

Action research with HIV-positive women and state service providers in Vietnam

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Challenges of participant observation

- Participant observation is a key method of anthropologists, a rite of passage in the discipline.
- Conceptual tension between the dual roles of participants and observers can frustrate collaboration between anthropologists and medical staff during research in health settings

What are anthropologists supposed to do when they observe?

Combining roles?

- Anthropologists who work in resource-poor settings are often confronted with requests for assistance. Hence their “participant observer” status can place them in an uncomfortable position.
- In public health action research, the goal is not just to learn but also to change and improve the status quo. Researchers and the persons studied, identify a problem, research the root causes and develop interventions
- Could anthropologists combine roles, as health practitioners and researchers?

Linking research to practice

- Research questions developed out of experience: Lack of attention to mothers in traditional PMTCT programs that provided little or no postnatal care and support for the mothers themselves, raising ethical and medical questions.
- A team of physicians and social scientists worked on a PMTCT program to improve access to care and support for HIV+ mothers, through the first Vietnamese support group of HIV+ mothers, the Sunflowers
- Data was collected over three years

Multiple roles but one goal

- Aim: reform the health and social service system in Vietnam for HIV-positive pregnant women and young mothers after delivery so that they could raise their children with a minimum risk of HIV transmission.
- A pilot demonstrates the approach in practice
- Research is a tool to advocate for policy changes.

Key challenges for medical anthropologists who are not practitioners

Three tensions can be distinguished for participant observation

- 1) Frictions between insider and outsider perspectives
- 2) Maintaining distance as opposed to being involved
- 3) Non-intervention versus intervention.

Insider vs Outsider: working with gatekeepers

- Gatekeepers -- people who are involved on the inside and who control access to information or people -- can be very useful resource persons directing outsiders efficiently to appropriate organizations, people and documents in their network.
- Gatekeepers are also well-known obstacles for journalists and researchers alike
- Health staff can be reluctant to have an anthropologist 'hang out'
- Outsiders may observe things that should not be seen, or interpreting what they see in an unfavorable way
- Anthropologists question biomedicine's claim to always know what is best for patients
- Patients who suffer from stigmatizing conditions, such as infertility or HIV also desire privacy

Insider vs Outsider: working with gatekeepers (cont.)

- As managers we had extensive "insider" knowledge of the state system and working relationships with important "gatekeepers."
- We had mobilized supporters at the policy-making level as well as in the community.
- As a foreigner working for an international NGO, we could avoid most internal Vietnamese political issues but still move around the system and in the community

Insider vs Outsider: working with gatekeepers (cont.)

- Specific negotiations and challenges of conducting fieldwork in transitional socialist countries, such as Russia and Vietnam, surveillance, bureaucracy, commodification and corruption.
- Health managers have systems and tools such as cost norms to deal with some of these challenges
- Dual role can help with assuring access to optimum care; a standard ethical requirement of research in medical settings.

Insider vs Outsider: working with gatekeepers (cont.)

- Consent forms required for researchers in any medical setting.
- Mandatory testing, HIV notification and lack of privacy ethically unacceptable in both roles, hence work in the community.
- Negotiate privacy: If people did not feel safe because we had disclosed our researcher's status, we risked losing them=>could be life threatening
- All the research assistants, except one HIV-positive male health practitioner, had 'insiders' perspective as mothers.

Maintaining distance as opposed to being involved

- Engaged anthropology: Rather than keeping their distance, medical anthropologists should reveal, discuss and address the broader socio-economic, cultural and political contexts in which health inequities are reproduced
- Benefits and risks of: 'Intersubjectivity,' shared cognition and consensus might increase the empathy with medical professionals **but** maybe at the cost of empathy with patients. Staff and patients are not always making the same decisions.

Maintaining distance as opposed to being involved

- Social scientists complain of 'project syndrome,' treating researchers as potential financial donors. We were program managers in these areas. Being seen as a donor was a clear and accepted part of our identity.
- A particular difficulty of my dual role (and still is) was that I should not be allowed to observe interactions in which doctors were bribed. It embarrasses everyone. And bribery is common.

Non-intervention versus intervention

- As the benefits of mother-focused PMTCT were clear, non-intervention versus intervention was never an issue.
- Dual roles allowed to see problems from multiple perspectives; patients complain about care. Health workers are often ill informed or ill equipped.
- Often the line between non-interference and intervening is blurred.
- Working in the field demands many decisions in a day, and research contexts in developing countries may be different from those in (well-funded and well-regulated) home countries.

Results of dual role

- The dual role allowed for efficient integration of research findings into improving program performance.
- Through the program women could access new opportunities provided by international donors. Almost all of the women and their children are still healthy today.
- HIV+ women and state service providers used the research results to promote mother-centered PMTCT.
- HIV+ women used the research to advocate for chans, advocacy training and support provided by the program.
- This collaboration was key to changing Vietnamese national policy: care and support for HIV+ women after delivery is now compulsory (MOH 2007)
