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Research with transgendered people

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CASE STUDY

Research with transgendered people

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This case study describes HP's experiences during an independently conducted exploratory study among a community of transgendered people. Trained in anthropology and public health, HP conducted the study for her Masters' dissertation in International Health. She was supported by a fellowship from a reputed European public health institution. She worked independently; her mentor abroad was a peer and essentially a sounding board. As a full-time employee of a local research organisation, she had to conduct this field work during her free time.

The study aimed to explore biological, psychological and social factors motivating people to join the hijra or transgendered community. It also intended to examine the impact of membership in this group, their lifestyle and behaviour on their health status. One objective was to identify the group's perceived health needs and health-related help-seeking behaviour. Given the paucity of work in this area, the researcher chose an exploratory qualitative approach. A total of about 200 individuals from the community from two cities in western Maharashtra were approached - using the snowball method - and 40 consented to be interviewed. Two cities were chosen where the community is more organised and visible, enabling the researcher to approach them.

The researcher spent six months on the project familiarising herself with the community and their culture, practices and norms, and another one year on the interviews. The initial time was also used to develop a rapport with the community and enable community members to become comfortable with the researcher's presence. Interviews were mostly in residences of research participants. In-depth interviews were conducted using interview guides allowing narratives from research participants. Community members generally live in groups of five to 10 people who function as a family. The researcher mostly worked independently.

The informed decision-making process

When prospective research participants were approached they were given reasonably detailed information: they were told about the research, its objective and relevance, and about the researcher's training and her fellowship. They were assured that data would be kept confidential and all necessary precautions would be taken to protect individual identities as well as other related identity markers such as city and location of the community; only aggregated analysis would be presented in the research reports. They were also told that there would not be any direct benefits to the community or to research participants, but that the research findings might be eventually used for policy formulation. They were informed of their right to decline to participate; and also that the researcher would do her best to help them get access to health services if they were needed.

No comprehension test was conducted to evaluate the extent to which they understood this communication. No written consent was sought; the researcher did not believe that written informed consent was required since the research did not involve any medical intervention which might pose risks. Additionally, she anticipated difficulties seeking written informed consent with non-literate people speaking various different languages. Four withdrew from the interview half way through, either because of pressure from their 'gurus' or because they were uncomfortable with the interview.

Gate keepers

The community is organised around the 'guru-chela' (teacher-student or leader-follower) relationship, one based on hierarchy and power. Gurus were also effectively gate keepers controlling the researcher's access to individual prospective participants. While individuals were approached independently, the 'guru-chela' relationship determined their participation in the study. For example, one large group could not be approached as the guru of that group denied the researcher permission. Four people withdrew half-way through the interview when their guru entered the room. In some cases, the researcher felt that the gurus' presence at interviews affected research participants' responsiveness and the quality of information. In two instances, individuals indicated that they wanted to participate despite their guru's refusal. The researcher spoke to them but did not include them as she anticipated risks to them after she withdrew from the field. By now she was aware of the strong social networks in the

community. Heavy penalties were inflicted on those who went against their guru's pronouncement. The researcher weighed the conflicting demands of autonomy and non-maleficence and judged that the latter was more important in this case. However, she still asks herself if this was indeed the best strategy for a researcher in such a situation.

Dealing with research participants' expectations

Over the year, interactions with this marginalised community gradually raised the community's expectations from the researcher. For example, one person reported having been badly beaten up for roadside prostitution which is illegal, and said she would file a case against the police the next day. The researcher helped with medical first aid. The TG person did not indicate that she had any other expectations but over the next few days she stopped talking to the researcher. When asked about this silence, she said the researcher had not done anything to help the TG person who was going through a rough period and wanted help to file a case and follow up. This was unexpected for the researcher.

The researcher found this difficult to address because though she understood the person's need she had neither the expertise nor the resources to help. There were many such equally compelling situations she could not do much about. For example TG persons looked for help getting ration cards made, providing guarantees for bank accounts, preparing loan applications, help getting housing and so on. Many wanted information on and references for sex change procedures. The researcher found this frustrating. In some situations - such as accompanying someone to the hospital, arranging for free care, providing space to discuss their health-related concerns - she extended whatever help was possible. This, she felt, was the least she could offer as a token of gratitude towards their cooperation for her research. She was not affiliated to any institution which might be better able to meet such needs in the research setting. This posed a serious concern for the researcher. To what extent should the researcher be equipped to meet with a community's wide ranging expectations? When and how should one limit the researcher's responsibilities towards the community and research participants? Are these responsibilities different for independent researchers than for researchers affiliated to institutions? Would this then imply different ethical standards for these categories of researchers?

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