A community-based study on induced abortions Bela Ganatra, Siddhi Hirve

The field of medical ethics in India has until recently revolved largely around issues in medical practice or research involving clinical interventions / contraceptive trials, etc. However, as more and more of us venture into health systems research that links with other social issues and probes sensitive and often private aspects of behaviour, we are using non-traditional research designs and qualitative methodologies – all of which bring us face to face with complex ethical dilemmas.

We illustrate this with the recent example of a study on induced abortion that we did at the KEM Hospital Research Centre, Pune, in 1995, in a rural community where the centre has been involved in both health care delivery and operations research for many years. Though abortion in India had been legal for over 25 years there were few data on abortion beyond its demographic, fertility or mortality aspects. Again, most available information was based on urban hospital populations or on secondary analysis of case records. Our own interest in the issue stemmed from our previous work in the same community that had shown a surprisingly low abortion-related mortality but also suggested that access to services was not uniformly available to all women, and that we knew little about where and how women in the rural context were accessing abortion services and how their choices and experiences were modified by their socio-cultural context. Only a communitybased study could have answered many of these critical questions. Yet, designing such a study posed many methodological challenges. Under-reporting of abortion events in the survey situation is common. The abortion event may be forgotten; 'denial' may be a psychological coping mechanism to deal with an unpleasant event. Some women prefer to label their induced abortion event as spontaneous.

Our study design was based on a method of case identification that relied on identifying women who had undergone an induced abortion during a defined reference period of 18 months using secondary sources of information: health service providers (both those providing abortions and those treating complications) in and around the community, health and development workers, women's groups and other community members. Cases identified through providers were enrolled prospectively; providers of services were asked to be the initial link with the women. The providers were expected to explain the study to the client and did not provide us information where they did not feel it in their or their client's interests for the subsequent interview to take place. Wherever possible we tried to arrange for the interview to take place in a clinic setting. Given the fact that follow-up visits post abortion are not the norm, not

Dr Bela Ganatra, Dr Siddhi Hirve, address for correspondence: Dept. of Population and Family Health, Johns Hopkins School of Public Health, 615 N. Wolfe Street, Baltimore, MD 21205, USA. Email: sidbela@vsnl.com. many interviews could be achieved in the clinic setting.

The community-based informants were also asked to serve as the link between the case and the researchers but not all were willing or able to do so. Thus we were faced with the dilemma of doing community-based interviews with two types of women - those who had agreed or knew of the impending interview, and those whom we had identified but for whom we had no knowledge of their potential willingness to participate. While approaching women who had previously agreed should have been a simple matter, it still did not deal with the fact that consent is dynamic and contextual and the woman could well have changed her mind in the intervening period, and neither the woman nor we would have control over the presence of others at the time of interview done at home. Though using secondary sources as sampling methods is fairly commonplace in anthropological studies, we felt that using this information to subsequently interview the women when the identification process had not assessed her willingness to share the information posed difficult-to-resolve dilemmas. Would approaching such women for an interview be a breach of confidentiality? Whose confidentiality? How could coercive participation be avoided?

Coming to terms with that dilemma in part at least, we felt, depended on how sensitive or private the issue was considered in the cultural context of the community. Over the course of a series of key informant interviews with women, health workers and providers that we conducted over the next three months, we gauged the sensitivity of the issue in that community and tried to determine areas of special concern in using such a method. Based on these inputs we realised that while for most married women who had undergone an abortion with the knowledge and support of her husband the issue was neither overly sensitive nor stigmatising, women who had out-of-wedlock pregnancies and some married women who did not have family support for their action could be at social risk if their induced abortions became public knowledge.

Where informants felt the woman was at high risk of being stigmatised by the interview process (e.g. unmarried women) we did not interview them at all unless it was possible in a setting like the clinic. All others were approached at home for an interview. We clustered women into geographic areas, and drew up a sample of women from the eligible couple list of the area among which were included the women who had been identified to us. Thus when the interviewers went out to the village they were looking for and interviewing both cases and non-cases (dummies) using the same questionnaire. When individual women were approached for the interview, the interviewer did not confront a case with the knowledge that she knew that the woman had an induced abortion. She instead asked her for permission to interview her on her health problems and past pregnancies and their outcomes. During the course of this pregnancy history, if the women mentioned the reference induced abortion we asked permission to continue interviewing her about the abortion experience and explained the full purpose of collecting the information. Women were free to discontinue the interview at this point, and in fact some did so. If the woman did not reveal her induced abortion or called it spontaneous, further questions regarding that aspect were not asked.

We tried to ensure that the person doing the interview was blinded to the fact that the respondent was a case or a dummy but this was not possible in every instance. However, the possibility of interviewers coercing the woman into admitting an abortion was minimised by stressing the research objective of studying the differences between the characteristics of women who acknowledged their induced abortion from those that did not. In fact by the end of the study, several women who were interviewed as dummies reported an induced abortion in the reference period and thus became cases.

While guaranteeing one-to-one privacy in the rural setting is difficult, attempts were made to create artificial privacy by using a 'team' of interviewers, where one person conducted the actual interview while the other interviewers (including a male) engaged other family members in one-on-one dummy interviews or conversations. While it was always easy for the family to identify the real interviewee, these dummies still served the purpose of allowing us a modicum of private time with the woman. The interviewers were also trained in being able to divert the interview subject when unwanted family members or outsiders insisted on listening in.

This strategy allowed us on the one hand to ascertain women's willingness to talk about her abortion without confronting her with information she may not have wanted to be confronted with. It allowed her a dignified way of refusing the interview and the framing of the interview within a broader focus and interviewing other women allowed her and us to present a non-threatening explanation of the study to family or others should her situation warrant it. Yet, this was achieved at the expense of being disguising the full and real purpose of the study. Again, while interviewing noncases and other family members provided privacy and minimised attention being focused on the women, data from the dummies who were interviewed were not used scientifically. While these women suffered little harm other than loosing the time spent on the interview and may indeed have benefited from the medical referral and linkages that were made available to them when they required it, their participation still presents some unresolved questions.

Consent at all the various stages that it was taken remained oral rather than written. Again, this was a deliberate decision since we felt that introducing a formal document would not necessarily give authenticity to the process but could in fact bring in a feeling of mistrust and suspicion. Ultimately, the quality of the consent procedure – written or oral — is as good as the researcher's integrity. A signed document is no guarantee that the woman's rights have been safeguarded. On the other hand how does one ascertain that women have indeed participated willingly and freely?

Again, while we did not provide monetary incentives to anyone, we provided medical referral linkages to all participants. We were fortunate to be backed up by a medical hospital so this was possible. Could the expectation of benefit as we were service providers have influenced participation? What are the implications?

The dilemmas we faced had no easy answers. A scientifically poor study is unethical by its very nature. At the same time, addressing scientific rigour often brought us in direct conflict with the ability to safeguard the participants' dignity, autonomy or confidentiality. The tension between these conflicts is increasingly being faced by those researching reproductive health issues and using qualitative methods which, though sensitive, also can be intrusive and potentially threatening. The recent code of conduct in social science research (1) is an exciting development. If this code is to have any meaning, we researchers need to be upfront, not defensive or evasive of the dilemmas that we confront. Good intentions and good faith are prerequisites but never enough in determining questions of ethics. The dilemmas do not detract from the science but only enrich it.

References:

1. National Committee for Ethics in Social Science Research in Health: Ethical guidelines for social science research in health. Centre for Enquiry in Health and Allied Themes, Mumbai, 2000.

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