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

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Gender inequalities

Several medical anthropologists such as Paul Farmer and Nancy Scheper-Hughes have argued that medical anthropologists have both a professional duty and a moral obligation to reveal, discuss and address the broader socio-economic, cultural and political contexts in which health inequities are (re)produced. (Farmer, 2005; Scheper-Hughes, 1992) Gender roles and identities are an important part of the broader context that affects health. Globally AIDS is a disease which affects women disproportionately. In various parts of the world it has been reported that women’s reproductive roles and identities as mothers and wives contribute to their biological vulnerability to contracting HIV, for example. (Amaro, 1995; S. Clark, Bruce, & Dude, 2006; Hirsch et al., 2007) There are, however, many obvious differences among women based on class, ethnicity, and age that are also relevant in the analysis of AIDS as they shape women’s ability to protect their bodies from HIV, control their reproductive health choices, and organise their maternity and maternal roles (Browner & Lewin, 1982; Farrant. W., 1985; Ginsburg & Rapp, 1991; Koenig & Moore, 2000).

In Vietnam HIV is still concentrated among male IDUs, which suggests that men can also be vulnerable to the disease because of male gender roles. Men can be at risk of contracting HIV because of the relationship between masculine identity and risk taking, including injecting drug use, the use of sex workers, drinking, and the expression of homosexual desire, for example. (Canaan, 1996; Doyal, 2001) Moreover, professions such as truck driving require men to spend time away from their families, and provide easy opportunities for them to engage in (unprotected) commercial sex. In other types of work in Vietnam, such as (illegal) mining, it is common for men to use drugs to help them endure the harsh conditions. (Nguyen Tran Hien, 2002)

The reproduction of gendered inequalities and vulnerabilities can be studied at different levels. Earlier feminist works focused on structural causes, such as how socio-political institutions, legislations, and macro-economic structures shape the opportunities available to women. (O’ Barr, 1982) However, these classic approaches did not always sufficiently recognise changes (or the lack of them) which are important for an understanding of reproductive health and fertility choices at different levels, such as socio-economic changes in communities, families, or within couples. (Chen, Phillips, Kanouse, Collins, & Miu, 2001; Europrofem Organisation, 2003; FHI,
2004; IPPF Inter-Regional Workshop Group Meeting, 2002) It is therefore useful to recognise the dynamic links between macro-economic changes and the transformation of gender roles and identities at the community and household levels in the Vietnamese context.

As a result of Đổi mới, male demand for commercial sexual services has risen, and the number of women working in factories and as domestic staff has increased, all of which has contributed to female migration from the countryside to urban areas and changing household compositions and gender roles in both urban and rural areas. (Nguyen-Vo Thu Huong, 2002; Walters, 2004) It has been suggested that men and women’s roles might no longer be clearly defined and that contemporary Vietnam family relationships have been profoundly changed by socio-economic progress, resulting in the gradual disappearance of the traditional social hierarchy, which ensured high levels of respect for men and little for women. (Le Thi Nham Tuyet, 1996) This supports the notion that if macro-economic and social relations are transformed, altered gender roles and definitions of “woman” and “man” emerge. (P. Brown & Jordanova, 1982)

Yet in Vietnam and elsewhere, traditional gender roles can be seen to be closely related to the impacts of HIV/AIDS upon women, and many of the specific HIV/AIDS related problems that make women more vulnerable to HIV are located in the family. These include: domestic violence (Dunkle et al., 2004; Garcia-Moreno & Watts, 2000; Maman, Campbell, Sweat, & Gielen, 2000) lack of support and increased expenses for informal care givers, (Ogden, Esim, & Grown, 2004b; Smith, 1994) inequality in marriage, (S. Clark, 2004; S. Clark, Bruce, & Dude, 2006; Glynn et al., 2001; Hirsch, Higgins, Bentley, & Nathanson, 2002; United Nations, 2000) and lack of access to education for girls. (UNDP, 2005b). Women’s social roles in their families and communities have important health effects, influencing, amongst other things, women’s ability to live positively with HIV or other (chronic) diseases. (Gielen, McDonnell, Wu, O’Campo, & Faden, 2001; Moneyham, Sowell, Seals, & Demi, 2000; S. K. Plach, Heidrich, & Waite, 2003; S. K. Plach, Stevens, & Heidrich, 2006) Moreover, in Vietnam, as in many other countries, families bear most of the burden of illicit drug addiction. (S. Murphy & Rosenbaum, 1999; United Nations, 2003; Vu Manh Loi, Vu Tuan Huy, Nguyen Huu Minh, & Clement, 1999)

The specific differential burdens of the HIV epidemic on women may not be easy to recognise. Women are under-represented in, and are sometimes noticeably absent from, the fora where AIDS policies are decided and funds are allocated. (UNAIDS, 2006a) Both women’s informal work (be it agricultural work, commercial, or domestic) and wage labour is largely invisible and consistently undervalued, by women themselves and others. (Fruzzetti, 1985; Moore, 1988) Examining the value of women’s labour is important because work is not just what people do in order to survive but there are also social values attached to particular kinds of work, which in turn, relate to the distribution of power. In Vietnam, as in others parts of the world, women are responsible for most household tasks, mothering and other caretaking work
such as tending to the sick and elderly, often have to forego paid work due to their domestic duties, and their unpaid work receives little recognition. When Vietnamese women run a business near the home, such as a food stall or a shop, and hence contribute to family income, this is still considered part of their “household work”. (Fyles & Vu Thi Thao, 2001) Women in Vietnam are also expected to pay for costs related to health and education for the whole household. (Tran Tuan, 2001)

HIV+ women might isolate themselves and hide their problems because of their fear of stigmatisation. Health-related stigma involves social disqualification of individuals and populations identified with a particular health problem, such as HIV infection. (Weiss, Ramakrishna, & Somma, 2006) The negative impact of stigma against HIV-infected persons on public health efforts to slow the epidemic has been well documented. (L. Brown, Trujillo, & Macintyre, 2001; Gerbert, Maguire, Bleecker, Coates, & McPhee, 1991; Herek & Glunt, 1988; Malcolm et al., 1998) Women and men may experience HIV-related stigma differently in some contexts, however. In Vietnam, for example, women may be blamed more than men for their HIV+ status. (Bond et al., 2003; Paxton et al., 2005; Voluntary Services Overseas-Regional AIDS Initiative of Southern Africa (VSO-RAISA), 2005) Fear of HIV related stigma has been found to cause women to avoid reproductive health services including antenatal care, VCT and formula feeding. (de Bruyn, 2004; Shapiro et al., 2003)

A number of authors have argued that HIV related stigma is part of a larger process that works to produce and reproduce power relations, reinforcing existing social inequalities, such as gender inequalities. (R. Parker & Aggleton, 2003; R. Parker, Aggleton, Attawell, Pulerwitz, & Brown, 2002) Stigma against HIV-infected persons often builds upon many other prejudices towards those infected, related to their economic status or race. In Canada, for example, HIV/AIDS disproportionately affects black women, women in prisons and “first nation” aboriginal women. In addition to coping with the stigma of HIV, these women also face racism, poverty and single parenthood. (Hough, Magnan, Brummitt, Templin, & Gedelrab, 2005)

Self-exclusion or self stigma is a psychological process that is not only related to a person’s HIV status but also to their social status and their other experiences of being excluded. The complex psychological and social ways in which power inequities are reproduced, resulting in the acceptance of the legitimacy of the unequal order by the “underdogs”, who become implicit accomplices to their continued exclusion from power, have been analysed by influential political thinkers such as Paulo Freire (Freire & Macedo, 1998), Amartya Sen (Sen, 1990) and Antonio Gramsci. (Gramsci, 1971; Paulo, 2000) An acknowledgment of the individual mental process which leads to socio-economic exclusion, including self-exclusion, is useful in that it recognises power as something that emerges, at least partially, from within individuals and hence is something that individuals themselves have the ability to transform.

The recognition of a process that involves women’s own agency and ability to act and to accomplish change is central to contemporary feminist dis-
discussions of empowerment. Naila Kabeer, (2001) for example, defined empowerment as “the expansion in people’s ability to make strategic life choices in a context where this ability was previously denied to them.” This dynamic approach to gender-based power relations, and the recognition of the need to build self-esteem to fight immobilising “victimhood” has received considerable interest among academics and development practitioners. (S. Evans, 1980; Gillis & Perry, 1991; Kling, Shibley-Hyde, Showers, & Buswell, 1999; Malhotra, Schuler, & Boender, 2002; Raphael, 1993; Schrijvers, 1985) Accordingly, an examination of a range of theoretical perspectives concerning the nature of female agency within the particular constraints of both the medical establishment and patrilinear family organisation in contemporary Vietnam will be included in this thesis.

Unlocking the “power within” in order to transform personal needs into a collective demand is both an implicit and often explicit view of power which is fundamental to self-help and grass roots groups of PLHIV and an underlying premise for interventions aimed at providing “psycho-social support”. As we will see in the empirical chapters, gender inequalities are reinforced and reproduced by HIV/AIDS at many levels, but the disease has also opened the door for the creation of groups of PLHIV that can help women overcome social isolation and to change the dynamics of their relationship with medical authorities as well as with their male partners and families.

Families living with HIV

Perhaps because of the original historical emergence of the AIDS epidemic among gay men in the developed world, HIV interventions have primarily focused on individuals rather than families. (Rotheram-Borus, Flannery, Rice, & Lester) Interventions typically placed particular value on individual justice and freedom, and were designed to focus on at-risk individuals, with programs that were age and gender segregated. Studies on social support in the rich northern countries during the early phase of the HIV epidemic, when it was concentrated among gay men and IDUs, revealed that friends provided most of the care and social support. (Burgoyne & Saunders, 2000; Friedland, Rennick, & McColl, 1996; Johnston, Stall, & Smith, 1995) But the situation in some of these resource-rich settings has changed, with the epidemic moving and spreading to different groups, often to poor persons of colour with marginalised socio-economic positions and very different life styles and household arrangements from the gay community. (Williams et al., 2005) That change implies that different strategies are needed to reduce the magnitude of the epidemic amongst the (relatively) newly affected populations.

The progress of the epidemic within the developing world, where PLWHIV live not only as individuals, but are firmly located within a familial context, raises theoretical and practical concerns about how both families and individuals are living with AIDS. In developing countries, families usually bear the costs of HAART and the burdens of care and support for AIDS orphans. Households
which have an infected family member invariably suffer from depleted savings and increased indebtedness. (Heymann, Earle, Rajaraman, Miller, & Bogen, 2007; Tatek & Aase, 2007). All over the world, being an informal palliative caregiver is reported to bring considerable economic costs because it means missing out on income-generating activities while experiencing high out-of-pocket expenses. (British Columbia Centre of excellence for women’s health, 2003; Greaves et al., 2002; Hendrick, 2000; Ogden, Esim, & Grown, 2004a; Smith, 1994; Timery et al., 1994)

Although women tend to do most of the raising of children, the roles of men (including their desire for children) in the reproductive health decisions of women have gradually become recognised. (Sauer, 2003), which has increasingly led to recommendations to involve men more effectively in reproductive health programs. (Chant & Gutmann, 2002; Doyal, 2001; Greene & Biddlecom, 2000; Hawkes & Hart, 2000; Mane & Aggleton, 2001; Ostlin, George, & Sen, 2001) Much of the daily care and support work in a Vietnamese household is done by women whose essential roles in the family as mothers are, as noted earlier, mandated by **thiên chức**, although this mandate is also a burden to women because they may be held responsible for problems over which they have little control, such as the drug addiction or HIV+ status of their children. Some studies in Vietnam suggested that men do play important roles in reproductive health decisions such as abortion. (Johansson, Ngo Thi Nham Tuyet, Nguyen The Lap, & Sundstrom, 1996; Johansson, Nguyen Thu Nga, Tran Quang Huy, Doan Du Dat, & Holmgren, 1998) Men and women’s gender roles and the consequent distribution of power within Vietnamese families could be conceptualised as a “paradox of power”. At one level, men’s social identity may be defined by the power they have over women and the power and status they compete for against other men. But at another level, men may have very little power over their own lives. (Pleck, 1981) In some contexts Vietnamese men might feel as dominated by their wives and children as their Western counterparts. (Harris, 1998)

Vietnamese couples are part of a larger family where men also have practical, social and symbolic roles. In the Confucian tradition, men pray to the ancestors, provide support to parents in their old age and guarantee the continuity of the family line. Men have specific responsibilities to the extended family, which includes maintaining relationships with other male family heads (such as uncles and brothers) and taking care of the family lineage. In these roles Vietnamese men can be empowered or, alternatively, shamed, humiliated, or dominated by other men. (Harris, 1998) When a man is addicted to drugs or infected with HIV he might have less economic power in the family and lack interest in marriage and children, but he is still part of the family. If he is the eldest or the only son he has to cope with certain fertility expectations about continuing the lineage in his family to avoid the shame and humiliation of failing to nourish the ancestors, in addition to the pressures of providing his parents with financial security and social respect in their old age. In a Vietnamese context we therefore need to look at the whole family in order to un-
understand fertility decisions among couples. (Gammeltoft, 2007) Obviously this also applies in relation to couples in which one or both party is HIV-positive.

The possibility that a partner might be HIV+ does not necessarily change couples’ fertility expectations. A study among marriage license applicants in rural China, for example, showed that only 36.8% of the couples agreed that they would not plan to have a baby on discovering that one or both of them was HIV+. (Liu et al., 2005) Studies in several culturally different countries such as the United States and Brazil also revealed that many HIV-positive men and women who know their status have fertility desires and intend to have children. (Chen, Phillips, Kanouse, Collins, & Miu, 2001) Personal health, which is improved by access to ARV, has been found to significantly affect HIV+ women and men’s desire for and expectation of children in the future. (Chen, Phillips, Kanouse, Collins, & Miu, 2001; Panozzo, Battegay, Friedl, & Vernazza, 2003)

The epidemic in which Vietnamese families are living is driven by IDUs. In practice this means that affected families are coping with HIV+ male adults who are often using drugs and paying for these drugs through criminal activity or by selling family property. Several studies in Vietnam have also reported a link between drug use and drug-related domestic violence against women in families with male addicts. (United Nations, 2003; Vu Manh Loi, Vu Tuan Huy, Nguyen Huu Minh, & Clement, 1999) However, what was initially a male epidemic is becoming increasingly feminised due to the growing care and support burdens, as well as infection risks among women. Because Vietnamese women are considered responsible for the behaviour of their children and the moral image of their family, women are most affected when families meet difficulties because male members are IDUs; they have to work harder to increase the family income and try to prevent their husbands and sons from committing crimes in order to obtain drugs. Fathers may also be shamed by the problems in their family but thiên chức protects them from being seen as equally responsible for raising their children. Although people in the community understand the difficulties of women whose husbands or children are drug users, they rarely provide them with practical help. (Vu Manh Loi, Vu Tuan Huy, Nguyen Huu Minh, & Clement, 1999)

How such gender roles and family situations can be changed is a complex question in many cultures, not least in Vietnam. A study in the US found that among HIV+ women, those who were married or who lived with a partner reported higher levels of anxiety and more HIV-related symptoms than those who were single. This might be due to the demands of carrying out the multiple roles of spouse/partner, homemaker, and in some cases mother, which may be particularly difficult when women themselves are sick and struggling to manage their own health problems. (Sowell et al., 1997). In addition, HIV-infected women reported feeling guilty about what their families had gone through because of their diagnosis. (Goggin et al., 2001; van Servellen et al., 1998). Several studies have suggested that women with chronic health problems such as HIV, who feel that they are able to function socially, also experience better health, especially less depression, than women who feel they are failing
A study among HIV+ women showed that the social roles for which rewards most clearly outweighed concerns were those of volunteer, friend and grandmother; the concerns of being a mother were particularly stressful. (S. K. Plach, Heidrich, & Waite, 2003) This may indicate that the dual aspect of motherhood – which can be understood as both repressive as well as providing social status – is manifested in the way that HIV+ women experience their physical and psychological health.

Because of women’s need to move beyond their social role as mothers, and share common concerns in order to help them cope better with family problems, I am particularly interested in the question of whether and how women use PLHIV support groups to transform their usual social role(s), and how this influences their well-being. This issue will be examined in some of the empirical chapters.

Are women disempowered by new reproductive technologies?

Feminist agree about the importance of reproductive freedom, but opinions about new reproductive technologies are divided. A growing body of feminist work has examined the social and political implications of changing birthing practices and new technologies such as in-vitro fertilization, amniocentesis, ultrasound and prenatal screening technologies, for example. (Browner & Press, 1995; Erikson, 2003; Gammeltoft & Nguyen Thi Thuy Hanh, 2007; Rapp, 1997) A number of authors have argued that new prenatal screening technologies medicalise pregnancy and child birth and are harmful to women because they expose women to unnecessary physical and psychological stress. In-vitro fertilization for example, is an expensive, physically invasive and emotionally stressful technology and is often unsuccessful. Some feminists argue that new reproductive health technologies also disempower women politically because they place a natural process into the hands of (male) medical experts. (Arditti, Duelli-Klein, & Minden, 1984; Corea, 1985; Spallone & Steinberg, 1987) Other points of concern are the voluntary nature of these medical interventions and the risks of transforming pregnancy into an “abnormality”, a disease. These new reproductive technologies are often considered as rather neutral objects that are transferable from one socio-cultural context in one part of the globe to another, ignoring some of the cultural and socio-economic differences between these countries, and burdening women with difficult moral choices yet without providing adequate support. (Gammeltoft, 2007; M. C. Inhorn, 2002) Although ultrasound technologies are increasingly available in many poor countries, where they are known to contribute to important demographic changes such as sex ratio, nearly all existing anthropological research about prenatal screening has been conducted in liberal countries of the affluent West. See, for example, (Browner & Press, 1995; Erikson, 2003; Rapp, 1999)
As reported earlier, the Vietnamese state, like neighbouring China, has taken a strong interest in fertility and population issues and has promoted family planning since 1963, partly as a response to concerns about land scarcity and food security. Reproductive health and family planning policies have been directed at women as mothers, have slowed down population growth and reduced maternal mortality, but have not necessarily served women’s broader interests. The Vietnamese government’s concern with both population growth and quality is reflected in a strong interest in science and technology, including prenatal screening technologies, such as ultrasound, and interventions to prevent HIV transmission to children, such as VCT and PMTCT. These technologies are increasingly available and accepted by women and health workers, because they make both parties feel more secure about children’s health. However, the changing sex-ratios suggest that these technologies are also used to determine the sex of unborn babies.

Vietnamese PMTCT policies have focused on detecting HIV+ pregnant women in order to prevent transmission of the virus to the child and have, like some other population policies, paid less attention to the health and social needs of the mother. The PMTCT process involves several relatively new medical technologies such as HIV testing of the mother, CD4 counts and the provision of ARV to the mother and polymerase chain reaction (PCR) tests for children. HIV testing during pregnancy is a good example of a supposedly neutral and “globalisable” technology. Although HIV disproportionately affects developing countries, little is known about the ways in which opt-out and VCT models of testing play out on the ground in the developing country context. Internationally, routine testing is increasingly being seen as a way to increase uptake of testing by those at risk and has been found to be acceptable in ANC services in African countries such as Botswana and Zimbabwe. (Etiebet, 2004; Perez, 2006) Opponents argue that routine testing is problematic because without one-to-one counselling prior to testing the individual’s right to informed consent for testing might be violated. However, this moral question might be different in a country such as Vietnam where the fertility choices of individuals are made within the context of the whole family. Asking an individual for their consent without taking their need to consult with their family into account might, therefore, burden this person with significant, unwanted responsibilities.

Further, in Vietnam HIV surveillance mechanisms to detect HIV during pregnancy are not simply a medical challenge, but they also expose new social inequities among citizens which are largely a product of Đổi mới, the renovation of the economy. Hence PMTCT interventions cannot just be considered medical interventions; they reproduce and (re)create socio-economic inequalities among mothers when they involve practices such as applying HIV testing selectively to pregnant women who are judged by rumour or appearance to be sex workers, drug users or wives of IDUs.

A key question, in my view, is whether, how and when women in different life-worlds perceive their rights as being violated by new medical technologies.
related to HIV. Women who are tested during ANC at provincial level or lower are not only informed about their test results in the facilities; they also receive their test results in their communities through the ‘notification’ system. All commune and district government health facilities in Hanoi have to notify the provincial authorities of suspected HIV+ cases. After confirmation, the provincial authorities inform local health workers at the district and commune levels, who then inform the patient and her/his family with the purpose of providing care and support. This system makes HIV+ women highly visible, often against their will, and can have important, negative social consequences.

A useful perspective at this juncture is Michel Foucault’s argument that diseases and women’s bodies have historically been (re)created and controlled by socio-political norms and practices which have been unconsciously internalised by both physicians and patients. (Sawicki, 1991) This suggests that women themselves have played a role in defining and (re)creating reproductive medical practices including prenatal screening. To understand the social meaning of, for example, different modes of HIV testing, the decision-making processes have to be examined from various perspectives – that of policy makers, patients, doctors, and the family - to understand how consensus is created and perceived and how people deal with a positive test result. Part of the attraction of new technologies could be that women consider them as enabling, even though they might be part of state population policies that aim to control women’s fertility choices. Jana Sawicki proposed that control is not secured primarily through violence or coercion, but through a process of normalisation in which certain tests gradually become part of the expected elements of women and motherhood, rendering particular processes the norm and excluding other options. (Sawicki, 1991)

The acceptance of certain socio-political norms by patients and practitioners regarding gender roles, family and lineage make some health practices, including harmful or medically useless practices, more acceptable than others. (Bhatia, 1993; Gammeltoft, 1999, 2003; M.C. Inhorn & Buss, 1994; Renne, 1993) A conceptualisation of reproductive health technologies, such as routine HIV testing and PMTCT, as normative, rather than coercive, may explain why both women and health workers in Vietnam accept and may prefer routine testing over individual opt-in models, which means that women do not have to make the choice of requesting a test, and justifying this to their families. I will examine the social dynamics underlying the acceptance of HIV testing in ANC from the perspectives of both the women who are tested and the health workers who conduct the state-run testing program. Recognition of the importance of the social-cultural norms and political context in which PMTCT technologies are offered is also essential in understanding if and how these medical technologies empower or disempower women. HIV testing during ANC might burden women with information about a problem that they cannot solve or understand, but it also makes HIV+ persons visible and eligible for any available services and may lead them to join PLHIV groups that can help them to change their situation.
Mobilising HIV+ women

In the 1960s and 1970s many theories of social and political change focused on larger structures; this focus was reflected in works that documented forms of collective political action such as revolutions, mass movements and insurrections. (J. Scott, 1976; E. Wolf, 1973) The rise of middle class social movements in the West in the seventies showed that deprivation alone did not lead to collective calls for social change. And, in contrast, poor people’s movements often failed because of a lack of resources and weak political leadership. (Piven & Cloward, 1977) Consequently some theorists focused on identifying why some activists were more effective and demonstrated how successful activists were often better able to mobilise resources including manpower, finances and communication technologies. (McCarthy & Zald, 1977)

Some argued that the emphasis which the new social movement theory placed on material resources was cynical and overlooked the psycho-social changes and emotional benefits that grassroots groups generate. Moreover, access to resources alone may not enable disenfranchised persons to change their situation. (Laverack, 2001; Malhotra, Schuler, & Boender, 2002; Rifkin, 1986) There are many examples of development project that failed because of an overemphasis on material support, for example. Water and sanitation projects rarely improve health status unless these resources are combined with efforts to support critical thinking and problem-solving skills. (Rifkin, Muller, & Bichmann, 1988) It may be useful to conceptualise increased access to material resources such as ART and micro-credit for HIV-infected women in developing countries, and psychological and social changes, such as HIV+ women feeling more confident and less stigmatised, as interlinked. ART and micro-credit can be considered material resources which enable HIV+ women to accomplish socio-economic change and enhance their social mobilisation. Yet once women have access to ART or capital they may gain more confidence and as a result of this they can express their ideas more effectively, which makes others, such as authorities and doctors, more willing to listen to their needs and concerns in other areas.

Foucault’s assertion that “where there is power there is resistance” (Foucault, 1976) has been central to increased attention to small forms of resistance, which are not clearly linked to larger emancipatory or revolutionary goals. The recognition of such forms of everyday resistance stimulated interesting research on the politics of daily life and (attempted) subversions of power by “muted” and vulnerable groups, such as factory workers carrying out small acts of sabotage of equipment to win a few minutes of calm. As a result, it was proposed that rather than accepting their fate, the poor, though weak, have their own weapons and assume different identities in different contexts. (Craton, 1982; J. Scott, 1985; Taussig, 1993; Turton, 1986; Willis, 1981)

An acknowledgment of different manifestations of resistance is attractive to feminists because women’s movements and modes of organisation have
often taken place at community level and focused on practical issues rather than grand collective political action. (Boesten, 2004; Koven & Michel, 1993) The acknowledgement and documentation of women’s contemporary “invisible” networks and subcultures is politically important, and also of theoretical interest, because it might reveal new aspects about collective political action. Such a documentation of women’s formal and invisible networks and recording of their “muted” voices is part of a global dialogue among women all over the world that has lasted for decades. (Ramusack & Sievers, 1999) Whether these dialogues can and should be translated into joint global political action is another, rather tricky, issue, however, because of experiences of conflict between the theory of women’s solidarity and the differences amongst women which have been manifested in practice, which have placed the legitimacy and the possibility of women’s collective political action into question.

A broader conceptualisation of resistance might also allow for an examination of mobilisation and organisation of civil discontent in one-party communist states, where distinctions between the state and “civil society” are blurred. Within the socio-political and cultural context of contemporary Vietnam, HIV+ citizens are likely to avoid being seen in public expressing dissatisfaction and discontent, and instead find other ways to accomplish change. Moreover, within the cultural context of Vietnam the family might limit or enable women’s abilities for political action. HIV+ women, just like other Vietnamese citizens, might need to formulate their problems in such a way that the historical ideals of harmonious relations between the state and citizens are maintained. This thesis includes a number of these issues through a detailed examination of the successful organisation of HIV+ mothers to access social and health services in Vietnam, and explores important questions such as how a group of HIV+ mothers managed to combine their desire to remain invisible with their need to access goods and services, including ART and loans.

In some Asian countries with epidemics concentrated among male IDUs, HIV+ women are currently a minority and need to make sure that their concerns are known. (Ainsworth, Beyrer, & Soucat, 2003; Beyrer et al., 2003; Birowo, Djoerban, & Djauzi, 2003; Celentano & David, 2003) Vietnam is an interesting context in which to study women’s self-help groups because millions of Vietnamese women are already organised and represented in mass organisations, notably the Women’s Union. Yet the Women’s Union and other mass organisations, including the Red Cross, are linked to the communist party in a one-party state and there are still only limited opportunities available to independent local organisations and NGOs. While HIV remains largely associated with drug use and sex work, both sex work and drug use are criminalised, which means that sex workers and drug users cannot freely represent and defend their interests in public. One of the questions in Vietnam is whether and how support networks established for and by HIV+ mothers, whose families are often clearly different from the state’s “cultural family” (gia đình văn hóa) ideal, can become accepted by the state as a group who can organise themselves and access the same services as other women who fit more readily with social norms.
There are many status differences between HIV+ women based on their presumed mode of infection (sex work, injecting drug use, heterosexual contact, and in isolated instances, perhaps, occupational) that can undermine collective action. Women who think that they have been infected by their drug-using male partners resent receiving the same social rejection and stigma as women who became HIV+ because of their own alleged drug use and/or sex work. (Khuat Thu Hong, Nguyen Thi Van Anh, & Ogden, 2004; Lohar & Shrestha, 2002; MacGregor, 2001; Paxton et al., 2005) They are also offended by having their role as a mother directly and indirectly questioned because of their and their partners’ health status, as well as the risk of transmission to their child. Such antipathies weaken women’s capacities for collective action. Such “identity politics” based on specific attributes of women (such as lesbian, black or aboriginal) have long raised conceptual and political problems because it “either leaves out some individuals who call themselves women or distorts the experience of some of them”. (Young, 1993) These thorny, gender-based “identity politics” can be immobilising, which might be one reason why the mobilisation of PLWHIV in policy and action frameworks such as “Greater Involvement of People Living with HIV/AIDS” a key policy area of UN and many international development agencies working on HIV, is conceptualised as gender neutral (see Table 1).

<table>
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<th>Table 1: Levels of Involvement of PLHIV</th>
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<tr>
<td><strong>Decision makers:</strong> PLHIV participate in decision making or policymaking bodies, and their inputs are valued equally with all the other members of these bodies.</td>
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<td><strong>Experts:</strong> PLHIV are recognised as important sources of information, knowledge, and skills who participate—on the same level as professionals—in the design, adaptation, and evaluation of interventions.</td>
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<tr>
<td><strong>Implementers:</strong> PLHIV carry out real but instrumental roles in interventions (e.g., as caregivers, peer educators, or outreach workers). However, PLHIV do not design the intervention or have much say in how it is run.</td>
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<tr>
<td><strong>Speakers:</strong> PLHIV are used as spokespersons in campaigns to change behaviour or are brought into conferences or meetings to “share their views” but otherwise do not participate. (This is often perceived as “token” participation, where the organisers are conscious of the need to be seen as involving PLHIV but do not give them any real power or responsibility.)</td>
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<tr>
<td><strong>Contributors:</strong> Activities involve PLHIV only marginally, generally when the PLHIV is already well known. For example, using an HIV-positive pop star on a poster or having relatives of someone who has recently died of AIDS speak about that person at public occasions.</td>
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<tr>
<td><strong>Target Audiences:</strong> Activities are aimed at or conducted for PLHIV, or address them as a group rather than as individuals. However, PLHIV should be recognised as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as “patients” at this level. They can provide important feedback which, in turn, can influence or inform the sources of the information.</td>
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Source: UNAIDS, 1999
The view outlined in UNAIDS’ approach to GIPA, whereby public policy making is characterised as the highest form of involvement of persons infected and affected with HIV, is certainly not limited to the UN. The Horizons/Alliance study (Horizons, 2002) provided a similar hierarchical framework of involvement with four categories starting with 1) Access to Services, 2) Inclusion, 3) Participation, and ending with 4) “Greater Participation”, the most “advanced” stage, in which PLHIV work in management and as significant actors in policy and strategic organisation. (Horizons, 2002)

High level policy changes can have significant effects on both gender relations and health, as is evident from many communist states like Cuba, China and Vietnam which all took serious political and legal steps to promote gender equity and have promoted women’s involvement in mass organisations. (Molyneux, 2001) However, a focus on policy and national level decision-making may overlook the important work of women and their networks within their communities, where many women may play leading roles.

Women all over the world have organised themselves in community based groups and networks which focus on the roles and tasks related to motherhood, despite the fact that maternalism has been criticized for celebrating self-sacrifice as an essential feminine attribute, and therewith reinforcing traditional gender roles. (M. Nash, 1995; Pedersen, 1993) States might emphasise the importance of motherhood and embrace maternalist discourses, such as thiên chức in Vietnam, that consider women as natural and unchallenged caretakers of the family and society. But states have also exploited women’s roles and identities as mothers and women’s networks for their own purposes, such as in the provision of services without pay to prevent social unrest due to economic changes due to liberalisation. (Boesten, 2004; Koven & Michel, 1993) Yet in many countries both HIV-infected and affected women are stigmatised and excluded from existing women’s or mother’s clubs and other social networks. This gives these women strategic options, such as trying to conform to accepted notions of motherhood, or trying to reform existing norms of womanhood, but at the same time such women are burdened by many practical HIV-related care and support tasks in addition to their other (unrecognised) household and income-generation work.

Maxine Molyneux proposed a distinction between practical and strategic gender interests to distinguish between women’s needs arising from immediate necessity, such as access to social services, and their longer-term interests, namely transforming social relations and enhancing women’s status. This distinction suggests a hierarchical relationship between grassroots women’s organisations which deal with practical issues, and those oriented towards policy reforms. It has been argued that such a hierarchical division contributes to development planning which is either strategic but impractical, or practical but non-strategic. (Wieringa, 1994) Studies on grassroots organisations in Peru and Brazil have, however, illustrated that women’s practical issues are directly related to national, strategic socio-economic issues. (Boesten, 2004; Corcoran-Nantes, 2000)
For HIV-infected women, access to ARV prophylaxis and ART are practical needs that reflect national medical and pharmaceutical policies and are also instrumental to their participation at familial, community and policy levels. The empirical chapters in this thesis examine the interlinked dynamics of the mobilisation of these practical and strategical interests at different moments of the PMTCT process. It is shown that rather than separating practical and strategic interests, these should be conceptualised as a continuum of urgent and chronic health interests interlinked with other gender-based interests.