 2008). The CAT is a relatively brief treatment lasting from 16 to 24 sessions.

Among the *group treatments*, the Systems Training for Emotional Predictability and Problem Solving (STEPPS; Blum et al, 2002, Blum et al, 2008) is based on a systems approach. The program includes two stages: a 20-week basic skills group, and a one-year, twice monthly advanced group program. In this model,

Figure H.4.1: Comparative summary of different psychotherapies for the treatment of borderline personality disorder.



BPD is understood as a disorder of emotion and behaviour regulation. The goal is to provide persons with BPD, other professionals treating them and closely allied friends and family members with a common language to communicate clearly about the disorder and the skills used to manage it. This helps to avoid splitting.

It remains to be seen whether the gap between the number of treatments and their availability in clinical practice widens or narrows. Lack of support for these treatments at the front line may dishearten clinicians and lead them to ignore or reject psychotherapy options. It is important to remember at this point that a competently delivered treatment – meaning one that adheres to recommendations – seems to produce results that are as good as those obtained with more complex treatments (McMain, 2007).



Click on the picture above to access the TARA website that provides information for sufferers and families (English). Click on the picture below to access a website that provides information in French.



Other treatments

Many teams are working all over the world trying to develop shorter treatments that cost less and are more acceptable to patients than the traditional long term psychotherapeutic ones. Condensed forms of long-term treatment may be able to offer help to more patients. In the same vein, psycho-education and consumer groups may provide valuable alternatives at a lower cost. Setting up a permanent hotline to offer support in difficult times, perhaps at the level of a health region or even a country, may be useful. Finally, prevention services may develop strategies to help parents with a view to reducing the incidence of these disorders in children.

CONCLUSION

BPD is a disorder that can be found in adolescents; it has the range of symptoms and problems found in adults. However, in this age group BPD is even more changeable. A psychotherapeutic approach would result in a fast reduction of symptoms in many cases. The challenge is to identify the patients that are most at risk of developing severe disorders and offer them the most comprehensive care available.

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SCHIZOPHRENIA AND OTHER PSYCHOTIC DISORDERS OF EARLY ONSET

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Jackson Pollock; untitled.

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Conflict of interest: none declared

Acknowledgement: thanks to Polly Kwan who vetted the Cantonese websites

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Suggested citation: Starling J, Feijo I. Schizophrenia and other psychotic disorders of early onset. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Psychotic disorders are associated with impairment in emotional, cognitive and social functioning, potentially leading to long term disability. There is also an increased risk of suicide and harm to others, particularly when acutely unwell. Early and expert treatment is crucial, with optimal results obtained with prompt referral to psychiatric services and intensive treatment by a mental health team, including a psychiatrist, in the acute phase of the illness. Furthermore, these disorders are highly stigmatized in most cultures, making treatment and integration into the community difficult.

Psychotic symptoms in children

Schizophrenia is an extremely rare condition in prepubertal children; psychotic symptoms in this age group need careful evaluation and may be due to many other disorders. This section discusses the presentations of these symptoms in children.

Childhood onset schizophrenia, where children's symptoms meet criteria for schizophrenia and where symptoms start before the age of 13, is a very rare disorder with a prevalence of less than 1/10,000 (Asarnow et al, 2004). The latest information about childhood onset schizophrenia comes from large research cohorts such as the Childhood-onset Schizophrenia Study at the NIMH (Rapoport & Inoff-Germain, 2000). These studies drew from a wide geographical area and had strict exclusion criteria. Information from these cohorts suggests that childhood onset schizophrenia is a severe form of the late adolescent/early adult onset disorder. Findings from these cohorts include more premorbid impairment than seen in those with later onset, with an increased prevalence of cytogenetic (Addington & Rapoport, 2009) and developmental abnormalities including pervasive developmental disorders and mental retardation (Rapoport et al, 2009). Premorbid social difficulties, motor abnormalities and a family history of schizophrenia were more common than in controls. The onset of the illness was often insidious with cognitive deterioration (Bedwell et al, 1999) and neuroanatomical changes (Arango et al, 2008) occurring

Terms used in this chapter

- *Psychotic* (symptoms) is a word used to describe situations when perceptions, thoughts or emotions are disordered so severely that contact is lost with external reality. The two most common mental illnesses where psychotic symptoms are a predominant feature are schizophrenia and bipolar disorder. Psychotic symptoms include:
  - *Hallucinations* (false sensory perceptions in the absence of external stimuli). Auditory hallucinations ("hearing voices") are the most common but visual hallucinations are also seen in children and teenagers with psychosis.
  - *Delusions* (strongly held beliefs, not shared by other members of the community, arising from an incorrect interpretation of external reality, incompatible with a person's social or religious background).
- *Positive symptoms* describe an excess or distortion of normal functions (such as hallucinations or delusions).
- *Negative symptoms* is used to describe a reduction or loss of normal functioning (for example loss of normal emotional reactivity or impaired cognitive functioning)
- *Prodrome* is the period of time before the onset of psychotic symptoms where functioning is impaired.
- *Acute psychosis* is the period of time when hallucinations and/or delusions are predominant and behavior is often disturbed.

early in the illness. However, few children with psychotic symptoms fulfill diagnostic criteria for childhood onset schizophrenia and by the time diagnostic criteria are met they are chronically ill, with significant disability.

Other psychotic disorders presenting in childhood include bipolar disorder (discussed in Chapter E.2). However, most children who present with psychotic symptoms do not have schizophrenia or bipolar disorder. They are more likely to show transient auditory hallucinations as well as mood or anxiety symptoms with associated distress. At first presentation these children often meet diagnostic criteria for depression, post-traumatic stress disorder (PTSD), anxiety or behavior disorders but not for any of the psychotic disorders. Many have a long history of developmental, behavioral and emotional problems and may display a confusing mix of symptoms. There are very few studies following up such children to see if they go on to develop schizophrenia but the available evidence is summarized below.



Click on the picture to access a video clip in which a young woman describes her psychotic symptoms that had started during her childhood (7:31).

Auditory hallucinations are not uncommon in non-psychotic children attending child psychiatry services (Dhossche et al, 2002). While most appear to recover, a subgroup of those with hallucinations develops a psychotic illness. In a clinic sample of 90 children it was found that half of the 15% who reported hallucinations initially were hallucination free at 12 months, while a third had ongoing symptoms and came close to meeting criteria for either schizophrenia or bipolar disorder (Askenazy et al, 2007). Sixty percent of a sample of 80 children with auditory hallucinations reported no hallucinations three years later but 16% had developed delusions (Escher et al, 2002). Hallucinations were more likely to persist in those with diagnoses of anxiety, depression or dissociative disorder. Other risk factors were behavior problems, negative symptoms and more frequent auditory hallucinations or hallucinations with negative content (Escher et al, 2004). Children and adolescents with PTSD are also more likely to report auditory hallucinations (Scott et al, 2007a). Children in community samples report auditory hallucinations relatively often, two studies reporting a rate of 8% (McGee et al, 2000; Scott et al, 2006). Hallucinations were more likely in children with anxiety, depression, family dysfunction and inattention or hyperactivity. When the cohort reported by McGee and colleagues was followed up 15 years later, at the age of 26, a quarter of those with psychotic symptoms at age 11 met criteria for schizophreniform disorder (Poulton et al, 2000).



Click on the picture to hear a university student talk about psychosis and what it is like to go through an early detection service (9:59).

In summary, the differential diagnosis of psychotic symptoms in childhood can be difficult and a longitudinal perspective is essential. It may be more useful to describe "diagnostic hypotheses" rather than a specific diagnosis, especially at first presentation (Lee et al, 2003). While the majority of children with isolated psychotic symptoms will not go on to develop schizophrenia, schizophrenia or bipolar disorder will develop in a significant minority either within one to two years of hallucinations first appearing or they will remain comparatively well in adolescence but develop schizophrenia as an adult.

Psychotic symptoms in adolescence

Psychotic disorders of all types increase in prevalence during adolescence, to a prevalence of one in 500 among 18 year olds. Retrospectively, about one third of adults with psychotic disorders report that their illness started before the age of 20 and the lifetime prevalence of all psychotic disorders in the adult population

Table H.5.1 Diagnostic criteria for schizophrenia

1. Two or more of the following present for at least a month:
   - Hallucinations
   - Delusions
   - Disordered thoughts and speech (speech can be incoherent or greatly reduced)
   - Severely disorganized behavior (including catatonia, or severe motor slowing)
   - Negative symptoms
2. Deterioration in social, educational or work functioning
3. Duration of illness of at least six months, including the prodrome, if present (if duration I less than six months, it is labeled *schizophreniform psychosis*)
4. Not due to another mental illness such as a mood disorder, or a medical condition.

is 2%-3% (Kendler et al, 1996). While some adolescents with psychosis come from similar high risk groups to those with childhood onset schizophrenia, the majority had previously normal functioning. In this group the typical illness course starts with a prodrome, with nonspecific symptoms including low mood, anxiety, cognitive and functional deterioration.

The risk factors for schizophrenia in adolescents and young adults are well described. These include a schizotypal personality, sub-threshold psychotic symptoms (such as brief, indistinct auditory hallucinations), functional decline and a family history of schizophrenia (Owens & Johnstone, 2006; Yung et al, 2004). Combinations of these symptoms have been described as the "ultra high risk" mental state. The likelihood of transition to psychosis with these risk factors was thought to be high, but recent studies suggest that, in help-seeking young people, the risk decreases from 40% to 16% (Yung et al, 2008). Poor functioning at presentation, low-grade psychotic symptoms, depression and a long duration of prodromal symptoms make transition to psychosis more likely.



Click on the picture to hear a young man describing his struggle with schizophrenia and its treatment (8:13).

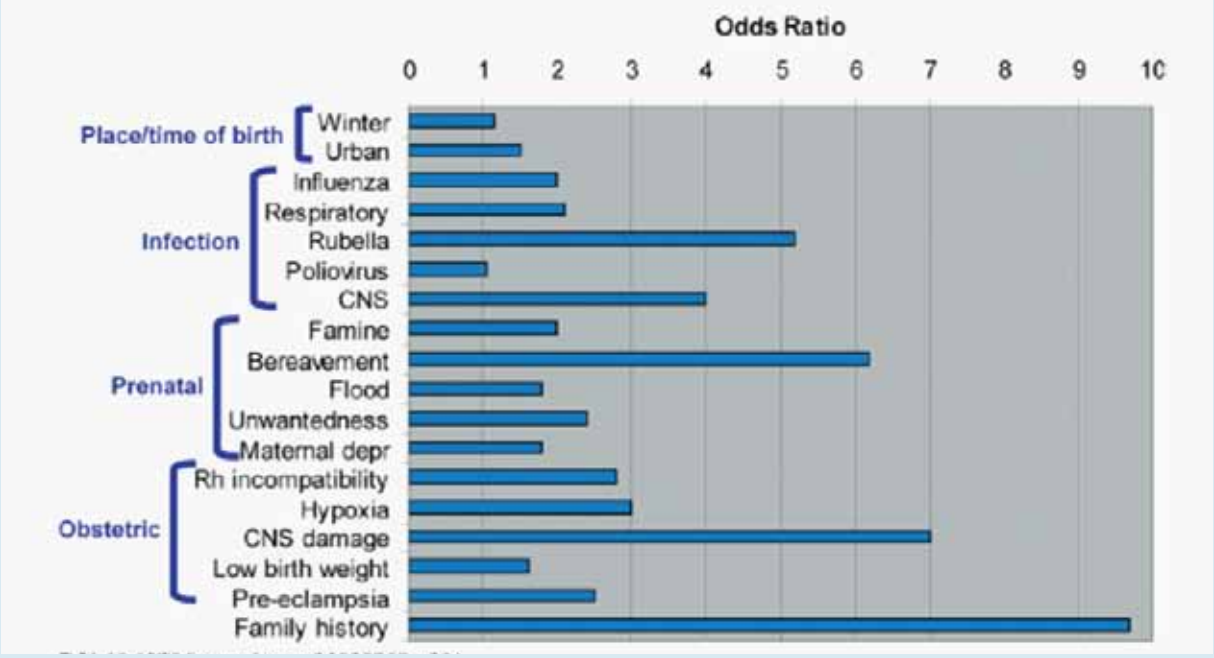
Currently, the debate in the adolescent-onset group is at what stage to treat the psychotic symptoms. Trials of antipsychotic medication have been shown to reduce the transition from the "ultra-high risk" state to a psychotic disorder, but as the risk of transition to psychosis drops in the clinic cohorts, the risk of using antipsychotic medication in adolescents who are unlikely to later develop psychosis becomes less acceptable (Yung et al, 2007).

ETIOLOGY

The pathophysiology of schizophrenia or any of the other psychotic disorders is still unclear. All psychotic disorders have a genetic vulnerability but there is no clear single gene implicated in causation. Recent research reports multiple genes associated with the development of schizophrenia, but most have a small effect. Most of these genes are nonspecific and some genes linked to schizophrenia are also linked to autism and bipolar disorder. There are also multiple other organic and psychosocial risk factors. A summary of risk factors and their associated odds ratios can be seen in Figure H.5.1. Additional risk factors include being male or an immigrant. Children, and to a lesser extent teenagers, with psychosis are likely to have more risk factors than those with a later age of onset.

When talking to young people and their families, the most easily understood

Figure H.5.1 Comparison of a selected set of relatively well-established risk factors for schizophrenia, focusing mainly on pre- and ante-natal factors.



CNS: central nervous system; depr: depression; Rh: Rhesus. Source: Sullivan PF. The genetics of schizophrenia.

model for the etiology of schizophrenia is the stress/vulnerability model. Risk factors (or vulnerabilities) for the development of schizophrenia include:

- Family history of psychosis, particularly in first degree relatives
- Personality in the schizotypal, schizoid or paranoid spectrum, and
- Being an older teenager or a young adult.

Factors that may precipitate a psychotic episode include organic factors such as illicit or medical drug use, a severe physical illness, trauma or other psychological stress such as starting a more difficult course of study.

SYMPTOMS OF PSYCHOSIS

Positive symptoms

- Hallucinations, most commonly auditory hallucinations or hearing voices. Visual hallucinations are more common in children than in adults (up to 50% in some cohorts)
- Delusions, generally persecutory or grandiose in nature

Negative symptoms

- Reduced motivation
- Flat or blunted affect
- Social withdrawal
- Impaired cognitive performance in domains such as attention, concentration, memory and planning.

These negative and cognitive symptoms best predict long term outcome and may precede the onset of hallucinations or delusions by many months. In addition changes in mood, anxiety and levels of agitation are common.

The two most common psychotic disorders are schizophrenia and bipolar disorder. Table H.5.1 summarizes the criteria for the diagnosis of schizophrenia. The prominent symptoms are hallucinations and/or delusions. People who are given a diagnosis of schizophreniform disorder have the same symptoms as those with schizophrenia but for less than six months. In both conditions there is also associated disturbed behavior and deterioration in functioning, including school performance and social functioning. In bipolar disorder, a distinct period of mood symptoms is the predominant feature, with mania (at least one episode of severely elevated mood affecting all areas of functioning including sleep and cognition for a period of at least seven days) being the most prominent. Delusions and hallucinations in psychotic bipolar disorder tend to be grandiose if the patient is manic and depressive (e.g., of guilt, ruin, worthlessness) in psychotic depression. The initial episodes of a bipolar disorder are often depressive, so diagnosis is not clear until after the young person has a manic episode (see Chapter E.2). The diagnosis of both schizophrenia and psychotic mood disorders have poor reliability at first presentation, with low agreement between clinicians and diagnostic instability over time.



Click on the picture to hear a description of psychotic phenomena she had as a teenager in a person with bipolar disorder (3:06)

COURSE AND OUTCOME

A good outcome in early onset psychosis includes not only the resolution of acute psychotic symptoms such as hallucinations and delusions, but also a reduction in negative symptoms and a return to education and friendship networks. A rapid recovery is more likely with early treatment, a more acute onset and an illness with fewer negative symptoms. Early onset is associated with a poorer prognosis, particularly childhood onset (Hollis, 2000), although those with illness onset prior to the age of 18 tend to have a worse outcome than those with adult onset (Schimmelmann et al, 2007). Male gender, ongoing substance use, pervasive developmental disorder, poor premorbid function and insidious onset are also associated with poorer outcomes.

Early treatment, not only reduces the severity of the first episode, but also helps prevent relapse. While recovery may be good after the first episode – about 20% of young people with schizophrenia will have only one episode – a relapse is not only extremely disruptive to educational, vocational and personal development but may also be less responsive to treatment. Active follow up after recovery from the first episode, including a clear plan to monitor for early warning signs (subtle signs of deterioration in mental state), as well as continuing antipsychotic medication for twelve months after recovery will reduce the risk.

PSYCHOSIS IN SPECIFIC GROUPS

Developmentally disabled

Young people with developmental disability, in particular pervasive developmental disorders, have an increased risk of psychosis but are also more likely to be wrongly diagnosed as psychotic. Pervasive developmental disorders, also called autistic spectrum disorders, are discussed in Chapter C.2. These disorders manifest themselves with deficits in social interaction, impaired verbal and nonverbal communication, restricted and idiosyncratic interests, and stereotyped behaviors. Because the core deficits in pervasive developmental disorders lead to difficulties in social interaction, repetitive or other unusual behaviors, and odd

preoccupations, it can be difficult to differentiate between these symptoms and other psychiatric disorders. Behaviors or cognitions associated with pervasive developmental disorders may appear similar to those of disorders such as anxiety, obsessive-compulsive disorder or even schizophrenia. The broad phenotypes seen more commonly in relatives of children with autism, such as delayed language, poor social functioning and executive control deficits are also risk factors for schizophrenia (Losh et al, 2008), suggesting some common causative factors.

There is so much overlap of symptoms between pervasive developmental disorders and psychosis that before the 1970s, the term childhood psychosis was widely used to refer to both childhood-onset schizophrenia and autism. Much of the later work in this area, such as the seminal studies by Kolvin (Kolvin, 1971), concentrated on identifying the differences between autism and schizophreni, including age at onset and differing outcomes. During the past two decades, the core syndromes of pervasive developmental disorders and childhood-onset schizophrenia have been clearly delineated and research has focused on the identification of comorbid psychosis and other mental illnesses in the pervasive developmental disorder population.

In clinical practice, the main difficulty is making a differential diagnosis in a young person with pervasive developmental disorders and either increasingly odd behaviors or a decline in functioning (Starling & Dossetor, 2009). It is important to consider beliefs and behaviors in a developmental context, particularly in young people with intellectual impairment. In this population, anxiety or depression can also manifest with unusual behaviors. Psychosis should not be diagnosed in individuals with pervasive developmental disorders without the presence of hallucinations or delusions, as disturbed behavior alone is not sufficient.

Young people with a history of trauma

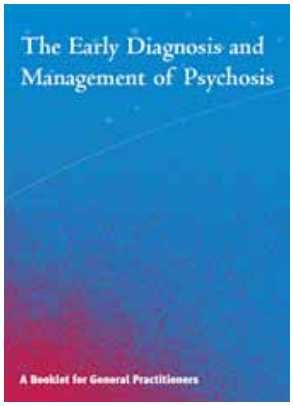
Rates of psychotic disorders are significantly increased in adults with a history of childhood sexual abuse (Cutajar et al, 2010). A history of psychological trauma or maltreatment also increases the risk of transition from prodromal symptoms to a psychotic disorder in young adults (Bechdolf et al, 2010b). There is less evidence of a link between trauma and psychosis in children and teenagers, but traumatized young people are more likely to report hallucinations, sometimes as a symptom of post-traumatic stress disorder (Shevlin et al, 2007).There is some debate about whether auditory hallucinations reported by young people with a childhood history of trauma are different from those without a history of abuse. Some studies found that hallucinations directly related to the trauma experience were more likely, while others found no difference in symptoms (Scott et al, 2007b).

A history of childhood trauma also increases the risk of aggression, self-harm, suicide attempts and substance abuse in patients with psychosis (Hainsworth et al, 2011). Clinically this means that young people with psychosis and a traumatic background are likely to be more difficult to treat and potentially more dangerous to themselves and others. They are also more likely to live away from their families or have less family support. It is important to be aware of the reasons for the disturbed behavior and also provide treatment for the trauma symptoms as well as for the psychotic disorder.

Substance use

The relationship between drug use and early psychosis is complex. There is good evidence that early cannabis use increases the risk of psychosis in later life, with some young people being more vulnerable than others. Research from a New Zealand cohort suggests that there is a tenfold increase in the risk of psychosis with cannabis use in people with a functional polymorphism of the catechol-O-methyltransferase (COMT) gene – associated with the production of dopamine in the brain – suggesting a gene-environment interaction (Caspi et al, 2005). Drug use, particularly cannabis, psychostimulants and hallucinogens can precipitate a psychotic episode, reduce response to treatment and increase the risk of relapse after recovery. Cannabis use can worsen cognitive deterioration. Acute drug intoxication can also mimic psychosis, although symptoms generally last only hours or days. Symptoms lasting days to weeks suggest either severe ongoing substance abuse or a psychotic illness (Volkow, 2009).

Illicit drugs may also be used to self-medicate distress in the prodromal stage of schizophrenia so, the psychotic illness predate the substance abuse, but ongoing use makes hallucinations and delusions less likely to respond to medication. Strategies for helping teenagers with psychosis and substance use are detailed on the EPPIC website.



Click on the picture to access an overview of the early identification, assessment and treatment of psychosis by ORYGEN Youth Health

ASSESSMENT

The goal of the initial assessment of a young person presenting with a psychotic disorder is not just to make a diagnosis but also to develop rapport and set the stage for the ongoing treatment of a frequently chronic illness. While going slowly and cautiously at this stage can be seen as wasting time, forcibly treating without adequate discussion, education and understanding of the patient and family, can lead to later avoidance of services and relapse or recurrence of the illness.

Individual assessment

Obtaining a history of psychotic symptoms can be difficult. Young people often avoid discussing such symptoms because they are frightened of being seen as "crazy". They need to be given the choice as to whether they would prefer to be seen alone or with the support of a trusted adult, often a parent – although seeing young people by themselves for a short period is always necessary, e.g. to assess suicidality. Starting the interview with a discussion of more neutral topics such as family, school, hobbies and friendships helps to build rapport and assemble a picture of their general functioning. The interviewer can then move on to ask about specific worries or concerns and explore those in more detail.

Asking about symptoms of anxiety and depressed or elevated mood is crucial, as is discussing thoughts of self-harm or suicide. Finally there needs to be specific enquiries about psychotic symptoms, where it is important to be neutral but direct, for example saying "*I am going to ask you some questions that seem really strange but are important to help me understand what is happening with your thoughts*". It may take several interviews to fully elicit symptoms; it can be difficult for confused young people to put the chaos of their thoughts into words. Examples of questions to use for a comprehensive assessment of psychotic symptoms are given in Table H.5.2.

Table H.5.2 A mental state assessment for psychotic symptoms

	Interview questions	Rationale for questions
Appearance and behavior	Observation at interview	Unusual behavior or dress should be described and if possible understood during the interview
Insight	– Could you tell me why you have come to see me? – Do you think there is anything that you need help with?	If they understand that they are unwell and if they see the need for treatment, cooperation is more likely
Mood: depressed	– Have you been feeling depressed or down recently? – Have you lost interest in things you usually enjoy? – Have you had problems sleeping? – Have you had thoughts of hurting yourself? – If yes to any of the above, ask also about eating, agitation, concentration, thoughts of guilt or hopelessness and suicidal ideas or plans	Checking for a current and past history of depression and risk of self harm or suicide
Mood: elevated	– Have you ever had a period of time where you were feeling so good, excited or hyper that you felt out of control, or did worrying things? – If yes ask for more details	A period of elevated mood may be a manifestation of bipolar disorder
Thought form	Observation of speech flow and thinking at interview	Thought disorder is often seen in psychosis and the type will help with diagnosis. Thought disorder is where thoughts are poorly connected. Speech can be also rushed in bipolar disorder or slowed in depression.
Perceptual abnormalities: hallucinations	– Did you ever hear things that other people couldn't such as noises or people's voices? – If yes, what did you hear and how often? – If voices, did they comment on what you were thinking or doing? – How many voices did you hear? Were they talking to each other? – Did you have visions or see things that other people couldn't? (ask for details) – Also ask about tactile,olfactory and gustatory abnormalities	These questions seek to elicit core psychotic symptoms. As hallucinations become more complex (more often, say more things, more than one voice) a psychotic disorder is more likely.
Thought content : delusions	Start with "I would like to ask you about unusual experiences people sometimes have" – Has it ever seemed that people were talking about you or taking special notice of you? – Have you ever received special messages from the TV, radio, or other things around you? – What about anyone trying to give you a hard time or hurt you? – Have you ever felt that you were especially important or could do things that others could not? – If yes to any, get further details	As delusions become more complex (e.g., not just people looking at me but having an elaborate plan to hurt me) a psychotic disorder is more likely. Paranoid delusions are most likely in schizophrenia spectrum disorders, and grandiose delusions in bipolar disorder.
Cognitive functioning	Ask about current and past functioning at school including concentration, motivation, ability to learn and academic grades	Premorbid cognitive functioning affects prognosis, while deterioration is not only seen in psychotic disorders but also in depression.

A discussion of the rules of confidentiality is also important. While a teenager's thoughts or feelings should be kept confidential, if they talk about harming themselves or others there is often a duty of disclosure for safety reasons. Similarly a history of past sexual or physical abuse may also require disclosure to the relevant authorities, depending on the laws of the country they live in.

It is important to remember that it is rare for a psychotic disorder to exist in isolation. Common co-morbidities include substance misuse (ask about tobacco, cannabis and stimulants), anxiety, depression, behavior disorders, a history of trauma or developmental disorders.

Other assessments

Parents can provide a developmental history including pregnancy (viral infections, maternal drug or alcohol use, other complications) birth trauma (such as emergency caesarian section, hemorrhage or hypoxia) or developmental abnormalities, and can also describe symptoms that the young person is reluctant to talk about or even unaware of. Siblings often have important information to add, particularly about interactions and social functioning. Past or family psychiatric history can be an important pointer for diagnosis.

Corroborative information from schools, about academic and social functioning, health services and other care agencies will also be needed for an accurate assessment not just of mental state but also of current and previous levels of functioning.

DIFFERENTIAL DIAGNOSIS

The first consideration is to decide if the reported symptoms are truly the manifestation of a psychotic illness or due to another disorder. For example a depressed teenager may describe hearing a voice saying that they are useless, but are actually talking about their own thoughts, or an anxious adolescent may see shadows by their bed and be convinced that burglars have broken into the house.

Symptoms may also appear related to a psychosis but do not meet full diagnostic criteria. Many individuals with schizophrenia have a prodrome, with disturbances in mood, thoughts and behavior and some deterioration in functioning. However, these symptoms are non-specific and can have other causes, such as an adjustment disorder or depression. Research has also identified *psychotic-like experiences* – bizarre beliefs, persecutory ideas and magical thinking. All these symptoms except magical thinking increase the risk of later developing psychosis (Yung et al, 2006).

Even if it is clear that the young person meets criteria for a psychotic disorder, it can be difficult to make a specific (e.g., whether schizophrenia or bipolar) diagnosis early. Many diagnoses made at first presentation are found to be incorrect later (McGorry et al, 1995). Thus, some experts prefer to use the term *early onset psychosis* because it reflects this diagnostic uncertainty and provides more treatment flexibility. If there is a definite psychotic illness, early treatment is crucial, irrespective of its nature (e.g., schizophrenia, mood disorder). The longer the duration of untreated psychosis the more difficult the symptoms are to treat and the greater the risk of long term disability (Leeson et al, 2011). It is also

Table H.5.3 Investigations recommended at baseline assessment for early onset psychosis

Investigation	Rationale
Full blood count	• Detection of pre-existing hematological disorders such as anemia • Monitoring side effects of mood stabilizers
Urea, electrolytes, liver function tests	• Exclusion of pre-existing abnormalities (rare, but polydipsia can be seen in psychosis). • Monitoring for medication side effects (some antipsychotics and antidepressants can cause hypernatremia, mood stabilizers can impair liver function)
Fasting glucose, cholesterol and triglycerides	• Detection of insulin resistance or lipid abnormalities. Initial and six monthly monitoring as most antipsychotics can cause weight gain and insulin resistance
Thyroid function	• Thyroid abnormalities can cause mood elevation or depression and are a side effect of lithium treatment
Calcium levels	• Abnormalities a rare cause of psychosis
Prolactin	• Exclusion of pre-treatment hyperprolactinemia (e.g., due to pituitary tumor). • To monitor possible antipsychotic induced hyperprolactinemia,
Brain imaging (Computerized Axial Tomography, CAT; Magnetic Resonance Imaging, MRI)	• Exclusion of preexisting neuroanatomical lesions (injuries, malignancy) • MRI preferable because of higher resolution image and less radiation exposure but noise and claustrophobia may not be tolerated by patient
EEG	• Exclusion of a seizure disorder
Urine drug screen	• To rule out recent drug use or identify illicit drugs taken recently

important not to miss depression or elevated mood and so to misdiagnose a mood disorder as schizophrenia.

Other differential diagnoses include pervasive developmental disorders, PTSD with flashbacks, delirium and drug intoxication or drug induced psychosis, as discussed earlier. Finally, it is important to exclude possible organic disorders that can be confused with psychosis such as delirium, neurological disorders and other medical conditions such as thyrotoxicosis or Vitamin B12 deficiency, by a physical examination and physical investigations as detailed below.

Investigations

Investigations are detailed in Table H.5.3. They are not only performed to exclude treatable organic causes for psychosis but also as a baseline to monitor, prevent and manage side effects of treatment. A full physical examination is also essential, with particular emphasis on developmental or neurological abnormalities. Weight, height, waist measurement, blood pressure and pulse need to be recorded initially and monitored regularly. There are acute autoimmune or inflammatory illnesses that can mimic psychosis, especially when onset is acute (symptoms in these cases could be of delirium). Appropriate pediatric or other medical consultations may be required.

MANAGEMENT

Least coercive treatment

Assessment should always consider risk, both to the young person and to others. Ideally assessment and treatment should occur while patients remain at home with their family, but an admission to hospital may be needed if:

- There are concerns about high risk of suicide
- There is risk aggression to others (e.g., because of delusional beliefs)
- The patient is at serious risk of exploitation by others while unwell
- The young person is homeless
- Carers are exhausted. For example when teenagers have required round the clock supervision for days and their family can no longer manage this
- There are physical symptoms such as fluctuating levels of consciousness that require urgent medical investigation.

Taking into account the risk, the option least restrictive of patient's liberty should generally be used. If the risk is high, admission may need to be involuntary if the consent of either the young person or their family cannot be obtained, or there is concern that the young person is not well enough to make rational decisions about treatment. The laws about involuntary hospitalization vary according to country, but many only allow treatment against an individual's wishes if there is serious danger to themselves or others. Click here to see an example of legislation for involuntary hospitalization.

While it is possible to admit a child under the age of sixteen with their parents' consent (in many countries individuals have the capacity to give consent to treatment at 16 years of age, see Chapter A.1), it is also important to respect the child's rights, including the right to have their views about treatment considered and to be protected from violence (protection from being hurt physically and mentally by caregivers). This means that, even if young people are admitted against their will, every effort should be made to discuss their treatment with them, take their preferences into account wherever possible and to keep the use of coercive practices such as restraint to an absolute minimum.

Summary of management

Biological

Antipsychotic medication is essential for the treatment of psychosis. Most treatments are extrapolated from the results of adult studies. Studies in children include one small randomized controlled trial (RCT) showing haloperidol to be superior to placebo (Spencer & Campbell, 1994), and a small RCT (21 cases) showing that clozapine was superior to haloperidol (Kumra et al, 1996). Studies in adolescents show similar efficacy to adults for olanzapine, risperidone and haloperidol, but with differing side effect profiles and a non-significant trend for olanzapine and risperidone to be more effective (Gothelf et al, 2003; Sikich et al, 2008). These findings are similar to those in adult treatment trials.

Table H.5.4 Common side effects of selected antipsychotic medications used in early onset psychosis

Medication	Dose (mg)	Extra pyramidal side effects	Sedation	Weight gain	Prolactin	Postural hypotension	Potential disadvantages	Comments
Risperidone	1-6mg	++	++	++	+++	++	• Galactorrhea, • Sedation	Most data comes from use in adolescents (including in autism)
Quetiapine	200-800mg	+	++	++	+	+	• Initial sedation, often settles	Useful for psychosis with mood disorders or anxiety
Aripiprazole	10-30mg	++	+	+		+	• Initial agitation	Sedation, weight gain and elevated prolactin are rare
Olanzapine	5-20mg	+	+++	+++	+	+	• Very significant weight gain • Sedation. • Not recommended long term	Sedating and calming when acutely unwell
Chlorpromazine	50-300mg	+	+++	++	++	++	• Weight gain, sedation	Sedating and calming when acutely unwell
Haloperidol	1-10mg	+++	++	+	+	+	• Severe extra pyramidal side effects including stiffness and agitation	Less sedating, strong antipsychotic effects

Pychological

Interventions include psychoeducation and cognitive behavioral therapy. Again, the evidence is from adult and late adolescent cohorts, with multiple trials showing benefit from these therapies (Bechdolf et al, 2010a).

Social

These therapies include family interventions and social skills training and again show benefit in multiple adult trials (Addington et al, 2005; 2010).

Pharmacotherapy

Acute sedation

If there is acutely disturbed behavior or imminent danger, emergency sedation may be needed. Rapidly acting oral medication such as lorazepam (1mg-2mg), risperidone (0.5mg-1mg) or olanzapine (2.5mg to 5mg) are preferred. Oral wafers are absorbed more quickly and also dissolve in the mouth so are difficult to spit out. If oral medication is refused, intramuscular lorazepam (1mg-2mg) or haloperidol (2.5mg-5mg) are recommended. Intramuscular sedation usually requires physical restraint and is very distressing for the child and family. It is important to use the least coercive method of sedation not only to respect young person's rights, but also because the first experience of mental health treatment can be very aversive and make the difference between ongoing compliance or avoidance of further treatment.

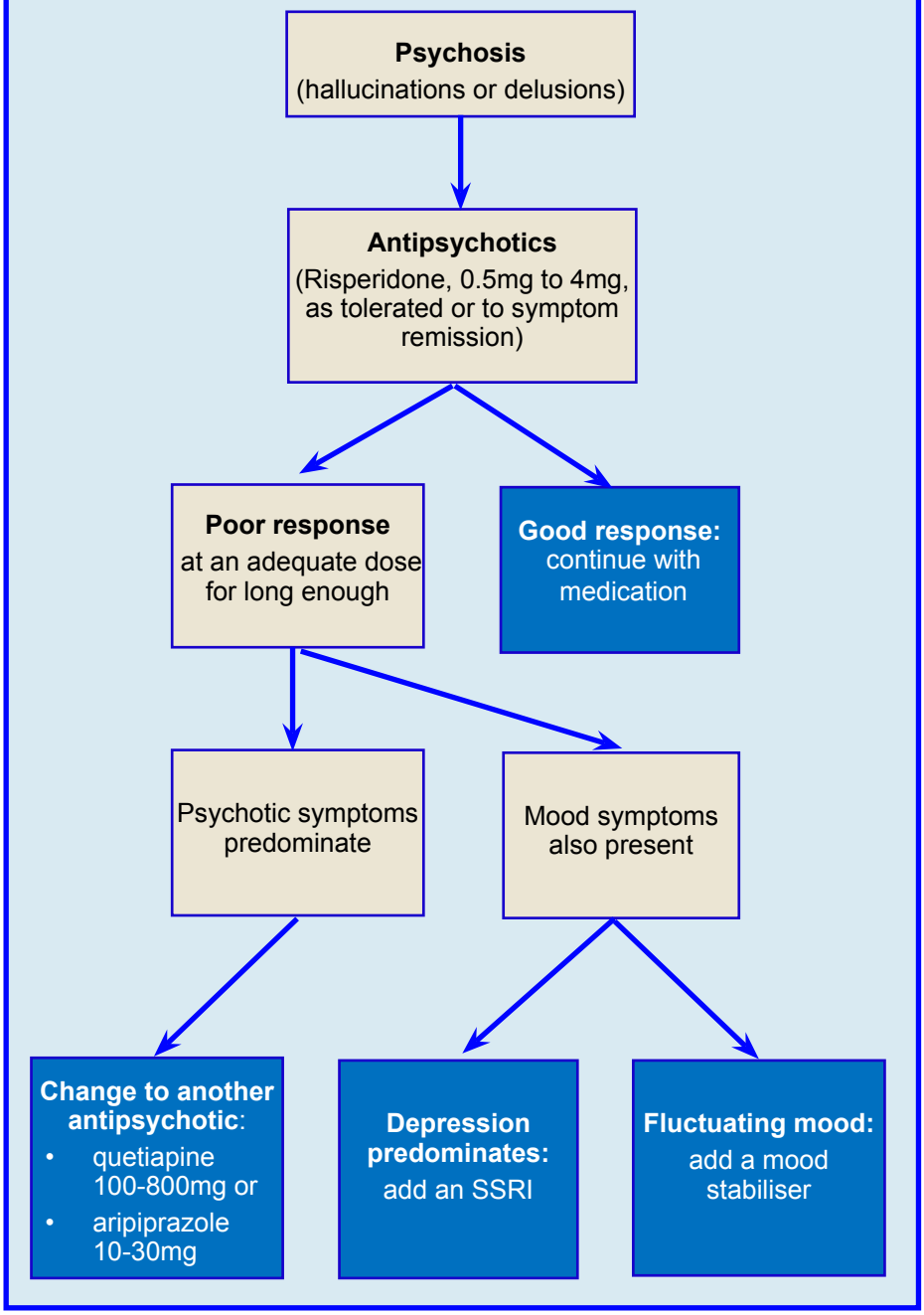
Ongoing management of medication

If no emergency treatment is needed, medication decisions in early psychosis aim to control psychotic symptoms and manage associated impairments as summarized in Figure H.5.1 (for management of psychotic depression and manic episodes see Chapters E.1 and E.2 respectively). An antipsychotic is used to treat hallucinations and delusions. In psychotic depression an antidepressant is added. When there is mania a mood stabilizer may be more appropriate. Table H.5.4 summarizes side effects of the most commonly used antipsychotic medications. It is recommended to *start low and go slow* with doses of antipsychotic medication. This is to avoid side effects and maximize adherence to treatment. (For a detailed, evidence based summary of treatment algorithms, the use of specific medications and side effects please see Taylor, 2012).

A second generation (atypical) antipsychotic is recommended as first line treatment if possible because of marginally better treatment outcomes in acute psychosis and the lower risk of movement disorder, particularly tardive dyskinesia, as demonstrated in individual RCTs and meta analyses (Davis et al, 2003; Leucht et al, 2009). However, second generation antipsychotics are expensive, so it may be necessary to use a first generation antipsychotic such as haloperidol, which is still highly effective (Schooler et al, 2005), although has more side effects than risperidone, for example.

When there is no response to antipsychotic medication after two weeks, a medication review is needed – some response in positive psychotic symptoms is usually seen by that time. If the maximum tolerable dose of a particular medication has been reached without effect a choice needs to be made about either changing medication or augmentation with another medication class (Figure H.5.1). Failure

Figure H.5.1 Simple flow chart for the treatment of an acute psychotic episode





Click on the picture to access a metabolic monitoring algorithm for young people prescribed antipsychotic medication

to respond to two or more antipsychotics for an adequate length of time and at adequate doses should prompt referral to a specialist service for consideration of clozapine.

Long term antipsychotic use increases the risk of obesity, type two diabetes and cardiovascular disease. It is crucial to monitor height, weight and waist measurement at the start of prescribing, and then at one, three, and then six monthly intervals, with intervention as needed (see metabolic monitoring algorithm in side box).



Click on the picture to access Get Help Early (Ontario Working Group on Early Intervention in Psychosis, Canada). It includes stories and artwork.

Clozapine for treatment resistant schizophrenia

Clozapine is an atypical antipsychotic that is extremely effective in schizophrenia; it should be used if there is a poor response to two other antipsychotic agents, each given at adequate doses for at least a four week trial. It is not recommended except for treatment resistant cases because of the risk of life threatening side effects and therefore the need for close monitoring. The minimum frequency of monitoring is weekly white blood cell counts for the first 18 weeks, with caution being used when neutrophils fall below 2 per 10^9/Litre. Clozapine should be ceased at a neutrophil count of 1.5 per 10^9/Litre. Many health services require registration of patients on clozapine so that these monitoring requirements are met before clozapine is dispensed. An example of the monitoring requirements can be found here.

Table H.5.5 Severe and common side effects of clozapine and their management

	Side effect	Signs and symptoms	Monitoring and treatment
Life threatening	Agranulocytosis or neutropenia	• Falling white cell count • Infections	• Weekly white cell counts as per clozapine protocols, regular temperature and health checks. • Stop clozapine if low neutrophils
	Cardiomyopathy	• Tachycardia • Fever • Fatigue • Chest pain	• ECG prior to starting clozapine, monitoring temperature and heart rate, troponin levels if available. • Stop clozapine if it occurs
Other common side effects	Sedation		• Give most of dose at night
	Hypersalivation	• Dribbling, especially at night	• Small doses of hyoscine
	Constipation	• Remember to ask patients about this	• High fibre diet
	Other cardiovascular effects	• Hypotension • Tachycardia.	• Monitor if minor, if significant refer to cardiologist
	Weight gain	• Can be severe (10kg and more)	• Monitor weight and waist measurement • Diet management
	Seizures		• Stop for a day • Reduce dose • Use anticonvulsant
	Bed wetting	• Seen in 1 in 5, possible worse on teenagers	• Reduce fluids at bed time • Change dose regime

Other common side effects are detailed in Table H.5.5, but this list is by no means complete. It is recommended that clozapine be prescribed only by specialists who are aware of the side effects and able to manage the risks appropriately.

Other interventions

There is good evidence of effectiveness for several other therapies in the treatment of early psychosis. All have been shown to reduce the risk of relapse and, most importantly, help young people and their families feel more in control of their symptoms and their treatment.

Psychoeducation

Psychoeducation is a structured way of providing information about psychotic disorders and their treatment for both young people and their families. There are manualised programs available and evidence that psychoeducation reduces the rate of relapse in early psychosis (Xia et al, 2011).

The ingredients of effective psychoeducation include:

- Providing information about the illness and treatment options
- Offering a forum for the young persons to discuss their illness and concerns
- Involving family members in the education process, whether with their children or in parent groups.

If successful, the rate of relapse is reduced by increased adherence to medication, reduction in maladaptive behaviors such as substance misuse, and early recognition of symptom return or deterioration. Coping skills and problem solving training can also be part of the education program (Xia et al, 2011).

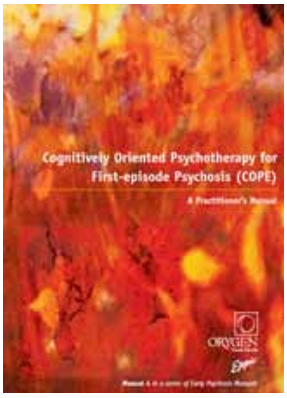
While face to face psychoeducation programs are useful they may not be available in remote or rural areas or may not be run at convenient times. Web based resources are also an excellent way of obtaining information and becoming part of a supportive network.

Cognitive behavioral therapy (CBT)

Some young people find CBT helpful in understanding and managing their symptoms. The goals of CBT vary depending on the symptoms of concern, but can include coping strategies for psychotic experiences and managing low mood. Directly addressing the psychotic symptoms is most effective in the recovery rather than the acute phase of the illness. However, CBT is also useful for managing residual symptoms such as hallucinations that persist despite antipsychotic treatment. Strategies include:

- Exploring and challenging delusional beliefs
- Finding coping strategies to minimize the impact of hallucinations
- Managing feelings of hopelessness and low mood using similar techniques to those used in CBT for depression.

Click on the picture to access the Cognitively Oriented Psychotherapy for First-Episode Psychosis (COPE) manual.



Working with families

As well as providing support, initial work with families involves a psychoeducational approach, providing information about the illnesses and how it affects thoughts and behaviors. Problem solving skills and communication strategies help families deal with difficult situations and reduce distress in the household. This

reduces the risk of relapse, as well as preventing family estrangement (Addington et al, 2005).

Maintenance medication and management of side effects

Use of antipsychotic medication is recommended for at least 12 months after symptom remission to reduce relapse. Careful monitoring and management of side effects is essential. Weight gain and associated metabolic abnormalities are the most frequent, but sedation and cognitive slowing can also cause distress. There is some evidence from meta-analyses – of adult treatment trials – that the second generation antipsychotics are more effective at preventing relapse than the first generation ones (Alvarez-Jimenez et al, 2011). Six monthly monitoring is required for:

- Involuntary movements (the recommended scale is the AIMS – Abnormal Involuntary Movement Scale)
- Weight, waist measurement, pulse rate and blood pressure
- Fasting glucose and lipids.

Movement disorders, including Parkinsonism and akathisia, are less common with second generation antipsychotics. If these occur, try small doses of an anticholinergic drug, for example benztropine 0.5mg a day. Reducing the dose of antipsychotic is often more effective. Tardive dyskinesia, a rare, chronic movement disorder, is often first seen as small movements in the face, togue or fingers. Early identification is important as tardive dyskinesia may persist after medication is ceased. The most commonly used mood stabilizers (in particular lithium carbonate, sodium valproate and carbamazapine) are teratogenic and this needs to be discussed with sexually active adolescents. The use of lithium requires clear instructions about the need to avoid dehydration and have regular lithium levels and thyroid function tests to monitor for possible toxicity (see Chapter E.2).

Prevention of relapse

The first step to relapse prevention is to develop an individual plan to detect warning signs such as difficulty sleeping, increased anxiety or the first signs that hallucinations or delusions are reappearing. If medication is being slowly reduced, recurrence of any symptom suggests that a return to the higher effective dose is required, or to resume previously effective medication if it had been stopped. Ongoing monitoring by mental health professionals during this time is essential. There are few studies examining relapse rates in children and adolescents but one study on first episode psychosis found a 17% relapse rate when medication was stopped after 12 months (Gaebel et al, 2011). As with the first episode, the earlier a relapse is treated the better the recovery. Relapses can also cause further cognitive and social deterioration.



Click on the picture to view a 25 minute documentary on schizophrenia. This website, which has information for patients and families, is sponsored by Janssen Pharmaceuticals

Services for early psychosis

While schools, general practitioners, pediatricians and other health care providers often identify young people at risk of psychosis, once early psychosis is identified it is essential that mental health services be involved if at all possible. In Australia these services include child and adolescent mental health services– community based teams who treat young people up to the age of 18 and youth mental health services, for ages 12-25. All these services use a *case management model*, with a case manager (mental health professional) and consultation with a

psychiatrist as needed. Some services also provide *assertive case management* (a more intensive case management used for difficult to treat patients, with active follow up including home visits), drug and alcohol services, general health and sexual health services or help with financial management, housing and employment.

Specialized services in remote or rural areas are few or non-existent. Local family doctors provide most of the care with support from a mental health worker, often a nurse. Internet resources listed can be useful both to guide treatment and to provide education for young people and their families.

RECOVERY, RETURN TO EDUCATION AND OUTCOME

It is important to be both optimistic and honest when talking to young people and their families. They need to know that, while acute psychotic symptoms almost always remit within days to weeks, negative symptoms such as poor motivation, concentration and cognitive slowing may continue for many months, particularly in the case of schizophrenia. While the majority of symptoms improve in the first six months of treatment, improvement can continue for up to two years. Schizophrenia spectrum disorders tend to have the slowest response, the highest rate of residual deficits and a lifelong risk of relapse of up to 90%. A better prognosis is more likely with a rapid onset of psychotic symptoms, prominent mood symptoms, good social and educational functioning prior to the illness and a rapid response to treatment.



Click on the picture to view a clip about early intervention and treatment from the US Maine Medical Centre's PEIR Program. Other useful websites are the one from the International Early Psychosis Association (IEPA), a network for people involved in the study and treatment of early psychosis, and the Early Psychosis Prevention and Intervention Centre (EPPIC) website. This Australian website has a wide range of information about the identification and treatment of early psychosis. Mental Health professionals can register with the site and log on for forums and education sessions.

As well as many of the websites already mentioned the Schizophrenia Fellowship and Arafmi are two Australian non-government organizations that provide support and information for family members and others who care for people with mental illness.

Returning to school may be difficult because of negative symptoms, cognitive difficulties or the amount of time missed, including explaining absences to others. Options depend on what local health and education services are locally available. Meeting with the young persons' school and negotiating part-time attendance is desirable. Where school counselors or similar are available, their involvement is crucial. Some countries offer education programs with smaller classes and staff trained to manage young people with psychological disorders. For those who have reached school-leaving age, institutions that deliver vocational training my provide support for these patients. Partial hospitalization (e.g., day programs) or work preparation programs may be needed for those whose recovery is slower. Additional evidence-based interventions such as social skills training or cognitive remediation strategies may also be useful (Poletti et al, 2010; Addington et al, 2010).

Incomplete recovery

Some young people with schizophrenia do not fully respond to treatment and have ongoing positive or negative symptoms. Reasons for incomplete recovery include:

- *Factors in the young person*, including adherence to treatment. Compliance may be poor because of lack of insight into their illness, concern about side effects such as weight gain or extra pyramidal symptoms. Comorbid disorders such as drug and alcohol abuse, a history of trauma or a pervasive developmental disorder make psychosis harder to treat
- *Illness factors*. Some young people have a more severe form of the illness with a long prodrome and prominent negative symptoms, which

takes longer to respond to treatment, or may never respond completely

- *Treatment factors*. Poor response is more likely if the first experience of treatment was coercive or patients do not have active follow up. Ongoing stress at school or in their family (e.g., high expressed emotion) make relapse more likely. Psychological treatments such as CBT or family therapy help to prevent relapse by teaching strategies to manage early symptoms and reduce and mange stress.

Support for family and other carers

Caring for young persons with a chronic mental illness can be exhausting for their families. As well as family psychoeducation, informative websites and support groups can help families and carers feel less alone.

SUMMARY AND CONCLUSIONS

Psychotic symptoms in children and adolescents can be confusing and difficult to assess in the early stages. However, early symptoms, such as functional decline or hallucinations, should be taken seriously. While many symptoms remit with time, early symptoms are associated with an increased risk of schizophrenia spectrum disorders in adult life. There is also good evidence that early treatment reduces the morbidity and mortality associated with this group of severe mental illnesses.



Encouraged by Henri Laborit, a French surgeon and researcher, the French pharmaceutical company Rhône-Poulenc synthesized chlorpromazine in 1950. The first systematic study of chorpromazine's effect on Schizophrenia, which included 38 patients, was published by the French psychiatrists Jean Delay and Pierre Deniker in 1952. Jean Delay created the word "psychopharmacology", propposed the definition of neuroleptic drugs (literally, "substances that take the nerves") and together with Deniker established the first classification of psychotropic drugs. Chorpromazine is still in clinical use today.

Photo: Delay (left) and Deniker

Resources in languages other than English

There is a wealth of resources available on the Internet, some examples are given below.

- Many international resources are indexed at schizophrenia.com
- The Quebec Early Psychosis Program (AQPPEP) has a site in French
- The Swiss Early Intervention site has interactive information in German, French and English
- P3 Programa de Prevención de Psicosis is a Spanish site with resources in Spain
- Chinese sites (Cantonese) include the Hong Kong Early Psychosis Intervention Society; EASY, an animated website for people aged 15-25 with information about psychosis, self-assessment, news, and where to get help; and Radio-I-Care, an online radio broadcast with a range of topics on mental illness, intervention, and how to live with psychosis.
- The pharmaceutical company Astra Zeneca funds an educational site about psychosis and bipolar disorders in several languages (German, Russian, Turkish and English).

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PROBLEMATIC INTERNET USE

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'Age of Empires III' computer game.
©Microsoft Corporation

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Conflict of interest: None declared

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Suggested citation: Chang J P-C, Hung C-C. Problematic internet use. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

The Internet has become the most popular medium utilized by the general population, especially by children and adolescents. It is as common for children to use a computer as it is to play with their favorite toys. Studies have shown that the percentage of students using the Internet has increased dramatically, for example from 24.5% to 79.5% between 1996 and 2001 in the US (Odell et al, 2000). The number of Internet users who go online regularly had surpassed 1.5 billion in 2009 —19% of them in China alone (Flisher, 2010). Converging modern technologies, such as cellular phones and the Internet, have allowed people to affordably communicate at long distances as well as facilitating many tasks, including science, commerce, shopping, paying bills, taking educational classes, working, and keeping in touch with loved ones. Children and adolescents also use the Internet for socializing and for leisure activities such as watching movies and television programs, listening to music, and playing online games. The Internet has made life more convenient, saves time and shortens the distance between people; as it becomes pervasive in the lives of youth, it presents risks and opportunities.



Internet gaming addiction leads to baby's death. Click on the picture to watch video.

The negative impact of Internet usage on individuals and their lives is often underestimated. Brown (2006) suggested that the choice of media individuals make is influenced by their character and the way they interact with the world; in turn, the way individuals interact with the media will be incorporated into their daily life, influence their behavior and views and even the development of their brain. Children and adolescents are more susceptible to trade off their real life activities with virtual reality ones. Young people are also more prone to use the Internet as a form of socialization without realizing the negative impact that may carry. Thus, when Internet use starts to take up a large portion of children's and adolescents' time, affect their mood, and jeopardize academic and social function and performance, Internet usage may become a problem that may require intervention.

Excessive Internet use in adults has been associated with failed marriages, unemployment, neglected children, and sleep deprivation (Young, 1998). Young's research on problematic internet usage (PIU) has documented associated symptoms and problems, including losing control, craving and withdrawal, social isolation, academic failure, financial problems, job loss, and marital discord. Moreover, spending more than 18 hours a day online may lead to physical problems such as back pain, eye strain and carpal tunnel syndrome (Young, 1998). Internet addiction is considered a public health issue in South Korea (Block, 2008), where 10 cardiopulmonary-related deaths in Internet cafes (Choi, 2007) and a game-related murder (Koh, 2007) have been reported. In addition, Internet videogames are now more sophisticated, more violent, and often incorporate multiple players when compared to online games two decades ago (Anand, 2007). A negative correlation has been reported between time spent playing Internet games and academic performance, and a positive association between violent Internet game-playing and aggression (Anderson & Dill, 2000). Not only does excessive Internet use has a negative impact on the mental and physical health of children and adolescents with PIU, it might also increase risk of violence in this age group.



World of Warcraft
Dangerous addiction or cultural phenomenon? Click on the picture to view.

Is Internet addiction an illness?

Since Internet addiction has not formally been accepted as a disorder yet, we will use *problematic internet use* or PIU as the term to designate Internet-related behaviors that cause significant psychosocial impairment. So, is Internet addiction

an illness? One current of thought upholds that PIU merits our attention since children and adolescents are more likely to indulge most of their time in Internet games, activities, and social networking at the expense of their school work and sports, and PIU can arise from involvement in a range of online activities (Beard, 2005; Davis, 2001; Griffiths et al, 2000; King et al, 2009; Young, 1996). Block (2008) has recently highlighted the increasing incidence of Internet addiction and its high comorbidity with other psychiatric conditions. He also proposed the inclusion of "Internet addiction disorder" in the forthcoming Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V). David Greenfield (1999) also considers Internet addiction a form of addictive disorder, pointing out that individuals with PIU tend to show symptoms of withdrawal and tolerance. Governments such as South Korea have declared Internet addiction a serious problem and a public health hazard (Block, 2008); Chinese psychologists also support Internet addiction to be recognized as a formal disorder by the World Health Organization (Flisher, 2010).

Some experts, however, do not see Internet use as an illness. They perceive Internet use as a medium for communicating and of avoiding dealing with underlying problems (Bell, 2009; Shaffer et al, 2000). For example, they believe depression or social anxiety to be the core issues in problematic Internet use rather than a new disorder itself (Bell, 2009; Shaffer et al, 2000). Moreover, some forensic psychiatrists believe that we should treat online gamblers primarily as *gamblers* rather than classifying them as Internet addicts (Lenihan, 2007). Therefore, more evidence is required to clarify whether PIU should be looked upon as a separate disorder.



Click on the picture to view a New York Post report on Internet addiction.

Definition and diagnosis

The first diagnostic criteria for *Internet addiction* were proposed by Young (1996) – a modified version of the DSM-IV criteria for substance dependence – since there are similarities between the tolerance and withdrawal symptoms of Internet use and those of substance use. She also developed an *Internet Addiction*

Box H.6.1 Young's diagnostic questionnaire for Internet addiction (adapted from Young, 1998)

Diagnosis suggested if there are five or more "yes" answers to:

- Do you feel preoccupied with the Internet (think about previous online activity or anticipate next online session)?
- Do you feel the need to use the Internet for increasing amounts of time in order to achieve satisfaction?
- Have you repeatedly made unsuccessful efforts to control, cut back, or stop Internet use?
- Do you feel restless, moody, depressed, or irritable when attempting to cut down or stop Internet use?
- Do you stay online longer than originally intended?
- Have you jeopardized or risked the loss of significant relationship, job, educational or career opportunity because of the Internet?
- Have you lied to family members, therapist, or others to conceal the extent of involvement with the Internet?
- Do you use the Internet as a way of escaping from problems or of relieving a dysphoric mood (e.g. feelings of helplessness, guilt, anxiety, depression)?

Questionnaire (Young, 1998) (Box H.6.1). However, evidence of its reliability and validity is lacking.

The term "Internet addiction" was changed to the less controversial "problematic Internet use" (PIU) by Shapira et al (2000). PIU can be defined as showing:

- A maladaptive preoccupation with Internet use, experienced as irresistible, for periods of time longer than intended
- Significant distress or impairment resulting from Internet use
- Absence of other psychiatric pathology that might explain the excessive Internet use, such as mania or hypomania.

PIU can also be classified into *specific* and *generalized* (Davis, 2001). *Specific* PIU refers to particular content that exists independently from the Internet, such as gambling and video games, whereas *generalized* PIU refers to specific Internet content including chat rooms, e-mail, and social networks such as Facebook and Twitter.

In our opinion, Internet use should be considered problematic or an addiction when children or adolescents exhibit the following characteristics:

- Salience: prominent use of the Internet
- Mood modification: moody when not being able to use the Internet
- Tolerance: need to spend more time on the Internet
- Withdrawal: feeling agitated and irritable when the Internet is inaccessible
- Conflict: conflict with family and friends when not able to access the Internet
- Relapse: fails to stay away from using the Internet after a period of abstinence from Internet use.

Common clinical presentations include a loss of sense of time or neglect of basic needs while using the Internet; becoming angry, restless and moody

Activities included in problematic Internet use (Davis, 2001)

Specific

- Net compulsion (online gambling addiction)
- Online game playing addiction

General

- Net compulsion (online shopping addiction)
- Online research addiction.
- Cybersexual addiction
- Cyber-relational addition (chat rooms: social networking, e.g., Facebook, Twitter; personal messaging; and e-mail addiction).

Box H.6.2 Ko et al's (2005) proposed diagnostic criteria for Internet addiction

A. Six or more of:

1. Preoccupation with Internet activities
2. Recurrent failure to resist the impulse to use the Internet
3. Tolerance: a marked increase in Internet use needed to achieve satisfaction.
4. Withdrawal, as manifested by either of the following: a) dysphoric mood, anxiety, irritability, and boredom after several days without Internet activity; b) use of the Internet to relieve or avoid withdrawal symptoms.
5. Use of the Internet for a period of time longer than intended.
6. Persistent desire and/or unsuccessful attempts to cut down or reduce Internet use.
7. Excessive time spent on Internet activities.
8. Excessive effort spent on activities necessary to obtain access to the Internet.
9. Continued heavy Internet use despite knowledge of physical or psychological problem caused or exacerbated by Internet use.

B. Functional impairment. One or more of:

1. Recurrent Internet use resulting in a failure to fulfill major obligations.
2. Impairments in social relationships.
3. Behavior violating school rules or laws due to Internet use.

C. The Internet addictive behavior is not better accounted for by another disorder.

when unable to use the Internet; needing better and more computer equipment and software and more time online; showing more negative behaviors associated with online activities such as lying and starting arguments, impaired academic performance and social relationships (Beard et al, 2001).

Ko et al (2005) proposed diagnostic criteria for Internet addiction (Box H.6. 2) and tested them in 468 Taiwanese high school students and 216 Taiwanese college students. These criteria showed good specificity (97%) and sensitivity (86%). However, larger studies on the validity and reliability of the diagnostic criteria for PIU are still needed.

There are several scales available to evaluate the severity of PIU. The more commonly used scales include the *Problematic Internet Use Questionnaire* (PIUQ) (Thatcher et al, 2005), the *Internet Addiction Test* (IAS) (Young, 1998), the *Goldberg Internet Addiction Disorder Scale* (GIAD) (Armstrong et al, 2000), the *Chen Internet Addiction Scale* (Yen et al, 2008) (CIAS), and the French *Orman Internet Stress Scale* (ISS) (Valleur & Velea, 2002).The characteristics of these scales are summarized in Table H.6.1.

Epidemiology

No reliable data exist on the global prevalence of this phenomenon. Estimates vary from country to country and from study to study. It has been estimated that 1%-18% of adolescents have PIU in both Western and Eastern societies (Cao et al, 2007; Jang et al, 2008). More specifically, about 1%-2% of Italian students have moderate to severe PIU (Poli & Agrimi, in press), 1%-12% of children and adolescents in Middle Eastern countries (Canan et al, 2010) and 2%-18% of children and adolescents in Asian countries appear to have PIU (Cao & Su, 2007). Small scale studies in Korea and China revealed that around 2% (210,000) of South Korean children aged 6 to19 years have PIU and many may require treatment (Choi, 2007), while around 10 million adolescent Internet users in China may meet criteria for Internet addiction (Cao & Su, 2007).

Previous studies had shown that adolescents with problematic Internet use tend to be boys, have poorer academic performance and are more likely to access Internet at home and Internet cafes than in school settings (Kormas et al, 2011).

Table H.6.1. Scales to measure Internet misuse

Scale	Problematic Internet Use Questionnaire (Thatcher & Goolam, 2005)	Internet Addiction Scale (Young, 1998)	Internet Addiction Disorder Scale (Goldberg, 2000)	Internet Addiction Scale (Chen, 2005)	Internet Stress Scale (Valleur & Velea, 2002)
Description	Quantitative 20 items	Quantitative 20 items	Qualitative 11 items	Quantitative 26 items	Quantitative 9 items
Scoring	5-point Likert scale	5-point Likert scale	Meeting >2 criteria indicates Internet addiction	4-point Likert scale	Score > 4 suggest addiction risk
Target population	Adolescents Adults	Adolescents Adults	Adolescents Adults	Adolescents	Adolescents

Individuals with PIU are also more likely to use Internet to converse in chat rooms, play interactive games, and access sexual information, and are less likely to use Internet for educational purposes (Kormas et al, 2011). Adolescents with PIU also have more behavior problems such as hyperactivity, conduct problems and worse overall psychosocial maladjustment than their peers (Kormas et al, 2011).

Pathophysiology

Researches have shown that some of the behavioral and neural characteristics of individuals with PIU are similar to those of individuals diagnosed with pathological gambling and substance use disorders (Ko et al, 2009). This is further supported by a recent functional magnetic resonance imaging study where a cue-induced online gaming urge activated similar brain areas as those activated by craving for drugs in people with substance addiction (Ko et al, 2009). Increased activation in the orbitofrontal cortex in gain trials and decreased activation in the anterior cingulate cortex in loss trials have been described in individuals affected with PIU (Dong et al, in press). Individuals with PIU also exhibit poorer executive control and poorer impulse control than non-affected individuals; for example affected individuals had longer reaction times and more response errors than their counterparts in the Stroop Test (Dong et al, 2011).

Interaction between environmental and genetic factors appears to play an important role in the development of PIU (see Figure H.6.1). The current understanding of addiction suggests that some individuals may be more susceptible to PIU than others due to their genetic vulnerabilities, but other factors are needed for those individuals to eventually develop Internet addiction or problems with Internet use.

Another hypothesis suggests that children and adolescents with PIU initially engage in Internet activities by trying to solve a problem, avoid stress or cope with an unwanted feeling, such as anxious or depressive mood (Lin & Tsai, 2002). Addiction to the Internet may then develop during this process.

Negative Consequences of PIU

- Impaired academic performance
- Impaired social interaction/family relations
- Decreased self-perceived acceptance by peers
- Increased drinking in males
- Lower self-worth in females

PIU-associated psychiatric symptoms and comorbidity

- Hostility
- Depression, irritability or mood changes
- Phobic anxiety
- Daytime sleepiness or sleep deprivation

Risk factors for PIU

- Greater hours per week spent online
- Increased need for social network
- Low self-esteem
- Poor quality of family relationships
- Loneliness

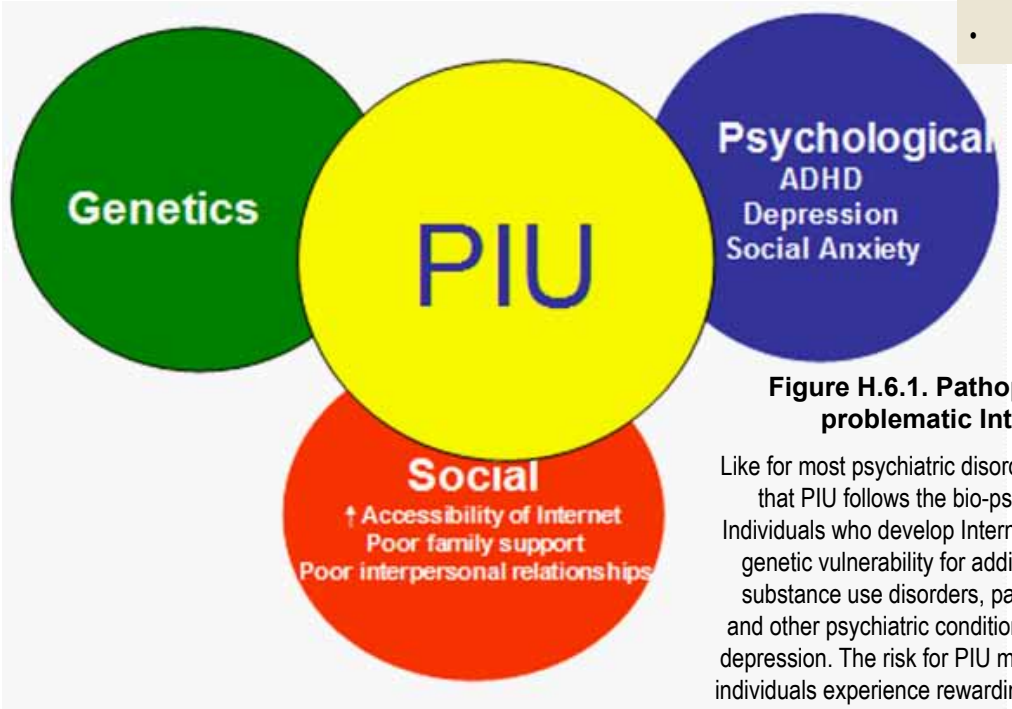


Figure H.6.1. Pathophysiology of problematic Internet use

Like for most psychiatric disorders, it is hypothesized that PIU follows the bio-psycho-social model. Individuals who develop Internet addiction may have genetic vulnerability for addictive disorders (e.g., substance use disorders, pathological gambling) and other psychiatric conditions such as ADHD and depression. The risk for PIU may also increase when individuals experience rewarding experiences through Internet activities such as online gaming.

Onset of PIU is most likely during late childhood and early adolescence (Pridgen, 2010). Adolescence is a period of biological, psychological and social change and navigating these changes is stressful for many youth. Adolescents with emotional and behavioral disorders are also more vulnerable to the negative effects of Internet use (Pridgen, 2010). Furthermore, affected youth often deny their problems with Internet use, denial being one of the main factors in maintaining PIU. Denial enables adolescents to continue engaging in Internet usage in spite of obvious negative consequences; it is also a way to protect themselves from seeing or feeling things that are unpleasant. Owing to denial, the impact of one's Internet usage is seldom fully appreciated until the consequences become serious.



Click on the picture to watch an interview with David Greenfield PhD on Internet and video game addiction

Some studies suggest that children and adolescents with ADHD (Yoo et al, 2004), depression, and those who are socially isolated (Armstrong et al, 2000) are at higher risk of PIU. PIU shares some risk factors with impulsive-compulsive spectrum disorders and addictions such as pathological gambling and substance use disorder (Yen et al, 2008). A recent US study of Internet use among young adolescents and adults showed that most males used the Internet on a weekly basis, while most females had not played more than a single Internet game in a year (Padilla-Walker et al, 2010). They also found that Internet video game playing, regardless of gender, tends to associate with negative social behaviors such as recreational drugs use, alcohol drinking, and impaired interpersonal relationships. Internet use for chat rooms, shopping, entertainment, pornography, and videogames are further associated with drinking, illicit drugs use, greater number of sexual partners and lower self-worth. Moreover, playing violent Internet games is associated with having more sexual partners and poorer quality of interpersonal relationships in this group. On the other hand, when Internet use is for academic purposes, there is a positive correlation with less substance use, greater self-worth, and better parent-child relationships (Padilla-Walker et al, 2010).



What is the Internet Doing to our Brains?

Click on the picture to view Dr Paul Howard Jones discuss the scientific findings about what technology is doing to us (26 minutes)

TIM

Tim, a 15 year-old boy, was brought to the psychiatric clinic by his parents due to his spending excessive time on the Internet and deterioration in his daily activities, performance at school and relationships with peers. Tim was first introduced to the Internet at school when he was working on an assignment in 3rd grade. In the last 2 years, he had joined online social networks such as Facebook and MySpace, where most of his friends share their activities and thoughts. He also prefers using text messages to telephone calls when he wants to communicate with his friends. He enjoys online role-playing games and often feels obligated to be online when his game-partners are also online. He spends more than 12 hours per day (90 hours per week) online, even cutting down his sleeping time. His grades have dropped recently and he has started to skip classes to be on the Internet. He feels happier and more empowered when online –he does not have to think about his grades and problems. Tim finds schoolwork increasingly difficult. He has more arguments with his parents, and quarrels are often associated with his Internet use. Thus, he has started lying to them about the hours he spends online. He feels restlessness, irritable and unhappy when at school or somewhere else away from the computer. When he first walked into the clinic, he told the psychiatrist "I know I should cut down on the hours I spend online and concentrate on my school work, but I just can't. I feel so anxious and joyless when not online." Tim feels his life is a failure, and that his parents dislike him. He had thought about suicide, but says he does not have the courage to do it. Tim's depressed mood had worsened in the previous 2 months, since the beginning of the new semester. The psychiatrist diagnosed Tim with depression and problematic Internet use.

TREATMENT

There are currently no treatments for PIU that are supported by evidence, which is not surprising considering that it is not yet an officially accepted diagnosis. No pharmacologic or psychotherapeutic intervention has received adequate testing in randomized controlled trials. Most interventions suggested for PIU are based on personal clinical experience, small anecdotal studies or trials without randomized double blind design. A recent systematic review showed several limitations in available clinical trials (King et al, 2011). These include:

- Inconsistencies in definition and diagnosis
- Lack of randomization and blinding
- Lack of adequate control groups, and
- Insufficient information concerning recruitment, sample characteristics, and treatment effect size.

These shortcomings are highlighted in Table H.6.2, which summarizes the characteristics of Internet addiction treatment studies currently available.

While there is no agreement on the diagnostic criteria for Internet addiction or PIU, there seems to be a demand for treatment for these problems, especially in China, Taiwan, and South Korea (King et al, 2011). Interventions for PIU range widely from *boot-camp* style programs in Eastern countries to clinics specializing in the psychological treatments including CBT, family and group therapy, social skills training, and addiction counseling (King et al, 2011). Programs often extrapolate treatments used for substance abuse.

Before going into details about intervention, a careful clinical evaluation and assessment of comorbid conditions is essential. For example, a depressed child may start leading a *virtual life* to boost his self-esteem at the expense of offline interactions and duties, hence treating the depression will be a priority in this child's treatment plan.

There has been no double-blind placebo-controlled study on the pharmacotherapy for PIU. Thus no specific medication can be recommended at this stage, although a wide range of them has already been tried, as summarized in Table H.6.2. The only randomized controlled study published so far allocated 56 adolescents aged 12 to 17 years into either active treatment (8-sessions of multimodal school-based group CBT) or no treatment (Du et al, 2010). While Internet use decreased in both groups, the active treatment group improved more in the areas of time management, emotional, cognitive, and behavior symptoms.

Children and adolescents affected with PIU may benefit from family based interventions, although there is no evidence so far that this is the case (Yen et al, 2007). For example, family therapy may help to improve communication within the family and teach Internet techniques to monitor Internet use better (Yen et al, 2007). Ironically, PIU may also improve with online educational programs (King et al, 2011). There are several online services, mostly based on the '12 step' self-help treatment philosophy.

Although other management options, such as intensive and expensive residential treatments, have received much attention from the media and the public in some countries, there are no empirical data about their effectiveness.

Behavioral strategies for clinicians and self- help tips for dealing with PIU

- Help patients identify their pattern of Internet use using a logbook.
- Set clear, specific goals with the patients.
- Limit and shorten Internet usage time. External prompts, such as timers may be helpful to remind them when it is time to log off.
- Negotiate a computer free day once each week.
- Write down negative consequences of Internet use on reminder cards and encourage patients to carry and read them.
- Help patients make a list of hobbies or interests they used to enjoy.
- Increase time spend on sports, hobbies and other non-Internet activities
- Join a PIU support group.

Websites that offer help for problematic Internet use

www.netaddiction.com

http://www.netaddictionrecovery.com

www.onlineaddiction.com.au

Table H.6.2 Available treatment studies for Internet addiction (adapted from King et al, 2011)

STUDY (COUNTRY)	DEFINITION OF INTERNET ADDICTION	TREATMENT	NUMBER (AGE)	COMMENTS
Du et al, 2010 (China)	Beard's Diagnostic Questionnaire	8 session CBT vs control	Treatment (n = 32) vs clinical controls (n = 24). (12-17)	The only controlled study available
Han et al, 2009 (South Korea)	Young Internet Addiction Scale > 50	8 weeks of methylphenidate	62 (8-12)	All subjects in the study had comorbid ADHD
Han et al, 2010 (South Korea)	>4h/day, 30h/week; Young Internet Addiction Scale score > 50	6 weeks bupropion sustained release	19 (17-29)	Small sample size (11) and no control group
Kim, 2008 (South Korea)	Korean Internet Rating Scale	5 weeks "reality training" group counseling vs untreated controls	25 (age not reported)	Limited information (e.g., age of participants not described)
Shek et al, 2009 (Hong Kong)	Young Internet Addiction Scale; Chinese Internet Addiction Scale	15-19 months multi-modal counseling	59 (11-18)	No control group
Su et al, 2011 (China)	Young's Diagnostic Questionnaire: Internet use of 14+ hr/week	Healthy Online Self-Helping Center (Natural Environment; Learning Environment, Non-Interactive) vs Control	65 (age not reported)	Limited information (e.g., age of participants not reported)
Young, 2007 (USA)	Internet Addiction Test	12 sessions of CBT	114 (age not reported)	No control group

TIM (continuation)

The psychiatrist worked together with Tim to devise a plan of action. This entailed asking Tim to keep a diary, particularly noting the time spent online, homework and house duties as well as other activities, and to rate his mood every day. Once a baseline was obtained, they worked on ways to increase participation in activities Tim used to enjoy apart from the Internet.

With Tim's agreement, his parents were invited to participate in the sessions and encouraged to discuss activities and hobbies they could do with Tim and rewards for time offline. After discussion, it was agreed by Tim and his parents to move Tim's computer from his bedroom to a more public space in the lounge room, that Monday would be an Internet free day for the whole family and a reward for Tim every time he was successful in doing that. Once this was in place, Tim agreed to limit his Internet use to one hour per day on the remaining weekdays and 2 hours on weekends. After a month of treatment, Tim's depressed mood had improved and he had reduced substantially his time online, although with some relapses. He began to be involved again in outdoor activities with his family and friends and there were fewer arguments at home. Temptations to use the Internet remained, particularly when frustrated with homework or after arguments with his parents.

Course and outcome

Due to the ready accessibility of the Internet, and the need to use it in modern life, relapse rates are high. Many adults with PIU started using the Internet when they were in grade school and Internet use usually became problematic without the affected individual being aware of it. However, little is still known about its natural history. Uncontrolled and anecdotal studies suggest that Internet addiction is often resistant to treatment and has high relapse rates.



Click on the picture to watch a news item about Internet addiction in China

Prevention

Online gaming seems to be a particular problem in many Asian countries, where much of the online gaming commercial promotion targets children and adolescents. Asian adolescents often face tremendous academic pressure, while online gaming can temporarily provide a stress-free virtual reality for many. Schools, governments and health departments should encourage research on this problem to clarify its causes and promote preventative interventions. For example, South Korea, a country in which multiplayer online games are very popular, has decided to introduce a ban from midnight to 6:00AM for Internet use by children and adolescents less than 18 years of age (Block, 2008). The South Korean government also has a system that slows down the Internet connection of Internet game players who played for more than 6 hours. China is another country experiencing problems with Internet use. The Chinese government restricts daily Internet game use among youth by demanding online game operators to set up a "game fatigue system" that encourages players under 18 to play less than 3 hours a day since 2007 (Block, 2008).

Conclusion

The Internet has revolutionized human life, is here to stay and has many positive aspects that can enhance youth learning and empowerment. The younger generations are growing up with and making Internet an integral part of their lives, however, in a few instances, Internet use becomes problematic. Is this a disorder that requires treatment or an example of medicalization of a social phenomenon? Because Internet addiction or problematic Internet use is not recognized by DSM-IV and ICD-10, the research evidence is very limited yet. This situation will need to change if we are to provide answers supported by evidence to the questions posed in this chapter.



Legend of Zelda: Ocarina of Time, one of the most popular video games

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Section I

PSYCHIATRY AND PEDIATRICS

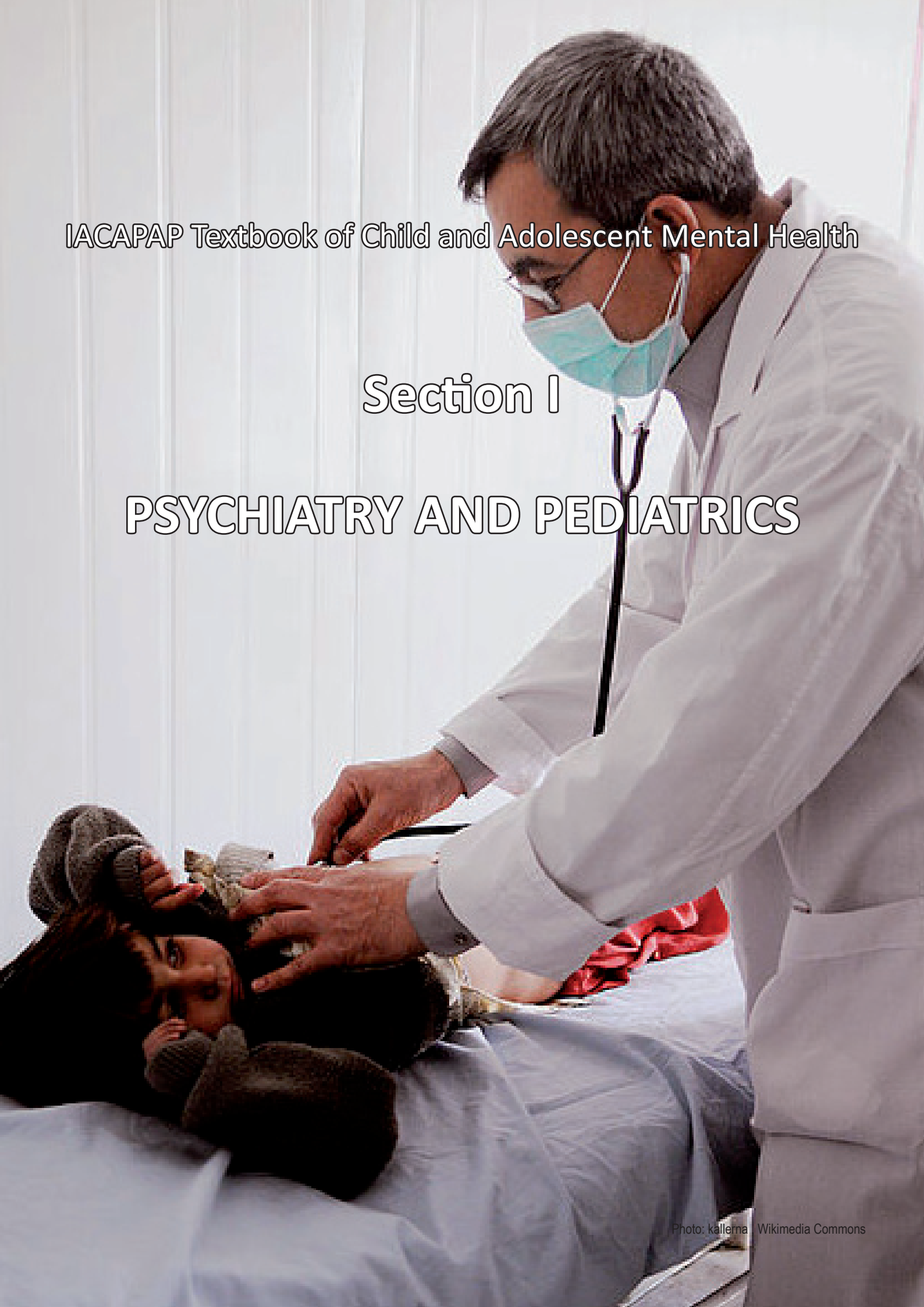


Photo: kallerna, Wikimedia Commons

SOMATOFORM DISORDERS

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The Sick Child. Gabriel Metsu (c1660) Rijksmuseum, Amsterdam

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Suggested citation: Fiertag O, Taylor S, Tareen A, Garralda E. Somatoform disorders. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Conflict of interest: none declared

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Conflict of interest: none declared

Physical (somatic) symptoms are extremely common in children and adolescents, who often find it difficult to express their feelings and emotions through language. Because of this, psychological distress may be expressed as physical (somatic) symptoms. Parents are usually aware that their children may sometimes experience somatic symptoms if they are worried about something or trying to avoid something. Most parents will naturally minimize the importance of these symptoms and try and find out the cause. This tactic aids children to learn to cope with everyday stresses. However, despite this, sometimes symptoms persist. It is thought that 2%-10% of children in the general population complain of aches and pains (e.g., stomach aches, joint pains, headaches) that are likely to be medically unexplained. The term medically unexplained symptoms refer to all bothersome or recurrent bodily symptoms that do not have a recognized medical illness explanation. Unexplained physical symptoms may cause little difficulty, however sometimes they lead to distress, impairment in functioning and healthcare-seeking behavior, as in somatoform disorders.

Functional impairment can occur in children with medically unexplained somatic symptoms at any age and at various levels of severity, and the symptoms, especially when multiple, tend to be associated with psychological problems. There is evidence that, even in very young children who are of nursery school age, those who present with frequent somatic symptoms are significantly more likely than children without symptoms to have associated behavioral and emotional problems, to miss nursery and to attend clinics (Domenech-Llaberia et al, 2004). These children may also be at increased risk of experiencing further physical symptoms and psychological difficulties later in childhood or adolescence.

There are many ways in which physical and psychological symptoms interact and, in reality, no illness is purely physical or psychological – after all one cannot separate the body from the mind. In patients who present repeatedly with physical symptoms especially, but not exclusively, if these are medically unexplained, it is vital to consider underlying psychological distress. This chapter will focus on psychiatric disorders that present with physical symptoms. Table I.1.1 summarizes the broadly different ways in which physical and psychological aspects are linked.

WHAT IS SOMATIZATION?

Somatization describes a constellation of clinical and behavioral features indicating that a person is experiencing and communicating psychological distress through physical (somatic) symptoms not accounted for by pathological findings; the person attributes these symptoms to a physical illness and this leads to seeking medical help. In somatization, the production of symptoms is usually *not* under conscious control, however, in children and adolescents it is particularly difficult to establish the level of conscious control.

Somatoform disorders

The current diagnostic manuals (DSM-IV and ICD-10) are under revision and it is thought that in the new versions (expected to be available in 2013), somatoform disorders will be redefined. The following describes their present classificatory status.

Table I.1.1 Ways in which physical and psychological aspects of illness are linked

Nature of Association	Example
Psychological distress / Psychiatric disorders can present with physical symptoms	Child presenting with recurrent abdominal pain of non-organic origin
Physical complications of psychiatric problems	Child presenting with liver failure after self- harming with a paracetamol overdose
Psychiatric consequences of physical illness and treatment	Child with sickle cell disease developing depression due to deteriorating physical health
Effects of psychiatric disorder on physical illness	Child with diabetes and needle phobia refusing treatment leading to disease progression

DSM-IV describes somatoform disorders as having:

(i) Physical symptoms suggesting a medical condition; however, no medical disease, substance misuse or another mental disorder can be found to account for the symptoms

(ii) The symptoms cause significant distress or impairment in social, occupational or other areas of functioning

(iii) The physical symptoms are not intentionally produced.

DSM-IV subdivides somatoform disorders into *somatization disorder*, *undifferentiated somatoform disorder*, *conversion disorder*, *pain disorder*, *hypochondriasis*, *body dysmorphic disorder* and *somatoform disorder not otherwise specified* (includes unexplained physical complaints, e.g., fatigue). Dissociative disorders (those where there is a disruption in the usually integrated functions of consciousness, memory, identity, perception) are categorized separately.

ICD-10 describes somatoform disorders as having:

(i) Repeated presentations of physical symptoms, with

(ii) Persistent requests for medical investigations despite negative findings and medical reassurance, and

(iii) The patient often resists attempts to discuss the possibility of psychological causation.

ICD-10 subdivides these disorders into *somatization disorder*, *undifferentiated somatoform disorder*, *hypochondriacal disorder*, *somatoform autonomic dysfunction*, *persistent somatoform pain disorder*, and *other somatoform disorders*. Other disorders, which also have somatization as a key feature such as *dissociative disorders* (conversion disorder in DSM-IV) and *neuraesthenia* (chronic fatigue syndrome), are categorized separately in ICD-10.

Of all these somatoform disorders, the most commonly seen in children and adolescents are *persistent somatoform pain disorder, dissociative /conversion disorder* and *chronic fatigue syndrome* (*neurasthenia*). A summary of the specific criteria for these disorders are outlined in Table I.1.2.

Table I.1.2 Criteria for diagnosis of somatization disorders common in children and adolescents

ICD-10	DSM-IV
Somatoform disorders	
• Multiple, recurrent and frequently changing physical symptoms of at least two years' duration • Most patients have a long and complicated history of contact with both primary and specialist medical care services, during which many negative investigations may have been carried out • Symptoms may be referred to any part or system of the body • The course of the disorder is chronic and fluctuating • Often associated with disruption of social, interpersonal, and family behavior.	• Physical symptoms suggest a medical condition. However, no medical disease, substance misuse or another mental disorder can be found to account for the symptoms • The symptoms cause significant distress or impairment in social, occupational or other areas of functioning • The physical symptoms are not intentionally produced • No diagnosable medical condition can fully account for the symptoms.
F45.4: Persistent somatoform pain disorder	**Pain disorder (Associated with psychological factors: 307.80; Associated with psychological factors and a general medical condition: 307.89)**
• The predominant complaint is of persistent, severe and distressing pain • It cannot be explained fully by a physiological process or a physical disorder • It occurs in association with emotional conflict or psychosocial problems that are sufficient to allow the conclusion that they are the main causative influences • The result is usually a marked increase in support and attention, either personal or medical.	• Pain in one or more anatomical sites is the predominant clinical presentation and is of sufficient severity to warrant clinical attention • The pain causes clinically significant distress or impairment in social, occupational, or other important areas of functioning • Psychological factors are judged to have an important role in the onset, severity, exacerbation, or maintenance of the pain. • The symptom or deficit is not intentionally produced or feigned • The pain is not better accounted for by a mood, anxiety or psychotic disorder.
F44: Dissociative [conversion] disorders	**300.11: Conversion disorder**
• A partial or complete loss of the normal integration between: memories of the past, awareness of identity and immediate sensations, control of bodily movements (There is additional specific guidance for clinical features occurring in each type of dissociative disorder: e.g., dissociative amnesia, fugue, stupor and motor dissociative disorders) • Medical examination and investigation do not reveal the presence of any known physical or neurological disorder • There is evidence for psychological causation, in the form of clear association in time with stressful life events and problems or disturbed relationships (even if denied by the individual) • *The possibility of the later appearance of serious physical or psychiatric disorders should always be kept in mind.*	• One or more symptoms or deficits affecting voluntary motor or sensory function that suggest a neurological or other general medical condition • Psychological factors are judged to be associated with the symptom or deficit because their initiation or exacerbation is preceded by conflicts or other stressors • The symptom or deficit is not intentionally produced or feigned • The symptom or deficit cannot, after investigation, be explained by a medical condition, substance abuse or a culturally sanctioned behavior or experience • The symptom or deficit causes clinically significant distress or impairment in social, occupational or other important areas of functioning, or warrants medical attention • The symptom or deficit is not limited to pain, does not occur exclusively during somatization disorder and is not better accounted for by another medical disorder.

Table I.1.2 (continuation)

ICD-10	DSM-IV
F48 : Neurasthenia (chronic fatigue syndrome)	
• Either persistent and distressing complaints of increased fatigue after mental effort, or persistent and distressing complaints of bodily weakness and exhaustion after minimal effort • At least two of: muscular aches/pains, dizziness, tension headaches, sleep disturbance, inability to relax, irritability, dyspepsia • Any autonomic or depressive symptoms present are not sufficiently persistent and severe to fulfill the criteria for any of the more specific disorders • Considerable cultural variations occur in the presentation of this disorder.	

Burden

Somatoform disorders tend to present repeatedly to primary care practitioners and pediatricians rather than psychiatrists because their presenting symptoms are physical and families tend to attribute the symptoms to organic, not psychological, causes. The medical help-seeking behavior that usually accompanies the symptoms often leads to numerous (potentially painful) medical investigations and treatments before their psychological nature is identified. Families are often skeptical about the usefulness of a psychiatric or mental health assessment and may continue to pursue investigation of an organic pathology. Over-investigation tends to reinforce the belief in the patient and family that there is an underlying physical cause. All of this can result in a huge burden on patients, their families as well as wastage of resources. Children will miss school to attend multiple appointments and parents may need to take time off work to care for their child and take them to appointments. Expertise is needed in the assessment and management of these cases to avoid the huge potential implications for patients, families, services and wider society.

EPIDEMIOLOGY

Little is known about the exact incidence or prevalence of the different somatoform disorders. However the epidemiology of somatic complaints in general, psychosomatic factors and medically unexplained symptoms is better documented.

Somatic complaints, medically unexplained symptoms and psychosomatic factors

Ten percent of children attending general practitioners or pediatric clinics are reported as having medically unexplained symptoms. However, when considering all children presenting with any physical complaint where doctors identify associated or contributing psychological factors, psychosomatic factors are seen in 25%-50% of them.

Surveys from various countries have found that approximately one in four children complain of at least one set of somatic symptoms weekly or fortnightly.

The most common somatic symptoms are abdominal pain, headaches and muscular or joint pains. Recurrent and troublesome somatic symptoms occur in 2%-5% of children and adolescents (Garralda, 2005).

Somatoform disorders

The German Early Developmental Stages of Psychopathology project examined the occurrence of somatoform disorders amongst 14-24 year olds finding that 12% suffered during their lifetime from at least one somatoform disorder. Having a somatoform disorder was linked to low socioeconomic status (except in the case of pain disorder which was more likely in those with higher educational status – university) (Lieb et al, 2000).

Chronic fatigue syndrome

In the US, the population rate of chronic fatigue syndrome-like symptoms in children and young people is estimated to be 2% (Jordan et al, 2000; Garralda & Chalder, 2005) but the full syndrome is much rarer (0.19 % in the UK) (Chalder et al, 2003; Garralda & Chalder 2005). There appears to be an uneven distribution of chronic fatigue syndrome across countries, with more cases described in Western countries in the Northern hemisphere.

Conversion disorder

Prevalence of conversion disorder across the world is unknown. However a national surveillance study of Australian children under16 years seen by pediatric specialists with a diagnosis of conversion disorder indicates that it is rare (incidence of 2.3-4.2 per 100,000 children) (Kozlowska et al, 2007).

Functional abdominal pain

Apley's (1975) study found that 10% (12% female, 9% male) of children in the general population had at least three episodes of functional abdominal pain severe enough to affect activity and function over a 3-month period, though only some of these children were affected to the degree expected in clinical somatoform disorders.

Age at onset and gender

Most pain and undifferentiated disorders start in childhood or early adolescence. However conversion disorder tends to arise later, with a median age of onset of 16 years. Abdominal symptoms increase in frequency from three to nine years of age and then steadily increase up to adolescence. Headaches are less common in preschoolers than in older children or in adolescents. In females, pain disorder has an age at onset of 11-19 years, whereas males have an age at onset under 13 (Lieb et al, 2000). Somatic symptoms and somatoform disorders generally occur more commonly in females than males.

ETIOLOGY

Somatization is likely to be caused by a combination of factors. A variety of individual, family and environmental factors have been proposed as predisposing, precipitating or perpetuating in somatization; these are summarized in Table I.1.3.

Table I.1.3 Risk factors for somatization in children and adolescents*

Individual	• Personal experience of physical illness • Enhanced focus on physical sensations • Conscientious, vulnerable, sensitive, anxious personalities • Particular concerns about peer relationships • High achievement orientation
Family	• Physical health problems • Mental health problems • Parental somatization • Emotional over-involvement • Limitations in the ability to communicate about emotional issues
Environment	• Life stresses e.g. school, teasing or bullying, • Academic pressure.

* Adapted from Gledhill and Garralda (2009)

Individual factors

People with a sensitive, conscientious or anxious temperament are more vulnerable to developing somatization symptoms in childhood. Those with a history of anxiety and emotional lability are also at increased risk. Precipitating factors include social stressors such as harsh comments about schoolwork or relationships evidenced by a temporal link between these stressors and the development of symptoms. Objectively, stressors may not be particularly severe; however, in combination with a sensitive and anxious temperament, they are interpreted in a more extreme way and are enough to precipitate an episode of illness. Even common life events may play a role; for example, preschoolers with frequent somatic symptoms have been found to experience an excess of common life events (e.g., birth of a sibling) in comparison to children without somatic symptoms. In some cases, somatization may appear to follow a recent physical illness (e.g., gastroenteritis being followed by severe functional abdominal pain; glandular fever being followed by chronic fatigue syndrome; physical injury preceding loss of function of a limb in conversion disorder; fainting episode occurring prior to developing pseudo-seizures). Careful consideration should also be given to the existence of other stressors, such as abuse or school-related stress impacting on the child. Previous abuse may also predispose or precipitate an episode of illness although this seems to be more of a risk factor for adults than for young people. Maintenance of somatization symptoms may be mediated by temperamental traits in the child (e.g., sensitivity, anxiety) and the child having subsequent difficulties adjusting to everyday issues due to them.

Family factors

Anxious, over-protective, emotionally over-involved families with high levels of maternal distress may predispose a child to develop somatization symptoms. In families where there are health problems, the child's unexplained medical symptoms may mirror other family member's illnesses (e.g., loss of mobility in a family where

a parent has suffered paralysis through an accidental injury). In addition, if there are physical health problems, somatization illness in family members, or frequent medical health care-seeking behavior within the families, this may contribute to the child's symptoms through attention being given to this type of behavior and through modeling.

Chronically stressful family situations (e.g., marital disharmony, ongoing school difficulties) may contribute to maintaining the child's unexplained symptoms or their recurrence. Parental distress about the child's symptoms and frequent reporting increase attention to the symptoms, reduce the use of alternative coping strategies such as distraction, and reinforce the child's somatizing behavior. Families' beliefs may be dominated by the thought that there is an underlying organic cause for the problems and if the families do not consider psychological explanations they may be resistant to psychosocial treatment, increasing the likelihood that symptoms will persist.

The effect of somatization in a child is likely to impact on the functioning of the family unit as well as the child. For example, it may result in parents having decreased leisure time, having to take time off work and subsequent financial implications. Families may need to reorganize themselves in their activities of daily living to accommodate caring for the sick child, which may increase overall family stress.

Environmental factors

Concerns about school in terms of academic pressure, peer problems, relationship with teachers and, in particular, bullying are common in children with somatization symptoms and can be predisposing or precipitating factors. These children are often sensitive to social interactions and have high educational expectations. This stress may manifest itself as an inability to perform educationally because of their symptoms; school absence making them worse. They often feel embarrassed, angry and misunderstood as well as sensitive about assumptions by others that they are trying to miss school. These concerns often lead to further non-attendance and, once they have stopped attending, the child may become very anxious about resuming school, which maintains the problem.

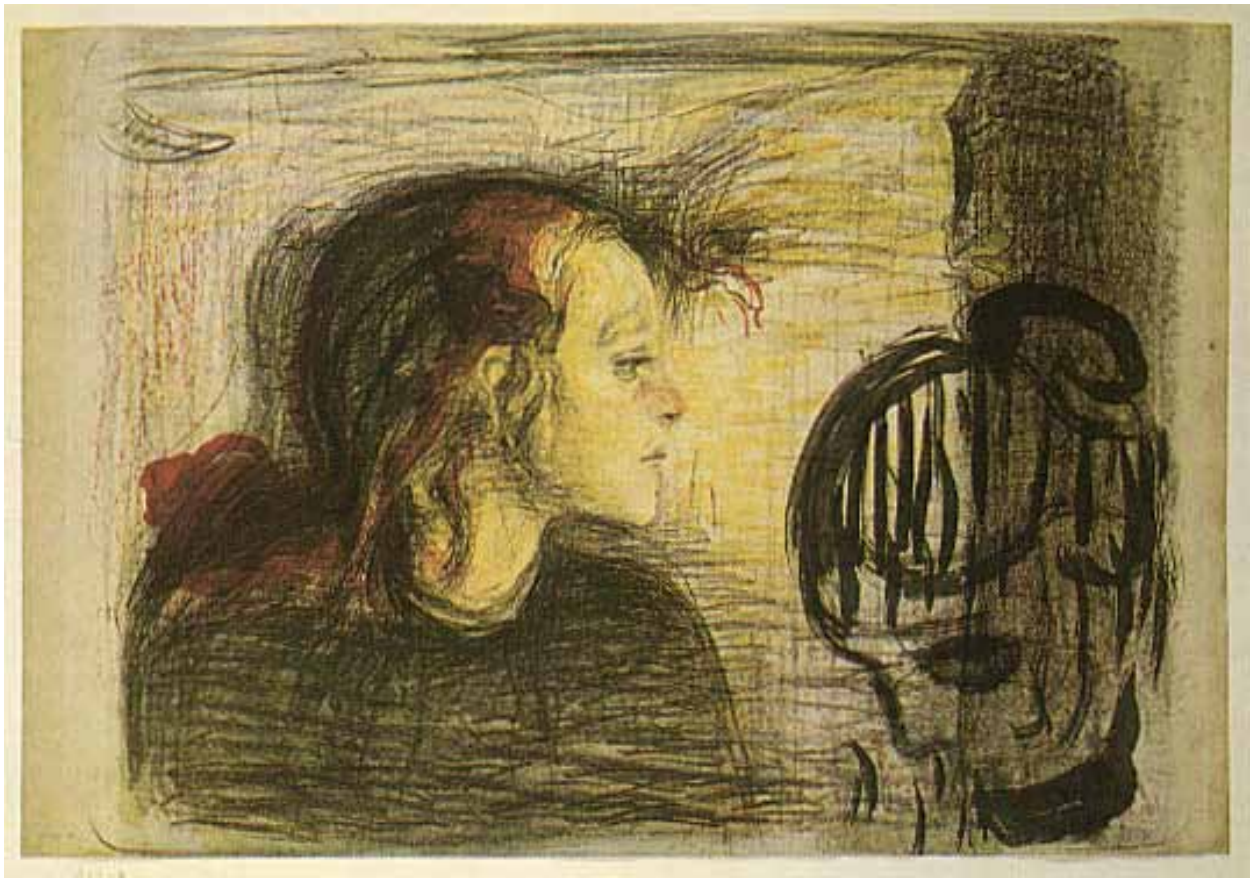
ASSESSMENT

Consider somatization if:

- There is a time relationship between psychosocial stressors and physical symptoms
- The nature, severity of the symptom or its resulting handicap is out of keeping with the pathophysiology
- There is a concurrent psychiatric disorder.

The family doctor, general practitioner or pediatrician is likely to be the first port of call for most children. The usual assessment, investigations and reassurance that there is no treatable medical disorder will often relieve concerns enough for the child to improve without the need for further intervention. However, sometimes symptoms persist.

Children and families with frequent, persistent symptoms and high anxiety levels may be referred to a specialist service. Because of the nature of these



The Sick Child. Edvard Munch (1885), the Munch Museum, Oslo.

problems, assessment at this stage needs to take particular note of both physical and psychosocial contributory and maintaining factors. The best approach is to use a bio-psycho-social framework, whereby the relative contribution of biological, psychological, family and social factors is considered. However, if symptoms persist even after this level of assessment and intervention, which includes targeting the identified bio-psycho-social factors, or if symptoms are particularly severe, or there is diagnostic uncertainty, the child should be referred to a mental health service.

Referral to a mental health service needs to be done in a sensitive manner with acknowledgement of the symptoms – many children and families in these circumstances fear that they are not being taken seriously and that referral to mental health services means their symptoms are not believed. During the mental health assessment, ascertaining the child and parental views of the illness is extremely important. Many parents may still be pursuing organic causes, therefore it is important to address all the physical symptoms, find out what medical disorders have been excluded, explore possible physiological explanations, and be aware of the ability for physical and psychological causes to coexist. Psychiatric assessment should include developmental and psychiatric history, mental state examination and family functioning. Psychometric assessments may be helpful, especially in determining if there is a disparity between the child's educational expectations and actual abilities. A detailed school history is needed, including days missed off school because of the symptoms.

Even after mental health assessment and intervention has been commenced, many families may not be receptive to psychological explanations and may want to continue seeking further investigations. Engaging the family early in the assessment process and working with them to achieve a common view is vital before effective treatment can be instituted. Prompt and accurate identification and naming of somatization can improve prognosis, whereas misdiagnosis or delay can lead to a negative impact on prognosis, family and societal burden.

Main clinical features

The most common somatic symptoms are recurrent abdominal pain, musculoskeletal pain and headaches, but multiple symptoms can coexist.

Persistent somatoform pain disorder

Abdominal pain, headaches, joint pains and other aches and pains may constitute persistent somatoform pain disorder when the pain is persistent, severe, distressing and occurs in association with enough psychosocial stressors to have etiological significance. Typically, functional abdominal pain presents as a diffuse or periumbilical intense pain. The pain tends to be worse during the day and does not occur at night or in school holidays. There may be accompanying altered bowel habit, vomiting, headache, lethargy and the child may look pale, which can reinforce the family's belief of an organic pathology.

Headaches are more likely than not to be characterized as tension headaches (frequent, bilateral, typically frontal pain like a band) but these can sometimes coexist with migraine attacks (a periodic, severe, unilateral pain with an accompanying aura, nausea and family history).

Chronic fatigue syndrome or neurasthenia



Click on the picture to hear 15 year old Sophie describe her chronic fatigue syndrome.

Chronic fatigue syndrome commonly starts with an acute flu-like illness or glandular fever. It can have an insidious, gradual onset and fluctuating course characterized by physical and mental fatigue and exhaustion after comparatively minor mental or physical effort. The fatigue is not relieved by rest and is associated with a decline in the ability to cope with, and withdrawal from daily activities. The young person is likely to complain of headaches, sleeping problems, aches and pains, poor concentration, dizziness, physical weakness, moodiness and worry about decreasing physical and mental health. The fatigue is chronic and is not explained by a medical illness, as it would be in fatigue related to concurrent medical disease. There is often comorbid psychopathology, particularly anxiety and depression. Typically, the family has sought multiple medical opinions and the child has received several diagnoses by the time of assessment. The functional impairment is often unusually long with lengthy school absence and prolonged periods of bed rest (Garralda, 1996; Garralda & Chalder, 3005).

Dissociative (conversion) disorders

These disorders involve partial or complete loss of bodily sensations or movements; loss or disturbance of motor function and pseudo-seizures being the most common presentations. Less frequently, children may present with loss of sight, hearing, sensation, consciousness, fugue or mutism. Symptoms are often brought on by a traumatic event and usually remit after a few weeks or months.

However, *belle indifference,* which refers to a lack of concern about the symptoms, is not particularly common in children.

Pseudo-seizures

Pseudo-seizures are seizures that do not have the typical features of an epileptic fit and are not accompanied by an abnormal EEG. Pseudo-seizures tend to be seen in Western countries and may be common in certain cultures. In a review of 883 patients in a pediatric epilepsy clinic, 15% had paroxysmal non-epileptic events. Of these, the numbers with pseudo-seizures were 3% in preschoolers, 43% in 5-12 year olds and 87% in 12-18 year olds. Pseudo-seizures and epilepsy can coexist but those with both conditions form a small proportion of patients with epilepsy. For example, Kotagal et al (2002) reported that 11 (1.5%) out of 746 children with epilepsy had psychogenic seizures. Pseudo-seizures can be similar to epileptic seizures leading to delays in diagnosis.

Fugue

Fugue is extremely rare in childhood. Dissociative fugue or psychogenic fugue is a rare disorder characterized by a total or partial, reversible inability to recall (amnesia) one's personal identity and memories. Fugue typically presents as unplanned travelling or wandering away from home. The state is usually short-lived (ranging from hours to days), but can last months or longer.

Differential diagnosis

Symptoms found in somatoform disorders, e.g., physical complaints and school non-attendance, occur in numerous psychiatric disorders such as:

- Separation anxiety disorder, school phobia and refusal and other anxiety disorders
- Eating disorders (e.g., anorexia nervosa)
- Depressive disorder
- Elective mutism
- Factitious illness (Munchasuen by proxy, fabricated and induced illness).

Comorbidity

Comorbid psychiatric disorders may precede the development of somatic symptoms but often develop during the course of the somatoform disorder. Among children presenting to services, one third to one half may have a comorbid psychiatric disorder; in chronic fatigue this may be as much as three quarters. In school age children, anxiety and depression are the most common comorbidities. Comorbid attention deficit hyperactivity disorder and oppositional defiant disorder are also frequent, especially in boys.

The Early Developmental Stages of Psychopathology study (Lieb et al, 2000) reported (a) that conversion disorders were associated with eating disorders and (b) pain disorders were associated with depression, panic disorder and post-traumatic stress disorder in older adolescents and young adults. Degree of impairment was shown to increase with the number of comorbidities.

Research diagnostic criteria for conditions such as chronic fatigue syndrome make the presence of mental disorders such as anorexia nervosa an exclusion criterion. However, somatoform disorders often coexist with other psychiatric diagnoses. Somatoform disorder should be the primary diagnosis when:

- The physical symptoms are more prominent than the emotional or behavioral symptoms
- The physical symptoms are the main cause of functional impairment

- There are unwarranted beliefs in the presence of a medical disorder and there is repeated medical help-seeking.

Somatoform disorders can also coexist with organic conditions. If there is a physical illness, it is necessary to establish what symptoms are congruent with the illness and which ones are more likely to be attributed to the psychosocial stressors or disorder.

Differentiating between various potential diagnoses, establishing comorbidities and initiating management can be complex, especially in cases where biological and psychological symptoms coexist, for example, in a child who has coexisting pseudo-seizures and epileptic seizures.

Rating scales

Instruments to measure physical symptoms and functional impairment are useful both for assessment and to monitor progress. Symptom diaries tailored to the individual's presentation are helpful also. By using a symptom diary to document severity and frequency of symptoms over time, a chart can be plotted to visually show to the patient that there has been improvement even before this is noticed subjectively. Visualizing this may help to maintain therapeutic optimism and motivation. In addition, the use of scales may help further engagement with treatment and rehabilitation. Some of the scales are listed in Table I.1.4. It may also be helpful to measure anxiety and depressive symptoms through appropriate scales if these symptoms are present.

Sarah

Sarah had a sudden and complete loss of movement in her arms and legs and headaches. She was diagnosed with conversion disorder despite the presence of an operable brain tumor. All her symptoms resolved following a joint medical and mental health intervention prior to surgery – the surgeons were not prepared to operate until all symptoms had resolved, which fortunately they did, and fully. Below is a quote from her parents:

"Our daughter was approaching her fifteenth birthday and seemed to be enjoying life. She had plenty of friends, was doing well at school and displayed a wide-ranging and vivid enthusiasm for learning and playing. After a family holiday in a foreign country came complaints of severe back pain. This developed into intermittent headaches and an inability to move her arms and legs. Upon admission to hospital it was clear that some of her symptoms did not have a physical origin. This did not mean that the problem was less real, only more problematic.

We were at a loss as to what may have triggered this behavior. There were none of the obvious causes; a grandparent had died but some years previously and of reasonably old age and there was no evidence of abuse or trauma. All we were left with were the concerns that are peculiar to puberty and adolescence, which are not part of the open discourse between parents and children. So, we were standing on the edge of a half forgotten sea, half remembered from our own adolescence but unknown with this individual and at a loss as to how it could relate to these symptoms.

It ought to be stressed that there was huge support from the medical team. Our daughter had physiotherapy, frequent reviews from the pediatric team and numerous interviews with the child psychiatrist. Her life was explored from a psychological, family and social perspective. Eventually a physical event was found: a brain tumor. This diagnosis led to a rapid mitigation of symptoms. It is possible – or probable – that the diagnosis of a physical illness gave her a face-saving way to retreat from her symptoms. What is sure is that her symptoms served a purpose. Certainly, we started the process with symptoms and no physical cause and we ended with a physical cause but no symptoms; a strange sequence."

This example illustrates the complexities of many of these disorders and the fact that a diagnosis such as conversion disorder can coexist with a physical illness, where the physical illness is not congruent with the symptoms, and psychosocial contributory factors are identified on the psychiatric assessment.

Table I.1.4 Rating scales

Rating Scale	What does it measure?	Comments
Child Somatization Inventory	35 symptoms and their severity in the two weeks prior to assessment	Identifies somatization disorder-related symptoms and their severity
Functional Disability Index	Functional disability in walking, travelling, daily chores, social and leisure activities, sleeping and eating	Rates the presence and severity of related impairment
Chalder Fatigue Self-Report Scale (Chalder et al, 1993)	Features of physical and mental fatigue	Rates fatigue symptoms

TREATMENT

General management strategies

Following from assessment, and once physical and psychiatric disorders have been addressed or excluded, management of the somatoform disorder should be planned. The first step is to engage the family. The following strategies may be helpful (many of these strategies will have also been helpful during the assessment process – see assessment section above):

- Make an effort to understand the family's beliefs about the illness, level of conviction for physical causes, satisfaction with investigations, and views about the mental health referral and treatment
- Do not question the reality of the symptoms
- Acknowledge that patients have a real illness disrupting their life and impacting on the family
- Explore alternative explanations for the symptoms
- Fully discuss any physical concerns preoccupying the family and the results of the physical investigations carried out
- Discuss fully the physiological mechanisms contributing to symptoms, e.g., contractures secondary to immobilization
- Make families aware of the high prevalence of medically unexplained symptoms (2%-10%). This may reassure parents about the absence of an organic cause
- Do not convey a sense of embarrassment when communicating a diagnosis of somatoform disorder or other psychiatric diagnoses.
- Emphasize that it may take time to recover but the majority of young people do very well
- Help the family and child develop ways of coping with the symptoms and reduce functional impairment.

Management setting

As already mentioned, assessment and initial treatment is usually initiated by the primary care/general practitioner or pediatrician, and use of the bio-psycho-social framework is encouraged from an early stage. When symptoms do not respond to this level of assessment and intervention, a psychiatric referral should be made. A psychiatric referral may also be helpful when there is diagnostic uncertainty,

when there is a comorbid psychiatric disorder, and when major family problems are affecting the resolution of symptoms. If a psychiatric referral is recommended, the referring clinician should establish the family's attitudes towards a psychiatric assessment and discuss this with the family, addressing their concerns prior to the referral.

Specific management strategies

Specific treatments may involve individual psychological work, family work, liaison with school and with social services. Coordination of all therapists and professionals involved is vital to ensure everyone is working towards similar goals. Treatment should aim to develop partnerships with the child, family and all professionals involved, including teachers, especially where school attendance is an issue. Specific strategies will vary depending on the exact nature of the somatoform disorder.

Psychological interventions

The specific psychological treatment and frequency of contact will vary depending on the nature of the disorder. Interventions may be provided by primary care clinicians, pediatricians, psychiatrists or other mental health workers. However, certain features are common to all; most will involve the following:

- An emphasis on reducing impairment
- Motivational techniques tailored to stimulate ambivalent children
- Collaboratively finding a way to get better that is acceptable to the child
- The use of diaries to monitor variations in symptoms, impairment and progress. This may motivate the patient and family to engage further with treatment
- Acknowledgment that rehabilitation may worsen symptoms initially and address concerns around this
- Developing techniques to deal with specific symptoms and impairments (e.g., distraction, muscular relaxation for headaches, graded physical exercise for muscular problems and fatigue, practical management of pseudo-seizures)
- Developing active, problem focused, coping strategies and attitudes
- A goal based, gradual rehabilitation program with achievable, consistent and agreed aims
- Exploration of expectations on ultimate goals as they may be unrealistically high
- Sleep hygiene and dietary advice
- Psychological interventions, such as cognitive behavioral therapy for comorbid emotional disorders
- Gradually shifting the burden of responsibility from clinician to parent and patient
- Use of family work to deal with family factors that may be contributing to the symptoms or interfering with their resolution.



Click on the picture to view a short presentation about pseudo-seizures or psychogenic non-epileptic seizures (3:53)

Table I.1.5 Elements of cognitive behavioral family intervention

- Discuss investigations and rationale for pain management
- Encourage self-monitoring of pain
- Reinforce well behavior
- Develop healthy coping skills: relaxation, positive self-talk, distraction, positive imagery
- Teach problem solving skills
- Encourage participation in everyday activities
- Reduce attention from parents in relation to physical symptoms
- Increase attention when symptom free by instituting pleasant joint activities

Family work

It is vital to engage families to facilitate an effective management plan; therefore, families need to have their ongoing concerns addressed at all times. The family plays a key role in aiding the child to learn new coping strategies and in reducing family behaviors that may be reinforcing the symptoms. Parental psychopathology, family dysfunction and family stress that might be contributing to maintaining the child's difficulties can be addressed in family work. Some family issues may not be apparent initially, so regular reviews and adding interventions as needed is required. Cognitive behavioral family therapy has been shown to be effective in recurrent abdominal pain.

Medication

There is no medication specifically licensed for use in somatoform disorders, although medication could be indicated to treat some comorbid disorders. For example, selective serotonin reuptake inhibitors may be helpful if there is associated depression or anxiety, which is often, and can make the rehabilitation process easier to implement in some children.

School liaison

Close school liaison to reduce school related stress and to deal with conflicting expectations between the child, family and teachers is important. Tailoring a school program to help the child cope with their symptoms within school (e.g., reduced timetable) is helpful. In case of pseudo-seizures, a clear management plan that includes ways of reducing their dramatic impact within school needs to be instituted. In severe situations where a child has been absent from school, a gradual reintegration should be arranged, with consideration of admission to a pediatric or psychiatric unit with educational provision.



Click on the picture to hear about the management of recurrent abdominal pain; it highlights the importance of school liaison in the treatment (8:30)

Hospitalization

Consider hospital admission if:

- The child is severely impaired
- Observation is needed (e.g., in the case of seizures)
- There is significant associated psychopathology
- Outpatient treatment has not been successful.

Hospitalization may help break the cycle of excessive anxiety and dependence of the child on parents and focus on rehabilitation. Specific inpatient interventions through a multidisciplinary approach may include physiotherapy, diet advice, occupational therapy, more intensive psychological work and family intervention.

Young people are usually admitted to a pediatric or psychiatric ward as joint pediatric and psychiatric wards are rare. Families may be reluctant to allow psychiatric admission, thus it is important to discuss their concerns and attitudes to enable the best possible package of care to be instituted.

Liaison with social services

Always consider child abuse and safety issues. In rare cases the somatoform disorder will be the expression of severe family dysfunction or child abuse. Close cooperation and communication between all professionals are essential to avoid differing opinions being relayed to the patient and family. If families are unwilling to engage in any type of treatment for the child, clinicians should consider whether it would be in the best interests of the child to be treated away from the family.

Janine

Janine, a 10 year old girl, was referred because of a one-year history of weekly presentations to casualty for multiple pains in all joints. Despite extensive investigations, including X-rays and MRI scans, no organic pathology had been identified. Janine had been in a plaster cast and wheel chair bound on five occasions despite no fractures being identified; as a result she had missed a lot of school. At the initial psychiatric appointment Janine was extremely distressed by:

- Severe aches and pains throughout her body (giving the pain a score of nine out of 10)
- One year history of bullying (mentioned for the first time at the assessment)
- Weight gain
- Deep sadness at the death of grandfather three years earlier ("It is as if it has happened yesterday").

As a result of her aches and pains Janine had missed a lot of school. Her mother's believed that Janine had a physical illness yet to be identified and was unhappy about being "sent" to see a psychiatrist. Both Janine and her mother described not communicating much as "talking makes things worse". Hence, Janine had remained silent about the bullying and about her feelings about her grandfather's death. Her mother dealt with stress by "burying her head in the sand" and used alcohol on occasions (following the example of some of her relatives).

The child psychiatrist knew that many people contributed to Janine's care, and all needed to be kept in mind. In addition to the family doctor who had referred her, school staff, emergency room staff and the physiotherapist, all needed to work together with Janine and her family. In spite of the family believing that Janine was suffering from a yet to be discovered physical illness, the child psychiatrist and the others involved in Janine's care, worked with Janine and her family in a model that incorporated the psychological, biological, family and social factors. Janine was offered individual therapy sessions using cognitive behavioral techniques, as well as facilitating emotional expression (including writing a letter to her deceased grandfather), positive self-talk, exploring alternative explanations for her pain, anger management, problem solving skills, relaxation exercise, and distraction when in pain. Alongside this, family sessions were arranged to encourage Janine's mother to reinforce well-behavior, to spend time helping Janine cope with stress, to problem solve with Janine, to have non-pain based talk with Janine, and to learn how to assess the seriousness of symptoms.

Soon after the first session, the previous weekly attendance to the emergency department stopped. Therefore, unnecessary use of medicines and procedures ended. When Janine was asked what had changed since starting treatment, she described that she had acquired an emotional language. She felt safe to speak to people about her fears about bullying and said she knew that talking was helpful as her aches and pains had got "half better". Writing a letter to her late grandfather as if he were still alive, about how much he had meant to her, helped her grief. She said that her aches and pains got better because "I had done activities more often". She was able to keep going "despite the pain" and she started to enjoy physical activities again, helped by using the distraction and relaxation techniques she had learnt. She said she was accepting "a bit of pain", which went away after a day following exercise. Janine's mother added that exercise had kept her joints working even though it hurt her. She spoke about how they had turned the TV off started talking and playing together.

This is a difficult issue to assess and would require close collaboration between clinicians and child protection personnel.

Patient support groups

These can be helpful sources of support to families. However, some groups may hold contradictory views, which may be unhelpful if they undermine the management strategy.

Effectiveness of treatment

The number of studies examining the effectiveness of treatment in somatoform disorders is limited. Case reports from pediatricians and child psychiatrists provide anecdotal support for the beneficial effects of the approaches described in this chapter. Helping patients and families understand the links between psychological and physical pain, tends to be greatly appreciated by parents and is thought to be crucial in reducing pain and helping patients manage it. Cognitive behavioral family interventions for unexplained abdominal pain have the best evidence of effectiveness; one study showed that, when compared with standard medical care, a cognitive behavioral family intervention achieved better pain reduction, lower relapse rates and lower interference with daily activities as well as increased parental satisfaction (Robins et al, 2005). In chronic fatigue syndrome several controlled trials in adults have shown cognitive behavioral therapy and graded exercise therapy to be beneficial (Whiting et al, 2001), which is promising.

The case of Janine highlights many of the features of assessment and management described in this chapter. In addition, this case illustrates that, when considering psychiatric referral, it is important to keep in mind that the family may feel "sent, and not customers of therapy" (De Shazer, 1985; Iveson, 2002).

Family may attend because they are asked to do so by their pediatrician rather than believing this is the right thing to do, potentially resulting in feelings of rejection and anger towards the doctor for being asked to see a mental health professional. In relation to management, this case illustrates that treatment not only help children and their parents manage the symptoms better, but also to communicate more effectively about psychological matters.

Prognosis

Recurrent physical symptoms in childhood have been linked to adult psychopathology and an increased prevalence of psychiatric disorders. Reassuringly, the majority of children with somatoform disorders seen in specialist services recover in the short term. However, symptoms can persist in some patients who subsequently may develop other psychiatric disorders (e.g., eating disorders, anxiety disorders). In a small proportion, symptoms continue into adulthood.

The majority of young people with chronic fatigue syndrome, even those markedly affected, eventually make either a complete recovery or improve sufficiently to lead near normal lives (Rangel et al, 2000). Nevertheless absence from school can last longer than a year and it may take longer than three years to achieve full recovery. Additionally, there are suggestions that these patients are at greater risk of developing further psychiatric disorders after recovery (Garralda & Chalder, 2005).

Kofi

Kofi is an 8 year old boy from a Nigerian family who presented with abnormal movements affecting all his limbs. At the same time he would suddenly stop responding to questions from others, make scary noises, sometimes stare at his family in a frightening way and he even attacked his family occasionally. The abnormal movements and associated behaviors lasted about 20 minutes at a time. His maternal grandmother suffered from generalized tonic-clonic seizures.

The family were concerned that he may be suffering from epilepsy but were equally concerned that Kofi's disturbed behavior resulted from being possessed by evil spirits. The family described Kofi as being cursed after an elderly man in their community had looked at him with an evil eye. They were keen to consult with a priest to perform an exorcism.

Psycho-social stressors included financial difficulties, housing problems, parental separation, peer relationship difficulties at school, poor school attendance and Kofi experiencing symptoms of anxiety.

Kofi's difficulties resolved with interventions involving the family, medical consultation to exclude seizures (including EEG), help with housing and financial support, liaison with the priest to ensure religious rituals did not harm the child and, finally, meetings with the school to support Kofi's attendance and reintegration with peers.

Similarly, a study of childhood conversion disorder showed that, even though 85% had recovered, one third had a mood or anxiety disorder at follow-up four years later (Pehlivanturk & Unal, 2002).

Indicators of favorable outcome include:

- Specific medical precipitants
- Good pre-morbid personality
- Good parental psychiatric adjustment
- Favorable social circumstances

PREVENTION

Childhood somatoform disorders are associated with a history of somatic symptoms in the family and to school non-attendance in the child. A tendency to somatize can be observed in children as young as preschoolers and throughout childhood, adolescence and adulthood. Therefore identifying families with high levels of somatic symptoms in the parents as well as the children and identifying those with frequent school absences may provide an opportunity for early intervention. This could be done via (i) primary care practitioners identifying parents who regularly attend with somatic complaints and providing guidance regarding strategies for coping with their own and their children's somatic symptoms (e.g., distraction techniques) and (ii) teachers and medical professionals identifying children who miss a lot of school because of physical symptoms and supporting them in developing coping strategies and feel in control of situations they find difficult. In children with established symptoms, addressing personality vulnerabilities and excessive academic and behavioral expectations may help prevent relapse.

CROSS CULTURAL PERSPECTIVES

Traditionally it was thought that somatization occurred mainly in non-Western countries. However, more recent research has identified it as a universal

Saira

Saira was a 12 year old girl of Pakistani background who had been diagnosed as suffering from epilepsy at the age of five. She had been treated with anti-epileptic medication and had been seizure free for four years. Saira presented to the local outpatient clinic with a recurrence of her fits. Her earlier fits had been grand-mal seizures, mostly occurring during the night, accompanied by incontinence. Her current episodes were not consistent with epilepsy, were occurring during the day and were prolonged, lasting half an hour at a time.

A stressor was identified; the family had decided that as Saira had completed her primary school education there was no need for her to continue with her schooling, she would stay at home to look after her youngest sibling so that her mother could return to attend to the family's livestock. A poor harvest meant that the family was under financial stress.

Treatment consisted of psychoeducation for Saira and her family, highlighting the close relationship of the body and the mind, and the co-occurrence of physical symptoms with psychological stresses. In individual meetings and later in family meetings, Saira was able to talk about her distress at the proposed plan, which would result in the loss of her friendships at school as well as the positive relationships she had with her teachers. Although financial considerations meant that no immediate change could be made to the planned arrangements, the family agreed amongst themselves to try and support her in continuing her education once the financial pressures had eased. They were happy to support her in continuing to meet with her friends. Saira's seizures subsided soon after.

phenomenon. A WHO study looked at somatization presentations in primary care in 14 countries (Turkey, Greece, Germany, The Netherlands, Italy, India, Nigeria, China, Japan, France, Brazil, Chile, the UK and USA) and found that somatization symptoms were common across all these countries and frequently associated with comorbid depressive and anxiety disorders (Gureje et al, 1997).

A cross cultural perspective is particularly important in the evaluation of somatization in terms of how symptoms are understood by the family within the context of their cultural beliefs:

- Although headaches, musculoskeletal pains and abdominal pains are the most common symptoms in somatoform disorders overall, there are culture- or geographic area-specific symptoms. For example, "numbness" and "feelings of heat" in Africa, "burning hands and feet" in India and "fatigue" in Western countries.
- Awareness of the cultural influence on how symptoms are understood or described is important because certain symptoms may be an accepted mode of expression of cultural or religious activities in some societies; thus they may be interpreted as a sign of spiritual or other non-medical process. This may result in families seeking help from alternative medicine practitioners or healers instead of, or in addition to medical practitioners. In cases where medical help has been sought, these patients are more likely to disengage with a traditional medical approach.

It is important to address family attitudes and beliefs about the symptoms within the appropriate cultural context, find out what interventions have already been tried including culture-specific interventions, and spend time with them discussing alternative explanations and engaging them in the treatment process. The case of Kofi is an example of this.

Although the cultural differences in the interpretation of symptoms, the broad types of etiological stressors (e.g., everyday school stressors such as bullying, or everyday family stressors such as financial problems) are comparable across cultures (see the case of Saira).

Barriers to implementation of evidenced based medicine in low income countries

A number of barriers to the implementation of evidence based practice for child and adolescent mental health problems have been described in the context of low-income countries (Knapp et al, 2006; Keiling et al, 2011) and are of relevance for the management of somatoform disorders. Low-income countries allocate a proportion of their gross domestic product to health but as this is low, the allocated resources are also considerably less than the need. There is moreover, little government funding available for professional regulation, allowing healthcare providers to offer treatments with limited evidence, without fear of challenge or withdrawal of their registration. In the absence of comprehensive governmental provision of care, patients and families need to self-fund their care. Poverty and lack of knowledge makes them vulnerable to unregulated providers.

The medical and nursing brain drain from low- to high-income countries has meant that there are insufficient human resources to meet the local need for health professionals. Those remaining are often not trained in using audit to improve care or in critically evaluating available evidence. In addition low-income countries often do not have a well developed and comprehensive primary healthcare system, and there is poor integration of mental healthcare within primary healthcare, leading to fragmentation of care.

Of direct relevance to the somatoform disorders, there is a paucity of trained professionals to meet the mental health needs of children and adolescents and barriers to care include poor identification and lack of specialized personnel. Hence attention needs to be focused on the training and supervision of professionals who are usually the first port of call for families, such as primary care physicians and pediatricians.

CONCLUSION

Recurrent, unexplained physical symptoms are common in children and adolescents. When they are severe, impairing, related to psychological factors and result in frequent medical help seeking behavior, they form the basis of somatoform disorders. In these cases, families tend to attribute the somatic symptoms to underlying physical pathology despite the absence of medical evidence for this. In some cultures families may explain the physical symptoms in religious or culturally specific ways.

Psychiatric comorbidity commonly occurs and this, together with the child's personality traits, family health problems, family response to the symptoms and problems in communicating effectively on emotionally laden issues, may contribute to the maintenance of the disorder.

Medical examination and investigation, recognition of parental and child attitudes to the symptoms and management strategies to help reduce impairment are core to successful management. Psychiatric treatment of comorbidities and instituting a child and family rehabilitation program are required.

The best evidence of efficacy comes from the use of family cognitive behavioral therapy. However, helping families communicate about and manage stressors for the child is often clinically efficacious. Engaging families during every step of the assessment and treatment is important and will aid recovery.

The lack of pediatric mental health facilities may impede this work in developing countries with low levels of investment in child mental healthcare, but psychoeducation by primary healthcare workers and educators may still be an effective means of preventing and managing these disorders across different countries and cultures.

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EPILEPSY AND RELATED PSYCHIATRIC CONDITIONS

Eduardo Barragán Pérez

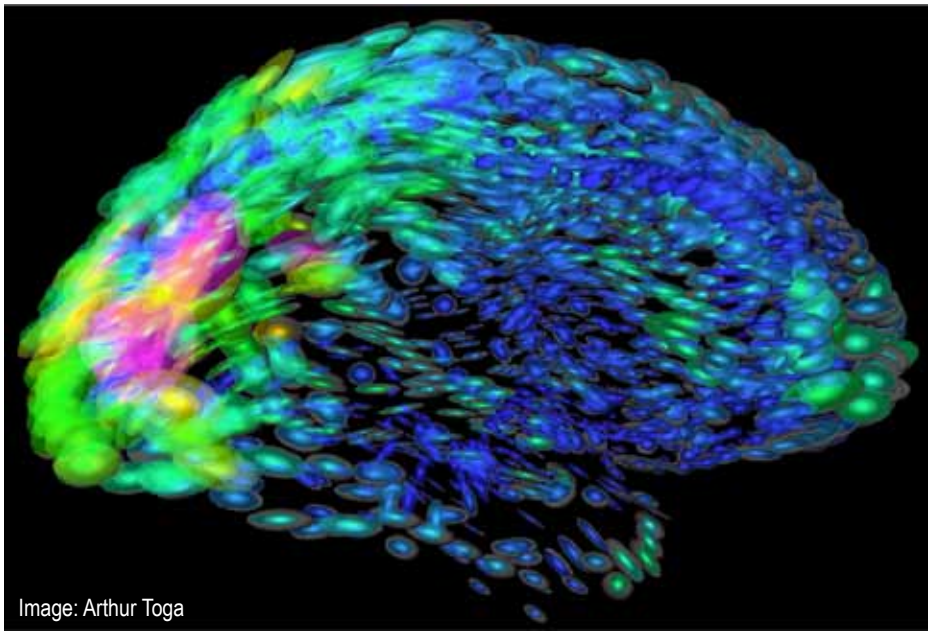


Image: Arthur Toga

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Conflict of interest: none disclosed.

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Suggested citation: Barragán E. Epilepsy and related psychiatric conditions. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Epilepsy (from the Ancient Greek ἐπιληψία (epilēpsía): *seizure*) is a group of chronic neurological disorders characterized by seizures, which are the result of abnormal, excessive or hypersynchronous neuronal activity in the brain (Engel, 2006). Epilepsies can be classified by the:

- Etiology (e.g., idiopathic, secondary – see side box)
- Characteristics of the seizures, such as absence, myoclonic, clonic, tonic, tonic-clonic, and atonic (Blume et al, 2001).
- Location in the brain where seizures originate:
  - Partial or focal onset seizures: simple partial (consciousness is not impaired) or complex partial (psychomotor seizure). Partial seizures may generalize (secondary generalized)
  - Generalized seizures
  - Frontal, temporal lobe
- Medical syndromes of which they are a manifestation (e.g., juvenile myoclonic epilepsy, Lennox-Gastaut syndrome)
- Event, if any, that triggers the seizures, such as reading or music.

Epilepsy is a worldwide problem that affects between 2% and 3% of the population, 75% of the cases begin before adolescence. Epilepsy can be caused by genetic, structural, metabolic or unknown factors. Among the structural factors, the most common causes in developing countries are infectious and parasitic diseases (especially neurocysticercosis), perinatal brain damage, vascular disease, and head trauma – all preventable (Barragan, 2004). The prognosis of epilepsy depends on the etiology of the illness as well as on early and sustained treatment. It is estimated that up to 70% of people with epilepsy can live normal lives if they receive proper care.

Epilepsy accounts for 0.5% of the global burden of disease, measured in disability adjusted life years (DALYs), with 80% of that burden corresponding to the developing countries; this illness accounts for 0.7% of the regional (Latin-American) burden of disease. There are no significant gender differences and the highest burden (2.8%) is found in the 5-14 age group.

The global incidence, prevalence, and mortality of epilepsy are not uniform, depending on several factors. Developing and developed countries have geographic, economic and social differences. The prevalence and incidence of epilepsy are higher in developing countries than in developed ones. However, within developing countries – even given the high incidence of epilepsy – the prevalence is relatively low, which may be due to high mortality of people with epilepsy. Prognosis in developing countries seems similar to that in developed ones. Because phenobarbital, carbamazepine and phenytoin are available and inexpensive, they are the drugs most often used in developing countries but they produce more psychiatric side effects. The most cost-effective way to decrease the treatment gap in developing countries would be to deliver epilepsy services through primary health care. All these issues have an impact on the existence of higher psychiatric comorbidity in developing countries.

Seizure types

Idiopathic (primary)

- Seizures start during childhood or adolescence
- Genetic origen
- Good respond to pharmacological treatment
- Good prognosis,
- No brain damage

Symptomatic (secondary)

- Seizures start at any age
- Multiple etiology
- Uncertain pharmacological response
- Variable prognosis
- Usually brain damage

EPILEPSY AND PSYCHIATRIC DISORDER

Mood, anxiety, psychosis, attention deficit hyperactivity disorder (ADHD) and autism are relatively frequent comorbidities of epilepsy. Traditionally, these



Click on the picture to view a short video explaining epilepsy and its types (10:42)

Table I.2.1 Prevalence of selected psychiatric disorders in young people suffering from epilepsy and in the general population

	Epilepsy sufferers (%)	General Population (%)
Depression	11-60	12-15
Anxiety	19-45	2.5-6.5
Psychosis	2-8	0.5-0.7
ADHD	25-30	2-10



The modern medical era of epilepsy began with three English neurologists: John Hughlings Jackson (pictured), Russell Reynolds, and Sir William Richard Gowers. In a seminal study, Jackson (1835-1911) defined a seizure as "an occasional, an excessive, and a disorderly discharge of nerve tissue on muscles." He also recognized that seizures can alter consciousness, sensation and behavior. Two independent teams of chemists created phenobarbital, which was marketed in 1912 by Bayer under the brand name of Luminal. Phenobarbital is the oldest antiepileptic drug and is still in clinical use.

psychiatric conditions were considered to be complications of the seizure disorder but a bidirectional relationship has now been demonstrated (Gaitatzis et al, 2004). Therefore, not only are patients with epilepsy at greater risk of developing these psychiatric disorders but patients with mood, attention deficit disorders and autism have a significantly greater risk of developing epilepsy also (Barragán & Hernandez, 2005). These bidirectional relationships suggest the existence of common pathogenic mechanisms operating in epilepsy and the major psychiatric disorders. An alternative explanation is that both epilepsy and psychiatric illness are the result of an underlying structural brain abnormality. Thus, identification of the underlying pathogenic mechanisms may shed light on the neurobiological bases of these disorders.

The existence of comorbid psychiatric disorders has a significative impact on the treatment of epilepsy (Kessler et al, 1994; Bijl et al, 1998). Epidemiological studies show that psychiatric disorders are more prevalent among people with epilepsy than in the general population (Davies et al, 2003; Devisnky, 2003) as shown in Table I.2.1. Prevalence rates in studies using ICD codes from administrative data (Bredkjaer, 1997; Gaitatzis, 2004) are highly variable due to unreliability of the recordings. Studies using structured interviews find even higher rates. However, prevalence of psychiatric conditions in clinic-based studies may be higher than in the general population because samples are biased toward individuals seeking medical attention (i.e., sicker). In summary, psychiatric comorbidity in epilepsy is high regardless of the ascertainment method used.

The presence of comorbid disorders also impacts on the response to antiepileptic drugs, particularly due to side effects, and on the quality of life of these patients. For example, a study by Tellez-Zenteno et al (2007) found that one third of patients with epilepsy had depression or anxiety, one in four had suicidal ideas and almost half had problems with attention or cognition.

Significance of the association between epilepsy and psychiatric disorder

There are several explanations for this association:

1. The comorbid psychiatric disorder is the result of an increase in psychosocial problems (e.g., stigma, impairment) associated with epilepsy
2. Repeated seizures actually increase the vulnerability for psychiatric disorder
3. Psychiatric disorder increases vulnerability for epilepsy

4. Both epilepsy and psychiatric conditions are caused by a brain abnormality

Epidemiologic studies suggest that a previous history of depression may increase the risk of epilepsy (four to seven fold), while the presence of epilepsy increases the risk of developing depression (five to 25 fold) (Kanner, 2005). This data suggest a bi-directional relationship between the two diseases. Other psychiatric disorders such as ADHD increase the risk of epilepsy 3.7 fold. A study in Wisconsin including 53 children with newly diagnosed idiopathic epilepsy using structured interviews showed that one quarter had a depressive disorder before the onset of the seizures, one quarter an anxiety disorder and one quarter ADHD.



Hans Berger, a German psychiatrist, discovered that it was possible to record the electric currents generated by neurons in the brain without opening the skull, and to record them on a strip of paper, which Berger named as the electroencephalogram (EEG). This discovery opened the door for a quantum leap on epilepsy diagnosis and research.

Psychiatric comorbidity

Depression

Using DSM-IV criteria, the lifetime prevalence of depression ranges from 12% to 16% and 1-year prevalence is about 5%. Mood disorders are the most common psychiatric conditions found in people with epilepsy. For example, Grabowska-Gryzb et al (2006) found a prevalence of depression of 49.5% in 203 patients with intractable epilepsy. Rates are highest in populations with intractable epilepsy (40%-60%) but are still high in people with epilepsy in the general population (about 20%). The timely identification and treatment of depression in epilepsy is increasingly recognized as an area requiring attention (Davies et al, 2003).

Anxiety

Lifetime prevalence of anxiety disorders in the general population ranges from 2% to 5% (Hunt et al, 2002). In people with epilepsy, prevalence ranges from 11% to 15%. Tellez-Zenteno et al (2005) reported a lifetime prevalence of 13% in a Canadian general population study in adolescents using structured psychiatric interviews. Anxiety disorders seem to be more common in patients with intractable epilepsy. Regrettably, depression and anxiety do not seem to lessen in patients with intractable epilepsy who underwent surgery for epilepsy.

Psychosis

The prevalence of psychosis in the general population ranges between 1% and 2% (Johns & van Os, 2001). Psychotic symptoms in people with epilepsy may be ictal (they occur during the seizure, e.g., complex partial seizure), postictal (after having a seizure), or chronic interictal (Table I.2.2). Prevalence of interictal psychosis in non-selected epilepsy population studies varies from 3.1% to 9%. They are more frequent in adolescents but children can also show these symptoms,

Table I.2.2 Subcategories of epileptic psychoses

- **Postictal psychosis:** psychosis that follows immediately after one or multiple seizures (mostly complex partial or secondarily generalized), occurring within one week of the last seizure
- **Acute interictal psychosis:** psychosis that develops when seizures have ceased or reduced significantly in frequency (alternative psychosis) or when seizures are unrelated to a recent increase in seizure activity
- **Chronic epileptic psychosis:** a psychotic state lasting more than six months in patients with epilepsy.

especially children with partial complex seizures. In studies of patients with temporal lobe or refractory epilepsy, prevalence ranges from 10% to 19%, which is almost double that found in non-selected epilepsy populations (Taylor, 1972). In children, it is important to highlight that some antiepileptic drugs can trigger psychotic symptoms (e.g., topiramate, levetiracetam and phenobarbital).

By contrast, the overwhelming majority of individuals with epilepsy never experience psychotic episodes, which leads to the long disputed question of whether there is a relationship between epilepsy and psychosis (Tadokoro et al, 2007). In cases of interictal psychosis, mostly in temporal lobe epilepsy, there is a long interval (greater than 10 years since the first seizure) until the onset of psychosis. Some have suggested the link between epilepsy and psychosis is non-specific and that psychosis in patients with epilepsy occurs not as a result of the epileptic activity itself but indirectly as a sequel to non-specific damage to vulnerable parts of the brain. This contrasts with Landot's (1953) view of psychosis as the result of a paradoxical normalization of the electroencephalogram in patients with epilepsy.

ADHD

Comorbidity with ADHD is common – it occurs in as many as 30% to 50% of patients – and may cause serious social and academic impairment (Barragán at al, 2005). The association is independent of epilepsy syndrome, seizure type, age of epilepsy onset and etiology of seizures. Pharmacologic intervention in patients with epilepsy and ADHD is particularly challenging due to the potential risk for the exacerbation of seizures by the ADHD medication. Treatment of ADHD has traditionally relied on the use of psychostimulants such as methylphenidate. Unfortunately, side effects like the possibility of increasing seizure threshold and the number of seizures limit stimulant use. Atomoxetine has shown to be effective for ADHD symptoms, does not worsen seizures and is generally well tolerated. The main side effects of atomoxetine are decreased appetite, headaches, nausea and weight changes (Barrágan & Hernández, 2005). There are no interactions between antiepileptic drugs and ADHD medications.

Do antiepileptic drugs exacerbate or even induce ADHD symptoms?

- Barbiturates and specifically phenobarbital may induce hyperactivity especially in toddlers
- Valproate may induce irritability in newly diagnosed children
- Lamotrigine may induce hyperactivity in the developmentally disabled
- Levetiracetam may induce hostility
- Topiramate may induce both slowing and hyperactivity.



Click on the picture to view a short video about how epilepsy is diagnosed (4:30)

SYNDROMES, SEIZURES, DRUGS AND MOOD

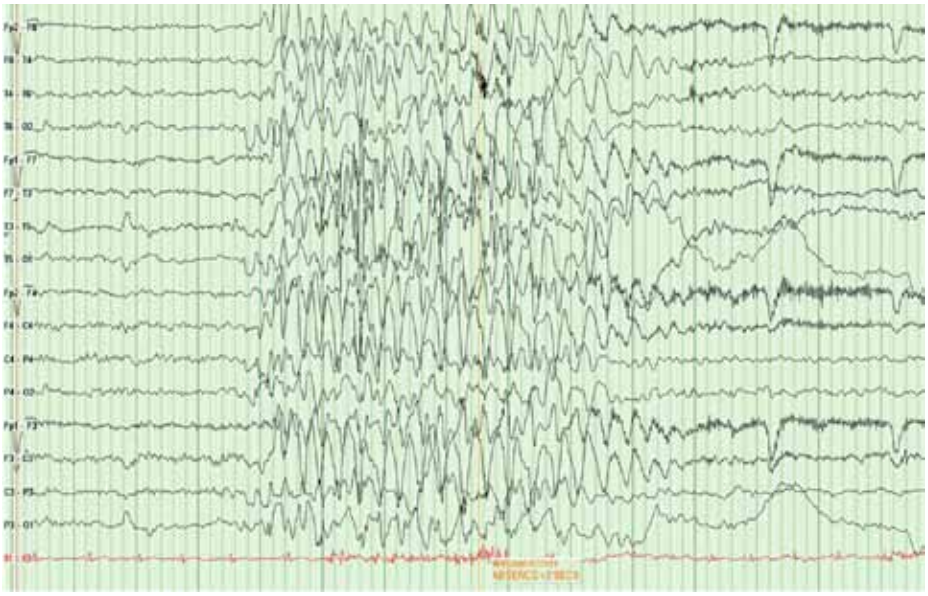
There has been considerable debate – still unresolved – as to the association between a particular type of epilepsy and depression. People with epilepsy resulting from lesions in the temporal lobe are more likely to have intractable seizures, and they are also more likely to take a larger variety of medications than those with temporal epilepsy without lesions. Overall, studies have shown that patients with temporal lobe epilepsy are more prone to depression, particularly those with temporal lobe epilepsy who had mesial temporal sclerosis. In general, there is agreement that patients with complex partial seizures (the more frequent type of seizures in temporal lobe epilepsy) are more likely to have a depressive disorder.

Antiepileptic drugs and depression

Interest on the role of antiepileptic drugs in precipitating depression has grown following the introduction of the new antiepileptic compounds (Mula & Sandeer, 2007), resulting in a revival of the concept of *forced normalization*. The antiepileptic drugs more often associated with this effect seem to be those which act at the benzodiazepine-GABA receptor complex (e.g., tiagabine, topiramate, vigabatrin, carbamazepine and valproate). It is not rare to see mood changes

Forced normalization

A hypothesized phenomenon by which the sudden cessation of seizures in people with intractable epilepsy would be followed by the development of psychiatric symptoms – usually psychotic, but depression is also reported.



EEG recording of an absence lasting 3 seconds

in children when they take these medications, even at low doses, especially in those with temporal lobe epilepsy. Anecdotal evidence (case reports) suggest that levetiracetam can often cause mood symptoms (depression, irritability) as well as disruptive behavior, which can be ameliorated with a combination of vitamin B6 and B12. There may also be interactions between antidepressant medications and antiepileptic drugs. This largely depends on liver metabolism, thus it is important to know where medications are metabolized and whether they induce or inhibit the metabolism of other medications (see Table I.2.3). Antidepressants may

Antiepileptic medications

Older drugs

- Benzodiacepines
- Carbamazepine
- Clobazam
- Phenobarbital
- Phenytoin
- Primidone
- Valproate

Newer drugs

- Felbamate
- Gabapentin
- Lamotrigine
- Levetiracetam
- Oxcarbazepine
- Pregabalin
- Topiramate
- Vigabatrin
- Zonizamide

Table I.2.3 Interactions of antiepileptic drugs with liver enzymes

Antiepileptic Drug	Induction	Inhibition	Enzymes
Carbamazepine	✓ (95%)		CYP3A4
Phenobarbital	✓ (75%)		
Phenytoin	✓ (90%)		CYP2C19; CYP2C9
Primidone	✓ (50%)		
Felbamate	✓ (50%)		CYP3A4
Lamotrigine	✓ (90%)		UGT (weak)
Oxcarbazepine	✓ (45%)		CYP3A4
Topiramate	✓ (40%)		CYP3A4
Felbamate		✓	CYP2C19
Oxcarbazepine		✓	CYP2C19 (weak)
Topiramate		✓	CYP2C19
valproate		✓	CYP2C19, UGT
Gabapentin			Without hepatic interaction
Levetiracetam			
Pregabalin			
Topiramate (<200 mg/day)			
Vigabatrin			

Table I.2.4 Common psychiatric medications and their effect on seizures.

Increase the risk of seizures:
- High risk: bupropion, clomipramine, chlorpromazine, clozapine
- Intermediate risk: tricyclic antidepressants, venlafaxine, thioridazine, olanzapine, quetiapine
- Low risk: fluoxetine, sertraline, paroxetine, trazodone, haloperidol, risperidone.

increase the risk of seizures (Mula et al, 2004). Table I.2.4 lists common psychiatric medications and their effect on seizures.

Types of aggravation of seizures
- Re-occurrence of seizures in previously controlled patients
- Increase in the frequency or severity of pre-existing seizures
- Emergence of a new type of seizure or status epilepticus.

BEHAVIOR PROBLEMS

Epidemiologic studies have consistently shown that children with epilepsy have higher rates of behavior problems than children with other chronic physical conditions. It is not clear when these problems begin but it is commonly assumed that they start after epilepsy is diagnosed. The reasons for these behavior problems are not well understood either. Presumed causes include:

- The effect of the seizures themselves
- Effects of medication
- Poor child and family adaptation to the illness, and
- Neurologic dysfunction that brings about both seizures and behavior problems.

With few exceptions, studies investigating behavior problems have been conducted on children who had suffered from epilepsy for many years. This makes it difficult to separate preexisting causes of behavior problems from those related to living with chronic epilepsy.

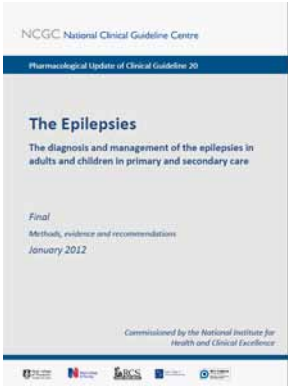
Hoare and Kerley (1991) compared psychiatric disturbance across several small groups of children. Children with new-onset epilepsy were diagnosed and treatment was initiated within three months before data collection. They found that 24% of the children either had behavior problems in the clinical range or were at risk for such; children with new-onset epilepsy had higher mean total behavior problems scores than children who had no further seizures. They hypothesized that central nervous system dysfunction might be a causal factor in both seizures and behavior problems.

If high rates of behavior problems before the first recognized seizure were to be found, then behavior problems could not be attributed to side effects of medication or to a negative emotional response to epilepsy, such as concerns about stigma. The percentage of children with previously unrecognized seizures who had behavioral problems in the clinical range (34.2%) is similar to the rate of psychiatric disturbance found in children with a brain disorder (including seizures) in the Isle of Wight study (34.3%). This finding of higher rates of behavior problems at the time of onset of seizures in children who had unrecognized epilepsy is consistent with Aicardi and Ohtahara's (2002) hypothesis that epilepsy can be a pervasive condition in children.

Thus, emotional and behavioral disturbances are common among children with epilepsy and can cause serious social and academic impairment with long-term effects. Management of the behavioral problem of these children is similar

to that of children without epilepsy (e.g., psychoeducation, parent management training, CBT and medication). Pharmacologic intervention in patients with epilepsy and disruptive behaviors is particularly challenging due to the potential risk for exacerbation of seizures by the medication. So far, very few data exist on the efficacy and safety of typical and atypical neuroleptic medications in epileptic children. Moreover, despite the apparent consensus among physicians, no conclusive data exist on whether commonly used psychotropic drugs such as SSRIs and tricyclic antidepressants worsen seizures (see Table I.2.4), but they need to be used with caution. Antipsychotics, such as risperidone and olanzapine, and methylphenidate can be safely used in patients with epilepsy.

Most of the available information on the use of neuroleptic medications in epileptic children comes from older reports using first generation neuroleptics, such as thioridazine and haloperidol. Although effective in reducing disruptive behaviors, nowadays these drugs are prescribed less frequently because of adverse effects, both neurological and cardiovascular (thioridazine, for example, is no longer available in some countries). Second generation neuroleptic drugs such as risperidone and olanzapine cause fewer extrapyramidal symptoms. Risperidone, and sometimes olanzapine, has been shown to be very efficacious in diminishing behavioral disturbance in developmentally disabled children in the short term, in those with autism and pervasive developmental disorder as well as in patients with epilepsy, without an increase in the number of seizures (Barragán et al, 2005).



Click on the picture to access the NICE guidance on the diagnosis and management of the epilepsies in adults and children.

SLEEP AND EPILEPSY

Since Aristotle and Hippocrates noted the occurrence of epileptic seizures during sleep, the relationship between sleep and epilepsy has intrigued physicians and researchers. Sleep is an example of a physiologic state capable of modulating seizures. The influence of sleep on epilepsy is supported by the observation that in specific epileptic syndromes seizures occur exclusively or primarily during non-rapid eye movement (NREM) sleep. In almost all epileptic syndromes, interictal epileptiform discharges are more prevalent during NREM sleep and less prevalent during rapid eye movement (REM) sleep.

The proportion of patients who have seizures that occur exclusively or predominantly during sleep ranges from 7.5% to 45% in several series studying sleep-related epilepsy. This wide variation may reflect differences among patient populations, with seizures more likely to occur during sleep in certain epileptic syndromes. Frontal lobe seizures are more common during sleep and temporal lobe seizures more common during wakefulness (Commission on Classification and Terminology of the International League Against Epilepsy, 1989). Herman and coworkers (2000) analyzed 613 seizures in 133 patients with partial seizures who underwent video-EEG monitoring finding that 43% began during sleep, the majority during stages 1 and 2 NREM sleep and none during REM sleep.

As the clinical manifestations of *nocturnal frontal lobe seizures* often include prominent tonic or motor manifestations, they are more likely to be noticed by the patient or family than complex partial seizures of temporal lobe origin – complex partial seizures that begin focally and impair consciousness are the predominant seizure type in temporal lobe epilepsy. However, the brevity, the minimal or lack of postictal confusion, the apparently psychogenic features (such as kicking, thrashing and vocalizations), and the frequently normal interictal and ictal recordings may

complicate diagnosis. Nocturnal seizures may suggest diagnoses of sleep terrors, REM sleep behavior disorder, psychogenic spells, or nocturnal paroxysmal dystonia.

Seizures originating in the sensorimotor area may be mistaken for psychogenic spells because of thrashing behavior, preservation of consciousness, absence of postictal confusion, and absence of interictal or ictal EEG activity. Diagnostic features supporting sensorimotor area seizures include (1) short duration (less than 30 seconds to a minute), (2) stereotyped nature, (3) tendency to occur predominantly or exclusively during sleep, and (4) tonic contraction of the arms in abduction. Psychogenic spells usually are of longer duration (one to several minutes), are nonstereotypic, and occur when the patient is awake or drowsy.

Nocturnal paroxysmal dystonia. This syndrome, initially termed hypnogenic paroxysmal dystonia and subsequently, nocturnal paroxysmal dystonia, is characterized by brief (15-45 seconds) stereotyped motor attacks consisting of dystonic posturing, ballistic or choreic dyskinesias and vocalizations during NREM sleep without clear ictal or interictal EEG changes.

Differential diagnosis

The differentiation of nocturnal seizures from non-epileptic spells during sleep can be challenging. First, in partial seizures occurring during wakefulness, patients may report postictal confusion or recall the beginning of a seizure (aura) that precedes loss of consciousness. These elements of the history support the diagnosis of epilepsy and frequently are absent in seizures occurring during sleep. Second, nocturnal events may not be observed properly. Bed partners may not be present or, if present, may not be fully awake and coherent. Complex partial seizures of temporal lobe origin in particular may lack vigorous motor activity and may fail to wake the bed partner. Third, a variety of sleep disorders are characterized by vigorous movements and behaviors that mimic seizures. Finally, certain types of seizures, particularly those of frontal lobe origin, are manifested by bizarre movements suggestive of a psychiatric disorder, including kicking, thrashing, and vocalizations. These epilepsies may be associated with normal ictal and interictal EEGs and normal imaging studies, making definitive diagnosis difficult.

Arousal disorders

NREM arousal disorders include a spectrum of confusional arousals, somnambulism (sleepwalking), and night terrors. These three disorders share the following features:

- They usually arise from NREM sleep stages 3 or 4 and, therefore, occur preferentially in the first third of the sleep cycle
- They are more common in childhood, and
- There is often a positive family history, suggesting a genetic component.

Broughton (1968) contrasted *confusional arousals* – characterized by body movement, autonomic activation, mental confusion and disorientation, and fragmentary recall of dreams – with the nightmares of REM sleep (in which subjects became lucid almost immediately and usually recall dreaming).

Somnambulism is a related NREM arousal disorder in which patients may wander out of the bedroom or house during confusional episodes. *Night terrors* begin with an intense scream followed by vigorous motor activity. Children often

are inconsolable and completely amnestic for the event. The subject appears to be awake but is unable to perceive the environment. If mental activity preceding the event is recalled, the images are simple (e.g., face, animal, or fire) compared with the complex plots of REM nightmares. Patients often report an oppressive feeling, such as being locked up in a tomb, or having rocks piled on their chests. Intense autonomic activation results in diaphoresis, mydriasis, tachycardia, hypertension, and tachypnea. In contrast to seizures, NREM arousal disorders are less stereotyped and commonly occur in the first third of the night. Patients with REM-sleep behavior disorders often present with vigorous motor activity during sleep and may injure themselves or their bed partners.

Sleep-related movement disorders

Movement disorders occurring during sleep that may resemble seizures include periodic limb movements, sleep-onset myoclonus, bruxism, and rhythmic movement disorder.

- *Periodic limb movements* in sleep may result in vigorous kicking or thrashing. A history of restless legs syndrome is commonly elicited. In contrast to seizures, periodic limb movements occur at periodic intervals (usually every 20 to 40 seconds) and involve a characteristic flexion of the leg, although the upper extremities occasionally may be involved.
- *Sleep-onset myoclonus*, also known as sleep starts, sleep jerks, or hypnic jerks, is a normal physiologic event occurring at the transition from wakefulness to sleep, often associated with sensory phenomena, including a sensation of falling. In contrast to myoclonic seizures, sleep-onset myoclonus is limited to the onset of sleep.
- *Bruxism*, stereotyped teeth grinding resembling the rhythmic jaw movements of epilepsy, may lead to excessive tooth wear, which does not occur in epilepsy.
- *Rhythmic movement disorder*, also known as head banging or body rocking, can occur during any sleep stage. It is manifested in a variety of ways, including recurrent banging of the head while the patient is prone or rocking of the body back and forth while on hands and knees. Vocalizations may accompany the repetitive movements. Rhythmic movement disorder can occur at any age, although it is more common in children than adults and is associated with mental retardation. Although complex partial seizures, particularly those of frontal lobe origin, may include similar behaviors, bilateral body rocking is more characteristic of rhythmic movement disorder. Body rocking may also occur in psychogenic seizures.

Psychiatric symptoms

Psychiatric symptoms during sleep that resemble seizures include panic attacks, post-traumatic stress disorder symptoms and psychogenic seizures. Some patients who have panic disorder present exclusively or predominantly with panic attacks that cause multiple abrupt awakenings. Symptoms on awakening include apprehension and autonomic arousal with palpitations, dizziness and trembling. In contrast with REM sleep nightmares, dreams are not recalled. In contrast with night terrors, which arise during deep NREM sleep, sleep panic attacks usually occur in the transition from NREM stages 2 to 3. Although a history of daytime panic attacks can be useful diagnostically, panic attacks may occur exclusively during sleep. An abrupt return to consciousness and autonomic arousal is more characteristic of panic disorder than of seizures, although these features may occur

in seizures. Simple partial seizures of parietal lobe origin may manifest occasionally as panic symptoms.

In post-traumatic stress disorder, repetitive rocking or head banging may occur, and the characteristic nightmares or flashbacks may arise at any stage of sleep. In contrast to seizures, patients often recall the traumatic experience. Psychogenic seizures may occur while the patient *appears to be* asleep. Diagnosis of these non-epileptic events is supported by the presence of a well-organized posterior alpha rhythm immediately before the onset of clinical changes despite the patient appearing to be asleep and the lack of ictal or postictal EEG changes. Provocative testing with suggestion may be helpful in confirming the diagnosis of psychogenic seizures.

QUALITY OF LIFE IN PEDIATRIC PATIENTS WITH EPILEPSY

One Latin-American study including more than 200 patients between six and 18 years of age showed that the quality of life of these patients was fair (López-Rojas et al, 2010). Almost half of the patients felt stigmatized. Income, the number of antiepileptic drugs and their cost, school performance and stigma were the factors which influenced quality of life. This is similar to results in other regions of the world (Devinsky & Penry, 1993).



Click on the picture to view a short video about living with epilepsy (4:21).

The type of seizure is important. The principal neurocognitive difference between the two types of focal epilepsy (frontal *vs* temporal) is IQ (mean IQ of 82 in frontal epilepsy and 97 in temporal epilepsy), with more impact in the working memory and visuospatial performance in children with frontal epilepsy. Patients with temporal lobe epilepsy have more problems with attention and long term memory tasks (Barragán et al, 2006).

ADHD, cognitive decline and academic performance is one of the principal mental health problems worldwide in childhood epilepsy. In another Latin-American study, important differences between countries were noted, especially in the severity of ADHD, academic performance (lower in Central American countries) and better response to treatment in countries with a better education system.

TREATMENT

Most low income countries have access to the four basic antiepileptic drugs (phenobarbital, phenytoin, carbamazepine, and valproate) but only at secondary and tertiary levels of care. Ensuring supply of these four medications is essential, taking into account that seizures can be controlled with monotherapy regimens in up to 70% of cases. In 1990, the WHO determined that the average cost of treatment (with phenobarbital) could be as low as US$ 5 per patient per year (World Health Organization, 2006). Public health services in most of these countries do not have access to the new-generation antiepileptic drugs, useful in treatment resistant cases but more expensive.

In the integrated management of people with epilepsy, consideration of psychosocial factors is essential and includes education for self-management; that is, measures and behaviors that people with epilepsy should adopt and maintain to control their illness. In some cases, complementary and alternative medicine

can also be helpful; including, for example, natural remedies, vitamins, relaxation techniques, a healthy diet, religious or cultural activities, and social support. Such measures are acceptable as long as the patient continues taking the basic drug therapy, which treats not only the seizures but also the psychiatric comorbidities.

Rehabilitation

The objective of rehabilitation is to improve the quality of life of people with epilepsy and help them integrate into society and work. The interventions selected will depend on the complexity of each case. Most people with epilepsy enjoy substantial autonomy and only a minority suffers from severe forms of the illness. This group includes persons with disabilities and people who are institutionalized or highly dependent on their families, in whom developing social and occupational skills is essential.

As already highlighted, there is a high proportion of psychiatric conditions comorbid with epilepsy, often unrecognized and therefore not treated properly. These disorders include depression, anxiety and psychosis, as well as cognitive and personality changes. Epilepsy associated with psychosis or dementia is often confined to psychiatric hospitals or social welfare institutions.

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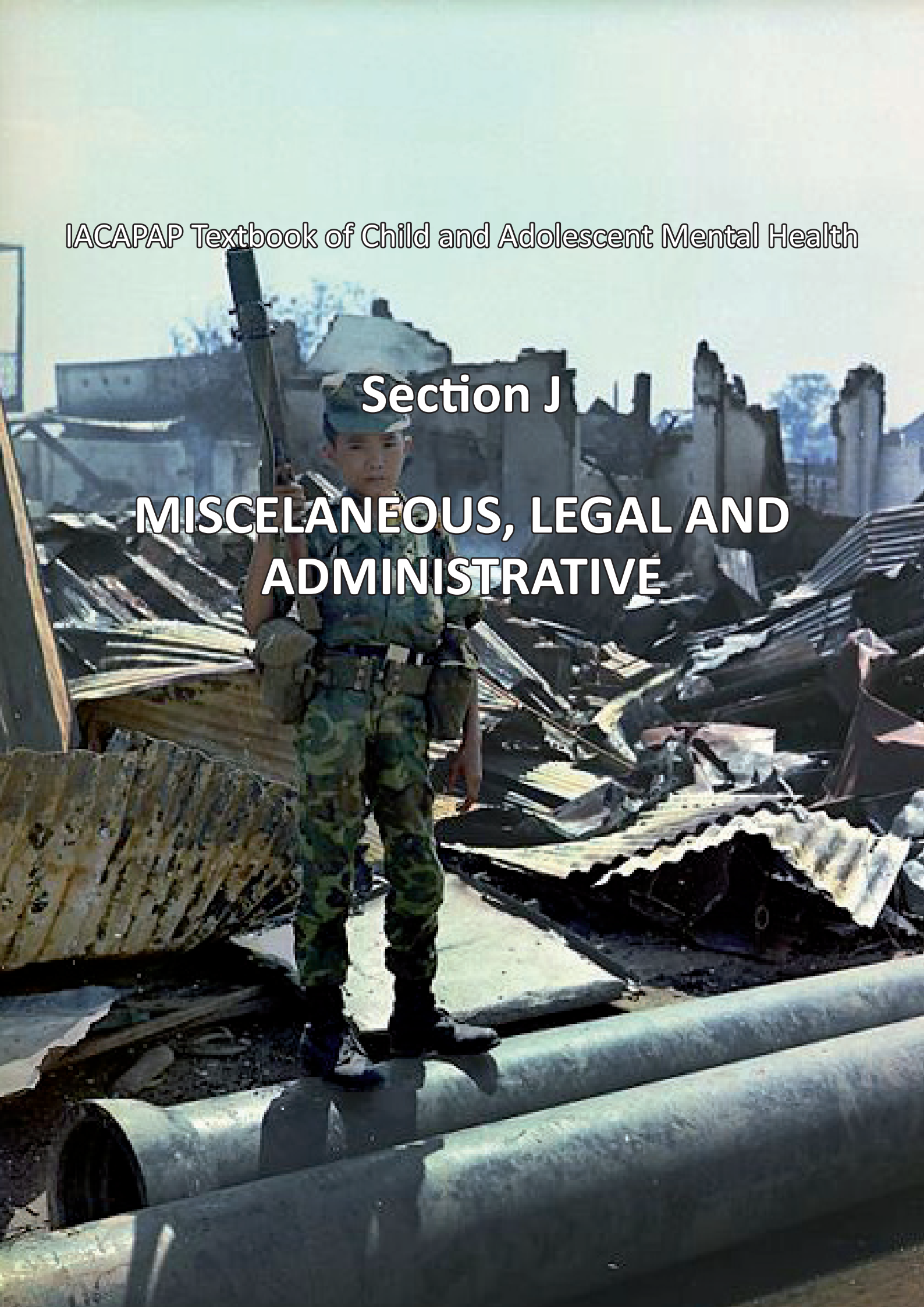
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Section J

MISCELANEOUS, LEGAL AND ADMINISTRATIVE

CHILD AND ADOLESCENT PSYCHIATRIC EMERGENCIES

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Suggested citation: Carandang C, Gray C, Marval-Ospino H, MacPhee S. Child and adolescent psychiatric emergencies. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

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Children and adolescents who present with acute mental health complaints require a concise yet systematic assessment to determine if the young person is suffering from an acute psychiatric disorder versus a mental health problem which presents with a crisis. However, before the urgent mental health assessment can proceed, acute medical complications emanating from the mental health problem need to be ruled out. Ultimately, urgent mental health assessment is needed to determine if a higher level of care is needed, such as referral to a psychiatric inpatient unit, crisis unit/step-up unit, or urgent mental health outpatient clinic.

EMERGENCY PSYCHIATRIC ASSESSMENT

An emergency psychiatric assessment of a young person in crisis can occur in an outpatient setting, but it is ideal to carry out this assessment within the confines of an emergency department (ED) of a hospital. The ED is most equipped to contain and triage the mental health crisis in a quick and safe manner. Also, the pediatric patient in crisis is often not cooperative and can present with out of control behaviors, which may require immediate containment to keep the patient and others safe.

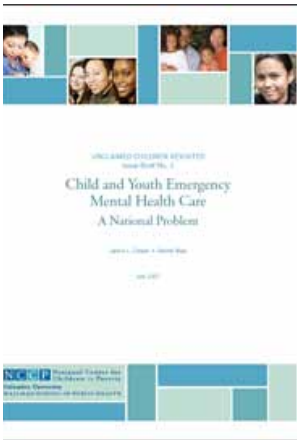
This chapter will focus on emergency psychiatric assessment in the ED. Increasing numbers of patients with mental health issues access pediatric emergency departments for care (Newton et al, 2009). This trend has been attributed, among others, to an increasing prevalence of mental illness in the context of limited availability of mental health resources and the growing use of substances, particularly alcohol and amphetamines, although this may vary between countries. The ED is a key entry point for crisis care, a link for community services and has been described as a *safety net* for patients and families in urgent need of psychiatric care. The most common mental health presentations to a pediatric ED in Western countries are substance abuse, overdoses, mood disorders, anxiety disorders and behavioral disorders (Newton et al, 2009). In addition, suicide behaviors and aggression will present to the ED and require quick, concise, yet systematic assessment and containment, for the safety of the patient and others. Assessment and management of child abuse in the ED are also discussed. This chapter gives clinicians an overview on how to conduct an emergency assessment, while at the same time diffusing the crisis and containing a potentially explosive and unsafe situation.

Goals of emergency assessment

The goals of emergency assessment are to:

1. Determine if the patient is at imminent risk of harm to self or others
2. Establish the presence of one or more psychiatric disorder(s)
3. Elicit the factors that may have caused or contributed to the initiation of these problems and to their persistence (genetic, developmental, familial, social, medical)
4. Evaluate patients' normal level of functioning and the extent this has been impaired by the illness
5. Identify areas of strength as well as potential supports within the family and the wider social environment,
6. Identify target problems for treatment and
7. Determine if inpatient psychiatric hospitalization is needed.

Assessment of a child or adolescent differs from that of an adult in several respects. Whereas most adults seek help on their own behalf, children rarely do so. In addition, depending on age and development, some children are simply unable to provide certain historical and clinically necessary information. Therefore, parents or caregivers are often the primary source of information (this does not mean that children should be excluded from the process, however). Greater emphasis is also placed on the importance of multiple informants, such as teachers, daycare providers or other persons who know the patient. Another crucial aspect of clinical assessment in this population is the developmental level of the child when considering appropriateness of behavior and functioning. To make accurate judgments about the child's behavior, a solid grasp of what is developmentally appropriate is required. Similar to assessing adults, however, clinical evaluation entails a detailed history, a mental status examination (and evidence of a recent physical examination), a formulation (integrating all available data regarding biological, psychological, and social aspects), diagnosis, and differential diagnosis. This integrated formulation needs to be conveyed to the patient and family, and used to negotiate a plan for treatment.



Click on the picture to access "Child and Youth Emergency Mental Health Care: A National Problem" by JL Cooper and R Masi. The National Center for Children in Poverty (2007)

General recommendations

Clinicians may differ in their views about how to structure clinical interviews, although most would agree that they vary according to the age and developmental level of the patient. Following a brief greeting and introduction, some prefer seeing adolescents on their own first and then together with the parents – or each group alone, if one expects too much conflict. For children, the opposite is often preferred: to see the child together with parents or parents alone first, and then interviewing the child alone. Children younger than 12 years of age are less likely to reliably answer questions about mood, onset and duration of symptoms, be able to compare themselves to their peers, and questions that require the child to use judgment (Granero Perez et al, 1998). Additionally, meeting with the parents first may provide direction for the clinician and areas of interest to be addressed when meeting with the child. During the interviews, particularly with younger children, it may be useful to talk about neutral topics first in order to set the child at ease. This approach also permits evaluation of the child's speech, discourse and thought patterns. Questions about behavior or emotions need to be simple (e.g., dealing with one concrete issue at a time: "Have you been feeling so bad that you have been crying often in the last few days?"). It is more useful to learn about how the child feels, thinks or behaves rather than probing for explanations as to why.

Adolescents value their privacy and independence and are more likely to share information if they know it will be kept confidential. Confidentiality should be discussed from the outset. Clinicians should outline the conditions under which they will share information with the parents – such as safety issues (suicidal and homicidal thoughts). When abuse is suspected, the role of clinicians as mandated reporters of abuse (in most countries) should also be explained. Because child protection is paramount, disclosures of abuse to the clinician from the child or others need to be shared with the local child protection agency. Sensitive issues such as substance abuse, sexual activity, and pregnancy would not necessarily warrant breaking confidentiality unless there are special circumstances, such as

a youth repeatedly operating a motor vehicle when intoxicated. It is generally appropriate, however, to encourage the youth to share this information directly with the parents.

Diagnosis

It is important to determine if the patient has a psychiatric diagnosis versus a mental health problem. Presenting with an acute psychiatric disorder usually has different treatment needs than someone presenting with adjustment problems after a break-up with their girlfriend or boyfriend. Acute psychiatric disorders and acute mental health problems are discussed further below.

Treatment history

An inventory and assessment of prior treatments, including pharmacotherapy and psychotherapy, is essential. A detailed review of prior treatments, their duration, drug dosages, adverse effects, adherence to treatment, hypersensitivities, and information as to whether the patient showed a positive or negative response is warranted.



Click on the picture to watch a video clip explaining what parents, children and mental health providers should expect when a child is transported to the emergency room for a mental health evaluation (8:45)

Co-occuring disorders

In emergency settings, the most prominent and acute disorder should be addressed first (for example, an adolescent with mania and ADHD should have the mania addressed in the ED setting). Co-occuring disorders that present with less acuity and severity should be addressed at another time in an outpatient setting.

Family assessment

For an urgent assessment, the focus should be on high risk family mental health problems, like suicide, substance abuse, mood disorders, and psychosis. A family history of psychiatric illness may suggest that the identified patient is at greater risk for developing the same illness.

ACUTE PSYCHIATRIC DISORDERS PRESENTING TO THE ED

It is important to assess if the patient presenting to the ED in crisis has an underlying psychiatric disorder. Listed below are common psychiatric disorders presenting acutely to the ED and brief clinical descriptions and mnemonics (Table J.1.1) (please refer to the corresponding chapters in the book for more details on these disorders).

Psychosis

Psychosis is a disorder of thinking (delusions) and perception (hallucinations) in which there is a gross impairment in reality testing. Youth with psychosis might experience a decline in their social and cognitive functioning prior to presenting with psychotic symptoms. Often, this decline manifests itself broadly via social withdrawal, worsening school performance, bizarre or eccentric thoughts and behaviors, self-neglect, suspiciousness, anxiety, irritability, hostility, or aggression. Patients might not come for medical care and they are often brought by relatives. The youth in the emergency department might be fearful, apprehensive, irritable, or agitated. The mnemonic **THREAD** (Table J.1.1) can help clinicians remember the criteria for psychosis.

Acute mania

The hallmark of a manic episode is the presence of irritable, elevated or expansible mood state, which represents a significant change from the youth's usual mood state and persists for at least a week. The **FIND** (**F**requency, **I**ntensity, **N**umber and **D**uration) strategy (Kowatch et al, 2005) is recommended to assess symptoms in a youth with mania. The change in mood state is usually accompanied by a change in the youth's perception of themselves manifested by grandiosity. During a manic episode, adolescents show a decreased need for sleep, pressured speech, experience racing thoughts, have increased interest in multiple activities, increased sexual behaviors due to poor impulse control and poor judgment, and may show a provocative change in clothing style. During the initial days of a manic episode, there might be an increase in productivity; however, this is usually self-limited due to growing distractibility. More than half of the adolescents with mania might develop psychotic symptoms, which are usually mood congruent (Yatham et al, 2009). The mnemonic for mania is **DIGFAST** (Table J.1.1), developed by William Falk (Ghaemi, 2003, page 13).

Depression

Youth with depression often present as irritable rather than depressed or sad. Up to 60% also have suicidal ideation and 30% attempt suicide (Birmaher et al, 2007). Depressed youth experience irritability or depressed mood, which persists for more than two weeks and is associated with deterioration in functioning. The youth may also exhibit anhedonia, social withdrawal, declining school performance, disrupted sleep patterns, changes in appetite or weight, and fatigue. A negative self-appraisal, low self-esteem and cognitive distortions in thinking lead adolescents to have thoughts of worthlessness, hopelessness, guilt, death and suicide. Children might present with somatic symptoms or behavioral problems, as they may not yet have the cognitive ability to verbalize thoughts of guilt and hopelessness or identify their own mood state (Baren et al, 2008). Psychotic or melancholic symptoms are less likely to present in children with depression (Rao et al, 2009). The mnemonic for depression is **SIGECAPS (**Table J.1.1), developed by Carrey Gross (Ghaemi, 2003, p11).

Anxiety disorders

There are multiple subtypes of anxiety disorders in youth, but we will focus on acute stress disorder, posttraumatic stress disorder, panic disorder and social phobia, as these disorders may require immediate attention in the ED.

Acute stress disorder

The presentation of youth with acute stress disorder is similar to that of posttraumatic stress disorder with respect to symptoms. However, as acute stress disorder is limited to one month following the traumatic event, the young person's subjective report of symptoms is more focused on the trauma than the re-experiencing of it. When young people discuss the traumatic event, they often describe having experienced it in a dissociative manner. For example, they may describe watching the event happening to them, lacking an emotional response to the event, or having incomplete recollection of the event.

Table J.1.1. Mnemonics for acute psychiatric disorders in children and adolescents.

THREAD (psychosis)
- **T**hinking may become disordered
- **H**allucinations may occur
- **R**educed contact with reality
- **E**motional control affected (incongruent affect, affective fattening)
- **A**rousal may lead to worsening of symptoms
- **D**elusions might occur.

DIG FAST (mania)
- **D**istractibility
- **I**nsomnia (decreased need for sleep)
- **G**randiosity
- **F**light of ideas
- **A**ctivity increase
- **S**peech pressured
- **T**houghlessness- reckless behaviours

SIGECAPS (depression)
- **S**uicidal thoughts
- **I**nterests decreased
- **G**uilt
- **E**nergy decreased
- **C**oncentration decreased
- **A**ppetite disturbance (increased or decreased)
- **P**sychomotor changes (agitation or retardation)
- **S**leep disturbance (increased or decreased)

TRAUMA (PTSD)
- **T**raumatic event
- **R**e-experience
- **A**voidance
- **U**nable to function
- **M**onth or more of symptoms
- **A**rousal increased

WILD (substance abuse)
- **W**ork, school and home role obligations failures
- **I**nterpersonal or social consequences
- **L**egal problems
- **D**angerous use

ADDICTeD (substance dependence)
- **A**ctivities are given up or reduced
- **D**ependence - physical - Tolerance
- **D**ependence - physical - Withdrawal
- **I**ntrapersonal (internal) consequences: physical or psychological
- **C**an’t cut down use or control use
- **T**ime-consuming
- **D**uration of use is greater than intended.

Posttraumatic stress disorder (PTSD)

PTSD requires the presence of a traumatic event in which the individual experiences extreme fear, hopelessness or horror. In younger children this may be expressed through agitated or disorganized behavior. The traumatic experience leads to re-experiencing the symptoms associated with the trauma, avoidance of stimuli associated with the trauma and hyper arousal, which causes significant distress or functional impairment. Most individuals exposed to severe trauma develop some of these symptoms but usually they do not last more than a month. When symptoms last longer than a month, a diagnosis of PTSD is warranted. Because the traumatic event is linked to the onset of the symptoms, children and adolescents may display symptoms or behaviors not present before. Parents not always know about their child's exposure to trauma – or they may be the perpetrators. A difficulty in establishing this diagnosis in the young is that the very feature of avoidance makes it difficult for the youth to report or recall the traumatic experience. Young children may reenact elements of the traumatic experience through play, experience frightening dreams without trauma-related content, become aggressive or develop separation anxiety or fears, which are not necessarily related to the traumatic experience. Older children and adolescents may present with general anxiety symptoms, substance use and self-harming behavior. The mnemonic for PTSD (Table J.1.1) is **TRAUMA** (Khouzam, 2001).

Panic disorder

A panic attack is the sudden emergence of intense fear and associated symptoms peaking within ten minutes: palpitations, shortness of breath, paresthesias, dizziness, sweatiness, shaking and the perception of choking. Children and adolescents can experience panic attacks in response to anxiety-provoking stimuli within any anxiety disorder, other mental disorders and some medical conditions. Youth could be considered to have a panic disorder when panic attacks are repetitive and happen with or without stimuli. They also worry about having future panic attacks and change their behavior in an attempt to avoid them.

Social phobia:

Children and adolescents with social phobia experience marked distress and fear of social situations, which results in a pattern of avoidance and anticipatory anxiety of these situations. Younger children might not be able to verbalize anxiety-provoking situations; thus, their anxiety may be expressed in tantrums or crying spells. Older children and adolescents might have somatic symptoms such as nausea, abdominal pain or headaches related to social situations. As a result, they may not attend or participate in activities that are unfamiliar to them or that demand their active participation. This can present on a spectrum from avoiding to raise their hand in class, to refusing to attend school or gatherings altogether.

Disruptive behavior disorders

Behavioral disorders can present to the ED with aggression and severe disruptive behavior. They include attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder and conduct disorder.

Attention deficit hyperactivity disorder (ADHD)

The core symptoms of ADHD are inattentiveness, hyperactivity and impulsivity. Children and adolescents with ADHD are symptomatic before the age of 7 years and their symptoms lead to functional impairment in at least two settings. Symptoms occur frequently and can be exacerbated when the youth is in a group setting or engaging in activities that require a concentration or lack novelty or interest. Symptoms of hyperactivity and impulsivity are more noticeable as the youth becomes disruptive and noisy or has difficulties remaining still or waiting; as a result of their hyperactivity they get injured often. Children with ADHD who present to the ED are usually brought due to aggression and disruptive behavior.

Oppositional defiant disorder:

The main feature is a pattern of developmentally inappropriate defiant, disobedient, negativistic and hostile behavior towards authority figures. This pattern needs to be present for at least six months and lead to academic, social or occupational impairment. Children and adolescents with this disorder are often argumentative with their parents or refuse to follow their rules, making the disorder more evident at home. These young people are likely to lose their temper and can become aggressive, usually verbally and without the serious aggression seen in conduct disorder.

Conduct disorder

Children and adolescents with conduct disorder have an inability to appreciate the importance of others' welfare and show little guilt or remorse about harming others. They show a repetitive and persistent pattern of behavior where the basic rights of others or major societal norms are violated. They often have a longstanding history of school suspensions, fighting, aggression and destructive behavior. Lies are often used to get out of a sticky situations and stealing is frequent. The four main clusters of symptoms are: aggression or threats of harm to people or animals; deliberate property damage; repeated violation of household or school rules or breaking the law; and persistent lying to avoid consequences (American Psychiatric Association, 1994). This pattern causes significant impairment socially, academically or occupationally.

Substance use disorders

Substance-using adolescents often present to the ED with intoxication or withdrawal. However, it is important to assess the pattern of substance use to establish if the youth has either substance abuse or dependence. Both are associated with psychosocial impairment or academic failure.

Substance abuse

The main feature of substance abuse is the continuous use of a substance despite the consequences, including actual or potential harm. The mnemonic for substance abuse (Table J.1.1) is **WILD** (Bogenschutz et al, 2001).

Substance dependence

After prolonged exposure to an addictive substance, the pattern of use becomes habitual and compulsive. The young person becomes unable to control their substance use, either the amount or frequency. Function is impaired as the youth increasingly prefers to engage in substance use at the expense of other activities

(friends, family, hobbies, school or work). The maladaptive pattern of use continues despite enduring physical and psychological problems caused or exacerbated by the substance. Along with this pattern of use, the youth develops tolerance, needing higher doses to achieve the same effect or experiencing withdrawal when use is reduced or stopped. The mnemonic for substance dependence (Table J.1.1) is **ADDICTeD** (Bogenschutz et al, 2001).

ACUTE MENTAL HEALTH PROBLEMS PRESENTING TO THE ED

Acute mental health problems can present to the ED with or without an acute psychiatric disorder. In addition to assessing for the presence of a psychiatric disorder, it is also important to assess for acute mental health problems, such as suicidal behavior, aggression, parent-child conflict, adjustment issues, abuse, and homelessness.

Suicidal behavior

A suicide attempt is the most common presentation of young people to the ED. Once patients have been medically stabilized, the ED clinician needs to determine the patients' suicide risk. Suicide is a major public health concern around the world. A recent study using data from 90 countries found a suicide rate of 7.4/100,000 for youth 15 to 19 years of age with a higher rate for males (10.5) compared to females (4.1). This same study found that suicide accounted for 9.1% of all deaths in this age group and represented the 3rd leading cause of death among females and 4th for males (Wasserman et al., 2005). In the US, suicide is the third leading cause of death among 15 to 24 year olds accounting for 12.2% of all deaths in this age group (Centers for Disease Control and Prevention, 2010).

Data from the US showed that in a one-year period, 14% of students in grades 9-12 had suicidal ideation. In addition, this survey also showed that in a one-year period, 11% of students had made a suicide plan, 6% had made at least one suicide attempt and 2% had made a suicide attempt requiring medical attention (Eaton et al, 2009) (see also Chapter E.4).

Assessing risk of suicide

Two important issues are degree of confidence (in the assessment) and changeability (of risk). It is important to remember that risk factors do not necessarily cause suicide, but rather are characteristics associated with suicidal behavior. As such, these factors may provide guidance in assessing a patient's vulnerability to suicide.

Engagement

Engagement is crucial to detection, assessment, and management of suicide risk. The level of engagement should be assessed, as it influences the confidence of the risk assessment. For example, lack of cooperation of the patient and inability of the clinician to engage may lead to poor detection and assessment, leading to low confidence of the risk assessment, thereby increasing the risk.

The first step is establishing a therapeutic alliance. There are many ways to do this but, most importantly in a busy ED, the clinician needs to sit down, make eye contact and not appear distracted or rushed (e.g., in an office rather

than interviewing the patient standing up in a corridor). Provide a calm and safe atmosphere. Be empathic. Youth will be far more likely to open up about their suicidal thinking and planning if they feel the clinician is interested in them and trying to understand. Also, it is important for clinicians to be aware of their own feelings towards patients who are suicidal – countertransference. Be open and accepting of youths' beliefs and feelings. In most cultures suicide is viewed negatively, however when assessing a suicidal child or adolescent, it is important to be non-judgemental, as this fosters the therapeutic alliance through open and honest communication.

The limits of confidentiality should be clearly explained at the beginning of the assessment. Confidentiality must be maintained unless the young person is at risk of harming themselves (suicide) or others (homicide) or if someone is harming them (child maltreatment). These situations allow breaking medical confidentiality.

Detection

Detection is about assessing personal risk factors, intent, lethality, mental status and collateral information. It is important to ask directly about suicidal thinking and planning; this will not increase suicide risk (Gould et al, 2005). As mentioned above, engagement is crucial in detection: introduce the topic gently and gradually through general questions, move gradually to more direct questioning, for example:

- Have you ever had the feeling that you didn't want to get up to greet the day?
- Have you ever had thoughts that you can't go on?
- Do you ever think that if you went to sleep and didn't wake up that that would be ok?
- Have you ever thought about ending your life?
- Have you ever thought of a plan to end your life?
- If yes – tell me about your plan
- How close have you come to acting on your plan?

Personal risk factors. Psychiatric illness is a risk factor for suicide. Psychological autopsy research has shown that among adolescents who completed suicide, approximately 90% had a diagnosable psychiatric condition, most commonly depression, but included bipolar, substance use and conduct disorders (Brent et al, 1993; Shaffer & Pfeffer, 2001). Psychotic youth may be at elevated risk for suicide, especially if they are experiencing command hallucinations telling them to kill themselves. Depression, particularly with high levels of hopelessness, carries significant risk of suicide. Thus, another important area to assess is the degree of hopelessness. Asking "Do you have hope that things will get better?" can be helpful in assessing this important factor. Patients who do not have any hope that things will improve are at higher risk for suicide. Asking about plans for the immediate future (i.e., coming weekend or that evening) as well as for the more distant future (i.e., upon graduation from high school) can help determine if patients see themselves in the future; patients with a lack of future orientation are at higher risk for suicide.

Having made suicide plans also carries a risk. In contrast, passive suicidal thoughts have lower risk. Having made a recent suicide attempt is a risk factor; youth who make a suicide attempt are at increased risk of subsequent attempts. Among suicide attempters, the period of greatest risk for completed suicide appears to be in the first year following the initial attempt (Gould et al, 2003). Recent major life events, especially losses (break up of a relationship, loss of a job), humiliations (resulting in shame, guilt, or anger), or disciplinary crises, are another risk factor. The timing of the suicide attempt is often associated with a stressful life event. Other risk factors for suicide include recent discharge (within last month) from a psychiatric inpatient facility and alcohol intoxication.

Youth with a family history of suicide are at increased risk of both completed suicide and suicide attempts. It is unclear whether this increased risk is due to genetic or environmental influences, or both. In terms of the genetic influences, this could be related to the transmission of a specific tendency for suicide or for psychiatric illness as these two factors often occur together (Gould et al, 2003).

Intent refers to whether the self-harming young persons actually seek to kill themselves or not (as in the case of non-suicidal self-harm) and, if so, how determined they are. Using scales of 1 to 10 can be helpful with youth who often struggle to express their thoughts and emotions. For example, "on a scale of 1 to 10, with 1 being no intention to follow through and 10 being definite intention to end your life, what is the likelihood that you would follow through with your suicidal plan?" Most people find it distressing to have suicidal thoughts and are more than willing to discuss these thoughts if they are asked about them.

Lethality

When assessing suicidal risk following a suicide attempt it is important to take a careful history of the events leading up to and following the attempt. Questions to ask regarding lethality include:

- Was the attempt carefully planned or impulsive?
- Was *rescue* anticipated or likely?
- Were there preparations and measures taken to ensure death was likely?
- Did they believe they would die?
- Were personal business finalized? (e.g., made arrangements for pets, debts, goodbyes and giving away possessions, letter)
- Was lethal means availabile?

Clinicians need to assess the lethality of the attempt – including both objective and subjective realities. Medical professionals know which medications are potentially lethal (e.g., acetaminophen) whereas patients may not; for example a patient may take a nonlethal overdose (e.g., penicillin) believing it was potentially lethal because it is a prescription medication. In gathering information about the circumstances surrounding a suicide attempt, it is important to also assess for the availability of help and potential to abort the attempt as this will provide more clues as to the degree of intent.

Start with open-ended questions such as "what happened to bring you here?" or "Can you describe what happened?" This allows patients to tell their story in



Intoxicated youth are increasingly presenting to emergency services (photo: Daniel Neves)

their own words. Then follow up with more direct questions to determine the patient's thoughts and emotions before, during and after the event. For example (in case of an overdose):

- How were you feeling the day before you took the pills?
- How did you get the pills?
- What were you thinking and feeling when you took the pills?
- Where were you when you decided to take the pills?
- Who was there? Were you alone?
- How did you take the pills? One at a time? All at once?
- What happened after you took the pills?
- How did you feel after you took the pills?
- How do you feel now that you didn't kill yourself?
- What do you think you have learned from all of this?
- How might you react next time?

In the US, where guns are prevalent in the population, access to firearms has been shown to increase the risk for suicide among youth. One study found that the risk of suicide completion was doubled in homes where there were firearms (Brent et al, 1991).

Mental state assessment

An *at risk* mental state may include severe depression, command hallucinations or delusions about dying, preoccupation with hopelessness, despair, feelings of worthlessness, severe anger, and hostility.

Collateral information

Collateral information is important to validate patients' accounts, to determine previous psychiatric diagnoses and treatments, and identify previous suicide behaviors. Information can be obtained from medical records, nursing reports, police, other health providers, and family physicians. Information from family and friends can help to establish whether the behavior is out of character, for how long it has been evident and if supports are available.

Changeability of risk

Risk status is dynamic and requires re-assessment. It is important to identify highly changeable risk status, as it will guide the clinician as to the safe interval between assessments. Alcohol intoxication in suicidal individuals is an indication of changeable risk and low confidence in the risk assessment because intoxicated individuals are unreliable in the information they provide and alcohol reduces self-control. A highly changeable risk implies the need for careful re-assessment and more vigilant management with respect to safety (e.g., re-assessment within 24 hours).

Confidence of risk assessment

The confidence (validity) of the risk assessment is influenced by many factors. The following indicate low assessment confidence:

- *Factors in the patient*: impulsivity, drug or alcohol abuse, inability to engage, lack of cooperation
- Factors in the social *environment*: impending court case, divorce with child custody dispute; and
- *Factors in the clinician's assessmen*t: incomplete assessment, inability to obtain collateral information.

Similar to high changeability of risk, a low assessment confidence implies a need for careful re-assessment (e.g., within 24 hours). More vigilant management is needed with respect to safety in the light of gaps in information or rapport.

Suicide risk levels and their management

Once the risk assessment has been completed, the next step is to determine the appropriate management. Youth deemed to be at high suicide risk will require admission to hospital to keep them safe. Uncooperative youth who do not wish to be admitted but are at imminent suicidal risk may need to be admitted involuntarily to ensure their safety (according to local laws and procedures, which may vary from country to country). Those deemed to be at low to medium risk require a well-organized discharge plan developed in consultation with the patient and family and will vary from person to person. This should include detailed, written information about follow up, important contact information, and medications (if any). Discussion should take place with parents/caregivers and the youth about creating a safe environment at home by removing access to means (firearms, medications). As a final component of the discharge plan, the youth and family

should always be reminded that they can return to the ED at anytime should there be a need.

High risk usually involves several of the following components:

- At-risk mental state (e.g., severe depression; command hallucinations or delusions about dying; preoccupation with hopelessness, despair, feelings of worthlessness; severe anger, hostility
- Suicide attempt or suicidal thoughts (e.g., continual/specific thoughts), evidence of clear intention, a previous attempt with high lethality
- Substance use (e.g., currently intoxicated with alcohol)
- Corroborative history (e.g., unable to access information or conflicting reports
- Strengths and supports (e.g., youth refuses help; lack of supportive relationships/hostile relationships).

High risk patients need a safe and secure environment. Consider involuntary hospitalization if no other reasonable options are available and *if* (1) suicidal thoughts or intention are persistent and intense; *or* (2) attempt is serious in nature; *or* (3) there is evidence of a severe mental disorder. If a patient who is considered at high risk leaves the facility, attempts to locate that person should be made including informing the police. Other options for the high risk patient include: voluntary hospitalization; observation at home (if family able to provide round-the-clock supervision and risk is not too high); and ongoing management and close monitoring. Contingency plans should be in place for rapid re-assessment if distress or symptoms escalate.



Click on the picture to view a clip explaining in general terms how an emergency room works (4:09)

If the high risk patient is not hospitalized, then a re-assessment should occur within 24 hours. For medium risk, the reassessment should occur within one week. For low risk, the reassessment should occur within one month. In cases of no foreseeable risk, referral to outpatient mental health or the family physician is warranted to address any mental health problems.

A caveat to this is that high changeability will influence the risk assessment, and it is prudent for the clinician to develop a safety plan and assure re-assessment within 24 hours. A low assessment confidence will also influence the risk assessment, so it is also prudent to keep the patient safe and reassess as appropriate.

Contracting for safety

Over the years, many clinicians have used the strategy of "contracting for safety" or "no-suicide contracts" when discharging patients with suicidal ideation from the ED. There is no evidence to support the use of such contracts and may give false reassurance (Garvey et al, 2009). Creating a safety plan for a patient is much more realistic; it should be developed in collaboration with the patient and family. A safety plan basically lists what a patient agrees to do should their suicidal ideation return or worsen. Key components of a safety plan include getting rid of means for completing suicide (such as removing firearms and medications) and listing:

- Triggers that lead to suicidal feelings
- Coping strategies the patient can use when feeling suicidal (such as exercise, listening to music, taking a bath, reading)

A 14 year old female was brought to the ED for crisis assessment. She appeared shy and quiet. She presented with superficial cuttings on her arms (about 50 cuts) and had been cutting herself for one year. She had told her parents about the cutting one month earlier. She typically cut herself when her mood was low. She denied wanting to die. However, she persisted with cutting herself and cuts were possibly becoming deeper. She reported intrusive thoughts of suicide with a recent increase in frequency and intensity and was being bullied at school. Despite these symptoms, her functioning was not impaired; she did well in school, was insightful for her age and stated she cut herself to relieve tension and to ward off feelings of loneliness. She described "dips" in her mood that seemed to be triggered by stressful situations, and did not sleep well. Family history was significant for depression on the maternal side. She denied substance or alcohol use and showed no signs of intoxication. She had a good relationship with her parents, who described her as a "good kid."

She was assessed as suffering from deliberate self-harm and possibly had a diagnosis of major depression. Suicide risk was assessed as low and discharged home with a referral to outpatient mental health services. She returned to the ED six days later following an outpatient appointment where she disclosed feeling suicidal, exhausted and wanting to "give up." She was vague about the suicidal ideation, but denied having a plan. She refused to talk to the crisis worker. Eventually she revealed that a good friend had died of suicide the day before. "My friend was always smiling and no one knew because she never talked to anyone –that is how I am." The patient was subsequently admitted voluntarily to the adolescent inpatient psychiatric unit due to high risk for suicide.

- Friends and specific family member the patient can call on for support if they feel suicidal
- Contact numbers for crisis lines, mental health professionals or peer support groups
- Circumstances for returning to the ED.

Aggression and out-of-control behavior

Aggression in children and youth includes a wide range of behaviors from lack of cooperation, loss of control, defiance, and non-compliance to outright hostility and violence. Young people displaying these behaviors are often brought to ED by relatives, the police or social services. Treating and containing the aggressive youth is one of the most challenging situations in the ED. Not only is skilled and empathetic staff needed, but also adequate facilities, security personnel and good liaison with the law enforcement, justice and child welfare systems. All these requirements should be set-up beforehand or else situations can get out of control and become dangerous to the patient, staff and others receiving care in the ED.

Most common psychiatric diagnoses associated with out-of-control behavior include disruptive behavior disorders (attention deficit hyperactivity disorder, oppositional defiant and conduct disorder), mood disorders (irritability with depression and with mania) and substance abuse (intoxication). Other diagnoses associated with aggression are developmental disabilities (mental retardation, autism), psychosis and general medical conditions such as head injuries, particularly if they occur in the context of a dysfunctional or over-stretched family.

In the ED, preventing the escalation in aggressive behavior can involve such measures as having a security team present, using metal detectors to detect weapons, using seclusion rooms as well as educating staff regarding the early

detection of potentially violent situations. Predicting actual violence or aggression is very difficult for even the most experienced clinicians.

The design of the ED can play an important role in the management of violent or aggressive patients. Having a mental health observation room with specially designed furniture that can not be thrown, a camera with video links to a nursing or security station to monitor patients, an exit door that swing outwards to allow staff to escape quickly if necessary, and duress alarms can all play a role in maintaining safety for all.

The management of acute violence or loss of control should initially involve verbal de-escalation techniques. Strategies to deal with potentially violent situations include:

- Give the individual as much space as possible
- Do not block exits and leave door to room open
- Situate yourself between the individual and the door
- Speak to the individual in an honest straightforward manner
- Listen, be empathic,
- Speak slowly and calmly
- Offer choices as much as possible
- Offer food or drink
- Be non-confrontational
- Avoid direct eye contact or sudden movements
- Stay at least an arm's length away
- Set limits ("I am here to help you with your difficulties, but I cannot allow you to continue with your threatening behaviors")
- Try as much as possible to respond to the individual's requests in the positive ("Sure we can get you something to eat, but first we need to…")
- Refrain from criticizing or arguing with the person
- Don't interrupt
- Avoid responding in a defensive manner
- Don't take the person's anger personally.

If the youth does not respond to verbal techniques then chemical restraint (also called rapid tranquilization) may be necessary. Chemical or physical restraint should only be used if the child or adolescent is actively trying to harm themselves or others. Parental consent should be obtained if possible. As a first step, medications should always be offered orally. Intramuscular injection should be used only as a last resort.

Three classes of medications are used for chemical restraint – benzodiazepines, typical antipsychotics and atypical antipsychotics. In children and youth, the tendency is to avoid high potency typical antipsychotics such as haloperidol because of the risk of acute dystonia, especially in young males. While benzodiazepines such as lorazepam can be used, there is potential for paradoxical reactions in children and youth producing increased agitation. Although there is no consensus or systematic evidence, most clinicians agree that the best choice of medication for

After an extended trip to Lebanon, a 15 year old Canadian female of Lebanese background had trouble readjusting upon her return home (her current school has few students from non-Canadian background and she feels "out of place"). Parents noticed a significant change in her behavior, and parent-child conflict ensued. The youth began to engage in high risk behaviors – staying out all night, not attending school, became defiant and disrespectful and, against parents' wishes, began visiting another community where there is a large representation of peers of Lebanese origin. This resulted in multiple visits to the ED with her overwhelmed parents insisting she was "mentally ill." On one occasion the youth had assaulted her mother, so much so that charges were laid and she was asked to leave home. The youth was unable to follow rules in the neighbor's home, where she had been provisionally placed.Aggressive outbursts led to more visits to the ED involving grueling meetings with the family and attempts to improve the situation.

While waiting for an outpatient mental health appointment, the family doctor prescribed risperidone for her impulsive aggression. Subsequently, following a fight with her mother, she got onto a bus and ingested about 10 tablets of risperidone. She then developed palpitations, became scared and called her mother who took her back to the ED, where she underwent monitoring and overnight observation. She told the crisis worker the next morning that she had not intended to kill herself. Hospitalization was offered but refused. However, she became more cooperative and agreed to initiate safety planning, which included temporary placement in an extended family member's home with constant observation. She was referred for outpatient mental health follow-up.

chemical restraint in children and youth would be the atypical antipsychotics such as olanzapine or ziprasidone.

Physical and chemical restraints should only be used as a last resort. Teams trained in the use of physical restraint can be mobilized if there is a risk of imminent harm to the patient or staff. Physical restraint should be used for the minimum amount of time necessary to calm the patient. Patients in physical restraint should be monitored frequently not only to ensure that they don't injure themselves while in restraints but also to determine the earliest point at which the restraints can be removed.

Parent-child conflict

Parent-child conflict can take many forms and occur for many reasons. Without the resources or abilities to solve these conflicts, parents may resort to taking their child to the ED when it gets out of control. Presentations include difficulty implementing discipline, repeated arguments, disobedience, frustration, anger and in extreme cases, violence.

Conflicts between children and parents can emerge at any age, but it is during the adolescent years when conflict tends to escalate. Adolescents' drive for independence and autonomy can be in direct opposition to parental wishes for continuing control over their child's actions and behavior. Emergencies usually occur following legal or disciplinary crises that result in the child losing control and becoming aggressive towards the self, others, or property in the context of chronic problems that may have lasted years.

The clinician needs to ascertain what the current problem is by interviewing child and parent, either separately or together, keeping in mind that there is a considerable amount of hostility and emotion on all sides, which needs to be contained. It is crucial to understand the problem at hand so that potential temporary solutions can be developed in a collaborative manner. This will require the parent and child together in the same room. It can be helpful to stress to

parents that the art of negotiation and compromise is learned in the home and that parents are well positioned to teach this to their children as developmentally appropriate. Determining what the actual underlying issue is may be difficult and the current argument is often a symptom of larger chronic problems.

The goal in the ED is to ascertain whether a serious physical or mental disorder is present and to defuse the situation so that the child can return home or to a safe environment. Discharge planning should include a referral to available community resources for family therapy and parenting skills training with the goal of developing more effective communication and problem solving skills. Parent-child conflict affects the whole family and ideally the resolution of the conflict should involve all family members.

Adjustment problems

Adjustment disorders are a common reason for children and youth to present to the ED. Adjustment disorders, by definition, are reactions to a specific stressor that are beyond the normal expected reaction or that cause significant impairment in functioning. Death of a loved one, move to a new city or a new school, bullying, break up of a romantic relationship, and poor academic performance are just some examples of events that could trigger an adjustment disorder in a vulnerable child or youth. Assessment should include a discussion about recent stressors precipitating the presentation to the ED. Despite not meeting criteria for a major depressive episode, patients with an adjustment disorder can be at significant risk for suicide, thus it is important to always screen for suicide risk. If there is no indication to admit the patient (e.g., low suicidal risk) then discharge planning should include a referral for outpatient treatment.

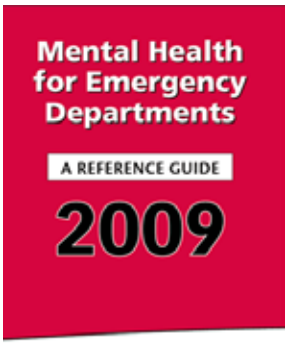
Abuse

Child maltreatment can take many forms and includes physical, verbal and sexual abuse as well as neglect (see Chapter B.3). By maintaining a high index of suspicion, the ED physician is well positioned to detect child maltreatment. Consultation with a child protection team, if available, can be invaluable in terms of making decisions regarding disposition for the abused child. Most countries have legal requirements in terms of reporting suspected abuse of children to local authorities and this should be done according to local legislation.

The patient is a 16-year-old, grade 9 girl who lives with her mother. Over the past two months, she had exhibited depressive symptoms characterized by tearfulness and disrupted sleep. The patient and her mother had been evicted from their apartment four months earlier and had to spend several weeks at a homeless shelter. They have since found an apartment to rent, but the patient is now worried that her mother will kick her out of the house because she recently turned 16, and her mother had been making comments that the patient should find a job because she has to take care of herself eventually. At times they did not have money to buy food. The patient and her mother fought constantly; she dropped out of school because her home life was too stressful to focus on schoolwork. The mother brought the patient to the ED because she was concerned about her daughter being depressed and dropping out of school, spending most of her day isolated in her room. The patient denied suicidal ideations. The patient was diagnosed with adjustment disorder with depressed mood and referred for outpatient mental health follow-up.

Homeless youth

Homeless youth regularly present to the ED with mental health issues and they are often brought by the police because of dangerous or risky behavior. It is important to be non-judgmental, open and empathic when conducting an assessment with any youth, but particularly with homeless youth who will already feel judged in a negative way. Their looks may be off-putting in that they may be dirty, disheveled, tattooed and have multiple piercings. In the US and other high income nations, homeless youth have often been in foster care or group homes and experienced major family dysfunction. They have often left home on their own accord because of conflict or abuse, are unlikely to be attending school and are often engaged in drug and alcohol use or delinquent activities. They have tenuous support systems consisting mostly of other homeless youths with similar backgrounds and behaviors. In contrast, homeless youth in other parts of the world particularly in low-income countries, may be homeless because of poverty, famine, war or political instability. Often in these situations, the homeless youth is with his or her family and not alone (see Chapter J.4).



Click on the picture to access a guide on mental health in the emergency department (not specifically for youth) produced by NSW Health, Sydney, Australia.

A recent German study looking at the prevalence of psychiatric conditions among homeless adolescents found that 80% of participants had a diagnosable psychiatric disorder (Aichorn et al, 2008). The most common diagnosis was substance abuse and dependence (65%). Other diagnoses included mood disorders, eating disorders and anxiety disorders. Over half had a history of self-harm and 25% reported at least one suicide attempt. This study also found that the longer a youth was homeless, the more likely it was for the youth to have a psychiatric disorder. Homeless youth engage in more risky behaviors than youth in the general population (Milburn et al, 2006). These high-risk behaviors include shoplifting, prostitution, substance use, multiple sexual partners, and gang involvement.

Establishing rapport will be of utmost importance in order to obtain accurate and honest information from the youth; sit down, make eye contact, be patient and be empathic. The evaluation must include a risk assessment for suicide and homicide as well as an evaluation of physical health status. It is also necessary to explore the patient's living situation and to provide information about housing, financial aid, educational and vocational supports. Referral for social services support and outpatient mental health follow-up may also be indicated; compliance with follow up is usually low.

MEDICAL ASSESSMENT OF THE MENTAL HEALTH PATIENT IN THE ED

Before an urgent mental health assessment can proceed, the presence of acute medical illnesses, whether emanating from mental health problems or not, need to be assessed. Young people with mental disorders can also suffer from unrelated acute physical illnesses. Medical complications of psychiatric illness or their treatment can have a high morbidity and mortality if not detected and treated promptly.

Overdose

Drug overdoses account for approximately one quarter of completed suicides. In many countries, intentional drug overdose of pharmaceutical, over-the-counter and natural products is the most frequent presentation of self-harm

in the ED. Most countries have poison centers that should be contacted to determine the specific management for each substance ingested. Acetaminophen and salicylates are discussed here as they are readily available and commonly used in overdose. Tricyclic antidepressants are also discussed as clinicians need to have a clear management plan for them and understand their significant threat to life.

Salicylates

Salicylates are widely used for their analgesic and antipyretic properties and can be purchased over the counter. Mild intoxication results from acute ingestion of 150 mg/kg of acetylsalicylic acid. Severe intoxication occurs at doses of 300-500 mg/kg. The most potent over-the-counter salicylate is oil of wintergreen; each five milliliters contains the equivalent of 7.5 g of acetylsalicylic acid (Olson et al, 2007). Even one drop of oil of wintergreen can be fatal in a young child and is a significant threat to life in the intentional overdose patient. Salicylates produce profound metabolic and respiratory disturbances when taken in overdose. The primary mechanisms of toxicity are:

- Central stimulation of the respiratory centre leading to *respiratory alkalosis*
- Increased *metabolic rate* through the uncoupling of oxidative phosphorylation
- Profound *metabolic acidosis* through inhibition of carbohydrate and lipid metabolism, which is manifested by tachycardia, tachypnea, hypoglycemia and fever
- Hepatocyte destruction
- Platelet inhibition

Vomiting occurs in the early phase after ingestion. Following this, patients report tinnitus, have severe tachypnea, lethargy, and hyperthermia. The clinical presentation progresses over time to include seizures, coma, pulmonary edema and ultimately cardiovascular collapse (Olson et al, 2007). In the absence of a known history of salicylate ingestion, intentional overdose should strongly be suspected with a mixed respiratory alkalosis and metabolic acidosis. Serum salicylate level, serum glucose, gas, electrolytes, complete blood count and coagulation tests (partial thromboplastin time /international normalized ratio) need to be conducted. A chest radiograph should be obtained at baseline to ascertain the presence or absence of pulmonary edema if clinical symptoms indicate.

Activated charcoal must be given if the patient presents within one hour of known salicylate ingestion. A second dose should be considered if the product was enteric coated or sustained release.

Close monitoring is required and treatment should be tailored to complications. The cornerstone of therapy is urine alkalinization. Decision to initiate treatment with bicarbonate is based on the presence of symptoms regardless of the serum salicylate level. Bicarbonate enhances the urinary excretion of salicylate by ion trapping. The goal of therapy is to maintain urinary pH at 7.5-8 and urine flow of 1 ml/kg/hour. A single IV bolus of 1-2 mEq/kg of sodium bicarbonate ($NaHCO_3$) is given followed by an infusion of 5% dextrose

(D5) with $NaHCO_3$ and 20-40 mEq/L of potassium chloride (KCl). Meticulous monitoring of urine output, urine and serum pH, serum potassium, mental status and pulmonary status must be performed.

Care should be taken to address the potential complications of salicylate ingestion including:

- Support airway with mechanical ventilation if required
- Management of hyperthermia with external cooling
- Management of seizures with benzodiazepines
- Replacement of fluid deficit with a crystalloid solution
- Correction of hypokalemia (in patients who are not anuric)
- Treatment of hypoglycaemia with dextrose

Hemodialysis is recommended in patients with refractory acidosis, profound electrolyte disturbance, severe CNS toxicity, or clinical deterioration despite urinary alkalinization. The clinical status of the patient is deemed to be more important in deciding which patients should undergo hemodialysis, but some reports suggest that a serum salicylate level greater than 1000 mg/L would be an additional indication (Olson et al, 2007).

Acetaminophen

Analgesics are the most frequent accidental and non-accidental overdoses (Bronstein et al, 2010). Acetaminophen can produce toxic effects with single ingestions over 200mg/kg. The primary organ affected is the liver. Toxicity occurs when the production of N-acetyl-pbenzoquinonimine (NAPQI) by cytochrome P450 enzymes exceeds detoxification capacity (Dart et al, 2006). NAPQI has a direct cytotoxic effect on hepatocytes. If the patient presents less than two hours after exposure, activated charcoal should be administered. Acetaminophen level, AST and ALT should be ascertained once the patient is at least four hours post-exposure and plotted on a Rumack-Matthew nomogram. If the exposure is in the toxic range, n-acetylcysteine has been shown to decrease mortality and limit hepatocellular damage (Dart et al, 2006). Both oral and intravenous forms of acetylcysteine are available and have comparable efficacy (Perry & Shannon, 1998).

Tricyclic antidepressants

Tricyclic antidepressants (TCAs) have an overall mortality rate of 6% (Eyer et al, 2009). Consults to the regional poison center and the local intensive care unit should be initiated promptly. Activated charcoal should be given if the patient arrives in the ED within one hour of ingestion. TCA overdose should be suspected in patients who present with an anticholinergic toxic syndrome as well as cardiac and neurologic dysfunction. The mnemonic for the anticholinergic toxic syndrome can be easily remembered: *Hot as a hare; blind as a bat; dry as a bone; red as a beet; mad as a hatter.*

Vital sign changes are variable depending on the state of the patient and can include extremes of either hyper or hypotension. Tachycardia and hypertension are more commonly seen, and are the result of inhibition of catecholamine reuptake. Hypotension is generally mild and is due to the tricyclic blockade on peripheral

alpha-adrenergic receptors leading to vasodilation and hypotension. Hypotension can generally be managed with the Trendelenburg position or a crystalloid bolus (Olson et al, 2007).

Direct *cardiac toxicity* and cardiac conduction disturbances occur as a result of inhibition of the sodium fast channel and membrane depressant effects. The single most important investigation is the electrocardiogram. *Widening of the QRS beyond 100 ms is the best clinical correlate to severity of toxicity* (Braden et al, 1986). The delay in repolarization is evidenced by prolongation of not only the QRS, but also prolongation of the QT and PR intervals. The patient is at risk for ventricular ectopy including ventricular fibrillation, ventricular tachycardia or asystole. Metabolic and respiratory acidosis further promote the tendency to cardiac arrhythmias. Sodium bicarbonate 1-2 mEq/kg may reverse membrane depressant effects and reverse sodium channel blockade, and is indicated when the QRS prolongation is greater than 100 milliseconds. Specific cardiac arrhythmias should be treated as per standard American Heart Association protocols. Procainamide should be strictly avoided in tricyclic overdose, as its mechanism of action may exacerbate cardiotoxicity.

Neurological manifestations of tricyclic overdose evolve over time after TCA ingestion. These patients initially present with significant agitation but may progress rapidly to a profound altered level of consciousness with loss of protective airway reflexes. Because 2 out of 3 of patients who present with an overdose have taken multiple agents, coma should be treated empirically with naloxone and glucose. Respiratory arrest and loss of airway reflexes can occur abruptly. The clinician should anticipate and prepare for early intubation when managing tricyclic overdose.

Seizures occur in 20% of patients with tricyclic overdose. Initial management should include a benzodiazepine. However, second line management is neuromuscular blockade with a non-depolarizing agent to prevent the hyperthermia and rhabdomyolysis that is associated with a prolonged seizure. Continuous EEG monitoring will be required if the patient is paralyzed and ventilated to assess for signs of cerebral seizure activity (Olson et al, 2007).

Self-mutilation

Self-mutilation is a complex group of behaviors resulting in the deliberate destruction of body tissue; it is common in self-harming youth without suicide intent and is associated with organic, psychological and psychiatric conditions. The most frequent manifestations of self-mutilation are cutting or burning of the arm and wrist region. In addition to a thorough screening for coexisting suicidal ideation and other psychiatric disorders, the wounds must be cleaned, sutured and dressed. The patient should be approached in a non-judgmental manner. Tetanus status must be documented, and updated as necessary. A discussion should take place to ensure the patient knows that sharing a razor or other sharp object to carry out the mutilation would place them at risk of HIV or hepatitis transmission (Dallam, 1997).

Intoxication

Intoxicated adolescents are a growing problem in EDs. While youth are intoxicated, their perception, coordination and decision making abilities are

altered. This puts the intoxicated youth at a high risk of injury, and thus a careful and complete physical examination is required to rule out co-existing injury. Ingestion of a known substance should not prevent the clinician from thoroughly considering alternative differential diagnoses. Head injury or physical assault can certainly co-exist with intoxication in a patient with altered level of consciousness.

Most substance intoxications are managed conservatively. Treatment is aimed at stabilizing vital signs or controlling troublesome side effects such as agitation. It is standard practice to perform an acetaminophen, acetylsalicylic acid and ethanol level in patients with known ingestion (see above). Broad spectrum urine drug screening is rarely indicated and is not done unless it would significantly alter the patient's management.

Epidemiologic trends in illicit drug use vary from city to city, country to country and year to year. The National Institute of Drug Abuse provides timely information on the emergency trends in drug use for a variety of centres in the US but these may be different in other countries. However, every clinician needs to recognize and manage ingestion of alcohol, cocaine, phencyclidine (PCP), opiates, ecstasy, ketamine, and *gamma*-hydroxybutyric acid (GHB).

Ethanol

Ethanol intoxication commonly presents as slurred speech, impaired judgment and loss of fine motor skills, but at higher blood concentrations can lead to respiratory and CNS depression, loss of protective reflexes and death (see also Chapter G.1). No routine blood tests are required aside from a glucose level for the mildly impaired patient. However, more significant impairment is often investigated with blood glucose, gas, osmolar gap, and ethanol level. Occult injury and co-ingestion of other substances must be investigated. Care is supportive.

Methanol

Ingestion of methanol and ethylene glycol has significant morbidity and mortality. Initially these patients are indistinguishable from standard ethanol intoxication. However, as both of these alcohols are metabolized, their breakdown products cause metabolic acidosis. In addition to the profound metabolic acidosis seen with methanol, its metabolite formic acid causes end-organ damage to multiple organs, most notably the eye. *Methanol ingestion can result in blindness*.

The buildup of glyoxylic acid from ethylene glycol metabolism presents with progressive symptoms beginning twelve hours after ingestion with hyperventilation, arrhythmias and later renal failure. There will be a wide anion gap metabolic acidosis with an osmolar gap with these two toxic alcohols. Methanol and ethylene glycol levels are not always immediately available. If there is limited access to these levels, empiric treatment with fomepizole should not be delayed. Significant metabolic acidosis should be managed with bicarbonate infusion. Folinic acid 1 mg/kg should be administered with methanol ingestion while thiamine and pyridoxine should be administered in ethylene glycol ingestions. These treatment regimens promote both less production and enhanced elimination of the toxic metabolites.

Ethanol infusion has been used extensively in the past to treat methanol and ethylene glycol ingestions on the premise that it acts as a competitive antagonist to these toxic alcohols. The significant side effects of respiratory and CNS depression

caused by ethanol make this treatment obsolete in light of the widespread availability of fomepizole.

Cocaine

Cocaine is a sympathomimetic leading to elevated heart rate, respiratory rate and temperature. Patients who have ingested cocaine are agitated, have increased motor activity and are at risk of rhabdomyolysis. Long term morbidity associated with cocaine use comes not only from its high rate of dependency, but from the serious cardiac and central nervous system complications associated with its use. These include myocardial infarction, cerebral infarction and cerebral hemorrhage. Treatment is supportive and directed at any complications. Benzodiazepines are typically used to treat agitation. Adjunctive measures to control hyperthermia or cardiac complications are used as needed.

Phencyclidine (PCP)

PCP may be used orally, intravenously, or intranasally and is often mixed with other substances including marijuana. PCP has sympathomimetic and dissociative properties. Supportive care should be provided. Physical restraints may be necessary in severely agitated patients. Extreme mood lability and behavioural problems may also be managed with benzodiazepines or an atypical antipsychotic such as olanzapine.

Opiates

Opiate overdose is easily recognized by pinpoint pupils, respiratory depression and altered mental status. Naloxone, an effective antidote, rapidly restores normal functioning. Supportive care including management of respiratory depression should be anticipated.

Ecstasy

Ecstasy is a stimulant and a hallucinogen. No specific antidote is available to treat ecstasy overdose. Treatment is aimed at restoring hydration, providing a benzodiazepine for agitation, and treatment of specific complications including hypertension, hyperthermia and rhabdomyolysis.

Ketamine

Ketamine is a recreational drug used for its dissociative properties. Users usually show tachycardia, hypertension, nystagmus and altered mental state. In overdose, ketamine users can develop hyperthermia, seizures and respiratory depression. Treatment is supportive with occasional use of a benzodiazepine as needed.

Gamma-hydroxybutyric acid (GHB)

GHB is an anxiolytic and sedative. Patients who have taken an overdose of GHB may present with respiratory and central nervous system depression, and are managed accordingly.

Serotonin Syndrome

Serotonin syndrome is a not infrequent complication of antidepressant medications, particularly when taken in combination with other pharmaceuticals or over-the-counter alternative remedies. Manifestations of the serotonin syndrome

encompass a wide spectrum of severity. Mild cases can be easily overlooked as the symptoms of diarrhea, restlessness and anxiety can have considerable overlap with the patient's underlying diagnosis. However, failure to recognize these early symptoms combined with an inappropriate dose increase of the antidepressant (e.g., serotonin reuptake inhibitor) can lead to a severe clinical presentation.

The triad of symptoms described with serotonin syndrome includes: mental status changes, autonomic hyperactivity and neuromuscular abnormalities. Autonomic hyperactivity includes:

- Tachycardia
- Hypertension
- Hyperthermia
- Mydriasis
- Diaphoresis
- Hyperactive bowel sounds
- Shivering

Early on, these patients may present with tremor. The other neuromuscular signs, which are often more pronounced in the lower extremities, include muscular hypertonicity and myoclonus. Ocular clonus has also been reported with serotonin syndrome. Those affected by serotonin syndrome appear agitated and have pressured speech.

Management of these patients is dependent on the severity. Patients on the milder end of the spectrum can be managed conservatively and with a benzodiazepine (e.g., diazepam). Physical restraint must be avoided: further muscle activity will exacerbate hyperthermia and rhabdomyolysis. Youth or children with significant hyperthermia (>41.1 C) need to be paralyzed, intubated and ventilated. The choice of paralytic substance is limited to a non-depolarizing agent (vecuronium) used to prevent muscular activity and further elevation of the temperature. It is critical that *succinylcholine be avoided* in this context due to the risk of rhabdomyolysis, hyperkalemia and subsequent cardiac arrhythmia. Serotonin antagonist therapy such as cyproheptadine may be used to control the syndrome. Other agents with significant 5-HT2A antagonistic activity such as olanzapine may also be used to control severe symptoms. The offending agent must be discontinued (Boyer, 2011).

Acute extrapyramidal symptoms

Acute extrapyramidal symptoms refer to a range of movement disorders that occur while a patient is taking a dopamine receptor blocker. These movement disorders are associated with antiemetics, calcium channel blockers (metoclopramide), calcium channel antagonists (flunarizine) and the antipsychotics. The atypical antipsychotics in contrast to the older drugs in this class have a lower, yet still persistent, rate of extrapyramidal symptoms (Dayalu & Chou, 2008). Extrapyramidal symptoms can be divided into acute or tardive syndromes. The acute syndromes comprise:

- Acute dystonias
- Pseudoparkinsonism
- Akathisia

Dystonias are due to the disruption of the dopaminergic-cholinergic balance. Approximately one half of the acute dystonias occur in the first forty-eight hours of medication use (van Harten et al, 1999). Patients experiencing an acute dystonic reaction will typically show twisting, repetitive movements or have an abnormal posture. This muscle activity is intensely painful for the patient. The most common dystonias involve the face, neck and throat and is represented by clinical syndromes such as oculogyric crisis, opisthotonus, trismus and torticollis.

Immediate IV or IM administration of benztropine 1 to 2 mg, or diphenhydramine 25 to 50 mg will result in rapid restoration of the patient's baseline status. Treatment can be repeated in 30 minute intervals. The prescribing physician should re-evaluate the choice of antipsychotic or concurrently use anticholinergic medication.

The most serious acute dystonic reaction is *laryngospasm*. This life threatening emergency occurs when there is complete spasm of the vocal cord muscles resulting in full glottis closure. Initially, the patient presents with stridor but will progress to complete airway obstruction if not recognized and treated promptly. This is an extremely rare complication of antipsychotics, but can be recognized by a panicked patient who is unable to breathe. Initial management of laryngospasm is directed at providing positive pressure ventilation to overcome the obstruction. The patient should be immediately given an anticholinergic (benztropine 0.5-2mg IM/IV or diphenhydramine 25-50mg IM/IV). If oxygen saturation continues to fall, administration of a muscle relaxant should facilitate positive pressure ventilation (Miller et al, 2009). Succinylcholine 4-5 mg IM is the relaxant of choice in an emergency situation when intravenous access is not immediately available. It is important to note that the patient who has experienced an acute dystonic reaction will require oral anticholinergics for a minimum of four weeks after discharge.

The presentation of *pseudoparkinsonism* includes at least one of the following symptoms: bradykinesia, rigidity, tremor, or postural instability. The tremor is present at rest and disappears with movement. Rigidity is defined as the increase in resistance elicited when moving a limb, the neck or trunk through passive motion, and the so called "cogwheel" rigidity can usually be elicited from the upper extremities, with the resistance to movement repetitively increased and decreased as if moving the lever of a cogwheel. The features of bradykinesia most often associated with antipsychotic use are a lack of facial expression and difficulty with fine coordination. Postural instability can be detected by the impairment of the normal righting reflexes to a challenge in posture. Pseudoparkinsonism is an intermediate reaction that can occur a few months into treatment. Symptoms will improve gradually when antipsychotics are stopped but it can take weeks or even months (Dayalu & Chou, 2008). In addition to removal of the offending dopamine antagonist, cogwheel rigidity can be relieved by administering oral anticholinergics.

Akathisia can be recognized clinically by pacing, an inability to sit still and repetitive motor movements. These patients report a sense of inner restlessness and anxiety. The risk of akathisia is as high as 20-40% with typical antipsychotics and is reportedly less with atypicals. The management of akathisia can be complex. The first steps should be a reduction of the antipsychotic drug or a change of

medication. Using a beta-blocker, anticholinergic or antihistaminic can also be considered.

Lithium toxicity

Despite having been in use for over 60 years the mechanism of action of lithium remains unclear. Significant long term effects include weight gain, thyroid disturbance, renal failure, diabetes insipidus and cognitive impairment (Waring et al, 2006). The spectrum of toxic effects is dependent on the clinical context:

- Acute toxicity in a lithium-naive individual
- Acute toxicity on chronic use
- Chronic toxicity (this often occurs as a result of lax monitoring and is not discussed here).

Acute toxicity on chronic use is a particular concern as the half-life of lithium is significantly prolonged in patients on longstanding lithium therapy compared to those naive to the medication (half-life of 51 hours versus 13 hours respectively). Patients who have taken a supra-therapeutic dose of lithium while on chronic therapy are at high risk of toxic effects.

Neurologic and cardiac features dominate the clinical picture of lithium toxicity. These patients appear intoxicated: have slurred speech, poor coordination and unusual behavior. At higher lithium levels, symptoms can progress to coma, seizures or death. Permanent neurological injury may result regardless of how the toxicity is managed. Cardiac issues arising from lithium include AV block, arrhythmia and non-specific ST-T segment changes.

Activated charcoal does not adsorb lithium to any great extent and is unlikely to be beneficial in the setting of acute overdose. Haemodialysis and continuous haemodiafiltration are both highly effective at lowering serum concentrations of lithium. Local availability and practice will determine which method is used to treat acute toxicity in a naive individual or acute toxicity on chronic use (Waring et al, 2006).

Traumatic Brain Injury

Children with mental health problems may be more at risk of traumatic brain injury than other populations. Risk taking behaviors such as drug use, and self-harming behavior can put these children and youth in situations which may result in a traumatic brain injury. Children who have had a head injury may experience headache, seizure, loss of consciousness, vomiting, amnesia, or confusion.

Children with a head injury need to be triaged by an experienced clinician. Children or youth who are medically unstable, have abnormal vital signs, a Glasgow Coma Scale (GCS) score lower than 15 or obvious focal neurological deficits need immediate medical stabilization. A large multicentre Canadian study determined that 4.1% of children/youth who present with a head injury have an intracranial bleed and only 0.6% required neurosurgical intervention (Osmond et al, 2010). A decision rule for the use of CT scanning in children with head injury was developed by Osmond et al (2010). Presence of any one of these factors

Table J.1.2 Common causes of delirium in children and adolescents

Medical

- Fever
- Nonconvulsive status epilepticus
- Childhood confusional migraine
- Cerebral systemic lupus erythematosus
- End stage HIV/AIDS

Medication related

- Anticholinergic
- Antipsychotic
- Benzodiazepine withdrawal
- Drugs of abuse

should prompt the clinician to order a CT scan in the setting of head injury:

- Glasgow Coma Scale score <15 at two hours after injury
- Suspected open or depressed skull fracture
- History of worsening headache
- Irritability on examination
- Any sign of basal skull fracture
- Large, boggy hematoma of the scalp
- Dangerous mechanism of injury.

Children who do not meet the criteria for CT scanning should be observed for a period of six hours and discharged home with a responsible adult. Caregivers should be instructed to seek medical care if the child's level of consciousness deteriorates, has repeated episodes of vomiting, worsening headache or new focal neurological symptoms after discharge. Approximately 20% of patients with an epidural hematoma will have a lucid interval and subsequently deteriorate within 24 hours. This underscores the importance of good discharge instructions.

Delirium

Delirium can present at any age and is more common in the pediatric population. Delirium is a reduced situational awareness and change in cognition that has developed over a period of hours to days and fluctuates over time.

There are a number of broad categories that are associated with a delirious state in children including, these are listed in Table J.1.2.

The clinical presentation of a pediatric patient who has delirium is very similar to that of the adult. Common symptoms include:

- Irritability and agitation
- Alteration in sleep-wake cycle
- Mood lability

However, nuances that can be observed in the pediatric population include regression of developmental milestones, reduced eye contact and inconsolability despite usual caregiver presence (Hatherill & Flisher, 2010). The presence of

parents and familiar objects may enhance resolution of the delirious state. Medical management of pediatric delirium is controversial. Agents for consideration include: haloperidol 0.15-0.25 mg/dose IV and risperidone 0.1-0.2 mg/kg orally. The use of benzodiazepines may have a disinhibitory effect on the patient and could possibly exacerbate the delirium.

CONFIDENTIALITY IN THE ED

Confidentiality is a key component of the physician-patient relationship. It is important that children, youth and their parents appreciate and understand when patient information will be kept confidential and when it must be disclosed to others such as child protection agencies. The limits of confidentiality should be clearly established at the beginning of the assessment. Although there may be variability in legislation or practice among different countries and according to the patient's age, confidentiality must be maintained unless information is obtained that the child or youth is at risk for harming himself (risk of suicide) or others (risk of homicide) or if someone is harming them (child maltreatment). These situations allow for the breaking of confidentiality to pursue appropriate assessment and follow up.

Youth presenting with mental health problems may be concerned about how much information will be shared with their parents. Delineating the limits of confidentiality should reduce these worries. If a child or youth understands the importance of maintaining confidentiality (with the exceptions outlined above), they may be more likely to open up and speak more candidly about their symptoms and concerns.

In general, clinicians can receive unlimited information from parents and other nonclinical sources (school personnel, police, caregivers) regarding the child or youth without requiring consent from the patient but should not share information with parents and nonclinical sources without a patient's consent (with the exceptions mentioned), though this may vary among countries.

Privacy legislation varies among countries and often within countries. Some jurisdictions will allow a clinician to communicate clinical information about a patient with other medical professionals deemed to be within the "circle of care" without written consent from the patient. There are also variations in the age at which patients can give consent for the release of medical information—16 in many countries. It is crucial that clinicians be up-to-date with their local privacy legislation (see Chapter A.1).

SUMMARY

Clinical assessment of child and adolescent psychiatric emergencies requires systematic yet concise and prompt evaluation of acute psychiatric illness, acute mental health problems and the acute medical complications that can arise in mental health patients. Assessment and treatment of acute psychiatric emergencies in children and adolescents in the ED require a team approach consisting ideally of a child psychiatrist, crisis worker or social worker, nursing staff, and an ED physician. Once the medical complications are addressed, the primary goal of an urgent psychiatric assessment in the ED is to determine the safety risk of the patient. If there is imminent risk of harm to self or others due to the psychiatric

illness or acute mental health problems, then admission to a psychiatric inpatient unit is warranted; at times this is done against the will of the patient and their family, to ensure the safety of the patient.

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TRADITIONAL AND ALTERNATIVE MEDICINE TREATMENTS IN CHILD AND ADOLESCENT MENTAL HEALTH

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Hua Shou. Expression of the fourteen meridians used in acupuncture (Tokyo, 1716). Source: Wikipedia Commons.

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Conflict of interest: grant from Lundbeck to study psychiatric evaluation in primary care.

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Suggested citation: Soh NL, Walter G. Traditional and alternative medicine treatments in child and adolescent mental health. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Traditional medicine is defined by the World Health Organization (WHO) as "the sum total of the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health, as well as in the prevention, diagnosis, improvement or treatment of physical and mental illnesses" (p1) (World Health Organization, 2000). Traditional medicine spans a wide range of therapies, from herbal or medicinal treatments to physical and procedural treatments such as massage, acupuncture, yoga and spiritual and mind-body therapies. When traditional medicine is used in populations for which it is not indigenous—such as in a developed country—it becomes known as complementary and alternative medicine (CAM). In this chapter, we will use traditional medicine and CAM interchangeably and refer to Western conventional treatments, which have a scientific basis, as *orthodox* or *scientific medicine*.



Click on the picture to hear Simon Singh talk about alternative medicine.

COMPLEMENTARY AND ALTERNATIVE MEDICINE IN DEVELOPED COUNTRIES

HERBS, HYPNOSIS AND MUSIC THERAPY

CAM is popular with the general public in developed countries, although the level of scientific evidence for efficacy is at best modest. In the case of child and adolescent psychiatry, the evidence is particularly scarce, partly due to ethical concerns in conducting trials in this age group. In Western, developed societies, CAM used in treating child and adolescent psychiatric conditions include St Johns wort for depression, kava for anxiety, omega-3 fatty acids for attention deficit hyperactivity disorder (ADHD) and depression, elimination diets for autism and ADHD, and valerian and lemon balm for anxiety. The evidence or lack thereof for these treatments' efficacy has been reviewed and discussed elsewhere (Rey et al, 2011; Soh & Walter, 2008) and is summarised in Table J.2.1.

"**Decoction** is a method of extraction, by boiling, of dissolved chemicals or herbal or plant material, which may include stems, roots, bark and rhizomes. Decoction involves first mashing, and then boiling in water to extract oils, volatile organic compounds, and other chemical substances." (Wikipedia)

Additionally, homeopathy may be considered a herbal treatment. Homeopathic pharmacy uses serial dilutions of source materials with *succussion* (shaking) at each stage. Considering the resulting, extremely diluted solutions, there would not be any of the source substances remaining in the tincture or *decoctions* administered. Homeopathy has been used to treat ADHD, but a Cochrane review found "no evidence that homeopathy has a significant impact on the overall severity, core symptoms or related outcomes of children diagnosed with attention deficit hyperactivity disorder" (p12) (Heirs & Dean, 2009).

Hypnosis

Apart from herbal and medicinal CAM, there are also procedural CAM therapies used to treat psychiatric disorders. Music therapy and hypnosis are the better known examples in Western countries. In the case of hypnosis, Cochrane reviews found insufficient evidence to support its efficacy in the treatment of schizophrenia. Nevertheless, hypnosis does not appear to have adverse effects and some patients found that it provided short-term benefits. However, the studies reviewed were conducted in adults only and are quite old, being published in 1973, 1983 and 1980 (Izquierdo de Santiago & Khan, 2009). Hypnosis has been used to treat conversion disorder, in both inpatient and outpatient settings. There is weak evidence hypnosis may be more beneficial than harmful, but effects on social functioning, interpersonal relationships and quality of life, and long term efficacy, are not known (Ruddy & House, 2005).



Click on the picture to hear Richard Dawkins talk about alternative medicine.

Table J.2.1. Summary of common herbal/medicinal complementary and alternative treatments used in developed countries for psychiatric conditions in children and adolescents (Rey et al, 2011; Soh & Walter, 2008)

Treatment	Indications	Administration/ mechanism	Evidence of efficacy	Comments and adverse effects
St John's Wort *(Hypericum perforatum)*	• **Depression** • **Anxiety** • **ADHD**	As an extract. Active compounds are thought to be hypericin and/or hyperforin	• Open label trials have indicated children with (mostly mild) depression improve significantly. More rigorous larger trials showed no significant benefit. • RCT in children and adolescents with ADHD found no difference between St John's Wort and placebo	• Generally well tolerated by children • Potentiate serotonergic effects of selective serotonin reuptake inhibitors and triptans • Reduces anticonvulsive effects of carbamazepine and phenytoin • Reduces bronchodilator effects of theophylline • Interactions with many other drugs and medications, including non-psychotropic drugs (Rey et al, 2011) • Seizures from overdose
Omega-3 fatty acids	• **Depression** • **ADHD** • **Bipolar disorder** • **Schizophrenia**	Long-chain omega-3 fatty acids (eicosapentaenoic and docosahexanenoic) improve cell membrane fluidity, are precursors to less-inflammatory cytokines, and may alter expression of neurotransmitter receptors. Children with ADHD have lower blood levels of long-chain omega-3s than children without ADHD	• Supplementation alters blood profiles of fatty acids • A few RCTs have been undertaken in children with depression or bipolar disorder, but used biologically active placebos. Modest improvements in those taking omega-3 supplements • RCT in youths at risk of psychotic disorder: those treated with omega-3 had significantly reduced symptoms and improved functioning compared with placebo	• Generally well tolerated by children and safe even at high doses (Clayton et al, 2007) • Relatively mild side effects reported: • Gastrointestinal problems (e.g., diarrhoea) • Fishy breath or aftertaste • Skin rashes and urinary problems are rare (Joy et al, 2006; Montgomery & Richardson, 2008) • At high doses, can increase the risk of bleeding (Feucht & Patel, 2011). Care should be taken in patients with a pre-existing haematological condition (Clayton et al, 2007) • Concerns of heavy metal contaminants from marine sources of omega-3



Table J.2.1 (cont.)

Treatment	Indications	Administration/ mechanism	Evidence of efficacy	Comments and adverse effects
Kava *(Piper methysticum)*	**Anxiety**	As an extract	• In adults, RCTS showed kava reduced anxiety symptoms but other RCTS found no improvement	• Hepatotoxicity • Not recommended for use in children
Valerian *(Valeriana officinalis)* **Lemon balm** *(Melissa officinalis)*	**Anxiety**	Valerian root extract combined with lemon balm leaf extract	• In combination, low doses reduced state anxiety in healthy young adults, in a cross-over study • Open-label study in children with restlessness and dyssomnia showed improvement in symptoms, but statistical tests of significance were not conducted (Müller & Klement, 2006)	• Inadequate evidence to recommend use in children
Elimination and exclusion diets	**ADHD**	Removal of dietary substances (mostly artificial flavours and colours, salicylates) which are associated with hyperactivity	• Trials show conflicting results • Some children may be sensitive to particular food chemicals and thus benefit from those chemicals being removed from their diets	• Artificial flavours and colours are nutritionally superfluous and can be removed from children's diets without nutritional detriment • Depending on which foods or nutrients are removed, the restrictions of an elimination diet means a child can be put at risk of other nutritional deficiencies • The diet can place a large burden on parents and children, in terms of time, lifestyle changes and finances • Exclusion diets not recommended as standard treatment in autistic spectrum disorder (Millward et al, 2008)
	Autistic spectrum disorder	Removal of gluten and casein	• Conflicting results from two studies assessed in Cochrane review (Millward et al, 2008)	

Music therapy

Music therapy is the planned and creative use of music to attain and maintain health. Music therapy focuses on meeting therapeutic aims, which distinguishes it from musical entertainment or music education. Music therapists seek to help patients improve their health across various domains (e.g., cognitive functioning, motor skills, emotional and affective development, behaviour and social skills, and quality of life) by using music experiences (a diverse range, e.g., singing, song-writing, listening to and discussing music, moving to music) to achieve treatment goals.

For music therapy as a treatment for depression, a Cochrane review assessed five randomised controlled trials (RCTs), but there were distinct differences in the types of music therapy used. Only one study was conducted in adolescents and the rest were conducted in adults. Four of the five studies (including the one of adolescents) found that patients undergoing music therapy had fewer depressive symptoms compared to those given standard care (hospitalisation and medication), psychotherapy, or wait-list controls, while the fifth study found music therapy yielded no significant change in mental state when compared with standard care alone (Maratos et al, 2009). Overall, the studies were of low quality and had small sample sizes. Also, there was great heterogeneity in the delivery of music therapy, such as a structured program compared with a more passive and unstructured approach of simply listening to music. The reviewers concluded that music therapy has at least short term benefits in improving mood above those of standard care alone but it is still not clear whether music therapy is an effective treatment for depression. Another Cochrane review found music therapy could significantly improve both verbal and non-verbal communicative skills in children with autism spectrum disorder in the short term, although there was no significant improvement in behavioural problems when compared to placebo treatment (Gold et al, 2006). Only three studies met the criteria for inclusion in the review and all had very small sample sizes and it is not known whether improvements in communication skills were maintained in the long term. Gold and his colleagues cautioned that music therapy should be conducted by individuals who have academic and clinical training in this field

More recently, a quasi-randomised controlled trial of a two-week active music therapy program for patients during an acute psychotic episode was conducted as an adjunct to medication. This trial found significantly reduced Brief Psychiatric Rating Scale scores (total and subscale scores) in both treatment and control groups following the program, with the treatment group's scores significantly lower than that of the controls (Morgan et al, 2011). The difference in improvement was not sustained at follow-up, although both groups' scores decreased significantly over time. The length of hospital stay was reduced by two days in patients receiving music therapy, but this was not statistically significant.

TRADITIONAL MEDICINE IN THEIR COUNTRIES OF ORIGIN

In some Asian and African countries traditional medicine forms the primary mode of health care for 80% of the population (World Health Organization, 2008). The remainder of this chapter will focus on CAM and traditional treatments for paediatric psychiatric disorders from low income countries, particularly treatments which are not common in Western nations. It will also cover treatments for schizophrenia and bipolar disorder, illnesses which often begin in young people. The chapter will review evidence for their efficacy and will also note traditional treatments which, effective or not, a psychiatrist or other mental health professional working in such environments is likely to encounter. Often, a patient will have already used such treatments before seeing a psychiatrist and although much of the literature focuses on adults, children from such cultural backgrounds may well have been treated with the same remedies before presenting for clinical assessment. In many countries, traditional and scientific medicine often go hand in hand,

Table J.2.2. Summary of traditional treatments

Traditional treatment	Examples	Indications
Herbal medicine	• Indian Ayurvedic • Chinese • Japanese	• Schizophrenia • Bipolar disorder • Tourette disorder • Depression
Meditation	• Concentrative • Mindfulness	• ADHD • Anxiety • Depression
Trance		• Both cause and treatment; illnesses not specified but includes spirits and deities as cause
Sorcery	• Animal sacrifices • Confessions • Exorcism • Purification ceremonies • Herbal treatments • Charms and markings • Witchcraft	• Both cause and treatment; illnesses not specified but includes evil spirits as cause
Astrology	• Astrologer recommends rituals as cure	• Planets' alignment as cause; illnesses not specified
Religious healing Shamanism	• Faith healing (eg Koranic) • Rituals and prayers • Talismans and amulets • Devil dancers • Pilgrimages • Exorcism • Charms	• Includes evil spirits and demons as cause; illnesses not specified
Acupuncture		• Depression • Autistic spectrum disorder

with scientific medicine used to suppress symptoms and traditional medicine to restore the body to its natural balance. Some practices described in this chapter may be antiquated, but are included for historical purposes and because there may be pockets of traditional practice in those countries. These examples also serve to highlight some of the challenges associated with combining traditional and orthodox treatments, or transitioning from one form of treatment to another. Traditional beliefs or interpretations of psychiatric disorders are important to the psychiatrist who aims to provide culturally sensitive and acceptable therapy. The treatments reviewed are herbal medicines, meditation, trance, sorcery, religious healing and talismans, and acupuncture.

Rauwolfia serpentina

Rauwolfia serpentina is one of the fundamental herbs used in traditional Chinese medicine, where it has the name *shégēn mù* (Chinese: 蛇根木) or *yìndù shémù* (Chinese: 印度蛇木). It was also used in India for centuries to treat a variety of conditions. Rauwolfia serpentina contains several bioactive chemicals, including yohimbine, and reserpine. The alkaloid reserpine was introduced into Western medicine as an antipsychotic in 1954. Although effective, side effects lessened its popularity. The ability of reserpine to induce depression (now questioned) and deplete brain amines became one of the pillars of the monoamine theory of mood disorders.



A variety of materials, vegetable and animal, are used in traditional Chinese medicine. In this picture, *ling zhi* mushrooms, dried snake, turtle shells, *luo han guo* (a type of fruit) and ginseng.

HERBS

CHINESE, INDIAN AYURVEDA AND OTHER

Patients' use of herbal medicines as complementary or naturopathic treatments is familiar to clinicians in developed countries. Herbal medicines may be used in developing countries because they are more accessible and affordable than Western pharmaceuticals. Tradition and familiarity also play a role in their popularity. While it is likely a psychiatrist will find that patients from such backgrounds have used herbal treatments before presenting for assessment, this does not mean that the traditional medicines are (or are not) effective.

Depression

Sarai (1992) reviewed herbal medicines used in Japan, among them: *saiko-ka-ryukotu-borei-to* for anxiety and depression; *yokukan-san-ka-chinpi-hange* for agitated depression and nightmares; *choto-san* for headaches; *and hoch-ekki-to* for "exhausted depression". Each of these herbal medicines is a complex combination of herbs; a novel aspect of Sarai's paper is that the ingredients for each medicine are listed, including quantities and dosages. However, Sarai also noted no double-blind controlled trials were available to test for efficacy. Further, the studies cited were in vitro and animal studies and the mechanisms of the medicines are mostly unknown. Thus, efficacy in humans is unknown.

More recently, Akhondzadeh et al (2005) investigated the efficacy of *saffron* (dried stigmas of *Crocus sativus* flowers), a traditional Persian treatment for depression. A double-blind RCT in 40 adults with mild to moderate depression found those taking a capsule of 15 g dried saffron extract/day had significantly improved at six weeks and this improvement was significantly greater than that experienced by the placebo group. The participants were free of psychotropic medications for at least four weeks before the start of the study. Side effects reported were mild. This is the first clinical trial of saffron as a treatment for mild to moderate depression and the sample size is small. Thus, larger trials are required

and it is not known whether saffron would be effective in paediatric depression. Another, very practical issue is the cost of treatment as saffron is the most expensive spice in the world.

Schizophrenia

Traditional Chinese medicine

In China, traditional medicine, including herbal medicines, was the main treatment for psychiatric illnesses until the advent of antipsychotic medications. In the Cochrane review of Chinese herbal medicines, there was no evidence that herbs on their own were more effective than antipsychotic medications in treating schizophrenia, but there was a possibility of benefit by adding the herbs to an antipsychotic regimen (Rathbone et al, 2010). The herbal medications may also attenuate the adverse effects of antipsychotic drugs, such as constipation, thus promoting compliance. None of the seven RCTs reviewed trialled herbs against placebo, possibly because of ethical considerations. The studies were conducted in adults and used a range of herbal medicines: two different versions of *dang guicheng qi tang* (five or seven different herbs) with an additional 17 herbs used as needed for blood stagnation and hallucinations, restlessness and insomnia; *xiaoyao san* (a mixture of 10 herbs); *ginkgo biloba*; *xingshen* (containing seven herbs); or a combination of *Hirudo seu Whitmania* and the rhizoma of *Rheum palmatum*. When *gingko biloba* was combined with antipsychotic medication, it yielded greater improvement in schizophrenia patients' mental state compared with the combined results of the other herbal data, though the reviewers cautioned that trials were very small (Rathbone et al, 2010).

The studies assessed in the Cochrane review of Chinese herbal medicine for schizophrenia were published from 1987 to 2001. The quality of the studies was modest at best: not all studies provided the dosages for herbs or antipsychotic drugs and not all studies were double blind. Another issue noted by the reviewers is that only one of the studies followed the traditional Chinese medicine's "pattern differentiation", where patients were assigned to one of two herbal medicine regimens in line with traditional customizing of treatment to the individual (Rathbone et al, 2010). Nevertheless, the potential efficacy shown by this preliminary data indicates the need for better-quality and larger studies for these herbal medicines.

Another traditional Chinese herb for treating schizophrenia is *Huperzia serrata* (*qianceng ta*), which is also used for contusions, strains, swelling and myasthenia gravis (Ma et al, 2007). An active ingredient, HupA, a strong reversible inhibitor of acetylcholinesterase, was isolated from *H serrata* in 1986. Ma et al's 2007 review focused on HupA and its semi-synthetic analogues and their potential for the treatment of Alzheimer's disease to improve cognitive function. However, the review cites only one study related to schizophrenia, where HupA significantly improved memory function in patients with schizophrenia.

In conclusion, it is premature to recommend traditional Chinese herbs for the treatment of schizophrenia. For clinicians managing patients with a Chinese background, it is useful to be aware their patients may have used these herbal medications.

Ayurveda

Ayurvedic medicine (also called Ayurveda) is one of the world's oldest medical systems. It originated in India and has evolved there over more than 3,000 years. The term "Ayurveda" combines the Sanskrit words ayur (life) and veda (science or knowledge). Thus, Ayurveda means "the knowledge of life" (Agarwal et al, 2010). The aim of Ayurvedic medicine is to integrate and balance the body, mind and spirit. This balance is believed to lead to happiness and health, and to help prevent illness. Ayurvedic medicine also treats specific physical and mental health problems. A chief aim of Ayurvedic practices is to cleanse the body of substances that can cause disease, thus helping to re-establish harmony and balance.



Click on the picture to watch a lecture on Ayurveda (1 hour 28 minutes) by Sudah Prathikani MD, explaining the philosophy behind Ayurveda and some of the modern research into its efficacy.

Ayurvedic (Indian) medicine

Ayurvedic medicine, a traditional Indian medicine system, is similar in its philosophy to traditional Chinese medicine (Agarwal et al, 2010). A Cochrane review of three RCTs, all conducted in India, found weak support for one herbal medicine (*brahmyadiyoga*) being more effective in treating schizophrenia than placebo, but it does not appear to be more effective than chlorpromazine. *Brahmyadiyoga* was also associated with nausea and vomiting. The studies are old (one published in 1976 and two in 1992) and short term. An important general issue is the cost of treatment, as Ayurvedic treatments are cheaper and therefore more accessible to poor people than chlorpromazine, let alone the more recent atypical antipsychotics. Psychiatrists working with patients from Indian subcontinent backgrounds should be aware that their patients may have used such traditional treatments prior to presentation or may continue using them.

The above studies of Chinese and Indian herbal medicines were conducted in adults, and schizophrenia is less commonly diagnosed in children and younger adolescents. Thus, caution is warranted in extrapolating such preliminary results to the younger population. However, it is possible that paediatric patients had been administered such treatments before presenting and family members and carers expect to continue using herbal medicines to manage a patient, regardless of age.

Toxic effects of a Chinese herbal medicine in children – when a herb is substituted

In 1993, the Centres for Disease Control (US) published a report of three cases of jin bu huan toxicity in children in Colorado, US (Horowitz et al, 1993). *Jin bu huan* is a Chinese herbal medicine used as an analgesic. In all three cases, the children (aged 13 months to 2 ½ years) presented with lethargy: two had low respiratory rates and were initially unresponsive. Analyses of the *jin bu huan* tablets showed they contained 36% levo-tetrahydropalmatine by weight. This substance is found in the plant genus *Stephania*, not *Polygala* (*Polygala* being the genus of the plant ingredient listed in the tablets' packaging). The children's reactions to the tablets were also consistent with those observed in animals exposed to levo-tetrahydropalmatine and suggests that a herb substitution had occurred. In one case, the child had ingested 60 of the tablets, prompting the authors to recommend child-proof packaging for herbal medicines.

Tourette's disorder

Tirodkar (2010) presented a case study of Ayurvedic medicine used to treat Tourette's disorder in a seven year old boy. The motivation of the patient's mother, who had searched the internet and read extensively about her child's condition, was her concern about the side effects of psychotropic drugs. Tirodkar reported that the Ayurvedic healer, instead of examining the child, asked the mother about her pregnancy and how it had progressed. The healer diagnosed "problem with the head/mind" and prescribed enemas, *shirodhara* treatment (where warm medicated oil, milk or water is poured onto a patient's forehead) and concentration exercises (meditation). Interestingly, this healer also recommended the child be moved to a school for the disabled if his behaviour became more problematic or he developed a more severe learning disability, and also that the child's sibling be provided with counselling, as he had become frustrated with helping to take care of the patient. However, whether the treatment was successful was not reported.

Borderline personality disorder (BPD)

While BPD is not generally diagnosed in adolescents, borderline features often emerge at this age. In the past decade, the Chinese herb combination *yi-gan san* has been used in Japan to treat behavioural and psychological symptoms in dementia. Recently, a 12 week open-label study investigated *yi-gan san* as a monotherapy in adults with BPD (Miyaoka et al, 2008). At weeks 2 and 12, there were significant reductions in depression, anxiety, hostility, suspiciousness, suicidal thoughts, impulsive aggression, motor retardation, uncooperativeness, excitement and somatic symptoms, and significant improvement in overall functioning compared with baseline, but no significant differences between weeks 2 and 12. Side effects were mild and few. The study was single-blind (the observer and data collector were blinded to the treatment); the authors conceded a double blind study of *yi-gan san* could not be conducted as the herbal powder mixture had a distinctive taste and smell and an appropriate placebo could not be developed.

This is the first trial of *yi-gan san* in patients with BPD and it is not yet appropriate to extrapolate the results to children and adolescents. However, *yi-gan san* was originally developed for restlessness and agitation in children in the 16th century and it is conceivable that paediatric patients from Far Eastern cultures may have received this treatment before presenting for psychiatric assessment.

Adverse effects of traditional herbal treatments

In terms of safety, caution is warranted for herbal medicines overall. That a herb has been used for centuries for religious or medicinal reasons does not necessarily mean it is safe, and apparent lack of toxicity in the short term does not guarantee the herb is not toxic with chronic use. Also, contaminants such as heavy metals, pesticides and herbicides, may be significant toxins in themselves (Gardiner & Kemper, 2000). Drug-herb interactions are also cause for concern. For example, *kava*, which is not recommended for paediatric use (Rey et al, 2011), may potentiate benzodiazepines, alcohol and central nervous system depressants, and *valerian* may potentiate sedatives and barbiturates (Gardiner & Kemper, 2000). Quality control of herbal medicines should also be considered, in that the quantity of active compounds may vary from dose to dose and according to the quality of the herbs used in their preparation. Thus, a dose of traditional herbal medicine may contain levels of active compounds too low to have an effect, or so high as to be toxic. There are situations where herbs within a prescribed mixture have been substituted with another which is toxic (see Box), or conventional pharmaceutical compounds have been included in a herbal medicine mixture (see Box) (Kenny et al, 2001). These concerns make it necessary for clinicians to ask patients and their families about the use of any herbal medicine. Patients will not necessarily disclose use and reasons for not doing so include fears their clinician will disapprove or not want to know about it (Walter & Rey, 1999), although a survey of Australian psychiatrists regarding St John's Wort shows this is not necessarily the case, and that very few psychiatrists would be dismissive of the information (Walter et al, 2000).

MEDITATION

Meditation is used in both religious and secular settings and may help achieve relaxation and an altered state of consciousness. The latter potentially has cognitive-behavioural benefits (Krisanaprakornkit et al, 2010b). Meditation can be divided into two types: *concentrative*, where attention is focused on an object and aims to achieve sustained attention and stillness of the mind, and *mindfulness*, where there is an open awareness to any thoughts and the practitioner aims to develop a sustained attentiveness without reacting to their thoughts or emotions (Krisanaprakornkit et al, 2010a).

Anxiety

A Cochrane review analysed two RCTs of meditation as a treatment for anxiety in adults and found only slightly supportive evidence for its efficacy, similar to that of relaxation therapy (Krisanaprakornkit et al, 2010b). The trials reviewed used active controls—i.e., receiving another therapy (a different type of meditation, biofeedback, or relaxation therapy). Participants also continued their anxiolytic medications. Both studies were conducted in the US and the reviewers were not able to identify any studies from India, China or Thailand which met their inclusion criteria. This is a potential bias as meditation techniques originated in the

Mindfulness: modernized meditation?

In recent decades, mindfulness-based therapies have become fashionable in developed Western countries. These include mindfulness-based stress reduction (developed in the late 1970s) for managing stress, mindfulness-based cognitive therapy for managing depression, dialectic behaviour therapy (which includes mindfulness as one of its elements) and acceptance commitment therapy. These therapies are based on Buddhism, yoga and meditation and generally focus on positive alternatives and non-judgemental acceptance of symptoms (Dryden & Still, 2006). Mindfulness-based therapies also attempt to utilize only the essence of meditation and remove the cultural, traditional and/or religious elements associated with it. Research into mindfulness-based therapies is still preliminary in children and adolescents, with small study samples and heterogeneous methodologies (Burke, 2010). Studies have investigated both clinical (e.g., ADHD, sleep disorders, anxiety) and non-clinical samples for the impact of mindfulness therapies on social skills, anxiety, attention, depression, sleep quality, substance use, aggression, behaviour, general mental health and academic performance. At this stage, research shows the therapies can be administered and are well accepted by children and adolescents, but their efficacy in this population is not yet known.

East and may be practised *more purely* in those countries. In summary, there is no evidence to show meditation is superior to medication or other psychotherapies. Meditation may be a useful adjunct to conventional treatments, but larger trials of better quality are required to show its effectiveness (Krisanaprakornkit et al, 2010b).

Attention deficit hyperactivity disorder (ADHD)

Another Cochrane review examined meditation as a treatment for ADHD. This assessed four RCTs in children but found the quality of the studies to be poor and there was insufficient evidence to recommend meditation in treating ADHD (Krisanaprakornkit et al, 2010a). Mind-based meditation did not produce outcomes different to that of drugs or standard therapy, although *Hatha yoga*, a physical-based form of meditation, showed some benefits, albeit inconsistently.

Adverse effects of meditation and compliance issues

Krisanaprakornkit et al (2010b) advised that those types of meditation which require physical effort, such as *Kundalini Yoga*, are not appropriate for patients who are not physically fit or who have cardiovascular or respiratory diseases; adverse side effects reported for this type of meditation include spontaneous pneumothorax from forced respiration. Also, lower chemosensitivity has been reported in Yoga practitioners, where they appear to have adapted to low arterial pH and high arterial carbon dioxide partial pressure. Krisanaprakornikit et al (2010b) warn that the risk/benefit profile of such an adaptation is not yet known. Other potential adverse effects of meditation include depersonalization and derealisation, and it may trigger a psychotic episode in patients who have an underlying psychotic condition. There is generally a dearth of information regarding adverse effects of meditation in children.

Effectiveness and potential adverse effects aside, meditation as an exercise or treatment requires considerable motivation and discipline, in the same manner that physical exercise routines do, which may be problematic in young people with anxiety or depression. Compliance concerns were highlighted by the high drop-out rates in the two studies of meditation and anxiety (Krisanaprakornkit et al, 2010b). However, for patients from some cultural backgrounds, meditation may already be a routine part of their lives, including in young people, such as in Thailand. In these settings, meditation is an accepted method of improving attention, temperament, discipline, character, morals and school performance, and is also used for religious reasons. In such environments, a psychiatrist can expect the patient to have already undertaken meditation before presenting for assessment and treatment. Interestingly, Kapur (1979) claims that in Ayurveda, the "mentally disturbed" (author's term) are forbidden to practice Yoga, although Yoga is recommended to promote mental growth in the healthy person.

Trance

Trance has a multitude of meanings, from stupor and daze to a sleep-like state usually characterized by partly suspended animation with diminished or absent sensory and motor activity. Trance is often described as a half-conscious state, between sleeping and waking, in which the ability to function voluntarily may be suspended and is associated with meditation, hypnosis, magic, and prayer. In spiritualism, trance is a temporary state in which a medium, with suspension of personal consciousness, is controlled by an intelligence from without and used as a means of communication, such as with the dead.

TRANCE AND SOCIALLY SANCTIONED DISORDERS

What is deemed a mental disorder in one culture may not be so in another. Cultural sanction of a mental illness influences how treatment is delivered, if required. This section looks at trance as a social phenomenon, as an illness and as a treatment.

Trance in its social context and as a disorder

Trance may be socially acceptable or have a socially acceptable explanation in some cultures. This is partly reflected in a case reported by Suryani and Jensen (1992) in Bali, Indonesia, where 45 out of 215 school children experienced dissociative disorder *en masse*. According to Suryani and Jensen, trance is a normal part of the Balinese Hindu faith in the sense that it is expected to occur in association with ceremonies and dances. What was different in this case was that the children were going into trance outside of culturally acceptable scenarios and in turn this led to significant disruption of the school's functioning (see Box).

Suryani and Jensen elegantly state: "The psychiatrist can help patients recover from symptoms of mental disorder as defined by Western psychiatry but cannot provide patients with necessary direct treatment for problems or illness caused by cultural beliefs or the supernatural. *The latter are best treated by those persons responsible for them."* (p312, our italics).

In this Balinese case, the people responsible were traditional healers and priests. Incorporating patients' cultural language and reference points when explaining and administering psychiatric treatment was also highlighted by Ahyi (1997) in Africa, describing treatment as "exorcising sorcery" with medication (see section on sorcery).

Trance as treatment

Trance can be a direct means of treatment. Skultans (1991) conducted fieldwork at a Mahanubhav healing temple in India in the 1980s. The female patients with mental illness who came to this temple as supplicants were usually recorded by the temple as either having *pida* (spiritual affliction) resulting from spirit possession, or *ved* (madness). Trance was associated with having *pida* but trancing also offered symptomatic relief to the patients. Also, female family members and caregivers of male patients at the temple would go into trance as a means of taking on the burden of the male patients' afflictions. In this scenario, trance is a means of redistributing the intensity of the illness. Skultans noted that no men were recorded as going into trance.

SORCERY

A descriptive study in Liberia, a West African nation, showed that mental illness was traditionally believed to be caused by breaking taboos, offending ancestral spirits and deities, being possessed by spirits, being *bewitched* or having a curse applied by a witch doctor (*zoe*), or was inherited through the family (Hales, 1996). Some of the beliefs in Arab societies, where illness is due to devils, sorcery, *jinn* (demons), the evil eye or ill-wishing from others, also apply to South Saharan Africa. *Treatments* include confession to doing wrong (e.g., breaking taboos), animal sacrifices to deities and spirits, and paying fees and exorcism, usually through physically beating the patient. Traditional Arabs may also seek out traditional healers to exorcise *jinn* (Fakhr El-Islam, 2008). Other treatments include purification ceremonies and herbal treatments. Charms and markings are also used as prophylactics. Some inherited mental illnesses are deemed incurable and patients may be restrained or left to die (Hales, 1996).

Sorcery as a cause for illness

Adjido (1997) discussed the association between psychosomatic medicine and sorcery in Africa, describing sorcery as "one of the central mysteries of African

Adulteration of African herbal medicine with western pharmaceuticals

Synman et al (2005) presented two cases where African herbal medicine had been adulterated with Western pharmaceuticals: a five year old child was admitted to intensive care with seizures after consuming a traditional herbal infusion to treat seizures; and a 30 year old woman was admitted with a ruptured uterus following consumption of a herbal medicine to induce abortion. Analyses of the infusions showed trimethadione (a drug used to treat petit mal seizures), in the one taken by the five year old, and propofol (an anaesthetic) and diclofenac (a non-steroidal anti-inflammatory) in the herbal medicine consumed by the 30 year old. The herbs used in the infusions were unknown.

Numerous cases of adulteration of Chinese herbal medicines with orthodox pharmaceuticals have been previously reported and both Chinese and Ayurvedic herbal medicines have been subject to contamination with heavy metals (Feucht & Patel, 2011), but this is the first published report of adulteration of African herbal medicine with orthodox medications.

Incorporating traditional beliefs in a psychiatric treatment plan

Suryani and Jensen (1992) reported a case in Bali where school children were experiencing trance en masse, causing much community disruption. Attacks were occurring from once to 30 times a day and continued for seven months, with each episode spanning about 40 minutes.

Prior to Suryani's intervention, a traditional healer, a *balian*, had provided treatment with ceremonies and offerings to appease gods and spirits and to compensate for an inadvertently desecrated old and buried temple. One village individual was blamed for the afflictions and expelled from the community while some of the afflicted children were transferred to another school. These treatments did not yield improvements, with children at the new schools also experiencing attacks. There was an appearance of contagion and non-affected community members were afraid that they would have an episode.

In her treatment strategy, Suryani settled on a diagnosis of *kesurupan*, meaning possession, which was understood by the Balinese, accepted as a normal part of life and also did not carry stigma. Community leaders, health, education and religious officials as well as psychiatrists were involved. A high priest acted as primary traditional healer, since the people believed the condition was due to supernatural forces as opposed to a disease. Another reason for selecting a traditional healer was because of logistical problems and inadequate psychiatric resources. A new temple in the correct orientation would be constructed (to replace a temple in the school grounds which was not correctly oriented according to the Hindu religion), school teachers were to teach traditional Hindu stories about benevolent spirits to reduce the children's anxiety, the village was closed to outsiders to reduce stress and fear from visitors (visitors and media were disturbing the normally isolated community and expected to witness episodes), and there was a back-up plan of individual psychotherapy. Within a month, trance episodes ceased and did not reoccur in the three years of follow-up.

life" (p266). It is difficult for outsiders to grasp and define sorcery due to the secrecy encapsulating sorcerers' societies and the social and cultural barriers surrounding sorcery enforced by the rest of African society. While not specifically focusing on psychiatric illnesses, Adjido noted sorcery's role in African society, the way it permeates African cultures and that sorcerers prefer children and adolescents with "psychosomatic personalities" as "victims" (the author's terms). In doing so, sorcerers are able to utilize the targets' suggestibility. Illness, through the lens of belief in witchcraft or sorcery, therefore results from an enemy's or spirit's attack, and cure is through exorcism. Adjido provided a case study of a 12 year old boy with psychosomatic symptoms who was successfully treated with psychotherapy and possibly magical rituals. The social history of this patient also revealed complex family issues preceding the psychosomatic symptoms and that ritual sacrifices had been conducted for his and his mother's protection before the patient presented for psychiatric treatment. Adjido describes "psychosomatic transfer" being used to destroy victims by exhausting them through "a micro-environment of suggestion-induced insecurity, source of a lethal anguish" (p277), leading to chronic illness or death.

Sorcery and its social role

Ahyi (1997) investigated the traditional models of mental illness in Benin, a West African country where the *Vodun* (Voodoo) religion has its roots. These models are considered applicable to a reasonably large proportion of Africa's population (Ahyi, 1997). Ahyi highlighted the difficulties reconciling Western orthodox and traditional African models of mental illness. This contrasts with Suryani and Jensen's (1992) experiences in Bali, where both traditional and Western models and treatments were successfully integrated in a treatment strategy. Ahyi states that in the African healing system it is understood that some facts should not be mentioned. Further, attributing the behaviours associated with mental illness (e.g., suicide attempts) to another person or spirit removes guilt from patients and their families. There are parallels to this in traditional Bedouin-Arab beliefs, where mental illness is attributed to external, supernatural causes and patients are less likely to believe the illness is their own fault (al-Krenawi & Graham, 1999).

Society's concealment allows protection for the guilty parties while they correct their behaviour. Also, if behaviours such as violence are attributed to a spirit, individuals may be seen as a vessel or medium through which spirits communicate instead of being viewed as criminals; that is, the individual is still accepted in society. Ahyi (1997) illustrated this with a Ghanian cult, *Tigari*, where a hysterical crisis was interpreted as a visitation from the spirit world. Such a person is thus not viewed as having an episode of a mental illness or as a sick person, but instead as a spokesperson for a spirit or deity and is thus accepted in society. This in turn allows patients time to develop a new life for themselves. In a similar situation, Li and Phillips (1990) reported a case in rural China where a female patient with a tentative diagnosis of schizophrenia was believed by others in the community to be in communication with spirits. As a result, community members began to ask the patient to see their sick relatives, who they believed were affected by evil spirits. Such a scenario may hinder patients from seeking treatment, as neither patients nor their families or community see that there is a problem.

Using the concept of sorcery in orthodox treatment

In a transcript of a verbal discussion, Ahyi (1997), as a psychiatrist, described clinical cases where he had "exorcised sorcerers" with medication and where he successfully treated cases of witchcraft which he called "fake witchcraft". In effect, Ahyi explained the conventional treatment within the patients' cultural reference points. However, he acknowledges that to use such a construct is to concede there is *genuine witchcraft*, which he had yet to personally encounter. Furthermore, some patients come to see a Western trained psychiatrist because they relapse after consulting traditional healers. Ahyi also highlighted the importance of social support and the social network in such societies, which are important for the patient, beyond what medication alone can provide.

Adjido (1997) and Ahyi (1997) showed how mental illnesses are interpreted in African societies and suggested how psychiatrists working with patients with these cultural backgrounds may need to frame their discussions to engage these patients and thus provide culturally acceptable care. The traditional religious and supernatural beliefs in South Saharan Africa lead to a common sequence of help-seeking for mental disorders: traditional healer, then a church for prayers or faith healing, and then, if the symptoms become worse, to a hospital (Odejide et al, 1989). Association with traditional and religious care systems may continue after effective hospital treatment. Thus, for psychiatrists working with patients from these communities, it is likely the patients will already have sought treatment from traditional healers and religious bodies before presenting, and will continue to do so after receiving orthodox psychiatric care. Odejide and co-workers also advise there are cultural and social limitations to Western-style psychotherapy in Africa due to common beliefs in the supernatural and a tendency to attribute mental illnesses to an external cause (as inferred by Ahyi above). This parallels the attitudes of some traditional Arab patients, where patients expect psychiatrists to cure them, as opposed to taking an active role themselves, as cognitive and behavioural therapies require (Fakhr El-Islam, 2008).

Clinicians treating patients from these backgrounds should ask what the patient and their family believe is causing their problem and what they have already tried as treatment. For patients and carers who believe the condition is caused by sorcery, have tried sorcery as a treatment, or plan to continue with sorcery and related rituals, a clinician should note if any of the practices are likely to be

Amulets or **talismans** are objects believed to possess supernatural or magical powers. They are intended to bring good luck, protection or health to their owner.

detrimental to the patient. This is not merely in terms of physical or medical harm but also includes potential financial burden. Permitting sorcerous or other culturally sanctioned rituals to continue if they are not harmful, while continuing to monitor the patient, may help to build trust and rapport. Explaining orthodox psychiatric treatment within a patient's cultural reference points—as Ahyi has by treating "fake witchcraft" and "exorcising sorcery" with medication—may improve patients' compliance with treatment and help retain their carers' support. Further, it may be of little practical benefit to openly challenge patients' beliefs regarding sorcery and the supernatural when their family and the community they live in share the same beliefs.



Example of an amulet which is supposed to protect against the evil eye.

RELIGIOUS HEALING, TALISMANS AND AMULETS

There is overlap across sorcery, religious and spiritual causes for mental illness and their use in treatment. Talismans and amulets are often used in conjunction with sorcery and religious healing. While it is beyond the bounds of this chapter to delve in depth into the various philosophies which underpin some traditional beliefs about mental illness and how they should be managed, it is useful for clinicians to be aware of them as they may influence how patients describe and view their malady.

Traditional Tibetan concepts of mental illness and religious healing

In traditional Tibetan medicine, mental illness is often described as an imbalance or disturbance of the *wind humour* or as a *wind humour illness*, with particular reference to the *life-bearing wind*. The term *srogrlung* may describe depressive or anxiety symptoms and may also include episodes of panic and psychosis (Jacobson, 2007; Millard, 2007). Jacobson (2007) translates *srogrlung* as the equivalent of "highly somaticised comorbid depression and generalised anxiety" (p236). Thus, an individual may report having *high wind*, meaning greater stress, exhaustion, hardship or irritability. There is also stigma attached to *srogrlung*, and some patients will therefore deny having the condition. Mental illnesses may also be attributed to *harmful spirits* or *gnod pa* (Millard, 2007), in which case the emphasis is on supernatural origins and reflects Tibetan religious beliefs. Millard observed that whether patients, their carers and community endorsed one etiology over another reflected socio-cultural differences across the Tibetan diaspora. Herbal medicines were prescribed to treat *srogrlung* while *gnod pa* illnesses would be confirmed by divination and treated by lamas or local healers (*jhānkri*). Millard reported such treatments included rituals and prayers to appease the spirits and fastening *blessed cords* (cords blessed by lamas) about a patient's fingers to seal a spirit inside the patient in order to communicate with it and thus discover the reasons for it attacking the patient. In his interview with a doctor practising traditional Tibetan medicine, the doctor—who worked in a clinic in the UK—described that an individual "becoming possessed by an emotion or a negative mode of thinking could be likened to [having] spirit possession", but religious rituals were not essential to treat such conditions. Instead, balance could be returned through medicine and future *possession* averted (p280).

Indian subcontinent: Spiritual and astrological causes

Indian Ayurvedic medicine, practiced by *Vaids* (a class of priests), not only involves herbs but also spans spiritual or supernatural causes and treatments for mental illness. Astrology is also involved. An old observational study described *Unmada* (mental illness) as being caused by heightened activity of any of the three humors or by noxious foods and the resulting imbalance of heat and cold, or sexual overindulgence (Kapur, 1979). Mental illness may also be caused by evil spirits (*Pischachis*) possessing the patient (Kapur, 1979). Traditional healers (*Mantarwadis* and *Patris*), whose roles extended beyond healing to include other duties such as appealing to rain deities in times of drought or flood and locating lost cattle, treat mental illness on the basis that the ailment is a divine punishment for the patient's misdeeds, either in the present or a past life. The punishment is carried out by spirits or by an unfavourable astrological alignment. Treatment may involve penance, a pilgrimage to a shrine, talismans and a monetary fee. A *Patri* acts as a medium for spirits and demons and treats a patient by going into a trance and being possessed by a master demon. In this situation, treatment involves the *Patri's* demon either exorcising the patient's demon, or asking the patient's demon what it requires to leave the patient. The latter may be a ritual feast, an animal sacrifice or a dwelling for the demon's use (Kapur, 1979). Kapur reported that the villagers he observed patronised both Western-trained doctors and traditional healers simultaneously and had observed both modern doctors and *Mantarwadi* conducting their rituals together at a patient's bedside. Religious treatment in India may be conducted alone or with a guru and may take the form of religious lectures, praying, bathing, fasting and religious rituals (Bagadia et al, 1979). Thus, various shrines and religious centres have evolved therapeutic programs (rituals and lifestyles) where patients (or pilgrims) seek religious help for their maladies. When a mental illness is deemed to be due to the planets, an astrologer will recommend rituals as treatment (Bagadia et al, 1979) (see section on trance).



JD Challenger: Wisdom of the Shaman.
Source: http://www.firstpeople.us/

In Sri Lanka, *aduras* (devil-dancers) were a popular choice of healer for mental illnesses in some rural areas (Wolffers, 1988), with orthodox medical treatment and Ayurveda being patronised much less frequently. *Aduras* use a number of treatments, including ceremonies and fastening strings around the patient's arm or neck, and if this does not yield results, a publicly conducted exorcism may follow. Western-style treatment would then be used if treatment by an *adura* fails.

Far East: China, Taiwan and shamanism

In the Far East, the combination of religion, shamanism and the supernatural is accepted and an individual or a community will not necessarily adhere to one dogma over another in their concepts of mental illness. Harrell (1991) reported the case of a 16 year old female patient who presented with psychoses in rural Taiwan in the 1970s, where he detailed a large mixture of folk or traditional treatments as well as explanations for the girl's illness. Diagnoses were made by spirit mediums or Taoist fortune tellers and included the patient having lost her soul, being attacked by ghosts, living in a haunted dwelling, her grandfather's failure to produce a direct male descendant, something being

wrong with her spirit or character, and bad luck. Treatments included writing of charms on spirit money or paper which were then eaten, used to make infusions for drinking or bathing in, or hung in various parts of the girl's dwelling, placating ghosts and ancestral spirits with ritualistic food offerings and burning of spirit money and incense. In this case, orthodox medicine was only used to provide a sedative. Harrell observed that the community this patient lived in did not consider that there was only one cause or diagnosis for her condition and accepted all offered explanations, including retrospective ones, whereupon the cause of the illness was decided on the basis of which treatment (temporarily) succeeded.

Li and Phillips (1990) reported on witch doctors (shamans) and mental illness in mainland China, particularly among the rural peasant population. They located 14 witch doctors in two communities in LiChang county from 1984-5, who were all peasants themselves (10 were illiterate or semi-literate) and none of whom had training in Western or Chinese medicine, psychology or religion. Their methods for treating illnesses were shamanistic and ritualistic, with a blend of Taoism, Buddhism and animistic beliefs. The case studies presented showed treatment rituals similar to those described by Harrell in Taiwan. Li and Phillips reported that 70% of patients in their Hubei psychiatric hospital surveyed admitted to consulting witch doctors before presenting to their outpatient clinic. Li and Phillips also noted that some rural patients never present for Western psychiatric treatment and only used traditional folk healers (witch doctors).

Dervish

Dervishes are individuals who follow a Sufi Muslim ascetic path or tariqah and are known for their extreme poverty and austerity, similar to the Christian mendicant friars or Hindu sadhus.

North Africa and the Middle-East: Spirits, demons and fortune-tellers

In Egypt, a culture-bound condition, Egyptian women's disease, is treated with *Zar* cult ceremonies. The illness parallels hysteria in Western medicine, but is believed to be due to possession by a spirit. The ceremonies, which include music, slaughter of a sheep, dancers and the female patient going into trance, allow the traditional healer to communicate with the spirit, find out its demands and to pacify it (el-Sendiony, 1974). However, this anthropological study is quite old and thus it is not clear how widespread this women's disease is today, nor how commonly the *Zar* cult ceremonies are performed.

In Bedouin-Arab culture, both traditional and Western health practitioners are patronised. Traditional healers in Bedouin-Arab culture include: *Dervish* healers, who treat mental illnesses with religious and cultural rituals, including exorcism; amulet writers who produce amulets to ward off evil spirits; fortune-tellers, who predict the future or diagnose by reading the dregs in patients' coffee cups; and Koranic healers, men who treat patients who have been attacked by evil spirits by using religious principles based on the Koran (al-Krenawi & Graham, 1999). The *Dervishes* may themselves have had psychiatric illnesses, in that a previous mental breakdown is viewed as a "blessing gift from God" (p224). There are some gender and social differences in how patients perceive the cause of their illnesses with women citing sorcery and spirits as the cause, educated men citing divine will-and-punishment (religious) causes and less educated men citing spirits. The *evil eye* (being the subject of another person's envy) is also reported as a cause of mental health problems in



Ginkgo biloba

many cultures. Further, as a result of the social environment they inhabit, women use sorcery as their means of coping with psychiatric problems. Al-Krenawi and Graham highlighted the difficulties Western-trained psychiatrists may face in accurately diagnosing patients from such backgrounds, because patients use proverbs, similes and metaphors to describe their symptoms and emotions. These descriptions are understood by traditional healers, who have the same cultural experience and language, but could be very difficult for clinicians from other backgrounds to interpret. For example, Al-Krenawi and Graham quote female patients describing despair and hopelessness as "my eyes are blind and my hand is shorter" (p232).

Clinical importance of religious healing

The above scenarios illustrate not only the traditional treatments patients and their families or communities may seek for mental illness, but also how people view, describe or interpret a mental illness through their cultural lens. As in the case of sorcery, being able to engage patients and families within their cultural reference points is important for psychiatrists working with patients from these backgrounds.

By clicking on the title, interested persons may read the WHO's reports:

Regulatory Situation of Herbal Medicines: A worldwide Review

and

Legal Status of Traditional Medicine and Complementary/ Alternative Medicine: A Worldwide Review.

ACUPUNCTURE

Acupuncture—a traditional treatment in the Far East (China, Japan)—has become popular worldwide. In acupuncture, fine needles are inserted into different points on the body to correct energy imbalances. A 2009 survey in Hong Kong found that 40% of children with autistic spectrum disorder reported previously using CAM, with acupuncture being the most popular CAM treatment (Cheuk-Daniel et al, 2009). A Cochrane review of acupuncture as treatment for depression in adults is available and assessed seven trials but found insufficient evidence to support its effectiveness (Smith & Hay, 2004). Aside from mental disorders, acupuncture is used in numerous conditions including the management of nausea and vomiting, chronic asthma, epilepsy, migraine, pain, substance abuse and insomnia.

Table J.2.3. Managing young patients and their families using or planning to use traditional medicines

- When taking a medical history, ask and record current and past use of traditional treatments.
- Note what the patient and family believe is causing the child's illness. This may provide information on the patient's and family's cultural reference points when psychiatric treatment is explained and administered.
- Ask if the family intends for the child to continue taking traditional treatments or whether they plan to commence using traditional treatments.
- Do not dismiss the use of traditional medicines lightly. Allowing patients to continue their traditional treatments (if harmless) encourage compliance. Also, because of the belief systems associated with some traditional treatments, the use of traditional therapies can lessen the stigma of the illness and allow patients and families to continue functioning in their community.
- Balance the above openness to consider traditional treatment with concerns about the interactions of herbal medicines with prescription medications, their safety, efficacy and potential burdens (including financial and time-related).
- Safety concerns are not exclusive to herbal medicines but extend to non-biological physical therapies as well. The importance of using properly sterilized needles in acupuncture, and potential injury by the more physically demanding types of meditation, are examples.

Severe, life-threatening or fatal events due to complementary and alternative medicine in children

In Lim et al's (2011) Australian survey of paediatricians, 29 CAM-associated adverse events were reported in a 36 month period (2001-3). Four resulted in death due to CAM treatments being used in place of orthodox medicine: one case of pulmonary embolism (anticoagulants should have been used); two cases of malnutrition leading to sepsis and death due to dietary restrictions and homeopathy; and seizures and death because anticonvulsants were not used. Other serious adverse events from substituting orthodox treatments with CAM included delayed management of severe cerebral palsy, undiagnosed urinary tract infections, and hyperglycaemia because the insulin dose had been reduced and diabetes was treated with naturopathy.

Adverse effects directly due to the use of CAM in children included argyria from administering colloidal silver, acute hepatitis and liver failure from multiple herbal treatments and minerals which subsequently required a liver transplant, mouth ulcers from homeopathic medicines, hypercalcaemia from oral and intravenous calcium, acidosis from crushed pearls and bleeding due to gingko and ginseng.

Adverse effects of acupuncture

Though uncommon, acupuncture can have adverse effects, such as headaches, palpitations, sleep disturbance, tiredness and dryness of mouth (Smith & Hay, 2004). Rare side effects include pneumothorax, cardiac tamponade, direct injuries to the spinal cord, injuries resulting from migration of broken needles, bleeding, local skin infections, and infections from improperly sterilized needles—such as hepatitis, HIV, sub-acute bacterial endocarditis, staphylococcal septicaemia and mycobacteriosis. Apart from adverse effects, conducting acupuncture in children is complicated by children's acceptance. Children often have a fear of needles and do not retain needles for as long as adults, reducing treatment duration (Jindal et al, 2008). For children under 6 years old, shorter needles are often substituted for the conventional longer ones.

LEGAL STATUS AND REGULATORY ISSUES

The regulation and legal status of traditional and complementary medicine varies widely from country to country. For example, in Germany, herbal medicines have the same legal status as all other medicines while in the US, herbal medicines were mainly regulated as foods and, more recently (as of 1994), as dietary supplements (World Health Organization, 1998). In other countries, traditional medicines may be completely unregulated in terms of source, manufacturing, quality control, dispensation and who is permitted to administer treatments, including procedural treatments such as acupuncture. Moreover, even in countries where herbal medicines are regulated, the standards to which they are held are usually lower than conventional or orthodox medicines. Thus, *regulation* does not automatically imply efficacy and safety (Rey et al, 2011). Where regulations and laws exist, these can also vary from region to region within one country (World Health Organization, 2001).

Regulation of traditional medicines, or the lack of it, also means that access can be much easier than for orthodox medicines. For example, in Australia, minors have been able to purchase St John's wort over the counter (Walter & Rey, 1999), implying they may even self-administer herbal medicines without their carers' knowledge.

RESOURCES

Click on the picture to access MedlinePlus: Drugs, Supplements and Herbal Information (also available in Spanish).



Click on the picture to access the World Health Organization website and publications on traditional, complementary and herbal medicine.



OVERALL RISKS AND ADVERSE EFFECTS

Apart from the risks and adverse effects detailed above for individual therapies, there is also the risk to children's health if conventional medicine or treatments are substituted with traditional treatments or CAM. Lim et al's survey (2011) highlighted these risks. Treatments involving dietary restrictions can lead to severe malnutrition and this risk is greatest for infants and children with chronic conditions.

CONCLUSION

There is a vast range of traditional treatments available and this chapter has covered only a selection of them. Currently, there is insufficient empirical evidence to support the efficacy of traditional treatments as a sole therapy for mental illnesses. Few, if any, traditional medicines or therapies, can be confidently endorsed by mental health professionals as *stand-alone* treatments for children and young people. However, many patients and their families may have already used various traditional remedies before presenting for assessment or intend to continue using them. Health professionals need to be alert to and observant of any traditional treatments a patient may use. A mental health professional working with such patients will need to balance the potential risks of traditional treatments (including interactions with orthodox medications, physical injury from some procedures and financial costs) with sensitivity to cultural beliefs, patients and their family's social standing and reputation and their beliefs about the patient's illness. Clinicians should also be aware that allowing a patient to continue with a traditional treatment which does not interfere with prescribed orthodox therapies, together with regular and close monitoring, may enhance compliance to therapy overall.

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FORENSIC CHILD AND ADOLESCENT PSYCHIATRY

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Source: Barbara Barry = Design 0101

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Suggested citation: van der Sloot E, Vermeiren R. Forensic child and adolescent psychiatry. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Although child and adolescent psychiatric practice preferably takes place within a voluntary patient-therapist relationship, this is not always so. In some cases patients enter the area of forensic psychiatry, which covers all psychiatric care that is provided in relation to legal processes. Forensic psychiatry covers both diagnostic and therapeutic issues but a substantial part of the forensic psychiatric work lies in the diagnostic field. In that context, the clinician is asked to assess an individual and make a report that can be used for legal decision making. The content of the report, which makes specific guidelines advisable (Kraus et al 2011), is thus open to people other than the clinician and the patient (and family). Therapeutic issues in the forensic field are controversial because it is unclear to what extent one may force a patient to undergo treatment.

For several reasons, minors and their families may be forced by law to become a *patient*. This may be because either:

- The (family) environment is considered suboptimal for the development of the child or
- The underage person is suspected to have committed a criminal act or has been convicted.

The first situation is rather specific to childhood as underage children largely depend on adults who carry the responsibility of taking care of them. When the caregiving adult does not fulfill this task properly, it is in the interest of the minor that legal authorities take over. This may happen, for example, when maltreatment or physical or sexual abuse is suspected or have occurred. A specific situation that has become increasingly common over the last few decades relates to parental conflict in case of divorce. This is a particularly complex and difficult area as parents frequently accuse each other of maltreating or abusing their children. The second situation in which minors are forced to accept treatment occurs when the children themselves harm society by their behavior. This often goes hand in hand with the first situation – when adults do not fulfill their caregiving responsibility – although this is not always the case. Children often break the law, resulting in contact with the police and courts. This chapter focuses on youths who receive psychiatric care as a result of having committed an offence; this issue poses specific challenges when considered in the international context.

The following paragraphs will focus on the goals of forensic psychiatry and the developmental and psychiatric characteristics of juvenile offenders. Some international conventions, guidelines and rules concerning juveniles are also described, highlighting differences in legislation between countries.

CRIMINAL LAW AND AGE

Overall, the penal system has two main roles: *preventive* and *retributive*. In regards to *prevention*, a distinction is made between general and specific prevention. *General* prevention refers to the effect of fear of being caught and punished in discouraging people from committing an offence. *Specific* prevention targets possible recidivism of the delinquent himself, who may abstain from offending because of wanting to avoid further punishment.

Retribution meets the needs of the victims by providing them with a feeling of redress by knowing that the offender has been punished. In juveniles, a specific role of the criminal law is re-education and stimulation of development. The underlying idea is that minors commit offences (at least partly) because of their

Minor

The terms "minor", "juvenile", "youth" and "child" in this article have the same meaning as the term "child" as defined in article 1 of the Convention on the Rights of the Child: "For the purposes of the present Convention, a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier."

Clinical tasks and skills related to forensic obligations

Custodial treatment

- Assess the mental health of the juvenile: for acute conditions (suicide, psychosis, substance abuse) within 24 hours of arrest or detention; for other mental disorders within the first few weeks
- Re-evaluate mental state frequently throughout the legal processes

Protection of the rights of the juvenile

- Be aware of the country's laws and procedures related to the task
- Evaluate adolescents' development in relation to the impact and consequences of legal procedures

Risk assessment

- Ascertain the risks associated with the minor's condition
- Be cautious when interpreting findings from risk assessment and present findings as temporary and weighted as part of the expected development of the juvenile.

immaturity. By enhancing healthy development, further offending may be avoided and help youngsters become law-abiding, well-functioning citizens.

Over the last few decades, emphasis has shifted away from protection and towards retribution (Snyder & Sickmund, 2006). Even when dealing with younger delinquents, the public demands that punishment must be strict and many governments and courts are responding to this request. A well-known case in this respect was the murder in the UK of 2-year-old James Bulger by two 10-year old boys. Some are convinced that an emphasis on punishment is the way to reduce crime, because it is considered to strengthen the general preventive aspect.

Age of maturity

In juvenile penal law, the challenge is to find a balance between protection, care and punishment. Because juveniles are immature, the goal is both to protect and stimulate development, and to prevent further harm to society. An important issue concerns the *age of maturity*: at what moment in life one considers underage persons mature enough to be fully aware and in control of their acts. Being able to evaluate developmental maturity is thus an important task of the forensic clinician (Kraus et al., 2011). Consideration of etiological factors, both environmental and individual, plays a role in this. The maturity of a person depends, for example, on the quality of parental care but also on broader societal issues such as education. In addition, the individual's characteristics are important (e.g., intelligence). Current knowledge about brain development shows that maturity is not yet fully achieved by the age of 18; development continues until the early- to mid-20s (Shaw et al., 2008). It is however unclear to what extent the immaturity identified by brain research has behavioral consequences. Interestingly, notwithstanding evidence on maturity, age of criminal responsibility varies considerably according to country, from seven in Switzerland and Nigeria to 18 in Belgium (see Table J.3.1).

Table J.3.1 Examples of age of criminal responsibility (Cipriani, 2009)

AGE (years)	COUNTRY
7	Liberia, Nigeria, New York (US), South Africa
8	Scotland, Sri Lanka, Zambia
10	Australia, England, Northern Ireland, Switzerland,Texas (US), Wales
11	Japan
12	Canada, The Netherlands, Turkey
13	Algeria, Greece, Guatemala
14	Bulgaria, China, Germany, Italy, Romania
15	Czech Republic, Denmark, Finland, Norway, Sweden
16	Argentina, Cape Verde

Procedural guidelines for clinicians in the forensic field

When doing diagnostic work in the forensic field, clinicians are expected to report on their findings to legal authorities. Therefore, it is important that they:

- Know beforehand who will be allowed to read the report and to communicate this to the patient
- Know exactly what the questions are they have to report on, and that patients know these questions and understand them
- Focus their evaluation work and their report on these questions.

In relation to forensic therapeutic work, it is important that clinicians:

- Remain in their therapeutic role, which means that obligations to follow through with therapy rest with the legal authorities
- Are open to patients about what will and what will not be reported to authorities.

JUVENILE PENAL LAW

Care, protection and risk taxation

Forensic psychiatry is at the boundary between psychiatry and the law. As already described, forensic child psychiatry, as compared to forensic psychiatry of adults, has specific characteristics resulting from the psychological immaturity of minors. The tasks of forensic child psychiatry have been described by Grisso (2004) as follows:

- *The custodial treatment obligation*. The obligation of society to help people with an illness. When young people become involved with the judicial system, society has the responsibility to make sure that illnesses are recognized and treated. This is particularly so when minors are being detained because they and their families then lose the possibility and freedom to seek help themselves. Because of the stress associated with being arrested and prosecuted, there is an increased likelihood of triggering the onset of illnesses. Conditions that need specific attention in these circumstances are psychotic deterioration, suicidal behavior and consequences of substance abuse withdrawal.
- *Protecting the rights of persons in contact with the juvenile justice system*. Legal decisions can have a substantial impact on the young person's life. Therefore, it is important to ascertain that youths understand the procedures and the potential consequences of their decisions (Kraus et al., 2011). Also, it is necessary to ensure that children are cognitively able and mature enough to understand the procedures. In the US, this is, for example, important in relation to "Miranda" rights – the right to refuse to give self-incriminating information and the entitlement to have legal counsel present at any interrogation. The person who waives this right must understand what the potential consequences are. In countries where young people can be transferred to adult courts, it is necessary to ensure that these young people are able to understand and undergo adult court procedures. Because adolescents are known to think short term and favor immediate gain (Reyna & Farley, 2006), they are more likely not to act in their best interests when undergoing adult judicial procedures. For example, during interrogation they may deny facts even in the face of incontrovertible evidence, or to confess to a crime they have not committed to get rid of an unpleasant situation.
- *Risk taxation*. Protecting society by predicting the likelihood of recidivism is also important. Risk taxation not only serves the interests of the wider population but also those of the young people themselves. However, risk taxation is a complex issue in juveniles. Because they are immature and thus still developing, risk factors are likely to change, even without intervention. Therefore, one needs to be careful when considering risk, and always emphasize it as a momentary situation, that needs frequent re-assessment.

In order to fulfill these tasks well, the forensic expert needs to be able to conduct a thorough diagnostic assessment, and weigh the needs of offenders against the requirement to protect society.

James Patrick Bulger

James Bulger was a boy from Kirkby, England, who was murdered on 12 February 1993, when aged two. He was abducted, tortured and murdered by two ten-year-old boys, Robert Thompson and Jon Venables. James disappeared from the New Strand Shopping Centre in Bootle, near Liverpool, while accompanying his mother. His mutilated body was found on a railway line two-and-a-half miles away in Walton, two days after his murder. Thompson and Venables were charged on 20 February 1993 with James' abduction and murder. The pair was found guilty on 24 November 1993, making them the youngest convicted murderers in modern English history. They were sentenced to custody until they reached adulthood, initially until the age of 18, and were released on a lifelong licence in June 2001. The case has prompted widespread debate on the issue of how to handle young offenders when they are sentenced or released from custody.

On 2 March 2010, the Justice Secretary, Jack Straw, stated that Venables had been returned to prison because of "extremely serious allegations", and stated that he was "unable to give further details of the reasons for Jon Venables's return to custody, because it was not in the public interest to do so." (Source: Wikipedia).

INTERNATIONAL CONVENTIONS, RULES AND GUIDELINES

Some international conventions and treaties concerning the rights of minors and their protection have a direct influence on national legislation. Therefore, it is important for clinicians to be knowledgeable about international rules and guidelines and how one's country of practice has implemented those rules. The most important children's rights instrument is the *United Nations (UN) Convention on the Rights of the Child* (hereafter referred to as "the Convention") grounded on the Universal Declaration of Human Rights. Besides the Convention, the UN adopted three important guidelines concerning juveniles, which had an influence on and can be used together with the Convention. In this section a brief description is given of the most important international conventions relevant to juvenile delinquents. For the scope of this chapter we will focus on the relevant articles only (for a more detailed description of the Convention see Chapter J.7).

Besides the Convention, three other rules provide guidelines for juvenile justice systems on three different levels (Meuwese et al, 2005):

(a) Implementing a juvenile justice system
(b) Creating social policies for prevention of juvenile delinquency, and
(c) Protecting the right of incarcerated juveniles for social reintegration.

These guidelines are derived from the so-called Beijing rules, Riyadh Guidelines and Havana Rules respectively.

Beijing Rules

On 29 November 1985, the General Assembly of the UN adopted the *Standard Minimum Rules for the Administration of Juvenile Justice (Beijing Rules).* The Beijing Rules provided member states with guidelines for the protection of the rights of juveniles with the establishment of a specific juvenile justice system. Although the Beijing Rules are recommendations – and have therefore no binding legal status – member states were requested to incorporate these rules within their national legislation. The Beijing Rules were already in existence four years before the Convention was adopted and influenced the wording of the Convention. Some of the principles of the Beijing rules are incorporated in articles 37 and 40 of the Convention and will be discussed later in the chapter.



Serious concerns raised as children criminalised at 10.View video by clicking on the picture.

Riyadh Guidelines

The UN Guidelines for the Prevention of Juvenile Delinquency ("Riyadh Guidelines") were adopted by the UN on 14 December 1990. The Riyadh Guidelines should be seen as a further clarification and concretization of the rights of the child, especially of article 40 of the Convention. These guidelines are *child-centred*, that is, the minor is seen as a person and not just as an object. The guidelines are comprehensive and encourage a pro-active approach to the prevention of juvenile delinquency (Meuwese et al, 2005). The Riyadh Guidelines provide countries with standards to prevent juvenile delinquency, focussing on juveniles who are at "social risk" and suggesting multidisciplinary measures to minimise risk to children coming in contact with the legal system. Like the Beijing rules, the Riyadh Guidelines are not binding, their influence is moral.

Havana Rules

The *UN Rules for the Protection of Juveniles Deprived of their Liberty ("Havana Rules")* were adopted by the UN in December 1990 and are a supplement to the Beijing Rules. They provide standards for the protection of juveniles within the criminal justice system. For example, incarcerated minors should be segregated from adults and incarcerated with peers of the same sex, age and personality. Also they should be provided with appropriate education or training. Although these rules are not legally binding they are consistent with articles 37 and 40 of the Convention.



Thomas Spence's book "Rights of Infants" is one of the earliest English-language statements of the rights of children. Thomas Spence (June 21, 1750 – September 8, 1814) was an English revolutionary and advocate of the common ownership of land, for which he was incarcerated several times. (Photo: the Thomas Spence Trust)

UN Convention on the Rights of the Child

The most important children's rights document is the Convention, which is grounded on the Universal Declaration of Human Rights. The Convention was adopted by the UN on 20 November 1989 and enacted on 2 September 1990. With the exception of the US and Somalia – among others – 193 countries have ratified the Convention, although many member states – for example the Netherlands (Declarations and Reservations to the Convention on the Rights of the Child, n.d.) – have made some reservations or declarations to the provisions of the Convention.

The Convention spells out the basic human rights that children all over the world should have and is legally binding for signatory states. By ratifying the Convention, member states commit themselves to the protection of the rights of children and to be monitored by the UN Committee on the Rights of the Child concerning the status of the rights of children in their country. Articles 37 and 40 of the Convention spell out the key principles for juvenile justice. Together with the leading principles of the Convention (General Comment nr. 10, 2007) these articles form the basis for the legal status of minors deprived of their liberty (Liefaard, 2010).

Looking at article 37 one can see that it sets the minimum conditions with which countries need to comply when a child is deprived of liberty. This article can be divided into two different sections. First, it sets the minimum conditions concerning deprivation of liberty itself. According to article 37 this can only take place "in conformity with the law," as "a last resort" and "for the shortest period of time." Second, once a minor is deprived of liberty, the juvenile should be treated "with humanity and respect" and the needs of the juvenile ought to be taken into account. For example, in the Dutch legal system – based on Constitutional Law in conjunction with the Convention – juveniles can only be limited in the execution of their rights when this is necessary for the implementation of a deprivation of liberty and the objectives thereof (Muller & Vegter, 2009).

Article 40 of the Convention defines the minimum conditions for dealing with juveniles who have broken the law:

- The right to due process
- Age appropriateness; the age below which juveniles cannot be held responsible for infringement of penal laws is explicitly stated.

Important concepts used in this article include: dignity and worth, innocent until proven guilty, promoting reintegration, legal assistance, access to an

UN Convention on the Rights of the Child

Article 37

States Parties shall ensure that:

(a) No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment. Neither capital punishment nor life imprisonment without possibility of release shall be imposed for offences committed by persons below eighteen years of age;

(b) No child shall be deprived of his or her liberty unlawfully or arbitrarily. The arrest, detention or imprisonment of a child shall be in conformity with the law and shall be used only as a measure of last resort and for the shortest appropriate period of time;

(c) Every child deprived of liberty shall be treated with humanity and respect for the inherent dignity of the human person, and in a manner which takes into account the needs of persons of his or her age. In particular, every child deprived of liberty shall be separated from adults unless it is considered in the child's best interest not to do so and shall have the right to maintain contact with his or her family through correspondence and visits, save in exceptional circumstances;

(d) Every child deprived of his or her liberty shall have the right to prompt access to legal and other appropriate assistance, as well as the right to challenge the legality of the deprivation of his or her liberty before a court or other competent, independent and impartial authority, and to a prompt decision on any such action.

Article 40

1. States Parties recognize the right of every child alleged as, accused of, or recognized as having infringed the penal law to be treated in a manner consistent with the promotion of the child's sense of dignity and worth, which reinforces the child's respect for the human rights and fundamental freedoms of others and which takes into account the child's age and the desirability of promoting the child's reintegration and the child's assuming a constructive role in society.
2. To this end, and having regard to the relevant provisions of international instruments, States Parties shall, in particular, ensure that:
   - (a) No child shall be alleged as, be accused of, or recognized as having infringed the penal law by reason of acts or omissions that were not prohibited by national or international law at the time they were committed;
   - (b) Every child alleged as or accused of having infringed the penal law has at least the following guarantees:
     - (i) To be presumed innocent until proven guilty according to law;
     - (ii) To be informed promptly and directly of the charges against him or her, and, if appropriate, through his or her parents or legal guardians, and to have legal or other appropriate assistance in the preparation and presentation of his or her defence;
     - (iii) To have the matter determined without delay by a competent, independent and impartial authority or judicial body in a fair hearing according to law, in the presence of legal or other appropriate assistance and, unless it is considered not to be in the best interest of the child, in particular, taking into account his or her age or situation, his or her parents or legal guardians;
     - (iv) Not to be compelled to give testimony or to confess guilt; to examine or have examined adverse witnesses and to obtain the participation and examination of witnesses on his or her behalf under conditions of equality;
     - (v) If considered to have infringed the penal law, to have this decision and any measures imposed in consequence thereof reviewed by a higher competent, independent and impartial authority or judicial body according to law;
     - (vi) To have the free assistance of an interpreter if the child cannot understand or speak the language used;
     - (vii) To have his or her privacy fully respected at all stages of the proceedings.
3. States Parties shall seek to promote the establishment of laws, procedures, authorities and institutions specifically applicable to children alleged as, accused of, or recognized as having infringed the penal law, and, in particular:
   - (a) The establishment of a minimum age below which children shall be presumed not to have the capacity to infringe the penal law;
   - (b) Whenever appropriate and desirable, measures for dealing with such children without resorting to judicial proceedings, providing that human rights and legal safeguards are fully respected.
4. A variety of dispositions, such as care, guidance and supervision orders; counselling; probation; foster care; education and vocational training programmes and other alternatives to institutional care shall be available to ensure that children are dealt with in a manner appropriate to their well-being and proportionate both to their circumstances and the offence.

interpreter, and minimum age.

As one can see, all the member states have been provided with the same guiding principles – in case of the Convention, mandatory – to protect minors and how to treat them in case minors transgress the law. In the next section we will see that, although the same guidelines are implemented, there are differences between countries which can influence clinical practice.

Country-specific legislation

The balance between protection and punishment concerning juvenile delinquents differs according to country. The juvenile justice laws in the Netherlands and Belgium are a good example. In every UN member state minors commit crimes and in every state minors can be held by the police, interrogated, sent to juvenile justice institutions, and often punished. Although these similarities between states are obvious, there are differences that cannot be ignored.

Firstly, implementation of the Convention is not homogeneous. Many countries have made reservations and declarations to the provisions of the Convention before their implementation. For example, in relation to articles 37 and 40 of the Convention, the Netherlands has made the following reservations upon implementation, which have somewhat modified the legal effect of article 37 and 40, and adjusted the articles to their own specific juvenile criminal law. Belgium however, has *only* made one interpretive declaration to article 40 (Declarations and Reservations to the Convention on the Rights of the Child, n.d.).

The Netherlands

- Article 37: "The Kingdom of the Netherlands accepts the provisions of article 37 (c) of the Convention with the reservation that these provisions shall not prevent the application of adult penal law to children of sixteen years and older, provided that certain criteria laid down by law have been met."
- Article 40: "The Kingdom of the Netherlands accepts the provisions of article 40 of the Convention with the reservation that cases involving minor offences may be tried without the presence of legal assistance and that with respect to such offences the position remains that no provision is made in all cases for a review of the facts or of any measures imposed as a consequence."

Belgium

- "With regard to article 40, paragraph 2 (b) (v), the Belgian Government considers that the expression 'according to law' at the end of that provision means that:
  - (a) This provision shall not apply to minors who, under Belgian law, are declared guilty and are sentenced in a higher court following an appeal against their acquittal in a court of the first instance;
  - (b) This provision shall not apply to minors who, under Belgian law, are referred directly to a higher court such as the Court of Assize."

As one can see there are considerable differences between the two. The Netherlands has two reservations on the implementation of the Convention to the Dutch legal system. Belgium *only* provides an interpretive declaration to clarify the meaning of an expression used in article 40.

Reservation and declaration

According to the Vienna convention on the law of treaties (n.d.) the following definition is used for a reservation made upon a treaty:
Reservation "means a unilateral statement, however phrased or named, made by a State, when signing, ratifying, accepting, approving or acceding to a treaty, whereby it purports to exclude or to modify the legal effect of certain provisions of the treaty in their application to that State."
Declaration is a clarification of a meaning of an expression used.

Besides the *regular* criminal law system for adults, the Netherlands also has adopted a juvenile criminal law system in which minors as young as 12 years of age can be held accountable for committing a crime and can therefore be convicted and punished. However, because juveniles are still developing, the juvenile justice system in the Netherlands acknowledges this and incorporates objectives such as re-socialization and education besides retribution and prevention. The Dutch juvenile justice system therefore emphasizes pedagogical support and re-education as part of the legal decision making, and the minor as a person is the primary consideration during this process. Belgium, on the contrary, has no separate juvenile justice system; minors younger than 18 years are protected by civil law (*Law on the Protection of Young People*), that is, juveniles under the age of 18 are considered to have no criminal responsibility. Therefore, judges can decide to impose measures upon the delinquent minor, which can have an educational or protective character (van Dijk et al, 2006); see Table J.3.2.



Life in prison for juveniles? View video by clicking on the picture.

Considering the above, one could conclude that the difference is the balance between considering juvenile delinquent acts as criminal or envisioning youngsters as immature persons who need help. In each country, the balance between punishment and a therapeutic approach varies, as well as the frequency in which specific consequences are given. In practice, forensic psychiatrists need to understand and have a good knowledge of the judicial framework they have to work with, which varies. Clinicians need to be aware of the different aspects of criminal law, namely general prevention, specific prevention and retribution and, for juveniles, re-education and promoting development. Clinicians need to use this knowledge when dealing with policy makers to explain how these roles must be combined appropriately.

DEVELOPMENTAL AND PSYCHIATRIC ISSUES

When dealing with delinquent youths, a number of developmental and psychiatric issues are of importance. Firstly, while many youths show delinquent

Table J.3.2 Differences between legal systems using The Netherlands and Belgium as examples.

The Netherlands:

- Juvenile criminal law applies to children aged 12-18.
- Consequences:
  - Punishment can be given, including detention in juvenile jail (maximum 2 years)
  - Offences are added to the personal penal record, some to be kept for life (sexual offences)
  - The rights of offenders are regulated, e.g., with regards to arrest, interrogation, and detention

Belgium

- There is no juvenile criminal law but civil protection law until age 18.
- Consequences
  - Only protection measures are possible, including detention
  - No personal penal record until the age of 18
- Regulation of rights in relation to being protected but not in relation to arrest.

In both countries, minors committing an offence at age 16 and 17 can be convicted as adults, under specific conditions of severity of the crime and maturity of the offender.

behavior over the course of their lives, only a minority become persistent offenders. The dual taxonomic model of Moffitt (1993) is useful to understand these pathways. Moffit's work has shown that, apart from an adolescent-onset delinquent group that tends to desist from crime later on (*adolescent-limited*), there is an early-onset group which has an increased risk of persisting in their delinquent behavior (*life-course persistent*). Offenders in the life-course persistent group have risk factors in the individual and environmental domains (Moffitt, 1993). They usually grow up in multi-problem families, with parents who all too often have psychiatric problems themselves. Individually, they are recognized as being impulsive and having lower intelligence, particularly in the verbal domain. In contrast to the life-course persistent group, the adolescent-limited group has fewer risk factors and often commits offences because of peer pressure. Risk of persistence in the long term is lower, and thus may not require intensive intervention. However, a small subgroup of the adolescent-limited group who abuse substances will persist in their offending behavior and need to be recognized. Although the life-course persistent group is estimated to comprise only 5% of the (male) population, they commit half of all offences attributed to adolescents. This group needs intensive intervention and society needs to be protected from them.

Secondly, individuals are vulnerable to committing offences until early in adulthood because of developmental immaturity. Current understanding of the development of cognition and executive functions suggests that in contrast to adults, who take decisions in the rational part of the brain, children and adolescents are more inclined to use lower brain areas. Consequently, they are more likely to make irrational and impulsive decisions (Reyna & Farley, 2006). An immature way of thinking is normative for adolescents resulting in an underestimation of negative consequences and in being more likely to come up with either/or responses than with a range of options. As a consequence adolescents are more likely to react inappropriately (e.g., aggressively) to others because they perceive messages as threatening more often and because they lack an adequate arsenal of reaction modalities. Further, they are less likely to perceive certain behaviors as risky (Cohn et al, 1995). As a result, they do not fully understand that an arrest and adjudication (legal judgment) are likely to harm their future drastically. It is known that moral development only comes to maturity in early adulthood (Colby et al, 1987). Because of this, juveniles do not empathize with others in the same way that we expect of adults; thus they do not fully understand the effect on others of their inappropriate behavior. Immaturity, as described here, does not only influence the likelihood of committing an offence but also an adolescent's attitude during the judicial procedures.

Thirdly, several studies have shown that a majority of incarcerated youth suffers from psychiatric disorders and that comorbidity occurs very frequently in this group (Colins et al, 2010; Vermeiren et al, 2006). Recent studies have demonstrated that apart from internalizing (i.e., depression and anxiety) and externalizing disorders (i.e., conduct disorder, oppositional defiant disorder, ADHD), psychosis-related symptoms as well as substance abuse and dependence are very common in juvenile delinquent populations (Colins et al, 2010). While most studies on adolescents in detention have focused on boys, some studies on girls are available (Teplin et al, 2002; Vermeiren, 2003). Although antisocial behavior is much less frequent in girls than in boys, psychiatric pathology may be

Children in legal proceedings

In legal proceedings, a juvenile younger than 18 years should always be considered immature, not only because of normative developmental data but also because of the consequences of frequently occurring psychiatric disorders. This has as a consequence that juveniles:

- Are more likely to commit crimes without fully understanding the consequences for the victim and for themselves
- Are more likely to react inappropriately during interrogation, either by denying even in the face of incontrovertible evidence or admitting to a crime they have not committed
- Are less likely to have a realistic view of the long-term consequences of legal decisions.

more prevalent among detained girls, in particular depression and post-traumatic stress disorder, while externalizing disorders and substance abuse and dependence may be similar in boys and girls.

In this chapter we have discussed a variety of issues forensic psychiatrists need to know for the practice of their profession. As described, the tasks of the forensic psychiatrist have to be performed always with a good knowledge of the developmental and psychiatric characteristics of juvenile offenders. Furthermore, countries vary considerably in the way they handle juveniles committing delinquent acts. On an international level, the implementation of conventions, rules and guidelines differ according to county. These differences substantially relate to the balance between protection and punishment, whether choosing a punishment or a therapeutic approach. For example, while some countries have adopted a juvenile criminal law system, others have not, considering that juveniles do not have criminal responsibility. One should however contemplate that the differences described are not all-embracing. In conclusion one could say that besides the characteristics and development of juvenile delinquents, a clinician should be aware of the national and international legislation and the judicial framework of their country of practice.

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THE MENTAL HEALTH OF CHILDREN FACING COLLECTIVE ADVERSITY

POVERTY, HOMELESSNESS, WAR AND DISPLACEMENT

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London Street Children by Edward R. King (1904) UCL Art Museum

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Suggested citation: Pacione L, Measham T, Kronick R, Meloni F, Ricard-Guay A, Rousseau C, Ruiz-Casares M. The mental health of children facing collective adversity: Poverty, homelessness, war and displacement. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Adversity can take multiple forms for children. It may stem from constitutional vulnerability, from parental and familial difficulties and dysfunction or from environmental stressors, all of which may jeopardize children's development and affect their mental health. Poverty, becoming orphaned, homelessness child labor and war all expose children to potentially harmful environmental stress. This chapter will describe the effects of these kinds of collective adversities on the mental health and well being of children. The experience of refugee children will be taken as an example to illustrate the approach to the mental health assessment and treatment of vulnerable children once they are in a situation of safety.

THE MENTAL HEALTH CONSEQUENCES OF POVERTY FOR CHILDREN

Defining poverty

Poverty is a difficult concept to define because it overlaps with many different cultural, social, and political dimensions. The "poverty line" is typically defined as the cut-off point that separates the poor from those earning what is considered to be an adequate level of income in a given country (Ravallion, 2010).

The World Bank defines the poverty line in two ways: A *relative poverty line* is one that depends on the income distribution within a given country and varies according to purchasing power. For example, the poverty line is often set at 50% of a given country's mean income. An *absolute poverty line* (also called *extreme poverty*) is defined using different methods, but is often determined in relation to the average cost of basic survival needs in the poorest 10 to 20 countries. In 2005, the World Bank defined the absolute poverty line at a household income of less than $1.25 (US) per day (Chen & Ravallion, 2010). This new value is an increase from the previous value of $1 (US) per day and is thought to better represent the cost of goods. Sometimes a household income of less than $2 (US) per day is used as a cut-off to better describe the scope of poverty in a given country or region. Using a cut-off of less than $1.25 (US) of household income per day, an estimated 1.29 billion people, or about a quarter of the population of the developing world, were living in absolute poverty in 2008 (World Bank, 2012). To put this in relative terms, the number of people living in absolute poverty is over 4 times the size of the US population as measured in the 2010 census.

A declaration and action plan developed at the UN World Summit on Social Development in Copenhagen in 1995 defined *absolute poverty* as "a condition characterised by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information. It depends not only on income but also on access to services." (Gordon, 2005). Poverty can therefore be interpreted as the state of having insufficient access to resources needed for survival. Given the concept of *relative poverty*, poverty can also be seen as a state of relative material and social disadvantage. These are obviously overlapping definitions but each has unique consequences for children's physical and mental health.

The multifaceted impact of poverty is captured by the United Nations (UN) official definition of poverty that was ratified by the heads of all UN agencies in 1998: "Fundamentally, poverty is a denial of choices and opportunities, a violation

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The section on child soldiers is partly based on: Denov M, Ricard-Guay A (in press). Girl soldiers: towards a gendered understanding of wartime recruitment, participation and demobilization. In *Gender and War: A Handbook*. Edward Elgar Publishers.

of human dignity. It means lack of basic capacity to participate effectively in society. It means not having enough to feed and clothe a family, not having a school or clinic to go to, not having the land on which to grow one's food or a job to earn one's living, not having access to credit. It means insecurity, powerlessness and exclusion of individuals, households and communities. It means susceptibility to violence, and it often implies living on marginal or fragile environments, without access to clean water or sanitation" (Gordon, 2005). Indeed, Mahatma Gandhi has described poverty as "the worst form of violence".

Mahatma Gandhi described poverty as "the worst form of violence"

Children are particularly affected by poverty because they are usually dependent on their parents or other adults and in a powerless and vulnerable social position (Boyden & De Berry, 2004; Lansdown, 1994; Scheper-Hughes & Sargent, 1998). Poverty therefore has unique impacts on children.

In 2006, the UN General Assembly adopted the first internationally agreed upon definition of child poverty:

"Children living in poverty are deprived of nutrition, water and sanitation facilities, access to basic health care services, shelter, education, participation and protection, and that while a severe lack of goods and services hurts every human being, it is most threatening and harmful to children, leaving them unable to enjoy their rights, to reach their full potential and to participate as full members of the society" (Minujin & Nandy, 2012 p3).

Measuring child poverty

Given the vulnerable social position of children, The UN Children's Fund (UNICEF) has urged that the conceptualization of child poverty be expanded beyond the concept of income poverty. An operational definition of absolute poverty for children has been defined as the severe deprivation of two or more basic human needs for children, including severe deprivation in the following areas (Gordon & Nandy, 2008):

- Food deprivation leading to severe malnutrition
- Water deprivation with access limited to surface water or water sources far from home
- No access to sanitation facilities (toilet or latrine)
- Health deprivation, including lack of immunization or medical treatment
- Shelter deprivation (i.e., severe overcrowding with five or more people per room, or dwellings with no flooring material)
- No access to professional education of any kind
- Information deprivation (i.e., children aged between 3 and 18 with no access to newspapers, radio, television, computers or phones at home)
- Deprivation of access to basic services (i.e., children living 20 kilometers or more from any type of school or 50 kilometers or more from any medical facility with doctors).

Of these measures, severe deprivation of shelter, sanitation, information and water are the most common worldwide, but the indices vary depending on the affected region (Gordon & Nandy, 2008).

The scope of child poverty

Given the difficulties in measuring poverty using general data about income, access to resources and services can provide a clearer picture of poverty and social inequality for children. Among the estimated 2.2 billion children in the world, one billion are estimated to live on less than 1$ a day (UNICEF, 2005a). Furthermore, for the 1.9 billion children who live south of the equator, there are:

- 640 million without adequate shelter (one in three)



Brot! (Bread!) lithograph by Käthe Kollwitz (1867-1945).

- 400 million with no access to safe water (one in five)
- 270 million with no access to health services (one in seven) (UNICEF, 2005a).

Although rates of absolute poverty are striking in developing countries, high levels of poverty in terms of relative economic and social deprivation are also found in Western countries. In wealthy countries, the risk of poverty is significantly affected by ethnicity, citizenship and immigration status. For example, in the US, Black and Latino children are disproportionately poor, lacking health insurance, and having limited access to social services and education (Fass & Cauthen, 2008; Guendelman et al, 2005). Citizenship may also influence a family's risk of poverty. In Germany, the number of children in non-citizen families living in poverty almost tripled from about 5% at the beginning of the 1990s to 15% in 2001, while poverty levels for children of German citizens did not change (UNICEF, 2005b).

There is a strong relationship between poverty, health, social inequality and denial of basic human rights (UNICEF, 2000; 2006a). Women are estimated

to make up 70% of the world's poor and are thought to be disproportionately affected due to gender-based systematic discrimination that limits women's access to education, health care, economic opportunities and control of assets (United Nations Women, 2010). Consistently, female children are often disproportionally affected by poverty and under conditions of absolute poverty, they are more likely than their male siblings to suffer malnutrition, have stunted growth and be denied access to primary school education (Khuwaja et al, 2005; Baig-Ansari et al, 2006; United Nations, 2010). In some countries, gender biases in property and inheritance laws and restrictions on acquiring assets perpetuate the cycle of poverty for women and girls (UNICEF, 2006a).

Poverty and armed conflict

Poverty also interacts with political instability, armed conflict, violence and discrimination in ways that specifically affect children. For instance, in cases of armed conflicts and dire poverty, family survival strategies may single out children as expendable, through abandonment, trafficking, or militarization (Boyden & De Berry, 2004; Einarsdóttir, 2006; Scheper-Hughes, 1987). Minors who are displaced by armed conflict, and who are often not recognized or protected by national states are particularly affected by poverty (Boyden & Hart, 2007). In 2006, the UN High Commissioner for Refugees announced that 5.8 million people were stateless and 13.5 million internally displaced (Bhabha, 2009). For these children, the entitlement to social rights that is, in principle, assured by a nation state, is often denied or granted on compassionate grounds, if at all. Another example of the particularly vulnerable role of children is the case of citizen minors who lack access to education or health care because their parents do not have legal status within their host country (Bernhard et al, 2007; Ruiz-Casares et al, 2010).

Developmental, emotional and behavioural consequences of poverty for children

The consequences of poverty for children can include long-lasting impacts on psychological and physical development. In fact, the harm suffered due to malnutrition and inadequate health care in early childhood often has severe consequences on a child's development and well-being (Brooks-Gunn & Duncan, 1997; Nandy et al, 2005; Seccombe, 2000; Simich, 2006). The higher prevalence of neurodevelopmental disabilities and lower educational achievement among children growing up in severe poverty may be explained by a number of factors, including protein-energy malnutrition leading to structural brain abnormalities, dietary micronutrient deficiencies, environmental toxins, lack of early sensory stimulation, anemia secondary to parasitosis, and the sequelae of infectious disease (Bergen, 2008).

Much of the research on the impact of child poverty on mental health has been conducted with children in developed countries who are exposed to relative poverty and social deprivation. These data indicate that poverty increases the risk of behavioural and emotional symptoms in children and may also negatively affect mental health in adolescence and adulthood. In a study of 5000 low-income families in 20 large US cities, homelessness or precarious housing status was associated with more internalizing and externalizing problems among three-year-old children compared to their more stably housed counterparts (Park et al, 2011).

In a large longitudinal study done in Australia, exposure to poverty in utero and at six months, five years or 14 years were all associated with higher rates of anxiety and depression in adolescence and early adulthood, and repeated experiences of poverty were associated with poorer mental health (Najman et al, 2010). A study of poor rural US families who moved out of poverty because of an income intervention demonstrated that among families who moved out of poverty, their children exhibited fewer symptoms of conduct and oppositional defiant disorders, but no change in symptoms of anxiety and depression (Costello et al, 2003). This raises the possibility that the effects of poverty on internalizing and externalizing symptoms in children may be moderated by different mechanisms. In wealthy societies, on a population health level, child well-being is associated with greater income equality and a lower percentage of children in relative poverty rather than average household income alone (Pickett & Wilkinson, 2007). Therefore, relative child poverty has been shown to have a lasting impact on both child and adult mental heath and may be related to both material and social deprivation and inequality. Reducing income inequality in wealthy countries may be an important goal in order to improve child well-being across society as a whole.

Reducing income inequality in wealthy countries may be an important goal in order to improve child well-being across society as a whole.

How child poverty leads to poorer mental health outcomes is not clearly established, but some data suggest that the physical and psychological stresses of poverty have lasting consequences on the developing child. Poverty may mediate its effect on mental health through alterations in the function of the sympathetic nervous system, which increases release of adrenaline and noradrenaline, and the hypothalamic-pituitary axis, which stimulates the production of the stress hormone cortisol (Evans & Kim, 2007). Furthermore, excessive stress during childhood is



Nepalese Boy.
Photo: shashish
http://www.flickr.com/photos/shashish/3527873250/

associated with architectural changes in different regions of the developing brain, including the amygdala, hippocampus, and prefrontal cortex, which are involved in emotional experience, stress regulation, learning and ability to cope with adversity (Shonkoff et al, 2012).

Resilience

Despite the harmful effects of poverty on children, it is important to take into account the resilience and the coping strategies employed by these children. Boyden (2004) remarked that factors such as gender, class and ethnicity play a significant part in shaping children's experience and their capacity to deal with adversity. A longitudinal study on a multiracial cohort of children exposed to chronic poverty has also shown the importance of children's role within the community, along with the presence of social networks and personal resources (Werner, 1993). Children are thus agents of their own development and, even in situations of adversity and chronic poverty, they can consciously act upon and influence the environments in which they live.

Conclusion

In conclusion, we need to understand poverty as the result of the interaction of a multitude of factors, including labor markets, government policies, family efforts, political conflicts, social discrimination, and personal strategies. For clinical practice, it is important to look at the influence of poverty and social inequality not through a restricted focus on children's deprivation, but within a much more extensive framework which includes wider cultural, social, political, and individual dimensions (Sen, 2008).

GROWING UP TOO FAST

ORPHANS, CHILD HEADED HOUSEHOLDS, STREET CHILDREN AND CHILD LABOR

In most middle and low income countries, the issue of poverty is clearly related to other major risks to child health and well-being, including orphanhood, homelessness, displacement due to disasters and conflict, street children and child labor. The most vulnerable children are those who do not have any adult caregivers. These children often assume adult roles in order to survive under conditions of severe deprivation and adversity; however, they are typically denied the rights and privileges afforded to adults in society.

ORPHANS AND CHILD HEADED HOUSEHOLDS

The number of orphans globally is estimated at 153 million (UNAIDS, 2010). This includes all children (0–17 years old) who have lost one or both parents – *single orphans* and *double orphans* respectively – through death, separation or abandonment. Of these 153 million, almost 12% have lost both parents and 11% of these have lost one or both parents to AIDS (UNAIDS, 2010). These proportions, however, vary enormously by country; for example, 16% of all orphans in Namibia have lost both parents and 58% of these have lost one or both parents to AIDS (UNAIDS, 2010). Diversity of definitions of what constitutes an orphan renders the comparative analysis of evidence difficult (Sherr et al, 2008). In

Introduction to Working with Children and Psychosocial Support



Participant's Manual

ANCHOR
Africa Network for Children Orphaned and at Risk

Click on the picture to access "Introduction to Working with Children and Psychosocial Support Participant's Manual". The workshop is designed to raise awareness around the issues that children who are affected by HIV are facing and how to offer support and build resilience (Hope Worldwide Africa, 2006)

the last decade, based on existing research evidence on the situation of orphans and non-orphans in many countries, UNICEF and most international organizations have widened their focus to include a number of factors that make children and families vulnerable other than orphanhood (e.g., household poverty, parental education, child labor, homelessness etc). The expression "orphan and vulnerable children" is therefore more commonly used.

To this day most orphans and other vulnerable children are still living within their extended families, often with their grandparents (Monasch & Boerma, 2004; Nyangara, 2004). Multi-generational households and child fostering have a long tradition in many parts of the world as a means to strengthen relationships and redistribute resources within families (Madhavan, 2004). While purposeful fostering of children within the extended family can reduce the impact of orphanhood, there is evidence that children from families with little regular contact with relatives are at greater risk of being abandoned if their current caregiver dies (Foster et al, 1997). Sometimes, relatives neglect, exploit or cast orphan relatives out (Foster et al, 1997). Relocation and housing insecurity frequently surround parental death (Foster, 2000). As a result of war and displacement, millions of children grow up in the absence of one or both parents, often separated from siblings and other family members.

As a result of abuse, poverty, and family separation in contexts of armed conflict, natural disasters, and the AIDS pandemic, *child- and youth-headed households* have emerged (Luzze, 2002). In some cases, child- and youth-headed households are created in response to the last wishes of the deceased parent, or the preference of children themselves (Foster et al, 1997). CHHs generally emerge after the death of the mother. Since the first child- and youth-headed households were recognized in Uganda and Tanzania in the late 1980s, this phenomenon has been documented in many other countries in the region. There are also non-orphan, "functional" child- and youth-headed households which arise in order to allow children to complete their education (Ruiz-Casares, 2009).

Orphaned children try to stay together as much as possible to help each other grieve; maintain sibling, family and community ties; secure assets; avoid abuse by relatives and obtain assistance and cultural guidance from elders in their communities.

The effects of parental separation due to a variety of causes have been studied in contexts of war, natural disasters and orphanhood. The loss of one or both parents is often compounded by separation from siblings and other family members, poverty, lack of access to basic services, stigma and exclusion (Cluver et al, 2008). Sibling dispersion among relatives is a common coping mechanism used in situations of orphan crisis, particularly when there are multiple infants and young children from the same family who require care (Foster, 2000). However, orphaned and separated children—particularly older ones – tend to try to stay together as much as possible (Germann, 2005). By remaining together in their parents' home, children are able to help each other grieve; maintain sibling, family and community ties; secure assets; avoid abuse by relatives and obtain assistance and cultural guidance from elders in their communities (Germann, 2005).

Risks faced by orphaned children or child headed households

Orphaned children with no parents or adult guardians are especially vulnerable (Donald & Clacherty, 2005). Particularly disadvantaged are girls because they are usually the first in the household to drop out of school, care for younger siblings and take on many adult tasks (Francis-Chizororo, 2010). Some

heads of child- and youth-headed households who are caring for multiple younger siblings are as young as nine years old (Roalkvam, 2005). Orphaned children are often forced into abusive situations and exploitative employment in an attempt to negotiate their survival (Cluver et al, 2008). Many children are forced into sex work, thereby exposing themselves to significant physical and psychological risks (Cluver et al, 2011). School dropout, serious health deterioration and a consequent loss of future are frequent consequences of orphanhood. Property grabbing by relatives or other community members is common and children are often not consulted about their preferred living arrangement after the death of their parent or other caregiver (Ruiz-Casares, 2009). In a study of more than one thousand children in Zimbabwe, orphans were found to suffer greater psychological distress compared to non-orphans. This distress was mediated by trauma, being out-of-school, being cared for by a non-parent, inadequate care, child labor, physical abuse, stigma and discrimination (Nyamukapa, 2010).

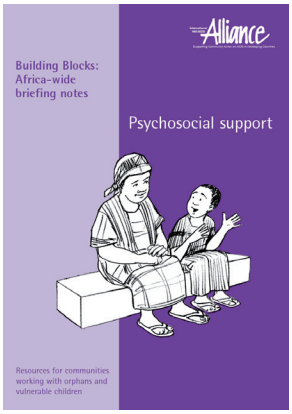
In the case of parental loss due to HIV/AIDS, not only are children often alone in carrying the emotional burden of caring for and watching a loved one suffer and die, but they may also experience stigma, discrimination, and a reduction in social status and family economic power (Nyamukapa, 2010). Children orphaned by HIV/AIDS often experience extreme or increased poverty because of expenses related to caring for sick parents and the loss of parental financial support, and many live in fear that they have the disease themselves (Bhargava, 2005; Cluver et al, 2008; Germann, 2005; Luzze, 2002). Many do (Hillis et al, 2012). A systematic review of empirical studies on HIV/AIDS and orphans found that orphaned children often have negative psychological and physical outcomes (Foster, 1998). Researchers have found, for example, elevated levels of psychological distress in orphans, including anxiety, depressive symptoms, anger, loneliness, low self-esteem, social withdrawal, and sleep problems (Bhargava, 2005; Makame et al, 2002; Ruiz-Casares et al, 2009; Zhao et al, 2009).



Nermine, Street Child in Cairo. Photo: Linda Forsell

Unaccompanied minors

Unaccompanied minors who are asylum-seekers, refugees or internally displaced in their home countries are a special population of homeless children who tend to face different challenges than non-migrant unaccompanied homeless children. They are often separated from their families in situations of armed conflict, natural disasters and political violence. Unaccompanied minors are defined by the UN Convention on the Rights of the Child as children less than 18 years of age "who have been separated from both parents and other relatives and who are not being cared for by an adult who, by law or custom is responsible for doing so" (Touzines, 2007). Unaccompanied minors can therefore be thought of as a high-risk subset of orphaned children. They report high rates of personal exposure to physical and sexual violence and have been shown to have high rates of mental health problems, including depressive symptoms and post-traumatic stress, which persist even after resettlement in a new country (Seglem et al, 2011). When compared to asylum-seeking children with families, unaccompanied minors seeking asylum have higher rates of psychiatric symptoms and disorders (Wiese & Burhorst, 2007).



Africa Network for Children Orphaned and at Risk

Click on the picture to access briefing notes about guidelines for programmes aimed at providing support to orphans and vulnerable children (International HIV/AIDS Alliance, 2003).

STREET CHILDREN

Children who are living on the streets, in poor urban slums or squatter settlements and those who are homeless because of armed conflict, natural disasters or political violence are amongst the most vulnerable and disadvantaged. These children suffer abuse, exploitation, sexual violence, and physical and mental illnesses. The problem of street children can be viewed from human rights, community mental health and economic development perspectives (McAlpine et al, 2010). Despite living under extremely harsh circumstances, street children display resilience and utilize effective coping strategies in their struggle for survival.

- The term *street children* is used to refer to children who work or sleep in the streets. There is no universally agreed upon definition of street children; UNICEF uses two definitions: *Homeless street children*, also called "street-based children" or "children *of* the street", who live and sleep on the streets in urban areas, often on their own, living with other street children, homeless family members or other homeless adults, and
- *Non-homeless street-involved children,* also called "home-based children" or "children *on* the street", who spend much of the day on the street but maintain contact with their families and typically return home at night (UNICEF, 2001).

In Western countries, the terms *homeless youth* and *street-involved youth* are used to refer to these two populations respectively. Street children therefore comprise a heterogeneous group of children who may sleep on the streets, sleep at home with their families or a mixture of the two; however, they tend to be unsupervised and unaccompanied for most of the day and are therefore at risk of abuse and exploitation. Based on these definitions, child laborers who work most of the day on the street as vendors, garbage collectors, porters, shoe and car cleaners, guards and street performers are also considered street children.

The number of street children cannot be accurately measured, but they are estimated to be in the tens of millions with some estimates as high as 100 million

(UNICEF, 2006). With increasing global population and high migration to urban areas, the number of street children is believed to be growing (UNICEF, 2006b). Some studies use a capture-recapture method to estimate the number of street children in a specific area. Studies using this method have demonstrated that the majority of street children are male, maintain contact with their families, sleep at home at least once per week and are wage earners who help support their families of origin (Bezerra et al, 2011; McAlpine et al, 2010). An estimated 80% of street children are boys, which may be the result of girls' perceived value as domestic workers (Abdelgalil et al, 2004; Le Roux, 1996).



Click on the picture to access "Guidelines for Working with Street Children" by Judith Ennew

The primary reasons that street children report for becoming homeless include family poverty, abuse and family violence, being orphaned or becoming separated from their parents during migration (Abdelgalil et al, 2004; McAlpine et al., 2010). Homeless children are much more likely to report having fled abuse in their families of origin compared to non-homeless street children (McAlpine et al, 2010). Unfortunately, once on the street, children are often exposed to more abuse. Children who are homeless and sleeping on the streets without contact with family members or caregivers are estimated to comprise around 15% of all street children (Bezerra et al, 2011). Street-involved children who sleep at home tend to report different reasons for street-involvement, including family poverty, being pressured by their parents to work or beg on the street and the desire to play or spend time with friends (Lalor, 1999).

The health of street children

Most studies on the health of street children are small and many focus on drug use, infectious disease, especially HIV/AIDS, and abuse. However, being in the streets exposes children to a multitude of health risks. Street children report high levels of abuse and harassment by police and other street children, inability to attend school, involvement in crime, and medical problems, including injuries and skin and respiratory infections (Ali & Muynck, 2005; Huang et al, 2004). In Brazil, thousands of street children have been murdered and the majority were believed to have been killed by death squads, the police or other types of criminal gangs (Inciardi & Surratt, 1998).

Both girls and boys living on the street report high rates of sexual assault by strangers and engagement in "survival sex", whereby children exchange sex for food, shelter or money, is common (Pagare et al, 2005; Sherman et al, 2005). In a study of street children in Rwanda, more than three-quarters of girls, including 35% under the age of 10 reported being sexually active and 93% reported having been raped while over 60% of boys reported having perpetrated rape (Save the Children, 2005). A high proportion of street youth are sexually active with multiple partners and do not use any protection against pregnancy or sexually transmitted diseases (Nada & Sulima, 2010). Homeless street children who are also orphaned may have even greater health risks than non-orphaned homeless children, including a greater risk of HIV/AIDS (Hillis et al, 2012). Trauma, stigmatization and marginalization limit street children's access to services for children affected by HIV/AIDS (Jones, 2009).



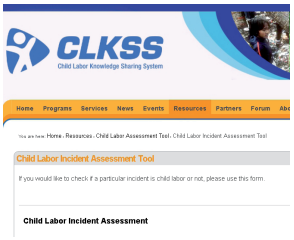
Click on the picture to access WHO's "Working with Street Children: A Training Package on Substance Use, Sexual and Reproductive Health Including HIV/AIDS" (WHO, 2002).

Rates of substance use are very high among street children and according to the WHO, between 25% and 90% use psychoactive substances, including alcohol, nicotine, stimulants, inhalants, cannabis and opioids (WHO, 2010). Among street

children inhaling volatile substances including glues, nail polish remover, lighter fluid, spray paint and other household products, perceived benefits included increased physical strength, decreased shyness, promoting sleep, promoting a sense of well-being and numbing physical and psychological pain (Sharma & Lal, 2011). Rates of mental illness among street youth, including substance use disorders, mood disorders, hyperkinetic disorders and anxiety disorders may be as high as 98%t (Scivoletto et al, 2011).

WORKING CHILDREN AND CHILD LABOR

Children, whether living with their parents, in child- and youth-headed households or on the street, often contribute meaningfully to their households by doing chores or other kinds of work. However, in the poorest regions of the world, children are often engaged in work that is hazardous or exploitative in order to ensure their own survival and that of their families. Child labor is a complex issue, and in addition to abuse and exploitation, the realities of child workers include socialization, participation, learning and skills development, independence, recognition, power, security and pride in their ability to contribute meaningfully to their households (Liebel, 2004). However, the majority of children and young adolescents in developing countries work out of financial necessity to support their families and many do not enjoy the work they do and would prefer to be in school (Mathews et al, 2003; Tabassum & Baig, 2002).



Click on the picture to access the "Child Labor Incident Assessment Tool". Quick on-line resource that allows you to check if a particular incident is child labor or not (Child Labour Knowledge Sharing System; Philippines).

There is significant controversy around whether children should do economic work at all, which kind of work may be beneficial or harmful, and the nature of work that may be considered appropriate for children and adolescents (Abebe & Bessell, 2011). Opinions on child labor are also informed by the meaning of *childhood*, which varies across cultures, and an understanding of children along a continuum from vulnerable, passive entities in need of protection to competent actors who can contribute meaningfully to society and act as agents of their own destinies (Abebe & Bessell, 2011).

Ennew, Myers and Plateau (2005) identified four key viewpoints on child labor:

- The *labor market* perspective, which views child labor as a sign of poverty and underdevelopment that will be overcome as nations develop
- The *human capital* perspective, which sees childhood as a protected time in which scholastic education is paramount and in opposition to participation in labor
- The *social responsibility* perspective that defines child labor as a cause and consequence of social exclusion, where children's work is seen as exploitative, alienating and oppressive and
- The perspective that emphasizes the right of children to be protected from exploitative labor.

Thus, while Western interests have often called for a complete ban on child labor, working children's organizations in developing countries have called for equal rights and participation, including the right to be included as members on the very labor advisory boards that aim to represent and protect them (Liebel, 2004 pp25-32).

Current status and definitions

According to the International Labor Organization (ILO), founded by the UN in 1919, there were an estimated 215 million children aged 5 to 14 years involved in economic work in 2008, mainly in Asia, Africa and Latin America (ILO, 2010). This represents a decrease from the estimated 222 million children who were employed in 2004, however, these estimates do not include children in modern forms of slavery including forced or bonded labor and or other forms of illicit work, including child soldering, sex work and drug trafficking. Furthermore, estimates do not include children, often girls, who do domestic work or raise younger siblings in their own households.

Based on definitions created by the ILO, children who do at least one hour of economic work per week are defined as being involved in the labor economy (Hagemann et al, 2006). These children are then divided into different groups based on their age and the type of work they do:

- *Economically active* or *working children* refer to children aged 5 to 17 years
- *Child labor* refers to working children aged 5 to 14 years
- *Children in hazardous work* refers to children aged 5 to 17 who work in dangerous occupations such as mining and construction, use heavy machinery, are exposed to toxins such as pesticides, or work more than 43 hours per week.

UNICEF uses a different definition that includes children who do excessive hours of domestic chores in their own households (at least 28 hours per week for children aged 5 to 14 years or at least 42 hours of combined domestic chores and economic work for children aged 12 to 14). However, this definition of child labor excludes children aged 12 to 14 who do less than 14 hours per week of economic work and less than 42 hours of combined economic work and household chores per week (Gibbons et al, 2005). When household chores are included, girls represent 38% of children involved in child labor worldwide (Gibbons et al, 2005).

In 1921 the ILO passed the first convention on child labor setting the minimum age for employment in industry at 14 years. More recently, increased attention has focused on eradicating the worst forms of child labor that are likely to harm "the child's health or physical, mental, spiritual, moral or social development" including child soldering, participation in the sex trade and other work that exposes children to the risk of physical or psychological harm. In 1992 the ILO ratified Convention 182 on the Worst Forms of Child Labor. However, many countries have not ratified these conventions, and as of 2008, 115 million children worldwide were engaged in hazardous work (ILO, 2010). By far, the majority of child laborers are unpaid family workers and 60% work in agriculture (ILO, 2010). Only 20% of working children are wage earners, however, in some households, children earn a large proportion of the household income (ILO, 2010). Even as unpaid family workers, children may work alongside their parents in small industries, including artisan production, trades and services such as mechanic and rug weaving. While often viewed as less hazardous, the children working in these

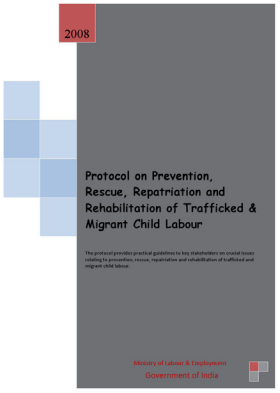
industries are frequently exposed to physical strain, long hours of work, low wages, and high exposure to noise, dust and chemicals without protective equipment (Nuwayhid et al, 2001).

Child labor has been described as the largest single cause of child abuse across the globe

Child labor as a risk to child health

Child labor has been described as "the largest single cause of child abuse across the globe" (Scanlon et al, 2002). The harms associated with child labor include risk of physical injury and illness, acute or chronic poisoning, risk of abuse, ill treatment, exploitation and exposure to harsh working conditions. Working children may also be unable to attend school. Both female and male children involved in prostitution and work with armed groups risk exposure to physical, emotional and sexual violence, infectious diseases including HIV/AIDS, low self-esteem and emotional and psychological harm.

Most studies that report the health risks of working children are small and populations of child workers are often hard to access, particularly those who are working in very hazardous or illicit industries, including forced labor and prostitution. Determining the impact of child labor on health is also made difficult by the long latency period before disease onset, under-recognition of health problems, difficulties in measuring developmental changes and psychosocial effects, and the "healthy worker effect" whereby the healthiest children are selected for work and children who become ill or injured are excluded (Parker et al, 2010). Consistently, studies that look at child workers in general often do not demonstrate an overall negative impact of working on child health, however, studies that look at specific populations of children doing hazardous work have demonstrated harm (Understanding Children's Work 2003a; 2003b).



Click on the picture to access briefing notes about guidelines for programmes aimed at providing support to orphans and vulnerable children (International HIV/AIDS Alliance, 2003)

The majority of the world's working children are employed in agriculture and risk acute and chronic pesticide poisoning as a result of occupational exposure (Corriols & Aragón, 2010). Certain agricultural industries, such as cocoa harvesting and tobacco production, have been shown to employ children who work without protective clothing and are exposed to multiple health risks, including risk of injury and exposure to toxins (McKnight & Spiller, 2005; Mull & Kirkhorn, 2005; Otañez et al, 2006). Working children who are exposed to solvents, such as those working in machine and artisan shops, perform worse on most neurophysiological and neurobehavioral tests compared to both non-working schoolchildren and to working children who are not exposed to solvents (Saddik, 2003; 2005). Unacceptably high blood levels of lead, a known neurotoxin that has been shown to lower IQ and cause behavioral problems, have been demonstrated in children working in ceramic-making, garbage scavenging and street vending (Ide & Parker, 2005). Children and adolescents exposed to dusty conditions in mining, stone polishing, pottery and brick making industries without protective equipment are at increased risk of developing silicosis, a chronic debilitating lung disease (Chiavegatto et al, 2010; Saiyed, 1995). Children and adolescents employed in industry, especially those who work with powered wood cutters, risk hand injury and amputation (Durusoy et al, 2011). The impacts of harmful work on children therefore include acute and chronic health risks and developmental insults that may limit children's cognitive potential.

One of the most frequent harmful consequences of child labor may be the inability or decreased ability to attend school. Clearly, child labor is intertwined

with the issue of poverty because poverty itself may both preclude a child's ability to attend school and force a child to work in order to help ensure family survival. While many children successfully balance work and school, high rates of child labor tend to be associated with poorer school attendance. For example, among African countries in 2004, Swaziland had a child labor rate of 10% and a school attendance rate of 78%, while Niger, at the other end of the spectrum, had a child labor rate of 72% and a school attendance rate of 30% (Gibbons et al, 2005). Child labor, and girls' involvement in particular, can be understood as contributing to a cycle of limited educational attainment, inter-generational poverty and poor health (Leinberger-Jabari et al, 2005). However, it should also be noted that for some children whose families cannot afford to send them to school, children's participation in the work force allows them to afford school fees, books and school supplies (Woodhead, 2001). Despite the efforts of children to improve their own situations, poverty and the need to work can interfere with their ability to attend school, achieve academically and transcend the cycle of poverty.

Child labor as a risk to child mental health and well-being

There are relatively few studies that look at mental health outcomes of child laborers. One study in Ethiopia that compared 528 child laborers 5-14 years of age to their non-working counterparts found that working children had significantly increased rates of behavioral and emotional disorders, including depression (Fekadu et al, 2006). Among child laborers, starting work at a younger age and working long hours are associated with poorer mental health (Caglayan et al, 2010). While there is a paucity of data on mental health outcomes of child laborers, there is a well-established link between poor child and adult mental health and physical, emotional, and sexual abuse and neglect in childhood (Gilbert et al, 2009). A high proportion of working children reports being emotionally, physically and sexually abused by their employers (Gharaibeh & Hoeman, 2003; Mathews et al, 2003). Furthermore, girls engaged in economic work may be at increased risk of sexual violence. Among girls in Nigeria selling goods on the street, working in shops or as domestic workers, 78% reported having been raped, the majority by customers, and the risk was increased among girls who were younger than 12, worked for more than eight hours per day or had two or more jobs (Audu et al, 2009). Unsurprisingly, girls who are employed as domestic servants are highly vulnerable to physical, psychological and sexual abuse (Banerjee et al, 2008).

"Being poor is in itself a health hazard; worse, however, is being urban and poor. Much worse is being poor, urban, and a child. But worst of all is being a street child in an urban environment."
Ximena de la Barra, UNICEF (de la Barra, 1998)

Orphaned and vulnerable children, poverty, homelessness and child labor

There is a clear relationship between poverty and reliance on child labor as a family survival strategy. A national survey in Guatemala revealed that poor households were more likely to use child labor and schooling reduction as strategies to cope with socioeconomic hardship (Vásquez & Bohara, 2010). Among a sample of poor families in Nigeria, thirty-nine per cent of parents indicated that they thought their school-aged children should be working in order to supplement family income, help with the family business and to allow children to gain work experience (Omokhodion & Uchendu, 2010). Children who are poor, orphaned and engaged in child labor have to cope with multiple interrelated challenges. For orphaned children in Zimbabwe, being engaged in child labor and not being in school are risk factors associated with greater psychological distress (Nyamukapa et al, 2010).

When the number of children orphaned by HIV/AIDS overwhelms the ability of families and communities to care for these children, orphaned children are at high risk of becoming homeless. In Brazzaville, Congo, an estimated 50% of street children are orphans (Nkouika-Dinghani-Nkita, 2000). Likewise, in Lusaka, Zambia, 58% of street children were orphans: 22% had lost both parents, 26% had lost their father, and 10% had lost their mother (Concern/UNICEF, 2002).

Impoverished families who take in orphaned relatives often have insufficient resources to support these children, resulting in financial hardship and the need for orphans to do economic work to help support the family (Balew et al, 2010). However, while orphans are often viewed as a burden to families, they also contribute meaningfully to family preservation through their work, for example, by caring for sick relatives (Robson, 2004). For orphans in Uganda, identified barriers to school attendance and academic success include hunger and being at school all day without eating, heavy domestic workload including early morning agricultural responsibilities causing late arrival at school, lack of school uniforms and books, and limited options for education beyond the primary level due to financial constraints (Oleke et al, 2007). Furthermore, some orphaned adolescent girls resort to engaging in sexual relationships with wealthy older males, commonly referred to as "sugar-daddies", as a way of securing funds to pay for school tuition and supplies (Oleke et al, 2007). Thus, under conditions of severe poverty and deprivation, orphans engage in complex negotiations regarding their health, emotional well-being and the possibility for a better future for themselves and their families.

Vulnerable children, including poor, orphaned and homeless children are at great risk of abuse and involvement in the most exploitative forms of child labor, including debt bondage and other forms of slavery, association with armed groups, begging, child prostitution and other forms of sexual exploitation.

Resilience

Despite the obvious dangers, severe adversity can lead children and adolescents to develop effective survival strategies that allow them to promote their own growth and development (Ruiz-Casares, 2009). Children under difficult circumstances can develop, among other things, practical survival and management skills, independence, the ability to cope with stress, make important decisions and develop a greater sense of self efficacy (Liebel, 2004). In her study of child- and youth-headed households in Namibia, Ruiz-Casares (2010) documented how children of all ages demonstrated an ability to obtain goods and services that they needed, and to maintain supportive community ties. Children in child- and youth-headed households display resilience in the way that they are able to mobilize their social networks, including siblings, friends and neighbors to provide emotional and academic support and material goods (Donald & Clacherty, 2005). Nonetheless, few studies have explored strengths or positive outcomes. A study looking at homeless street children in Kenya found that compared to non-street children, they displayed a high degree of adaptability and flexibility in the face of adversity which allowed them to remain remarkably well adjusted (Ayuku et al, 2004; Luna 1991). Orphaned, poor, homeless and working children can also thus be seen as agents of their own development who are trying to cope the best they can with the difficult


Child Soldier in Darfur. Outpost Magazine. Photo: Marie Frechon

circumstances in which they find themselves. Children should therefore not be seen solely as passive victims, but also as active participants in their families and communities who have a voice and are deserving of respect.

CHILD SOLDIERS

Issues of poverty, street children and child labor are intertwined with the problem of minors being associated with armed forces or armed groups. Not only do poverty, homelessness, forced child labor and, of course, the presence of war and conflict constitute risk factors for recruitment of child soldiers, these issues also represent challenges in the rehabilitation and reintegration of former child soldiers back into civilian life.

Child soldiering is considered convenient and cheap (Wessels, 2006). Children – boys and girls alike – are perceived as highly obedient and easily manipulated (Denov, 2010; Wessels, 2006). According to the Coalition to Stop the Use of Child Soldiers (CSUCS), this may partially explain why the use of child soldiers is widespread in countries and regions affected by war (CSUCS, 2008). Acknowledging the difficulty in getting accurate figures, the CSUCS (now called Child Soldiers International) estimated in its 2004 report that 250,000 children were part of fighting forces in both state and non-state armed groups (CCUCS, 2004). Since then, between 2004 and 2007, while the Coalition reported a decrease in the number of child soldiers following peace agreements and demobilization programs in different countries, armed groups in 24 countries are known to have recruited children under 18 years old (CSUCS, 2008).

Terminology and definitions

The commonly used term of *child soldier* is contested in scholarship and considered problematic in many aspects (Denov, 2010; Wessells, 2006; McKay et al, 2010). Like any other label, *child soldier* is applied to a wide range of children and youth with highly diverse experiences. As highlighted by some authors (Denov, 2010; Wessells, 2006), the notion of "soldier" carries some archetypal image of well-trained combatants embodied mostly by a male figure in uniform. Yet this imagery obscures the multiplicity of the roles and tasks they undertake. Child soldiers are not only active combatants carrying guns, they also spy, cook, guard, porter, messenger or are forced into sexual slavery.

In an attempt to acknowledge the varied tasks of child soldiers, the term *children associated with armed forces or armed groups* has been introduced, and has been defined in the UN Paris Principle (2007) as: *"Any person below 18 years of age who is or who has been recruited or used by an armed force or armed group in any capacity, including but not limited to children, boys and girls, used as fighters, cooks, porters, messengers, spies or for sexual purposes. It does not only refer to a child who is taking or has taken a direct part in hostilities."* (United Nations, 2007, p7)

However, this definition is still problematic. The notion of "childhood" itself is a highly contested concept. As a social construct mainly based on Western views and on biological age, the concept of children as being under the age of 18 years may disregard the varying meanings of childhood across cultures. Finally, while the majority of child soldiers are adolescents, a large number of children younger than ten years are associated with armed groups (Machel, 2001).



Click on the picture to access "Psychosocial Adjustment and Social Reintegration of Children Associated with Armed Groups: The State of The Field and Future Directions" (Betancourt et al, 2008).

Experiences of child soldiers

Child soldiers may become involved with armed groups through forced or unforced recruitment (Denov, 2010; Wessells, 2006). Means of *recruitment* are diverse, and while violent abduction and forced recruitment are pervasive in many conflicts, the line between forced and unforced involvement is often unclear and the notion of *voluntary* child recruits should be considered carefully (Wessells, 2006). Based on testimonies, studies have shown that when not forcibly abducted, boys' and girls' decision to join armed groups are often made in contexts of deprivation, hardship and maltreatment. Many reasons may drive girls and boys to join armed groups (Wessells, 2006; Denov, 2010; Brett & Specht, 2004):

- Poverty and the opportunity to obtain food and shelter
- Lack of socio-economic opportunities
- To seek protection
- To flee abuses from their family of origin
- For religious or political beliefs
- To gain a sense of family or peer group
- To avenge the deaths of parents, other family members or friends
- Soldiering may also be attractive for the uniform or prestige.

Therefore, over-simplifying the dichotomy between forced and non-forced recruitment methods can be problematic as it is often difficult to distinguish between unwilling victim and willing perpetrators of violence.

Recent studies have gone beyond narratives of victimization to explore how, despite extreme violence and controlling environments, children do deploy some forms of agency and resistance strategies (Denov, 2010; Denov & Maclure, 2007; Wessells, 2006). Testimonies from former child soldiers, boys and girls alike, illustrate how experiences in armed groups are marked by an oscillation between victimhood and resistance, or active participation in violence (Denov, 2010): "... children's experiences reveal that they *continually drifted between committing acts of violence and simultaneously being victims of violence by others.*" (Denov, 2010, p129). The process of militarization of boys and girls includes powerful indoctrination, harsh training, and the use of threats and violence to promote terror and compliance (Denov & Maclure, 2007). Adjustments to a militarized and highly violent environment entail shifts in behaviour, relationships, self-perception and sense of identity (Veale & Stravou, 2007; Denov & Maclure, 2007; Wessel, 2007). Sometimes, obedience may become an imperative to survival (Denov, 2010). These factors will have important consequences in the process of reintegration into civilian life.

According to the Child Soldiers Initiative, an estimated 40% of child soldiers are girls and they take on roles as varied as boys (Child Soldiers Initiative, 2010). However, evidence shows that girls, because of their gender, will experience armed conflict differently than boys (McKay & Mazurana, 2004). One dimension of their gendered experiences is the pervasive sexual violence perpetrated against girls. Testimonies from former girl soldiers in Northern Uganda, Sierra Leone and Mozambique reported extensive sexual violence, including rape and gang rape (McKay & Mazurana, 2004; Coulter, 2009). Girls also reported being forced into sexual slavery by being ordered to *marry* males within the armed group and become their sexual property, also known as being *bush wives* (Coulter, 2009; Denov, 2010). This would allow protection from random sexual assaults from other male combatants, while being obligated to be constantly sexually available for their "husbands" (Coulter, 2009). Forced marriage to powerful commandants can be a survival strategy, and as such, both a source of protection and violence. In addition to the psychological and social consequences, sexual violence also exposes girls to sexually transmitted infections, most notably HIV/AIDS, unwanted pregnancy, and severe injuries resulting from violent sexual assault (ACQUIRE Project, 2005). Girls' brutal experiences of violence are thus important to acknowledge. In contrast, in some conflict settings there are strong prohibitions against the sexual victimization of girl soldiers and girls report feeling protected (Keairns, 2002). Girls' victimization is only one facet of their lived realities and much of the recent literature has sought to challenge the unidimensional portrayals of girl soldiers as victims (Coulter, 2009; McKay et al, 2010; Denov, 2010; Veale & Stavrou, 2007). While often carrying out female roles and domestic work, such as cooking and sexual service, girls' roles also include military duties and participation in combat activities (Denov, 2010).



Click on the picture to access the Child Soldier Treatment Centre database: organizations and centres that specialize in the treatment, rehabilitation, education and rehabilitation of former child soldiers, abductees or child victims of war, sorted by country.

The aftermath: psychosocial consequences

In the aftermath of participation in armed violence, whether the conflict has ended or not, former child soldiers face critical transitions as they attempt to reintegrate into civilian life (Denov, 2010). The term *reintegration* is contested, as it tends to assume that former child soldiers return to their family or community

of origin and to their normal and previous lives'; however, this is rarely the case. Moreover, former child soldiers may have been affected by war in very different ways and thus may not require similar support. Some may be disabled, orphaned or injured; some girls may be mothers or widows, or none of the above. They may have been forced to commit atrocities – killing and raping – or may have carried out domestic work. Some have been violently abducted, sometimes to the extent of being forced to kill family members. This diversity needs to be acknowledged in the understanding of their post-war lives (Wessells, 2006).

Given the profound psychosocial implications of exposure to violence, the mental health and well-being of former child soldiers is key in the process of reintegration to civilian life (Wessel, 2006). Acute war experiences and exposure to extreme violence will affect former girl and boy soldiers in many ways, both physically, such as through injuries, disabilities and infectious diseases, and psychologically. A handful of studies examining mental health outcomes have reported symptoms of post-traumatic stress disorder (PTSD), anxiety and depression among former child soldiers (Derluyn et al, 2004; Betancourt et al, 2008). Among former child soldiers studied in northern Uganda, 97% reported symptoms of PTSD (Derluyn et al, 2004). Importantly, it is not only girl soldiers who report sexual violence. Male soldiers also report sexual violence and being forced into sexual servitude, which is associated with higher rates of symptoms of depression and PTSD, social dysfunction and suicidal ideation compared to their combatant peers who did not experience sexual violence (Johnson et al, 2008).

However, as pointed out by some scholars, the scarce literature on mental health outcomes of former child soldiers almost exclusively focuses on the signs and symptoms of PTSD. This trauma-focused Western medical approach has been criticized for its emphasis on pathology and deficits (Wessells, 2006; Betancourt et al, 2008; 2010; Klasen et al, 2010). Furthermore, PTSD may represent only a fraction of the wide range of psychosocial implications of wartime violence (Betancourt et al, 2010; Wessells, 2006). Using a resilience frame, a few studies have explored the positive adaptation, psychosocial adjustment and adaptive capacities of former child soldiers (Klasen et al, 2010; Wessells, 2006). Girls – as much as boys – are not only victims of war trauma, they adjust to their new life and employ creative coping strategies in the face of their many struggles (Betancourt et al, 2010; Klasen et al, 2010; Denov, 2010).



Mental health and psychosocial support in humanitarian emergencies

The target group for WHO work on mental health and psychosocial support in emergencies is any population exposed to extreme stressors, such as refugees, internally displaced persons, disaster survivors and terrorism, war- or genocide-exposed populations. Click here to access key documents related to this field.

Disarmament, demobilization, reintegration and rehabilitation

Post-demobilization experiences are inevitably shaped and constrained by many other factors apart from war-time experiences, including gender, ethnicity, socio-economic status, ability, position within the community and access to social support. Poverty, displacement and loss of home following demobilization have profound psychosocial implications (Wessells, 2006). What stands out in recent studies regarding reintegration and rehabilitation of former child soldiers is that exposure to violence only represents part of the picture (Wessells, 2006), and does not exclusively account for mental health problems or well-being (Betancourt et al, 2008; 2010; Kohrt et al, 2008; Klasen, 2010). Post-conflict factors may have positive or adverse effects on the mental well-being of former child soldiers who

face diverse challenges, including social stigma and limited access to education, health care, sustainable livelihoods and economic opportunities (Worthen et al, 2010; McKay et al, 2010; Wessells, 2006; Denov, 2010).

Social stigmatization and the discrimination experienced by former child soldiers have been identified as key post-conflict factors contributing to adverse mental health outcomes (Betancourt et al, 2008; 2010; Klasen et al, 2010). In this regard, girls face particular and unique challenges affecting their post-conflict lives. In addition to the physical and emotional scars resulting from sexual violence, many former girl soldiers face greater risk of stigma following reintegration because they are viewed as sexually impure or even unfit for marriage, which can have important psychosocial consequences (Betancourt et al, 2008; McKay et al, 2010; McKay & Mazurana, 2004). On the other hand, community and family acceptance and support have been identified as critical factors for successful reintegration and enhanced psychosocial adjustment (Betancourt et al, 2010). Access to education and socioeconomic opportunities are also important positive post-conflict factors.

The transition to civilian life – meaning abrupt shifts in relationships, behavioural patterns, and expectations – entails a reshaping of identities, from *militarized* identities to civilian life (Veale & Stravou, 2007; Denov, 2010). In fact, identity transformation and negotiation constitute a core challenge in the reintegration process (Veale & Stravou, 2007, p286). The process of *making* child soldiers – through abduction, harsh training and indoctrination – means that complex identity negotiations are required to *unmake* child soldiers upon demobilization (Denov, 2010; Denov & Maclure, 2007).



Click on the picture to access "Humantrafficking.org" a web resource for combating human trafficking (multiple countries). Contains resources useful for children who are trafficked for labor or sexual purposes

Disarmament, demobilization, reintegration and rehabilitation (DDRR) is used to describe the process by which child soldiers are returned to civilian life. This process is also used for adult combatants, but child-specific programs are common and take different forms in different regions. As previously discussed, disarmament is not always necessary because children fulfill many non-combatant roles within armed groups. Despite being in widespread use, there is little data on the success of DDRR programs. One study in Sierra Leone (Williamson, 2006) identified nine areas of intervention contributing to successful family and community reintegration:

- Community sensitization to the returning children
- Formal disarmament and demobilization
- A period of transition in an "interim care center"
- Family tracing and mediation
- Family reunification
- Traditional cleansing and healing ceremonies and religious support
- School or skills training
- Access to health care for those in school or training, and
- Individual supportive counseling.

One study in Mozambique that followed former child soldiers for 16 years showed that long term reintegration and self-sufficiency was facilitated by community acceptance and forgiveness, traditional cleansing and healing rituals, livelihoods and apprenticeships (Boothby et al, 2006).

Interim or transitory care centers are typically the first places where demobilized children stay after returning from the armed groups with which they were affiliated. In one such center, the Goma Transitory Care Centre in eastern Democratic Republic of the Congo, 250 children are grouped into *families* of around 30 children, each with its own dormitory and staff counselors (Humphreys, 2009). The children in each family group come from mixed ethnic backgrounds and armed groups. In addition to limited individual counseling for children with specific issues, the family groups are designed so that the children can listen to and support each other. The children spend three months at the center before being reintegrated into the community.

Conclusion

In summary, within the context of reintegration, former child soldiers face many other challenges in addition to coping with the scars of war experiences. Indeed, access to education and employment, financial security, community acceptance and many other factors related with their post-conflict life conditions have psychosocial implications. An understanding of the impact of multiple war-related and post-conflict factors is important for identifying appropriate intervention targets. (Betancourt et al, 2010).

THE MENTAL HEALTH OF WAR-AFFECTED CHILDREN

This section will limit itself to the effects of war on children who have needed to leave their home countries because of war and have migrated to a new host country. Practical approaches to assessment and treatment planning will be outlined to address these children's mental health needs.

Research suggests that war trauma can affect children's mental health. The effects of this trauma are complex, given that experiences of war entail exposure to multiple stressors including violence, displacement, family separation, loss and bereavement, disruption of education and the breaking of social ties.

Exposure to violence has been linked with psychological difficulties in children ranging from sleep difficulties and anxiety to post traumatic stress disorder (PTSD) (Fazel et al, 2011; Hjern et al, 1991, Rothe et al, 2002). It appears that the severity and quantity of violence exposure is important: children with multiple exposures to violence over longer periods of time continue to exhibit mental health difficulties up to nine years after seeking asylum. In contrast, children who have experienced fewer adverse events tend to become asymptomatic more rapidly (Montgomery, 2010). The exposure of parents to violence also affects children's well-being. Studies have demonstrated that children's mental health is negatively impacted if their parents have been tortured (Almqvist & Brandell-Forsberg, 1997; Cohn et al, 1985; Daud et al, 2008; Fazel et al, 2011). One study has also noted that a child's knowledge of a parent being detained is associated with the development of PTSD (Montgomery and Foldspang, 2006).

Children of war are sometimes separated from their families and forced to flee alone. Separation from family, itself, was associated with PTSD in one study (Geltman et al, 2005). Being unaccompanied when seeking asylum puts young people at greater risk of mental health problems (Hjern et al, 1998). Children whose



Hunger
Käthe Kollwitz (1867-1945)
(permanent loan by Gudrun & Martin Fritsch to the Käthe Kollwitz Museum, Berlin)

families are continuing to undergo adversity (for example, if a parent is detained or still in a war-torn country) tend to have worse psychological functioning. On the other hand, children's mental health appears to be protected when their families remain cohesive and supportive (Fazel et al, 2011; Rousseau et al, 2004). Positive school and peer experiences are also correlated with wellbeing in refugee children (Fazel et al, 2011; Geltman et al, 2005, Sujoldzic et al, 2006).

Experiences of migration

Families who have experienced organized violence prior to migration can sometimes face difficulties in their welcoming countries including violence (Jaycox et al, 2002), racism (Gunew, 2003), poverty (Beiser, 2002), and uncertain immigration status. Ongoing experiences of discrimination (Hassan & Rousseau, 2008; Rousseau et al, 2009), and barriers to securing care will influence children's psychological well-being as well as the trust and collaboration that can be fostered within the care-provider relationship. One study of Somali adolescents who had

fled to the US demonstrated that depression and PTSD were associated with the youth's experiences of discrimination in the host country (Ellis et al, 2008).

It is important for clinicians to keep in mind that families fleeing war are also often met with many barriers when trying to seek asylum. This too has an impact on children's psychological well-being. In fact, some longitudinal studies suggest that post-migratory stressors are a stronger predictor of depression in refugee children than are past conflict-related events (Sack et al, 1993). One such stressor is immigration detention. Many industrialized countries have policies of detaining children and families who are seeking asylum. For children fleeing war, detention is potentially re-traumatizing and correlates with high rates of psychiatric difficulties.

Migrating families are in a period of adaptation that is sometimes very stressful. The process of understanding difficulties and proposing solutions are tasks that need to be worked together with families, taking into account a family's strengths, their readiness and ability to cope with difficulties, their understandings of the causes of their difficulties and their feelings about solutions proposed to address them.

Resilience

On the path to rebuilding a life there is a a new balance to be made between maintaining some continuity with the past and adopting new coping strategies to deal with the unknown. In general, research suggests that the process of acculturation in asylum seeking children is complex, and that no one path is more protective or harmful for all children (Fazel et al, 2011). Spirituality plays a central role for many families (Boehnlein, 2007), either in the form of personal prayer or the support derived from attending religious rituals and celebrations. These ethno-religious social networks may also give children a sense of belonging. However, they may also act as a traumatic reminder when religion was associated with trauma. Artistic activities, sports, work, and study, if they establish continuity with meaningful aspects of the life of a child before the experience of migration and traumatic disruption, are important strengths. The same activities may also be new to a child and, when given the appropriate support to learn these new roles, they can represent positive dimensions of their adaptation.

It is important to acknowledge that all outcomes of war do not solely lead to loss and disability. Traumatic events can promote creative coping skills, and be transformed into a source of strength and resilience (Rousseau et al, 1999).

Dealing with the consequences of war: the assessment and treatment of war-affected children

Intervention for children affected by war as well as other humanitarian disasters has been considered along an intervention pyramid, where the base of the pyramid represents advocating for basic services to ensure safety. The next layer of the pyramid involves strengthening community and family supports, followed by more focused non-specialized person to person supports. Specialized mental health services form the top of the pyramid. It has been advocated that all of these interventions are ideally implemented concurrently. A practical guide to addressing the provision of psychosocial and humanitarian support in humanitarian crises is

available in a number of languages from the Interagency Standing Committee (IASC, 2010)

Assessment

Accessing care: primary care, prevention and interpretation

A number of practical points can help support the assessment and treatment of children who are experiencing mental health difficulties as a result of war, as well as their families. Efforts to support schools, primary care workers and community workers to help address the needs of these children and their families are important, as these children's difficulties frequently present first to these persons. Children and families have been offered help in community settings such as schools (Kataoka et al, 2003; Ngo et al, 2008; Hodes 2008; Duncan & Kang, 1985) and primary care clinics, where front-line professionals are supported by mental health teams. This support at the front line level can also facilitate access to more specialized care when needed.

School and community-based prevention programs can also play a key role in promoting the mental health of children from migrant and ethno-cultural communities. Classroom-based activities can support children in assimilating past and present experiences by presenting these as learning opportunities, facilitating emotional expression with respect to their experiences and promoting the development of positive relationships within the classroom and society (Green et al 2005). Some prevention programs use specific treatment modalities such as artistic expression to support the transformation of past and present adversity through creativity and metaphorical representations and by fostering the development of solidarity among children (Rousseau & Guzder, 2008). Successful support of families and children at the community level also marks the beginning of a process of alliance building and service provision that supports the biopsychosocial needs of children who have experienced war and their families.

Finally, families who speak a language other than the dominant language of the health care system should be offered interpreters to help support the assessment and treatment process. Interpreters facilitate the clinical encounter by providing translation and, in some cases, may support assessment and treatment by acting as cultural brokers and co-diagnosticians to help understand, reframe or transmit cultural knowledge (Hsieh, 2007; Rousseau et al, 2011)

Self-reflexivity in the clinician

Exploring cultural references in clinical encounters requires a clinical openness to acknowledging the clinician's own identity, a capacity to reflect on how others see oneself, and an openness to perceiving oneself as a tool in the therapeutic work (Kirmayer et al, 2003). This will facilitate the assessment and will help the clinician to explore such areas as explanatory models of illness and approaches to healing. Familiarity with ways of addressing cultural elements in mental health practice , such as the cultural formulation of the DSM-IV and work providing guidance about how to adapt the cultural formulation to child mental health care practice (see for example Ecklund & Johnson, 2007; Measham et al, 2010) can help support an assessment that is attuned to cultural issues.



Child mental health rating scales in war-affected and traumatized children

Click on the picture to access several rating scales (the Children's Revised Impact of Event Scale, CRIES; Depression Self-Rating Scale for Children, DSRS; Post-traumatic Cognitions Inventory, cPTCI, the Self-Report for Childhood Anxiety Related Disorders, SCARED and others) (Children & War Foundation)

The assessment process

The assessment of children and families who have experienced war includes an exploration of several important themes:

- The family's experiences in their home and host country
- The child's symptoms
- Symptoms experienced by other family members
- Familial and individual strengths
- Resources and previous help-seeking trajectories; and
- A negotiation of the complex reconstruction of the family and its social network.



Click on the picture to access "Working with Distressed Children Toolkit". Includes information on identifying and communicating with distressed children and psycho-social intervention and cultural considerations (Action for the Rights of Children, Working with Children, Revision version 01/01)

Attention to the therapeutic alliance is of great importance when addressing the consequences of war on children. Families and children are often meeting with unfamiliar persons and are guarded about who to trust and how much to trust. In addition, some family members may remain in situations of peril, so that confidentiality of the therapeutic space is of paramount importance.

While it is important to explore children's and families' experiences of war trauma, the timing of these inquiries, the ways in which this information is solicited and cultural values around disclosure need to be understood. Soliciting disclosure in a Western way with respect to events that are culturally taboo can be harmful, and addressing disclosure with children needs to take into account their development and the effect of disclosure on parent-child relationships and trauma transmission. Cultural brokers can help to understand what is at stake around understanding traumatic experiences. In the case of children, approaching disclosure in a modulated way, including an acknowledgment of the role of parents as gatekeepers who can help their children understand their experiences is helpful. Indirect methods to assess trauma through art, play, and metaphor may also reveal important information for assessment, while not being experienced as overly intrusive by family members (Measham & Rousseau, 2010).

When family survival is at stake, attention needs to be paid to the family's pressing needs such as asylum, housing, security and education. Similarly, in a refugee child mental health assessment, a systemic appraisal of the family's pathway to survival is needed. Therapeutic efforts directed at interrupting further traumatic losses and the negative chain of consequences that can ensue from these are important (Miller & Rasmussen, 2010). Symptoms and the meaning of diagnoses also need to be addressed. It is important to note that diagnoses can have important ramifications outside the therapeutic space. In particular, a diagnosis that does not recognize the post-traumatic aspects of symptoms can inadvertently be unsupportive to people whose refugee status is in question as the PTSD diagnosis is well accepted in legal circles, where it is often seen to lend credibility to a traumatic story, and its absence is– falsely – considered proof that the person alleging trauma is lying (Stein et al, 2007)). On the other hand, the victim identity associated with the PTSD label, while encouraging empathic responses, may also unduly medicalize problems and disempower the family and social network. Seeing psychiatrists and receiving diagnoses may also be stigmatizing, and the effects of receiving a diagnosis on children needs to be addressed.



Refugee camp in Kenya, home to Somalis fleeing famine and conflict

Finally, the importance of identifying individual and family strengths and of reinterpreting family roles in the context of post traumatic adaptation will help in the building of treatment plans. For example, children's *parentification* toward the nuclear or extended family is often negatively perceived as a burden, while this role may also be reassuring during the period of post-traumatic reconstruction. Although parentified children may be suffering, their sense of having a purpose and a mission is often simultaneously protective.

Treatment

Symptom reduction and reconstruction of the social world

Treatment involves a reconstruction of the personal, family and sociocultural worlds with the aim of restoring a sense of normality for a child by allowing life to go on (social integration) and overcoming the paralysis that terror and grief can cause (symptom reduction). Gain in terms of reduction of impairment and improvement in functioning need to be considered, and it is important to note that their relation to symptom relief is not linear (Pynoos et al, 2009). The main implication of this for treatment is that it is just as important to restore the continuity of life by facilitating a child and family's social integration into the host country as it is to reduce symptoms.

From precarious status to stability

Clinicians may feel uneasy when asked to help asylum claimants with their immigration papers. The support provided by a clinician to asylum-claiming families through a letter supporting their immigration application is an explicit testimony that the clinician acknowledges the authenticity of the family's refugee experience (Rousseau & Foxen, 2005). When such testimony enables asylum seeking families to obtain secure immigration status, this relieves considerable psychic suffering and symptomatology given that a precarious immigration status

is associated with poor mental health (Bean et al, 2007; Bodegard. 2005; Nielsen et al, 2008). Moreover, this support, even if families do not gain secure immigration status with the clinicians efforts, can partially counteract the destructive impact of a rejection of the asylum claim, which can be profoundly re-traumatizing.

Meeting basic needs

Solving everyday problems plays a key role in achieving a certain normality that allows the establishment of routine. Most refugee families will request some type of practical help from community organizations, primary social and health care services, or even from schools, in resolving settlement problems. Sometimes, reestablishing contact with families from the same homeland through community organizations may facilitate the development of a social network. However, many communities torn by organized violence are fragmented and remain in conflict even when the community is in exile. Thus, the clinician needs to understand which social contacts can provide a social shield, and which can result in further stressors.

Psychotherapeutic modalities: therapy, medication and traditional healing

Trauma-related anxiety disorders (mainly studied with respect to PTSD), and depression, stemming from multiple losses in an exile setting, can be treated through various forms of psychotherapy. Short-term therapy, either cognitive behavioral therapy (CBT) or narrative exposure therapy , have been promoted for refugee children and adolescents not because they provide a complete resolution of trauma-related suffering, but because they are helpful in alleviating symptoms and can realistically be implemented in settings including schools (Ehntholt & Yule 2006; Kataoka et al, 2003: Ngo et al, 2008).

While psychopharmacology is an option for these children, we recommend caution given that there is little to no evidence of efficacy for refugee children and adolescents, so that evidence for efficacy is extrapolated from studies with non-refugee children with similar diagnoses. Therapies that integrate traditional elements show promise in the medical literature. Creative arts based therapies, such as art therapy, are sometimes preferred by refugee families, in part because these therapies often emphasize nonverbal therapeutic methods, thus helping persons who are reluctant to engage in verbal therapy. This may reflect either cultural attitudes or the fact that verbal approaches may be seen as being disrespectful of certain avoidance strategies. While Western treatment methods may favor a more direct working-through of trauma by focusing therapeutic work *on* trauma, other cultural traditions may prefer to work *around* trauma (Rousseau et al, 2005). Finally, the unilateral imposition of either Western expertise or culturally sensitive modalities may be experienced as coercive if the family's or child's choice of opting in or out of their own culture at a particular time is not taken into account.

Drawing up an inventory of available resources in a particular community is essential for a realistic treatment plan. In many settings, specialized psychotherapy may not be widely available, but committed community workers and primary care professionals may provide excellent therapeutic support and a forum for empathic listening that may begin to give relief to children and their families.

Conclusion

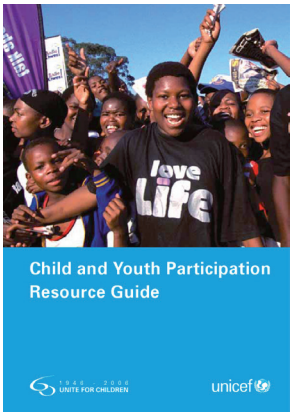
Addressing the consequences of war on refugee children whose families

have experienced pre-migratory trauma requires a combination of cultural knowledge and trauma therapy methods that encompass not only individually focused psychotherapies and traditional therapeutic approaches, but also systemic interventions addressing the consequences of organized violence on the family's social relationships. Primary care institutions, including clinics, schools and community organizations, because they are very close to the family's living environment, may be particularly helpful in establishing a support network around a refugee child and his or her family. They may however experience more difficulties in providing specialized therapy. Efforts to strengthen preventive and community-based supportive approaches to address the consequences of war on children, while ensuring access to specialized mental health services as needed, will help to address the multiple needs and strengths of refugee children and to provide the right kind of support at the right place and the right time.

CONCLUSIONS

Child mental health services need to address the adversity stemming from social and environmental stressors. Although different forms of treatment may help to alleviate symptoms and support the resiliency of a child and family, an acknowledgment of the collective nature of social suffering and a validation of a child and family's experience may be key. Mental health professionals in all countries can play an important role through intersectorial forms of intervention that help buffer this stress and even in some cases prevent it. Respecting the Convention on the Rights of the Child (see Chapter J.7) is a long term goal. In high income countries this could entail recognizing equal rights to health and education for non-citizen children and other vulnerable children. In low and middle income ones it could be linked to the implementation of protective measures to decrease children's exposure to multiple adversities and improve their health and well-being.

Although these social changes are beyond the mental health professional's mandate, health professionals can have a critical role in advocating for the social changes that can improve the mental health and well-being of children.



Click on the picture to access the UNICEF's "Child and Youth Participation Resource Guide". This guide has resources on child and youth participation from Asia, Europe, North America, Latin America, Africa, Australia and the Pacific. Most of the materials are available in electronic form. The main audiences for this resource guide are practitioners and managers involved in promoting child and youth participation in government, community-based organizations, child-led organizations, NGOs, UN and donor agencies (UNICEF, 2006c).

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ORGANIZING AND DELIVERING SERVICES FOR CHILD AND ADOLESCENT MENTAL HEALTH

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Conflict of interest: none declared

This publication is intended for professionals training or practicing in mental health and not for the general public. The opinions expressed are those of the authors and do not necessarily represent the views of the Editor or IACAPAP. This publication seeks to describe the best treatments and practices based on the scientific evidence available at the time of writing as evaluated by the authors and may change as a result of new research. Readers need to apply this knowledge to patients in accordance with the guidelines and laws of their country of practice. Some medications may not be available in some countries and readers should consult the specific drug information since not all dosages and unwanted effects are mentioned. Organizations, publications and websites are cited or linked to illustrate issues or as a source of further information. This does not mean that authors, the Editor or IACAPAP endorse their content or recommendations, which should be critically assessed by the reader. Websites may also change or cease to exist.

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Suggested citation: Servili C. Organizing and delivering services for child and adolescent mental health. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Mental health is a critical determinant of health and quality of life across the life-span. According to the World Health Organization (WHO, 1948), health is defined as "a state of physical, mental and social well-being". During childhood and adolescence, many factors can influence children's and adolescents' psychosocial well-being and their capacity to develop to their optimal potential, cope with the normal stress of life, and contribute to their communities. These factors can operate at the level of the individual, family, school or neighbourhood, and at a broader societal level. Among others, these factors include inadequacies in the nurturing and stimulating nature of their environment, parents' mental health, exposure to violence, abuse or neglect, nutritional deficiencies and chronic medical illness (Kieling et al, 2011; Walker et al, 2007; 2011).

The more risks people experience early in life, the worse their developmental outcomes and the higher the probability of experiencing psychological distress or mental health disorders (Sameroff et al, 2003). On the contrary, the more opportunities they have in childhood and adolescence to experience and accumulate the positive effects of protective factors that outweigh negative risk factors, the more likely they are to sustain mental health and wellbeing in later life (Currie & Todd, 2003). According to international evidence, 10%-20% of children and adolescents experience a mental health problem in any given year (WHO, 2001). Yet, in most countries only a small minority of young people with mental health problems is able to access appropriate resources for recognition, support and care (Morris et al, 2011). Health services for children and adolescents who are at risk but who do not yet exhibit clinical symptoms are even more inadequate (Knitzer, 2000).

INTERVENTIONS FOR CHILD AND ADOLESCENT MENTAL HEALTH (CAMH)

Meeting the mental health needs of children and adolescents requires the setup of multi-layered care systems that include a range of promotive, preventive and curative services. Table J.5.1 provides an overview of effective interventions that can be implemented in countries with different levels of resources, including low- and middle-income countries (Kieling, 2011; mhGAP Evidence Resource Centre). These interventions are delivered in a variety of settings, such as schools, homes, communities, and health facilities, and target diverse populations.

Among the preventive interventions, some of them (the so-called universal interventions) target all children or adolescents in a particular locality or setting. School-based physical activity programs, life skills training and restricting access to means of self-harm are examples of universal interventions. Others (selective interventions) focus on children exposed to risk factors for mental health problems, for example in the case of school-based psychosocial group interventions. Indicated interventions target children and adolescents experiencing subclinical symptoms; early stimulation programs for children with developmental delays belong to this category. Broad psychosocial strategies for mental health promotion in schools and communities need to be coupled with targeted interventions addressing the specific needs of young people with mental disorders and their families.

Table J.5.1 Examples of interventions for the prevention and management of mental health problems in children and adolescents

Interventions for developmental disorders	
Prevention	• Maternal and child nutritional and micronutrient supplementation • Prenatal and perinatal care • Reduction of prenatal exposure to alcohol • Immunization programs, malaria prevention • Early stimulation programs.
Management	• Family psychoeducation and orientation about locally available educational, social and rehabilitative services (including community-based rehabilitation services) • Parenting skills training • Promotion of human rights of the child and the family • Provision of support to carers • Cognitive behavioral therapy targeting problem behaviors
Interventions for behavioral disorders	
Prevention	• School-based preventive interventions involving training of teachers • Brief behavioral parent training intervention (integrated into child health services)
Management	• Family psychoeducation • Parenting skills training • Cognitive behavioral therapy and social skills training • Support to carers and families (to handle social and familial problems and address carers' mental health needs) • Pharmacological treatment for ADHD (prescribed by specialists, for children older than 6 years of age).
Interventions for internalizing disorders	
Prevention	• School-based physical activity programs and life-skills training • School-based psychosocial group intervention for at-risk children
Management	• Family psychoeducation • Interpersonal psychotherapy • Cognitive behavioral therapy • Adjunct treatments (structured physical activity programs, relaxation training and problem solving treatment) • Pharmacological treatment when appropriate
Interventions for suicidal behavior	
Prevention	• Development of policies to reduce harmful use of alcohol and restrict access to means of self-harm (such as pesticides and firearms) • Assist and encourage the media to follow responsible reporting practices of suicide events
Interventions for psychosis	
Management	• Psychoeducation for the young person and carers • Pharmacological treatment • Psychosocial interventions such as family therapy, social skills training and rehabilitation

Sources: Kieling et al, 2011; mhGAP Evidence Resource Centre

Professionals at different levels of the health care system need to be engaged in order to ensure timely recognition and management of specific mental health needs and vulnerabilities. Besides mental health specialists, health staff working at primary health care level, teachers, social workers, families and other community resources play important roles. The delivery of a comprehensive package of child and adolescent mental health interventions (including services described in Table J.5.1) requires not only the right mix of trained personnel but also mechanisms for integration of mental health into general healthcare, mechanisms for collaboration and liaison within the health system and across sectors, guidelines and clinical protocols for management of mental disorders in children, quality monitoring programs, and adequate supply of medications (WHO, 2007).

The following sections describe guiding principles and required step-wise actions for planning child and adolescent mental health services. Possible care models for the organization of services, particularly at primary health care level, are also presented.

PRINCIPLES FOR THE ORGANIZATION OF CHILD AND ADOLESCENT MENTAL HEALTH SERVICES

The organization of services for child and adolescent mental health needs to take into consideration several strategic recommendations. Some are consistent with the principles underpinning the organization of mental health services for adults; others are based on specific considerations for this age group.

Child mental health specialists play an important role in sensitizing governments on child mental health needs. They may act as expert advisors and contribute to the planning and evaluation of mental health services. Furthermore, changes in the conceptualization of services have direct implications on child mental health specialists' role. A good understanding of the main guiding principles is therefore important for child psychiatrists and other professionals in the field.

Training of mental health staff, Asmara, Eritrea, 2009



The guiding principles listed below are based on strategic directions proposed by the WHO and on available international evidence from implementation research (WHO, 2005a; 2008a; WHO and World Organization of Family Doctors, 2008; Eaton et al, 2011).

- **Integrate mental health in general health services**

  Physical and mental illness frequently coexist. Somatic complaints are common presentations for mental health problems in children and adolescents (Campo et al, 2004). In addition, children with chronic medical illnesses are more prone to develop emotional and behavioral problems. Mainstreaming mental health into general health services contributes to improved recognition of mental disorders and ensures that physical healthcare needs of children with mental disorders are not neglected.

- **Improve equity and access to care by provision of care as close to communities as possible**

  Many people with mental disorders do not consider themselves to be in need of psychiatric care. Parents and adolescents may perceive psychiatric care as stigmatizing. Utilization of mental health care services often improves when services are provided as part of primary health care. Provision of mental health care at primary care and community levels has the potential to increase access to treatment and equity in access to care by making available services closer to user's homes and by reducing users' direct and indirect costs (e.g. travel expenses).

- **Promote a continuum of care**

  Addressing the mental health needs of young people requires the coordinated action of health professionals employed at various levels of the health system. Even when mental health problems are recognized by primary care workers, consultation with or referral to specialists may be necessary for further assessment and management. Families of children with chronic mental disorders, for example, developmental disorders, often report inadequate coordination between pediatric and adult services. Procedures for coordination between community care and specialized services and with adult facilities improve the perceived quality of care.

- **Ensure inter-sectorial coordination**

  Children with mental disorders and their families have complex needs requiring multi-sectorial responses. They need to have access to appropriate educational and occupational opportunities and social and rehabilitation services. New staff competences and structured mechanisms for inter-sectorial coordination and multidisciplinary team approaches are needed.

- **Adopt an ecological approach**

  The psychosocial well-being of children is closely linked to the mental health of parents and the quality of the family and school environments. Many psychiatric disorders that have their onset during adolescence are connected with family problems and social difficulties, and are only understandable

when viewed against this psychosocial context. Management of mental health problems in young people requires assessing the needs and resources in the family and active engagement of carers and teachers in treatment plans.

- **Adopt a life-cycle approach**

  Children have specific vulnerabilities as they grow up and acquire a set of skills to cope with the adverse circumstances that will occur along their path. Their mental health and well-being is influenced by early experiences and, even beyond that, by maternal exposure to nutritional deficiencies, hazardous agents and stressful circumstances during pregnancy (Foresight Mental Capital and Well-being Project, 2008; Fisher et al, 2011). If untreated, mental disorders with onset during childhood and adolescence are likely to persist and lead to poor health, educational and occupational outcomes later in life. When planning services for children's mental health promotion and care it is important to consider the entire range of opportunities for addressing early determinants of child mental health, as for example by including maternal mental health assessment and treatment in antenatal and postnatal visits.

- **Adopt a human rights-based approach to care**

  Children with mental disorders are often stigmatized and discriminated against and, because of that, may be denied opportunities for adequate healthcare and education. They have the right to access quality mental health services that are appropriate to their needs, culture and gender. Healthcare workers can play a key role by promoting behavior change in families, schools and communities, and informing young people and their carers about their rights.

- **Promote users' participation**

  Adolescents and children have the right to be informed about their health problems and participate in decision-making about their treatment (whenever possible, according to their age and developmental level, see Chapter A.1). Carers and other available resources within the family, school and community need to be engaged and empowered to assume active roles in promoting the psychosocial well-being and functioning of young people.

- **Mainstream health promotion interventions in primary health care settings**

  Interventions based on strategies for reducing risk and strengthening resilience have proved effective for the prevention of mental disorders and promotion of psychosocial wellbeing in young people. Because of the huge reach of primary care services, the delivery of health promotion by general practitioners can have a significant impact on youth mental health. This opportunity is often untapped. The need for a paradigma shift in the role of primary health care professionals to assume increased responsibility for health promotion has been repeatedly emphasized (WHO, 2008b). Besides the role of medical services, schools and families offer opportunities for sustainable health promotion interventions. Parenting skills training and life skills training are examples of health promotion interventions in the family and school setting respectively.

PRACTICAL IMPLICATIONS OF ADOPTING THESE GUIDING PRINCIPLES IN THE DELIVERY OF CAMH'S INTERVENTIONS

Organization of services

Figure J.5.1 shows the optimal mix of services pyramid, a framework developed by the WHO to provide guidance for the organization of mental health services. It also applies to CAMH services. The pyramid highlights the fact that tertiary and specialist services are very expensive and needed by only a small portion of the population, while informal, community-based and primary health care services can be provided at a relatively low cost and are more frequently needed.

Young people use a variety of primary care services, such as maternal and child health outpatient clinics, outreach services for vaccination and growth monitoring, outpatient services for HIV counseling and testing, and family-planning services. These are all potential entry points for providing mental health promotion and care to children and adolescents in need. Trained primary care providers can address specific concerns about psychosocial distress and clinical symptoms for mental disorders. In some cases they also ask and assess for the presence of specific symptoms as part of their routine work. As an example, child development monitoring and early detection of developmental difficulties can be part of routine child-well visits. In many countries child mental health services are provided by specialists in secondary and tertiary care settings only and increasing access to mental health care in primary care settings requires a shift in the organization of services and in the allocation of financial and human resources.

Community-based and informal care consists of services provided mainly by peers, parents, school staff and influential community members. They play a major role especially in terms of community sensitization on mental health needs, promotion of attitudinal changes and promotion of psychosocial well-being.



Figure J.5.1 The optimal mix of services pyramid (WHO, 2007)



Attendees and Faculty, IACAPAP Study Group in Abuja, Nigeria, 2010

Community-based health workers may also be engaged in the delivery of services relevant to child mental health and they can be considered an "extension" of the primary care services. Human resource policies have to consider the specific training needs and incentives for peers, parents, teachers, community leaders, and community health teams according to their respective roles.

Policies and procedures for coordination and collaboration between services

National policies need to define pathways for coordination between services within the health sector and across sectors (i.e., with schools, social services and other community services), including mechanisms for referral and referral back. Traditionally, the organization of primary health care has relied on referral of all mental disorder cases to specialists. In most countries, specialists are available at secondary or tertiary care levels only. Delivery of child mental health services at a primary health care level requires the establishment of structured mechanisms for collaboration and team working, allowing primary care staff opportunities for regular consultation and supervision with specialists in mental health and related disciplines (Bradley et al, 2003). In some cases, mental health specialists (e.g., psychiatric nurses, psychologists) are made available at primary health care level and patients are referred by general practitioners to primary health care-based mental health specialists, who assume responsibility for providing treatment. This model is called the *replacement model*.

In *collaborative models*, general practitioners retain the primary responsibility for care but professionals with complementary skills (traditionally mental health professionals) work as part of a package of care, liaising with both patient and health worker to increase the overall effectiveness of treatment. Collaborative approaches are based on a strong partnership between front line health workers and other professionals with diverse expertise and mandates who work together to meet the users' needs. This implies task-shifting and task-sharing among a multidisciplinary team of professionals. Collaborative approaches increase the feasibility of assessment and management of mental disorders by busy health workers in community-based settings, while also promoting the provision of good

quality and comprehensive mental health care. Evidence suggests that training of general practitioners and establishing collaborative care models may lead to greater impact on the overall quality of care and promote a better and more equitable use of scarce specialized personnel.

Human resources policy

While human resources are the most valuable asset of mental health services, many countries face difficulties with availability of trained staff, especially in rural settings and community-based services. Careful planning of training, specification of the tasks to be performed and deployment of workers is critical. A reallocation of staff from institutions to community-based services and from urban to rural areas may be needed, together with the recruitment and training of a wider range of workers at primary health care level. Strategies to improve staff retention and motivation are equally important. They may include provision of ongoing education and support through team meetings, consultations and supportive supervision.

Capacity building

General health care staff need to be trained in order to acquire basic mental health competencies for the detection of common mental disorders, provision of basic treatment and psychoeducation, and referral to other community-based and specialist services when necessary. Training materials address concerns about human rights and promote attitudinal change to reduce stigmatization and discrimination towards children with mental disorders and their families. Capacity building materials ought to increase primary health workers' awareness of their role for the promotion of mental health. These new skills need to be updated and refreshed with regular supportive supervision and on-site consultation and training.

Specialists in child mental health (pediatricians, mental health nurses, psychiatrists, neurologists, child psychiatrists) require adequate skills to work

World Mental Health Day 2009, Jordan



collaboratively with general health workers and multidisciplinary teams and provide them with supervision and support. In addition, the curriculum for a range of non-health professionals (e.g., social workers, community-based workers) has to include a mental health component when relevant to their functions.

Monitoring quality of care

The definition of standards for and indicators of quality of care is key to assessing the effectiveness of organizational changes and capacity building efforts. Important parameters for the evaluation of quality of child mental health care include:

- Access and equity of access
- Acceptability to users and staff
- Users' and carers' satisfaction
- Utilization of primary care services by children with mental disorders
- Reduced number of cases requiring admission to in-patient services or tertiary level outpatient visits
- Reduced clinical symptoms and improved functioning in daily life.

IMPROVING SERVICES FOR CAMH: A STEP-WISE APPROACH

How to operationalize the theoretical considerations mentioned above? Where to start planning or improving services for CAMH? There are a number of key actions needed. They are summarized in Figure J.5.2. It is not important to strictly follow the order of suggested actions, it is much more important to ensure ownership throughout the entire process by a comprehensive team of local stakeholders and active participation of users' representatives.

An example of a global initiative for scaling up mental health care: the mhGAP program

The World Health Organization recently launched the Mental Health Gap Action Program (WHO, 2008a; 2010) aiming to increase coverage of key mental health interventions, particularly in low- and middle-income countries. The program provides technical guidance for the development and implementation of national strategies for scaling up mental health care. It adopts a life-cycle approach and targets children and adolescents, among other age groups. The following are the critical assumptions:

- Mental health care has to be integrated into general health services and mainstreamed in primary care settings
- Non-specialist health care professionals at primary health care level, when receiving appropriate training, can recognize common mental, neurological and substance abuse conditions and provide first-line interventions.

Figure J.5.3 illustrates the mhGAP suggested approach for improving availability of and access to treatment for children and families in need. Core components of the program are the definition of the package of interventions and development of strategies for increasing coverage of those interventions. A template for a package of interventions that can be provided at primary and

Figure J.5.2 A step-wise approach for improving services for CAMH

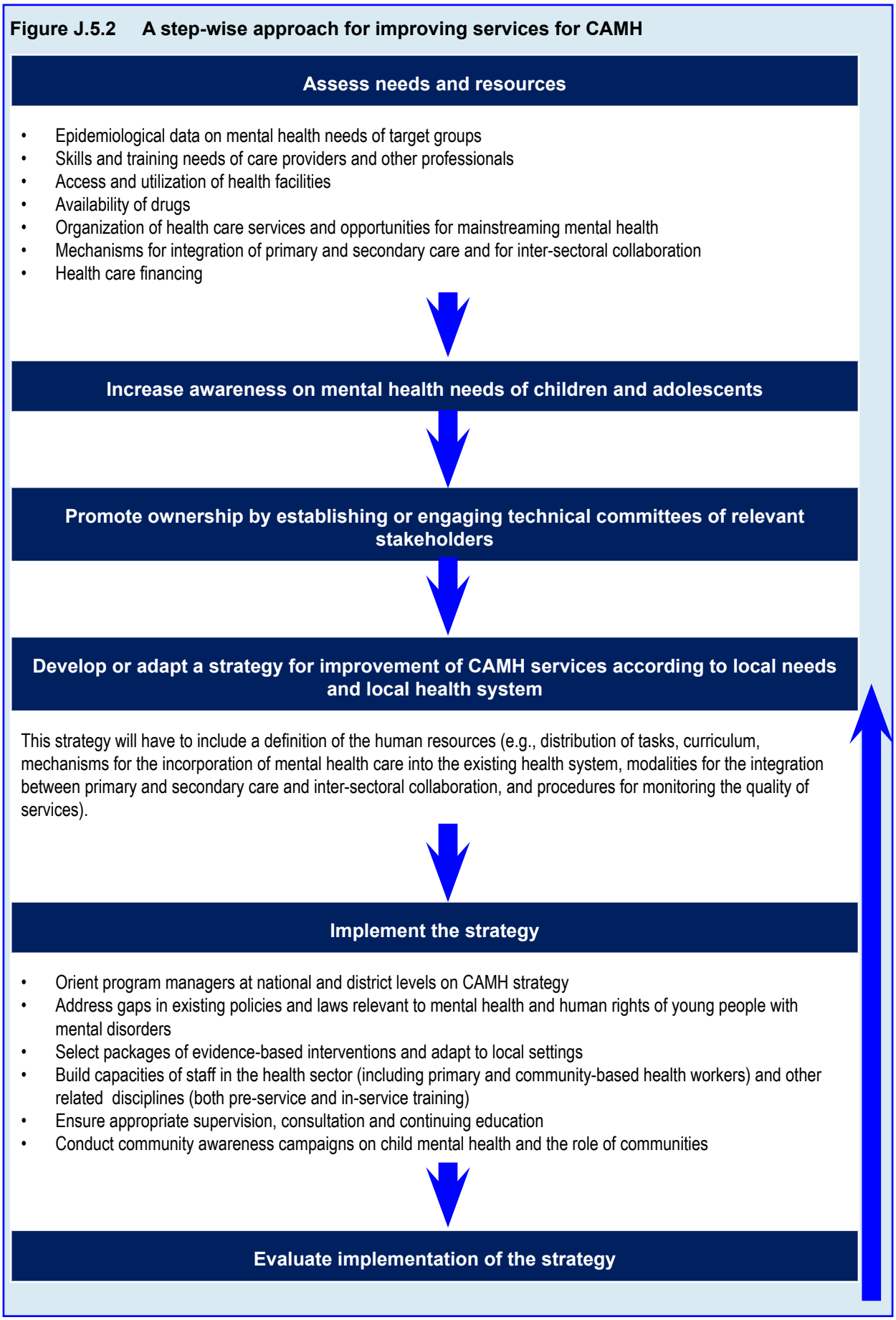


Figure J.5.3 mhGAP framework for action.



secondary care levels by non-specialist health care workers has been made available to countries (Dua et al, 2011) but it needs to be adapted to the local context. A team of international experts (Guidelines Development Committee) defined the content of the mhGAP intervention package on the basis of available scientific evidence and agreed criteria. Mental, neurological and substance use disorders that represent a high burden (in terms of mortality, morbidity and disability), cause large economic costs, or are associated with violations of human rights were identified as priority conditions. Cost-effective, acceptable and feasible interventions for prevention, detection and management of these conditions were then included in the package. The interventions are directed at individuals or populations.

Mental disorders in children were identified among the priority conditions. Developmental and behavioral disorders are specifically addressed in the mhGAP intervention package. Specific interventions for the management of depression, epilepsy, psychosis and alcohol and drug abuse in children and adolescents are also included. Table J.5.2 provides examples of evidence-based recommendations for assessment and management of mental disorders in children that were developed by the guidelines development committee.



Click on the picture to access evidence-based clinical guidelines for the management of priority conditions by non-specialist health care providers at primary health care level. It provides flowcharts to guide assessment and management and is available in several languages.

At country level, a technical task force has to define mechanisms for the delivery and scale-up of the intervention package: at what level of the health care system the interventions will be delivered, who will be responsible for delivering the interventions, and what changes in work tasks, training curricula, and procedures are required. For example, assessment and management of developmental disorders at a primary health care level implies the establishment of structured collaboration mechanisms with mental health specialists, schools, and social and rehabilitation services. As a consequence there may be a need to modify the

Table J.5.2 Recommendations for child and adolescent mental health conditions by mhGAP guidelines development committee

Maternal mental health interventions	CAMH 1. For at-risk children, parenting interventions promoting mother-infant interactions, including psychosocial stimulation, should be offered to improve child development outcomes. To improve child development outcomes, mothers with depression or with any other mental, neurological or substance use condition should be treated using effective interventions (see recommendations for treatment of depression and other mental, neurological or substance use conditions).
Parent skills training for behavioral disorders	CAMH 5. Parent skills training should be considered for the treatment of emotional and behavioral disorders in children aged 0-7 years. The content should be culture sensitive but should not allow violation of children's basic human rights according to internationally endorsed principles.
Parent skills training for developmental disorders	CAMH 6. Parent skills training should be considered in the management of children with intellectual disabilities and pervasive developmental disorders (including autism). Such training should use culturally appropriate training material.
Child abuse	CAMH 2. Non-specialized health care facilities should consider home visiting and offer parent education to prevent child abuse especially among at-risk individuals and families. They should also collaborate with school-based "sexual abuse prevention" programs where available.
Intellectual disabilities	CAMH3. Non-specialized health care providers should consider assessment and regular monitoring of children suspected of intellectual and other developmental delays by brief locally validated questionnaires. Clinical assessment under the supervision of specialists to identify common causes of these conditions should be considered. CAMH 4. Non-specialized health care providers should consider supporting, collaborating with, and facilitating referral to and from community-based rehabilitation programs.
Behaviour disorders (attention deficit hyperactivity disorder)	CAMH 7. Non-specialized health care providers at the secondary level should consider initiating parent education/training before starting medication for a child who has been diagnosed as suffering from ADHD. Initial interventions may include cognitive behavioral therapy (CBT) and social skills training if feasible. Methylphenidate may be considered, when available, after a careful assessment of the child, preferably in a consultation with the relevant specialist and taking into consideration the preferences of parents and children.
Pharmacological interventions for children with disruptive behavior disorders or conduct disorder or oppositional defiant disorder	CAMH 8. Pharmacological interventions (such as methylphenidate, lithium, carbamazepine and risperidone) should not be offered by non-specialized health care providers to treat disruptive behavior disorders (DBD), conduct disorder (CD), oppositional defiant disorder (ODD) and comorbid ADHD. For these conditions, the patients should be referred to a specialist before prescribing any medicines.
Somatoform disorders	CAMH 9. Pharmacological interventions should not be considered by non-specialized health care providers. Brief psychological interventions, including CBT, should be considered to treat somatoform disorders in children, if adequate training and supervision by specialists can be made available.
Antidepressants for children with depression	CAMH 10. Antidepressants should not be used for the treatment of children 6-12 years of age with depressive episode/ disorder in non-specialist settings.
Antidepressants for adolescents with depression	CAMH 11. Fluoxetine, but not tricyclic antidepressants (TCA) or other selective serotonin reuptake inhibitors (SSRI), may be considered as one possible treatment in non-specialist settings of adolescents with depressive episodes. Adolescents on fluoxetine should be monitored closely for suicide ideas/ behavior. Support and supervision from a mental health specialist should be obtained, if available.
Pharmacological interventions for anxiety disorders in children and adolescents	CAMH 12. Pharmacological interventions should not be considered in children and adolescents with anxiety disorders in non-specialist settings.
Behavior change techniques for promoting mental health	CAMH 13. Non-specialized health care facilities should encourage and collaborate with school-based life skills education, if feasible, to promote mental health in children and adolescents.

description of management tasks of primary care workers to include liaising with social services and community resources, providing advice to teachers and, when feasible, skills training to parents. Organizational changes and modification in the distribution of tasks and health professionals' curricula at various health care levels are often required. For example, whenever a parent expresses concerns about their child's development, the primary health care staff at the outpatient service can assess the problem, manage any co-occurring medical condition, provide family psychoeducation, and then refer the child to other primary health care outpatient services for follow up and more intensive psychosocial interventions (including parent skills training).

The assessment of needs and available resources is a critical preliminary activity that informs the adaptation of mhGAP template to the local needs, the design of national and regional strategies for its implementation, and prioritization and phasing of interventions. Success in the implementation of the program depends on political commitment at country level. The development/improvement of relevant policy and legal frameworks is important to ensure conditions favorable to the implementation of the program and respect of the human rights of children and adolescents with mental health problems.

A monitoring and evaluation framework is built into the program. A variety of tools is available or being developed to assist countries in its implementation, including an orientation guide for program managers, templates for the adaptation process, questionnaires for the needs assessment, training materials, and supervisory checklists.

Maternal, child and adolescent mental health in the Eastern Mediterranean Region: strategic planning towards improved care

The World Health Organization Regional Office for the Eastern Mediterranean Region has recently undertaken concerted efforts towards the improvement of maternal, child and adolescent mental health services in countries of the region encompassing the crescent extending from Pakistan in the East to Morocco in the West.

The WHO initiated and led a participatory process for the development of Regional Strategic Directions and Actions for Maternal, Child and Adolescent Mental Health Care by working closely with Ministries of Health in the region and availing itself of the technical support of experts in the field. The regional strategic document was discussed during an Intercountry Meeting on 26th-28th July 2010 in Cairo. The meeting was attended by mental health focal points from 21 of the 22 member states of the region in addition to WHO staff and experts.

Participants reached an agreement on key strategic actions to be promoted and undertaken at regional and country levels in the six years' operative period (2010-2015). In particular, the need to assess mental health service gaps and map available resources for child and maternal mental health care was emphasized. Development of human resources, integration of MCAMH interventions within existing primary health care services, promotion of mental health, and strengthening research and monitoring and evaluation were identified as critical needs to be addressed.

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CHILD AND ADOLESCENT MENTAL HEALTH POLICY

Gordon Harper



Refugee Mother and Child

William H. Johnson (1901-1970); Smithsonian American Art Museum, Gift of the Harmon Foundation.

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Conflict of interest: none declared

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Suggested citation: Harper G. Child and adolescent mental health policy. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

Public policy for child/ adolescent mental health aims to mitigate disparities that stand in the way of children's attaining their full potential:

- Differences in endowment
- Differences in life circumstances
- Differences in access to services

Other discussions of policy emphasize the mobilization of political will (Richmond & Kotelchuck, 1983), the translation of knowledge into practice (Harper & Cetin, 2008), or the evolution of public attitudes to children (Wise & Richmond, 2008). This chapter focuses on the mitigation of disparities. To that end, it will review recent changes that have influenced policy:

- Increased knowledge of disparities and their consequences
- New knowledge of interventions, on both the individual and the community level, to mitigate these disparities
- Increased professional and political readiness to act.

As children's emotional development is embedded in their overall development, disparities in mental health are necessarily examined in the light of disparities in overall health and well-being.

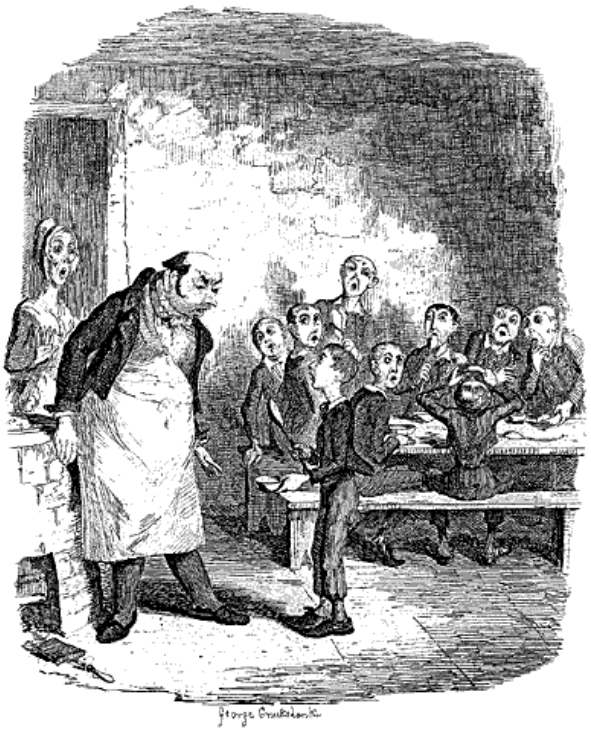
Children's lives in the literature

- Dickens: Oliver Twist, David Copperfield
- Stowe: Uncle Tom's Cabin
- Hugo: Les Misérables

DISPARITIES – SCOPE AND CONSEQUENCES

Disparate endowment

Pre-modern societies did not recognize childhood as a separate developmental stage or they regarded differences in children's endowment as of little consequence. The presence in the home of extended family members and flexible role expectations often proved relatively tolerant of differences among children. But modernization has changed children's lives in several ways.



"Please, sir, Can I have some more"

Illustration for "Oliver Twist" by George Cruikshank (ca. 1837).

First, with urbanization and increased inter-generational mobility (away from birthplace), fewer children grow up in multi-generational families. In nuclear families, two parents alone (or, often, a single parent) have less "buffering capacity" to accommodate childhood differences than did the aunts, uncles, and grandparents of the extended family.

Second, increasingly standardized education, starting in preschool, is less flexible in the face of different endowments and developmental trajectories. To prepare children for standardized jobs, schools need to classify students. Accordingly, systems for testing of children were created, starting with the work of Binet in France in the early 20th century, which sorted children into "normal" and "abnormal" (Binet, 1903).

Third, as differences in temperament, learning style and social endowment were increasingly recognized, "different" children –initially thought to be a homogeneous group – were divided according to categorical disorders (e.g., dyslexia, receptive and

expressive language disorders) and along dimensional lines (e.g., overall ability, social perception, inattention and hyperactivity). Such recognition gave rise to advocacy and research organizations *grounded in an appreciation of diverse endowments* (e.g., in the US, All Kinds of Minds and Mind Institute) and to the creation of specialized services – educational, social, and clinical (Harper, 2011).

Fourth, once it became clear that children with special needs needed special programs, many came to feel that such services should be available according to need, not limited to those with family resources. Services could be made available to larger numbers through private initiatives, non-governmental organizations (NGOs), legislation, or rights-based advocacy (Harper, 2012)

Disparate life circumstances

The depiction in 19th-century literature of children who grew up in conspicuous adversity (poverty, slavery, orphanhood, child abuse) increased public awareness of disparities in children's lives (e.g., Shengold, 1989). In response, universal public education was begun and destitute children were separated from the mixed populations in publicly supported "poor houses". Civic charities supplemented the traditional role of religious organizations in caring for orphans. New institutions advocating for abused children were created, starting in New York City in 1875 (New York Society for the Prevention of Cruelty to Children; see History).

In the 20th century, public policy in many countries, notably in Scandinavia, promoted the equalization of opportunity (Hilson, 2008). Even in developed countries with incomplete commitment to that goal, like the US, civic organizations advocated on behalf of all children. Some of these started with professionals (Ptakowski, 2010; see also the websites of Child Welfare League of America and of the American Academy of Child and Adolescent Psychiatry). Others had no guild affiliation (e.g., Children's Defense League).

Such efforts have been greatly strengthened by demonstrations that *adverse childhood experiences* not only cause suffering to the child, but have measurable long-term effects (see Table J.6.1). Using methods developed by the Centers for Disease Control in the US, studies have shown the effects of disparities in early life experience on later health and well-being. In the UK, a different methodology – using the Cambridge Early Experiences Interview – has likewise demonstrated

Table J.6.1 Adverse childhood experiences

What are they?
• Psychological, physical, and sexual abuse • Violence against mother • In household – substance abuse, mental illness, prison history
For what do they increase the risk?
• Alcoholism and drug abuse • Depression and suicide attempts • Smoking • Many sexual partners, STDs • Inactivity and severe obesity

Source : Edwards et al (2005), Felitti et al (1998)

adverse effects in adolescence (Dunn et al, 2011). Similar effects can be shown to occur in a developing country: higher numbers of adverse childhood experiences predict health-risk behavior in adolescents in the Philippines (Ramiro et al, 2010).

This argument links readily to increasing knowledge of brain development (Spenrath et al, 2011). In the US, the American Academy of Pediatrics, invoking an eco-biodevelopmental model, uses the evidence that toxic stress from adverse experiences and environmental influences leaves a "lasting signature on the genetic predisposition" of the child (Shonkoff et al, 2011) to argue for a transformation of child healthcare (Garner, Shonkoff 2012).

Public awareness of the persisting effects of disparities has been fostered by research on inter-generational social mobility (DeParle 2012; Jäntti et al 2006). These studies have shown different rates of social mobility in some countries (notably the US) than in others. That is, despite popular belief in "upward mobility", children's class of origin powerfully shapes their future well-being.

Disparate access to services

In the US, Knitzer (1982) and others criticized existing services for troubled children. They showed that:

- Most troubled children received no mental health services at all
- Available services were often fragmented between schools, mental health and social services
- Conventional services often disempowered parents who already felt alienated and helpless.

Initiatives to decrease disparities in services supported by foundations and the federal government followed. These initiatives, operating in dozens of



Yoo Soon Taek, wife of UN Secretary General, Ban Ki-moon, visiting the Centre for Neurodevelopment and Autism in Children (BSMMU).
Photo: Bangladesh Association for Child & Adolescent Mental Health

States and communities, have increased screening for emotional-mental-behavior disorders and encouraged new kinds of services (e.g., National Initiative and Substance Abuse and Mental Health Services Administration www.samhsa.gov/samhsa) meant to be more respectful and inclusive of parents.

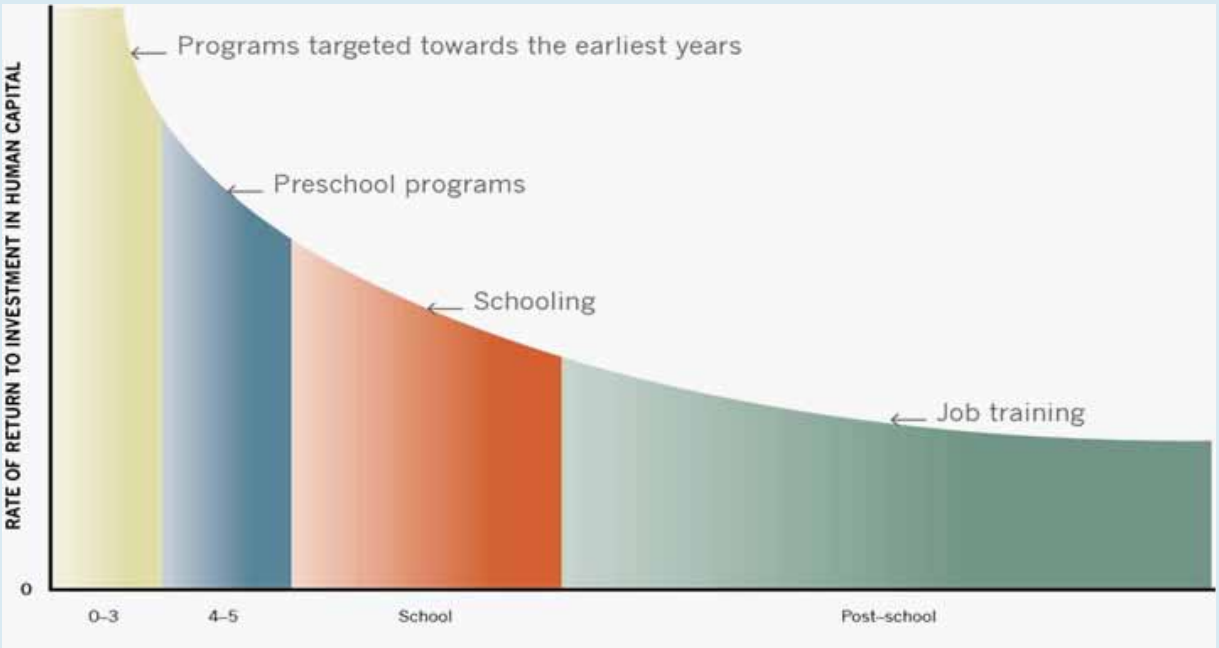
EFFECTIVE INTERVENTIONS TO MITIGATE DISPARITIES

The public in many countries increasingly recognizes that disparities in childhood endowment, life experiences and access to services need not simply be accepted but can become the focus of public policy. This awareness led to action on behalf of children, constituting a "global movement for health equity" (Marmot et al, 2012) in which mental health must take its place (Raviola et al, 2011).

Reflecting what Sridhar (2011) called the shift from clinical gaze (medicine) to community gaze (epidemiology) to economic gaze, clinical evidence has been supplemented by evidence from health policy and economics. A review of efforts to mitigate inequality in early childhood (Walker et al, 2011; Engle et al, 2011) indicates that:

- Adverse life experiences include nutritional deprivation and toxic/infectious exposures as well as events like child abuse
- Early–life adversity measurably impairs functioning in later childhood and adolescence
- Interventions ranging from iodine supplementation to early childhood parenting support have a mitigating/protective effect
- These interventions extend from iodine supplementation to wealth transfers to family group conferencing (Titcomb et al, 2005)
- Intervention is more effective early than late (see Figure J.6.1).

Figure J.6.1 Effectiveness of interventions



Source: Heckman JJ. Schools, skills and synapses. Economic Inquiry 2008; 46: 289-324. Reproduced with permission.

The limitation of the economic argument, of course, is that it provides no support for the humane and promotive care of those whose disabilities limit their potential as "human capital." The counter position argues in terms of the burden of disease and invokes human rights (Kieling et al, 2011).

The challenge of effecting and evaluating such interventions is very different in developed and developing countries. In the US, much emphasis has been placed on demonstrating processes, like increased participation in care and the degree to which implementation adheres to intentions (fidelity), as opposed to child- and family-level outcomes. Process, indeed, is much easier to measure than outcomes. A private agency, the National Quality Forum, has generated some developmental and mental health indicators, mostly focused on what providers *do* (screening, follow-up, etc).

To move beyond measures of process (access, participation, fidelity, etc), the concept of the "Triple Aim" has been promoted by the Institute for Healthcare Improvement (Berwick et al, 2008). The "Triple Aim" looks at health outcomes, consumer experience, and cost per member. Similarly, in the UK, the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA), developed by the University of Manchester and the Royal College of Psychiatrists looks at actual functional outcomes of children and youth with mental illness. Measures have been developed by various governments. For instance, in Scotland the government has published a detailed set of indicators, encompassing both mental health and mental illness (Scottish Government, 2011).

Triple Aim (Berwick et al, 2008)

- Health outcomes
- Consumer experience
- Cost per member

While disparities persist in developed countries (e.g., Canada; Kutcher et al, 2010), special challenges attend the needs and the policy responses in less-resourced (developing) countries. These challenges have been described for less-resourced countries as a group (Belfer, 2008; Omigbodun, 2008; Eaton et al, 2011) and for particular countries: Brazil (Couto et al, 2008), Mexico (Espinola-Nadurille et al, 2010) and Lebanon (Fayyad et al, 2010). The challenges include low levels of resources to support care, unreliable networking infrastructure, and tension between traditional and modern approaches to healing. The World Health Organization mhGAP report (Dua et al, 2011) specifically addresses these challenges.

Another approach to balancing appreciation of what is done (process) and what is being sought (outcome) is to use a "logic model". This approach makes

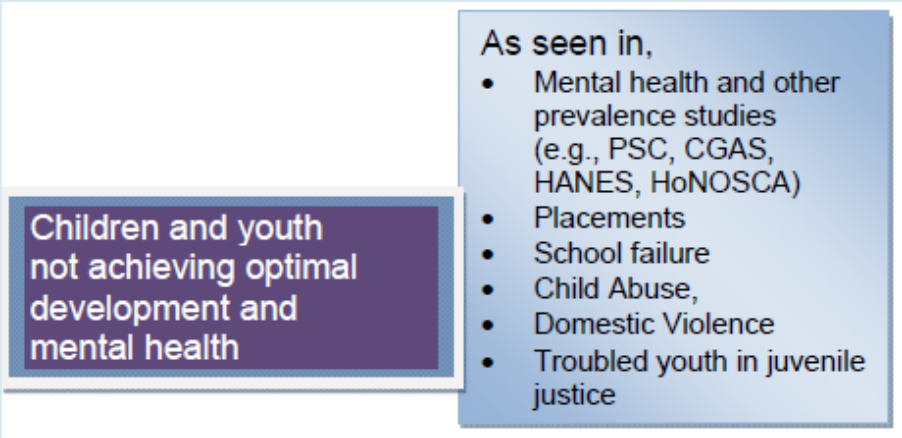


Staff and children at a mental health service in Duhok, Iraq.
Photo: Abdulbaghi Ahmad

explicit the outcomes that matter while making it possible to test both the analysis of the identified problem and the relative contributions of each intervention to the desired outcomes. The logic model goes through several steps, starting with specification of the problem to be addressed and how it is assessed (Figure J.6.2). In the next step, the desired goal is similarly stated, also specifying how it is to be assessed (Figure J.6.3). The problem is then analyzed, in terms of contributing factors that lend themselves to intervention (Figure J.6.4). Finally, with intervention, change in each identified factor is measured and related to change in the original problem (Figure J.6.5).

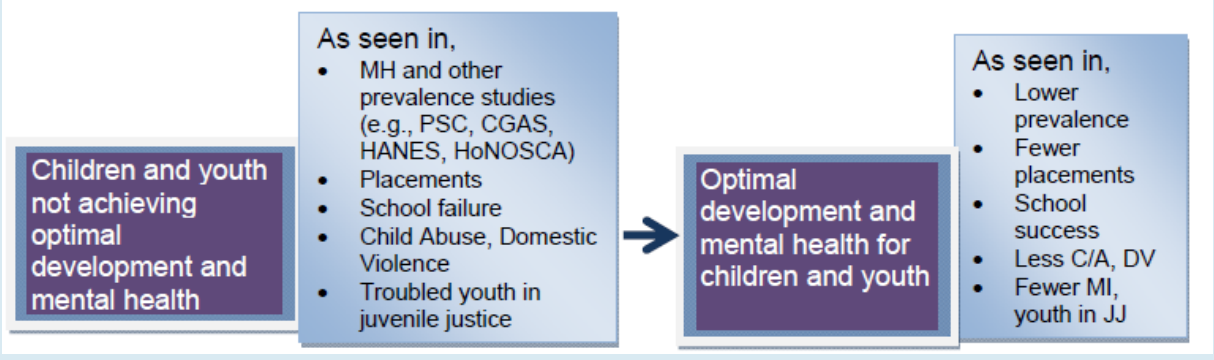
The evidence for effective intervention has been reviewed (Kieling et al, 2011) as well as the obstacles to implementation of better-evidenced practices (Hoagwood, 2003). Creative approaches include the location of practice in a "meta-system," (Kazak et al, 2010). Illustrative examples include the work of Fayyad and colleagues in Lebanon (2010) to train community health workers to identify and help troubled children at the village level and the ambitious program in Brazil (Couto et al, 2008), to develop centers of psychosocial care at the community level throughout the country. An approach to early intervention

Figure J.6.2 Logic model: defining and measuring the problem



PSC: Pediatric Symptom Checklist; CGAS: Children's Global Assessment Scale; HANES: Health and Nutrition Examination Survey (of the US Centers for Disease Control); HoNOSCA: Health of the Nation Outcome Scales for Children and Adolescents.

Figure J.6.3 Logic model: defining and measuring the goal



PSC: Pediatric Symptom Checklist; CGAS: Children's Global Assessment Scale; HANES: Health and Nutrition Examination Survey (of the US Centers for Disease Control); HoNOSCA: Health of the Nation Outcome Scales for Children and Adolescents.

Figure J.6. 4 Logic model: analyzing the problem – identifying contributing factors for intervention

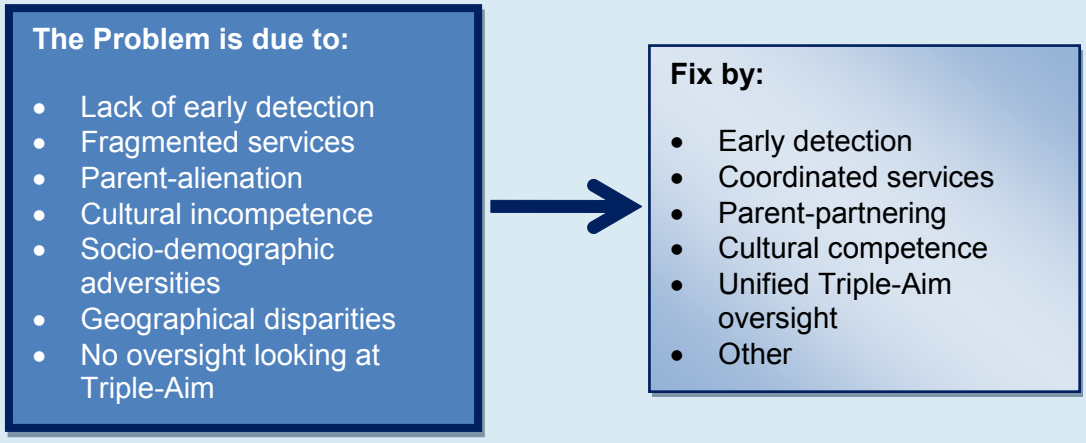
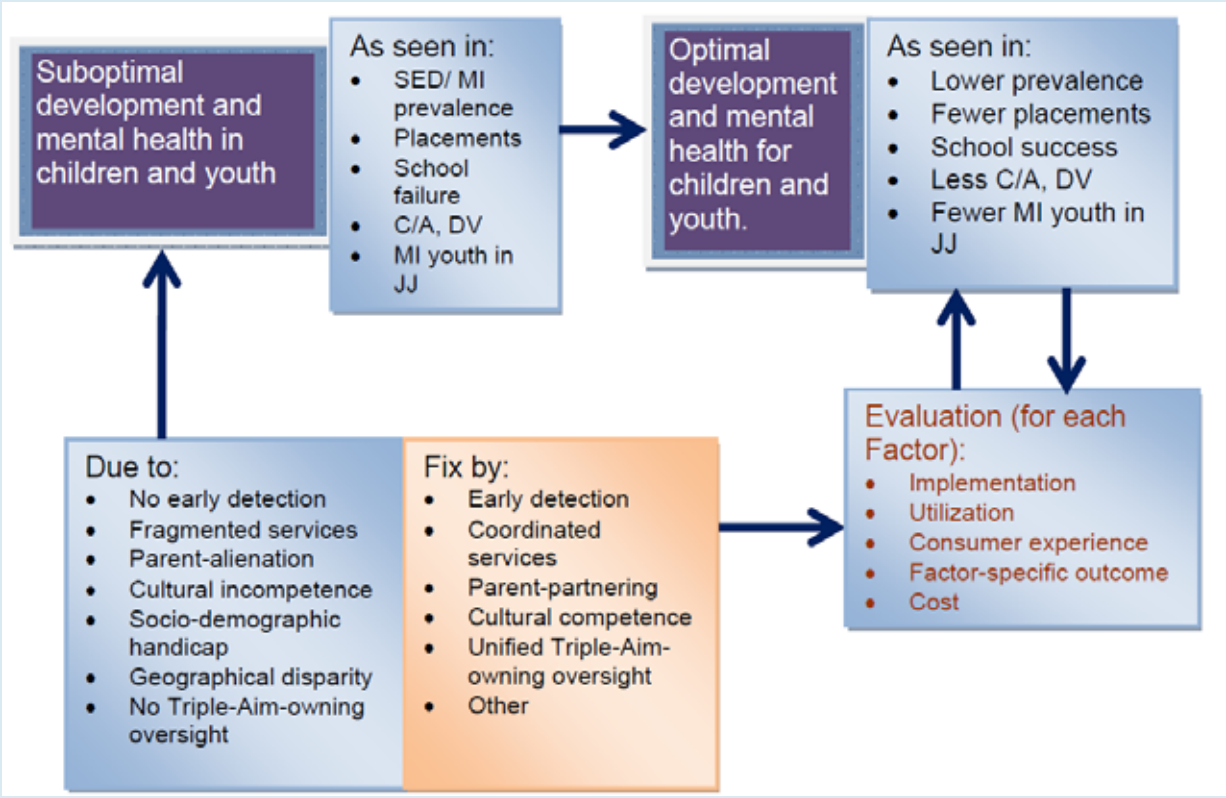


Figure J.6.5 Logic model: which factors have changed? How have they helped the problem get better?



PSC: Pediatric Symptom Checklist; CGAS: Children's Global Assessment Scale; HANES: Health and Nutrition Examination Survey (of the US Centers for Disease Control); HoNOSCA: Health of the Nation Outcome Scales for Children and Adolescents; C/A: child and adolescent; DV: domestic violence; MI: mental illness; JJ: juvenile justice; SED: serious emotional disturbance.

used in diverse communities is the fostering of the parent-infant relationship, both through the "Touchpoints" method developed by Brazelton (Sparrow, 2010; Sparrow et al, 2011) and "Supporting Security" developed by Wittenberg (2009).



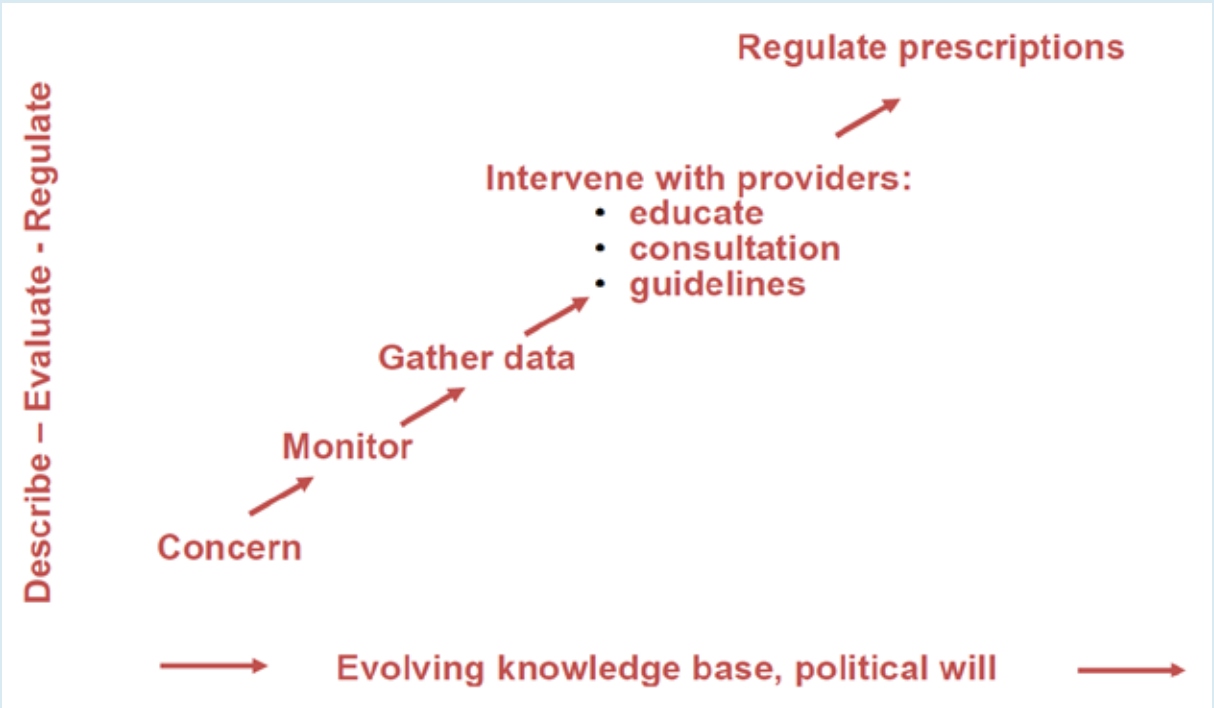
Click on the picture to view a short video (5:08) about Touchpoints.

Touchpoints

The Brazelton Touchpoints Center has used a strengths-based, developmental, relational, and culturally informed approach for family-self strengthening and community-self strengthening in over 160 communities. Social connectedness, parental self-efficacy and community collective efficacy revive the capacity to envision the future of children and community with hope. Such connection and hope are critical ingredients, often overlooked, for one generation to be able to nurture the next. In addition to connecting to others and to the future, families and communities also draw strength through connecting to the past through cultural identity. Rooted in dynamic, developmental systems theory, this approach empowers parents and other family members to discover and rely on the resources within themselves, their children and their communities.

Touchpoints does not exclude the contributions of professionals and their institutions. Nor does it minimize the impact on children, families and communities of adversities such as food, air and water insecurity. It offers a way of being, along with specific ways of doing and saying that re-equilibrate the power imbalance and disrupt the monopoly on knowledge and technology deemed pertinent to childrearing. Touchpoints also applies this attitude and strategies to organizations and systems of care. Such a paradigm shift creates different relationships between professionals and agencies and the children and families they serve. This approach also connects families with each other and with what we call traditional and informal community resources.

Figure J.6.6 The evolving state role regarding psychoactive medications



Evolving public awareness, professional and political will

The growth of public and professional awareness of disparities in children's lives and of the possibilities of intervening is evident in many places. In the US, the National Institutes of Health has established a National Institute on Minority Health and Health Disparities which has funded close to a dozen centers focused on health disparities around the country. However, none of these seems to be devoted specifically to child health, let alone child mental health.

Regarding mental health, the WHO mhGAP report mentioned above details the enormous distance between need and what is provided. The case for national policies for child development and child mental health has been pointed out in countries as diverse as Canada (Kutcher et al, 2010) and Brazil (Couto et al, 2008) and on the international level (Belfer, 2008). A more active role for youth themselves is seen in the use of "peer mentors" in the US and of young people as "health agents" in Tanzania (Kamo et al, 2008).

The degree of organized activity around the world on behalf of children's mental health, far greater than imagined even a decade ago, is reflected in the *Bulletin* of the International Association of Child and Adolescent Psychiatry and Allied Professions (IACAPAP).

AND THE CHALLENGES…

Although children in many countries now benefit from public awareness of disparities, their impact, and effective interventions, challenges remain. Several of these bear mentioning:

- How to balance the competing appeals of models of care that are professionally driven (and may be parent-alienating) and those that are parent-driven (and possibly anti- or non-professional)?
- How can we use innovations like peer mentors/ peer specialists to diminish troubled youths' sense of defect and enhance their sense of mastery?
- How to balance interventions early, for prevention, and those later, when disability and dysfunction have appeared?
- In countries where services in the mental health, educational, and social services have developed apart from each other, how can services be integrated?
- Where health insurance is used to support mental health service, how to balance the requirements to demonstrate "medical necessity" with preventive needs and with the need for help beyond the acute phase?
- Amid promotion from manufacturers and the appeal to parents of medications that promise to be effective and easy, how to keep child mental health from becoming a reductionistic, single-perspective field?
- How to define a comprehensive, population-based approach to child development and child mental health, given competition among those, parents and professionals alike, who would focus on one group to the exclusion of others (as happens currently, with those who advocate for and those who fear the consequences of increased entitlements for those with some form of autism)?
- Finally, as interventions for child mental health become more

recognized, more potent, and potentially harmful, policy must address the challenge of ensuring that services are safe and effective, not just remunerative to provider and satisfactory to consumer. The stages of development of the State's role in overseeing medication services, evolving from bystander to interested observer and enabler to monitor and standard setter is represented in Figure J.6.6.

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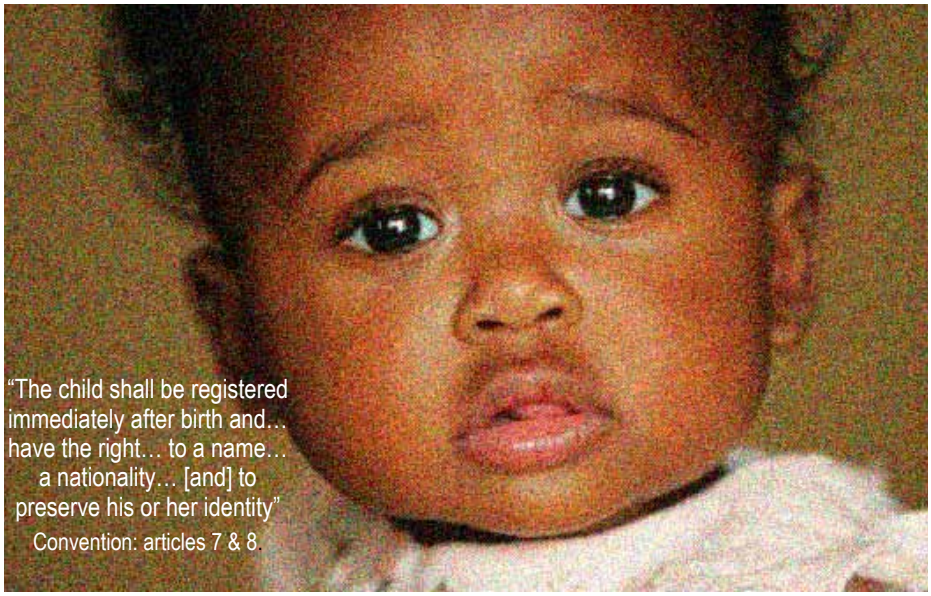


Grade 8 students taking part in the pilot phase of the Respect 4U intervention at a secondary school in Masiphumele, a township outside Cape Town, South Africa. Photo: Julius Oatts

THE UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

AND IMPLICATIONS FOR CLINICAL PRACTICE, POLICY AND RESEARCH

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Acknowledgement: This

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Suggested citation: Belfer ML, Song S. The United Nations Convention on the Rights of the Child and implications for clinical practice, policy and research. In Rey JM (ed), *IACAPAP e-Textbook of Child and Adolescent Mental Health*. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2012.

The *United Nations* (UN) *Convention on the Rights of the Child* (Convention) and subsequent related documents have the potential for greatly improving the lives of children (birth to 18 years of age, but dependent on culture) in several dimensions, offering protection from abuse, strengthening children's relationship with families and ensuring the realization of individual potential. These documents go well beyond having implications for governments and should be considered in relation to all professional activities that impinge on the lives of children including clinical practice, research, participation and education.

Currently, there is tension between the community of "disabled" and those with "mental disorders" with significant implications for progress in child related human rights. Is a mental disorder a "disability"? Will inclusion of those with mental disorders weaken or distort advocacy for those with non-mental disorder disabilities? At a time when there are great opportunities for advocacy this issue needs to be addressed because in the current era it may be one of the greatest barriers to the promotion of the needs of those with mental disorders in the context of human rights as put forth in the Convention and the recently adopted *UN Convention on the Rights of People with Disabilities* (CRDP). The issues of exclusion and disenfranchisement are common to all with disabilities and certainly to those with mental disorders.

The historical understanding of children and childhood must be appreciated to realize how children, in particular, can suffer drastic consequences as a result of being considered disabled (Hibbard & Desch, 2007). In the modern history of civilization children were seen as property (Slee, 2002). The role of children was to increase the productivity of the family and propagate to continue the family line (Slee, 2002). There was, until the past century, no concept of a developing child with potentials that could be enhanced or thwarted by environmental or attitudinal factors. There was little understanding of a developmental trajectory for children and that they were not simply little adults. Lastly, in many cultures it was felt that *children should be seen and not heard* and that they did not have a claim on the right of inclusion. Both because of a better scientific understanding of child development and the evolution of social thinking, children are now viewed differently by many, but certainly not by all segments of society. However, the potential of children with disabilities, for the most part, continues to be ignored: "…widespread underestimation of the abilities and potential of children with disabilities creates a vicious cycle of under-expectation, under-achievement and low priority in the allocation of resources." www.unicef-irc.org

Emotional and behavioral problems affect between 10% and 20% of children worldwide (Belfer, 2008). Recognizing childhood emotional and behavioral problems in the context of disability rights, remains a challenge and, to date, has not had the prominence warranted (Stewart-Brown, 2003). Data on the cost to society of mental disability in children is yet to be fully calculated, but the studies that are available show dramatic costs, comparable to those of other disabilities and with equal issues related to participation in society. The emotional and physical disability resulting from exposure to war, famine, disasters and HIV/AIDS is nearly incalculable. The approaches to understanding and intervening in these situations not only involve concerns with the rights of children, in the usual framework, but extend to those who seek to engage in research with these vulnerable populations. This chapter attempts to focus a light on the barriers which

chapter is in part based on a chapter to appear in "Mental Health and Human Rights" to be published by Oxford University Press entitled "Missing voices: Speaking up for the Rights of Children and Adolescents with Disabilities" prepared with Diana Samarasan. The views expressed in this chapter do not necessarily reflect those of Ms Samarasan.

children with disabilities continue to face in being considered active members of society, and the need for responsible research.

CONSEQUENCES OF DISABILITY

In many countries, children with disabilities are placed in institutions at birth or as toddlers and remain there until death. All available data show that children in institutions do far worse socially, educationally, medically and psychologically than children raised in supportive community settings (Groce & Paeglow, 2005). Human Rights Watch found that the death rate among institutionalized children with disabilities was almost twice that of the general population and of children kept at home. In some institutions in some countries the mortality rate exceeds 75% (Human Rights Watch, 2001).

According to the United Nations and UNICEF, girls with disabilities are twice or three times more likely to experience sexual and physical abuse than their non-disabled peers. Where the ability to contribute economically to family survival is critical, children with disabilities have little value other than as objects displayed for pity or money. The most common employment around the world for disabled people is begging (Groce, 1999). Isolation both self-imposed and socially created is common, particularly for those who look different.

CONCEPT OF PARTICIPATION

Approaches to clinical care for people with disabilities are too often conceived from a *deficit model* focusing on individual impairment. This has consequences for how the person is viewed and unreasonably limits expectations. The Convention (article 12) redefines the role of children in society as participants and, through their participation, as critical contributors to their own health and that of the community in which they live. If the clinician and policymaker move from a deficit model to the concept of *maximizing participation* and focus on the barriers faced by people with disabilities in seeking full participation, then many opportunities for creative programming are opened. It requires a considerable shift in the mindset of clinicians and policymakers but once adopted can be seen as freeing up opportunities or identifying barriers that can readily be overcome.

The efforts to include children and adolescents in mainstream education have met with varying levels of success. Low and middle income countries, as defined by the World Bank, have demonstrated some of the more innovative approaches, often out of necessity.

The World Health Organization has attempted through the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2) to disseminate a model for professionals to use to approach care for people who have impairments from the perspective of participation. The ICIDH-2 covers three dimensions of disability:

- Impairment in bodily functions and structures
- Limitation in activity, and
- Restriction in participation.

This classification recognizes that someone with an impairment may or may not have a limitation in activity or even a disability, depending on the environment

RIGHTS OF THE CHILD

The first United Nations statement devoted exclusively to the rights of children was the Declaration on the Rights of the Child, adopted in 1959. This was a moral rather than a legally binding document. In 1989 the legally binding Convention on the Rights of the Child was adopted by the United Nations. In 54 articles the Convention incorporates the whole spectrum of human rights—civil, political, economic, social and cultural—and sets out the specific ways these should be ensured for children and young people. In May 2000, two Optional Protocols, one on the involvement of children in armed conflict and a second on the sale of children, child prostitution and child pornography, were adopted to strengthen the provisions of the Convention in those areas. The Convention on the Rights of the Child is the most endorsed human rights treaty in the world, ratified by all but two countries. View the Convention and related documents by clicking on the picture below.





"…the child who is capable of forming his or her own views [has] the right to express those views [and] the right to freedom of… thought, conscience and religion."

Convention: articles 12-14.

Photo : http://syinghana.com/?p=137



Click on the picture to view a short animation explaining the Convention to children (by the Children's Rights Alliance) (www.childrensrights.ie)

Table J.7.1 The United Nations Convention on the Rights of the Child summarized according to article (Carlson, 2001).

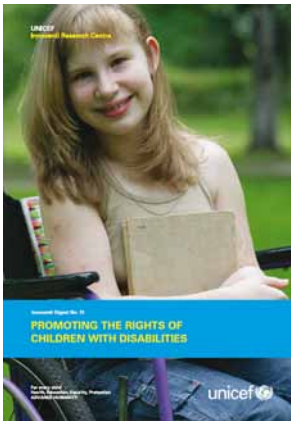
Principles	Provisions	Protection	Participation
A2: Non-discrimination	A5: Guidance	A19: Abuse and neglect	A13: Expression
A3: Best interest	A7: Name/nationality	A21: Adoption	A14: Thought
A6: Survival and development	A8: Identity	A22: Refugee	A15: Association
A12: Respect for child's views	A9:Parent separation	A32: Labor	A17: Information
	A16: Privacy	A33: Drugs	
	A18: Responsibilities	A34: Sexual exploitation	
	A24: Health	A35: Abduction	
	A25: Social security	A37: Torture and deprivation of liberty	
	A27: Standard of living	A38: Armed conflict	
	A28 and A29: Education	A39: Rehabilitative care	
	A31: Leisure	A40: Juvenile justice	

and society (Clark & MacArthur, 2008). The human rights approach to disability also shifts the focus from the limitations of individuals to the barriers within society that prevent the full participation of people with impairments on an equal basis with others.

UN CONVENTION ON THE RIGHTS TO THE CHILD

The content of the Convention by relevant article is summarized in Table J.7.1. The Convention clearly advocates for the inclusion of all children in the life of the community with strong recommendations for access to education and services. Furthermore, it argues against discrimination of any kind. However, experience with the Convention has shown that it has lacked meaningful implementation (WHO, 2005). In particular, children and adolescents with disabilities, including psychosocial disabilities, have not seen meaningful inclusion.

The Convention has been incorporated into national legislation in at least 50 countries, but fewer countries have implemented programs to operationalize the provisions of the Convention. National independent human rights institutions for children have been established in some countries leading the effort to provide a meaningful realization of children's rights (Pais & Bissell. 2006).



Click on the picture to view document

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Going one step further, the CRDP, drafted with the strong activism and unprecedented participation of persons with disabilities, mandates the involvement of people with disabilities (including children with disabilities) and their representative organizations in the implementation and monitoring of programs concerning them.

The CRDP attempts to address a gap in justice which has occurred not because people with disabilities were explicitly excluded from other more general



"…a child shall not be separated from his or her parents against their will… [and shall be permitted to cross national borders] for… family reunification…."

Convention: articles 9 & 10.

(Source: http://www.creativespirits.info)

human rights legislation (in fact, in the Convention, children with disabilities were specifically included), but because the moral platform which is used to interpret such documents has been skewed to leave out certain populations. The social model of disability, from which the Convention and CRDP are derived, places the obligation for inclusion squarely back on the shoulders of society. In this model, disability is not inherent in the person but rather, occurring with the interaction between a person with impairment and societal, attitudinal and environmental barriers.



Click on the picture to view a video on dealing constructively with disability discrimination in sport.

In a way, the existence of the CRDP points to the fact that it is (again) the larger philosophical construct of the omnipotent "we" which is the problem. Since the Enlightenment, as previously marginalized segments of society have demanded and realized their voice, the conception of who "we" are has gradually expanded. Sixty years after the adoption of the Universal Declaration on Human Rights, thanks largely to the persistence of the disability rights movement (whose slogan is "nothing about us without us"), there is recognition that disability is part of the human experience.

As law professor Amita Dhanda writes, "It is my view that the Convention on the Rights of People with Disabilities has done the following for persons with disabilities: it has signaled the change from welfare to rights; introduced the equality idiom to grant both the same and different to persons with disabilities; recognized autonomy with support for persons with disabilities and most importantly made disability a part of the human experience" (Dhanda & Narayan, 2007). Whether the CRDP and the growing disability rights movement will give a voice to children remains to be seen.

Rights-based approaches to children with disabilities

It is an indictment of society that children and adolescents have not seen meaningful inclusion and participation when they have been born with impairments or suffered disability. Remedies have been proposed, and in some cases demonstrated to be effective, but their implementation is patchy and often not sustained. Two prominent examples of initiatives to address the lack of voice for the rights of children with disabilities are the Guardianship Councils in Brazil and the Social Charter of the European Union. These are very different approaches but both draw heavily on legal remedies and due process with respect for the plaintiff.

Guardianship Councils

The 1988 Federal Brazilian Constitution emphasized popular participation in governance. Municipal Participatory Administrative Councils were formed. The child rights perspective embedded in the authorizing legislation and implementation has transformed a disadvantaged population of children into a population of citizens whose current and future rights should be respected (Duarte et al, 2007; Rizzini et al, 2003). The authorizing legislation covers all children under the age of 21 and, notably, does not single out one *at risk* group. The legislation is broad but focuses on the entitlement to rights. The legislation determined that children's rights will be guaranteed through the activities of municipal Administrative Councils. The Brazilian Child and Adolescent Rights Act mandates that every one of approximately 5,700 Brazilian municipalities should have two Municipal Child Councils: a Child Rights Council and a Child Guardianship Council. In addition each state should have one State Child Rights



"No child shall be subjected to arbitrary or unlawful interference with his or her privacy…nor to unlawful attacks on his or her honour and reputation."

Convention: article 16.

Arab water carrier girls, Egypt (Brooklyn Museum)

Council. The Child Rights Council has the responsibility for addressing child and adolescent rights at the macro level. The Guardianship Councils ensure that children in need or at risk receive the best possible assistance. Their task is to make referrals and guarantee the delivery of services, but not act as a provider. Access to the Guardianship Councils can be by the children themselves, parents or a wide range to other interested parties.

European Social Charter

The European Social Charter (Council of Europe) is a rights-based document that can and has been applied in the case of apparent discrimination of people with disabilities. A notable example is the successful appeal by Autism Europe to the European Committee of Social Rights complaining that in France "…children and adults with autism do not, and are not likely to, effectively exercise in sufficient numbers and to an adequate standard, their right to education in mainstream schooling or through adequately supported placements in specialized institutions that offer education and related services." In essence, the complaint alleged that France is not taking enough action, as required under the revised European Social Charter, to secure children and adults with autism a right to education as effective as that of all the other children. While this is a specific example that has led to remediation, the articles themselves serve as a model. The Code of Social Action states that "…whenever the aptitudes of the person with a disability and the capabilities of the family so allow, ensure access to the minor or adult with disability to those institutions open to the whole population." "Social and medico-social action shall…promote the autonomy and protection of individuals…prevent exclusion and correct its effects. It shall be based on continuous evaluation and needs and of expectations…in particular of those people with disabilities." "… action shall respect the equal dignity of all human beings…" It will be interesting to see if and how models such as these gain uptake in implementation of the new Convention on the Rights of People with Disabilities.

Paradigm shifts for clinicians

"Integrating the principles of children's rights, equity and social justice into practice will require a fundamental shift in the education of child health professionals at all levels of training." (Waterston & Goldhagen, 2008). If a high priority is to be given to providing rights-based services to children with disabilities, it will be increasingly necessary to engage, train and prepare non-government organizations, professionals, parents of children with disabilities and children with disabilities themselves to work together to effect change. Professional training programs today still focus on medicalization of disability. The focus on specialization for working with differing populations of children with disabilities thwarts the desire to lessen discrimination in services and the participation of children in the mainstream of society. Professional concern goes beyond clinical care to research with who may be most vulnerable.

IMPLICATIONS FOR RESEARCH

Contemporary mental health related research initiatives in low and middle income countries have exposed yet another dimension of the need for human rights protections and ethical standards. In low and middle income countries impacted by war, natural disaster and displacements, researchers have engaged in practices that need to be subject to human rights scrutiny. As regards children in research in general, the justification of non-therapeutic research (studies that do not purport direct benefit to participants) versus therapeutic research in children has been debated (Ramsay, 1976; McCormick, 1976). It has been argued that the use of children as research participants is never justified if they cannot derive benefit from participation (Ramsay, 1976) while others believe that as long as research involves no discernible risks, pain, or inconvenience, research is ethically permissible (McCormick, 1976). United States federal regulations (Protection of

The Convention on the Rights of the Child goes well beyond having implications for governments and should be considered in relation to all professional activities that impinge on the lives of children including clinical practice, research, participation and education.



Children must be treated "…without discrimination of any kind, irrespective of… race, colour, sex, language, religion…or other status."

Convention: article 2.

Photo: Joe Healy and his family (Galt Museum & Archives)

Human Subjects) allow for non-therapeutic research that poses more than minimal risk with children, if:

1. Risk is a minor increase over minimal risk
2. Procedures are commensurate with general life experiences of participants
3. Findings are likely to yield knowledge of vital importance about the participant's condition; and
4. Parental permission and assent of the child are obtained.

History of medical and psychiatric ethical standards and guidelines

Ethical issues arise since youth are typically incorporated under the sub-heading "vulnerable populations." Youth cannot care for or protect themselves independently and become more vulnerable when suffering from a mental illness. Some of these ethical issues around treatment, medication and research have been discussed in the field of child and adolescent psychiatry and psychology (Munir & Earls, 1992; Belitz & Bailey, 2009; Frank et al, 2003). Specific to psychiatric research, Roberts (1999) has developed a conceptual analysis of ethically sound psychiatric research protocols. Hoop et al. (2008) reviewed these topics in relation to research with youth. An extensive resource listing for psychiatric research ethics has been developed (Roberts et al, 1998). However, these guidelines are primarily for domestic trials, where researchers have authorizing institutional review boards, standards of care, and access to (often) multiple forms of "best treatment."

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1977) allows studies that expose children to greater than minimal risk without intent to benefit participants when knowledge obtained is important to the future welfare of children. Sufficient evidence should be provided to show that: 1) research-induced pain or stress is not severe; 2)



"…a child who is seeking refugee status or who is…a refugee…[shall] receive appropriate protection and humanitarian assistance…"

Convention: article 22.

potential harms are reversible; 3) researchers are qualified; and 4) the setting is appropriate for the study (Fisher et al, 2007). However, when large asymmetries of power exist, it is unclear if the settings are appropriate to perform studies that do not provide benefit to participants.

Current medical and psychosocial guidelines for international research

The emergence of researchers from high-income countries conducting trials in low-income countries, particularly related to HIV/AIDS, challenged the Helsinki Declaration's framework for work in developing countries (Zion et al, 2002). In 1993, the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* was produced to describe how the Declaration could be effectively applied to developing countries (Council of Medical Organizations of Medical Sciences, 1993). The Emanuel framework, though not specific to youth, addresses medical ethical issues that arise when performing research in low-resource countries (Emanuel et al, 2000).

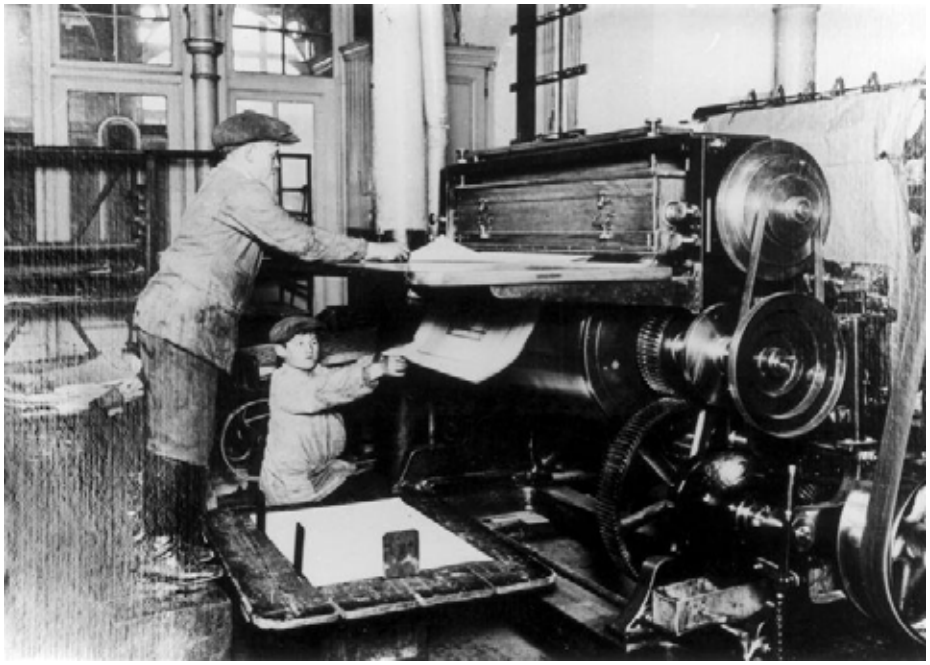
The psychosocial humanitarian field has ethical guidelines (Sphere Project, 2000; Morris et al, 2007; IASC, 2007; Allden et al, 2009) Others have suggested frameworks for research in low-resource, refugee, and international settings (Schenk & Williamson, 2005; Fisher et al, 2002; Leaning, 2001). These guidelines primarily aim at emergencies, conflicts or disasters, or focus on refugee youth in high-resource countries. Though the nature of child and adolescent psychiatry and allied professions demands knowledge of ethics (Munir & Earls, 1992), there is little training on ethics considering cultural or global contexts in the mental health field and, in particular, for those with disabilities.

Human rights of vulnerable populations

Vulnerable populations are special groups of people who lack the ability to protect their basic rights and liberties, making them open to exploitation. Children, in general, are such a population. War situations that create orphans who are not under the legal protection of an adult compound the issue of rights protection. War can also include specific populations (e.g., survivors of gender-based violence or child soldiers) that may be heavily stigmatized by the community and may be at potential harm from research if findings are released to the government, rebel forces, or the community.

Researchers engaged in therapeutic or non-therapeutic research should take ethical precautions and be sensitive to the needs of vulnerable groups. Children may not feel comfortable telling foreigners or adults about their experiences, especially in areas of political instability, where adults were involved in the conscription of children into armed forces. Revelations may place children at increased risk. Speaking at a child's developmental level, researchers should be clear from the start about their roles, what data will be collected, how it will be used, who will have access to it, and what the limits of confidentiality are. Special care should be taken to ensure that the collection, storage, and analysis of interviews or data are secured so participants can be reassured that their information (such as status as a former child soldier) will not be released to the government or rebel forces which could lead to further stigma and discrimination.

With limited access to resources for survival, families may be desperate to help their children and may view researchers as foreigners, whom they are used to seeing as humanitarian aid workers or as providers of food and material aid.



Children must be "protected from economic exploitation ... from [hazardous] work [and] all other forms of exploitation."

Convention: articles 32 & 36.

Child labour in a printing company (kinderarbeid in drukkerij). Nationaal Archief/Spaarnestad Photo

Informed consent in low-income and post-conflict countries

Nontherapeutic research or the investigator's intent to not benefit participants is *related* to informed consent. Informed consent includes examination about information, decisional capacity, and voluntary capacity (Roberts, 2002). Information should be relayed about the research process, timeline, methods to be used, and risks and benefits of participation in the study. Decisional capacity (Applebaum et al, 1982) is provided to researchers when individuals:

- Can communicate a voluntary non-coerced decision
- Can communicate an understanding of the risks and benefits of accepting or declining the treatment and potential outcomes of alternative treatments, or research
- Can appreciate the significance of the choice, and
- Are sufficiently cognitively intact to understand the consenting process and content.

Voluntarism capacity is equally important in war-affected countries, as being able to express ideas without coercion or threats to their true wishes (Roberts, 2002).

Informed consent should also take into account cultural variables, including education, concepts of youth, and respect for persons (Roberts, 2002). In areas with a high degree of illiteracy, the signing of a consent form may signal mistrust or dangerousness, especially in countries where the government has previously tricked people into relinquishing rights, as was the case in the former Soviet Union or Cambodia for example (de Jong, 2002; Ellis et al, 2007). In many low-resource countries, children enter the *labor* force as early as age five, and communities may have a different concept of who can provide consent for youth (Schenk & Wiliamson, 2005; Boyden, 2004). Researchers should have input from the community that is familiar with age, gender, social roles and expectations for child development and behavior (Schenk & Williamson, 2005). In a collective-society, an individual may consent to participate in research out of direct or indirect pressure from the

community, challenging autonomy (Ellis et al, 2007). The focus should be more on the achievement of true informed consent, rather than the final product of a signed document. This can be attained through research advance directives, which are discussions between researcher and subject, about the subject's motivations for joining the study, discussion about the likely outcomes of the study, and the protocol or procedure that will occur. Should subjects later enter a state where they lose ability to express preferences, the document will be able to direct next steps. Another way of solving this problem is by the use of verbal informed consent in the presence of a family member or friend (European Medicines Agency, 2009). Assent rather than consent is often used. This more passive approach to ensuring that the subject is informed is often easier to obtain in more naturalistic settings but runs the risk of not truly ensuring an informed subject population.

Asymmetries of power and information

When researchers from high-income countries come to devastated and socio-economically severely disadvantaged communities to conduct mental health research, local people may be at high risk of being exploited, as a researcher's social status can impact on research participation (Boyden, 2004). With limited access to resources for survival, families may be desperate to help their children and may view researchers as *foreigners,* whom they are used to seeing as humanitarian aid workers or as providers of food and material aid. As such, they may interpret participation in a study to be linked to the provision of assistance. Some child psychiatry research protocols offer clinical monitoring, which may be a strong incentive for those in war-affected areas that do not have clinical care accessible (Hoop et al, 2008). Moreover, well-trained Western mental health researchers may try to adapt their models of healing to a population foreign to them, and local communities may not have the free agency to decline participation, discuss negative effects or the impact on their local beliefs and practices, may feel coerced, or may report what they think the professional wants to hear (Fisher et al, 2002; Allden et al, 2009; Ellis et al, 2007). The asymmetry may extend to the involvement of local clinicians and researchers who compromise their local identity and concern for their constituents to be part of a more prestigious and sometimes more lucrative enterprise.

Contemporary mental health related research initiatives in low and middle income countries have exposed yet another dimension of the need for human rights protections and ethical standards.

There can be asymmetry in the prioritization of needs as well. Researchers and clinicians who are foreign to the local community may not have research priorities that are congruent with local ones, despite the best interests being in mind. Often, foreigners have control over how funding will be used, program development and planning, determining who will receive services, and who will ultimately be trained to provide those services. Local governments are dependent on donors to fund research on donor-determined needs. This dependence on external funding and hence external researchers, may exclude local academics or Ministries from the opportunity to engage in an ethical analysis about subject communities, projects, and implications.

Ethical challenges inherent in therapeutic research

The definition of *therapeutic* research in low-resource settings is challenging, as a mental health researcher's role in these settings can vacillate between being an investigator and a provider of care. Moreover, the field of mental health is underdeveloped in these countries, causing Western clinicians to import and

adapt interventions to different cultural contexts. The roles of researchers and the identification of the most appropriate intervention will be discussed below.

The boundary between researcher and clinician

The primary intent of a clinician is to provide help; whereas the primary intent for a researcher is to answer a scientific question. Inherent in the work with vulnerable children is the more porous boundary between researcher and clinician. Often there are no mental health clinicians, and the researcher is the first person to ask potentially emotionally charged questions about a child's experience in war. Interviews themselves are interventions. The researcher may knowingly or unknowingly become a clinician. Though the goal of a researcher is neutral–to collect data–each contact with a child is potentially a clinical one. There is some evidence that sharing a common stance with clients is valuable (Lustig et al, 2004), but likewise certain interventions may be harmful (Morris et al, 2007; Goodman, 2004). Psychiatrists, specifically, face additional difficulties in the field, as physicians may be confused about the divide between being a provider versus using patients to answer research questions (Jesus & Michael, 2009).

Conducting research without ensuring that appropriate services are available to those researched is unethical (Allden et al, 2009). Providing narratives of recent traumas, particularly in conflict situations, can put people at risk for psychological harm when not supported (Goodman, 2004). Interviewees with mental disorders, prior trauma, and low social support may be at higher risk for emotional distress (Dyregov, 2004; Jorm et al, 2007). However, there may not be a formal mental health system in war-affected, low-resource countries, with few clinicians or institutions to refer them to (de Jong, 2011; World Health Organization, 2005), and even in high-income countries like the United States, there are regions where many have difficulty accessing mental health services (Wang et al, 2005). Though researchers may not have the skills or means to provide support or assistance, there should be an obligation to learn about and access such resources (where they exist) prior to commencing research, or to develop supports for those who may express distress in the course of the research.

Identification of the most appropriate intervention

The *Declaration of Helsinki* proposes the *best current intervention* for the active comparator in a clinical trial. There are multiple established mental health interventions the superiority of which is debatable, depending on expert opinion. Randomized trials evaluating a school-based intervention (including trauma-processing activities, cooperative play, and creative-expressive elements) for war-affected youth in low-income settings in Indonesia (Tol et al, 2010), Sri Lanka (Tol et al, 2011), Nepal (Jordans et al, 2010) and Palestinian territories (Khamis et al, 2004), found promising improvements on select outcome measures for specific sub-groups, and others with no main effects on specific outcomes (Tol et al, 2011). In Uganda, a randomized control trial of interpersonal group psychotherapy with war-affected and displaced adolescents found effects for depression with girls only, and no effects for anxiety symptoms, conduct problems or functional impairment (Bolton et al, 2007). A randomized control trial in Bosnia-Herzegovina found improvements in posttraumatic stress disorder (PTSD), depression, and maladaptive grief with children receiving school-based trauma and grief-focused group psychotherapy, and improvements in PTSD and depression, but not

maladaptive grief in a classroom-based psycho-educational and skills intervention (Layne et al, 2008). A review of the evidence for interventions described as Sphere standard mental and social health indicators "suggests that even effective interventions can be harmful if applied at the wrong time, or targeted at the wrong segment of the population" (Morris et al, 2007).

CONCLUSIONS

It is remarkable that in the modern era the rights of children with disabilities remain such a challenge. Maltreatment of children with disabilities must be considered a critical public health issue (Hibbard et al, 2007). Contrast the availability of resources for children with a host of medical illnesses to those available to children with disabilities. International agreements are in place to end the era of isolation, abuse and neglect. The challenge is to increase awareness of the current situation and to educate a broad range of individuals to exercise their rights. Incrementally increasing participation of people with disabilities will lead to a lowering of the barriers that now prevent full participation in society.

The ethical evaluation of non-therapeutic research for vulnerable and war-affected youth demands researchers and clinicians to be *sufficiently* cautious with their work with vulnerable populations who are living in contexts with inherent asymmetries of power. Obtaining true informed consent from caretakers and assent from children should be a minimum standard for non-therapeutic research. Those conducting therapeutic research also have ethical considerations with the porous boundary between researcher and clinician, and how to determine the most appropriate therapeutic intervention to study. The benefits to society of documenting the effects of stress, evaluating the need for and access to mental health and other services, and the effectiveness of services for war-affected youth, all of which have potential to help society in the future, should be weighed against the mental health risks of conducting research in these settings.

The Convention and the CRDP offer hope for a new era respectful of human rights in the conduct of society and in research to find evidence for appropriate care. "The inclusion of children with disabilities is a matter of social justice and an essential investment in the future of society. It is not based on charity or goodwill but is an integral element of the expression and realization of universal human rights."

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