Cultural sensitivity and ethical practice: An example from rural India

Bilkis Vissandjée, Shelley Abdool and Sophie Dupéré discuss the appropriateness of focus groups (see Chapter 5) for their research on women's autonomy and health behaviour in rural India, in part because of strong local oral traditions. However, they also note that the method must be adapted for local conditions, taking into account the research topic, the participants, and the social, political and cultural context of the study area. This raises a number of ethical considerations for researchers, who must think through how to adapt research designs in order to facilitate relatively disempowered participants in expressing their views, and ensure that the research is conducted in an appropriate ethical manner – namely, that it is 'culturally competent'.

The project setting for their study was a rural area of Gujarat, with 25 relatively small villages that had little contact with outsiders. The research team were aware that this

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posed potential problems in establishing good relationships. First, the villagers might be distrustful of outsiders, especially those from outside the country (there were Canadian researchers on the team) who might hold negative views of Indian society. Second, the topics they were asking women to discuss were not traditionally those on which women were encouraged to hold views, and some local men were concerned that the researchers were intending to 'change' the women. Finally, the presence of an overseas research team may raise (false) expectations of aid or policy action. To address these concerns, the researchers embarked on a period of field preparation, in which they built relationships with community leaders and members. They did this in partnership with a local Community Health Volunteer (CHV), who knew the local villagers well. The team were careful to match genders at this point, as it would not have been appropriate to have women walking unaccompanied through the villages, or for a male researcher to talk to the local women. The CHV also helped with focus group recruitment, assisting in door-to-door recruitment of potential participants. Recruiting door-to-door was essential in rural areas; not only did it facilitate communication in an area with no telephones and limited literacy, but it also enabled the researchers to ask women to participate in the presence of the men in the household, who might otherwise feel hostile about the groups.

The researchers had to take into account local power relationships, including those of caste and family relationship. It was not culturally possible to hold separate group discussions for the different castes in the village, but in the groups higher-caste women inhibited lower-caste women from speaking. Similarly, mothers-in-law had more authority than daughters-in-law in discussions. Here, the composition of groups entailed ethical decisions that offset the need for cultural appropriateness (including everyone) with the need for hearing disempowered voices. Vissandjée and colleagues note that even if they had run more homogeneous groups that included only low-status women, in an area where 'everybody knows everybody' women may feel that anything they say will be reported back, and would therefore still be constrained in discussing their views.

Written consent to participation was inappropriate, so the research team gave only verbal assurances of confidentiality. Written papers, in this context, would be negatively associated with government documents.

The closeness of rural communities also has an impact on the researchers' ability to ensure confidentiality. The team had to consider how far they were responsible for any of the consequences of women's behaviour in the focus group, given that they would be seen as representatives of their families, and whether any disapproved behaviour or talk would probably be communicated back to the family. In these circumstances, the focus group moderator had to stress that the research team would treat the data generated with confidence, but also had to guard against 'over-disclosure' (participants feeling so comfortable that they revealed more than they had intended) in the group, given the possible future consequences for participating women. Given also that the researchers were asking women to reflect on their own lives in ways that were potentially very destabilizing, it was also useful to provide follow-up opportunities for private discussion and reflection on participation in the group discussion.

The authors were working within a participatory approach, where the key ethical dilemmas faced were the need to balance 'empowerment' for women in the community with the potential risks to individual women as a result of their involvement in the project. One ethical risk of this kind of project, they noted, is that once the researchers disappear, individual women may be left with a sense of developing awareness but with a feeling of dissatisfaction that there is nothing they can do, as they are too busy or

isolated to discuss the issues raised with other women. An essential step to minimize the risk of this happening is to disseminate any findings from the study at a village level, and to work with local health care providers to develop follow-up local activities.

Reflective questions

You are researching women's ability to attend local health promotion activities but in order to take part in the study the women's husbands or fathers have to give permission. This in itself creates something of an ethical dilemma for you the researcher as this seems to contradict the values explicit in the participatory focus of your study. The situation is then made worse by one woman's father insisting that he have access to the recording of his daughter's responses. Using the kinds of techniques outlined in the case study described above, sketch out some of the ways in which you might resolve (or not) this dilemma. What factors might you need to bear in mind?

Feedback

To have to get a man's permission about a woman's activity might reinforce prejudices and stereotypes about women's social place; on the other hand it may be culturally appropriate and in fact the only way to proceed with the study. This would be something to discuss with the research team/ethics committee but perhaps also at a community level meeting. With the father-daughter issue, care should be taken not to isolate or stigmatize her or her father, particularly since the repercussions might continue long after the research team have left. Possible strategies to address these dilemmas might be to organize parallel data collection amongst the men and then request equivalent 'permission' from women. Similarly, the issue of the 'strict father' might be something to discuss within a group of him and his peers, or perhaps with a respected local community leader (priest / union representative / school teacher).

Covert observation of psychiatric hospitals

Rosenhan was interested in how reliable and valid diagnostic measures of 'sanity' were, and whether psychiatric staff were able to distinguish the sane from the insane. He devised an experiment in which eight 'normal' people got themselves admitted to US psychiatric hospitals by claiming to hear voices that said 'hollow', 'empty' or 'thud', but by otherwise presenting their 'real' medical and social histories to admission clinic staff. All were admitted with a diagnosis of schizophrenia, except one with

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a diagnosis of manic depressive psychosis. On admission, the researchers behaved normally and cooperated with hospital routines. Given that they spent considerable time in the hospitals waiting to be discharged, their undercover status provided an opportunity for covert observation. Rosenhan's paper reports on their experiences of being hospitalized, and the ways in which the diagnostic label they had received at admission shaped the interpretation of their behaviour by staff. None of the researchers were identified as sane pseudo-patients by staff, although interestingly many other patients challenged them, assuming that they were undercover journalists or researchers. In general, they were discharged with diagnoses of 'schizophrenia in remission'.

Rosenhan's findings were important. Not only did he contribute to the debate around the social construction of labels such as schizophrenia, but the reports of his pseudo-patients were an important contribution to our understanding of the effects of both hospitalization and labelling. Labelling someone as mentally ill shapes the interpretation of all their behaviour. As patients with a diagnosis, the everyday behaviours of the researchers, such as writing notes or being anxious in the new hospital environment, were seen as symptoms of their disease. Rosenhan's descriptions of many aspects of hospitalization, such as the low level of interaction between staff and patients, the occasional abuse of patients and lack of privacy, were a significant development in our understanding of how institutions lead to depersonalization and may contribute to mental ill health, rather than cure it. With other studies of long-term institutions, this pseudo-patient study was an influence in the gradual policy shift in many countries away from asylums and towards other forms of care for those with mental health problems.

However, the design of the study raises a number of ethical questions. First, there are the problems of deceit. Except in one case, neither the hospital staff nor other patients knew that they were participants in the research (though some patients did guess), and had not consented to take part. Rosenhan defends the concealment (though he does admit it is 'distasteful') on the basis that it was necessary. It was the only way that these data could have been gathered. If hospitals were warned that researchers would try to get themselves admitted, there would be no way of knowing whether the process of admission and experiences on the wards were typical or not. The hospitals and staff are not named in the report: Rosenhan is not interested in exposing poor practice (as an undercover journalist might) but rather in generalizing from his data to say something about the ways in which mental illness is dealt with in the American health care system. The defence against breaching normal expectations of informed participation is thus a public interest one, based on utilitarian principles. In short, the ends (furthering public knowledge with the aim of improving services for some of the most marginalized people in society) could be said to justify the means. Arguably, though, Rosenhan's study 'spoils the pitch' for future researchers attempting to study psychiatric services in more open ways, making mental health professionals defensive and less willing to consider change. If these disadvantages are taken into account, the benefit in terms of service improvements may be less likely. A final ethical consideration is the safety of the research team. Once admitted to the hospitals, most of the researchers wanted to leave very quickly, as they found them unpleasant places to be. It is, however, difficult to get discharged at short notice, and they spent between 7 and 52 days as patients. This experience may be distressing, and there was also the danger of having to take unnecessary medications.

Reflective questions

If this experiment had been proposed in the current era of ethical responsibility it almost certainly would never be approved or funded. Can you think of other more recent examples where health research has raised ethical issues? Are there any issues of current practice that you feel are, or perhaps one day will become, open to question? Can you suggest why the ethical issues that are debatable in some historical periods come to be seen as clearly unacceptable in another?

Feedback

Recent trials of medications have had serious adverse reactions on the volunteer human participants; and the storing, without the permission of the next of kin, of the tissue and organs, for research purposes, of children that had died in Alder Hey Hospital in the UK caused a great deal of public consternation.

Current research on live animals for medical research is one area that is becoming contentious in medical research and may one day be considered unethical.

Shifts in epistemological perspective or social values change some ethical considerations, for instance, by making some questions no longer legitimate to ask.