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"It is Easier for Me to Shoot Up": Stigma, Abandonment, and Why HIV-positive Drug Users in Russia Fail to Link to HIV Care

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Abstract

Many HIV-positive people who inject drugs (PWID) globally are not receiving HIV care. This represents a major challenge among key populations to end the global HIV epidemic. This

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qualitative study explored the process and associated barriers of linking HIV-positive PWID who are in addiction treatment to HIV care in St. Petersburg, Russia. We conducted three focus groups and seven semi-structured interviews with participants in the LINC ("Linking Infectious and Narcology Care") project at addiction and HIV hospitals in St. Petersburg. The sample consisted of 25 HIV-infected patients with opioid dependence and seven health care providers, including addiction and infectious disease physicians and case managers.

A variety of intertwining factors influence effective engagement of PWID with HIV treatment. Stigma, problematic patient-provider relationships, and fragmented health care were the main challenges for HIV care initiation by PWID, which were further exacerbated by injection drug use. Effective linkage of PWID to HIV care requires acknowledging and addressing stigma's role and different perspectives of patients and providers.

Keywords

HIV care; linkage to care; addiction treatment; barriers; Russia

Introduction

Among those living with HIV, people who inject drugs (PWID) are more likely to avoid or delay HIV care until disease progression (Giordano et al., 2005; Samet et al., 1998; Tobias et al., 2007; Torian, Wiewel, Liu, Sackoff, & Frieden, 2008), particularly in Russia (Bobrova, Sarang, Stuikyte, & Lezhentsev, 2007; Tkatchenko-Schmidt et al., 2010), where injection drug use accounts for most new HIV cases (Federal AIDS Center, 2014). Research indicates that facilitators of HIV care include case management, psychological and social support, opioid agonist therapy, integrated addiction and HIV treatment, acceptance of HIV status, and addressing HIV and drug stigma (Kamarulzaman & Altice, 2015; J. D. Kelly, Hartman, Graham, Kallen, & Giordano, 2014; Samet et al., 1995; Shaboltas et al., 2013). However, this prior work is largely quantitative and not specific to PWID, providing limited insight into how these factors affect care utilization among PWID. This qualitative study with patients and providers used rapid assessment principles (Beebe, 2001) to assess factors influencing HIV care among PWID in St. Petersburg, Russia.

Methods

Design

From November 2011 through January 2012, we conducted three focus groups (FGs) with HIV-positive PWID and seven semi-structured interviews with health care providers, all recruited from narcology and infectious disease hospitals in St. Petersburg, Russia.

Study Setting

St. Petersburg bears a disproportionate burden of HIV in Russia (Heimer & White, 2010). Diagnosed persons must register at the City AIDS Center to receive free HIV treatment either from the AIDS Center, Botkin Infectious Disease Hospital, or district infectious

disease clinics. HIV testing is routinely performed at the City Addiction Hospital (CAH) providing drug and alcohol addiction ("narcology") treatment.

Study Participants

FG participants were HIV-infected PWID, 18 years or older, who had received addiction treatment. They were recruited through provider referrals from CAH (two FGs, n=16) and Botkin Hospital (one FG, n=9). Patients provided written informed consent and received 1000 Rubles (US$35) as compensation.

We conducted individual semi-structured interviews with purposively selected health providers of HIV-positive patients with opioid dependence: four physicians (three infectious disease physicians and one addiction specialist) and three case managers employed as hospital staff. All provided written informed consent and received 2000 Rubles as compensation.

The study was approved by the IRBs of First St. Petersburg Pavlov State Medical University and Boston University Medical Campus.

Data Collection

All FGs and provider interviews were conducted at participating facilities using guides developed by our research team based on current literature. We collected basic demographics: age, gender, years injecting drugs, years since HIV diagnosis. FG questions explored attitudes and barriers encountered by individuals needing HIV care, and how a case management intervention should be designed for HIV-positive PWID in Russia.

Individual interviews with providers explored their perceptions of case management to link addiction patients with HIV services, as well as perceptions of organizational context and barriers to implementation of such an intervention.

FGs and interviews were conducted in Russian, audio-recorded, transcribed verbatim, and translated into English for analysis.

Data Analysis

Researchers (TK, AG, and KL) reviewed interview transcripts, developed a coding frame, and coded and analyzed the data to identify emerging themes (Braun & Clarke, 2006). We revised codes in subsequent analytic cycles and organized them into broader themes (Jain & Ogden, 1999).

Results

Of the 25 FG participants (8–9 participants each), 40% were female, mean age 32 years, mean period of IDU 11.1 years, and mean time since HIV diagnosis 5.3 years. Four participants currently received HIV care and ART.

Of the three case managers (all male) and four physicians (three male), professional experience ranged from five to 21 years.

Themes describing barriers to linkage to care for Russian PWID were: (1) stigma and poor patient-provider relationships and (2) fragmentation of health care.

Stigma and Poor Patient-Provider Relationships

From patients' perspectives, poor communication with patients and stigmatization from providers emerged as the most prominent issues. Most reported alienating experiences with non-supportive and unsympathetic providers. Participants described dehumanizing treatment at facilities, where staff labeled them as: "not like human beings," "unlike people," "like criminals."

> *You are nervous but ready to open up, to talk about your problem… and they look at you like at a wall*. – Female, FG1

Although there are exceptions ("*My doctor explained everything to me…, I felt I could trust her*" – Female, FG3), most FG participants reported feeling rejected or neglected, including in HIV clinics or other care settings. PWID attributed poor treatment to health providers' negative attitudes towards drug users.

> *The doctors just have this attitude: if you are a drug user, you are not a human being. You do not deserve being medically treated*. –Male, FG3

Such stigma and exclusion related to their drug use and HIV infection lowered respondents' self-confidence and their care-seeking behavior.

Fragmented Health Care

Across all FGs, patients mentioned fragmentation of the Russian health system, emphasizing the complexity of navigating between narcology and HIV care. Both patients and providers acknowledged that lack of service integration or direct connections between addiction and HIV care hindered PWID access to HIV care; addiction patients received formal referrals to the AIDS Center, but often did not act upon them.

> *Both types of care, for HIV and addiction, are needed and should be provided simultaneously. Not getting rid of your addiction, you will not be able to treat HIV. One issue cannot be solved without addressing the other one*. – Female, FG3

FG participants described the complicated steps necessary to get into HIV care. Inconvenient location, cost- and time-consuming transportation, long waiting times, and complicated, stigmatizing registration procedures compromised access to HIV services for PWID.

> *I cannot go to the [HIV] clinic, because so many tests and certificates are required, that this is just impossible… It is easier for me to shoot up.* – Male, FG2

> *To start ART, they [patients] have to wait in line, visit so many doctors, obtain a review from a medical commission… That requires real motivation.* – HIV physician

Respondents emphasized the importance of improving HIV care accessibility, bringing services closer to clients. Some suggested that linkage-supporting services could help with initial linkage to care.

It would be good to receive HIV care closer to one's place – so that we did not have to commute to the AIDS Center. – Male, FG1

A social worker or case manager could act as an elder companion, could motivate, could say – "What are you waiting for?" Where to go, how to go, what bus to take… They could even go with you on the bus. – Male, FG3

While both narcologists and HIV physicians stressed the importance of active delivery of HIV services for PWID, each expected the other to facilitate linking patients to HIV care.

The AIDS Center staff should be proactive; they should motivate patients, bringing them into HIV care more actively. – Addiction physician

Case management should be initiated from the addiction care side, as drug use is the main barrier to engagement in HIV treatment. – HIV physician

Discussion

This study explored patient and provider perceptions about HIV care engagement in St. Petersburg, Russia and found both HIV and drug use stigma—and related discrimination from providers—as barriers to HIV care, findings seen in prior research (J. Kelly et al., 2014; Magnus et al., 2013; Mahajan et al., 2008; Mimiaga et al., 2010). The intersectionality of these stigmas is consistent with developing work on this topic (Burke et al., 2015). This study supports previous findings that health providers often perceive patients with substance use disorders as "problematic" (van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). Such stereotyping results in mutual lack of trust between PWID and providers, compromising care engagement (Kamarulzaman & Altice, 2015; Ware, Wyatt, & Tugenberg, 2005; Westergaard, Ambrose, Mehta, & Kirk, 2012). Providers need to realize their own potential to stigmatize the patients they serve and empower themselves and their patients to engage in effective communication.

The Russian narcology system provides universal HIV testing but no direct linkage services. Siloed HIV and addiction care systems in the country further hinder connection to HIV care, with patients describing this fragmentation as prohibitive and demoralizing. Case management and patient navigation can connect separated health care systems (Mugavero, Norton, & Saag, 2011; Pecoraro et al., 2015) and facilitate engagement with HIV care (Bradford, Coleman, & Cunningham, 2007; Gardner et al., 2005). Such an approach was shown promising in pilot research from Russia (Shaboltas et al., 2013).

Study limitations include the use of few and narrowly targeted FGs and interviews with HIV-positive PWID and providers from clinical settings, potentially precluding saturation and limiting generalizability. Findings are consistent, however, with themes found in other recent work (Kuznetsova et al., 2016). Additionally, use of rapid assessment is more often deductive and explanatory than the inductive exploratory approaches of "traditional" qualitative research.

Findings of this study suggest that patient-focused, empowering interventions addressing stigma and facilitating narcology and HIV care connection may support HIV care utilization

among PWID in Russia and other countries with similar HIV epidemics. HIV care delivery models that offer case management could facilitate patient-provider communication and help create connections across Russia's fragmented health care system.

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