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

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Abstract

On a global scale, AIDS is increasingly a women’s disease. Yet women’s concerns continue to receive little attention, and women are politically underrepresented in the fora where AIDS policies are decided. In countries with epidemics concentrated among male IDUs, HIV+ women form a stigmatized minority. This study explores how Vietnamese mothers infected with HIV have been able to organise themselves successfully to access vital social, medical, and economic support and services. Motherhood is a double-edged sword. 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 services that they and their family members need. Our research findings suggest that women’s practical and strategic needs are better conceived of as a continuum, rather than as hierarchical and separate. Because of fears that their children will be socially excluded, many HIV+ mothers are still unwilling to appear in public to challenge the cultural assumptions and policies associated with Vietnamese motherhood which burden them with many HIV-related care and support tasks, in addition to their other domestic work.

Key words: Gender, self-help, Vietnam, care and support, HIV/AIDS

Introduction

Globally women are increasingly infected and affected by AIDS. (Dworkin & Ehrhardt, 2007; UNAIDS & WHO, 2006a) Women living with HIV/AIDS face specific problems that make them more vulnerable, such as domestic violence; (Dunkle et al., 2004; Garcia-Moreno & Watts, 2000; Maman, Campbell, Sweat, & Gielen, 2000) lack of access to education; (UNDP, 2005b) poor support and increased expenses as 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 illicit drug addiction. (S. Murphy & Rosenbaum, 1999; United Nations, 2003; Vu Manh Loi, Vu Tuan Huy, Nguyen Huu Minh, & Clement, 1999) In many countries, gender roles restrict women’s opportunities to organise themselves and to participate in state decision-making processes on...

Historically, female contributions to the transformation of public services as community leaders and activists have been undervalued, because of the low social status of women and motherhood. (Cott, 1987; Dore & Molyneux, 2000; Kaplan, 1997; Koven & Michel, 1990, 1993; Woolf, 1929) Today, in many countries, women work hard in the fight against AIDS, but their concerns continue to receive little attention. (Kmietowicz, 2004) Women remain under-represented in, and are sometimes conspicuously absent from, fora where AIDS policies are decided and funds are allocated. (UNAIDS, 2006a)

The need for HIV-infected women to organise themselves may be even greater in Asian countries with epidemics concentrated among male IDUs, where HIV+ women form the minority. (Ainsworth, Beyrer, & Soucat, 2003; Beyrer et al., 2003; Birowo, Djoerban, & Djauzi, 2003; Celentano & David, 2003) These women have many immediate practical - as well as more strategic political - needs and concerns. As sexual partners of male IDUs, their numbers are increasing, but access to services such as PMTCT is improving only marginally. (GSO, NIHE, & ORC Macro, 2006; MOH, 2004; UNAIDS, 2006b; WHO, 2006) As real or alleged drug users and sex workers, they face social rejection and criminalization. (Khuat Thu Hong, Nguyen Thi Van Anh, & Ogden, 2004; Lohar & Shrestha, 2002; MacGregor, 2001; Paxton et al., 2005) Within their families they bear the brunt of household work and care (Beneria & Sen, 1981; Boulding, 1983; Desai, 2000)

Forming or joining a support group can offer opportunities for all PLWHIV to improve their quality of life, by learning about accessing and coping with treatment and sharing personal experiences. For women who have low status in their own households, the emotional and practical support provided within such groups might be even more important than for men. The groups that could help HIV+ women to organise themselves and pursue practical and strategic gender-based needs are shaped by larger contexts, however. The relationship of citizens to the state, the cultural context, class and racial divisions, as well as the issues around which groups and identities are formed, are all factors that have been found to shape self-help groups. (Gidron & Chesler, 1994) In one-party communist states, such as Laos, Vietnam, and China, the distinction between the state, civil society, and political and non-political “mass organisations” such as the Women’s Union are unclear; opportunities to form independent groups are increasing, but still limited. Nevertheless groups for PLHIV have rapidly expanded in Vietnam over recent years; the number of self-help groups not directly under state authority has nearly doubled between 2006 and 2007, from 34 to 74.(Health Policy Initiative, 2007)

In many Asian countries it is the state, not civil society or (I)NGOs, that provides most social and health services. (Levine, 2004) This suggests that the quality and quantity of the services that HIV-infected and -affected persons need might be most efficiently improved through capacity-building and reform of state institutions, rather than by establishing parallel structures, and
that strategic alliances between PLHIV and the state can be instrumental in increasing their access to health and social services.

However, in these same countries, intravenous drug use, sex work, and sometimes migration are heavily restricted and often criminalized, limiting the scope for the development of alliances between vulnerable populations and the state. In Vietnam, for example, drug use and sex work are considered “social evils”, and a significant proportion of the IDU population spends time in Soviet-style rehabilitation centres. (CSIS, 2006b; UNODC, 2007) Hence the involvement of HIV-infected women in HIV/AIDS programs requires that they have an “appropriate” civil identity that is acceptable to their families and the state in order to be effective representatives of PLWHIV.

Based on this identity, they can find a way to organise themselves and transform their individual needs into successful collective action. This case study explores how HIV+ Vietnamese mothers organised themselves to access vital social, medical, and economic support and services. What identities were developed to negotiate between the needs of their families, other infected and affected women, and the state? How did these identities contribute to collective forms of organisation and a strategy to access the services that they and their family members needed? The barriers that hinder HIV+ women from becoming politically active are also explored: to what extent are HIV+ women mobilised within self-help groups willing and able to take public political action?

**Respondents and Methods**

In this action research we followed the conceptualisation, foundation and organisational development of the first support group for HIV+ mothers in Vietnam over a period of three years. We collected data in November 2003 for a rapid HIV/AIDS situational assessment. We conducted semi-structured interviews on HIV, AIDS interventions, gender, health and poverty with 15 key government stakeholders in Hanoi, and seven officials in two rehabilitation camps for IDUs and sex workers in Ba Vi. Following the analysis of these interviews, a workshop was held in December of the same year with key authorities and PLWHIV, in order to develop an action plan to address the problems identified.

From the first meeting in April 2004 until early 2007, we followed the first Vietnamese support group of and for HIV+ mothers, the Sunflowers, in their interaction with both governmental and non-governmental health, social and economic services. Over the period studied, the Hanoi-based group grew from four mothers to 305 mothers and caretakers and expanded to three other provinces, Thai Nguyen, Quang Ninh and Cao Bang. This study focused on the pioneering group in Hanoi and the first Sunflower group launched in Thai Nguyen in 2005.

We conducted participant observation during group program activities and at almost all official meetings between group representatives and the authori-
ties. Minutes of meetings and program documents, including financial and narrative reports, were collected every three months. Economic data such as the income and capital assets of each group member, as well as loan repayment rates, were collected every six months. State economic support to the group was audited quarterly.

Bi-weekly participatory program observations in Hanoi and monthly program observations in Thai Nguyen allowed researchers to follow the wellbeing of the women and their partners, children and families. Early in 2005 we conducted 275 interviews with health care workers and key stakeholders in HIV/AIDS in Thai Nguyen and Hanoi. With their informed consent, we interviewed 56 HIV+ women in Hanoi and 28 Thai Nguyen. In addition, 34 HIV+ men in Hanoi and 13 in Thai Nguyen joined the interviews. In Hanoi, seven mothers in law and 10 in Thai Nguyen participated in the study. In Hanoi we also interviewed two fathers of HIV+ women, one sister, one sister in law and one brother in-law. For all 153 persons, we used semi-structured questionnaires on PMTCT, care and support, family, HIV, VCT, and ARV. To protect their privacy we have changed all interviewees’ names.

All but one respondent were of Kinh ethnicity, and hence belonged to the largest cultural group in Vietnam. The HIV+ women in the groups and their male partners came from a variety of social and economic backgrounds. Most of the women were between 20 and 30 years old, and all were literate. All the women had been or were still married, and all the husbands (alive or dead) had a history of intravenous drug use, visiting sex workers, or both; they had probably infected their wives. The husbands were usually in worse health than their wives because of drug-related health problems and their longer history of infection with HIV.

Results

Shaping identities of HIV+ women

A number of scholars have emphasised the fact that self-help groups tend to develop distinct cultures and identities which define group membership and how members relate to each other. Specific cultural traits emerge among different groups, such as certain uses of language, symbols and rituals, and formal organisation. Gidron & Chesler, 1994) While there must be a sense of cohesion and shared concerns in order for people to be organised and mobilised, (Goodman et al., 1998; Laverack, 2001) self-help groups enable members to engage with others who share similar life experiences and problems, which can create an instant, shared identity. (Gidron & Chesler, 1994) Such groups benefit individuals both on a personal level, by allowing people to validate their own experiences as relevant, and on a group level, by helping them pursue their collective interests. (Klass, 1992; Powell, 1987)

The creation of a support group for HIV+ mothers was strongly influenced by the public health concerns of state institutions, notably the staff of national
and provincial hospitals, university researchers, the Women’s Union, and the Vietnamese Red Cross. When these authorities met with two HIV-infected women in late 2003, HIV+ women were not accessing the treatments technically available to them. In 2002, only 500 out of the approximately 6000 seropositive women who gave birth in Vietnam were detected in the health care system.

In the national obstetric hospital in Hanoi, a referral hospital for all of North Vietnam, less than 30 cases of women were detected and treated with ARV prophylaxis. Pioneering doctors who provided ART reported being unable to reach the potentially HIV+ female partners of their male patients:

“Women do not want to stay for treatment in hospital. They do not want to risk being seen and known to be HIV+. I think this is because they fear negative social consequences for their children.” (Senior doctor, Hanoi, provincial-level hospital, November 2003)

Isolated, HIV+ women lacked opportunities to improve the social and health care service providers that were failing to support them. Yet women expressed particular concern that without treatment for them, their children would be orphaned.

State representatives and HIV+ women therefore agreed that women needed to organise themselves in order to improve access to the medical, social, or economic care available, but stigma related to drug use and sex work limited opportunities for HIV+ women’s collective action. As one Red Cross representative noted, “Drug users really need our support, but if we allow a group of known users to meet in our building we might get in trouble with the police” (Dong Da, 2004). However, a group of HIV+ mothers without a history of drug use and sex work could meet in a public place and hopefully attract HIV+ partners of HIV+ IDUs. A drug-free group could create a socially acceptable environment for families who might otherwise not allow their female relatives to join.

The first challenge was for women who were troubled by their HIV status and their role as mothers (views which corresponded to broader pessimistic and negative attitudes to PLWHIV’s suitability as parents; (Oosterhoff, Nguyen Thu Anh, Pham Ngoc Yen, Hardon, & Wright, 2007b) to mobilise and establish a sense of shared group identification while adhering to positive norms of Vietnamese womanhood and motherhood – in other words, to carefully navigate identity issues. Sunflower was chosen as the name of the group because members wanted a positive and attractive symbol to counter the prevailing negative associations with HIV/AIDS in Vietnam. In the early days, the group’s outreach materials emphasised that the Sunflowers were HIV+ mothers who had no history of drug use and sex work, and group members suspected of drug use had to do a drug test.

Indeed, members soon established status differences based on their husbands’ and their own proximity to “social evils”. Women whose husbands
were not known publicly as IDUs and had not been in a rehabilitation camp or prison for drug use presented them as normal Vietnamese men who went to play (đi chơi) with sex workers. Women who could not “save face”, because their husbands were in rehabilitation centres or in prison, talked more openly about the problems this caused. In the early days many members avoided saying openly that they lived with a drug user. Over time, some relaxed their guard slightly, admitting that their husbands might have tried drugs “a few times”.

This denial of proximity to drug use was repeated by hundreds of new members in all groups in other provinces, with the exception of Cao Bang where the Sunflowers group went public with a performance on drugs and HIV, produced by members in collaboration with a troupe of break-dancers.

The process of learning to validate one’s own experiences and adopt a new frame or meaning system in which one (re)interprets one’s personal situation has been described by various observers of self-help groups, (Katz & Bender, 1976) which have been considered “experiential learning communities” (Borkman, 1990) They can be places for the (re) formation and (re) socialization of beliefs and behaviours. (Weber, 1982) Being able to connect to others with whom one can share experiences and opinions can be particularly important in situations where people have a stigmatising disease or are considered socially deviant, (Kaufman, Freund, & Wilson, 1989; Kurts, 1990; Mack & Berman, 1988) as individuals are provided with an opportunity to redefine their identity. (Gidron & Chesler, 1994) These HIV+ mothers, living in a patrilinear and patrilocal society, felt isolated from their own families in the households of their in-laws, and were infected by a stigmatizing disease. They reported emotional relief and increased confidence because they were able to listen and learn from other women at the weekly group meetings.

“I felt alone and weak. I used to keep my feelings to myself because I was afraid that I would not be accepted if I spoke about my problems. I am confident in myself now that I have been able to share with so many women like me and they have told me that they feel better listening to me.”
(28-year-old HIV+ woman 2005)

Over a period of three years, the Sunflower groups gradually increased members’ understanding of the broader contexts that shape the lives of women and children in the HIV epidemic. Members’ attitudes towards male IDUs and sex workers gradually became more sympathetic due to their greater understanding about the structural causes that limit individual ability to make choices, for example. As mutual trust evolved among members the authorities were no longer requested to carry out drug tests, although it remains an important part of the informal and formal Sunflower culture and group identity that members abstain from using drugs.

Attitudes towards domestic violence also changed. In 2005, a widow who left her child with her in-laws to live alone was criticised by the group for being a poor mother, even though her in-laws openly approved of her husband’s
physical abuse. But within a year, the group understood that she should not accept physical abuse, and that she had been unable to take her child with her because she had to work, and was too poor to hire care. Leaving her child with her in-laws, who could provide for it, had been the best solution. In another sign of increased sensitivity to this issue, two members now work in shelters for trafficked women and victims of domestic violence in Hanoi, run by the national Women’s Union.

By 2006, the groups began to relax their eligibility criteria to include HIV-infected widowers with children, and the caretakers of children of HIV+ mothers. Yet although grandparents and single male parents have been eligible for membership for some time, male involvement remains limited, partly because of female members’ experiences of living with husbands who are IDUs - as the following discussion on male participation in a group meeting in Thai Nguyen in 2007 illustrates:

Group Leader A: “We have to help children infected with and affected by HIV. We could invite widowers to join our meetings and learn to take better care of their children. Maybe we’ll need someone to take care of our children someday.”

Group Leader B: “Well, I don’t think they are very useful to us. These men all use drugs. That’s why their wives died of AIDS.”

Member: “Well, men could be useful for doing some heavy jobs. Our office roof needs fixing.”

The group laughed and agreed that HIV+ fathers could attend the group for advice on fatherhood and help to access health services. This decision reaffirmed members’ central identity as mothers, as well as their new identity as managers, not beneficiaries, of care and support for HIV+ women and their children.

Mobilisation of support

The Sunflower groups’ ability to organise and access services was enabled by strategic partnerships with the state. The original group was a joint initiative of HIV+ women and the state, notably the Red Cross and state health care providers, who wanted to improve health care services for HIV+ women who had previously been unable to mobilise themselves and gain access to state resources. The organisation was constituted as an offshoot of the Red Cross, and had its offices in a Red Cross building. In part, obviously, this reflected legal necessity: in Vietnam; almost all independent groups must be sponsored by state-approved mass organisations. But it also reflected members’ own ambivalent desire to be protected by and from the state, and to be able to rely on the state to represent their interests when this was to their advantage.
Members benefited from the fact that their identities as HIV+ mothers were acceptable to their families and to various state service providers. State authorities wanted to help HIV+ women because they felt these women were more in need of assistance than men, and that a partnership with such women would achieve better results than the previous emphasis on working with male IDUs.

The Sunflower groups and the Red Cross negotiated the selection of group leaders, which was a learning process on both sides. Both members and the authorities agreed that group leaders should be elected by members, and should receive a stipend for their duties. Initially, few women were interested in positions of responsibility; hardly any considered themselves potential leaders. One older individual, an experienced peer educator, was encouraged by the Red Cross to lead the original group, and members agreed. However, shortly after being selected, this woman (mis)used her position in attempting to persuade a hospital to give her ARV medications, misrepresenting herself as a Red Cross staff member. (Group members suspected that she intended to resell the medication.) This prompted both members and the Red Cross to take leadership elections more seriously, and to establish transparent rules and decision-making mechanisms for the group. Thus, within only several months, members had recognised the need for accountable and responsive group management. However, management requirements also excluded less educated women, who were not familiar with formal working methods, from becoming leaders. One of the first members, a woman much respected for her wisdom and kindness, whom we will call Thanh, explained her refusal to become a leader:

“I do not want to represent the group because I cannot write very well. My parents were poor, so I am not very educated, and I feel very insecure about my writing and way of speaking.”

This lack of confidence was not permanent, however. Thanh was among the first women to take out a loan when the group entered a strategic alliance for microfinancing with the Women’s Union. When members and state authorities discussed what interventions would be helpful to the women in the groups, almost all members suggested income-generating activities, such as loans and vocational training. (Oosterhoff, Nguyen Thu Anh, Pham Ngoc Yen, Hardon, & Wright, 2007a) But most women were slow to take advantage of these opportunities when they were made available. Unusually, Thanh took literacy classes, then a proposal writing workshop at a national university. At the time that she joined the group her daughter was excluded from school because of her parents’ HIV status, but Thanh gained enough confidence to discuss the issue of discrimination with the school headmaster, who reinstated her daughter. She is now a leader in the group and advises national level authorities, though she still refuses to appear on camera and avoids public, media-reported events.

Members’ increased confidence reflected not just the group process that allowed individuals to validate their experiences among peers, but also the ability of members to successfully pursue their collective interests by working together.
Indeed, some activities were conducted by the group without state support, especially household-level initiatives, where a visit from the authorities might arouse suspicion. Group members have, for example, taken action against domestic violence. At one group meeting in Thai Nguyen, a woman complained bitterly about the violent behaviour of her husband, an IDU, a domestic experience shared by many members. After an hour of commiseration, one woman suggested that the group visit the house of the abused member, which they did the same day, inviting the mother-in-law to attend the group’s meetings to discuss the problem. This intervention apparently prompted the mother-in-law to prevent her son from abusing his wife.

Sunflower group members’ transition from recipients to partners in, and managers of, care paralleled the group’s increased access to available health services, such as ARV prophylaxis for pregnant women and ART (at first for adults, then, by the end of 2005, for children as well). In 2004, HIV+ women were in many ways disenfranchised from access to health care; by 2006, the group’s initial members had become gatekeepers in the system, working as peer counsellors with health staff.

Hence, as the table above illustrates, through strategic alliances with health service providers, Hanoi members progressed from a situation of poor adult access to ARV and no access to medicine for children, to one where all children and their parents have free access to ARV. In both provinces most pregnant women are now able to access PMTCT, and are able to access ART for themselves and their immediate family. In the group’s first year, the husbands and children of several members died because they were unable to access treatment (roughly a third of Sunflower children born in 2004 were HIV+, some of whom died). This is rare today, because members are able to access services more rapidly. The rise in the number of referral networks of the groups, from two to 32 sites in Hanoi and 8 to 15 in Thai Nguyen reflects both the increasing number of the services available and the ability of the groups to enter strategic alliances to access them. By 2007, all members had access to ARV prophylaxis for their children and to ARV for themselves, for example. In Thai Nguyen a similar trend occurred.

In both provinces about half of the members completed a PDP to prioritise their medical, economic, and social needs. Based on the plan they received tailored support to access other state services, such as loans, job counselling and state-provided legal advice on the registration of land rights and other vital bureaucratic procedures. Group members in both provinces were almost universally enabled to gain access to school for their children, who had previously been excluded; these included both HIV+ children and some with severe developmental difficulties. While the number of children, including HIV+ children, of members in both groups increased, by 2007 only three HIV+ children in Hanoi and four HIV+ children in Thai Nguyen could not go to school, reflecting members’ increased negotiation skills with the authorities involved.
Table 1: Support group growth and increase in access to state service providers between December 2006 and June 2007

<table>
<thead>
<tr>
<th></th>
<th>Hanoi</th>
<th></th>
<th></th>
<th>Thai Nguyen</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of mothers</td>
<td>4</td>
<td>150</td>
<td>155</td>
<td>4</td>
<td>62</td>
<td>120</td>
</tr>
<tr>
<td>Children of members</td>
<td>4</td>
<td>120</td>
<td>170</td>
<td>4</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>Other family members involved</td>
<td>0/4</td>
<td>50</td>
<td>150</td>
<td>0/4</td>
<td>100</td>
<td>113</td>
</tr>
<tr>
<td>Number and proportion of children &gt; 6 years of age who completed the school year</td>
<td>1/1</td>
<td>25/25</td>
<td>29/29</td>
<td>3/4</td>
<td>58/58</td>
<td>73/73</td>
</tr>
<tr>
<td>Number of HIV positive children &gt;2 that want but are not able to go to a regular public school</td>
<td>-</td>
<td>8</td>
<td>3</td>
<td>1</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Number and proportion of members who submitted a completed personal development plan</td>
<td>2/4</td>
<td>120/210</td>
<td>155/305</td>
<td>0/4</td>
<td>62/162</td>
<td>115/193</td>
</tr>
<tr>
<td>Number and percentage of mothers who submitted a business plan and received loan based on business plan</td>
<td>0/4</td>
<td>18/150</td>
<td>12/155</td>
<td>0/4</td>
<td>29/62</td>
<td>58/120</td>
</tr>
<tr>
<td>Number of facilities providing ART, PMTCT and OI treatment in the referral network at national- and provincial-level with trained staff and visible posters, leaflets, and name cards of the support groups out of the total number of potential participating facilities</td>
<td>1/2</td>
<td>6/6</td>
<td>6/6</td>
<td>0/1</td>
<td>1/1</td>
<td>2/2</td>
</tr>
<tr>
<td>Other health facilities that provide services in the referral network with trained staff and visible posters, leaflets and name cards of the support groups</td>
<td>1</td>
<td>25</td>
<td>26</td>
<td>0</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Number of health facilities in the referral network that work directly with peer counsellors that are elected by the group</td>
<td>0</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
At some key national health sites, where ART and other AIDS-related health services are increasingly available (mostly funded by international donors), member-peer counsellors began working with health staff to refer women between hospital-based and community services. In many areas of Vietnam, substantial progress has been made in transitioning AIDS treatment from a hospital-based setting, to a community-based treatment model more suitable for chronic diseases. Through their referral networks, the Sunflowers played a significant role in enabling this transition in Hanoi and Thai Nguyen. In 2004 there was no referral system between obstetric hospitals that provided prophylaxis, ART providers, and community based groups. This meant that after delivering with ARV prophylaxis for PMTCT, women would not know where to go for care and support for themselves or their families. By 2006 Sunflower members were working directly in seven health care sites in Hanoi to refer pregnant women and mothers to and from the various groups and services available, for example. They also established links with other groups who provided services to male partners and IDUs.

Although some national-level health staff initially worried about the capacity of PLWHIV to understand treatment regimes, this changed over time. Medical tests suggested that patients who were able to talk to peer counsellors in the hospital and join community-based groups adhered well to treatment because they were monitored and supported better.

“I was a bit worried about the peer educators because their educational level is low. But I can now see that they are very useful to us. Patients tell them things that they do not want to tell us, and actually, frankly speaking, we have no time to listen anyway.” (medical doctor, national-level hospital, 2007 Hanoi)
Members who work in partnership with national hospitals have presented their work to national authorities and policy makers. At one hospital, peer counsellors have formalised roles, with terms of reference. But while this suggests a certain political empowerment and recognition for Sunflower members, such empowerment remains within the limits of their traditional, private roles of mother and caretaker.

**Political involvement**

From the outset, group members struggled to balance their desire to raise public awareness and mobilise new members with their fears of being rejected by and losing protection from state authorities. Soon after the first group was launched, four members and several Red Cross staff appeared at a World Bank Innovation Day event dressed in ao dai, traditional Vietnamese formal dress, to counter negative stereotypical images of PLWHIV. Yet while the proposal Sunflower members presented for a public campaign against stigma and discrimination was among the winners, members delegated Red Cross staff to accept the award, as they were too fearful to disclose themselves.

The women have participated in the production of several media outputs, including a radio documentary on isolation and a fiction film on the unequal treatment of men and women infected with HIV. Members took part in installation art performances on the rights of HIV+ mothers to raise their own children, performances which were broadcast on national and international television. The fixed component of the installation art piece is on display at the National Museum for Women, but during the performance associated with the installation, group members wore heavy makeup and wigs, and the museum exhibit includes no close-up pictures which might identify them.

These examples reveal how although members have been able to gain access to services that were previously denied them, and have worked in new ways with service providers to evaluate and improve the quantity and quality of service delivery, which can be considered political acts, some of their accomplishments (as well as their unmet needs) remain invisible because these HIV+ mothers refuse to enter the public political sphere, where they would risk losing their anonymity. While a number of the poorest members have agreed to appear in public to talk about stigma and discrimination in order to obtain funding for personal reasons, this has caused tensions.

**Discussion**

Support groups aimed at helping HIV+ women organise themselves and pursue practical and strategic gender-based needs are shaped by interpersonal and internal processes within the group, as well as larger contexts. The need for members to share a common identity as well as interests and needs has been documented in studies that examined the conditions for community empowerment. (Laverack, 2001; Wegelin-Schuringa, 1992) The founding
Sunflower group reshaped a negative HIV+ identity, associated with social deviance, into a more positive identity as HIV+ mothers, which attracted new members and was acceptable to both families and the authorities. Although the specific approach of the Sunflowers was unique at the time of the group’s inception, this process of identity formation and interaction with the state reflects the experiences of PLHIV self-help groups more generally in Vietnam. (Health Policy Initiative, 2007)

In Vietnam, women’s roles as mothers put them at particular risk of contracting HIV, yet motherhood also grants women a certain social status, while being childless is stigmatized. As HIV+ mothers, Sunflower members reported feeling like unfit mothers, a reflection of negative broader social opinions on HIV and its association with “social evils”. This negative identity was transformed through membership of the group. Moreover, when the first group was founded, both members and the authorities shared a view of HIV+ women as beneficiaries of state interventions, not partners. This changed as members started to formally work with authorities at health service delivery sites, contributed to planning and evaluation processes, and were invited to give comments on policy drafts.

Several studies identified a connection between the ability of community change. (Eisen, 1994; Fawcett et al., 1995; Hildebrandt, 1996; McCarthy & Zald, 1977) In the Sunflowers’ case, the group managed to mobilise access to lifesaving medicine, as well as other critical services. However, access to resources alone may have limited social and political impact. Water and sanitation projects, for example, can provide resources without this resulting in improved health or increased ability to think critically and solve problems. (Rifkin, Muller, & Bichmann, 1988) A number of authors have emphasised the importance of the development of such reflexive skills in social and political change. (S. Evans, 1980; Paulo, 2000; Sen, 1990) Our findings suggest that critical thinking skills and increased access to resources may be interlinked. Having access to services, in particular medicines, gave women greater confidence in themselves and their relationship with the authorities. Once their immediate needs were taken care of, members had the space to reflect about other issues, such as domestic violence and the needs of other people affected by HIV/AIDS such as caretakers.

Molyneux proposed a distinction between practical and strategic gender interests to distinguish between women’s needs arising from immediate necessity, based on the sexual division of labour, and their longer-term interests in transforming social relations and enhancing women’s status. This distinction suggests a hierarchical relationship between grassroots women’s organisations that deal with practical issues, and those oriented towards policy reforms. It has been argued that such a division contributes to development planning which is either strategic but impractical, or practical but non-strategic. (Wietringa, 1994) Yet studies on grassroots organizations in settings such as Peru and Brazil have demonstrated that women’s practical issues are directly related to national, strategic socio-economic issues. (Boesten, 2004; Corcoran-Nantes, 2000)
Our findings suggest that practical and strategic needs are better conceived of as a continuum rather than hierarchical and separate. While ART is an immediate practical need for all PLWHIV, as HIV+ mothers Sunflower group members had, and continue to have, both urgent practical needs and long-term strategic needs. The women increased access to resources through an improved referral system with many service providers. The strategic alliances between the group and service providers were actively negotiated and created with the help of the state, partly because initial capacity for leadership and strategic networking by the group was limited. In the case studied, the state took the lead in the establishment of a referral system between the group and various services, while the group elected their own internal leaders. This can be seen as a form of pluralistic leadership. (Goodman et al., 1998)

Our findings indicate that such pluralistic leadership is possible within existing power and gender structures in Vietnam, where the state has traditionally emphasised the importance of motherhood, and has embraced maternalist discourses that consider women as unchallenged mothers and caretakers of society. Sunflower members’ embrace of maternalism as a means of accessing previously restricted state services has a certain strategic value:

It diversified access to such services, though within traditional gender roles. A maternalistic strategy is not new, and has been criticised for celebrating self-sacrifice as an essential feminine attribute, and therewith reinforcing traditional gender roles. (M. Nash, 1995; Pedersen, 1993) States have responded differently to women’s grassroots networks at various times, but have also used such networks to rely on the provision of services without pay, in order to prevent social unrest caused by economic changes, for example. (Boesten, 2004; Koven & Michel, 1993) In the long run, whether or not the Sunflower women will be able to effect the kinds of policy changes that could really ameliorate their HIV-related care and support tasks, in addition to their other (unrecognised) household work, depends on their willingness to appear in public and challenge some of the assumptions of Vietnamese motherhood.