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

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Citation for published version (APA):

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CHAPTER 4
Dealing with a positive result: Risks and responses in routine HIV testing among pregnant women in Vietnam
(Printed - AIDS Care- July 2008)

Summary

HIV testing is an essential component of PMTCT. It can be offered to pregnant women through different testing models, ranging from voluntary counseling and testing (VCT) to routine and mandatory testing. This study was conducted in Hanoi, Vietnam, where HIV prevalence is low among the general population, but high among young, urban, sexually active male intravenous drug users. Women who want to deliver in a state hospital are routinely tested for HIV, in the absence of well-defined opt-out procedures. In-depth interviews with a convenience sample of 38 seropositive pregnant women and mothers and 53 health workers explored the acceptability of routine testing. Patients and health care workers appeared to accept routine “blood” tests (including HIV tests), because they feel uncomfortable discussing issues specific to HIV-testing.

To avoid having to inform women directly about their HIV status, health workers at routine testing sites rely on the official notification system, shifting the responsibility from the hospitals to district and commune health staff. The notification system in Hanoi informs these local officials about the HIV status of people living in their catchment area without patients’ consent. Our study shows that this non-confidential process can have serious social, economic and health consequences for the HIV positive women and their children.

Introduction

Prevention of mother to child transmission (PMTCT) is a strategically important intervention to slow the spread of HIV/AIDS. In Vietnam the national prevalence of HIV/AIDS was an estimated 0.5% in 2005. The epidemic is concentrated among young male intravenous drug users (MOH, 2006b), 50% of them are between the ages of 20-29 (Nguyen Tran Hien, 2007).

This study was conducted in Hanoi, in the North of Vietnam, where rapid economic growth and rather easily available heroin are associated with increased intravenous drug use. HIV prevalence among male IDU is 20-70% (MOH, 2006c) National AIDS Stading Bureau and FHI, 2001; (Nguyen Tran Hien et al., 2001; Nguyen Tran Hien, Le Truong Giang, Phan Nguyen Binh, & Wolffers, 2000) The HIV rate among female commercial sex workers was 6.5% in 2005 (SRV, 2005; Tran Nam Trung, Detels, Hoang Thuy Long, & Hoang Phuong Lan, 2005) The prevalence rate among pregnant women increased from 0.02% in 1994 to 0.37% in 2005 (MOH, 2006c) and is up to 1.25% in Hanoi. A pregnant woman
found to be HIV positive in ANC will be stigmatized as a possible sex-worker or drug user (Khuat Thu Hong, Nguyen Thi Van Anh, & Ogden, 2004).

In Vietnam, pregnant women can be tested at ANC facilities or at voluntary counseling and testing (VCT) sites. By 2006, there were around 50 VCT sites in the country (MOH, 2006b). The new HIV/AIDS law (January 2007) legalizes a dual system of both voluntary and compulsory HIV testing (the latter in ‘certain’ still to be specified circumstances (SRV, 2006c) Government health facilities have had the responsibility to test for HIV among people who are at risk since 1995 (SRV, 1995c)

Current practice is that HIV tests are routinely offered to pregnant women in hospital before delivery and through ANC services in district health centers. HIV tests are one of a set of tests including blood count, hematocrit, blood type, blood sugar, hepatitis B, and syphilis, carried out when women are 7-8 months pregnant. HIV testing is not available at commune level, so women who use the commune health center for both ANC and delivery will not be tested. When a HIV test is positive, health workers at district or commune are asked to inform the HIV-positive women in their communities. Despite such routine testing in ANC and delivery services, few women seem to be detected by this system: in 2005, 659 pregnant women were reported to be HIV-positive in the whole country. The number expected from surveillance data was 7,000-8,000 (MOH, 2006b; SRV, 2005) The World Health Organization (WHO), the Joint United Nations Program on AIDS (UNAIDS) and the US Centers for Disease Control and Prevention promote routine testing for HIV, now accessibility to anti-retroviral medication is increasing. They recommend that such routine testing should be accompanied with clear opt-out procedure (CDC, 2006; WHO & UNAIDS, 2004) As HIV programs scale up, documentation is needed on how opt-out and VCT models work in practice. This qualitative study examines how patients and their families, and health providers, experienced VCT and routine HIV testing, disclosure and notification in the Hanoi health system, a low HIV prevalence setting with high ANC coverage, where both models are available but routine testing is promoted.

**Respondents and Methods**

We used semi-structured question lists to interview a convenience sample of 38 seropositive women in Hanoi, 36 of whom had recently delivered. Because HIV prevalence is low, and interviewing women just before or after receiving a positive result is practically and ethically difficult, the women were recruited from support groups and from national and provincial obstetric hospitals. Pregnant women identified as HIV positive at government facilities in Hanoi are increasingly referred to support groups, where they receive medical, social and economic support.

The first interviews took place at the support group office outside the hospital, after the women had signed consent forms. The bias in this sample is that all the women were active; they had come to a support group for care
after a positive diagnosis. HIV positive women who terminate their pregnancy may be more likely to keep their status secret, and less likely to join support groups: they are under-represented in our sample.

The topics covered in our interviews were ANC, VCT, routine opt-out and mandatory HIV tests, counseling, disclosure, social-economic support, care and health. Partners or a relative of 33 of the women were interviewed separately. The other women did not have partners or family members willing to be interviewed.

The women and their partners came from a variety of social and economic backgrounds. Most (32/38) were 20-30 years old; five women were 30-35 and one was over 40. Only two had a history of sex work and injecting drug use. In contrast, all of the partners had a history of intravenous drug use, visits to sex workers, or both. Six of the women were AIDS widows. Four women had been to university and all but two had completed a high school education.

We also conducted semi-structured interviews with 53 healthcare workers on the quality and quantity of PMTCT services in Hanoi. Workers at all national and provincial hospitals providing PMTCT or anti-retroviral therapy (ART) were selected; all provide VCT and routine HIV testing before deliveries. The sites included the National Obstetric Hospital, Hanoi Obstetric Hospital, Bachmai hospital, Dongda Hospital, and the National Pediatric Hospital. We visited their VCT facilities and ANC departments. We interviewed the department heads and at least one lower level staff with at least one year’s relevant experience. To interview health workers at lower levels, we selected the district with the highest HIV prevalence, Dongda, where we included all district health facilities that provide HIV testing, ANC or maternity services. The district has 21 communes; we selected four with the highest HIV prevalence. We interviewed all the department heads, who at this level also treat patients, if they had worked there >1 year.

Our respondents had learned about their HIV positive status in the following ways:
- Through the notification systems, after testing in ANC: 18 women
- At a VCT center attended after husband/child was found to be HIV+: 19 women
- Through mandatory testing at rehabilitation center 1 woman

The sample included only two women who had had an abortion after receiving a positive test result at a VCT center. All the other women were young mothers who had delivered within the last 30 months.

**Acceptability of offering routine and mandatory tests for pregnant women**

Eighteen women received results from routine testing at ANC facilities, which is usually done at 7-8 months of pregnancy. The pregnant women perceived the offering of both routine HIV tests during ANC as reasonable. Frequently heard arguments from women and their families were:
“Doctors need to know certain things in order to do their work.”

“HIV tests are just like other tests.”

“They need to know that to help me.”

“Doctors need to be able to protect themselves during their work.”

The interviewed women saw no differences in principle between an HIV test and other medical tests, like that for hepatitis B. All hospitals, except the National Obstetric Hospital conduct mandatory testing prior to delivery. Many women explicitly stated that mandatory testing was acceptable because of the association of HIV with socially stigmatizing behavior. They argued that women do not want to have to ask for an HIV test because that might suggest that they had socially unacceptable behavior. They said:

“HIV tests should just be more normal.”

“All women should be tested, not just a few based on their or their husbands’ appearance.” (as drug user, authors)

“I would be afraid to ask for an HIV test, because the doctors might think something.”

All 38 women stressed the importance of HIV testing during pregnancy for having healthy children, but the thought that the timing of the tests was too late in the pregnancy.

“I would not have had a child if I had known that I was positive.”

“I would not have taken that risk myself.”

A few of them commented that if the tests were voluntary, some patients might decline them to save money (a user-fee has to be paid for the tests).

**Acceptability of routine and mandatory tests to health staff**

The health workers interviewed were unanimously in favor of routine HIV testing. They stressed the importance of testing for PMTCT

“It is easier for us to prevent transmission if we know who among the patients is infected with HIV.”

“We need to know who is infected with HIV in order to help them get treatment.”
Only a few health care workers mentioned that patients needed counseling. In their view:

"Women should know what is included in an ANC check up, and how many tests they will have and why."

They did not see counseling as a way to enable women to decide for themselves whether or not they wanted a test. Health workers at district level and below liked routine testing at seven months’ gestation because testing at that time meant that they did not have to deliver HIV+ women at their clinic. Without prompting, staff noted greater worry about hepatitis B than HIV, because hepatitis B is more contagious, and because they cannot refer pregnant women with hepatitis B to higher-level hospitals to avoid the risk of infection. Health workers at all levels also pointed out the normalizing effect of routine testing (as a standard set of blood tests) in an environment where HIV is socially stigmatized.

“I am afraid to offer people HIV tests because they might get angry at me and think I am judging them.”

Some health workers mentioned that in “suspicious” cases they would not want to wait for the routine tests late in pregnancy, due to concern over their own and the woman’s health. Reasons for suspicion were: looking like a drug user, being accompanied by somebody who looked like a drug user, having certain jobs, such as “hotel work”, being married to “drivers”, simply “looking bad”, or medical symptoms such as opportunistic infections or very low weight.

Six health workers in one hospital and two in the ANC clinic, mentioned doing blood tests on patients without informing them:

“We only tell them we’re taking a blood test, because if we say ‘HIV test,’ they refuse to take the test…. Only in a few cases can we tell them directly that we are giving them an HIV test.”

All health staff argued in favor of offering HIV testing for free, so that cost would not be an obstacle. They mentioned technical and economic restrictions to offering HIV testing earlier in the pregnancy.

“The results could change during the pregnancy, which could be dangerous for the woman’s health at the time of delivery. If we do separate or repeat tests early and late in pregnancy it is also very expensive.”

Acceptability of VCT

The 19 women who went to VCT centers after their husband or child became
sick considered VCT a very important service for people who want to know their status.

Three of these women went for VCT early in pregnancy, two opted for abortion when the test was positive. Surprisingly, all 18 women who had initially found out they were HIV positive through routine testing subsequently also visited a free VCT site.

“I just could not believe that I was positive. I went three times. After I kept getting the same result I had to believe it.”

“I know that my child must have received the virus from me. But I went for testing to be sure and to learn more about the disease.”

All the health workers considered VCT primarily an intervention targeting drug users and sex workers. They stress that VCT cannot replace routine testing during ANC.

**Two parallel systems of counselling: counselling in the hospital and through notification**

Pregnant women tested at VCT centers and national sites also get their results there. Those who are tested during ANC at provincial level or lower are not only informed about their test results in the facilities; they also receive their test results in their communities through the ‘notification’ system. All commune and district government health facilities in Hanoi have to notify the provincial authorities of suspected HIV+ cases. After confirmation, the provincial authorities inform the local health workers at the district and commune levels, who then inform the patient and her/his family.

Most of the 18 women who had ANC at a lower level received their results from a health worker through the notification system in their community (see Table 1).

<table>
<thead>
<tr>
<th>Testing site</th>
<th>Nr. of women who received counseling at a health facility about their test results</th>
<th>Nr. of women informed about their HIV status in their homes through the notification system</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>VCT</td>
<td>19</td>
<td>0</td>
</tr>
<tr>
<td>ANC</td>
<td>13</td>
<td>5</td>
</tr>
</tbody>
</table>

*One interviewee was not included in this table because she was first tested and counselled in a rehabilitation camp.*
In all cases of routine testing, women reported that one or several visiting family members were informed, without the woman’s consent, during hospitalization for delivery. Five women were, in fact, not informed about their status at all. Three of them said that they understood the staff’s decision not to disclose the HIV+ result to them. They emphasized that both their families and the health staff probably “wanted to protect” them. Two of these non-informed women objected. One was told at the delivery table that she was positive:

“They gave my husband counseling but he did not tell me because he was afraid that I was too weak at that time. That’s why I breastfed my son until my husband told me the truth after two months.”

Her son died of AIDS.

Family members reported that they did not feel prepared to inform their daughters-in-law.

“I just could not bring myself to tell my sister in law that she was positive. Her husband had just died.”

Health care workers at routine testing sites did not have to use the community notification system to inform their clients of their status, but found it difficult to inform and counsel patients about a positive HIV test result. They gave various reasons for avoiding informing women directly about their status. Some mentioned “the weak health” of the women. Being “too busy” to inform all patients because “staff has to focus on the delivery” was mentioned several times by both patients and health staff as a reason for the staff not to inform the patient.

District and commune health workers stressed the public health benefits of the community notification system for both the community and the individual.

“How can you help people if you don’t know where they are or how many there are?”

Women complained about the information provided by commune health counselors who came to notify them at home. One woman was told not to eat at local food stalls and not to have her hair washed at a local salon. When she bought equipment to make fresh sugarcane juice, she was warned by health staff not to sell food or drinks. Another woman was told to use formula feeding, which she could not afford.

When health workers come to present test results in uniform, they are noticed in the community.

“Whenever they visited my home, they still wore their white coats; that is unusual so it attracted attention from neighbors which is not good. I prefer to visit the clinics myself and only when somebody is really sick.”
Several interviewees described negative effects on mental health from this public notification:

“I just lay in bed for three months after they came to the door.”
“My husband became depressed and escaped into drugs.”

After notification by a healthcare worker, many young mothers, especially if the first to be diagnosed in a household, find that they and their husbands and children are treated differently by people around them. Almost all families introduced some segregation for both husband and wife, at least temporarily, after notification. For example, they and their partners could no longer eat at the same table, or share dishes or share the toilet; a few were thrown out of the house. Several women described feeling insecure about their own or their children’s future in the household.

“My mother-in-law likes my sister-in-law’s baby more than my son. When the two children play together, she always wants to separate my son. She beats my son. She already told us that when we die our son has to go to an orphanage.”

Others described losing jobs after notification. A hairdresser who worked at the market was unemployed because:

“Somebody who works in the market saw the health workers at my in-laws house to counsel my in-laws while I was at the market. My husband died and my in-laws do not pay for my food but I cannot work in the market anymore because now everybody knows.”

Authorities are aware that many HIV+ people are poor and some started programs to help people listed as HIV+. However, women who needed these activities refused because they “cannot afford to be on the list” or were skeptical about the intentions of the social support programs.

Some of our respondents said they tried to avoid notification, by giving the wrong address at the ANC site. One couple, of which the woman had tested positive during ANC at the provincial level, moved house immediately after they found out from the support group members about the notification procedure and the associated lack of confidentiality.
Discussion

The women in this study comprise two groups – women who see themselves at risk and go for VCT where their test results are treated confidentially, and women who are not aware of their risk, are detected at ANC sites and are notified in their community. Our findings suggest that health care workers and patients agree on the medical importance of offering the tests as a standard procedure, also because it allows both to avoid requesting tests for a stigmatizing disease. However, the HIV positive women, who are informed about their test results through the notification system, report that they feel stigmatized because their privacy is not respected.

Worldwide, increased access anti-retroviral medications have led to policies that promote routine testing with opt-out procedures (Bayer & Fairchild, 2006; CDC, 2006; Jayaraman, Preiksaitis, & Larke, 2003; Simpson, Johnstone, Goldberg, Gormley, & Graham, 1999; Walmsley, 2003; Weiser, Heisler, Leiter, Percy-de Korte, & Tlou, 2006) Routinization and normalization of HIV testing is further enabled by the introduction of new rapid testing technologies (including oral tests). Health systems no longer need complex confirmation procedures that act as barriers to counseling, and lead to delays in notification and loss to follow-up (Bramson, 2003).

HIV prevalence is relatively low in Vietnam; the average woman has a low risk of receiving bad news, but our findings suggest that a positive HIV test can have very serious social and health consequences. The quality of post-test counseling in the hospitals and district levels of health care is not good enough, yet. Rapid tests are also not yet used in Vietnam, so women have to wait for confirmation of their test results.

When positive results are received from the confirmation centers, health workers are uncomfortable about informing women. This reflects their lack of communication skills and technical knowledge, but also the cultural values of saving face and showing care by protecting people from bad news.

Technical knowledge may be improved quickly by training and routine application of new rapid tests can facilitate the process, but the cultural norms of saving face and showing care by discretion are unlikely to change rapidly.

The fact that many women went for repeated tests makes clear that good quality counseling and better collaboration between testing sites are needed. Our findings suggest that providing a combined system of routine testing in ANC with appropriate post-test procedures including good counseling, along with good quality VCT for women already concerned about their status, would lead to a higher uptake of testing in Hanoi (and fewer repeats). It is essential that women who are at risk are more aware of the need to have HIV tests early in pregnancy, when abortion is still possible And it is essential that the system provides them with opportunities for testing in a non-threatening environment and with the counseling they need to make their own choices.