The Rights of Pregnant IDUs in Ukraine: HIV Testing and Antenatal Care

Since 1987, 182 000 cases of HIV have been officially registered in Ukraine.[1] However, this statistic does not reflect the real scale of the HIV/AIDS epidemic, as only those who receive a confirmatory test in order to begin treatment at a state AIDS Center are included in the official register of HIV infection. In addition to those who are tested, but do not register at an AIDS Center, many individuals are unaware of their HIV status. Estimates suggest that 360 000 people aged 15 years and older are living with HIV in Ukraine,[2] or 1 33% of the adult population. This prevalence rate is one of the highest in Europe.

Ukraine's HIV epidemic has historically been driven by injecting drug use (IDU), and while heterosexual transmission is increasing, 34% of HIV transmissions in 2010 were attributed to IDU.[3] Ukraine introduced legal substitution therapy (ST) for IDUs in 2004; however, despite women making up 26% of all IDUs,[4] as of March 2011, only 20% of substitution therapy clients were women, including 13 pregnant women.[5] Women make up an ever-increasing percentage of those who are HIV-positive in Ukraine—currently 44%—and this increase has been led by the recent increase in heterosexual HIV transmission (45% of all transmissions in 2010).[6] Of those HIV-positive women who are pregnant, 21% report current or past injection drug use.[7] The current, overall mother-to-child transmission rate in Ukraine is 6 2%,[8] but the rate is much higher (22 9%)[9] for those who do not receive ARV prophylaxis. These statistics indicate that care for pregnant women, particularly for those who are drug involved, is not accessible as required by Ukraine's policies on HIV testing and care.

To understand the degree to which national policies dictating the provision of HIV testing for pregnant women are upheld, HealthRight International conducted a case study in 2009 and 2010 of women's experiences with HIV testing during pregnancy in the Donetsk region, which has among the highest levels of HIV prevalence in Ukraine. The case study included (1) a qualitative research component of semi-structured interviews with 25 medical providers and 60 pregnant women who had been tested within the past 60 days; and (2) a narrative collection component of interviews with 30 HIV-positive women about their experiences in the year following HIV testing during pregnancy, including their subsequent medical care.

The study focused primarily on HIV counseling and testing of women during antenatal care, and secondarily on HIV testing and services for pregnant IDUs. The issues that were explored include pre-test

[1] Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011
[2] Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #34, 2010
[3] Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011
[4] Estimation of the number of groups of high risk of HIV infection in Ukraine: Analytical report, Berleva G., Dumchev K., Kobyshcha Y., other, 2010
[5] Ukrainian Institute on Public Health Policy http://www.uiphp.org.ua/ua/resource/zvedeni-danni
[6] Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011
[7] The European Collaborative Study (ECS) Progress in prevention of mother-to-child transmission of HIV infection in Ukraine: results from a birth cohort study. Claire Thorne et al., 2009
[8] Ministry of Health of Ukraine Newsletter "HIV-infection in Ukraine" #35, 2011
[9] The European Collaborative Study (ECS) Progress in prevention of mother-to-child transmission of HIV infection in Ukraine: results from a birth cohort study. Claire Thorne et al., 2009

counseling, identifying IDUs among pregnant women, discrimination of IDUs in the community and medical settings, and medical workers' knowledge and understanding of substitution therapy.

The study methodology was designed by researchers at the University of North Carolina at Chapel Hill and supported by the Open Society Foundations.

Key research findings include the following:

- Only 20% of women were asked about their risk behaviors during pre-test counseling.

Most women reported being asked, in the course of registering at women's clinic for antenatal care, if they used drugs, usually as part of a battery of questions about substance use. They were told of the risks posed by drug use and unprotected sex.

Women reported that they were not asked about drug use during pre-test counseling. One woman said that a medical worker would not press the issue of drug use in conversation, since an indication of injecting drug use would be visually apparent:

"They won't aggressively broach this subject [of drug use], since after all not every person says that he's an addict. But when they do an examination, they'll look over [her] veins and see."

- Few women reported receiving thorough post-test counseling. Only 5% of all women who tested for HIV were asked about risk behaviors during post-test counseling.

Some women expressed the opinion that a medical provider would be able to spot a drug-using person without asking about her behaviors:

"*They only asked if I use or no. I said no. Isn't it obvious when a person uses drugs?"*

- Sentiment was divided on whether a woman known to be IDU had the right to choose whether to take an HIV test.

Two HIV-negative women felt very differently about the issue of choice:

"If the doctor doesn't know [her HIV status], then of course, the doctor will propose that she get tested, but with her agreement, if she wants to – that's her right."

"Of course [she should be tested] right away. You need to even drag her!"

- Most medical providers reported that they had never encountered a pregnant IDU at their clinic.

Women and medical providers were asked whether they thought a pregnant woman IDU would feel comfortable asking for medical help in order to cope with drug addiction:

"*I think, no. I never came across this, though. I suppose, it would be uncomfortable, of course."*

"You know, I think our ladies know that on the stage of maternity counseling we can provide them with no support at all, unfortunately. There are substance abuse professionals who work with HIV-positive ladies, also there are psychologists in specialized anonymous counseling offices, there are centers which work with these ladies. We tell them that there they can find more support, and they can be helped better. We, unfortunately, will not be able to do anything here."

- Women and providers expressed varying attitudes about injecting drugs users, including some strongly negative perceptions on the part of both women and providers.

When women were asked how they thought medical personnel would respond to a patient if they knew she was using drugs, there was a range of responses. Some HIV-negative women said that medical workers would treat drug-using women like other patients, only perhaps taking additional precautionary measures. One woman witnessed medical workers treat someone (who she assumed was a drug user) without discrimination. Other women expressed the belief that even if a provider personally harbored negative feelings toward drug-using women, that he or she would continue to treat them.

At the other end of the spectrum, some women, regardless of their HIV status, believed that medical workers would respond negatively to a drug-using patient, with at least one woman speculating, based on her own feelings about drug users, that a drug user might be refused treatment:

"I think it would be negative. I have the most negative [feelings], but that's just my personal opinion... Even though they try to talk to them and help them, there's a saying that 'the grave cures a humpback.'"

Some HIV-positive women expressed strongly negative feelings regarding drug users:

"If you use drugs, why are you giving birth – better to go have an abortion."

"You see, they [medical providers] worry about the baby, so that he's healthy. If she decides to ruin her life, children aren't to blame."

- Very few providers demonstrated an understanding of drug treatment options, what substitution therapy is or of the facts regarding its safety of use during pregnancy.

Medical providers were asked about substitution therapy, such as methadone and buprenorphine. Misunderstandings about ST and opposition to its use were more prevalent among providers working in a semi-urban clinic. Some providers had never heard of it at all, and others had never heard of it being used during pregnancy. One provider was unclear that ST is a legal treatment for drug dependency in Ukraine, and not an illicit substance. One provider had heard of ST, but did not realize that her understanding of its purpose was incorrect.

When providers were asked if they would support the use of ST in a drug-using patient's pregnancy, opinion was divided. Some providers said they would support it, while others were opposed:

"Substituting one drug for another is no way out of the situation."

"The child of an addict is born with withdrawal syndrome in any case. I consider it a crime to give birth in such a situation."

- Only 53% of the women who received HIV-positive results within 60 days of being interviewed were given information about their local AIDS Center or organizations serving people living with HIV/AIDS.

According to policy, medical providers should refer individuals with HIV-positive test results to the Regional AIDS Center for further medical and psychological services. Only two of the medical providers interviewed reported providing patients with information about other service agencies. Several of the HIV-positive women reported that they received information during post-test counseling about local organizations and social benefits available for HIV-positive mothers. In general, almost no women recalled being told about where they could get social or peer support in coping with their diagnosis and the implications of life with HIV.

Based on the results of this research, the following conclusions can be made:

- Medical workers in women's clinics are poorly informed about drug use as a disease, treatment methods, substitution therapy, substitution therapy in the context of pregnancy, and services available to drug-using women.

- Stigma and discrimination is rampant within the health service system.

Recommendations:

- Providers must receive further, specialized training. This, together with further availability of harm reduction (including substitution therapy) and counseling targeted to women IDUs, could improve service uptake and prevent mother-to-child transmission of HIV.
- There is a need to establish a Ministry of Health order on substitution therapy procedures for pregnant women suffering from drug dependence.
- A wide-spread campaign to end stigma against drug-using women must be endorsed by civil society and state actors in order to reduce discrimination and improve access to high quality care and support.

The full case study report is available on www.healthright.org.ua