MEETING REPORT

This is no low risk game: social science researchers reflect on their work

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The ethics of conducting social science research is a largely unexplored field in India even years after the development of guidelines on this activity. It is often believed such enquiry does not pose any risk to participants; no experimental drugs are administered, no blood samples are taken, and no invasive tests are conducted, so the ethical dilemmas that biomedical researchers commonly face do not exist in this type of research. Some ethics committee members seem to view social science research as "just a bunch of questions", approving these proposals without proper review. However, people can and do face harm as a result of their participation in such research. And researchers often face difficult decisions related to the ethics of their work.

In November 2009, the Centre for Studies in Ethics and Rights in Mumbai conducted a two-day consultation at which investigators in large community-based projects presented case studies on the ethical challenges that they faced in the course of their work.

The observations below give a flavour of the discussions that followed

Do we really need research?

The first question concerned the ethics of doing research itself. Why do we need research to tell us what we already know? How do we justify the resources that are spent on such research? One of the researchers at the meeting mentioned that she spent two years doing a community survey when the same information could have been collected from available secondary data.

The discussions highlighted the importance of properly done research. For example, evidence gathered in behavioural research can help us to design interventions to positively alter a particular behaviour or habit. Research can also gather evidence to convince decision makers regarding important policy matters. Many times the numbers or figures in a well documented report will convince authorities to act when they have failed to see what is right there in front of their eyes. Decisions based on systematic research will have greater impact than decisions made without complete information, or without taking into consideration the peculiarities of the region. Ethics committees who review research proposals, and research organisations that carry out the studies, should keep this in mind.

Further, sometimes there is a need for an independent study even if secondary data are available. This will give the researcher a better perspective about the situation which might be different from what is depicted by official figures or secondary data.

Researchers also obtain a lot of qualitative information while in the field, regardless of whether they are doing a quantitative or qualitative study. Such insights provide faces to the numbers and figures that appear on official reports and documents.

One also needs to think about translating research into action. Research ethics does not end with data collection, analysis and finalisation of a report. It is the ethical responsibility of the researcher or research organisation to share the findings with all stakeholders and make efforts to ensure that results are used in a fruitful way. This addresses the ethical dilemma that the researcher faces about the utility of doing a particular study.

On ethics and methodology

If the first step in research is to answer the question: "Is this research really necessary?", the next is to recognise that the social scientist's actions have an impact on the community that is being studied. However, little attention is paid to the agency of the researcher. This "invisiblisation" of the researcher seems to be an inheritance from the biomedical approach to research ethics. As social science researchers we should place participants and ourselves in a matrix of social relations to understand what exactly is meant by harm, and informed consent, and what the implications are of accepting one's own agency.

Many participants during the ethics consultation articulated the need to do "research on research". Writing a project report is not the end of the enquiry; it is the beginning. It enables researchers to distance themselves from their own work and view some of their choices in a different light.

One of the studies documented health indicators across gender, caste, class and location in Maharashtra in order to identify problems that limit vulnerable groups' access to healthcare. One problem that researchers faced was how to treat the consent of the woman who participated because of familial pressure. Should they treat it as true consent? And what about the woman who was pressurised by her family into refusing consent? Did her exclusion from a state-wide survey affect the generalisability of the findings?

Another participant noted that researchers, who are usually outsiders to the village, go door to door asking people very personal questions. Why would women reveal their gynaecological details to an outsider? Would researchers answer questions about their own bodily functions and sexuality?

On the other hand, such research could be conducted through unstructured interviews allowing the women to share experiences, rather than a survey that seems to embody a top-down approach. It might reveal a lot more on the gendered nature of social realities. Wouldn't sharing experiences women feel freer to talk? Of course, this process would bring its own ethical dilemmas.

It was pointed out that in order to be able to give "concrete" findings and conclusive data, we give up a more engaging process of ethnography and choose surveys that allow us as researchers to remain outsiders and often the more powerful of the two. We all operate in a matrix of power and cannot ignore the fact that this matrix shapes social relations and, by extension, social research.

The ethics of the researcher-respondent relationship

The ethical implications of the researcher-respondent relationship were discussed extensively in the presentations.

Social science researchers do not want to restrict their work to identifying specific problems and producing data on these problems. In a study on living conditions of women prisoners in Maharashtra, researchers found that many of the women they interviewed complained of sexual harassment. As researchers they could only ask the women to complain to the authorities but the women did not view this as an option. In the discussion that followed, a number of participants reported facing a similar dilemma. For example, research participants may expect some help from the researchers who interview them. The researchers, on the other hand, can only give them information. They may advise them to complain to the authorities, or they may refer them to the nearest health service. But they are aware that these agencies have failed to fulfil their duties, and asking the people to go back to these agencies is certainly not a solution. Researchers were acutely aware of the ethical dilemma in mutely collecting data, while knowing they could do nothing about the problems of the people whom they interviewed.

Researchers also described the problem of the gatekeeper's interference in the research environment. In the research conducted in prisons, they had to get prior permission from the prison authorities to schedule their visit. The prison authorities deliberately make the situations look better on the day of the researchers' visit. This meant researchers had to report on what they saw though they knew the reality was otherwise.

Another issue that provoked discussion concerned "off the record" comments from respondents. Respondents have sometimes given valuable information which is directly relevant to the research, but then asked that it be kept "off the record". Since the respondent has not consented on the use of that piece of information, researchers are not able to report it. Several dimensions of this issue were discussed. This was seen by some as reflecting the personal relationship between the respondent and researcher. The respondent may have given that information in the hope that the researcher would do something about it in the future. It might also be a means to vent one's feelings. In any case, researchers felt frustrated because they had useful information that they could not use for the research.

The need for ethics review

Social science researchers have always felt that social research is far too complex to be subjected to the framework of the biomedical research model set up on the four pillars of beneficence, malfeasance, justice, and autonomy. A strong, equity-driven human rights vision was all that social scientists thought to be important in order to undertake good research. It was felt that procedural issues like ethics reviews, consent, and norms to be followed by researchers - largely imported from the biomedical ethics model - would automatically fall in place if the fundamentals were sound.

However, the research case studies presented at the consultation were distinct for their reflection and self-criticism.

For example, the research study to improve reproductive health in 600 villages across Jharkhand dwelt at length on sample selection and study design. Jharkhand is a region ravaged by intermittent conflicts, lacking even basic reproductive health services, with a largely dysfunctional government infrastructure and with no large non-governmental organisations. After considering how to select the control area in the study, the researchers decided to do away with the control arm for fear of withholding an intervention to a group that was deprived of even minimum access to basic reproductive health services. This decision led to concerns about the scientific strength of the study design. Indeed, modifying the study design in this case called for striking a balance between ensuring scientific validity and retaining minimum access to basic health services.

A number of case studies presented subsequently recorded the trade-offs between sound scientific design and ethical issues. Several ethical issues emanated from the very situations and contexts in which the projects remained embedded. Indeed, it takes courage on the part of researchers to present and simultaneously provide a critical review of their own case studies.

In the animated discussions that took place after each presentation, both logistical as well as methodological issues that lead to ethical problems came to light. Only ongoing ethical oversight would help identify the different types of issues and help develop solutions to ethical, logistical, and methodological problems.