Self-Disclosure and Response Behaviors in Socially Stigmatized Contexts on Social Media

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DEDICATION

In memory of my parents.

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ABSTRACT

Social computing platforms are often celebrated for their capacity to connect; yet expressing one's identity, and seeking as well as providing support on these platforms can be difficult when people experience distress and stigma. In this dissertation, I theorize social media behaviors such as sensitive disclosures and interactions around them. I address how we can design social computing systems that facilitate disclosures of difficult and stigmatized human experiences and enable supportive interactions to form around them. I focus on pregnancy loss, as a common reproductive health experience that is often traumatizing and not disclosed in spite of potential disclosure benefits such as access to social support.

First, I contribute a framework to explain direct pregnancy loss disclosures and non-disclosures on social media. I conducted in-depth phenomenological interviews with women in the U.S. who are social media users and had experienced pregnancy loss within the past two years. This framework includes six types of decision factors related to the self, audience, network, society, affordances and platform, and time. I also introduce the novel concept of *network-level reciprocal disclosure* to describe broadcast disclosures that happen in response to and in anticipation of others' disclosures and a perceived reduction in stigma.

Second, I contribute a typology of indirect disclosure strategies and an understanding of decision factors informing indirect disclosures of sensitive experiences across social media platforms. Indirect disclosure strategies include hinting about an experience or an identity facet in such a way that the audience must infer the full message, or explicitly sharing information through another person. Factors related to the self, audience and affordances, and time motivate individuals to disclose pregnancy loss in an indirect manner, although in distinct ways compared to direct disclosures.

Finally, responses to sensitive disclosures are important to understand if we aim to design social computing systems that encourage supportive interactions. I used interviews and designed vignette instruments to provide a response decision making framework (RDM) that explains factors informing whether and how individuals respond to sensitive disclosures from their social media connections. This framework includes factors related to the self, poster, and disclosure context. I identify empirically grounded design and research implications to support potential disclosers and responders in sensitive or stigmatized contexts on social media.

CHAPTER 1. INTRODUCTION

Announcing exciting news and life transitions is common on social media sites. People joyfully share online announcements of a new dream job, getting married to a beloved partner, or becoming parents of healthy children. However, when people experience distress or trauma, they may find it difficult to use social media to talk about it or seek support, and struggle on their own. 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 (Rimé, 2009). However, many do not, and sometimes they suffer as a result of this inhibition due to the psychological distress associated with keeping a secret (Quinn et al., 2014). Other times, when people do disclose, they face negative consequences such as social rejection or added distress (Bonanno & Kaltman, 2001), 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 when facing difficulties, and social media sites provide new contexts for seeking and providing social support (Ammari & Schoenebeck, 2015a; Andalibi, Haimson, De Choudhury, & Forte, 2016; Andalibi, Ozturk, & Forte, 2017; Gray, Ellison, Vitak, & Lampe, 2013; Haimson, Brubaker, Dombrowski, & Hayes, 2015a; Newman, Lauterbach, Munson, Resnick, & Morris, 2011; Semaan, Britton, & Dosono, 2017; Vitak & Ellison, 2013a). Social support is also linked to improved well-being (Mattson & Hall, 2011).

By sharing about stigmatized and distressing experiences and emotions, people may signal their need for support to others in their social networks, both online and in-person. These expressions, as I will discuss in this dissertation, could take on direct and explicit as well as indirect and ambiguous forms. When others are disclosed to, they make their own decisions about whether and

how to respond. How are such disclosure and response decisions made in the social media context and why? This is an important question to address not only because of the resulting theoretical contributions, but also due to its implications for designing technologies that promote human well-being by being more inclusive of those at the margins experiencing distress and stigma, facilitating safe sensitive disclosures, reducing stigma surrounding difficult human experiences, and facilitating social support provision and sympathy. As a result, designing such technologies is one way to influence societal change and well-being.

In this dissertation, I examine: (1) how and why people share negative emotions and experiences with their online networks, (2) how and why others decide to respond to these disclosures, (3) the conditions in which self-disclosures are likely to lead to supportive interactions, and (4) how social media can be designed to promote positive outcomes for people who disclose negative experiences and for others who come across them. I address how we can design social computing systems that facilitate disclosures of difficult human experiences and enable supportive interactions to form around them. To achieve this goal, I focus on pregnancy loss as a central context of inquiry.

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 (Savitz, Hertz-Picciotto, Poole, & Olshan, 2002). Pregnancy loss can be isolating, socially stigmatized, traumatizing, associated with negative feelings (e.g., shame, guilt) and depression, and difficult to disclose to others (Silverman & Baglia, 2015), but receiving support is dependent on the disclosure of the loss. It is unknown how people decide to share their experiences with pregnancy loss on social media platforms and why, or why they may not disclose their loss.

Additionally, 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 (Stinson, Lasker, Lohmann, & Toedter, 1992). Access to social support is a factor in narrative reconstruction after pregnancy loss (Jennifer Leanne Fairchild, 2009); however, there are no grief rituals for pregnancy loss in the

American culture, and this loss remains largely absent from societal narratives (Hardy & Kukla, 2015). Little do we know about the ways social media users, as potential responders, make decisions about support provision and engaging with disclosures of pregnancy loss or other sensitive or difficult experiences when they do occur on these platforms. This knowledge can help inform how social computing systems can be designed to encourage supportive and helpful responses when sensitive disclosures do occur.

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, support seeking, and support provision. 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 disclosure decisions and the forms they take as well as the factors that inform response decisions. I expect the findings I present here to apply beyond the context of pregnancy loss to explain disclosures of other stigmatized experiences such as the #MeToo movement.

I first conducted an in-depth phenomenological interview study with 27 American women who used social media and had experienced pregnancy loss within the past two years to understand how they decided to engage in disclosure about pregnancy loss on social media. I also conducted in-depth interviews with 11 social media users who had come across what they considered sensitive disclosures (e.g., mental illness, abuse, pregnancy loss) on social media to uncover the processes behind deciding whether and how to engage with a sensitive post. Additionally, I designed vignette instruments about pregnancy loss to systematically collect data about responses to online pregnancy loss disclosures. Through these studies, I addressed the following overarching questions:

- Why and how do people who have experienced pregnancy loss decide to disclose feelings and experiences related to this experience on social media platforms?
- Why and how do people decide to respond when they encounter sensitive disclosures on social media, such as but not limited to the loss of a pregnancy?

- What technological affordances and constraints play a role in facilitating disclosures, responses to them, and perceptions of disclosures and responses in the context of social technologies? How can the design of social computing environments encourage supportive interactions?

The rest of this dissertation is structured as follows:

In Chapter 2, I review the literature that informs this dissertation. This chapter includes a discussion of: (1) Pregnancy, Pregnancy Loss, and Social Media; (2) Self-Disclosure on Facebook and Other and Social Media Platforms; (3) Indirect and Ambiguous Self-Disclosure Strategies in Non-Computer Mediated Contexts, (4) Indirect Disclosures on Social Media; (5) Responses to Sensitive Self-Disclosures, and (6) Responses to Pregnancy Loss Disclosures.

In Chapter 3, I discuss my methodological approach to research as interpretivist and phenomenological. I also detail the recruitment, methods, participants, data, and analysis process.

Chapters 4, 5, and 6 include findings. In Chapter 4, I develop a disclosure decision making framework to explain pregnancy loss disclosure decisions on social media platforms. I found that self-related, audience-related, platform and affordance-related, societal, network-level, and temporal factors guide disclosure decisions on social media. I 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 social media. Additionally, findings include how anonymous disclosures on other sites help facilitate disclosure on identified sites such as Facebook, and how social media awareness campaigns provide a socio-technical context within which sharing about pregnancy loss is possible for many who would not disclose otherwise.

In Chapter 5, I develop a typology of indirect disclosure strategies and an understanding of decision factors informing indirect disclosures of sensitive experiences on social media platforms. By drawing on prior literature, and by uncovering these disclosure strategies, I also provide a clear description of indirect social media disclosures and how they are different from direct disclosures,

adding to the conceptual clarity of this disclosure behavior in the research literature concerned with social media. Social media indirect disclosures involve sharing of explicit content by a third-person (proxy), or of non-explicit and vague content by the self or others. Content may be created by self or others. In contrast, direct disclosures are defined to be explicit and shared by the self. I found that factors related to self, audience, time, and platform inform indirect disclosure decisions. Findings include how people intentionally adapt social media and indirect disclosures to meet psychological and social needs associated with loss and how sometimes, indirect disclosures led to future direct disclosures on social media.

In Chapter 6, I develop a response decision making framework that explains factors informing whether and how individuals respond to sensitive disclosures from their social media connections. The elements of the framework I introduce include: self-related factors, poster-related factors, and disclosure context-related factors. I also identify socio-technical features of social media platforms that influence these response decisions. This work identifies factors guiding support *provision* decisions in the context of sensitive social media disclosures. Findings include how people make complicated decisions to balance their own needs (e.g., privacy, well-being) as well as the posters' (e.g., support) when seeing what they consider sensitive posts on social media.

In Chapter 7, I discuss the implications of findings presented in this dissertation and situate them in the context of prior work. I provide design implications and guidelines grounded in in-depth understanding of people's behaviors and perceptions that have the potential to improve well-being through: facilitating helpful and safe disclosures, reducing stigma surrounding difficult human experiences, and facilitating social support provision. I also provide implications about how clinicians can better support individuals who experience pregnancy loss. I discuss how the disclosure decision-making framework I introduce is related to traditional disclosure models introduced in the context of dyadic non-computer-mediated settings, and identify research and design implications for the novel concept of *network-level reciprocal disclosure*. I highlight ways to enrich algorithms (e.g., news feed algorithms) with signals of distress in indirect disclosures

while raising questions about the ethics and value of associated interventions. I identify empirically grounded insights and information that social media designs could surface to support both potential disclosers and responders, arguing that social media sites should provide privacy controls for both disclosers *and* responders, given that when there has been a focus in the past it has been largely on potential disclosers. I also share insights about potential connections between disclosure and response behaviors grounded in people's decision making processes. I then provide a summary of contributions made through this dissertation, and discuss directions for future research informed by this work.

CHAPTER 2. LITERATURE REVIEW

This dissertation is informed by prior research in Human-Computer Interaction (HCI), Social Computing, Communication, Psychology, and Medical domains. In what follows, I will review this relevant body of research as it relates to this dissertation. Topics include pregnancy, pregnancy loss, and social media; self-disclosure on Facebook and other social media; indirect and ambiguous self-disclosure strategies in non-computer-mediated contexts, indirect disclosures on social media; responses to sensitive self-disclosures; and responses to pregnancy loss disclosures.

Pregnancy, Pregnancy Loss, and Social Media

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., (Ammari, Morris, & Schoenebeck, 2014; Asiodu, Waters, Dailey, Lee, & Lyndon, 2015; Gibson & Hanson, 2013; Morris, 2014; S. Y. Schoenebeck, 2013)). Apps and interventions also exist to meet certain needs among these populations. For example, some allow pregnant women to monitor pregnancies in stages (Johnson, 2014). Others help new parents of preterm infants track health data (G. R. Hayes et al., 2014). "Pregnancy ecology" is a proposed paradigm in designing pregnancy apps for use by not only the mother, but also others who play supportive roles (Peyton, Poole, Reddy, Kraschnewski, & Chuang, 2014), such as partners and mothers, who are often a woman's most important supporters after having a child (Prabhakar et al., 2017). 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 (Weiss, 2001), and some experience fear, anxiety, symptoms of Post-Traumatic Stress Disorder (PTSD) (MS, 2009), and depression (Neugebauer et al., 1992). In addition to psychological distress, the loss also alters family and social relationships; when family members are unsupportive, family communication is often disrupted (Burleson, Albrecht, & Sarason, 1994). 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 (Moulder, 1994). The portrayal of pregnancy loss as a non-event can make a bereaved woman feel like an "unperson" in Orwellian terms (Brierley-Jones, Crawley, Lomax, & Ayers, 2015). Women's social identities as patient, mother, and full citizen are "spoiled" after a pregnancy loss (Brierley-Jones et al., 2015), and many feel they can never be "cured" (Jennifer Leanne Fairchild, 2009). Spoiled identities obligate intensified impression management efforts and performances (Goffman, 1986); 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 (Agostini et al., 2011). Those who can find support are four times more likely to find meaning in the loss (Murphy, Johnson, & Lohan, 2003). Pregnancy loss survivors sometimes construct narrative stories about their pregnancy and loss, and social support is a factor in narrative reconstruction (Jennifer Leanne Fairchild, 2009). In the U.S. there are no grief rituals for pregnancy loss, and this loss remains largely absent from societal narratives (Hardy & Kukla, 2015). Countries like Japan on the other hand have developed rituals for grieving pregnancy loss (Elson, 2017). Successful identity repair work is a required process for recovery after pregnancy loss (Brierley-Jones et al., 2015). 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) (Kersting, Kroker, Schlicht, & Wagner, 2011), however, this design area remains largely unexplored. Beyond popular press articles about pregnancy loss and social media (e.g., (Nsoesie & Cesare, 2017)), what little academic research exists about online pregnancy loss disclosure has mainly focused on the practice and benefits of anonymous sharing in online support groups (Geller, 2012) and has noted the reluctance of many women to share outside of anonymous contexts (Killeen, 2015). Yet, we see that some women do disclose

pregnancy loss on identified SNSs such as Facebook. In this dissertation, I address this gap to understand the socio-technical factors facilitating and inhibiting disclosures of pregnancy loss on identified SNSs where one's identity and the identity of one's connections are known.

Self-Disclosure on Facebook and Other Social Media Platforms

Finding social support can be both a motivator and an outcome of Facebook use (Goldner, 2008; Kwon & Wen, 2010; Ross et al., 2009). 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 (A. E. Marwick & boyd, 2011). Some employ the "lowest common denominator" strategy by disclosing only what they perceive to be appropriate for all of their network (Hogan, 2010). When dealing with context collapse on Facebook, individuals need to prevent anticipated identity-threatening situations (Lampinen, Tamminen, & Oulasvirta, 2009), and sometimes they do so using "preventive strategies" to avoid potential unwanted outcomes in the future (Lampinen, Lehtinen, Lehmuskallio, & Tamminen, 2011). 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 (Burke & Develin, 2016).

Several models have been proposed to understand self-disclosure in dyadic contexts in non-computer-mediated settings (e.g., (Chaudoir & Fisher, 2010; Derlega & Grzelak, 1979; Greene, Derlega, & Mathews, 2006; Omarzu, 2000)). Among these models, Greene et al. propose that reasons for disclosure and non-disclosure in non-computer mediated contexts are self-focused, other-focused, interpersonal-focused, and situational-environmental focused (Greene et al., 2006). Some of the other models have been applied to disclosure behavior on social media such as Facebook. For example, an interview study (Vitak & Kim, 2014) about self-disclosure goals on Facebook identified motivations proposed by prior models (Derlega & Grzelak, 1979; Omarzu,

2000) (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 (Bazarova & Choi, 2014). Intimate public updates (versus private) are perceived as inappropriate and lead to less liking of the poster (Bazarova, Taft, Choi, & Cosley, 2012), in contrast to research in dyadic contexts, which indicates intimate disclosures often increase the extent to which the discloser is liked (Archer & Cook, 1986).

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 (Rimé, 2009). In particular, when people experience shame and guilt—feelings associated with pregnancy loss (Leon, 1992)— or traumatic life events, emotional disclosure is restrained (Rimé, 2009). The most traumatic personal experiences are often concealed (Larson & Chastain, 1990) for reasons including self-presentation and impression management concerns (Goffman, 1959). On Facebook, people report sharing more positive emotions than negative compared to face-to-face settings (H. Lin, Tov, & Qiu, 2014; Reinecke & Trepte, 2014). 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. Similarly, when they do not disclose, it is important to uncover why.

Shifting to intimate and sensitive disclosures, research suggests that features of computer-mediated communication such as a lack of non-verbal cues (e.g., (Tidwell & Walther, 2002)) or increased anonymity (Andalibi et al., 2016; Suler, 2004) 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) (Tobin, Vanman, Verreynne, & Saeri, 2014). 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 (Brubaker, Hayes, & Dourish, 2013); similarly, an analysis of Facebook memorial pages suggests that the site is a suitable space for sharing memories and grief with one's friends (A. Marwick & Ellison, 2012). 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 (Newman et al., 2011). Other vulnerable populations, such as transgender individuals find Facebook both a site of stress and support (Haimson et al., 2015a). For veterans transitioning into civil society, while barriers to disclosure of struggles exist, reenacting camaraderie triggers disclosures (Semaan et al., 2017). Groups such as fathers (Ammari & Schoenebeck, 2015b) and Low-SES, 1st generation college students (Morioka, Ellison, & Brown, 2016) 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 (Zhang, 2017). 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 (Bazarova, Choi, Whitlock, Cosley, & Sosik, 2017).

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 I 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 and

others do not? How do they decide to disclose, or not, and what potential risks and benefits do they perceive?

Indirect and Ambiguous Self-Disclosure Strategies in Non-Computer-Mediated Contexts

Research has long recognized directness as an important dimension of disclosure (Greene et al., 2006). For example, Edgar proposed direct - indirect as one dimension of disclosing stigma, with indirect disclosure as a strategy for limiting stigma (Edgar, 1994). For example, "I just found out that I got a promotion" is more of a direct disclosure than "It's nice to finally have something good happen at work" (Petronio, 1991). Similarly, "I have HIV" is more direct than "I have been sick" (Petronio, 2002). Ponse found that lesbian individuals make comments that *imply* homosexuality without directly and explicitly stating the fact – this is an indirect way of disclosure relying on inferences and implications (Ponse, 1976). Relatedly, in the context of disclosures of homosexuality, Dindia found that individuals drop hints about their identities, wear clothing that symbolize gay identity, or wear freedom rings as a symbol of gay pride (Dindia, 1998). Other times when verbal disclosure is hard, people employ symbolic disclosures such as tattoos (Greene et al., 2006). This way of disclosing information is different from that defined by Jourard (Jourard, 2008) (i.e., letting the audience know with "no shadow of a doubt" what one is feeling), or from "the matter of fact" disclosures of Goffman (Goffman, 1986) in that the information is symbolically or indirectly communicated, and not explicitly and directly.

Indirectness of disclosure can take the form of social coding, as discussed above, or by indirectly delivering a message either through others. In a "second-hand" or "third party" disclosure, someone else shares the information (Afifi & Steuber, 2009; Bouillon et al., 2007; Derbez, Pauw, Stoppa-Lyonnet, & Montgolfier, 2017). Moreover, research indicates a negative association between relationship closeness and enacting second-hand disclosure strategies (Venetis, Chernichky-Karcher, & Gettings, 2017).

Indirect disclosures (e.g., hinting, third party) can reduce the chances of face threat for the discloser or the disclosure recipient: The stigmatizing information that could make both parties vulnerable to bias is detectable only to those who are in the know and most likely sympathetic (Brown & Levinson, 1987; Hara & Kim, 2004). Indirect disclosures of HIV by men who have sex with men were believed to be an adequate form of disclosure since those who needed the information would understand the message and infer their own risk (Serovich, Oliver, Smith, & Mason, 2005). Recipients too sometimes prefer indirect disclosure as a more discrete way of sharing sensitive information. For example, Chinese college students who associated mental illness with stigma preferred to learn of others' experiences with mental illness through indirect disclosures over direct disclosures (An & McDermott, 2014).

The research above explores the role of indirect disclosures in non-computer-mediated communication, particularly in the presence of social stigma. Now I shift my attention to social media research.

Indirect Disclosures on Social Media

Much of the self-disclosure research in computer-mediated-communication, HCI, and social computing has focused on direct forms of self-disclosure. This research has explored the content and motivations associated with direct self-disclosure on social media in general, as well as in sensitive contexts such as abuse, gender transition or romantic relationship breakups (e.g., (Andalibi et al., 2016; Choi & Bazarova, 2014; Haimson, Andalibi, De Choudhury, & Hayes, 2017; Haimson et al., 2015a)). A growing body of research focuses on computationally detecting signals of distress (e.g., mental illness) from social media content (e.g., (De Choudhury, Counts, & Horvitz, 2013)). Indirect disclosures, however, have not been a focus of much HCI scholarship nor have they been conceptualized and described clearly.

A notable exception is boyd and Marwick's discussion of "social steganography" as a way that teenagers code information on social media (boyd & Marwick, 2011). Through "hiding in plain

sight," social steganography works because the poster knows that different audiences will interpret the message differently (boyd & Marwick, 2011; Petitcolas, Anderson, & Kuhn, 1999). By sharing content in a way that only certain audience members can decode, teens enact privacy in public. Strategic ambiguity or vague-booking can be seen as a type of indirect disclosure, where the message is intentionally vague, and may lead to several interpretations (Bavelas, 1983). Strategic ambiguity has been linked to less use of privacy controls on Facebook (Child & Starcher, 2016), implying that individuals see it as their own way of managing privacy. What the ambiguous message does *not* say is more important than what it does (Janet Beavin Bavelas, Black, Chovil, & Mullett, 1990), rendering it an appropriate medium for sensitive topics (Rosenfeld, 2000). In the context of grief, bereaved parents' use of strategic ambiguity in sharing about the death on Facebook enables protecting sensitive information and impression (McBride & Toller, 2011). For instance, bereaved parents may garner support and build community by posting abstract content that does not reveal specifics such as cause of death, or any other information they deem sensitive.

Intentionally indirect disclosures, which often require the audience to draw inferences, are a common way to share stigmatizing information. However, there has been scant work to examine the factors that inform decisions to engage in indirect disclosures on social media, the range of ways they are enacted, or the design implications of this communication method. I build on this body of research by investigating how and why people indirectly disclose pregnancy loss on social media and discuss potential implications for design and algorithms in the Dissertation.

Responses to Sensitive Self-disclosures

What happens once disclosures are made? They receive or do not receive responses from an audience. There is a rich research literature about online forums and support groups where people seek and provide support in socially stigmatized contexts (e.g., mental illness, abuse). The advantages of online supportive exchanges among strangers have been well documented (e.g., (Barak, Boniel-Nissim, & Suler, 2008; Tanis, 2008)). Often these spaces provide opportunities for

anonymity that facilitates disinhibition (Suler, 2004) and provide a safer space to engage in seeking support and disclosing sensitive information (e.g., (Andalibi et al., 2016; Rubya & Yarosh, 2017)). The type of support people seek can influence the type of support they receive in response; for example asking questions can lead to gaining informational support and in-depth self-disclosure can lead to gaining emotional support (Andalibi, Haimson, Choudhury, & Forte, Under Review; Wang, Kraut, & Levine, 2015). Additionally, online forums and support groups often are specifically dedicated to a topic, bring together strangers who want to discuss that topic, and provide opportunities for anonymity. Here, I focus on disclosure and responses on identified SNSs like Facebook, where people are typically connected to others with whom they have an existing relationship (Hampton, Goulet, Rainie, & Purcell, 2011) and are not anonymous; characteristics linked to "positivity bias" (i.e., favoring authenticity about positive events and emotions over negative ones) (Reinecke & Trepte, 2014) and "context collapse" (i.e., the flattening of members of various social networks and life contexts into one big group) (A. E. Marwick & boyd, 2011) — less likely to occur in anonymous online forums.

Several studies have found that "negative" self-disclosures are less willingly received than "positive" ones both in non-computer-mediated (Caltabiano & Smithson, 1983; Cayanus & Martin, 2008; Hecht, Shepherd, & Hall, 1979; Miller, Lee Cooke, Tsang, & Morgan, 1992) and in computer-mediated contexts (Bazarova et al., 2012). For example, in a 1993 paper, Pennebaker and Harber observed that, following the 1989 Loma Prieta earthquake in California, people became fatigued by hearing about others' earthquake-related thoughts and feelings and some even wore t-shirts that read: "Thank you for not sharing your earthquake experience." Pennebaker and Harber called this phenomenon "social constraint" (Pennebaker & Harber, 1993). When experiencing stigma or distressing life events, people may find themselves confronted with similar "social constraints." In fact, Bonnano and Kaltman suggested that people who are grieving and constantly express pain might drive away those who might potentially provide social support. They further explained that this may be due to the norms for temporal frames where one's audience believes

that: "you should be over it by now" (Bonanno & Kaltman, 2001). Another study found that those who visibly struggle suffer more isolation and rejection than those who act as if they are coping well with crises (Wortman & Lehman, 1985). Some features of this phenomena extend to the online experience too: through an experiment with students, a recent study found that on Facebook people are less willing to comment on "negative" status updates compared to "positive" ones, but that they are more likely to engage in private conversations to respond to "negative" disclosures (Ziegele & Reinecke, 2017). Other research suggests that weak ties are not as willing as strong ties to respond to requests for support on Facebook (Stefanone, Kwon, & Lackaff, 2012). In computer-mediated and non-computer-mediated contexts, individuals under major stress need supportive interaction, yet have difficulty finding support (Silver, Wortman, & Crofton, 1990).

Research on response behaviors suggests that a sense of intimacy and relational closeness with a discloser affects how people respond to a disclosure. Schoeman's subjective intimacy framework suggests that people assess the intimacy level of a piece of information based on who else it is shared with, and how "special" it is (Schoeman, 1984). Self-disclosure has been found to increase liking for the discloser, as long as the disclosure is perceived to be appropriate (Chaikin & Derlaga, 1974). For example, highly intimate disclosures too early in the development of a relationship may not enhance liking (Altman & Taylor, 1973) and may be thought of as inappropriate by strangers (Collins & Miller, 1994). Similar phenomena have been observed in computer-mediated settings. In online communities, the more one likes a requester, the more likely they are to comply with their request (Kraut & Resnick, 2008). An experimental study found that intimate public disclosures may increase perceptions of closeness from the viewers' perspective, however social attraction may be reduced when the disclosure was thought as inappropriate (R. Lin & Utz, 2017). An experimental study found that Facebook users deem positive daily status updates to be more appropriate than negative, and negative updates are perceived to be more appropriate to share privately (Bazarova, 2012a). Another experimental study found that "negative" posts with perceived high intimacy levels lead to less social attractiveness of the discloser (Orben & Dunbar, 2017). Moreover, a survey

study found that "negative" disclosures have a higher impact on acquaintances' than on friends' perceptions of the discloser compared to "positive" ones (Rains & Brunner, 2015). Lastly, an experiment with university students suggested that the extent to which one believes information has exclusively been shared with them, leads to perceptions of more intimacy and contributes to assessments of how much the discloser "likes" them (Bazarova, 2012b), finding support for the concept of "disclosure personalism" (Jones & Archer, 1976) on SNSs.

Researchers have also studied the content and frequency of online responses to disclosures. For example, Facebook status updates including positive emotions receive more likes than those with more negative emotions, and posts with positive emotions receive fewer comments while posts with negative emotions receive more comments (Burke & Develin, 2016; Team, 2010). Responses to Facebook posts with negative emotions have been found to contain supportive and emotional language (Burke & Develin, 2016). Responses to mental-health related disclosures on Instagram have been found to be supportive; specifically, posts including personal narratives receive more supportive comments and posts seeking support attract more comments compared to those that do not (Andalibi et al., 2017). Tweets that include intense expressions of loneliness have been found to receive fewer public Twitter replies (Kivran-Swaine, Ting, Brubaker, Teodoro, & Naaman, 2014). A study of bulletin boards about involuntary permanent childlessness found evidence for supportive interactions in the safety of anonymity provided by the forum (Malik & Coulson, 2013). However, little work has been done to understand *why* people respond or do not respond when they come across such disclosures on social media and how they make decisions. This is another gap I address in this dissertation.

Responses to Pregnancy Loss Disclosures

In non-computer-mediated contexts, there is abundant evidence suggesting that after a pregnancy loss, responses from women's primary social ties (i.e., friends, family) are perceived to diminish the experience and as such are not perceived to be supportive (Moulder, 1994). People who respond

often try to reframe the experience as a positive event (e.g., "It's better to have a loss than to have an unhealthy child"), or try to replace the lost pregnancy with a new one (e.g., "You will have another child in future anytime you want"); such responses do not help with grieving the loss (Luebbermann, 1994; Renner, Verdekal, Brier, & Fallucca, 2000; Shapiro, 1993). Society and one's network rarely encourage women to express their emotions, to talk about loss, and to assume the role of a bereaved individual (Stack, 1984). When people are disclosed to, many believe that if the pregnancy was planned, the loss was traumatic, but if it was not, it was not traumatic or distressing (Renner et al., 2000). The disparity in valuative meaning (i.e., the gravity associated with the event that is related to one's experiences and are typically shared among people with similar experiences) between those who have experienced pregnancy loss and people around them partially explains the unsupportive reactions (Renner et al., 2000).

The literature on stigma suggests that sometimes people avoid certain others due to social norms (e.g., feelings such as anger or blame), and sometimes due to disease avoidance and fears of contamination and disgust (L. Li, Liang, Lin, Wu, & Wen, 2009). In fact, the latter may promote "avoidance of people who appear to be healthy, but who have become linked to disease-related knowledge by a label" (Oaten, Stevenson, & Case, 2011). Some suggest that "confusing terminology" (i.e., spontaneous abortion vs. abortion by choice) and a "norm of silence" (i.e., not disclosing pregnancy until after the first trimester) contribute to the difference in responses to pregnancy loss compared to other types of loss (Beil, 1992; Renner et al., 2000).

The body of work I discussed in this section provides us with important knowledge about perceptions of sensitive disclosures including those related to pregnancy loss, but we do not know much about how people experience online sensitive disclosures of others and the factors that guide their decisions about whether and how to respond to them. This is an important gap to fill for grounding the design of social computing systems that encourage supportive interactions in an in-depth understanding about the reasons people behave the way they do.

In summary, in this chapter, I identified gaps in our knowledge of how people decide to disclose stigmatized experiences on social media and what forms these disclosures can take, how others decide to respond, and the socio-technical features that encourage or discourage these disclosures and responses to them. This dissertation addresses these gaps through two in-depth interview studies that aim to answer the following research questions:

RQ1. How and why do individuals who have experienced pregnancy loss decide to engage in direct disclosures related to this event on social media? (Chapter 4)

RQ2. How and why do individuals who have experienced pregnancy loss decide to engage in indirect disclosures related to this event on social media? (Chapter 5)

RQ3. How and why do social media users engage with or respond to others' sensitive disclosures (e.g., pregnancy loss disclosures) shared on social media? (Chapter 6)

CHAPTER 3. METHODS AND METHODOLOGY

In this chapter I share the methodological approach I took in this research. I then share details about recruitment, participants, data, and analysis for the following findings chapters.

Methodological Approach

In this section I discuss the methodological perspective I have taken in this work. Burrell and Morgan developed a classification of existing sociological theories based on four mutually exclusive paradigms: interpretivist, functionalist, radical humanist, and radical structurist (Burrell & Morgan, 1979). Here, I discuss where I position my work at a high level.

This work is concerned with understanding how people perceive the socio-technical factors that lead to their disclosure, nondisclosure, engagement and non-engagement behaviors and decisions from *their* perspective. My approach in investigating these phenomena is interpretivist and phenomenological. The philosophical foundation for interpretive work is phenomenology (Boland, 1986). An interpretivist approach takes on the view that reality is socially constructed. In interpretivist research the focus is on how the participant experiences the world around them; in order to understand a phenomena, one would need to understand the meanings people assign to it (Wilson, 2002). For the phenomenologist the world is one of intersubjectively constructed meanings; as such, understanding the phenomena I am investigating requires understanding it in the lived context of people who have experienced it (Myers & others, 1997). Interpretive work does not have a priori dependent or independent variables, instead it emphasizes on the full complexity of sense making practices as the situation emerges (Kaplan & Maxwell, 2005). As Wilson (Wilson, 2002) puts it: "*Phenomenological ideas underlie virtually all of those schools of thought that hold that it is necessary to understand the meaning attributed by persons to the activities in which they engage, in order to understand their behavior.*"

This research is fundamentally socio-technical. I investigate both how technology shapes people's disclosure and engagement with disclosure practices, and how disclosure and engagement

might inform the use and design of technologies. Interpretive research in information systems is *"aimed at producing an understanding of the context of the information system, and the process whereby the information system influences and is influenced by the context"* (Walsham, 1993), and so is the research presented in this dissertation.

Methods for Investigating Disclosure Decisions

Findings presented in Chapters 4 and 5 are grounded in what I detail below. I 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

I sent out a brief screening survey on Facebook and Twitter (starting from the my network) as well as flyers posted locally. The online call for participants was widely shared by people outside of my network. For example, some participants voluntarily shared with me that they learned about the study in various support groups that I was not a part of. 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. I did not screen based on gestational stage of loss, as the grief experience is not dependent on it (Moulder, 1994). The study was open to transgender and non-binary people who had experienced a pregnancy loss, but none responded. I 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 [1] and I received a total of 90 responses. Among survey respondents, 36 had not directly disclosed the loss on any platform, 51 had directly 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. I made several systematic passes through the survey data prior to and during the interview data collection period to select potential interview participants with the aim of covering a wide range of experiences with loss, disclosure, social media use, and age in aggregate. For example, I made sure I invited survey respondents for interviews in different age ranges and to include individuals who reported having disclosed about the loss on social media and those who reported non-disclosure. Once I had interviewed several people of similar ages, I stopped inviting new interviewees in that age range, and focused on recruiting other age ranges. I stopped recruiting new interview participants well after I reached saturation and stopped uncovering new themes and experiences. Those chosen for interviews were contacted via email with study information and a link to an online consent form.

Participants

I 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 of their loss; 19 reported direct online disclosures (e.g., Facebook profile, Facebook

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[1] In the United States, October is Pregnancy and Infant Loss Awareness Month, and October 15th is Pregnancy and Infant Loss Remembrance Day. While the recruitment timing was not planned with this in mind, it is possible that commencing recruitment in the months following October may have contributed to my successful recruitment, as well as having participants in the sample who believed social media awareness campaigns during October can facilitate disclosures as I discuss in this dissertation's findings.

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. No participants reported directly disclosing pregnancy loss on Instagram or Twitter. All participants reported using Facebook at the time of the interview, except one who only used Instagram and Twitter and had stopped using Facebook. In Chapter 4, I share findings from these 27 interviews related to direct disclosure decision making.

My first round of analysis – as I describe in the Analysis Section in this chapter – showed that 13 participants reported making indirect disclosures of their experience with pregnancy loss on Twitter, Facebook or Instagram. Chapter 5 solely focuses on indirect disclosures; as such, there I draw on these 13 interviews. Specifically, I report on experiences of 13 women aged between 27 and 39 (average = 32.5) who engaged in indirect disclosures across a variety of social media platforms (e.g., Facebook, Instagram). The 27 participants had experienced losses in various stages of pregnancy including stillbirth. 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

I conducted semi-structured interviews, which freed participants to explain their experiences and allowed me to systematically cover important data points. I conducted all interviews via participants' preferred method of video or voice call. On average, the 27 interviews lasted for 92.7 minutes (SD = 12.5, range: 62-115). The subset including the 13 interviews reported on in Chapter 5 lasted for 98 minutes on average (SD = 10, range: 82-114). Only audio was recorded and transcribed for analysis. I began by sharing the study's goals, ensuring participants knew what it entailed, and asking permission to record the conversation. Then I 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, I asked for specific examples.

Analysis Method

The constant comparative method, central to and popularized by grounded theory, drove the data analysis. I conducted iterative open coding on the 27 transcripts, "*through which categories, their properties, and relationships emerge*" (A. Strauss & Corbin, 1998, p. 66), looking for patterns in the data. Open coding allowed for flexibility and creativity in the codebook development (A. Strauss & Corbin, 1998). I also wrote memos to facilitate a reflective analysis process. I discussed, refined, and reviewed the emerging themes with another researcher.

The analysis started with open coding and identifying patterns in the dataset of 27 interview transcripts. As participants referred to indirect disclosures, codes related to this concept were created and iteratively allocated to larger categories. This process revealed that 13 out of the 27 interview participants had engaged in indirect disclosures of pregnancy loss on social media – which is the focus of Chapter 5. Indirect disclosures were not a topic I had thought of investigating when I first set out to investigate disclosure decisions and the screening surveys were not designed to surface this type of disclosure behavior. However, by including participants with a range of experiences, and employing semi-structured interview style and the constant comparative method, I was able to uncover this important phenomenon.

Opportunities and Limitations

This study focused on women in the U.S. and their experiences with pregnancy loss and disclosure. Future research could explore cultural differences in disclosure decisions and partners' experiences. Another important future investigation is understanding unique challenges faced by individuals whose multiple identity facets make them more likely to face negative well-being consequences, such as those with intersecting marginalized identities (e.g., people of color, low socio-economic status). Similar to many interview studies, the goal of this work is not

generalizability; future work could evaluate these findings with larger samples or other populations. Future work could also explore the links between personality measures (e.g., introversion) and social media disclosure decisions (e.g., indirect disclosures).

Privacy, secrecy, concealment, and self-disclosure have been subjects of research and are related concepts. In this dissertation, I directly draw on the self-disclosure, social support, and well-being literature, because: 1) self-disclosure is a concept that has been linked to well-being traditionally and on social media; 2) there is a rich body of work related to disclosures of stigma and health conditions in traditional communication, psychology, disclosure, and social support literature; and 3) enactment of social support (often dependent on disclosure) and other kinds of responses to stigmatized disclosures are key elements in my work. These are not prevalent themes in the broader literature usually categorized under the "privacy" theme. It is important to note that the self-disclosure literature I draw on (e.g., (Greene, Afifi, & Afifi, 2009; Greene et al., 2006)) in this dissertation is fundamentally rooted in the privacy literature (Altman, 1975; Petronio, 1991, 2002). However, this body of work identifies specific and concrete factors that inform sharing behaviors in stigmatized contexts – which is in line with my research questions in this dissertation. The most relevant privacy-related work to this dissertation is that of Petronio's. In light of Petronio's Communication Privacy Management (CPM) theory (Petronio, 2002), self-disclosure can be conceptualized as a mechanism to maintain privacy through maintaining self-boundaries. Boundary management is a rule-based process. This rule-based management system depends on three privacy rule management processes to regulate revealing and concealing information: privacy rule characteristics, boundary coordination, and boundary turbulence (Petronio, 2002). Privacy rule characteristics (i.e., culture, gender, context, motivation, risk/benefit ratio) (Petronio, 2002) are closest to what I call "decision factors" in this dissertation, but do not provide an insightful parallel given this work's research questions. Taking a privacy lens, future work could use CPM to provide new insights about other dimensions of privacy management such as boundary coordination and boundary turbulence. For example, CPM provides a useful lens to investigate information co-

ownership, and can be used to uncover couples' pregnancy loss disclosure decisions rather than individuals.

As I discuss in the dissertation, the socio-political landscape plays a big role in disclosure and support seeking decisions, particularly through technological means. Future work could investigate how disclosure and support seeking behaviors shift when the socio-political landscape changes (e.g., access to healthcare and medical procedures), or when concerns around data misuse such as that of the Cambridge Analytica (Granville, 2018) go beyond the technology industry and are manifested in the fabric of everyday life.

Methods for Investigating Response Decisions

I used a phenomenological interview approach including both a semi-structured protocol and structured vignette prompts to understand people's perceptions of online disclosures and disclosers and to surface the decision making factors that precede different response types. I report on these findings in Chapter 6.

Recruitment

I sent out a brief screening survey on Facebook and Twitter (starting from my network) to find eligible interview participants. The call was widely shared by people outside of my network. The survey included information about the study and participation criteria: being at least 18 years old, using social media, and living in the U.S. The survey asked which online platforms respondents used, and whether they have come across posts about negative feelings or stressful situations. If they answered yes, we asked them to briefly describe the posts and platform. I also asked about age, gender, where they lived, and contact information. I received a total of 82 responses. The process of selecting and inviting survey respondents to participate in the interview was iterative and strategic. I wanted to collect data not only related to pregnancy loss responses but also responses to other sensitive posts, and to have a diverse sample with respect to age, gender, and social media use. Specifically, I used screening survey responses to identify a sample of interview

participants who varied in age, gender, and the type of sensitive disclosures they had encountered in order to obtain a rich dataset. Once I had divided potential interviewees into categories representing different ages, genders, and types of disclosures encountered, I began recruiting from each group to ensure inclusion from each. I emailed some potential interview participants, noted who responded, conducted some interviews, and emailed more potential participants based on the data I had already gathered. I continuously reviewed data for coverage of novel experiences and stopped recruiting interview participants when I reached saturation, i.e. when I began to hear the same data with no new additions. This is a common method for non-probabilistic sampling that can be found throughout the HCI and methods literature and provides no grounds for establishing a "correct" sample size. Through this iterative process, I emailed 20 survey respondents with study information and a link to an online consent form. 11 individuals completed the consent process and participated in the study. I did not invite survey respondents who reported no exposure to sensitive posts or who lived outside the United States (as proxy for broad cultural similarity). One person identifying as non-binary responded to the survey; however, they did not respond to the interview request once invited. Participants were offered a $25 Amazon gift card as a token of appreciation.

Participants

I interviewed a total of 11 participants (7 women, 4 men). The average age was 32 (range: 23-50). Participants had seen a variety of sensitive posts online including posts about mental illnesses, sexual abuse, pregnancy loss, loss of loved ones and pets, chronic or serious illnesses, eating disorders, drug abuse, finances, experiences with sexism/racism/LGBTQ discrimination, police brutality, and abortion. Seven of the eleven participants specifically reported having come across posts about pregnancy loss on Facebook; when that was the case, I asked them to reflect on coming across disclosures of pregnancy loss in addition to other experiences. Participants used a variety of social media, however they primarily reported using Facebook with a wide range of ties (e.g.,

family, colleagues, acquaintances, friends). All participants lived in the U.S. Two participants were

not able to complete the vignette portion of the interviews.

Data Collection

Here I detail my data collection process through interviews and vignettes.

Interviews

I conducted all the interviews via participants' preferred method of video or voice call. The

interviews were semi-structured and lasted for 80 minutes (*SD* = 23.4, range: 40-105) on average.

Only audio was recorded, and subsequently transcribed for analysis. The interviews started with

background questions about general social media use. They then shifted into instances of

encounters with sensitive posts on social media (including questions about examples of coming

across sensitive disclosures participants had mentioned in screening surveys), how and where they

had come across them, what it was about, who it was from, how this exposure had made participants

feel, and whether, why, and how they had or had not engaged with these posts in the past. For the

seven participants who had mentioned having come across posts about pregnancy loss before, I

asked them to reflect back on that experience and probed as described above. For any specific

instance participants mentioned, I probed to uncover the factors that contributed to what they did

in reaction to disclosure. I then asked about participants' own disclosure behaviors. This phase of

the interviews covered a wide range of experiences, beyond seeing pregnancy loss disclosures.

Next, participants were provided with links to the vignettes about pregnancy loss. They read the

vignettes one by one and in the same order starting from V1. I asked them to imagine that the

vignettes were posts they come across on their social media they used most. I asked them to describe

both how and why they and potentially others would respond to each one if they saw them on the

social media that they used. By this point in the interview I knew about their generic social media

use, so I framed these questions accordingly. Sometimes they went back and forth between

vignettes to compare them. If it did not come up organically, I further probed by asking how they

would feel if this post was from different people (e.g., friend, coworker, family member) and why. This phase of the interviews, provided me with data about response decision making when coming across pregnancy loss disclosures specifically and the role of the factors incorporated in my vignette designs. Next I discuss my process for designing the vignettes.

Vignettes

Vignettes as research instruments. Vignettes are "short stories about hypothetical characters in specified circumstances, to whose situations the interviewee is invited to respond." (Finch, 1987) Vignette-like methods are common in HCI research (e.g., (Brubaker, Dombrowski, Gilbert, Kusumakaulika, & Hayes, 2014; Carroll, 2000; High, Oeldorf-Hirsch, & Bellur, 2014; Tawfiq Ammari, Meredith Ringel Morris, & Sarita Yardi Schoenebeck, 2014)), where scenarios and imagined interface designs have figured prominently for years; however, I adopted the vignette method from the social sciences where extensive guidelines exist for collecting data for theory development rather than interface design. I used vignettes to collect systematic data on how and why people engage or do not engage with various kinds of pregnancy loss disclosures on SNSs. I chose to design vignettes about pregnancy loss because it is a rich context for understanding responses to sensitive self-disclosures on social media due to the stigma associated with it and the complications that accompany responses to it as we discussed in my review of the literature. Vignettes help us explore social norms by uncovering participants' attitudes and beliefs about a situation, without requiring participants to have been in the situation and allow for systematic comparisons of group interpretations of a situation (Emma Renold, 2002): "*The use of vignettes is considered to be an appropriate method for the study of normative material where the direct and abstracted approach of eliciting responses to specific issues is not possible*." (Rahman, 1996) As reviewed in (Rhidian Hughes, 1998), researchers have used vignettes in studying sensitive topic areas such as suicide, sexual standards, rape, relationship violence, and deviance.

Vignette design. I followed best practices in designing vignettes (e.g., (Barter & Renold, 2000; Emma Renold, 2002; Finch, 1987; Rhidian Hughes, 1998)) and based them on self-disclosure and support seeking literature. Specifically, the Sensitive Interactions Systems Theory describes direct and indirect support seeking (Barbee & Cunningham, 1995). Direct support seeking entails stating a problem and asking for help, whereas indirect support seeking involves hinting at a problem. Direct methods are more likely to lead to helpful support (Barbee & Cunningham, 1995). I ensured that my data represented response decisions for both direct and indirect forms of support seeking by designing vignettes for each. Note that indirect disclosures and indirect support seeking are not the same concepts. As detailed in Chapter 5, social media indirect disclosures involve sharing of explicit content by proxy, or of non-explicit content by self or others. Direct disclosures are explicit and shared by the self. Direct disclosures may entail indirect or direct support seeking.

Self-disclosure content can also vary based on depth, breadth, and duration (Altman & Taylor, 1973; Cozby, 1973; Omarzu, 2000). Traditional communication research defines depth as "*the degree to which information shared through disclosure is deemed to be highly private or intimate*" (Chaudoir & Fisher, 2010) or "*the degree to which it disclosed personal information, thoughts, and feelings.*" (Barak & Gluck-Ofri, 2007) Breadth refers to the amount and number of shared topics (Chaudoir & Fisher, 2010); for example, a vignette that discusses topics such as health condition long before pregnancy, long journey to pregnancy and struggles with infertility, details of the pregnancy loss experience itself, emotional experience of loss, physical complications of loss, loss of other family members, perceived difference between other kinds of loss and pregnancy loss, future plans for pregnancy, and impact of loss on one's life has more breadth compared to one that talks about the loss and being thankful for having another baby. Finally, duration refers to the amount of time the individual spends on making a disclosure (Chaudoir & Fisher, 2010). In the context of social media posts, I define duration as the amount of time it would take one to write a social media disclosure message; therefore, it is conceivable to think that the longer a post is, the higher the duration. Barak et al. (Barak & Gluck-Ofri, 2007) had three ratings for disclosure depth:

high, little, and no disclosure. No disclosure is not relevant to this study, because I am interested in what happens when people do disclose some kind of personal information, thought, or feeling. Otherwise, I adopt these categories from Barak et al.'s seminal study. "Low disclosure" would be statements that include less depth, breadth, and duration compared to "high disclosures". This definition of disclosure degree has also been used in more recent social media research, where the length of a post is a significant predictor of the degree of disclosures in generic Facebook posts (Wang, Burke, & Kraut, 2016). A longer post about multiple topics and feelings, with more emotional intensity and personal information, has higher duration, breadth, and depth ("high disclosure") compared to "low disclosure". I designed high and low disclosure vignettes to collect data about response decisions for each.

To validate vignettes, I gave definitions of high/low disclosure and direct/indirect support seeking to five researchers (not collaborators) and asked them to independently code the vignettes. Codes indicated 100% agreement that the scenarios are representative of the associated categories. After the first interview I made minor edits to details of V1, to ensure I collected potentially relevant data to the type of detail provided in V1 (leading to V1a and V1b as two variations of V1). The reason for this adjustment was that in the first interview I noticed the participant noted that the specific kind of detail in the post (about the poster's husband) would make the audience take sides and angry at the husband; so I wanted to see if tweaking this detail to something more generic would still be noticed by participants (and I found that it was overall). This was appropriate because my data collection and analysis was an iterative process, and was improved by analyzing prior interviews as is common and expected in semi-structured interviews. Vignettes are available in appendices. Figure 1 shows the overall vignette design.

Note: The designed vignettes include content about pregnancy loss.

Analysis Method

I used the constant comparative method to identify reoccurring concepts in interview transcripts. I applied line-by-line coding to the data "through which categories, their properties, and relationships emerge automatically taking us beyond description and putting us into a conceptual mode of analysis" (A. Strauss & Corbin, 1998, p. 66). This involved iteratively looking for consistencies and differences in the data. I treated the data from both phases of the interviews as a whole.

Support Seeking

	Direct	Indirect
Low	Vignette 1	Vignette 3
High	Vignette 2	Vignette 4

(Disclosure — row label)

Figure 1. Vignette instrument design. Vignettes are included in the appendix.

Throughout analysis iterations, I met with another researcher to discuss and refine the emerging themes resulting from my analysis.

Opportunities and Limitations

The potential differences between reported behavior and actual behavior has always been a challenge for social science research, and vignettes are not exceptions. However, studies suggest that people behave similarly in "real life" as they respond to vignettes, particularly in sensitive settings (e.g., (Rahman, 1996; Reed, 1992; Renner et al., 2000)). I used vignettes as research instruments to uncover beliefs and attitudes about sensitive disclosures. My vignettes were not representative of all sensitive disclosures or even all pregnancy loss disclosures and were used as vehicles to uncover people's beliefs. However, combining vignettes as prompts and recruiting participants who had reported coming across sensitive topics in the past allowed me to learn new

things about response behaviors in sensitive settings on SNSs. My sample was 64% women and all participants lived in the United States. Future work could address response behaviors in and across different cultures. Although my goal was not to generalize across cultures, I acknowledge the limitations of this sample.

Future work could use experimental methods and vignettes to test my findings and find correlational results for example between the variety of uncovered decision factors; however, my goal here was to provide a framework that makes it possible to do future work that is grounded in phenomenological knowledge of the world.

Social support – one concept I focus on in this dissertation – and social capital are related concepts and often confounded with each other (Vitak, 2014)**.** They both involve interpersonal resource exchanges, but social support is more concretely and narrowly focused on exchanges that enhance well-being (Shumaker & Brownell, 1984) and *can* contribute to social capital. Understanding supportive exchanges can provide insights into how social capital functions (Vitak, 2014). I find that contributing to "visible aggregate network-level support" is one mechanism by which social support provision is enacted in socially stigmatized contexts on social media, when taking into account the provider's perspective. Future work could investigate the relationships between response decision factors uncovered in this work such as "visible aggregate network-level support" or "relational context" (e.g., perceived closeness) and other relevant concepts such as bridging and bonding social capital perceived by the poster or responder. For example, it is likely that posters who receive responses motivated by "visible aggregate network-level support" end up perceiving higher social capital as a result. Future studies can also investigate links between specific kinds of supportive exchanges (e.g., emotional, informational, esteem, network, instrumental), perceived tie strength (e.g., weak, strong), and how they may contribute to the poster's perceptions of social capital. Such future investigations can further highlight conceptual differences and connections between various kinds social support and social capital as mediated through social media platforms and among ties of varying strength.

Ethical Considerations

It was important to me that participants felt their grief and other feelings were respected throughout the interview. Additionally, I anticipated that some participants may feel uncomfortable to talk about having come across others' social media posts about painful experiences even though they knew what the study entailed in advance. I adopted guidelines posed by Kasket (Kasket, 2009) 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, and I found them to be extremely helpful.

Conducting research in sensitive settings often accompanies challenges to researcher's well-being as well (Andalibi & Forte, 2015; Moncur, 2013). Due to the emotionally challenging and deep nature of these interview conversations, I engaged in self-care practices that I had learned through my prior research projects or that I organically decided to experiment with during this research. I share what I found helpful for me below and I encourage other researchers to consider these tips in their own work:

First, I acknowledged that I am a human and a researcher who cares about the individuals she speaks with, and that it is okay to feel the pain that participants share with me and trust me with.

Second, at times, I conducted one interview a day and took several hours off of heavy intellectual or emotional work during which I engaged in activities that were calming for me. While I had decided to, and been advised to, not conduct more than one interview a day, sometimes this was impossible due to participants' schedules which was a top priority for me. In those cases, I tried to take extra care of myself following the interview sessions.

Third, I had a considerate, supportive, and understanding network of people I lived or worked with whom I could share how I felt with if I needed to, or who would encourage me to take time off.

Fourth, I took notes after interviews to reflect on my own reactions and emotions. This journaling was part of my research process to reflect on participant experiences and to facilitate taking a reflexive stance in my own role in this research.

Finally, I reminded myself of the importance of this work and my reason for doing it. I also reminded myself of participants' kind comments about the value that the interview experience brought to them as well as the research itself. I found that these activities and reflections were helpful to maintain my emotional well-being while conducting this research during data collection, data analysis, and writing.

Moreover, because I learned that this study was of importance and value to participants as well as to me, I plan to write public blog posts to share the results with those who have been affected by pregnancy loss and the general public. To this end, I have also spoken with popular press journalists about the research and its implications (Manning, 2018; E. Strauss, 2018) and will continue to do so in the future. I will share this dissertation and associated publications with participants who requested. Sharing results in an accessible format will allow me to contribute back to participants and the population I worked with. The study was approved by Drexel University's IRB.

CHAPTER 4. A DECISION-MAKING FRAMEWORK FOR STIGMATIZED DISCLOSURES ON SOCIAL MEDIA

Introduction

In 2015, Facebook CEO Mark Zuckerberg announced on the site that he and his wife Priscilla Chan were expecting a baby girl. He posted on the site:

"*We want to share one experience to start. We've been trying to have a child for a couple of years and have had three miscarriages along the way. You feel so hopeful when you learn you're going to have a child. You start imagining who they'll become and dreaming of hopes for their future. You start making plans, and then they're gone. It's a lonely experience. Most people don't discuss miscarriages because you worry your problems will distance you or reflect upon you—as if you're defective or did something to cause this. So you struggle on your own.*"

Social computing platforms are often celebrated for their capacity to connect; yet expressing one's identity, and seeking or providing support on these platforms can be difficult when people experience distressing and stigmatized events such as pregnancy loss. How and why do people who have experienced pregnancy loss decide to disclose feelings and experiences related to this experience on social media platforms? Why do some people disclose in identified networks where they are connected to others they know in-person? What potential risks and benefits do they perceive? These are the questions I address in this chapter.

Through a series of 27 semi-structured interviews with women in the United States who had experienced a pregnancy loss within two years and who used social media, I investigated support seeking after pregnancy loss. In this chapter, I focus on the experience of disclosure on Facebook as a primary example of an *identified social network site (SNS),* that is, an SNS where one's identity and the identity of one's connections are known. Although I 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 "offline" connections (e.g., family, friends, co-workers). This made Facebook an important potential disclosure and support seeking venue for

them. In this chapter, I focus on disclosures on Facebook, an *identified SNS,* where people's networks are typically comprised of connections they know from other contexts (Hampton et al., 2011), and in which they typically use their physical world names and identities.

Analyzing these data, I developed a framework to explain pregnancy loss disclosures on identified SNSs. This framework includes six types of decision factors: self-related, audience-related, societal, platform and affordance-related, network-level, and temporal. I 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. I 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, I 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, I 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 the exchange of social support.

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.

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

- Self-related

- Audience-related

- Network-level

- Societal

- Temporal

- Platform and affordance-related

Self-Related Factors

Self-Related Factors Contributing to Disclosure

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 (Massimi & Baecker, 2011) 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 (Jennifer Leanne Fairchild, 2009). 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 (Brierley-Jones et al., 2015). Some believed that socially acknowledging and sharing the loss would facilitate their grief process, enabling them to approach a "new normal," (Massimi, Dimond, & Le Dantec, 2012) 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 (Côté-Arsenault & Freije, 2004).

Self-related Factors Contributing to Non-Disclosure

Self-related factors that inhibited disclosures refer to those about one's perceptions of their own personality and other circumstances perceived as personal, rather than those related to their network, audience, or society more broadly.

History, upbringing, and norms in family. Participants cited family history and norms (e.g., family loss history, private family or marriage, perceived non-existence of privacy within family) as well as the ways they were socialized and brought up (e.g., conservative, ought to carry their own struggles) as factors that led to non-disclosure of loss on social media. For example, P2 said: "*We have a weird family history of loss, my mom's generation, so I've always been very restrained.*" Relatedly, P19 reflected on her upbringing and said: "*It probably goes back to the idea that I should carry all of my own problems myself. I don't want to be this heavy dark spot in people's days. If they're feeling good and then they come across this really sad post or something I don't want to be that person. I like lifting people up and making them feel good. It just feels hard to ask someone help you carry something.*" For some participants, the ways they were brought up and their family history led to their attitudes about asking for help and contributed to their non-disclosure decisions. This theme reflects the participants' own meaning-making of their cultural backgrounds and how they were perceived to inform non-disclosure decisions.

Feelings and perceptions of self: Generic or loss-related. Participants' perceptions of themselves broadly or their emotional state as a result of the loss contributed to non-disclosure decisions as well. For example, some participants saw themselves as largely private or anxious individuals, and believed that played a role in non-disclosure of loss for them. Others had feelings of shame, guilt, or felt less of a woman due to the loss and that made it hard for them to talk about their experience with pregnancy loss. As P8 said: "*I imagine that there is a bit of shame there because, 'Was it something that I did, was it something that I ate? Was it that Advil that I took? Was it the fact that I wasn't on prenatal vitamins when I got pregnant?' All those kinds of things can go to your head of, 'It is not my fault because something happened, but could it have been my fault? Could it have been anything that I did, any one particular thing that I did on this hour, on this day that made it so that it wasn't a viable pregnancy?'*" Relatedly, P27 said: "*I kept it secret because I was ashamed and I was embarrassed. I felt like less of a woman.*" For some, the very deep and difficult feelings evoked by the loss led to non-disclosure. As social psychology literature

suggests, feelings of shame and guilt are some of the most difficult to disclose (Rimé, 2009). These feelings also made it difficult to disclose pregnancy loss to participants' online social network.

The meaning and emotional effect of disclosure. How participants thought about the *meaning* of disclosure to themselves impacted their decisions. Some participants did not disclose on Facebook, because to them this meant admitting failure. Participants were also concerned that by talking about the loss experience, the loss would feel more real; so they did not engage in disclosure. As P11 said: "*Because it evoked all of the feelings I was feeling about not being pregnant anymore. Every time I had to say it out loud it made it more real. The way that I deal with grief, just like my father who I was mentioning before, is to not think about it. Every time you have to express it you have to think about it. It was just physically painful every time.*" Sometimes, people wanted to avoid being defined by the loss experience as P7 put it: "*I really do think that you feel there's something wrong with you. I don't know. I relate it a lot to the grief about my mom and my brother. It's really, really hard to talk about something that devastates you…It's not something you want to define you, so you don't talk about it.*" The meaning one gave to their own disclosure and how they felt about this meaning, led to non-disclosure through suppression for some. Suppression involves inhibiting ongoing emotion-expressive behavior, and might create a sense of discrepancy between the inner experience and outer expression, and could lead to less social support and negative well-being effects (Gross & Levenson, 1997).

Other times, disclosure of loss went beyond simply disclosing loss. As P26 said: "*I was intrigued when you asked if I shared about it on social media. As a 42-year-old woman you say, 'God, no!' That is a public announcement rather than a personal conversation you have. If you announce to someone that you have miscarried, you are announcing that you are trying to become pregnant. As a 42-year-old woman that's a pretty strong statement.*" For some, disclosing the pregnancy loss meant disclosing other information as well, such as intending to grow the size of their family, getting pregnant, and making changes to their life rendering disclosures of loss even more challenging.

Personal perceptions and judgments about others' disclosures. Participants' perceptions of other people's pregnancy loss disclosures or how participants felt when they saw someone else's post about difficult situations influenced non-disclosure decisions as well. In particular, when participants felt uncomfortable or judgmental about others' sensitive disclosures, they avoided disclosure themselves too. On this note, P3 said: "*The problem that I have with social media sometimes is that I feel like people post things to win up each other or they do it to get a billion likes.*" Similarly, P24 said: "*I guess because I know that I can be judgmental like that, I didn't want people to look at me, to judge me and to look at me that way. I grew up in a family where you don't talk about the bad things.*" People formed particular ideas about what was and was not appropriate to do online. Particularly, if one saw others behaving in certain ways and judged them for it, then they did not behave similarly either. This resonates with findings about non-disclosures of relationship breakups on Facebook (Gershon, 2010; Haimson et al., 2017), where those who did not think it was appropriate for others to announce a relationship breakup on the site, did not do so themselves either.

Tension between needs to be seen *and* perceived norms. Some participants cited concerns around wanting to be deeply seen and known as whom they are in their totality, but felt exposed and vulnerable. Participants felt the need to be online and genuine but also protected and private. These challenges related to their individual needs sometimes led to non-disclosure of pregnancy loss on Facebook. As P19 said: "*I'm a really communicative person, so there's this tension. Then I also have that feeling of wanting to be deeply known. All the things I've been through and all the things that I'm thinking. It's a really good feeling to know that somebody sees you, sees all of that. There's a tension that I sit in with social media between wanting that feeling of people knowing me and seeing me, and also feeling like I shouldn't share some things. Some things are just too private, or too personal.*" Participants felt that they could not genuinely express themselves on the site, due to perceptions of the inappropriateness of sharing those things, whatever those perceptions were perceived to be rooted in (e.g., upbringing, anticipated audience response, etc.)

Other concurrent life events. Some people had a particularly rough mixture of life events at the time of the pregnancy loss (e.g., job change, moving, health problems) that made it difficult to share anything related to any of these events. For example, P22 said: "*It was a combination of I was sick and going through the emotional stress and I also had a difficult week at work. Just, I think the combination of other life circumstances at that moment, it was just not the time to do anything, share anything.*" The additional layer of distress due to other life circumstances that went beyond the pregnancy loss led to some participants' non-disclosure on social media. This signals that when people are most vulnerable as a result of several negative life events, the difficulties of seeking support may be even stronger.

Audience-related Factors

Audience-related Factors Contributing to Disclosure

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 (Chaudoir & Fisher, 2010), and I use the term *preventive disclosure*, which has also been used in the context of gay identity disclosures outside of SNSs (Cain, 1991). 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.

Audience-related Factors Contributing to Non-disclosure

This theme refers to non-disclosure on social media due to (1) putting audience's needs before one's own needs, (2) prior sensitive disclosures and unsupportive reactions to them, and (3) anticipated reactions to disclosure on social media. I provide a detailed examination of the various types of anticipated responses that inhibited disclosures of loss on social media platforms.

Protect others' needs rather than the needs of self. Protecting other people and their feelings was a factor leading to non-disclosure of pregnancy loss on social media. For instance, P1 shared: "*It felt like we were ignoring that child because we knew she was a girl and we had named her Anne. And so that one really made me feel like we can't... Like the only people we're protecting when we don't tell anybody about our miscarriage is other people because we're still sad and we still miss that baby. And all those plans we had. And we still remember what her heartbeat sounded like and how she looked on the ultrasound. I still have ultrasound pictures cause we were getting*

a lot of ultrasounds. And so really the only people you protect when you don't tell anybody is everyone else from feeling sad." Some participants felt like by talking about their experiences and feelings they would put this big sadness on other people too and contribute to their worry and concern, or remind them of their own loss and difficult memories. As P2 said: "*People didn't know we were pregnant, so putting out there that we were and then weren't felt like more of a share, more of an imposition because they didn't know, they didn't need to know that ... we didn't have to put that on them.*" While some did not disclose the loss due to this reason, they did feel the need to talk about their experience with their networks.

Some participants also considered currently pregnant women and how they may feel uncomfortable by hearing about others' pregnancy loss or how they may feel anxious about their own pregnancies. As P16 said: "*A lot of pregnant women are pretty anxious about their pregnancies and sometimes while you're pregnant, it doesn't help to hear what can go wrong. Obviously it's different if people are much further along and I think it's different if you're very close to someone, maybe. You have a more sort of not quite as close a relationship, it just felt to me like I just felt uncomfortable. I felt like I was raining on their parade sort of or that I would be.*" The concern that by disclosing their loss, pregnant women in their networks would feel anxious about their own current pregnancies, led to non-disclosure for some participants.

Past audience reactions to disclosures of loss or other sensitive topics. Prior unsupportive or hurtful experiences of disclosing pregnancy loss on or outside social media sites, or negative interactions in other sensitive contexts (e.g., gun control) online was another factor leading to non-disclosure of pregnancy loss on social media. Such prior experiences led to anticipating similar reactions if one were to disclose the loss on the site, and as such led to non-disclosure altogether. For instance, P23 reflected back on their disclosures outside of social media: "*There were good friends of ours who had comments like 'oh you can get pregnant again.' There was one person that knew about us having a miscarriage, but she never said anything to us, or anything about it, which that is fine in itself, but then in a group of people she just went on, and on, and on about how much*

she and her husband had baby fever. It was like within two weeks of the miscarriage, and I was really hurt by that. I guess some of those comments and things probably prevented us from telling other people." Having experienced negative interactions in the past extended to anticipating them in the future, and thus contributed to non-disclosure decisions of the loss on social media.

Anticipated audience reactions: judgment and pre-judgment by the audience. Participants were concerned about being judged by their audience. These concerns were around the audience judging one's identity (e.g., defining them by the loss) and how they were seen (e.g., weak), blaming them for the loss, or questioning their motivations for engaging in social media disclosures (e.g., attention seeking, wanting others to feel bad for them). For example, P17 said: "*I think about it often that I still might put myself out there, 'This is what we went through.' Just so that many more friends can see, but I just know there will be people that read it and they'll think to themselves something smug that would irritate me, like, 'Why didn't they just adopt?' As if that's easy. Or they'll think, 'Why did she just tell everybody that?' As if you shouldn't tell everybody that. It's that fear of some kind of judgement. I guess I'll never know that they thought it, they won't say it to me, but it's that that keeps me from doing it*." Fear of judgments for one's most intimate feelings was important for participants to the extent that it led to non-disclosure, even if they anticipated that the audience would not express these potential judgments to them at all or ever.

Sometimes fears of judgment went beyond participants' current networks and included potential future connections or others who may seek information about the participant for personal or professional reasons. Concerns about threats and judgments from actors such as employers or parents of kids' classmates and being "pre-judged" due to having lost a pregnancy stopped some people from sharing about their loss on Facebook. As P16 said: "*I'd rather be a little more blank to a prospective employer or school or a playmate for my kid or whatever. I prefer not to have the ability for someone to like pre-judge me*."

Similarly, research in the context of gender transition on Facebook shows how transgender individuals find it difficult to manage their identity on the site in part due to not being able to predict

whom their connections would be in the future and what they would want them to know and see about them and their past (Haimson, Brubaker, Dombrowski, & Hayes, 2016). In the context of pregnancy loss experiences, participants did not disclose the loss to their online networks due to concerns around potential *future* interactions or opportunities.

Anticipated audience reactions: avoid questions from the audience. Sometimes, participants did not disclose about pregnancy loss because they wanted to avoid questions and conversations that may have followed if they did disclose. Avoiding certain questions (e.g. progress of pregnancy) was a motivation for disclosure on Facebook for others as discussed earlier. However, the concerns leading to non-disclosure revolved around questioning the couples' or the participant's choices that may have been impacted by the loss experience (e.g., deciding to adopt a child, not wanting to get pregnant again). On that note, P17 said: "*I've considered declaring [on Facebook] like, 'We're officially having an only child.' To people just so that in a way to kind of say too, we've been through infertility, we've stopped with that. I don't want to hear somebody say, 'Well just wait you never know what'll happen. Or why don't ya'll adopt a second?' Just something like that, that just kind of like I don't want to explain my choices, we've made them.*" Having to explain one's choices was a conversation some people did not want to have with their connections, and thus would not make a disclosure that may prompted those conversations.

Anticipated audience reactions: dismissing, ignoring, or glossing over one's vulnerability. Imagining or anticipating that the post in which participants made themselves so vulnerable would be glossed over and dismissed was a big factor leading to non-disclosure on identified social media. Liking a post or leaving a comment *and* then moving on with one's feed and scrolling down without signaling a "pause" was one audience behavior that participants perceived to be dismissive. Additionally, participants thought those in their audience who may not really relate to their experience and see the post, might just gloss over and ignore their post and move on with their browsing. As P21 said: "*I think just the fact that it was such a painful experience for me it makes me cringe about the thought, the idea of it being devalued or ignored.*" Additionally, P19 talked

about how she did not want social media interactions that did not "mean" much: "*Sometimes people go through their feed and like, like, like just because you're supposed to like people's posts. You do it out of this obligation not out of a sincere appreciation or liking. It's like, 'Well, if I don't like it then they'll see that I didn't like it.' I didn't want people to be going through and then see my post and say 'I'm so sorry,' and then just go on liking the next post and the post after that. That would take away from the heaviness of my real experience. I guess I just didn't want people to know if they wouldn't pause to understand what I was going through. It feels like it's so much easier with Facebook for that to happen. I didn't want to be glossed over, just another like that didn't mean anything.*" For some, the anticipation that they would receive responses or reactions from some of their audience without much pause and attention felt like devaluing their experience, leading to non-disclosure decisions.

Finally, P19 shared a perspective that was informed by her experience of living as a woman: "*It's weak to be vulnerable, especially for women. There's just this thought like well no matter what kind of birth a woman has it's just she's a woman that's what happens, so she deals with it. Miscarriage is just a part of life. This is just what happens and you move on. It's like women have to be twice as strong, because we're seen as so emotional, and that makes us weak when we're emotional. It's hard to be emotional in this public space without worrying about being brushed off.*" For some participants, the anticipation that their audience would brush their pain off and label them as weak for feeling and sharing the pain led to non-disclosure. This concern often had a gendered element to it; as in, participants felt that just by the virtue of being a woman, they were expected to deal with life's difficulties, move on, and would be brushed off if they do express their pain.

Anticipated audience reactions: reactions from those who may not understand what it is like to lose a pregnancy due to not having experienced it. The potential of receiving comments from those who do not understand what it was like to lose a pregnancy was another factor that led to non-disclosure of pregnancy loss on social media; these were not perceived to be hurtful necessarily, rather considerably unhelpful due to lack of similar experience. As I will discuss in the

Network-related Section, not knowing others in one's network who have also had a loss experience was a factor leading to non-disclosure for some. This theme here refers to reactions from those whom participants believed would not deeply understand what they were going through. For instance, P6 said: "*I feel like I don't do it because when I have a miscarriage, I really only am interested in communicating with other women who know what I feel like. When you go on social media, you are in this forum that's made up of lots of different kinds of people at different stages in their lives. Although it might be helpful for a young woman to see a conversation like that happen, depending on how they react or it might be helpful for men to view a conversation like that, it's not necessarily helpful for the woman's experiencing it to be subject to their comments or to feel like those people who don't necessarily understand what it feels like to be participating in that conversation.*" Participants cited tensions between the value of disclosure for self and the value of disclosure for others. They felt like they would find value in connecting with those who have experienced a loss, while acknowledging that exposure to their loss disclosure may be helpful to others such as younger women or men. Ultimately, anticipating receiving comments from those who did not have a deep and personal understanding of the experience led to non-disclosure decisions for some participants.

Anticipated audience reactions: generic, impersonal, superficial, or insincere comments from non-close ties. Generic comments or comments from people that one did not really know well (e.g., acquaintances) but had on their Facebook, sometimes felt insincere or superficial, especially when they did not lead to exchanges in-person contexts. As P10 said: "*I know the generic comment. 'I'm so sorry for your loss.' Maybe it's because I've done it before. When people that I don't know very well at all post really personal things, I feel obligated to respond, and I don't have any personal information to respond in any kind of real personal way. It's superficial. It's not actual comfort. It's not understanding. I don't think it would ever make me feel good. We don't have a relationship. I think it would have compounded my grief about it, rather than helped anything, because it wasn't personal, and there was no actual interaction.*" While generic comments coming

from connections one was not particularly close to were not perceived to be hurtful per se, they were not perceived to be deeply comforting or meaningful for some, and thus leading to non-disclosure decisions online.

Anticipated audience reactions: hurtful comments on social media. The potential and anticipation of receiving hurtful, insensitive, criticizing, or invalidating comments was a factor leading to non-disclosure. As P9 said: "*I often got burned from people saying very insensitive things about my loss with [P9's brother who committed suicide] or even my infertility, and I was that much more raw with the pregnancy loss. I wasn't willing to open myself up to insensitive comments from people. It was a way of protecting my heart.*" Relatedly, P4 said: "*Because I feel like if you open yourself up on your own wall, you really open it up to people leaving whatever they want.*" When the perceived risk of receiving hurtful comments was high, participants avoided disclosure on social media altogether to avoid that.

Participants' reflections on the potential impacts of hurtful interactions suggest concerns about causing friction in relationships and ruminating on these negative interactions; this was particularly salient when these ties also existed in-person and were not solely or largely online. For example, some anticipated running into people in-person who may have been hurtful on social media, and this perception of hybrid intertwined computer-mediated and non-computer-mediated relationships complicated disclosures of pregnancy loss on a site like Facebook. For example, P14 said: "*If I put something out there to my regular friends, and they're jerks about it, I can still run into them in my day to day life. There can be hurt feelings in the future, whereas people that I don't know, I can just avoid if there are hurt feelings.*" Facebook in particular, was a platform where participants were connected to those whom they knew to some extent in-person. Anticipating the impact of hurtful comments on these relationships and future in-person interactions led to non-disclosure on the platform for some participants.

Anticipated audience reactions: mismatch between reaction expectations and anticipated reactions from certain audience members. An anticipated mismatch between the type of reaction

or support that one needed and what they thought they would receive if they did disclose led to non-disclosure altogether. As P10 said: "*When you expect something out of people, and they don't come through, it's awful. When you expect this, and something else happens, it just messes with you a bit. I think if I'd put something up there, I would have definitely had expectations for certain people. Not having them come through was probably a decent reason as to why I didn't do it. I think it would have broken me on a different level. If I had thought that this friend that I had, we were really close when we were in sophomore year of high school, didn't say anything at all, I think that would have upset me more than I should have been upset, because I was so sensitive at the time, so I didn't want to open myself up to expectations from people that I couldn't trust*." People had expectations from certain individuals they were connected to on social media. The impact of certain audience members not meeting one's expectation was sometimes detrimental to some, leading to avoiding disclosure altogether.

Anticipated audience reactions: reactions of family members to using social media as an outlet. Concerns about reactions of certain close ties (e.g., family members) if one did disclose online hindered disclosure sometimes. For instance, participants were concerned that close ties such as family would think that the topic is too private, sharing reflects badly on the family, information is also shared about the family, or that one should only share positive things and deal with their struggles privately. It was not necessarily the case that participants did not share the pregnancy loss with their close ties, they often times – but not always – did either through more private means. Yet concerns about *reactions* of those ties if they were to share *online* persisted in unique ways. As P15 said: "*I guess if a friend or a co-worker for some reason came to me and was like, 'What the heck why would share this it's really attention grabbing or I didn't need to know this about you,' I would probably feel like that says more about them than it does about me. If someone first off I find it really unlikely that it would happen to begin with, but if someone did react in that way I would be like, 'Well what's wrong with you I don't need your friendship or like it's really rude that you said that in response.' Whereas for the people who I am actually considering in terms of why I wouldn't*

share it it's because I'm thinking that it may be hurtful to them that I shared it. That they may feel like it not necessarily that it reflects on them, but you are sharing something really personal about yourself and I'm your family member. For that reason, you are sharing something personal about me too." Anticipating responses in general was a concern, however, it was also particularly a concern when it came to close ties, different from weaker or unknown ties. For example, P6 said: "*If you're not positive, all the people who can take credit for raising you would also need to take credit for your complaints, right? It would reflect poorly on them. I think that's one of the things, why we're expected to be positive. Because my family is on Facebook, I tend to be more restrained there.*" These data illustrate how close ties and anticipating their reactions led to non-disclosure decisions for some.

Anticipated audience reactions: audience composition, diversity, size, and perceived closeness and trust. Participants assessed their relationships with their audience in terms of diversity, size, as well as closeness and trust. They had a wide range of people in their networks (e.g., family, close friends, colleagues, acquaintances) in various demographic groups and with perceived potentially different values; as such most participants shared primarily positive and not-loaded content with their online networks, and some sought other spaces such as specific groups or forums to connect and talk about pregnancy loss. For example, P16 said: "*The relationship I have with most of my Facebook friends is not really that close and so, if I were in person with them, I wouldn't be sharing any particular little thing.*" Similarly, P10 said: "*A lot of my Facebook friends are people I don't really interact with other than, 'Hey, it's cool we went to high school together, and I'd like to see little parts of your life,' but I don't want them knowing my super personal things. I don't trust that. I like my personal page to be just kind of happy bullshit vacation pictures. There's not a lot of reality that exists there, because I don't trust those people.*" The diverse nature of one's Facebook audience led to less perceptions of trust when it came to one's most intimate feelings, leading to non-disclosure decisions. The size of the audience was also important. For instance, P7 said: "*It feels like telling like a huge group of people something really personal. It's like too many*

people." In reflecting on different values, P26 said: "*I do not have a homogenous groups of Facebook friends. Of course I have people who would be jerks. You have your partners second cousins that you think their political views are pretty awful and God knows you don't want to discuss abortion with them, but they're still your Facebook friend.*" In general, many felt like their audience was too large and too diverse with little feeling of closeness and trust, leading to non-disclosure of negative or difficult experiences, including but not limited to pregnancy loss.

Sometimes the wide range of audience people had in their networks that went beyond those handful of people whom they knew would be supportive anyways, made it hard to anticipate what kinds of responses one would receive from their network if they were to disclose something about their experience with pregnancy loss. For example, P11 compared sharing on social media with writing an email, saying: "*It would have been harder [to post on social media], I think. Because of the anxiety about performance attached to posting things on Facebook, or for an audience. When I was writing those emails the hardest part about them was the grief part, was what I was feeling. I was only writing to people I was close enough to that I didn't care what the content of the email looked like. These were all people who were not going to care what words I used or how I said it. Social media, I feel like I would have lost that forgivingness. It would have been for an audience that was not my close friends. Once you add this layer of other people, even random forum people who don't know me, there's an audience. Having to think about audience at that moment would have been just impossible, just impossible.*" For some, thinking about and performing for an audience that was not the handful of people they were close to and fully trusted, even if they were unknown others, was too hard that led to non-disclosure. Participants were aware of their mixed audience on social media, which added more complexity to the disclosure process due to the need to think about them and anticipate and consider their reactions. This was too difficult for some, adding extra stress that they were not able to or willing to handle. Sharing with only close connections whom one was not concerned about their judgments was an alternative some participants took.

Network-level Factors

Network-level Factors Contributing to Disclosure

Network-level factors are related to the composition and structure of one's total (egocentric) social network as articulated on Facebook. I 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. I 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 thought 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.

Network-level Factors Contributing to Non-disclosure

Perceptions of difference from one's network on several dimensions led to non-disclosure decisions on social media. These included perceptions of direct experience of one's network with pregnancy loss, indirect experience with pregnancy loss or the level to which they were informed individuals about this reproductive health complication, and the degree to which pregnancy and parenthood were concerns in one's network. These factors could be thought of as dimensions of perceived homophily with one's network, which when not enough, led to non-disclosure decisions of pregnancy loss on social media.

Perception or assumption that no one in one's network has directly experienced pregnancy loss. Not knowing anyone in one's network who had also experienced pregnancy loss

or assuming that no one in their network has experienced pregnancy loss, was a key factor in deciding to not engage in disclosures about pregnancy loss on social media. For example, P24 said: "*With my personal Facebook profile I wasn't aware of anyone else who had miscarried because no one really talked to me about it. I feel like I'm standing up in the middle of an auditorium and I'm like, 'Hi, I'm [P24's name]. I miscarried,' and people don't know what to say or they think like why are you posting this? Do you want us to feel badly for you?*" Not knowing others within their network who had a similar experience was a barrier to disclosure, as people felt that those who do not share the experience would not know what to say or may be unsupportive.

Not seeing others post about pregnancy loss was one way participants formed perceptions about their network's experience with pregnancy loss. As P3 said: "*It's hard to be that first person to stand up and say, 'This is what I've gone through.' It's easier for everyone to follow. It's a very vulnerable thing to put yourself out there and reopen those wounds and that hurt and that sadness,*" suggesting the importance of the network-level reciprocation procedure discussed earlier. Similarly, P21 said: "*I think not being the only one. I really think that that is probably the thing that would've made the key difference.*" She did not want to be the only person talking about pregnancy loss on social media.

Sometimes the perception that no one else in one's network has experienced pregnancy loss was a result of previous disclosures in contexts outside of social media. Particularly, when disclosure of loss did not lead to reciprocal disclosures in in-person contexts, participants formed the perception that they are the only ones in their network who have experienced pregnancy loss, leading to non-disclosure on Facebook. As P5 put it: "*Once I'd shared with a few people that I'd had a loss and they shared that they never had had any, then I kind of stopped sharing. Just the coincidence of, 'Oh, I told six people and they all said no, they'd never had a miscarriage.' I just stopped sharing that I'd had a miscarriage. Being able to talk to someone that was a real person that I actually knew, would have been wonderful. I just didn't even know anyone.*" Not having found others who had similar experiences in the physical world made some feel like no one they actually

knew had experienced pregnancy loss, and therefore they stopped talking about their experience with people they knew on social media and in-person; many participants would have appreciated talking about their experience with someone they actually somehow *knew*. However, when people had formed a perception that their network did not have direct experience with pregnancy loss, sharing stopped.

Perception that one's network is not well-informed about pregnancy loss. For some participants, the perception that their network was not aware of pregnancy loss a phenomenon that happens led to non-disclosure on social media. For example, P6 said: "*That there would be this common understanding like we understand that it happens. If you see someone liking or reading something about that, it legitimizes the occurrence. If it's a psychological reaction that you're having after a miscarriage, if you're seeing people that you trust consuming information about mental health, then I think it destigmatizes it, and it creates this assumption that they know, they get it, they understand that it happens.*" The perception about one's network was sometimes in part based on observing what kinds of content one's network consumed or interacted with. Not having observed interactions with content about pregnancy loss led to forming beliefs about the network's knowledge about pregnancy loss and consequently to non-disclosure. Relatedly, P15 added: "*I think if there was that acknowledgment that it is a thing that happens to people and it is a measure of grief that people have, then if that was the case I would probably have felt more comfortable sharing it. Because it's maybe more common to share and I would think that if I did share it people's reaction would be more one of comfort rather than, 'That's inappropriate in some way for her to share that.'*" For some participants, believing that one's network does not know much about pregnancy loss and what it means for those experiencing it, led to a belief that they would deem it as inappropriate to talk about, leading to non-disclosure decisions. In other words, perceptions of unfamiliarity with the experience (i.e., indirect experience through knowledge or exposure) led to non-disclosure to one's network.

Perception that pregnancy and parenthood is not a concern for one's network. Believing that one's network was not concerned about pregnancy as a life experience in general (for example based on demographics or profession) was a hindrance to disclosure of the loss for some. For example, P27 shared: "*I was embarrassed because I felt like, especially I think the area where we live in Silicon Valley, we live right where Google is headquartered. It seems like everyone here is extremely career driven, very well-educated, and I felt like I was falling behind from the norm in this area."* For some participants, the perceived difference of goals and concerns in life between them and their network broadly led to non-disclosure. Not perceiving a similarity in terms of broader life agenda (e.g., wanting to have a child) and instead feeling difference with one's network lead to non-disclosure.

Societal Factors

Societal Factors Contributing to Disclosure

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 (Hardy & Kukla, 2015). Society does not provide a repository of stories about pregnancy loss, and this makes it challenging for people to make sense of the event (Hardy & Kukla, 2015). I found 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.

Societal Factors Contributing to Non-Disclosure

There were also perceptions of societal stigma about pregnancy loss leading to non-disclosure on identified online social networks. Factors related to stigma perceptions included feeling like it is socially unaccepted and inappropriate to talk about pregnancy loss since so few people publicly talk about pregnancy loss face-to-face or on identified social media, expectations and norms surrounding pregnancy announcement, and the perceived social stigma surrounding abortion. These themes are concerned with broad views and perceptions of the human society, going beyond one individual's network and illustrate the ways these perceptions informed non-disclosure decisions.

Perceived stigma surrounding disclosing pregnancy loss. Participants thought that the inappropriateness of talking about pregnancy loss in many face-to-face contexts is extended to their online social networks. For example, P6 referred to "*the lack of dialogue we have just basically in our face to face culture about talking about difficult things, miscarriage, or things regarding*

women," to illustrate how she perceived similar expectations in in-person and social media contexts, leading to non-disclosure on social media.

The observation that people seldom share about their pregnancy loss experiences on Facebook or in face-to-face contexts, and that people instead mostly share about happy pregnancies that proceeded as hoped, added to the perception of social stigma around pregnancy loss for participants to the extent that it stopped them from sharing about the experience and feelings associated with it on Facebook. Finally, P14 said: "*I think the more people that talk about it, the easier it is. In the breastfeeding space [a Facebook group P14 was part of and she talked about pregnancy loss in], lots of those people had already talked about it, so my post about it was one of many. Whereas on my wall, there are not a lot of people talking about miscarriage publicly. Then mine becomes one of few instead one of many. I think if more people posted personally and publicly about it, then it becomes more normal, people learn when it's okay to say and what's not okay to say and what's helpful and what's not helpful as they have more and more experience with people sharing that information. When it doesn't happen very often, people don't know what to say, I don't know what to share, what not to share. Just because it's not normal, so to speak. It's not talked about often.*" Participants believed that not talking about pregnancy loss leads to more stigma around it, more difficulty talking about it, and less experience and education about how to respond to it when disclosed. On the other hand, they noted that when more people talk about their experiences with loss, more people would feel comfortable to talk about theirs as well and the society would start to learn how to respond to pregnancy loss.

Norms around not announcing pregnancies. Participants had formed perception of societal norms and expectations that one is not supposed to announce a pregnancy until after the first trimester. To a large extent, this perception of norms hindered disclosures of pregnancy loss too, and to the surprise of many of participants. In the interviews, many came to reflect on their experience and wondered if the reason this has become a norm is so that women will not talk about pregnancy loss systematically. Moreover, participants felt like because they had not told people

that they were pregnant, now they cannot go to them and say they were pregnant and now they are not. Participants felt lonely as a result and grieved in isolation. For example, P26 said: "*We can also talk about the tradition of women not announcing their pregnancy until after they finish their first trimester because of the high risk of miscarriage. I had a friend tell me about his wife's pregnancy last night and when her due date was and immediately you go through is it safe to say it yet? Or is it not real yet? I also had a friend tell me that when his wife was like six weeks pregnant, like really, really early, and she miscarried that one. He said later that he was really glad he had told the world because the whole world was there to support him. In some ways, there are so many societal undercurrents that say you shouldn't discuss it because well, you know, there's the superstitious part. There's the knowledge that one in four pregnancies end in miscarriage so it's not an infrequent thing. Is it a question of just advertising without knowing? Then there's the whole question of sharing pain.*" Similarly, P15 shared: "*After the miscarriage occurred I wished that I had told them that I was pregnant, because I felt like it was very wonderful that I had my one friend's support. Again it was such a huge thing that had happened to me and I felt like there was a lot that the people who were close to me couldn't understand about what I was going through, because they didn't know this very big thing. At the same time unless if it was like a situation of obnoxious drinking or a situation where the topic actually specifically came up. I didn't feel like it was something that I could just approach out of nowhere so yeah.*" She further explained why she had not disclosed the pregnancy itself to more people than she did, citing perceived societal expectations: "*I didn't tell other people I guess because it seemed like it was the social expectation. First off my mom and my husband's parents were like, 'Now don't tell anyone and especially don't tell anyone at work,' so obviously I didn't listen to that. Then even just reading things online, like I did participate in some social media on Reddit so I saw what other women were doing even just from reading other forums and not participating. I saw what other women tended to do, I witnessed other women and men telling about their wives and girlfriends who were becoming pregnant and when it occurred and their justification.*"

Sometimes people cited resources such as books as sources that informed their decisions to not announce pregnancies, and regretted it later after the loss. As P27 put it: "*I think if I had seen or heard more stories about it from the beginning or if I had known that it was more common, I think I would have been more prone to posting about my experience and I think my pregnancy experience in general. I think I would have been a bit more open. I also think that if the books I was reading, I have this book called 'Day by Day' and 'What to Expect When You're Expecting'. In both of them, they say around 12 weeks is a safe time to tell people. I think if I had not read those books, I probably would have shared a bit more.*" Many did not share about their pregnancy loss because they had not disclosed the pregnancy due to the perceived societal expectations around non-disclosure of pregnancy in the first trimester. This made it particularly hard to announce the loss as well and hindered support seeking.

Abortion. Some participants believed that part of the difficulty of openly talking about pregnancy loss for them was the controversy around abortion in the society. For example, P23 said: "*Our culture's at this juxtaposition because birth control, and abortion and different things like that have one definition for what a fetus, and the life of that is. Then, a miscarriage you're thrown of whether is this a loss of a person? Do I get to mourn it like that? Or, is this just a procedure that happened. I think part of why society doesn't always know how to address, or sympathize with miscarriages, is thinking you could just get pregnant again, have another baby, you never met them, things like that. Of the people we told, we had friends who said things like' it's really common', or 'you can get pregnant again', or things that they thought were helpful. It felt like this is not things that you would say if someone lost a parent. 'Oh, it's really common to lose your dad'. You're like, well that doesn't make it less hard. Or like, maybe your mom will remarry, or something like that. You're like, no you don't replace this totally, even though granted, a relationship that you've had for your whole life is different than one that you knew about for a few months, but it still felt like the loss was counted very differently in people's minds.*" Participants discussed how abortion and pregnancy loss are two distinct experiences, and yet, raised questions around what the

similarities between these experiences mean for how legitimate mourning a pregnancy loss is and ought to be.

Participants also raised concerns that they felt society expects one to either hold pro-choice values or does not consider and experience pregnancy loss as painful, traumatic, and grief-worthy. As P24 said: "*Society kind of views early pregnancy as pregnancy tissue or like it's not a baby. It is to some people, but we can't say that ... If we acknowledge that somebody who's six weeks pregnant actually has a baby, like that's a living life, then we are saying that by aborting, having an abortion at seven weeks you're killing a human. I'm not against abortion. I have very conflicting feelings about it. I'm just saying that society doesn't really, it's not like super popular to say that well life begins at conception, so I'm going to acknowledge that you just lost a baby but also then say abortion at six weeks is okay. I just think it's a really, really complicated issue and it's a very, obviously, emotionally charged issue. For whatever reason, it's this thing that we're not supposed to talk about because it makes people feel uncomfortable and we don't want to cause more pain.*" Some individuals mentioned that while holding pro-choice views, it becomes more difficult to publicly discuss pregnancy loss, because it is complicated to convey that one can feel both devastated by the loss of their pregnancy and hold pro-choice views at the same time. As a result, participants were concerned about how others would view them due to this complication if they did disclose their experience with pregnancy loss on Facebook.

Temporal Factors

Temporal Factors Contributing to Disclosure

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 (Silverman & Baglia, 2015), 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 (Quadara, 2008). Semaan et al. (Semaan et al., 2017) found that transitioning veterans share their struggles on social media after time had passed and call such disclosures "delayed disclosures." While I 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.

Temporal Factors Contributing to Non-Disclosure

There were factors related to the time since the loss as well as the time since a potential disclosure that lead to non-disclosure on social media as well.

Time has passed – hurts to reopen wounds. For some participants, disclosure on Facebook after some time had passed from the loss was challenging because they did not want to "reopen the wounds." For example, P20 said: "*I guess I didn't want to be upset about it even though I knew it was okay to be upset about it. Telling myself that I was okay when perhaps maybe I wasn't or talking about them might have brought out another sort of emotion that I didn't know that I had.*" Similarly, P3 said: "*I feel like I'm just happy to have a baby that I don't want to bring down the vibe. Then I feel like, it's been a year and a half since the miscarriage happened, so you get to a point where it's like, is it worth sharing years later?*" Some participants preferred to leave the loss box closed since it hurt to open it and talk about it after time had passed.

Too close and raw emotions, or too distant and no more needing sympathy. Sometimes participants felt like they did not need the sympathy resulting from disclosure anymore, because time had passed, leading to non-disclosure. Other times because they were temporally too close to the event with raw and intense emotions, they decided to not disclose about the loss on Facebook. As P14 said: "*When you're still having those emotions tied to it, if you don't talk about it, it's easier to put those emotions aside, and go about your daily life. If you talk about it then you're thinking about and its current emotions. Then you keep thinking about it after the conversation, you then invite that upset back into your day on the day that you're having that conversation. Whereas when the emotions are over, like they are in the context of having a baby since then I'm able to talk about it but I'm not longer upset it. Once I'm done talking, I might make me upset while I'm talking about, depending on the context and who I'm talking to, but when the conversation is over, I look at the*

baby and I'm not longer upset. I can move on with my day. Whereas if I didn't have the baby, then I'd spend the rest of my day being like, why can't we get pregnant again, or I wish that we had that baby. I feel like I would just keep thinking about it instead of being able to talk about it and move on." While some participants would have needed sympathy from others when they were temporally close to the loss, their disclosure – if they were going to make one – would not have been at attempt to receive sympathy after enough time had passed. This shift could be because their emotions changed (e.g., due to carrying a future pregnancy to term). On the other hand, when they were too close to the loss, emotions were too raw and intense, and thus harder to disclose because they perceived such disclosures as rumination that would have extra negative emotional effects on them.

Time has passed – will not receive support if disclosed. Other than not wanting to reopen wounds after a while had passed as discussed earlier, some participants felt like although they still feel the loss and would like to talk about it regardless of their current circumstances, their audience may not be supportive or understanding as to why they are discussing their loss after the passage of time. Some participants anticipated that their loss will be ignored by their audience exactly because some time has passed; for example, if participants now had a child after the loss, they felt that their audience might find them "bragging" about their subsequent carried-to-term pregnancy, or find them to be unthankful for their now child none of which were the intention for sharing. Thinking about a pregnancy loss she had before, P5 said: "*I thought that they would think that I was being too, not like oversharing, too open. That polite society doesn't talk about miscarriages. It's similar to how I think our society has trouble dealing with death, in general. We don't have a set mourning period that's in our society. People are very sympathetic when someone very first dies, but then there's a very short window, or weeks even, before they're like, 'Well, we'll just never mention this person again, and they won't be sad then' The person who has experienced loss is still grieving, for months and years, and society ignores it. I think I felt like women would feel the same, like if you're sharing about your miscarriages that you had before, you should just be quiet about things like that, because nobody wants to hear about sad, gross things. I don't think there's as much*

sympathy around it. If I said I had breast cancer, I feel like I would get a lot more sympathy than if I said I had miscarriages, oddly enough." Disclosing a pregnancy loss *after a while* was perceived to receive unsupportive or dismissive responses, and as such led to non-disclosure to one's online social network.

 Future perceptions of self by audience as a result of disclosure now. Another temporal factor that led to non-disclosure of pregnancy loss on Facebook was the anticipated impact of disclosure on how one or one's audience would perceive them at a *future* time. On the one hand, fear of regretting disclosure in the future was a concern for some. As P6 said: "*It might help me process, but five years from now would I wish that I hadn't done it? I think that I might.*" On the other hand, some participants raised concerns about others viewing their other social media posts *in relation to* pregnancy loss or for the audience to always see them as the person who lost a pregnancy. As P14 said: "*If I were to post while I was having a miscarriage, and then the next day I posted running around the playground with my kids, then you get less sympathy for the miscarriage, because clearly you're feeling fine, hypothetically. Whatever combination of stuff you're posting on Facebook is how they think of you. Miscarriage plus Starbucks plus playground, who knows what that means, but they're going to see all those things together as cluster of who you are. Miscarriage and then you post about a job loss later, then people have the thought of thank goodness you're not pregnant, because you now don't have a job.*" The ways one imagined their audience would perceive them and all of their online activities in the future and in the context of each other, led to non-disclosure of the loss on Facebook for some. Particularly, participants believed that what their audience thinks of them is the aggregate of all the things they share about and present about themselves. Sharing about a loss and then an ordinary or happy-looking content raised concerns about their audience wondering if participants were *really grieving*. This anticipation of how others would see them and their future online activities – outside of pregnancy loss experience and expressions related to it –led to non-disclosure of loss on social media for some participants. This is an example of how audience-related factors interact with temporal factors.

Platform and Affordance-related Factors

Platform and Affordance-related Factors Contributing to Disclosure

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 (Vitak & Ellison, 2013b; Wohn, Lampe, Vitak, & Ellison, 2011). In sensitive contexts, a study (Haimson et al., 2017) 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, I 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 (Vitak & Ellison, 2013b; Wohn et al., 2011), 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 (Walther, Van Der Heide, Kim, Westerman, & Tong, 2008), and lowers the cost of communication because, for example, there is no need to schedule for it (K. Wright, 2000). I 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., (Andalibi et al., 2016; Ma, Andalibi, Barkhuus, & Naaman, 2017;

Suler, 2004)). I 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.

Platform and Affordance-related Factors Contributing to Non-Disclosure

There were also factors related to the design of Facebook as well as perceived norms around its use that lead to non-disclosure of pregnancy loss on the site. These findings show how platform-related factors interact with other decision factors such as audience and temporal considerations.

Non-anonymity and being connected to known others. For some, the very fact that they were connected to people on Facebook who knew them, and their judgments was a concern leading to non-disclosure on the site. As P24 said: "*My mom's family is a family that you don't talk about bad things. You don't talk about negative things. when something bad happens to me I have this automatic need to tell people because it's going to make me feel better. It's going to make me feel like I'm not alone. Kind of the compromise there then is telling people anonymously. There's just something safer about being anonymous. That way if you post something on your Facebook page then everyone knows this about you. They may judge you one way or the other for it. I didn't feel comfortable putting it on my page whereas it felt safer to do it anonymously because those people don't know me and I have no connection to them and no one knew who I was.*" Many felt the need to talk about their experience. The fact that one would not be able to be anonymous on Facebook and they were connected to those they knew, led to feeling unsafe about potential hurtful judgments from the audience who knew them. This led to non-disclosure of the loss on Facebook.

Permanence of content and how others will remember. Participants who were concerned about the permanence of the content shared on Facebook, felt so, largely because they felt the post and the audiences' interactions with it will always remain there and would define them and their identity. Participants cited concerns around how their audience will (1) remember and (2) react to

the post when they read it, and compared it with face to face conversations where they are able to see how someone reacts and where there are more communication cues. As P6 said: "*It doesn't belong to you anymore once it's gone. For me there's more of an anxiety about how is it going to be remembered or reacted to...*" She further elaborated on this point: "*When we think about ourselves, we can have those moments of just really bad parenting, depression or financial bad straits, and we can know that in another 10 minutes, another day, or another hour it'll get better. When you create a post, it's like this snapshot. It makes it forever. It's like this is what I am. It doesn't change… When you send a tweet or when you create this Facebook post, it's this really concrete thing. Then if you are talking about having a bad parenting moment, are you a bad parent in people's minds forever or as long as that post lasts or as long as people remember it.*" Not being able to assess what one's audience *really* thought after seeing their post and the perception that the information and the meanings people make of it will permanently remain out in the world led to non-disclosure on Facebook.

Asynchronous communication and not seeing the audience's reaction. Asynchronicity sometimes meant that participants would not know how their audience would react in real time. As P6 said: "*You don't know what's on the other side of what they're thinking and feeling when they're reading this. Whereas if you're having the face to face, you can tell. I can tell how they're feeling and how they're reacting.*" Not being able to make this assessment led to non-disclosure for some people. Earlier, I discussed how the very same feature allowed some to disclose because it enabled them to take care of their own needs in times of extensive distress. This instance illustrates how the role of affordances was dependent on other disclosure needs and criteria. Lack of visual cues in this kind of computer-mediated communication is sometimes a drawback that can be overcome over time (Walther, 1996; Walther, J. B. & Parks, M. R., 2002). However, this process becomes complicated when people think about one-time sensitive broadcast disclosures that do not occur gradually and over time.

Fearing the loss of privacy control. Perceptions of the potential for loss of privacy and privacy controls due to understandings of how the site worked, was another factor leading to non-disclosure. Sometimes participants were not clear whom among network members that the post was visible to, would actually see their post if they did disclose on Facebook. For instance, P7 described this concern as: "*Posting to like just a bunch of people who you don't even know who sees it and who doesn't.*" Making one's self vulnerable and perceptions of losing control over their information or not knowing who would end up having that information led to non-disclosure decisions on the site for some.

Participants also feared that unintended audiences such as friends of friends would see their post because the post would pop up on their news feed. As P3 said: "*You open up a piece of your life onto someone else's page, it may be others that you know who didn't know you went through that, or others that don't know you at all, now suddenly know. 'Oh, hey, this girl that I don't know just opened up about her miscarriage on my friend's Facebook page.'*" Whether or not a post shows up in unintended audience's feed is a separate issue from the worry participants cited about their post ending up on some unintended audience's feed. It is these fears, perceptions, and concerns that I uncover, regardless of whether the technology does what the participants fear. This finding highlights how concerns about losing privacy controls were partially informed by perceptions of site design.

Perceptions about disclosure norms on the site. Participants' perceptions about how most people use Facebook influenced their decisions related to pregnancy loss disclosure on the site. These factors included feeling like sharing on Facebook would cheapen their pregnancy loss experience as most people shared largely positive and happy content on the site, and they found it shallow, too positive, and unreal. Many participants had this connotation of "unreal" and "positive" about the site. This perception of positivity also led to thinking that it is not appropriate or polite to talk about sad events on the site. As P4 said: "*Facebook is just supposed to be fun and I didn't wanna share something that personal and that hurtful on Facebook where I feel like it's a very*

shallow and... I didn't want my post about my miscarriage to be mixed in with other people's post about partying, or their pet wearing a costume, or anything like that. I just felt like it would cheapen it." Participants viewed what they may have shared in the larger context of all the content that existed on the site, and felt that it did not fit in there. These did not refer to perceptions of pregnancy loss in one's network in particular, rather, referred to the way participants felt most people use the site more broadly. Some other participants who did not disclose about the pregnancy loss on Facebook held the ideology that this platform is not for truly personal content or interactions such as but not limited to pregnancy loss. They believed a post on Facebook about their experience to be more like a public announcement and not appropriate for their experience. As P26 said: "*The truly personal should be physical. For the important communication should be on paper.*" The ideologies surrounding appropriate ways of discussing certain topics with others, led to non-disclosure decisions on identified social media for some individuals.

In this section, I discussed perceptions of platform features and characteristics that influenced people's disclosure and non-disclosure decisions. It is important to note that these factors interface with other elements (e.g., audience-related factors, self-related factors) and do not function in isolation. However, providing in-depth descriptions on perceptions of these features provides unique additional insights into platform features and affordances' role in sharing decisions.

Conclusion

Pregnancy loss is a common experience that is often not disclosed in spite of potential disclosure benefits like social support. To understand how and why people disclose or do not disclose pregnancy loss online, I interviewed 27 women in the U.S. who are social media users and had experienced pregnancy loss within the past two years. Based on their experiences, I developed a six-factor decision framework explaining pregnancy loss disclosures on identified social network sites (SNS) like Facebook. 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 chapter, I 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 such as the #MeToo movement. I encourage researchers to evaluate my framework in other contexts. Within this framework, I 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, I 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. In Chapter 7, I discuss the conceptual and design implications of these findings.

CHAPTER 5. INDIRECT DISCLOSURES OF SOCIALLY STIGMATIZED EXPERIENCES ON SOCIAL MEDIA

Introduction

Disclosing sensitive personal information to others can be difficult and even frightening. Particularly on social media, letting people know about difficult experiences such as a job loss (Burke & Kraut, 2013), an abuse experience (Andalibi et al., 2016), a mental illness (De Choudhury & De, 2014), or a pregnancy loss – as discussed in Chapter 2 – can be daunting. Although most HCI research conceptualizes self-disclosure as direct sharing of information about oneself, many disclosures mediated through social media are less clear. Did a friend post a link to an article about living with depression because they struggle with it themselves? Was a meme about cancer posted as a way of disclosing a diagnosis? Did a friend re-share someone else's #MeToo social media post as a way of signaling their personal experience with sexual abuse and harassment? A poem about losing a pregnancy may or may not directly tie to the poster's personal experience. Indirect disclosures on social media allow for privacy in a networked public, explored in past work on social steganography (boyd & Marwick, 2011) and saving "face" (McBride & Toller, 2011).

Self-disclosure is broadly understood as communicating information about oneself to others and much of the foundational literature focuses on dyadic, face-to-face communication. Several scholars have proposed more targeted definitions of this concept that focus on intention and directness. Sidney Jourard defines "willful disclosures" as those whose goal is to "let another person know with no shadow of a doubt what you have done, what you feel, etc." (Jourard, 2008), but disclosures take different forms. Literature on disclosure explores both direct means of information sharing (i.e., unambiguous content shared by the discloser) (Jourard, 2008), in contrast to ambiguous and indirect styles which may be open to interpretation by the receiver (Edgar, 1994). Additionally, third party involvement buffers disclosures, and is typically considered a type of indirect disclosure (Hara & Kim, 2004), although the content shared by a third party may not

necessarily be ambiguous. Direct disclosures in socially stigmatized contexts (e.g., mental illness, infertility, pregnancy loss) are complicated by social risk (e.g., appearing needy, disclosing vulnerabilities) and competing impression management goals (Omarzu, 2000). Indirect disclosures allow individuals to communicate while limiting personal risk, but because they are often ambiguous, they may also position disclosers poorly to receive support from others, and may increase the chance of negative or unsupportive responses (Birnkrant & Przeworski, n.d.), or of being ignored or misunderstood (Barbee & Cunningham, 1995).

As I have discussed before, pregnancy loss is an experience that is often hard to disclose, socially stigmatized, traumatizing, isolating, and associated with negative well-being effects (Silverman & Baglia, 2015). In the U.S., it occurs in approximately 20% of recognized pregnancies; however, a large 55% of people believe it is rare (Savitz et al., 2002). Lack of support can cultivate stigma and may increase the risk of depression after a pregnancy loss (Stinson et al., 1992); however, communicating about the loss is mandatory for receiving support. Thus, pregnancy loss is an important and rich context for investigating indirect disclosures of difficult or socially stigmatized experiences on social media. In Chapter 4, I established a decision-making framework for *direct* disclosures of pregnancy loss on an identified SNSs. Here, I investigate *indirect* disclosures of pregnancy loss not only on identified SNSs, but across social media platforms due to the distinct functions and roles of this disclosure method.

Particularly, how does the broadcast nature of social media posts affect decision making about indirect disclosures? What motivates people to disclose indirectly on social media and what are their disclosure expectations and experiences like? In this chapter I draw on interviews to answer the question: How and why do individuals indirectly disclose pregnancy loss experiences on social media?

Findings reported here draw on a subset of 13 interviews out of the 27 interviews I conducted with women who had experienced pregnancy loss (as described in Chapter 3). These 13 individuals had engaged in indirect disclosures of pregnancy loss on social media. In addition to indirect

disclosures, five of these 13 participants also had shared about the loss directly to their Facebook networks, often following indirect disclosures. Four participants did not engage in any direct disclosures across social media platforms (e.g., Facebook, anonymous support groups). Six individuals engaged in direct disclosures on support groups where they felt safer than their own identified social media profiles, out of which three had also directly disclosed the loss on Facebook. One participant wrote a blog post about the loss on a platform where she felt anonymous and not connected to people who knew her identity.

I found that participants used four strategies for achieving indirectness, varying based on (1) content explicitness, (2) who created the content, and (3) who shared the content. Factors guiding indirect disclosure decisions of pregnancy loss on social media were related to the self, audience, platform and affordances, and temporality.

Indirect Disclosure Strategy Typology on Social Media

Disclosure strategies varied by the explicitness of the content, who originally created it, and by whom it was shared on social media. Table 1 summarizes these strategies with example summaries. Participants often decided to share content that was non-explicit with respect to pregnancy loss, lacked ties to their own experience with pregnancy loss, or was symbolic. For example, they shared meaningful content (e.g., dinner photo at the night of the loss) without referencing pregnancy loss,

Content explicitness	Content created/shared by	Example
Explicit content	Created by self and-or others, shared by others	Facebook post by spouse explicitly announcing the loss
Non-explicit content	Created by self, shared by self	Instagram post by the individual about staying at home with no reference to the reason (i.e., loss)
Non-explicit content	Created by self, shared by others	Painting created by the individual that symbolically depicts the loss is posted on Facebook by spouse. There is no explicit mention of the loss.
Non-explicit content	Created by others, shared by self	A blog post that someone else wrote about pregnancy loss is shared by the individual with no commentary about her own experience with pregnancy loss or the reason for posting.

Table 1. Indirect disclosure strategies of socially stigmatized experiences on social media. "Created by self and-or others" refers to posts that *may* be collaborative. "Self" refers to participants. "Others" refers to individuals other than participants.

or created symbolic representations of their experience (e.g., painting) and shared those without any explicit explanation. Participants also invoked others (e.g., spouse) to share content on social media. These third party disclosures were sometimes explicitly about the loss (e.g., announcing the loss by spouse on social media) and sometimes ambiguous (e.g., sharing symbolic art). Participants also shared content created by someone else without commentary on *their* reasons for sharing or any tie to their own pregnancy loss experience – thus rendering it an indirect disclosure (e.g., sharing a blog post about pregnancy loss written by someone else). Sometimes participants collaborated with a third party (e.g., spouse) in creating the content that was explicitly about the pregnancy loss, but did not share it with others themselves, rendering it an indirect disclosure.

Direct disclosures refer to sharing explicit content about the self and created by the self. By instead identifying *indirect* disclosure strategies on social media, I provide a useful understanding of how they are different from direct disclosures while I add to the conceptual clarity of indirect disclosures in the literature. As a result of this analysis, I define indirect disclosures on social media through the strategies I identified in Table 1. Specifically, I conclude that social media indirect disclosures involve sharing of explicit content by proxy, or of non-explicit content by self or others. Content may be created by self or others.

Indirect Disclosures of Pregnancy Loss on Social Media

Figure 2 shows factors guiding indirect disclosure decisions on social media. These high-level categories of considerations overlap with four out of six categories explaining direct disclosures of pregnancy loss on social media as I wrote in Chapter 4 (See Figure 2); however, as I will discuss, the details in each category differ from those in direct disclosures, thus extending the framework proposed in Chapter 4 to the context of indirect disclosures. As Figure 2 suggests, societal and network-level decision factors are specific to direct disclosures. I will return to this point in the Discussion section.

Self-related Factors

Keeping a personal record, eliciting support from certain audience members and finding similar others, self-expression and catharsis, solidifying and conveying identity, and protecting emotional

Direct Disclosure Factors

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

(Indirect Disclosure Factors)
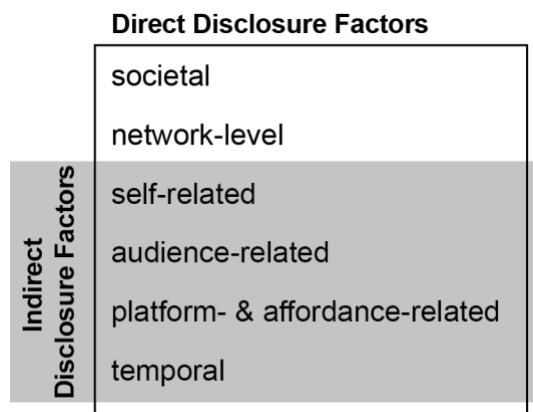
Figure 2. Factors guiding direct and indirect disclosure decisions of stigmatized information on social media. All six categories guide direct disclosure decisions, while four categories explain indirect disclosure decisions.

well-being of self while also sharing the news were self-related factors that guided indirect disclosure decisions of pregnancy loss.

Keeping a personal record. Indirect disclosures of pregnancy loss were sometimes motivated by a desire to keep a record of the reality of the experience for the self, without having to put all the information out for others' consumption. For instance, P17 reflected on indirect disclosures on Instagram:

"*A lot of my posts are during that worst time. I'm posting a picture of something and to me it means a lot more than what the picture is… There's a picture of us having dinner, I know I'm having a miscarriage, and that it's a horrible day and I almost passed out at the restaurant, but for everyone else it's a picture of us eating dinner. I wish I could be more honest about it instead of just put a picture of us smiling. That just feels easier, but I printed the whole feed because to me it's a story that I want a record of, but the real stuff's not even written down with it.*" The same participant also shared happy-seeming photos of a party at which she experienced a second miscarriage. Sharing these photos with no explicit reference to

the loss was a private way of capturing what mattered. These kinds of disclosures were nearly impenetrably coded.

Photos are generally believed to be more open to interpretation than text (Barthes, 1978) and among participants, they were used more often than text for indirect disclosures. Sometimes participants shared a photo that reminded them of the time period during which the pregnancy loss happened, or the dark times they had gone through, but explained that their audience would not be able to tell what the image was "really" about. The photos did not explicitly depict pregnancy loss, nor did any potential text accompanying them. This content was self-created and directly reminiscent of the loss for the poster but would mean something different to the audience. This allowed participants to meet their self-related need of keeping a personal record and private reminiscence without risking judgments from others (an audience-related consideration) or other unwanted consequences that they feared might result from an alternative direct disclosure.

Eliciting support and finding similar others. Some participants indirectly disclosed the loss to find similar others and find support, which was a self-related need. By using coded cues, they avoided potential judgement by a broad audience who might not understand their experience while signaling to those who had been through a loss and would be more likely to be supportive and empathetic.

For example, P24 described a post on Facebook in which she had written that she lost somebody special to her one year ago but that she was now blessed with a three week old: "*It was like, I want to talk about this but I feel like I'm not supposed to so I'm just going to hint at it. I think I did get out of it what I was hoping for. I had a few people reach out to me, other people that had been through this. It was enough of support and enough of me being able to talk about it. The vagueness and the hinting about it on Facebook, obviously, was enough that some people realized what was going on and the people who wanted to reached out to me and talked about their experiences or asked me about my experience. It was helpful.*" Indirect disclosures allowed some participants to filter their audience and elicit reciprocal disclosures in some cases from invisible similar others.

P17 explained her role as an intended recipient: "*There's definitely things I could see a friend post and I think, 'I bet she's struggling with infertility.' I might reach out. I was also doing that, I was dropping little clues to people to again, connect with those friends that I think will be empathetic and supportive.*" By sending clues in ways that posters thought only those who have been through a similar experience would rightly interpret, participants were able to maintain their desired privacy while disclosing to certain audience members.

Participants reflected on how their social media connections responded to such indirect disclosures. Their perceptions suggest that those audience members who did not understand the "real" meaning behind the indirect disclosures, either did not respond or responded in a way that confirmed they did not correctly interpret the hint. However, when the audience included people who already knew about the loss, participants largely felt supported. When people did not find similar others for support, or their message was not decoded, they understood that the indirectness of the message was the reason. They acknowledged that it was okay because that was the level of risk they were willing to take, and those who would not get the hint were not in the intended audience to begin with. Some people who did not know about the loss before, but gauged the meaning behind the posts, reached out to the poster privately and offered their support, or wanted to share their own experiences. Still, the support garnered through indirect disclosures did not satisfy all participants' needs as P24 explained: "*It obviously wasn't enough because I still have that sense of I want to talk about it, but I can't and I'm not.*" The need for direct disclosures and openly sharing about her loss persisted.

Self-expression and catharsis. Sometimes indirect disclosures were driven by a need to express oneself, not to communicate or elicit support. These disclosures were indirect and symbolic with respect to content, and were shared by self or via another person. Some participants created original artistic or expressive pieces about the loss (e.g., poetry, painting, music). On social media, sometimes participants mentioned that they had put up a new post on their blog without saying what it was about or linking to it, so that only those who actively read their blog would know what

it was about. Other times, they shared the artwork through others such as their spouse, and some who knew about the loss already or would gather from the post, provided support. For example, P27 said: "*I had thought about making a post about my experience. One way I grieved was I paint and my husband, he's a musician. He'd play music and I'd paint at the same time. He ended up writing a song for one of our children that had passed away. I ended up painting a painting of the two of us, my husband and I. In the painting, we're looking up at the sky and I made four stars to symbolize our children. My husband said, 'Maybe we should post this on Facebook and let people know what we've been through.' He put it in my mind. I said at the time I wasn't ready for it. I said, 'I don't mind if you post the picture' because he really liked the picture. I was like, 'You can post a picture of the painting if you want. I don't mind that.' He ended up posting the picture and a lot of people really ended up liking it on Facebook. A few of the people that we had told, like our parents said, 'Oh, it's so beautiful. I really like the four stars.' I think people were hinting at it on his Facebook that they supported us and really liked it. That was like a gateway into me feeling a little bit more comfortable sharing our experience on social media. It was a very personal painting to me. The fact that a lot of people really liked it made me feel good. He just posted the photo and said, 'I love this painting that my wife made.' He didn't post anything directly I think more so because I didn't want him to at the time. Maybe he would have if I was okay with it.*" Here, P27 was able to disclose the pregnancy loss indirectly (content-wise) and through her husband via creating and sharing expressive artwork.

When artistic expressions of the loss were understood and well-received by people who already knew about the loss, participants felt supported and encouraged to share their loss more directly on social media than they did before the indirect disclosure. Indirect disclosures through symbolic expression are a disclosure strategy in non-computer-mediated contexts (Greene et al., 2006), and catharsis is an established disclosure goal (Greene et al., 2006). Here I show how symbolic expression serves indirect disclosure on social media, and how that self-expression relates to needs for support.

Solidifying and conveying identity. A need to be seen and have one's pain and strengths recognized by others also motivated indirect disclosures of pregnancy loss. As P19 reflected: "*I just remember this one post on Instagram. I said something like, 'It's been really hard, but things are looking better' something like that. That was the most I said about it… maybe a part of me just wants to be known and to be seen. That was the furthest I could go. That was the most I could say about it and still feel comfortable. I guess just feeling good I wanted to share that feeling that day. It was a good day and I was feeling a lot of hope. Things were going to get better, and they were getting better. I took a picture and I wanted to share that good feeling*." This indirect disclosure was not explicitly about the experience of pregnancy loss, and there was no explicit reference to the reason the poster has been going through a hard time. However, this type of post still met the need of communicating and reinforcing important aspects of identity, specifically strength and resilience in the context of major difficulty.

Protecting oneself emotionally while sharing the news. Some individuals felt it was important to share news of their loss but were not ready to talk about it. Some had left social media following the loss or were not prepared for an exchange about the loss. For those reasons, they asked others such as a partner to deliver the news of loss. Some participants explained that they were not emotionally prepared to be the point of contact, not able to write out the experience because it was too painful, or expected to break down in conversations. While participants mentioned asking others to share the news via other channels (e.g., email, face-to-face conversations) as well, here I report on disclosures via others on social media.

Some participants did not appear in social settings and left social media after the loss, yet they felt like they had to tell others because they had announced the pregnancy. As P2 said: "*I took a complete Facebook break while we were in the hospital. I didn't post anything. My husband posted and tagged me so that people I was friends with would also see. We would discuss what was in the post before he posted it, so I was helping him craft. I didn't want to put anything out. It's not that I wanted to be private. I didn't want to be the point of contact. Everything he put out there, he put*

out for both of us so everyone that I was friends with could see it as well, because we wanted that information out." By asking others to communicate on their behalf, participants tried to protect themselves emotionally while sharing the news.

These examples show that indirect disclosures of pregnancy loss were intentional strategies for meeting needs related to the self. Specifically, these indirect disclosures were a means of keeping a personal record, developing a sense of self and solidifying identity, curating a potential safe support network, protecting oneself from more emotional harm, and expressing oneself cathartically without risking a direct disclosure.

Audience-related Factors

Some participants feared that their audience would judge them or their motivations for directly sharing their pregnancy loss, in particular giving the impression that they were seeking attention or "fishing for responses." Others feared rejection or other negative reactions to a direct disclosure of the loss. These audience-related factors guided indirect disclosure decisions on social media.

Avoiding judgments by the audience. Some participants had concerns around audience judgment or reactions if they directly disclosed the loss, therefore, they engaged in indirect disclosures. For example, P17 said: "*Maybe we send these little clues to people who we think would be empathetic and compassionate without opening ourselves up too wide to the people that we think are going to be judgmental.*" Through indirect disclosures, participants avoided the judgment of some audience members, while also leaving the door open for potential helpful connections.

Similarly, P19 reflected on the lack of trust she felt in her social media networks. She barely knew many of her contacts closely and this made her wary of being judged and rejected. When she wrote an expressive poem about her experience and shared it on her blog, she simply posted on social media that she had posted a new poem on her blog, without saying what it is about or linking to it: "*I think there's a fear that I'm not a very good poet. If it's just my close friends that go to look at it it's like there's no fear of rejection. They will take it to heart no matter how good it is. Since I*

don't know so many of the people on Twitter and Facebook it feels a little more vulnerable to actually say go look at my blog, or go read the poem I just wrote that's really personal to me. It's probably a fear of rejection, or not being as good as I hope to be." She contrasted close friends who would not judge her for the quality of her poem with a large portion of her network whom she thought might critique the quality of her poems. She also gained some degree of privacy and protection by not posting the link or reason for the poem, so only those whom she thought would not judge her would read. Overall, participants explained that direct and explicit disclosures were difficult in part due to concerns around audience judgment and reactions, such as being judged as seeking for attention or fishing for specific kinds of responses; leading to indirect disclosures.

 Feeling out the audience and testing the waters. Indirect disclosures allowed participants to test the waters and gauge what types of responses they *would* get *if* they disclosed directly. This allowed participants to not only speak to the narrower audience who understood their experience and intention without them having to spell it out, but to also gain a better sense of the broader audience without committing to the stigma attached to pregnancy loss. As P5 said: "*I think that when we really want to share but don't feel comfortable sharing, we flirt with that idea by sharing other things and seeing what happens. Seeing what responses we get. Then we still have the opportunity to say 'Oh, just kidding. No. It was just a quote. I just like this quote.' And not have that stigma of being cheated on or being raped or having miscarriages.*" Indirect disclosure enabled assessing one's social media audience and aided in potential future direct disclosures or rendered future disclosure decision-making processes easier.

Platform and Affordance-related Factors

Participants used a variety of platforms to engage in indirect disclosures. Not surprisingly, support groups and forums explicitly dedicated to discussing pregnancy loss, anonymous or not, were not used for indirect disclosures.

Seeking anonymity and lack of overlap with everyday networks. The ability to post anonymously or pseudonymously was an affordance that enabled indirect disclosure, particularly for those participants who were reticent or perceived more risk. Many wanted to avoid sparking confusion and open questions that might arise on non-anonymous platforms. Feeling more anonymous and a lack of overlap with their day-to-day social networks engendered a sense of safety. While some participants shared content created by themselves, others shared content created by others to indirectly talk about pregnancy loss. These included behaviors such as retweeting a blog post someone else had written or sharing a meme or picture that others had shared online. For instance, P16 reflected on how she felt more anonymous on Twitter compared to Facebook and said: "*I re-tweeted stories that other women have written about miscarriage but that's like as close as I'd come. It's not my name. On Twitter, I mostly follow people I don't know like writers or whoever. For me, Twitter is sort of low stakes, like I'm not really vulnerable there. It's not attached to my personal public self and so any interaction I have there, I could kind of discount. I just felt like it resonated with me…*" Sharing content created by someone else was a way of indirectly talking about pregnancy loss. Doing so on a platform where one felt more anonymous provided yet an additional layer of privacy and safety. Participants were able to partially and safely express themselves without risking a direct and explicit disclosure or reciprocal disclosure on their side. While anonymity was not *required* by all participants for indirect disclosures, it was for some.

Temporal Factors

Sometimes participants disclosed indirectly because they felt too close to the loss experience to directly seek support; they were not ready to process and share their emotions. For example, P18 said she posted a photo of her dog keeping her company as she was working from home, captioning the photo that the dog hated when she worked from home, without saying what the context of the photo was to the audience. To her the photo was a marker of how she was feeling at the *time* of the loss, to others – who did not know why she was working from home – it was a photo of her dog

and her working from home: "*I don't think anyone really knew and nobody probably would have read into it at all. I don't think at that point anyone could have said anything really. Everything was just awkward because that was pretty soon after. I had support in real life, person to person. It was just awkward and I just hadn't had time to process everything. It wasn't a good time to be seeking support. I think I wasn't ready to really deal with those emotions until I had a baby, until I had what I wanted.*" This is an example where the temporal closeness to the loss made it challenging to verbalize thoughts and feelings; but this participant still needed to express feelings associated with the loss. Other times, participants shared emotional expressions that hinted at difficulties, without explicit references to pregnancy loss. They were able to engage in this type of disclosure as they had started to feel a bit better – due to the passage of time – but were not yet comfortable with direct and explicit sharing about the loss.

Conclusion

Indirect disclosure strategies include hinting about an experience or an identity facet in such a way that the audience must infer the full message, or explicitly sharing information through another person. These strategies lend themselves to sharing stigmatized or sensitive experiences such as a pregnancy loss, mental illness, or abuse. In this chapter, I investigated the important role of indirect disclosures on social media platforms for women who have experienced pregnancy loss.

I report on 13 interviews with women in the U.S. who use social media and had experienced pregnancy loss, and make several novel contributions to HCI and social computing. I first contribute a typology of indirect disclosure strategies differentiating according to content explicitness, original content creator, and content sharer. I then contribute an understanding of decision factors informing indirect disclosures of sensitive experiences across social media platforms. I find that decision factors are related to the self, audience, platform and affordances, and time. I discuss how people intentionally appropriate indirect disclosures on social media to meet psychological and social needs associated with pregnancy loss. Indirect social media

disclosures have lower risk compared to direct ones. Importantly, sometimes indirect disclosures paved the way for future direct disclosures. I discuss implications for research and design in the Discussion section.

CHAPTER 6. A DECISION-MAKING FRAMEWORK FOR RESPONDING TO SENSITIVE DISCLOSURES ON SOCIAL MEDIA

Introduction

It is common to feel unsure how to respond when a friend shares bad news or a painful experience. What do you say when learning about a friend's serious illness or the death of a loved one? What about when the sharing happens on social media? What if an acquaintance posts that they were struggling with depression? People often need to share painful emotions and experiences and receive support from others (Rimé, 2009). Social network sites (SNSs) are a place where individuals maintain relationships that can be a source of social support (Ellison, Steinfield, & Lampe, 2007; Gray et al., 2013). In this chapter, I explore response behaviors when people disclose sensitive information through posts on SNSs, and we use pregnancy loss as a central example.

When people make difficult decisions to share sensitive information about themselves, they do so in anticipation of a response (an immediate reaction) and an outcome (a change in situation or relationship) (Grinberg, Kalyanaraman, Adamic, & Naaman, 2017; Magsamen-Conrad, 2014). Research has established the importance of the receiving audience in disclosure outcomes (Burke & Kraut, 2016). When disclosures include socially stigmatized or sensitive content, reactions and responses are especially crucial; negative and unsupportive responses lead to stress, negative well-being, perceptions of reduced social integration, lower self-esteem, and fewer future disclosures (Haimson, Brubaker, Dombrowski, & Hayes, 2015b; Tobin et al., 2014). On the other hand, receiving support on SNSs has been linked to well-being, life satisfaction, and future network activity (Lampe, Gray, Fiore, & Ellison, 2014; Trepte, Dienlin, & Reinecke, 2014). Once disclosures are broadcast to an online social network, what happens next? Responses to sensitive disclosures are important to understand if we aim to design social computing systems that encourage supportive interactions.

In this chapter, I investigate why and how people respond when they encounter sensitive disclosures online, such as the loss of a pregnancy. Pregnancy loss is simultaneously a common

experience among women of childbearing age and perceived as stigmatized and uncommon (Luebbermann, 1994; Renner et al., 2000; Shapiro, 1993). When disclosed, people frequently report receiving unsupportive responses and reactions (Moulder, 1994). Therefore, pregnancy loss is an ideal context for studying response to sensitive disclosures. I draw primarily on an interview study with 11 participants who had come across sensitive disclosures on SNSs, including but not limited to pregnancy loss.

The interviews included both an open, semi-structured phase and a phase in which I used vignettes as instruments to evoke responses to disclosure scenarios systematically. In this chapter, I detail the factors that guided decisions to engage or not engage with disclosures that participants perceived to be sensitive. While I did not focus on any particular platform for this study, participants referred to Facebook as the platform they primarily used to connect with others in their daily lives, which is consistent with prior research (Hampton et al., 2011).

I contribute a response decision-making (RDM) framework (Figure 3) that explains factors that form decisions about whether and how people respond to sensitive disclosures on SNSs. The RDM framework includes three major types of factors:

- self-related (i.e., personal and professional expertise, attitudes towards the topic and sharing about it, impression management, privacy, and personal well-being),

- poster-related (i.e., disclosure content, frequency of posting, perceptions of poster's intentions and expectations, visible aggregate network-level support), and

- context-related (i.e., relational, temporal, and wider social) factors.

I organize findings around three types of decision factors (Figure 3) that influenced whether and how participants responded to sensitive disclosures on social media: Self-related, poster/discloser-related, and context-related. In the next sections I describe each of the factors and provide example of decision making that relies on each.

NOTE: This section includes content about people's reflections on seeing content from those in distress on social media.
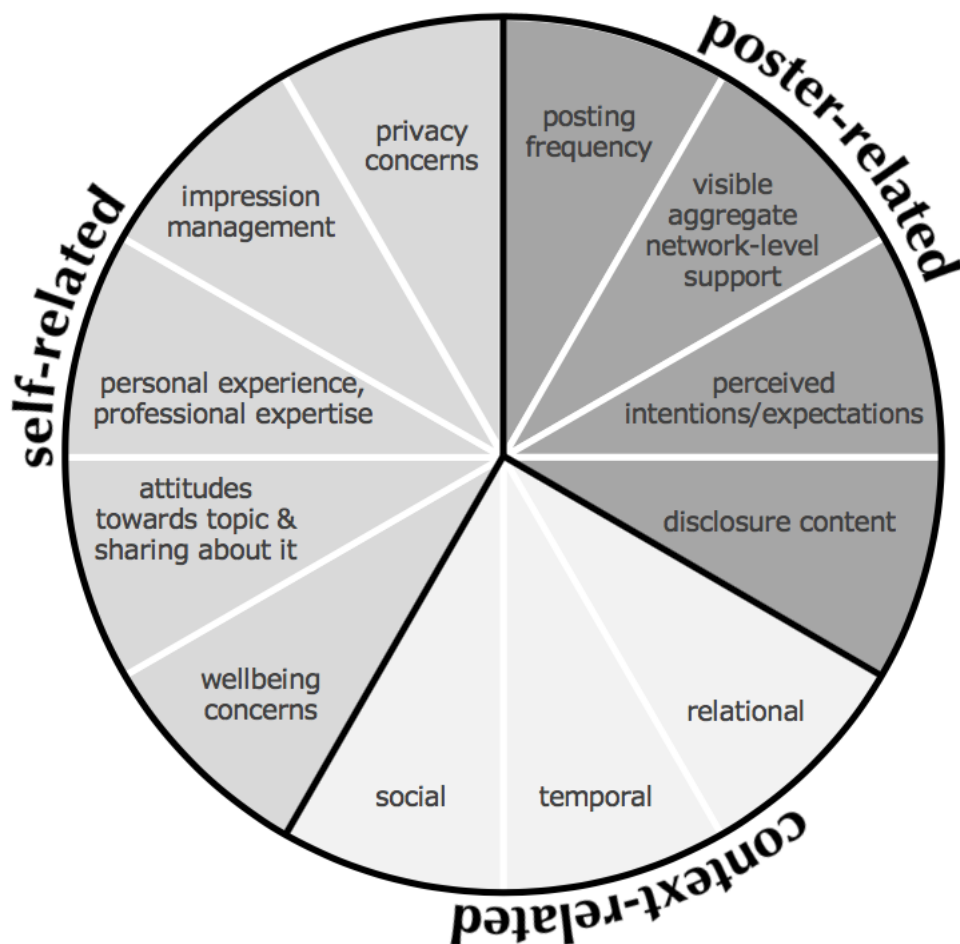
Figure 3. The RDM Framework: Factors that contribute to response decision making in the context of sensitive disclosures on social media

Self-related Factors

Factors related to self that impacted response decisions included: personal experience or professional expertise, attitudes towards the topic and sharing about it, impression management, privacy, and personal well-being.

Personal Experience and Professional Expertise

Personal experience. Participants reflected on whether they had similar experiences when deciding whether to respond. Some respondents felt that it was important to have a close proximal experience, i.e. an experience that was very similar to the discloser. For example, P2 noted that

"*When it comes to things that are sensitive material posts, I try to really only comment on things that I have personal life experience I can bring to bear on it. With something like pregnancy difficulty, I've never been pregnant. I don't feel like I'm coming from a place of expertise or that I have a lot to offer other than generalized sympathy. With things like that, I do feel like that dissuades me from making any sort of comment or interaction. I feel pretty strongly, a personal belief if I am not an expert on something, and I don't have personal experience on it, I'm not an anecdotal expert, it's really unhelpful for me to clutter someone's mental and emotional space by commenting. Especially when this person asked specifically, they asked a question, and they're looking for advice, and I don't feel like I have advice for them.*"" Not having had a proximal experience led to not engaging with a post, generic condolences, or a lightweight reaction such as a "sad face."

People found it hard to relate to, empathize with, or have what they deemed to be a meaningful interaction with the poster in the absence of a similar experience; however, past experiences playing a supportive role also led to the personal experience people deemed necessary for a meaningful response. P8 felt more confident supporting a colleague after a pregnancy loss due to past experiences helping a friend: "*I've never had children. I've never tried for children so it's not something that I knew much about, but having been there for one friend, I felt I could at least be there for another.*" In spite of not having had a personal experience with pregnancy herself, she felt that she understood enough to know what support would be helpful.

Less proximal experiences also evoked and informed responses particularly when participants were able to relate to specific dimensions of the disclosed experience. For example, P8 suggested how people could empathize if they had not had a pregnancy loss experience and the resulting personal experience: "*Even if somebody has not experienced a D&C or if someone hasn't experienced a termination of a pregnancy before carrying it to term, you can relate to spending time in the hospital with a family member or relate to their grief of losing a family member or not being ready to try for a child for whatever reason.*" Similarly, others connected with the grief

expressed in some of the vignettes, without having experienced a pregnancy loss. As P9 said: "*Everybody can relate to that in some way in their lives. Doesn't have to be just like pregnancy. People like to rally around people that are feeling down*." Even others responded empathetically to vignettes based on their experience with healthy pregnancies. As P3 reflected on V2: "*If it was someone I was closer with, it'd be really hard not to respond. I think through the whole pregnancy with my wife I was never relaxed for a moment. I'd probably spend hours and hours thinking about it before I said a word because I'd be really conscious about how sensitive every little thing is when you're in that state of grief and anxiety. It just amplifies everything*." P3 was able to feel for the poster, based on his experience with having a child and not having dealt with pregnancy complications in their pregnancy. In summary, when participants came across sensitive disclosures, they connected with the post either by virtue of a having had a similar personal experience or connecting to specific aspects of the experience. Familiarity and experience on a personal level provided grounds for empathy, which is an important feature of online support groups (K. B. Wright & Bell, 2003). Here, I show that when personal experience was not present, people were less likely to respond to sensitive disclosures.

Professional expertise. Professional expertise refers to education and training that gives people confidence that their responses will be useful in the absence of personal expertise. For example, P5 was in school for East Asian Medicine and knew about postpartum depression because of her profession. She said: "*Medically, I've had to treat people who are depressed and who are in grief states and I know what helps. From a medical perspective, from a physical, emotional standpoint. So I would engage with that more on that level and less on the level of wanting to be a parent or the pregnancy. Because I feel like I can't speak to that part of it*." When in distress, people may need various kinds of support (i.e., emotional informational, esteem, instrumental, network) from others in their network (Cutrona & Russell, 1990). While some may have personal expertise and may be better suited to provide emotional, esteem, or network support, others may be better equipped to provide informational support and advice because of their professional expertise.

Not having this professional expertise on the other hand, sometimes inhibited responses and engagement. For instance, P3 reflected back on a Facebook friend's posts about suicidal thoughts: "*I think a lot of it had to do with almost a violent tone that she was taking where I don't think I had the skills, I was like this person needs professional care and therapy that I'm not capable of. We're definitely not close enough to where I'd be the one who would make that call like push for that, but I think I know my limitations about the things I'm willing to engage in.*" The relational context within which these disclosures happened combined with the tone of the disclosures and the participant not having the required professional expertise led to non-engagement with the social media post about suicide. Similarly, P9 reflected on V4: "*I feel like this is one of those that's like it's got so much detail and so much specificity that it's like this person needs to be talking to a professional counselor not just like a random group of friends and acquaintances… I feel like, again, it's like one of those things that falls into like, this is so personal. It's so intimate and it's so specific that there are professionals trained to help people with this as opposed to putting it out into the greater world and hoping for the best. It's like the whole idea of going to Google to look up your symptoms and then convincing yourself that you're diagnosed with whatever Google tells you versus going to a doctor… My initial response is like, 'You need professional help with this,' like, 'I can't help you with this.' I think it's like, I mean they specifically say, 'I'm lost, I'm in an emotional mess, I haven't been able to function. I feel guilty or don't trust myself.' They are using lots of questioning language, lots of like 'I'm not a good person' language or questioning their ability as a human. I think that that's what triggers me also to think that like this person needs somebody that's professionally trained to deal with somebody that's in such an emotional state.*" In summary, when participants felt they were not able to connect to a post on a personal level, having relevant professional expertise was a secondary factor that contributed to engagement and response decisions.

Sometimes to make up for the lack of personal experience and professional expertise, participants engaged or imagined information seeking online and offline to gain some level of expertise through other means. For instance, P8 reflected back on when her friend posted about pregnancy loss on Facebook: "*I think that a lot of people responded to her post. Being since she didn't come from the most supportive family, the people that responded were kind of the family that she chose in*

her life as well as the people from the community of women who had experienced miscarriages... I was worried it was empty words... Initially the first thing I did was I sort of googled 'How do you comfort somebody after a miscarriage?' I looked it up because I didn't know. I didn't feel like I could ask because she had so much going on in her life and so much grief. She shouldn't have to educate me on how to help her so I kind of looked up how to talk to somebody who's had a miscarriage. I know this sounds so cheesy of a thing to do, but I was like ... I didn't know where else to look but the internet. That's not something my mom and I ever talked about. I didn't really know much about miscarriage, only that it happened to some women. I didn't know how common it was, but I kind of learned from some advice column. 'Hey. These are the things you don't say, and here are the things you do say.' So I've kind of tried to use that as a script to open the conversation to always remember that she had two daughters even though they weren't able ... Even though they didn't survive for medical reasons." Similarly, P6 reflected on V2 and said he would ask his mom – whom he knew had personal expertise – if she would be willing to speak to the poster: "*I think if I actually did see this the first thing I would do is go and talk to my mom because I know that she has had a miscarriage. I would ask her if she were willing to talk this person because I know my mom if she were willing would have a lot more to offer to her than I would. Depending on what my mom said I might comment like, I might tell them that she is willing to talk to them.*" While these participants did not have the expertise or experience to provide help initially, they solicited others' expertise and experience to provide helpful support to the poster.

Attitudes Towards the Topic and Sharing About It

Recipient's attitudes about the topic and whether it is appropriate to share sensitive content on social media helped them decide whether to respond to sensitive posts.

Participants made it clear that unwillingness to share their own struggles online made them uncomfortable with engaging with such posts from others. As P2 said: "*I think the fact that I'm more reticent to share personal information of a sensitive nature on social media means I am also a little bit more reluctant to comment on things of a personal nature. In part, I think that's because it almost feels unfair. I'm not willing to open up on social media, so I shouldn't comment on other people opening up on social media, either in a positive or negative or any sort of way. I don't feel that I have the space to comment if I'm also*

not being forthcoming." In this way, P2 suggests that openness should be reciprocal, and if they could not reciprocate, they avoided interactions around sensitive disclosures altogether. The social exchange perspective suggests that when disclosures are made in dyadic relationships, an informational imbalance is created and people try to rebalance by reciprocating with information about themselves (Archer, 1979). This process becomes complicated on social media when reciprocation would mean disclosing to a large group of people, instead of one.

Some participants believed sharing negative, sensitive, or personal content is not appropriate or useful, and this led to hesitation in engaging with these kinds of posts. As P11 said: "*For me it doesn't seem appropriate to post things like that on social media. It feels like you really need attention or you really need to feel like you have some sort of online support, and I don't think Facebook is really conducive for that type of supportive environment, sometimes it gets really annoying, I think that posting sensitive topics on social media is not really going to get people anywhere.*" The meanings people associated with sharing sensitive content and perceptions of appropriateness were also important factors in response decision-making.

Finally, not sharing ideology about a relevant topic with the poster informed the decision to refrain from responding. For example, P9 held pro-choice views and had seen a post about pregnancy loss from someone who held pro-life views. This difference made it difficult for P9 to provide support to the poster: "*She's anti-abortion, and she continually posts stuff about being anti-abortion and so I think the whole miscarriage thing and that became this intertwined interaction possibly at the time she posted it.*" People evaluated the poster's ideologies and values, and when the difference was somehow meaningful to them, they did not engage with sensitive posts of that topic, even if posts expressed feelings of grief and sadness.

In summary, not being comfortable posting about one's own struggles, not having a favorable view towards public intimate disclosures on social media, and not sharing the same ideologies and values with the poster were factors leading to non-engagement for some participants. Perceptions

of similarity with the discloser in terms of values, ideologies, and social media behavior are important factors in response decisions.

Impression Management

When deciding if and how to respond to a sensitive disclosure online, participants considered how a public performance of support would reflect on them. Specifically, being judged as inauthentic or having an otherwise improper response caused people to remain silent or strategically engage is less visible ways.

P2 observed that: "*When I see other people making comforting comments or sympathetic comments on someone's post or making unsympathetic comments on someone else's post, I think of it more as them posturing and saying this is the person that I am. I'm someone who is comforting. I'm someone who is religious. I'm someone who is X, Y, or Z, rather than them actually wanting to comfort a person.*" This perception of performing for an audience rather than the poster who is in distress, led some people to not engage with posts in public forms. This perception is in part enabled by the potential visibility of a responder's activity to people other than the original poster. Prior work (e.g., [17,38,82]) suggests that public engagements with posts through "reactions", "likes" or comments are gestures of support provision. Here we see a different interpretation of these interactions by potential respondents who view them as performative and not genuine, leading to the decision to not respond. P2 also commented on the lack of cues in social media to help guide responses: "*It's a lot easier for me to converse with people when I can see how they're reacting in real time, and so it does feel very vulnerable, even though I'm not the one who's sharing the sensitive material to begin with, it feels vulnerable to comment on it because you're not sure how people are going to respond.*" This shows how social media users have impression management concerns when considering interacting with a post they deem to be sensitive.

Sometimes participants addressed impression management concerns by combining communication channels with different levels of publicity (i.e., liking, commenting, private messaging). For example, some perceived "liking" as less performative, less visible to others, and

"more anonymous" to others compared to commenting. P5 noted that liking a post: "*feels more anonymous, because it's like ... I don't think it's very likely that somebody's gonna scroll down all the likes and look at who likes it. So it feels like a less ego-driven way of supporting somebody in a very minimal way. And then you have the option to engage more intensely if that seems appropriate.*" This example illustrates how the platform enabling various kinds of interactions with different levels of perceived visibility and resulting anonymity help with impression management concerns. P10 reflected on such an occasion for "more intense" communication when a friend had posted about pregnancy loss and she initially commented on her post, but then decided to reach out privately as well: "*Well I wanted to comment first and see if she would reach out and I know there were a bunch of comments all saying the, the vast majority of them saying the same thing. I was like, 'I think I should reach out to her personally because I'm also her friend'. So that was my decision to reach out to her privately...I wanted to see if she would reach out because I didn't want to also overstep my boundaries if she didn't want to reach out but I just also wanted to like, I guess social media has this way of like, you can see overall how much support you get, and I wanted to at least show her that I'm part of a community that does stuff for her online. 'Cause if she's willing to post that online, I mean she's kind of seeking, I feel like she should get some reassurance...affirmation from it. So showing that there's a lot of people that support her and I want to be at least one of them that supports her too. So that's why I did that. I didn't want to also be seen as like someone that's like, comments online and then leaves her alone. Especially, since I'm pretty close to her. I wanted to make sure that I was reaching out to her in a more private, like, one-on-one connection.*" Her decision to engage with her friend's post in several ways was informed by (1) her impression management needs related to being an individual who reached out in a more "intense" and private way to a close friend in need while also ensuring that no boundaries are crossed, and (2) contributing to the poster's visible aggregate network-level support.

Sometimes communication was motivated by how not reaching out would come across to the poster in particular, especially when those who may not be particularly close to the poster may also be engaging in public demonstrations of support.

In summary, participants considered how their interactions in any form (i.e., comment, "reaction", private contact) would be received by the poster or by others whom they would be visible to. Concerns around anticipated negative judgments or receptions led to non-engagement for some participants. Prior work suggests that imagining oneself in negative interactions on Facebook is linked to lower feelings of belonging, self-esteem, control, and meaningful existence (Karlen, 2011). Here I show that it could also lead to not engaging with others' sensitive disclosures or requests for support. By not engaging with sensitive disclosures, some participants attempted to protect their own "face" (Goffman, 1959) due to concerns about their interactions not being received well.

Privacy Concerns

Because responses to posts are currently governed by the privacy settings of the poster, participants described carefully considering the privacy implications of a potential response. As P8 said: "*I do check if the privacy setting on their post is public. That will sometimes affect if I comment or if I message them privately to offer support. It will affect the extent to which I am open in my comments. I have one friend where everything he posts is a public post. I don't want to call anybody an over-sharer, but he's just like - His audience is the world when it comes to Facebook. I actually don't feel comfortable posting anything super personal because I know that like a lot of people follow him on Facebook.*" Some participants reported they were less likely to engage with posts in order to protect their own privacy.

Other participants suggested that spaces like Reddit or online support groups would make it easier to provide advice and detailed responses, because anonymity and/or topic-specific spaces reduce the need to worry about who is watching or what the consequences would be. For instance, P4 said: "*Since Reddit is a lot more anonymous, people also tend to want to give their advices to strangers. On Facebook you don't feel like you can just knowledge dump on people and have it be okay… I guess it's also the culture of Reddit, in addition to anonymity … People are going there with that in mind. Someone who feels like they have something to say can be pretty blunt, doesn't necessarily have to worry about offline socialization.*" This shows how the lack of overlap between one's audience on Reddit with that of

their physical world (similar to Facebook) network enables more disinhibited responses and privacy regulation. Similarly, P9 said: "*I'm in a moms group specifically, a private closed [Facebook] group. It's a more private group where it's not just anybody and everybody that you're friends with. If it's in there, I would be more likely to comment just because that group is set up for that kind of support system, otherwise I probably really wouldn't comment.*" Control over one's privacy sometimes through enacting anonymity and sometimes through having a specific audience and topic made it more likely for some to engage with sensitive posts. While prior scholarship (e.g., (Haimson et al., 2016; A. E. Marwick & boyd, 2011; Vitak, 2012; Vitak & Kim, 2014)) and Chapter 4 of this dissertation has uncovered aspects of privacy concerns (e.g., context collapse) that make disclosures on social network sites challenging, here I show that concerns about audience and privacy affect decisions about how, why, and when support or other response kinds are offered following disclosures. These concerns are directly informed by platform features such as degrees of anonymity and identifiability, control over audience and visibility of responses to them, or topic-specific spaces. I return to these in the Discussion chapter.

Personal Well-being

Some participants felt that engaging with a post, or seeing others' responses to the post would be emotionally draining. For instance, P5 reflected on V4 and said: "*With this, just by reading it, the person is asking us to do some emotional labor for them. She is unloading online so that anyone that catches it is holding some of that pain. But I think that not everybody wants that. Not everybody wants to read about really difficult things that people are going through.*" Participants described exposure and responses to painful or sensitive disclosures as a kind of emotional labor that the poster asks the audience to do. Sometimes this led to non-engagement because participants did not want to do that emotional labor. P7 explained: "*I wouldn't respond. One of my biggest things is to try to reduce sadness in my life. If I respond to it, then I'm drawn into it, and I don't want to be.*" On another note, P2 said: "*I'm not as comfortable commenting on either things I don't have experience with or that are just, it's almost too tender and raw for me, too vulnerable for me personally.*" The emotional labor of exposure to such posts or

interactions around them was linked with triggering feelings or being drawn into discussions that one did not want. Experimental large-scale research has found support for the "emotional contagion" (Hatfield, Cacioppo, & Rapson, 1993) phenomena on Facebook, meaning people pick up on emotional states without a need for direct interaction (exposure to content is enough) (Kramer, Guillory, & Hancock, 2014). Here I show that for some participants, awareness of how their own well-being may be affected by responding to others' sensitive posts or requests for support led to non-engagement.

Poster-related Factors

Factors related to the poster and the ways they disclosed their experience played a role in how and whether participants decided to respond. These included disclosure content (i.e., direct vs. indirect support seeking, disclosure message details), frequency of posting, perceptions of poster's intentions and expectations, and opportunity for what I refer to as "visible aggregate network-level support" (i.e., the perceived amount of support available to a person in aggregate from their network).

Disclosure Content

Perceived directness of support seeking. Sometimes a discloser explicitly asked for help or some kind of reaction from the audience. This meant participants did not need to guess the needs of the poster or their motivations for posting. For instance, P5 reflected on V1a: "*I do think that because the person is asking a pointed question, that they're gonna get responses. Because they put it into question format at the end. So then the person that is reading it knows that they're being asked for information. They're being asked advice. So that as the reader we're not just reading someone's thought, but we're also asked to engage with it very, very specifically, very directly.*" Also, P6 reflected on V2: "*It's easier with this one because they specifically say they are looking for help and just the way they are talking about it seems a lot more involved and calm even though they are obviously upset. It's just a lot easier, I feel a lot more invited to offer them my help.*" Often, specifically asking for support made it more likely that people would respond

or have an easier time deciding. Vagueness and indirect support seeking made it harder and less likely that participants would respond.

Participants suggested that direct support seeking prompts reciprocal disclosures from those who have had similar experiences. As P3 reflected on V2: "*I would expect to see other people sharing their own horror stories of hospitals and death and whatnot. I feel like people need to talk about those things and don't often get the chance to, so when someone specifically ask for other people's experiences and how they dealt with it. I think it frees people up to really share that*." Direct support seeking meant participants felt more comfortable with sharing their own relevant experiences with the poster compared to indirect support seeking. Conversely, when intentions of the poster were not easily comprehendible for the participants, they were less likely to respond. For example, P7 reflected on V4: "*I don't really understand what she's trying to convey or what she's asking for, or maybe she's not even asking for help. That's the thing. I don't even know how to respond*." Similarly, P9 reflected on V3: "*I guess because I just I don't feel like they're necessarily needing a response, they are not necessarily reaching out for help or advice*."

Participants organically noticed when a discloser sought support directly (e.g., by asking a question) or indirectly (e.g., by hinting at a need). In face-to-face contexts, direct support seeking is more likely to lead to helpful support while indirect methods can be misunderstood or ignored (Barbee & Cunningham, 1995). Prior work suggests that mental health related disclosures on Instagram with direct support seeking receive more comments than those that do not directly seek support (Andalibi et al., 2017). Here, I provide insights about why prior research has observed these behaviors on social media.

Disclosure level. The level and amount of information included in a disclosure message led to different perceptions of need and different response behaviors. Some thought a detailed post conveyed that the poster was in need, as described by P4 reflecting on V2: "*It's long, so clearly they're putting effort into this or want to get something off their chest.*" Others thought that a short post signaled

intense pain. As P2 put it looking at V3: *"...almost like they're hurting too much to give more detail. It would almost be more painful for them to give more detail."*

Some participants shared how lack of detail made it difficult to respond in helpful ways and encouraged lightweight interactions such as liking a post. For example, reflecting on V3, P2 said: "*It feels like when someone is more forthcoming, you can be more forthcoming. On a post with more detail, you feel like you can respond with a little more detail. With something like this, it's very just a broad statement and a short statement. I feel like the best short statement I could give back would be to just 'like' that.*"

Detailed disclosures were seen to prompt responses such as suggesting professional help, probing questions, or reciprocal disclosures. Reflecting on V4, P3 said: "*I feel like [this post] might even trigger some sort of kind of like not angry but more like probing questions. Because it's a lot to share, it's a lot of personal stuff to share. I wouldn't be surprised though if there were people with similar stories to share. I think it goes back to the amount they're sharing. It welcomes people to offer.*" Yet, detail could also be perceived as "too intimate." Especially in the absence of a close relationship, too much intimate detail led to non-response. As P1 said of V4: "*Some of the things that's talked about in this post are just a little bit too personal, too intimate that I wouldn't want to make them feel uncomfortable and talk to them about it.*" The perceived intimacy of the content had to be proportionate to the perceived closeness of the relationship for a comfortable response act to take place.

The amount of time passed since the distressing event communicated through the disclosure message also informed the resulting sense of urgency and contributed to response decisions. For example, reflecting on V3, P6 said: "*This person isn't or at least they wouldn't seem at the epicenter of their problem, of their distress. Just the amount of time that's passed, I would feel like it was less urgent that they be supported so thus less compelled to I don't know comment.*" In this sense, when posters shared distress about an event that happened some time ago, responders did not always feel there was an urgency to help. On the other hand, where perceptions of urgency and the poster being in the heat of the moment existed, some were more likely to reach out to provide support, or example by privately connecting with the poster. For instance, reflecting on V4, P9 said: "*Really the one that*

sticks out to me the most is the last one that makes me feel uncomfortable in the way that this person actually

needs help or I'm worried that this person is in a situation where ... I wouldn't say that it implies suicide or

anything like that, that I would feel weird about not, almost feel weird about not responding in that case of

like, 'Does this person really need help or they're going to do something that's dangerous to themselves or

somebody else?' In that case I feel like it's almost like a human responsibility to respond to somebody or to

have some kind of interaction with that person. I think if it were to be a little bit more doomsday then I would

possibly respond just based on that." These examples show how the perceived level of urgency and

the time passed since the distressing event communicated through the social media post content

informed response decisions in different ways.

In summary, details sometimes made it easier or felt as more necessary to connect with a post

but sometimes raised barriers if they made the post too intimate. Participants formed perceptions

about how the poster was feeling and coping based on the level and kind of details provided in the

disclosure. Prior work has identified post details that are likely to attract responses (Andalibi et al.,

2017; Feng, Li, & Li, 2016). Here, I provide evidence about why provision of details leads to more,

no, or less engagement.

Frequency of Posting

The frequency with which the poster disclosed feelings and information about a distressing event

affected how their audience reasoned about potential responses. Specifically, I heard repeatedly

that it was exhausting to come across frequent posts. Some wondered about attention seeking and

had concerns about investing emotional labor, others wondered if responding to the post would

mean or change anything. These thoughts made participants reluctant to engage with a frequent

poster. In this context, P8 said: "*Their network might be emotionally exhausted from supporting this*

person." Relatedly, P10 reflected that: "*If this person is always disappointed and depressed... no matter*

what I do it doesn't feel like they're supported. I would kind of be turned off in saying something. Because no

matter what I say, I don't feel like it's going to help." P11 suggested that frequent posts were a type of

attention-seeking behavior: "*When people start posting it repetitively, it gets annoying, honestly because*

it feels like they're looking for attention." Prior work in face-to-face settings suggests that constantly expressing pain might drive away those who might have otherwise provides social support to a discloser (e.g., (Bonanno & Kaltman, 2001)). I found that frequent social media posts led to feelings of exhaustion and powerlessness as well as negative perceptions of attention seeking, all of which affected response-related decision making.

Perceptions of Poster's Intentions and Expectations

Participants quickly assessed why the poster had shared the post and who they expected to view it and respond. These assessments informed response behaviors. Some participants described audience cues in the content; for example, comparing V1a and V1b, P6 said: "*It almost feels they are asking just people who are actually in their lives, people that are close to them to answer the question (V1a). In the second one (V1b) it implies that there aren't those people, that no one is there to answer the question really. It's much more of an invitation for people who aren't so close*." Other participants also reflected that the intended audience for V1b were people the poster was not close to. Reactions to these vignettes demonstrated how perceptions of intended audience helped participants to decide how to respond to disclosures.

The poster's identity and relationship with the participant helped the participant decide whether they were part of the intended audience. This was important because if participants did not feel like part of the intended audience, they refrained from responding. P4 described two main criteria for assessing whether they were among the intended audience when reflecting on V1 if he saw it on his Facebook feed: (1) If the poster would say the same thing in person, and (2) if they were close and/or in recent contact with each other: "*It doesn't really feel like my place, even though they're posting this to a space that I can see it, it doesn't feel like it's directed at me in any way, if I don't really interact with them much… If I can't imagine the person posting would say it to me in person, I think that plays a pretty major role in whether or not I feel comfortable commenting on it*." He further explained how this goes beyond the vignette example: "*I think it's not necessarily about this, but more generally, if I post something to Facebook, I have a group of people, whether or not I realize it, I have a group of people that I am thinking*

about, reading this. The people I interact with or the people are on my mind, people I assume with like and respond to this, or whatever. If I haven't been interacting with this person, I assume I'm not one of those people."

Some participants also assessed the poster's needs, not just when they first made a disclosure, but long after. For instance, P8 had checked in with her friend who had posted about pregnancy loss periodically, because she believed her friend needed her to not forget her loss. She said: "*... I try to reach out both posting but also checking in with her regularly. I try to check in with her every six months at least even though we live far apart…. I think what she really wanted most and she conveyed really well was for people not to forget that she had two daughters before…It's still hard. Miscarriage is not her fault. Biology sucks. But just like have her friends not forget that she had two daughters before and to acknowledge those deaths, to acknowledge her and her husband in grief…I would really ... I would kind of want to be able to put on my calendar to remind myself 'Hey, I should check in with so and so' without necessarily making that public data. Right? I think it's really easy to forget about people on Facebook sometimes because it moves so fast.*" Assessing the need to not be forgotten after time had passed, led to some participants' periodical check-ins with closer ties after their initial disclosure of the distressing experience, although sometimes remembering to do so was challenging.

Finally, the perception of a carefully curated online network (by the poster) was linked with feeling like they were part of the intended audience. P3 reflected on his own experiences: "*If Facebook was curated more carefully by everyone… I'd feel like this person is definitely someone who values what I have, like my ideas or my input so they're sharing with me as well, not just sharing it to the masses. If you have friends who have 70 or 80 friends on Facebook, and I know because I'm one of them that they are speaking to me, but it would depend on who is posting that. It falls under that category of who is the person posting this because if it's somebody with 3,000 Facebook friends or someone with 70 or 80. It's a little different situation maybe.*" The perception that messages were broadcast to a large crowd reduced the feeling of being part of an intended (and valued) audience. This perception was in part formed by Facebook enabling one-to-many disclosures to sometimes very large audiences. I will come back to this in the Discussion chapter.

In summary, sometimes the disclosure message helped participants assess who the intended audience of the poster was, other times relational closeness or perceptions of the poster's network played an important role. Prior work suggests that people have an imagined audience when they post on SNSs, and this imagined audience fluctuates (Litt, 2012). Here I find that when people come across a sensitive disclosure, they assess if they were within the poster's imagined audience as a response decision-making factor.

Visible Aggregate Network-Level Support

Some participants suggested that when posts attract public responses, that means that the poster has some "overall" support, and this will help the poster feel better. The perception that public interactions with a post, even if lightweight, communicate that the poster is supported, led them to engage with posts to be a part of this overall aggregate support. Of course, this aggregate support would only be materialized if others also publicly engaged with the post prior to or following the participant. I call this "visible aggregate network-level support." P4 reflected on how he would feel if his sensitive disclosure did not attract public interactions: "*If I were to post some issue I was having, on Facebook, it would be because I wanted some sort of swell of support from a bunch of people I know or barely know. If no one sees it and it gets like two likes and a comment, that doesn't feel particularly good, it feels like you don't have support.*" P6 further explained how a comment to an acquaintance would be valuable only accompanied by others' responses: "*For me not knowing them very well it probably would be more like a quantity thing, like if they saw just how many people cared it would impact them in that way. Otherwise I don't think my comment would have much individual importance.*" Relatedly, P2 said: "*I feel like if they go away and come back to Facebook, and then it had 50 likes, they'll feel that support of people having read it and acknowledged them.*" Although some participants described generic comments or light-weight interactions as unhelpful, here I find that in aggregate they can be intended to be part of a supportive community.

Getting responses has been shown to be important from the poster's perspective, even if the quality is not high since it shows that someone cares for the author of the update (Gray et al., 2013).

Here, I show that participants sometimes engaged with sensitive disclosures or requests for support publicly, not because they thought the individual interactions were meaningful on their own necessarily, but because they wanted to contribute visibly to visible aggregate network-level support. The visibility of interactions with a post in aggregate (e.g., number of interactions) contributed to this factor's role in response decisions. In other words, if seeing this aggregate support was not a possibility, then contributing to it would not be a concern or possibility either. I will return to this in the Discussion chapter.

Factors related to the Disclosure Context: Relational, Temporal, and Social

I found that relational, temporal, and social features of the context in which sensitive information was disclosed or support seeking occurred, affected response decisions.

Relational Context

Most participants described being likely to engage more with a disclosure if they had a close relationship with the poster. P5 explained: "*The more I know someone, the more likely I am to engage with them, in general. I think there's a hierarchy of engagement where something feels like a very minimal support that you can offer and it's quick and low commitment and then there's an escalation of commitment and time and emotional labor.*" Similarly, P2 described a spectrum of responses dependent on relational closeness: "*I think there's a certain spot on the spectrum to I don't know you at all to I know you really well where it's like yeah, I'll like it, and a little further along, I'm like yeah, I'll comment, and then a little further, like yeah, I'll make a phone call.*" Participants used insightful metaphors such as a "spectrum" or "hierarchy" to refer to the different ways they were able to engage with a sensitive disclosure based on the relational context in which the disclosure had occurred. I return to this ability to engage with disclosures on a spectrum in the Discussion chapter.

Close relationships frequently resulted in multiple responses in both more public and private channels and sometimes only private channels like phone calls or direct messages. For example, P1 explained that when a good friend "*posted about her miscarriage two years ago, I posted on Facebook.*

But I also picked up the phone and actually called her. I was close enough to her that I felt comfortable calling her. I wouldn't just do that to all of my friends." Others chose to privately message the poster in addition to publicly engaging with it in order to allow the poster to respond on their own time. P8 said: "*Depending on the relationship, I would reach out privately if we were close. I would not if we were not. I would want them to have the opportunity to process that offering without the pressure of a response.*" Another reason for private messaging with close connections was desiring a private space for conversation. On this note, P4 said: "*It's just the idea that it doesn't feel like I want some other person entering this conversation with us, it feels like I want this to be a space for the two of us.*" Others noted that if they learned that a close friend had suffered a pregnancy loss through a social media post, they might feel excluded or hurt that the news was not delivered more personally, but would still respond.

Participants described being more willing to respond to posters with whom they wanted to strengthen or maintain a relationship. P11 explained a non-response reflecting on a prior experience: "*There wasn't anything that I could say that I felt like I needed to say it in order to increase the value between our relationships.*" P4 suggested that trying to maintain or reestablish a connection would lead to a response, particularly following other interactions: "*There are people who have fallen out of my life, just since we live in different places, and have other friends. Every once in a while, I'll comment on a photo of theirs, they'll comment on a photo of mine, whatever. That is trying to maintain or reestablish a connection. If soon after that they also post something like this, then it seems like it's more appropriate [to respond].*" When participants felt engaging with a post would not change their relationship with the poster or did not desire to strengthen a relationship, they decided to not engage with the post, when they wanted to strengthen a connection, they responded.

Prior work suggests that relational closeness and recency of communication both influence expectations of feedback from Facebook connections (Grinberg et al., 2017), although closeness is not linked to Facebook communication behavior, but interaction reciprocity is (Vitak, Ellison, &

Steinfield, 2011). Here, I find that closeness, relationship maintenance, and interaction reciprocity all inform decisions to respond to sensitive disclosures on SNSs.

Temporal Context

Some participants mentioned that the amount of time they have or the time of day during which they see a disclosure plays a role, although not the most important role, in response decisions. P9 said: "*I think it probably comes down to like where I'm at in my day, and if I'm really spending time on social media or not.*" Similarly, P1 said: "*Closeness is probably the first priority, but I would also say that the amount of time I have for a proper response plays a small role.*" Many explained how often they mindlessly browse social media in a rush when they see sensitive content. Because of the seriousness these kinds of posts required in response, many would not respond to them or would engage in light ways, if the time was not right and they could not pay attention to the post at that moment.

Social Context

Responses from others affected participants' decisions about how and whether to respond. Participants commonly used others' comments to assess what needs the poster had, and what type of support they were getting. As P2 said: "*I did purposefully go through and read the comments… I wanted to make sure that she had some support because whether or not I know her very well, this is super difficult, and I feel very sad for her. To kind of comfort myself almost, I wanted to make sure there were people reaching out to her.*"

In some cases, the existing comments chilled responses. For example, seeing comments that deviated from their beliefs (e.g., religious views), as P7 said: "*I'm looking back to this, I did not respond to it. That's the thing is, I didn't know how…People were talking about, 'I'll pray, I'll pray, I'll pray for you.' But since I don't pray, I don't write that.*" In other words, sometimes others' comments acted as cues for what would be expected or appreciated, and to decide how to respond. When participants felt they were not able to provide that kind of response or support (e.g., prayers in the

example above), they decided to not engage with the post. If the poster seemed to get support from closer friends, participants were also less likely to engage with the post. P6 said: "*Suppose I didn't know them very well I would probably look at the other comments to see if other people that they do know well are offering them this help and if there was a lot of that, I probably wouldn't leave something.*" Participants used others' comments to assess whether they could offer something meaningful in the context of other social interactions. Reflecting on V4, P3 brought up the case of defending the poster against potential negative responses as a meaningful form of support: "*I wouldn't respond unless I saw they were being attacked for this post, then I would like to think I'd be the kind of person that would defend them.*"

In summary, others' comments worked as heuristic cues about others' opinions and the poster's support network and helped in deciding whether and how to respond. In online communities, through the mechanism of "social proof" (Cialdini, 2001) people are more likely to comply with a request if they see others have done so as well (Kraut & Resnick, 2008). An experimental study with students posting about roommate conflict on student.com also found an association between the supportiveness of others' comments and the quality of readers' supportive messages (S. Li & Feng, 2015). Here, I find that others' comments helped participants evaluate the poster's needs as well as whether they were being met and informed decisions to respond. The visibility of others' comments or interactions that came before one considered responding to a sensitive disclosure was an important feature to enable the assessments that some participants made to make their decisions. I will come back to this in Discussion.

Conclusion

When people disclose information on social media that is sensitive or potentially stigmatized (e.g., mental illness, pregnancy loss), how do others decide to respond? I used interviews and vignettes to provide a response decision making framework (RDM) that explains factors informing whether and how individuals respond to sensitive disclosures from their social media connections. This is important because to design social computing systems that encourage supportive interactions,

designers need to understand how people decide to respond on social media to others who are in need. Using pregnancy loss as a central example, I make a novel contribution to HCI and social computing by providing RDM. These factors are broadly related to the self, poster, and disclosure context (i.e., relational, temporal, social), as I detail. I also uncover the socio-technical features of social media sites that inform these decision factors. These include: flexibility to engage with disclosures on a spectrum, interactions' anonymity and identifiability degrees, visibility level of one's own and others' interactions, specific dedication of a space to a topic, and the one-to-many nature of social media disclosures. I discuss implications for research and design in the Discussion section. Findings include how people's decisions are complicated by balancing their own needs (e.g., privacy, well-being) as well as the posters' (e.g., support) when seeing what they consider sensitive posts on social media. While prior work argues that social media sites should attend to needs of those who may want to engage in sensitive disclosures and seeking support, here I uncover how they should also meet the needs of potential responders and those who may come across these shared content and may want to provide support. Designing for seeking support is not enough, and once that happens designs should facilitate support provision. I also argue that social media sites should facilitate the visibility of network-level support, particularly in socially stigmatized contexts, as while more intimate and private conversations could follow disclosures particularly from closer ties, privacy enhanced ways of making visible interactions around sensitive disclosures plays key roles in response decisions as I discuss. I outline avenues for future research and design that facilitate support seeking *and* provision in stigmatized contexts on social media in the Discussion chapter.

CHAPTER 7. DISCUSSION

In this dissertation I address a foundational problem: how we can design social computing systems that facilitate disclosures of difficult and stigmatized human experiences and enable supportive interactions to form around them. I make theoretical contributions to our understanding of stigmatized disclosures, seeking *and* provision of social support across social media platforms, and how disclosures and response behaviors are interconnected. I also provide design concepts and guidelines to improve the experiences and well-being of marginalized and in-distress populations as well as others in their networks who may come across certain social media posts from individuals expressing distress. In what follows in this chapter, I discuss the findings presented in Chapters 4, 5, and 6 respectively.

Direct Disclosures of Stigmatized Experiences on Social Media

Based on interview data, I 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, I 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. I 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. I 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. A timely example of how these findings may extend beyond the pregnancy loss context

is the #MeToo movement that gained traction on social media platforms to raise awareness about sexual abuse and assault. The theory of Network-Level Reciprocal Disclosure suggests that it is likely that by seeing others say #MeToo, those who did end up saying #MeToo as well, were inspired and felt safer to do so themselves, and wanted to be a source of support for others. It is likely that others' disclosures made them feel like they were not alone, and that there are others they know in their life who have also experienced abuse. Seeing reactions to others' posts could have made it easier to gauge their potential audience's reaction as well. Some may have used #MeToo to take control of their story, share as part of healing, receive support from others, and contribute to constructing a societal conversation about abuse. Survivors who did not say #MeToo at all or those who said #MeToo without sharing details may have also considered similar decision factors I uncovered in this dissertation leading to non-disclosure or less disclosure.

Disclosure Decision-Making Framework

My decision-making framework shares some features of a model proposed by Greene et al. that explains disclosure decisions in non-computer-mediated dyadic settings (Greene et al., 2006), as referenced in Chapter 2. 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). Self-focused non-disclosure reasons are about psychological and physical risks of disclosure (e.g., fear of rejection, losing privacy). Other-focused reasons for disclosure refer to the responsibility to inform and a desire to educate others, while other-focused reasons for non-disclosure refer to the perception that the recipient cannot or will not provide help, or wanting to protect the recipient from feeling hurt or upset. Relationship-focused reasons for disclosure are concerned with having an intimate and trusting relationship with the disclosure partner, while relationship-focused reasons for non-disclosure are concerned with losing the relationship, dissimilarity, a superficial relationship, or the idea that the information is not

relevant or significant in the context of the relationship. Finally, situational-environmental reasons for disclosure refer to the disclosure recipient's availability, whether the recipient demands disclosure, or whether the recipient is involved as the disclosure's subject matter. Situational-environmental reasons for non-disclosure refer to cases where the potential disclosure recipient is either not available or already knows what is being considered for disclosure. In my 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 the data I collected and analyzed, my analysis illustrates that these factors are substantially different in the context of Facebook than in dyadic offline disclosures; as such, I 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 (Greene et al., 2006) 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 (Cain, 1991). 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 I 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 (Dindia, 2002; Laurenceau, Barrett, & Pietromonaco, 1998). 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 (Archer, 1979).

Reciprocity could also be a function of modeling, where the confidant emulates the discloser's behavior due to being unsure about social norms (Rubin, 1975).

In this dissertation study, some participants disclosed their pregnancy loss on Facebook because others in their network had disclosed on Facebook. Others did not disclose because they believed they are not similar to their networks in terms of direct experience with pregnancy loss or parenthood and life goals more broadly and that their networks are not well-informed about pregnancy loss as a human experience. When others in one's network disclosed their own experiences with pregnancy loss, perceptions leading to non-disclosure shifted. 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 (De Choudhury & De, 2014), addiction recovery (Rubya & Yarosh, 2017), sexual abuse (Andalibi et al., 2016)) 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 (Semaan et al., 2017, p. 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 (Prabhakar et al., 2017). Here, I find 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 Social Media

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 (Chung, 2017). Other work suggests that awareness social media campaigns can reduce stigma associated with experiences such as mental illness (Sampogna et al., 2017) and other health topics (Huang et al., 2015), and have the possibility to change knowledge and attitudes at the population-level (Sampogna et al., 2017).

I 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. I 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

I 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 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 (Haimson, Ringland, Simpson, & Wolf, 2014), 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. I have pursued some of these ideas in proof-of-concept design prototypes (Andalibi, Marcu, Moesgen, Mullin, & Forte, 2018). 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. I 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.

I 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. I acknowledge that tie-based anonymous networks come with their own challenges (Ma et al., 2017), and that prior attempts such as Rooms (in which Facebook users could create an anonymous chat space), failed. However, I see potential for future systems to explore anonymous disclosure and support exchange in ways that mitigate the challenges inherent in identified platforms.

Clinical Implications

I discuss potentials for how clinicians could better support individuals who experience pregnancy loss. Doctors, nurses, or therapists could consider providing resources to individuals who experience loss that may facilitate support seeking and engaging in healing loss disclosures. These resources could suggest considering joining support groups with accessible instructions on how to find and join them or other ways to seek support and find similar others such as through social media platforms. In contrast to what might be assumed, thinking about finding support and similar others was not trivial for many participants. Even when it was, some were still unsure where to turn to, or what the benefits of doing so would be. Because clinicians are often the first point of contact when loss is identified, they would be a suitable stakeholder to provide these resources. It is important for such resources to be inclusive of various identities (e.g., sexual orientation) and ideologies (e.g., religious orientation).

Additionally, medical facilities could partner with individuals who are willing to be a source of support for similar others who receive treatment in the same center. Upon opting in, such a program can put individuals who are likely in close geographical proximity to each other in touch with each other to connect and exchange support should they wish to do so. This would be a valued intervention consideration because not knowing others who have experienced loss and with whom one can connect was a challenge for many. Medical facilities can act as responsible hubs to put individuals who can and want to help each other in touch with one another.

Finally, participants valued interactions from medical professionals that validated the emotional aspects of pregnancy loss and did not merely treat it as a routine medical procedure. Findings from this dissertation drawing on the lived experiences of individuals who experience pregnancy loss could be valuable to clinicians to help cultivate more understanding and empathy. Future collaborations with clinicians would be valuable to evaluate and refine these ideas with the goal of better supporting individuals who experience pregnancy loss.

Indirect Disclosures of Stigmatized Experiences on Social Media

In Chapter 5, I uncovered how women use social media for indirect disclosures of pregnancy loss and how these disclosures meet psychological (e.g., keeping a personal record) and social needs (e.g., feeling out the audience) associated with loss. The participants *intentionally* disclosed their experiences of loss *indirectly* in accordance with specific psychological and social goals. They deliberately balanced needs for support, validation and expression with those for obscurity, using a variety of indirect methods. Even in cases where their needs for support were not completely satisfied, they still felt in control of the communication and no one reported feelings of regret for engaging in indirect disclosures or that their strategy broke (e.g., unintended audiences decoding their posts).

Indirect disclosures are known to be important for conveying stigmatizing information (Mattson & Hall, 2011), and are not extensively understood in HCI and social computing

scholarship. In Chapter 5, I contributed a typology of the strategies people employ to engage in indirect disclosures, as well as the factors that guide indirect disclosure decisions on social media. Future work should explore specific needs associated with indirect disclosures such as anonymity, negotiation of emotional trust in social networks, proxy disclosures of sensitive information, and experiments with comment-controlled posts. In what follows, I discuss implications of this work for algorithmic detection of distress and supportive interventions. In particular, I explore the possibility of detecting more subtle signals in addition to explicit disclosures in these algorithms and raise questions about what this may mean for future social computing systems and interventions. In doing so, I also raise caveats about needs for anonymity, privacy, and control that may be at odds with such signal detection. The most helpful offerings may be aids that facilitate disclosure and self-initiated, opt-in, support seeking and provision.

Extending the Disclosure Decision-Making Framework to Indirect Disclosures

I found that factors related to the self, social media audience and affordances, and time motivated individuals to disclose pregnancy loss in an indirect manner. The Disclosure Decision-Making Framework developed in Chapter 4 suggests that these factors, along with network and societal factors, guide decisions to engage in *direct* disclosure of pregnancy loss on social media. Although self, audience, platform, and time shape both direct and indirect disclosure decisions, the ways these factors influence indirect disclosure decisions are distinct from direct disclosures. In what follows, I first explain the absence of network and societal factors in the indirect disclosure context, and then review how indirect disclosures are influenced by self, audience, platform, and time factors in ways that are distinct from the literature on direct disclosures.

As noted in Figure 2, there are two categories of direct decision-making factors that do not appear in these data about indirect disclosures: network-level and societal. As discussed in Chapter 4, when people disclose due to network-level factors, they are motivated to disclose as a result of reduced stigma and in solidarity with others in their network who disclosed directly; the resulting

disclosures are direct and explicit, because their goal is to reciprocate disclosures at the network level. Similarly, disclosures guided by societal factors need to be direct in order to be effective. These disclosures often take the form of activism and calling upon one's network for political support on reproductive health issues; their goal is to create change at the societal level, beyond one's audience or network. Although I did not uncover evidence of these factors in the data about indirect disclosures, future investigations could test these interpretations by remaining sensitive to potential societal and network-level motivations for indirect disclosures.

Factors Related to the Self

To build a *personal* record, participants shared content that was personally meaningful and directly relevant to their loss but would not be associated with pregnancy loss (e.g., a photo of working from home with one's dog) by most viewers. Prior research suggests that one function of social media is to keep a personal record and archive meaningful facets of life for the self (S. Schoenebeck, Ellison, Blackwell, Bayer, & Falk, n.d.; Vitak & Kim, 2014; Zhao et al., 2013); however, these studies did not investigate negative or difficult life experiences and sharing about them on social media. A study about direct relationship breakup disclosures on Facebook observed similar uses of social media for personal record and presentation, where some changed their relationship status and made the status visible only to themselves and not to others (Haimson et al., 2017). In Chapter 4, I showed that people engage in direct disclosures of pregnancy loss on Facebook to keep a *social* record of their experience. When direct forms of disclosure meant making the experience more "real" or ruminating on the experience, participants chose to not engage in disclosure at all. In Chapter 5, I found that some people use social media to keep a *personal* record, and use indirect disclosure strategies to protect their privacy in doing so due to the sensitivity of the content.

Indirect disclosures also acted as signals. Abstract images and other signals were emitted with the hope of eliciting support from others who had experienced pregnancy loss. Finding similar

others and social support is a motivator and outcome of social network use (Ellison et al., 2007; Kwon & Wen, 2010; Ross et al., 2009), but seeking support comes with risks (Omarzu, 2000). Prior work describes how teenagers make certain content encoded and understandable only to certain audience members, and not to others; thus enacting privacy in a public space (boyd & Marwick, 2011). Similarly, by indirectly disclosing and signaling *only* to those whom the posters imagined would understand the *real* point of the post, participants sought support without making themselves more vulnerable than they wanted. The ambiguity in social media indirect disclosures was intentional: If members of the audience did not "get" the message, they probably were not the intended or imagined (Litt, 2012) audience. I note that eliciting social support, a self-related decision factor is closely related to the perception of one's audience as a likely source of support.

Factors Related to the Audience

Concerns about judgments from the audience, including but not limited to fear of being judged as fishing for support or attention, led some to opt for indirect disclosures. I observed that indirect disclosures were guided by a desire to test out the waters and assess their audience's readiness for a potential future direct disclosure. Indirect disclosure allowed participants to get to know their audience better and anticipate the supportiveness of specific individuals and groups. These findings extend previous research on anticipated audience reaction as a factor in direct disclosure decisions (Omarzu, 2000). In Chapter 4, I showed how anticipating support from the audience was a factor leading to direct disclosures, and anticipating negative and hurtful ones was a factor leading to non-disclosure decisions. Indeed, sometimes direct disclosures occur as preventive disclosures (Cain, 1991; Lampinen et al., 2011), where one does share information to avoid certain unwanted future interactions (e.g., questions such as "how is the pregnancy going?" as described in Chapter 4). In Chapter 5, I show that when estimations of support and desired reactions cannot yet be made, people may engage in indirect disclosures.

Factors Related to Platforms and Affordances

I found that feeling more anonymous provided an additional layer of safety needed to share content about pregnancy loss for some. For some participants, this was true even when there was no explicit reference to the participant's personal experience with loss in the post, in an anonymous space. Prior work (e.g., (Andalibi et al., 2016; Ellison, Blackwell, Lampe, & Trieu, 2016; Suler, 2004)) has established the importance of anonymity for direct sensitive disclosures or requests for support on social media. In Chapter 4, I discussed how prior anonymous participations contributed to direct disclosure decisions in identified contexts, and how not being able to be anonymous on identified spaces like Facebook led to complete non-disclosures on the site for some. In Chapter 5, I showed that for some individuals, the risks of talking about a stigmatized experience require anonymity *and* indirect disclosure in tandem. I highlight that it is not only for direct disclosures of stigmatized experiences that anonymity perceptions can be helpful, but also for more indirect disclosure forms for some social media users who may not be ready to engage in direct disclosures even when they feel anonymous.

Factors Related to Time

Time was also a factor guiding indirect disclosure decisions. Some participants needed to share the news but felt they were too close to the loss and not ready to process their feelings by direct disclosures. Chapter 4 and prior research suggest that it is common for direct disclosures of stigmatized experiences such as abuse or pregnancy loss to be delayed (Quadara, 2008; Semaan et al., 2017). In Chapter 5, I found that even indirect disclosures could be challenging, and sometimes for some participants, the passage of time made it possible to hint at their experience and the difficulties they had endured, without explicitly and directly talking about their pregnancy loss experience. Additionally, in the time after the loss, some had retreated from social media and in-person social settings. These social environments were threatening at that time: participants did not want to be caught off guard and feel pressured into a direct disclosure. Some felt isolated in these

settings. For those who had not retreated socially, temporal proximity to the loss still made direct disclosure of loss feel *emotionally* impossible. To limit additional emotional injury, these individuals asked a third party (such as their spouse) to make a direct disclosure. Such disclosure by proxy has also been suggested to be a strategy in sensitive disclosures in non-computer-mediated settings (Afifi & Steuber, 2009; Bouillon et al., 2007; Derbez et al., 2017). These findings indicate the various roles of temporal proximity to the event and where one is in the recovery process as a factor that may lead to indirect disclosures. Future research could use quantitative methods to explore the variety of disclosure needs and behaviors over long time periods.

I show how the Disclosure Decision-Making Framework developed in Chapter 4 that explains direct disclosure decisions of pregnancy loss on social media also explains indirect disclosure decisions. While the considerations within each decision factor are different for direct and indirect disclosures, I show how the broad decision factors help explain indirect and direct disclosure decision-making of stigmatized experiences on social media platforms.

Design, Research, and Algorithmic Implications and Futures

Future work could explore opportunities to support indirect disclosure as a way of seeking social support. For example, it may be possible to enable third party disclosures. For some, invoking close friends or partners to disclose difficult news allowed them to share without the emotional burden of follow-up communication that would have ensued had they posted the information themselves. Those who do not have such a proxy might benefit from a service that finds someone to disclose on their behalf or otherwise controls the conversation. This work also highlights ways to enrich algorithms with signals of distress in indirect, sometimes image-based, disclosures while raising important questions about the ethics and value of associated interventions and futures. I discuss these possibilities in the following sections.

Proxy Disclosures

I found that many people who have experienced pregnancy loss want to share their loss directly and explicitly, but are not ready to deliver this news themselves. This is especially true in the time immediately following the loss. Third-party disclosures, usually through spouses who shared the news on social media, were a helpful strategy for some. While participants did not mention having wanted someone else to post for them without success, it is conceivable to think that not everyone who experience pregnancy loss has someone to provide this voice and role (e.g., partners). Additionally, while I did not interview partners, participants alluded that it was also hard for their spouses to engage in such disclosures. Future work could explore ways in which social computing systems can support disclosure needs of those who do not have partners or whose partners are unable or unwilling to assist in the disclosure process. I envision an individual who *wants* to disclose (but is not comfortable doing so directly) might be able to do so with the help of a third party system or a specialized, comment-controlled post.

Art projects provide inspiration for how this disclosure by proxy might be done. As an example, the Humans of New York (HONY), is a photography project where the subject of the photo shares often incredibly intimate and stigmatizing information about themselves to the audience of the photographer, and now perhaps theirs as well by proxy. While this is a different example on several fronts (e.g., the subject does not seek out the photographer), future work or activist research projects could explore potentials for art projects with social media components that help individuals communicate the loss through a third party such as a photographer.

Relatedly, one way third parties have been employed in current technologies is the Facebook legacy contact, drawing on the concept of stewardship (Brubaker et al., 2014) where Facebook users can choose an individual to manage their data once they pass away. Facebook recommends that stewards not be close individuals because of the emotional pain these contacts will be going through after the death of the account owner – which may be helpful for those bereaved by a pregnancy loss also. I envision design explorations that allow individuals to choose someone to

share the news on their behalf, far in advance of a loss or traumatic event. While designs should be developed in working with relevant user groups, potential ideas include the chosen contact to be able to post on the bereaved individual's profile, and be the primary point of contact for the post, while making it clear to the audience that the account owner did not post the content personally.

Finally, in conjunction with or independent of proxy disclosures, social media sites could experiment with a type of comment-controlled post that is flagged with a message that the poster asks that people hold their comments and refrain from contacting them about the topic.

Disclosures, Algorithms, and Ethics

This dissertation's findings have implications for socio-technical futures, in particular modeling of psychological behavior and algorithmically generated interventions.

A growing body of scholarly research is concerned with computationally detecting direct and explicit disclosures of distress in social media footprints (e.g., (De Choudhury, Counts, Horvitz, & Hoff, 2014)). Social media platforms such as Facebook and Instagram have also explored ways to support those in distress, particularly those with potential suicidal thoughts. For example, in 2016 Facebook added a feature that allows users to flag concerning posts for review by the company. The interface then provides the user with options including sending a private message to the person in distress, or sending a message to another friend to coordinate support. It also notifies the original poster of a friend's concern and provides three options: talk with a friend, contact a helpline, or get tips (Callison-Burch, Guadagno, & Davis, 2017). The company recently launched artificial intelligence tools to "prevent suicide" by identifying those who show signs of distress (Zuzkerberg, 2017). Another example is the Radar app. In 2014, Samaritans – a European charity aimed at providing emotional support to individuals in distress – launched an app named Radar (Orme, 2014; "Samaritans Radar," n.d.). The app monitored Tweets for expressions of distress and alerted users when people they followed posted about suicide or depression. Backlash due to privacy concerns prompted permanent termination of the app.

These algorithmic and intervention approaches largely focus on direct, explicit, verbal disclosures. That said, more recently, researchers have employed machine learning and facial recognition tools to detect indirect markers of depression from Instagram images claiming to outperform practitioners' success rate for depression diagnosis (Reece & Danforth, 2017). In Chapter 5, I contribute an understanding of how people indirectly disclose stigma and emotional distress on social media by sharing visual and textual content. Rettberg argues that algorithms may be able to detect what Barthes refers to as the "studium" (i.e., the literal content of the photo) but not the "punctum" (i.e., "*'the wound'* that makes a photograph poignant to an individual") (Rettberg, 2014, p. 55). This may be changing with new computational approaches (Reece & Danforth, 2017). Participants in the present research shared indicators of both the felt wound (even if it was only discernable to them) along with the literal contents of a photo (be that a picture of a restaurant or a sentence about staying at home). In light of the findings presented here, I ask, how can algorithms understand the emotional experience *underlying* posts and- *should they*? Rettberg writes "Sometimes, our own lists of data and the quantified charts that track aspects of our lives might even give us the sense of punctum that Barthes wrote of seeing in certain photographs, though others would see nothing but a studium." (Rettberg, 2014, p. 62) If there are conditions under which it is ethical for algorithms to find punctum in photos posted during difficult life events, how can this knowledge be employed to serve users rather than invade their expectations for privacy or bring unwanted feelings (e.g., reminding one of a devastating loss when they were not ready for it) to the surface? One direction for future work could be to identify the language or visual markers of such indirect disclosures and use them as features in machine learning algorithms. This approach could help detect not only overt cries for help, but also the less obvious signs of distress that I found typical of indirect disclosures; however, crucial questions about the efficacy and ethics of this approach remain.

Specifically, many of the participants sought anonymity, privacy, and control—needs that were met through indirect disclosure. I wonder what would be lost if algorithms teased out the distress

embedded in indirect disclosures, even if it is with the aim of providing help. I suggest such questions should be considered and discussed in the HCI and CSCW communities about indirect *and* direct disclosures. Are there conditions under which it is ethical for a system that is not *perceived* or *felt* as a support system by a user, to detect vulnerability and/or to offer support or intervene based on their *direct* or *indirect* disclosures? When is it ethical and helpful to use these data to show people content from their past, which they may have intended to hide in plain sight, with the design goal of reflecting on emotions and past? Future studies could investigate relevant expectations and needs from the users' perspective, when considering such algorithms and interventions. Opt-in approaches merit exploration, for example ones that explicitly ask if users want their data analyzed to make inferences about their emotional well-being, if they want to be informed of associated results, and if they welcome resulting socio-technical supportive interventions. Opting out should be usable and accessible, and of course it should be clear how these data is stored and distributed. Such a potential approach could experiment with including users in creating their own training datasets with identifying what constitutes a direct or indirect disclosure in their own perspective. I note that these are not proposed solutions, rather speculations in response to my posed open questions aimed at privacy-preserving and ethical algorithmic interventions for well-being as a necessary immediate discussion stemming from this dissertation's results and what they may mean for technological futures. I studied how and why people engage in indirect disclosures of emotional distress and stigma on social media, and brought to light a unique, important, and under-explored social media disclosure behavior. As a result, and in considering what this work means for the ever-increasing algorithmic approaches and interventions to detecting signs of distress through social media data, I pose these immediately relevant and critically open questions and opportunities for the HCI and CSCW communities. I advocate that before jumping to algorithms that detect and intervene with emotional support or trying to reduce the possibility of false positives, researchers grapple with these questions.

Response Decision-Making in Stigmatized Contexts on Social Media

The response decision-making (RDM) framework that I have presented explains factors that guide decisions about responding to sensitive disclosures on social media. The RDM framework includes:

- self-related factors (i.e., personal and professional expertise, attitudes towards the topic and sharing about it, impression management, privacy, and personal well-being),
- poster-related factors (i.e., disclosure content, frequency of posting, perceptions of poster's intentions and expectations, visible aggregate network-level support), and context-related factors (i.e., relational, temporal, and social).

I have provided a foundation for investigating potential correlational links or interaction effects in the future. Future work could use experimental and survey methods and vignettes to test these presented findings and find correlational results at the large scale and across different sensitive topics. I also uncover socio-technical features of social media sites that help inform these decision factors. In addition to conceptual contributions such as uncovering the perceived impact of social media broadcast sensitive disclosures on interpersonal relationships, this work also led to design implications and directions for research through design that I discuss in this section.

Disclosure Personalism on Social Media

I found that when people see a close connection share sensitive content on social media without a corresponding prior private disclosure, they wonder if they are indeed as close and trusted as they believed they were. I also found that in trying to assess the poster's intended audience, some believed that they are not in the poster's intended audience if: (1) they are not close, (2) they are not in frequent online contact, or (3) the poster has a large and un-curated network. The subjective intimacy framework in non-computer-mediated contexts suggests that people assess the intimacy level of a piece of information based on who else it is shared with, and how "special" it is (Schoeman, 1984). An experimental study (Bazarova, 2012b) with student social media users lends support for the concept of "disclosure personalism" (Jones & Archer, 1976) phenomenon on social media, suggesting that when people believe that they have been exclusively trusted with

information, they perceive more intimacy and feel "liked" by the discloser. This dissertation's findings extend this work by illustrating *how* and *why* the "disclosure personalism" phenomenon plays a role in decisions to *respond* to sensitive disclosures on social media platforms.

To clarify this point, it is important to think of responses in the context of disclosures that precipitated them. Social media users make complicated decisions to share sensitive or stigmatizing information (e.g., abuse, mental illness, pregnancy loss experience) about themselves. As reported in Chapter 4, sensitive disclosures on social media are guided by a variety of decision factors including: (1) self-related factors (e.g., eliciting social support, healing, remembrance, and controlling identity narratives), (2) audience-related factors (e.g., preventing unwanted interactions from one's audience members if they were to not disclose), (3) platform and affordance-related factors (e.g., one-to-many sharing, asynchronous communication), (4) societal factors (e.g., activating one's connections to take political action, reduce social stigma), (5) temporal factors (e.g., the amount of time passed since the event), and (6) network-level factors (e.g., being a source of support for others now or in the future). For example, on Facebook, one-to-many disclosures allow people to avoid a large number of painful and emotionally challenging one-on-one conversations with others, allow them to elicit social support from a large number of their connections, or activate them for political action to change societal narratives and reduce social stigma around the topic of disclosure (e.g., pregnancy loss). Additionally, asynchronous communication allows people to take care of their own needs in times of deep distress rather than others' who may see their posts, because synchronous sharing of deeply troubling experiences is incredibly painful for many. In Chapter 6, I illustrate how while such social media disclosures serve disclosers in a variety of ways, they also have the potential to alter perceptions of interpersonal relationships from the receivers' perspective, whereby they may reevaluate or reflect on what kinds of relationships they have, and this is one way that disclosure personalism is enacted on social media. It is not just the response behaviors (e.g., providing support or not and reasons for doing so) that I uncover, but rather their context, meanings, and mechanisms for those who perform them.

Socio-technical Features Informing Response Decisions

Through my analysis I uncovered the socio-technical features that inform response decision making by influencing the variety of self-related, poster-related, and context-related decision factors. Social media designers and researchers should consider these features to balance support seeking and disclosure needs and support provision and response needs on social media platforms. I summarize these below.

Flexibility to engage with disclosures on a spectrum. As I discussed in the Relational Context section on Chapter 6, the possibility of engaging with disclosures in multiple ways that are perceived to differ in degrees of intimacy, emotional labor, and commitment enabled various response decisions and behaviors for different relational contexts, for example depending on the level of perceived closeness and intimacy between the participant and poster. Participants referred to this as a hierarchy or spectrum of engagement that existed sometimes within one platform (e.g., Facebook comments and private messages) and sometimes went beyond that (e.g., Facebook comments and phone calls).

Interactions' anonymity and identifiability degrees. As discussed in the Impression Management and Privacy Concern sections of Chapter 6, the level to which people thought their responses or interactions with a sensitive disclosure would be associated with their physical world identities, impacted response decisions through informing privacy and impression management concerns. The perceived lack of overlap between one's audience on a platform like Reddit with that of their physical world (similar to Facebook) network in tandem with using pseudonyms enabled some degree of anonymity outside of their network of known ties. This in turn, enabled more disinhibited responses as potential responders were able to meet their own privacy needs; this was important because it eliminated concerns around follow-up reactions in the physical world. While on Facebook people typically use their physical world names and identities, participants found detours that would make them feel more anonymous on the platform. Some enacted levels of anonymity through what they deemed to be "less visible and thus more anonymous" forms of

interaction such as "liking." Even when participants used their physical world identities, engaging in less visible interactions led to feeling more anonymous and enabled responses to sensitive disclosures for some.

Visibility level of one's own and others' interactions. I found that visibility of responses and reactions to sensitive disclosures informed disclosure decisions through their relevance to visible aggregate network-level support, social context, impression management, and privacy concerns (as reported in respective sections in Chapter 6). First, if aggregate network-level support was not visible, then contributing to it (which was a motivation for some to engage with associated disclosures) would not be a concern or possibility either. Second, the visibility of others' comments or interactions that came before one considered responding to a sensitive disclosure was an important feature to enable the assessments participants made to make their decisions. Sometimes others' comments acted as cues for what would be expected or appreciated, and when participants felt they were not able to provide that, they decided to not engage with the post. Third, participants assessed how their interactions in any form would be received by the poster or by others whom interactions would be visible to. The degree to which one's own interactions were visible to others contributed to the impression management decision factor. Finally, related to privacy concerns was also the ability to control whom one's interactions with sensitive disclosures would be visible to. When this need was not met, for example due to the poster's privacy setting dictating the responders' privacy settings, non-response could follow.

Specific dedication of a space to a topic. Another feature that facilitated responses to sensitive disclosures was being able to meet one's privacy needs through engaging with posts in dedicated online spaces such as subreddits or Facebook support groups, rather than individual Facebook profiles. Some perceived these spaces to be "set up" for these kinds of disclosures and responses, in contrast to individual profiles or spaces not dedicated to a topic as we found in the Privacy Concerns section. Topic-specific spaces could make it easier for some to respond to sensitive disclosures through meeting privacy needs.

The one-to-many nature of social media disclosures. One-to-many disclosures impacted how potential responders thought about the poster's intentions and expectations, as I found in reporting the perceptions of poster's intentions and expectations section in Chapter 6. As I discussed in the Disclosure Personalism on Social Media section above, while this feature is sometimes useful for disclosers as also found in Chapter 4, other times it contributes to non-response decisions on the other side, due to perceptions about the discloser's intentions and goals.

Design Implications

The analysis provided in this dissertation, particularly that of Chapter 6, provides future design and research directions that would support the needs of potential responders on social media sites when they come across others' potentially sensitive or stigmatized disclosures and as they make decisions to engage or not engage with these social media posts.

Offer insights to potential responders on providing helpful support. I found that sometimes people are unsure how to react, what to say, what the poster's expectations are, or what the wider societal norms are; sometimes they actively observed others' interactions with the post to make these assessments; this uncertainty sometimes led to not engaging with a disclosure or engaging in lightweight ways (e.g., liking, hearting, or other one-click "reactions"). When participants did not have expertise and were not sure what would be helpful, they sought out expertise from other sources. For example, some reported having Googled how to offer support to someone who has experienced a pregnancy loss, or imagined they would ask individuals who had the required personal expertise to offer support to the poster instead. Script Theory elaborates how humans observe cultural phenomena and form unconscious behavioral models for certain situations (Tomkins, 1978). In the case of pregnancy loss, however, few scripts exist in the American society (Silverman & Baglia, 2015), making it harder to decide how to respond. Future system designs could explore providing suggestions to those in one's audience, without making potential responses feel not genuine. For example, if one comes across a disclosure of pregnancy loss or mental illness,

articles or resources could pop up to offer ways to help or respond to a person in that situation. Additionally, because sometimes people decided to engage with a poster in both more public and private ways, future designs could make these options more readily available or recommend sending a private message after one leaves a comment or interacts with a post publicly. It would be interesting to investigate if such prompts would have any impact on response decisions and outcomes (e.g., helpfulness perception) for various kinds of ties.

Offer resources to potential disclosers to find the type of response they want to elicit. I found that in indirect support seeking (i.e., hinting at a problem, without specifically asking for help), people have a hard time assessing what the poster needs, or if they need anything at all, leading to less or no engagement (particularly if there was not a close relationship.) People engage in indirect support seeking often when asking for support directly is too big of a "face" threat (Barbee & Cunningham, 1995; Goffman, 1959). In comparison, I found that on the potential responder's side, when posts included direct support seeking (e.g., asking a question) it was easier to make a decision to respond or not, often leading to engagement if possible. This is important, because both indirect and direct forms of seeking support do occur on social media, and in this work I examined how potential responders perceive them. In fact, potential disclosers do try to anticipate what the audience's response would be like if the disclosure were made (Greene et al., 2006). It is possible that if people in distress who are considering posting on social media about their experiences are able to make a reasonable guess about the responses they would or would not receive, they would be able to make more informed decisions and formulate their disclosures in ways that benefit them the most depending on their own particular needs. Future design explorations might include machine learning approaches to detect if an individual is posting an indirect support seeking post and system responses that provide the poster with resources or even guidance on finding the kinds of support or responses they want to elicit.

Offer insights about interactions and tie strength between potential responders and a discloser. I found that participants who are closer to the poster may be more likely to engage with

a sensitive post privately or in multiple ways. People also assess their relationship closeness as well as other cues such as the frequency or recency of communication to assess if they were among the poster's intended audience. I also found that perceptions of similarity with the discloser in terms of values, ideologies, and social media behavior are factors in response decisions. Homophily measures the feelings of similarity towards another person (McPherson, Smith-Lovin, & Cook, 2001), and can be measured on social media. On Facebook people expect feedback on content they deem to be more important and more personal, particularly from closer friends (Grinberg et al., 2017), and tie strength can be predicted between Facebook friends (Gilbert & Karahalios, 2009). I also found that the relationship between the poster and participants was an important factor in support provision. Future work could explore what would happen if potential responders are able to see a visualization of the recency or frequency of interactions between them and the discloser, dimensions of the tie strength based on the social network data of the two parties (i.e., discloser, potential responder), or the degree and ways in which they are similar to the discloser, to help with assessments they make when coming across sensitive disclosures. While people do tend to make these assessments to make response decisions themselves, there currently exist no tools that inform these assessments. One strength of research through design is that we can show designs to people and gauge their reactions and learn more about them, their preferences, and needs.

Provide privacy and impression management control for responder and poster, and facilitate the visibility of network-level support. I found that potential responders have significant privacy and impression management concerns, that could lead to non-engagement or private forms of interaction. For example, some participants thought public comments are performative and not genuine, because they are not visible only to the poster. Further challenges related to participants' impression management concerns around the reaction from the poster or others in their network if they did engage with a post.

While private interactions were a likely option for closer ties, they were often deemed to be inappropriate for weaker ties. Additionally, the publicness of the *visible aggregate network-level*

support was perceived to be a driver for public interactions for many; in other words, participants wanted to make the poster feel that there are a large number of people who publicly care for them. As found in Chapter 4, witnessing high levels of support when others disclose stigmatized information helps people decide whether to disclose sensitive information themselves: as a potential discloser when people observe others disclosed sensitive information and received supportive responses on social media, they become more likely to engage in disclosure as well through *network-level reciprocal disclosures* – as a result of reduced perceived stigma. As a potential responder, I found that seeing others' responses to a sensitive post helps with deciding whether and how to respond to a sensitive post. Therefore, I argue that public forms of interactions around sensitive disclosures are useful for both potential disclosers and others in their networks. System designs could explore ways to balance the visibility of aggregate network-level support with appropriate privacy controls. For example, designs could explore privacy-enhanced ways of engaging with a post that make comments visible only to the poster or to those whom the commenter is also connected with; showing the quantity of interactions in various forms (e.g., "reactions", comments) instead of the content; or allowing comments that are visible but with the identity of the commenter cloaked. Some social media platforms provide more control related to interaction visibility. For example, one way WeChat, which is a popular social media platform in China, provides designs for (in)visibility is that posts in one's "moments" (similar to status updates on Facebook) are available to one's chosen audience, but only the poster can see all the comments, and a commenter can only see another comment if they are connected independently as well. Ideally, designs would allow assessments of the poster's support network (in terms of quality and quantity) and norms, even possibly educate the public about interacting in a considerate way, while also preserving the poster and commenters' privacy.

Facilitate responsiveness and support over time. I found that especially in close relationships, participants wanted the poster to know that they were cared for and sometimes checked in with the poster after a while to see how they were doing. Sometimes they were

concerned about forgetting or for their friends in distress to feel forgotten after a while. Kelly et al. introduced the concept of "responsiveness" to a communication partner, which conveys that one is thinking about the partner to communicate "effort" in the relationship (Kelly, Gooch, Patil, & Watts, 2017). Chapter 4 suggests that remembrance, acknowledging, and honoring a difficult experience (e.g., pregnancy loss) as well as healing and gaining support are some of the motivators for disclosing it on social media. Future system designs could explore reminders about a friend who had posted about a difficult experience and prompt one to check-in with them to communicate effort and care. One design challenge would be that disclosers may not appreciate being reminded of their difficult experience. Additionally, as Kelly et al. suggest, people may see communication as less valuable and genuine when they are known to stem from prompts or reminders (Kelly et al., 2017). Future designs could explore balancing the potential needs for forgetting (Haimson et al., 2016), and responsiveness and remembrance in tandem without hurting the level to which communication is perceived to be meaningful and genuine.

Curate human-centered news feeds. Findings of Chapter 6 suggest that frequent disclosures by the same person led to feelings of annoyance and judgments about that person's intentions (i.e., attention seeking). Details were a double-edged sword and sometimes helped with connection and engagement, other times they were overwhelming and perceived as inappropriate. Potential responders also had emotional well-being needs of their own, and sensitive disclosures— particularly those with much detail or responses to them—felt disruptive to some potential responders' personal well-being needs. Additionally, although personal expertise was sometimes a factor leading to engagement, other times it meant the disclosure was too triggering or "close to home" for a potential responder; therefore, they avoided the post to avoid personal distress. Social media sites could explore a human-centered approach to news feed algorithms that enable users to input preferences that allow them to identify sensitive topics that they may want to avoid or engage with in certain time periods.

I also found that when potential responders encounter a post in their daily life when they do not have the sufficient time and attention that engaging with important and personal content requires, they refrain from engaging with them and *sometimes* remember to go back to those posts at a later time. News feed algorithms can experiment with showing people posts that require thoughtful interactions at times when they are more likely to have time (e.g., based on their past interaction histories).

Exploring Connections Between Disclosures and Responses

In Chapters 4 and 5, I illustrated how individuals experiencing distress assess a variety of factors related to themselves, their audience, their network, as well as society, time, and platform features and norms to make decisions about disclosures on social media. In Chapter 6, I showed how responders who see these eventual disclosures make decisions as to whether and how to engage with these posts. Potential responders evaluate factors related to themselves (i.e., personal well-being, professional and personal expertise, impression management, privacy concerns, and attitudes towards the topic and sharing about it), the poster or discloser (i.e., posting frequency, visible aggregate network-level support, perceived intentions and expectations, and disclosure content detail and directness level), and the context (i.e., social, temporal, and relational). Because I did not study real-life relationship dyads in the two interview studies (i.e., discloser and responders who are actually connected to each other), I do not provide concrete connections between these two decision making frameworks. However, this work provides a baseline through which these connections can be explored in the future for example through recruiting dyads connected on social media. That said, there are conceivable connections that can be made between these decision behaviors. I describe some of these connections below.

On the one hand, in discussing factors related to the self, contributing to non-disclosure decisions, I found that those who perceived others' sensitive disclosures on social media as inappropriate did not engage in such disclosures themselves either. This phenomenon has also been

observed in disclosures of romantic relationship breakups on Facebook (Haimson et al., 2017). When potential disclosers appreciated others' sharing, I observed network-level reciprocal disclosures. On the other hand, as I discuss in in my analysis of response decision making factors related to the self (potential responder), I found that the potential responder's attitudes about the topic and sharing about it was a factor that informed response decision making for them. In other words, when considering to disclose and making disclosure decisions, people sometimes rely on their own views on others who have disclosed sensitive information in the past to make their disclosure decisions. As potential responders, people assess their own views on the topic under discussion and sharing about it on social media.

In my analysis of response decisions' factors related to the poster, I found that when posters directly seek support through their social media posts, it is often easier for potential responders to decide how and whether to respond to them. However, coming up with disclosure content that included direct and explicit support seeking was not easy for many participants. These difficulties were sometimes due to self-related factors such as family background and audience-related concerns about one's close ties' reactions to seeking support on social media.

Others' disclosures and being a source of support were network-level motivating decision factors for disclosures. In contrast, perception that one's network does not have a direct experience with pregnancy loss, perception that one's network is not knowledgeable about pregnancy loss, or that one's network is not concerned about pregnancy in general led to non-disclosure decisions. Moreover, anticipating responses from those who do not have a deep understanding of the experience via their similar experiences was reason for non-disclosure for some. In my analysis of response decision making, I found that when people felt they had personal or professional expertise and proximity to the topic of disclosure, they felt more compelled to engage with disclosures about the topic on social media as well.

While the relational context (e.g., closeness) informed response decisions, they also informed non-disclosure decisions; in particular, when people did not feel enough closeness or trust towards

their audience they did not engage in talking about their intimate feelings and stories. Additionally, anticipating negative reactions from close ties as a result of sharing about the loss on social media, and anticipating generic responses from non-close ties was reason for non-disclosure for some because they were expected to not lead to any physical world interactions. In my analysis of response decisions, some potential responders mentioned how closeness to the poster mattered in their response decisions, and some felt generic responses from them - who are not close to the poster - would be meaningless and unhelpful.

Moreover, traditionally strong ties usually provide more effortful, empathic support, while weak ties may be less willing to provide these kinds of support and instead provide access to new opportunities (Granovetter, 1973). I found that perception of tie strength (a dimension of relational context) is only one factor among others that inform support provision decisions. Consistent with Granovetter's work, if one felt close to the poster, they often engaged in several effortful ways of communication publicly and privately; however, weaker ties were also likely to provide effortful, emotional, and empathic support if for example they had similar personal experiences with the poster. In fact, when sensitive disclosures did happen, sometimes the most helpful reactions and meaningful interactions came from individuals traditionally labeled as "weak ties" (e.g., acquaintances) who connected with the poster on a personal level (e.g., over a shared experience), therefore complicating the notion of tie strength.

Receiving one-click interactions such as likes or short comments without the audience pausing, meant to some that the response did not "mean" much to the responder who left them, and that their disclosure of their most difficult experiences were glossed over and devalued. This led to non-disclosure decisions for some. In my analysis of response decisions, I showed how some potential responders perceived likes or short comments as performative and not genuine or helpful at all as well. Yet, there were disclosers who did perceive likes and comments as support communication, and responders who thought although such responses may not be individually valuable, they show aggregate support, and found that to be an important and different way of communicating support.

For example, when a potential responder did not feel close enough to the poster to privately contact them and were not able to leave a personable message, they sometimes still engaged in short public generic interactions to contribute to this aggregate support.

In this section, I showed how decision factors related to disclosures and responses draw on similar or closely linked criteria on both the discloser and potential responder sides.

Summary of Contributions

In summary, I have made the following contributions through this work:

- Develop a disclosure decision making framework to explain pregnancy loss disclosure decisions on social media platforms (Chapter 4)

- 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 social media (Chapter 4)

- Develop a typology of indirect disclosure strategies and an understanding of decision factors informing indirect disclosures of sensitive experiences on social media platforms, and provide a clear definition of social media indirect disclosures (Chapter 5)

- Develop a response decision making framework that explains factors informing whether and how individuals respond to sensitive disclosures from their social media connections (Chapter 6)

I have also elaborated on the following themes in discussing this work's major findings':

- Provide design implications and guidelines grounded in in-depth understanding of people's behaviors and perceptions that have the potential to improve well-being through: facilitating helpful and safe disclosures, reducing stigma surrounding difficult human experiences, and facilitating social support provision (Chapter 7)

- Provide implications on how clinicians can better support individuals who experience pregnancy loss (Chapter 7)

- Highlight potentials to enrich algorithms with signals of distress in indirect disclosures while raising questions about the ethics and value of associated interventions (Chapter 7)

- Draw connections between disclosure and response decisions (Chapter 7)

I have drawn on several fields and disciplines including Human-Computer Interaction (HCI), Computer-Supported Cooperative Work (CSCW), Social Computing, Health Informatics, Medicine, Nursing, Communication, and Psychology. These contributions are valuable to both HCI and social computing research and practice. They are also valuable to the other fields that have informed my work due to the interdisciplinary nature of the problem space I address and the ubiquity of social technologies in everyday life. Because of these reasons, not accounting for the role of social and personal technologies in people's communication and disclosure behaviors – which are subjects of inquiry in fields such as Psychology and Communication – would mean not taking into account the complexities of people's socio-technical environments and the realities of their lives as mediated through technology. This dissertation makes foundational theoretical contributions to our understanding of stigmatized disclosures, as well as seeking *and* provision of social support on social media platforms. Along with potentials for clinicians, this work also provides design concepts and guidelines to improve the experiences and well-being of marginalized and in-distress populations, as well as those connected to them, and paves the way for future impactful research and design.

Future Directions

My research addresses the critical problem of understanding how social computing systems can be designed to not only enable people to share information, but also to facilitate meaningful interaction, realize opportunities for social support, and maximize human well-being. My work to date has provided first steps toward understanding supportive online interactions and facilitating a

more just, civil, empathetic, and humane Internet. Making this a *reality* remains a challenge for social computing that I will pursue in the next stage of my career. Below are some potential inter-connected future directions:

Algorithmic and Interactive Design for Sensitive Disclosures and Reduced Stigma

I will investigate the possibility of designing social technologies in ways that can facilitate reducing stigma over time. There is considerable social stigma surrounding many difficult human experiences including and not limited to the contexts I have studied. Perceived stigma is not only linked to low well-being, but it also inhibits many who face difficulties to seek support, and hinders others from providing it. Thus, uncovering the roles social technologies play in reducing or perpetuating social stigma in a wide range of contexts is of societal importance. My work suggests that perceptions of one's network as related to a specific topic is important in seeking and providing support; when people believe their network does not understand their experience, they are less likely to talk about it. What *algorithmic* and *interactive* designs can allow people to realistically perceive their network's attitudes or knowledge about a certain topic? For example, with appropriate privacy protections, machine learning techniques could be employed to surface *network-level* attitudes, and interactive designs could give people the tools they need to make more informed assessments about their network's collective experiences and knowledge.

Anonymity Within One's Network of Known Ties

One consistent finding in my past work (Andalibi & Forte, 2018; Andalibi et al., Under Review, 2016) and this dissertation has been the importance of anonymous participation not only in seeking but also providing support; yet anonymity can also facilitate uncivil behavior (Suler, 1997). As discussed in Chapter 4, people value seeking support from and providing support to those they have offline bonds with, in a way that feels different from connecting with anonymous strangers. I will explore ways to facilitate supportive interactions with flexible levels of anonymity *within* one's social network of known ties. Successful designs that proscribe uncivil behavior (e.g., harassment) and promote supportive interactions would be useful to many who experience distress or stigma.

Health care, Vulnerable Populations, and Social Technologies

Social media and virtual environments are pervasive but changing resources for those with health care needs, especially when facing stigmatized experiences related to reproductive health. I have consulted with health care professionals in my past work (e.g., (Andalibi et al., 2017)) and will amplify my collaborative focus on supporting health needs through social media design. I will pursue increased collaboration with clinicians, research with families and partners, and others who are involved in the lives of individuals experiencing psychological distress or stigma with the goal of improving Interpersonal communication among key actors, technology's role in it, ways to design technology for supportive interpersonal communication in the context of health needs. Examples include exploring designs that would help family members of all ages (e.g., children, adults) communicate with each other in times of distress and process difficult events in ways that foster their well-being.

Personal Resilience and Technology

Resilience is "bouncing back" when facing adversity, trauma, stigma, or discrimination, focuses on individuals' strengths to help them thrive in spite of difficulties, and is linked to improved well-being (Fergus & Zimmerman, 2005). This dissertation and my other work focuses on social support and coping mediated through social media; however, coping is only one outcome of resilience (Fergus & Zimmerman, 2005). While a growing body of social computing research focuses on social support, questions remain about how technology can be designed and used for personal – rather than community – resilience and its potential to help people, for example, cultivate hope for the future, reframe the situation, embrace self-worth, reiterate core identity anchors, remain aware of oppression, participate in social activism, or act as a positive role model (Buzzanell, 2010; Singh, Hays, & Watson, 2011). I will explore the role of information and communication technologies in developing personal resilience, and design prototypes that help people develop resilience skills before, during, and after facing adversities or stigma. By understanding and designing for improved

resilience we can improve vulnerable individuals' well-being. While design features would be co-developed with participants, this dissertation provides promising directions. For example, by browsing past social media posts about a prior difficult experience, bereaved women believed in their strength and developed hope. Perhaps purposeful reflections could help people to develop hope and resilience in future technology designs. Building resilience is not a way to change systematic biases; societal change remains crucial. By understanding and designing for improved resilience we can improve vulnerable individuals' (e.g., members of minority and/or stigmatized groups) well-being.

I will continue my research goal of understanding how computing systems can be designed in service of a more empathetic and inclusive world where vulnerable individuals are more empowered and their well-being is enhanced.

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APPENDICES

Appendix 1. Protocol for Responding to Participant Distress

Protocol for Responding to Participant Distress, Adapted Version for Telephone/Skype

Notes: This protocol for responding to research participant distress over the telephone has been adapted from the one devised by Cocking (2008). Adaptations have been made to reflect the fact that interviews may not always take place face to face.

Steps taken prior to commencement of interview questions:

1) Consider giving questions to the participant in advance so that the participant can acclimate to the idea of these questions being asked.

2) Seek the first and last name of participant and the town/city of current residence, in order to facilitate contacting emergency services if necessary.

3) Obtain emergency contact number from the participant. The participant should be informed in the informed consent that if the researcher has significant concerns about the participant's safety, and/or if the telephone conversation is terminated in the context of severe distress, the researcher may need to use this emergency contact.

4) Appropriate helpline(s) in each participant's area should be identified by the researcher in order to be able to offer participants immediate further sources of support if distress arises in an interview.

Mild distress:

Signs to listen out for:

1) Sounds that indicate participant may be weeping, e.g., sniffling, hesitation.

2) Voice becomes choked with emotion, or the participant has difficulty speaking or has a tremulous voice

3) Verbal signals such as "This is really hard for me to talk about", or "I didn't realise it would affect me so much to talk about it".

Actions to take:

1) Ask participant if they are okay to continue

2) Offer them time to pause and compose themselves

3) Remind them they can stop at any time they wish if they become too distressed

Severe distress:

Signs to listen out for:

1) Uncontrolled crying/ wailing/heavy sobs, inability to talk coherently

2) Expressions of strong feelings of personal guilt or responsibility for a negative event or harm to others (if applicable to topic)

3) Signs of high anxiety or panic attack, as heard by researcher and/or as reported by participant, e.g., hyperventilation, shaking

Actions to take:

1) The researcher should intervene to terminate the interview

2) The debrief will begin immediately

3) Relaxation techniques will be suggested to regulate breathing and reduce agitation

4) The researcher should acknowledge the participant's distress, and reassure him/her that (for example, according to topic) the experience that they're describing can be quite traumatic or difficult and can sometimes result in traumatic stress reactions.

5) If any unresolved issues arise during the interview, accept and validate the participant's distress, but suggest that s/he discuss with mental health professionals and remind the participant that this is not designed as a therapeutic intervention.

6) Offer details of counselli9ng/therapeutic/helpline services available to participants (see point 4 under "steps taken prior to commencement of interview questions", above)

Extreme distress:

Signs to listen out for:

1) Severe agitation, lack of coherence, especially coupled with sudden termination of telephone connection.

2) Verbal indications of suicidality, especially coupled with sudden termination of telephone connection.

Action to take:

1) If termination of telephone connection has occurred, attempt to re-contact. If this is unsuccessful, and termination occurred in the context of a level of agitation or emotionality that caused the researcher concern for the participant's or others' safety, inform emergency contact and/or local emergency services.

2) If the researcher has concerns for the participant's or others' safety and the participant is still on the line, s/he will inform them that s/he has a duty to inform the emergency contact provided and/or local emergency services.

If the researcher believes that either the participant or someone else is in immediate danger and the participant is still on the line, then the researcher will suggest that the participant presents him- or herself to the nearest Accident & Emergency department, and it may also be necessary for the researcher to contact the emergency contact.

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Appendix 2. Demographic Questionnaire

All interviewees across all two studies filled this information in at the end of the interview.

1. What is your age?

2. What is your gender?

3. If you have children, how many?

4. What is your marital status?

   (Single/Married/Partnered/Divorced/Separated/Widowed/Other)

5. What is your highest education level? (Some high school/High School/Some College/College/Some Graduate School/Graduate Degree

6. What best describes your current employment status? (Employed full-time/Employed part-time/Out of work and looking for work/Out of work but not currently looking for work/Stay-at-home-parent/A student/Military/Retired/Unable to work)

7. What is your household income? (Less than $1,000 per year/$1,000-$29,999/$30,000-$49,999/$50,000-$74,999/$75,000+)

8. What is your present religion, if any?

   (Protestant/Catholic/Orthodox/Jewish/Muslim/Buddhist/Hindu/Atheist/Agnostic/Something Else(Specify)/Nothing in Particular)

9. What country were you raised in? (If more than one, choose the country you spent the most time in during your childhood)

10. What is your email address? (This is necessary to receive the gift card)

Appendix 3. Study 1 – Screening Survey

Thank you for agreeing to participate in this screening survey. We are interested in disclosure and social support practices on social media in sensitive settings. This survey will help us to determine who is eligible to participate in our interview study. You may be selected if you have experienced a miscarriage during the past 2 years, are at least 18 years old, use social media regularly, and live in the US.

This screening survey will take 2-5 minutes to complete. If you are chosen for the study itself, we would like to have a conversation with you about your experiences via your preferred mode of voice communication (e.g., Skype) or in person if you are local to Philadelphia. This interview will take about 60-90 minutes. You will receive a $25 Amazon gift card for participating in our study and helping us.

Responses to this survey are private and confidential. We ask that you enter your email address only so that we can get in touch with you if you are eligible for the study. We greatly appreciate your input.

1. What online platforms do you use? Check as many as applicable.

Facebook (other than Facebook support groups), Facebook support groups, Instagram, Twitter, reddit, other support forums/groups/websites [please specify], Whisper, Secret, Yik Yak, Koko, Tumblr, other [please type in].

2. Have you ever considered sharing your experiences and feelings related to your miscarriage experiences using any of the above platforms? Yes, I remember considering it; Yes, I know I've thought about it but it's not easy to remember the details, No, I have not considered it.

3. Did you actually end up sharing anything related to your miscarriage experience (directly or indirectly) on any of these platforms? Yes, No, I'm not sure.

4. If you answered "yes" to question 3, where did you share it? [Please type in the name of the platform(s), and to the best of your recollection, a short description of what you shared.]

5. What is the month and year of the most recent miscarriage you have experienced? [please type in]

6. What is your age? [please type in]

7. What is your gender? [please type in]

8. Do you live in the US? [yes/no]

9. What is the best email address to contact you in case you are eligible to participate in the interview study? Please type in.

This research is conducted by a researcher who is a member of Drexel University.

If you have any questions or concerns please feel free to contact the lead researcher, Nazanin Andalibi at naz@drexel.edu

Faculty advisor: Dr. Andrea Forte [website: http://andreaforte.net/] [email: aforte@drexel.edu]

Lead researcher: Nazanin Andalibi, PhD Candidate [website: http://nazaninandalibi.net/] [email: naz@drexel.edu]

Appendix 4. Study 1 – Interview Protocol

Thank you so much for volunteering to share your experiences with me. I know that parts of this conversation might be difficult for you, and I can't emphasize enough how much I appreciate you participating in this. There is no right or wrong answer. By learning from you, I want to find ways to design social media to be more supportive and safe in times of distress. I believe it is impossible to do so without understanding experiences of people who have experienced those moments.

Please know that you can pause or stop this conversation at any time without any explanations or penalties. This is *your* interview. Also, if you need to take some time away, please feel free to do so, and let me know how and if I can help. I'll be recording our conversation with your permission. Do you have any questions for me before we start?

Story and disclosure

This is a study about miscarriage and how people communicate about their experience and feelings, so to start, just tell me your story. What was your life like when you found out you were pregnant? What happened?

[What did you do? How did you feel? How do you feel now that some time has passed?]

- Disclosed pregnancy?

Phase II. Disclosure and Non-Disclosure

Did you tell anyone about your experience using any type of social media?

If disclosed via social media:

Tell me about that...

[Questions such as: Who did you share your experience with? How did you do that and with what technology? What did you tell them? Can you describe your relationship with that person/audience? How did they react? How did that make you feel?]

Relationship trust: did you tell them to not tell others?

Shaming the support seeker: did you receive any response that you didn't like or that you felt judged by?"

[When specific channels are mentioned by participants, I will ask questions such as: things they like about it, things they don't like about it, how they use it, who they connect or don't connect with, what they share or don't share, how they manage audiences for content they share, how they like others to use or don't use it, and why]

I may repeat the previous questions and ask about more examples and comparisons until they are done talking about it.

Was there a situation where you considered or wanted to share your story or feelings on social media, but you did not? Tell me about an example.

[Questions such as: Why did you decide not to? Who were you going to share with? How would you describe your relationship with them? What did you think happens if you share? What did you want to happen? How did you feel?]

If did not disclose via social media:

You said that you did not share your feelings and story with others on social media, but you use social media in general. Tell me more:

[Was there a situation where you considered or wanted to share your story or feelings somewhere on social media, but you did not? Tell me about an example. Why did you decide not to?]

[Questions such as: Why did you decide not to? Who were you going to share with? How would you describe your relationship with them? What did you think happens if you share? What did you want to happen? How did you feel?]

Response to Other People's Disclosure

Have you ever come across other people sharing their miscarriage-related experiences and emotions or other sensitive negative experiences on social media? Give me an example.

[Questions such as: What did you come across? Who was it about? How would you describe your relationship with the poster? How did you come across it? What was the communication channel? Did coming across that content affect you in any way? How?]

Did you respond in any way?

If responded:

How did you respond? Why? What was that experience like?

If did not respond:

Can you tell me a bit about why you did not? What was that experience like?

How would you have responded if you knew you could respond without worrying about [reason they said they didn't respond]?

Do you know if other people responded?

[Questions such as: How did they respond? How did that make you feel?]

Closing

Think about [the channels you used and did not use to disclose and respond]. Now think about people who may want to share their personal stories such as yours, or those who want to provide support to those who do. What would have made it easier for you or others to share these experiences?

Is there anything else you would want to share and talk about that we have not covered?

I know this was not an easy conversation, and I am very grateful that you shared your experience with me today. I have gathered some resources about miscarriage. Would you want me to share these with you? If so, I can email them to you or name a few before we end our conversation.

http://www.miscarriageassociation.org.uk/support/

http://community.babycenter.com/groups/a6260505/miscarriage_support

Thank you very much for sharing your experience with me.

Appendix 5. Study 2 – Screening Survey

Thank you for agreeing to participate in this screening survey. We are interested in disclosure and social support practices on social media in sensitive settings. This survey will help us to determine who is eligible to participate in our interview study. Minimum eligibility criteria include being at least 18 years old, living in the US, and using social media regularly.

This screening survey will take about 2-5 minutes to complete. If you are chosen for the study itself, we would like to have a conversation with you about your experiences via your preferred mode of voice communication (e.g., Skype) or in person if you are local to Philadelphia. This interview will take about 60-90 minutes. You will receive a $25 Amazon gift card for participating in our interview study and helping us.

Responses to this survey are private and confidential. We ask that you enter your email address, so that we can get in touch with you if you are eligible for the study, and to process the gift card compensation. We greatly appreciate your input.

1. What online platforms do you use? Check as many as applicable.

Facebook, Facebook support groups, Instagram, Twitter, reddit, support forums, Whisper, Secret, Yikyak, Koko, other [please type in].

2. In your daily life when you browse social media, have you ever come across posts expressing negative feelings such as shame, guilt, anxiety, or stressful situations such as dealing with depression, divorce, loss of a loved one, miscarriage, and things like that? Yes, No

3. Please provide some examples of what you have seen and who shared it. Examples could be as simple and short as: "I have seen posts about depression on Instagram from my cousin", or "I have seen posts about miscarriage on Facebook from a coworker"

4. Please type in your email address that we can use to contact you if you are selected to participate [please type in]

5. What is your age? [please type in]

6. What is your gender? [please type in]

7. Do you live in the US? [yes/no]

This research is conducted by a researcher who is a member of Drexel University.

This research is approved by Drexel University's IRB.

Faculty Advisor: Dr. Andrea Forte [website: http://andreaforte.net/] [email: aforte@drexel.edu]

PhD Candidate Researcher: Nazanin Andalibi [website: http://nazaninandalibi.net/] [email: naz@drexel.edu]

If you have any questions or concerns please feel free to contact Nazanin Andalibi at naz@drexel.edu

Appendix 6. Study 2 – Interview Protocol

Thank you so much for volunteering to share your experiences with me. I believe that by listening to you, I will learn important things about social media use in situations that may not be that cheerful and happy. Please know that you can pause or stop this conversation at any time without any explanations or penalties. I'll be recording our conversation with your permission. Do you have any questions for me before we start?

Response to Other People's Disclosure

When asked about your exposure to other people's shared content on social media, you mentioned that you have come across X on platform Y [insert X and Y from the screening survey]. Can you tell me a little bit more about that?

[If you can access it now, please take your time and bring it up on your computer. If not, please think about the time this happened.]

Have you ever come across other people sharing their miscarriage-related experiences and emotions or other sensitive negative experiences on social media? Give me an example.

[Questions such as: What did you come across? Who was it about? How would you describe your relationship with the poster? How did you come across it? What was the communication channel? Did coming across that content affect you in any way? How?]

Did you respond in any way?

If responded:

　　How did you respond? Why? What was that experience like?

If did not respond:

Can you tell me a bit about why you did not? What was that experience like?

How would you have responded if you knew you could respond without worrying about [reason they said they didn't respond]?

Do you know if other people responded?

[Questions such as: How did they respond? How did that make you feel?]

Are there other examples where you might have come across such posts? (e.g., mental illness, miscarriage, etc.)

Repeat the above questions for more examples

Disclosure and Non-disclosure Behavior

So, when you filled in the screening questionnaire, you mentioned that you use these platforms [Name platforms from the screening survey].

Have you ever shared something that you considered to be negative? What made it negative?

If disclosed via social media:

Tell me about an example…

[Questions such as: Who did you share your experience with? How did you do that and with what technology? What did you tell them? Can you describe your relationship with that person/audience? How did they react? How did that make you feel?]

Relationship trust: did you tell them to not tell others?

Shaming the support seeker: did you receive any response that you didn't like or that you felt judged by?"

[When specific channels are mentioned by participants, I will ask questions such as: things they like about it, things they don't like about it, how they use it, who they connect or don't connect with, what they share or don't share, how they manage audiences for content they share, how they like others to use or don't use it, and why]

I may repeat the previous question and ask for more examples and comparisons until they are done talking about it.

Was there a situation where you considered or wanted to share your story or feelings on social media or tell someone, but you did not? Tell me about an example.

[Questions such as: Why did you decide not to? Who were you going to share with? How would you describe your relationship with them? What did you think happens if you share? What did you want to happen? Hoe did you feel?]

If did not disclose via social media:

You said that you did not share your feelings and story with others on social media, but you use social media in general. Tell me more:

[Was there a situation where you considered or wanted to share your story or feelings somewhere on social media, but you did not? Tell me about an example. Why did you decide not to?]

[Questions such as: Why did you decide not to? Who were you going to share with? How would you describe your relationship with them? What did you think happens if you share? What did you want to happen? Hoe did you feel?]

Vignettes

Now, please take a look at these stories [show vignettes 1-4 one by one].

Tell me how you think *other people may* feel and respond when they come across this online.

[Questions such as: Why do you think that is? What are possible explanations for these responses?]

Now tell me how *you* would feel and respond if this was from a [tie type: friend, coworker, family member, acquaintance, stranger]

[Questions such as: Why? Why not? How would you describe your relationship with [tie type]?]

Closing

Is there anything else you would want to share and talk about that we have not covered?

Thank you very much for sharing your experience with me.

Appendix 7. Vignettes

Below are the vignette instruments presented to participants.

V1 – Direct support seeking and low disclosure detail

Today was my due date. My partner says it's been months and I need to get past it. How do I make him understand?

V1a – Direct support seeking and low disclosure detail

Today was my due date. I keep thinking of what it could have been. How do I get through this?

V1b – Direct support seeking and low disclosure detail

Today was my due date. I don't feel supported. How do I make others understand that this is difficult?

V2 – Direct support seeking and high disclosure detail

Several years ago when we got married, I was diagnosed with a life threatening condition and lived in a coma for a few months. I survived, but it was several years before I was cleared to get pregnant. After a year of trying, we started fertility treatments and we got pregnant with twins. After several weeks we learned that one did not make it but the other one was thriving and we had an ultrasound picture with a strong heartbeat. A week before this Christmas, and a week later at our last doctor visit, we were told there was no heartbeat. We got more scans, same results. I didn't and still don't believe. All doctors recommended D and C. I started to have an infection from carrying the babies. I agreed. I had to. I cried from the moment I got to the surgery room to the moment I was taken to the OR. Three days after the surgery, I had horrible complications and serious blood loss. I spent a few days in the hospital but I still have pain and bleed. It's now been three weeks after the D and C. I am devastated. I have lost family members in the past but I have never grieved

like this. I need to heal for months before trying again. I am trying to be hopeful while still working, studying, and taking care of my marriage. If anyone has any feedback or advice as to how to get myself out of this pit, I would be so thankful. I miss these babies so much and it just feels like it will not get better, ever. Looking for help.

V3 – Indirect support seeking and low disclosure detail

Almost three years. Still terribly painful to have lost my baby although I have one daughter I love.

V4 – Indirect support seeking and high disclosure detail

I had a chemical miscarriage a few nights ago. It was terrible and the pain was unbearable. The worst thing was that I never even knew I was pregnant. So I didn't even think I was having a miscarriage and I thought it was just some painful cramps that made me want to vomit. I had cold chills and couldn't walk. I had to grab onto something to be able to breathe through the pain. I just I wanted to run away from my own body; it was THAT bad. The whole thing went for about 7 hours on and off. So I went to the doctor on Friday and he told me that it sounded like a chemical miscarriage. I had thought it was just my period, cause it started on Monday with some light spotting (not normal for me), but no pain and was like that for 4 days until Thursday night when it got that bad and painful. I'm lost. I am an emotional mess. I haven't been able to function at all. I have always wanted a baby, but I wasn't trying to. Not only I lost my baby, but also I didn't even know it existed. I feel so guilty and can't trust myself anymore. I don't know if I can feel better.

Appendix 8. Disclosure decision making models in communication research

Omarzu's Disclosure Decision Model. In 2000, Omarzu (Omarzu 2000) proposed a disclosure decision model (DDM) (depicted below), that outlines a cognitive process by which disclosure decisions are made. In this model, decisions influence the content, depth, breadth, and duration of disclosures. At least one of the five goals of self-expression, self-, social validation, relationship development, and social control must be made clarification accessible so that the disclosure gets activated. Then the individual goes through the steps outlined in the figure below. The goals in this model are based on the functional approach to disclosure by Derlega and Grzelak (Derlega and
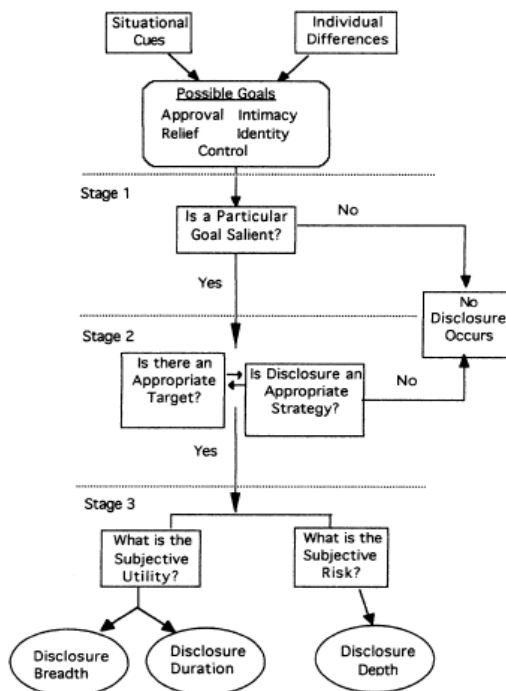
Grzelak 1979).

Omarzu suggests that his model is mostly suited for predicting initial disclosures, disclosures in new relationships, and in highly strategic situations and is likely less useful in predicting disclosure in long term intimate or highly scripted social interactions.

Greene et al.'s disclosure decision model. In 2006, Greene et al.proposed a disclosure decision model based on the work from Derlega and Grzelak (Derlega and Grzelak 1979) and Petronio (Petronio 2002) briefly discussed in the history section as well as Omarzu (Omarzu 2000) discussed

above. As depicted below, this model is also a step-wise cognitive model of decision making; yet

it does bring to light some contextual complexities that may go into the decision making process.