

Experiences in health research with women

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Conventionally one conceptualises the research relationship as one between two sets of free agents — researchers and participants — who may have different levels of control over the research process. However, conducting research on women inevitably absorbs into the interaction several other players without whose assent women may not act.

It is true that every researcher and participant is entangled in a network of power relations as funders, the state, employers, landlords and others influence the direction and scope of research and the actions of researchers and participants. However, they usually influence the direct players as a class, and can be engaged with as a class (participants may collectively ignore a ban imposed by the employer, or an entire village may boycott a survey). In the case of women, however, each individual woman must negotiate her participation, with her own household, as must the researcher. Researchers are usually caught between legitimising the authority of men or older women to dictate the actions of women, and ignoring or resisting their control at the risk of retaliation.

Negotiating with authority figures

Both women participants and researchers build alliances with men. Women involve strategic male members in the research process to protect themselves from possible danger posed by researchers. Researchers may use men to legitimise their authority, gain access to women, ensure their safety, and preclude possible disruption or opposition.

However, men's involvement also introduces complications. The research process then involves a continuous process of negotiation and bargaining, in which the women participants are particularly vulnerable. And for either group, this strategic move **foregrounds** patriarchal subordination and reinforces the existing power structure.

Lack of autonomy and research priorities

In the context of women's health research, another important issue relates to the relevance and control of knowledge. Women have suffered as much as they have benefited from social research. Much health research has concentrated on improving acceptance of an undemocratic contraception programme, and effecting behaviour change among disempowered sex workers and poor mothers. Family planning, safe sexual behaviour and more informed child-rearing practices are meaningful only in a context where women can exercise their free will. Research which aims to change women without changing their context is not relevant unless it examines the pressures and constraints that may prevent women from acting in ways beneficial to themselves.

Women also have very control over researchers' knowledge. They have very limited access to education,

they are often unable to travel far from their homes and too intimidated to enter offices. Researchers' legitimacy is partly because they can speak a language comprehensible to those in power. They are thus able to speak for women. On the other hand, without education, women do not possess the means of using the knowledge they have helped produce. It must be debated whether the research community does not have an ethical responsibility to bridge the knowledge gap between participants and themselves.

This relates to both the politics and the ethics of research. Participants who gain access to the written word could judge what is produced on them, and also counter the monopoly of researchers to speak for them. This may fundamentally alter relationships between researchers, policy makers and the community, and compel us to heed women's voices.

It is against this general background that I reflect on the experiences of a research study conducted while working in a structured research organisation. I describe the ethical dilemmas which emerged, and our attempts to resolve them.

Household survey on women's health

In 1996, we conducted a household survey in Nasik district to document illness, utilisation of health care and health expenditure. Although information was collected on all family members, there was a specific focus on women. We introduced probing (a list of symptoms) to record morbidity that is perceived but not reported. The team consisted of women investigators between 18 and 25 years, research assistants and three researchers. Our investigators were living in Nasik and Bombay and had 10-12 years of formal education. Their fathers/husbands were industrial workers, petty traders or in the lower rungs of the service sector.

The survey covered rural areas of Igatpuri taluka and Nasik city. The households selected represented a cross section of the population of the district. In the rural phase, researchers visited the selected villages, established contact with the local leaders and women in the community. We also conducted key informant interviews with women and men in the villages. This initial visit was also used to fix the time and date of the survey. The gap between the researchers' first visit and the team's arrival was sufficient for news of the survey to spread by word of mouth. In almost all villages, we also held a public meeting for women in the *balwadi*, *samaj mandir* or temple to give information about the study, its objectives, the date and the process involved.

This process continued simultaneously with data collection. Thus, while the survey was going on in one village, the researchers would establish contact in the next village. Often, women from one village would have natal homes in the next sampled village. This network of relationships was useful in reaching out directly to women and households without the mediation of the established local leadership.

Each interview took an hour and a half, which included the time spent by investigators to introduce themselves and

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the study. A pamphlet with key information — on the organisation, research objectives, the planned use of data and the rights of participants (to confidentiality, to withdraw from the survey and to refuse to answer specific questions) and researcher's and coordinator's names— was signed by the researchers and the co-ordinator, read out and given to the respondent prior to the interview.

The only difference in the urban areas was that no community meetings were held in the clusters of bungalows and apartment blocks. Each household was approached individually.

Issues

Typically, surveys concern communities rather than individuals and hence in this study too, we approached the 'community' before starting the survey. The idea was to obtain 'informed consent', not merely from individual respondents, but also from the community. However, it is difficult to define what constitutes the community's consent.

We resolved this problem by holding public meetings prior to the survey where we explained the nature of the survey, its objectives, the method of sampling and the interview. We took care to ensure that more than half of the participants in these meetings were women. We also held as many meetings as required to ensure the participation of women of all the identifiable groups in that community (including dalits, the different tribal groups, minority communities and migrants) We invited questions in these meeting and clarified doubts. The community meeting was a way of indicating that we recognised the existence of the collective apart from individual women, and were also accountable to the collective. A meeting is a public space where women felt more secure in raising doubts because they could rely on other women for support. It also indicated that we were willing to face them as a group. If we felt that the group was not convinced or that they had not entirely grasped the information, we held another meeting just prior to the survey. If we sensed insurmountable opposition to the exercise we did not conduct the survey in that particular community.

The consent of elected representatives and local leaders was also sought, for both ethical and pragmatic reasons. However, at no point did we use their consent as a proxy for the consent of the actual participants.

In two instances, in spite of the exhortations of the sarpanch to conduct the survey, we did not do so because we surmised that the actual respondents did not want it. When we examined why an entire community refused to participate in the survey, we found that in both cases, the women were particularly vulnerable within their own communities. While in one village, there were numerous widows whose husbands had died while foraging for scrap metal in the ammunition range, the women in the other village were left to fend for themselves in the absence of their men who spent most of the year working as contract labourers in the city.

Among other significant issues relating to this research study was the relationship between the main researchers and the investigators. It was understood that unless investigators had internalised the research methods and

objectives, they would not be able to do justice to the study. So they were trained rigorously, especially with the intention of making them sensitive to the issue and receptive to women.

Although the training equipped our team intellectually and ideologically, we had not anticipated the emotional burden that investigators would have to carry. The survey was a large-scale exercise involving a team of 20 people and considerable material resource. The pace of work was guided by logistics as well as the imperative to interview all the households within the same season. Thus, as the survey progressed the pace became more and more punishing as we attempted to make up for unforeseen delays.

Each pair of investigators encountered four to five households and met 10-12 women a day. Each day brought its store of traumatic stories of death, suffering and loss. Women broke down and it was not unusual for the investigators to join them. Even the most experienced investigator found herself getting involved in the lives of the woman she interviewed. As the team leaders it was our duty to keep the work moving. Often, we had to goad reluctant investigators out of one house and into the next.

The fear was not merely that precious time would be lost but also that the investigators would spend enormous amounts of physical and emotional energy generating information that we could not use. Our investigators justifiably got angry at our attempts to put the research above the natural impulse to listen, console and counsel. The brevity of the contact itself became the source of much distress. The result was bouts of skepticism about the exercise and a reluctance to continue working in this way. Things were not made easier by the fact that investigators continuously faced questions from participants about what was to be gained by this exercise. While they had been trained to explain the long-term objective of gender-sensitive research, they often did not believe their own answers.

After the third or fourth week of field-work, all the stories sounded vaguely familiar. It was necessary to evolve a way out that would allow us to continue working without feeling burnt out, and also preserving the honesty of our responses.

We therefore institutionalised the evening team meeting, to be held in any private place, at our Nasik headquarters, in the jeep or at a restaurant on the way back. The meeting would take stock of the work accomplished and the problems encountered. The investigators spent hours relating what various women had told them and what they had experienced themselves. The meetings helped us release pent-up frustrations and articulate our anger and helplessness. We realised how important it was for even the most junior researcher to be able to distance herself from the issue and view it within a perspective.

All of us also brought our share of personal problems that made the field-work even more difficult. This space was used to resolve those issues. The meetings were never entirely professional, but involved a lot of personal sharing of physical contact, of expressions of concern and affection as well as annoyance and irritation. It is largely on account of these meetings that we were able to complete the survey successfully and divert some of our frustration creatively into writing field-notes and diaries.

Apart from the ethical issue of exposing juniors in the team to experiences that they may not have been prepared for, the larger issue relates to the relationship between researchers. One recognises the need for role differentiation and hierarchy in the research team. However, it is still important to ask why certain ways of writing legitimise research more than others. This is particularly relevant in women's research where qualitative techniques are used extensively and sensitive issues are probed in detail. The richness of the data lends much to the quality of the research, and investigators and assistants who conduct the actual interviews and group discussions are very important players. Their sensitivity, understanding of the issue and skill are pre-conditions for good data collection. Not only are they involved intensively in this phase of the research, a participatory mode of functioning may actually equip them with additional skills.

Our own experiences indicated that the meetings and discussions imparted certain skills to investigators that are normally associated with research writing. They learnt how to abstract, generalise and analyse situations from what we would understand as a 'sociological' point of view. Their writing skills were poor because of their level of education, but these skills can be acquired with effort and inputs. While our investigators may have been too junior and ill-equipped to manage all phases of research, investigators with more formal education and training may become capable of doing research independently and competently. It is important that designation does not define roles, and space is created for junior members to share in the writing.

Are our institutions open enough to absorb people who may raise themselves from below? This issue is distinct from sharing research with participants, as is the norm in 'participatory research' where they have a say in designing the methodology and the conduct of the research as well as in the use of it. While participants share the gains of the research largely through changes which result in the community after the research (such as an improvement in the PDS), junior researchers could share the professional gains and prestige associated with research. It would involve changing the policies of institutions and implementing measures that seriously challenge existing institutional hierarchies. The material gains too would be distributed and serious questions would be posed about the social structure of research organisations and the class structure that they reflect.

Conclusion

While some of these issues are gender specific, some are of a general nature. The teams involved resolved the ethical dilemmas by responding to problems, as they arose evolving a consensus through discussion and self-reflection.

Thus we must debate whether the household's consent can be accepted as the woman's consent. Likewise, gain accruing to the household may not necessarily amount to gain accrued to the woman. Where most women are illiterate, sharing the knowledge with the community in a written form in front of the elders and community leaders may, in fact, expose women without benefitting them. What will women

do with knowledge that they are not empowered to use? In a situation where vulnerable women seek the intervention of others, what stand should we take when they try to set up a system of checks and balances between the researcher and the authority figures, who are conventionally bound to protect them? By accepting their legitimacy, one automatically endorses their right to share the knowledge resulting from the research. Does this compromise our commitment towards women who are the rightful recipients of that knowledge? How does one then confront the same authority figures?

Finally, one must address the problems within. An important agenda for women's studies has been to widen the definition of knowledge and challenge norms governing the hierarchy of knowledge. However, as women's studies get recognised and institutionalised, new hierarchies are being established in new institutions. Research in women's issues, especially women's health is not confined to activist groups and dissidents among the academic community. Apart from the state, which continues to conduct research *on* women, there are large research institutions in the mainstream, large non-governmental organisations and multi-lateral agencies, many of whom claim to be conducting research *with* women. These agencies are spread across a wide ideological spectrum. Nonetheless, is it sufficient to claim that women participants are partners? What about the woman research investigator (who also forms the informal sector of the research industry, indispensable and yet highly substitutable), who should legitimately share the direct gains of research, both material and social?

(This paper draws on the experiences of two research studies conducted while I was working at the Centre for Research into Health and Allied Themes (CEHAT). I would like to acknowledge the contribution of my team members to the discussions that led to the writing of this paper. In particular, I would like to acknowledge Rupashri Sinha and Padma Deosthali, with whom I not only discussed but also lived these experiences and to whom much of the credit for this paper should legitimately go. However the views expressed in this paper are mine only.)