Values and obligations in qualitative research

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Ethics, as a code of conduct, go beyond the law. Based on values and morals, they are grounded in the culture of the land, and are open to different interpretations. In addition, ethics in research are modulated to some extent by the culture of "science." It is encouraging that ethical guidelines for social science research in health in India have been formulated recently (1). Researchers should use such guidelines as a starting point for critical thought and reflection, rather than adhere to them blindly.

Often researchers consider ethical questions only while developing research proposals. Proposals are formulated so that they meet the standards and format set by funders or research institutions. In practical terms, ethical considerations are often reduced to obtaining informed consent and writing a few lines on how confidentiality and privacy of the "research subjects" will be maintained. Ethical concerns and considerations should, in fact, ideally be on the agenda throughout the research process, from research design to data collection, from data analysis to dissemination. Consideration of ethical issues in research needs to be a dynamic process that involves not only the principal investigator but also the whole research team, especially members who collect data in the "field." In this paper I will make a case for considering ethical issues throughout the research process by illustrating how the practical aspects of conducting research challenge our understanding and application of ethical principles. I will conclude by suggesting how some ethical dilemmas in research may be resolved.

The gray and the not-so-gray

Ethical principles that seem clear in theory become less clear when applied to a particular research project and become hazier still in the field setting. Black and white merge into infinite shades of gray. Ethical principles, distinct and mutually exclusive on paper, may be in conflict or violate each other. For instance, when we think of autonomy we usually have a responsible adult in mind. When the research subject is a child, most researchers agree that the permission of parents or the guardian is necessary. But the procedure to be followed is less clear when the research subject is an adolescent. Most researchers agree that the autonomy of the "subject" is primary. In a research project concerning fifteen-year-olds, would it be adequate to obtain the research subject's consent? Would the procedure depend on the research topic (for example, sexual behaviour)? A strong argument could be made that the parent's or guardian's permission should be sought. On the other hand, the

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adolescent may be willing to participate only if complete confidentiality is assured. This dilemma was faced in a research project on adolescents. A via media was found by obtaining the permission of the school and its teachers and interviewing the adolescent on the school premises. This "solution" is working but the researchers are still uneasy. It is not clear whose interest should be given precedence: the adolescent's or the parents' and teachers'.

In another project, the bid to maintain privacy violated confidentiality. In a study on infectious disease, in order to maintain privacy while conducting interviews, the researchers obtained a separate room in a clinic. However, this made easy it for study subjects to be identified.

Notions of autonomy, privacy, confidentiality and consent have been evolved largely in medical research projects in Western institutional settings. These concepts cannot be transplanted to studies that are conducted in the community settings with diverse cultures and ethos. The researcher faces many dilemmas, especially in community-based studies, even in terms of informed consent and disclosure of purpose of the study (2). Consent has to be obtained from community representatives or gatekeepers, family members and the individuals, and the purpose of the research has to be explained to them. Does the researcher prepare a common statement of purpose for all these actors? If not, would it be ethical to have a different version for each group? If one is doing research on a stigmatised disease such as tuberculosis, should one tell community members that the research is on an infectious disease or on tuberculosis? Taking the first option protects the study subjects but is not entirely truthful. If the nature of the study is disclosed, it might have negative consequences on study subjects. Then again, it may not affect all study subjects in the same way. Men may feel minimal discrimination; women, especially young married women, may face severe discrimination. Some may be even forced to return to their natal homes.

Interaction between research methods and ethics

There is an interaction between research methods, ethics and the research setting. Research no longer need be conducted in a physical world; it can also be done in cyberspace. I am not going to deal with the cyberspace quandary, but address the questions that arise regarding the intricate link between choice and application of research method and ethics. A recent report on the ethical aspects of research on the Internet (3) identifies the survey research method as being relatively risk-free to participants as compared to more "intrusive" methods. Was the report categorising methods used for collecting qualitative data as 'intrusive'? As a medical anthropologist mainly involved in qualitative health research, I found this disturbing, and my first reaction was to deny it. Upon reflection, I have to admit that there may be some truth in this observation.

The researcher chooses a research method most likely to elicit the data needed to fulfil the objectives of the research.

All research methods are likely to lead to ethical quandaries. In this article I focus on qualitative research methods. Researchers conducting qualitative research on sensitive topics such as alcohol or drug use, sexual behaviour or violence, routinely use repeat interviews, as it is important to build rapport. This repeated contact, essential for collecting data, may put the participant at risk of being identified and may violate confidentiality (4). Often, when in-depth repeat interviews are conducted, after rapport is established, participants reveal sensitive information because it provides catharsis. Sometimes later the subject may have second thoughts about having revealed as much as they did.

In-depth interviews that are capable of eliciting sensitive information also arouse emotions and feelings that the interviewer has to be capable of handling. Time has to be given to respond to the participant's emotional needs. In research on topics such as sexual abuse or coercion the subject may need professional help. In a research project on sexual behaviours of street boys, the researchers came across instances of sexual coercion, but the researchers made a conscious decision not to probe into this unless the boy wanted to disclose this information voluntarily. The researchers felt that they could not cope with the emotions that it would bring out. This decision was made despite the fact that the researchers had links with mental health professionals since it was felt that the capacity of existing services might be inadequate. Nevertheless, the researchers ensured that those boys who had traumatic experiences, and needed counselling, received these services.

During research the researcher becomes privy to information that directly affects others — the spouse, the family or the larger community. What should the researcher do if she finds out that a young woman has active tuberculosis? The researcher may decide that as the family members have been exposed to the infection already and they are not showing any signs of having contracted the disease, it may not be necessary to reveal this information, and the most important thing would be for the young woman to get prompt treatment. A slightly altered situation may call for a different decision. If the woman has a young malnourished, uninfected child who may get infected in the short duration that it takes for the drug to make the woman non-infectious, the researcher may have to advise the woman to take certain precautions that may reveal to other family members that she has an infectious disease.

Even the choice of variable for analysis has major ethical implications. Should the researcher analyse a certain data set by caste, class, religion or ethnicity? What would the fall-out of this be? Similarly, there are many ethical questions regarding the dissemination of results. There is increasing pressure on the researcher to disseminate results quickly and to use the popular media. This can lead to distortion and misrepresentation. Most scientific findings are couched in caveats that are simply ignored when results are presented in the popular media. Researchers also have to be increasingly careful of what they present in small scientific gatherings, as snippets can be spread rapidly and out of context through the Internet (5).

Indisputably, research findings must be communicated to the community where the research was conducted. Here again, the researcher has to be careful about what is said and how it is said, because communities are seldom homogeneous and the results will be interpreted according to existing cleavages in the community. Qualitative research that entails familiarity with community and the study participants may help to anticipate the risks to participants of divulging sensitive information (6).

One way of keeping ethical issues in focus may be to include substantive discussion on ethical issues encountered in publications and papers. This would take the researcher beyond the formulaic sentence or two about informed consent to ethical questions that arose during the research and how these were tackled. In addition, consideration of ethical issues needs to be integrated into courses on research and research methods. Development of case studies that illustrate the complexities of applying ethical principles in different circumstances may be useful. Further, the participatory process and dialogue and debate that contributed to the development of the social science health research guidelines must be sustained.

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