Ethical and methodological conflicts in sexuality research

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*T*his essay is based on issues relating to a study of sexuality among low-income college students in Mumbai. Low-income students were made the focus because: existing urban studies are on English speaking students in 'elite' colleges; sex education programmes had not really started in 'non-elite' colleges, and these students' behaviour could be affected by their lack of resources. Data were collected during 1996-1998, from four colleges catering to low income students in the city. Boys and girls in the **eleventh** standard in high school and in third year undergraduate college were interviewed. In the first phase, qualitative data were gathered using 10 focus group discussions and interviews with 87 students. This was used to design a survey which used a self-administered questionnaire. A total of 966 students participated in the survey.

A novice in sexuality research may not seriously consider the ethical dimensions of such an enquiry. S/he is usually more concerned about conceptualising the study, choosing the appropriate methodology, and working out the logistics involved in executing the study. The squestion that haunts the researcher is: "Will people talk about their sexual experiences, especially about taboos such as premarital sex?"

Having no prior experience in such research, I too was troubled by this question when starting off, but I was not unduly worried because sexual experiences were only one part of my study which was meant to explore a range of issues related to sexuality- sexual socialisation, knowledge and attitudes to sex, peer socialisation, erotic exposure and so on. I reassured myself that if people did not share their sexual experiences with me, I still would have a lot of useful data to analyse. Besides, the refusal to respond tells you whether a group is willing to disclose personal information. It can also tell us the strengths and weaknesses of methodologies for sexuality research.

A review of existing sexual behaviour studies showed that a percentage of young people report pre-marital sex and that more young men report pre-marital sex than young women. Some authors attributed this gender difference to over-reporting by boys and under-reporting by girls, but did not state the evidence for this belief. They apparently assumed that girls refrained from admitting pre-marital sex, fearing the possible negative consequences of such a disclosure. On the basis of my study, I now believe that fewer girls than boys actually engage in pre-marital sex, in order to avoid various negative consequences: a 'bad name' for themselves and their families, the possibility of future marital discord and domestic violence, and so on. While one must be aware of the possibility of over-reporting and under-reporting, it may be best to base one's beliefs on sufficient evidence.

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At the beginning of the study, therefore, I was mainly concerned about the methodological aspects of gathering reliable data, and how to gain students' confidence and trust.

However, I was not fully prepared for the consequences of people disclosing their personal experiences. While methodological aspects of the research were considered in detail, the ethical aspects of were considered only briefly. This has changed in the last five years. Sexuality research has tackled many methodological issues and is now discussing the ethical dimensions more seriously. Our experiences may be useful to ongoing discussions.

The research team's concerns

Our first concern was to deal with the methodological and ethical problems at our end: Are we comfortable asking those questions? Is our language appropriate? What are our prejudices? Are we sensitive to young respondents' anxieties? How much should we probe into their lives? Working on these was a protracted exercise.

The research team consisted of young men and women just out of post-graduate or undergraduate courses — almost a sub-sample of our study sample, similarly biased and ill informed on sex and sexuality. But they were very enthusiastic and, above all, well informed about the social and cultural milieu in which the study was located. Prior to data collection, we had meetings on the objectives, methodologies and logistics of the study. We spent considerable time talking about sex and sexuality, clarifying misconceptions and filling in information gaps. We also held a two-day workshop on conducting group discussions, interview techniques and note taking and transcribing. The only ethical issue that the workshop resource people discussed was to 'respect' and be 'sensitive' to the respondent's views. More detailed discussion on ethical issues should have been an integral part of that workshop.

The returns of research

Although ethical issues were not at the forefront of our research concerns, they kept cropping up. During our meetings, research staff raised the question of appropriateness of our research. They perceived it a one-sided relationship in which respondents 'give' and the researchers 'take'. Are we providing them nothing in return? they asked.

In the tradition of social science research that I was trained in, researchers did not provide anything in return to respondents. The returns of research were not perceived in terms of their immediate benefits. Benefits accruing from such research would result from a lengthy process: research findings would enhance our understanding of society, which circulates to benefit the whole group. In other words, the job of the researcher is to generate critical 'knowledge' that has some value for society as a whole.

Such arguments were not acceptable to my young staff. They raised several questions: Why should people spend

their time and put themselves at risk talking to you if you are not going to give them anything in return? Is it morally correct? It is only natural that they expect something from you.

Intervention research

Looking for a solution to this dilemma, I came across several research protocols prepared by international agencies in the area of health research, advocating what they call 'an intervention component' as part of the study itself. This intervention could be by way of services provided after the completion of the study, or basic services such as health care, counselling, awareness programmes or IEC materials provided during the study itself.

Our study was one of four studies on adolescent sexuality in India, funded by Rockefeller Foundation. The others were conducted by agencies already providing services, for whom the studies were to feed into their services, making 'intervention' the overall aim. Our study was to generate understanding that would feed into programmes organised by various agencies, both government and non-government, for youth groups, especially school- or college-based programmes.

The 'intervention component' is increasingly becoming part of research conducted outside traditional social science research institutions such as universities and special centres. I believe that this 'new perspective in research' arose in the context of two developments. First, voices were raised against the use of the bulk of research funds on researchers' comforts even as the respondents lived in abject poverty or in stigmatised conditions. Second, as non-governmental organisations (NGOs) became increasingly involved in research, some of them criticised 'ivory tower' research in favour of more humane research that took into account some of respondents' immediate needs.

My gut feeling was that this trend of 'built-in intervention' has more to do with the politics of large international funding for research in poor countries. While this approach seems logical and also reflects some ethical concerns, I am not sure of its methodological appropriateness or its resolution of ethical issues. Could it amount to an inducement to participate? And could the anticipation of a reward, however small, alter the nature of data? I am still not sure.

Social science research has generally held that data gathering should avoid any form of inducement as it can seriously affect the data. However, researchers are expected to intervene in life-threatening situations and other serious crises involving respondents, their immediate families, or the community, and not remain 'dispassionate observers' to 'document the outcome'. It seems ethically correct to provide services to respondents suffering from reproductive tract infections in a study of reproductive health. But what do we do in studies of voting behaviour, or of employment outcomes?

Much social science research is seen as a collaborative effort of the researcher and the researched. It is true that research findings often do not get translated into benefits for the respondents. In many cases, no one pays heed to the researcher's findings or the respondents' interests, unless the researcher is backed by influential agencies. However, the 'intervention component' may thwart the efforts of small-budget studies carried out by individuals in lesser-known institutions. Is this a way to make 'ivory tower' research redundant, and to promote NGO research? (Of course, I do not hold that all institution-based research is 'relevant' and I do believe that some NGOs are doing 'very useful' research.) The intervention component is particularly characteristic of large projects. By now we also know that conditionalities (hidden or explicit) are attached to large-scale funding, whether for 'development projects' or 'research'.

A related question is: how is intervention designed? Do we ask the respondents what they need, or do we decide what to give? What if they really need something which we cannot give? What if there are conflicting demands? What if most respondents are not particularly concerned about the rewards? Such issues in sociological research on sexuality become difficult to resolve, while it may be easier to do in a more specific health research project.

After much discussion within the group we decided that we would try 'to do something for the students', based on our financial and other capacities as well as students' demands. In order not to let it influence respondents' decisions to participate, we decided not to announce any intervention but informed those who asked about it.

The study's returns may not benefit all respondents equally — or for that matter any of them. However, it may have more significant indirect effects. To illustrate, we were surprised when the principal of one of the colleges was quick to grant permission to conduct the study. Later, he mentioned that an unmarried student who became pregnant had been "dismissed" from the college at the management's behest, an action he felt was "unfair" to the student. He felt sex education could help prevent unwanted pregnancies, but needed concrete findings to convince the management of its need. Here we saw some benefits accruing from our study, perhaps not to the participants specifically but to the students in general. After the study, our efforts have been to communicate the findings to parents at large, educators and other agencies, in the hope that it will benefit young people. One organisation finds the study useful in its programmes for youth in a rural setting. These issues of `benefits and relevance' need to be brought to the centre of social research, particularly because of the blurred boundaries between types of research - market research, action research, intervention research, theoretical research and so on. The agencies and players in these types of research have different agendas and objectives.

We tried to meet an obligation to 'pay back' in different ways. Wherever possible, we tried to provide information on specific topics, and specific services to those respondents who asked. We also asked the students if they wanted a programme organised for them, and if so, what the content should be. Some wanted a meeting with an 'outside expert' to answer their personal queries. This was arranged and the students seem to have found it useful.

Confidentiality

It was not difficult to convince the research staff of the importance of data confidentiality and protecting respondents' identity, but I soon realised that this was not enough. Most research reports only state that 'confidentiality of the data' was assured but do not speak of how they did this. I realised that these young researchers were discussing 'interesting details' with their peers and family members, disclosing the identity of the college. At the same time, college authorities were pressurising them to divulge the names of other colleges where the study was being conducted and the staff felt it was 'okay' to share the information between colleges. 'Leakages' occurred despite many efforts, particularly in the initial stages of the study till the staff became habituated to 'guard it as a secret'. It was also difficult to ensure that trained staff who leave the study for better jobs, continue to maintain confidentiality.

Respondents' identities were easier to maintain as we did not ask their names and their interviews were linked only to a code number. However, another problem arose here: after the transcriptions, I needed more information in some cases, but could not go back to gather it. In an exploratory study unanticipated responses come up which need to be followed up.

Informed consent

This seemingly straightforward ethical requirement turned out to difficult to implement. One practice suggested for literate populations is to obtain respondents' signatures on informed consent forms. Our research population consisted of highly literate college students (16-22 years), but getting their signatures on consent letters seemed to go against our assurance of protecting their identities. The most convincing way we could assure protection of their identities was by not recording their names anywhere. Instead, informed consent was operationalised as follows: In order to recruit students for focus group discussions, members of the research team addressed classes, informing them about the study's objectives and our organisation. A meeting was announced for those willing to participate in the discussions. On the appointed day, many students did not turn up: the reasons given by those present were that some changed their minds, some were absent, and some were not free. We restated the purpose of research and who we were, and how we would maintain confidentiality. We said if they wished to discontinue, they could do so. We began the group discussions a few days later, by which time some more students had dropped out. Once the group discussions began, the participants stayed on through the multiple sessions conducted with each group.

This two-layered recruiting procedure may have helped ensure the ethical requirement of informed consent. But from a sociological angle, I would have been equally interested in talking to those who wished to stay away from the discussions. Such a self-recruitment procedure is methodologically weak as it tends to leave out important groups, compromising the validity of data. The objective of an exploratory study is to arrive at a general understanding of the issue, for which it is important to have as many diverse experiences and representations as possible.

Similarly, in individual interviews and in the survey, students were informed of the survey's objectives and nature, the confidentiality of the data gathered and also about us. Their willingness to participate was taken as their consent. However, some of those interviewed did not wish to answer some of the questions and they were not probed. Then, in the self-administered questionnaire, students chose not to respond to some of the questions, and the no response was recorded. On the whole, once they opted to participate the 'no response rate' was low.

Looking back, I wonder if our over-enthusiasm to ensure that the students' participation was completely voluntary ('choice' is something which they are not used to in an institutional context) actually provoked some students' curiosity and generated peer pressure leading to their participation. Some students asked to be included in the study as their friends had been interviewed. Does this violate the rule of `informed consent'? There could also have been herd behaviour: "Others are doing it, so I must do it too..." Our understanding is that these young people are not used to being given choices. Once college authorities permit an activity by an external agency, it is expected that students cooperate. Of course, students do subvert authority. Besides, any activity that is not `compulsory' is generally not seen as an important activity by students. Even before we talked about the study, many asked, "Is it compulsory?", and some lost interest when told it was voluntary. The value of `voluntarism' was obviously in conflict with the culture of authoritarianism in our educational institutions.

Recently someone asked me how consent was obtained from students under the age of 18. I had not thought about it in such strict legal terms. All were treated equally except that younger (high school) students were given a more detailed explanation.

Should we have intervened?

There were two instances when girl respondents refused to answer questions of sexual experience in a manner which suggested that they had traumatic experiences. The interviewer respected their 'choice' and merely recorded her observations. Later we wondered whether we should have probed further and at least offered to help them. As a researcher I felt that we should have made efforts to collect more sensitive information. Perhaps neither an institutional setting like a college nor a family setting is a suitable location for such data gathering.

Conclusion

Looking back, I feel that important ethical and methodological issues are meshed together especially in areas such as sexuality research. Attempts to protect individual rights may compromise the quality of information, and vice versa. How do we deal with such issues? They cannot be dealt with separately, but should become part of methodological training and debates in social sciences.