

CASE STUDY

Ethical quandaries in anthropological fieldwork in psychiatric settings

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The difficulties discussed in this case study were encountered by me during my doctoral research on mental illness among urban women. The objective of the research was to qualitatively explore the meaning of mental illness in the lives of a cohort of hospitalised mentally ill women and their families in Delhi. In addition I also examined the diagnostic and therapeutic practices of doctors to understand how cultural notions of health and illness configure their clinical work. Fieldwork was carried out in the psychiatry department of a public hospital in Delhi. The hospital was chosen as a field site for various reasons: I had visited the psychiatry department on a number of occasions during the course of my post-graduation in social work. When I later approached the departmental authorities for permission to do fieldwork for my doctoral thesis, the head of the department showed an interest in my work and a willingness to co-operate. This personal rapport proved invaluable, since it gave me unlimited access to the time, resources and personnel of the hospital. In addition to providing me the necessary credentials to approach patients and their families for the purpose of research, I was allowed to regularly participate in the routine activities of the psychiatry department, such as the medical consultations, ward rounds and case conferences. I also had free access to the patients' medical records. Indeed, without the assistance of the medical staff, it would not have been possible to accomplish this piece of research.

Conducting social science research in psychiatric settings poses certain unique ethical predicaments. It forces the researcher to examine definitions of mental illness, the social and legal status of the psychiatric patient and the role of the family. Issues of confidentiality and informed consent, not doing harm and doing justice derive meaning when the social and legal implications of psychiatric diagnosis and treatment are taken into account.

Although I had been exposed to the research ethics principles of confidentiality, informed consent, beneficence and equity, in reality it was extremely challenging to ensure compliance with them in a meaningful way. Exploring mental illness from the perspectives of patients, families and doctors conjoined with unlimited access to the infrastructure and personnel of the psychiatry department threw up some additional ethical dilemmas that I had to confront in the course of fieldwork.

For instance, although I had permission to read the case files of ward patients, I had to be mindful not to do so without seeking their permission, if not also of their family members. While introducing myself and my research, I assured both the

patients and their family members that the information they gave me would not be revealed to anyone. Several levels of confidentiality had to be ensured. First, the information would not be passed onto the doctors unless otherwise desired by either the patient or the family. Second, I also told the patients I interviewed individually that whatever they told me would not be communicated to their family members either. Since I had the privilege of attending case conferences where the case histories of persons I was interviewing were discussed, relatives would often insist on me telling them what had transpired. At these times, I had to refrain from giving any information on the grounds that I was privy to confidential information at the institutional level.

It was a very challenging experience to be at the intersection of so many levels of communication and to preserve both the confidence of the different actors and the integrity of the research. Both rational judgement and instinct played a role in helping me negotiate this tangled web of interactions.

Since I was perceived as part of the hospital, I did not come across any overt refusal to participate in the research project. While gaining access to potential informants through alignment with formal institutions such as hospitals and schools may ensure co-operation, one needs to be mindful of the fact that there is an element of duress, a kind of underlying institutional pressure on them not to refuse. This goes against the spirit of voluntarism that participation in research should ideally be based on.

Feeling that my association with the hospital might act as a coercive factor on patients and families, I took greater pains to assess the relative willingness of participants to be part of the research. I conducted several informal interviews giving details of the research project and how I sought their co-operation. I clearly stated that there was absolutely no obligation to participation, since their treatment and my research project were not at all connected. I gave them the time and opportunity to ask questions and think over my request and make an informed decision. In this way I was able to weed out participants who had doubts about being interviewed even though at an initial level they had agreed to participate.

This issue was further complicated by hierarchical patterns of social interactions in our Asian culture where submission to authority is the norm. Educational and class distinctions further accentuate the inequalities between researchers and participants in the context of public health settings. Researchers

need to be mindful of these nuances and not take participants' expressed willingness to participate in research for granted. Extra efforts need to be made to ensure that participation is indeed voluntary.

The issue of informed consent is particularly complicated when it comes to persons with a diagnosis of mental illness. Surrogate consent is more often the norm on account of the legal presumption of incompetence of the mentally ill person. However, I was not willing to fall into the conventional pattern of treating the mentally ill as incompetent to give consent. Apart from periods of acute psychotic episodes, the right of the mentally ill person to make decisions needs to be respected in principle and honoured in practice as well. At times caught between the unwillingness of the patient and the willingness of their family members to participate in the research, I chose to privilege the former because I felt that the patient had a right to refuse to become a research subject under all conditions.

Though they were clearly informed that there was no relationship between my research and the treatment that the patient was receiving, families often continued to believe that participation in the research might lead to additional privileges at the treatment level. Hence relatives tended to goad the patient into being part of the research. I had to be mindful of this manoeuvre

and actually desist from talking to patients whose families were a bit too eager to participate.

Informed consent involves the capacity for comprehension. This is affected in episodes of acute mental illness, when patients are most often hospitalised in the Indian context. How did I assess that a particular patient could satisfactorily understand the research project and be in a position to make an informed choice? First, I chose not to interview patients who had not been under treatment in the ward for a few days. As a participant observer in the ward, I was approached by patients out of curiosity. In some cases a spontaneous rapport would develop. At the time I was not aware of any competency tests to administer to arrive at an objective assessment. In addition to my own interactions with the patients, I sought the advice of attending doctors and only then decided to consider the patient as a potential research subject. In the end of course the patient and the family made the final decision.

The above account highlights some of the ethical quandaries that social science researchers in psychiatric settings may face. Indeed, given the complexity of the clinical context and the legal riders around mental illness and its treatment, it only touches the tip of the iceberg.

DRUG PRICES

Impoverishing the poor: pharmaceuticals and drug pricing in India. LOCOST/JSS, Vadodara/Bilaspur, December 2004. Suggested contribution: Rs 100.

This publication addresses pricing and related issues of the Indian drug industry, drawing upon the insights of people who have worked for access to less expensive, safer, and more rational medicine. The immediate context is a pending Supreme Court case on the Pharmaceutical Pricing Policy, 2002.

India has one of the largest pharmaceutical industries in the developing world. It can produce affordable and quality generic drugs for the entire country's needs. But it does not. Instead, the market is filled with irrational and hazardous drugs, and essential drugs are overpriced and unaffordable.

Price regulation in the pharmaceutical sector can ensure that the poor have access to essential drugs but the number of drugs under price control has been reduced from 347 to some 30 drugs, many of which are irrelevant to public health.

The articles and documents in the book provide information on and analysis of the Pharmaceutical Pricing Policy, 2002; the anarchy in retail drug pricing in India; why the market doesn't work to regulate drug prices and the dangers of focusing on economic criteria, and so on. Also included are useful documents and website urls.

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