

Background

Ukraine, with an estimated adult HIV prevalence of 1.4%, remains the worst-affected country in Europe. The goal of this research was to analyze information about the needs of HIV-positive pregnant women and mothers in Ukraine.

Methods

The research was conducted using four focus-group discussions (FGDs) with a total of 27 HIV-positive mothers who delivered babies in the previous two years and were 18 years of age or older. PATH's local NGO partners sent out invitations to participate through their existing networks. The research was held in April 2005 on the premises of local NGOs in Sevastopol' and Mykolayiv. The FGDs were organized according to pretested guides. Data analysis was conducted using coded categories and data grouping.

Conclusions

- Stigma and discrimination are widespread, especially at maternity houses.
- Voluntary counseling and testing does not exist at antenatal clinics and maternity houses.
- Confidentiality is frequently violated.
- Peer support is highly valued.

Key recommendations

- Pre- and posttest counseling should be provided, regardless of the HIV test result.
- Stigmatizing attitudes and discriminatory behavior on the part of medical professionals towards HIV-positive women must be reduced to effectively remove obstacles in preventing further HIV transmission.
- Medical staff must respect the rights of patients to confidentiality and privacy.
- Standard precautions should be followed by all medical staff, regardless of a patient's HIV status, which may or may not be known.
- Special attention should be paid to improving interpersonal communication and counseling skills.
- Medical workers need information about existing referral resources.
- Peer counseling, to the extent possible, should be made available to HIV-positive women in maternity houses and antenatal clinics.
- Information dissemination and training need to reach beyond physicians and midwives to include nurses and orderlies as well.

Next steps

The data collected are being used to improve the quality of VCT, the uptake of PMTCT services, and the availability and quality of psychosocial support.

These data also are serving as a basis for IEC material development for pregnant women and HIV-positive mothers and their families.

VCT is an essential entry point to convey prevention information and assess personal risk behavior and, therefore, is critical to overall efforts to prevent further spread of HIV in Ukraine.

Results

Most FGD participants said that it is very difficult for an HIV-positive woman to get the medical care she needs (Box 1). Most participants complained that medical staff did not treat them and their children respectfully (Box 2), and they attributed this behavior to lack of knowledge among providers about HIV transmission (Box 3). All FGD participants believed that confidentiality is violated in medical facilities (Box 4). Almost all participants said that no one explained that they were to take an HIV test or what the test involved (Box 5). They also said that women do not know about their rights

to voluntary counseling and information before testing (Box 6), they do not know that they can refuse testing, and they are not familiar with the legislation of Ukraine regarding their rights.

Most participants felt that women who learn of their HIV-positive status (Box 7) should have immediate access to psychosocial support. This could be a doctor or other medical worker as long as they will listen, understand, and explain (Box 8). Most FGD participants believe that peer counseling is very important (Box 9).

1

Is it easy to get a medical care for an HIV-positive woman?


“They do not want to assist the delivery and try to shift us.”

“Having learnt my status, the midwife refused to examine me. She said that such women should be examined at the cemetery.”

2

Medical staff attitudes toward HIV-positive women

“I felt disregarded in the maternity house. You feel like a calf, a sheep, you are afraid to ask people. The doctor said: ‘You do not live yourselves and do not let other people live.’ She gave me an injection, which stopped the delivery, and left, and I was in labor the whole day long.”



What women have to know about VCT

3

Lack of knowledge among providers about HIV

“I was not allowed to keep my food in the fridge and leave the ward. I could not drink from the kettle, could not go out.”

“... They did not let me go out to the hall and make phone calls.”

“...HIV is not transmitted through a good attitude. That is why it would be so good if doctors could treat us well. It is not dangerous.”

4

Violations of confidentiality

“I gave birth in the maternity house where there were problems with confidentiality. The nurse took the medical list and shouted all over the hall, ‘HIV positive!’”

“...in the registry I was told in public: ‘Go and take infant formula. You are HIV positive after all.’ And at the same time, a whole group of people was standing nearby. I felt like turning and running out of there.”


“This [HIV status] is underlined by different colors in the medical records or the records themselves are crossed by black or red colors...”

5

Women’s experience with HIV testing

“The [blood] analysis was done while I was pregnant. No one told me anything before testing—I was just given the list of tests.”

“You are taking a blood test and do not know why you are doing it.”



Stigma and discrimination related to HIV

This is an example of an exercise used during the training that was based on the results of the FGDs. It conveys the roots of stigma and resulting discrimination.

6

VCT

“They did not suggest [an HIV test]...they made me take this test.”

“I did not know until recently that I have the right to refuse testing in the ANC.”

“Before testing, doctors have to prepare patients for any result, and at least a little bit for a positive one.... Pretest counseling is extremely important...”

7

Presentation of positive HIV test results

“I was informed about my positive test result on the phone.”

“There was no counseling, nobody asked for my consent for testing, and after receiving the results, nobody explained... They just ‘showered’ me with the results and gave up on me, leaving me alone.”

8

Needs of women immediately following an HIV-positive test result

“I don’t like the way doctors inform us about our HIV status. It is awful. They do not counsel and send you to an HIV Center if you have any questions.... That day, when I knew that I was HIV-positive and was referred to the AIDS Center, it was late and the doctor there had finished his consultations. He said, ‘Come tomorrow.’ It was pouring cats and dogs. The doctor did not provide any counseling. How to reach the morning with this information? I hardly waited for the next morning. What to do? How to live? All night long, I did not know what to do, how to live with that problem. I almost committed suicide.”

9

Needs in peer counseling

“It is very important to talk to someone who has gone through all this. Neither mom nor dad can substitute for such a person.”

“I wanted to talk to the same person as I was.”

“... I had a volley of questions when I learned that the counselor was HIV-positive himself. I wanted the counselor to get in touch with me, as I was shy to ask first.”