Attitudes towards people living with HIV and people who inject drugs: A mixed method study of stigmas within harm reduction programs in Kazakhstan

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ABSTRACT

Background: High levels of stigma towards people who inject drugs (PWID) and people living with HIV (PLWH) exist in Kazakhstan, yet little is known about the role of stigma in harm reduction service settings. In this paper, we use a mixed method design to explore and describe the actionable drivers and facilitators of stigma among harm reduction service providers. Additionally, we describe the manifestations of stigma among PWID who are living with HIV (PWID/LWH), and the impact that stigma has on harm reduction and healthcare service utilization.

Methods: Eight focus groups with 57 PWID/LWH were convened between March 2016 and July 2016 to describe manifestations of stigma from the perspective of syringe exchange program (SEP) clients. Additionally, we surveyed 80 nurses, social workers, outreach workers, and providers of HIV care at SEPs between January 2017 and July 2017 to assess stigmatizing attitudes among staff within the SEP environment. Joint displays were used to integrate quantitative and qualitative data.

Results: The actionable drivers of stigma identified in this study include negative opinions and moral judgements towards PWID/LWH. Facilitators included included stigmatization as a social norm within the service provision environment, a lack of awareness of anti-discrimination policies, and lack of enforcement of anti-discrimination policies. Qualitative findings highlight manifestations of stigma in which PWID/LWH experienced denial of services, perceived negative attitudes, and avoidance from service provision staff. PWID/LWH also described segregation in healthcare settings, the use of unnecessary precautions by providers, and unauthorized disclosure of HIV status.

Conclusions: This paper highlights the urgent need to address stigma in the harm reduction and HIV service settings in Kazakhstan. These findings have implications for informing an actionable model for stigma reduction for providers who deliver services to PWID/LWH in Kazakhstan. Drivers, facilitators, and manifestations of stigma are multifaceted and addressing them will require a multilevel approach.

Introduction

Kazakhstan is experiencing one of the fastest growing HIV epidemics in the world. Though the epidemic is increasingly being driven by sexual transmission, the prevalence of HIV remains highest among people who inject drugs (PWID) at 8.5%, compared to 0.2% in the general population (UNAIDS, 2016). There are approximately 127,800 PWID in Kazakhstan, and injection drug use is responsible for over 50% of all HIV cases (Degenhardt et al., 2017; UNAIDS, 2016). The United Nations has set ambitious targets, referred to as 90-90-90, to “end AIDS” by 2020. That is, 90% of all people living with HIV (PLWH) will know their HIV status, 90% of PLWH will receive antiretroviral therapy (ART), and 90% of PLWH on ART will reach viral suppression (UNAIDS, 2014). It is estimated that approximately 81% of PWID living with HIV (PWID/LWH) in Kazakhstan are aware of their status, 39% are on ART, and only 21% are virally suppressed (Republican AIDS Center of Kazakhstan et al., 2017). Criminalization of drug use, policing, and stigma contribute to the underutilization of syringe exchange programs.
(SEPs), which are critical to halting the onward transmission of HIV among PWID (Aspinall et al., 2013). A recent study of access to care among PWID in Kazakhstan reported that only 11.1% of injection drug users have ever utilized services at a SEP (Shaw et al., 2017). Due to the rising rates of HIV infection among PWID and low rates of viral suppression and SEP utilization, there is an urgent need to engage PWID in harm reduction services and HIV care; yet little is known about barriers, such as stigma, to these services in Kazakhstan.

Globally, PWID/LWH experience multiple stigmas, (Burke et al., 2015; Calabrese et al., 2016; Earnshaw, Smith, Cunningham, & Copenhaver, 2015) and studies have shown stigma to be both a driver of HIV infection and a barrier to HIV healthcare utilization (Katz et al., 2013; Lan, Lin, Thanh, & Li, 2018; Rueda et al., 2016). Stigma is defined as the social devaluation and discrediting that is associated with certain characteristics, behaviors, illnesses, and social statuses (Goffman, 1963). Stigma is typically characterized as being: enacted through experienced interpersonal acts of discrimination; perceived through perceptions of stigma and expectations during intrapersonal interactions; internalized when beliefs associated with PWID/LWH are personally endorsed; or anticipated based on stories or witnessed accounts of how other PWID/LWH have been treated in the past (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Turan et al., 2017). Stigma attached to HIV/AIDS is layered upon pre-existing stigma associated with drug use, making the pathways of stigma mutually reinforcing and difficult to disentangle in healthcare settings (Chan, Yang, Zhang, & Reidpath, 2007; Chan, Stoove, Sirgernyuang, & Reidpath, 2008; Reidpath & Chan, 2005).

Key populations such as PWID often face multiple stigmas associated with HIV, including stigma associated with illicit drug use, incarceration, commercial sex work, and minority sexual/gender status (Chan et al., 2007; Levi-Minzni & Surratt, 2014). PWID/LWH may also face stigma in harm reduction and medical care environments (Schuster et al., 2005). In these environments, HIV-related stigma manifests through a wide range of discriminatory and stigmatizing practices. These practices include patient neglect and isolation, differential treatment, denial of care and testing, the provision of substandard services, disclosure of a patient’s seropositive status without his or her consent, verbal harassment, and gossip (Andrewin & Chien, 2008; Feyissa, Abebe, Girma, & Woldie, 2012; Mahendra et al., 2007; Reis et al., 2005; Tanzania Stigma–Indicators working group, 2005). Perceived stigma within the healthcare environment has shown to predict lower utilization of healthcare and drug treatment services (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009).

Despite the HIV epidemic being fueled in Kazakhstan by injection drug use, few studies have examined stigma related to HIV and/or PWID, and none have focused on stigma among PWID/LWH in the Central Asian context. Smolak and El-Bassel (2013) examined multi-level stigma and HIV testing among Kazakhstani women and found that HIV stigma operates on the individual, family, and community levels to hinder HIV testing uptake. The 2015 People Living with HIV Stigma Index for Kazakhstan represents the first study of HIV related stigma among people living with HIV in the region (Amanzholov, Yakovleva, & Kamaldinov, 2016). The People Living with HIV Stigma Index reported that one in three people living with HIV in Kazakhstan has experienced fears of gossip, 18% reported being denied medical care, and 28% of reported that a healthcare worker has disclosed their status without their consent. Furthermore, they found healthcare providers to be the primary perpetrators of HIV stigma in Kazakhstan, as compared to other civil servants, friends, and/or family and thus concluded with several strategic objectives to ensure PLWH live free of stigma and discrimination, the first of which is to reduce HIV-related stigma in healthcare facilities in Kazakhstan.

Evidence from research outside of Kazakhstan suggests that stigma related to injection drug use impacts utilization of harm reduction and health-related services (i.e. syringe access, medical care, and drug treatment) (Paquette, Syvertsen, & Pollini, 2018; Rivera, DeCuir, Crawford, Amnesty, & Lewis, 2014). Only one study to date, however, has examined drug use stigma among service providers in the Central Asian context. Ibragimov et al. (2017) study in neighboring Tajikistan, highlighted prejudicial attitudes towards PWID among pharmacists. They found that stigma resulted in pharmacists’ refusal to sell syringes to PWID.

Significant research gaps remain in understanding these co-occurring stigmas and their possible impact on health in the Central Asian context. The current study will build upon the People Living with HIV Stigma Index findings by using mixed methods to elucidate PWID/LWH experiences of stigma and discrimination within the harm reduction service provision setting. Further, we extend the findings of the People Living with HIV Stigma Index by including surveys with service providers designed to examine attitudes of towards PLWH and PWID, training related to stigma, facility level policies and protocols, and norms related to stigma and discrimination.

Theoretical framework

To inform the aims of this paper, we used the Stigma and Discrimination Framework for Program Implementation and Measurement presented by Stangl et al. (Stangl et al., 2010; Stangl, Brady, & Fritz, 2012; Stangl, Lloyd, Brady, Holland, & Baral, 2013). According to this framework, the process of stigmatization in healthcare settings may be broken into specific domains: actionable drivers, facilitators, and manifestations of stigma. Further, stigma may exist at the individual level through attitudes and behaviors of individual healthcare providers, at the institutional level through social norms and discriminatory practices, or at the policy level in which policies to protect healthcare providers and patients are enforced. According to the Stigma and Discrimination Framework for Program Implementation and Measurement, actionable drivers of stigma include individual-level factors that negatively influence the stigmatization process such as a lack of awareness of stigma and its consequences, the fear of HIV infection through contact with PLWH, and negative social judgment towards PLWH and key populations at highest risk of HIV infection (Nyblade & Carr, 2004). Facilitators include social norms related to stigma within the service provision setting, the availability of supplies and protocols to reduce the chances of HIV transmission, awareness of facility policies related to stigma and discrimination, and the perceived enforcement of such policies. Finally, this framework describes manifestations of stigma as specific instances of stigmatization. This paper aims to use the Stigma and Discrimination Framework for Program Implementation and Measurement to describe the actionable drivers and facilitators of stigma among service providers at SEP facilities. Further, this paper also aims to identify and describe the manifestations of stigma and their impact on harm reduction and healthcare service utilization.

Methods

The Institutional Review Board at Columbia University & the Ethics Committee of the Kazakhstan School of Public Health approved this study. Informed consent was obtained from all participants prior to the initiation of all research related activities. The guidelines for good reporting of a mixed methods study (GRAMMS) were used (O’Cathain, Murphy, & Nicholl, 2008).

Study design

Data for this analysis was collected during the pre-implementation phase of project Bridge. Bridge is a step-wedge, cluster-randomized study that tests the effectiveness and implementation outcomes of a linkage to HIV care intervention for PWID (McCrinnmon et al., 2019). This data was collected using a sequential (QUAL → QUANT)
transformative mixed method approach in which qualitative data collection and analysis informed the selection of assessments to be delivered during quantitative data collection. Our justification for the use of mixed methods was twofold. First, the use of mixed methods allowed for the mutual corroboration of quantitative and qualitative results. Second, the use of mixed methods provided a more comprehensive account of stigma experiences by exploring the phenomenon from multiple vantage points. We chose the transformative mixed method approach due to the nature of the research question. Specifically, a study is said to be “transformative” when research is change oriented and guided by a framework for examining social inequalities and/or marginalization. Consistent with the transformative paradigm, we sought to highlight the voices of PWID/LWH by giving the qualitative and quantitative data equal priority.

Recruitment

To recruit participants for focus groups, we relied on a convenience sample recruited in the Kazakh cities where Bridge is being implemented. Participants were recruited through flyers distributed by the AIDS Center and by community partners (NGOs). Additionally, we recruited focus group participants through peer-driven snowball recruitment. Trained research assistants conducted a brief, anonymous screening with potential participants for the following eligibility criteria: 1) aged 18 years or older; 2) self-report injection drug use in the past year; 3) self-report being HIV-positive; 4) basic Russian fluency as determined during informed consent; and 5) cognitively unimpaired and able to take part in a focus group (assessed by the research assistant during informed consent). Fifty-nine participants were screened and 57 participants were deemed eligible for focus group participation.

We recruited service providers for quantitative surveys and PWID/LWH for focus groups who were part of the Bridge project. The current analysis uses data collected from surveys completed at three time points (January 2017, July 2017, and January 2018), across three sites (Almaty, Shymkent, and Karaganda/Temirtau) prior to the implementation of project Bridge. We selected 80 staff to participate in the survey. The staff were recruited by the Republican AIDS Center of Kazakhstan. For participants whom we had repeated stigma measurements (because they were interviewed at more than one time point), we selected the most recent survey measures before the implementation of project Bridge.

Data collection

PWID/LWH focus groups: Overall, eight focus groups were completed with PWID/LWH clients; each lasted approximately two hours. Trained research staff from the Global Health Research Center of Central Asia facilitated all focus groups using a semi-structured focus group discussion guide (Appendix A). Focus group topics included experiences and engagement with HIV services and barriers to receiving HIV services faced by PWID/LWH. Stigma was not explicitly asked about during focus groups; however, it emerged as an important barrier to service utilization. Focus groups were audio recorded, transcribed in Russian, and then translated to English. Participants received a compensation of 3500 tenge ($10 USD) for their time and transport.

Service provider surveys: Service providers completed a battery of surveys assessing the organizations readiness to implement the Bridge intervention. Research assistants administered surveys in-person and participants’ responses were entered directly into a secure Web-based data entry system. Surveys took approximately two and a half hours to complete. Service provider participants received 5300 tenge ($15 USD) for their time and transport compensation.

Quantitative assessments

Stigma drivers and facilitators were measured using the “Measuring HIV Stigma and Discrimination among Health Facility Staff” questionnaire which is publicly available through the Health Policy Project website (Health Policy Project, 2013; Nyblade et al., 2013). Actionable drivers measured included stigma and discrimination training, fear of HIV transmission, opinions about PLWH, and the desire to provide care for PWID. Facilitators included social norms within the service provision setting, availability of supplies and protocols to reduce HIV transmission, awareness of S&D policy, and S&D policy enforcement within the service provision setting. Participants were allowed to choose “not applicable” if the question assessed an activity that was not performed as part of their regular job duties. Additionally, all Likert-scale items were dichotomized to Yes/No, Worried/Not Worried, and Agree/Disagree. This questionnaire has shown to be a valid measure of stigma, and of drivers and facilitators of stigma across diverse country contexts (Cronbach’s α = 0.67 - 0.77) (Nyblade et al., 2013).

Data analysis

Qualitative data analysis began with an initial open coding as a starting point, providing analytic leads to identify initial codes and a preliminary coding structure. Open coded results were then sifted, sorted, and categorized into a provisional framework for second cycle coding. Second cycle coding included two trained researchers who used the provisional codebook developed during first cycle coding to simultaneously code two transcripts. Incongruences were discussed, resolved, and modified in the codebook. This process was repeated once more applying the modified codes to three transcripts. Once complete, each coder coded half of the remaining transcripts using the final modified codebook. Final categories of codes included type of stigma (PWID, HIV, other), the way in which stigma manifested (i.e. gossip, unauthorized HIV disclosure, denial of services, etc), and the location where the stigma was experienced (i.e. SEPs, AIDS Center, in the community, etc.). These categories were then sorted into overarching themes. The overall percent agreement across all codes was 95.59%. To maintain confidentiality, all participants’ names were removed and replaced with pseudonyms. Quantitative data analysis consisted of descriptive statistics (frequency and percentages) for all items, and was obtained using SPSS version 21 (IBM, 2012).

Data integration

Data were integrated by weaving the qualitative findings through the description of quantitative findings (narrative approach); and visually depicting potential associations between qualitative and quantitative findings (joint display) (Fetters, Curry, & Creswell, 2013). When appropriate, joint displays are presented throughout the results section that contain both quantitative and qualitative results in the form of tables. The construction of the joint displays were guided by the core concepts of the Stigma and Discrimination Framework for Program Implementation and Measurement, which include actionable drivers, facilitators, and manifestations of stigma. Specifically, the pairing of actionable drivers and facilitators of stigma as reported by service providers with the manifestations and outcomes of stigma as reported by clients enabled the assessment of coherence between qualitative and quantitative findings (confirmation, expansion and/or discordance). Integration of the findings was independently conducted and assessed by two investigators (KLS and TM) who met to discuss the findings and achieve consensus.

Results

For the qualitative phase, we conducted eight focus groups with 57 participants who reported both living with HIV and engaging in injection drug use. Focus group participants included 32 females (56.14%) and 25 males (43.86%). The mean age of focus group participants was 40.19 years (range = 21–53 years). For the qualitative phase, 80
surveys were administered to nurses (n = 23), social workers (n = 7), outreach workers from SEPs (n = 45), and nurses employed by the AIDS center (n = 5).

**Actionable drivers of stigma**

Table 1 is a joint display that contains quantitative data on actionable drivers of stigma from service providers as well as qualitative manifestations of stigma as described by PWID/LWH. The drivers we explored concerned (i) training/knowledge regarding HIV-related stigma and discrimination, (ii) fear of HIV transmission, and (iii) social judgement toward PLWH and PWID.

Training/knowledge regarding HIV-related stigma and discrimination: One question was designed to evaluate whether participants had received specific training related to stigma and discrimination in the last 12 months. Eleven participants left the question blank. Of those who did answer this question, 84.06% of our service provider participants reported having received stigma and discrimination training and discrimination training in the last 12 months.

Fear of HIV Transmission: Service providers were asked several questions concerning fear of transmission and the use of extra precautions taken with PLWH. In responding to these questions 17.50% of providers reported they would be worried if they had to draw blood from an HIV infected patient and 27.50% would be worried if they had to dress the wounds of a PLWH. Few participants reported they worried taking the temperature of a PLWH (2.50%) or touching the clothing of a PLWH (7.50%).

Self-reported stigmatizing avoidance behavior driven by transmission fear: Service providers reported using a variety of extra precautions when caring for PLWH. 37.50% reported wearing gloves during all aspects of care for PLWH, 15.00% reported wearing double gloves, 13.75% reported avoiding physical contact, and 30.00% reported using some type of extra measure that they felt was necessary for the protection of themselves.

The qualitative excerpts located in Table 1 corroborate and expand upon survey results by presenting these same stigmatizing infection control strategies from the viewpoint of the client (Quote 1–2). Specifically, PWID/LWH reported client avoidance and the use of masks during patient care. As exemplified by Quote 2 located in Table 1, participants also reported that providers either would outright deny care to PWID/LWH, delay the provision of services, or would refer them elsewhere for care because they did not want to provide services to them. Some participants reported feeling as if these behaviors were standard policy and they did not want to be seen providing services to PWID/LWH. “I’m afraid to go there, because we are afraid of disclosing our status.—”Eva”, 43 year old female, Almaty

**Table 1**

<table>
<thead>
<tr>
<th>Healthcare Provider Surveys</th>
<th>N (%)</th>
<th>N (%)</th>
<th>N (%)</th>
<th>PWID/LWH Focus Group Stigma Manifestation Excerpts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training/Knowledge of HIV-related S&amp;D</td>
<td>Yes</td>
<td>No</td>
<td>Not Applicable</td>
<td></td>
</tr>
<tr>
<td>Fear of Transmission</td>
<td>58 (84.06)</td>
<td>11 (15.94)</td>
<td>11 (13.75)</td>
<td></td>
</tr>
<tr>
<td>Worry when conducting the following activities:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Took the temperature of a patient living with HIV</td>
<td>2 (3.00)</td>
<td>27 (41.25)</td>
<td>31 (40.62)</td>
<td></td>
</tr>
<tr>
<td>Touched the clothing of a patient living with HIV</td>
<td>6 (9.00)</td>
<td>6 (9.00)</td>
<td>50 (65.00)</td>
<td></td>
</tr>
<tr>
<td>Dressed the wounds of a patient living with HIV</td>
<td>23 (34.50)</td>
<td>24 (35.00)</td>
<td>37 (43.75)</td>
<td></td>
</tr>
<tr>
<td>Drew blood from a patient living with HIV</td>
<td>14 (21.00)</td>
<td>31 (45.00)</td>
<td>25 (30.00)</td>
<td></td>
</tr>
<tr>
<td>Stigmatizing Avoidance Behavior</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You do typically use any of the following measure when providing services to a patient living with HIV?</td>
<td>Yes</td>
<td>No</td>
<td>Not Applicable</td>
<td></td>
</tr>
<tr>
<td>Avoid physical contact</td>
<td>11 (16.25)</td>
<td>67 (97.75)</td>
<td>0.00</td>
<td></td>
</tr>
<tr>
<td>Wear gloves during all aspects of patient's care</td>
<td>12 (18.75)</td>
<td>41 (60.00)</td>
<td>29 (38.75)</td>
<td></td>
</tr>
<tr>
<td>Use any special measures that you do not use with other patients</td>
<td>28 (43.75)</td>
<td>37 (50.00)</td>
<td>35 (46.25)</td>
<td></td>
</tr>
<tr>
<td>Opinions about People Living With HIV</td>
<td>Agree</td>
<td>Disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV is a punishment for bad behavior</td>
<td>18 (27.50)</td>
<td>6 (9.00)</td>
<td>65 (92.50)</td>
<td></td>
</tr>
<tr>
<td>Most people living with HIV do not care if they infect others</td>
<td>40 (60.00)</td>
<td>40 (60.00)</td>
<td>28 (37.50)</td>
<td></td>
</tr>
<tr>
<td>People living with HIV should feel ashamed of themselves</td>
<td>9 (13.75)</td>
<td>71 (100.00)</td>
<td>11 (15.94)</td>
<td></td>
</tr>
<tr>
<td>Most people living with HIV have had many sexual partners</td>
<td>30 (45.00)</td>
<td>50 (71.25)</td>
<td>29 (38.75)</td>
<td></td>
</tr>
<tr>
<td>People get infected with HIV because they engage in irresponsible behaviors</td>
<td>49 (73.75)</td>
<td>31 (45.00)</td>
<td>28 (37.50)</td>
<td></td>
</tr>
<tr>
<td>Women living with HIV should be allowed to have babies if they wish</td>
<td>76 (112.50)</td>
<td>4 (5.75)</td>
<td>50 (90.00)</td>
<td></td>
</tr>
<tr>
<td>Stigma Towards PWID</td>
<td>Agree</td>
<td>Disagree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I had a choice, I would prefer not to provide services to people who inject illegal drugs</td>
<td>13 (19.25)</td>
<td>67 (97.75)</td>
<td>28 (37.50)</td>
<td></td>
</tr>
</tbody>
</table>
because they engage in irresponsible behaviors” (61.25%), followed by “Most people living with HIV do not care if they infect others” (50.00%), and “Most people living with HIV have had many sexual partners” (37.50%). While focus group participants cannot speak directly to the attitudes and belief system of the service providers, they described service providers who interacted with clients in a biased and judgmental fashion and that such attitudes resulted in discomfort in accessing services and clients avoiding services (Table 1, Quote 5–8).

One question in the “Measuring HIV Stigma and Discrimination among Health Facility Staff” questionnaire is designed to measure stigma towards PWID. This question asks participants if they agree or disagree with the following statement: “If I had a choice, I would prefer not to provide services to people who inject illegal drugs.” Among our sample, 16.25% of participants agreed that they would prefer not to provide services to PWID. For those who agreed with this question, they were asked why they would prefer not to provide services to this population. Of the 13 participants who reported they prefer not to provide services to PWID, five indicated they prefer not to provide services to this population because “They put me at a higher risk for disease”, and three indicated they preferred not to provide care to PWID because “This group engages in immoral behavior.” Only one participant stated that they prefer not to provide services for this population because they have not received training to work with this group. Four participants did not provide any reason for their preference not to provide care to PWID. Focus group participants reported instances in which HIV care providers would deny care to clients referred from SEPs because of their status as a PWID (Table 1, Quote 4).

**Facilitators of stigma**

Facilitators we explored included (i) social norms related to S&D towards PLWH within the service provision setting, (ii) availability of supplies and protocols to reduce the chances of HIV transmission, (iii) awareness of facility policy related to S&D, and (iv) perceived enforcement of policies related to S&D. The joint display in Table 2, integrates quantitative results from service providers with qualitative quotes expressing the manifestations of stigma perceived by PWID/LWH.

**S&D Related Social Norms:** To measure institutional-level social norms around stigma, we asked participants how often they had witnessed stigmatizing or discriminatory actions by other service providers towards PLWH. Results suggest that stigmatizing actions towards clients is fairly normative in the service provision setting. Over one third of service provider participants reported witnessing healthcare workers being unwilling to provide care for PLWH (32.25%), providing poorer quality of care for PLWH (33.75%), or talking badly about PLWH (31.30%). These findings are in accord with PWID/LWH focus group findings as discussed above.

**Supplies and Protocols to Reduce HIV Transmission:** We asked participants about the availability of supplies and the existence of procedures and protocols to reduce their chances of becoming infected with HIV. The majority (83.75%) reported that their facility provided supplies to reduce their chances of becoming infected with HIV. Further, over 93.00% reported that there are protocols in place at their facility to reduce their chances of HIV infection.

**Policies related to S&D:** Regarding policies against HIV related stigma, 67.50% reported their facility has guidelines to protect PLWH from discrimination, focus group discussions with PWID/LWH, however, revealed that some facility policies may actually reinforce stigma through unauthorized disclosure. Specifically, participants reported instances of patient segregation and labelling (Table 2, Quotes 1–2) which led to unauthorized disclosure of their HIV status. PWID/LWH participants also described the displaying of facility logos during outreach events and the practice of having a separate entrance for SEP service users as policies that unintentionally disclose their status as a PWID or PLWH (Table 2, Quotes 3–4). Furthermore, while over 67% of participants reported the existence of policies to protect people from stigma and discrimination, only 30.00% reported they would get in

<table>
<thead>
<tr>
<th>Facility Provider Surveys</th>
<th>N (%)</th>
<th>N (%)</th>
<th>PWID/LWH Focus Group Stigma Manifestation Excerpts</th>
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</thead>
<tbody>
<tr>
<td><strong>Facility Norms Regarding Stigma and Discrimination</strong></td>
<td>At Least Once</td>
<td>Never</td>
<td>Stigmatizing Policies: Quote 1: When my husband was dying in a hospice, I was on standby there, he had a stroke. And, in principle, no one had to be aware of his status. He was placed in a separate room, and everybody shielded away from this room. And when the nurses came in they saw me kissing him... they told me: “why do you come up to him?” He has AIDS, he’s infectious!” And everybody in this hospice, including cancer patients, dying grandmothers, treated him like a horrible person.— “Valeria”, 50 year old female, Almaty Quote 2: When I arrived, I did not tell them about it, and then I disclosed it. They turned away all other women in childbirth from the ward and hung an “HIV” sign on the door, and all women were barred from entry to my ward. Imagine my condition! A long corridor, my ward at the end, and I’m there alone.— “Alla”, 40 year old female, Almaty Quote 3: It should be noted that the AIDs Centers SEP entrance is separate.—“Mikaela”, 34 year old female, Termitau Quote 4: Moreover AIDS Center has a car with the inscription “AIDS Center” – well they drive up to my house, my neighbors see and say: what’s that?! I always ask them to leave a car couple of blocks away from my house. —“Boris”, 49 year old male, Almaty <strong>Need For Policy Enforcement:</strong> Quote 5: Anyway, this [SEP] must hire a person who is well aware that HIV status is not dangerous to others, that we have to come and it is not necessary to wear a mask and jump aside and look askance at us, let it be a coordinator who will supervise them and treat us just like all other people. We do not pose any threat to them. — “Viktorya”, 44 year old female, Almaty Quote 6: You come to the AIDS center [for syringes] and the outreach worker is absent, it is necessary to wait... You come and they say – “go away from here”... These are not just words, I can prove what I say -I have records... I even visited the Chief Doctor and swore why there was such an attitude towards us. I tell them – ‘you behave so as if you are sick, and I am a doctor.’ Strict control is needed.—“Nazar”, 48 year old male, Shymkent</td>
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trouble if they were to discriminate against PLWH indicating a failure to enforce such policies. Focus group participants also noted a need for better policy enforcement and staff oversight within the service provision environment (Table 2, Quotes 5–6).

**Manifestations of stigma**

Qualitative interviews with PWID/LWH describe manifestations of enacted and anticipated stigma within healthcare settings that give context to the quantitative data provided by healthcare providers above.

Enacted Stigma: From the clients’ perspective, there is a consensus that PWID/LWH are commonly stigmatized in both the harm reduction and HIV care service provision environments due to their PWID and HIV status. In addition to the above manifestations of stigma, participants frequently described negative dispositions from service providers, in which PWID/LWH patients are treated as inferior:

- They just like to behave themselves in such a manner – [healthcare workers] humiliates us [because] he is a healthy guy, he achieved everything himself, but you’re flawed and came for syringes. — “Inna”, 37 year old female, Almaty
- The problem is in medical workers attitudes towards PWIDs. When all is good with a man, there are no problems. But when a man has no place to live, they can’t link him to services, they begin to create a lot of barriers making everything rather complicated. — “Martemyan”, 45 year old male, Shymkent

Focus group participants reported enacted stigma from both service providers and other clients in the service provision environment:

- Yes, there is such an attitude that as soon as they get to know about the status, not only the doctors jump aside, but other people do as well – they point their fingers at me – look, HIV, she’s HIV infected! —“Viktoriya”, 44 year old female, Almaty

One participant recalled that, when visiting an SEP located within an AIDS Center, PWID are asked to provide proof of injection drug use before workers will provide them with syringes. He describes this as a barrier to the utilization of SEP services:

- When guys come [to the AIDS Center] to get syringes, they have to prove that they are drug-users! They [staff] ask them: “well, show traces from injections – you don’t look like user”. There were almost scandals. Our guys didn’t manage to get syringes… You see… let’s assume, a person comes once, and they look amiss at him, say amiss – next time he doesn’t want to come. Why should he come, prove that he’s user, etc? — Daniyar, 45 year old male, Shymkent

Further, participants reported stigma in ancillary services as well. The most commonly mentioned healthcare facilities (other than HIV care and harm reduction services) that participants reporting experiencing stigma in were hospitals, dentists, narcology dispensaries, and facilities that provide tuberculosis care. Stigma in these environments manifested in denial of care and unauthorized disclosure of HIV status:

- The AIDS Center should have a dentist because dentists at regular clinics don’t want to see PWID. — “Ulyana”, 48 year old female, Karaganda
- And a hospital… they hardly admit you to a hospital. They do not refuse directly, they smile and do not want to render services under any circumstances. We have to attract some connections/contacts to be admitted, especially in case of surgery.— Elnara, 50 year old female, Almaty

PWID/LWH were very aware of the double stigma that they may encounter, even when accessing ancillary health services:

- Yes. The same attitude is in narcology dispensaries, i.e. stigma, and double stigma that you are living with HIV and inject drugs – “Martemyan”, 45 year old male, Shymkent

Finally, two participants reported that female PWID/LWH faced stigma when accessing reproductive and maternity health care services. One participant reported that she was placed in a separate room marked with a sign outside the door that indicated she was living with HIV (Table 2, Quote 2). Another participant reported that providers often suggest abortion for pregnant women who are PWID/LWH:

- I know– as far as pregnancy is concerned – they often suggest abortion. However, being a doctor she should explain all risks, pluses and minuses, provide counseling and information for pregnant women. But they always advice abortion for some reason. My wife was told so. Daniyar, 45 year old male, Shymkent

Anticipated Stigma: PWID focus groups revealed significant anticipated stigma around the utilization of harm reduction services and disclosure concerns. The most commonly reported theme around stigma was the concern that participants would be seen accessing HIV services and/or harm reduction services by family, friends, or acquaintances. In policlinics – which provide general primary care services to the community as well as syringe exchange services for PWID – participants often reported being concerned that their status as a PWID would be inadvertently disclosed if they were to be seen in or around these clinics, or if they were seen accessing community-based harm reduction services. They anticipated that this disclosure would lead to instances of enacted stigma, such as gossip:

- Everybody will know, our district is small, my neighbors visit this polyclinic, and will then gossip. — “Alla”, 40 year old female, Almaty
- If neighbors see outreach workers, they will start to talk about me. — “Aidana”, 39 year old female in Temirtau

In response to anticipated stigma, PWID/LWH reported avoiding HIV care and harm reduction services, and in particular, avoiding SEPs located within policlinics. This is of particular concern because it discourages harm reduction utilization and HIV testing:

- I sometimes don’t even want to see doctors at the primary care clinic because I am afraid to meet acquaintances there. They may spread rumors about me. — “Rosalina”, 48 year old female in Karaganda
- I wouldn’t go there. I have many acquaintances there. If someone sees me, then rumors will be spread around the city. — “Nikkita”, 37 year old female in Karaganda
- People are reluctant to go to AIDS Center – I know 5 persons whom I can’t drag there by force. They think that if somebody will see them in AIDS Center he/she will think that they have AIDS (are HIV-positive). It is psychologically difficult for people, who want to be tested, to visit AIDS Center. — Latipa, 34 year old female in Almaty

Participants recounted witnessing service providers within SEPs and primary care clinics disclosing the status of other PLWH. Participants reported that witnessing this leads to the belief that if they were to disclose their status to staff in this facility that their privacy would not be maintained either:

- I had a case in the primary care clinic… Doctors in the clinic made a noise about my friend as if she was leper, they told everybody that she had HIV. A doctor doesn’t even know if I know or not, but starts telling me about her…I’m afraid to go there, because we are afraid of disclosing our status.— “Eva”, 43 year old female, Almaty
Discussion

A substantial amount of literature exists on the effects of HIV stigma on healthcare access and utilization (Ekstrand, Ramakrishna, Bharat, & Heylen, 2013; Feyissa et al., 2012; Nyblade, Stangl, Weiss, & Ashburn, 2009); however, stigma related to injection drug use and the experience of multiple stigmas among PWID is poorly understood. Such an understanding is critical in Kazakhstan, where HIV is primarily driven by injection drug use. Utilizing a mixed-method approach, we used the Stigma and Discrimination Framework developed by Stangl et al. (2010) to explore the manifestations of stigma, their impact on harm reduction and HIV care service utilization within primary care settings. The present study makes several noteworthy contributions to our understanding of stigma among PWID/LWH in the region by highlighting the lived experiences of stigma and by providing a better understanding of the manifestations of multiple stigmas experienced by PWID/LWH. Further, while the People Living HIV Stigma Index (Amanzholov et al., 2016) provides some understanding of HIV stigma from a client perspective, the quantitative arm in this study provides the first assessment of stigma from the perspective of service providers in the region. Moreover, our findings build upon the People living with HIV Stigma Index by identifying actionable drivers and facilitators that future interventions can target for stigma reduction.

Similar to findings reported in the People Living HIV with Stigma Index, PWID/LWH in this study reported fear of gossip by other community members when utilizing HIV or harm reduction services and this fear translates into a lack of utilization of services. Excerpts from our focus group discussions describe instances similar to those reported in the People Living HIV with HIV Stigma Index, in which HIV stigma within healthcare settings resulted in denial of care, unnecessary precautions, and unauthorized disclosure of HIV status. Beyond what was examined by the People Living HIV Stigma Index, our focus group participants reported experiencing stigma related to their status as a PWID and that this additional stigma led to the avoidance of harm reduction and HIV service settings, and the receipt of substandard care. In surveying service providers, we found that a substantial proportion of service providers reported having received training in stigma, having the necessary supplies and protocols to reduce HIV transmission, and the existence of policies to protect patients from stigma and discrimination. Nevertheless, PWID/LWH participants reported frequently encountering stigma in the service provision environment and over a third of service provision participants reported witnessing other service providers being unwilling to provide care, providing poorer quality of care, and talking badly about PLWH. In addition to HIV care and SEP settings, participants reported experiencing stigma in narcology dispensaries, TB clinics, and places that provide reproductive and maternal health care services.

The integration of data through joint displays provided valuable insights into conflicting perspectives of stigma within the service environment as expressed by providers and clients. The findings from this study highlight a discrepancy between service providers and clients, in which providers may not be aware of the effect that their behaviors have on their client population. Quantitative data from service providers revealed some endorsement of stigmatizing attitudes, behaviors, and negative opinions of PWID/LWH. Qualitative interviews with PWID/LWH clients of HIV and SEP services, however, describe frequent encounters of enacted stigma. Though fear of transmission and avoidance behaviors were not particularly high as reported by service providers, many clients describe situations where service providers take unnecessary precautions by using masks, actively denying care, and segregating clients who were living with HIV and/or PWID from other clients. Furthermore, many of the actions that providers use to stop HIV transmission led to unintended consequences in which clients feel discriminated against, and, as a result avoid preventative services and health facilities. Additionally, quantitative surveys indicated that the majority of service providers are aware of anti-stigma and discrimination guidelines but only less than one third reported that these policies were enforced. Further contextualizing these findings, our qualitative data demonstrate how facility policies may facilitate stigma by inadvertently disclosing their status as a person living with HIV and/or PWID through actions such as segregating clients, discussing a client’s status in front of others, or displaying facility logos during outreach events.

With its focus on actionable drivers and facilitators, we found the Stigma and Discrimination Framework for Program Implementation and Measurement to be a useful framework by which to organize our findings and to identify suitable targets for intervention. Actionable drivers and facilitators are individual and facility level factors which have been shown reduce stigmatizing attitudes and behaviors as a result of interventions (Stangl et al., 2010). Based on this study’s findings, there is a need to address the following drivers and facilitators of stigma in this setting: fear of HIV transmission, a lack of knowledge about the ways in which stigma manifests, a lack of policy enforcement, and a culture where stigmatizing treatment of PWID/LWH clients appears to be an acceptable social behavior. Intervening on these drivers and facilitators will be critical for reducing the multiple stigmas faced by PWID/LWH in Kazakhstan if harm reduction and HIV prevention measures are to be successful.

Given that stigma is a multi-faceted social construct, a multi-pronged approach to stigma reduction is necessary. Further, stigma reduction interventions must address multiple stigma domains (i.e., stigma related to HIV, injection drug use, incarceration, and other marginalized statuses) at multiple levels (i.e. individuals, organizational, policy) in order to effectively address health inequities in populations that face multiple stigmas. Interventions that aim to increase knowledge of what stigma is, how it manifests, and the negative consequences of stigma are essential for raising awareness (Nyblade et al., 2009; Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010). The finding that stigma towards PWID/LWH appears to be an acceptable social behavior identifies this setting as one that may particularly benefit from interventions that integrate professional role models into existing training structures. The White Coats, Warm Heart (WCWH) intervention (Li, Lin, Guan, & Wu, 2013, 2013b), implemented across 40 county-level hospitals in China, could serve as a prototypical model for stigma reduction in Kazakhstan. The WCWH intervention is multilevel stigma reduction intervention that utilizes professional role models to promote a non-stigmatizing healthcare environment in combination with the provision of infection control supplies and education concerning universal precautions. The WCWH intervention utilizes popular opinion leaders to disseminate stigma reduction messages including information concerning universal precautions and occupational safety, equal treatment of all patients, improving the provider-patient relationship, and reducing of HIV-related stigma. In addition to the popular opinion leader component, the WCWH intervention incorporates structural level changes including the provision universal precaution supplies, information packages on the use of universal precautions to prevent HIV transmission, and the development of a Universal Precaution Oversight Committee. Training on universal precautions and the provision of adequate infection control supplies (i.e., gloves, sharp disposal containers, hand washing stations, etc.) helps mitigate transmission driven fear and decreases stigmatizing avoidance behaviors. Moreover, popular opinion leaders serve as change agents within organizational structures by promoting a culture of non-stigmatizing service provision. The reduction in stigmatizing attitudes and behaviors among service providers produced by the WCWH intervention have shown to be sustainable at 12-month follow up.

At the institutional level, it is paramount that policies prohibiting stigma and discrimination are implemented and enforced. The development of policies through a participatory method that involves healthcare workers have proven to be the most effective. Participatory policy development allows participants to explore their personal values and behaviors, while improving their awareness of stigma and
discriminatory attitudes and behaviors (Nyblade et al., 2009). Moreover, participatory methods allow for the tailoring of policies to each unique context. Once policies are in place, discrimination consequences must be clearly stated and well known amongst all employees. One way to ensure policy enforcement is to mandate the monitoring of attitudes and behaviors of service providers, and establish benchmarks that facilities can use to monitor their progress. A successful example of this has been implemented by the government of Vietnam, where national hospital regulations include stigma reduction and hospitals are required to conduct regular monitoring to ensure compliance (Nyblade et al., 2009).

Strengths, limitations, and future directions

A mixed method approach enabled us to provide contextual evidence for HIV and drug-use related stigma within healthcare facilities from both the patient and provider perspective, and the integration of qualitative and quantitative research strategies capitalizes on complementary strengths and nonoverlapping weaknesses. The sequential approach to mixed methods data collection used in this study allowed us to use stigma findings that emerged from the qualitative interviews among PWID/LWH to inform the selection of quantitative surveys that measured HIV and drug-use related stigma among healthcare workers (Zhang & Creswell, 2013). Although findings from this study add to the limited body of evidence regarding discrimination and stigma among PWID/LWH populations in Central Asia, this study is not without limitations. The sequential approach used, obtained data in different populations (i.e. qualitative interviews among PWID/LWH and quantitative surveys with providers). As such, service providers were not able to elaborate on their attitudes and behaviors towards PWID/LWH through qualitative methods, and we were unable to quantify manifestations of stigma as reported by clients. Future studies could consider focusing more in-depth on either population to create a deeper understanding of stigma from each perspective.

Furthermore, participants were not selected at random, thereby limiting the external validity of findings. Service providers and administrative staff were selected by senior leadership for their knowledge and expertise, whereas PWID/LWH participants were recruited using flyers and peer-driven snowball sampling. As a result, some degree of selection bias may exist. Additionally, focus group participants were both living with HIV and PWID, which limits our ability to disentangle the separate experiences of these stigmas. However, the mixed methods approach used in this study provides diverse perspectives from patients and service providers to give a comprehensive overview of stigma and discrimination in a region where HIV is primarily attributed to PWID. Furthermore, participants were selected from active AIDS Centers and SEPs in three major regions of Kazakhstan and thus our findings are likely representative of PWID/LWH populations and of SEP service providers within the region.

Another limitation lies in our measurement of stigma towards injection drug users. Specifically, only one quantitative question directly measured stigma towards injection drug use. While the percent of providers who reported they prefer not to provide services to this population was relatively low (just over 16%), it is probable that a higher proportion of providers endorse stigmatizing views and/or engage in discriminatory practices towards PWID that were not captured in our survey. In fact, our qualitative results provided evidence that stigma related to PWID status was frequently encountered by PWID/LWH in harm reduction and HIV care settings. These results call for a need to further investigate experiences and manifestations of stigma specific to injection drug use in the region. There is particularly a need to disseminate the stigma related to HIV from that related to injection drug use and to understand the extent that injection drug use may lead to stigma beyond concerns related to HIV infection.

Finally, the current study emanated from the pre-implementation phase of a larger study designed to test effectiveness and implementation outcomes of a linkage to HIV care intervention for PWID. As such, focus group questions and probes focused on general experiences with, and barriers to, SEP services and HIV care. It was only after qualitative data collection that stigma emerged as a key barrier to SEP and HIV service utilization. It possible that we would have identified an even greater range of stigma experiences and have been able to elicit an even more nuanced understanding of the topic of stigma were a focus group topic. Future research is therefore needed to confirm our findings and to provide a greater understanding of stigma related to injection drug use and HIV in Kazakhstan. There is a specific need for the examination of how these stigmas may interact with other social statuses such as gender, race, and history of incarceration.

Conclusion

Our findings support the recommendation that reducing HIV-related stigma in healthcare settings should remain a top priority in Kazakhstan, and we extend this recommendation to include a need to address stigma related to injection drug use. Measuring the attitudes and behaviors of service providers and identifying points of intervention is the first step in successfully meeting this challenge. Results from this study support and build upon the HIV Stigma Index findings by providing actionable drivers, facilitators, and context for HIV and substance use related stigma reduction interventions to be implemented. This study highlights the urgent need to address stigma in the harm reduction and HIV service settings in Kazakhstan. The actionable drivers and facilitators of stigma within healthcare settings identified in this study include stigmatizing behaviors seen as normative, lack enforcement of anti-discrimination policies, lack of knowledge about the ways in which stigma manifests, and fear of HIV transmission. These findings may be used to guide an actionable model for stigma reduction in the context of harm reduction and HIV care settings in Kazakhstan. Ultimately, for stigma reduction strategies to be effective, multiple interventions will need to be combined in order to address multiple stigmas at the individual, facility, and policy level.

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Conflicts of interest

The authors declare that they have no conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed.

We further confirm that this study was conducted with the ethical approval of the Institutional Review Boards at Columbia University and the Kazakhstan School of Public Health.
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Appendix A. BRIDGE Focus Group Discussion Guide

1 Introduction by Facilitator

We want to thank you again for taking the time to meet with us today. My name is ___________ and this is ___________ and we would like to talk to you about your experiences and engagement with HIV services at trust points and AIDS Centers. Specifically, we would like to discuss your thoughts on barriers facing people who use or inject drugs in their access to receiving HIV services. There are no right or wrong answers. Specifically, we will be asking about services that you feel could be useful for people who use or inject drugs at trust points and AIDS Centers.

The focus group should take an hour and half. We will be recording the session because we don’t want to miss any of your comments. Because we’re on tape, please be sure to speak up so that we don’t miss your comments. As stated in the consent form, all responses will be kept confidential. This means that focus group discussions will only be connected to any information you provide during these focus groups. Remember, you don’t have to talk about anything you don’t want to and you may end the participation at any time.

Are there any questions about what I have just explained? Can we get started?

2 Trust Points
- What is your experience of attending trust points and the services that trust points provide?
- How do you or other PWID choose which trust point in your city/town to go to for services?

3 What are things trust points could do differently to better meet the needs of PWID in your community?

4 Outreach workers
- What are your and other PWID’s experiences with outreach workers?
- What could outreach workers do differently to better meet the needs of PWID in your community?

5 HIV/AIDS
- How is HIV/AIDS perceived among your community of PWID?
- How do PWID perceive the consequences of getting HIV?
- What experiences do PWID have with HIV testing?
- Given a choice, where would PWID prefer to go for HIV testing: AIDS Center, or to a trust point, or to another place? Why?

6 Linkage between trust points and AIDS Centers (and barriers to linkage)
- In your community, how are HIV-positive people introduced to HIV care at the AIDS Center for the first time?
- What role do trust points and trust point staff play in referring HIV-positive people to HIV care at the dAIDS Center?
- What are some barriers that PWID experience in getting services at the AIDS Center based on a referral from a trust point?
- How long does it take PWID from the time they are diagnosed with HIV to be linked to care?

7 Experience at AIDS Centers
- How do PWID in your community perceive the AIDS Center?
- What is the experience of HIV-positive PWID when they try to access HIV care at the AIDS Center?
- In your community, how well-understood is the concept of viral suppression?
- How easy or difficult is it for PWID to adhere to ART medication to achieve viral suppression?

8 Barriers to care & community support
- Please describe some of the barriers people who inject drugs in your community may face in visiting trust points, interacting with outreach workers, or visiting the AIDS Center? Are there different barriers for men and women?
- How do PWID support (or not support) each other when it comes to HIV testing and adherence to ART?
- What could the AIDS Center do differently to better meet the needs of HIV + PWID in your community?
- What is the most difficult thing about being HIV + in your community?

9 Closing
- Are there any concerns related to HIV that PWID have in your community that we haven’t discussed today? Are there aspects specifically related to women’s experiences as PWID?
- Is there anything else we have not talked about that might be important for us to link PWID to HIV care and treatment?
- Debriefing and Closing

References
