Making Sense of Miscarriage Online

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The idea that the institutions and practices of medicine shape our bodies and bodily experiences is by now familiar. Being “pre-hypertensive,” living with cancer, having a disability or a chronic illness, and even being male or female are all bodily states and experiences that are thoroughly mediated by medical institutions, routines, procedures, and meanings. Not only does conventional medicine intervene on most bodies in developed nations, through surveillance, testing, diagnosis, and treatment, but it imposes a temporally complex narrative structure on our embodied lives. This structure is often demarcated in precise quantitative terms. As we are brought into the fold of medicine, we come to structure our lives around the times between appointments, between doses and labs and stages, and between receiving readings we get on various tests and screens. Consider how the life cycle of women and men is medically differentiated: many women have annual pap smears for decades, then mammograms, then tests for osteoporosis; many men begin their lives with circumcision, are routinely checked for testicular cancer after puberty, and launch late middle age by entering their prostate testing years. These medical units and markers of time and bodily status are not enclosed within a bounded medical space. Instead, they are integral narrative signposts within rich social and personal identities that are essentially bound up with medicine. Being a depressive, or a cancer survivor, or a diabetic, or someone trying to conceive involves inhabiting a social identity embedded in clusters of narratives and meanings that are given meter and determinacy by medicine.

Miscarriage, against this background, is a strange event—one that many women experience as uncanny. In one sense, it is an event with medical significance: going from pregnant to not-pregnant because of fetal demise constitutes a significant shift in medical status. And yet, in an important sense it happens outside of medical space and attention, or perhaps more precisely, it often signals the end of medical attention. Not only does medicine offer no tools for reliably predicting or preventing miscarriage, but also, when women stop being pregnant, they typically cease to be of medical interest. From the point of view of health care professionals overseeing a pregnancy, miscarriage constitutes the end of a medical narrative rather than an event within one. Routine miscarriages are accompanied by no particular follow-up care, despite being bloody events that are often painful and traumatic. When fetal demise is detected from a screening test such as an ultrasound, often women are sent home to wait out the expulsion of the fetal body in their own domestic space. Sometimes they are
referred elsewhere for a surgical extraction at some future date. But health professionals do not treat such a procedure as an emergency, nor do they usually treat it differently than a regular abortion, so women who are waiting for and then receiving this procedure may get no miscarriage-specific attention or care. When it comes to bodily events and changes, we are used to using the tools, discourse, and practices of medicine and its expertise as a frame within which to understand our own experience. But miscarriage can leave women in an oddly unhelpful relationship to medicine.

Women who miscarry can find themselves bereft of public tools and resources for understanding and mediating their experience. And yet, many experience miscarriage as a momentous or even an identity-defining event. For many women, miscarriage ends a wanted pregnancy; for others, miscarriage may be a relief. Sometimes a woman may learn she was pregnant only when she miscarry. In all these cases, emotionally processing the event and giving it sensible articulation may be challenging. Whatever a woman may feel about her pregnancy, miscarriage can be a physically dramatic and often scary event that involves not only blood and pain but also abrupt hormonal changes. And miscarriage is almost always unexpected. Against all this background, miscarriage can bring women’s attempts to understand and articulate their experience to a crisis point. The loss of a potential child, whether that child is wanted, unwanted, or a source of ambivalence, frequently constitutes a narrative rupture. More broadly, in the face of a miscarriage, women can lose the ability to make sense of what they are experiencing and how it fits in with their larger life story, plans, social identity, and embodied sense of self.

In this article, we explore how women work to give narrative shape to their experience of miscarriage through online spaces such as Facebook, discussion boards, and blogs. These sites provide frameworks that are interestingly defined by their outsider relationship to medical spaces. Formal institutions of medicine exert a structuring force over them, yet they do so, in part, by their absence or silence. For instance, medicine is riddled with numbers: when one is under medical care, one measures time and bodies in weights, weeks, blood cell counts, viral load counts, and more. In online efforts to articulate their embodied experiences from outside medical spaces, women often use quantitative and numerical markers that mimic medical discourse, yet they mark this discourse as separate from official medical discourse.

We are interested in how temporality gets structured through these conversations and engagements, given that a lot of the narrative content in a miscarriage story involves waiting—waiting for the fetus to expel itself, waiting for an appointment for a surgical extraction, waiting for grief to lessen or for the medical go-ahead to try for another pregnancy. Because it might seem empty or open-ended, waiting is difficult to narrate and articulate, and medical professionals and institutions have no interest in these waiting times. Yet, as we will see, women often do not experience these as passive or empty periods of time, but as periods of anxiety, including epistemic anxiety, and as saturated with
complicated bodily and social meanings. We will track how women articulate their experience online, including their use of discourse structured by medicalized logic, to give narrative shape and stability to otherwise unstable experiences.

One of our central interests is in how the process of articulating and negotiating the experience of miscarriage online is bound up with the project of shaping narrative identity for many women. Indeed, as we will see, often women are constructing multiple narrative identities simultaneously that are crafted for different contexts, some of which may be reasonably stable and permanent and others of which may be quite fleeting or strategic. Although it is not our task to defend this broad theoretical claim in detail, we take it as both given and important that there is a rich interplay between the construction of a presented identity, performed in discursive space and given narrative form, and actual lived identity.

Work on relational autonomy and narrative identity by feminist philosophers\(^1\) (among others) has emphasized at least two (in our view interdependent) points. The first is that personal identities are fundamentally collaborative achievements; they emerge in and alongside specific communities that are enabled by the spaces that contain them. We enact our identity in social space, and unless others give uptake and recognition to what we do and who we are by responding appropriately, holding us accountable for who we claim to be, we cannot in fact be successful at this enactment. As Hilde Lindemann puts it, the maintenance of identity requires that others “hold us in personhood” by giving concrete uptake that sustains us and entrenches us in our identities.\(^2\) The second is that in presenting an identity that others can recognize and hold us to, we need to give that identity recognizable narrative form. Doing so requires that we draw on the sense-making resources of the various communities in which we are embedded. Lindemann argues that “personal identities consist of a connective tissue of narratives—some constant, others shifting over time,” and that this tissue depends also on the stories of others.\(^3\) But narrative that makes sense in one context, allowing for the meaningful uptake that enables it to continue, may well not make sense in another.

Putting these two points together, we find that personal identities require sustenance from communities within which they are recognizable. When we present ourselves as enacting specific narratives, we also help constitute our own narrative identities, by exerting control over how others will both recognize and respond to us and thereby further direct and determine our narratives. Accordingly, as Lindemann also insists, there is “a complicated interaction of one’s own sense of self and others’ understanding of who one is.”\(^4\) Which communities we inhabit will affect both the sense-making resources available to us and what kinds of identities we can meaningfully perform and sustain.

Against this background, the impact of miscarriage on women’s attempts to give narrative form to their identities is at least doubly interesting. On the one hand, as we have already suggested and others in this issue also discuss,
miscarriage is a distinctively hard-to-articulate experience that resists easy assimilation into a widely recognizable narrative. On the other hand, as we will see, many women who have had a miscarriage have made use of the sheer proliferation of communities online and of the relative ease with which such communities can be created and shaped. The Internet provides an unprecedented and dizzying source of communities united by common experiences, as well as equally unprecedented tools for creating new communities. Women are using these new resources to find ways of getting uptake for and giving shape to narratives that were previously resistant to articulation.

Some of these communities are highly ad hoc, and women may enter them only temporarily, such as discussion boards for women who are currently in the process of a miscarriage. Others may evolve into more stable communities that become more multifaceted and develop in unforeseen ways; some popular blogs provide good examples of this phenomenon. Furthermore, women may well enter into many online communities simultaneously, constructing different narrative self-presentations for different contexts. As far as we can tell, many women feel under no pressure to create one single, integrated narrative identity. For some theorists such as Christine Korsgaard, David Carr, Alistair MacIntyre, and Charles Taylor, narrative integration of the self across time is practically and ethically necessary, at least as an ideal. We do not presume the practical necessity of such integration, and empirically, we see many women sustaining multiple narrative threads that may be in tension with one another. Virtual technologies make the sustenance of such multiplicity dramatically easier.

New communication technologies are not merely helpful props for traditional narrative articulation. In our view, they offer complex new tools that are changing what projects of narrating identity look like. They do much more than just increase communicative access to a wide range of people, although it is important that they do this as well. Our interest is in exploring how, in light of the disconcerting reality of miscarriage as an event both inside and outside of medical space and time, these online spaces are changing the experience of miscarriage and its aftermath, partly by changing how women build identities and perform them, with the help of others. As we will see in more detail, through their functional structure, these spaces create possibilities for qualitatively new kinds of collaborative interactions, communities, and communicative performances. Our goal is not to either glorify or vilify these new tools; like most tools, their use can be liberating, troubling, or (typically) both.

Before we plunge into our analysis, we want to be careful to make its limited scope clear. Ours is not a project in either ethics or armchair psychology. We are not in a position to make claims about how these various technologies and discursive negotiations are actually impacting women’s lives, or whether they are making them better or worse. Nor do we wish to speculate about the details of the phenomenological states of the women whose texts we are examining. We are interested here in a set of texts—texts that have both written and visual elements. We want to see how these texts play off of one another and
evolve, and how new technological possibilities enable and constrain discursive possibilities. We are interested in tracking how identity and experience and time are negotiated and represented within these texts. As we just argued, we also believe in a rich interdependent relationship between discursive self-presentation and lived identity. But our materials are the texts themselves, and not the presumed feelings or events behind them.

**Miscarriage Discussion Boards: BabyCenter.com**

There are hundreds of discussion boards and online communities devoted to miscarriage and failed pregnancies; these feature a wide variety of themes and emphases. Some have a religious orientation; some are specifically for teens, and so forth. We will focus on the miscarriage boards at BabyCenter.com, using them to explore how this sort of platform can provide possibilities for self-presentation and self-articulation.

BabyCenter.com hosts a variety of online communities related to pregnancy, childbirth, and parenting. Participants in any of these discussion groups get to them via a home page that includes discussions of baby names and queries about doulas or obstetricians for a given area, with a banner housing stable links for “Birth Clubs,” “Mom Answers,” and “Shop.” The site also hosts numerous active discussion boards concerning failed pregnancies, including discussion boards titled “ Miscarriage Support (MS),” “Miscarriage Worries and Concerns (MWC),” “Recurring Miscarriages (RM),” and “Miscarriage, Stillbirth, and Infant Loss Support (MSILS).”

By whatever route contributors find the BabyCenter.com miscarriage boards, they enter through the BabyCenter.com gateway. While some women go directly to the miscarriage groups, all participants in the groups are virtually surrounded by narrative and communal spaces in which they could have previously participated, spaces where they would now be out of place. In other words, they are there as members of a larger community related to pregnancy and childbirth even as their narratives turn in other directions. In many cases, these participants have been to BabyCenter.com before for earlier pregnancies. Others start there with questions about viable pregnancies and may join a birth club linked to their due date before migrating to a miscarriage board. Some, in the event of a miscarriage, continue to participate in multiple boards on the site. Unlike other discussion boards within this site, however, the miscarriage boards carve out an alternative space for those who have departed from conventional pregnancy narratives. Contributors to the miscarriage discussions may find themselves precipitously left without the support and shared stories that typically go along with pregnancy. Some participants will look to start a conversation or communities with other women who started out on their “birth month board”—that is, the board for people whose babies were due the same month—but who are now experiencing a miscarriage.

As we discussed above, women who have had a miscarriage may feel that their reactions and experiences do not make sense or fit into a rational and
recognizable story that can be publicly consumed or produced. The boards can be used as a place both to express this frustration and to try to forge this kind of articulable sense. In turn, others give uptake that affirms women’s reactions as meaningful, appropriate, and comprehensible. For example, joshiesmum89 writes:

OK, very few people knew I was pregnant and that I had suffered a mc. And its not their fault and I shouldn’t be selfish and ruin their excitement. But dam it today I’m going to be a selfish, irrational bitch. Today I almost hate them. Today I envy them. Today I want what I’m missing. Today I long to have my head down the toilet, having not eaten all day and not being able to see my feet... Sorry for the completely irrational rant, but I needed it. Thanks for reading. (MSILS 3/11/14)

And owlsgirl67 responds:

I don’t think any of what you have said is irrational. I have all of those feelings too, it’s good to have somewhere like here where we can vent them with others who understand x (MSILS 3/11/14)

It is important to point out, however, that the boards are not a free space of creative articulation. Even as they allow for narration and response, they also impose constraints both explicitly and implicitly. For instance, some discussion groups urge participants to tell their stories with care: the moderator of “MSILS” warns newcomers “NO PG Announcements or Live Birth announcement this includes ‘Success Story’ post. We are glad that you are PG or have had a baby. Not everyone is afforded that gift. The threads will be locked or deleted. You might find it more helpful to direct your post to these groups Pregnancy After Loss or Raising children after losing children” (MSILS, “The Rules,” 5/23/11). These guidelines suggest that one purpose of the group site is to actively enable narratives that focus on events that are otherwise covered over or crowded out by more conventional stories of conception, childbirth, and parenting. But in doing so, they also limit the kind of articulation that can go on. Less explicitly, the boards display various recurrent tropes (for instance that the miscarried baby is an “angel” and live births a “blessing”) that constrain storytelling even as they enable it.

The relationship between the conversations on the boards and traditional medical conversations is complex. Women often come to the boards specifically because they experience themselves as abandoned by the health care system, or because they don’t feel that traditional medical tools are helping them make sense of what they are experiencing. Women may be in the forum for free advice, for fear of not being taken seriously elsewhere, or because they take themselves to be in the middle of an immediate traumatic event that cannot wait for a visit to the doctor. Karla211992 writes:

I’m 21 years of and my boyfriend and I were trying to get pregnant before he leaves to the navy. This past Tuesday we found out we were pregnant. 4 weeks and a half according to my dr. On Friday night I started bleeding heavily and called my dr and he informed
me that from what I was telling him it was a miscarriage. . I haven’t been to the hospital (he told me it wasn’t necessary) but the pain won’t go away. . What can I do? Or take? (MSILS 3/9/14)

Here Karla211992 flags both that she is experiencing what feels like a medical event that requires consultation with her doctor and might require hospitalization, and that her doctor is effectively keeping her miscarriage outside of literal medical space. Not only does she get several suggestions but also two days later Butterflythesky writes “Just checking in . . . how are you?” (MSILS 3/11/14). In such cases, we see the boards serving as a kind of alternative to traditional medical space, with user-provided care and follow-up.

The group entitled Miscarriage Worries and Concerns (MWC) is careful to announce when it is created that it “is not intended to replace the advice of medical professionals. This group is available to offer support to those who believe for whatever reason they may be experiencing a miscarriage. The group is intended for those who have not yet received a confirming diagnosis of a miscarriage” (MWC, “Welcome please start here,” 02/15/11). In spite of the disclaimer messages, contributors routinely ask for opinions and diagnosis; for instance, one thread includes photographs of home pregnancy tests taken twice a day for three days along with descriptions of spotting (Pharmercolee MWC 1/5/14). But even in more general miscarriage discussions, postings can involve specific queries about physical symptoms as they occur: “I passed something about the size of an almond and it looked like tissue. It was not a blood clot. I had an unusually long AF–two weeks. I took a HPT and I had a very faint positive. Does that count as a Miscarriage?”7 (MWC 1/2/14)

The boards do not simply provide an alternative to medical space; rather, the discourse on them is often thoroughly structured by the language of medicine. Often it is riddled with the kind of quantitative markers that give it at least the rhetorical air of medical and scientific legitimacy and comprehensibility. Entries may include hormone levels, reports on blood tests and ultrasounds, and shorthands for various conditions and procedures. For example, TashaKanna reports “My first HCG level was 220 then it reduced to seventy nine after two days. Now again it increased to 112 today. Just getting scared with my levels. Dont know whats happening. Now I was scheduled for OB US8 on Monday. Does anyone come across this. I’m worried that now it might be ectopic” (MWC 3/14/14).

A contributor may frame her identity through a precise chronology, noting efforts to conceive, date of conception, dates (and details) of visits to the doctor, miscarriage date, and due date. Many participants append a visual (and sometimes animated) timeline noting conception, miscarriage, and due date in the signature space of each message (see Figure 1):

7 early losses and 1 ectopic. We’re finally expecting our rainbow in March!

Often contributors will include in the signature space lists of other births and miscarriages, such as snwbrdrlz who signs her postings as “5 angel babies ~
m/c: 05/03, 04/08, 08/09 ~ EP (surgery): 09/27/09 and 2nd EP (MTX): 4/15/13 at 6w4d (edd 12/5/13) ATTC #1 Since October 2011” (MSG 5/6/13). These references establish a contributor as a proper community member, both physically and discursively. But they also establish the space created by the boards as one that is still importantly constituted in relationship to traditional medical space, discourse, and experience.

In the context of miscarriage, women often seek to give articulate shape to temporal phases of waiting. Of necessity, medical practices are not much concerned with mere waiting. Indeed, waiting is demarcated, from the patient’s point of view, as the time in between medically meaningful or addressable events. But its narrative meaning can be quite different from a mere absence. Women who are waiting to find out if they are miscarrying, or waiting, once they have learned of fetal demise, for the fetus to expel itself, often experience these waiting periods as emotionally complex and intense. They are liminal and anxiety-producing times during which women cannot predict what their bodies will do, and during which they inhabit a difficult status in between expectant mother and grieving miscarriage sufferer.

Through Internet discussion, women can give shape to such waiting periods as narrative episodes and find communal uptake for their reality and difficulty. Tmill12 writes:

I found out 3 weeks ago I had a blighted ovum. I was 8 weeks along. The baby stopped developing after implantation at about 5 weeks the doctor said. She told me I would probably naturally miscarry soon but we could discuss options if I didn’t. Its been 3 weeks since that appointment and nothing has happened. I am scheduled for another sonogram next week but I was wondering if this is normal. Has anyone else waited this long? Am I in danger by waiting so long to naturally miscarry? This waiting is terrible and I feel like I need something absolute to happen so I can progress with my grieving. (MS 3/1/14)

Part of what is interesting about this quotation is it shows vividly how from the doctor’s point of view, there is simply no relevant involvement until the wait is over. Thus this is medical dead time, which adds to its emotional complication for the waiting woman. Tmill12 gets a host of replies from others who talk about how the waiting period has been especially painful, and a recurring theme is how women cannot “start the grieving process” until the wait is over.

Some participants appear on, return to, or remain in the discussion after—sometimes long after—the event of the miscarriage itself. Kinduvabrata, for
instance, reports her difficulties articulating grief weeks after experiencing a miscarriage in the hospital:

Still confused and disbelieving, recognize that its almost 11 weeks later and havent had a period so concerned about my future considering my age. i didnt want anyone there because this felt so personal, i did not feel anyone could understand or feel the pain i was feeling, [...] i bring it up to him in a certain but undetailed way and hes supportive and thankfully not forcing but now, 11 weeks later is the only time i’ve “talked about it”... i still cant bring myself to get rid of the few baby items or take my name off registries or even remove myself from baby sites. (MS 8/12/13)

This quotation picks up on several narrative strands in the author’s life. We see here the complexity of the relationship between her miscarriage narrative, her lost but expected pregnancy narrative, her medical narrative, and her broader life narrative. These narratives would typically find their homes and uptake in different spaces: the clinic, the home, and the social world. One interesting feature of the passage is its exploration of the tensions between these threads, rather than their forced integration. This writer makes vivid her difficulty in making sense out of all of these threads simultaneously while going through something that is so deeply framed as inarticulable and private.

Women who post to the miscarriage boards may be out of place in the larger pregnancy community of BabyCenter.com, and many express feeling out of step with family and friends. But once they post they quickly find themselves in a community of others who have been through or are going through the similar experiences—or at least, a community of others who are quick to affirm that they “feel the same way” or “went through the same thing.” Whether or not their experiences are as similar as they make them out to be, this ritual affirmation of a shared experience clearly plays a key role in enabling women to take themselves as having a comprehensible story. At the same time, these stories and self-presentations need not be unitary. In the introduction, we pointed out that one of the powers of the Internet is that it allows for multiple identity constructions and self-presentations. We see this vividly on BabyCenter.com, where many women participate in multiple discussion boards simultaneously (and may of course also maintain Facebook accounts, blogs, and other sorts of online presence). The different character of each community will likely inflect their self-presentation in each.

The spaces offered by the discussion boards can be repositories of historical group knowledge. Some contributors check in with the miscarriage boards regularly, creating a community that can respond to members’ new crises and developments with an ongoing, shared set of experiences. ImAjay is a contributor who reports on multiple boards in December 2013 that she will have to undergo a surgery that will endanger her pregnancy. When ImAjay posts “I’m back” and reports that she has indeed miscarried, it’s clear that she has been on the miscarriage boards in the past (MSIL 1/8/14). One contributor responds, ‘I’m so sorry. I’ve read some of your stories before... you’ve been through a lot. Hugs and
praying for your comfort” (MSIL 1/8/14). Mylil1rox, who comments on ImA-
jay’s story, uses a signature line that reads “Mother of 7: 1 living DS10 born 6/
10, 1 DS born still at 37 weeks on 12/7/2011, 4 M/Cs and 1 in the oven” (MSIL
12/20/13). The presence of contributors like these who have miscarried and then
returned, sometimes even during a viable pregnancy, suggests that these spaces
serve as fixed communities and maybe as safe havens in case they are needed
when the narrative takes a certain turn.

The group discussions thus serve as places to develop a collective interpre-
tation of the experience of miscarriage and of personal identity and community
in the wake of miscarriage. The discussions on Babycenter.com come with
boundaries and limitations, in part because the technology allows for immediate
conversation, and in part because they are dedicated to predetermined, focused
topics. But they also allow for varying and at times flexible self-representations.
These representations can develop across multiple spaces and accrue meaning
through what might be brief or extended periods of time. In the midst of this
messy complexity, miscarriage narratives are articulated and given social recog-
nition through this emerging common space.

Miscarriage on Facebook: Justice for Mason

The technological syntax of Facebook allows for very different kinds of
communication and constructions than we saw on discussion boards. Users can
build a self-presentation over time by adding to their wall, and anyone who
clicks on a user’s name will be able to see the entire history. Facebook easily
supports the addition of photos, audio files, videos, links to other sites, and other
sorts of images in various modalities. Individual updates allow for comments,
responses, “likes” and more. Facebook, unlike discussion boards, also easily
allows the possibility of retrospectively revising and eliminating posts and com-
ments. This allows users to control, revise, and fine-tune the self-presentational
text they create to a much greater degree than on discussion boards. All this
makes the overall text created by any one user into a multidimensional, nested,
interactive construction—one that is governed but not entirely controlled by its
author.

“Justice for Mason” is a Facebook page hosted by Terra, a teenage girl who
delivered a stillborn baby boy on April 22, 2013.11 As of December 30, 2013,
the site had 4,084 followers, dozens of posts, and hundreds of comments. Terra
was deeply upset not only by the loss of the baby, but by her treatment in the
hospital, when a nurse flushed away the fetal remains without her consent. Her
page began, nominally, as an effort to “to raise awareness for the mistake this
Hospital made,” but over time it morphed into a memorial page, and a place for
Terra to construct an identity for herself as a mother and for her lost baby as a
child with a specific identity.12

The premise for the page is Terra’s need for a space that is defined by but at
the same time pushes back against how her pregnancy loss played out in medical
space: it is precisely because she feels that the medical narrative went wrong that she wishes to establish an alternative space in which her loss can be articulated differently. More specifically, she experienced institutionalized medicine as failing to give recognition to the personhood of her baby, and she sets up a space in which the construction and recognition of this personhood is front and center. At the same time, the official purpose of the page is to find “justice” to counteract the medical narrative gone wrong. Since Terra has no particular activist or policy agenda, “justice” here is probably best interpreted as a matter of recognition of an alternative to the narrow medical narrative. This pushback shows up in specific posts as well, in which she contrasts the official medical telling of her narrative with her own, and presents the former as injurious:

Sitting in the horrible hospital for abdominal pain, a nurse asks if I have children, i explain I lost Mason to stillbirth and she says well then you aren’t a mother you have no kids! Ugh!!! Then they bring me for an ultrasound and put me in the room where Mason lost his heartbeat!!!!! So done I never want to come back. (7/13/13)

Unlike a discussion board, Facebook offers Terra a medium in which she can build a multimedia identity and a narrative for herself and for her unborn child that can be absorbed synchronically or diachronically. Furthermore, we see here again the primary role that time and temporal markers play in structuring the presentation of her experience during and after her loss. She marks her baby’s original due date, anniversaries of his passing, and so forth. The narrative she creates is structured by these dates. For example, much of the page was dominated for many weeks by posts leading up to a balloon release she had planned for his due date (August 26, 2013). These weeks are not empty waiting time, but time that she uses to plan, talk about, and look forward to the event.

Like many posters on discussion boards and other forums, Terra makes heavy use of numbers to mark out her narrative, and in particular to resist the narrative she feels has been imposed on her or expected of her:

Mason, it has been three months since you lost your heartbeat. I am trying my hardest to get Justice for you! It is surprising that I am still here without you. It seems like the days are getting longer I cry more than I did 2 months ago. (7/22/13)

“You’re 30 weeks pregnant – 10 weeks to go!”- Thanks calendar for reminding me I should be 30 weeks pregnant for Mason:( (6/17/13)

Facebook here gives structure to what would otherwise simply be the absence of a pregnancy. By the time her due date comes around, she has long since fallen off of the radar of the medical eye, but the prescribed medical narrative continues to structure her experience in different ways. Indeed, the temporal structuring places constraints on her posting; her posts dropped off considerably after August 26, when there were no further obvious temporal markers on the horizon.

Terra uses Facebook and imaging technology to visually and textually construct a maternal–child relationship and a maternal identity that would be
otherwise unavailable to her. In addition to photos of memorial teddy bears and plaques, pictures of her pregnancy, her memorial tattoo, and so forth, there are spliced images where she uses ultrasound photos to stand in for her child in “family photos” (see Figure 2). She thereby presents Mason as embedded within a larger family, with a social identity as well as a physical identity.

A distinctive feature of this process of identity construction and temporal narrative management is the extent to which Terra can stage-manage what she presents. She often posts meta-commentary in which she complains about or appreciates responses to her page, and she sometimes asks commenters not to use certain sorts of language or not to criticize her for something in particular. On at least one thread, she notes that she has removed comments that she found upsetting or inappropriate. The commenters on her page help her to craft her self-presentation whether or not they mean to, because she initiates a kind of call-and-response dialogue with her followers which allows her to use their responses as platforms for her own posts, and to adjust and respond to their comments as she sees fit.

One of the few posts on the page from after her projected due date picks up on several of the themes we have brought out:

I try not to post on here as much, for the simple fact that people are constantly bashing my grieving ways. But I came to the conclusion that I will post as much as I want to
because I owe to Mason to live on and keep his memory alive. Mason had so many people waiting for his arrival, And here or not, we still love him! He is My son! My angel! <3333
Justice For Mason. (10/4/13)

Here Terra begins by acknowledging that her posting is dropping off. Her interpretation is that people are critical of her for continuing her grieving for too long, past the timetable that has medical meaning. In response, she re-establishes and rearticulates Mason as a person—one who can be the proper target of moral obligations, for instance—and insists on an alternative narrative. She then switches to a collective voice and the first-person plural, reinserting Mason into a larger community and reaffirming his more robust social identity, as opposed to a private identity defined only in terms of her personal experience.

For our purposes, a large part of what is fascinating here is how the technological infrastructure of Facebook, together with the quickly evolving culture and set of social norms surrounding its use, enables Terra’s engagement in new kinds of identity presentation for both herself and her lost child. This presentation is complex and carefully orchestrated in its temporal, visual, and communicative structure. Facebook gives her the tools to creatively and insistently produce a robust, embodied, narratively structured version of her identity as a mother to her child—an identity that she takes medical institutions to have pointedly foreclosed.

**Blogging about Miscarriage: Jack Joseph’s Mom**

Compared to the interactive online spaces of discussion boards and Facebook, blogs can more closely resemble conventional print genres such as diaries, first-person journalism, or essay writing. One way to build a community on a blog site like Wordpress is to read, like, and comment on others’ blogs, so in this sense community is active and reciprocal. But in contrast with the communities we see in discussion boards, each blogger’s identity is housed in a dedicated space of authorship, and even the most active discussions have to work within the author/reader hierarchy in a given space. The space of the blog thus enables a more traditionally author-based identity creation, one that can develop and morph over time in the presence of a fluid audience that may or may not respond.

“Jack Joseph’s Mom (JJM)”13 is a blog that has been active on Wordpress since March 2013. Unlike some of the more immediate uses of online spaces to process the experience of miscarriage, this blog, like Terra’s Facebook page, reveals an effort to shape a narrative and assert an identity some time after the miscarriage has occurred. The site consists of sections including “my story,” “jack’s memory box,” and “challenges: fitness, fun, and faith in me” in the banner and “letters to jack” and a calendar square announcing “Jack’s First Birthday in Heaven” in a right menu bar. In mid-March 2014, the site listed 1,004 followers and approximately 28,500 views; many comments suggest that
commenters found the site after the author first found theirs. In “my story,” JJM reports that at the time of starting the blog she was thirty-six years old and single. She became pregnant accidentally in a relationship with a man who was working overseas at the time of the miscarriage and who was not interested in resuming the relationship when he returned. She explains in a post entitled “great expectations,” under “my story,” that “Jack’s father has expectations, too. He expects me to get over it like he did. And I can’t. I wish I could move on so quickly like he did, but I can’t.” She miscarried in August 2012 and estimates her due date as February 18, 2013, a month before the blog was created; this date anchors the temporal experience of the blog, both through the stable “first birthday” square in the right column and through the author’s ongoing narrative references to Jack’s imagined development.

J JM started the blog after someone else created a Facebook page in her name announcing her miscarriage, broadcasting a personal event she meant to keep private. The narrative she hopes to reclaim is presented pseudonymously and carefully controlled as a result. The identity and story she presents are also explicitly intended for a new community. She explains at the end of the “my story” post,

And what I want everyone to know is that until you have been through what I have been through, you can’t even begin to understand what I feel.

I don’t trust anyone. So why start this blog? Because I can do it anonymously and I have found that strangers are kinder and more considerate and sensitive than the people I have loved and supported all through my life.

JJM states clearly that she wants to distance herself from loved ones and from her own identity as she processes the experience of her miscarriage. Her initial aim is to take back the narrative of her miscarriage and her relationship as they were misrepresented on Facebook. To do so, she takes on a pseudonym that is itself built on a created identity for the fetus that was lost. She explains in an early posting, “Why Jack?,” that she has a strong feeling that her baby was a boy, that she dreamed of him during Three’s Company reruns on late night television (hence the “Jack”), and that “Joseph” is the father’s name (3/31/13). The blog’s full title is “JJM: if love could have saved you, you would have lived forever,” but in an interesting slippage of identity, postings are made under the author name “Jack Joseph.”

Within the authorial space of the blog, JJM builds an alternative story, including a series of letters to Jack. Ironically, then, her attempt to correct a misrepresentation of her story flowers into a fabricated narrative that does not even purport to accurately represent reality. These imaginings shape the temporal structure of the blog. For instance, the fortieth letter, posted December 25, 2013, begins “Hi my sweet baby boy! I missed you a lot this morning. The tree should have had presents underneath it for you.” Other milestones and holidays are also noted, discussed, and often illustrated in “Jack’s memory box,” which archives
numerous baby items (Detroit Tigers baby gear, infant shoes, a toy tractor, and so on.) that belong or would have belonged to Jack. There is a further link to “Photos of Jack I wish I had,” in which JJM explains, “I want this page to show various pictures of others babies in pictures and settings of how I could have had Jack’s pictures taken as he grew up.” This photo gallery contains potential birth announcements printed with Jack Joseph’s name, photographs of infant boys in various outfits, and a “milestones” chalkboard filled out for Jack at one month (see Figure 3); readers are also directed to JJM’s Pinterest board for more photos.

JJM creates a narrative space around the experience of parenting that she has missed: as JJM, she fills in events that did not occur in her son’s life with a series of imagined moments and borrowed images. Thus her miscarriage brings an end to a pregnancy narrative but also allows, through the space of the blog, for an ongoing enactment of story. As JJM develops her blog, her pseudonymous maternal identity accumulates meaning and history—the history of her failed relationship and miscarriage, but also a growing, open-ended chronology of moments with her imagined child. While some of JJM’s narrative details are openly fabricated, and hence explicitly do not reflect her actual lived narrative in any direct way, we think it would be naïve to take them as independent of the process of identity construction. As JJM builds an audience and a community, she receives recognition for alternative narratives through which she seeks to interpret herself as an actual survivor of miscarriage. There are complicated looping effects between her presentation of her alternative fantasy narrative as a mother, her conversations around this presentation, and her implicit presentation of herself as someone who is grappling with an absence in her life caused by miscarriage.

Most early postings revolve around the problematic relationship with Joseph and her miscarriage, but over time JJM begins to blog about unrelated aspects of her daily life as well. In August 2013, she begins a thirty-day blog challenge, “Fitness, fun, and faith in me,” which she continues each month. She notes holidays outside of the Letters to Jack section, adding recipes and photos of decorations. These postings sometimes include a reference to Jack. On Thanksgiving, for instance, JJM posted twenty photographs of food and her apartment as she described her holiday; the last photograph featured, without
comment, a onesie embroidered with the phrase “My First Thanksgiving.” By this point in the blog, we see JJM weaving together (presumably) real and fabricated narrative details. Other later postings mention work, family, exercise, and other aspects of daily life, with only the author’s name—Jack Joseph—to remind readers that the writing is taking place in a space that continues to be anchored in the post-miscarriage narrative she has created. The initial “my story” post lists 97 responses, and since then, the number of comments on a given posting can range from zero to eleven or twelve, to which JJM almost always responds directly in the same thread. In this authored space, JJM creates a new virtual identity, with the miscarriage at its core, which builds out in an ongoing conversation into other parts of her life.

A letter posted on February 18, 2014, titled “Happy 1st Birthday Angel,” brings several of the themes we have discussed together:

Today Jack would be celebrating his first birthday.

Well, if he would have been born on the date some app on my iPhone calculated based on conception criteria.

That’s 12 months, 4 seasons, 52 weeks, 365 days, 8760 hours, 525600 minutes, 31536000 seconds and countless beautiful moments and firsts my beautiful little boy wasn’t here to share with this world.

That’s a lot of time spent missing someone I never got to meet. That’s a lot of time creating in my mind what a special little man he would have been.

This letter makes vivid the both the gap and the interplay between the two narrative spaces that JJM has constructed on the blog. At the same time, it displays similarities to several of the other texts we have discussed, both in its use of quantitative markers and temporal measurements, and its attempt to give form to what would otherwise risk being empty narrative space. Like Terra, JJM uses a smartphone calendar as a marker of her experience of time since conception and after her miscarriage, and she designates her period of grief with precise temporal measurements. This grieving time “spent missing someone I never got to meet,” turns into time she uses to imagine or create an identity, “a special little man.”

JJM creates the JJM blog as a place to reclaim and stabilize her identity, but that identity is framed by the story and the persona she has created for a community that knows her only by her pseudonym. She tells one person who comments on a post, “Blogging has helped. I met a community of people who have been through what I have been through, and their support and knowing that others know how I feel helps. It’s getting me back to me . . . which has allowed me to find humor again, and start exploring my other interests. Thanks again.” Yet when she and another blogger start a friendship and decide to exchange email addresses for a one-on-one conversation, she shares an email address that bears the name “JJM,” and “JJM” has her own Twitter feed and Pinterest and Instagram accounts. So while JJM claims she is “getting back to me” in the complex construction of her blog, this “me” is a complicated fabrication—one that is
sustained and managed over time with support from a carefully chosen community. This self-understanding, continuously filtered and focused through the experience of her miscarriage, constitutes an abiding alternative identity that she can hold in tension with other identities over a long period of time.

**Conclusion**

While common themes emerge in our three examples, there are a few dimensions along which they are interestingly different. For one, as we progress from discussion boards to Facebook pages to blogs, we see important differences in the structure of the authorial voice. All three allow for the negotiation and representation of identity and narrative in a communicative, collaborative space. But discussion boards have an inherently conversational, bottom-up structure, with no one participant having any special authority or power more than the direction of the discourse. They also represent real-time dialogues comprised of relatively short, text-based interventions, with little opportunity for editing or stage-management. In contrast, on Justice for Mason, Terra is the central anchor for the narrative and the main manager of the discourse. Yet her control is imperfect and the resulting textual product remains collaborative, with long comment threads under each post that reinterpret and situate the original entry, sometimes in ways that Terra dislikes. Finally, JJM creates a much more traditional single-voiced text with a masterful author, even though comments are possible. The blog calls for an audience more than for interlocutors or participants, and she uses it to gradually construct an elaborate (and, as we saw, tension-ridden) identity for herself.

Another interesting contrast between the three cases is in their effective distance, both temporal and representational, from the literal lived bodies of their authors. While nothing guarantees that the participants on the discussion boards tell the truth, the function of the boards is to record real-time conversations about actual current events and feelings, often including bodily events. The relationship between Terra’s actual body and life and her virtual presence on her blog is noticeably more mediated. She uses manipulated images and counterfactual timetables to present a highly managed version of herself in virtual space. Finally, as we saw, JJM creates an identity and narrative for herself, including concrete embodied events, which are explicitly fabricated, including symbols and pictures representing nonexistent events and objects. Thus while all these various writers are creating virtual identities to some extent, the relationship between their virtual and real identities moves along a complex continuum.¹⁴

Miscarriage is, of course, not the only sort of event that can fracture our identity and render it hard to articulate, narrate, and navigate at a bodily and a social level. Nor is it the only event that situates us in complicated ways both inside and outside of medical space, and potentially trapped within a waiting period with unclear narrative or temporal form. Being menopausal and being a “cancer survivor” are two quite different examples that leap to mind, and there
are many more. In the twenty-first century, communication technology plays an integral role in self-comprehension and self-articulation in the face of such complex experiences.

Still, miscarriage is unlike these other situations, in that it is an event that others might maintain is, in essence, the absence of a story. As we and others in this issue have discussed, miscarriage is an event that is typically excluded from social narrative space and particularly hard to articulate. Furthermore, it creates an identity that can be experienced as inherently problematic and unresolvable: it can position women as neither mother nor childless, neither sick nor well, neither having experienced pregnancy nor having not experienced it. When social space does not provide a full repository of stories about a certain sort of event or experience, it is challenging for anyone involved—whether first- or third-personally—to make sense of what has occurred.

Dedicated discursive communities can be places where such stories are built and shared, making new narrative possibilities recognizable. To take an example familiar to feminist philosophers, in “Anger and the Politics of Naming” Naomi Scheman points out that women’s anger is often short-circuited by the fact that it does not receive uptake as anger, because it is more often interpreted as a mere hormonal reaction or a disorderly and inexplicable mood. Women’s articulate, comprehensible anger—at least at the time she was writing in 1980—was not something we had the cultural resources to interpret well, and in turn it could not be enacted because its narratives were truncated and nonsensical. She explored how spaces such as consciousness-raising groups could provide sense-making resources that allow not only the recognition but also the constitution of new narratives. Similarly, miscarriage narratives may find new possibilities for articulation and enactment in proper communities providing specialized discursive resources.

But there are vastly more Internet communities than there ever could be consciousness-raising groups, and they are considerably more accessible. They are unconstrained by geography and mostly unconstrained by economics, and they can easily cross traditional demographic lines. They are also far easier to create and often easier to shape and direct. They can be transient or lasting. For all these reasons, they dramatically alter our sense-making resources. The social and technological tools the Internet offers are far from homogeneous: these tools allow women to constitute miscarriage narratives that often unfold in multiple timeframes and along multiple paths, and to build an identity and sense of their own experience collaboratively. These narratives and identities are woven in relationship to medical spaces, measures, and timetables, but they are also essentially outside traditional medical space. Against this background, the Internet can provide a formidable social tool for articulating, renegotiating, and restructuring what women experience during and after miscarriage.

Our goal, however, is not to paint a utopian picture. Collaborative negotiation of individual narratives within a specific community always risks being
limiting and oppressive. Within any given community, there are norms concerning what sorts of reactions, experiences, and emotions are allowed and how stories may be told. Some miscarriage boards explicitly disallow “success stories” about pregnancy after miscarriage. More subtly and probably more dangerously, others have very formulaic ways of inscribing maternal and “child” identity—as angels with birthdates, for instance—and it is not clear that there is social room for other ways of conceiving the identity, or lack thereof, of a miscarried fetus. On Facebook and blogs, flaming and trolling 18 are not uncommon, and civility is an ongoing and fragile project. Hence, far from being free palates for self-expression, the kinds of Internet forums we have examined are morally and materially complicated sites of social negotiation. Like all such sites, they both provide options and pose threats, and building and articulating an identity within them takes ongoing work. We hope to have shown that they offer some powerful new possibilities for this sort of identity negotiation.

Both authors contributed equally to all stages of the writing of this article; our names are listed alphabetically. We have worked on this article in various incarnations for an embarrassing number of years now, and it would be cumbersome to name here the many people to whom we owe gratitude for helpful conversations and feedback. But we are grateful in particular to Dan Steinberg, the editors of this issue, and two anonymous referees for extraordinarily helpful comments on earlier drafts. Research grants from the Hampden-Sydney College Professional Development Committee also made face-to-face collaboration easier.

Notes


2 Lindemann, Holding and Letting Go.

3 Lindemann Nelson, Damaged Identities, 72.

4 Ibid, xi.

5 Other top listings are often similarly embedded within pregnancy web sites, such as babyandbump, momtastic.com and justmommies.com.

6 Here and throughout, we retain misspellings and other such infelicities from the original posts. Since people tend to write sloppily on the Internet, to put it mildly, there are many such errors, and it would be unwieldy for us to add “sic” each time. All such mistakes should be assumed to be in the original.

7 AF = “Aunt Flow,” or menstrual period. HPT = home pregnancy test.

8 OB US = obstetrical ultrasound.
This signature contains many nonobvious acronyms, which is part of what solidifies its user as a member of a discursive community. M/c = miscarriage. EP = ectopic pregnancy. MTX = methotrexate, an injectable abortifacient drug. ATTC = actively trying to conceive.

In March 2014, the page was deactivated, although not deleted. Terra has kindly given us permission to quote and discuss material from her page in this article. It is worth noting that she asked us to use the language of stillbirth rather than miscarriage when discussing her case and we have respected that, although by our calculations she lost her baby at only four and a half months’ gestation.

http://jackjosephsmom.com/

It would be fascinating to analyze all of these phenomena through the lens of embodiment theory, and to think carefully about virtual embodiment and how it is related to traditional embodiment. Unfortunately we can only gesture at the issue here.


Reprinted in Scheman, Engenderings.

There is a growing body of literature on the pervasiveness of online incivility and its effects on discourse and on users’ psychology. Unfortunately, we do not have the space or expertise to discuss this important dimension of online discourse here. See, for instance, Ashley A. Anderson, Dominique Brossard, Dietram A. Scheufele, Michael A. Xenos, and Peter Ladwig, “The ‘Nasty Effect:’ Online Incivility and Risk Perceptions of Emerging Technologies,” Journal of Computer-Mediated Communication 19, no. 3 (2014): 373–87; and Claire Hardaker, “Trolling in Asynchronous Computer-Mediated Communication: From User Discussions to Academic Definitions,” Journal of Politeness Research 6, no. 2 (2010): 215–42.