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# Social Computing Researchers, Vulnerability, and Peer Support

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CHI'16 Ethical Encounters in HCI: Research in Sensitive and Complex  
Settings Workshop

**Abstract**

Social computing is exciting partially as it provides a way to investigate aspects of human behavior that have not always been easily accessible. For example, disclosures of phenomena such as depression, harassment experiences, and sexual violence are commonly encountered in online spaces. The relative ease of accessing these online experiences means that researchers needn't conduct clinical interviews to obtain data about highly sensitive topics and those who investigate these topics are from increasingly diverse fields such as HCI. We pose the question, should research ethics address protections not only for the creators of the vast troves of online data that are being subjected to the scientific gaze, but also for the researchers themselves? In this autoethnographic piece, we examine the issue of the impact of work on researchers from the perspective of occupational vulnerability and propose pragmatic ideas to discuss and explore at the workshop and in the HCI community in large to help build support networks for researchers.

**Introduction**

*Looking through images, I see a long shot of a woman's legs. She is naked, sitting in a bath. I can't see her face or torso but her legs give the impression of youth, not age. And they are*

*covered with cuts—self-inflicted lacerations that look swollen and painful. I tag it with relevant terms. The next image portrays a woman’s frighteningly emaciated frame and is adorned with a comment thread full of complements. I tag it with relevant terms. Next is a mirror selfie of an anorexic teenager in the very privacy of her bedroom saying how ugly and unlovable she thinks she is. I tag it with relevant terms. Other images in this batch include text that suggest the poster is suicidal, but there is nothing I can do, the images were posted weeks ago. So I tag them with relevant terms.*

Many occupations expose people to distressing information. Lawyers, doctors, police officers, and mental health professionals are some obvious examples of people who are vulnerable to occupation-related distress. Less visible vulnerable populations include people who work for tech companies to review flagged content [3], or people who curate and index content libraries such as that of the Shoah Foundation’s oral histories of genocide.

In this paper, we argue that some social computing research can also be counted as a vulnerable occupation. Vulnerability is a core concept for understanding the protection of research participants, and research ethics guidelines have been discussed in the context of online research for decades, but generally with respect to the participants. In this position paper, we draw on occupational vulnerability literature and an autoethnographic narrative to open up a discussion about the potential risks posed by social computing research to researchers themselves, and how these risks might be mitigated.

To understand how HCI researchers are influenced by their work in sensitive settings, Moncur [6] surveyed researchers investigating technology design in the context of end of life, and reported on three themes: personal experience (i.e., researcher’s background, emotional engagement and meaning making, effects on the researcher), institutional practice, and informal coping mechanisms (i.e., peer support, family and friends, working practices – structure and distraction). Moncur's observations align with that of "empathic approach"[2] to HCI research where researcher understands the research phenomena through meaningful emotional interactions with participants.

### **Occupational Vulnerability**

Occupational vulnerability is the threat of distress brought about by performing professional duties. One profession that has at least partly embraced its practitioners’ vulnerability is mental healthcare. Empirical research suggests the effects of distress and impairment on mental health professionals are serious [5]. Psychologists, psychiatrists, and social workers are examples of professionals whom we might expect to acknowledge the stressful aspects of their jobs; however, as discussed in [1] the prevalence of stigma associated with psychological distress and the belief that mental health professionals should not be affected by their work, can still contribute to a "conspiracy of silence" about occupational vulnerability.

Now that the availability of data on human behaviors is bringing many non-clinicians in contact with distressing content, the kinds of issues that mental health professionals regularly encounter are creeping into the everyday work lives of social computing researchers. We suggest that we, as social computing researchers,

can learn from such other occupations in acknowledging their vulnerability and appropriating their methods of dealing with that.

### **An Autoethnographic Case Study**

There are millions of images on Instagram that are tagged with depression-related terms. Searching for #depression on Instagram leads to often times intense, intimate, and sometimes triggering images captioned and tagged with depression-related text. We wondered about the impact of sharing these images on the sharers and about their media consumption and production habits, so we developed an interview protocol to learn more about their experiences and began recruiting. What follows is an auto-ethnographic report based on the experiences of the first author doing Internet research in the context of psychologically vulnerable self-disclosures using a combination of publicly available online data and interviews. We then discuss these experiences as a case study of Internet researchers' vulnerability.

#### **A PERSONAL NARRATIVE FROM THE FIRST AUTHOR**

The visceral impact of depression-related images is part of what attracted me to the research topic in the first place. Something important was happening here. People were publicly sharing deeply personal and distressing accounts of feelings and experiences – why? Did it help them? Did it hurt them? Were they interested in similar others'? These are the kinds of questions that require a phenomenological approach to research, and I felt I could not see the answers in the online data alone. So I started interviewing.

My most successful strategy for recruiting Instagrammers who posted depression-tagged content was to use private direct messages to people who were sharing such content and ask if they would be interested in participating. Among people who responded to our hundreds of messages, the majority reported that they were younger than 18 but that "*they would still love to talk to us.*" Some intimated that it would have to be at a time when their parents would be absent. I had to decline further contact.

Our recruitment strategy had failed, but the impact on me was bigger than disappointment in a failed protocol. I had had contact with young people who were suffering. Having gone through countless public Instagram profiles, seen countless despairing images and now having realized that these young people were indeed looking for someone to talk to, I felt powerless to help. I was fully aware of my role as a researcher and that I am not a mental health professional but accessing these images had exposed me to issues I also could not simply ignore. I was aware that teenagers are among the most vulnerable populations; yet seeing their messages in my inbox that they would like to talk to someone and having to tell them "*I am so sorry, I cannot talk to you if you are under 18*" felt eye-opening. In the end, I did interview two young adults who met the participation criteria. I asked them personal questions and I listened to them as they talked about their feelings and social media behavior. I listened to them as they scrolled through their images and told me personal stories and feelings behind them. I listened to them as they said "*I am really glad that you are doing this, because I feel this gives me a voice*" or "*I am here because I think someone needs to talk about these and there is a lot of stigma surrounding*

*depression*". As important as I thought this line of work was, and as glad as I was that they were happy to have talked to me, I felt emotionally drained.

Unable to recruit enough adult participants for the interview study, we changed our strategy. We decided to look at publicly available data through the Instagram API, to characterize these sensitive disclosures, comments associated with them, and the relationship between disclosures and responses to them.

Utilizing qualitative visual and textual analysis, and going thorough the images, captions, tags, and comments was a moving experience. Coding images in this context means carefully examining (sometimes really graphic) self-harm images, people expressing their suicidal thoughts, people sharing tragic life stories, and more. Additionally, going through the captions accompanying these images provides richer and deeper understanding of world through their eyes and what they are going through. Sometimes they ask for help, sometimes they want people to leave them alone – which appears ironic because they seem to be actually reaching out by sharing. Thinking through this data and understanding it has been challenging not only because of the complexity of the content itself, but also because of the nature of it and how it affects me as a human. At times I have felt guilty for involving my collaborators in coding this content, due to being concerned about the impact this activity might have had on them too. This study was my foray into the research in sensitive settings, and although my collaborator who coded the data with me and I occasionally talked about how it impacted us, we did not engage in collaborative reflection and peer support as much as in retrospect I think we would have found

helpful. This might have been due to limited experience as well as the dynamics of the relationship between researchers; participants in [6] also reported that the relationship between research team members might factor into this process.

In another study [7] with a different research team, we characterized the presentation of eating disorders online. In a more [1] recent study, we qualitatively coded posts on subreddits dedicated to sexual abuse. In these last two studies, the researchers who coded the data engaged in frequent and substantial sharing about their experience in engaging with the data, and all reported that they felt it helped with the emotional effect of the work on them. Perhaps, more experience as well as the dynamics of the relationship between the researchers who coded the data also contributed to finding this approach helpful.

## **Future Work and Anticipated Challenges**

In this section, I use the points that Moncur [6] suggests HCI researchers consider as they embark on research in sensitive contexts as a framework to organize the anticipated challenges in my dissertation.

I study self-disclosure and investigate ways in which social computing systems can be designed to allow people to disclose negatively-perceived or stigmatized aspects and find support in their networks. In my dissertation, using in-depth interviews and behavioral data, I plan to take miscarriage as a context that is socially stigmatized, traumatizing, associated with negative feelings, and hard to disclose to investigate online disclosure and response practices around

stigmatized and traumatizing topics with the goal of improving both theory and social media design.

I find the concept of sensitivity to be closely related to researcher's wellbeing through its connection to personal experiences. Sensitivity is about being able to give meaning to the data and connect the concepts to each other as the researcher discovers them [3: 43]. Glaser and Strauss suggest personal experience, familiarity with the literature, and professional experience could be used towards more sensitivity in research. I have not had a personal experience with miscarriage, but I have experienced traumatic loss of loved ones and have dealt with disclosure and non-disclosure in mediated and non-mediated contexts about it. As Glaser and Strauss suggest [3: 48], this provides me with a comparative base for asking questions and defining meanings in the context of my dissertation studies. I believe it will also help me in being more empathetic in the research process, but I am also distant enough from the context of miscarriage that will help with being more open to what the participants' experiences are like.

It is not possible, nor desired for me to be completely emotionally removed in various phases of these studies. Of course I care about those who are confiding in me to tell me about their most vulnerable experiences, and of course I will feel sad. The challenge for me is to remain sensitive enough to conduct reliable research while also maintaining my own wellbeing. Similar to many other institutions, there are no formal opportunities designed to support researchers in sensitive contexts in my university. So, I would need to draw upon informal sources such as friends and colleagues. What makes this challenging is that there

might be people around me who have experienced miscarriage, and not knowing that, talking to them might put them in an uncomfortable situation.

## **Discussion**

We have shared an autoethnographic narrative to highlight one kind of vulnerability as researchers engage with the wide range of human experience that social media data make accessible. Other kinds of vulnerability also exist—researchers of online phenomena are generally transparent about their identities and affiliations, which, while it helps to establish credibility and responsibility for ethical conduct, also means that researchers of sensitive topics (e.g., cybercrime, deviant behavior, gender) may themselves become targets of harassment.

We have pointed to occupational vulnerabilities in other professions in order to make the case for discussing how we might be influenced by our research practices and topics. We do not equate mental health professions with psychologically related Internet research, but use the analogy to provide empirical evidence about how one's profession might affect one's own mental wellness, especially when it involves interacting with people going through difficulties. This comparison also provides a living example of how other professions have taken the lead to discuss how they might be influenced by their work. For instance, developing techniques for stress management, time management, relaxation, leisure, and personal renewal as discussed in [8] could be included in researcher training, especially for junior PhD students.

Literature on occupational vulnerability discusses how both the person doing the work and the context in which the person finds herself contributes to the

potential for distress and impairment. Researchers like psychologists may be more susceptible to harm at certain times in their lives. Some researchers may be more at risk than others due to personal history or personality traits. An important part of managing one's own vulnerability is reflexivity. Understanding one's self and one's relationship to the research. Reflexivity is a part of many human-centered research traditions and being able to characterize one's own assumptions, personal biases and limitations as a researcher are already important considerations for critical work. For many, understanding vulnerability would not involve a dramatic departure from current practice.

Importantly, we emphasize that building support networks is critical. We know that semi-anonymous or anonymous online spaces such as reddit disinhibit sensitive disclosures and support seeking in vulnerable contexts [1]; researchers doing sensitive work often experience emotional challenges, especially if there is personal connection to the research phenomena [6]. As such, they may find value in talking through their feelings, reflect, seek, receive, and provide support. One potential idea to discuss is to create an online space where HCI researchers share their experiences responsibly and develop a support network that could engage in supportive interactions more than in workshops. Additionally, many might have difficulty talking with their collaborators or might not have a support network within their home institutions [6]. The pseudonymity as well as temporal and anonymous identities afforded by reddit [1] could make it a useful candidate for this proposed online space. Researchers may or may not wish to identify themselves in this potential subreddit, and subreddits may be moderated.

We suggest issues discussed here be considered and discussed as guidelines from government agencies and professional associations continue to evolve and as new generations of researchers are trained. The first step though, is to recognize, reflect on, and define our vulnerability as a community. There is potential danger in ignoring, shaming, or denying the risk inherent in confronting difficult data. We want researchers to continue and expand research on sensitive topics while minimizing harm to themselves.

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