

Article

**Exploring Ethical and Methodological Issues
in Internet-Based Research with Adolescents**

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Abstract

Internet-based research is a relatively new and growing field that presents a number of ethical challenges regarding privacy, confidentiality, and informed consent. In light of a study examining discussions regarding the human papillomavirus (HPV) vaccine on a publicly viewable Internet message board among primarily American, Australian, and Canadian female adolescents and young adults, the author discusses the methodological and ethical concerns surrounding Internet-based qualitative research with youth. The author first provides some contextual background about the study and issues surrounding the HPV vaccine. She describes her methods of data collection and analysis and provides a summary of the results. The author then explores a number of ethical issues that arise in Internet-based research and examines her own ethical decision-making as informed by existing discussions and guidelines in this area.

Keywords: Internet, methodology, ethics, online research, adolescents, HPV, vaccination

Author's note: I thank various advisors of the McMaster Research Ethics Board, especially Dr. Karen Szala-Meneok, for their help and advice, as well as Dr. Wayne Warry, Dr. Ann Herring, and other members of McMaster's Anthropology Department for their feedback at earlier stages of this project and versions of this paper. I also thank the three anonymous reviewers for their helpful comments and suggestions. An earlier version of this paper was presented at the Annual Meeting of the American Anthropological Association in San Francisco, CA, November 19–23, 2008.

Introduction

Much of the literature regarding decision-making authority about vaccination of children and adolescents concerns the tension between public health officials and parents (Sturm, Mays, & Zimet, 2005). What is often absent from the discussion is what authority older children and adolescents have to make decisions about vaccination. They are too often left out from research that is essential to inform health policy and improve health care for adolescents, partly because of ambiguity about the legal and ethical rules for including adolescents in studies (Santelli et al., 2003).

Noting the lack of focus on the perspectives of the adolescents themselves in the public health literature on HPV (human papillomavirus) vaccination, there is an obvious need for qualitative research with adolescents, especially regarding issues related to immunization and sexual health. Online research is one way to gain access to data from adolescents without necessarily requiring parental consent and a lengthy ethics review process.

Internet-based research is a relatively new and growing field, with so far only a relatively small number of larger works examining in depth the use of the Internet for qualitative research (see Batinic, Reips, & Bosnjak, 2002; Buchanan, 2004; Hine, 2000, 2005; Johns, Chen, & Hall, 2004; Jones, 1999; Mann & Stewart, 2000; Markham, 1998; Markham & Baym, 2008; Thorseth, 2003), though the literature is quickly expanding. Virtual ethnography, or cyberethnography, is of particular interest for anthropologists, as online communities constitute rich sources of qualitative data (Eysenbach & Till, 2001; see also Wilson & Peterson, 2002, for a discussion of the anthropology of online communities). However, it presents a number of ethical challenges regarding privacy, confidentiality, and informed consent.

I conducted a small exploratory study on adolescent girls' and young women's perspectives on the HPV vaccine and their roles in the decision-making process for receiving or not receiving the vaccine. I used the Internet as my field site; specifically, a discussion or message board targeted at adolescent girls and young women was my data source. This study, while minimally invasive or intrusive, still required a significant amount of ethical consideration and reflection. My methods are presented here in the context of broader continuing discussions on ethics in online research and research with adolescents, in response to calls from researchers such as Bober (2004) for others to write more about how they thought about and addressed ethical issues in their own research.

I first provide some contextual background about my study and issues surrounding the HPV vaccine and the existing literature on STI vaccination in adolescents. I describe my methods of data collection and analysis and provide a summary of my results. I then explore a number of ethical issues that arise in Internet-based research and examine my own ethical decision-making as informed by existing discussions and guidelines in this area. I hope to provide some guidance for future research, at least in highlighting a number of issues to consider.

Study summary

Purpose of the study

Whereas in the past adolescents have been called “the orphans of immunization practices” (Boyer-Chuanroong, 1997, p. 249), today immunization for adolescents is an expanding field. Vaccinating adolescents, particularly those in the transition between childhood and adolescence, presents specific challenges (Humiston & Rosenthal, 2005), especially in the case of vaccination against a sexually transmitted infection. The recent development of vaccines against HPV has received substantial media attention and ignited public debates among parents and government policymakers as to whether these vaccines should be given to young adolescent girls in school. Yet, we know little about what adolescents think about the HPV vaccine (Lo, 2006) or how they are responding to the implementation of HPV vaccination programs, school-based or otherwise, in many countries around the world.

The new Gardasil® vaccine protects against four types of the sexually transmitted human papillomavirus, including types 16 and 18, responsible for 70% of cervical cancers. Ideally, from a public health perspective, children would be vaccinated before they become sexually active and face exposure to the virus. This vaccine has been approved for girls as young as 9 years old and young women up to age 26, and may also be approved for boys once the clinical trials in males are complete. Australia began providing Gardasil to 12- and 13-year-old girls in school (Year 8) at no cost (the full course of three shots would cost several hundred dollars if purchased privately) in the spring of 2007. The United Kingdom planned to do the same starting in September 2008 (National Department of Health, 2007), using a different vaccine against HPV, Cervarix®. In Canada, some provincial governments began similar programs, whereas no school-based programs had yet been implemented in the United States during the study period (2007-2008). Although studies have found that most parents are in favor of having their children receive the HPV vaccine, some parents and groups have expressed reservations, worried that it may encourage promiscuity or earlier sexual debut (Gonik, 2006; Zimet, Mays, et al., 2005). Many parents and doctors are hesitant to even bring up the subject of a vaccine against a sexually transmitted virus with their children or patients because they worry the very discussion of it would be “an assault on their innocence” (Stein, 2006, p. HE01).

In searching through the existing medical and social science literature on HPV vaccination, I was struck with the realization that attitudes about vaccination against HPV and other sexually transmitted infections (STIs) had been studied among parents (see Brabin, Roberts, & Kitchener, 2007; Davis, Dickman, Ferris, & Dias, 2004; Gonik, 2006; Mays, Sturm, & Zimet, 2004; Rosenthal, 2005; Sturm et al., 2005; Zimet, Mays, et al., 2005; Zimet, Perkins, et al., 2005), young adults, and older adolescents (see Hoover, Carfioli, & Moench, 2005; Kahn, Rosenthal, Hamann, & Bernstein, 2003; McClelland & Liamputtong, 2006; Moreira et al., 2006), but rarely the younger adolescents, who would be the likely recipients of in-school immunization programs. A joint role in decision-making is also not emphasized enough in the literature on adolescents and STI vaccination in general. Noggle (2007) noted that one aspect of adolescent vaccine research that requires further study is “the effect that adolescent attitudes have on actual vaccine delivery” (p. 55). Noggle also reported an anecdotal observation that students involved in a meningococcal vaccine study made the final decision on whether to receive the vaccine, even though they had parental permission.

Thus, I decided to explore adolescent attitudes toward the HPV vaccine and their roles in decision-making regarding HPV vaccination for the purposes of credit in a graduate course in the

anthropology of health in early 2008. I was aware of existing discussions about HPV vaccination on an Internet message board to which I belonged, and believed that such discussions might reveal a picture of more active adolescent engagement in HPV vaccination than was evident in the existing research literature and suggest directions for future research regarding vaccination for HPV and other sexually transmitted infections.

Data collection and analysis

I investigated the possibility of using data from more than one Internet message board, but was unable to locate others with a similar depth of discussion on this topic. The message board is run by a nonprofit organization and geared toward adolescent and young adult women, although there are a few male and transgendered members. The website provides various forums for discussion of a range of topics, including politics, books, movies, sports, school, and general discussion of random topics. The members are drawn from countries around the world, though Australia, Canada, the United Kingdom, and the United States are the most common and the majority of members are Americans. I had been a member since 2004 and at the time of the study was a moderator-in-training.

In addition to being informed by the guidelines offered by Ess and the AoIR Ethics Working Committee (2002) and other articles on ethics in Internet-based research, to protect the participants, I followed the “criteria for exemption from ethics review” proposed by the General Research Ethics Board (2007, p. 16) at Queen’s University as well as the suggestions of my university’s research ethics board (REB). In particular, I do not name the website from which the data are obtained, nor do I use names, user names, or verbatim quotes that could identify the site or its members. I obtained permission to conduct the research from the administrative team of the website, who also expressed an interest in reading the finished paper. I then sent a notice to each of the participants in the discussion threads in question, describing the research project and providing the members involved with the option of withdrawing their data from the study, as well as offering to share copies of the completed paper. Many replied expressing their enthusiasm for the project (one member told me that she was pleased to see an anthropologist studying something “at home” rather than in some remote locale) and asking for a copy of the finished paper.

I also drew on my knowledge and experience as a long-time member of this message board in informing my use of the data. For example, I examined discussion occurring in a forum on the site dedicated for “lighter” topics and for asking poll questions of the members, as opposed to other forums in which discussion is understood to be of a more deeply personal or emotional nature and which are intended, for example, to provide support for members struggling with various issues. Fortunately, the HPV discussions of interest here all occurred in the former type of forum.

I examined the responses of 72 female participants (including myself) in three separate discussion threads responding to the question, Are you getting the HPV vaccine? which took place over the course of the 2007 year in the months of May, September, and November. There were 67 separate replies from 51 individuals to the May thread, 51 replies from 13 individuals to the September thread, and 18 replies from 8 individuals to the November thread. As the volume of data was fairly small and the study intended to be exploratory, only limited manual coding was employed.

Kleinman (2004) noted that determining the population demographics of online communities can be a challenge. Using either information provided within those threads or by searching other threads on the website that asked members, How old are you?, I was able to determine the ages of

68 of the 72 participants. For the 4 remaining participants whose exact ages could not be established, 1 was determined to be over 18 years of age, 1 was at least 18, 1 was in high school (and therefore likely under 18), and 1 was graduating high school in 2007 (and therefore likely around age 18). Of those 68 with established ages, the average and median ages of the participants was 18, and 18 was also the mode, or most common age. The youngest participant was 13, and the oldest was 31 years old. Of those whose nationalities were determined, the highest number of participants was from the United States, followed by Australia. There were also participants from Canada, at least 1 from the United Kingdom, and 1 participant from Trinidad who was studying in the United States.

Although I participated in two of the threads, 1 post out of a total 67 replies in the May thread and 2 posts in September, there is no evidence that my participation had a significant impact on the overall course of the discussion.

Summarized results

In the discussion threads examined, members generally expressed overall positive attitudes toward the vaccine. Most planned to receive it, and many were in the process of receiving their course of shots. Many expressed the opinion that it was best to get it done now and not have to worry about it again, whether or not they planned to become sexually active in the near or distant future.

Those who did not plan to receive it had differing reasons: Some were concerned about potential long-term side effects of the vaccine, whereas others had no plans to be sexually active at any time in the foreseeable future.

Many respondents wanted to receive the vaccine but found it far too expensive. These were most often those members aged 18 or over who were now responsible for paying for medical expenses such as this on their own. Several older adolescent members (age 18 and over) indicated that they would like to get the vaccine but would wait until they could have the cost covered by a student health insurance plan in university or college.

Focusing on those members under age 18, for whom personal out-of-pocket cost was less of a concern, most did say that they planned to get it at some point. These under-18 members often used language that implied that they would either be making the decision for themselves or would have some joint role in the decision-making process. However, two members described experiences of their mothers telling their doctors to give them the vaccine without consulting them.

Many of the members from Australia received the vaccine free in school, where several grades (years 7 and 10 to 12) were vaccinated that year. For those who received it in school, there was less emphasis on the decision-making process as they did not have to actively seek it at a clinic or doctor's office but, rather, gave consent through a permission form or similar procedure.

At the beginning of the discussions, some members talked about the HPV vaccine as a vaccine against cervical cancer. This was quickly corrected, however, by other members who pointed out that it is a vaccine against HPV, a virus which can cause cervical cancer. Only one member, age 17, responded that she did not know what the HPV vaccine was.

Discussion: Ethical issues of Internet-based research with adolescents

As a consequence of ambiguity about the legal and ethical rules for including adolescents in studies, they are too often left out from research (Santelli et al., 2003). Data on children or adults might be used instead (Santelli et al., 2003), which is problematic as adolescents are a unique population (Humiston & Rosenthal, 2005). Often regulations do not distinguish between children and adolescents (Santelli et al., 2003) even though chronological age is not necessarily related to the ability to understand informed consent (Susman, Dorn, & Fletcher, 1992) and adolescents over age 14 have abilities comparable to adults in terms of the capacity to make decisions about participation in research (Santelli et al., 2003).

Although the same ethical principles in play offline also apply online, how exactly to put them into practice can be less clear in the latter case (Wilson & Peterson, 2002). For example, online research might be perceived as intrusive, especially by members of groups whose purpose is to provide support for people dealing with difficult circumstances, such as a chronic disease (Eysenbach & Till, 2001). Although the group website or message board might be publicly viewable, members might regard it as a private space or at least a semiprivate one. This is especially likely if registration is required to gain access and if there is a specific policy that defines who can become a member (Eysenbach & Till, 2001). Thus, even if the data posted are technically public, as Kitchin (2003) has argued the Internet largely is, a great deal of ethics work is still required.

Ethical standards of confidentiality that apply to offline studies apply online as well, even though participants' personal information might have been posted publicly on the Internet (Moreno, Frost, & Christakis, 2008). Moreover, although participants in online communities might be officially anonymous and use pseudonyms or aliases, they might still provide enough information to be identifiable (Jacobson, 1999), or they might wish to keep their online identities confidential as well. Löfberg (2003) has argued that adolescents' online and real-life identities should be equally protected in research. Furthermore, Rutter and Smith (2008) agree with Paccagnella (1997) that changing participants' pseudonyms or usernames as well as their real names demonstrates respect for "the *social reality* of cyberspace" (Ethics of research section, para. 1, emphasis in original). Protecting participants' online identities in addition to their real-life identities might necessitate much more caution than might usually be the case for offline research. For example, direct quotations from participants may not be possible because a search engine could then be used to identify the original source. However, this poses a challenge to efforts to retain original meanings and nuances when results are reported, which is also a problem in cross-cultural online research (Graffigna, Bosio, & Olson, 2008).

In addition, obtaining informed consent in the form of a signed consent form might be problematic in cases in which participants are anonymous to the researcher and may wish to remain so (Jacobson, 1999) or in which the transient nature of the Internet in combination with anonymity means that some users might be impossible to track down (Whiteman, 2007). In such cases, alternative means of obtaining consent to participation in research must be explored. In some cases, consent might be deemed unnecessary; Moreno, Parks, and Richardson (2007) used information on publicly viewable MySpace profiles of adolescents and did not contact any of the individuals whose profiles were included in the study. Although there appears to be no general agreement on whether formal ethical guidelines specific to online research are needed (Thomas, 1996), it is clear that online research raises new ethical questions that require attention as more and more researchers are drawn to the Internet as a field site.

In the case of research with adolescents on social networking websites, Moreno, Frost, et al. (2008) noted that there are three levels of consent to address: the research participant and/or guardian, the community of members, and, finally, the company or organization that owns the website. Different websites or online communities might require different ethical approaches. Members of a small online support group might constitute a community from which collective consent might be required, whereas users of a website like MySpace might be “as much of a community as cellular telephone users” (Moreno, Frost, et al., 2008, p. 159). Warner (2009) has found that overall, studies of virtual worlds are more problematic for issues of consent and privacy than other online communities or data sources such as blogs or social networking sites.

In offline studies on STI immunization researchers might ask adolescents to discuss their peers rather than themselves to minimize the effect of social desirability; however, this can also increase optimistic bias, which is “the tendency to perceive others at greater risk than oneself” (Webb, Zimet, Mays, & Fortenberry, 1999, p. 321). In contrast, Sade-Beck (2004) observed that studies in online communities have found that this form of communication allows users to “freely express emotions and reach a high level of self-disclosure” (p. 4). What adolescents might not discuss face-to-face with one another, especially with classmates and friends, among whom disclosures about topics related to sexuality might affect social relationships, they often readily share such things in a virtual space, particularly one in which they do not fear being judged or harassed (the website examined here has a strict policy against such things). Graffigna et al. (2008) have suggested that in focus group research the format of an online forum is useful for examining “cognitive and rational attitudes to health related issues” and for gaining “a detailed and well-meditated description of personal experiences” (p. 284). By contrast, they indicated that research using a chat format is best suited to obtaining affects and emotions, while face-to-face focus groups are useful for examining sociopolitical aspects.

Because of ethical concerns as well as time constraints for this study I used only publicly accessible information that had already been posted in response to the poll question discussion topics on the HPV vaccine. Although often the replies were brief and I would have liked to ask the members to elaborate, eliciting further information from minors for research purposes would have likely required parental permission and involved a much more complex and lengthy ethical process beyond the scope of this limited study. Such constraints can create difficulties later on. For example, Ellett, Lane, and Keffer (2004) found that an institutional review board (IRB) requirement that no personal information other than e-mail addresses be collected from participants led to problems in publishing certain results of their infant colic study as the relevant demographic data were lacking. Yet, Bober (2004) has observed,

Leaving young Internet users to discuss issues of their choice among themselves and in an environment where they feel comfortable produces topics that users consider important, without the research “artificially” imposing topics on the group or the researcher’s presence giving rise to socially desirable answers. (p. 299)

Thus, the advantages of Internet-based research must be weighed against the disadvantages, which might include limitations on the type of data obtained.

Another issue to consider in my study was whether members would feel that their conversations had been private, despite being publicly viewable, and as such that research attention would be perceived as intrusive, as discussed above. However, both my long-term membership on the message board in question (as an active member and not a “lurker”) and the nature of the website (a discussion board for a variety of topics from homework to entertainment to politics, rather than a support group for a specific identity or health issue) made this unlikely, and indeed no concerns

were raised once confidentiality (in particular, not identifying the website directly or indirectly) was addressed. Furthermore, although one must register with the message board to take part in conversations and members often reveal personal details about their lives, members are frequently reminded that the site is viewable by anyone and thus they should not to post information such as their full names, addresses, or, especially for minors, the schools they attend. They are also warned not to post any sexually explicit material to keep the site stalker free, and all of these rules are enforced by moderators.

Eysenbach and Till (2001) have mentioned two main ways in which informed consent can be obtained from online mailing lists, and they apply to message boards as well. The first is to send a message to all members (or, in the case of a message board, post a notice) describing the research and allowing participants to withdraw if they choose. The second is to send a message to each participant individually. The first approach is the most intrusive (Eysenbach & Till, 2001), and I opted not to use it primarily because to post a message on the board would then make the website searchable (e.g., through Google) and negate all my other precautions to protect privacy and confidentiality. Eysenbach and Till have called the second approach “cumbersome and time consuming” (p. 1105) and noted that e-mail addresses might have changed. However, I found that it took only about an hour to send messages to all 72 participants and that my knowledge of the website (the search function for the site was also an available option) allowed me to identify which members had since changed their user names so that I could make sure to send the notice as a private message through their current user name or e-mail.

Eysenbach and Till (2001) quoted one respondent to an online researcher’s request as saying,

The researcher isn’t familiar with [the] culture [of the website or group] – problems akin to those occasionally experienced by anthropologists when they try to interpret the behavior of cultures they really don’t understand. And on the rare occasions when I’ve seen someone who’s part of that culture attempt to study the group he/she is part of, it resulted in a rippling sense of resentment and betrayal among those who find such things underhanded. (p. 1104)

To address the first comment, my long-term participation in the website from which my data were obtained might be thought of as long-term participatory fieldwork. This connects to the second issue of studying one’s own group. Because of my understanding of the culture of this message board community, I knew that use of information posted in certain forums would be unlikely to raise objections and even be welcomed, whereas to use data from forums dedicated to supporting members in difficult emotional situations might cause distress or discomfort. I also knew that by sharing the results of my research (the finished paper or papers) with the participants, they would feel more like partners in the research rather than objects of study. This accords with Chen, Hall, and Johns’s (2004) recommendations of “an acclimation process” and “a sharing mentality” for online social research (p. 172). Kleinman (2004), too, observed that long-term participant observation allowed her to become familiar with the online community she was researching, including knowledge of individual members and past discussions. Although it is not strictly necessary to have been a long-time member of each online community one studies, it is important at least to understand the different purposes and functions of the group or website in question before research is attempted.

This discussion brings up the issue of my dual identity in this study of both researcher and long-time member of the message board community from which the data was obtained. In terms of ethics, I not only had to consider possible risks to the participants but also to myself. In some cases those interests aligned with the same methods, such as in the choice to contact participants

about the study privately rather than to post a public notice on the message board. In other cases, those interests had to be balanced. For example, I had to balance participants' right to information against my desire to maintain my privacy and control over the extent of my anonymity within the community insofar as revealing my real-life identity (full name, location) to only a handful of members. Therefore, in my letter to participants I did not include my name apart from my user name. In the letter I offered the option for participants to contact either me or the administrative team of the website if they had any concerns or wished to withdraw from the study, and the administrative team did have access to my full name and contact information should any concerns have arisen that required this information. In addition, those participants who requested copies of the completed paper did gain access to my real-life identity, but those were a handful of individuals rather than the entire group. An alternative would have been to create a new user name, thus separating my two identities entirely. However, this felt unnecessarily deceptive, given the solution I described above, and could have created a sense of intrusion from a presumed outsider, again without need.

As Warner (2009) has observed, some universities have developed ethics board guidelines for Internet-based research, but most have not. Warner noted that institutional ethics boards look favorably on precedents set by other institutions or professional associations in terms of ethics guidelines as well as examples of previous studies. As I mentioned previously, I found the guidelines offered by Ess and the AoIR Ethics Working Committee (2002), "criteria for exemption from ethics review" proposed by the General Research Ethics Board (2007, p. 16) at Queen's University, and published articles on ethics in Internet-based research to be helpful during my consultations with my university's REB. Regarding cyberethnography in particular, Warner (2009) has suggested that the American Anthropological Association develop a statement on Internet research ethics as it would smooth the approval process with institutional ethics boards. Eysenbach and Till (2001) have also called for best practice guidelines to be established for Internet-based research, and this would be nowhere more needed than for online research with adolescent minors. Ess (2004), however, argued that existing ethics codes should usually be adequate for guidance of Internet-based research, with the assistance of the published literature. This article is intended to contribute my experience with ethical decision-making in a small Internet-based project to these larger conversations.

Conclusion

In this article, I have examined a number of ethical and methodological issues raised throughout my brief exploratory research project on youth perspectives and decision-making regarding the HPV vaccine, in which I used publicly accessible information from an online message board. The use of the Internet as a research site for this topic offered advantages in terms of reduced time and cost, probable lessened impact of social desirability, and the opportunity to collect data from minors without parental consent. However, disadvantages included limitations on the data collected, including inability to ask follow-up questions and incomplete access to demographic details. The specific findings of this study were not intended to be generalizable or representative, as they represent a specific population of adolescents belonging to one Internet message board community. Rather, they bring to light the active role adolescents can and do play in health care decision-making as well as important aspects of youth engagement with HPV vaccination which deserve further attention.

I have focused here on my ethical decision-making process in this project, with comparison to other published work. To summarize, I accessed publicly available, unsolicited information, which technically might not have required permission to use. Thus, consent from parents or guardians was not sought, but permission was sought from the administrative team of the website

and participants were informed of the use of the information and provided the opportunity to withdraw it from the study. They were also offered copies of the finished paper. I considered how members regarded the space (how private, how public) and used information only from a nonsensitive area of the message board. I also believe that the fact that the research request came from an active member and not a “lurker” limited any sense of intrusion. In addition, I had to consider my privacy as a continuing member of the board. Finally, I protected participant members’ online identities as well as their real-life ones and took steps to ensure that the website was not identifiable through a search engine by not publishing user names or direct quotes.

Whether or not new guidelines are developed for Internet-based research with adolescents, researchers and ethics board members have to be aware of how to apply existing general ethical rules and principles to online settings as ambiguity in the interpretation of any rules or guidelines will continue to exist. Furthermore, the Internet will continue to change and evolve ahead of any guidelines. Thus, researchers will need to continue to reflect on the ethical aspects of their online research and make decisions based on the context of their particular online community, participants, and research questions, with guidance from previous studies. With this article, I hope to add my experience and explorations to ongoing thinking about ethics in this relatively new and evolving research setting with a particularly challenging group, adolescent minors.

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