CASE STUDY RESPONSE

Rapport building and blurring identity

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Renu Addlakha (RA) sensitively portrays ethical issues and dilemmas inherent in anthropological research, particularly in research projects carried out in institutionalised settings among marginalised and stigmatised populations (1). As a conscientious researcher, well attuned to the nuances and shades of ethical questions and concerns, she was consciously and consistently reflective. Thus, she managed to identify and address competing and conflicting ethical concerns.

While working in a psychiatric setting, an anthropologist has at least three sets of 'informants' or 'respondents': health care providers, patients and their families. Each of them may have differing ideas and definitions of mental health and also different expectations regarding the desired outcome of institutional care.

Blurring identities

Building rapport is crucial to anthropological research, and the time invested in building relationships yields rich, complex data. RA notes that "... personal rapport proved invaluable, since it gave me unlimited access to the time, resources and personnel of the hospital". The process of building rapport often leads to a blurring of the researcher's identity – for hospital personnel as well as for patients and family members. Though the anthropologist may initially be viewed as a researcher, in time health personnel may regard her /him as a colleague, friend and confidant. Similarly, patients and their family members will view the researcher as an understanding and sympathetic 'health personnel', who has more access to the health resources than they do.

Anthropological methods such as participant observation and informal interviews are often not seen as research tools in the same way as a questionnaire or survey instrument is. Moreover, anthropological research is long term, and familiarity leads to development of intimacy and shedding of inhibitions. This opens up hidden areas to the researcher who is then is viewed not as an 'outsider' but as a 'quasi-insider' privy to much more sensitive information than an outsider would ever have. Even those 'respondents' who want to control the anthropologist's access to information and the observations made may find it hard to do so. Patients and family members drop their guard and discuss sensitive family matters and reveal their feelings and emotions.

Informed consent

In such situations, formal processes of obtaining informed

consent, developed in the context of structured research in medical settings where the identities and roles of the researcher are more clearly defined, may not be suitable. The emphasis on standardised written procedures for obtaining informed consent and the requirement of a formal signature have proved to be deterrents to 'full' participation by certain types of respondents. This may not be a barrier in medical institutional settings where signatures are obtained as a matter of course. Unfortunately the spirit behind informed consent is often forgotten, and it becomes a routine, standardised procedure. As RA points out, in anthropological research of a long duration, it is imperative to renew, renegotiate and reaffirm informed consent. This would be especially important if the patients' health status is in flux, if they have mood swings, and so on. Even when there is conscientious and systematic explanation of the nature of research, people with medical problems and their family members will find it difficult to comprehend that no direct benefit may accrue to them (2).

RA made a proactive decision to privilege the patient over family members, and did not include patients who were reluctant to participate even if their family members were keen. In some ways this was an easier situation to tackle, though the patient could have suffered adverse consequences. It would have been worse if the opposite had happened: if the patient wanted to participate while the family members refused, fearing stigma. Recruiting participants when their families disapprove could adversely affect the relationship between patients and care givers.

RA raises the issue of shared confidentiality between the researcher and patients and family members on the one hand, and between researcher and health personnel on the other. It is a challenge to maintain this shared confidentiality over a period of time in an institution with well-defined hierarchies. It would have been useful to examine this further with illustrations of situations where confidentiality was threatened and efforts made to maintain confidentiality, and where confidentiality had to be compromised in the interests of the patients or the institution.

Reference

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- Molyneux C S, Peshu N and Marsh K. Understanding of informed consent in a low-income setting: three case studies from the Kenyan coast. Social Science & Medicine 2004; 59: 2547-2559.