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# Ethical challenges of researchers in qualitative studies: the necessity to develop a specific guideline

Mahnaz Sanjari<sup>1</sup>, Fatemeh Bahramnezhad<sup>1</sup>, Fatemeh Khoshnava Fomani<sup>1</sup>, Mahnaz Shoghi<sup>2</sup>, Mohammad Ali Cheraghi<sup>3\*</sup>

<sup>1</sup>Nursing PhD Candidate, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran;

#### Corresponding Author:

Mohammad Ali Cheraghi

Address: School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran.

Email: mcheraghi@tums.ac.ir

Tel: 98 21 66933600 Fax: 98 21 66941668

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#### Abstract

Considering the nature of qualitative studies, the interaction between researchers and participants can be ethically challenging for the former, as they are personally involved in different stages of the study. Therefore, formulation of specific ethical guidelines in this respect seems to be essential. The present paper aimed to discuss the necessity to develop explicit guidelines for conducting qualitative studies with regard to the researchers' role. For this purpose, a literature review was carried out in domestic and international databases by related keywords. Health care providers who carry out qualitative research have an immense responsibility. As there is no statistical analysis in qualitative studies, the researcher has to both evaluate what he or she observes and to interpret it. Providing researchers with the necessary skills and applying stringent supervision can lead to better extraction of reliable information from qualitative studies. This article presents a debate in order to illustrate how researchers could cover the ethical challenges of qualitative studies and provide applicable and trustworthy outcomes. Researchers face ethical challenges in all stages of the study, from designing to reporting. These include anonymity, confidentiality, informed consent, researchers' potential impact on the participants and vice versa. It seems of paramount importance that health care providers, educators and clinicians be well informed of all the different aspects of their roles when acting as qualitative researchers. Hence, these adroit roles need to be well defined, and the use of practical guidelines and protocols in all stages of qualitative studies should be encouraged.

Keywords: qualitative research, ethical challenges, researcher's role, guideline

<sup>&</sup>lt;sup>2</sup>Assistant Professor, School of Nursing and Midwifery, Iran University of Medical Sciences, Tehran, Iran;

<sup>&</sup>lt;sup>3</sup>Associate Professor, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran.

#### Introduction

In the recent millennium, the constant trend of change in the demands of the community as well as transforming the trend of knowledge production has highlighted the necessity for researchers to adopt a more comprehensive approach. Increasingly, many academic disciplines are utilizing qualitative research (QR) as the qualitative method investigating the why and how of the process of a developed concept (1, 2). Qualitative research is sometimes defined as interpretive research, and as interpretations can be incorrect or biased, the findings may be controversial (3). However, qualitative research is not only useful as the first stage of quantitative research, but can also play a key role in 'validating' it or in providing a different viewpoint on the same social phenomena (4).

Qualitative studies tend to use methods that result in text production rather than numerical outputs. Given that the researcher is considered to be the research instrument, and the plan of inquiry needs to be developed and altered as the study progresses, a qualitative researcher cannot depend upon traditional approaches to address certain concerns such as bias and credibility. Therefore, learning from a series of mistakes is often considered an integral part of qualitative research (5, 6).

In this study, a literature review was carried out in international electronic databases including PubMed, Web of Sciences, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus, Ebsco, EMBASE and Science Direct without any time limitation, using the search terms "qualitative research", "researchers' role", "ethical challenges" and "ethical guidelines". These keywords were also searched on national electronic databases including Scientific Information Database (SID), Iran Medex and Medical Articles Library (Medlib) using the same strategy.

Authors of the present article endeavor to shine a light on the ethical issues affecting researchers and propose strategies to face the ethical challenges of qualitative studies, so as to provide applicable and trustworthy outcomes. This could be the basis for the formulation of specific ethical guidelines in this regard.

## An overview on qualitative research in health care

Up to the 1970s, qualitative research was solely employed by anthropologists and sociologists. During the 1970s and 1980s, however, it was favored by various disciplines and experts of

different branches of science and humanity such as health care, <u>psychology</u>, nursing, management, <u>political science</u>, education, and <u>communication studies</u> (2, 7).

Qualitative research has been conducted in the field of nursing in order to identify, describe and explain related concepts, experiences and phenomena and to develop the nursing knowledge. Nursing professionals simultaneously introduced qualitative research to their peers. Since 1970, qualitative research has been performed to achieve the concepts of patient care and other main perceptions in the nursing profession. Qualitative studies provide nurses with sensitivity to the lived experiences of individuals from different nursing care aspects (4, 8).

#### Role of researchers in qualitative studies

In the case of nurses who perform qualitative research, ethical issues are raised when the nurse-patient relationship in the research area leads to some degree of therapeutic communication for the participants (9). Thus, nurse researchers must be aware of the impact of the questioning on the participants, and in order to decrease such harmful effects on human subjects, the "reflexive approach" is recommended (10).

In qualitative studies researchers are often required to clarify their role in the research process (11). In the QR procedure the researcher is involved in all stages of the study from defining a concept to design, interview, transcription, analysis, verification and reporting the concepts and themes. Therefore, whenever instruments are involved in qualitative research, a human being will be an integral part of the process (12).

It is argued that humans have increasingly become the "instrument of choice" for naturalistic research due to certain characteristics: they are highly responsive to environmental stimuli, have the ability to interact with the situation, pull together different pieces of information at multiple levels simultaneously, and perceive situations holistically; moreover, they are able to process findings the instant they become available, can present immediate feedback, and feel unusual responses. Nevertheless, researchers need to improve the abilities that make them appropriate human instruments and consequently, their interpersonal skills are of major importance in natural settings and study processes (Table 1) (13, 14).

Table 1. Researcher's role in qualitative methods at a glance

Qualitative method	Researcher's role
Phenomenology	The main task of researchers in the phenomenological method is transformation of data to live the experience. They bring individual experiences into words in data collection, and then attempt to understand those experiences based on the statements, and to categorize the themes in the next stage. In the last stage, investigators record the essence in writing, which results in a comprehensive description of the phenomena (6, 15).
Grounded theory	Considering the significance of personal relations in grounded theory, researchers act as a component of daily events and must therefore be completely aware of their values. Since there is no control in this natural field, investigators are not detached from the research process, and ought to be conscious of their prejudices and potential influence on the study. Researchers need to be able to perform data admission and coding concurrently, and should consequently be equipped with proper analysis skills in order to criticize and conduct abstract thinking (16, 17).
Ethnography	In ethnographic studies, researchers function as instruments that understand and analyze the culture. Therefore, ethnographic investigators need to be immersed in the culture and to live among the study population. However, ethnographers have to be notified of their role as research instruments while collecting and analyzing data (18).

#### Ethical challenges in qualitative studies:

The researcher-participant relationship

The relationship and intimacy that is established between the researchers and participants in qualitative studies can raise a range of different ethical concerns, and qualitative researchers face dilemmas such as respect for privacy, establishment of honest and open interactions, and avoiding misrepresentations (19). Ethically challenging situations may emerge if researchers have to deal with contradicting issues and choose between different methodological strategies in conflict arises. In such cases, disagreements among different components such as participants, researchers, researchers' discipline, the funding body and the society may be inevitable (20, 21). Some important ethical concerns that should be taken into account while carrying out qualitative research are: anonymity, confidentiality and informed consent (22).

According to Richards and Schwartz' findings (22), the term 'confidentiality' conveys different meanings for health care practitioners and researchers. For health care practitioners, confidentiality means that no personal information is to be revealed except in certain situations. For researchers, however, the duty of confidentiality is less clear and involves elaboration of the form of outcome that might be expected from the study (22, 23).

The researcher must endeavor to minimize the possibility of intrusion into the autonomy of study participants by all means. When highly sensitive issues are concerned, children and other vulnerable individuals should have access to an advocate who is present during initial phases of the study, and ideally, during data gathering sessions. It is

sometimes even necessary that the researcher clarify in writing which persons can have access to the initial data and how the data might be used (24, 25).

Informed consent has been recognized as an integral part of ethics in research carried out in different fields. For qualitative researchers, it is of the utmost importance to specify in advance which data will be collected and how they are to be used (26). The principle of informed consent stresses the researcher's responsibility to completely inform participants of different aspects of the research in comprehensible language. Clarifications need to include the following issues: the nature of the study, the participants' potential role, the identity of the researcher and the financing body, the objective of the research, and how the results will be published and used (27).

Informed consent naturally requires ongoing negotiation of the terms of agreement as the study progresses (26). Many people consider it necessary to participate in research that their peers, community and/or society may benefit from. Therefore, qualitative health researchers need to clarify that the research they carry out will benefit science and can contribute to the improvement of health policy (5).

Research design

The qualitative method is utilized to explain, clarify and elaborate the meanings of different aspects of the human life experience. Therefore, researchers can interpret people's experiences because they are involved in human activities. The principle of 'no harm' to participants ought to be considered by researchers, who should be aware of the potential harms that might be inflicted upon study subjects. Obviously, sometimes a conflict

between the right to know (defended on the basis of benefits to the society) and the right of privacy (advocated based on the rights of the individual) may happen (27, 28).

There are several effective strategies to protect personal information, for instance secure data storage methods, removal of identifier components, biographical details amendments and pseudonyms (applicable to names of individuals, places and organizations) (27). Researchers have the responsibility of protecting all participants in a study from potentially harmful consequences that might affect them as a result of their participation. It is getting increasingly common for research ethics committees to seek documented proof of consent in a written, signed, and ideally, witnessed form. Researchers can only do their best to protect their respondent's identity and hold the information strictly confidential as there would be no guarantee for it otherwise (29). Furthermore, in investigations of sensitive topics where written consent puts the informants at risk, audio recorded oral consent would be more appropriate (30).

Development of personal relationships with participants may be inevitable while collecting certain data. Therefore, researchers should seriously consider the potential impact they may have on the participants and vice versa, and details of such interactions should be clearly mentioned in research proposals (23). Overall, the role of the researcher as (a) stranger, (b) visitor, (c) initiator, (d) insider-expert or other should be well defined and explained (3). As Brenner quoted Kvale state that, preparing an ethical protocol can cover issues in a qualitative research project from planning through reporting (30).

Data gathering and data analysis

In qualitative research, data are collected with a focus on multifaceted interviews and narratives to produce a description of the experiences. The researchers, therefore, play the role of a mediator between the experiences of the respondents and the community of concerned people (28, 31). The post-interview comment sheet could assist the researcher to note the feelings of informants, as well as interpretations and comments that occurred during the interview (32).

Data collection needs to be as overt as possible, and findings should be recorded. Although there is no guarantee of absolute confidentiality, openly recording field notes assists participants to decide what they wish to have on the record. In health care research, the problem may be even more exaggerated as the researcher is sometimes the health provider as well (33).

In comparison with other research methods, ethnography has singular characteristics. When a researcher aims to study the culture of certain people, living amongst them is inevitable. This method of collecting data is a subject of debate

from an ethical point of view. Long presence of the researcher amongst people of a particular culture necessitates informed consent. Participants should always be aware of the information that has been obtained and is being recorded, and consent to it. Sometimes this cannot be achieved easily and conflicts may happen, as in studies of cultural and ethnic characteristics (18).

The physical presence of the researchers within the culture requires them to be responsible for their role and potential consequences on the field. For instance, when criminals or a group of war veterans suffering from a disease are the subject of a study, the risks involved in living amongst them should be considered. Ethnographers must be vigilant about any distractions stemming from close interactions that can be potentially harmful to participants in the long run (33, 34). Researchers can benefit from supervision sessions directed at learning, mentoring and skill development, all of which can foster their ability to carry out research without risking their health. Adequate professional supervision (which may be outside of the university) can be of service to researchers in dealing with the potential stress associated with the study (35 - 37).

In order to gain explicit data, ethnographers need to know the role of instrument details. There are eleven steps defined in ethnography which are meant to assist researchers. These steps include participant observation, ethnographic record, descriptive observation, taxonomic analysis, selected observation, componential analysis, discovering the cultural theme, cultural inventory, and finally writing ethnography (38, 39).

Researchers should always be aware of the precise reason for involvement in a study in order to prevent undesirable personal issues. The probability of exposure to vicarious trauma as a result of the interviews needs to be evaluated. Interviewers should be properly scheduled to provide the researcher with sufficient recovery time and reduce the risk of emotional exhaustion, while allowing ample time for analysis of the objective and emotional aspects of the research. It is also necessary for the researcher to be familiar with signs of extreme fatigue and be prepared to take necessary measures before too much harm is done (40 - 42).

#### Conclusion

In qualitative studies, researchers have a great responsibility and play many different roles. It is argued that qualitative research that deals with sensitive topics in depth can pose emotional and other risks to both participants and researchers. Clear protocols for dealing with distress should be in place so that both parties involved in research can use them if necessary. It is not usually easy to predict what topics are likely to lead to distress,

and researchers should therefore receive sufficient training in predicting traumatic situations.

Preventive measures for researchers who carry out sensitive qualitative studies should include official arrangements for a peer support program consisting of a list of researchers who are involved, or a constellation of researcher support activities aiming at improving psychological fitness in the form of a professional confidence building module. Other such measures include offering adequate supervision to provide opportunities for self-development and self-care, and facilitating the process of self-reflection and self-monitoring.

Strategies for emotional distancing need to be considered and adopted if the research topic or participants have the potential to be emotionally challenging. An appropriate planning should be in place before the commencement of the fieldwork, and it must be perfectly clear how the study should be conducted and what level of relationship development is necessary. Measures must also be taken so that levels of self-disclosure, objective displays of emotion during the interviews, and strategies to end the relationships are well defined and communicated.

One of the most prominent tasks of qualitative researchers is to minimize the flaws in observation and endeavor to gain truthful knowledge. Therefore, it is necessary for researchers to continuously update their investigation skills in terms of methodology and find novel techniques to better carry out studies in the field of health and sociology.

As explained before, qualitative research is carried out in natural settings, which requires researchers to work in close collaboration with other members of the team and under direct supervision to discuss and resolve issues as they arise. Therefore, development of practical strategies and communicating them to researchers can be of great benefit and assist them in conducting more perceptive qualitative studies. It is noteworthy that

such research should be directed towards making a difference in people's lives, improving care delivery in different settings and at all levels, and providing a framework for health sciences without any ethical disturbances.

As a result of the extensive body of research in the field of medical sciences, patients comprise a large proportion of the public who are frequently subjects of studies. Research Ethics Committees are formed to provide independent advice to participants, researchers, funders/sponsors and healthcare organizations on the extent to which research proposals comply with universally endorsed ethical standards.

In the history of social and medical science, there have been a few research studies that seriously injured people, and many more in which their welfare was not sufficiently protected. Nations and research associations have taken steps to prevent hurtful and intrusive research. To return to the matter of privacy, the researcher should not rely solely on the informant to identify possible intrusion, but needs to work at anticipating it in advance. Confidentiality does not necessarily preclude intrusion, as anonymity by itself is not enough to protect a person's privacy or prevent disclosure of personal issues. Investigators should refrain from soliciting private information that is not closely related to the research question.

Considering the aforementioned challenges, it is recommended to conduct further research in order to provide meticulous and explicit ethical protocols, guidelines and codes with respect to qualitative studies.

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#### References

- 1. Jones R. Why do qualitative research? Brit Med J 1995; 311(6996): 2.
- 2. Denzin NK, Lincoln YS. The Sage Handbook of Qualitative Research, 3<sup>rd</sup> ed. CA: Sage Publication; 2005.
- 3. Stake RE. Qualitative Research: Studying How Things Work, First ed. New York: Guilford Press; 2010.
- 4. Pope C, Mays N. Qualitative Research in Health Care. John Wiley & Sons; 2008.
- 5. Holloway I, Wheeler S. Qualitative Research in Nursing and Healthcare, 3<sup>rd</sup> ed. Malaysia: Wiley-Blackwell; 2010.
- Speziale HS, Carpenter DR. Qualitative Research in Nursing: Advancing the Humanistic Imperative. Wolters Kluwer health: 2011
- 7. Grbich C. Qualitative Research in Health: An introduction. Sage Publication; 1999.
- 8. Grove SK, Burns N. The Practice of Nursing Research. Elsevier; 1993.
- 9. Eide P, Kahn D. Ethical issues in the qualitative researcher—participant relationship. Nurs Ethics 2008; 15(2): 199-207.
- 10. Clarke A. Qualitative interviewing: encountering ethical issues and challenges. Nurse Res 2006; 13(4): 19-29.
- 11. DeWalt KM, DeWalt BR. Participant Observation: A Guide for Fieldworkers. AltaMaria Press; 2010.
- 12. Fink AS. The role of the researcher in the qualitative research process: a potential barrier to archiving qualitative data. Forum Qual Soc Res 2000; 1(3): 4.
- 13. Erlandson DA, HarrisEl, Skipper BL, Allen SD. Doing Naturalistic Inquiry: A Guide to Methods. Sage Publication; 1993.

- Nastasi BK, Schensul SL. Contributions of qualitative research to the validity of intervention research. J Sch Psychol 2005; 43(3): 177-95.
- 15. Smith BA. Ethical and methodologic benefits of using a reflexive journal in hermeneutic-phenomenologic research. Image J Nurs Sch 1999; 31(4): 359-63.
- Corbin J, Strauss A. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 3<sup>rd</sup> ed. Sage Publication; 2008.
- 17. Chiovitti RF, Piran N. Rigour and grounded theory research. J Adv Nurs 2003; 44(4): 427-35.
- 18. Li J. Ethical challenges in participant observation: a reflection on ethnographic fieldwork. Qual Report 2008; 13(1): 100-15.
- 19. Warusznski BT. Ethical issues in qualitative research. In: Van den Hoonaard WC, Walking the Tightrope: Ethical Issues for Qualitative Researchers. University of Toronto Press;2002, p. 152.
- Punch M. Politics and ethics in qualitative research. In Denzin NK, Lincoln YS, Handbook of Qualitative Research. Sage Publications; 1994.
- 21. Truscott D. Fieldwork, participation and practice: ethics and dilemmas in qualitative research. Sci Ed 2004; 811-3.
- 22. Richards HM, Schwartz LJ. Ethics of qualitative research: are there special issues for health services research? Fam Pract 2002; 19(2): 135-9.
- 23. Guillemin M, Gillam L. Ethics, reflexivity, and "ethically important moments" in research. Qual Inquiry 2004; 10(2): 261-80.
- 24. Morrow V. Using qualitative methods to elicit young people's perspectives on their environments: some ideas for community health initiatives. Health Educ Res 2001; 16(3): 255-68.
- 25. Agar M. Culture: can you take it anywhere? Int J Qual Methods 2006; 5(2): 1.
- 26. Hoeyer K, Dahlager L, Lynöe N. Conflicting notions of research ethics: the mutually challenging traditions of social scientists and medical researchers. Soc Sci Med 2005; 61(8): 1741-9.
- 27. Orb A, Eisenhauer L, Wynaden D. Ethics in qualitative research. J Nurs Scholar 2001; 33(1): 93-6.
- 28. Bloor M, Wood F. Keywords in Qualitative Methods: A Vocabulary of Research Concepts. Sage Publication; 2006.
- King NMP, Henderson GE, Stein J, eds. Beyond Regulations: Ethics in Human Subjects Research, First ed. USA: University North California Press; 1999.
- 30. Brenner ME. Interviewing in educational research. In: Green JL, Camilli G, Elmore PB, eds. Handbook of Complementary Methods in Education Research. 2006.
- 31. Todres L, Holloway I. Descriptive phenomenology: life-world as evidence. In: Rapport F, New Qualitative Methodologies in Health and Social Care Research. Routledge; 2004.
- 32. Guion LA, Diehl DC, McDonald D. Conducting an in-depth interview. http://edis.ifas.ufl.edu/fy393 (accessed in 2011).
- 33. Tolich M, Fitzgerald MH. If ethics committees were designed for ethnography. J Empir Res Hum Res Ethics 2006; 1(2): 71-8.
- 34. Hammersley M, Atkinson P. Ethnography: Principles in Practice, 2<sup>nd</sup> ed. NY: Routledge; 1995.
- 35. Dickson-Swift V, James EL, Liamputtong P. Undertaking Sensitive Research in the Health and Social Sciences. USA: Cambridge University Press; 2008.
- Kitson GC, Clark RD, Rushforth NB, Brinich PM, Sudak HS, Zyzanski SJ. Research on difficult family topics: helping new and experienced researchers cope with research on loss. Fam Relat 1996: 45(2): 183-8.
- 37. Ridge D, Hee A, Aroni R. Being 'real' in suicide prevention evaluation: the role of the ethnographer's emotions under traumatic conditions. Aust J Prim Health 1999; 5(3): 21-31.
- 38. Hedgecoe A. Research ethics review and the sociological research relationship. Sociol 2008; 42(5): 873-86.
- 39. Hoffmaster B. Can ethnography save the life of medical ethics? Soc Sci Med 1992; 35(12): 1421-31.
- 40. Dickson-Swift V, James EL, Kippen S. Do university ethics committees adequately protect public health researchers?. Aust N Z J Public Health 2005; 29(6): 576-9.
- 41. Dickson-Swift V, James EL, Kippen S, Liamputtong P. Doing sensitive research: what challenges do qualitative researchers face? Qual Res 2007; 7(3): 327-53.
- 42. Rowling L. Being in, being out, being with: affect and the role of the qualitative researcher in loss and grief research. Mortality 1999; 4(2): 167-81.