Pressure to bear: gender, fertility and prevention of mother to child transmission of HIV in Vietnam
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Citation for published version (APA):

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An engaged medical anthropological approach

As a medical anthropologist and political scientist working in a biomedical environment, I empathise with Byron Good’s description of his sense of himself as a “tiresome sceptic among medical staff while feeling like a remnant of outmoded enlightenment thinking among anthropologists”. (Good, 1994) Yet my fieldwork was not only shaped by my ambivalent sense of self within two disciplines. During fieldwork there are many potential tensions between the roles of engaged practitioner/activists and social researcher, for example. For many years anthropologists and other researchers working in poor and developing countries have described the difficulties they faced during their fieldwork including having to manage the expectations of vulnerable populations and authorities who expected (fast) measurable results of collaboration. (Malinowski, 1967; J. Nash, 1975; Powdermaker, 1970; S. Scott, Miller, & Lloyd, 2006; Stocking, 1983) Nowadays most social researchers acknowledge that fieldwork is not only shaped by their sense of self, but also specific local contexts, institutional cultures, as well as the position of the researcher and that it is a process that involves many negotiations.

Nancy Scheper-Hughes described her difficulties in positioning herself as a researcher in a Brazilian community after she had lived and worked with the same people as a community organiser and social activist, for instance. (Scheper-Hughes, 1992) The community organisers with whom she worked neither understood nor were satisfied with her detached role as a researcher, and they expected her to continue to accompany them during their struggle for social justice. The women in her research gave her an ultimatum and she consequently assumed the double role of anthropologist and activist that was dictated to her by the men and women in “her” research site.

Similarly, when embarking upon this study, interviewing people as a researcher was a very different experience for me from meeting with these same people in my role of program manager, and required careful negotiation and reflection about these different roles. In addition, over the years I had collected many personal stories from people during my program work, but using these stories would raise ethical questions about informed consent. For the research I therefore used a consent form for individual interviews enabling people to “officially” tell me the story that he or she felt ready to share with me as a researcher. This formalized method of data collection is different from the long-term participatory observation that anthropologists conduct during field-
work in other settings, but is a required method for researchers in a medical setting. In my role of researcher some people provided me with information that was interesting for me as a manager, such as political gossip about the promotion of certain colleagues, but the disclosure of such information could get them into trouble so I retained it for research purposes only.

After each semi-structured interview had been completed I turned off the tape recorder and in many cases spent time discussing and attempting to address some of the problems that were raised during the interview, hence reverting to my role as program manager. HIV+ women and their families mostly asked questions about how to access free health services, but were also keen to discuss normally taboo subjects such as being suicidal, domestic violence and drug addiction. Health staff and other state authority representatives who had been interviewed often asked about our plans for the research, our opinions of their services, our experiences in other provinces and suggestions to improve their own work or their relationship with other stakeholders.

My dual role as researcher and program manager brought some advantages. As the fieldwork for this thesis took place in the context of an operational program, I had access to data that independent researchers would not normally have. Such information included detailed budgetary information, minutes of meetings, contracts and activity plans. I also had daily interactions with representatives of various levels and kinds of authorities, and was directly involved in many related trainings, workshops and media productions as part of my work. This allowed for intense observation of the interactions between the authorities and the beneficiaries, as well as for immediate feedback on preliminary research findings. Nevertheless, my dual role required me to make special efforts to be very clear at each interaction about my separate responsibilities as a researcher, reassure informants that criticism was welcome and limit any expectations concerning the material and financial benefits of the research.

OVERVIEW OF DATA COLLECTED

Timing of study

This study was linked to an operational program that was developed in late 2003 and became operational in April 2004 when the first Sunflower group was established in Hanoi. The program observations and follow-up interview in the Hanoi sites continued until the end of 2007 until the researchers had followed the experiences of each group member for two years. The development of the research action plan and review of documents in Thai Nguyen started in November 2004. The in-depth interviews with health authorities and HIV+ women and their families in both sites were conducted between March 2005 and March 2006. HIV+ women in Thai Nguyen and the local authorities decided to start a Sunflower group in July 2006. The program observations and follow-up interview in the Thai Nguyen sites continued until
the end of 2007, again until we had followed each group member for one year. Program observations, notably micro-credit plans and results, and group discussions with Sunflower support groups during their weekly or bi-weekly meetings as well as individual interviews with women in the context of the operational program in Quang Ninh and Cao Bang took place between July 2006 and December 2007.

**Site selection**

Qualitative data were collected in Hanoi and in Thai Nguyen City. Both are similar urban areas and have relatively high HIV prevalence rates for Vietnam, a characteristic which is necessary to recruit enough women given the low overall prevalence nationally and the high stigma associated with an HIV epidemic that is mainly concentrated among injecting drug users. Thai Nguyen city is a rather sleepy provincial town with a rural feel while Hanoi is a bustling capital, hence allowing an exploration and comparison of the meaning of gender and the impact of HIV in women's lives in two different settings.

The sites have differences in the quantity and quality of HIV related services, including PMTCT. Hanoi has two hospitals that have offered ARV prophylaxis for PMTCT treatment since 2000 and several free ART sites; the oldest started in 1997. In Hanoi, women planning to deliver in a hospital are routinely tested for HIV at 7-8 months of pregnancy. Thai Nguyen is 80 km north of Hanoi; one free ART program was started in 2006. Hospitals in Thai Nguyen routinely test women just before delivery but may offer earlier testing when they suspect HIV infection based on symptoms. At the time of the study, PMTCT treatment existed only on paper and ART prophylaxis was not available there.

In each province the sampling of study sites was based on the availability of services in these sites and their level and function in the vertical state health care system. Six national and provincial state hospitals that provide ARV and PMTCT in Hanoi and one national and one provincial state hospital in Thai Nguyen were selected because they are the main providers.

Within Hanoi and Thai Nguyen, each district with the highest HIV prevalence was selected. In these two districts we carried out interviews and observations at all levels of the health system involved in PMTCT; district health centre, district maternity ward, district project for family planning and mother and child health, and the preventive health care services, including the testing site. Within each of these two districts we also selected the two communes with the highest HIV prevalence and visited health care stations in these communes to conduct further interviews and observations.

**Research process**

The research team which I led consisted of four members with medical backgrounds and three with social science backgrounds. The team also included one translator and one field administrator.
Interviews were conducted in Vietnamese, English or French. I am fluent in both English and French, hence I conducted interviews in these languages myself. Although I can understand quite a bit Vietnamese, especially when HIV/AIDS programs, maternal and child health and PMTCT are discussed, I almost always worked with a translator for the interviews which I conducted in Vietnamese as this was more efficient when more complex issues were being discussed. I communicated that I understood the progress of the conversation by making brief comments in Vietnamese.

In this thesis I use both my own interviews and interviews that were conducted by other team members. However, I only use qualitative data collected by others if I had met the person interviewed at least twice to check statements and observations. The data presented in the thesis has been checked by the other research team members for factual inaccuracies.

**Definition of PMTCT and its operationalisation**

Table 1 lists the aspects of each pillar of PMTCT defined by WHO that were assessed for this study. In order to get a good overview of each PMTCT service and the relationship among the various players within the health system, I selected provider respondents for each of the services. Because of the vertical fragmentation of the Vietnamese health system there are many units that provide services that are part of the four pillared model of PMTCT. As a result, a relatively large number of interviews (275) had to be conducted with health workers located at many different sites in the two cities. In order to understand the linkages among and within service levels and health workers’ perceptions of their roles, every semi-structured interview covered all four pillars. As harm reduction, psycho-socio care and economic support are provided by other sectors, representatives of DOLISA and the Women’s Union also had to be interviewed to get a complete picture of current services.

**Semi-structured interviews with health workers and other key informants**

HIV-positive pregnant women, HIV-positive mothers, their partners, family members, and health workers were all interviewed about desire for children, HIV infection, PMTCT, ARV, health care, social and family support. In each district the research team interviewed staff involved in PMTCT. Inclusion criteria for health workers were (1) responsible for and/or directly involved in services for women with HIV or women seeking PMTCT and (2) at least one year’s experience in their current job.

We also interviewed Vietnamese policy makers, social service providers and other key informants and reviewed popular media. Again, only respondents who had at least one year’s experience in their post were selected. Collaborating organisations and institutes provided the research team with private rooms in which to conduct all interviews.
Table 1: Elements of PMTCT assessed, in relation to each PMTCT “pillar”

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<tr>
<td>■ Behaviour change communication on safer sex, how to use condoms, risk of mother to child transmission.</td>
<td>■ Referral links between VCT and family planning services.</td>
<td>■ Good, functioning ANC services</td>
<td>■ Follow up medical, psycho-social care and economic support for HIV positive mothers and their partners</td>
</tr>
<tr>
<td>■ Testing services including pre- and post test counselling</td>
<td>■ Accessibility of safe abortion services</td>
<td>■ Access to HIV testing early in pregnancy</td>
<td>■ Follow-up medical, psycho-social care and economic for infants</td>
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<tr>
<td>■ Harm reduction programs (including needle-exchange, education about safe injecting and substitution therapy)</td>
<td></td>
<td>■ Provision of safe and effective ARV prophylaxis</td>
<td>■ Social support for PLHIV, their families and communities</td>
</tr>
<tr>
<td>■ Condom provision</td>
<td></td>
<td>■ Counselling and support for safe infant feeding</td>
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In-depth interviews with people infected and affected by HIV/AIDS

In Hanoi and Thai Nguyen, we interviewed a total of 153 persons. We interviewed 56 seropositive women in Hanoi, and 28 in Thai Nguyen. In addition, 34 HIV+ men in Hanoi and 13 in Thai Nguyen joined the interviews. In Hanoi, seven mothers in law and 10 in Thai Nguyen participated in the study. In Hanoi we also interviewed two fathers of HIV+ women, one sister, one sister in law and one brother in-law. Of these interviews we used different subsets to answer the different research questions which are discussed in each chapter. The selection of the interviews to be used was directly related to their relevance to the study question. For example, in the chapter on testing we only selected HIV+ women in Hanoi who were pregnant or who had delivered in the last year. This is why only 38 of the 56 interviews in Hanoi were used for this chapter. For chapter five on lineage we included pregnant women or women who had delivered within the last year in Thai Nguyen and excluded, for example, women who had delivered before that, to reduce recall bias and because the situation in the health system had changed (notably access to ARV) which could also influence their responses. For the micro-credit chapter we only used the data from the first borrowers in Hanoi because it takes at least a year before one can assess if the micro-credit has made a change in a program in which loans are provided over a one-year period. For the chapter on widows, obviously we only included the widows in both provinces. And
lastly for the chapter on the group development we used all available data concerning group progress.

Respondents were identified by different self-help groups such as the Sunflower support groups, Bright Future support groups, and the Women Union’s sympathy groups. Potential respondents were informed that they could also invite their partners or family members for interview. In addition, we invited newly infected persons who had not yet joined support groups to join the research by circulating an invitation leaflet through PMTCT services. They were advised that they could contact the team at a time and location at their convenience. All HIV-infected persons who participated in the study were provided with information about access to care and support services. Interviewees were given a small reimbursement for their time and travel expenses.

All respondents except one, were of Kinh ethnicity, and hence belonged to the largest and dominant cultural group in Vietnam. Most of the HIV+ women interviewed were young, from 20 to 30 years of age, and all were literate. All the women had been or were still married, and all their husbands (alive or dead) had a history of injecting drug use, visits to sex workers, or both, and had probably infected their wives.

**Health site observations**

We also conducted observational site tours at ANC, abortion, opportunistic infection (OI), ARV prophylaxis, ART treatment, and STI treatment departments in 19 health care service sites at national, provincial, district and commune levels.

**Data collection tools: semi-structured questionnaires**

We developed the semi-structured questionnaires in stages, beginning with loosely structured interviews around the study themes related to the four-pillared continuum of care model. The whole team joined the first few interviews, in order to exchange ideas and learn from the individual interview styles of each team member, before breaking up into smaller teams of two. Based on these loosely structured interviews, we developed question guidelines for health care workers and PLHIV, their partners and family members. The order in which themes were introduced depended on the flow of conversation, but all themes were covered during the interview. Researchers were also authorised to pursue any new, unexpected themes that emerged during interviews.

**Data recording and processing**

Prior to starting any interview, researchers invited the respondent to read and sign the consent form, and asked their permission to record the interview on
tape. All interviewees were informed that they could stop the interview at any time they wanted. Almost all respondents agreed for their interview to be recorded. Those who did not were all males with a self-reported history of drug use. Notes were also taken during each interview. At the end of the interview, the tape recorder was stopped and researchers invited interviewees to ask questions and provide comments. Researchers shared experiences and note-taking skills in bi-weekly meetings. All tapes were transcribed and NVivo software was used for further in-depth analysis.

**Triangulation**

The data presented in this study were triangulated using information from a number of different sources. Economic data, for example information on income and capital assets, were collected every six months by the Women’s Union, core members of support groups, and a member of the research team. Bi-weekly participatory program observations also allowed researchers to follow the wellbeing of the women, their partners, children and families.

In addition, information from the following sources was also used for triangulated analysis:

- Secondary data, including policy documents, program reports, and research studies on HIV, PMTCT, gender, and ART.
- Household visits to observe income-generating activities engaged in by Sunflower support group members;
- A review of Personal Development Plans (PDP). Each member of the Sunflower group makes a plan based on an analysis of her medical, social and economic needs and presents this to the authorities in order to receive formal support. All Sunflower members who participated in this study had made such plans.
- A review of five publications of the Women’s Union, and a qualitative analysis of all “help letters” received by these publications relating to subjects relevant to the topics under study, in which readers wrote about their situations and difficulties and asked for advices from experts including doctors, social workers and especially psychologists. These letters were answered through the publications in separate sections in which the whole or part of each letter was printed alongside the response. None of the names of the letters’ authors were published, in order to protect confidentiality. This review took place over a one year period from June 2004 to June 2005.

In addition, we were able to observe and monitor group development, leadership development and other trends with four further Sunflower groups in other non-research provinces on a monthly basis for one and a half years. These groups were established in the second half of 2006 and had a similar approach to accessing social, health and economic services to the original Sunflower group. This allowed us to explore the development of the group and its members in a broader context.
Ethical issues

As already noted, free and informed consent was obtained from all participants in the study. All interviewees signed consent forms that explained the purpose of the research and were informed that they were free to abstain from participating, and if they chose to participate could end the interview at any time. Respondents were not asked their names, addresses or any other identifying information, in order to ensure privacy and confidentiality, although it should be noted that in many instances we knew their names due to our earlier program work. However, no full names or addresses were recorded for the research. All data sets, questionnaires, and tapes were stored in a secure office. All names have been changed to protect confidentiality.

Challenges and limitations

Several qualitative social researchers have discussed the specific negotiations and challenges of conducting fieldwork in transitional socialist countries like Russia and Vietnam. (DeSoto & Dudwick, 2000; Reid-Henry, 2003) Three particular concerns which have been highlighted are a powerful centralised state in control of the nation’s political culture, commodification (in other words the transformation of information and services into a commodity), and a dominant positivist research culture.

Obtaining official approval to conduct independent fieldwork can be a complex process in transitional socialist states. (Marr, 1993) Although some of these problems are common to the bureaucracies of other developing countries, there are particular problems in getting stamps and permissions in transitional states that reflect the shared political cultures and histories of these particular countries. Indeed, many senior scholars and high level officials in Vietnam were trained in Eastern Europe and the former Soviet Union and it may be the case that many of them have adopted the bureaucratic emphasis on formalities to which they were exposed overseas. Currently in Vietnam, as in some other communist countries that are suspicious of foreigners from “the west”, researchers cannot travel independently and talk to people without the approval of a state official, hence we first had to obtain official permission before conducting interviews. It is, perhaps, worth mentioning that getting permissions to visit places and talk with certain people is not a specific barrier posed to researchers. International development workers, diplomats, journalists and foreign officials also have to obtain permission and approval before they can visit and meet with state service providers, or interview citizens, for example. Possibly a long history of aggressive foreign interference in Vietnam might also have contributed to a perceived need to both monitor and control foreigners. I personally did not feel controlled but I do, however, agree with other observers that the shared local understanding between older local “gatekeepers” of information and older researchers on the importance of approval systems can be challenging for the increasing number of foreign
and local researchers who have been trained in other parts of the world. (S. Scott, Miller, & Lloyd, 2006)

Although Vietnam’s HIV/AIDS policies are, as discussed earlier, strongly oriented towards public health, social control and surveillance, our research team found that authorities were open and cooperative. It helped that before we started the research we already had extensive knowledge of the state system as well as working relationships with important “gatekeepers”. The data collection for this study was linked to a pilot program providing comprehensive care to women infected and affected by HIV/AIDS and drugs, supported by MCNV since 2004. The project provides a wide range of PMTCT services to seropositive mothers and pregnant women through a network of national services that are linked together and made accessible through a support group. Because of this project, which was judged a successful pilot, government authorities knew us and may have trusted us more than if we had been attempting to establish a new relationship. Although we did have to do paperwork, such as sending letters to inform the head(s) of the various research sites about the purpose and needs of our study, this was also to our benefit because it allowed “gatekeepers” to plan ahead and set up appointments with the staff which we asked to meet.

While conducting our fieldwork we moved around all levels of the fragmented, vertical health system. We quickly learned that workers in this system are often ill-informed or ill-equipped to do the work which is assigned to them. For example, by law pregnant women should get free HIV tests but the health authorities who should implement this procedure have been given neither the budget nor the training nor the exact information about this law. We learned about many misunderstandings between PMTCT providers at national and provincial level. For example, the drug Nevirapine, for example, might not be available at national level because national agencies expect that provincial level institutions will request the medication directly, despite the fact that provincial agencies are unaware that they are required to submit such requests. When such medicine is dispatched it arrives at the Department of Reproductive Health which is in a different building and department than that in which women deliver, and both departments do not know how to proceed. All of the bureaucratic uncertainties which were uncovered taught the research team to ask very practical questions in order to assess what relationships health staff had which each other and how this affected the care and treatment of women. Rather than assuming that health workers are willing and able to refer patients to services, for instance, it is useful to check whether there is a (working) phone at a facility that a health worker could use for such a referral.

A second particularity of research in transitional economies is that the privatization of state services has reportedly contributed to a “commodification” of the data collection process. (Croll, 1994) This is in a context where the salaries of state health sector employees are insufficient to pay for some of the goods and services that used to be free before Đổi mới and their options for earning money with private side-businesses, such as a private
Pressure to Bear: Gender, Fertility and Prevention of Mother to Child Transmission of HIV in Vietnam

clinic have increased (similarly, many Vietnamese researchers combine their academic work with the generation of extra income by tutoring, translations and other private businesses such as consultancies for development organisations). Hence, under the constraints of the market, authorities have less time and attention to cooperate with research without compensation. Following the new logic of the transitional market economy it is therefore common that state representatives, such as health workers, try to make extra money by asking a fee or a stipend for their participation in an interview. The problem of underpayment of state officials is also endemic in other non post-communist countries in the region, such as Indonesia and Cambodia. However the erosion of pride in being an official serving the country, and the depreciation of honourable but unpaid social work in mass organisations or community-based associations are relatively recent changes in Vietnam.

Further, all service providers and several HIV+ persons and their families in both provinces where research was conducted had experience with foreign projects that often provided remunerations at levels far beyond their salary and which were also beyond our project’s modest cost norms. We encountered a small group of individuals who could be categorised as “professional PLHIV”.

The language and choice of discussion topics of these people living with HIV seemed targeted to convince us to provide them with material support, which we noted with interest, and could be the topic of a study in itself. Similarly, certain higher-level officials gave the impression that they felt a pressure to “get a project out of us” in return for the time and work they invested in our research. Hence in some interviews, high level representatives of state authorities and leaders of PLHIV support groups tried to balance giving us an optimistic image about their institution and its accomplishments, with qualifying statements which suggested that continuing or new development assistance was still required.

On several occasions lower level staff apologised to us following the interviews, for what they reported to consider as greedy and impolite behaviour of higher level staff (my response was to first thank them for their openness and add that as a manager I understand that bosses have to take care of the future of their institutions). In this sense, both research sites suffered from what has been called “project syndrome”. (S. Scott, Miller, & Lloyd, 2006) Like other researchers in Vietnam we were often at risk of being perceived as a donor as much as being a researcher. (Christoplos, 1995)

Yet although a focus on material and financial benefits was one aspect of the interviews we conducted among state officials and civilians, it should be noted that both service providers and patients identified national PMTCT guidelines as an urgent need, which was strategic identification of an issue that provides no immediate material benefits to either interest group. In fact, in some senses the perception of the research team as a donor by the respondents was justified because we helped support the national authorities to develop these PMTCT guidelines by providing funding and technical sup-
port through the program with which the study was affiliated. Helping state
service providers and end beneficiaries jointly identify a problem and develop
better policies is an accepted element of participatory action research. (Hart &
Bond, 1995; Meyer, 2000)

A third particularity of fieldwork in socialist states in transition is the
dominance of a strong positivist paradigm in empirical research. (E. Clark &
Michailova, 2004; Mazurkiewicz, 1992) In practice this means that research-
ers and policymakers have a better understanding of and a preference for
“apolitical” quantitative research methods. (Chuan & Poh, 2000) Both re-
searchers and state authorities are more familiar with methods such as ques-
tionnaires, mapping, and surveys and may prefer these to qualitative methods
such as participatory observation, semi-structured interviews and the collec-
tion of oral histories. Though the preference for quantification is not exclusive
to Vietnam, I have often been struck by the quantity of numbers that officials
at all levels are required and actually manage to produce for various reports to
higher level national authorities and international donors. At commune health
stations I found myself interviewing staff whose desks, floors and cupboards
were stacked with reports, all often neatly organized by names and numbers,
containing hand-drawn and written tables of different colours. What has im-
pressed me most as a researcher and a program manager is not just the ad-
ministrative burden of producing such vast amounts of quantitative data, but
people’s diligence in this work.

In the field of HIV/AIDS the emphasis on surveillance has resulted in large
numbers of quantitative studies and reports, but the quality of the data is, in
spite of all the hard work that has gone into data collection and recording, not
always reliable. We found irregularities in almost all health records. A com-
mon mistake, for example, was the conflation of the number of patient visits
with the number of patients, which suggests that more people are reached
than is actually the case. It is worth noting that sometimes resources are al-
located on the basis of such data, which means that data manipulation can
have advantages.

Given the lack of quality of many quantitative reports it is understandable
that some have given up reading them, and dismiss them not only as inac-
curate, but superficial or “sweeping diversity under the carpet”. (Christoplos,
1995) However, I think it is, in principle, more constructive to see quantita-
tive and epidemiological reports as diagnostic tools that help researchers to
understand what is going on where, while qualitative tools help to under-
stand why this is taking place and to reveal conflicts of interests underlying
larger trends. This thesis, therefore, treats quantitative and qualitative data as
complementary. Only quantitative data which was found to be reliable and
consistent was used for this study. I have checked the various quantitative
data sources with several epidemiologists and public health experts. Most im-
portantly, the research involved collaboration with my Vietnamese colleague,
Thu Anh Nguyen, with whom I also started the operational work with the
Sunflowers. She is an epidemiologist and a medical doctor and is specifically exploring some of the flaws in the quantitative data on PMTCT as part of her own PhD on PMTCT at the Amsterdam School of Social Science Research and as part of her work at Hanoi Medical University, and so could advise on the relative validity of different data. Working regularly and directly with HIV+ women, their families and a wide network of social, health and economic service providers also helped to detect discrepancies between official reporting and the reality on the ground.

A fourth aspect of fieldwork more particular to Vietnam is the Confucian cultural heritage with its intense respect for authorities and teachers that contributes to a general reluctance to question and criticise. In Vietnam, as in most places, there are remarkable differences between policy and practice, but researchers have noted particular difficulties finding out whether statements describe actual situations or the “official” prescribed situation that ought to be in place. (Croll, 1994; Gammeltoft, 1999) We encountered many examples of idealised portrayals at first meetings and at the beginning of the conversations and interviews which took place as part of the study. Once a relationship was established it was often possible to learn about the actual situation by paying very close attention to both what was said and not said. Formal conversations with health officials about medical assistance to HIV+ pregnant women often started with a very impressive listing of available services, for example. Rather than making the hasty conclusion that an official was trying to present things as they ought to be rather than as they were, researchers learnt to follow this opening by asking questions such as “How many pregnant women visited your service last year?” In many of my personal interviews with officials, asking probing questions about the actual coverage of services, following a description of the “on paper” situation, led to a long list of problems that required greater attention.

A fifth challenge for researchers in Vietnam is the desire to keep harmony and maintain relations, another aspect of Confucianism that can reportedly affect the collection of data on conflicts, including conflicts between men and women, in focus groups or via other group methods. (S. Scott & Truong, 2003) In the case of the women we interviewed, the “harmonious” picture which they presented of their lives in the group and when interviewed individually often meant that their husbands were not using drugs, but just “went to sex workers with their friends”. These same women decided who we would
interview from amongst their family. By inviting their husbands, who often openly admitted that they used drugs, these women were allowing us to discover the real situation while also maintaining harmony and their good image as women who were protective over their husbands.

Some couples indirectly but decidedly put me in the middle of their conflicts, however. For example one couple had an infected child who was on ART. The boy was not supposed to know that he had HIV, and was being told that the medicine he was taking was for his lungs. The wife told me that she wanted to wait to inform the child of his HIV status until he was older. She also said that she kept her son indoors because children in the neighbourhood called him “AIDS child”. In tears, the husband invited me to their house to “meet their child” and learn about the “real” situation after I had turned off the tape recorder. I felt that I was actually being asked to tell the child that he was HIV-positive. I did not know what to do and did not dare visit their house. Instead I asked their pediatrician to talk with them both about their child, which he did. A few weeks later the wife thanked me for my “Vietnamese solution”.

**Table 2: Overview of Data Collection Methods in Relation to Research Questions**

| **How do women find out that they are HIV positive and what are the social consequences of different testing models that are offered to pregnant women?** |
| **Data collection method** | **Inclusion criteria** |
| Interviews with 38 seropositive women, of whom 36 recently delivered, in Hanoi. | A convenience sample of women recently delivered in Hanoi. Recruited for the study from support groups and national and provincial level obstetric hospitals in Hanoi. |
| Separate interviews with 33 partners/ husbands or close family members. | Women proposed (own parents and in-laws, grandparents and siblings). |
| Semi-structured interviews with 53 health care workers on the quality and quantity of services in PMTCT in Hanoi. | Doctors and nurse/midwives who had been working in PMTCT for >1 year at national and district hospitals and in commune health stations. |
| Interviews with 15 pregnant women; at national and provincial levels (4) and at district and commune levels (6), as they exited the services. | A convenience sample of pregnant women presenting at ANC sites. |
### Why do HIV infected women want to become or stay pregnant, and how and why can these women and their families realize their fertility ambitions in the health system?

<table>
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<tr>
<th>Data collection method</th>
<th>Inclusion criteria</th>
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<tr>
<td>Semi-structured interviews with 275 health staff involved in PMTCT.</td>
<td>A convenience sample of staff from all levels from the national to the commune level (1) responsible for and/or directly involved in services for women with HIV or women seeking PMTCT, and (2) at least one year of experience in their current job in Thai Nguyen and Hanoi.</td>
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<td>In-depth interviews with 56 seropositive women, in Hanoi (38) and Thai Nguyen (18)</td>
<td>Mothers in Thai Nguyen and Hanoi who recently delivered or had recently been pregnant or who planned to have children.</td>
</tr>
<tr>
<td>In-depth interviews with 42 partners/husbands or close family members of the seropositive women.</td>
<td>Respondents proposed by women interviewed (own husbands/partners, parents, parents-in-law, grandparents and siblings).</td>
</tr>
<tr>
<td>Eight semi-structured interviews with Vietnamese policy makers and social service providers.</td>
<td>Key national and provincial level policy makers and social service providers with &gt;5 years experience in HIV and/or drug addiction.</td>
</tr>
<tr>
<td>Follow-up interviews at the support group office and during program activities in different locations around the two cities.</td>
<td>All 56 seropositive women, in Hanoi (38) and Thai Nguyen (18).</td>
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<tr>
<td>Review of popular media.</td>
<td>Five largest national publications of the Women’s Union; all “help letters” relating to child desire, HIV infection, family, PMTCT, drugs and sex.</td>
</tr>
</tbody>
</table>

### Why do HIV infected women want to become or stay pregnant, and how and why can these women and their families realize their fertility ambitions in the health system?

<table>
<thead>
<tr>
<th>Data collection method</th>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular follow up of 14 women who borrowed money through the support group between April 2004 and January 2006 over a two year period after taking out the first loan.</td>
<td>Women who wanted to start a business could apply for an interest-free loan of up to 5 million Vietnamese dong (approximately 300 USD) for a period of nine months.</td>
</tr>
<tr>
<td>In-depth interviews with partners or husbands or first and second line family members.</td>
<td>Women signed for the loan themselves, but when the business involved their families’ property, time or other resources, the families had to be interviewed to assess their agreement.</td>
</tr>
<tr>
<td>Each household visited bi-annually to monitor loan and business performance as part of loan program.</td>
<td>All 14 female borrowers.</td>
</tr>
<tr>
<td>Follow-up interviews at the support group office and during program activities in different locations around the two cities.</td>
<td>All 14 female borrowers.</td>
</tr>
</tbody>
</table>
Participatory observation of performances of three other micro credit programs for HIV+ women with 58 loans.

In 2006 new Sunflower support groups with the same services and procedures were founded in three new provinces. We interviewed these women, the staff of the Women’s Union and read progress reports based on household visits.

<table>
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</thead>
<tbody>
<tr>
<td>Semi-structured interviews with 24 HIV infected AIDS widows, in Hanoi (17) and in Thai Nguyen (7).</td>
<td>A convenience sample of 24 widows, all of them infected with HIV and all recruited for the study from six PLHIV support groups under the umbrella of the Vietnamese Women’s Union (2) or the Vietnamese Red Cross (2) or two independent self-help groups for PLHIV (Bright Future).</td>
</tr>
<tr>
<td>Semi-structured interviews with 16 of the widows’ family members, in-laws and boyfriends.</td>
<td>Women proposed the close family members.</td>
</tr>
<tr>
<td>Follow-up interviews and participatory observation of the widows during two years of program activities in Hanoi and during one year in Thai Nguyen at the support group office and on different locations in the two cities.</td>
<td>All widows who were originally interviewed.</td>
</tr>
<tr>
<td>Semi-structured interviews with 8 Vietnamese policy makers and social service providers.</td>
<td>Key national and provincial level policy makers and social service providers with &gt;5 years experience in HIV and/or drug addiction.</td>
</tr>
<tr>
<td>Interviews with 27 ART providers/addiction experts, in Hanoi (18) and Thai Nguyen (9).</td>
<td>A convenience sample of staff from national and provincial ART and addiction treatment sites in Thai Nguyen and Hanoi who were (1) responsible for and directly involved in ART, and (2) had at least one year of experience in their current job.</td>
</tr>
</tbody>
</table>

What are the actual experiences of and opportunities for HIV+ AIDS widows setting up a new life for themselves in a patrilinear and patrilocal setting where HIV is stigmatized?
Table 2: Overview of Data Collection Methods in Relation to Research Questions (Continued)

<table>
<thead>
<tr>
<th>Data collection method</th>
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</tr>
</thead>
<tbody>
<tr>
<td>In-depth interviews with 15 government stakeholders in Hanoi and 7 officials in two rehabilitation camps during rapid HIV/AIDS situational assessment.</td>
<td>A convenience sample of national level experts working in and nearby Hanoi. First key persons proposed by the director of the HIV/AIDS centre at Hanoi Medical University who proposed and introduced me to other national experts.</td>
</tr>
<tr>
<td>275 semi-structured interviews with health staff involved in PMTCT.</td>
<td>A convenience sample of staff from all levels from the national to the commune level (1) responsible for and/or directly involved in services for women with HIV or women seeking PMTCT and (2) at least one year of experience in their current job in Thai Nguyen and Hanoi.</td>
</tr>
<tr>
<td>In-depth interviews with 56 seropositive women in Hanoi and 28 in Thai Nguyen</td>
<td>Seropositive women in Thai Nguyen and Hanoi most of whom had recently delivered or had recently been pregnant or who planned to have children.</td>
</tr>
<tr>
<td>In addition, 34 HIV+ men in Hanoi and 13 in Thai Nguyen joined the interviews. In Hanoi, seven mothers in law and 10 in Thai Nguyen participated in the study. In Hanoi we also interviewed two fathers of HIV+ women, one sister, one sister in law and one brother in-law.</td>
<td>Women proposed (husbands/partners, own parents and parents-in-law, grandparents and siblings)</td>
</tr>
<tr>
<td>Semi-structured interviews with 8 Vietnamese policy makers and social service providers.</td>
<td>Key national and provincial level policy makers and social service providers with &gt;5 years experience in HIV and/or drug addiction</td>
</tr>
<tr>
<td>Follow-up interviews at the support group office and during program activities in different locations around the two cities.</td>
<td>All 56 seropositive women, in Hanoi (38) and in Thai Nguyen (18).</td>
</tr>
<tr>
<td>Review of popular media.</td>
<td>Five largest national level publications of the Women’s Union, all “help letters” relating to child desire, HIV infection, family, PMTCT, drugs and sex</td>
</tr>
<tr>
<td>Participatory observation of interaction of Sunflower support groups with state authorities in three other support groups in Quang Ninh and Cao Bang provinces.</td>
<td>In 2006 new Sunflower support groups with the same services and procedures as in Hanoi were founded in Thai Nguyen, Cao Bang and Quang Ninh (2). We interviewed these women, the staff of the Women’s Union and read the progress reports on the social, health and economic services provided and received.</td>
</tr>
</tbody>
</table>