The Ethical Implications of Studying Privacy in a Vulnerable Population

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Abstract

A case of studying privacy in a vulnerable population is presented to demonstrate an extreme example of identifying and responding to ethical challenges around collecting data and mitigating risk to participants. We highlight how we have worked to protect young Azerbaijani dissidents who participate in research about their use of technology to speak out against the regime; consequences of these actions can be severe so we must go beyond the standards in the Belmont Report to protect participants from harm.

Author Keywords

Privacy; risk; ethics

ACM Classification Keywords

K.4.1. [Computers and Society]: Public Policy Issues – *Privacy*

Introduction

Privacy research is naturally rife with ethical challenges. Investigating individual privacy attitudes and behaviors, regardless of method, requires sensitivity and great concern for risk assessment. These ethical challenges are further complicated—and perhaps amplified—when working with more vulnerable populations. As researchers, we are ethically obligated to minimize risk associated with participating in our research, especially when participants are concerned vulnerable. That said, it is challenging to inquire about, document, and analyze privacy acts of vulnerable participants, when the actions associated with the study may expose those participants and the strategies they employ for privacy maintenance and identity protection. This position paper discusses work the authors have carried out in a series of studies of the offline and online privacy-related behaviors of young dissidents in an authoritarian state, as well as the strategies used by the researchers to mitigate participant risk when studying privacy with a vulnerable population.

Background

Assessing and mitigating risk is required in all human subjects research, but is of particular importance when researching vulnerable populations. This can be amplified when the research content—in our case, privacy of dissidents in an authoritarian regime—also

calls for heightened concern for potential risks for participants. This is a unique case where risk assessment and management is not only increased but has severe consequences.

In our previous work, we have documented young Azerbaijani dissidents' privacy management strategies, including avoiding and/or deactivating social media, visibility manipulation, self-monitoring and self-censorship, content regulation, network regulation, and staged and targeted disclosure [10, 11]. Asking participants to disclose protective behaviors that hide stigmatized—and sometimes illegal—activities, and subsequently recording, writing, and publishing about these disclosures, requires great care from the researchers, as consequences for these behaviors can be severe (e.g., imprisonment, disownment).

Research Challenge: Risk Assessment

One of the challenges in working with vulnerable populations is that participants' lived experiences of risk, conceptually, do not align with risk as described in the Belmont Report. The report's risk-benefit calculation stipulates that the risk of harm should not be greater than what the individual would "ordinarily encounter in daily life or during the performance of routine physical or psychological examinations or tests" [19]. Vulnerable participants, such as those living in non-democratic nations, may be predisposed to additional harm and lack the liberties detailed in the U.S. Constitution, making them open to exploitation [2,7]. As such, ongoing monitoring of participants' risk is required [6]. Researchers may remove open access versions of published articles to reduce the likelihood of the work being used against participants. During one fieldwork trip, a political crackdown intensified, with

substantially increased arrests and harassment of dissidents. Participants' risk concerns were heightened, and researchers took greater care to diversify interview locations to reduce the likelihood of surveillance. Interviews deviated more from the original protocol to allow participants more opportunities to share their feelings about the crackdown, if they so chose. Finally, as the political environment becomes more repressed, researchers, out of safety concerns and/or difficulties in accessing field sites, have opted for research at a distance, conducting interviews via video chat or having secure encrypted online surveys.

Moreover, the ability to predict future outcomes related to research—and thus assess risk—is very difficult in such environments [3,5,12]. Even the most innocent of studies can be used by various government groups against participants [14]. In Azerbaijan, data collection is challenging because risk is ever changing. Things that did not seem risky in the past are suddenly risky because of a new regime initiative. Thus, from an ethical standpoint, we must be even more conservative in our risk assessment than the current political environment dictates. The researchers also take care to decrease becoming targets of the regime itself, as association with a blacklisted researcher may also increase risk for participants.

Researcher Response: Mitigating Risk

In most studies, researchers mitigate risks to participants by taking steps to ensure confidentiality, debriefing when appropriate, and allowing participants to skip questions or end participation without penalty. When working with vulnerable populations, researchers must be constantly be assessing risk before, during, and after data collection [9]. In our case, we go to

great lengths to communicate with participants via different channels to reduce digital traces being used for triangulation. This reflects to concept of *obfuscation,* which Bunton and Nissenbaum [1] have described in the context of protests as a way for people to interfere with data collection and surveillance. In the case of our studies in Azerbaijan, the researcher asked a research assistant to schedule interviews with participants without identifying the researcher. The PI never communicated with participants outside of the face-to-face interview. Interviews were recorded digitally, with consent, without any identifying information disclosed, and immediately uploaded via a VPN connection to a secure server, and then deleted permanently from the recording device. The researcher's notebook uses codenames when taking interview notes and the researcher digitally scanned the notebook, uploaded the pages to a secure server, and destroyed the notebook before leaving the country. The researcher always carries devices (laptop, phone, tablet) on her person, encrypts the hard drives, and enables remote wipe functions. While most researchers working in Western contexts may not think to take these steps, it has become standard practice when working in authoritarian regimes.

Researchers can take additional steps to mitigate risk during analysis, writing, and publication. For example, researchers may engage in *disutilization* to minimize the potential usefulness of the research for negative purposes [5] through self-censorship, or publishing in ways or venues that reduce non-scholarly interest in the work [13,15,16,17]. Another method is fabricating composite participants [8]. We publish our work in academic journals and while we do have open access

version of the work available, one would have to seek it out directly in order to find it.

Finally, we obscure our research participants' demographic information as well as identifying characteristics, going beyond what is required by our IRB. This is an important point because most researchers follow the minimum requirements set forth by their ethics boards; however, there are an increasing number of situations that require them to use additional precautions. Vitak et al. [18] have identified a number of situations in social computing research where this applies; it is even more critical when studying technology use by vulnerable populations.

Conclusion

Considering ways to mitigate risk for vulnerable participants provides an extreme case for researchers to consider the ethical implications of research, especially related to privacy—both for the data and participants. In our work on young Azerbaijani dissidents, participants have disclosed strategies that they use to protect themselves from government surveillance, as well as engagement in stigmatized and sometimes illegal activities. The act of recording, analyzing, and writing about such activities is itself increasing participant risk; however, when the study is designed to minimize risk, the data provide meaningful insights to the broader academic community.

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