Pressure to bear: gender, fertility and prevention of mother to child transmission of HIV in Vietnam
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Lines of inquiry

Thu is a young Vietnamese mother with a healthy two and a half year old son just like mine. We were pregnant at the same time; she was six weeks ahead of me. We discussed ordinary topics that pregnant women like to discuss, such as sleeping at night, morning sickness, mothers-in-law and whether your husbands want sons or daughters. One big difference between her and me though, was that she was HIV infected and I was not. She was worried that she would infect her child and that she would not live to raise him.

Women like Thu can have a 95% or even higher chance of having a healthy child with PMTCT. PMTCT was introduced at the global level at a time when ARV were still so expensive that treatment access in poor countries was problematic. The use of ARV to reduce transmission from mother to child, however, was considered feasible. (Connor et al., 1994; Dabis et al., 2000)

In Vietnam the government program has officially provided a single dose of Nevirapine regimen (SD-NV) since 2002.

In 2003 when I started to assess the needs and gaps in HIV/AIDS programs in Vietnam, I learned that most women like Thu were infected by injecting drug users (IDUs). Both drug use and HIV infection are socially stigmatised. Health workers often could not contact HIV+ women after a positive test result because they had given a false address. Doctors mentioned that women with severe AIDS just refused to stay in a hospital bed for fear of being seen; in the matrilineal and patrilocal structure of the Vietnamese family these women seemed to sacrifice themselves to save the face of their families, and died alone.

Even as the global prices for were ARV falling, Vietnamese women were excluded, or excluded themselves, from accessing the increasingly available ARV. At that time health workers, academics, policy makers and AIDS activists in other countries had come to similar conclusions. Many people on the ground knew that women avoided the services because the “M” in PMTCT programs was being ignored. Somehow this idea had not reached Vietnam. Vietnam’s strong state, its cultural reverence of the mother role, its strong economic growth, its robust health system (which had just successfully combated Severe Acute Respiratory Syndrome; SARS), and its pilot ARV programs made me very hopeful that a mother-oriented approach to PMTCT was feasible. During the assessment I met a Vietnamese medical doctor who...
agreed with my belief that more women would access the PTMCT medicines available if we could offer high quality social, medical and economic services that would help both the mother and the child. We believed that the state would also be willing to provide these services, if it received feedback from these women and saw results.

In 2004, together with a group of authorities who were willing to try a new approach, we therefore initiated the first support group for Vietnamese HIV+ mothers and pregnant women, the Sunflowers. Thu was one of our first four members.

Like most mothers, Thu thought that she was the best person to care for her child. The emphasis on saving the child in PMTCT programs raises questions, however, about the moral implications of choosing to treat the mother only to help the child, and about the cultural attitudes that make this approach not only acceptable but even perhaps preferable to other possible interventions as part of a more comprehensive approach to HIV control.

Until 2004 the World Health Organisation promoted a three-pronged or three-pillared approach: the prevention of (a) new infections in parents-to-be, (b) unwanted pregnancies in HIV infected women, and (c) transmission from an HIV infected mother to her infant. But the postnatal care and support needs for the young mothers themselves, such as access to ART, economic- and psycho-social support, were conspicuously absent from this approach. In the same year that we started our group, WHO and UNAIDS added a fourth pillar: care and support for HIV-positive mothers and their children and families. (WHO & UNAIDS, 2004) This fourth care and support “pillar” is built upon the other three.

Within weeks after we met, Thu showed us that we had been naïve in our assumption that the third pillar, medical intervention for PMTCT, was accessible. PMTCT programs and medicines existed on paper, and the medicines were available in hospitals with trained staff. But they were still somehow not given to women like her who needed them. Thu had been to a national hospital but had not been given information about PMTCT by the various services that she visited. The two of us, with our pregnant bellies, and accompanied by a delegation of Vietnamese and international colleagues, then went to the national hospital in Hanoi to discuss how we could help the hospital to improve PMTCT treatment, especially Thu’s treatment.

We made an offer to the obstetric hospital: we would take care of the post-delivery care in the new support group so that women would be able to live longer and healthier, while the hospital could follow up the effectiveness of their medical intervention to prevent the transmission of HIV from the mother to the child. The hospital management informed us that hospital workers were confused by all the new ideas and technologies they had been presented with. They were concerned that staff would give incorrect information about the illness of the mother, or raise expectations about the postnatal care available when giving a prospective HIV+ mother the name card of the HIV+ mothers’ support group for referral. They wanted more training for vari-
ous staff members from the various departments that have a role to play in PMTCT. We expected to train a limited number of counsellors and staff from the infectious disease department.

When we saw the list of staff that was involved we were flabbergasted; it seemed like we were being asked to train almost every department in the whole hospital. We learned that the main reason for this was that staff in many departments was both afraid and uninformed about HIV transmission, and both women patients and staff might move between departments depending on medical needs.

Mother to child transmission (MTCT) can take place 1) during pregnancy, 2) during labour and delivery, or 3) through breastfeeding. Even without an intervention, almost two-thirds of children will not be infected, but the risks of transmission differ considerably according to circumstances. Because the risk of transmission is highest during labour and through breastfeeding, most PMTCT interventions target the peripartum period and replacement feeding. (Mofenson & McIntyre, 2000; Piwoz & Preble, 2002) Prevention of mother to child transmission of HIV was, and still is, often presented as a simple intervention. Medical authorities agree that a simple combination of a single dose of Nevirapine at the right time and replacement feeding can dramatically reduce the risks of HIV transmission. (Center for Disease Control, 2001; Lepage & Hainaut, 2000; Mofenson & McIntyre, 2000)

However, program managers in other health projects found, as we did, that actually implementing this relatively straightforward treatment regime is not so simple. (McIntyre & Gray, 2002; Piwoz & Preble, 2002) The technologies are multifaceted and subject to change, and they interfere with a wide range of reproductive practices, such as where and when to give birth and how and whether to breastfeed. (Piwoz & Preble, 2002) In fact, all PMTCT technologies are complex. Interventions to directly prevent mother-to-child transmission during pregnancy, labour, and delivery and during the postpartum period include voluntary counselling and testing (VCT), ARV prophylaxis, antenatal care, optimal obstetric practices, and intense postnatal support, including counseling and support for safe infant feeding and comprehensive child health services. Hence the very long list of departments that required training. In order for PMTCT to work effectively, practically an entire obstetric hospital has to know where to send an HIV+ pregnant patient, and when. But what would a PMTCT program that pays attention to mothers actually look like?

This thesis takes as a point of departure that Vietnamese cultural notions about gender roles and lineage are underlying PMTCT practices that do not advance the rights of mothers to live as long as possible. This lack of attention to mothers’ needs is problematic for medical and ethical reasons as it results, for example, in lower adherence to and attendance of PMTCT programs. But women also make active choices and interpretations regarding the use of PMTCT technologies, whereby they negotiate between collective and individual gendered rights and duties.
They also exhibit agency in their quests to find information about living with HIV after a positive test result, in negotiating access to public schools for their children, by speaking out in public about stigma, and by working with health care and other social service providers to improve these services. PMTCT technologies might reinforce existing gender imbalances, but I will explore how women can also use their gender roles to actively negotiate access to material and non-material resources that can enhance their longevity and quality of life.

The development of our pilot program required hours of discussion, and tours along crowded halls and through waiting rooms and wards with two to four pregnant women in each bed. We learned that healthcare providers had their own perspectives on PMTCT, which needed to be acknowledged and taken into account. Each of the PMTCT technologies presents health workers and patients with difficult medical, ethical and social choices. There are, for example, options in terms of the kinds of ARV that can be prescribed; some are given immediately before delivery, while others are provided several weeks earlier. There are advantages and disadvantages to routine testing, natural deliveries, and breastfeeding. Who makes the decisions about each of these interventions, how, and why?

Health workers are presented with changing technical demands and conflicting political and socio-cultural opinions. International recommendations such as voluntary counselling and testing might not be feasible, not only because of financial reasons, but also due to cultural constraints. The cultural requirement of ‘saving face’ can for example affect both health workers’ ability and willingness to make recommendations as well as patient responses, such as asking for and following up on appointments for medical procedures. In theory, a VCT program includes pre- and post-test counselling, with assurance of confidentiality and privacy, which takes space, staff and time that are often not affordable or available in resource-poor settings. When men and women all seem to agree that all pregnant women should be tested, but at the same time say that they themselves would never ask for an HIV test, then one starts to wonder for whom VCT, according to which people have to explicitly ask for a test is “appropriate”. Further, we found that health workers were not only worried about making medical mistakes but were concerned about their own and their families’ health. A pregnant health worker whom we met in those first days, for example, disclosed that she was scolded by her mother in-law for working with HIV+ pregnant patients. She was accused of not protecting her own unborn child from this very stigmatizing disease.

The people who looked scary and acted rude to Thu appeared to us also confused, defensive and scared. We managed to establish a relationship with the relevant departments at the hospital where Thu delivered. This allowed us to understand who was responsible for what aspect of PMTCT and learn about concrete treatment obstacles that individual staff faced, such as getting test results from the laboratory and obtaining ARV prophylaxis from the phar-
macy in time to provide effective treatment. Many problems were related to a lack of communication between and within departments and could be solved by setting up a better referral system.

As a result of the relationship we established with the hospital, Thu was able to receive ARV prophylaxis and she had an otherwise uneventful delivery of an HIV- son. As we became more deeply involved in reforming the PMTCT program, we were increasingly forced to ask ourselves some provocative questions.

Do these health workers, who are part of the same culture with its very strong preference for male offspring, understand HIV+ women’s desire for children? Most group members argued that they would never have chosen to become pregnant if they had known their HIV status. Health care workers also unanimously agreed that HIV+ women should not have babies, for the sake of the child. But at the same time, both patients and health staff also maintained that all Vietnamese women have to have a child. So what does motherhood mean to all of these women? Thu contracted HIV through trying for a child. Was she “vulnerable” because pressure to become a mother had put her at risk for HIV, or “empowered” by motherhood as it gave her status and rights in the family she married into (a status which radiated also into her own family), or both? Why did some women become pregnant after they knew their HIV+ status? Were they exercising their “reproductive rights”?

The activities we conducted in our support groups outside of the health care delivery setting also began to provoke profound questions about the role which the social and cultural constructions of gender roles and relationships play in structuring HIV+ women’s options. Volumes of books, guidelines and decrees have been written about “involving men in reproductive health”. When we started with the group I thought that most women would be rather resentful of their husbands because they had infected the women with HIV. Further, some men seemed to want to control their wives. Several women had been rather badly beaten up, or complained about physical and mental abuse when they came to the group. We saw husbands waiting in front of the building during group meetings. Their wives reported that this was because their husband did not trust them and wanted to make sure that they knew where they were. In contrast, other men supported their wives by bringing them personally to the group so that they were more comfortable and did not have to wait for the bus. We learned that women were very concerned about the health of their husbands. When Thu’s husband, a recovering drug user, became ill with AIDS, she made it very clear that she had to keep him alive and she seemed willing to pay almost any price to do this. In Thu’s case it was clear that there was real affection between the two. But did all the other women push us to advocate for better treatment for their husbands because they loved them?

It is commonly understood that Vietnamese women still have to follow ancient Confucian patriarchal rules of submission to their fathers, husbands and eldest sons, and that women have to provide care and support to the family.
But if this is the case, then why did Thu’s husband, as well as numerous other husbands of HIV+ women, show up at a cooking class to learn to cook for his son? Did his HIV infection change traditional dynamics in the family?

What is the “practical” meaning, i.e. the effects of, HIV in the day-to-day experiences and distribution of power in intimate relationships, and can women use these relationships to their “strategic” advantage? What is the role of men in the success of some of these women? And what happens to women who lose their men and become widows, especially widows without a son?

As we began to provide micro credit programs for the women in the group, we were forced to confront an issue which many studies have examined: the relationship between poverty, gender and HIV in different cultural contexts. A large number of studies have highlighted how HIV epidemics might differ in their main modes of transmission but that they are also concentrated among poor and marginalized populations. Within these populations certain infected and affected groups, notably women, also become more impoverished than others as a consequence of the epidemic. (Ogden, Esim, & Grown, 2004b; Smith, 1994; UNAIDS, 2006b; UNDP, 2005a) Accordingly, the subsidy granted by the Netherlands government to fund this project was explicitly provided for research dedicated to clarifying the relationship between gender, poverty and HIV/AIDS. Since the International Conference on Population and Development (ICPD) in Cairo in 1994, more attention has been paid to the empowerment of women as a pre-condition to their increasing their control over their bodies and fertility. Many studies have investigated the impacts of micro-credit and have reported positive health effects for women and children. (Chávez, Pimentel, Dohn, Dohn, & Saturria, 2004; Hadi, 2001; Nanda, 1999; Tesoriero, 2006) It is therefore not surprising that recently some policy makers and academics have proposed that micro-credit might also help to empower HIV infected women. (Kim & Watts, 2005) Therefore, one obvious line of inquiry of this study is whether micro-credit can help to empower HIV infected women, who bear special, often costly, health needs of their socially stigmatizing disease. What is the relationship between micro-credit, access to AIDS care, gender relations and empowerment? To what extent can access to micro-credit empower HIV+ women, particularly in the sphere of reproductive health?

Since we started, the Sunflower support group has become the largest group of HIV-infected mothers in Vietnam. We now have six groups in four provinces supporting around 1000 women, care givers and children. The groups are successful in mobilizing access to ARV and PMTCT treatment for the women. We have lost only two women in three years; in both cases the groups had just been started. The death of members was used by both groups to remind authorities to speed up access to the available medicines. The group has received both international and national attention; its members have met the wife of Kofi Annan, Jackie Chan and many other high profile visitors from around the globe. They have addressed Vietnam’s National Assembly, and co-facilitated lectures at universities and hospitals. The National Women’s Mu-
seum has hosted performances and an art show on the right of these women to raise their children themselves.

It would seem that the women in the Sunflower groups have been “empowered”. But what exactly is empowerment and how can it be measured? How is female empowerment constrained and enhanced by the norms and values of Vietnamese patrilocal and patrilinear family structures?

Almost all of the pioneering members are still with us; most have become active in improving HIV/AIDS prevention, testing, detection, care and treatment in the community. Quite a few of our members make a living now as peer educators. For some time Thu was a peer counsellor at the same hospital where she delivered, for example. Some women, including Thu, have started their own groups. These days there are many groups for HIV-infected women. What does it mean for these women to be involved in the fight against AIDS while they are infected themselves? Are they lobbying for care and support in their own right, or are they mobilised as mothers to provide care to people whom the state is not able or willing to support?

The research problem

The overall objective of this project is to enhance understanding of how gender roles and identities reinforce medical and social practices of PMTCT that do not advance the right of mothers to live as long as possible in Vietnam, and yet how these same roles and identities are also used by women to increase their ability to make strategic life choices. I will explore, for example, how cultural notions regarding gender and lineage, such as ideas about motherhood, are a double-edged sword that women can also use to increase their options and quality of life. I will examine these ‘double edges’ of motherhood at different temporal points, as well as how motherhood itself can be transformed during the course of the PMTCT process in both the private and public spheres. Women’s ability to make strategic life choices at key moments in the course of a PMTCT program, at the individual, household and support group levels, is explored through the following research questions:

1. 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?
2. 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?
3. What is the contribution of micro-credit, offered through a support group, to women’s empowerment at household level?
4. What are the actual opportunities for HIV+ AIDS widows to set up a new life for themselves in a patrilinear and patrilocal setting where HIV is stigmatised?
5. What is the role of self-help groups in transforming the private needs of women into collective action?
“Pressure to bear”: some personal insights into the social duties of Vietnamese women

Vietnamese women are burdened by many familial and reproductive duties. Some of these duties, such as having a happy family, i.e. a family with two children, are both culturally constructed and imposed by the state and state agencies such as the Women’s Union.

Other normative injunctions, such as that these children should be an elder girl and a younger boy, or that babies (of a certain sex) should be planned for certain lucky years, yet also within the first year of marriage, are additional imperatives grounded in folk wisdom. A married couple is not regarded as a real family, and is considered “incomplete”, without children. During pregnancy and early motherhood the social pressures on women are intense. It is hard to describe to people who are not familiar with Vietnamese culture how exhausting these pressures can be and how difficult they are to resist because their verbal and physical manifestations are so profuse and widely shared. Not only HIV+ mothers, but all of my colleagues, including trained medical doctors, have shared stories about how during pregnancy and breastfeeding they felt pressurised to comply with some rule or belief they did not agree with, such as not eating chocolate because “the child will be dark” or not drinking coffee because “the child will have a hot temper”. I have seen women from all walks of life complain with tired smiles how their own mothers, their mothers-in-law, the neighbours and even complete strangers in the market have been actively mobilised or felt compelled to participate, uninvited, in discussions aimed at convincing them of the importance of conforming to prevailing social norms of motherhood.

The pressures are created not simply by what people say, but also by what they do not say. As a foreigner who was pregnant and raised young children in Vietnam, I have only experienced a fraction of these pressures. But I have many examples of situations where I became so tired with all the advice that I either conformed to the “Vietnamese way” or fled and hid. One sunny autumn day for example, I was happily swimming laps in the pool of a large hotel with my sleeping three-month-old baby strapped in his chair next to the pool. In one of the neighbouring rooms a large wedding was going on with hundreds of guests. I was just getting started on my laps when a group of fifteen older female wedding guests in exquisitely decorated áo dài appeared on the poolside with towels gesturing and pointing at my child. The child was still asleep but his facial muscles were twisting suggesting that he would wake up soon. I climbed out of the pool to meet the delegation. The ladies informed me politely but firmly that I was spoiling my milk and my health by exposing my body to the cold water. The water was at least 23° C and thus warm by Dutch standards. My husband was sitting in an armchair observing the session amusedly, with our two-year old daughter standing next to him. The ladies looked at him and complimented me on his young good looks.
Then they looked at each other, nodded, looked at my husband again and the oldest said with a concerned voice that exercise in cold water would make the skin of Vietnamese women age. Then with the same concerned polite expression their eyes moved to a gorgeous young Vietnamese woman by the pool in a leopard skin bikini and high heels. More and more women appeared to join in the health counselling session. They turned to my husband and informed him about Vietnamese beliefs about the dangers to my milk for my child caused by exposure to cold water. The conversation was conducted with the nicest of smiles, and with many references to cultural differences and compliments on Dutch tulips. But within minutes I left the pool with my child to hide in the dressing room hoping that they would disappear.

This is one of the situations where I felt that I understood what Vietnamese women mean when they say that any discussions is pointless and exhausting and that the best solution is to thank profusely, smile politely and exit the scene. I have many such examples of being “counsellled” on pregnancy, how to raise my children and how to treat my husband, by well meaning, caring and concerned strangers. It has made me and my family feel very safe and cared for. But I have also become frustrated when my explanations and ideas have been dismissed with silent, knowing looks that made me feel like a beloved, naughty and rather slow child.

As a foreigner I am always visible, always an outsider in public spaces, but at least I have the luxury of being able to disappear into my house, if not without passing the neighbours and their many different kinds of smiles that may signify emotions as diverse as happiness, disapproval, complicity, and embarrassment. Unlike Vietnamese women I have my own room where I can be invisible. It seems to me that for Vietnamese women, gendered normative pressures are omnipresent. Over the last four years, I have spent hundreds of hours talking with women from all ranks of life about the pressures related to marriage, having babies, feeding children, children’s sleep habits, and keeping one’s in-laws happy. As a non-Jewish woman married to a Jewish American, I have had to contend with my own mother-in-law on some of these same issues. Many Vietnamese women have given me their heartfelt and wise advice, helping me to laugh and deal with pressures in my own family. Women, especially HIV+ women, have to contend for almost every inch of personal space in Vietnamese families. Yet over the years I have seen women transform their relationships in their families and communities to share their many care and support tasks. One thing that will become abundantly clear over the course of this thesis is the multiplicity of techniques HIV+ Vietnamese women have developed for coping with all the pressures of being a mother while also managing their own health problems.
Introduction

Structure of the thesis

A central theme of the research presented in this thesis is how Vietnamese cultural notions concerning gender roles and family lineages mould and shape not only the medical practices designed to prevent mother-to-child transmission of HIV, but also the ways in which the agency of the target population of mothers is circumscribed or empowered.

The thesis is divided into several sections. The first three chapters present the socio-political background of the HIV epidemic and a theoretical and methodological framework that informs the five empirical chapters.

In Chapter 1, “HIV Control Under Renovation,” I provide the reader with an outline of the socio-political context and the key epidemiological characteristics of the HIV epidemic in Vietnam during the Đổi mới (renovation) period. Although the transition to a market economy has been effective in alleviating poverty, the state also faces new challenges such as increasing crime, injecting drug use and HIV. The Vietnamese state in transition approaches women as moral and physical reproducers of the nation, with population policies that aim to both limit population growth and assure a healthy future generation. In their role of reproducers women are made responsible for protecting the family and the nation from “social evils” (tệ nạn xã hội), notably illicit drugs and working in prostitution, as these are seen to bear serious consequences for subsequent generations. These moral and practical responsibilities can be simultaneously understood as burdens and sources of status and power for women.

In Chapter 2, “A Double-edged Sword: Theoretical Concerns”, I explain my theoretical framework and introduce key concepts and themes such as gender inequity, resistance, families living with HIV, new reproductive health technologies, mobilization and collective action.

Chapter 3, “Methodology and Methodological Issues”, provides the reader with an overview of the types and methods of data collection and data processing which were undertaken. I also discuss some of the advantages and challenges of conducting qualitative action-based research on gender issues, including gender-based tensions and conflict, in a transitional socialist country and within a cultural context in which considerable value is placed upon the maintenance of harmonious relations.

The subsequent five chapters present empirical case studies. Each chapter explores different temporal points before and after the delivery of a child, when HIV+ women have to make life-changing choices. The chapters are presented as articles, most of which have been published or are under submission for publication by international peer reviewed journals. The five chapters highlight various issues of PMTCT in a drug-driven HIV epidemic and in a cul-
tural context of family preference for sons, which matches the environment of several other emerging HIV epidemics in East and South-East Asia (such as China and Indonesia), but differs from other HIV epidemics, such as that in East Africa, for example. The HIV epidemics in Asia and the technologies available to cope with them are changing rapidly, and the issue is urgent.

I have therefore chosen a thesis format that allows my busy colleagues either to access the findings in smaller, thematic portions or to read them in their entirety, organised within the larger theoretical and conceptual framework of this thesis. This approach reflects my personal and intellectual commitment to engaged academic practice. The five empirical chapters are as follows:

Chapter 4, “Dealing with a Positive Result: Risks and Responses in Routine HIV Testing Among Pregnant Women in Vietnam”, examines the different ways in which women find out that they are HIV positive and the social consequences of different testing models that are offered to pregnant women. Prenatal screening technologies such as HIV testing are part of national population policies, including policies to prevent transmission of HIV from mother to child that target women in their roles as future mothers. Because of the stigma attached to HIV both patients and health care workers feel uncomfortable asking or recommending HIV tests, and prefer routine “blood” tests. When the test results are positive health workers are ill-prepared to inform the women and instead rely on the official notification system, according to which local officials have to inform the patient. This chapter shows that the immediate social, economic and health consequences of these policies for women and their children are mostly negative. However, prenatal screening also makes HIV+ women visible, a necessary step for both accessing treatment and collective action for better services.

Chapter 5, “Holding the Line: Vietnamese Family Responses to Pregnancy and Child Desire When a Family Member has HIV”, explores the cultural reasons why HIV infected women want to become or stay pregnant, and how and why these women and their families realise their fertility ambitions in the health system. Medical guidelines for HIV positive women who are pregnant, or who want to become pregnant, and for women with HIV-infected partners, often pay little or no attention to the role of the family in fertility decisions. This chapter shows that both HIV+ women and men want children for many different reasons and are also pressurised to have (male) children by their close family due to the perceived importance of honouring the ancestors and continuing the ancestral lineage. PMTCT provides families living with HIV with new opportunities to have healthy children, and continue the lineage, just like other people. PMTCT also raises new moral and socio-economic questions about the relationship between fertility choices, women’s status in the family, and the spread of HIV.

Chapter 6, “Zest for Life: Microcredit, Medicines and Women’s Empowerment in North Vietnam”, explores the contribution of micro-credit offered through a support group to a number of different dimensions of women’s
empowerment at the household level. It is demonstrated that women actively use the gendered roles that assign care to women to mobilise resources for their families and themselves in a private setting. Although Vietnamese women cannot escape the caring roles assigned to them by their society, they can, however, subvert these roles within the limits of Vietnamese motherhood.

This chapter also shows that access to ART and changing gender roles may be a condition to the empowerment of HIV+ women through micro-credit, instead of a result. No clear relationship was identified between increased income and increased reproductive freedom, suggesting that socio-cultural fertility expectations and gender roles within the family are key factors in women’s (dis)empowerment.

Chapter 7, “Recreating Kinship: Stigma, Support groups and Coping Options of AIDS Widows in North Vietnam” looks at how their HIV+ status not only stigmatises and marginalises AIDS widows but also allows them to create new family arrangements that avoid some of the limitations of the patrilineal and patrilocal system. This chapter follows the life trajectory of Vietnamese HIV+ AIDS widows in their families over a period of two years after the death of their husbands. Before the loss of their husbands, these women faced numerous challenges while living at their in-laws’ homes, in a situation they could not change by themselves, not only because of patriarchal and patrilocal cultural norms but also because of economic constraints, the criminalisation of drug use and HIV-related stigma. In some households the lives of women of different generations revolve around the support they provide to male drug users, reinforcing their roles as mothers/caretakers and depleting them financially. Although widows have very low socio-cultural status, for some HIV+ women the death of their spouse can be a relief or a liberation, as it forces them to create a new living situation.

Chapter 8, “Contested Motherhood: HIV+ mothers Organising in Vietnam”, examines how support groups for HIV+ women employ motherhood as an aspect of identity which helps members organise themselves to fulfil their practical and strategic needs. Although women are vulnerable to contracting HIV in their roles as wives and mothers, motherhood also provides women with social status and an identity that can be used to develop a collective form of organisation and a strategy to access the social, economic, and health services that they and their family members need. Our findings suggest that women’s practical and strategic gender needs in relation to PMTCT are best conceived of as a continuum, rather than as hierarchical, separate needs.

In the final chapter “Conclusions: Resisting the Pressures”, I analyse the individual case studies presented in the five preceding chapters within the wider theoretical framework that was outlined in Chapter 1. Although HIV in many ways reinforces gendered inequities, the disease also creates new opportunities for transforming relations between men and women within families and allows women to organise themselves and enter into strategic alliances with the state that alter the relationship between patients and the (medical) establishment.
Presentation of the thesis

Working as a social scientist in a medical setting means working with different academic publishing styles and traditions that needed to be addressed for the publication of results in this thesis. Following medical publishing rules, most of the chapters in this thesis are the same texts which have been submitted to various journals. I have abided by the formats and styles required by these journals, such as the number of words, the structure and referencing systems, and mention in each chapter where they have been submitted or published. In medical science it is acceptable to present the texts exactly as they were published in the journal in a PhD thesis even when fonts, font size end line spacing in the different journals are different. But while this makes it visible that the articles have been published and peer reviewed, it can also create a format that “divides” a PhD thesis, rendering it less consistent. To illustrate that the empirical chapters are part of a coherent argument in a PhD thesis in the social sciences I therefore use the same font, font size, alignment and line spacing in all the chapters of the thesis. For the chapters which have not been submitted to journals I follow the format and style of the journal AIDS Care. For the literature references throughout the thesis the names of Vietnamese authors are given in full because many authors have the same last names. The tables have the same numbers as submitted and/or published in the journals.