Access to comprehensive prevention of mother-to-child transmission program: obstacles and implications
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Summary
The United Nations General Assembly Special Session on HIV/AIDS adopted the target of reduction of “the proportion of infants infected with HIV by 20% by 2005, and by 50% by 2010”. This could be achieved by reducing HIV among pregnant women but also by preventing transmission from mothers to children (PMTCT). The low HIV prevalence among pregnant women in Asian countries increases the feasibility and affordability of PMTCT. However, in 2006, only 2% of HIV-infected pregnant women in the region were receiving ARV prophylaxis.

In recent years, PMTCT has developed from a simple intervention at delivery to a comprehensive set of interventions throughout pregnancy and after delivery. Pregnant women should have access to HIV testing with pre- and post-test counseling to guide them to a PMTCT program if needed. When women learn their status early enough, they have the choice between abortion and other interventions that will help them to have a healthy child. HIV-infected pregnant women should have access at least to ARV prophylaxis, and where available, to the complete package of adequate counseling, HIV infection staging, ARV prophylaxis, and infant formula.

Many studies in high HIV prevalence settings have reported low coverage of PMTCT services, but there have been few reports from low HIV prevalence settings, as in Asian countries. This research was undertaken in Hanoi to develop better understanding of the state of PMTCT services in an urban setting and to explore the obstacles that HIV-infected women encounter in accessing these services. The results led us to provide recommendations and to advocate for the development of better policy documents as well as the improvement of the PMTCT program to address the challenges identified.

The HIV epidemic in Vietnam is still concentrated among high risk populations, including IDU and FSW. Government response has therefore focused on recognized high risk populations, mainly young male drug users. This focus may leave other populations under-protected or unprepared for the risks and consequences of HIV infection. In particular, attention to women’s risks of exposure and needs for care may not receive sufficient attention as long as the perception persists that the epidemic is predominantly among young males. Women in Vietnam are increasingly at risk of HIV transmission but that risk is under-reported and under-recognized; the reported number of infected women may represent as little as 16% of the real number. Although modeling predicted that there would be 98,500 HIV-infected women in 2005, only 15,633 could be found in reports from the health system. That could mean that when this research
began, as many as 83,000 women infected with HIV were not detected by the health care system.

A household survey conducted in Hanoi showed a high uptake of HIV testing (at least 85%) among pregnant women. However, in spite of the wide availability and high uptake of HIV testing in this urban capital setting, there appeared to be considerable underutilization of PMTCT services, which suggests that there are gaps in the system that should be providing those services. The narrow focus generally applied by PMTCT programs seems to be both ineffective and inefficient, from the medical, public health and sexual and reproductive health and rights perspectives.

Lack of PMTCT choices for pregnant women was found to be one of the key obstacles in their accessing PMTCT services. Moreover, many HIV-positive pregnant women were either not detected or not referred to appropriate care and support services. The main limitations of current PMTCT services were that HIV testing is not available at commune level and that it is offered too late in gestation to give the women a choice. In addition, the notification system of test results lacked confidentiality, so that a population with higher probability of HIV infection might have avoided the HIV test offered during pregnancy. In addition, both the quantity and quality of the pre- and post-test counseling were inadequate to ensure that women who were positive would access PMTCT.

The study also found that in this context, only approximately 44% of HIV-positive pregnant women had access to minimal services (HIV testing and ARV prophylaxis for mothers and children). Perhaps it is not surprising that only 20% of infected women received the comprehensive service (HIV testing with counseling, HIV infection staging for treatment, ARV prophylaxis for mothers and exposed children, and infant formula). Nine women did not receive any services at all, and 22 of them received no counseling at all. While struggling to find their way to appropriate care among the fragmented services, the women experienced a number of problems including a high degree of felt stigma, lack of knowledge and information due to poor counseling, and gaps in PMTCT services. HIV testing was done too late for optimal interventions and the women frequently mentioned the poor quality of care given them by health staff.

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 still limited in geographic reach, but follow-up care was lacking even in the capital city Hanoi, despite the availability of the medical
care there. Principal causes were the lack of quality counseling, lack of referral and the 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. Even when they knew something of available services, many HIV-infected women reported that their fear and experience of stigma strongly reduced their access to those services. No social mechanism exists to provide non-medical support for HIV-infected women. Additionally, the fragmentation of the health care system into specialized vertical ‘pillars’, including a vertical program for HIV/AIDS, is a major obstacle to providing a continuum of care.

From the health workers’ point of view, factors that lead to their failure to give good quality PMTCT included their own fear of HIV infection, lack of knowledge on HIV and lack of counseling skills. They also noted the lack of staff and consequent high workloads, the unavailability of HIV testing at commune level, inadequate stocks of ARV, and lack of operational guidelines. Health workers considered their negative attitude during counseling and provision of care, treating the women in a separate area, and avoidance of providing services to be the result of their own fear of becoming infected and to their distrust towards almost all HIV-positive patients, whom they associate with people exhibiting antisocial behavior.

The results suggest that there are several interventions that could improve the quality of PMTCT services. Firstly, provider-initiated and anonymous HIV testing should be offered to all pregnant women during the first trimester leading to two main choices for those who are found to be HIV-positive: either abortion, which is legal in Vietnam, or continued pregnancy and early prophylactic intervention. The quality of culturally appropriate counseling that takes into account women’s varying needs should be improved at all levels for both HIV-positive and -negative pregnant women, by greater investment in capacity building, increased support and motivation for health workers and the provision of PMTCT guidelines. Health facilities should not only make ARV available but also develop a client-friendly approach to the distribution of medication, together with adequate counseling on its use and adherence, to fulfill the basic requirements of good patient management. Prophylactic NVP should be provided in a small package for health facilities that serve a small number of HIV-exposed children per day.

Secondly, a practical strategy needs to be developed to strengthen and adapt the referral system to increase access to postnatal care by HIV-infected mothers and their children. Integrating a PMTCT program into the existing district-based adult HIV care and treatment services is likely to make it easier for HIV-infected women to have contact
and access to appropriate post-natal care and care for their children. 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 and sexually-transmitted infections. Exchange is especially needed among high level health staff able to make decisions, for them to update and exchange information on services available and to provide and receive feedback on the quality of the referral system.

Lastly, medical intervention alone is insufficient to assist women in the comprehensive way proposed by the WHO PMTCT approach, given the complex needs of HIV-infected pregnant women in a society in which HIV is highly stigmatized and considered a “social evil”. Self-help groups, with peer counselors working inside the health system to ensure good relations between clients and service providers, appeared to be a good model to empower women to obtain the health and other care they need. From the perspective of health care providers, donors and policy makers, it could be attractive to promote patients’ associations. If such groups result in increased self-reliance of individual patients, they could, for example, reduce some of the burden of the state.

It is perhaps encouraging that although the results of this research program revealed many weaknesses in the provision of PMTCT to HIV-positive women, the needed improvements could be made by application of a number of highly feasible interventions; what is needed is sufficient motivation within the system and sufficient demand by the women and their families.