

Announcing Pregnancy Loss on Facebook: A Decision-Making Framework for Stigmatized Disclosures on Identified Social Network Sites

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ABSTRACT

Pregnancy loss is a common experience that is often not disclosed in spite of potential disclosure benefits such as social support. To understand how and why people disclose pregnancy loss online, we interviewed 27 women in the U.S. who are social media users and had recently experienced pregnancy loss. We developed a decision-making framework explaining pregnancy loss disclosures on identified social network sites (SNS) such as Facebook. We introduce *network-level reciprocal disclosure*, a theory of how disclosure reciprocity, usually applied to understand dyadic exchanges, can operate at the level of a social network to inform decision-making about stigmatized disclosures in identified SNSs. We find that 1) anonymous disclosures on other sites help facilitate disclosure on identified sites (e.g., Facebook), and 2) awareness campaigns enable sharing about pregnancy loss for many who would not disclose otherwise. Finally, we discuss conceptual and design implications. CAUTION: This paper includes quotes about pregnancy loss.

Author Keywords

Self-disclosure; social support; well-being; stigma; pregnancy loss; miscarriage; stillbirth; prenatal; reproductive health; women's health; maternal health; grief; Facebook; social media; network-level reciprocal disclosure; preventive disclosure; awareness campaign; Pregnancy and Infant Loss Awareness Month

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

INTRODUCTION

Announcing exciting news and life transitions is common on social media sites. People joyfully share online

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announcements of a new dream job, getting married to a beloved partner, or becoming parents. However, when people experience distress or trauma, they may find it difficult to use social media to talk about it or seek support. In some cases, crises (e.g., disease diagnoses, abuse, pregnancy loss) involve stigma and can be prohibitively painful to share with even the closest of friends.

People often need to socially share stigmatized life events and emotions associated with them [67]. However, many do not, and sometimes they suffer as a result of this inhibition due to the psychological distress associated with keeping a secret [65]. Other times, when people do disclose, they face negative consequences such as social rejection or added distress [11], particularly when confidants are unsupportive. These risks are real, and when people consider making themselves vulnerable by disclosing sensitive experiences, they must balance benefits with costs. Access to social support is crucial. By sharing stigmatized and distressing experiences and emotions, people can signal this need to others in their social networks, both online and face-to-face.

Pregnancy loss—here broadly defined as loss due to stillbirth or miscarriage—happens in approximately 20% of recognized pregnancies in the United States; yet 55% of Americans believe it is a rare event [72]. Pregnancy loss can be isolating, socially stigmatized, traumatizing, associated with negative feelings (e.g., shame, guilt) and depression, and difficult to disclose to others [75], but receiving support is dependent on the disclosure of the loss. Moreover, lack of support from others, especially friends, can contribute to a sense of stigma and may increase risk of depression in the wake of a pregnancy loss [76].

The potential for improved well-being through access to social support makes pregnancy loss a productive context for research on designing social computing systems for safe disclosures and support seeking. Because pregnancy loss is common yet perceived as rare, researching social media disclosures in this context can benefit a large number of people. Many individuals do not disclose the loss of a pregnancy, but some do, and little is known about factors that guide these disclosures when they do happen.

We conducted 27 semi-structured interviews with women in the U.S. who had experienced pregnancy loss within two years and who used social media, to investigate support

seeking after pregnancy loss. In this paper, we focus on the disclosure experience on Facebook as a primary example of an *identified social network site (SNS)*, that is, an SNS where one's identity and one's connections' identities are known. Although we did not set out to focus on any particular SNS for this study, all participants (except one who had stopped using Facebook) discussed Facebook as a site that includes their physical world connections (e.g., family, friends, co-workers). This made Facebook an important potential disclosure and support seeking venue for them. In this paper, we focus on disclosures on Facebook, an *identified SNS* where people's networks are typically comprised of people they know from physical world contexts [32], and where they typically present their physical world names and identities.

Through analyzing these data, we developed a framework to explain pregnancy loss disclosure decisions on Facebook. Our framework includes six types of decision factors: self-related, audience-related, societal, platform and affordance-related, network-level, and temporal. We find that participation on unidentified (i.e., anonymous or pseudonymous) online platforms (e.g., Reddit) can help people feel more comfortable with disclosing the loss on Facebook. We also find that one-to-many disclosures on Facebook—to one's known social network—is appreciated because it enables avoiding many painful one-to-one disclosures. Importantly, we find that the Pregnancy and Infant Loss Awareness Month social media campaigns provide a socio-technical context within which sharing about pregnancy loss is possible for many who would not have disclosed otherwise, due to reduced perceptions and concerns of stigma. Finally, we introduce the concept of *network-level reciprocal disclosure* as a novel theoretical construct that can motivate social computing system designs to better facilitate sensitive disclosures and social support exchange.

RELATED WORK

Pregnancy, Pregnancy Loss, and Social Network Sites

A growing body of HCI scholarship has studied pregnancy, parenthood, and technology. Parents and expecting parents use social media for support or self-expression (e.g., [2,7,24,55,73]). Apps and interventions also exist to meet these populations' certain needs. For example some allow pregnant women to monitor pregnancies in stages [38]. Others help new parents of preterm infants track health data [34]. "Pregnancy ecology" is a proposed paradigm in designing pregnancy apps for use by not only the mother, but also others who play supportive roles [62], such as partners and mothers, who are often a woman's most important supporters after having a child [63]. Studies related to parenthood, motherhood, and pregnancy in HCI have largely focused on pregnancies that do not lead to a loss.

After a pregnancy loss, many women feel hurt, alone, unworthy, and unloved [84], and some experience fear, anxiety, symptoms of PTSD [57], and depression [59]. In addition to psychological distress, the loss also alters family

and social relationships; when family members are unsupportive, family communication is often disrupted [15]. For example, it is rare for someone to say "you will have another spouse" after a spouse dies; yet, it is common to say "you can have another baby" after a pregnancy loss [56]. The portrayal of pregnancy loss as a non-event can make a bereaved woman feel like an "unperson" in Orwellian terms [12]. Women's social identities as patient, mother, and full citizen are "spoiled" after a pregnancy loss [12], and many feel they can never be "cured" [37]. Spoiled identities obligate intensified impression management efforts and performances [26]; unsurprisingly, women who experience a pregnancy loss face a difficult decision when deciding whether, how, and to whom they disclose it.

During life events that cause sustained psychological distress, access to support is crucial to readjustment [1]. Those who can find support are four times more likely to find meaning in the loss [58]. Pregnancy loss survivors sometimes construct narrative stories about their pregnancy and loss, and social support is a factor in narrative reconstruction [37]. In the U.S. there are no grief rituals for pregnancy loss, and this loss remains largely absent from societal narratives [33]. Successful identity repair work is a required process for recovery after pregnancy loss [12]. Being able to disclose the loss is a prerequisite to accessing social support and identity repair work.

Research on technology use after pregnancy loss is scarce. One study suggested Internet-based interventions could reduce negative mental health effects associated with pregnancy loss (e.g., grief, depression, anxiety, PTSD) [40], however, this design area remains largely unexplored. What little research exists about online pregnancy loss disclosure has mainly focused on the practice and benefits of anonymous sharing in online support groups [23] and has noted the reluctance of many women to share outside of anonymous contexts [41]. Yet, we see that some women do disclose pregnancy loss on identified SNSs. In this paper, we address this gap to understand the socio-technical factors facilitating disclosures of pregnancy loss on identified SNSs.

Self-Disclosure and Social Network Sites

Finding social support can be both a motivator and an outcome of Facebook use [27,42,68]. Access to both weak and strong ties can be a benefit of Facebook use, yet context collapse (i.e., when members of various social networks are flattened into one big group) poses a challenge, especially when people do not want to share information they deem sensitive with their entire Facebook network [50]. Some employ the "lowest common denominator" strategy by disclosing only what they perceive to be appropriate for all of their network [35]. When dealing with context collapse on Facebook, individuals need to prevent anticipated identity-threatening situations [44], and sometimes they do so using "preventive strategies" to avoid potential unwanted outcomes in the future [43]. A recent large-scale study of Facebook suggests that people share larger amounts of both

positive and negative emotions when their Facebook networks are denser and smaller [14].

Several models have been proposed to understand self-disclosure in dyadic contexts in non-computer-mediated settings (e.g., [17,21,28,61]), and some of these models have been applied to disclosure behavior on Facebook. For example, an interview study [82] about self-disclosure goals on Facebook identified motivations proposed by prior models [21,61] (i.e., self-expression, self-clarification, social validation, relationship development, social control) and added that people also use the site to keep a “personal record.” However, participants in that study viewed Facebook primarily as a place for sharing positive news. A survey study using the same models found that for one-to-many status updates, social validation and self-expression were primary disclosure goals and that Facebook users use different functions for disclosures with different levels of intimacy, depending on their goals [8]. Intimate public updates (versus private) are perceived as inappropriate and lead to less liking of the poster [10], in contrast to research in dyadic contexts, which indicates intimate disclosures often increase the extent to which the discloser is liked [6].

While these studies contribute important knowledge about disclosure goals on Facebook, they do not focus on stigmatized and emotionally difficult experiences. This is important, because the literature in non-computer-mediated contexts tells us that people share negative emotions in safe settings with audiences that are likely to provide supportive feedback [67]. In particular, when people experience shame and guilt—feelings associated with pregnancy loss [47]—or traumatic life events, emotional disclosure is restrained [67]. The most traumatic personal experiences are often concealed [45] for reasons including self-presentation and impression management concerns [25]. On Facebook, people report sharing more positive emotions than negative compared to face-to-face settings [48,66]. If and when people do disclose negative experiences in spite of the difficulties, it is important to understand the reasons and socio-technical contexts that facilitate these disclosures.

Shifting our attention to intimate and sensitive disclosures, research suggests that features of computer-mediated communication such as a lack of non-verbal cues (e.g., [79]) or increased anonymity [4,78] can facilitate sensitive disclosures. HCI and social computing scholarship has examined how people use social media when they possess stigmatized identity facets or when they experience life changes that may induce psychological distress. Broadly, this line of research suggests both positive outcomes (e.g., access to support and social capital) and negative outcomes of self-disclosure and SNS use (e.g., negative well-being effects due to unsupportive reactions) [80]. Several scholars have investigated interactions related to grief of loved ones (e.g., family, friends) on Facebook, suggesting that Facebook enables expansions of public mourning [13]; similarly, an analysis of Facebook memorial pages suggests that the site

is a suitable space for sharing memories and grief with one’s friends [51]. An interview study with people facing significant health concerns found that emotional support, motivation, accountability, and advice were reasons they participated in online spaces such as Facebook and health communities [60]. Other vulnerable populations, such as transgender individuals find Facebook both a site of stress and support [30]. For veterans transitioning into civil society, while barriers to disclosure of struggles exist, reenacting camaraderie triggers disclosures [74]. Groups such as fathers [3] and Low-SES, 1st generation college students [54] experience barriers to sharing information on Facebook due to positivity bias and fear of judgment or stigma; Disclosure of stressful events on Facebook moderates the link between stress and mental health, enabling young adults to elicit support [87]. Finally, college students who use Facebook who experience distress, have more self-presentation concerns, yet still sometimes engage in vulnerable self-disclosures on the site [9].

The literature covers a large range of human experience, including parenthood and loss of loved ones; yet it does not investigate disclosures of loss and grief in stigmatized contexts like pregnancy loss in which the discloser may know of no-one with similar experiences in their network. The work we have reviewed suggests that such disclosures are difficult and accompanied by uncertain outcomes, yet they do happen. Why do some people disclose in settings such as Facebook? How do they decide to disclose and what potential risks and benefits do they perceive?

METHODS

To answer these questions, we designed a phenomenological interview study to investigate how and why women who use social media disclose experiences of pregnancy loss, both in computer-mediated and non-computer-mediated contexts.

Recruitment. We sent out a brief screening survey on Facebook and Twitter (starting from the authors’ networks) as well as flyers posted locally. The online call for participants was widely shared by people outside of the authors’ networks. The goal of the screening survey was to find eligible interview participants and yield a strategic sample both in terms of demographics and experiences (e.g., age, used social media, disclosure and non-disclosure on social media). The survey included information about the study and inclusion criteria: having experienced a pregnancy loss during the past two years, being at least 18 years old, using social media, and living in the United States. We did not screen based on gestational stage of loss, as the grief experience is not dependent on it [56]. The study was open to transgender and non-binary people who had experienced pregnancy loss, but none responded. We asked about social media use and their disclosures of the loss as well as demographic and contact information. The survey was active November 2016-January 2017 and we received a total of 90 responses. Among survey respondents, 36 had not disclosed the loss on any platform, 51 had disclosed on one or more,

and three could not recall. Among the 51 who had disclosed on one or more platforms, 41 briefly shared how they did so, out of which 22 had shared about their experience on their Facebook profiles. Those chosen for interviews were contacted via email with study information and a link to an online consent form.

Participants. We interviewed 27 women. The average age was 33.6 (range: 27-42). One participant was in a lesbian relationship, and 26 were in relationships with men. Eight participants reported no online disclosures about their loss; 19 reported online disclosures (e.g., Facebook profile, Facebook groups, Reddit, GOMI, Glow, BabyCenter). Of these, 12 had disclosed on their Facebook profiles, one commented on a friend's post and perceived it as disclosure, and 14 disclosed in support groups. Nine participants disclosed in at least two platforms. All participants reported using Facebook at the time of the interview, except one who only used Instagram and Twitter at the time of the study. Participants had experienced losses in various pregnancy stages including stillbirth. No participants reported directly disclosing pregnancy loss on Instagram or Twitter. All participants were raised and lived in the U.S., and were offered a \$25 Amazon gift card as a token of appreciation.

Data collection. We conducted semi-structured interviews, which freed participants to explain their experiences and allowed us to systematically cover important data points. The first author conducted all interviews via participants' preferred method of video or voice call. On average, the interviews lasted for 92.7 minutes ($SD = 12.5$, range: 62-115). Only audio was recorded and transcribed for analysis. The interviewer began by sharing the study's goals, ensuring participants knew what it entailed, and asking permission to record the conversation. Then the interviewer asked what the participant's life was like when they found out they were pregnant, and what happened next. Follow-up topics included disclosures and non-disclosures of the pregnancy and pregnancy loss in computer-mediated (across platforms) and non-computer-mediated contexts, general use of social media, and reasons and thought processes leading to disclosures and non-disclosures. When possible, we asked for specific examples. In this paper, we only report on themes related to disclosure on Facebook.

Analysis. The constant comparative method, central to and popularized by grounded theory, drove the data analysis. The first author conducted iterative open coding, "through which categories, their properties, and relationships emerge" [77:66], looking for patterns in the data. Open coding allowed for flexibility and creativity in the codebook development [77]. Throughout the analysis, the authors discussed, refined, and reviewed the emerging themes.

Limitations

This study focuses on women in the U.S. and their experiences with pregnancy loss and disclosure. Future research could explore cultural differences in disclosure practices and partners' experiences. In this paper, we focus

on factors leading to disclosures on Facebook; in other work, we investigate non-disclosure and other platforms. Similar to many interview studies, the goal of this work is not generalizability; future work could evaluate our findings with larger samples or other populations.

Ethical Considerations

It was important to us that participants felt their grief and other feelings were respected throughout the interview. We adopted guidelines posed by Kasket [39] for conducting interviews with bereaved people either remotely or in person, based on earlier guidelines for in-person interviews. These guidelines provide signs of different stress levels that interviewers can respond to. Moreover, because we learned that this study was of importance and value to participants as well as to us, we plan to write a public blog post to share the results with those who have been affected by pregnancy loss and the general public. Sharing results in an accessible format will allow us to contribute back to participants and the population we worked with. The study was approved by our institution's IRB.

FINDINGS

Participants ranged widely in disclosure experiences, but a common thread in all but one was discussion of Facebook as an important social platform that they considered as a potential disclosure venue even if they did not ultimately disclose their pregnancy loss there.

We found that the decision to disclose a pregnancy loss was motivated by six primary types of factors. In the following sections, we explain how each of these factors contributed to disclosure decisions:

- self-related
- audience-related
- network-level
- societal
- temporal
- platform and affordance-related

Self-Related Factors

Participants frequently reported that pregnancy loss disclosures on Facebook served as self-help mechanisms for seeking psychological benefits and aid. These included remembrance, taking control of the parenthood narrative, processing the loss, and eliciting support.

Remembrance. Some participants shared about the loss on social media in order to remember, honor, and acknowledge their experience and their loss. For example, P1 described the decision to announce the loss on Facebook: "*My husband started crying. And the doctor came in, and he said, 'I'm so sorry. You're right. The baby, her heart stopped last week.' And I said to my husband, 'We were gonna announce [the pregnancy on Facebook].'* And he said, '*And we didn't.*' And I said, '*It's like no one will know she was here.*' So he said, '*I think we should put something on there for her, because people should know she was here, and that she changed our world.*'" Posting on Facebook was a way of honoring and remembering their baby. Prior work [52] addressing other kinds of loss suggests that the relationship does not die when a loved one does. In this sense, by sharing about their loss,

some participants tried to create a social life for what was lost. Many participants needed to socially honor and remember their loss, and sharing on Facebook was one way of doing so for them.

Taking control of the parenthood narrative. The lost pregnancy was only part of a story, and many participants reported they wanted to take control of the narrative of their parenthood story and did so by sharing about it with their social network. On sharing on Facebook, P24 said: *“I had this pregnancy and I want people to know about it because that little baby was part of my story and I don't want to forget that. I don't regret any of it. I think going through that experience really, really made me appreciate my second pregnancy and just appreciate the whole process and how it's such a little miracle. Without that first pregnancy, I wouldn't have my son now, who is amazing.”* Pregnancy loss survivors construct narratives about their pregnancy and loss, and social support is a factor in this narrative reconstruction [37]. Socially acknowledging the loss within the context of one's whole journey enabled participants to begin taking control of this narrative.

Sharing about the loss as part of the healing process. Additionally, sharing with the social network was part of the grief and healing process for some, whereby they would publicly acknowledge what had happened, not hold on to a secret anymore, and continue processing the loss. As P20 said: *“I didn't want it to fester, I feel like it would have festered in that I wouldn't have been able to move on with my life if I didn't get it out there. I felt like I knew since we wanted another baby, I had to get over it, I could get over our loss and continue on and hope we have a healthy pregnancy.”* Sharing about difficult experiences is a process by which one may engage in identity repair, which is necessary for recovery [12]. Some believed that socially acknowledging and sharing the loss would facilitate their grief process, enabling them to approach a “new normal,” [53] and pursue their goals such as growing their family.

Eliciting social support. Anxiety and needing support motivated some to disclose the loss on Facebook. As P1 said: *“We went on social media and we posted, ‘You know, we've been here twice before and we're very scared and we're very worried. And we would just like everyone's thoughts and prayers and support during this pregnancy.’ And I think that post got like 300 comments from all of our family and friends.”* In some cases, the disclosure of the loss on Facebook was not only to gain support in coping with the lost pregnancy, but also about anxiety related to a current pregnancy. This resonates with research suggesting that pregnancies after loss can be healing but can also be anxiety-producing due to fear of another loss [19].

Audience-Related Factors

Audience-related factors were primarily about control: preemptively disclosing the loss in order to avoid unwanted conversations about the lost, future, or current pregnancies, and gaining control over what personal information was

known to and discussed by others. These motivations were avoidance-based [17], and we use the term *preventive disclosure*, which has also been used in the context of gay identity disclosures outside of SNSs [16]. It is also noteworthy that eliciting social support, a “self-related” need and decision factor described above, also depends on the perception of one's audience as a likely source of support.

Preventive disclosure: avoiding follow-up questions and taking control of information sharing. Some disclosure motivations on Facebook focused on avoidance and taking control. In these cases, people disclosed the loss in an attempt to stop further queries or rumors. As P2 put it: *“The posts that we made to Facebook were basically so people... so rumors weren't happening. They were clarifying, ‘This is what's happening. We appreciate your support.’”* Participants wanted to gain control over what information was shared about them, so they took initiative to share the information themselves.

Preventive disclosure: avoiding conversations about the lost or future pregnancy and related plans. Some people disclosed the loss on Facebook because they had widely disclosed the pregnancy on Facebook or through other means. Avoiding questions about the lost pregnancy (e.g., “Where are the baby pictures?”) or questions about a future pregnancy (e.g., “Don't you want another baby?”) were examples of these anticipated questions that led to disclosure of the loss on Facebook for some. For instance, P1 explained: *“Because we had made the [pregnancy] announcement, we had to make the announcement that we had lost the baby, to everybody. And that was a really hard position to be in.”* Participants were concerned about others asking them about the progress of the pregnancy either in person or online. As another example, P20 stated that by sharing about the loss on Facebook she wanted to avoid questions about having kids: *“You know you always get asked when you have one child, everyone is like, ‘When are you going to have another one?’ You know like, ‘So and so could really use another sibling,’ type of thing.”* Engaging in these conversations about pregnancy was incredibly difficult for some, and thus they tried to avoid such conversations by sharing the information once and for all.

Network-Level Factors

Network-level factors are related to the composition and structure of one's total (egocentric) social network as articulated on Facebook. We differentiate network-level from subgroup, community, or dyadic relationships that might be performed on the site and that might be the subject of audience-related considerations. We define *network-level reciprocal disclosures* as disclosures to one's network that are motivated by observing others' disclosures. They do not serve the purpose of strengthening or maintaining any particular relationship because although they may be precipitated by seeing others' posts, they are not *in response* to those posts. Instead, they are a response to a perceived reduction in stigma. Some disclosures motivated by network-

level factors happened in the context of social media awareness campaigns. These campaigns provided additional safety, leading to less perceived stigma, and enabled disclosures that may not have occurred otherwise.

Inspired by others' pregnancy loss disclosures and responses to them in one's network. Seeing other people post about their loss experiences and the supportive comments associated with those posts made it easier for some to post about their own experience. As P17 shared: *"I came to the decision to make it public on Facebook this past week actually, because a good friend of mine, she posted her experience about having a stillbirth. I think that opened up my eyes because I saw that everyone was being very supportive of her. All of my fears about, I don't know, they seemed like silly fears now, I guess, but just not feeling woman enough, feeling like a failure. I feel like she was very brave and to post that because it's such a sensitive personal issue. I think there's a need to make it more visible to the world, so I appreciated her doing that. She really inspired me to post about my miscarriages."* Similarly, P18 emphasized that *"It's been helpful in general just to see that someone else, my age, that I knew experienced a loss and has been brave enough to talk about it."* When others that one knew openly shared about their loss on Facebook, and participants observed responses they perceived as positive, they felt motivated to share their experiences as well.

Additionally, the Pregnancy and Infant Loss Awareness Month social media campaigns facilitated *network-level reciprocal disclosures* of pregnancy loss on Facebook. The perception and observation that more people share about loss in the awareness month led some to share about their experiences. For example, P15 said: *"I think that, similar to how the pregnancy-related subreddits are a space in which it's appropriate to share information about pregnancy, that awareness month creates a context in which people feel like it's not totally arbitrary. They are participating in something."* Awareness campaigns provided a context where some felt that sharing about their experience was legitimized because others were also sharing; they were part of a larger network-level experience.

Participants described feeling less alone and safer about sharing their own experience after seeing others post. Others' disclosures made them feel like they were not the only people disclosing difficult experiences that made them feel vulnerable, and seeing reactions to others' posts made it easier to gauge their potential audience's reaction.

Being a source of support for current, past, and future invisible similar others in one's network. Disclosure was not only a network-level reciprocation but also sometimes served to signal openness to future reciprocation by others in the network. Some people disclosed the loss on Facebook because they wanted to be a source of support and hope for connections who may have been, are, or will be in a similar situation. For example, P9, who shared about her experience on Facebook during Pregnancy and Infant Loss Awareness

Month, said: *"Anybody that I talked to in real life, my mom or my friends or even my husband, I don't feel like it was the kind of support I needed. They tried, I mean they love me, it's not like they weren't trying to help me, but I needed somebody who had been through it and had similar circumstance to feel like they understood... I was putting it out there just in support of anybody who might be experiencing a miscarriage and feel alone, because I felt very alone. Just to extend, not only to let people know that it happened to me and to acknowledge the loss publicly as a way of healing, but also to let anybody know that if they were going through it themselves and wanted someone to talk to, that I was available for that."* The awareness campaign provided a context within which P9 shared about her experience to be a source of support for others, and to let them know that they are not alone.

Relatedly, P18 framed her disclosure as a beacon for those who might be suffering in the positive glow of others' everyday Facebook posts: *"I wanted to be able to provide a personal story since so many people go through the same thing... when I was dealing with it I didn't know anybody. I mean, my mom had had miscarriages and my mother-in-law had but I didn't know anybody my age who had. It would've been nice to be able to relate, because I do think especially on social media there's so much showing of only good things and it sort of feels like everybody else is getting pregnant and having successful pregnancies and you're alone when you're not."* Sometimes participants needed forms of support that they believed would only come from someone who had been through a loss as well, or who shared certain characteristics (e.g., age) in addition to the loss experience. Many did not have access to this kind of support when they needed it most themselves, and this lived experience motivated some to share about their loss on Facebook. By doing so, they hoped they could be helpful to others who may feel alone and isolated, like they did at that time – unable to identify others in their network, sometimes with certain characteristics, who had experienced pregnancy loss and who could potentially be supportive.

Societal Factors

Some participants disclosed their loss experience in an attempt to reduce societal stigma around pregnancy loss, or as a call for political action related to reproductive rights.

Disclosure as activism: fighting stigma and increasing awareness. Some participants shared about their loss on Facebook to fight the stigma surrounding the experience, and to raise awareness among those who may experience a future pregnancy loss and others. Many felt frustrated by the perception that they were not *"supposed to"* talk about their experiences, that they should keep pregnancy loss a secret, and that they felt attacked when they disclosed. As P1 put it: *"I made a long post after we found out that we lost the baby. I said, 'You know, I have realized that people think that this is for attention, or that they would never post until they knew everything was okay. But I never really understood why we*

do that. Why do we keep it such a secret? Because I feel pain, no matter what, if I tell you or I don't tell you. I'm still sad that my baby's gone. And my husband is sad that his baby's gone. We had plans. We had hopes. And we're not just, we know the birthday of all of them. We know how old they'd be right now. We don't forget them, so why shouldn't we share that? If you're our friend, if you care about us, wouldn't you wanna help us? If it was your child that passed away, or when your mother or your grandmother or your, a family member, passes away, people don't just go, 'Well, you shouldn't talk about that until you're through it.' They say, 'What can I do? How can I help you?' And we acknowledge that loss, that absence." This is an example of a participant who wanted to challenge her audience and the stigma around talking about pregnancy loss by sharing a critical and intimate post on Facebook.

Other participants wanted to educate the public about pregnancy loss, raise awareness about pregnancy loss and women's reproductive health, fight stigma, or encourage political action. P13 reflected on her experience sharing on Facebook: *"Probably, the scariest post was writing about my ectopic and emergency surgery... The first time I wrote about it was in relation to reproductive rights and the idea of a personhood amendment and it was scary. That's the word that keeps coming up to me. It was scary... I don't want people to feel sorry for me but I want them to learn about miscarriage. I want them to learn about these issues. I want them to learn how to support people who are going through them and I want them to take action when there's some policy or legislation that can affect women in these ways."* The frustration surrounding perceived stigma about pregnancy loss motivated disclosures aimed at fighting this stigma by activating social networks for political action.

The Pregnancy and Infant Loss Awareness Month social media campaigns provided a context for disclosures motivated by societal factors. For instance, P2 had several loss experiences. She did not share the first loss with many people because she had not shared the pregnancy and sharing the loss was challenging. They got pregnant again and experienced a loss after birth, and then got pregnant a third time. Awareness month provided P2 with a context to start sharing about her experiences on Facebook. She said: *"When the next October came around and it was the awareness month, I thought it's important; this is important information and people need to be aware, so I started sharing. I shared my story on Facebook. By that point a lot more people knew because we were pregnant again. I made a big post on Facebook about our story and how people don't know the statistics, and how important it is for women to know that going in so that they're prepared because it feels like a punch in the gut when you had no idea that it would be that common. So yeah, made a couple of posts throughout October last year about loss awareness... I put some of the statistics in there, like one in four."* For some participants, raising awareness was a major motivator for disclosure and fit within the context of awareness month social media

campaigns. While these disclosures often had other motivations such as seeking support, raising awareness was a major goal.

Pregnancy loss is an event largely excluded from social narratives, and can fracture one's identity and make it difficult to narrate and articulate at bodily, emotional, and social levels [33]. Society does not provide a repository of stories about pregnancy loss, and this makes it challenging for people to make sense of the event [33]. We find that people disclosed on Facebook to actively construct this *societal* narrative. When participants talked about non-computer-mediated disclosures, societal factors were less salient and did not include the goal of activating one's network to take political action and reduce stigma broadly.

Temporal Factors

The amount of time that had passed since the loss was another factor influencing disclosures on Facebook. As time passed and especially once another pregnancy was likely to be carried to term, some participants were more likely to share about the loss on Facebook. For example, P24 reflected: *"I think with just more time going by and me not having the anxiety of miscarrying again. Even though I know there was a very small chance that something could have gone wrong in the second or third trimester with my baby, we did a bunch of genetic testing since I am over 35 and everything came back looking great. It gave me a huge peace of mind. Just with some more time and with more confidence in my second pregnancy I just felt more comfortable talking about it."* Other times, participants felt that just by the virtue of time passing, they were more comfortable disclosing the pregnancy loss to others in their life, since they had progressed in the healing and grief process. As P9 said: *"I had almost nine or ten months since the actual miscarriage, so it wasn't like it was so fresh. I was finally able to talk about it and feel like it would be okay to be out there in public."* Pregnancy loss creates a type of trauma that needs to be managed over time [75], and some women shared about the loss as part of this management with time as a critical factor. It is not uncommon to wait before disclosing difficult experiences; for example disclosures of childhood abuse are often delayed [64]. Semaan et al. [74] found that transitioning veterans share their struggles on social media after time had passed and call such disclosures "delayed disclosures." While we sometimes observed "delayed disclosures," the passage of time was not always a factor leading to disclosure, and in fact sometimes inhibited disclosures as participants feared invalidating responses such as those implying that "they should be over the loss by now."

The Pregnancy and Infant Loss Awareness Month social media campaigns sometimes helped make disclosures that had been impeded by the passage of time possible. Particularly when one had shared about other topics on social media (i.e., non-intimate and positive), the awareness day campaign helped facilitate disclosures by making them fit within the larger narrative of one's Facebook use, and

Facebook in general. As P14 said: *“Most of what I post on my wall is, hey, my kid just did this cute thing today. I don’t actually post a lot about myself. A post about a miscarriage that’s not even happening right now, feels like it will be out of place and out of context... there’s an awareness month, October. I feel like in that context, by next October, I can share, because other people will be, because there’s the context of, hey, it’s awareness month, so here let me tell you. It gives me that excuse to share or reason to share, as opposed to just out of the blue. I just can’t figure out how I would share that out of the blue, so I just don’t.”* Some participants had difficulty finding a meaningful context for sharing about their pregnancy loss after time had passed; social media awareness campaigns provided that context.

Platform and Affordance-Related Factors

Socio-technical features of Facebook influenced disclosures of pregnancy loss, including both technical affordances and the ecology of social media that participants used.

One-to-many disclosure: avoiding many one-to-one disclosures. For participants who had decided to share about their loss, the broadcast nature of Facebook posts motivated disclosure there because they would not have to engage in many individual conversations about the loss. As P2 put it, *“The easiest way to tell a lot of people that something drastic has happened in your life without having that one-on-one conversation over and over and over again is just to put it out there and be like, ‘This is a thing that happened and my entire life is changing.’”* Telling others about a loss one-to-one was difficult for participants, as P22 said: *“I didn’t have bandwidth to call everybody and tell them.”* Additionally, the size of one’s Facebook network was a relevant factor when adopting the one-to-many disclosure approach. As P18 mentioned *“knowing it would reach more people if I were to put it on Facebook, so I put it on Facebook,”* compared with Instagram where her audience was much smaller.

The prospect of having individual conversations over and over again was painful and emotionally challenging for most participants who decided to disclose on Facebook. Prior work in non-sensitive contexts suggests that people appreciate being able to “broadcast” content to their Facebook network, and ask questions from them [81,85]. In sensitive contexts, a recent study [29] on relationship breakups on Facebook found that announcing a breakup on the site was “efficient;” however, their survey data did not provide an explanation as to why. Here, we demonstrate that people engage in an intimate disclosure in a one-to-many approach, not just because they wanted support as in the case of [81,85], but because they needed to avoid many emotionally charged and difficult one-to-one disclosures.

Asynchronous communication: need not worry about the audience’s feelings. Some participants found it helpful to share the information without having to worry about the audience’s feelings as they would if they disclosed over the phone or in a face-to-face conversation. For instance, P13 reflected: *“I didn’t want to talk to people about it because I*

didn’t want to deal with their feelings about it. I didn’t want to feel like I had to manage their feelings... That’s easier on social media because they’re not in front of me. I definitely have friends who cried when I told them. I don’t want to deal with somebody else’s tears about it. You don’t have to do that on Facebook.” In this sense, asynchronous communication made it easier for the participants to talk about their experience on Facebook compared to more synchronous settings, and allowed them to take care of their own needs rather than others’ in difficult times. Prior work suggests asynchronous communication enables more deliberate self-presentation [83], and lowers the cost of communication because, for example, there is no need to schedule for it [86]. We identify sensitive disclosures as another helpful use of asynchronous communication modes.

Anonymous disclosures in other online spaces. For some people, prior participation in more anonymous online spaces (e.g., BabyCenter, Reddit) made it possible to share on Facebook, where they used their physical world identities and their networks were comprised of connections they knew. Interactions in more anonymous spaces provided participants with feelings of safety and courage – an enabler of disclosing to one’s known network. Processing their experiences on more anonymous sites helped people decide exactly what and how to share, and reduced anxiety about sharing. For instance, P9, who eventually shared about the loss on Facebook, described how using Reddit during the year after her loss made her comfortable enough to share on Facebook later: *“I felt more comfortable putting it out there. If I didn’t have Reddit, I don’t think I would have coped as well.”* Similarly, P22 said: *“I think that sharing on BabyCenter, in a sense, gave me the courage to do it on Facebook. I think if I had not shared before, I would not have known what to share, I would’ve been very worried about it.”* Anonymous disclosures paved the way for disclosures on Facebook. This finding extends prior work that suggests people often have an easier time disclosing stigmatized experiences anonymously (e.g., [4,49,78]). We found that anonymous disclosures, while needed, may not be sufficient, and may help people who feel the need to disclose difficult experiences to their social networks in identified contexts such as Facebook. This finding indicates the important, distinct, and complementary roles of disclosures in identified and anonymous online spaces.

DISCUSSION AND IMPLICATIONS

Based on interview data, we developed a disclosure decision-making framework comprised of six major factors that inform pregnancy loss disclosures on Facebook. Disclosure decision-making factors are related to self, audience, network, society, passage of time, and the platform being used to disclose. Although these decision factors were observed in the context of pregnancy loss disclosures on Facebook, we expect that they would motivate decision-making about disclosures of other stigmatized identity facets or life events in other or future identified social networks, where people use their physical world identities to connect

with others they know. We introduce the concept of *network-level reciprocal disclosure* to describe broadcast disclosures motivated by or in anticipation of others' disclosures, and in response to a perceived reduction in stigma – a form of disclosure that is largely unique to SNSs. We also show that social media awareness campaigns prompt disclosures that may not have materialized on SNSs otherwise, and uncover some of the distinct and complementary roles of sensitive disclosures in anonymous and identified online platforms.

Disclosure Decision-Making Framework

Our decision-making framework shares some features of a model proposed by Greene et al. that explains disclosure decisions in non-computer-mediated dyadic settings [28]. Greene et al. proposed that self, other, interpersonal, and situational-environmental-focused reasons contribute to disclosure decisions. In that model, self-focused reasons are concerned with the psychological and tangible benefits to the discloser (e.g., catharsis, self-clarification, and seeking support). Other-focused reasons refer to the responsibility to inform and desire to educate others. Relationship-focused reasons are concerned with having an intimate and trusting relationship with the disclosure partner. Finally, situational-environmental reasons refer to the disclosure recipient's availability, whether the recipient demands disclosure, or whether the recipient is involved as the disclosure's subject matter. In our analysis, the self-related theme resonates strongly with Greene et al.'s self-focused theme. However, although elements of other-, relationship-, and situational-environmental reasons can be found in our data, our analysis illustrates that these factors are substantially different in the context of Facebook than in dyadic offline disclosures; as such, we use a different nomenclature.

For many participants, the societal influence that can be asserted by like-minded networks politicized the disclosure of pregnancy loss on Facebook. Disclosure as activism eclipsed the desire to "educate others" as discussed in Greene et al.'s [28] dyadic disclosure model, to become a highly public vehicle for affecting widespread social change. This is similar to gay identity disclosures; some come out in order to make homosexuality more visible and reduce misconceptions [16]. Situational-environmental factors in the dyadic disclosure model focus on relational factors and availability of the intended recipient of disclosure, but in the SNS context, situational and environmental factors are very different, involving features and affordances of social computing systems as we find.

Network-Level Reciprocal Disclosure

In dyadic non-computer-mediated communication, reciprocal disclosures happen when one person discloses information, and the other reciprocates with information of a comparable intimacy level. In these contexts, the occurrence of reciprocal self-disclosure is one of the most consistent findings in disclosure research [22,46]. From a social exchange perspective, intimate disclosures create an imbalance and to re-establish balance, the disclosure partner

might disclose something about themselves to reciprocate [5]. Reciprocity could also be a function of modeling, where the confidant emulates the discloser's behavior due to being unsure about social norms [69].

In the present study, some participants disclosed their pregnancy loss on Facebook because others in their network had disclosed on Facebook. While these disclosures made by others were one-to-many and not directed at participants, they enabled reciprocal disclosures. We call these disclosures *network-level reciprocal disclosures*. By seeing others post, people knew and felt pregnancy loss was not unique to them; by observing posts that did not receive negative responses, participants felt that sharing about their loss may be more appropriate than they originally thought. Even if that was not the case, they would at least not be the only people deviating from the perceived norm of "not posting about pregnancy loss" on platforms like Facebook. *Network-level reciprocal disclosures* also enabled people to provide support to potential future similar others within their network. This is a departure from our knowledge about dyadic reciprocation, as well as online contexts dedicated to specific topics. Disclosures that happen in online spaces dedicated to specific kinds of difficult experiences, (e.g. forums for mental health [20], addiction recovery [70], sexual abuse [4]) are expected. *Network-level reciprocal disclosure* becomes relevant when context collapse, stigma, and perceptions that others in one's social network have *not* experienced something similar conspire to dampen opportunities for disclosure. The effects of *network-level reciprocal disclosures* are not restricted to a group of self-identified similar others, whether anonymous, identified, known, or strangers. For instance, Semaan et al. labeled such behaviors "triggering disclosures," and described how a veteran made a difficult disclosure about mental health on her Facebook page after perceiving a reduction in stigma and seeing other veterans, who set aside norms among military populations, post about their struggles [74:396]. This example of *network-level reciprocal disclosure* in a different stigmatized disclosure context suggests that the concept can provide traction for understanding how literature on reciprocity can be used to understand network-level disclosures beyond the pregnancy loss context.

Prior work suggests that a pregnant woman's most helpful and important support network during and after pregnancy consists of family such as a mother or partner [63]. Here, we saw that when a pregnancy is lost, many found that the most meaningful forms of support came from those who had experienced a similar loss, not necessarily from their partner or mother. Discovering others with similar loss experiences within one's network of known ties was helpful, and although support groups and connecting with similar others outside of one's social network could also be helpful, it was often deemed insufficient. Participants believed that online connections who might experience a pregnancy loss would have similar support needs that could be best met by others in their social network. Thus, some disclosed their pregnancy

loss on Facebook to affect change at the network level (rather than as political action at the societal level) and become a source of support for invisible and currently silent similar others in their network.

Awareness Campaigns as Facilitators of Sensitive Disclosures on SNSs

Researchers have studied awareness campaigns on SNSs in terms of the content people share, and have criticized their effectiveness. For example, an analysis of tweets about breast cancer during Breast Cancer Awareness Month found that most tweets were of promotional and fundraising nature, rather than personal [18]. Other work suggests that awareness social media campaigns can reduce stigma associated with experiences such as mental illness [71] and other health topics [36], and have the possibility to change knowledge and attitudes at the population-level [71].

We argue that these campaigns can act as disclosure enablers that help alleviate some of the concerns around disclosing sensitive content on identified SNSs, by reducing perceived stigma. In the United States, October is Pregnancy and Infant Loss Awareness Month, and October 15th is Pregnancy and Infant Loss Remembrance Day. We found that social media campaigns that encouraged sharing personal stories enabled disclosures that may not have occurred otherwise. For some, the awareness campaigns contributed to disclosures motivated by network-level, societal, and temporal factors or a combination thereof. Increased posts during awareness campaigns helped participants feel less alone, more comfortable with sharing, and perceive less stigma.

Design Implications

We provide implications for how SNSs and researchers could design for *network-level reciprocal disclosures*. First, systems could enable finding similar others within one's social networks. Sensitive disclosures could be surfaced by newsfeed algorithms when they do happen, particularly to those who are demographically likely to share the experiences. This could lead to reduced perceived stigma and reciprocal disclosures at the network-level. Another idea, which has similarly been proposed in the context of depression [31], is to help people see the prevalence of pregnancy loss in their network by predicting how many in one's network may have experienced a pregnancy loss (e.g., based on demographics) or by eliciting these data and presenting it in an anonymized or identified form. We are pursuing some of these ideas in design experiments. Furthermore, algorithms during Pregnancy and Infant Loss Awareness month could boost posts with content about pregnancy loss to increase the visibility of this content, thus potentially enabling disclosures for those who would appreciate seeing others' disclosures and stories. We acknowledge that with visibility comes potential drawbacks or unintended consequences, such as visibility to unsupportive network members. Algorithm designs must balance visibility and discretion and further work is needed to understand the tradeoffs.

One way Facebook in particular could help reduce stigma surrounding pregnancy loss is to add an "I experienced a pregnancy loss" life event. Facebook allows people to add "life events" such as getting married or starting a new job. This feature currently includes options such as "expecting a baby" and "loss of a love one," however it does not acknowledge pregnancy loss as a significant life event. While people can create customized life events, platforms could make it easier and perhaps influence social norms by implementing more inclusive design choices.

We found that sensitive disclosures are sometimes only possible on Facebook because of prior anonymous disclosures elsewhere. Future work could experiment with a system that allows disclosing to one's Facebook network anonymously. We acknowledge that tie-based anonymous networks come with their own challenges [49], and that prior attempts such as Rooms (in which Facebook users could create an anonymous chat space), failed. However, we still see potential for future systems to explore anonymous disclosure and support exchange in ways that mitigate the challenges inherent in identified platforms.

CONCLUSION

This work contributes a framework that explains disclosures of pregnancy loss on identified SNSs. This framework includes six types of decision factors: self-related, audience-related, societal, platform and affordance-related, network-level, and temporal. While pregnancy loss was the focus in this paper, we suggest that this framework could be applicable to other sensitive disclosures on identified SNSs where people connect with others they know and use their physical world identities. We encourage researchers to evaluate our framework in other contexts. Within our framework, we introduce a theoretical construct, *network-level reciprocal disclosure*, as a concept that can motivate social computing system designs to better promote sensitive disclosures and social support exchange. Further, we found that prior anonymous online participation facilitated disclosures of pregnancy loss on Facebook, that one-to-many disclosures on Facebook are appreciated because by doing so people in distress can avoid many painful one-to-one disclosures, and that social media awareness campaigns prompt disclosures motivated by network-level, societal, and temporal factors. Taken together, awareness campaigns, the efficiency of one-to-many disclosures, and opportunities for anonymous lower-risk disclosures elsewhere contribute to women's decisions to disclose pregnancy loss experiences on identified SNSs, which, through the mechanism of network-level reciprocation, creates an increasingly disclosure-friendly context for those who come after.

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