

Self-disclosure and Response Behaviors in Socially Stigmatized Contexts on Social Media: The Case of Miscarriage

Nazanin Andalibi

Drexel University
Philadelphia, PA 19104, USA
naz@drexel.edu

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the Owner/Author.
Copyright is held by the owner/author(s).
CHI'17 Extended Abstracts, May 06-11, 2017, Denver, CO, USA
ACM 978-1-4503-4656-6/17/05.
<http://dx.doi.org/10.1145/3027063.3027137>

Abstract

I investigate self-disclosure and the ways in which social computing systems can be designed to allow people to disclose sensitive or stigmatized experiences and find and provide support in their online social networks. My prior work has given me insight about online disclosures of mental illness and sexual abuse, the role of anonymity in support seeking, the ways that people respond to such disclosures, and nuances of supportive interactions. In my dissertation I focus on miscarriage as a context to investigate online disclosure and response behaviors around often stigmatized and traumatizing topics with the goal of improving both theory and social media design practices.

Author Keywords

Social media; self-disclosure; social support; pregnancy loss; miscarriage; stigma; life events; identity; grief.

ACM Classification Keywords

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

Motivation and Problem Statement

All humans experience unwanted emotions in their lives. Stigmatized identities may be concealable (e.g.,

HIV) or visible (e.g., race, certain physical disabilities), 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 [17]. 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., [7,16]) 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 [6] terms. Goffman posits that people want to create positive impressions of themselves [6], and sharing more positive rather than negative events and emotions has been linked to such positive impressions [8]. Individuals experiencing positive events are more motivated to share these events with their networks than those experiencing negative events [18]. Yet, if communicated, difficult disclosures can serve as a way to find support. HCI researchers have investigated the design and use of online environments for support. For example, 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 [4], signaling the important role of the disclosure audience. **How do people disclose sensitive information and potentially stigmatized experiences as they use social media? Under what conditions can these disclosures lead to supportive interactions?** Important questions remain about how these complex social performances are enacted or best supported in computer-mediated environments. I tackle this space in my dissertation.

Pilot Work

In pilot work, I have examined what I term sensitive disclosures (i.e., those that make disclosers feel vulnerable) on Instagram to understand how shared media like photographs create opportunities for people to disclose negative emotions and mental health-related experiences and how others respond [2]. Noting that Instagram accounts are often pseudonymous, 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 [5] 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 anonymous accounts that are not linked with their primary reddit identities. In a current project, I am investigating potential differences in the types of responses that anonymous and identified sexual-abuse disclosures on reddit attract.

Overarching Problem Statement

How do we design social computing systems that allow people to disclose stigmatized experiences, and seek and provide support in their online social networks?

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?

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 stigmatized or sensitive experiences, but also encourage development of emergent support networks that can help people feel less alone and receive more sympathy. In my ongoing dissertation work, I take miscarriage as a context to examine how and when people share negative emotions and experiences in online networks, the conditions under 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.

Miscarriage

Past work has framed miscarriage primarily as a medical problem; however, it is also a psychologically and socially complex and difficult experience and is associated with many negative well-being effects [11]. Miscarriage is often socially stigmatized and is difficult to disclose, often traumatizing, and associated with negative feelings such as shame and guilt, depression, and PTSD. It is challenging to many people's sense of identity and often influences their relationships [12–14]. Though miscarriage is a loss that many need to grieve, others in one's life do not always acknowledge it as a loss that deserves to be grieved; thus, reactions are sometimes not supportive when people do disclose [3]. Miscarriage has not been investigated in computer-mediated-communication settings in the past, is a common phenomenon, and is valuable for studying sensitive disclosures and support seeking/providing practices.

Proposed Dissertation Studies

Study 1: *Semi-structured interviews with people who have had miscarriages about their beliefs and practices with respect to disclosure, non-disclosure 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 processes behind disclosure and non-disclosure on social media of miscarriage-related feelings and experiences, and the factors that influence these decisions. I delve into the perceived socio-technical, relational, cultural, and individual factors that influence disclosure decisions. This study contributes 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 primarily addresses RQ1 and RQ3, and partially RQ2.

Study 2: *Semi-structured interviews and vignettes:* The purpose of this study is to delve deep into reactions of people who come across perceived negative and stigmatized disclosures as they browse social media, and the reasons and mechanisms behind those. The results of this study address RQ2 and RQ3 and 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 sensitive disclosures. In addition to interviews, I 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

Methodology. I investigate how people *perceive* the socio-technical factors that lead to their disclosure, nondisclosure, engagement and non-engagement practices from *their* perspective. My approach is *interpretivist* and *phenomenological*.

Methods. Interview is common across my proposed studies. In-depth interviewing enables understanding the lived experiences of people and the meanings they associate with them. By interviewing people about their disclosure and supportive communication behavior, I can gain an in-depth knowledge about the *meaning they ascribe to* communication acts, the *rationale* behind them, and the *perceived impacts* of socio-technical features on these behaviors. Study 2 employs vignettes (short descriptions of situations shown to respondents) in order to elicit judgments, social norms, and attitudes about responding to disclosures. Study 3 uses content analysis and statistical models to uncover the nature of disclosures, responses, and the link between them.

because people likely use a variety of media, I do not focus on any particular one. Instead, I take an ecological perspective and follow up on particular channels participants use as needed and as they come up in the interviews. I also use participants' social media data where possible to understand the phenomena better. I analyze interview data using the constant comparative approach, starting with open coding allowing for more flexibility and creativity [10].

Study 3: *Semi-structured interviews with redditors about their disclosure, non-disclosure, and response practices on miscarriage-related subreddits, content analysis of posts and comments, and investigating the role of anonymity afforded by throwaway accounts:* I chose reddit because these disclosures already happen on this platform, and two levels of identifiability are allowed: using a pseudonym, and using a throwaway account that is a proxy for anonymity [9]. This allows me to not only ask participants about their disclosure and response behavior on reddit, but also to understand their overall social media practices in this context and to complement studies 1 and 2. In addition to interviews, I use qualitative thematic content analysis methods to characterize disclosures and responses, and quantitative methods to understand the links between disclosures and surrounding interactions.

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 computer-mediated environments and how and in what contexts supportive interactions occur. Goffman's [6] work was situated in a time before social media. Social media have created

new contexts that facilitate face-work in ways that Goffman had not anticipated. I will extend our understanding of impression management concerns in the context of stigmatized identities and sensitive disclosures and interactions forming around them. With respect to response behaviors, I will contribute to the stigma literature a further understanding of how people stigmatize others [10,15]. Finally, I expect to provide further understanding of how people utilize multiple social media platforms in the context of sensitive disclosures and seeking help. My work will also contribute to the medical and psychological domains by providing new knowledge about the very experience of miscarriage. 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. 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 useful social support. I believe by using vignettes in conjunction with interviews, I am also introducing a new way to understand people's response behavior in sensitive settings to the social computing community. Last, but not least, my work makes visible the experiences and lives of people who go through the miscarriage experience and helps to tell their stories.

Acknowledgments

I am extremely thankful to my advisor, Andrea Forte, and my other committee members Elizabeth Churchill, Gabriela Marcu, Aleksandra Sarcevic, and Sarita Yardi

Schoenebeck for their continued guidance and support. This work is supported by the NSF grant #1253302.

References

1. Nazanin Andalibi, Oliver L. Haimson, Munmun De Choudhury, and Andrea Forte. 2016. Understanding Social Media Disclosures of Sexual Abuse Through the Lenses of Support Seeking and Anonymity. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), 3906–3918. <https://doi.org/10.1145/2858036.2858096>
2. Nazanin Andalibi, Pinar Ozturk, and Andrea Forte. 2017. Sensitive Self-disclosures, Responses, and Social Support on Instagram: The Case of #Depression. In *Proceedings of the Conference on Computer Supported Cooperative Work & Social Computing* (CSCW '17). <https://doi.org/10.1145/2998181.2998243>
3. Cecilia Bosticco and Teresa Thompson. 2005. The Role of Communication and Story Telling in the Family Grieving System. *Journal of Family Communication* 5, 4: 255–278. https://doi.org/10.1207/s15327698jfc0504_2
4. Moira Burke and Robert Kraut. 2013. Using Facebook after losing a job: Differential benefits of strong and weak ties. 1419–1430.
5. Shelly D. Farnham and Elizabeth F. Churchill. 2011. Faceted identity, faceted lives: social and technical issues with being yourself online. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work & Social Computing*, 359–368. <https://doi.org/10.1145/1958824.1958880>
6. Erving Goffman. 1959. The presentation of self in everyday life.
7. K Greene, TD Afifi, and WA Afifi. 2009. An integrated model of health disclosure decision-making. *Uncertainty and information regulation in interpersonal contexts: Theories and applications*: 226–253.
8. Mark R Leary and Robin M Kowalski. 1995. The self-presentation model of social phobia. *Social phobia: Diagnosis, assessment, and treatment*: 94–112.
9. Alex Leavitt. 2015. “This is a Throwaway Account”: Temporary Technical Identities and Perceptions of Anonymity in a Massive Online Community. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work & Social Computing*.
10. Thomas R. Lindlof and Bryan C. Taylor. 2010. *Qualitative Communication Research Methods*. SAGE.
11. Christine Moulder. 1994. Towards a Preliminary Framework for Understanding Pregnancy Loss. *Journal of Reproductive and Infant Psychology* 12, 1: 65 – 67.
12. Joann O’Leary PhD MPH MS. 2009. Never a simple journey: pregnancy following perinatal loss. *Bereavement Care* 28, 2: 12–17. <https://doi.org/10.1080/02682620902996004>
13. R. Neugebauer, J. Kline, P. O’Connor, P. Shrout, J. Johnson, A. Skodol, J. Wicks, and M. Susser. 1992. Depressive symptoms in women in the six months after miscarriage. *American Journal of Obstetrics and Gynecology* 166, 1 Pt 1: 104–109.
14. R. Neugebauer, J. Kline, P. O’Connor, P. Shrout, J. Johnson, A. Skodol, J. Wicks, and M. Susser. 1992. Determinants of depressive symptoms in the early weeks after miscarriage. *American Journal of Public Health* 82, 10: 1332–1339.
15. Megan Oaten, Richard J. Stevenson, and Trevor I. Case. 2011. Disease avoidance as a functional basis for stigmatization. *Philosophical Transactions of the*

- Royal Society B: Biological Sciences* 366, 1583: 3433–3452. <https://doi.org/10.1098/rstb.2011.0095>
16. Julia Omarzu. 2000. A Disclosure Decision Model: Determining How and When Individuals Will Self-Disclose. *Personality and Social Psychology Review* 4, 2: 174–185. https://doi.org/10.1207/S15327957PSPR0402_05
17. Bernard Rimé, Catrin Finkenauer, Olivier Luminet, Emmanuelle Zech, and Pierre Philippot. 1998. Social

- Sharing of Emotion: New Evidence and New Questions. *European Review of Social Psychology* 9, 1: 145–189. <https://doi.org/10.1080/14792779843000072>
18. Jessica Vitak and Jinyoung Kim. 2014. “You can’t block people offline”: examining how facebook’s affordances shape the disclosure process. 461–474. <https://doi.org/10.1145/2531602.2531672>