Social Computing Researchers As Vulnerable Populations

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Abstract

Social computing is exciting in part because it provides a way to investigate aspects of human behavior and experience that have not always been easily accessible. For example, phenomena like depression, self-harm, suicide, bullying, and sexual violence are commonly encountered in mediated environments. 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. 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 position paper, we examine the issue from the perspective of occupational vulnerability.

Author Keywords

Ethics, Internet Research

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 [1], or people who curate and index content libraries such as that of the Shoah Foundation's oral histories of genocide. We argue that some social computing research can also be counted as a vulnerable occupation. 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.

Occupational Vulnerability

Occupational vulnerability is the threat of distress or impairment brought about by performing professional duties. One profession that has at least partly embraced its practitioners' vulnerability is mental health. Empirical research suggests the effects of distress and impairment on mental health professionals are serious [2, 3]. 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 [4] 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 appropriate their methods of dealing with that.

Internet and Human Subjects Research Ethics

Vulnerability is also 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 always with respect to the participants. The Internet introduces some novel challenges when it comes to upholding the basic ethical principles underlying human subjects research as outlined in the Belmont report. For example, supposedly anonymized social network data can be deanonymized [5], threatening the confidentiality of large datasets and with it the ethical standard of *beneficence*. It has also been argued that analyzing public data simply because it is accessible exhibits a lack of *respect for persons* who may not have understood that their communications were public.

Such conversations about the ethics of using the copious data that social computing puts at our fingertips have largely been about novel challenges to protecting research participants. We would like to broaden that conversation.

An Autoethnographic Case Study

There are millions of images on Instagram that are tagged with depression-related terms. If you search for #depression on Instagram, you will often see intense, intimate, and sometimes disturbing 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 depression-related Internet research 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 others' similar content? 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 post depression-related 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 many 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 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, this was not news; 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 how they felt, what they thought, and what they did on Instagram. 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, not surprisingly, I was left emotionally drained.

Unable to recruit enough adult participants for the interview study, we changed our strategy. We decided to look at publicly available data available via Instagram API. At the time of writing this position paper, we have been using visual and textual content analysis methods along with some computational methods on the data we gathered over a three-week period.

Going through the images, captions, tags, and comments has been 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 and tags 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 person. At times I have even felt guilty for involving my collaborators in coding this content, as I am concerned about the impact this activity might have on them too.

On the other hand, I am extremely motivated to continue this project because I think it is important to understand how people are adopting social technologies to share intimate and often controversial feelings. Because I think it is important to design for the type of support that people need when they are at their most vulnerable. And lastly, because of the personal reward of possibly making life a little bit better and happier for someone.

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 (cybercrime, deviant behavior, or gender for example) 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 psychological 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 [6] could be included in researcher training.

Literature on occupational vulnerability discusses how both the person doing the work and the context in which the person finds herself or himself contributes to the potential for distress and impairment. Researchers, like psychologists or social workers, may be more susceptible to harm at certain times in their lives and 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 researchers, understanding vulnerability would not involve a dramatic departure from current practice.

Lastly, we believe that building support networks is critical. CSCW culture in particular should welcome the sharing of narratives and experiences to create awareness about occupational vulnerability into our daily lives and research settings. 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. 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.

References

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