Access to comprehensive prevention of mother-to-child transmission program: obstacles and implications
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CHAPTER 6

SELF-HELP GROUPS CAN IMPROVE UTILIZATION OF POST-NATAL CARE BY HIV POSITIVE MOTHERS

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Abstract

HIV prevention within maternal-child health services has increased in many developing countries, but many HIV-infected women in developing countries still receive insufficient postnatal care. This study explored the experience of 30 HIV-infected women in Vietnam in accessing HIV-related post-natal care, the role of felt and enacted stigma in accessing services, and the effects of participation in a self-help group on utilization of available services. Many HIV-infected women were not provided with adequate information on postnatal care by health workers. Most women reported both felt and enacted stigma that affected their access to care. Involvement in self-help groups improved the women’s self-esteem, increased knowledge about HIV, and had a positive effect on both felt and enacted stigma from family, community, and health services. These findings suggest the need for better information provision and better referral systems within the health services and suggest that establishing self-help groups can diminish felt stigma and facilitate access to services for women and their children.

Key words: prevention of mother-to-child transmission; post-natal care; stigma; self-help group; Vietnam
Introduction

In developing countries, prevention of mother-to-child transmission (PMTCT) of HIV infection has been considered to be a simple intervention, consisting mainly of providing medication during delivery (Holmes, 2005; Piwoz & Preble, 2002). But the current World Health Organization (WHO) PMTCT approach is more comprehensive, with four prongs promoting (a) interventions to prevent new infections, (b) prevention of unwanted pregnancies in HIV-infected women, (c) prevention of transmission from mothers to infants, and (d) provision of care and support for HIV-infected mothers and their families (WHO, 2007). Such an approach is not simple; it requires good collaboration among different services.

In the context of Vietnam, Hanoi is a relatively well-resourced setting where HIV testing and counseling, antiretroviral prophylaxis, antiretroviral treatment (ART), and follow-up care are available free of charge. But making resources available does not necessarily mean that people are able and willing to use them. Socially, HIV infection is perceived as a “death sentence,” closely related to “social evils” (drug use and commercial sex work), and is therefore highly stigmatized. For HIV-infected pregnant women to get the PMTCT care they need, they must interact with their families, communities, and the health care providers. HIV-infected women can only get access to services if they disclose their infection status, at least to health workers. Disclosure puts the women at risk for public recognition as having HIV, and also at risk for discrimination by health workers, families, and communities. HIV-infected women in Vietnam are usually assumed to be either drug users or sex workers or both, leading to double stigma and discrimination (Khuat TH, Nguyen TVA, & Ogden, 2004). High loss to follow-up and post-natal care for HIV-infected women and their children because of their failure to make use of available services has been reported (Manzi et al., 2005; Piwoz & Preble, 2002; MCNV, 2007).

Stigma may be divided into felt/perceived stigma and enacted stigma. Felt stigma is the fear of real or imagined societal attitudes and potential discrimination arising from an undesirable attribute or disease (such as epilepsy or HIV), or association with a particular group (such as drug users) (Brown, Trujillo, & Macintyre, 2001; Scrambler, 1998; Khuat TH et al., 2004). Enacted stigma refers to the real experience of discrimination, for example, losing employment, health benefits, or friends (Brown et al., 2001; Scrambler, 1998).
Traditionally, women’s responsibility is to maintain the “good face” of the whole family. Kinship pressures may form an additional negative factor in women’s willingness to access health care, particularly in relation to a highly socially stigmatized condition like HIV (Gammeltoft, 1999; Go et al., 2002).

The literature suggests that stigma can be reduced by creating an enabling environment that provides information, care and support, and advocacy for community members and health workers. Self-efficacy can be improved by providing counseling, treatment, and psychotherapy (Heijnders & Van Der Meij, 2006). An enabling environment and improved self-efficacy can change the behaviors and attitudes of people in society, making access to care easier for vulnerable people. One approach is through self-help groups whose members share the same problems. Such groups can provide information, improve self-esteem, strengthen coping skills, and increase social integration for the person being stigmatized, and can help to change the attitudes of families, communities, and health workers (Plach, Stevens, & Heidrich, 2006). Successful examples have been documented among tuberculosis (TB) patients (Demissie, Getahun, & Lindtjorn, 2003), HIV-infected people, alcoholics, drug users, and patients with chronic illnesses and mental problems (Elaina, Humphreys, & Loomis, 2002).

We investigated the experiences of a group of HIV-infected women to determine the role of stigma from different sources on their health-seeking behaviors and the effects of their participation in a self-help group on their perceptions of and responses to stigma and on their access to all kinds of care. The findings will support the development of an effective program to cover the fourth prong (post-natal care) of the comprehensive WHO PMTCT approach.

Methods

The research team participated in a program of the Medical Committee Netherlands-Vietnam (MCNV) aimed at strengthening PMTCT in Vietnam (MCNV, 2007) by working with mass organizations and local hospitals to establish and maintain a self-help group (the Sunflowers) for HIV-infected mothers in Hanoi. Group members delivered publicity materials to create a referral network among 26 health facilities in Hanoi. Core group members visited hospital and voluntary counseling and testing sites to make informal contact with potential members and refer them to the group. Hospital staff also referred
HIV-positive pregnant women to the group. The study included members of the Sunflower group who had learned they were HIV-infected before or during a pregnancy and chose to complete the pregnancy. Thirty women agreed to participate. We interviewed HIV-infected women about their experience of felt and enacted stigma in their family, community and health facilities, their response to it, and its influence on their use of available services.

The first in-depth interview was conducted at the time women joined the Sunflowers in 2004. During this interview, information was collected on socio-demographic characteristics and on obstacles in using post-natal care as part of PMTCT. The women attended bi-weekly meetings in the office in the Red Cross building of Dong Da district, during which they shared their experiences when seeking health care with the researchers who also attended through intensive interviews. Additional information was collected during household visits and counseling via a telephone hotline over the whole period. After women had participated in the Sunflower group for 2 years, they were interviewed again, using in-depth interview guidelines to obtain information about the changes in their social and health situations. In-depth interviews were also conducted with husbands and mothers-in-law at the start and after 2 years. The numbers of participants of different types are presented in Table 1.

Table 1. Study participants

<table>
<thead>
<tr>
<th>Type of study participant</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-positive mother</td>
<td>30</td>
</tr>
<tr>
<td>Husband of HIV-positive mother</td>
<td>23*</td>
</tr>
<tr>
<td>Mother-in-law of HIV-positive mother</td>
<td>18**</td>
</tr>
</tbody>
</table>

* 7 women were widowed  
** 12 women who had a mother-in-law died

The investigator also joined core members of the self-help group, “peer counselors,” when they accompanied women and their children to different health services, which provided opportunities for participant observation. Field notes were taken at the health facilities providing care for HIV-infected adults and their children. Researchers and peer counselors shared their findings and experiences during monthly meetings.

Institutional approval for both scientific and ethical aspects of the study was obtained from the Scientific Committee of Hanoi Medical University; written informed consent was obtained from all interviewees. A code book was developed focusing on key findings.
and terminologies. The transcripts of the semi-structured interviews were coded, entered, and analyzed, using N-VIVO software 2.0, which identifies repeated themes and concepts, expressions, and linked or associated themes that therefore appear to be important results (QSR International, 2006).

When the 30 HIV-infected women entered the cohort, they were between 25 and 35 years of age. The youngest child belonging to these women was under 1 year of age. Most of the women ($n = 28$) were poor or middle-class, working in the non-state sector. All were married and reported having been infected by their husbands. Eight had graduated from college or university; 20 had completed secondary and high schools, and 2 had only primary school. All had received prenatal PMTCT and delivered at health facilities in Hanoi.

**Results**

The first part of the results consists of the clarification on the role of stigma in the low utilization of services by HIV-infected women. During interviews, all 30 HIV-infected mothers referred frequently to both felt and enacted stigma from family, community members, and health workers, who appeared to believe that HIV appeared only among people who partook of antisocial activities.

**Perceived and enacted stigma**

*Family stigma.* Many of the mothers reported that their families were afraid to take care of them and would not have meals together. Some women had to leave the houses of their families-in-law with their children and husbands. One mother-in-law stated: “They use drugs and then have AIDS. I will throw them all away.” Widows were more often rejected by their families-in-law than those who still had their husbands. They often received no support from the in-laws and might even be treated as strangers. A 24-year-old HIV-infected woman explained: “The day after I learned of my HIV-positive status, my younger sister-in-law escorted all our other family members to go to VCT to get blood tests. She boiled all our bowls and chopsticks. After that, she sold her house and moved away; she doesn’t want to live with my husband and me.”

Another HIV-infected woman said: “Since my husband died and I cannot work to provide food for my family-in-law, they treat me with a cold heart. I cannot live there anymore. My mother-in-law sold the house that my husband and I built because it was
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not yet registered in our names."

In some families, if they know that the baby is not infected with HIV, they forbid the infected mother to care for the child, thinking that will help to avoid HIV transmission to the child. From a mother-in-law of an HIV-infected woman:

I forbid my daughter-in-law to be near my grandchild because he may be infected with the disease from her. I asked my daughter-in-law’s family to take her back. She can visit her son, but not more than once a week. But even then, I never let her hold my grandchild; she can just look at him.


Community stigma. Mothers also feared the lack of confidentiality around results of HIV testing, which may lead to enacted stigma not only from health workers but also from the community. Several told us that their test results were given to health workers at community level, as is routine in Vietnam. They felt insecure about their privacy, kept to themselves, and tried to avoid social contact. HIV-infected people usually have to receive home visits by commune level health workers or members of the Women’s Union or Red Cross, whether they want them or not. An HIV-infected husband said: “If the Women’s Union knows the family has an HIV-positive person, they will make things crazy.” And a 24-year-old HIV-infected mother told: “I felt very afraid. If they [health workers] come to my house with white coats, my neighbors would wonder why the nurses came to my house and provided such good care. That’s why I tried to avoid them.”

Many women, their husbands, and families expressed their fears of “losing their jobs and having people keep away.” They tried to hide the HIV infection, with the result that by avoiding potential stigma they also kept away from the care and support they needed. A mother-in-law told us: “I don’t dare to tell anyone in the family about their [son and daughter-in-law’s] disease. I asked them to keep it secret. We may lose our business and everything. Anyway, they will die in the future and should not make others die with them.”

In many cases, HIV-infected women faced enacted stigma in their community. A 27-
year-old HIV-infected woman shared: “The food seller did not want to sell food to me with her bowl and asked me to go home and take my bowl because she was afraid that I would sit there and affect her customers.” In some cases, children of HIV-infected women were not able to go to school if people living around knew the mothers’ HIV status.

The impact of stigma may affect the whole family, which may be seen as a source of transmission. Often, neighbors, relatives, and friends tried to avoid contact with the family. Two mothers-in-law said, “If people around know, my other son and daughter can hardly get married,” and “My relatives know their [son and daughter-in-law’s] HIV-positive status. That’s why they don’t come to see us any more. They are afraid of getting infected if they come to my house.”

Notification of the community also contributes to stigma and subsequent loss to medical follow-up. Several respondents said they would not attend the out-patient clinic because they had to provide their home address and identity number and feared that information on their status would be transferred to the health station in their own community. A 28-year-old HIV-infected woman commented: “At the community health station, it was clear from how they looked at us when we came for medicines or health checks. So we usually went to private clinics but hid our HIV status. During the first 3 years, we did not consult or contact anybody about HIV; we were too deeply sad and depressed.”

A 30-year-old HIV-infected woman said: “My family used to make billboards and signs for shops but when the ward found out I was HIV-positive the clients stopped coming. We had to close the store. Now we make money by packing baby clothes in boxes at home.”

Health worker stigma. Many women experienced discrimination during ANC, and all the women told us they were put in separate rooms after delivery:

When they knew my HIV status, they shouted at me and did not allow me to sit, even when I was bleeding and weak. They asked other patients to keep away from me. Then they transferred me to a special room. When I gave birth, there was no staff with me. (32-year-old HIV-infected mother)

The doctors treated me well when they didn’t know my status. But right after my delivery, they found that I was infected and then they became rude. They did not tie
the umbilical cord immediately. I was in so much pain. (24-year-old HIV-infected mother)

When doctors did not know my son was HIV-positive, they provided many medicines. Once they knew his status, he did not receive any medicine except fish oil pills. They didn’t do any physical examination, just sat far away and asked questions; they did not touch my son at all. (30-year-old HIV-infected mother with HIV-infected son)

Health workers and staff of counseling services should be good sources of information and support for the women. However, the women lacked information mainly because they did not receive adequate, concrete, and specific counseling on what they should do after delivery and how to access the available services. Nearly all of the information given to infected women during counseling sessions was aimed at protecting other people from infection. This included advice to use a condom with their husbands, to not breastfeed, to be careful when caring for their children, and to practice hygiene to protect caregivers and others. Very little was explained about the potential risks to their own health or how they could keep healthy. There was no advice about risks of getting opportunistic infections from people around them or from unsafe foods or unclean water (see Table 2). A 40-year-old HIV-infected mother commented: “They told me to avoid transmission to other people. With my status, they said I should not have another baby, should use a condom. Leaving the hospital, I had no idea about my own health care.” Most of these women were not asked to come back for health checkups later; only 6 of the 30 mothers were given appointments to return for checkups.

Table 2. Contents of post-delivery counseling for HIV-infected mothers in Hanoi

<table>
<thead>
<tr>
<th>Content of counseling</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother received post-delivery counseling</td>
<td>25</td>
</tr>
<tr>
<td>Be hygienic and safe during daily activities to avoid transmission to others</td>
<td>22</td>
</tr>
<tr>
<td>Don’t breast feed to avoid transmission to the child</td>
<td>18</td>
</tr>
<tr>
<td>Use condom to protect sexual partner</td>
<td>16</td>
</tr>
<tr>
<td>Methods to stay healthy</td>
<td>6</td>
</tr>
<tr>
<td>Available services for HIV-infected people</td>
<td>4</td>
</tr>
<tr>
<td>How to disclose HIV status</td>
<td>3</td>
</tr>
<tr>
<td>Making next appointment for health follow-up</td>
<td>6</td>
</tr>
</tbody>
</table>
Experience with stigma by health workers during the delivery period discouraged mothers from trying to access the care they and their children needed. As a 23-year-old HIV-infected mother said, “After delivery, I never went to a health facility because they had a terrible attitude. If I got ill, I would go to a drug store.”

Gender-related discrimination. Many of the HIV-infected mothers reported additional, gender-related discrimination. For example, although it is likely that most of the women in the study were infected by their husbands, they were blamed by their families-in-law for “not being able to protect their husband from social evil behaviors” or for “being a source of transmission to a beloved grandchild.” A husband who was an HIV-infected drug user and transmitted the infection to his wife said:

*Men are forgiven. Women would not be forgiven. Women are more blamed even if they are unlucky and sleep with a husband who used to sleep with many girlfriends or is an IDU and brought the disease to his wife. It is our culture.*

While the women were apparently infected by their husbands, “women are often exposed to more stigma than men,” said another husband, also an HIV-infected injection drug user.

A daughter-in-law has the lowest position and least power in the family. In most three-generation households, the mother-in-law has a strong influence. An HIV-infected woman shared:

*When my son was 1 year old, I had to look after him but also wash motorbikes to earn money while my husband went out. When I told him that I was tired and couldn't work so hard, he hit me. When my mother-in-law heard me being beaten, she shouted up from the first floor, "What a whore!" I have a low position in the family. When my husband got AIDS, I had to earn money to cover his hospital fees.*

The women’s identity is central to their roles in “keeping face” for the whole family. A mother-in-law said: “The good must always be shown off, but the bad must always be hidden. That’s the women’s task.” An HIV-infected person may bring stigma to the whole family, resulting in loss of business, loss of face, and loss of relationships. HIV-infected women were expected to hide their status and to act as happy young mothers who had just delivered a healthy baby. With this image, HIV-infected women often decided to not disclose their HIV status, even when that meant missing out on care and support.
The families often did not want to spend money on an infected daughter-in-law and her child who were perceived as a lost cause. As a mother-in-law said, “Anyway they will die in the future, no matter how much money we spend on them. It’s a fatal disease. So it’s better to use money properly.”

Responses to stigma

The response of the women to felt or enacted stigma greatly affected their utilization of available services. Because of the heavily stigmatized environment, HIV-infected mothers suffered from low self-esteem. They were ashamed of their infection because they often shared the common social perception associating it with the type of people who practice “social evils,” even when they did not practice those behaviors.

Mothers dealt with this problem in different ways. Some went into denial, trying to live a normal life pretending that they and/or their children were not ill, while others accepted being infected and gave up, thinking there was nothing they could do. Both coping strategies often resulted in failure to use services that were needed and available for both mothers and children.

Many mothers said they did not seek care because they were afraid to deal with the disease. They tried to convince themselves they were not infected; they expressed their fears:

I feel so afraid of whenever I hear about HIV. I do not dare to even look at books or leaflets or talk about HIV. (23-year-old HIV-infected mother)

I knew from a friend that there was free medication in that hospital. But I did not go anywhere because I felt so sad. (31-year-old HIV-infected mother)

We [wife and husband] lied to ourselves that the test results were wrong. We did not go to any hospital until she got TB. (HIV-infected husband)

Mothers were often too afraid to test their children, even though tests are free. A 40-year-old HIV-infected mother with an uninfected child recalled: “The doctor asked me to come back after 18 months to test my daughter. But I only dared to bring her after the third invitation letter, when my daughter was 23 months old.”

Inadequate counseling means that mothers lack knowledge about how to care for themselves and their children. Many mothers perceived HIV as a “death sentence” and were unaware that they should go for health checks. They knew nothing about the symptoms of OI or how to deal with them, and had no idea about the possibility of ARV
treatment to prolong their lives. A 28-year-old HIV-infected mother said: “My neighbor said that I seemed to have a high fever. I did, but I only took paracetamol. Only after I lost 5 kg, I went to see doctor who said that I had TB. By that time, my CD4 count was only 32 (cells/mm³).”

Some mothers were sure that their children must be infected with HIV and would die, so they did not consider bringing the children for HIV tests or health checkups. “I raised my child as other mothers do until he was 2 years old. He often got sick. But I knew nothing, never thought about an HIV test although I thought he must be infected” (30-year-old HIV-infected mother). Only a few mothers were aware of the need for OI prophylaxis for their children or that a PCR test was available for free to determine whether the child was infected.

Some mothers did try to find information and to get care after learning their HIV status. However, the majority were immediately confronted with negative attitudes from health workers and others from whom they expected support. The few women who did receive support from family and/or health services were active in seeking care. An HIV-infected mother shared: “The doctor was very warm to me. She told me to come back and have my child tested. She also said that I could get treatment free of charge if I went to Hospital A to register. My family is very supportive. After discussing with them, we [husband and wife] went to Hospital A for health follow-up.”

Self-help groups

One of the possible solutions to the problems described in the previous section was to increase the women’s self-esteem as well as their knowledge about PMTCT through self-help groups. Such self-help groups can take over many tasks that could be considered the jobs of doctors or social workers. The group members studied here had gained a remarkably comprehensive overview of the health system and the services available. Most group members knew the way to get ART, prophylaxis for opportunistic infections, and nutritional support for HIV-infected persons in the health care and other systems better than did many health workers.

The self-help groups contributed to improving the women’s use of health services in a number of ways, related to each of the barriers described above. Infected and affected persons shared their experiences and feelings freely with peers in the groups. Many members from the self-help groups were trained in how to manage a group or joined communication trainings to improve communication within and outside the group. At the
beginning, the Sunflower members shared little, quarreled, and gossiped. Training in communication skills helped them to share and to support each other. Most interviewees confirmed that the group had been a major source of emotional support. Many group members learned how to do peer support work, run a business, or keep a job. One 28-year-old HIV-infected woman said, “I have come to life again and don’t suffer from an inferiority complex any longer,” and a 23-year-old woman said, “Being a member of the group had a strong influence on our life. We received financial and emotional support. But more important, we could share with peers and had peaceful time as if we were normal people.”

Many mothers in the group actively sought care and started to help others to access services. After the death of her child, one active member of the self-help group became a volunteer working in a pediatric hospital as peer counselor to make a link between health workers and patients: “The group means so much to me, as the second family. I could not imagine why I could be so passive in the past. Now I use all of my knowledge and capacity to help all HIV-infected people to have better life.”

Providing information and peer counseling. In the group, the women received plenty of information about the health care needs of HIV-infected mothers and children. They followed courses on specific topics such as nutrition and immunization, but they also exchanged information with the Red Cross and health workers during regular meetings. They made plans for their lives, including getting health care, with guidance from peer counselors and other members who had had positive experiences. The peer counselors established a network to facilitate contact with the different levels and institutions in the health care system. They developed a reference list, updated monthly, of health care services with contact details, criteria for registration, and how to prepare for going to each health facility.

A few key health sites accepted peer counselors to work in the counseling room, to provide information to all women and families. Many women confirmed a preference for contact with a person who shared their problems, who was also infected with HIV, as acknowledged by a 32-year-old HIV-infected mother of an HIV-infected 4-year-old girl, “I feel very open when I talk with them [peer counselors]. They are HIV-positive like us. They understand and sympathize with our problems. Doctors are always busy and hard to talk to.”
However, even when they had information, many HIV-infected women did not dare to seek health care, for the reasons described above. Most importantly, the women stressed their need to weigh the risk of being known as having HIV against the opportunity to get the health care they needed, as an HIV-infected woman explained, “What would happen if they [doctors] knew my status and would not give me good care? What would happen if because I went to hospital, my family, my neighbors would know that I was infected? I could lose everything.”

Peer counselors offered to accompany group members to health facilities. Active members of the self-help group not only went for the care they needed but also helped other women to get that care.

HIV-infected women reported that they felt stronger when they came to the health facilities in a group of four or five. After a few women managed to obtain good health care, their good examples stimulated others to seek health care. One woman with a CD4 count of 32 cells/mm³ was very ill; the group expected her to die. But she got access to ART and became healthy and beautiful. She also secured free ART for her husband, then joined a micro-credit scheme, raising pigs to improve her income. As her husband explained: “We realized that when we disclosed, we received more support from health facilities, even medication free of charge. They [health workers] provided more counseling. They even gave gifts to us.” She was very proud and no longer hid her HIV status in public. Her example had a strong influence on other members.

Reducing stigma in families. When the group members’ self-esteem improved, they also dared to stand up to their families-in-law. When HIV-infected women received external support, increased their incomes, became more confident, and were visibly healthier, their positions in their families improved.

As the families of the group members became more familiar with the disease and saw that the lives of their infected family members were no longer hopeless, the stigma from them gradually declined. A mother-in-law said, “In the beginning, I had no idea how HIV is transmitted. All of us [family members] were very afraid of it. But H. [a peer counselor] came and told us that she was infected but had a good job and was very healthy. We were very surprised. She explained to us how HIV is transmitted and that HIV-infected people could have a normal life like hers. She came several times. Now I feel so sympathetic to my son and daughter-in-law. I wish I had not been so awful to them.”
Self-help groups can improve utilization of post-natal care by HIV-positive mothers

Most of the women eventually received more support from their families, although some still had the feeling that their families remained afraid of HIV transmission, particularly to other children in the family.

Involving family members in some group meetings gave them an opportunity to see and then report to others how helpful the self-help groups were. A mother-in-law shared her opinion about the self-help group: “I used to feel so ashamed of myself. I have always tried to do well in my life and be useful for society. But I failed with my daughter. I was embarrassed to come to the group, but now I feel this is my second home. I can talk freely now.”

Reducing stigma in health facilities and communities. Peer counselors went to hospitals and communities to talk about their HIV infection and the need for care from health facilities and communities. The HIV-infected women had a healthy appearance, were well-informed, and were confident in presenting their information. Their appearance was a reassuring factor, demonstrating that not all HIV-infected people lived an antisocial and destructive lifestyle threatening to the family or community. An HIV-infected woman said, “I feel more confident. I speak with my peers in the group and the seropositive community. When I tell people, they all love and sympathize with me and think that HIV/AIDS is not so scary. Since then I come to group meetings and other activities.”

The women had a key role in improving communication between health workers and patients, reducing stigma, and improving understanding on both sides. An HIV-infected woman who often brought her child to the hospital for ART said, “Doctors now treat us much better than before because they understand that we will not harm them, that HIV is not easy to transmit.”

By the end of the study, we observed a significant reduction of stigma in families, communities, and health facilities; although the sample size was not big enough to generalize to other situations (see Table 3). HIV-infected women and their children in the self-help group received needed health care; they were treated appropriately for HIV, opportunistic infections, sexually transmitted infections, and tuberculosis, and children were tested for HIV. They also received better social and economic support. The only HIV-infected child lost to AIDS was lost before the support system was well established.
Table 3. Change in social and health situation after joining a self-help group for HIV-infected women

<table>
<thead>
<tr>
<th>Items</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Change in Social and Economic Situation</strong></td>
<td>((N = 30))</td>
<td>((N = 30))</td>
</tr>
<tr>
<td>Women perceived stigma (among people who knew their HIV status) from:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Family</td>
<td>25/27</td>
<td>0/30</td>
</tr>
<tr>
<td>- Community</td>
<td>13/16</td>
<td>2/28</td>
</tr>
<tr>
<td>- Health workers</td>
<td>20/30</td>
<td>0/30</td>
</tr>
<tr>
<td>Women attended weekly meetings</td>
<td>NA</td>
<td>30</td>
</tr>
<tr>
<td>Women lost a business (among those having a business)</td>
<td>18/24</td>
<td>2/24</td>
</tr>
<tr>
<td>Women received loan or job from self-help group</td>
<td>NA</td>
<td>15</td>
</tr>
<tr>
<td><strong>Change in health care provided to women</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Women had record for health follow-up at ART sites</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>- Women received ART (when needed)</td>
<td>1/9</td>
<td>15/15**</td>
</tr>
<tr>
<td><strong>Health care provided to children</strong></td>
<td>NA*</td>
<td></td>
</tr>
<tr>
<td>- Children received immunization as national standard</td>
<td>30/30</td>
<td></td>
</tr>
<tr>
<td>- Children infected with HIV</td>
<td>6/30</td>
<td></td>
</tr>
<tr>
<td>- HIV-infected children had record for health follow-up</td>
<td>6/6</td>
<td></td>
</tr>
<tr>
<td>- Children received ARV</td>
<td>6/6</td>
<td></td>
</tr>
<tr>
<td>- Children died of AIDS</td>
<td>1/6</td>
<td></td>
</tr>
</tbody>
</table>

* NA: Not applicable
** 6 developed AIDS in 2 years

Discussion

Experiences of women and their families in accessing care

Worldwide, about 2 million HIV-infected pregnant women deliver infants annually. Many efforts have been made to reduce the risk of HIV transmission to the child, but less attention has been paid to follow-up care and support for not only the child but also for the mother. After delivery, most mothers are in good health, but they need careful follow-up to avoid opportunistic infections and other HIV-related diseases. Children born
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to infected women should be tested for HIV and should receive prophylaxis for opportunistic infections and ART as needed (Piwoz & Preble, 2002). However, even in the relatively well-resourced setting of Hanoi, most HIV-infected women encountered problems in accessing and using PMTCT services (Nguyen TA, Oosterhoff P, Yen PN, Wright P, & Hardon A, 2008), especially postnatal care. Most of the women’s problems appeared to originate with the real and perceived discrimination against women infected with HIV. We report the experiences of 30 HIV-infected women and their families, followed during 2.5 years, exploring how stigma and discrimination limited access to post-natal care and how joining a self-help group could help to overcome stigma and improve care.

The PMTCT program in Vietnam has focused on reducing the risk of transmission of HIV to exposed children, rather than on a broader model of care and support for women and their children. The PMTCT program is limited in geographic reach (MCNV, 2007), but follow-up care is lacking even in Hanoi, despite the availability of the medical care. The main causes are the lack of quality counseling/referral and social pressures, including felt and enacted stigma. HIV-infected women experienced many problems when they tried to find care for themselves and their children. They were not given adequate information on post-natal care, as confirmed by a study showing that counseling to pregnant women in the Hanoi antenatal care system was weak in both method and content (Bale B, 2006). Even when they knew something of available services, many HIV-infected women reported that fear and experience of stigma strongly reduced access to those services. In Vietnam, no social mechanism exists to provide non-medical support for HIV-infected women, as occurs in other countries (Parker & Aggleton, 2003; Piwoz & Preble, 2002).

Around the world, and in Vietnam, HIV is a highly stigmatized infection. In Vietnam the epidemic is mainly concentrated among drug users and sex workers who may also use drugs. This association of HIV infection with two highly socially unacceptable behaviors means that women who have HIV are often seen as either drug users or sex workers or both. The enacted stigma is directed not only at the fear of HIV but also at the fear of people with such antisocial behaviors (Khuat TH et al., 2004; Piwoz & Preble, 2002). Women felt and experienced enacted stigma from their families, their communities, and the health workers from whom they sought care. Felt stigma among HIV-infected women included fear of societal attitudes and potential discrimination because of their HIV status. Enacted stigma by family and community included avoiding contact even to purchase products or provide services, failing to provide care and
support for HIV-infected people, and isolating infected people. Discrimination by health workers resulted in reluctance of the HIV-infected women to seek health care; when they did seek care, they received a lower quality of care. Both felt and enacted stigma were perceived as major factors limiting access to health care for people with HIV (Holzemer & Uys, 2004; Khuat TH et al., 2004; Lindau et al., 2006). In many ways the situation is similar to that for other communicable diseases such as tuberculosis or sexually transmitted infections, which also elicit high stigma and fear of transmission. Health workers were often afraid of these patients and had poor general knowledge about treatment and cure (Macq, Solis, & Martinez, 2006; Malta et al., 2007).

One way to reduce enacted stigma against such patients is to educate the public and health workers about modes of transmission and about treatment of the disease. In the case of HIV, learning how difficult it is to become infected could reduce fear and, therefore, stigma; although the lack of good treatment and cure may limit the effectiveness of increasing technical knowledge. However, when HIV is associated with socially stigmatized conditions such as drug use and sex work, increasing knowledge about transmission will not affect the stigma enacted to those conditions. In fact the women in our study did not use drugs and were not sex workers, but the close association meant that people still enacted stigma on the assumption that they did use drugs or were sex workers.

All HIV-infected people in Vietnam suffer stigma, but women usually suffer more than men, especially within the family (Khuat TH et al., 2004; Go et al., 2002). The respondents in our study had to struggle between their needs for health care and their needs to avoid exposing the whole family to potential stigma and discrimination. In response to the highly stigmatized and discriminated environment, the majority of women either went into denial, avoided thinking about the fact that they and possibly their child could be infected, or gave up and refused to seek care and support (Lindau et al., 2006).

**Effects of participation in a self-help group**

Empowerment is defined as “the process of enhancing an individual’s or group’s capacity to make purposive choices and to transform those choices into desired actions and outcomes” (Alsop, Bertelsen, & Holland, 2006, p.1). Empowerment can enable vulnerable people to cope with stigma from society and the family, which can also increase access to health services (Burgoyne, 2004; Hough, Magnan, Brummitt, Templin, & Gedelrab, 2005; Plach et al., 2006). An intervention with self-help groups is
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one effective approach to empower people, and to increase their spiritual, social, and economic strength, and confidence in their own capacities to improve their lives (Rankin, 2007; Ussher, Kirsten, Butow, & Sandoval, 2006).

The HIV-infected women in this study made the transition from women as victims of stigma and discrimination to empowered women able to challenge and change the context in which they lived. The self-help group played an important role in this shift. Once HIV-infected women were able to disclose their HIV status to others, they could use it as a source of social capital. Learning about the benefits of treatment from peers helped HIV-infected women make better decisions about seeking access to health care. They also organized care for themselves through a peer counselor system with continuously updated information. Group members provided good examples of visibly improved health that motivated other HIV-infected women who had hesitated to seek health care. The support also increased the women’s self-esteem, resulting in less felt stigma. It appeared that self-stigma among HIV-infected women was not static; it could be changed if they received support to improve their self-esteem. Joining a self-help group clearly provided the support the women needed to acquire the confidence to seek the care they needed for themselves and their children. As the findings were from intensive interviews with HIV-infected women but not from standard quantitative instrumentation, these cannot be generalized in the traditional quantitative sense. Therefore future research should entail quantitative methods to test the intervention of introducing self-help groups to reduce stigma.

The findings show that medical intervention alone was insufficient to help the women in the comprehensive way proposed by the WHO PMTCT approach. Self-help groups can provide part of the solution. Participation in the self-help group is voluntary and members’ identities remain confidential, which encourages many women to participate. By the end of 2007, there were almost 500 HIV-infected mothers in the groups, and they brought 1,000 family members and children into the program as well. Joining a self-help group provided many kinds of support, including some that could have been expected from the existing health and social services. For example, counseling by health services should be improved to give women better choices for better health care. “Free treatment” should include the whole package of testing (both CD4 for mothers and PCR for babies), ART, and prophylaxis and treatment for opportunistic infections. Group members acted as peer counselors who supported timid members when they sought health care, and helped them to show their families that there was hope for a relatively normal life if appropriate care was provided.
Health systems and PMTCT programs should acknowledge and try to deal with social barriers to accessing HIV-related post-natal care. Self-help groups with peer counselors working inside the health system to ensure good relations between clients and providers could be a good model to empower women to obtain the health care they need. From the perspective of the health care providers, donors, and policy makers, it could be attractive to promote patients’ associations. If that resulted in increased self-reliance of individuals, it would reduce some of the burden of the state.

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