

Observations on action research with HIV-positive women and state service providers in northern Vietnam

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This article examines some of the challenges and opportunities of combining the roles of a health professional and a medical anthropological researcher, based on the author's experiences combining PhD action research with management of interventions on prevention of mother-to-child transmission of HIV in Vietnam. She examines the opportunities and the challenges of these dual roles to resolve three distinct anthropological dilemmas: 1) the friction between insider and outsider perspectives; 2) maintaining distance as opposed to being involved; and 3) non-intervention versus intervention. In this case, a combination of roles was efficient. Using existing rules, procedures and structures of the program had various important practical, methodological and ethical advantages. The dual role allowed for efficient integration of research findings into improving program performance and for developing realistic and evidence-based policy recommendations that resulted in a new national policy that acknowledged the rights of HIV-positive mothers to receive treatment and support.

[action research, medical anthropology, AIDS, PMTCT, gender, Vietnam]

Participant observation can be a frustrating professional experience for anthropologists. As there is a conceptual tension between the dual roles of participants and observers, anthropologists can be unclear about what they are supposed to do when they observe. In many situations there is considerable pressure and stress due to the hope, even expectation, that the research will yield concrete and measurable outcomes for the population or the institutions being studied. Anthropologists who work on medical issues in hospitals in resource-poor settings, for example, are likely to be confronted with requests for assistance or advice from staff, patients and their families. Hence their social, professional and ethical position as a 'participant observer' can place them in an uncomfortable position. In this article, I examine some of the opportunities and challenges of combining my own roles as an international health professional and action researcher on HIV/AIDS in a resource-poor but stable country in transition. 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 (Hart & Bond 1995; Meyer 2000; Black 2001). Since 2004, I have worked as a senior health advisor on HIV/AIDS and gender programs for the Medical Committee Netherlands Vietnam in Vietnam. During my PhD research in northern Vietnam from 2005 to 2008, I combined my professional role with my PhD candidacy at the Amsterdam School of Social Science Research in medical anthropology and action research on prevention of mother-to-child transmission of HIV (Oosterhoff 2008).

I will explore some of the opportunities and challenges of these dual roles during the formulation of the research problem and the implementation of the action-research project, such as the data collection and the analysis and use of the research results, followed by a discussion on the relevance and limitations of my experience. In order to clarify some of the disadvantages and advantages of the dual role, it might be useful to identify some of the tensions that can surface when one takes on the roles of researcher and health professional. Three distinct tensions emerged: 1) frictions between insider and outsider perspectives; 2) maintaining distance as opposed to being involved; and 3) non-intervention versus intervention. I will also discuss some of the ethical implications of managing a dual role, specifically balancing work and the psychological burdens of the double role.

Developing research questions out of experience

The formulation of the hypothesis, data collection and data analysis for my PhD thesis was linked to a pilot intervention that provided a wide range of prevention of mother-to-child transmission (PMTCT) services to seropositive mothers and pregnant women in Vietnam. PMTCT is a commonly used term for programs and interventions designed to reduce the risk of mother-to-child transmission of HIV. The program in which I was involved aimed to remedy the lack of attention to mothers in traditional PMTCT programs that provided little or no postnatal care and support for the mothers themselves, such as access to antiretroviral treatment (ART) and economic- and psycho-social support. In Vietnam, as in other low-income or developing countries, few pregnant women used the PMTCT services that were available because there was no support for them to stay alive and raise their own children. In many countries, AIDS workers involved in care and support programs, such as myself, watched young mothers die while expensive PMTCT facilities were underutilized.

My colleagues and I knew that policymakers often have goals (electoral, financial) other than clinical effectiveness, or the social environment may not be conducive to policy change (Black 2001). But we believed that we could reform the system in Vietnam by improving comprehensive care and support for HIV-positive pregnant women and young mothers after delivery so that they could raise their children with a minimum risk of HIV transmission. To do this, we needed a pilot project to demonstrate the approach, to collect concrete medical, social and economic indicators to measure program progress, and to use the evidence to advocate for mother-focused national-

level policy changes. To us, combining the roles as anthropologists and health practitioners in action research and program development seemed an efficient way to learn how the existing program could be improved.

The data collection for the PhD research covered a period of three years, during which a multidisciplinary team of medical doctors and social scientists followed the conceptualization, foundation and organizational development of the first support group for HIV-positive mothers in Vietnam (Oosterhoff 2008a). From the first meeting in 2004 until early 2007, the lead researchers followed and worked with the first Vietnamese support group of and for HIV-positive mothers, the Sunflowers, in their interaction with a network of governmental and international non-governmental organizations that provided the health, social and economic services that these women needed. In the period studied, the group in Hanoi grew from four mothers to 305 mothers and caretakers, later expanding to three other provinces: Thai Nguyen, Quang Ninh and Cao Bang.

Insider versus outsider perspectives

Gatekeepers – people who are involved from 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 (Lewin 1947; Hammersley & Atkinson 2007). In order to pass them and get access to the people of their choice, researchers have employed a variety of tactics and strategies. Frequently mentioned ploys are taking part-time jobs to study a work situation (Pettinger 2005), disguising their interests (Chambliss 1975) and loitering around, hoping to make contact (Anderson 2006). In exceptional cases anthropologists have gone completely undercover, which invariably raises questions about their professional and political engagement and identity. Nancy Scheper-Hughes, for example, went undercover for her research into the human organ trade. Although she did get past the gatekeepers and gained insight into the workings of this controversial business, she still wondered how one should investigate covert and criminal behavior anthropologically. To whom does one owe one's loyalties when crimes are being committed (Scheper-Hughes 2004)? Besides negotiating with gatekeepers, researchers have to manage their image to people who are not familiar with research, but who are part of the social setting(s) being studied. Some of those being studied may suspect that the researcher is an undercover tax collector or internal affairs investigator (Hunt 1984). There are researchers who take years to establish a relationship with a group before telling them what the purpose is (Wolf 1991). Although researchers may not inform everyone who they are and what their purpose is, it is rare that no one involved knows about the research. It is more likely that some people are kept in the dark while others are informed (Hammersley & Atkinson 2007).

Hospitals are a particularly difficult place for researchers who do not have a professional role. How will health staff introduce an anthropologist when the patient's pri-

vacy needs to be protected? Some anthropologists have observed that health staff can be reluctant to have an anthropologist 'hang out' because they worry about outsiders observing things that should not be seen, or interpreting what they see in an unfavorable way (Van der Geest & Sarkodie 1998). This fear is well founded: a number of anthropologists and other social scientists have questioned the legitimacy and purpose of biomedicine, emphasizing the dehumanizing aspects of the 'medical gaze' and the controlling features of biomedicine (Foucault 1963). Indeed, there have been cases where health staff prevented the publication of social science research, using the argument of patient privacy (Van Danzig & De Swaan 1978; Van der Geest 1989). Health staff may want to hide the payment of under-the-table fees, dirty toilets, stigmatization and discrimination of the poor, beds with unattended patients, or worse, which are well-documented features in hospitals, particularly, though not exclusively, in many developing countries (Savedoff & Hussman 2006; Lifton 2004). However, it may not just be health staff who do not welcome outside researchers; patients who suffer from stigmatizing conditions, such as infertility or HIV, generally desire privacy (Inhorn 1996). Skeptic anthropologists are justified in questioning biomedicine's claim to always know what is best for patients. Yet one cannot seriously deny the health benefits of antiretrovirals for people with HIV or artesunate for those suffering from malaria. An emphasis on biomedical reductionism – a critical attitude towards authorities, including health authorities – combined with their lack of medical knowledge and working experience in a health setting, may have caused unnecessary pessimism among anthropologists about the possibility of making positive changes. These attitudes and beliefs may also have reinforced some of the perceptions among health professionals of anthropologists as rather prejudiced outsiders (Van der Geest 1995).

The dividing lines between insiders and outsiders are actually rather blurred. Note that patients, researchers and health staff spend most of their lives outside hospitals. The external social context is important in shaping the moral sentiments and ethics behind medical decision-making inside hospitals, such as the use of prenatal diagnostic technology, for example (Gammeltoft 2007; Rapp 1997). Hence, health workers sometimes support the decision of their patients against their own medical judgment for cultural rather than medical reasons (Oosterhoff 2008). One of the reasons why hospitals are such interesting places for medical anthropologists is because they are spaces where doctors, nurses and patients find evidence for various, and possibly contradictory, values and beliefs (Van Amstel & Van der Geest 2004).

A number of qualitative social researchers have discussed the powerful role of a centralized state when it comes to specific negotiations and challenges of conducting fieldwork in transitional socialist countries, such as Russia and Vietnam (De Soto & Dudwick 2000). Obtaining official approval to conduct independent fieldwork can be a complex process in Vietnam (Marr 1993). Researchers in Vietnam may find a number of police divisions at different state levels involved in their fieldwork. These can be very helpful, for example, as sources of information on crime statistics. But they may also require the researcher to submit considerable paperwork, such as detailed research plans, and the names of proposed interviewees for 'security' reasons. The names of these divisions can be intimidating to outsiders. For example, Division

A37 is the Office of Counter Espionage from Western Countries (Cục chống gián điệp các nước tây âu) and PA25 is the Office for Protecting Cultural Ideology and Interior Security (Phòng bảo vệ an ninh nội bộ và văn hóa tư tưởng). Both as researchers and as health professionals we had to obtain official permission before meeting any officials whether for the operational program or the research. An advantage of our existing program was that my colleagues were used to this and had request letters ready on our computers to be printed and signed. Researchers who have not worked in former communist countries, or who have been trained in other parts of the world, and do not have the benefits of working through an experienced local organization, not surprisingly find this system complex and hostile (Scott, Miller & Lloyd 2006). It is not uncommon for programs of study in Vietnam to be derailed because of bureaucratic requirements. Several researchers thought they could get access to data and people through an international non-governmental organization (NGO), only to discover upon their arrival that the NGO was not authorized to give them authorization to do the research. Some worked through a local research institute or NGO, which readily cleared their paperwork and provided research assistants, but they then found that the individuals supplied had no skills or experience. In some instances these individuals could not be fired or replaced because the local organization, not the researcher, was the main employer. A number of researchers learned perfect Vietnamese but failed to obtain permission to visit their research site, thus they had to rely exclusively on local assistants, over whom they had little control, to conduct the interviews. Managing a pre-existing operational program made it far easier for us to avoid and overcome bureaucratic hurdles.

Besides specific state-imposed restrictions, 'traditional' anthropological research is difficult to conduct in crowded urban Vietnamese settings, such as Hanoi, where there is little privacy yet many social taboos. Because of the HIV notification system, in which households with a HIV-positive individual get the test results in their home, many families are particularly worried about visitors (Oosterhoff et al 2008d). Spontaneous visits, which anthropologists prefer, are not always appreciated. Visits by foreigners, researchers or people who are considered wealthy can be a problem for all Vietnamese families, not just for people infected and affected by HIV and addiction. Some household members may still have memories of a time following the American War when Vietnam operated a highly sophisticated system of state agents who reported on everyone's moves. (Many older Vietnamese still have the habit of cutting up a chicken with scissors, as the sound of a meat cleaver on a chopping board would let their neighbors know they had managed to get meat during a time of food rationing).

Local authorities still keep lists of drug users and HIV-positive persons; the names on these lists are a 'public secret.' All over Vietnam, government officials use megaphones several times a day to announce a variety of news: reminders for dog owners to bring their animals in to be vaccinated at a certain hour, reminders for the poor to pick up their insurance cards, for the elderly to pick up their pensions, or news about the war in Iraq. When names of middle-class HIV-positive persons in some communes in Hanoi are broadcast over the community megaphones, along with the names of the poor who have been selected for special food assistance, everyone thinks they know

what this means, fuelling gossip. Fieldwork in this context is challenging and could even cause harm. To avoid any potential embarrassment by our presence, in Hanoi we conducted interviews in the Red Cross office; in Thai Nguyen we met people in a state cultural house where social clubs such as “the good mother club” and “the two child club” also gather.

I did not encounter some of the problems that many foreign researchers face. Before we started conducting our research, we already had extensive knowledge of the state system, as well as working relationships with important ‘gatekeepers.’ As a program manager at an international non-governmental organization I had already obtained permission to work in the country and had mobilized a network of people who supported our work at the policy-making level as well as in the community.

My team and I had selected sites for the pilot intervention based on public health criteria such as HIV prevalence, the organization of the health system, the absence of other programs (to avoid overlap) and the willingness and ability of authorities to cooperate. It is therefore not very surprising that during the research, our team found that authorities were open and cooperative; they were either the same people, they were in the same network or they had heard of our program and approved of our work. The selection of research interviewees followed similar criteria as the intervention. The culture of ‘saving face’ in Vietnam, combined with knowing whom to ask permission, also helped to make the data collection go smoothly. The corollary is that people who do not like your project or your questions (for whatever reason) tend to avoid you. There were bureaucrats who probably knew how to avoid us in person and delegated the meeting and the handover of documents to a different person, who would be assigned to tell us that so-and-so was ‘too busy.’

Because of our roles as health professionals we were insiders in some aspects of the lives of the people we studied. It was relatively easy for us to find HIV-positive women because we could offer these women access to a high-quality package of socio-economic and medical services, and many of them knew us already. Assuring access to optimum care is a standard requirement of research in medical settings, (Katz 2006, Office for Human Research Protections 2005). If anthropologists want to conduct research in medical settings they need to be informed about these protective measures for patients and make specific preparations. The ease with which we found HIV-positive women to interview and track contrasts with the difficulty many other HIV researchers have experienced in locating subjects because of HIV-related stigma, in addition to socio-economic problems such as poverty, unemployment and racism (Wu 2007, Swartz 1998). An explicit aim of our work was to create a ‘safe space’ where HIV-positive women could share private concerns that they could not share elsewhere. A concern was how to keep the relationship of trust once we revealed to the women and the authorities that we were also planning to conduct research. If people did not feel safe because we had disclosed our researcher’s status, we risked losing them. If they chose to discontinue treatment because of our research efforts the results could be life threatening.

As health professionals we had to continue the relationship with both the women and the authorities after the research. For an honest and productive relationship it

seemed both logical and practical to us to make an explicit research bargain with open and clear procedures that allowed people to have an informed choice about the research. Over the years, as health professionals we had collected many personal stories from people during my program work, but using these stories would raise ethical questions about informed consent. Therefore, for this research project, we used pre-tested and semi-structured questionnaires that asked about HIV care and support, family participation and experiences with counselling and testing, PMTCT and antiretroviral treatment (Oosterhoff 2008).

Consent forms are a required method for researchers in any medical setting and Vietnam is no different. Medical ethical review boards demand to see semi-structured questionnaires. The formalized procedures and informed consent from various gatekeepers, such as doctors and nurses and the HIV-positive women, worked well for us in the sense that we received answers to questions and cooperation, the latter of which is partly reflected and documented in signed consent forms. As the relationships with the women and the authorities continued for years after the research it seems we managed as researchers to protect the safe space we had helped to create as health practitioners.

The potential importance of common personal empathy in the analysis of events shared or observed during the research process is well documented in the social sciences. One of the premises of Sunflowers, the support group for HIV-positive mothers that we work with, is that the personal experiences of members living with HIV helps members to understand and support other women living with HIV. In some Sunflower groups all members have to be mothers who are living with HIV, while in others, members can be HIV-positive women without children. Empathy is a complex emotion or attitude. As many doctors can attest, it is possible to understand people's situations or problems and help them without feeling sympathy or empathy for them. Nor is empathy a prerequisite for a medical anthropologist. Yet empathy can help interviewers to ask the right questions or provide insights into motivations for behavior that one is not used to (Fainzang 2007). Well known, for example is Renato Rosaldo's description how he only understood the relationship between grief and rage when his spouse died, and how his own rage helped him understand what the Ilongot headhunters from northern Luzon, the Philippines, had shared with him when they described their feelings of release when they took a head after the death of a loved one (Rosaldo 1980). His first explanation that this may be some kind of population control was utterly unintelligible to the Ilongot. It was only after his wife's accidental death in the field, that Rosaldo came to understand why the Ilongot men took heads for their loved ones. His unbearable rage and sorrow led him to see what drove the Ilongot.

It is therefore also probably worth mentioning that as a Dutch woman, I am clearly an outsider in Vietnam in many ways. But I and my colleagues, and all the research assistants, except one HIV-positive male health practitioner, all had another 'insiders' perspective that may have helped us to access information. The lead researchers were all women with children of less than six years of age at the time. In a Vietnamese context, where motherhood is revered and childlessness is highly stigmatized, being married and being a mother is very important for one's social status, and for being

considered a worthy person to talk to about family matters. It is easy to feel empathy and sympathy with a tired young mother if one has also been woken up several times in a night by a hungry infant. As mothers we usually carried something in our bags – pencils, notebooks or candy – to keep our own children busy in public spaces. So we always had something to keep the children of the mothers we were interviewing occupied. When we organized activities such as playgroups and childcare, discussions about being a mother felt natural. As mothers we could cope well with and bond over the tantrums of their two-year olds, teething and tired babies even though as health professionals or researchers crying children can also be considered an inconvenience.

It should also be noted that as a cultural outsider, I could also ask some questions which my Vietnamese colleagues reportedly did not feel comfortable asking, such as whether a woman had ever wanted to commit suicide, and whether she had the means, a time and a place to kill herself. Women who wanted to commit suicide reported feeling extremely relieved about these ‘insensitive’ questions because it gave them an opportunity to share feelings that they had felt guilty about because of the social taboos on suicide, especially on suicidal mothers. I feel fairly comfortable asking such questions because I have substantial experience addressing substance addiction and depression among members of my family. Having dealt with depressed mothers of healthy, young children for many years I have some experience with asking questions in a way that allow the women to save face.

Keeping distance as opposed to being involved

The discussions on the tensions and contradictory impulses between keeping one’s distance versus being involved are part of standard textbooks on research methods and classes in anthropology (Bernard 2005). Several well-known medical anthropologists, such as Paul Farmer and Nancy Scheper-Hughes, argue that 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 (Farmer 2003, Scheper-Hughes 1992). Others such as Byron Good have added that a distant, non-involved approach, as opposed to an explicitly action-oriented one, may lead to inaction, and expose anthropologists to criticism of unwarranted complacency (Good 1994, Wilson 2004).

For anthropologists who believe that the social sciences should be involved, combining the roles of health professional and social science researcher offers a practical means of both observing and participating. A number of medical anthropologists, from W.H. Rivers and Robert I. Levy to Paul Farmer and Arthur Kleinman, forged a professional role for themselves in hospitals because they had their primary training in medicine, nursing, psychology or psychiatry.

Such dual roles offer practical advantages, for example having a natural relationship with colleagues and patients with whom one can regularly discuss research directions and ideas. It also provides action-focused researchers with an existing organizational and institutional context that can provide immediate support in terms

of human resources, methods and tools for data collection, and can possibly facilitate the implementation of any recommendations without much delay. Working with authorities might help to influence our moral judgment of behaviors in a biomedical setting. It might allow for greater empathy, both with medical professionals and patients because it enables the researcher to better understand the context in which decisions are made. A joint working experience could help to establish '*intersubjectivity*,' a shared cognition and consensus about the situation we study. However, it might increase the empathy with medical professionals at the cost of empathy with patients. Staff and patients are, after all, not always making the same decisions. Perhaps as a researcher one could distinguish the context in which decisions are made (medical professionals) and in which treatment is experienced (the patients) and examine the links between these worlds.

Our formalized and structured data collection methods, after a very intense period of direct program involvement, differed from the traditional anthropological approach of taking up long-term residence with a community and trying to gain the confidence of subjects. Having initiated the intervention in partnership with a Vietnamese medical lecturer and researcher, four HIV-positive women, the Vietnamese Red Cross and a Vietnamese doctor who had access to antiretrovirals in a district hospital, we were extremely involved. We identified the HIV-positive women, trained social, medical and economic service providers, wrote proposals to raise the money for these trainings and other activities HIV-positive mothers needed, provided counseling and conflict resolution to individuals and groups, talked to the media, took women to hospitals, drunk liters of strong tea listening to long lists of complaints and problems, played with children, wrote and corrected speeches, and did simple menial jobs (arranging chairs and tables, buying food and office supplies, and washing dishes). In the early pilot phase we were frequently annoying our families by being on the phone until 10 p.m., text messaging until 2 a.m. to monitor a delivery and were back on the phone again by 6 a.m. After a year we could and had to delegate the work because we grew too big, had enough money and knew ourselves how to work with the system to keep these mothers and their children alive.

Social scientists have noted that 'project syndrome,' treating researchers as potential financial donors, was particularly strong in 'project areas' in Vietnam (Scott, Miller & Lloyd 2006). We were actually already program managers in these areas so it was a clear and accepted part of our identity. We reimbursed each interviewee, including health staff, with a small amount of money for their time and effort as many researchers in medical settings do. Fees were based on program stipends and, as part of our standard operating procedures, were compared with stipends in other research programs to ensure they were reasonable. When there were individual requests for favors or money, we could politely show people cost norms, a reimbursement scale in print, which quickly ended any discussion.

Hospitals, in contrast, did not always have such procedures and we had more stressful experiences in those settings. Commodification, the transformation of information and services into a sales item, has also been described as a specifically frustrating feature of research in transition countries like Vietnam (Christoplos 1995). Commodi-

fication of information can take many forms. Researchers commonly complain among one other about having to pay for what seems to be public reports or reports with data that they think should be freely accessible. This can be very simple information, such as a book with compiled statistical data on social service usage in a district. Commodification of services in the hospital was problematic for me during this research both as a researcher and as a health professional. A particular difficulty of my dual role was (and still is) that I should not be allowed to observe interactions in which doctors were bribed. A number of women wanted to pay money to the doctor to get services even if they were free, and they did not want me or my colleagues to be present because as international health professionals who promote public access to health we would be obliged to complain.

This phenomenon of paying to access free services is a public secret. (The practice is not limited to the health sector; it is also common to give teachers gifts or money for 'Teacher's Day' or for 'long working hours' before an exam.) We informed the women that they did not have to pay for services while in the hospital but they did so in order not to go against the advice of their families. These payments can and often do make a difference in the quality of care. Although under-the-table fees are very common, the women were embarrassed to be seen handing over the money. As researchers and health professionals we reluctantly complied with their wishes by withdrawing rather than trying to stay involved and solve the problem, which felt like giving in to the very practice we wanted to change.

Non-intervention versus intervention

Although many anthropologists argue for a hands-off, non-interventionist approach there are also textbook examples of anthropologists who choose to intervene as part of their data collection process, showing that an intervention can be as effective as a method. Evans-Pritchard for example helped one of his assistants to become an apprentice of a witch doctor in order to gather information. Audrey Richards used her own funds to pay organizers to hold an initiation rite for girls that had not been held for some years in order to study it (Richards 1956). Also, in working with and inside health systems, anthropologists can gain insights from methods that actively perturb the system, and then measure and observe the responses in order to learn more about the cultural norms and values of people in that system (Cassell 2002).

In some cases the non-intervention of a researcher could even be considered immoral. For example, most would consider it wrong for an anthropologist who had a surplus of malaria medicines with her, to not share her medicines with the community she studied who suffered from this disease because of fears that it would interfere with their ability to develop natural resistance (Cassell & Jacobs 2007). But knowing when and where to draw the line between non-interference and intervening is not an easy task. Working in the field demands many decisions in a day, and research contexts may be different from those in their (well-funded and well-regulated) home countries. Van Amstel, a Dutch physiotherapist and anthropologist worked for three years as

a researcher and a health practitioner in a hospital in the Highlands of Papua New Guinea, a place that is infamous for its violence. He believed, as I do, that it would be an efficient combination. As a health professional it is easy to observe hospitals and authorities during one's daily work, but one also learns a lot about operational and budget management. He was able to combine these roles to some extent, but quit his medical job after he became 'more deeply involved' in the daily activities of the hospital. It appears his dual role became difficult because of his hospital's position as an important institution for retribution in compensation claims of physical damage in cases involving violence or an accident (Van Amstel & Van der Geest 2004).

Medical professionals with their focus on interventions and problem solving based on evidence, sometimes have little patience for scientists who seem to lack an interest in solving problems (Holstein & Miller 1993). It would have been fascinating to repeat the experiment of posing as a patient or trying to be treated as a patient in a local setting (Van der Geest & Sarkodie 1998). I could have tried to convince our gatekeepers to allow me to deliver my own baby in one of the state hospitals where we worked as part of the research. But given what we had seen and heard during our work, neither I, nor anyone from our team (all Vietnamese), wanted to risk being exposed to that quality of treatment and instead used private services.

After hearing many horror stories from HIV-positive women through the support groups, we asked to be taken around the hospitals as if we were real patients, i.e., a pregnant woman who wants to have an abortion, a pregnant woman who knows she has HIV, a pregnant woman who comes in for antenatal care who does not know she has HIV and a pregnant woman who finds out during an antenatal visit that she is HIV positive. This experiment revealed the fragmentation of the Vietnamese health services, with services scattered across various geographical locations, especially in the city of Hanoi. Each site has different working schedules, which are not posted. And if one calls the contact telephone numbers that are advertised the phones are almost never picked up. Health care services are not linked. Staff appeared unwilling to refer us to other departments. The chaotic nature of services in Hanoi is such that to date we have been unable to complete a flowchart of PMTCT services, although literally dozens of attempts have been made. Even something as simple as how blood results are relayed through the system ended up as a messy bundle of lines and arrows on papers and screens.

We moved around at all levels of the fragmented, vertical health system, and learned that workers in this system are often ill informed or ill equipped to do the work that is assigned to them. This is frustrating to listen to as a health professional because many of these people seemed eager to do a good job but were unable to do so because they worked within dysfunctional structures. For example, it is not clear to which department HIV-positive persons who want to obtain family planning services should go. The family planning department may send them to the preventive health department where there is supposed to be HIV-specific experience. Staff at this department may, however, send the person back because they lack experience and materials for family planning.

Both patients and health staff in the HIV departments were also under pressure, not just from a heavy workload, but also because of a lack of knowledge about HIV

transmission and the fears of being exposed to infectious opportunistic infections, such as tuberculosis. Health staff expressed concern about the risk of infection and they were anxious about their perceived lowered social status by working with HIV patients, which is a low-level position, especially for young women, because of the association between the disease and drug use. Such perceptions were not entirely unjustified. There were patients, their husbands or their families who violated hospital rules by injecting drugs or dealing drugs on hospital grounds. Some behaved aggressively or unpredictably by threatening to kill a nurse or themselves. Yet health staff had no recourse or physical protection. Moreover, training on counseling and conflict mediation is not part of the curriculum in medical schools.

We examined the immediate possible program implications of our findings. Because the program and the research were conducted in a participatory fashion, we discussed some of our questions about the data with the HIV-positive women themselves. For example we found that a number of husbands mentioned that they contracted HIV from using drugs but their wives said they had been to a sex worker instead. We reported this difference back to the women, who conceded that they were covering up for their husbands. They gave many examples about how they protected their husbands and what would happen if they did not uphold the public face of the family – information that was useful for the program and the research. Because of the discussions in the group where women expressed their extreme worry about not having a son, I re-visited my data and found that only HIV-positive women who had no sons and who were married to a ‘lineage holder’ were willing to take the risk and try for a child. While finding out that ‘son preference’ does not stop in families living with HIV may be an interesting finding, as a researcher it is frustrating from a management perspective as ‘son preference’ in an Asian context is certainly not something a program will be able to change any time soon.

However, based on the action research and the pilot we were able to conduct several interventions in order to improve a continuum of care. Almost all the women with whom we started the work and their children are still alive and well today. They are, with a few exceptions, in much better shape than when we met them. We did take the lead in changing a national policy that made care and support for women after delivery compulsory (MOH 2007). This provided us with some relief as researchers and practitioners. But it also raised the next operational and research questions: how can mother-centered care and support actually be scaled up at a national level in remote areas in a country as diverse as Vietnam?

Discussion and conclusion

The experience of working as a healthcare professional while conducting research for my PhD was largely a successful one. While inevitably there were conflicts, the dual perspectives of insider and outsider actually complemented each other well. As someone already working in a program with the Vietnam healthcare system, the paperwork and lengthy approval process unique to Vietnam, was only a minor inconvenience, as

opposed to being a stumbling block it would be to a complete outsider. As an outsider – a foreigner working for an international NGO – I was not part of the Vietnamese health system in the same way a local doctor or nurse is, and had more opportunities to move around the system and to follow patients in the community. Another advantage of being a researcher is that it requires critical reflection about the meaning of the daily work, which requires distance. I readily acknowledge that I did not always maintain a traditional professional distance. When one of the women in the program became very ill we visited her in her last days, and we attended the burial services with her family and members of the Sunflowers' group. Her death was devastating yet we were comforted knowing we all had done what we could and had not kept our distance.

'Outsiders' and 'insiders' of the health profession in hospital- and community-based settings could agree on the goal of HIV-positive pregnant women to prevent vertical transmission to their unborn children and helping mothers to raise their children. Medical professionals in Vietnam make their decisions, however, within a highly fragmented verticalized and commodified health system in a transitional economy where the interests of healthcare workers and those of the patients are all too often at odds. The research and the pilot project allowed us to move inside and outside the health system, which helped to develop 'intersubjectivity' at many levels. But I agree with Fainzang (2007) that there are no clear casual relations between empathy, sympathy and the production of knowledge and understanding. I understand that many of the women we worked with feel pressured to get married and have children, and may therefore feel that they have to accept having children with a male intravenous drug user. But I do not accept that they are in situations with such limited options. I understand how the system works and can empathize with the pressures both patients and health staff are coping with, yet I feel little sympathy for some of the financial practices I have seen between patients and health staff.

The issue of non-intervention versus intervention was never an issue for me in either role. As the benefits of mother-focused PMTCT were crystal clear to me from an ethical, medical and human rights perspective we wanted to intervene to help these women raise their own children and prevent the children from becoming orphans.

I had little time to worry. I was responsible for a 1.4 million euro program, a team of seven employees and a dozen consultants who coached around a hundred staff and support group leaders at partner organizations. I also had the competing demands of being a mother of two young children in addition to being a PhD student. The multiple roles also meant I did not experience many of the problems that other researchers have described to me: loneliness, a fear of individual personal bias (although one can never get rid of bias, just minimize it), or the inefficiency of trying to get access to sites. When I worried if my perspective was intelligible to others I was able to confer with colleagues or Sunflowers members.

Despite these apparent benefits, there are methodological dilemmas to this approach. For example, were the research 'subjects' able to distinguish my dual roles as practitioner and researcher, given that they had previously known me only as a practitioner? Our solution to the ethical problem of disclosure of my research status to the people who had known me as a program manager, and the risks of being seen

as violating the safe space we had created, was to create an interview space where people had an opportunity to speak on-the-record after signing a consent form. This change in status was methodologically practical. Setting conversations up in a more formal way made it clear to all that this was a different form of interaction, distinct from the informal interpersonal conversations we shared during a cooking class or another group activity. And by revealing and clarifying this more public purpose it allowed women to not disclose more private information on-the-record, although we had heard it off-the-record in a different context. Although it worked to clarify the public and private information of each individual, I cannot claim that we forgot all the other information we had previously heard. The benefits known to be associated with the operational side of work could have shaped the information people gave in the research, such as requests for money. An advantage of our dual role was that we were used to responding to requests for various kinds of assistance. As health professionals we have developed systems and procedures to respond to expectations and requests for assistance.

The question can be posed, however, whether this dual role was necessary for this research. I am convinced I would never have finished my PhD if I had not also had a full-time job that forced me to take a step back from academic work and vice versa. I think it is motivating for a researcher to know that research findings, which have practical program implications, can be implemented immediately. Being able to tell women with confidence that they can access good services and being able to make sure that these women really do benefit in terms of improved access to services is an ethical luxury and a personal relief for a researcher working with such marginalized groups. I think the program would not have been so successful if we had not conducted the research, which forced us, for example, to actually visit every service related to the PMTCT system in a city, a district and a commune. We understood the system to which we referred HIV-positive women, which helped us improve referral practices. We understood the contexts in which some moral decisions were made, although it raised the question of how a researcher should react in situations that are culturally shaming to the individual or the family observed. I am still unsure where and when a health professional should behave differently from a researcher.

Yet somehow we reached a consensus about the medical and ethical reasons why prevention of mother-to-child transmission should focus on empowering women to raise their own children. We were able to change the national policy on PMTCT to include care and treatment for both mother and child and this went into effect in November 2007. In my view this success was at least partly based on the pilot program, which empowered these women to access services, including medicines that made them healthy. We used the research to improve the program to help prioritize access to ART and other health services when starting with a new group of women. With our research findings we could explain the components of a program, as well as the logical order in which program activities should be carried out.

The research was key but not the only ingredient in communicating the need for mother-centered PMTCT. We found that women accessed treatment, loans and social and psychological support through the program, which stabilized them in these areas.

ARV treatment also became increasingly available in Vietnam with support of large donors such as President's Emergency Plan For AIDS Relief (PEPFAR) and the Global Fund. We helped women to access services, including treatment, by referring them to service providers, and together with the women we built the capacity and interest of the staff to provide more and better services to mothers from the grassroots level all the way up to the Ministry of Health. As part of their efforts to gain confidence and respect, some group members who were ready to appear in public, dressed up in 'ao dais,' the traditional formal Vietnamese dress. These pioneering women were not simply elegantly dressed, but well informed about the research data, which they, with our help, presented to policy makers, such as members of parliament and the media. They gave power point presentations using the same technology as other professional presenters at public meetings. We helped them practice what they wanted to say in front of the National Assembly and at other high-level venues. We trained HIV positive mothers to work in partnership with health staff as peer counselors at national level hospitals, such as the national pediatric hospital, which improved the treatment results and also diminished the workload of the health. Some of the staff of these national level institutes are responsible for advising national policy makers in various boards and committees and they can propose revisions in medical procedures and laws. These higher (national) levels are also responsible for training provincial levels on new medical procedures. We supported workshops where key national-level staff, who had seen and experienced mother-centered PMTCT, advocated this approach to colleagues working at the provincial levels, while we the researchers sat in the back of the room.

Once it appeared there was support to change the law at the national level, the researchers were able to provide technical and financial assistance to rewrite it with funding by the research program, to send the drafts to the provinces and to legal reviewers in the Ministry of Health for comments and organize a multi-sectoral consensus workshop. We had reserved funding to address a priority problem, which the researchers identified as well as for advocacy to a more general public. We built public support through public performances and films. We had, for example, public installations based on the women's own stories and key messages in a sports stadium with more than 3,000 people in the audience, most of them weeping with television cameras recording. I do not think that we would have had the same impact if the researchers had presented the results alone. It was the fact that HIV-positive women, who were living proof of the research conclusions of the effectiveness of focusing on the mother's own health in PMTCT programs, also presented the results that made the information compelling. It was a combination of hard data and emotional communication that made it work. That first year, the women who were considered ill were often complimented by policy makers on how healthy and beautiful they looked. After three years they received compliments on how smart they were.

Notes

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