**Community gatekeepers and the conundrum of confidentiality and coercion**

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

The issue described by the researcher in this case is very common in public health research, especially the ones based in the community. Two years ago, I was involved in a community based qualitative research to understand the experiences of women who suffered stillbirths in the public health facilities of Tamil Nadu. Our team accessed through the Village Health Nurses (VHN), 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 a vital role as a bridge between the community and the primary health care 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 VHNs as she is the face of the public health system in the community. We also faced a similar issue as described by the researcher, in which we were worried that the presence of the VHN during the interviews could breach the confidentiality of the families whom we interviewed.

There are multiple ethical concerns in this case study described by the researcher. I would like to discuss two main confidentiality concerns. The first concern is whether it is appropriate for researchers to access communities for research through the gatekeepers? Frontline health workers are the vital link between communities and the health system. The community members sometimes reveal very sensitive private information about their health to the community health workers in order to seek their help and support to access the health system. Often the community health worker is part of the community herself. So, by being an insider, she is privy to some private information about the members and the community. Therefore, just like the fiduciary doctor-patient relationship and its inherent covenant of confidentiality, the community health worker- community relationship must also be bound by the confidentiality clause. The trust in the community health worker-community relationship is strongly influenced by this confidentiality. (1) Therefore, while community health workers are used as access points for members of the community, mistrust develops among the community members towards the community health worker. (2) Sometimes the illness under research is stigmatizing such as tuberculosis, sexually transmitted illnesses, infertility etc. and when such sensitive information is shared with researchers, it leads to breach of trust. We have seen this happen often, but it is never mentioned or discussed because of the power imbalance between the community health workers, who are representatives of the health system and the community members who are the beneficiaries. For example, in Tamil Nadu, the VHN is the controller of the Dr. Muthulakshmi Reddy maternity cash incentive scheme and many such welfare schemes, and the community would not want to alienate her, lest they face troubles availing these welfare benefits. Therefore, utilizing the intimate knowledge of a community health worker about illnesses in the community for research recruitment can be unethical and can erode trust in the community health worker community relationship. Before utilizing the community health workers to access research participants, the researcher must implement active community engagement. Community members must be notified of the research study and that the potential research participants will be accessed through the community health worker. Before accessing the potential research participant through the community health worker and before obtaining their details, the community health worker must be encouraged to talk to them and obtain their permission to share their details with the researchers. This helps preserve the trust in the community health worker as well as takes adequate measures to protect the confidentiality of patient information.

Secondly, presence of the community health worker at the site of the research data collection can violate the privacy and the confidentiality of sensitive health information of the research participant. In this case, not only did the researcher access the couple with infertility through the community health worker, she also conducted the interview with the worker close by. In low resource settings like many villages in India, it is highly challenging to secure a private space for conducting qualitative in-depth interviews in the community. Moreover, if the community health worker is accompanying the researcher to help identify the house, it may be difficult to ask the worker to leave the place during the interview. Not only might this be viewed as rude, it may be unsafe in some places to keep the health worker standing outside the house or sending her away elsewhere. In our study on experiences of women who suffered stillbirths we adopted a few strategies to overcome this issue. Wherever possible, we tried to get the address and landmark details of the mother from the VHN and went to her house on our own. Wherever taking the VHN with us was unavoidable, we attempted a private interview with the mother. When this was also not possible, we did not delve much on sensitive confidential information during the interview, but established follow-up contacts with the mother later through phone and asked that information in private. It would always be good practice to emphasize the risks and benefits of participating in the qualitative interviews while obtaining informed consent from the participants. We made sure that we told the mothers whom we interviewed that the mothers may have to recall and relive some of the painful and traumatic experiences of delivering a still-born child. We also explained that we may request some sensitive information, and if they felt uncomfortable sharing them in front of the team, they need not. We made sure that both the mother and the health worker are comfortable and felt respected and valued during the process of the interview.

Sometimes accessing the research participants through the community health workers can end up coercing the potential participants. As discussed earlier, the VHN in rural Tamil Nadu wields significant power and controls the delivery of several important welfare schemes in the state. Therefore, when the VHN brings a researcher to the house of a potential research participant, it hampers the autonomy of the potential participant, as they may feel obliged to say yes. We have found that making it clear that the study is purely voluntary helps the VHN understand that there is no pressure from the higher up authorities to do this study. Many health workers are habituated to working to meet targets, for example, counselling at least 10 months to accept sterilization surgeries, bringing all eligible children for vaccination etc. Sometimes they are incentivised for meeting the targets, and many times they are penalized for not meeting them. Therefore, they tend to think of identifying potential research participants as one of their many health-related targets and tend to adopt coercive measures to get people to participate in research studies. In order to avoid this problem, we have found that it is very useful to declare up front that the research is not part of the health system function. We also attempted to clarify that identifying research participants for us will not impact in any way on their performance, incentives, appraisal or career. This greatly helps reduce coercion. In one of our studies, after initial experiences of possible coercion of research participants to respond to our interviews, we modified our recruitment strategy. We requested the VHN to convey the information about the study to the potential participants and get permission for us to contact them. From that point onwards the research team took over the entire recruitment, consent, interview and reporting formalities, leaving the VHN off the picture to avoid coercion.

It is very important to gain access to communities through trusted community health workers. Not only does this provide credibility to the researcher, it also creates a level of comfort for the research participant to actively involve in the interview or discussion during data collection. However, there are key issues of confidentiality and potential coercion of the research participants, which are both very important ethical considerations in the design and conduct of community based public health research. (3) These issues must be considered and discussed by the researcher at the design stage and subsequently by the ethics committee during ethics review of the research proposal.

**References:**

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