Social Vulnerability, Health Behaviors, and Political Responsibility: HIV testing and treatment for female sex workers in St. Petersburg, Russia

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By

“The number of HIV-infected Russians will grow in the next few years, but helping them will become a lot more difficult…” was the introductory line in a front page article in *Moskovskie Novosti* on December 1, 2011 (World AIDS Day). According to the article, as of 2012, the Russian government will be the sole financier of HIV-prevention programs, which have in the past been financed by international donors, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria. The Global Fund had invested nearly 400 million dollars into establishing HIV prevention programs for vulnerable populations, such as drug users, sex workers, and men who have sex with men (Global Fund, 2012). Given that Russia is now a higher middle-income country according to the World Bank classification, it is no longer eligible for funding from the Global Fund. The nongovernmental organization (NGO) representatives and the director of the Federal Center for the Prevention and Control of AIDS, who were interviewed for the article, expressed concern that the government’s efforts will not be used to help those most vulnerable to HIV-infection, especially given the government’s tendency to “promote traditional family values and sexual abstinence” (Kozlov, 2011).

The human immunodefiency virus (HIV) epidemic in Russia is one of the fastest growing in the world. St. Petersburg, the second largest city in Russia, has consistently experienced one of the largest HIV prevalence rates within the country; and in 2010 there were 46,402 registered cases of HIV in the city, with an additional 18,375 cases in Leningradskaya oblast’, the territory around the city (Federal AIDS Center, 2011). The populations that are most vulnerable to HIV-infection in Russia include groups that are often socially marginalized. Approximately 80% of HIV cases in the country are among people who inject drugs (UNAIDS, 2005; Volkova et al., 2006); and it is estimated that nearly a third of injection drug users in St. Petersburg have HIV (Sokolovskii et al., 2005). Approximately one-third of women who inject drugs in St. Petersburg are involved in sex work (Kozlov, 2006), making this population extremely susceptible to HIV infection. The most recent estimate of HIV-infection among street-based female sex workers was found to be 48% in St.

Petersburg (Humanitarian Action, 2006). In fact, women who are involved in both injection drug use and sex work are believed to be the most vulnerable to HIV in Eastern Europe (WHO, 2005).

Despite the efforts of NGOs in Russia, there are arguably inadequate programs and policies in place to address the HIV epidemic. Harm reduction is the public health term for strategies that strive to reduce the negative consequences of drug use (for example through the provision of clean needles and syringes, overdose kits, and condoms). HIV risk can potentially be reduced by providing safer spaces and facilitating safer practices. The more than two million injection drug users in Russia are served by only 70 needle exchange programs (Harm Reduction International, 2010). There are limited options available for drug rehabilitation and treatment services. Methadone, an opiate substitution treatment used in many other countries, is illegal in Russia. Coverage of treatment for people living with HIV/AIDS is also inadequate. The St. Petersburg City AIDS Center offers counseling and testing services and serves as a gateway for access to treatment and care, yet a significant number of people living with HIV/AIDS are not utilizing the services (Volkova, 2006; Yakovleva, 2008). The barriers and facilitators to accessing these services have not yet been thoroughly explored. Female sex workers in St. Petersburg are at a particular disadvantage for access to services given the lack of opportunities for addressing their drug use, the nature and illegal status of their work, the dual vulnerability for HIV-infection associated with drug use and sexual behaviors, and their social vulnerability.

Women, in general, are vulnerable to experiences of abuse, incompetence, and conflict with providers in their encounters with health care services (Rivkin-Fish, 2005). In the Russian social context women's sexuality is highly stigmatized and women are often blamed for their illnesses because of what doctors' label "promiscuous behavior" (Rivkin-Fish, 2005). Stigma can be defined as the "process by which the reaction of others spoils normal identity" (Goffman, 1963); and the process of labeling, stereotyping, separating, experience of loss of status, and exercise of power (Link and Phelan, 2006). What does this stigmatization and blaming mean for women who inject drugs or are involved in sex work? How would their status as women, drug users, sex workers, and for some an HIV-positive serostatus intensify their marginalization within the health care system or influence their likelihood of utilizing health care services?

In my research on HIV, I consider both the behavioral and social aspects of the illness. I examine individual-level factors (such as perception of risk, not knowing where one can get tested for HIV, perceived importance of not sharing injection drug equipment, or missing information or

misperceptions about HIV treatment options) that may influence the likelihood that an individual will utilize HIV testing and treatment services. On another level, I investigate the structural-level or social factors (such as poverty, discrimination, or gender roles) that can potentially influence an individual's access to such services. It was this intersection of the individual and social influences on health and how they interact together that led to my research questions about female sex workers' access to HIV testing and treatment services. Over the course of working on various HIV research projects in Russia, I inquired among my colleagues about female injection drug users and was told that it is difficult to recruit them for clinic-based studies because these women are often involved in sex work and it is hard for them to come in to participate in a research project. I would later learn from outreach workers that a separate mobile van was created to serve female sex workers specifically because they were not able to access the larger harm reduction mobile van due to the timing, locations, and nature of their work. During my first night accommodating some of the outreach workers on a mobile van out to "the field", ideas of vulnerability, stigmatization, and social marginalization emerged in my understanding of HIV prevention among this population, along with a strong desire to hear these women's stories and hopefully, begin to understand how public health (including, HIV testing and treatment) programs could be developed or adapted to address the needs of women involved in street-based sex work.

I spent ten months in 2008-2009 in St. Petersburg, conducting research specifically with female sex workers to learn about the barriers and facilitators that influence their access to and utilization of HIV services. During this time, I witnessed the important impact that NGO services have on the lives of otherwise marginalized populations. As one NGO service provider told me during a preliminary site visit: "We are providing a service that the state should be and is not." My fieldwork consisted of spending time on an outreach van that provides HIV prevention services (among other medical and psycho-social support services) such as distribution of condoms and clean syringes. I also made site visits to a state-run infectious disease hospital, the City AIDS Center, a support program for new mothers who are HIV-positive and their infants, and health education sessions in apartment-based brothels. I spoke with researchers, heath care providers, psychologists, and NGO representatives about their perceptions on the factors that influence female sex workers' participation in HIV prevention, testing, and treatment services. I conducted semi-structured, in-depth interviews with female sex workers, who accessed the services of an outreach van and/or a program for pregnant women who have HIV. Subsequently, I led a quantitative survey of female sex workers in order to assess the extent to which certain individual and social factors correlate with the utilization of HIV testing and treatment services. The results of my research project are discussed in detail in my

dissertation (King, 2010), and in forthcoming articles. In this piece, I limit my description to a summary of my key findings in their relation to understanding issues of access to HIV testing and treatment services for female sex workers. My research illuminated the ways in which female sex workers' access to HIV services is influenced by individual-level behaviors and by their social vulnerability.

All of the women who participated in my study resided in St. Petersburg, and nearly all of them were born in St. Petersburg or Leningradskaya oblast'. Many of the women I interviewed talked about being mothers, wives, girlfriends, daughters, sisters, and friends. However, a few women did mention that they were completely on their own, without family. Nearly all of the women I spoke with were currently using injection drugs (namely, heroin). All of the women I interviewed had been tested for HIV, at least once. It is important to note that many were tested in routine settings (places where testing is offered automatically, and in some cases may be perceived as mandatory) such as jails, hospitals, drug rehabilitation services, or part of hospital protocol. More than a third of the women I interviewed disclosed an HIV-positive status. None of the women I spoke with during the in-depth interviews were currently on antiretroviral therapy. The only mention of accessing HIV treatment was during pregnancy, when women participated in prevention of mother-to-child transmission (PMTCT) programs.

The major barriers to getting an HIV test centered around fear of learning the results, worrying that other people would think they were sick, and the distance need to travel to obtain services. Women who knew someone who had HIV were more likely to have had a recent HIV test. When asked about reasons to get (or not get) tested for HIV, the perceived barriers and facilitators were embedded within the social context. For example, a sex worker may perceive the distance needed to travel to get an HIV test to be a barrier. This finding has more meaning when taking into consideration that the woman may not live in the region of the city in which she is officially registered (and thus has no access to state-run health care services in the area where she physically lives). Past experience of being treated poorly by a health care provider, and perceived stigma from the health care providers were additional reasons why women said that they did not utilize HIV testing and treatment services (and general health care services as well). Though it is important to note that the additional perceived stigma of testing positive for HIV, being viewed as someone who is sick with HIV, or fear of disclosure of HIV status to others are additional layers of perceived stigma that are specific to the utilization of HIV testing and treatment services. These feelings of stigma and discrimination in the health care setting exist within larger perceptions of stigma and experienced discrimination from neighbors, clients, and society (poignantly illustrated by the high prevalence of physical violence against

female sex workers). Arguably, targeting individual behaviors to increase the utilization of HIV services will be much more effective when the social, cultural, political, and economic context is given adequate attention.

The research project I describe in this article was informed by the theoretical frameworks of the Health Belief Model and structural violence. The Health Belief Model is what in public health we refer to as value expectancy theory in that a person must place some value on avoiding illness and have the expectancy that a specific behavior can prevent or reduce the illness (Janz et al., 2002). The constructs of the theoretical model include: perceived susceptibility to the illness (such as HIV), perceived severity of the illness, perceived barriers to adopting a behavior (such as getting tested), perceived benefits of adopting a behavior, and cues to action in the environment that may encourage the person to adopt a behavior. The concept of structural violence allows us to look beyond individual behavior to consider the broader contexts and the "the social structures- economic, political, legal, religious and cultural- that stop individuals, groups, and societies from reaching their full potential," (Farmer 1996, 2005). In combining the theoretical frameworks at the individual-level and social-level, we obtain a more complex and comprehensive basis for understanding how and why female sex workers in Russia may or may not utilize HIV testing and treatment services.

It is likely Russia is entering a new era with its HIV epidemic given the shift in funding sources. It is evident through discussions with my colleagues working in the NGO-sphere that programs are already suffering financially, and they worry about their ability to continue to provide services, which people have come to rely on (such as outreach services that provide clean needles and condoms to female sex workers). As the author of the article in *Moskovskie Novosti* predicts, there will be less resources available for HIV prevention among vulnerable groups (namely injection drug users, sex workers, men who have sex with men) and more emphasis on general population health promotion. Specifically, what will happen now that the Russian government is the main source of funding for HIV programs and services? What will be the role of the NGOs that have provided outreach services to vulnerable populations? What services will remain, what new ones could be made available, what services will be cut? Who will have access to these services? Particularly, what will the effect be on female sex workers' possibilities for HIV prevention, and accessibility to testing and treatment services?

With an adult HIV prevalence of over 1%, the epidemiological indicators demonstrate that the epidemic is continuing to spread in Russia (UNAIDS/WHO, 2010; Niccolai et al, 2009). Female sex workers continue to be a particularly vulnerable population. Unsafe injection drug use continues to play a critical role in the spread of the virus in Russia;

however, sexual transmission is increasingly becoming a major factor in the expanding epidemic (UNAIDS, 2010). While there is still no cure or vaccine for HIV, there have been more and more medical advances in the care and treatment of the disease, in addition to the countless public health interventions with demonstrated effectiveness. As Russia defines its national approach to addressing HIV/AIDS, the social context will in no doubt remain important for behavioral scientists' understanding of the behavioral risks, HIV testing behaviors, and the utilization of HIV treatment services.

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