

Ethics in Qualitative Research

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Purpose: To critically examine ethical issues in qualitative research.

Organizing Construct: The ethical principles of autonomy, beneficence, and justice are guides for researchers to address initial and ongoing tensions between the needs and goals of the research and the rights of participants.

Methods: Research literature, ethics literature, and researcher experiences.

Conclusions: Ethical principles can be used to guide the research in addressing the initial and ongoing issues arising from qualitative research in order to meet the goals of the research as well as to maintain the rights of the research participants.

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Ethical issues are present in any kind of research. The research process creates tension between the aims of research to make generalizations for the good of others, and the rights of participants to maintain privacy. Ethics pertains to doing good and avoiding harm. Harm can be prevented or reduced through the application of appropriate ethical principles. Thus, the protection of human subjects or participants in any research study is imperative.

Violations of human rights in the name of scientific research have been among the darkest events in history. From 1932-1972 more than 400 African American people who had syphilis were deliberately left untreated to study the illness. Although the Tuskegee syphilis study was sponsored by United States Public Health Service, the disclosure of the 40-year study caused public outrage (Caplan, 1992). Another example of unethical research is the experiment conducted between 1950-1952 in which more than 1,000 pregnant women were given diethylstilbestrol to prevent miscarriages. These women were subject to a double-blind study without consent. Only 20 years later, when the children of these women had high rates of cancer and other abnormalities did the participants learn they were subjects of these experiments (Capron, 1989).

The nature of ethical problems in qualitative research studies is subtle and different compared to problems in quantitative research. For example, potential ethical conflicts exist in regard to how a researcher gains access to a community group and in the effects the researcher may have on participants. The literature provides few examples of ethical issues in qualitative health research. Punch (1994) claimed that one hardly ever hears of ethical failures in qualitative research. However, Batchelor and Briggs (1994) claimed that the failure of researchers to address ethical issues

has resulted in those researchers being ill-prepared to cope with the unpredictable nature of qualitative research.

Qualitative researchers focus their research on exploring, examining, and describing people and their natural environments. Embedded in qualitative research are the concepts of relationships and power between researchers and participants. The desire to participate in a research study depends upon a participant's willingness to share his or her experience. Nurse researchers have to balance research principles as well as the well-being of clients (Ramos, 1989).

Qualitative health research is focused on the experiences of people in relation to health and illness. Yet nurse researchers may find that their roles as researchers and as clinicians may be in conflict. Qualitative studies are frequently conducted in settings involving the participation of people in their everyday environments. Therefore, any research that includes people requires an awareness of the ethical issues that may be derived from such interactions. Ethics in health research includes appropriateness of the research design, the methodological design, and the funding sources, as well as behaviors in reporting data. The purpose of this paper is to show these and related ethical issues and ethical principles to be used in qualitative research.

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Issues in Qualitative Research

Although ethical review boards scrutinize most nursing research proposals, the researchers are ultimately responsible for protecting the participants. Dresser (1998) said that the administrative burden of ethical reviews and procedures is balanced by the protection of participants. She suggested close monitoring of high-risk studies. In qualitative studies, researchers rely heavily on collecting data through interviews, observations, written materials, and audiovisual material. While in the field, researchers should negotiate access to participants to collect data; thus the quality of social interactions between researchers and the participants may facilitate or inhibit access to information. Once access to the field has been granted and the first steps of data collection are taken, researchers may experience ethical dilemmas that may not have been anticipated in the research plan (Field & Morse, 1992).

Ramos (1989) described three types of problems that may affect qualitative studies: the researcher/participant relationship, the researcher's subjective interpretations of data, and the design itself. For example, a researcher's deception or disclosure of damaging information can occur. Humphrey's study of homosexuals is one example (Punch, 1994). His controversial research method of participant observation using deception shocked American academics who wanted to revoke the researcher's doctoral degree. He observed men in a public bathroom and followed them to their homes under the guise of working on a different project (Punch, 1994). Clarke (1996) used deception in a forensic unit, claiming that this approach was necessary to obtain "uncontaminated" data. She used participant observation over a period of 6 weeks while working as a nursing auxiliary. Clarke did not disclose her role as researcher. She retreated to the restroom to take notes or to speak into a small dictaphone. Clarke justified this method stating that some degree of deception is permissible when "dealing with sensitive aspects of subjects' behaviour" (p. 38).

When preparing research protocols, nurse researchers should consider the potential ethical issues that can be anticipated in the study, such as informed consent, confidentiality, data generation and analysis, researcher/participant relationships, and reporting of final outcomes.

The Process of Data Collection

The purpose of qualitative studies is to describe a phenomenon from the participants' points of view through interviews and observations. The intention of the researcher is to listen to the voice of participants or observe them in their natural environments. The researcher's interpretation of these experiences is usually described as an emic perspective (Field & Morse, 1992). The acceptance of this statement means that researchers recognise that participants are autonomous people who will share information willingly. A balanced research relationship will encourage disclosure, trust, and awareness of potential ethical issues. Kvale (1996) considered an interview to be a moral endeavour, claiming

that the participant's response is affected by the interview, and that the knowledge gained through the interview affects our understanding of the human experience. The personal interaction between researchers and participants is crucial in data gathering by keeping in mind the research focus and being clear about the role of researchers. The researchers' perceptions of field situations are determined by personality and the nature of the interactions (Punch, 1994).

Although qualitative research methods make it difficult to predict how data will be collected through interviews or observation (Streubert & Carpenter, 1999), researchers have the obligation to anticipate the possible outcomes of an interview and to weigh both benefits and potential harm. For example, in the case of interviewing victims of violence, the interview may trigger painful experiences and the participant may become distressed during the interview. In this case, the researcher is confronted with an ethical dilemma—to continue with the interview and gain more insight about the topic under study or to stop the interview and give advice or refer the participant to an appropriate treatment or counseling service. Deciding to continue would indicate that the researcher considers that the value of the data obtained from the distressing experience outweighs the participant's distress. Smith (1999) wrote about the potential therapeutic benefits of participants' reviving unpleasant memories and also the importance of seeking ongoing consent. Hutchinson, Wilson, and Wilson (1994) identified the benefits of qualitative interviews as catharsis, self-acknowledgment, sense of purpose, self-awareness, empowerment, healing, and providing a voice for the disenfranchised. Stopping the interview and searching for possible solutions for the participants' distress indicates that researchers are aware of the vulnerability of participants and their rights. The moral obligation of researchers is to refer participants to counseling or ensure that they have regained control of the situation by talking. In some cases, a follow-up phone call or visit may be appropriate.

Ethical dilemmas that may rise from an interview are difficult to predict but the researcher needs to be aware of sensitive issues and potential conflicts of interest. An interview is usually equated with confidentiality, informed consent, and privacy, but also by recurrence of "old wounds" and sharing of secrets. The interview opens new risks to both researchers and participants. Researchers may be required by law to report information about child or elder abuse, drug traffic, or crimes. Courts for domestic and criminal proceedings may subpoena researchers' records. In some studies in the US, researchers may wish to consider obtaining a Certificate of Confidentiality from the Department of Health and Human Services (Lutz, Shelton, Robrecht, Hatton, & Beckett, 2000).

The following example is one of those ethical dilemmas that are silent in qualitative health research literature. During an interview, a participant revealed to a graduate student doing the interview that she was involved in drug dealings; the student was advised by one of the supervisors to delete such interviews. A year later the participant's spouse was dead from drug abuse. Researchers who are doing qualitative

health research must be aware not only of the promise to maintain confidentiality but to search vigorously for ways to deal with the ethical and legal issues they may encounter.

Ethical codes and guidelines for research projects do not have answers to all of the ethical issues that may arise during research. Subsequently, ethical dilemmas that are not part of the study may arise (Field & Morse, 1992) during an observation in a clinical area. A novice researcher observed the following event. An elderly woman asked to be taken to the toilet; a nursing staff member said that was not a convenient time and moved along to the next patient. In this situation the researcher is witnessing an unethical behaviour. In this case, Codes of Ethics indicate the rights of patients but do not indicate to the researcher how to respond to this situation. Such situations require careful examination of the moral responsibility of researchers. For example, based on his past experience, Patton (1990) recommended full disclosure of the purpose of the study when doing participant observation. He claimed that false or partial explanations are too risky and add unnecessary stress. Qualitative researchers are expected to describe the research experience in an authentic manner, often contrary to their own aims (Munhall, 1988). The research protocol also should provide enough information ensuring protection of human subjects. Moreover, such protocols must give details of the manner in which the study will be conducted, followed by details of access to participants, informed consent, and access and storage of data.

Ethical Principles

The difficulties inherent in qualitative research can be alleviated by awareness and use of well-established ethical principles, specifically autonomy, beneficence, and justice.

Autonomy

Several authors have claimed that the protection of human rights is a mandate in health care research (Dresser, 1998; Kvale, 1996; Munhall, 1988; Raudonis, 1992). Capron (1989) said that any kind of research should be guided by the principles of respect for people, beneficence, and justice. He considered that respect for people is the recognition of participants' rights, including the right to be informed about the study, the right to freely decide whether to participate in a study, and the right to withdraw at any time without penalty.

In a qualitative research study this principle is honored by informed consent, which means making a reasonable balance between over-informing and under-informing (Kvale, 1996). It also means that participants exercise their rights as autonomous persons to voluntarily accept or refuse to participate in the study. Consent has been referred to as a negotiation of trust, and it requires continuous renegotiation (Field & Morse, 1992; Kvale, 1996; Munhall, 1988).

Informed consent is dynamic, for example, in studying responses of family caregivers to caring for chronic patients, determining who needs to give informed consent may be necessary. For example, it may pertain only to caregivers or

consent from patients or other family members may also be required.

Beneficence

A second ethical principle closely linked with research is beneficence—doing good for others and preventing harm. Beneficence in some situations may be taken to the extreme as paternalism. A paternalistic approach indicates the denial of autonomy and freedom of choice. For example, the researcher may want to study the problem of violence among elderly women but may decide not to include them because they may be too vulnerable. In this case, the researcher is not giving elderly women the opportunity to decide for themselves and for their experiences to be heard.

Research strategies used to collect data and selection criteria also have ethical implications. For example, Raudonis (1992) indicated that considerable thought was given to inclusion criteria during the recruitment of potential participants for a nursing study of hospice patients' perspectives of empathy. Those patients who were unable to give consent or unable to participate in open-ended interviews were not asked to participate.

If researchers are maintaining the principle of beneficence, overseeing the potential consequences of revealing participants' identities is a moral obligation. The use of pseudonyms is recommended. However, this strategy may not be sufficient if the study is conducted in a small community where participants could be easily recognised. In such cases, circulation of the study may need to be restricted, for instance, reports of a study conducted with a group of Aboriginal nursing students may be restricted until the participants graduate from the nursing program. Such a group is small and can be easily recognised by the nursing community. Protection of participants' identities also applies to publications. Participants should be told how results will be published. Quotations or other data from the participants, even though anonymous, could reveal their identity. Ideally, participants would approve the use of quotations used in publications.

Confidentiality and anonymity can be breached by legal requirements such as when researchers' data are subpoenaed for legal purposes. If legal reporting is required, such as cases of child or elder abuse, participants should be informed that this information would be excluded from confidentiality and anonymity. Despite the need for confidentiality, qualitative research requires confirmability, that is, documentation of all activities included in a research study. This audit trail is there for other researchers to follow (Streubert & Carpenter, 1999). This process may create an ethical dilemma regarding confidentiality and anonymity. In some cases, participants may need to know that other researchers may review the process and the data.

Justice

The principle of justice refers to equal share and fairness. One of the crucial and distinctive features of this principle is avoiding exploitation and abuse of participants. The researcher's understanding and application of the principle of

justice in qualitative research studies is demonstrated by recognising vulnerability of the participants and their contributions to the study. For example, if researchers during analysis of the data consider that a concept or a heading of the report will be based on the contribution of a particular participant, ethically the researcher should request permission to use such a concept or at least discuss the issues with the participant. In this way, the contributions of that participant are acknowledged. Another way of implementing the principle of justice is listening to the voices of the minority and disadvantaged groups as well as protecting those who are most vulnerable, such as children, prisoners, the mentally ill, and the elderly.

Capron (1989) said that practical problems arise when researchers try to implement the principle of justice. For instance, the implementation of the principle of justice should not further burden the already burdened vulnerable group of participants. An example was the situation in which the consent forms for a group of Ethiopians for a rabies vaccine trial were not translated to the local language (News in Brief, 1999). A similar case also was reported in a malaria project with children from Zambia and Malawi, in which parents were not informed about the experimental nature of the trial. Unfortunately in these cases, like in many others (Capron, 1989), the participants were among the most powerless people in society.

Implications for Researchers

Having these ethical principles in mind, those researchers who are also clinicians should reflect on their roles as researchers and in comparison to their previous roles as clinicians. At times, however, researchers have to revert rapidly to their roles as clinicians. The separation of these two roles is not easy. Clinicians usually advise and treat clients for their complaints. Clinicians, in this new role of researchers, should listen to participants about what they want to say or to observe without interfering. For someone who has been used to being in charge or helping, this apparent passivity may cause discomfort and some level of stress.

Moreover, conducting qualitative research in an area in which the researcher works or is already known raises several issues and ethical considerations. The clinician/researcher may get better results because of knowing the situation and having the trust of participants. However, the known researcher may get less information. Patients and staff may feel coerced to participate and may limit the information they give. According to Field and Morse (1992) conducting research in one's work area creates problems related to the validity, reliability, and meaningfulness of the data. Conducting research in another setting may mean that researchers have to spend more time and effort establishing rapport and learning the new setting. But, this change may result in more objective observations.

Negotiation of the researcher's role on a clinical unit is important. If the role of the researcher is clearly identified by the group and the purposes of the study are discussed, the researcher will be regarded as such and not as someone who is doing something dubious. It also will reduce the group's false expectations. Perceiving the researcher as another pair

of hands who can be used during busy periods is an attractive idea. The negotiation of the role will also promote a clear understanding of the researcher's role during data collection. Gaining the trust of the group and their willingness to support the researcher's role is a step in the right direction, but it is the recognition of the relevance of ethical principles that must guide any research study.

Conclusions

In this paper, we have examined the common ethical concerns that qualitative health researchers confront and have highlighted the ethical principles that can guide research and researchers. These principles cannot ensure ethical research but they can contribute to an understanding that ethical responsibility in qualitative research is an ongoing process. Qualitative researchers should report the incidents and ethical issues encountered in their studies to ensure discussion, analysis, and prevention of future mistakes. Nurse researchers must always respect the mandate of maintaining ethical principles as an issue of protection of human rights, important in both patient care and research. [JNS](#)

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