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‘Recurrent losers unite’: Online forums, evidence-based activism, and pregnancy loss

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ABSTRACT

Women with recurrent pregnancy loss face unique challenges associated with the social invisibility of their condition, patchy medical knowledge about it, and often intransigent positions of doctors. We approach online forums as sites of knowledge production and examine discussions among women with recurrent miscarriages. We observe that some forum participants gather, summarize, and share experience-based and research-based information in order to challenge certain medical conceptions. We describe these efforts as an example of individual patients' evidence-based activism enabled by new media platforms and other technoscientific tools available to the public.

1. Introduction

In this paper, we consider knowledge production practices in online fertility forums, focusing specifically on discussion among women with recurrent pregnancy loss (RPL) and how their informational practices relate to evidence-based activism. The concept of evidence-based activism has been suggested to capture the increasing involvement of patients' organizations with how certain health conditions are defined and researched. The term refers to a blend of experience-based and research-based knowledge used by patients' organizations to affect practices “from within” medical institutions (Akrich et al., 2013; Rabeharisoa et al., 2014). We extend previous research by demonstrating that the concept of evidence-based activism also applies to individual patients’ efforts as they are enabled by new media technologies—such as online forums—and other technoscientific tools increasingly available to the public, including sensitive home pregnancy tests (Layne, 2009; Robinson, 2016).

Although women have different experiences of miscarrying and different reactions to it, losing one's desired pregnancy several times often brings suffering and frustration. Miscarriage is a misfortune made worse by how it is socially constructed; new tools—such as sensitive pregnancy tests and vaginal ultrasound—allow for early diagnosis of miscarriage, but miscarriage cannot be prevented or reversed (Layne, 2003, 2006b). Women with RPL also often face the lack of information about their condition and clinicians' frequent inability to explain it. Frustration with not having answers is common, and posts from online fertility forum participant CZ illustrate this frustration. Writing after her 8th miscarriage and 4 years of trying for a second child, CZ finds it “hard emotionally to deal” with her experience because “there is no explanation or reason” and 8 “is too many to lose just to bad luck.” For CZ, “this ‘keep trying’ business is simply not good enough.” In the absence of adequate answers about what caused her miscarriages, CZ is unsure about her next steps, “If I physically cannot have another child, why should I let it happen over and over again?” To keep trying is emotionally exhausting yet giving up would not end her suffering: “it is not about the individual miscarriages anymore” but “the unrequited love I have for a missing child.” Another forum participant observes that CZ has been through so much that she “probably know[s] as much as [her] local doctors.”

In this paper, we examine how women who have experienced recurrent pregnancy loss — a “disorder defined by two or more failed pregnancies” (ASRM [Practice Committee of the American Society for Reproductive Medicine], 2013, p. 63) — articulate their perspectives in response to the social and medical construction of their condition. We approach online fertility forums that enable such reflection and articulation of shared experiences as sites of knowledge production. Indeed, this paper's title reflects the name of one participant-generated thread in an online fertility forum; it suggests that at least some women are trying to make sense of their collective experience in the medical and cultural contexts that leave them disempowered.

As we consider the production of knowledge in online discussions, we emphasize the work of select individuals who actively gather,

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summarize, and share information in effort to challenge certain medical conceptions. We describe this work as "evidence-based activism" (Akrich et al., 2013; Rabeharisoa et al., 2014). While earlier research has focused on patients' organizations, we offer a new understanding of evidence-based activism as a network of mediated individual efforts. We thus suggest that not only patients' organizations but also individual patients might be acting to change how their conditions are defined and treated. Their efforts are likely to target areas of perceived medical uncertainty and ignorance, and this work is enabled by new media platforms such as online forums.

We begin with a review of literature on the challenges faced by women with RPL, discuss online forums as sites for evidence-based activism, and explain our research methods. The subsequent sections present excerpts from forum discussions that demonstrate how women use online forums to reflect on their experience, articulate concerns, and produce new understandings. We then discuss knowledge production practices on the forums, including instances of individual evidence-based activism.

2. Literature review

2.1. Challenges of the existing social and medical construction of miscarriage

Women with RPL face several challenges stemming from the existing social and medical construction of miscarriage. These challenges — social invisibility, liminality, and especially the lack of actionable explanations — potentially increase suffering of women with RPL and complicate efforts to articulate what happened and why.

Though common, miscarriage is a socially invisible experience, steeped in silence and even shame (Layne, 2003). Miscarriage is rarely portrayed in the media or discussed publicly. The experience of miscarriage is typically not visible or announced to others (Cahill, 2015). Those who have not experienced it often know little about it; some women learn that others close to them had miscarriages only after their own miscarriage (Frost et al., 2007). The common practice of not announcing one's pregnancy until 12 weeks, when the risk of miscarriage decreases, contributes to the social invisibility of pregnancy loss; with earlier announcements, women would also have to publicly acknowledge their miscarriages.

Miscarrying is also a liminal event. The embryo is between life and death, and the woman is between being pregnant and not being pregnant, between being a parent and not being a parent (Miller, 2015; Reinheld, 2015). Experiencing miscarriage as a liminal event is in part constructed by the tools used to confirm pregnancy. With the new tools for early confirmation of pregnancy, "more and more women learn they will miscarry before they actually start to do so" (Layne, 2006a, p. 610). These tools include ultrasensitive home pregnancy tests, serum beta hCG (Human Chorionic Gonadotropin) tests, and vaginal ultrasound. After a woman starts spotting and her blood pregnancy tests do not progress as expected, or after disappointing ultrasound results, she can spend days and weeks in this in-between state. This is often a period of heightened uncertainty, and the woman might seek medical advice or support from those who have undergone similar experiences.

Yet pregnancy loss "can leave women in an oddly unhelpful relationship to medicine" (Hardy and Kukla, 2015, p. 107). Pregnancy loss has been medicalized; that is, it is an area of human experience that has been redefined as a medical problem, and it now falls under the jurisdiction of medicine (Conrad, 2008). Women's experience of miscarriage is now typically shaped by pregnancy tests and ultrasound, and possibly by medical tools to help resolve miscarriage (e.g., dilation and curettage procedure, known as D&C). But there are generally no tools to prevent or treat miscarriage — and there is often no explanation, even for RPL. First-time miscarriages are referred to as "spontaneous" and typically left unexplained. Women with RPL might undergo multiple tests that still often fail to provide a diagnosis. A commonly repeated statistic is that 50% of all recurrent miscarriages are unexplained (ASRM, 2012); pathophysiology of pregnancy loss from various causes — and multiple causes can be at play — is also poorly defined. This lack of coherent medical explanation is particularly surprising in a context where death itself has become highly scientized; people can no longer die of just "old age," and death certificates must specify cause of death (Frost et al., 2007; Bowker and Star, 1999).

We approach medicalization of miscarriage as a problem of patchy production of medical knowledge (Frost et al., 2007) — with a corresponding production of areas of ignorance (Kuchinskaya, 2014; Proctor and Schiebinger, 2008). The emergence of these areas of ignorance is partially the consequence of the increased visibility of miscarriage due to the emergence of the more sensitive tools. Some physicians question, for example, the commonly quoted 1% rate of prevalence of RPL since it is "based on studies conducted 30 years earlier at a time when detecting early pregnancy loss had limited possibilities" (Christiansen, 2014, p. xii). In other words, pregnancy loss is detected earlier and thus more frequently, but it remains unexplained. One "almost universally asked question" for those who have experienced pregnancy loss is why it happened and whether it would happen again (Brier, 1999). Asking for an explanation does not mean that women necessarily want more medical attention (Simmons et al., 2006). But the uncertainty associated with going through miscarriage and the dearth of confirmed explanations and solutions might turn into a particularly acute problem for women with RPL.

Though the social invisibility and the frequent lack of answers persist, there have also been some transformative developments. An increased willingness to discuss miscarriage might be emerging, as exemplified by the 2015 Facebook post by Mark Zuckerberg, CEO and co-founder of Facebook, in which he acknowledged his wife's three miscarriages prior to her successful pregnancy. Increased scholarly attention to miscarriage and RPL are demonstrated by the 1st and 2nd World Congress on Recurrent Pregnancy Loss in Cannes, France, in 2016 and 2017 (see also Fordyce, 2013, p. 130). Finally, one of the most consequential changes is the potential use of assisted reproduction technologies as treatment for RPL. Pre-implantation genetic screening (PGS) with in-vitro fertilization (IVF) ensures that no chromosomally abnormal embryos are selected for implantation. This addresses one common cause of miscarriages but also transforms, through technoscientific inventions, the nature of how a pregnancy is achieved, thus illustrating the process of *bio*medicalization of RPL (Clarke et al., 2010). The effectiveness of this approach is debated, and IVF with PGS is not currently recommended as a routine solution for RPL (ASRM, 2012).

In short, RPL remains an area where women face significant areas of medical uncertainty and ignorance. Our focus is on patients' own knowledge production activities in response to RPL and how it has been medically constructed.

2.2. Evidence-based activism and online forums

Online health forums have become a popular tool for learning more about one's health condition. Participants might provide each other with information, and also with emotional support and even occasional practical assistance (Civan and Pratt, 2007; Sanderson and Angouri, 2014; Schaffer et al., 2008). From the perspective of knowledge production, forums provide an opportunity for participants to pool their "collective intelligence" about their health conditions and related experiences (Radin, 2006).

Online forums (as well as message boards and email lists) can thus be viewed as spaces for knowledge production. Collective articulation of shared experiences gives individual patients new information, new tactics, and new kinds of evidence to use when interacting with doctors and the medical system (Dumit, 2006). This knowledge production makes individuals "stronger when facing a disease or physicians," and online discussions can also "initiate a collective reflection on the necessary condition for change" (Akrich, 2010, para. 2.4). At least some