Internet Research and Ethics: Transformative Issues in Nursing Education Research

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As practice in the educational and clinical settings seeks to be evidence based, faculty are increasingly required to conduct research and publish the results to advance the science of our profession. The purpose of this article is to discuss transformative research ethics because Internet use is an increasing component of current research studies. How nurse educators can engage in research-utilizing methodologies inclusive of technology while adhering to ethical standards developed before the advance of the Internet is reviewed. Recommendations are cited to address the new questions that arise at institutional review board meetings resulting from potential ethical implications of using students or research participants in cyber space. (Index words: Internet research ethics; Nurse researchers; Nurse educators) J Prof Nurs 30:124–129, 2014.

AS NURSING FACULTY, we assume many roles: teacher, clinician, researcher, school citizen, and affiliate liaison. Because practice in the educational and clinical settings seeks to be evidence based, faculty are increasingly required to conduct research and publish the results to advance the science of our profession. How do nurse educators engage in research utilizing methodologies inclusive of technology while adhering to ethical standards developed before the advance of the Internet? The purpose of this article is to discuss transformative research ethics because Internet use is an increasing component of current research studies. New questions arise at institutional review board (IRB) meetings resulting from potential ethical implications of recruiting and using research participants in cyber space.

Research Ethics Background: Regulations

Human participant research is defined by the Code of Federal Regulations (CFR) as that which involves any intervention or interaction with another person for gathering information or in which information is recorded by researchers in a manner that holds the potential for a person to be identified (CFR, 2001). Conducting survey research and asking questions, however seemingly benign, constitute human participant interaction. The history of research is replete with instances of abuse and atrocity. Prompted by the grave wrongdoings of the Tuskegee Syphilis Study (1932–1972), the Stanford Prison Experiment (1971), and the Milgram Study (1974), IRBs were given federal regulatory status in 1974 and revised in 1981 by the Department of Health and Human Services. The resulting CFR: Title 45 (Public Welfare) Part 46 (Protection of Human Subjects) is today referred to as 45 CFR Part 46 or the "Common Rule." The CFR primarily addresses biomedical and behavioral research and applies directly to all federally conducted or funded research. The CFR is concerned with six major areas of research that address risk reduction and safety:

- Minimize participant risks through sound research methodology [46.111a(1)]
- Risks appropriate to benefits [46.111a(2)]
- Equitable subject recruitment [46.111a(3)]
- Informed consent [46.111a(4) and (5)]
- Monitor data for participant safety [46.111a(6)]
- Appropriately protect privacy and confidentiality of participants [46.111a(7)]

The most recent revision to the Common Rule was in 2005, and the Office of Human Research Protections is collecting comments as part of the plan to overhaul research regulations.

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Along with the development of IRBs, the National Commission for the Protection of Human Subjects issued the Belmont Report in 1978 to ensure that the rights and welfare of human participants of biomedical and behavioral research are protected. The document outlines that research on humans must take care to respect autonomy—free will, beneficence—minimizing harm and preserving privacy and justice toward human participants. Boundaries must be established between the practice of accepted therapies and those deemed research. Belmont Principles of respect, beneficence, and justice are to be applied when conducting informed consent, risk/benefit assessment, and the selection of research subjects (Lewis, Gonzalez, & Kaufman, 2011).

Both the Belmont Report and the CFR recognize limitations and offer rationales for exceptions from general requirements, for example, when it is understandable and allowable not to seek informed consent. Both documents were created prior to the Internet and offer general principles and practices rather than instructions about specific media. Individual IRBs can go overboard with them as applied to Internet research and contribute to the view of university IRBs as a major obstacle to research progress (Stark, 2012). Guiding documents for Internet research ethics include Ethical and Legal Aspects of Human Subjects Research on the Internet (American Association for the Advancement of Science, 1999), Ethical and Policy Issues in Research Involving Human Participants (Frankel & Siang, 1999; National Bioethics Advisory Board, 2001), and Ethical Decision Making and Internet Research (Ess & AoIR Ethics Working Group, 2002).

Human Participant Research in a Digital Age

In their research on U.S. IRBs, Buchanan and Hvizdak (2009) found that the overwhelming majority (94%) of respondents stated that the most frequently reviewed type of research was on-line survey research. This is understandable in light of the many advantages of on-line survey research, which readily and conveniently opens access to large numbers of potential participants while still maintaining low cost regardless of numbers of participants. On-line surveys are flexible when compared with traditional mail surveys, yet similar to CATI telephone surveys where the researcher can pose different questions to people depending on their response to previous questions. On-line survey administration is less error prone because data are compiled automatically, so there is no need for human keying or transcription of data. Furthermore, study data are compiled in real time, so the researcher can begin to see results almost instantaneously.

On-line survey research also has numerous disadvantages. On-line surveys are characterized by low response rates. There is also response bias when the same individual answers the same on-line survey multiple times. These problems may be mitigated when a previously identified sample of individuals is invited to participate in an on-line survey, for example, a textbook publisher surveying nursing faculty can issue passwords for accessing a site, and Internet protocol (IP) addresses can be tracked.

Perhaps, the greatest disadvantage is external validity and the generalizability of the findings from an Internet sample. There is a lack of control over the research environment: using on-line surveys means that there is no face-to-face communication, and so, obtaining informed consent presents different kinds of challenges. What do we do if someone assumes a different on-line identity, for example, how do we identify underage participants? “At present there are no reliable methods for determining the age of internet users” (CITI, 2009). There is also no way to prevent someone else signing on to another's Facebook page. Yet, the CFR stipulates that human participants' research must provide benefit either to participants or to scientific understanding, and there can be no benefit unless data are valid and reliable. Despite these serious issues, over one third of respondents in the Buchanan and Hvizdak (2009) did not regard the privacy and security policies of commercial tools as part of their protocol review process. Security is poor in commercial products, and data are not safe. Even Apple has been breached: within days of the 2010 launch of the first iPads, AT&T servers were hacked, and personal data belonging to 120,000 iPad users were stolen.

To address security problems, institutions such as Georgia Tech (http://www.cc.gatech.edu/~asb/ethics/) and Marian University, Wisconsin (http://www.marianuniversity.edu/interior.aspx?id=13714), have developed guidelines for Internet research. Loyola University has an on-line survey research policy and has created a checklist to screen survey software systems for approved use (http://www.luc.edu/irb/irbonlinesurveys2.shtml). A few institutions are attempting to create their own on-line survey software, but this remains uncommon. It has been recommended that an open source tool collaboratively developed by an academic consortium would be better than commercial products to stop the “outsourcing of research” (Buchanan & Hvizdak, 2009).

It is critical that the researcher realize that research methods are research ethics and be able to articulate why using the Internet is required in meeting the research aims. Ease and convenience of data collection are insufficient reasons for using the Internet. The CFR and the Belmont Report were developed pre-Internet, and so, the ethics of on-line surveys are different from traditional research ethics to the extent that they are not comparable, much like “apples and oranges.” Instead, researchers and IRBs must consider how best to translate ethics from one environment to another (Buchanan & Hvizdak, 2009). Regulations that do not strictly translate must be applied metaphorically. Spirit and intent, not letter, often must be used to interpret digital equivalents, for example, locked file cabinet and signed consent. IRB panels make individualized, case-by-case decisions often based on local institutional history (Stark, 2012). Panels are not always equipped to understand nuances of Internet data