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Implementing Ethically-Sound Research on Online Health-Related Support Groups

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ABSTRACT

Purpose: The purpose of this article is to review the benefits and dilemmas associated with ethically-sound literary research and to provide guidelines for qualitative research within the context of online health-related support groups. **Summary of Key Points:** The Internet is a significant resource for the acquisition of healthcare information for healthcare consumers. For those seeking assistance with health-related disabilities, online support groups provide opportunities to share information, to share experiences, and to obtain support. Healthcare professionals recognize the text-based communications used by these groups as a rich data source for client-centered qualitative research. This article highlights the possible risks arising from Internet research to the rights and safety of research participants. Potential rewards to be gained from this type of research include improved patient-centered outcomes, improved service delivery models, and improved education programs for clients and professionals. This article presents a summary of Internet research literature and currently accepted research methodology to explain the ethical challenges related to balancing the benefits of listserv research with protection of individual rights. Recommendations for ethically-sound research within the context of online support groups are summarized based on traditional research policy and guidelines, recommendations from interdisciplinary groups, and opinions from experienced online researchers.

INTRODUCTION

The increasing use of the Internet has radically changed how people communicate with each other. The Internet is one of the tools healthcare consumers use to exchange information, to share experiences, and to obtain support. Approximately 113 million Americans are reported to have used the Internet to search for health information, and approximately 84 percent of Internet users report using the web to obtain information from an online community.¹⁻² The listserv or Internet mailing list is a popular online support group format for those seeking assistance for health-related disabilities, especially for those who are limited in their ability to attend face-to-face support groups.³ The National Institute of Health provides a link to more than 10,000 public listserv lists on the Internet; with as many as 50,000 listservs reported by other sources.⁴⁻⁵ In the early days of the Internet, people had the misconception that text-based conversations or computer-mediated communication (CMC) could not possibly compare to the richness of face-to-face (FTF) communication.⁶ Yet, according to recent research findings, online support groups are able to provide a rich social context for coping with disease-related challenges. For example, parents of children with cancer participating in an online support group, express positive benefits related to coping with the demands of caring for their child with cancer, and women with breast cancer participating in an online discussion board, report an increase in positive well-being related to participation in the Internet community.⁷⁻⁸

These types of studies provide essential evidence to inform clinical practice. Evidence-based practice, considered the gold standard for quality healthcare, consists of making clinical decisions using the best available information while integrating clinical expertise to guide healthcare practice.⁹ A critical component of this decision-making process is integrating the client perspective

at all levels of healthcare. Qualitative research is well-suited for research projects designed to gain the client's perspective. Recognizing the comprehensive nature of written material on the Internet, qualitative healthcare researchers identify CMC as a rich data source to gain in-depth, unobtrusive information regarding healthcare consumer perspectives.⁹⁻¹² Qualitative research via CMC offers an opportunity to assess quality of life, evaluate outcomes, improve educational programming, improve therapeutic interventions, and improve service delivery models in a client-centered approach. Naturally, most researchers are mindful of ethical implications associated with this type of research, with respect to protecting the online support group member.^{5,11-13} Specifically, researchers must be cognizant of methodological challenges related to protecting the privacy and confidentiality of participants. The purpose of this article is to describe the ethical challenges associated with researching listserve health-related support groups and to provide recommendations to promote quality ethically sound research.

LISTSERV OVERVIEW

A discussion of listserv technology provides a foundation to understand the complexity of ethical issues related to online research of health-related support groups. Essentially, listservs are automated Internet mailing lists made up of members with similar interests.⁴ The term listserv is actually a trademark name of L-Soft International, but has been generalized in recent years to denote any mailing list system (regardless of mailing list host).¹⁴ In keeping with contemporary trends, the term listserv is used in this article to generically describe any online mailing list.¹⁴ Participants must register or subscribe to become members of a listserv community. Each listserv has at least one list owner who is responsible for the administration of the list.⁴ The registration component of the listserv allows the virtual community to establish boundaries and restrict who has access to their postings.⁵ One of the most attractive attributes of the Internet, crossing geographical boundaries, provides access for hard to reach populations on a 24-hour basis.¹⁵⁻¹⁷ The listserv communication format is asynchronous, meaning messages are sent as emails and not instantaneously, versus instant message or chat room talk, which are instantaneous and synchronous. The benefit of this asynchronous format is members have the convenience of waiting to compose replies.

Technological aspects of listservs allow numerous opportunities for breaches in confidentiality for an online support group participant. Messages sent by listserv individuals are automatically broadcast to the rest of the members as facilitated by a series of computer hosts (servers) on a network.¹⁴ Anywhere along the pathway of transmission, the email message has the potential to be archived or stored on another computer. Most often, archived listserv messages are posted for public viewing and typically do not require membership or a password to access. An important concept to remember is listserv messages may be stored anywhere along the network for an extended length of time; often times after the author has forgotten the email.¹⁸

Commonly, listserv archives are posted in date and/or thread format. Emails in the date format are organized sequentially according to date and time of the message, whereas emails organized in the thread format are indexed according to subject heading. The ethical importance of listserv postings relates to the researcher's pursuit to correctly interpret meanings of the communications within the context of the email conversation.¹⁸ The thread format tends to be more conversational which helps the reader understand the context of the message, although researchers need to compare the date and thread formats because some archives are incomplete. Although the listserv member serves to gain potential benefits from this type of research, the next section will more formally discuss methodological challenges with associated risks to the listserv participant.

ETHICAL ISSUES ASSOCIATED WITH LISTSERV RESEARCH

Researchers recognize listservs as powerful resources for client-centered information but are faced with the methodological challenges of how to collect data, how not to destroy the environment while the information is collected, and how to protect the individual rights of the participant. The type of design chosen will ultimately determine the ethical challenges encountered. Types of listserv research are primarily defined by the degree of researcher intrusiveness and may be organized into three categories.¹¹ In the first category, the researcher passively analyzes text messages and is not actively involved with group discussions. Examples of research using this type of category are studies that examine issues related to colorectal cancer, breast cancer, Alzheimer's, and eating disorders.¹⁹⁻²² In the second category, a researcher interacts on a limited basis as a participating member. The researcher in this second category typically poses questions to the listserv group for the purpose of gaining additional information or to make the group aware that research is being conducted. The third category incorporates semi-structured interviews as led by the researcher, via the listserv. As implications for ethical research are different for each of the different categories, this article will focus on ethical challenges associated with the first category, with an emphasis on shared accountability between the researcher and listserv member.

Privacy and Confidentiality of Listservs

Standard operating procedure for any type of research involves determining whether a research environment is a public or private domain.²³⁻²⁴ At the most simplistic level, listservs with publicly-available CMC systems are considered public venues.²⁵

The most recent rules and regulations related to Internet privacy have been summarized in a posting from the Privacy Rights Clearinghouse (established at the University of San Diego Center for Public Interest Law).

There are virtually no online activities or services that guarantee absolute privacy... According to federal law, it is not illegal for anyone to view or disclose an electronic communication if the communication is 'readily accessible' for the public. (Electronic Communications Privacy Act, 18 USC § 2511(2)(g)(1)). For example, a message that an individual posts to a public newsgroup or forum is available for anyone to view, copy, and store. In addition, your name, electronic mail (email) address, and information about your service provider are usually available for inspection as part of the message itself. Most public postings made on the Internet are archived in searchable files... Thus, on the Internet, your public messages can be accessed by anyone at anytime-- even years after the message was originally written.²⁶

An ethical dilemma is recognized with the realization that some users have a naive misconception that the Internet is a safe, intimate environment for sharing and providing personal information, with no concept that their messages may be read by others, besides the intended recipient.^{25,27} In addition, many users do not understand postings from listservs are often publicly archived with content easily accessed by search engines. One of the leading concerns related to search engines is the potential of lifting comments out of context, possibly increasing the likelihood of harm or unpleasant experiences to an individual.²⁸ Based on information gathered from informal email postings and listserv surveys, an awareness is raised that some online support group members may resent their discussions being analyzed for research purposes.¹¹ Whether or not these opinions represent the majority of online community members, the following questions must be raised: Is there a sense that people do not want their interactions online studied? Do members of online groups consider the researcher as being voyeuristic? Are the researchers taking advantage of those in distress? These questions do not have well-defined answers but are very similar to questions addressed within traditional research undertakings. Issues regarding confidentiality and privacy motivate the ethical online researcher to invest time and reflection on whether listserv environments are perceived to be public or private domains by the listserv members. The determination of whether or not the listserv is a public environment is directly related to informed consent.

Informed Consent

Government, private, and professional groups debating the dilemma of whether or not to receive informed consent for online studies are aware that a difference exists between physical research and virtual research.^{5,11,23,27} Federal regulations exempt researchers from receiving informed consent if data collection occurs in a public place, and the identification of the subject is protected from disclosure.²⁹ Analyzing public domain listserv data is likened to looking retrospectively at hospital records.¹¹ Historically, IRBs set precedence stating informed consent is not required for medical record searches if patient identifiers are removed because the data collection is non-intrusive and privacy is maintained.^{11,30} However, an online researcher must consider additional factors to avoid damage to the research process.¹⁰ The researcher does not want to cause unwarranted distress for a listserv member or community who finds their email postings have been used without their consent, even though informed consent is not required for observational research within a public domain. The researcher's fear is that these members may become distrustful of the listserv group which once provided them with support; furthermore causing a lack of trust in the research community.¹⁰

Ethical listserv researchers should discern the degree of intrusiveness to determine whether a listserv site is a public or private domain for the purpose of receiving informed consent --- considering *perceived* privacy does not always correlate with ease of Internet access.²³ As previously discussed, the researcher must be guided by determinations of whether the listserv community considers their group to be a private or public forum, and whether the researcher is a group member.³¹ As one can easily understand, the definition of public and private virtual venues is not always straightforward just as some physical domains do not have clear boundaries. Consider the following "real world" illustration to help understand a parallel concept in the virtual world. A porch is a transitional zone between a private and a public domain with degree of privacy mostly determined by cultural convention.³² Similarly, listservs have been likened to "virtual front porches" where diverse populations of people have opportunities to meet for meaningful conversation. Regardless of current rulings and best practice guidelines, some researchers argue the merits of obtaining informed consent as an ethical responsibility no matter the level of intrusion.²³ This viewpoint is considered extreme in the eyes of most contemporary researchers.

Another method of dealing with informed consent is known as negotiated consent.¹⁰ This method involves obtaining permission from the listserv owner to show there is shared power in the decision making of the research process with the listserv community. If the listserv is an active group, the group administrator or the researcher (with permission from the administrator) may post an announcement to make group members aware of the purpose of the research and the presence of the researcher collecting data. The problem with negotiated consent is that it does not take into account the continual change in group

membership and culture. In addition, the listserv administrator does not solely represent the interests of all group members. Individual and community property rights of listserv communities present the final point for discussion.

Intellectual Property

An issue plaguing online researchers is the question, Who owns the messages posted on the Internet?^{10,33} Theoretically, Internet listserv members have copyright to their posted messages that includes not only legal ownership of intellectual creativity but also "... the right to copy, modify, distribute, run (on a computer) or transmit a work."¹⁶ However, literal enforcement of CMC copyright violations would mean no one has the ability to download or read Internet messages. In contemporary times, implied license is assumed by society to access information on the web, further challenging Internet researchers to establish ethical policies to safeguard consumers. The application of Internet domain terms, public and private, serves as a partial solution to the question of data ownership as discussed earlier. In this ambiguous area, a common practice is to receive permission from listserv authors of long quotes. This practice serves to empower listserv members to play an active role in whether their words will be published and whether they want to be credited.¹⁰

Exploring ethical issues provides the opportunity to reflect about the relationship between the goals of research and online research processes.³⁴ In response to ethical challenges, researchers from a wide array of fields and studies are engaging in on-going conversation exploring the benefits and risks of online research.^{11-12,19-23,27,35-37} The discussion of ethical behavior certainly should include a caution to avoid self-righteous presumptions that ethical standards are absolute and may be generalized to any situation.³⁴ Regardless of a lack of formal guidelines, academic and professional organizations emphatically insist online research should be self-regulating and ethically sound with an emphasis on researcher accountability.^{5,11-12,16,27-28,35,38}

RECOMMENDATIONS

The healthcare researcher must adhere to general ethical principles to minimize potential harm to the listserv member even though research involving passive analysis of public Internet transcripts is considered exempt from human-subjects regulations.^{12,25} The primary source of potential risk which must be addressed is breach of confidentiality. In addition, establishing an awareness of mutual support and collaboration with a listserv group is equally important to address challenges related to perceptions of privacy, to prevent distrust about research processes, and to address potential biases of the researcher.³⁹⁻⁴⁰ Based on traditional research regulations, recommendations from interdisciplinary professional group consortiums, and wisdom from experienced Internet researchers, recommendations are offered to promote ethically-sound research on online health-related support groups.^{10,14,23-24,27,35,41-42} The reader should bear in mind discussion workgroups assembled to discuss these ethical issues have not reached consensus. (Refer to Appendix A for a checklist of items to be addressed prior to implementation of research).

- 1) Foremost, the purpose of the research should serve the members of the listserv group being studied.⁴³ The sole outcome of the study should not be for isolated data collection, but to benefit the lives of listserv members (either personal direct benefits or overall long-term member benefits).
- 2) Listserv research protocols should be developed with forethought on a case-by-case basis to protect the participant within the context of the specific listserv culture. Similar to traditional ethnographic studies, the initial task of a listserv researcher is to become immersed in the lives of a culture that is being studied through prolonged observation -- even though the researcher in this circumstance functions as a passive observer.^{39,44} Observing online interactions over time either as a listserv member or studying listserv archives helps the researcher understand group norms and culture.¹² During the early stages of research development, the initial task of the researcher is to evaluate barriers to listserv access, study the listserv's initial mission and objectives, develop strategies to promote collaborative relationships with the group, learn lingo and language specific to the group, learn social conventions, and define early themes for later data analysis.^{10,39}
- 3) All listserv studies should be cleared by the appropriate governing institutional board, even if they decide informed consent is not warranted.^{12,31} IRBs should include members familiar with virtual communities and the inherent dangers of online research to make informed decisions for the protection of listserv participants. Though not mandatory, the researcher should consider obtaining written permission from list owners or from each participant quoted in the study (especially those with long quotes). If informed consent is warranted, a statement should be added to an online research-informed consent form stating absolute confidentiality cannot be assured. Under any condition, whether or not informed consent is received, the data must be anonymized at the earliest stage of data collection.
- 4) The researcher should foster a collaborative relationship with the intended listserv group.³¹ The purpose of this relationship is to facilitate trust and to prevent problems that group members might feel about a real or perceived lack of control of the researcher over their lives.¹⁰ Negotiated consent should be established early in the research process. Gaining access through the list owner is considered essential as this person is likened to a gatekeeper.¹⁰ The list owner

is ultimately responsible for the operation of the listserv even though they do not have the capacity to speak for all members. This person is helpful in gaining a more in-depth understanding of the listserv culture of the group, along with values and beliefs, to guide in making specific decisions regarding sensitivity and vulnerability of the group (including making decisions regarding whether the group is a perceived private or public forum).³¹ For example, support groups formed with respect to addiction, sexually transmitted diseases, or abuse, require stricter privacy guidelines as compared to other groups. As a final point, the listserv owner is a good resource in determining how the data will affect the group if the group name is used in publications, to resolve issues regarding informed consent, or to substantiate findings.

- 5) A listserv member's identity should be protected regardless of whether the listserv is deemed to be a public or private domain.^{37,42} Efforts should be made to maintain confidentiality and to remove all identifying information (headers, signatures, names, etc.) from the email postings within reported findings.³¹ Technological consultation regarding data collection and storage should be obtained prior to data collection, to protect the consumer. It should be noted that even though great efforts are taken to insure anonymity for listserv participants, Internet search engines may be able to pick up the original posting - thus identifying the listserv participant.
- 6) During the process of data analysis, the researcher should solicit listserv members to interpret or substantiate findings to strengthen internal validity of the study.¹⁰ The ultimate goal of this type of research is to represent the general views of the listserv members and to avoid misrepresenting the words and meanings based on textural references even if the views are contradictory.¹⁰ If a listserv member requests portions of the findings to be deleted, the researcher should respect the wishes of the listserv participant even if the researcher thinks the information is important to the study.³⁹
- 7) Researchers should develop a plan to debrief the community at the publication stage of the research process as a final offering of faith towards the trust relationship built between the researcher and the listserv community at the onset of the study.^{10,39}

CONCLUSIONS

Lagging behind media studies and social science research, the healthcare professions have been slow to use listservs as viable data sources.⁴⁵ The purpose of this article is to review issues related to ethically-sound research within the context of online health-related support groups. The text-mediated context of the online community provides intriguing opportunities for careful analyses of client-centered perspectives. The dilemmas have been described with more questions put forth as compared to absolute answers given. In the face of gaining valuable insight from the healthcare consumer's point of view, the challenge for the allied health research community is to balance the importance of online research with the protection of individual rights. The Internet way of life is here to stay and serves as a vast source of first-person narratives previously unavailable for research.⁵ Potential rewards to be gained from high quality, ethically-sound research include improved patient-centered outcomes, improved effectiveness of therapeutic interventions, enhanced service delivery models, development of alternative intervention programs using the Internet, and expansion of instructional resources for today's allied health professional.⁹

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APPENDIX A

Checklist for Online Research

The following questions should be answered prior to collecting data on-line.

Informed Consent

- Is the web site a public or private domain?
- If you are collecting data passively, do you need to have informed consent?
- Who is the intended audience? (Is the researcher part of the intended audience?)
- Does the list owner have the right to answer for the virtual community?
- How will the collection of data affect the group?
- How do you obtain the consent?

Privacy and Confidentiality

- How do you protect individuals from the capacity of powerful search engines to find individual quotes?
- Do members of virtual communities mind being researched, or do they consider it an intrusion?

Intellectual Property

- Is there implied license to use material on the web?
 - Who owns the messages?
-