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Ethics of qualitative research: are there special issues for health services research?

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Background. An increasing volume of qualitative research and articles about qualitative methods has been published recently in medical journals. However, compared with the extensive debate in social sciences literature, there has been little consideration in medical journals of the ethical issues surrounding qualitative research. A possible explanation for this lack of discussion is that it is assumed commonly that qualitative research is unlikely to cause significant harm to participants. There are no agreed guidelines for judging the ethics of qualitative research proposals and there is some evidence that medical research ethics committees have difficulty making these judgements.

Objectives. Our aim was to consider the ethical issues which arise when planning and carrying out qualitative research into health and health care, and to offer a framework within which health services researchers can consider these issues.

Results. Four potential risks to research participants are discussed: anxiety and distress; exploitation; misrepresentation; and identification of the participant in published papers, by themselves or others. Recommended strategies for reducing the risk of harm include ensuring scientific soundness, organizing follow-up care where appropriate, considering obtaining consent as a process, ensuring confidentiality and taking a reflexive stance towards analysis.

Conclusions. While recognizing the reservations held about strict ethical guidelines for qualitative research, we argue for further debate of these issues so that the health services research community can move towards the adoption of agreed standards of good practice. In addition, we suggest that empirical research is desirable in order to quantify the actual risks to participants in qualitative studies.

Keywords. Ethics, qualitative research.

Introduction

Over the past decade, there has been an increase in the volume of qualitative health services research published in the mainstream medical journals[1] and a growth of interest amongst health service researchers in qualitative research methods.[2] However, with few exceptions,[3,4] articles about qualitative methods in health services research have not dealt with ethical issues. Articles which do address ethical issues have been published mostly in nursing journals.[5,6] To date, debate about the ethics of qualitative methods in health services research has been informed mainly by sociological[7] and anthropological[8] literature.

Ethical guidance for medical research is provided by, amongst others, the British Medical Association,[9] the British Sociological Association[10] and the major research funding bodies such as the MRC.[11] The codes of practice published by these bodies are included in a manual designed for use by research ethics committees.[12] With the exception of that published by the British Sociological Association (discussed below), these documents relate to quantitative research, making little specific reference to qualitative research.

Compared with health professionals engaged in research, social scientists have paid far more attention to ethical aspects of qualitative research.[13] The British Sociological Association's Statement of Ethical Practice[10] offers guidance for researchers involved in qualitative studies. It addresses in detail the nature of power relationships between researchers and participants; consent and anonymity; and privacy and confidentiality. However, the Statement is "meant primarily to inform members' ethical judgements rather than to impose on them an external set of standards". Despite this code,

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some social scientists are cautious about the value of codes of ethical practice for qualitative research because of three concerns. First, codes of practice cannot replace practical judgement; secondly, they may try to enforce ethical standards that are unrealistic in the real life setting; and thirdly, they may be too lax and contain loopholes.[14]

Whilst recognizing the scepticism that exists about strict ethical guidelines, we argue that in relation to qualitative health services research, there is a need for guidance, at least to stimulate debate about the ethics of qualitative research. Unlike social scientists, health professionals are generally not trained in the philosophical underpinnings of research and may not be as well placed to formulate ethical judgements based on first principles. In addition, the debates about the ethics of qualitative research in the social sciences may be considered inaccessible to health services researchers. However, a major reason for advocating guidelines for qualitative health services research is the growing evidence that medical research ethics committees have difficulty assessing ethical issues arising in relation to qualitative studies.[15]

This paper aims to highlight the main ethical issues in qualitative health services research and to provide some guidance for those doing or reviewing such research. We first consider the potential risks to participants, and then offer some suggestions for minimizing these risks.

Risk to participants in qualitative health services research

The lack of emphasis on ethical aspects of qualitative health services research may relate to a belief that it is unlikely to harm participants.[16] Risk to participants has been recognized by social scientists, who point out that taking part in research can lead to anxiety in and exploitation of participants, and that publication of research findings may damage the reputation of participants or members of their social group.[17]

Anxiety and distress

Qualitative research aims at an in-depth understanding of an issue, including an exploration of the reasons and context for participants' beliefs and actions, so is often designed to be probing in nature. Interviews, the commonest qualitative method in health services research, are particularly well suited to the collection of data on sensitive topics. These characteristics of the method may provoke anxiety or distress in participants. The questions which lead to anxiety and distress depend on the personal biography and experience of individual participants and cannot always be predicted accurately. Even when prediction is possible, the open-ended nature of qualitative research means that these topics cannot be avoided reliably. For example, in a study of chest pain carried out by HR, the focus of the interviews led some respondents to express anxieties that episodes of chest pain which they had previously considered to be insignificant might signify serious disease.

Exploitation

The importance of power relationships and the potential for research to exploit as well as exclude women have been debated extensively by feminist theorists.[18,19] Others have argued more generally that there is an inevitable power imbalance in the research relationship, "even when the researcher has an intellectual and emotional commitment to the people being studied"[17] (p. 274).

When a researcher is also a health professional, this power imbalance is exaggerated in two ways.[20] First, the participant may feel pressurized to participate in research because of a sense of duty, or because they depend on the good will of their carers.[5] Secondly, although it is often assumed that a qualitative interview, which allows the participant to speak in their own terms, can be therapeutic,[21] this feature can also potentially lead to exploitation and harm. If the interview becomes confused with a therapeutic encounter, a researcher may be tempted inappropriately to ask sensitive questions and participants may divulge more information than they had anticipated when consenting to the study. These problems are more likely to arise when one person fulfils the dual roles of researcher and health professional, especially if they are directly involved in the care of the participant.[22,23]

Misrepresentation

The analysis of qualitative data inevitably is influenced by the theoretical framework, epistemological commitments, personal characteristics and preconceptions of the researcher. The interpretative nature of qualitative research means that the published results are only a version of 'the truth', and the validity of the findings must be judged in relation to the care with which the data were analysed. Although all research is, to some extent, socially constructed, it is in qualitative studies that participants are more likely to feel that their views have been misrepresented or taken out of context. Personal narrative comprises a person's sense of individual identity, and when participants lose control over how their narratives are interpreted and generalized upon, they also risk losing control over self-identity.[24] By constructing identities for their participants, qualitative research risks seriously breaching respect for participants' autonomy and may also lead to negative stereotyping.

These issues are particularly relevant to health services research. First, most health services research projects are designed to answer specific questions about the patients' perceptions and behaviour and as such are strongly directed by preconceived theories. Secondly, sampling strategies are often determined by these theories, and participant characteristics which are considered significant, such as gender and socio-economic status, are built into the study design. Thirdly, there is some evidence that the dynamics of the qualitative interview[25] and the nature of data collected [26] can be affected by the professional background of the researcher.

Identification of the participant by self or others

Qualitative health services research studies collect large amounts of information about participants' health and illness, lifestyles and views about health care, as well as information about members of their families and social groups. If identification occurs, it potentially may lead to serious harm such as prejudice and reprisal to the participant or their wider social group. Interview transcripts contain multiple clues to the person's identity, such as their name, employment details, place of residence and events which have occurred in their communities. It is therefore impossible to anonymize interview data at the stage of analysis, and the identity of participants often will be known to the person carrying out the transcription. Even after protocols of anonymization are applied, quotations, speech mannerisms and context may provide enough information for participants to be identified by themselves or others, and it is not always easy to predict which data will lead to identification.

Inconvenience and opportunity cost

As well as the serious potential risks outlined above, the inconvenience and opportunity costs involved in participating in qualitative research are often underestimated. Most qualitative studies in the health services involve in-depth interviews with participants. Such interviews normally last for at least an hour and necessitate the participant travelling to a research centre or allowing the interviewer into their home. In some studies, participants will be asked to take part in a second interview.

Reducing the risk of harm

Scientific soundness

A fundamental ethical requirement of all research is that it is scientifically sound. It should be properly designed and carried out by researchers with adequate levels of expertise and supervision. It should also be 'worth doing', in the sense that the results are likely to lead to tangible benefit.

The issue of training and supervision is particularly relevant to qualitative research in which the researcher can be regarded as the 'research instrument' and will often be working in relative isolation. To ensure that agreed standards are met, it may be necessary for ethics committees to include or refer to experienced qualitative researchers when assessing qualitative research proposals.

Follow-up care

Research into health and health care may raise participants' expectations that help will be forthcoming, especially when they know that the interviewer is a health practitioner. In addition, researchers who are also health practitioners are arguably more likely to recognize that participants are in need of further care. Explicit ethical guidelines define the duty of follow-up care for participants in quantitative research involving therapeutic interventions,[27] but to date there has been no ethical guidance recognizing the special issues which arise when the researcher is also a health practitioner. The potential for distress to participants can be minimized by the researcher/practitioner being clear about his or her role boundaries, and by ensuring that appropriate information and support are available.

Consent

Informed consent is a prerequisite for all research involving identifiable subjects, except in cases where an ethics committee judges that such consent is not possible and where it is felt that the benefits of the research outweigh the potential harm. A minimum requirement for an interview study should be that written consent be obtained from the participant after they have been informed, verbally and in writing, about the following issues: the purpose and scope of the study, the types of questions which are likely to be asked, the use to which the results will be put, the method of anonymization and the extent to which participants' utterances will be used in reports. Participants should also be given time to both consider their participation and to ask questions of the researcher.

It is in the nature of qualitative research that unexpected themes can arise during the analysis; therefore, at the time of the interviews, the potential uses of the data are not always clear to the research team. In addition, researchers may wish to archive interviews which could then be accessed for future research. If so, participants should be informed and given the opportunity to withdraw consent for the use of their data. There are two approaches to ensuring that adequate consent is obtained in qualitative studies: participants can either be asked to give very general consent at the beginning of the study (which in our view diminishes the value of this consent) or researchers can treat consent as an on-going process rather than a one-off event. The British Sociological Association's Statement of Ethical Principles[10] stresses the desirability of involving participants in decisions taken at all stages of the research process and suggests that consent should not be regarded as "a once and for all event but as a process, subject to renegotiations over time". The principle of involving participants in the planning, implementation and dissemination of research is long established in sociology,[28] and is increasingly recognized by the academic medical community[29,30] and funding bodies.[11]

There are practical and ethical drawbacks to treating consent as a process. Despite the small sample sizes of most qualitative studies, researchers may consider re-contacting participants to be costly and, with participants and researchers who are geographically mobile, impractical. More importantly, repeat contacting of participants may, in some circumstances, be regarded as unnecessary harassment. In spite of these drawbacks, and given the unpredictable nature of qualitative research, we advocate treating informed consent as a process.

Some special issues of consent arise in relation to qualitative health services research. First, in order to minimize the risk of exploitation and coercion, the professional background of the researcher should be made clear to the participant, particularly whether or not he or she is a health professional. Secondly, participants should be informed that the research is not intended to be therapeutic or to be an adjunct to their medical care. Thirdly, participants should be reassured that refusal to participate will in no way jeopardize their health care.

Misrepresentation and misinterpretation

Several measures can be employed to minimize the risk of misinterpretation. 'Respondent validation' refers to the process whereby researchers feed back the analysis to the participants before the findings are published. However, that practice has limitations. Like treating consent as a process, it involves repeated contact with participants which may be impractical and considered to be harassment. A more fundamental objection is that data obtained through respondent validation are subject to the same process of interpretation as the primary data.[31]

Misinterpretation of data is most likely to occur when a researcher is working in isolation. This risk can be minimized by ensuring that novice researchers are closely supervised and that experienced researchers have sufficient contact during the analysis with a co-worker who can play the role of 'devil's advocate'. A less direct approach to minimizing the risk of misinterpretation is for researchers to be aware of and explicit about their possible biases. In practice, this requires researchers to state their theoretical approach to the topic, and, for health professional researchers, to consider the ways in which their personal and professional characteristics may affect their interpretation of data.[26]

Confidentiality

Qualitative studies collect large amounts of detailed personal information. Not only are there practical barriers to concealing this information, but such contextual data are often an essential component of the analysis. In some circumstances, participants may not wish to remain anonymous: identification with their expressed beliefs may help participants to maintain ownership of the content and meanings of their narratives. Willingness to be identified with their narratives was observed in a project designed to disseminate patients' views and experience of illnesses, in which many participants agreed to the publication of video-clips of their interviews on the Internet (www.dipex.org).

In most cases, qualitative health services research aims for anonymity and confidentiality, and should use foolproof strategies for the secure storage of tapes and transcripts. Pseudonyms or initials should be used in transcripts and, where possible, other identifying details should be altered. The failure to address these issues can lead to the identification of participants and may make it easier, through a process of elimination, to identify others.

For health care practitioners, confidentiality means that no personal information is passed on except in exceptional circumstances. For researchers, the extent of the duty of confidentiality is less clear (though it is often assumed to be absolute), and this difference can lead to conflict for practitioner/researchers.

Conclusion

The detailed guidelines which exist for carrying out medical research have been designed largely for use in relation to quantitative research. Although the ethical principles governing qualitative and quantitative research are essentially the same, we have outlined a number of special ethical issues which arise in relation to qualitative health services research. (i) Researchers should consider treating informed consent as a process rather than a one-off event, and they should be aware that an interview may take on the mantle of a therapeutic encounter. (ii) Because of the possible confusion with a therapeutic encounter, researchers should ensure that information and support for participants are available when necessary. (iii) Qualitative data by its nature is full of clues to participants' identities, so care is required to ensure the anonymity of participants in published work. (iv) The risk of misrepresentation can be minimized by ensuring that researchers are adequately trained and supervised, and by encouraging reflexivity about the influence of researchers' personal and professional characteristics. In addition, in order to guarantee ethical practice in qualitative health services research, researchers, funding bodies and reviewers should fully understand the scientific basis and methodology of qualitative research.

We have summarized the possible drawbacks of guidelines for qualitative research: that they may be overprescriptive, inadequate or impractical. However, we maintain, for the following reasons, that such guidelines are required for health services research. Unlike social scientists, many health services researchers are not trained in philosophical and political aspects of research, so may require more guidance on the ethical issues. In addition, there is growing anecdotal evidence, both locally and internationally, that researchers and ethics committees have difficulty judging the ethical soundness of qualitative projects in health services research.[15] Finally, although it is often assumed that involvement in qualitative research is relatively harmless, the actual risk to participants is unknown.

Research is needed in order to ascertain the risk to participants in qualitative studies. Indeed it has been suggested that there is "a need for a survey of qualitative researchers to answer this question and to determine what the risks and rates of their occurrence are"[16] (p. 3). In addition, further debate is required involving health professionals, social scientists and ethicists in order to establish ethical guidelines for qualitative research so that agreement can be reached about what constitutes good practice.

Key messages

- The detailed literature on the ethics of qualitative research in sociology and anthropology has not pervaded the medical literature, and there is evidence that medical research ethics committees have difficulty assessing qualitative projects.
- Risks which are particularly relevant to participants in qualitative health services research include anxiety and distress; confusion of the research process with a therapeutic encounter; coercion; and the identification of need for further help and misrepresentation.
- These risks may be minimized by researchers being clear about the boundaries of their research; by treating informed consent as a process; by being explicit about and reflexive toward their professional backgrounds; and by ensuring that they are adequately trained and supervised.
- Whilst recognizing the potential drawbacks of codes of ethical practice for qualitative research, we argue that they are required to inform and guide health services researchers
- In order that such guidelines can be formulated, research is required into the actual risks to participants as well as further debate and examination of the basic ethical principles.

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