Access to comprehensive prevention of mother-to-child transmission program: obstacles and implications
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CHAPTER 8

DISCUSSION
Discussion of the findings

PMTCT programs have often been seen as a simple medical intervention, just giving prophylactic pills to prevent HIV transmission from mothers to their children. However, this intervention alone fails to address the long-term needs of HIV-infected women and children. Therefore, the World Health Organization (WHO) has promoted the implementation of a four-pronged approach, aimed at improving the health and welfare of HIV-infected women and their children. The four-prongs focus on: (1) primary prevention of HIV/AIDS, (2) prevention of unwanted pregnancy in HIV-positive women, (3) prevention of virus transmission from HIV-positive mothers to children, and (4) provision of care and support for HIV-positive mothers and their children and families.

The implementation of the full four-pronged approach requires the availability of a range of services, including information provision and counseling, HIV testing, ARV prophylaxis and treatment, health care follow-up, safe infant feeding, and early HIV tests for exposed infants. However, even in places where these services exist, quite a substantial number of women cannot, or do not want to, use them. This study aimed to identify the main obstacles that reduced access to the nine steps in a comprehensive PMTCT service (as identified by WHO) in the relatively well-resourced setting of Hanoi, focusing on two dimensions: service users and providers. Although Vietnam is a country with limited resources for controlling HIV and which, as yet, cannot provide good health services nationwide, in the capital city Hanoi, services and resources are at a much higher level; access to comprehensive PMTCT services should not therefore be limited in this location. This study identified many of the factors that result in too many women in Hanoi either not getting care or receiving inadequate care.

Availability of PMTCT services in Hanoi

Perhaps the most obvious reason for the failure to provide a comprehensive package of services for pregnant HIV-positive women would be that the services are simply not available, which might be expected in a poor and developing country. But in the study site of Hanoi, that is not the case; at least the elements needed to provide a comprehensive service are apparently available. For example, PMTCT starts with testing for pregnant women, which is provided through the existing ante-natal care (ANC) system at district or higher level health facilities. HIV testing is offered routinely for all pregnant women, usually in the 7th or 8th month of gestation, and often too late for optimizing choices for PMTCT. Early testing for HIV is available at any hospitals if
Discussion

pregnant women request. In addition, several stand-alone VCT sites offer HIV testing and counseling services where timely testing is also available. If a pregnant woman is found to be HIV-positive, she can choose to terminate her pregnancy at a public or private health facility (abortion is legal in Vietnam), or she can choose to continue with it. In the second case, she should be recommended to have ARV prophylaxis which is available free of charge at provincial and national maternity hospitals. At the time of the study, there were two ARV prophylaxis regimens available in Hanoi: SD-NVP or triple-combination ARV prophylaxis, enough for all HIV-positive pregnant women in the city. In addition to using ARV prophylaxis, HIV-infected women are encouraged to bottle-feed and are provided with infant formula free of charge. ARV treatment for adults is provided free of charge in out-patient clinics at district health centers or provincial and national general hospitals, while pediatric ARV is provided only at the national pediatric hospital. PCR testing for exposed infants is presently available only at one provincial hospital in the capital.

Clearly, therefore all of the services necessary for a comprehensive PMTCT program were found to be already available in Hanoi at the time of the study, many of them even free of charge. The availability of the services might lead to the assumption that many people would therefore have easy access to and benefit from them, but that proved not to be the case.

How many women actually access PMTCT services?

Around the world, access to PMTCT services is limited, particularly in poor countries, due to lack of services. However, several studies have revealed that even when the services were available, HIV-infected women experienced many problems trying to obtain better care for themselves and their children.

In Vietnam, most women enter pregnancy not knowing their HIV status. There could be a very few women who do know it; most of these would probably choose abortion which is legal and freely available. There are very few who are aware that they are HIV-positive yet want to complete a pregnancy, for many good reasons (Oosterhoff, Nguyen Thu Anh, Pham Ngoc Yen, Hardon, & Wright, 2008). These women require informative counseling and appropriate medication and follow-up.

HIV testing is critical for HIV-positive women entering a PMTCT program. In many countries, the proportion of women who have an HIV test during their pregnancy is relatively low. (avert.org, 2008b) In Vietnam, only 16.5% of women nationwide reported
having had an HIV test during their pregnancy in the last two years. (General Statistic Office & United Nations Children's Fund, 2006) In contrast, in our Hanoi study site, we found that the great majority of pregnant women in Hanoi reported having had an HIV test. Those who said they had not been tested might therefore represent a population at higher risk (Boxall & Smith, 2004; Jayaraman, Preiksaitis, & Larke, 2003; Lindau et al., 2006; WHO, 2002). We could not explore that possibility because we were not able to test the women who participated in the study.

As described in Chapter 4, in Vietnam, the HIV test is usually provider-initiated. In provincial and national hospitals, according to health care workers, the uptake may reach 100%. Indeed, most women interviewed, whether they were HIV negative or positive, felt that it was acceptable to test all pregnant women for HIV. However, the number of HIV-positive pregnant women detected by the system may represent as little as 16% of the real number, (Nguyen Thu Anh et al., 2008) suggesting that the women who will be reached by the services represent a small fraction of those who need them.

Although there is high uptake of the HIV test in Hanoi, a problem arises from the fact that more than 90% of pregnant women were tested after the 22nd week of gestation, which is the cut-off point for safe and legal abortion. That means that a woman who learns she is HIV-positive from the routine care available would no longer have the opportunity to choose an abortion and would not be able to take advantage of the benefits of early and more effective ARV prophylaxis. (WHO, 2007)

Along with testing, counseling about PMTCT should be given to pregnant women at all stages and at every facility that provides ANC. However, poor counseling or even no counseling at all has been reported at each stage of the potential PMTCT intervention (pre-test, post-test, and post-natal) in different countries in the world, even in developed countries like the USA, for different reasons. (Coleman, Morgan, Carlson, Hawks, & Schulkin, 2008; Hyodo, Tanaka, & Kobayashi, 2000; Sinha et al., 2008) In this study, as few as one-fifth of pregnant women with unknown status (Chapter 4) and only about half of HIV-positive pregnant women reported that they received counseling on PMTCT. Women can get some information on PMTCT from other sources, such as the health education program on HIV or maternal and child health centers. A key problem with counseling in Vietnam is that most of it is directed at prevention of transmission, because most PLWHA are male drug users. Information/education/communication programs therefore usually focus on condom use and safe injection, targeting the known ‘high-risk’ populations. Poor or no counseling means few or no women seek PMTCT interventions.
Globally, by the end of 2006, only 11% of HIV-positive pregnant women were receiving ARV prophylaxis for PMTCT, ranging from 77% in Eastern Europe to 29% in Latin America, 3% in West Africa, and 2% in South Asia. (WHO, 2007) In this study we estimated that only 10% of HIV-positive pregnant women in Hanoi had access to ARV prophylaxis for PMTCT. Even among a group of 52 HIV-positive pregnant women in Hanoi who had relatively good access to care and support services in general, the proportion only reached 60%. (Nguyen Thu Anh, Oosterhoff, Pham Ngoc Yen, Hardon, & Wright, 2008) In a well-resourced setting, the proportion is expected to be higher, and could even be close to 100%. (Kamanga et al., 2006)

Access to pediatric ARV prophylaxis was also limited at our study site. Even among those who received ARV prophylaxis, inappropriate counseling on ARV use and adherence, poor case management, impractical administrative procedures, and lack of knowledge and information among both users and providers has made HIV-positive women use medication inappropriately, which may lead to ineffective prophylaxis. (Kamanga et al., 2006)

In Vietnam and many other Asian countries, breastfeeding is socially desirable and encouraged by the health care system and workers. But HIV-positive mothers are usually encouraged to bottle-feed because the virus can be transmitted through breast milk. (MOH, 2007) However, HIV-positive mothers who decided not to breastfeed their child have had to confront social and cultural barriers, even in developed countries such as the US or the UK. (Avert.org, 2008a; Oosterhoff et al., 2008). Among the women who decided not to breastfeed, many received inadequate counseling, lacking instructions on safe preparation of formula, which may lead to a high risk of diarrhea and other diseases for the newborn. (Kamanga et al., 2006; Morch, Nguyen Thu Anh, Do Quan Ha, & Nguyen Thi Thuy Hanh, 2006). Our study identified similar problems, in that HIV-positive women were under pressure to practice traditional feeding patterns. Women often felt pressurized to reveal their HIV-positive status in the family and community as justification for not following tradition by choosing not to breastfeed. A more in-depth study is needed to identify socially, culturally and at the same time medically appropriate feeding options for Vietnamese women.

Access to follow-up care for mothers and early HIV testing for children can be very limited due to the limited follow-up provided after the women were informed about the HIV test result and/or after delivery. (Manzi et al., 2005; Piwoz & Preble, 2002). Only 3% of our group of HIV-positive mothers received health care follow-up. None of their children were offered the PCR for early diagnosis of HIV infection. Sadly, lack of post-
natal care is quite common in Vietnam even for non-HIV-infected women (MOH, UNFPA, & Research Center for Rural Population and Health, 2006) and appears to be even worse for HIV-infected women. When the situation is complicated by HIV, stigma and discrimination appeared to be among the most important factors inhibiting HIV-positive women and their children to come for follow-up care (Chapter 6).

Table 1 below, which combines the results from our different surveys, summarizes how pregnant women were able to access the nine core steps of comprehensive PMTCT services in Hanoi, It reveals how limited access was found to be. The data for the HIV-positive women came from a rather small sample, however, which may not be representative for the whole city; a larger study would confirm the extent of the problems. By the end of the two-year follow-up, it appeared that none of the women and children had been able to get full access to all nine core services.

**Table 1.** Percentage of HIV-infected women and their children accessing the nine core steps

<table>
<thead>
<tr>
<th>Step</th>
<th>Service studied</th>
<th>HIV unknown (N = 670)</th>
<th>HIV-positive (N = 52)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>HIV test during pregnancy</td>
<td>85%</td>
<td>96%</td>
</tr>
<tr>
<td>2</td>
<td>Informed test result within two weeks</td>
<td>93%</td>
<td>100%</td>
</tr>
<tr>
<td>3</td>
<td>Access to information about PMTCT options</td>
<td>19%</td>
<td>52%</td>
</tr>
<tr>
<td>4</td>
<td>Access to abortion</td>
<td>10%</td>
<td>0%</td>
</tr>
<tr>
<td>5</td>
<td>Access to ARV prophylaxis for mother</td>
<td>NA</td>
<td>60%</td>
</tr>
<tr>
<td>6</td>
<td>Access to NVP prophylaxis for infant</td>
<td>NA</td>
<td>46%</td>
</tr>
<tr>
<td>7</td>
<td>Access to safe infant feeding</td>
<td>NA</td>
<td>46%</td>
</tr>
<tr>
<td>8</td>
<td>Access to follow-up care for mothers*</td>
<td>NA</td>
<td>3%</td>
</tr>
<tr>
<td>9</td>
<td>Access to early test for the child*</td>
<td>NA</td>
<td>0%</td>
</tr>
</tbody>
</table>

NA: not applicable

* N = 30

Clearly, although the PMTCT services are available in Hanoi, many women and children who need them do not have access, for a variety of reasons related to different steps in the process.
Main obstacles in accessing to PMTCT service in Hanoi

The most recent report by WHO on factors impeding implementation of an effective PMTCT program indicated that while several factors vary among countries, there are some issues common to many countries, as listed in Table 2. (WHO, 2007)

Table 2. Common Factors Impeding Global PMTCT Scale-Up (WHO, 2007)

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Biomedical Factors</strong></td>
<td>- Limitations in identifying pregnant women in need of ART</td>
</tr>
<tr>
<td></td>
<td>- Impact of diverse co-morbidities (TB, Hepatitis B and C, malaria, anaemia)</td>
</tr>
<tr>
<td><strong>Operational Factors</strong></td>
<td>- Limited human resources and infrastructure for scale-up</td>
</tr>
<tr>
<td></td>
<td>- Low utilization of maternal, newborn and child health (MNCH) services</td>
</tr>
<tr>
<td></td>
<td>- VCT services are not routinely offered as an integral component of the MNCH services</td>
</tr>
<tr>
<td></td>
<td>- Weak health care systems</td>
</tr>
<tr>
<td></td>
<td>- Lack of an integrated framework for the scale-up of comprehensive PMTCT</td>
</tr>
<tr>
<td></td>
<td>- Lack of demonstrated government leadership, commitment and accountability</td>
</tr>
<tr>
<td></td>
<td>- Limited functional linkages or integration of service delivery (ANC, MCH, ART, and RH)</td>
</tr>
<tr>
<td></td>
<td>- Lack of a champion to bolster interest and commitment among international community</td>
</tr>
<tr>
<td></td>
<td>- Weak linkages with HIV care, support and treatment</td>
</tr>
<tr>
<td></td>
<td>- Lack of monitoring, follow-up or tracking of women and children post-delivery</td>
</tr>
<tr>
<td></td>
<td>- Weak supply management systems</td>
</tr>
<tr>
<td></td>
<td>- Lack of technologies for early testing of infants</td>
</tr>
<tr>
<td><strong>Global and Local Factors</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Lack of data on impact of PMTCT programs</td>
</tr>
<tr>
<td></td>
<td>- Sustainable funding for scaling-up national programs</td>
</tr>
<tr>
<td></td>
<td>- Lack of coordination among partners</td>
</tr>
</tbody>
</table>

The table does not include a category of social or cultural factors, such as stigma, which may differ among countries but will always be present and will limit which aspects of PMTCT services are offered and which are used (Medical Committee of the Netherlands Vietnam, 2007; Nguyen Thu Anh, Oosterhoff, Pham Ngoc Yen, Hardon, & Wright, 2008; Oosterhoff, Nguyen Thu Anh, Pham Ngoc Yen, Hardon, & Wright, 2008; Oosterhoff et al., 2008). This was confirmed in our study.
Several of the factors identified by WHO are not relevant to the Hanoi context. For instance, Hanoi has a very good ANC system, from commune to national level, with a high utilization rate; nearly all deliveries occur in health facilities attended by trained staff. HIV testing has been introduced, integrated into the ANC system. Moreover, HIV testing is provider-initiated, an approach that can result in a high uptake of HIV testing. (WHO, 2007) The key services such as ARV prophylaxis for both mothers and children, infant formula, and PCR for children are provided free of charge, suggesting that the financial burden is not the main barrier to utilization. Safe abortion and safe delivery are widely available. All of these factors may help to improve and increase access to PMTCT programs in Hanoi.

However, certain factors that have also been reported from other countries were also identified as barriers in this relatively well-resourced setting. The key obstacles we identified were (in approximate order of importance): (1) poor counseling, (2) stigma and discrimination, (these two were not mentioned in the WHO list), (3) impractical administrative procedures, (4) limited clinical resources, (5) a fragmented system, and (6) an inappropriate policy environment.

Stigma and discrimination

Many HIV-infected women reported that fear of stigma and experience of stigma discrimination negatively affected their access to health care. An HIV test is not simply about information; it involves social relationships and strong emotions. Most HIV-infected people are fearful of the result and of other people knowing their status and believe that if they are found to be positive, their test result will not remain secret. (Nguyen TA, Oosterhoff, Pham NY, Hardon A, & Wright P, 2008; Oosterhoff, Nguyen TA, Pham NY, Hardon A, & Wright P, 2008)

Sources of enacted stigma and discrimination are the family, community and health workers. Although all people with HIV-related diseases may suffer from stigma, usually women with stigmatized diseases suffered more than men, especially in the family (Chapter 6). Disclosure of HIV-positive status is closely linked with other cultural and social issues (position of women in society, family pride, child care and education, family relationships, ways of earning an income, power abuse, and bribes). (Oosterhoff et al., 2008) These issues shape the health seeking behaviors of HIV-infected women, creating barriers to their access to adequate care and support both for themselves and their children.
Women experienced stigma and discrimination at all points of seeking service: counseling, ANC visits, abortion, delivery and post-delivery care. Careful and not always kind attention was paid to HIV-infected women, which led to perceived stigma and discrimination among those receiving care. Another factor was lack of motivation and dual fear among health workers working with HIV-infected people. Health workers complained that they had to deal with patients of “bad behavior” while they received a low salary and inappropriate compensation (Chapter 7), hence justifying their negative attitude towards HIV-infected people. In addition, as the HIV epidemic has evolved in Vietnam, HIV/AIDS policy and practice has been directed foremost at controlling the spread of the virus. (SRV, 2004) Thus, HIV-infected persons were seen by health staff as a source of contamination, which should be isolated (an approach as they had been taught in the past for other diseases such as leprosy and cholera). However, this approach was manifested in enacted stigma and discrimination in different forms, such as HIV-infected clients being isolated in separate rooms, not being allowed to sit, not receiving good quality services, being spoken to rudely, etc. While the need for care is real, given the highly stigmatized and discriminated health service environment, the majority of HIV-positive pregnant women either go into denial, avoiding thinking about the fact that they ad possibly their child have HIV,, or they give up, and refuse to seek care and support and accepting the consequences (as described in Chapter 5 and 6).

Health workers are caught in the middle themselves – not only are they a source of stigma from the perspective of HIV-infected people, but those who work with HIV-positive patients also became recipients of stigma from colleagues and their families, because of their exposure to HIV-infected patients, as revealed in Chapter 7.

Counseling

In many countries, the key problem of the PMTCT program is the low uptake of HIV testing, which prevents the unidentified HIV-positive women from accessing services. The key problem in the Hanoi setting, where there is a high uptake of HIV testing, however, was the lack of counseling or provision of only poor quality counseling services for pregnant women. As was identified in a previous study (WHO, 2002), poor counseling was reported and observed in every step when women tried to access PMTCT services.

We also found that counseling was one of the main limiting factors for optimal use of available PMTCT services, as revealed in Chapters 4, 5 and 6. In the context of Vietnam, where IDU and FSW have been considered as the predominant group at risk
in the HIV epidemic, pre-test counseling was usually not given because priority was
given to ‘professional’ tasks rather than counseling. Even if pre-test counseling was
given, it was often given only to ‘suspicious’ pregnant women, which in the health
workers’ judgment included drug users’ wives, drug users, commercial sex workers,
those who had recently left a rehabilitation center or those who had specific clinical
syndromes such as genital warts or syphilis. However, many women who do not have
one of these “markers” could also be HIV positive and in need of advice.

Post-test counseling should be provided at all stages of ANC, to create every
possible opportunity for PMTCT services to be offered: at the time HIV test result is
given to women (irrespective of their result) and during ANC follow up and post-natal
care for HIV-positive women. (WHO, 2007) However, the study found that post-test
counseling was provided only to HIV-positive women. Many women in the general
population had limited knowledge about the possibility of HIV transmission from mother
to child and that there are effective interventions to prevent that. Even among our group
of HIV-positive pregnant women, many reported that they had not been aware about the
possibility of PMTCT. Of those who received ARV prophylaxis, many did not know how
to, and therefore did not, take their medication correctly. Their incomplete knowledge
and incorrect practice suggest that most of them did not receive good counseling when
they were first tested for HIV, or even when they knew their positive test result and
received some PMTCT services.

As described in Chapter 7, several reasons were given by health workers for their
poor performance in counseling: high workload, lack of knowledge and inadequate skills
due to lack of training and up-to-date information, and lack of PMTCT guidelines.
Moreover, findings from interviews with both users and providers revealed that health
care workers prioritised returning HIV test results for HIV-positive women only. Many
health care workers were not aware of the importance of giving test results, together
with other information, to HIV-negative women. Prophylactic ARV was not available at
all PMTCT sites, which provided health workers with an excuse for their reluctantance in
providing counseling to HIV-infected women. (Medical Committee of the Netherlands
Vietnam, 2007; Morch, Nguyen Thu Anh, Do Quan Ha, & Nguyen Thi Thuy Hanh, 2006)

Many infected women expressed their dissatisfaction about the way they were
treated by some of the counselors. Inappropriate behavior during communication about
HIV status may result in women avoiding the health services in future, which means
they will not access the continuous treatment, care and support they will later need.
Discussion

Operational and policy factors

**Impractical administrative procedures.** Several factors that could be changed to improve the program do not receive adequate attention, for instance, the long waiting time before receiving ARV, the unwanted disclosure of HIV test results due to the notification system, the late HIV testing during pregnancy initiated by health workers (too late to provide full choices for the pregnant women), and the inappropriate form of NVP syrup for pediatric prophylaxis.

**Limited clinical resources.** Although Hanoi can be considered a relatively well-resourced setting, its comprehensive PMTCT program still lacks some components. HIV testing is not available at commune health stations (where many women go for ANC) and NVP prophylaxis was not consistently available at facilities that should offer PMTCT. The health workers at health facilities providing services for HIV-positive people lacked protective materials and equipment and were often poorly motivated to work with PLWHA. They also labored under a high work load at high level facilities while services at lower levels were underutilized.

**Fragmented system.** The fragmented nature of the health care system into specialized vertical pillars, including a vertical program for HIV/AIDS, was shown to be a major obstacle to providing a continuum of care. The vertical organization of the health care system and the contradictory mandates within and among different sectors obstructed effective collaboration and referral between the different HIV-related services that women and their families need to access. A lack of multi-sectoral collaboration limited effective and necessary information exchange between sectors and organizations. This problem has been found in other countries, including those with relatively successful PMTCT programs, such as, Thailand and Brazil.(WHO, 2007)

**Inappropriate policy environment.** The HIV epidemic in Vietnam is still concentrated among high risk populations, including IDU and FSW. In order to prevent potential generalized epidemic, the Vietnamese government has focused on these recognized high risk populations, mainly young male drug users. This concentration on one particular high risk population may leave other populations under-protected or unprepared for the risks and the consequences of HIV infection. Women in Vietnam are increasingly at risk of HIV transmission but that risk is under-reported and under-
recognized. The reported data may represent as little as 16% of the real number. That could mean that in 2005, up to 83,000 women infected with HIV have not been detected and served by the health care system. (Nguyen Thu Anh et al., 2008) Availability and accessibility of HIV care and support remain very low, but HIV-infected women may have even less access compared to other groups. The reason for that is partly because infected women have been less visible to the policy-makers and planners than male IDU. To develop appropriate intervention strategies for women, a clearer understanding is needed of their place in the HIV epidemic in Vietnam.

The Vietnamese government has issued several PMTCT-related policy and legal documents following global recommendations. However, due to the complexity of the health system and the geographical administrative system, it takes time to put policies that can benefit PLHIV into practice.

Focus on prevention. Preventive medicine services in Vietnam focus largely on controlling infectious diseases, mostly by applying classical measures such as surveillance, the use of protective clothing, isolation of infected cases, and community mobilization against the spread of the disease. These strategies are the basis for some of the stigmatizing behaviors of the health workers such as placing HIV-infected women in separate rooms and wearing excessive protective clothing. While appropriate strategies for prevention have their place the social aspects of the disease cannot be neglected, as this study has demonstrated.

How to bring about change?

Medical intervention alone seems to not work in the context of complexity of needs (social, psychological and financial) of HIV-infected women and a society which stigmatizes against HIV and “social evils”. In the following section, several interventions that take into account the social aspects of HIV and could contribute to solving identified problems will be presented.

Reduction of stigma and discrimination by introducing self-help groups

We found that stigma/discrimination was the main obstacle to access PMTCT services, in the experience of both pregnant women and health workers. Empirical interventions for reducing stigma and discrimination often aim to provide information on HIV
transmission with the aim of improving the attitudes of the community and of health workers towards PLHIV.

However, interventions to reduce stigma and discrimination should address not only the source of stigma but also its recipients. We found that even in few cases where enacted stigma did not occur, HIV-infected women still feared potential stigma and discrimination, and that led them to denial or to avoid using services, even when these were available. The introduction of self-help support was able to bring about the dual effects of reduced stigma by interfering on two sides: with both service providers and users. The self-help group, at the same time, can provide different methods of communication for community and health staff and empower its members to make appropriate choices and to transform these choices into desired actions. Empowerment of HIV-infected women can be achieved through different methods. The key is that the intervention must address the needs as identified by the women themselves, in their complex living context, and not only the needs recognized by the people responsible for carrying out the intervention. Peers as mentors and role models often provide motivation for women to bring about change. Last, but not least, giving women opportunities to change their lives by providing different types of support is very important.

Making resources available and accessible

Reports in the international literature suggest that the health system can be transformed to bring about improvements in access to health care. However, one of the main challenges in a low-prevalence and low-resource setting is that the investment in infrastructure and human resources for comprehensive HIV related services targeting a relatively small number of patients must ensure quality and also be cost-effective.

Improvement of the HIV testing and counseling service

The strength and potential benefits of a PMTCT program are that it provides an opportunity to provide information on HIV through counseling as well as HIV testing to pregnant women, irrespective of their socio-economic status and point of entry in the health care system. We found that women’s choices for reproductive health care suggested opportunities for interventions to improve accessibility: more than 80% of them sought ANC in the first trimester and made more than three ANC visits. Most health care workers and 76% of women interviewed thought that all pregnant women should be tested for HIV. We therefore propose that HIV counseling and testing should
be offered at points where women receive ANC. In other provinces, where almost all pregnant women come to commune health stations for delivery, HIV should be offered at that level. However, the investment required creating skilled and knowledgeable human resources at all 10,000 commune health stations, and then to maintain competence over the years is prohibitive. We propose that coverage of HIV diagnostic services can be achieved by increasing the mobility of service providers. Evidence suggests that physical distance can be compensated for by increased quality and anonymity, which are more critical factors for access to HIV-related services.

Therefore, we recommend that HIV counseling and testing services should be offered routinely at the district level and that cluster districts should become the providers of all other facility-based HIV- and PMTCT-related interventions. Women cannot and should not be prevented from accessing services at provincial and national level if they choose to do so, but the emphasis of efforts to establish comprehensive services should be at the cluster district level to increase accessibility and avoid excessive work loads at higher administrative levels. The catchment areas and choice of districts to be clustered could be decided by the provincial authorities, based on population size, number of districts, HIV prevalence, resources and local capacity. As the features of the HIV epidemic change and as capacity and financial resources increase, new cluster districts with smaller catchment areas may be established.

In addition, our results suggest that it would be better to make HIV testing anonymous for pregnant women and to allow HIV-positive pregnant women choose the routes of HIV status disclosure, as well as where to access services. HIV testing should be offered at the first trimester to give the women the choice between abortion (which is legal in Vietnam) and continuing the pregnancy and entering early prophylactic intervention.

The quality of counseling needs to be improved, to take into account culturally appropriate approaches and women’s needs, as became clear from the results described in Chapters 4, 5, and 6. Counseling needs improvement at all levels in all health facilities, for both HIV-positive and negative pregnant women. This could be achieved by investing more in capacity building for counselors and by making PMTCT guideline available so that counselors and health workers have consistent and standardized information to share with their clients.
Improving provision of ARV prophylaxis

Despite a sufficient supply of prophylactic ARV in Hanoi, lack of these medications was observed in some facilities at certain times. We recommend that the health facilities should not only ensure that ARV are available at all times, but also develop a client-friendly approach to distribute the medication, with adequate counseling on its use and adherence, to meet basic requirements for good patient management. Prophylactic NVP should be provided in a small package for health facilities that will receive only a small number of HIV-exposed children per day.

Capacity building

Two of the main causes of poor counseling and observed enacted stigma towards PLHIV among health workers are fear of infection due to lack of knowledge, and lack of counseling skills. We recommend that training, periodic re-training, and coaching should be given for health workers to provide them with knowledge and skills on HIV transmission routes, counseling and communication, universal precautions, and post-exposure prophylaxis.

District-based program to increase access to a continuum of care and support

An HIV-positive woman’s presence in an ANC site that offers HIV-related services is an opportunity to establish first contact with care and treatment and with support groups. Early contact may increase her ability to access such services later when she requires them. Integrating the PMTCT program into the existing district-based adult HIV care and treatment services could make it easier for HIV-infected women to make contact and get access to post-natal care and care for themselves and their children. Pediatric departments at district hospitals should make referrals to facilities that conduct PCR testing, possibly with the assistance of the members of the support group.

On the provider side, the network of related services needs to be strengthened. Frequent meetings between different service sites should be organized, with the involvement of health workers from different services: PMTCT, pediatric and adult care and treatment, family planning, STI and others. It will be especially important that high level health staff meet in order to share information on services available and provide feedback on the quality of the referral system.

We strongly recommend that support groups for HIV-positive women be established in the cluster districts. Instructions on their functioning should be included in the
guidelines for PMTCT, and official budget lines for running costs should be made available by local government and/or the health system. Women should also be encouraged to make contact with support groups, preferably soon after a positive HIV test result, and at least prior to delivery. If HIV infection is diagnosed only at the time of labor, women should be encouraged to contact support groups before they are discharged from the hospital. The case manager may assist in linking patients to self-help groups, but of course only when the patient has given her consent.

Policy

PMTCT-related policy and legal documents have been issued in Vietnam. We recommend that the Government should take further steps to support the local health systems to implement these policies and documents. Detailed guidelines on how to implement the PMTCT program should be developed and distributed to health workers at all levels. More investment and attention should be given to the PMTCT program, not only, as is presently the case, to the programs aimed at the high-risk groups that make up the most visible HIV-infected population.

How the lessons learnt could lead to changes in Vietnam?

When this research commenced, there were serious gaps in the policy and practice guidelines concerning PMTCT in Vietnam. Since then, over the past few years, several findings from the study have been used to inform improvements in the documents guiding the PMTCT program in Vietnam. As a member of the National Technical Working Group on PMTCT, I have personally had the opportunity to provide technical inputs to the government on the development of the PMTCT program in Vietnam and have therefore made use of the research results in a way that may directly benefit the women who participated in the study, as well as other women in future.

Development of policy document

As the research revealed, although several policy documents were issued to create a more positive environment for PMTCT implementation, there is still a lack of detailed instructions on how to implement PMTCT in practice. In 2007, as a member of the National Technical Working Group on PMTCT, I was able to contribute to the development of a new PMTCT protocol.
Discussion

This protocol regulates the activities of the national PMTCT program, in both public and non-public health facilities, and assigns implementing organizations different activities. The protocol indicates that district level is the key level at which health facilities should implement PMTCT activities. In addition, the protocol specifies which organizations/agencies should coordinate with the PMTCT program at all levels in order to be able to establish an effective referral system.

A clear protocol on how to perform HIV testing and counseling is described. The protocol emphasizes that counseling should be provided for both HIV-positive and HIV-negative women with detailed information and instructions. HIV-infected women should receive prophylactic ARV and safe ANC and delivery services. Follow up care and support is mentioned as one of the critical components of the intervention, to provide post-delivery counseling for mothers and their families with consent, safe care for infants, referral to ART sites for long-term management including medical, psychological, financial and social support, and referral for medical care for children (OI prophylaxis, counseling, growth monitoring, confirmation of HIV status, immunization and OI/ARV treatment if necessary). Universal precautions should be applied for all women, no matter what their HIV status.

Continuing Sunflower group – the self-help intervention

As described in the study, several of the HIV-infected women who participated in the study were recruited from the Sunflower group. Although the study has ended, the self-help group is still growing and expanding its coverage as well as its interventions, with my support as project officer.

The self-help group provides medical, social and economic care and support to HIV-infected mothers, their children and their families. Interventions through the group to improve the health of members and their children used and strengthened the capacities of the health facilities involved in the study. Simultaneously, the intervention built the capacities of mass organizations such as the Women’s Union and the Red Cross to improve the quality and quantity of their social-economic services. The capacity of the mothers and their families to receive and provide peer support and to access improved services were strengthened by means of the self-help group.

An important activity of the group has been to establish a referral system in which peer counselors work as part of the health services team to help patients make links with and between medical, social and economic services that they and their family need.
and have the right to receive. Since mid-2006, the intervention program has been expanded to three other provinces with high HIV prevalence and available but underused services. There are, at the time of writing, six self-help groups in Thai Nguyen, Cao Bang, and Quang Ninh provinces. Almost 1,500 persons, group members and their children, now have access to follow-up care and ART, along with access to loans and social support. All members who need prophylaxis to prevent HIV transmission from mother to child can access it. Almost 90% of the members (both adults and children) who need antiretroviral therapy can obtain it and the group contributes to achieving excellent adherence, with almost no loss to follow-up. Increased confidence of both service providers and end-users was observed. Several senior government authorities (e.g. the Prime Minister, leaders of the Party and Vietnam Administration for HIV/AIDS Control, National AIDS Committee) and international authorities (e.g. the wife of the UN General Secretary, Dutch Ambassador, Dutch Minister for Development Cooperation and Dutch AIDS Ambassador, American Red Cross leaders) have visited the program. All of these notable people considered the support group to be a successful and good model that should be scaled up to help women nationwide.

Development of comprehensive PMTCT program

In 2004, the Global Fund project started to support the PMTCT program under the management of the Vietnam Administration for HIV/AIDS Control (VAAC), the national authority in charge of HIV/AIDS. The main activities of the project are to provide health care and ARV treatment for PLHIV, including VCT and PMTCT services. Although the project is implemented in 20 provinces, the PMTCT program was introduced in seven national and provincial hospitals in four provinces to provide HIV counseling and testing only. In 2006, when the Global Fund issued the call for proposals for Round 6 for new funding, the lessons learned from this research were presented to the VAAC leaders. Several discussions on how to improve the PMTCT program were conducted between VAAC leaders, program implementers, and the author. For the proposal under the new funding round, several additional services were proposed to be added to the existing PMTCT program, to make it into comprehensive PMTCT. Out of 20 project provinces, the comprehensive PMTCT will now be provided in 14 provinces. Together with the six provinces funded by PEPFAR (USA funding), that means that comprehensive PMTCT will be provided in 20 provinces with a high HIV prevalence. To make the PMTCT services available at the facilities that the majority of pregnant women attend for ANC,
they will be provided at district level, where ART can also be provided, in line with the new recommendation by WHO and with our own recommendations, described above. The services to be provided include:

- Information on HIV and PMTCT and community based IEC activities through the networks of the Women’s Union (a mass organization which has staff at all administrative levels and millions of members around the country) to reduce stigma and discrimination;
- HIV testing and counseling, free of charge for pregnant women who come for ANC at health facilities at district or lower level;
- Prophylactic ARV free of charge;
- Baby milk formula and counseling on safe replacement feeding, free of charge;
- Equipment for universal precautions for health staff;
- Capacity building for staff at all levels of the health system and of mass organizations as well as for key members of self-help groups;
- Referral network for medical and psychosocial care and support, including self-help groups;
- Strengthening of the multi-sectoral and multi-level collaboration in order to provide comprehensive PMTCT services;
- Research on the effectiveness of the newly established PMTCT program to extract lessons learned and strengthen both existing and future programs.

The proposed project would address many of the key problems identified in our research. The Global Fund Round 6 proposal has received almost 30 million $US for its interventions for the period of 2007-2011.

The success of the intervention based on strengthening the network of services and strengthening the capacity of HIV-positive women through self-help groups in our four provinces and the Global Fund proposal can help to increase the coverage of the comprehensive PMTCT program. However, the coverage would still be very limited compared to the estimated number of HIV-infected mothers; rural women still have virtually no access to such groups, for example. The planned expansion of our project activities to four more provinces with support from the Royal Netherlands Embassy in Hanoi will contribute to solving the problem and hopefully lead the way until all women have access to good PMTCT services.
Chapter 8

The results of this study have not only guided improvements in providing PMTCT in Vietnam but may also contribute to the understanding of PMTCT in other low-prevalence countries, especially in Southeast Asia, which may share features with the better-described services in sub-Saharan Africa but in other ways are surely different, and may need particular investments in order to improve them. We hope that our findings and the application of these findings in the development of the PMTCT program in Vietnam will, in turn, contribute to the improvement of such services for women who need them in any country.

References


Discussion


WHO. (2007). *Prevention of mother-to-child transmission (PMTCT). Briefing Note: Department of HIV/AIDS.*