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CASE STUDY RESPONSE

Challenges in research in tribal communities

Shelley Saha

It must have been difficult to work with a tribal community as Mr Rajan Patil has. The questions he asks are valid and tricky to resolve or reach a consensus on. The researcher's willingness to speak on these problems in the public domain must be appreciated; such dilemmas are often not even acknowledged publicly, let alone discussions being generated around them. However, the presentation also indicates that steps could have been taken to make this research ethically more sound. The following issues emerge.

Adequacy of information

Were research participants provided with essential and adequate information? The account indicates that the informed consent form had information on the purpose of the study and possible risks involved. However, it is not clear whether other important information was communicated to prospective research participants to facilitate their decision-making. These include: the number of blood samples to be taken; who would have access to the samples; for how long the samples would be preserved; whether the samples would be used for future research; disposal of the samples, possible benefits of participating other than treatment and, the most important, their right to withdraw or decline to participate.

Community consent

Can community leaders' consent substitute for that of individual research participants? In traditional tribal communities, community leaders, who are selected by community members, are expected to hold that position with the prime aim of serving their community. The relationship between the community leader and members, ideally speaking, is that of mutual trust. However, it could become paternalistic and authoritarian. Thus, it can be disastrous to make general assumptions about community leadership. Any researcher working with communities, tribal or rural, must understand the social organisation of the community before even planning the research.

At different levels, non-formal (traditional) or formal community leaders, family elders, husbands and mothers-in-law can all be gatekeepers, whom researchers must approach before seeking access to individual married woman. The challenge is to be respectful to the community culture and any other protocols, without violating principles of research ethics. Thus, while there are guidelines, there are no set procedures for facilitating the informed decision-making process. Individual researchers and research teams must develop situation-specific strategies, which ensure compliance with ethical guidelines in their spirit. Often, there are no clear solutions to ethical dilemmas and there can be multiple perspectives. What is needed is sound ethical reasoning.

In this case, the researcher felt the need to comply with cultural practices and the ethics advisors insisted on compliance with ethical guidelines. The problem was resolved without a critical look at either cultural or ethical norms, and without a creative operationalising of the ethical guidelines. The fact that research participants offered their written consent demonstrates that the researchers' initial thinking was unjustified.

The article also raises some other issues. For example, the procedure and interview were conducted in public spaces. This raises questions about the need to maintain privacy.

Service provision and inducement

By providing health services to both participants and non-participants, the researcher abided by the ethical principle of justice. Providing health services to research participants does not amount to inducement, and since this service was not a pre-condition for participating in the study, it therefore does not amount to violating autonomous voluntary participation.

It might be helpful to remember that conceptualising research designs and methods of facilitating individuals' decision-making requires an understanding of the community, its

social organisation and the local dynamics. Second, gatekeepers' approval must not be considered equivalent to the consent of prospective individual research participants. Finally, shortage of time in field-based research cannot be a justification for short-cuts, especially in seeking informed consent and other aspects of the ethical conduct of research.

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