Social Media for Sensitive Disclosures and Social Support: The Case of Miscarriage

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Abstract

I study self-disclosure and investigate ways in which social computing systems can be designed to allow people to disclose negatively-perceived or stigmatized experiences and find support in their social networks. My prior work has given me insight about online disclosures of depression and sexual abuse, the role of anonymity in support seeking, and the ways that people respond to such disclosures. In my dissertation I will use miscarriage as a context to investigate online disclosure and response practices around stigmatized and traumatizing topics with the goal of improving both theory and social media design practices.

Problem Statement

All humans experience unwanted emotions in their lives. Stigmatized identities may be concealable (e.g., miscarriage, HIV) or visible (e.g., race, physical disability), and may include experiences of trauma (e.g., miscarriage, death of a loved one, sexual abuse). People can benefit from socially sharing such events and emotions associated with them [10]. However, many people inhibit socially and/or personally-perceived negative aspects of their lives and identities,

and sometimes they suffer as a result of this inhibition. Other times, when they do disclose, they might face negative consequences such as social rejections. On the other hand, there are potential benefits such as enactment of various forms of social support in disclosing such experiences and emotions associated with them. Social science literature provides us with several models (e.g., [9] [6]) to describe and explain disclosure practices in non-mediated and dyadic contexts. However, understanding self-disclosure practices when mediated by technology and with larger audiences is still an open and complex area of inquiry.

Social computing platforms are often celebrated for their capacity to connect; yet when people experience distress, they often find it difficult to use social media to seek support. I frame seeking support as a type of self-disclosure that often involves risking one's "face" in Goffman's [5] terms. Goffman posits that people want to create positive impressions of themselves [5], and sharing more positive rather than negative events and emotions has been linked to such positive impressions [7]. Individuals experiencing positive events are more motivated to share these events with their networks than those experiencing negative events [11]. Yet, if communicated, difficult disclosures can serve as a way to find support. Other HCI researchers have investigated the design and use of online environments for support. For example, research indicates that when people post on Facebook about a stressful event like a job loss, their strong ties provide support; however, the presence of strong ties may also exacerbate feelings of embarrassment and increase stress as well [3], which pertains to the important role of the disclosure audience. How do people disclose sensitive information and potentially stigmatized emotions as they use social

media? What are the conditions in which these disclosures could lead to supportive interactions? Important questions remain about how these complex social performances are enacted or best supported in computer-medicated environments. I plan to tackle this space in my dissertation.

Pilot Work

In pilot studies, I have examined depression-related photo sharing on Instagram to understand how shared media like photographs create opportunities for people to disclose negative emotions and how others respond [2]. Noting that Instagram does not have a "real name" policy and people could use pseudonyms, I found evidence of emergent support networks. Most importantly, interactions around depression-tagged images are mainly supportive and rarely include aggressive or negative remarks. I have also investigated sexual-abuse disclosures on reddit [1]. In this work, I found that affordances that support anonymous disclosures and faceted identity performances [4] are important: people are more likely to seek support anonymously, and men (who face more stigma as victims of sexual abuse) are more likely to disclose abuse using throwaway accounts that are not linked with their primary reddit identities. In a current project, I am using content analysis methods to investigate potential differences in the types of responses that anonymous and identified sexual-abuse disclosures on reddit attract.

Proposed Dissertation Work

My pilot studies and prior work suggest that there is potential for social media to be designed in ways that not only enable safe sharing of negative experiences, but also encourage development of emergent support

Research Questions

RQ1. How do people who have experienced miscarriage decide to disclose feelings and experiences related to this experience online, to whom, when, through what channels, and why?

RQ2. How do people decide whether and how to respond to disclosures that they perceive to be negative or stigmatized on social media?

RQ3. What technological affordances and constraints play a role in mediating 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?

networks that can help people feel less alone and receive more sympathy. In my dissertation, I plan to take miscarriage as a context that is often socially stigmatized, often traumatizing, associated with negative feelings, and hard to disclose in order to examine how and when people share negative emotions and experiences in online networks, the conditions in which self-disclosures are likely to lead to supportive interactions, and how social media can be designed to promote positive outcomes for people who disclose stigmatized experiences. My specific research questions are described in the sidebar, and I plan to conduct the following studies to address them by taking a phenomenological approach.

Study 1: Semi-structured interviews with people who have had miscarriages about their beliefs and practices with respect to disclosure, nondisclosure and responses to others people's disclosures: The first purpose of this study is to gain a deep understanding of the goals and decision-making process behind disclosure and nondisclosure on social media of miscarriage-related feelings and experiences, and the factors that influence these decisions. I will delve into the perceived sociotechnical, relational, cultural, and individual factors that influence disclosure decisions. This study will contribute to understanding the contexts that encourage or inhibit miscarriage disclosures on social media, such as where (platform choice), when, how, and why people disclose or do not disclose. This will primarily address RQ1 and RQ3, and partially RQ2.

Study 2: Semi-structured interviews and vignettes with people about response practices when facing other people's disclosures: The purpose of this study is to

delve deep into reactions of people who come across negative and stigmatized disclosures as they browse social media, and the reasons and mechanisms behind those. The results of this study will address RQ2 and RQ3 and will contribute to a richer understanding of the decision making processes around responding or not responding to sensitive disclosures, and factors that inhibit or disinhibit various types of response behavior in the face of such disclosures. In addition to interviews, I will also use vignettes that I have designed and ask participants to tell me how they would react to a miscarriage disclosure by particular members of their network (e.g., friend, family, etc.).

In both of these studies, because I cannot predict what sharing platforms are important to my participants, and because people likely use a variety of mediums, I will not focus on any particular one. Instead, I take an ecological perspective and I will follow up on particular channels participants use as needed and as they come up in the interviews. I will also I will use participants' social media data where possible to understand the phenomena better. I will analyze interview data using the constant comparative approach.

Study 3: Semi-structured interviews with redditors about their disclosure, non-disclosure, and response practices on miscarriage subreddits, content analysis of posts and comments, and investigating the role of anonymity afforded by throwaway accounts in disclosure and response practices: In this study I will interview participants who post on miscarriage-related subreddits. I choose reddit because these disclosures are already happening there, and two levels of identifiability are allowed: using a pseudonym and using a throwaway account that is a proxy for

anonymity [8]. This will allow me to not only ask these participants about their disclosure and response behavior on reddit, but also follow up to understand their overall social media practices in this context and to complement studies 1 and 2. In addition to interviews, I will use qualitative content analysis methods to characterize disclosures and responses and quantitative methods to understand these variables' disclosures and interactions around them.

Expected Contributions

I expect to improve our empirical and theoretical understanding of how and in what contexts sensitive disclosures (i.e., disclosures that make people feel vulnerable) happen in computermediated environments and how and in what contexts supportive interactions occur. Although in most of this work I focus on miscarriage, I expect some of my results to go beyond this specific experience and be applied to other stigmatized and sensitive contexts that make people feel vulnerable and where social support following disclosures would be helpful. Finally, by understanding the role of technological affordances in disclosure and response practices, I will be able to recommend social media design improvements that will better enable safe and sensitive disclosures and more social support. To me, my dissertation is the beginning of a research career that in addition to the intellectual contributions, tries to give a voice to underrepresented and stigmatized populations and make the world just a bit more supportive, compassionate, and open to live in.

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