Access to comprehensive prevention of mother-to-child transmission program: obstacles and implications
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CHAPTER 1

INTRODUCTION
Rationale

The HIV/AIDS epidemic is an important global public health issue and, increasingly, the burden of the disease falls on women. Of the estimated 200 million women around the world who become pregnant each year, about 2.5 million are HIV positive. (UNAIDS & WHO, 2006) HIV prevalence among women attending antenatal clinics has risen throughout the past decade, leading to an increase in the number of HIV positive children born to HIV-infected mothers. (UNAIDS & WHO, 2006)

Prevention of mother to child transmission (PMTCT) was first proposed as a global health policy in the late 1990s. (WHO/UNAIDS, 1998) Impetus for action in resource-poor settings came from a trial completed in 1998 in Thailand, which found that a relatively short 25-day course of twice-daily oral Zidovudine (AZT) was safe, well tolerated, and, in the absence of breast-feeding, lessened the risk for mother to child transmission of HIV by 50%. (Centers for Disease Control and Prevention, 1998, Shaffer et al, 1999) These findings and those from other concurrent trials (Dabis et al., 1999, Wiktor et al., 1999, Dabis et al., 2000) prompted the World Health Organization (WHO) and UNAIDS to develop guidelines on the safe and effective use of antiretroviral (ARV) medications for the prevention of mother to child transmission. (WHO/UNAIDS, 1998) ARV prophylaxis in HIV-positive pregnant women had already been used in Europe and America for half a decade.

Initially, WHO and UNAIDS recommended a three-pillar strategy: PMTCT programs should aim at (1) preventing new infections among parents, (2) preventing unwanted pregnancies in HIV-infected women, and (3) preventing transmission from HIV-infected pregnant women and mothers to children (WHO, 2003:5). In 2002, however, a WHO meeting proposed to include a fourth pillar: providing care and support for mothers, their infants and their families (WHO, 2003:13). This fourth pillar was endorsed at the global high-level forum on the prevention of Mother to Child Transmission of HIV in Abuja, Nigeria (UNFPA, 2005). At that time, ARV treatment had become available in resource-poor countries, due to global mobilization for universal access to treatment.

It became clear that PMTCT would not be so easy to implement when UNICEF conducted pilot studies in Botswana, Burundi, Cote d’Ivoire, Honduras, India, Kenya, Rwanda, Tanzania, Uganda, Zambia, and Zimbabwe. (UNICEF, 2003) On average in the eleven pilot countries, thirty percent of women who visited the antenatal care (ANC) sites were not informed about PMTCT. Of those women who did receive information
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about PMTCT, 30 percent did not receive an HIV test. More detailed findings from Kenya and Zambia revealed that one quarter of women who were tested did not come back for their test results. As to the provision of prophylactic ARV treatment, just over half of the women who tested positive for HIV never received it. (UNICEF, 2003) Similar trends in inadequate follow-up have since been reported in a several studies of PMTCT programs conducted in high HIV-prevalence countries in Africa. (Etiebet, 2004, Bajunirwe & Muzoora, 2005, Coulibaly et al., 2005, Bwirire et al., 2008) For example, Manzi et al. (2005) reported that while 95% of pregnant women attending antenatal care in Malawi had an HIV test, only 45% of the HIV-positive pregnant women and only 34% of the babies born to HIV-positive mothers received ARV prophylaxis. Coulibaly et al. (2005) found that in a PMTCT program in Abidjan only 36% of 1,829 HIV-positive pregnant women received AZT. A variety of institutional and cultural reasons are given for the poor follow-up: women are worried about taking drugs during pregnancy; women fear stigma and discrimination, husbands oppose the PMTCT program, long waiting times at the facility, and inability to afford transport costs for follow-up visits. Painter et al. (2004) found that underlying mistrust in the health facilities and disbelief in test results contributed to low uptake of prophylactic drugs. Several authors argued that quality of care needs to be improved to increase the uptake of testing services and prophylaxis medication. Key institutional barriers that need to be addressed include stigmatizing behaviour of overburdened health workers, and low frequency, duration and quality of pre- and post-test counselling in routine PMTCT services. (Delva et al., 2006)

Vietnam was one of the first countries in South East Asia to introduce Nevirapine for PMTCT. A sub-committee on PMTCT was set up very early, in 1995, under the National Committee for AIDS, Drug, and Prostitution Prevention (NCADP). The Vietnamese government made a commitment to "reduce the proportion of infants infected with HIV by 20% by 2005, and by 50% by 2010" at the United Nations General Assembly in June 2001. (UNGASS, 2005) The strong health care system in Vietnam, particularly the public health focus on primary health care and prevention and the widely accessible ANC system, renders the implementation of a good PMTCT program a real possibility. Several policy documents regarding the PMTCT program have been issued. According to these documents, routine HIV testing should be performed in antenatal clinics, from the district to the national level. All HIV-positive pregnant women should receive single dose Nevirapine free of charge. The provision of Nevirapine has been supported by the company Boehringer Ingelheim, targeting all HIV-infected pregnant women in 34 of the 64 provinces nationwide. In 2006, of 506 facilities providing ANC services, 107 facilities
(21%) provided the basic minimum package of PMTCT services. This package includes a single-dose NVP (Nevirapine) regimen provided in the national program, and more recently, the three-combination ARV prophylaxis (PEPFAR-supported) for HIV positive pregnant women. In addition to ARV prophylaxis, HIV-infected women are encouraged to bottle-feed and are provided with formula free of charge.

However, the program has faced several challenges. The National Plan of Action for PMTCT was approved in 2006, yet the guidelines for operationalization of the Plan are currently still under development. With these unfinished (as part of the PMTCT guideline and the restructure of the health and HIV program system), the implementation of the plan is negatively affected and the promotion of PMTCT is inconsistent.

Additionally, making resources available for PMTCT does not mean that HIV-positive pregnant women will benefit. The percentage of pregnant women reported to have an HIV test during ANC visits remains low and has slightly decreased: in 2004, 22.4% of pregnant women reported having had an HIV test in the last year; (MOH, PMU-Project HIV/AIDS Global Fund, & National Institute of Hygiene and Epidemiology, 2005) in 2006, 16.5% reported having had the test in the last two years. (General Statistic Office & United Nations Children's Fund, 2006) As a result, only 500 of an estimated 6,000 HIV positive mothers were identified through routine screening in 2002. The low detection rate of HIV-positive pregnant women inevitably limits the coverage of PMTCT interventions. Among those HIV-positive pregnant women who were identified, as few as 25.4% received prophylactic Nevirapine. (UNGASS, 2005) Little is known about low PMTCT access in settings where most of the requirements for a PMTCT program exist.

The study was undertaken in Hanoi to develop better understanding of the state of PMTCT services in an urban setting and explore the obstacles HIV-infected women face in accessing these services. Although many studies have been conducted about PMTCT, most of them investigated the uptake of testing; few examined the quality of follow-up care. The study followed up a group of HIV-infected women to investigate the quality of follow up care, resulting in recommendations on improvements to policy-making as well as the implementation of the PMTCT program.
Study objectives

This thesis was undertaken as part of the joint regional research project “Towards a continuum of care in prevention of mother-to-child transmission programs: Participatory action-research in Vietnam and Indonesia”. A rapid assessment on comprehensive and continuum PMTCT service carried out between August 2005 and March 2006 by this researcher provided a broad picture of factors influencing access to comprehensive PMTCT.

This study explored issues in more depth in order to provide better understanding about the state of PMTCT services and to assess the main obstacles to accessing comprehensive PMTCT service faced by HIV-positive women in an urban setting in Vietnam (Hanoi). The findings are intended to contribute to the development of a practical, effective, and comprehensive PMTCT program, as recommended globally by WHO.

The specific research questions which the study explored were:

1. To what extent and when do pregnant women have access to an HIV test? Why is HIV not detected among a large proportion of HIV-infected women?
2. To what extent do HIV-positive pregnant women have access to comprehensive PMTCT services, which include access to information about PMTCT options, abortion, ARV prophylaxis for mother and children, safe infant feeding, continuum of care for mother, and early testing for children?
3. What are the causal factors behind health care workers’ failure to provide access to comprehensive PMTCT?
4. Which factors influence access to comprehensive PMTCT?

Study framework

The four-pronged PMTCT approach was introduced by WHO in 2002. The approach has been considered as a comprehensive strategy to prevent HIV infection among infants in different epidemiological situations and service delivery settings. The strategy recommends that PMTCT is not provided as a single service but includes several services, depending on the local context.
An "access-flow" model (Figure 1) adapted from the WHO four-pronged approach was used to identify and investigate the primary obstacles in providing comprehensive PMTCT access in the context of Hanoi, a city with various HIV-related resources. The first prong, primary prevention of HIV/AIDS, was not included in the study because numerous studies have already been conducted on this topic. The "access-flow" model includes nine core steps, which are considered essential to an effective PMTCT program:

1. Access to an HIV test
2. Access to HIV test result
3. Access to information about PMTCT options
4. Access to abortion
5. Access to ARV prophylaxis for HIV-positive pregnant women
6. Access to Nevirapine prophylaxis for infants born to HIV-positive mothers
7. Access to safe infant feeding
8. Access to follow-up care for mothers
9. Access to early test for the child

We investigated two major, alternative dimensions: the characteristics of the population versus the characteristics of the delivery system. In the study, we looked at the point of view of pregnant women as service users versus the view of health workers as service providers to understand the reasons why in a setting with a high level of resources for PMTCT programming, still many women have no or limited access to PMTCT services. Is it because women do not want to use the services, or they have no access to them? Or is it because health workers do not want to provide PMTCT services, or they want to, but cannot do so? Figure 1 shows that HIV-infected women and their children need several services, which are provided at different facilities, and at different levels. This study, therefore, examined the complex referral systems, both horizontal and vertical; to explore the factors affected the linkages between these services.
Figure 1. Access-flow model: a minimum access to comprehensive PMTCT

We looked at several factors that can provide answers to the study questions, as presented in Table 1.
Table 1. Factors affecting access to the nine core steps of the PMTCT service

<table>
<thead>
<tr>
<th>From user side</th>
<th>From provider side</th>
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<tbody>
<tr>
<td>Knowledge of HIV, PMTCT services</td>
<td>Knowledge of HIV and PMTCT services</td>
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<tr>
<td>Felt stigma</td>
<td>Attitude towards PLHIV and “social evils”</td>
</tr>
<tr>
<td>Perceived need for health care</td>
<td>Counseling and communication skills</td>
</tr>
<tr>
<td>HIV status</td>
<td>Workload</td>
</tr>
<tr>
<td>Perceived quality of services</td>
<td>Performance of case management</td>
</tr>
<tr>
<td>Acceptance of HIV test</td>
<td>Administrative procedure</td>
</tr>
<tr>
<td>Living area (urban versus suburban)</td>
<td>Availability of services (nine core services)</td>
</tr>
<tr>
<td></td>
<td>Appropriateness of the PMTCT guidelines</td>
</tr>
<tr>
<td></td>
<td>Capacity</td>
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<td></td>
<td>System of notification for HIV test result</td>
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<td>Referral system</td>
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<td>Availability of self-help group support</td>
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</table>

Inspired by the new field of cultural epidemiology (Weiss 2008), this study aimed to uncover how both service-related factors and socio-cultural factors constrain access. Combination of methods was used to explore the factors that promote or limit the access of pregnant women to the nine core services of the PMTCT program. Stigma and discrimination were expected to be a key factor in Vietnam.

Many studies have documented the stigma attached to HIV infected persons in health care settings all over the world (Brown, Trujillo, & Macintyre, 2001). Several authors divide stigma into felt or perceived stigma and enacted stigma (Brown, Trujillo, & Macintyre, 2001; Jacoby, 1994; Scrambler, 1998; Atre S. et. al., 2004). Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease (such as epilepsy, tuberculosis or HIV), or association with a particular group. For example, an individual may refuse to go for
testing, deny his/her risk of HIV or refuse to disclose HIV status for fear of the possible negative reactions of family, friends, and community. Enacted stigma refers to the real experience of discrimination. For example, HIV status could lead to loss of a housing lease, employment, health benefits, or friends. Felt stigma can be seen as a survival strategy to contain the risk of the occurrence of enacted stigma, for example, when people fail to disclose or lie about their HIV status in order to avoid being ostracized. In the study, HIV-infected women were interviewed about their experience of stigma and discrimination in their family, community and health facilities, and how they responded to and confronted it.

The Vietnamese epidemic is still largely concentrated among male injecting drug users (IDUs), suggesting that gendered roles, often related to risk-taking, can make men vulnerable to become infected with HIV. Several authors have argued however, that in an Asian context, women are significantly more likely to experience discrimination than men within the family and the community (Bharat, Singhanetra-Renard, & Aggleton, 1998; Paxton et al., 2005). Forms of enacted stigma experienced by HIV-positive women include ridicule and harassment, physical assault, and being forced to change place of residence. Vietnamese women are under strong pressure from their families and society to uphold the moral status of the family. A woman who is infected is possibly criticized because she is regarded as having violated a core moral norm of the society (Khuat Thu Hong, Nguyen Thi Van Anh, & Ogden, 2004). In Vietnam, as in many countries, women are paid less and educated less than men in the same social circumstances; the difference is even greater among poor families (National Committee for the Advancement of Women in Vietnam, 2002; UNDP, 2005). Lack of education contributes to communication difficulties between women and health care workers, often amplified by the low willingness of health care staff to listen to women’s concerns.

The study required close cooperation with the HIV positive pregnant women who provided information and personal perspectives. In the context of low HIV prevalence among pregnant women and high stigma from society, it is very hard to find a representative sample of HIV-positive pregnant women who both have or not had access to comprehensive PMTCT. The study combined quantitative methods to evaluate the accessibility of HIV testing for pregnant women with qualitative methods to follow a group of 30 HIV positive pregnant women through the process of gaining access to continuum and comprehensive PMTCT.
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Study methods

This study was conducted as a part of the larger research project: “Towards a continuum of care in prevention of mother-to-child transmission programs: Participatory action-research in Vietnam and Indonesia”. A baseline study conducted among HIV-infected women for the wider project showed that HIV-infected women and their children did not receive the proper care and treatment services that they need. (Medical Committee of the Netherlands Vietnam, 2007) However, the scope of the problem and the underlying reasons remained unclear.

To explore the factors affecting access to the nine core steps of comprehensive PMTCT services, data was collected using a mix of methods (quantitative and qualitative) in order to triangulate findings. As HIV testing is the first essential step of an effective PMTCT program,, the first phase of this study explored routine HIV testing programs in antenatal clinics and the extent of their coverage using existing data, by means of a rapid assessment on continuum of care on PMTCT, and a household survey carried out among 670 pregnant women. The second phase followed up 52 HIV positive pregnant women and 30 families of HIV-infected mothers using ethnographic methods to determine gaps in access to comprehensive PMTCT services. This was supplemented by a quantitative household survey and a qualitative study among health workers who were selected based on their function, position and experience in the development and implementation of the PMTCT program in the city. Informal conversations were used to verify findings, while preliminary findings were presented for feedback to project partners and representatives of various groups involved in the process. Detailed information about each method is presented in the Methods Section of chapters 3 to 7.

A range of information sources was used to triangulate the analysis. These consisted of:

- Secondary data from more than 300 policy documents, program reports, and research studies.
- Collection of quantitative data through household-based survey among 670 pregnant women who had delivered in the preceding 12 months.
- Collection of qualitative data via in-depth interviews with HIV-infected women, their husband and mother-in-law. Collection of qualitative data was conducted as a circle. At each level, information was enriched and cross-confirmed.
• Semi-structured interviews with health workers, following consistent interview
guidelines.

• Observation of health facilities

My work with mass organizations and local hospitals in establishing and maintaining
a self-help group for HIV-infected mothers in Hanoi, the Sunflower group, since April
2004, enabled me to make contact with the study population of HIV-infected women.
Sunflower members delivered posters, leaflets, and name cards of the group to create a
referral network among health facilities at all levels in Hanoi. At each facility,
information, education and communication (IEC) materials were posted in waiting
places, testing sites, examination wards, and other places where pregnant women might
find them. Core members visited obstetric hospitals, general hospitals, pediatric
hospitals, and voluntary counselling and testing (VCT) sites to make informal contact
with potential members and refer them to the Sunflower group.

Data collection tools

The semi-structured questionnaires were developed in stages. Interviewers began by
conducting interviews loosely structured around the study themes which related to the
four-pillar continuum of care model. The whole team participated in the first few
interviews in order to exchange and learn from the individual interview styles of each
team member, before breaking up into smaller teams of two people. Based on these
loosely structured interviews, we developed three question guidelines for different types
of interviewees: HIV-infected women, pregnant women, and health workers. The order
in which themes were introduced depended on the flow of conversation, but all study
themes were covered during each interview. Researchers were also free to explore any
new, unexpected themes that arose during the interview.

Data recording and processing

The interviewees gave written permission for the interview to be recorded. Prior to
starting the interview, researchers invited each interviewee to read and sign the consent
form, and asked their permission to record the interview on tape. Interviewees were
informed that recording could be stopped during the interviews if there was a sensitive
question that the interviewees did not want recorded. All interviewers took notes during
the interview.
Chapter 1

All transcripts of in-depth interviews and semi-structured interview were coded, entered and analyzed using N-VIVO software, which can be used with Vietnamese script. A code book was developed by a team of interviewers, focused on key findings and terminologies.

Quantitative data were screened before being entered into EPI INFO 6.04. Data sets were transferred to SPSS 12.0 for statistical analysis. Analysis included frequencies, cross-tabulation, and factor analysis.

Ethical issues

Institutional ethical approval was obtained from the Scientific Committee of Hanoi Medical University and written informed consent was obtained from all interviewees. Interviewees were informed that they had the right to end the interview at any time. Participants were not asked their names, addresses or any identifying information, to ensure privacy and confidentiality. Tapes recording of in-depth interviews were carried out only after the consent form was signed. All data sets, questionnaires, and tapes were kept in a secure office and were not freely accessible to anyone outside the research team. Tapes were destroyed when the study was completed. Interviewees only received a small compensation to cover their travel expenses.

Structure of the dissertation

This thesis is divided into 8 chapters. Chapter 1 presents the rationale of the study and study objectives, namely the development of a better understanding of the state of PMTCT services in an urban setting in Vietnam, and the assessment of the main obstacles faced by HIV positive women in accessing comprehensive PMTCT services. The chapter also describes the study framework, study sites, and study methods.

Chapter 2 provides important context for the following chapters. An overview is provided of the country situation, the socio-demographic characteristics influencing the HIV epidemic in Vietnam, the trajectory of the epidemic, and changes in the national response to the epidemic and PMTCT program over time.

Chapter 3 reveals how women’s risks of exposure to HIV and the needs for care amongst HIV-positive women may not receive sufficient attention as long as the perception persists that the epidemic is predominantly among young males. It appears
that the risk of HIV transmission among women in Vietnam has been underestimated; the reported data may represent as little as 16% of the real number. For both detection and prevention, these women can be divided into sub-groups with different risk characteristics. Based on this information, policy-makers and planners can develop better prevention and care programs that not only address women’s needs among each sub-group but also reduce further spread of the infection within the general population.

Chapter 4 investigates how easily pregnant women can find out about and use HIV counseling and testing, and whether their current choices for reproductive health care offer opportunities for better PMTCT delivery systems.

According to Vietnamese policy, HIV-infected women should at least have access to HIV testing and Nevirapine prophylaxis, and where available, to adequate counseling, HIV infection staging, ARV prophylaxis, and infant formula. In Chapter 5, the experiences of HIV-infected women in a well-resourced setting who needed to access these services is presented.

Although much progress has been made in increasing the coverage of HIV prevention in mother to child services, still very few women and their children receive postnatal care and treatment mainly because of stigma and discrimination. Chapter 6 details HIV-infected women’s experiences of stigma and discrimination in their family, community and health facilities, and their reactions. The chapter highlights the potential for involving self-help groups as motivated partners which can contribute to a reduction in stigma and discrimination in order to increase access to care.

Chapter 7 outlines the factors that contribute to health care workers’ failure to provide good quality PMTCT, according to their own perception of their work with HIV positive women.

Chapter 8 presents a discussion of the study findings, based on the “access flow” model, and recommendations.
Chapter 1

References


