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THEME: CASE STUDIES IN PUBLIC HEALTH RESEARCH ETHICS FROM INDIA

Maintaining confidentiality while gaining access to the community

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Keywords: *Gatekeepers, privacy, research access, ASHA, confidentiality, sensitive information*

Introduction

Qualitative research is used to enhance the understanding of many issues but this method poses certain unique difficulties and ethical dilemmas for the researcher. These tend to be magnified when researching sensitive topics (1). The use of gatekeepers adds another layer of ethical issues or dilemmas. The term "gatekeeper" describes individuals, groups, and organisations that act as intermediaries between researchers and participants (2). A gatekeeper occupies an important position in the research process by helping the researcher access the participants. This serves to save the researcher's time and resources during the research process, and also to guarantee the researcher's legitimacy to the participants (2, 3).

The case

The qualitative component of a community-based study used in-depth interviews to understand treatment-seeking pathways among couples with infertility[1]. Given the challenges of locating couples with infertility within the community, the researcher recruited participants through various gatekeepers including a specialist at an infertility clinic, friends, and health workers (Accredited Social Health Activist or ASHA[2] who is from the same community). Community members in general and women in particular are wary of outsiders collecting information about the intimate details of families. The ASHA can help recruit study participants as she is familiar with the families in the community, and also reassures them about the researcher's credentials.

The researcher would contact the ASHA explaining the purpose of the research, and ask for help locating study participants. The ASHA would identify potential study participants and obtain interview appointments with them; she also usually accompanied the researcher to the appointment. Though the researcher would inform the ASHA of the research topic as well as its sensitiveness, the ASHA usually stayed with the researcher during the data collection process, to reassure herself that the researcher was not discussing anything other than what she had been informed about. However, when possible, the researcher revisited the participants without the ASHA worker being present, in order to probe sensitive issues that needed exploration. All interviews were conducted after obtaining the participants' informed consent.

In one case, the researcher interviewed a woman who had undergone in vitro fertilisation (IVF). The ASHA accompanied the researcher to the participant's house. She did not actively listen to the conversation between the researcher and the participant; there was an anganwadi[3] attached to the participant's house, and the ASHA chatted with the mothers who came to drop their children there. The participant narrated details of the treatment that she had undergone. She said that she was found to have defective ova production because of which she had been unable to conceive after repeated IVF treatments. She eventually underwent IVF with donor ova and subsequently delivered a child.

At the end of the interview, the woman told the researcher that her use of donor ova was confidential and only close family members knew about it; not even the husband's family was aware of it. The researcher reassured the participant that this information would not be shared with anyone.

As the researcher was about to leave the house, she was summoned back by the participant's mother who expressed her discontentment in her daughter being asked personal questions. She was also worried that the ASHA worker may have overheard the interview on this sensitive topic. The mother scolded her daughter for sharing the information with the researcher. Although the researcher reassured the mother that the data would not be shared with anyone, the mother was worried.

Questions

1. What are the key ethical issues at stake in this situation?
2. Should community-based workers be used to identify subjects for participation in research on sensitive or stigmatising health conditions? Why, or why not?
3. Can steps be taken to ensure confidentiality when a third party is present during the data collection process?
4. How can we ensure that the process of recruitment for such research is not coercive?

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Notes

[1] In this study, a "couple with infertility" has been defined as a couple who have been married for a minimum of one year, and are seeking treatment, or have a history of treatment, for achieving pregnancy.

[2] ASHAs are trained female community health activists. Selected from the community itself and accountable to it, the ASHA is trained to be an interface between the community and the public health system.

[3] The Anganwadi or "courtyard shelter" is the focal point for delivery of the government's Integrated Child Development Services, through which children under the age of 6 are given supplementary nutrition, immunisation and pre-school education, and mothers are given supplementary nutrition.

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Community gatekeepers and the conundrum of confidentiality and coercion

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Sunu Thomas has described (1) a research study in which she gained access through a community health worker to members of the community seeking treatment for infertility. One of the research participants who had undergone such a sensitive treatment and her family were concerned that the community health worker's presence during the interview would breach the confidentiality of their health information. In this commentary, I will discuss the issues of balancing accessibility versus confidentiality, and of coercion in the process of approaching community members through gatekeepers of the community.

Frontline community health workers are often the gatekeepers through whom public health researchers access community members to conduct their research. The health workers are usually themselves members of the community and so have first-hand information about the potential research participants. In a typical rural context in India, public hospital records and health system information may not be reliable, making access to patients difficult. Moreover, even if a researcher got the address details of a potential research participant through hospital records, the complex layout of streets, lanes and houses in rural India makes locating people arduous. Therefore, public health researchers largely depend on community health workers to identify potential research participants.

The issue described by the researcher in this case is very common in public health research, especially when it is based in the community. Two years ago, I was involved in a community-based qualitative research project to understand the experiences of women who suffered stillbirths in the public health facilities of Tamil Nadu. Our team approached, through the village health nurses (VHN), the families of women who had suffered a stillbirth. The VHN is the frontline community health worker in Tamil Nadu who takes care of a population of about 5000 individuals and plays the vital role of a bridge between the community and the primary healthcare system. Many of the mothers whom we approached had lost their babies during delivery in the public health system and so had a sense of anger and resentment against the health system. Some of them were even angry with the VHN, as she is the face of the public health system in the community. As described by the author, we too had been worried that the presence of the VHN during the interviews could breach the interviewees' confidentiality.

Multiple ethical concerns have been raised in this case study. I would like to discuss two main confidentiality concerns. The first is whether it is appropriate for researchers to gain access to communities through frontline health workers. Frontline health workers are the vital link between communities and the health system. The community members sometimes reveal very sensitive information about their health to community health workers, in order to secure their help to access health system facilities. Often, the community health worker is part of the community herself. So, being an insider, she is already privy to some personal information about the members and the community. Therefore, like the fiduciary doctor-patient relationship and its inherent covenant of confidentiality, the community health worker's- relationship with the community

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