The Ethics of Qualitative Nursing Research

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Nurse researchers conducting qualitative studies need to be acutely aware of the unique ways ethics, both nursing and research ethics, affect all phases of the qualitative research process. Decisions about what to study, which persons will be asked to participate, what methodology will be used, how to achieve truly informed consent, when to terminate or interrupt interviews, when to probe deeply, when therapy or nursing care supersedes research, and what and how case studies should be documented in the published results are all matters for ethical deliberation. This article seeks to examine some of the less obvious, yet very important, ethical concerns that nurses face throughout the research process and build a common core of values that can lead to meaningful process and socially responsible research results. (Index words: Ethics; Informed consent; Qualitative research; Research ethics) J Prof Nurs 11:45-48, 1995. Copyright © 1995 by W.B. Saunders Company.

The SPIRIT, process, and form of qualitative research are woven together with the gossamer thread of ethics. A break in the thread can lead to a weakening or even destruction of the cloth. As Parahoo (1991) states, the means and consequences of research are very much guided by a research ethic. Although ethical consideration and issues impact quantitative research, they do so in unique and more fragile ways in qualitative research.

In qualitative research, questions of ethics arise within the context of the shifting focus of the study, the unpredictable nature of the research and the trust relationship between the researcher and the participant. Because many dilemmas are resolved in private by appeals to the conscience of the researcher, forethought and sensitivity are needed about how ethics influences the totality of the research.

The thread of ethics in qualitative research will be examined in this article as it binds the philosophical underpinnings of the paradigm with the process of obtaining informed consent, the immersion of the researcher in interviewing and observing activities, the data analysis phase, and the case-reporting and publishing phase. "Ethics is critical to the life and advancement of the profession" of nursing and "must support and structure scientific inquiry in nursing" (Fowler & Fry, 1988, p. 145).

As a profession, nursing has embraced and rigorously defended a "profound reverence for human beings and their experience" (Munhall, 1988, p. 150). Naturalistic inquiry, with its human tools of instrument and the involvement of respondents in data generation and phenomenon explication is an interactive human endeavor. Unlike quantitative research methodology there is little distancing between researcher and subject creating a greater imperative for ethical regard.

Munhall (1989) outlines the ethical underpinnings particularly relevant to qualitative methodology:

Human beings are as they are. Actions of individuals are in some sense free. There is a reverence for the human experience de novo. The researcher does not predetermine the reality through his/her own assumptions and language (p. 23).

The process of engagement, discovery, and understanding the phenomenon being studied relies on dynamic human interaction. Current regulations and standards for protecting humans in research are, as Lincoln (1990) clearly points out, wholly inadequate for qualitative research. The "granting of rights of dignity, agency, freedom and independence to our respondents creates a situation where our own, often specialized, knowledge is nevertheless only one form of knowledge that is available" (p. 83). How the researcher behaves, how the respondent is invited, and how the respondent is viewed as an active participant in the research process create new and more difficult ethical responsibilities for the researcher. There can be no deceit, no injury, or disregard for the respondent as has been documented in quantitative research.

Embedded in this concern for researcher-respondent ethics is the question: to what degree are people used as a means to further knowledge? In duty-based ethics of nursing, individuals are seen as ends in themselves. Although this problem may seem en-
demic to all research involving humans, it is particularly evident and acute when there is a close trusting relationship built between people. "Empathizing with and attending to the process" is an on-going, ever-present responsibility of the researcher (Munhall, 1988, p. 155).

Regard for respondent, as well as self, as a foundation for the philosophy of the constructivist paradigm is translated early into action as the researcher seeks participants and their informed consent. Thought must be given as to how persons are selected and who knows about the selection process. The publicly acknowledged guidelines "for human experimentation" are of little help. The Nuremberg Code, the Declaration of Helsinki, and the practice of consulting institutional review boards developed from the positivist paradigm with attention to risk-benefit calculations, scientific experimental procedure, and voluntary consent (Veatch, 1977). These are important but of inadequate scope when applied to a qualitative research endeavor. Likewise, professional ethical guidelines such as the "Code for Nurses," "Human Rights Guidelines for Nurses in Clinical and Other Research," and the "Human Rights Guidelines for Research in Nursing Specialties," (Notter & Hott, 1988) although instructive and helpful when establishing initial informed consent, do not disallow for secrecy and deception to "get the kind of data you really want" and do not address the unpredictable nature of emerging data (Robinson & Thorne, 1988). The content of all of the researcher's questions "are unknown at the outset" and emerge from the dialogue (Ramos, 1989, p. 59).

Raudonis (1992) examines the use of vulnerable populations in health care research such as those in hospice and calls for sensitivity among qualitative researchers to the "development of risks to participants throughout the entire research process" (p. 240). The risk/benefit ratio is unclear because benefits to the participant of some research are often intangible and unidentifiable or in some cases unexpressed. Persons may wish to participate despite the objections of paternalistic caregivers. Raudonis calls for the use of process informed consent that can be adjusted as the study develops over time (with each interview or participant observation).

The persons selected as research participants are usually those who serve the purpose of the research. An ethical basis for selection would also involve attention to the inclusion of those whose voices need to be heard: women, minorities, children, the illiterate, and those with less personal or professional status. Social responsibility calls for attention to diversity. The degree to which the nurse researcher anticipates being able to understand the language, conditions, and differences between herself and the participant need to be clearly examined.

Of particular concern to nurse researchers is the question of to whom is the respondent giving consent—the nurse or the researcher—when the nurse is a more well-known entity than nurse researcher (Fowler, 1988; Robinson & Thorne, 1988). The researcher role must be emphasized and defined. The need for intuitive sense, ethics education, and ongoing attention to the tenuous nature of consent in the process of interviewing and observing are examined by a number of authors on the subject (Ford & Reutter, 1990; Hutchinson, 1985; Lincoln & Guba, 1989; Ramos, 1989).

Closely linked with informed consent is the promise of anonymity, confidentiality, and privacy of research participants. Lincoln and Guba (1987) say that such protection is difficult to secure, particularly in qualitative research because of the nature of detailed reporting of data and the ease of recognition especially of unique points of view by others in the community. The political nature of much social and nursing research can create reactions in the respondents that vary from mild embarrassment to outright rejection and retribution (Glazer, 1980). Guarding against disclosure that may create unacceptable risks for the respondents is accomplished in part by respecting the need for withdrawal of revealing material during the interview process, and in part through the process of member checking and negotiated outcomes. Freedom of speech does not allow the researcher the same liberties as an investigative journalist (Swazey, 1980).

Although most methods of gathering data for qualitative research are considered ethical if informed consent, based on the principles of human dignity, autonomy, privacy, confidentiality, anonymity, and safety are followed, the ethics of conducting participant observation in nursing research is fraught with
difficulties. Martin Johnson (1992) examines the moral problems inherent in complete participant observation and argues against secretly invading the privacy of others despite the apparent lack of tangible harm. He explores the issue from both the positive and negative and suggests that if the researcher does not plan to obtain informed consent, one must show how the data can only be gained in this manner. Stringent justification is necessary if participant observation is proposed.

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As the researcher moves into face-to-face contact (Lincoln & Guba, 1987) with chosen respondents and the interview/observation process is begun, a new set of ethical dilemmas emerge. At risk is the personal relationship built between researcher and respondent. There is a vulnerability experienced by both that occurs as each is known to the other. Myron Glazer (1980) in his article entitled, "The Threat of the Stranger" examines the impact on the respondent when sensitive personal material is revealed or when "community issues in a highly politicized environment are uncovered" (p. 25). Vulnerable patients, fellow professionals or students are encouraged to speak openly, often coming in touch with emotional or painful experiences in their lives or revealing thoughts otherwise never expressed that may threaten their loss of self-control and integrity. Hutchinson (1985) reports such experiences as participant observer in a level-3 neonatal intensive care unit. She says that "to gain entry to an alien environment, one must gain access to the heart" (p. 26). In so doing she found a need to be with the participants, develop a trust relationship particularly with certain nurses for whom she had strong positive regard and to feel the emotion of daily events. Lincoln (1987) says, "Such highly personal interactions create vulnerability as knower and known exchange roles, barter trust and reconstruct identities" (emphasis added) (p. 29).

Recognition of such vulnerability is important, but so is acknowledging that though respondents can exercise free will when it comes to disclosure, some reveal great amounts of information that a listening ear encourages. Guiding the depth of an interview, protecting the trust of respondents, being open to the data, realizing a certain degree of dependency exists in some respondents, anticipating the need for therapeutic intervention in some situations, and constantly permitting flexible communication and discussion of emergent problems—all call attention to a humane, moral, and responsible way of conducting research (Cowles, 1988; Ramos, 1989).

Nurses have repeatedly written about an ethical dilemma unique to the nurse researcher—role conflict (Cowles, 1988; Fowler, 1988; Munhall, 1999; Ramos, 1989; Robinson & Thorne, 1988). This occurs when the ethics of protecting the person as patient clashes with the role of researcher. Patients and the public, as indicated previously, find it more familiar to cast the nurse researcher into the nurse role than the researcher role and therefore often interact with the researcher at this level. Although it is wise to inform and remind respondents of what can be expected of the researcher, the "role of nurse supersedes that of researcher" (Fowler, 1988, p. 110). If a person has need for counseling, referral should be arranged. If the respondent runs a high risk of harm, he/she should be removed from the study with concomitant help and support. It is clear that ethical priorities of nursing lie with the person as respondent rather than the research.

As data is collected, the researcher, with respondent as advisor, analyzes the data for meaning, searches for reality in transcription, and awakens to the emergent design of the research. Description in the most authentic way possible recognizes the value of the respondent. Trust and negotiation built over time "demands forthrightness, clear and fair explication of the purposes of the research and authentic presentation of the researcher's self" (Lincoln & Guba, 1987, p. 30). All of this is an on-going process and relies heavily on the researcher's inner moral strength and knowledge of self.

Reporting and recording data is most frequently done using case studies. The goal is to present the most evocative material in factual but compelling ways. Thick description is indispensable to this record. Dena Davis (1991) discussed thick description thus: "...we learn from our experiences and we need to present the fruits of that learning in a full-bodied way that invites our audience to share that experience with us, and also to judge the legitimacy of our results" (p. 13). Although this is a description of rich cases of ethics, we need only add "and transferability" after "legitimacy" to apply it to qualitative research
reporting. Davis explains that by writing or narrating a thick description we risk revealing the identity of everyone concerned. The more richly endowed description may jeopardize confidentiality, privacy, and anonymity. What we learn from and convey by thick description, however, can be vitally important to the life and meaning of our research. The answer to the dilemma from several perspectives (Cowles, 1988; Davis, 1991; Lincoln & Guba, 1987) seems to be two-fold: if the narrative requires it, retain it and return to the respondent for permission, verification, and justification.

Selection of data to include in the case report may well be influenced by the funding agency underwriting cost for the research or the community group contracting for the study. These considerations must be analyzed early and thoroughly alongside the perspectives of the study's respondents. The question arises, "whose reality gets presented" (Lincoln & Guba, 1987, p. 35). Lincoln and Guba appeal to the principle of human dignity when stating that the participants "own" the data and "have rights to shape its use and dictate the purposes to which they will lend their names and information" (p. 35).

The filament of ethics that wends its way throughout qualitative research gets its tensile strength through a respect for the dignity, autonomy, and rights of the respondent. Care must be taken to realize that the same principles apply to the researcher. Subjectivity and collaboration makes the researcher vulnerable. Emotionally immersed in the lived experience of others, continually sensitive to the potentially injurious nature of language, and experiencing the rights of passage as an interviewer/observer—all require an inner strength that can be enhanced by self-care. The researcher can use the ethics committee as a guide and support throughout the process. She can use debriefing to explore personal responses and weigh risk/benefits. Personal education in ethics and consultation with experts when it is believed that the nurse-researcher is being hurt is advocated.

Ethics is woven into the fabric of qualitative research and must be given serious thought throughout the process. Examples of ethics dilemmas should be shared among nurse researchers—at conferences and in print. The constructivist paradigm is young in its development, therefore the need for dialogue about such matters is crucial.

References


