

Reflections on research ethics

Health, households and women's lives: a study of illness and childbearing among women in Nashik district, Maharashtra. Neha Madhiwalla, Sunil Nandraj and Roopashri Sinha. Mumbai, CEHAT, June 2000. 141 pages.

The objectives of this survey of 1,193 households in rural and urban areas of Nashik district, Maharashtra, were to study women's health problems and the health care they receive, and how these were influenced by factors such as age, marital status, caste, class and women's position in the household.

The published study comments in some detail on ethical issues faced in the course of the research. It is suggested that certain modifications in methodology were made to better capture women's experiences, as well as in response to ethical dilemmas presented by such research. These special efforts were reflected in a significantly higher reporting of morbidity.

The findings also indicated the extent to which women tolerate illness without treatment. Overall, as many as 45 per cent of reported illness episodes went untreated.

One recommendation is that efforts to improve women's access to health services should address family power relations which deter some women from seeking care. However, they must also address the general context in which the women live: pervasive poverty and unemployment, and inadequate health services.

Why do research?

The team reported facing ethical predicaments at the very outset of the study, particularly in their role as professional researchers whose work is not directly linked to service provision. They were going into an community in which they had no roots, into an area which had been the subject of "innumerable surveys, government sponsored and others, in the past." The "subjects" of such repeated surveys do not expect that the survey will change their lives for the better.

The researchers justified their decision

to carry out the study despite knowing it would be of no immediate benefit to the community. "We reasoned about the need to generate knowledge and information about problems that remain unnoticed or ignored because they concern only marginalised groups." Effectively, *not* doing the research would be doing the community a disservice.

Separately, the survey structure is often associated with processes which exercise control over people. However, it was felt that the survey design was best suited to the needs of the study.

No accountability

In the course of their work, researchers were acutely aware of the fact there is no mechanism to monitor researchers' functioning. While interviewees were expected to bare their lives to researchers, researchers had no such obligations to the community. "All our efforts to maintain transparency about our organisation and our objectives, to seek informed consent and to give information and help when it was sought, were entirely voluntary." The community can refuse to participate, but that's about all it can do. A proposed code of ethical guidelines for social science research would be one step towards reducing research abuse (1). However, even this code would have to be voluntarily adopted by the research fraternity.

In response to these issues, researchers included a number of open-ended questions and extensive probes to capture the complexities of women's experiences. They depended women interviewers exclusively. Finally, community meetings and repeated contact before the survey actually began established a good rapport with women in the community. The information leaflet read out to interviewees states that a summary of the findings would be provided to the community.

The community seems to have responded enthusiastically to these efforts to democratise the research process. The more interviewees felt involved in the interview, the more detailed and non-linear their narratives became. "Women consistently spoke

about much more than what was being investigated, the investigators reciprocated by recording all this information, out of conviction that this information was as relevant as what had been recorded in the columns of the schedule. The dilemma for us has become to integrate this varied and dispersed information into our analysis." The stories presented in the introduction try to convey these experiences.

The burden of knowledge

Interestingly, the response also made researchers more conscious of their limitations. "We found ourselves listening to life histories and even offering solace and advice... We felt a sense of helplessness that arose from the realisation that not only could we offer very little help to the woman, but that the relationship itself was not long enough to be emotionally satisfying. All that could be achieved was that we learned to reflect on what we had heard and seen."

This process of reflection raises a number of critical issues for discussion which could be explored further. Are there circumstances in which one should talk of service provision as a condition for research? How does the researcher address the intrusiveness of research on people's health, finances and spending behaviour — and the fact that such research is usually more possible in poor communities? Is there a need to document informed consent? (This is not discussed in the published study.)

The researchers have argued that they constructed the research process in such a way that the women interviewed became active participants, even dominating the information collection process. This resulted in a more participatory, less controlling, process. Women, though they received no direct benefits, profited in the process of telling their stories. "Talking about these problems and acknowledging them was like making a beginning in the long process of change."

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Reference:

1. CEHAT: Ethics in social sciences and health research - a draft code of conduct, *Issues in Medical Ethics* 2000; VIII (2): 53-57.

