Marginalized Populations and Research Ethics Online

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Abstract

To respectfully and accurately represent marginalized peoples' experiences in online communities research, great care must be taken to ethically approach such research. In this position paper, we explore and ask questions about the ethical gray areas that occur when studying marginalized groups online. We argue that greater input and feedback from members of study populations, during the research and the peer review process, could help marginalized communities by increasing accurate and respectful representations of group members' experiences and by improving design recommendations that come from research results. We offer several suggestions going forward for CSCW online communities researchers.

Author Keywords

Research ethics; online communities; marginalized populations

ACM Classification Keywords

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

Introduction

Considering the massive volume of fascinating content posted constantly in online forums, social media sites, chat logs in virtual worlds, *etc.*, it is not surprising that many CSCW researchers approach such content as data for analysis. Particularly when this data is generated among marginalized populations' online communities, researchers may find much value in analyzing it to gain insights both about the target community and about broader sociotechnical practices. However, when conducting such research, researchers must keep in mind their own group memberships, identities, and potential lack of knowledge about that group's experiences, challenges, and values. Many researchers collect online data without user knowledge or consent. In such cases, the research may misrepresent the behaviors, challenges, or identities of the study population. Because online community members are not traditional "research participants," researchers may choose not to or do not have the means to clarify potential misrepresentations.

To respectfully and accurately represent marginalized peoples' experiences in online communities research, great care must be taken to approach such research ethically. In this position paper, we explore and ask questions about the ethical gray areas that occur when studying marginalized groups online. Ultimately, we argue that greater input and feedback from members of study populations, during the research and the peer review process, could help marginalized communities in two ways: by increasing accurate and respectful representations of group members' experiences and by improving design recommendations that come from research results.

Background

Previous work has laid important groundwork for understanding how to ethically study communities online. For instance, Amy Bruckman has published a series of guidelines for students interested in conducting research with online communities [3].

As highlighted by Bruckman [3], it is important for researchers to understand the community they work with, because the community's norms about what is ethical can be quite different both from the researcher's norms and from the norms of other communities. Even within the United States, subcultures will have differing expectations about privacy and what is considered sacred. For example, some Native American tribes consider certain aspects of tribal life sacred and inappropriate to share with outsiders [11].

Due to the differences in each community that might be studied (and this is true offline and online), researchers must be attuned to the specific needs of the community of interest. To this end, community-based collaborative research is often employed in marginalized communities. Researchers committed to community-based or action research work closely with members of the community while conducting their research. Cooperative and Participatory Design are prominent research approaches that include participants in meaningful roles, and Action Research is another framework that enhances the democracy of the researcher-community relationship [5]. As was highlighted a recent workshop hosted by the Center for Collaborative Research for an Equitable California (CCREC), community-based collaborative research is an approach that not only involves participants in the research process, but aims to use research results to affect positive social change for the involved communities [11].

Working with a community while conducting research requires the researcher, who inevitably is in a position of power in the research relationship, to take extra precautions not to harm members of the community [2]. In their handbook about conducting ethnographies in virtual worlds, Boellstorf *et al.* dedicate an entire chapter to ethics [2]. Their "principle of care" [2:129] proscribes researchers from causing harm to community members verbally or in writing, deceiving community members, and compromising community members' right to anonymity. Several research projects that have clearly demonstrated the ability to follow these tenets [1,2,4,7,8,10] by making their presence known as researchers whenever possible, gaining consent from individuals with whom they have more in-depth conversations and interviews, and showing an understanding of what is private versus what is public. As Hudson and Bruckman argue, it is not always appropriate in online studies to ask for consent, but the risks of the research must be carefully weighed against the benefits of the research outcomes [6].

Ethical Gray Areas

In CSCW research on online marginalized communities, many open questions and ethical gray areas remain, making it difficult for researchers to know how to conduct research respectfully and ethically. Understanding how to ethically conduct research among marginalized communities can highlight issues of consent and representation that are important for CSCW and social computing research more broadly. We briefly explore a few of these areas, not to offer answers, but to open up a space of discussion about how to approach such scenarios. How does Boellstorf *et al.*'s "principle of care" [2] hold up in each of these instances?

Methodological Differences

When large volumes of data are pulled from online sources, researchers can analyze and report results in aggregate, using methods such as natural language processing and statistical modeling to generate large-scale insights without exposing particular user content. Does the aggregation and de-personalization of the research results justify gathering such data without consent from those who generated the online data?

In contrast, when using methods such as grounded theory or content or discourse analysis, data is analyzed and presented at a more granular level, potentially leading to sensitive user content appearing in research papers. When those whose content is used do not have knowledge or consent that they are research subjects, is it ethical to present quotes and recollections of personal experiences as research data?

"Public" Websites vs. "Private" Forums

Though much online data is technically public, users perceive certain online venues as more public than others. For example, YouTube videos, which are often produced with the intention of being watched by an audience, may be perceived as more public than online forum posts, which are often shared to gather input from a small group of people in a particular online community. Even though privacy settings for the two may be identical, is it equally ethical for researchers to gather, analyze, and publish results about data from both sites?

Suggestions Going Forward

There is a big difference between analyzing an online community's data and being accountable to that community. We discuss the possibility that peoples' identities, challenges, practices, or values may be misrepresented, particularly when their data is collected and analyzed without their knowledge and consent (thus eliminating the researcher's ability to clarify potential misrepresentations with community members). Further, technological interventions or designs based on faulty assumptions may eventually harm the community of study and other users. This goes against Boellstorf *et al*.'s "principle of care" [2] and should be taken seriously.

Thus, we offer several suggestions for CSCW online communities researchers. We present these with the caveat that although group members' lived experiences give them a sort of expertise, this does not mean that each member of a group understands the full scope of what it means to be a member of that group, and that one or several people could "speak for" an entire complex, intersectional, diverse group.

1. When possible, clarify research intentions when interacting with an online community, be it through forums, establishing material presence in a virtual world [8], and/or interacting with community members directly.

2. Ask for feedback from members of the population of study. A community outsider often does not know what they may be misunderstanding – after all, one doesn't know what they don't know. Feedback from community members can eliminate misrepresentations and offensive language and framing.

3. When possible, have a member of the community review the paper. Though there are likely few members of each particular marginalized group in the broader CSCW/CMC/HCI community, there are probably some, and an in-group reviewer may catch some of the problematic aspects of research papers. We could imagine an anonymized database of CSCW academics belonging to particular marginalized groups, and having that database recommend reviewers to ACs and journal editors. Of course, having a member review an academic paper is not possible for many communities, such as children with autism.

We must remember that just because we are writing for an academic audience, does not mean we are not also accountable to our non-academic audience. Although institutional review boards (IRBs) do important work in ensuring that ethical guidelines are met, and often work with community members to do so, emerging online settings may present new situations where ethical gray areas surface. When working with marginalized online populations, it may be appropriate to also discuss ethics with the community itself. For instance, CCREC recommends that researchers make a "Memorandum of Understanding" between researchers and communities, to ensure that the community understands and agrees to research goals, that the research is mutually beneficial, and that ethical guidelines are met [11]. Online communities research can be fascinating and important, but we must keep ethics at the forefront to make sure that such research is not done at the expense of those who create the data.

References

[1] Boellstorff, T. *Coming of Age in Second Life: An Anthropologist Explores the Virtually Human*. Princeton University Press, 2010.

[2] Boellstorff, T., Nardi, B., Pearce, C., and Taylor, T.L. *Ethnography and Virtual Worlds: A Handbook of Method*. Princeton University Press, 2012.

[3] Bruckman, A. Teaching students to study online communities ethically. *Journal of Information Ethics*, (2006), 82–95.

[4] De Choudhury, M., Counts, S., Horvitz, E.J., and Hoff, A. Characterizing and Predicting Postpartum Depression from Shared Facebook Data. *Proceedings of CSCW* (2014), 626–638.

[5] Hayes, G.R. The relationship of action research to human-computer interaction. *ACM Transactions on Computer-Human Interaction* 18, 3 (2011), 1–20.

[6] Hudson, J.M. and Bruckman, A. "Go away": Participant objections to being studied and the ethics of chatroom research. *The Information Society* 20, 2 (2004), 127–139.

[7] Nardi, B. *My Life as a Night Elf Priest An Anthropological Account of World of Warcraft*. University of Michigan Press, 2010.

[8] Pearce, C. and Artemesia. *Communities of Play: Emergent Cultures in Multiplayer Games and Virtual Worlds*. MIT Press, 2009.

[9] Ringland, K.E., Wolf, C.T., Dombrowski, L., and Hayes, G.R. Making "safe": Community-centered practices in a virtual world dedicated to children with Autism. *Proceedings CSCW* (2015).

[10] Taylor, T.L. *Play Between Worlds*. MIT Press, Cambridge, MA, 2006.

[11] The Need for Ethical Examination. Center for Collaborative Research for an Equitable California, 2010. http://ccrec.ucsc.edu/research/ethics-collaborative-research.