

*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?*

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*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?

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*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

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*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.

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*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.

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*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

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*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

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*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.

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*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.

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*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.

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*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.

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### *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 changes, 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).