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

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In this thesis I examined how both HIV as a disease and medical technologies and associated state policies and practices aimed at the prevention of mother-to-child transmission of HIV in Vietnam not only build and reinforce gendered inequities between men and women, but also provide new spaces and opportunities for women to resist and transform traditional gender roles and identities, and also to change state approaches to tackling HIV. The application of PMTCT technologies can be seen to be founded upon conventional gender norms, notably socio-cultural notions of motherhood. Although both men and women can be vulnerable to HIV/AIDS due to their specific gender roles and identities, HIV+ women may be more vulnerable economically and socially due to stigmatisation, increased health expenses, and possibly the loss of a spouse. Although many of these practical, feminine burdens of the epidemic are invisible at high policy levels, they are important in shaping women’s lives at community, familial and couples levels. Rather than presenting a fixed and unchangeable view of gender relations in which women are victimised, I have emphasised women’s agency and proposed a more fluid, dynamic and negotiable approach to gender relations, stigma and women’s (dis)empowerment. In order to understand if and how these changes empower women I have tracked women’s lives over a period of time. Once diagnosed as HIV+, women must make choices regarding their fertility, such as whether or not to continue a pregnancy or try to have a child. Within the broad four-prong PMTCT model, there are specific moments that are of particular theoretical and empirical interest, as they shed light on the negotiation and construction of individual, familial, and collective views of women as mothers and as caretakers of society as a whole. I have examined a number of these key moments in chronological order, as HIV+ women encounter them in their own lives.

In Vietnam, as in other developing countries, the prominent role of the familu means that many choices including decisions about fertility, control over income, household assets and health expenditure are not made by individuals alone. Being a HIV positive mother can be seen as a double-edged sword. Women are in some ways burdened by state-controlled population policies such as “cultural family policies,” which aim to mould women’s identities and roles, as well as HIV surveillance. But at the same time, the cultural and political importance of motherhood, together with the increased visibility
of HIV+ women, also offer opportunities for women and the state to organise themselves and improve services and opportunities for different different classes of HIV+ women in modern Vietnam.

HIV+ women may be politically and legally marginalized because of their HIV status, or because of illicit drug use in the household of their in-laws. Being publicly known as a person infected with HIV can limit the range of jobs or business opportunities available to such women, but being HIV+ can also open the door to various new and relatively lucrative job opportunities, such as working as a peer educator that are not available to those who are not HIV infected. In each chapter my study questions have explored the double edges of motherhood at different temporal points in course of the PMTCT process; HIV testing and discovery of HIV+ status, deciding about having children, making a living as a HIV+ person, dealing with the loss of a spouse, seeking practical support and recreating new social networks. Having described the experiences of these women and their families in the preceding empirical chapters, I now examine in my conclusion what it means for women to live with these gendered normative pressures and inequities.

Fertility, child desire and HIV

In Vietnam, with its strong patrilinear and patrilocal Confucian tradition, women who are married to the eldest or only son are under particular pressure to produce a male heir who can continue the lineage. Women and men also want to have children for various personal, familial and cultural reasons. It is difficult for Vietnamese women to openly challenge the dominant normative view of the “natural” role of women as wives and mothers. For women who cannot have children there are some, though scarce, opportunities to adopt children, or they may have to share their husband with another woman who can bear his children. These negative social consequences of an apparent inability to bear children are not unique to Vietnam, but have been found in culturally diverse settings. Having a child may, therefore, give a woman personal emotional satisfaction, nearly always gives her status in the household of her husband, and allows her to participate in formal and informal networks of other women.

Most women consulted in this study in Hanoi learned about their HIV status during HIV testing when they were pregnant, because testing is mandatory before a hospital delivery, but others learned about their disease because their husband or child became ill with AIDS. Routine “blood” tests (including HIV tests) during ANC are acceptable to women and health staff because both feel uncomfortable discussing issues specific to HIV-testing because of the stigma related to HIV. This discomfort also explains why health workers at routine testing sites rely on the official notification system, shifting the responsibility to inform the women from the hospitals to district and commune health staff, which can result in stigmatisation by families and communities.
This study corroborates previous research findings, reported earlier, that in a Vietnamese context we need to look at the whole family in order to understand fertility decisions among HIV+ couples. When we looked into the factors influencing decisions about fertility in families with an HIV-infected member we found that men and women both have limited authority.

Instead, the whole family takes a crucial role in deciding whether a woman should become pregnant and whether she will keep her child. Women who were detected HIV-positive at ANC services reported regretting having been tested late in pregnancy because they felt ill-prepared and unsure that they could raise their child well. One reason suggested by the results of our study of people’s actual decisions over a period of time: that although people may expect to have children, few take the step of actively trying once they are infected.

The HIV+ couples that actively tried to have a child despite their HIV status decided to do this in the context not only of the close family but also under the influencing presence of the ancestors in Kinh culture. In 18 out of 20 cases where women felt pressured to have a child she was married to the eldest and/or only son, hence the “lineage holder” responsible for continuing the family line, and was pressurised by the family to have a male child. The Confucian cultural notion of the need for parents and grandparents to have male offspring to continue the lineage is therefore critical to fertility decisions within families. The relative lack of authority of men over fertility found in this study is probably related to the history of drug use of most of the HIV+ men who were included. These men are likely to have very low esteem because of their addiction, they know that their family suffers but they cannot stop using drugs without adequate professional help and substitution drugs like methadone which are currently not accessible in Vietnam. The role of elder men in family fertility decisions deserves to be further explored. The HIV+ women and men we met did not propose to invite these elder men to join the research and we respected their wishes. However when we spoke with the older women it seems that some of these decisions were taken in the name of these elder men and for his family lineage, but not one older or younger woman person referred to discussions in which these elder men had been directly consulted or given their opinion. It is therefore possible that elder Vietnamese women consider it part of their thiên chức to take care of their husbands’ family lineage without directly discussing this with them and in a way disempowering them in their own households.

We found that health workers shared common cultural ideas about preferred family composition. They support men and women in the quest for male offspring, which is facilitated by the presence of PMTCT technologies that significantly reduce the risks of having an unhealthy HIV+ child.
The availability of ARV prophylaxis not only gives women and their families’ new fertility options but also poses new moral questions, although patient–provider interactions, especially counselling on HIV, PMTCT and fertility issues can certainly improve some of these moral choices and dilemma’s that cannot be answered by health workers alone.

HIV-infected families need to take into account certain social stigma towards persons infected with HIV as well as structural considerations when they make fertility decisions. Health workers, women and their families are not just concerned about the health of the child itself but they are aware of the broader social difficulties of rearing a child in a family both infected and affected by HIV and which might also be coping with addiction related problems. These personal and familial choices about fertility are made in a context of the privatisation of the national health care system and national dependency on international donors to provide funding for ART. The reluctance of HIV women and men to actually take the step of trying to have a child should also be understood in the context of uncertain access to medicine and other health services that HIV infected persons need for the rest of their lives.

**Gender, HIV surveillance and the state**

Life in most of the households consulted during this study is dominated by the illicit and socially stigmatizing drug addiction of one or more male members. This study suggests that HIV testing in Vietnam is both based on medical symptoms and on socio-economic attributions such as “hairstyles”, “clothing” that are linked to social deviant behaviour notably drug addiction and sex work. The symptomatic testing in a way reflects and builds upon these other “social deviant symptoms” and social differences between women and turns it into a new medicalized “at-risk” subject that needs testing.

Routine testing on the one hand normalizes the testing procedure and this is an important reason why both health workers and women prefer this mode of offering tests to symptomatic or opt-in testing. Yet, on the other hand any HIV testing, including routine testing, creates a medical distinction between HIV+ and HIV- persons that has a social significance. Both symptomatic testing and routine testing results at the provincial levels and below are communicated to communities through a HIV+ notification system that informs HIV+ individuals, their families and communities, about their positive result. Though this notification system is intended to assure the provision of care and support to PLWHIV we found it also often results in social isolation and stigma. Through such notification, the HIV+ status becomes a symbolic marker that is placed upon families who can become socially isolated in their own homes and communities due to HIV-related stigma.

Stigma can be seen as an example of the internalisation of structural power inequities that have been described by Sen and Freire, making HIV+ persons
to a certain extent complicit in their own social isolation and marginalization. The counselling that HIV+ women receive from the various authorities that make home visits to PLWHIV is irrelevant in helping women understand their rights and improve their situation.

However, it was found that HIV+ women regularly take action to change their lot by actively seeking HIV counselling and information about living with HIV at VCT sites after inadequate counselling during routine testing and through the notification system. Although at first glance or at first meeting with these women one might get the impression that their situation is hopeless, and that they suffer from some or various kind(s) of “false consciousness,” this study found also that over time the women developed new coping options and abilities to change their marginalised positions. While HIV systems of surveillance and notification may have isolated these women through actual and felt stigma, it also made them visible and a much sought-after target of both national and international funding and support, creating many new opportunities and capacities for them to negotiate power inequities. Many self-help groups for PLWHIV in Vietnam aim to improve individual coping mechanisms with psycho-social support from peers. These groups help women not just in addressing HIV related stigma and building self-esteem but also in accessing economic and medical services. And while HIV+ stigma can create a self-made or self-perpetuated “prison” it can also enable the establishment of new networks and groups that provide individuals with new freedom, based on their HIV status.

**Families living with HIV**

The life stories of several women in this study reveal how drug addictions create and reinforce differences among women both within and outside the family. Elder women in families with male IDUs do not merely fail to inform the girlfriends of male drug addict members. Some women actively hid the drug problem and HIV+ status of their sons and brothers, sometimes in an effort to rehabilitate the family by the marriage of its drug-addicted member.

In most of the families consulted during the study the younger women have to obey their in-laws, especially the mother-in-law, perform unpaid household work and contribute labour to family businesses over which they have little, if any, control. Although studies suggest that the economic situation of Vietnamese women has overall improved since Đổi mới, most of the women in this study are married into poor and lower middle income households, do unpaid work in the household, and they and in some cases their husbands mostly work in the informal sector or in insecure jobs in the private sector in urban areas. Moreover, in a Vietnamese urban context it is very difficult for women to abandon a difficult marriage or remove themselves from a problematic family situation and live alone for both financial and social reasons.
The increasingly available ART in Vietnam not only creates new health opportunities, but also moral and economic obligations for women in families living with AIDS. The advent of HAART has changed the kinds of care and support that HIV+ persons need from a hospital setting to a community and familial setting. With HAART, AIDS has become being a chronic disease and in developing countries such as Vietnam families carry the burden of care and the financial costs of such treatment. For the women who are infected with HIV themselves there is pressure to help their husbands to stay alive and access the new medications, which means that they have to find money to improve their husbands’ health, especially the costly analyses of their liver function.

The structure of families, their earning capacity and life cycles are all affected by HIV and the effects are different for men and women. This study suggests that gender roles and identities within these families can put women at risk for HIV and can burden women with many responsibilities. However, our data on AIDS widows revealed how the HIV epidemic allows some HIV+ women to create new family and social support structures and avoid some of the restraints of the communist model “cultural family” and Confucian patrilocal ideals.

Empowerment, gender and HIV

There is now a wealth of studies on AIDS, vulnerability and disenfranchisement, and the empowerment of women is now a much cited recommendation on reducing the spread of the epidemic. Some of the literature on HIV/AIDS links the spread of the disease to globalisation, larger economic structural causes and international and national policies. It is clear that the price of ARV is key in shaping the lives and opportunities of individuals. This price is indeed determined by economic forces such as the pharmaceutical industry and global, international political initiatives such as the Global Fund and Clinton Foundation. But an emphasis on global or national structures and policy-making in the public arena might reflect a view of state power and gender relations that cannot well describe changes that alter power configurations at the grassroots level.

In Vietnam, just like the rest of the world, women are increasingly infected and affected by HIV/AIDS, and there is a feminisation of the epidemic. However, it is important to keep in mind that the epidemic is IDU-driven, and remains concentrated among men of reproductive age. These men are vulnerable to addiction because of their gender roles and identities as risk takers, their exposure to professions and environments where drug use is common, and even promoted (such as mining and truck-driving), and where drugs are cheap and readily available. The vulnerability of women to HIV infection is related to their gender roles as mothers and wives, but our study suggests that the women who become infected also lack power in other domains due
to their educational and economic status which shows the importance of the socio-economic context on vulnerability to HIV.

While the Vietnamese state has systematically promoted gender equality, in many ways gender roles continue to restrict the opportunities of women, especially poor women, to organise themselves and participate in decision-making processes by the state on socio-economic and health development. Yet while women can be considered to have low status in many spheres, motherhood is revered in Vietnam. This is why the Women’s Union has been able to establish groups for the mothers of HIV+ male IDUs to support drug users (“sympathy clubs”) even though drug use is criminalised. Yet these clubs can also be seen as confirming the moral obligation of mothers to take care of their sons; rather than enabling adult male IDUs to take care of themselves. Yet while the men in this study also had a history of disempowering drug use and often had few opportunities for paid work, when they were given the opportunity to challenge their traditional roles and take care of their children and household work they accepted this. This illustrates that gender roles can change and suggests that Vietnamese mothers and wives might be disempowering men by taking too much care and enabling selfish behaviour.

The key concerns of mothers and other women infected and affected by HIV, such as their own physical and mental health, continue to receive little attention, especially when compared to general prevention. These women like other women in other parts of the world are attractive to donors and national authorities in their role as mothers but remain under-represented in the national fora where AIDS policies are decided and funds are allocated. The experiences of establishing a self-help group for HIV+ mothers revealed how, compared to other PLWHIV, such women have the advantage of an instant “acceptable identity”: their identity as mothers tends to be regarded as morally unimpeachable by other social actors, allowing them to form support groups more easily. Under the umbrella of the state such a group can also network efficiently with various service providers, and although referral networks might not be visible they are instrumental for the successful accessing of services. Although HIV+ women who join such groups may be isolated and feel powerless as individuals, being in a group and interacting with other women who might have different backgrounds but some similar experiences, allows for a positive transformation of ideas and prior prejudices.

Yet although motherhood is a socially acceptable and strategic identity for HIV+ women in Vietnam, their capacity to become publicly active is constrained by their fear of stigma, especially the stigmatisation of their children. This fear may be unfounded. It was found that almost all children of HIV+ mothers who were members in self-help groups were able to attend school after these women gained self-confidence and skills in interacting with state authorities.
Rather than dismissing women’s grassroots groups, as an example of maternalism that celebrates self-sacrifice of women and reinforces traditional gender roles I propose for the recognition of different levels and centres of power. Behaviour that appears to suit people’s needs at one point might be seen rather differently at another level. Women’s requests for information about how to take care of an AIDS-infected son, and apparent success in organising themselves might, for example, result in them being burdened with further care and support tasks. Women’s desire to marry into a richer urban family and become a mother might give them status but can also put them at greater risk of contracting HIV through an unwitting marriage to an IDU. Although it might be because of traditional gender roles that women mobilised themselves in order to access ARV prophylaxis and ART, the political meaning of this act can be considered in different ways, and partly depends on original expectations. If the objective of these groups were to improve access to AIDS treatment then the 100% access they have reached on PMTCT and ART is as good as it gets.

If these groups are assessed according to whether they structurally transformed gender relations, our conclusions are less positive. We found that women’s practical, immediate and strategic gender interests are an interrelated continuum of needs and capacities. The Sunflowers, under the umbrella of the state, were able to effectively organise and mobilise themselves as individual HIV+ mothers and as a special interest group around practical issues. Over the course of time their understanding of gender relations and their relationship to the state changed and they were able to make some social and health care services more patient-centered and responsive to their specific needs. But their HIV status made health concerns, especially access to ART a priority over, for example, access to economic services such as loans. Yet once access to these vital, life-saving medicines was assured, then members were able to focus on other issues, such as socio-economic support.

Empowerment is a process that involves the recognition that women have agency, their own capacities and abilities to act, rather than being victims. This study showed how being part of a group and having access to micro-credit helped to empower women in five dimensions at the household level, especially economic empowerment, socio-cultural empowerment, and psychological empowerment. At the same time, however, it appeared that a change in gender relations and division of labour at the household level were at least partially a condition for, not a result of, women’s empowerment by micro-credit as we saw that only the women with husbands who helped and supported them were able to retain the profits of the increased income. Relatively little progress seemed to be made in increasing women’s reproductive freedom and changing the importance of the lineage to family decision-making on fertility issues.
The legal and political independence of all grassroots groups are restricted by the overall political situation in Vietnam, and it is not possible for any group to operate outside of the communist state. However, the state and mass organisations played a key role in actively facilitating and mobilising women, resources and providing leadership during the start-up phase of the original group, when members were isolated at home, tried to establish status vis-a-vis each other, refused to take on the role of leader or take member voting seriously. Within the groups, women learned how to interact and collaborate with authorities in ways that improved the quality of the services, which gave them and the state representatives personal as well as professional confidence and satisfaction. Being HIV-infected helped these women to develop friendships, networks and relationships with authorities and other HIV+ women around their traditional roles and identities as mothers.

But the Sunflower group also helped some women to transform traditional roles by using the group and their HIV status to convince their male partners to take on domestic and childcare responsibilities while they went out to work as peer educators or to run their own businesses. Hence, ironically, although these women had been infected while trying for a child due to the traditional roles and pressures associated with being wives, becoming infected liberated them from some of the restraints of motherhood.