

Researcher Subjects: Gaining Access and Building Trust in an Online Breast Cancer Support Group

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ABSTRACT

This poster presents an analysis of some of the challenges in gaining access and building trust in an online breast cancer support group. Although the group itself is not a closed group and is freely available on the Internet, divergent participant beliefs about privacy and public access to this website, as well as conceptions of research methods and ethical concerns, offer provocative insights into the perceptions online participants have about research, the role of researchers, and the juxtaposition of researchers and subjects within the context of this particular online community.

Keywords

Online Communities, Health Informatics, Online Ethnography

1. INTRODUCTION

Ethnographers have long described the challenges of gaining access for the purposes of conducting naturalistic research of social worlds. Communities are often suspicious or fearful of a researcher's motives and may initially be wary of engaging in interactions [1]. Prior membership in a group often confers greater legitimacy in the views of participants than approaching a group from the outside; however, gaining entry can also be facilitated through intermediaries with close ties to a community [2][5]. Familiarity with a community's norms and practices, or possessing attributes similar to community members, also facilitates acceptance [4]. However, even when a researcher can claim familiarity and similarity, questions and challenges can arise upon entry into a community.

The Breast Cancer Mailing List (the "List") is an online support group founded in the mid-1990s, comprised primarily of breast cancer patients and survivors, as well as advocates, researchers, family members, and medical professionals. Although the List requires a subscription to post messages, it is otherwise freely available to anyone wishing to read the archives. The List currently has between 400-500 subscribers, most of whom live in the United States, although there are participants from approximately 20 other countries.

With the intent to conduct research as a participant-observer, I approached the List to learn how health information is exchanged, how participation in the group influences health practices and outcomes, and how the group is integrated into their everyday lives. As a researcher with background knowledge of the group as

well as familiarity with health information seeking and breast cancer survivorship, I anticipated minimal access problems; however, the reception was mixed. Gaining access to the group and eliciting trust comprised intensive interactive and iterative processes wherein wariness and suspicion were interspersed with expressions of welcome and hopefulness.

2. NEGOTIATING ACCESS

In accordance with IRB approval, my first message to the List revealed my status as a researcher, a Ph.D. student, and a breast cancer survivor. Responses included a range of reactions. Participants expressed concerns about my legitimacy, fear of how the research might be used, confusion about my role in conducting ethnographic research, and apprehension about use of quotations. Some participants expressed feelings of trepidation and vulnerability but were tentatively open to research on the group. Other participants were fully supportive, offering to assist in any way possible. To assuage concerns, it was essential to be totally open in providing information that would assure them that the research was legitimate and that I had no intentions of exploitation. I answered every question in great detail, sent out copies of my IRB form, and revealed personal information in the spirit of sharing as any other List participant would. In essence, the roles of researcher and subjects became intertwined as questions and evidence accrued.

2.1 Researcher Subjects

Online forums offer the potential for people to assume identities and deceive others for various reasons [4]. In online breast cancer support groups, participants are often dealing with serious issues in their lives, making them feel particularly vulnerable [3][6]. During my initial entry into the community, List members reported previous instances of marketers posing as researchers who tried to sell them products as well as researchers recruiting them for seemingly questionable studies. These experiences were viewed as both disruptive and intrusive, causing participants to seriously appraise newcomers identifying themselves as researchers. However, this process of appraisal illustrates the dual role in which I was cast: as a researcher I also became a subject of inquiry.

List members are highly educated and savvy, and due to their status as breast cancer patients and survivors, some have participated in clinical trials and most are very aware of trials occurring on an ongoing basis. Discussions about clinical trials as well as other health research occur frequently, often several times

a week. The constant reporting of medical research published in journals and news stories results in a List population that is sensitized to researcher and subject roles.

List participants' experiences with both legitimate and spurious research practices converged upon my appearance. Although there was recognition of the value of being research subjects, especially in clinical trials, ethnographic research was less familiar and elicited questions about my objectivity as well as my integration into the community. Participants became interested in verifying the genuineness of my research as well as the legitimacy of my methodology, and several did their own research to ascertain what ethnography constituted.

2.2 Privacy and Public Access

Within the context of my accessing the List, members expressed varying levels of understanding about their exposure on the Internet and who might be reading their words or observing their interactions. Some participants were fully aware that anything they wrote was completely accessible while others had not thought about the reality that their private expressions on the List were available to anyone. Some also expressed discomfort with the idea of a researcher using quotes from their discussions while others gave permission immediately. Throughout these interactions I assured participants that I would use quotations only with their express permission, subject to my IRB approval as well as my commitment to their privacy.

2.3 Building Trust

Throughout the access negotiation period, various List members expressed several attributes of valued participation. Most important, beyond establishing my credence as a researcher, was interest in my breast cancer journey. Participants began to feel more comfortable with me as my own story became known to them. Being an active participant was also essential to their overall acceptance of me. Although there was recognition that lurkers and infrequent participants were likely a substantive portion of List readers, as a researcher who was also a participant-observer, it was critical to be active. As their own stories unfolded, I offered responses when they were appropriate, both through acknowledging comments as well as descriptions of my personal experiences.

Another significant element to building trust was participation in the List's face-to-face Gathering. Despite the group's primary presence as an online resource available to anyone needing support with breast cancer and its aftermath, a major component to the List's interactions is its yearly fall meeting. The Gathering

occurs somewhere in North America and is open to anyone who is a List participant, as well as family members and friends. Although a relatively small core of members attends, it is an opportunity to meet in person and solidify the bonds people have formed through their online interactions. Within days of my joining the List, several members invited me to attend as a way to meet me in person, assess who I was, and to become more comfortable with my presence. Through participation with List members both virtually and face-to-face, I was able to establish a foundation for a trust-based research relationship.

3. CONCLUSION

Gaining access to the List and building trust with participants comprised multiple components, all of which blurred researcher and subject roles. Throughout the process, I acted both as researcher and subject while List participants conducted their own inquiries about me. To gain trust and establish credibility as a researcher and a participant-observer, it was essential to openly answer all questions. It was also important to be an active participant, sharing personal experiences and engaging in dialog with List members. Last, meeting List members in person amplified their trust and acceptance of me.

4. REFERENCES

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