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"Who are You and What are You Doing Here?": Social Capital and Barriers to Movement along the HIV Care Cascade among Tajikistani Migrants with HIV to Russia

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Abstract

Tajikistani migrants who work in Russia and acquire HIV seldom receive HIV treatment. Barriers to engagement in the HIV care cascade were identified from in-depth, semi-structured interviews with purposefully sampled Tajikistani migrants (n = 34) with HIV who had returned from Russia. Data were analyzed using thematic analysis, drawing from Putnam's theory of social capital, showing how bridging and bonding social capital relate to poor engagement. We identified three barriers to Tajikistani migrants' movement through the HIV care cascade: (1) Russia's migration ban on people with HIVinterrupts social capital accumulation and prevents access to HIV treatment within Russia; (2) mistrust of authority figures, including healthcare providers, leads to avoiding treatment and harm-reduction services upon their return to Tajikistan; and (3) because of pervasive discrimination, Tajikistani migrants form weak social ties while in Russia,

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Ethical Approval Study protocol was deemed exempt by the Yale Ethical Review Board (IRB Protocol ID: 2000025077) and was approved by the Ministry of Health and Social Protection of the Population of the Republic of Tajikistan.

Consent to Participate Verbal informed consent was obtained prior to the interview.

which exacerbates risk, including with Russian citizens, and deters engagement with HIV care. Deploying a treatment as prevention strategy and abolishing Russia's ban on people with HIV would improve both individual and public health.

Keywords

HIV treatment cascade; Eastern Europe and Central Asia; HIV; Migration; Social capital

Introduction

With every fifth Tajikistani citizen living in the Russian Federation, migration has defined life for Tajikistani people since the early 2000s when post-war economic and social conditions resulted in a large exodus of mostly male labor migrants. At the same time, Eastern Europe and Central Asia has been the only UNAIDS region globally with a consistently increasing HIV-related incidence and mortality.

On one hand, HIV risk for Tajikistani migrants is well-described in the public health literature [1–8]. On the other hand, social networks shape life for Tajikistani and other Central Asian migrants in the Russian Federation in complex ways, with inclusion, trust, and social ties and support (all constituents of social capital) associated with greater well-being [9, 10]. The connection between social capital and HIV risk for this population has been touched upon tangentially [7, 11], but notexplicitly studied.

In this paper, we argue that a lack of bridging social capital in Russia, and bonding social capital upon return to Tajikistan, produces HIV riskand impedes the uptake of prevention and treatment [12]. In particular, we present findings from in-depth interviews (n = 34) with returned migrants with HIV in Tajikistan, presenting facilitators and barriers to the HIV care continuum, including their HIV diagnosis, linkage to care, and treatment. Further, Zotova and Cohen [13] have previously argued that migration serves as a mechanism for building (cultural, financial, and social) capital for Tajikistani migrants. As Leonard and colleagues found that social capital can exclude some people from communities [12], we argue that while migration does indeed build capital for this population, law and stigma against people with HIV (PWH) has turned HIV into an impediment to the production and maintenance of social capital and therefore migrant class mobility.

Social capital is not a standardized term; however, political scientist David Putnam [14] defines social capital as" features of social organizations, such as networks, norms and trust that facilitate action and cooperation for mutual benefit." Putnam [14] identifies two key elements of social capital: *bridging* and *bonding* social capital. Bridging social capital is understood as networks that connect distinct groups (i.e., Tajikistani migrants with Russian citizens in the Russian Federation), and the relative strength of connections in these networks. Bonding social capital, on the other hand, is more exclusive and is defined as the strength of relationships *within* a given group (i.e., Tajikistani migrants who return to Tajikistan and interact with their home social networks).

This paper begins with an overview of the social and epidemiological situation of migration and HIV in Russia and Tajikistan. Then, we describe our research methods and analysesconducted in Dushanbe in 2019. In the final sections, we recount our participants' migration narratives, consider how discrimination precipitates poor bridging social capital and trust. Then we discuss how lack of trust leads to poor HIV testing and treatment uptake. Finally, we present how the new context of Russia, and the weak and often shallow social ties our participants form there, shapes engagement in risk behavior, including drug use. In conclusion we point to potential intervention strategies that stem from addressing HIV risk among Tajikistani migrants in Russia through the lens of social capital theory.

Background

History of Migration from Tajikistan to Russia

Tajikistan, the poorest country in Central Asia, descended into a civil war following its independence from the Soviet Union in 1991. Political and financial instability ensued, with high rates of unemployment that remain. Consequently, Tajikistan's young labor force sought employment beyond the country's borders and, by 2000, labor migration became a defining aspect of the country's economic system. By 2019, remittances accounted for 25% of Tajikistan's GDP, one of the highest proportions of any country [15]. In parallel, Russia increasingly relied on migrant labor to meet its labor needs, especially from Central Asian Republics like Tajikistan. As of 2019, over 2,000,000 Tajikikistani migrants were residing in Russia, with nearly 1,000,000 there for work [16].

HIV Epidemic in Eastern Euripe and Central Asia

The Eastern European and Central Region (EECA), including Russia and Tajikistan, has the highest HIV incidence and mortality globally [17]. The higher HIV incidence in Russia places migrants at elevated risk for HIV. Multiple studies have documented that having worked in Russia was an independent correlate of HIV for people returning to less affluent EECA countries [2, 3, 18–23], including Tajikistan. The mechanisms underlying this association are not well understood; however, the policy and social environment in Russia is hypothesized to be a contributing factor [8, 19, 24].

Economic and Social Relations in Tajikistan

With a GDP per capita of $870 in 2019, the average Tajikistani must survive on just over $2 per day [25]. For a low-income and largely rural country like Tajikistan, migration offers a rare opportunity to build capital and enter a small and nascent urban middle class [13]. In rural Tajikistan, married couples traditionally practice patrilocal residence, where a bride is expected to live with her husband and in-laws after marriage. Urban Tajikistani women may work in several professions, but significant, gendered employment and pay gaps persist, forcing many urban women to rely on spouses and male relatives for financial support [26]. The gendered economic relations, and social and religious norms that posit that a man's responsibility is to provide for his family, coupled with poor economic prospects in Tajikistan, all strongly incentivize men to migrate to and stay in Russia for work. While the number of Tajikistani women immigrating to work in Russia has increased in recent years,

they remain only 18% [27] of the total Tajikistani labor migrant population and only 16% of all Tajikistani migrants living with HIV [24].

HIV Risk in Tajikistan

Geographic factors in Tajikistan also shape HIV risk. Tajikistan shares its longest and most porous border with Afghanistan, the world's largest producer of opium and its derivatives. Although most (80.7%) of Tajikistani migrant workers who acquire HIV do so through unprotected heterosexual intercourse, a significant minority (18.3%) do so through injecting drugs, mainly heroin. In Tajikistan, about a third of all HIV cases occur due to sharing of unsterile injection equipment, and most new infections are concentrated among people who inject drugs (PWID) [28]. Although drug injection contributes greatly to HIV transmission risk for migrants in Eastern Europe and Central Asia, almost all previous studies of HIV risk focus on sexual transmission [3–8, 29].

HIV-Related Prevention and Care in Tajikistan

Healthcare and service provision for PWID in Russia and Tajikistan differ markedly. Tajikistan has a robust harm reduction service network, with one of the highest rates of syringe service program (SSP) coverage in Eastern Europe and Central Asia. Methadone, the gold standard treatment for opioid use disorder, is available to all PWID in Tajikistan free of charge, although it is inadequately scaled-to-need [30]. The HIV epidemic in Russia is also concentrated among PWID; however, Russia has banned all forms of opioid agonist therapies (e.g., methadone or buprenorphine); therefore, PWID seeking evidence-based HIV prevention and treatment for opioid use disorder are barred from doing so [31].

Healthcare in Tajikistan, a vestige of the Soviet Semashko system, is overwhelmingly public (98.4% in 2015), and as a consequence, most physicians are employed by the state. At the same time, healthcare is underfunded [32], and the average monthly salary of physicians hovers around $38 per month [33], or $100 in the capital. Consequently, unofficial payments are commonplace; despite espousing universal care, Tajikistan has one of the highest (unofficial) rates of out-of-pocket costs for medical expenditure in the world, estimated to be upwards of 80% [32, 33]. These high prices disincentivize accessing care, and as a result, Tajikistanis generally prefer to avoid seeing a physician when possible. While antiretroviral therapy (ART) is provided for free through international donors like the Global Fund which entirely funds HIV prevention and care in Tajikistan, the extent to which patients must pay for HIV care using informal payments in Tajikistan is unknown.

Russian Migration Law

In 2007, Russia instituted work permit quotas for labor migrants from the Commonwealth of Independent States (CIS) [34]. As a result, Russia encourages a great deal of informality in its migration system. Only two of the six million migrants currently residing in Russia have formally registered [34] (By 2015, migrants from Tajikistan to Russia had to apply for a *patent* (a type of worker registration) to have legal status as laborers [34] and were required to obtain health insurance and test for HIV [35] as part of their *patent*. Migrants sometimes purchase false (negative) HIV test results to obtain a *patent* [34].

Migrant Healthcare in Russia

While Moscow has considerable health infrastructure overall, it also provides healthcare services and medical advice to Central Asian migrants [35], including through the NGO Shagi Foundation which has successfully overcome some barriers to obtaining ART through informal networks [36]. Such services, however, seldom exist outside Moscow, with migrants mostly providing self-treatment within informal, community-based networks [37]. These networks often guide migrants to obtain treatment recommendations, healthcare information, and general help navigating the Russian medical system [38].

Russia's HIV Migration Ban

In 1995, Boris Yeltsin, Russia's president, introduced a law that required HIV testing for most foreign nationals attempting to enter and stay in the Russian Federation for more than three months [39]. People who screen positive for HIV, as a consequence of this law, are denied entry and residence. For non-citizens identified with HIV within Russia, ART is not covered [35]. Consequently, healthcare for migrants does not include HIV treatment or care. Moreover, foreign nationals with HIV are sometimes added to Russia's Federal Migration Services' State System for Electronic Migrant Registration [40], rendering them deportable and barring their re-entry into the country [40]. Russia has, however, implemented some basic services country-wide for migrants including free emergency care even for those without insurance and three days in hospitals before being charged. Additionally, specific hospitals around the country are required to provide childbirth delivery services to migrant women regardless of their legal status or ability to pay [38].

Liminal Legality

Since introducing the "work permit quota" and decreasing the allowed number of migrants in 2007, a policy that reflected the global financial crisis and the rising anti-immigration sentiment among the Russian populace, the boundary between migrant legality and illegality has become increasingly blurred [41]. Many Central Asian migrants occupy an ambiguous legal space where Russia's "open border" policy towards post-Soviet nations and the restrictive work permit quota are combined to create irregular and uncertain migrant documentation requirements at both regional and federal levels [41]. Facing complicated long-term migration policies, while also being able to enter the country "legally" with relative ease, Central Asian migrants often rely on quasi-legal practices shaped by intermediaries to obtain forged documentation or fast track the procurement of legal documentation [42]. Informal and semi-legal practices migrants engage in on their path towards "legalization" create underground economies for the production of documentation both forged and legal, and help employers cut costs by hiring legally ambiguous migrants [42]. The liminal legality of Central Asian migrants as they seek out work permits and citizenship through backward channels, or choose to remain in the country through bribery shapes their social networks and interaction with individuals and local institutions [43]. Legal statuses create privileges of labor force participation, service accessibility, and sociocultural experiences that differ for those with liminal legality [43]. While there is a general vacuum of information available on the interaction between quasi-legal migrant statuses and the health of Central Asian migrants to the Russian Federation, research has

shown that a migrant's status significantly affects their health risks and health-seeking behavior [44]. The interaction between Central Asian migrants and healthcare in Russia reflects a similar ambiguity as they rely on their close social networks or a system of informal payments to Russian healthcare workers [41]. It is difficult to prioritize health when navigating the many economic, cultural, and social barriers of the quasi-legal migrant landscape-a landscape that is integrated and reflective of the precarity of migrant healthcare [38].

Previous research has suggested that multilevel determinants of health influence HIV risk among migrant populations. In a systematic review by Weine and colleagues, the most common determinants of HIV risk identified were prolonged and frequent absences from home, depressed socio-economic status, and harsh living and work conditions (policy-level); social and cultural norms, family separation, and lack of social support (socio-cultural-level); and substance use, co-infection with other STIs, mental health comorbidities, lack of testing, and unsafe sexual and injection practices (individual-level) [45]. Like for many other populations, HIV is syndemic with a number of social, behavioral, and biological health states [46]. While HIV risk behaviors of Tajikistani migrant laborers in Russia have been well-document [1–4, 8], what happens when these same Tajikistani migrants become infected with HIV and return home is not well understood.

Methods

Participants

Participants were recruited when they came for HIV care between July 1 and August 25, 2019. Providers referred patients to a research assistant if the patient was 18 years or older, had documented HIV, and reported having returned to Tajikistan from working in the Russian Federation, including recently (past year) and more remotely. This was done to facilitate inclusion of both temporarily returned and permanently returned migrants in the sample. To ensure diversity in the sample, providers purposively invited migrants from the National AIDS Registry [47] who were members of groups who might otherwise be underrepresented (women, PWID, Pamiris/Isma'ili Muslims). Thirty-seven individuals were invited to participate, and ultimately 34 [8 women and 26 men] participants consented to the study.

Setting

Interviews were conducted at the Republican AIDS Center in Dushanbe, Tajikistan's capital. Each of Tajikistan's 64 districts, including Dushanbe City, has its own respective AIDS Center. Although it functions as the administrative senior to the other centers, it also provides HIV testing and care, including ART. The AIDS Center does not provide harm reduction services for people who inject drugs (PWID) or non-HIV related medical services. The Center is funded entirely by the Tajikistani government and is administered directly by Tajikistan's Ministry of Health. Antiretroviral therapy is funded entirely by the Global Fund and is provided to all PWH for free. Laboratory testing and other services require a fee.

Study Design and Sample

Staff at the Republican AIDS Center reviewed the HIV registry for people who might meet eligibility criteria and referred them to research assistants who further screened them and, if eligible, completed informed consent procedures. Eligibility included having confirmed HIV, having been to at least one appointment for HIV and having been a migrant worker in Russia. Interviews (N = 34) were conducted in Russian (N = 31) or Tajik (N = 3), depending on participant preference. Because some participants were willing to be interviewed but did not allow voice-recording (N = 19), detailed notes were taken by two interviewers (DJB and MMT) during the interview. Immediately after the interview, the two researchers compiled and reviewed notes to fill in any gaps.

Interviews were semi-structured, guided by the principles put forth by Braun and Clark [48]; interview guides were constructed, and broadly covered stories of migration, and experience of being diagnosed with HIV. Based on the expected demographic stratification of interviewees, a minimum sample size of 25 was set before the onset of research, based on recommendations put forth by Hennink and colleagues, whose empirical findings suggest that 16–24 interviews are sufficient to reach meaning saturation [49]. Interviews were conducted until theoretical saturation; that is, the authors coded each transcript after the interview, and continued collecting interviews until no new themes were identified [50]. All Russian-recorded interviews were transcribed and coded in Russian. None of the Tajik-language interviews were recorded and all notes were taken in English. Participants received 100 TJS (9 USD) for their time and to offset transportation costs.

Analysis

All interviews were coded by DJB and MMT, including recorded and transcribed interviews and content of detailed notes, using thematic analysis [48]. DJB and MMT coded all interviews using NVivo.

The study protocol was deemed exempt by the Yale Ethical Review Board (IRB Protocol ID: 2000025077) and was approved by the Ministry of Health and Social Protection of the Population of the Republic of Tajikistan.

Results

The mean age of participants was 37.9 (SD: 7.7) and 8 were women. Through the interviews, the key themes that were identified included mistrust of Russian authority and health professionals, experiences of ethno-racial stigma and discrimination, difficulty accessing HIV treatment and care, and increased risk-taking following migration.

Story of Migration

In the aftermath of the civil war, Tajikistan was in disarray. Without a source of income, Tajikistanis started to leave to the Russian Federation to work. Migration to Russia occurred at different times and over several waves, but the unifying reason to migrate was largely the same.

Younger interviewees, who did not necessarily remember the fall of the Soviet Union and the ensuing civil war, had similar reasons to leave to Russia: to provide for themselves and their families in the context of large scale unemployment and very few career prospects. There were some exceptions to this general story; one highly educated interviewee left for Russia because he wanted the experience of a new, exciting country, and another interviewee went to Russia to earn a degree at a military academy. One interviewee had no desire to go to Russia herself, but moved there because her husband had decided to relocate, and she had no choice but to join him. Everyone we interviewed had gone to Russia for the first time when they were young.

While some participants had family members already living there, most migrated to Russia without any close contacts. While there, some entered romantic relationships with ethnic Russians, others made friends with Tajikistanis or other Central Asians. A few respondents recalled making friends with ethnic Russians as a source of social support. Overwhelmingly, participants were involved in informal rather than formal social communities [14] leading to a less purposeful and organized social life. While six participants obtained formal registration to work in the Russian Federation, most did not, meaning they could avoid HIV testing.

Living and working without a registration permit or a *patent* did not seem particularly difficult for those interviewees that did not get one. One participant lived and worked in Russia for over 20 years without registration, or even a passport from any country. Some participants got a *patent* when they first moved to the Russian Federation but then chose not to renew it either because they were diagnosed with HIV and therefore became ineligible, or because the costs associated with getting the registration were too high, and it was not necessary to continue living and working.

> Interviewer: Did you register?
>
> Participant: No, even without registration it was fine. They wouldn’t have given me a registration. I worked illegally, because I knew I had this [positive HIV] status. If I got tested again, I thought this is the capital you know. I could get deported. I didn’t want to return to Tajikistan then. I worked unofficially. (interview 11, man, 34 years old).
>
> Interviewer: And when you went [to Russia] without a patent, were you given medicine here [in Tajikistan] to take with you?
>
> Participant: Oh yeah
>
> Q: For how many months were they given?
>
> A: [Enough] for 6 months. I worked there [in Russia] and called [the clinic] here. They gave the medications and my wife brought them [to Russia] on an airplane. (interview 15, man, 41 years old).

The majority of respondents had frequent interactions with the Russian police but reported being able to easily get away from them by offering a bribe. Some respondents had been sent to pre-trial detention (SIZO) or prison in Russia.

Many of our respondents were diagnosed with HIV in Russia. Some were never formally diagnosed, but suspected that they had HIV, and therefore avoided formal testing until they returned to Tajikistan. Others were diagnosed when they returned to Tajikistan, and thereafter returned to Russia. Many of these respondents reported not receiving any HIV counseling after being diagnosed with HIV in Russia.

Respondents reported similar phrasing by medical professionals when diagnosed: “go back to your homeland (*rodina*) if you want to live”. Despite this grim warning, often interviewees stayed in Russia for years, even after diagnosis. Unable to get any HIV medication in Russia, the respondents only returned to Tajikistan when they had no other choice:

> “A little while after diagnosis I started feeling unwell. They brought me from the airport in a stretcher. They showed me a girl at the hospital who had AIDS, soon after they showed me her, she died. They told me look-you don’t take the medication and you have a family, don’t do this to yourself.” (interview 3, woman, 34 years old).

> He fell sick one day while in Russia. He was working on a construction site when he developed a high fever and persistent diarrhea. He found out that he had tuberculosis, hepatitis C, and HIV all in the same day. He didn’t know what hepatitis or HIV were before his diagnosis. He returned to Tajikistan immediately after he was released from the hospital. He was told that he could not receive treatment in the Russian Federation for his diseases outside of the hospital, because he is not a Russian citizen. (interview 20, man, 44 years old).

The most consistent problem relating to staying in Russia was the complete absence of legal or affordable HIV treatment within the country.

While Russian law in theory calls for migrants with HIV to be expelled when their status is disclosed, there is little resources allocated on the part of the government to follow through with deportation [51]. Instead, migrants are added to a list of individuals barred from re-entering the Russian Federation [51]. Because of the high unemployment rate in Tajikistan and the heavy reliance of the Tajik economy on remittances from the Russian Federation, labor migrants feel strongly compelled to remain in Russia unregistered.

Importantly for the progression of HIV infection, Russia does not provide any federally funded treatment for HIV. Therefore, as long as migrants with HIV stay in Russia, their HIV necessarily gets worse. Upon return to Tajikistan, life was substantially more difficult for the majority of our respondents. The participant’s HIV impended major life steps like getting married, building social connections, getting a job or even getting medical care. As health is positively correlated with strong social networks [14], the well-being of participants was limited as their HIV diagnosis prevented them from generating a sense of connectedness in their lives and creating formal and informal social ties.

Although most participants shared a common negative outlook on their current situation, there was also one exception. One respondent recalled being deeply depressed after her HIV diagnosis, to the point that she experienced suicide ideation. With the help of a peer

health worker, however, she was able to recover and continue with her life. That peer health worker's organization eventually gave the woman a job providing support and counselling to people recently diagnosed with HIV, and now she makes more money than she ever did in Russia. She is grateful for the way her life turned out, as the reason for her journey has been fulfilled – albeit in an unexpected way. She reports thanking God every day for her HIV status, as it has led to her finding purpose and self-fulfillment in life.

"Who are You and What are You Doing Here?": Violence, Discrimination, and Weak Bridging Social Capital in the Russian Federation

The bridging of social networks between diverse groups and communities is useful "for linkeage to extranal assets and for information diffusion."[14] Bridging social capital is effective not only for the improved livelihood of individuals but also for the entire communities they belong to [14]. As our participants began their lives in Russia, they reported being systematically excluded from the accumulation of bridging social capital with ethnic Russians as informal and systemic discrimination isolated them and their communities in work, living and healthcare environments [14].

While having trouble making friends was a frequently described experience, participants described a range of relationships with ethnic Russians from negative such as bias, discrimination, harassment, or violence to being treated well, and sometimes even entering romantic relationships with them.

In the participant's work life, discrimination was most evident in pay disparity. Lower pay than that received by ethnic Russians for similar work was a commonly and consistently reported experience; however, many felt that that was not discrimination but an expected reality of working in Russia as a migrant. One respondent stated that she did not feel like she was being discriminated against despite knowing she received lower pay than ethnic Russians.

Although many respondents felt comfortable seeking medical care in the Russian Federation and reported no feelings of discrimination on the part of medical professionals, others reported negative experiences. Some respondents found healthcare professionals in Russia to be rude and cold and made them reluctant in seeking medical care.

Migrants who chose to stay in Russia illegally after finding out their status experienced multiple veils of stigma, including being Tajikistani, a person with HIV and potential other issues like being a substance user. Some respondents experienced incidents of violence at the hand of ultra-nationalists in Russia or hooligans or employers. One participant still had a scar from his attack in Moscow in 2010 where people he described as Nazis stabbed him outside of a grocery store.

> "It was late because we were working at the warehouse, and the bosses trusted me with the key to the warehouse and told me to close late. At half past ten I closed, we worked on Gorkovskaya, and I lived on Sokol. One stop, but the distance was ok. I rode back on a bike, four people stopped near my house, and I, being a kind person, stopped too. When I saw their bats, it was already too late. They began to interrogate me: 'who you are? What are you doing here?

> I told them that I live in this house. I knew the hostess and the owner knew by name, and said that I live with them. They began to ask for money. I told them—here are two thousand rubles, go, if you want to drink, if you want, take it. They began to ask me more. Well, at one time I got angry because I had to work so hard. And what, for them? To bring them money? We started to brawl. I hit two, I managed to, but the other two behind them had clubs, they had bats that is" (interview 12, man, 34 years old).

Lack of Trust: "They Give us ART so that We will Die"

As Putnam notes: "in virtually all societies 'have-nots' are less trusting than 'haves,' probably because haves are treated by others with more honesty and respect."[14]. Moreover, according to Putnam, "victims of crime and violence – wherever they live – express reduced social trust, a perfectly intelligible updating of their views about the trustworthiness of others."[14] As a result of the experiences of violence and discrimination we discuss in the previous section, our participants developed deep distrust of Russian society and state. In this section, we discuss how this distrust shapes engagement with HIV prevention and care [14].

While respondents were generally trusting of their peers, respondents were deeply distrustful of authority. As many of the migrants held quasi-legal or outright illegal migrant statuses in Russia, their lived experience was shaped by police harassment and wrongful imprisonment, healthcare discrimination, denial of labor rights, and a necessity to participate in bribery for basic rights and services. Often Tajikistani migrants lived outside Russia's complex migration law, and as a result, few legal rights and protections were extended to them. Because of their relationship with society and state, both Russian and Tajikistani, respondents are wary of public health measures intended to help them. Several of the respondents did not trust medical professionals outright and thought that the Russian doctors were lying when they diagnosed them with HIV.

Respondents showed deep mistrust of medical professionals in Russia. One participant reported believing that dentists in Russia were ruining his teeth on purpose. One interviewee even believed that a prison guard in Russia injected him with HIV.

A Pamiri man who injected drugs told us that, although he was familiar with a methadone clinic in Khorog, he would not go on methadone. His friends told him that methadone is dangerous and synthetic and is a drug just like heroin is (*tokoy zhe narkotik kak i geroin*). He believes his fellow drug injecting friends more than he did doctors or NGO workers.

This lack of trust sometimes has a protective effect. One interviewee, for example, mentioned that he did not use drugs in Russia because he did not trust the dealers there. Another interviewee, a Pamiri man, reported only sharing needles with people who were also Isma'ili Muslims, thereby reducing the likelihood of infectious disease entering his injection drug use network. More often, however, this lack of trust causes negative consequences. One interviewee reported intense emotional distress because he was suspicious that the doctors in his village had told members of his rural mosque community that he had HIV. He was almost sure that people knew about his status, even though no

one ever confronted him directly about it. The lack of trust in medical professionals also prevented interviewees who inject drugs from getting methadone, though it is free and legal in Tajikistan:

> "And then, the acquaintances whom I asked said: "What are you doing! (Ты что!) Methadone will kill you. All your bones will rot. The government makes this especially for drug addicts, to destroy drug addicts. And then for two years I did not dare to go to methadone …I didn't take it, because those people on methadone who took ART, they gave up on it several times. They are now dead, these people. They are not there. They always told me: "Do not take ART, the government gives it to us specifically to kill HIV-infected people. We are specially put on ARTs so that those with HIV and AIDS will die. …I believed them and did not accept ART. Therefore, my immunity went down…And then when I walked for a month in this state, nothing helped me, my legs were swollen, because I had erysipelas." (interview 34, woman, 45 years old).

"This is not the Anasha You Have in Tajikistan:" Increased Access to Information, Sex and Drugs While in Russia

In this section, we discuss how migration to the Russian Federation and the weak social ties that participants formed there shaped engagement in HIV risk behavior. The cultural landscape of Tajikistan and Russia differ greatly. Traditionally, Tajikistanis center their lives around core family and younger family members often remain in family homes or communes even after marriage [52], thus limiting opportunities to engage in risk. In Russia, migrants generally live apart from families, often with peers who encourage risk and in a setting with more drug opportunities, including new drugs. One Tajikistani migrant began snorting heroin with fellow soldiers in Tajikistan as a teenager, and described it as "just playing around." When he got to Russia, however, he was introduced to other drugs, including injectables:

> Before he left for Russia, he served in the army as a presidential guard (between 1995 and 1999). He started using heroin when he served in the Tajikistani army. One parin, one fellow boy serving in the army, brought some heroin to the brigade and shared it with the other soldiers. He described his initial use of heroin as just playing around (balovanya). He only snorted it in Tajikistan.
>
> When he moved to Russia, the type of heroin there was different, and he started to inject drugs while there. In Russia, he used all the drugs he could get his hands on: coaxil, heroin, methadone [SIC]. If he couldn't get heroin, he would go to the pharmacy and get abulphen, coaxil, polyphen, pyramidol [SIC], or other drugs and take those. He had tried homemade drugs as well (semetchki mostly; also khayan, chernaya), but he didn't like those as much. Mostly he took heroin and street methadone. (interview 20, man 44 years old).

Often use of new drugs derives from misunderstanding of the Russian context, which is unfamiliar and permissive of new risks. This is exemplified by a woman explaining her experience accidentally taking what is likely a synthetic cannabinoid from new friends she met while in Russia. Hemp was first domesticated in Central Asia [53], and smoking

of cannabis (*anasha* in Russian slang), while stigmatized, is relatively widespread in both Tajikistan and Russia [54]:

> "Then they told me, we'll bring it, but don't smoke a lot, this is not the anasha that you have in Tajikistan. Smoke a lot and it will be bad.
>
> I was warned, and I said out of greed that after heroin, anasha won't do anything to me. That's what I thought to myself. Then I smoked two puffs, and for about fifty minutes I felt sick. I began to vomit, my eyes began to cross, and, you know, I began to choke. I ran into the shower, into the cold water, bent to the waist in the bathroom and began to pour cold water on my neck and chest. With cold water to make myself recover. As soon as I raise my head, I leave the bathroom, I begin to feel sick again. I feel dizzy, my eyes cross again like that. I tell them that this is not anasha, anasha does not do this." (interview 34, woman, 45 years old).

Participants reported a host of new experiences once they arrived in the Russian Federation, not just illicit drug use. For some migrants, Russia was the first time they had sex, started smoking, purchased sex work, or even worked for money. Sometimes, migration to Russia elevated risk. One respondent, reported purchasing sex in Tajikistan and Russia, yet in Russia, his increased income allowed him to purchase more sex and more frequently. Another respondent reported much heavier alcohol use in Russia than in Tajikistan.

Discussion

Three main barriers to Tajikistani migrants' transition through the HIV care cascade were identified: (1) Russia's migration ban on PWH counterproductively prevents access to HIV treatment, notable in that study participants had not been deported after learning of their HIV status and instead chose to stay in Russia until their deteriorating health prevented them from remaining there, (2) mistrust of authority figures, including healthcare providers, leads to avoidance of treatment and harm-reduction service utilization with most participants trusting the medical advice of their peers rather than their doctors, and (3) due to pervasive discrimination [55] and self and socially perceived lack of social capital, Tajikistani migrants form weak social ties in the Russian Federation, which exacerbates risk and deters engagement with HIV care.

In this paper, we argue that HIV risk and barriers to HIV prevention and treatment for Tajikistani migrants to the Russian Federations should be understood through the lens of social capital theory and viewed as either bridging or bonding social capital [14]. Bridging social capital involves the broader experience of interactions with others (i.e., local Russians where they migrate and the system imposed on them while there), while bonding social capital involves the lived experience of migrants who return to Tajikistan and how they interface with family and peers. As Leonard [12] argues, social capital is not always benign, as it can serve as a means of exclusion. In this case, there are inequalities among Tajikistani migrants in terms of how much capital different people can accumulate. HIV status precipitates one such inequity, as Russia's migration law interrupts capital accumulation for those who test positive (Table 1).

The migration experience is linked to low socio-economic status, harsh living and working conditions, family separation, lack of social support, new socio-cultural norms, increased despair and substance use, and heightened risk behaviors that are closely associated with HIV. Tajikistani migrants occupy a social status while in Russia that is further complicated by the post-Soviet landscape. In using a social capital framework, we show how the social state of the Tajikistani migrant experience in post-Soviet Russia shapes HIV risk and creates barriers to HIV treatment and care. While Tajikistani migrants gain financial capital by earning money, they struggle with bridging social capital when they confront the politics of the Russian state that criminalizes HIV, outlaws evidence-based prevention, perpetuates anti-immigration sentiments, and forces Central Asian migrants into quasi-legal or illegal migrant statuses. Tajikistani migrants experience "double jeopardy" where they seek to balance economic necessity with heightened social and legal oppression in Russia, that often results in elevated HIV risk and confrontation with adverse health consequences as they try to maintain social capital in Russia.

When migrants accumulate enough social capital, they emerge with a sense of temporary "belonging" [56, 57] – so that a person feels that they belong in the new setting, that they are "at home" there, they feel comfortable with the new way of life, social norms, and values, and they feel accepted [56, 57]. In contrast, those migrants who do not bridge well may very well remain as "outsiders" [58]. Social capital accumulation is not an event that happens once, but it is a process – it is constantly acquired and reacquired through the daily actions of people, and this bridge can be strengthened or weakened over time. Therefore, we argue that the feeling of "thwarted belonging" of Tajikistani migrants living with HIV in Russia can be reversed with changes in social capital [58].

The migration experience also involves frequent absences from home as migrants travel back and forth, resulting in insufficient time to develop and sustain bridging or bonding capital. As they return to the Russian Federation, they often have to rebuild social capital in the following work season by re-establishing ties to their community in Russia, if they lost their old connections. As reported by Kashnitsky and colleagues [35], migrants with HIV are incentivized to (informally and illegally) participate in this cyclical migratory process. For example, they stock up on free, government sponsored ART while in Tajikistan, and illegally bring it to Russia because ART is inaccessible to them there. This ultimately myopic strategy, seems beneficial to Russia as they receive inexpensive migrant labor and do not acquire costs for treating migrants with HIV. The perceived cost savings by Russia, however, do not incorporate costs associated with HIV transmission from Tajikistani migrants to Russian citizens in the absence of ART [31]. HIV treatment as prevention, an evidence-based doctrine endorsed by the World Health Organization, would render HIV as untransmissible between individuals when a PWH is on ART and virologically suppressed [59]. A more grounded policy would be for the Russian Federation to legalize the migration of PWH and provide accessible, low-cost (or free) ART – the small price of doing business. Alternatively, if ART were not provided, they could consider allowing migrants with HIV to legally transport it from their home countries. Treatment as prevention policies not only provide a sound public health strategy for controlling the volatile HIV epidemic in Russia, but also reduces stigma for all people with or at risk for HIV and meets international human rights standards. Such a strategy also aligns with sound economic policies and would

reduce corruption by removing incentives for bribery as many migrants bring things illegally (including ART) and do so with bribery. As such, informed policies would align both public health and safety mandates for migrants in Russia, as well as for Russian citizens.

Pervasive discrimination by governmental and non-governmental actors, leads to Tajikistani migrants forming weak bridging social capital in Russia as they struggle to create meaningful networks, trust and reciprocity outside of the migrant community. Weak bridging social capital shapes HIV risk behavior and mistrust of authority figures, including healthcare providers. HIV stigma, on the other hand, produces weak bonding social capital within Tajikistani and migrant communities. Even when migrants return to Tajikistan, HIV discrimination continues to produce weak bonding social capital and contributes to local myths and misrepresentations about ART and harm reduction services (e.g., methadone or SSPs).

The stigmatization and exclusion of Tajikistani migrants from the available HIV treatment and care system in Russia results in reliance on informal knowledge acquired through social networks. Informal knowledge and social networks can function as both a resource and a liability for migrants. Previous studies on undocumented migrants show that the way migrants experience their situation and handle crises changes over time, as their social networks, and consequently, their knowledge is less developed at the beginning of their migration journey [60]. The importance of migrants establishing social networks in the absence of their families and local communities is counteracted by the dangers that come through new social relationships in the context of migration [60].

The first step to address bridging social capital impediments for Tajikistani migrants as they transition through the HIV cascade is abolishing the migration ban on PWH in Russia. This alone can alter social capital impediments for Tajikistani migrants, including how they interact with Russian nationals. Such a structural change can also address factors like stigma and discrimination. Presently, according to Russia's migration law, foreigners with HIV, with some exceptions, cannot reside on Russian territory. The additional ban on ART for migrants further undermines bridging social capital. In practice, the high instances of police corruption and the underfunding of deportation mechanisms lead to low deportation rates following positive diagnoses, principally by how Tajikistani migrants must bribe authorities and ingratiate themselves to others to remain there. HIV criminalization further weakens their bridging social capital as it pushes migrants into a space outside Russian law where they are deemed "illegal". The deterioration in health migrants experience in Russia due to the HIV ban disrupts their migration trajectory as they are forced to return home and seek treatment there – i.e., the engagement and viral suppression components of the HIV care cascade involves returning to Tajikistan. The interruption of their migration trajectory further weakens migrants bonding social capital as they lose both financial resources from their work, but also the social systems of support they build in migrant communities in Russia, and are forced to return home to engage in HIV care, often facing heightened discrimination because of their HIV status and a deteriorating financial position as they lose their economic livelihood by returning [60–61].

Migrants oscillate their social relationships between necessity and vulnerability, as their social ties shape their risk factors and their access to knowledge and resources [60]. For example, mistrust of authority figures in Tajikistani migrant communities leads to a reliance on migrant peers for medical advice and exacerbates HIV risk as migrants avert harm reduction and other healthcare services. The social capital of migrants is also limited by the social and cultural structures in their new country [62]. If countries like Russia do not provide migrants with institutional support such as healthcare, migrant dependence on informal but not necessarily reliable social structures creates insecurity [63], and can increase their risk for illness such as HIV. The stigmatization and exclusion of Tajikistani migrants from the regular HIV treatment and care system in Russia creates a reliance on informal knowledge acquired through social networks. Informal knowledge and informal social networks can function as both a resource and a liability for migrants. Previous studies on undocumented migrants show that the way migrants experience their situation and handle crises changes over time, as their social networks, and consequently, their knowledge is less developed at the beginning of their migration journey. The importance of migrants establishing social networks in the absence of their families and local communities is counteracted by the dangers that come through new social relationships in the context of migration. To address the problem of fragile social networks, Tajikistani public health policymakers can invest in building networks of community educators that can work with Tajikistanis with HIV, PWID, and migrant laborers more generally. There are already existing peer health worker groups for PWH and PWID in Tajikistan (e.g., SPIN-PLUS, Equal Opportunities, and the Tajik Network of Women Living with HIV), which could be expanded to increase participation and broaden the influence of the organization within local communities. The one respondent who had a positive outlook on her life now that she is HIV-positive reported high engagement with and support from a peer health network. A policy of increasing the role of community health workers is likely to be particularly effective as the participants in our sample consistently trusted their peers more than doctors or others in positions of power when it came to healthcare knowledge.

Despite the many important findings, limitations remain. Due to ethical concerns, participants were asked for permission to record the interview. Many, however, refused to be recorded, opting for the interviewer to transcribe verbatim notes instead. A lack of recorded interviews limits the subtlety of coding. Additionally, the interviews were made anonymous to guarantee the safety and privacy of the interviewees. Anonymity of participants meant that the researchers could not follow up with participants to validate statements made about clinical status by the participant. All interviews were conducted in Dushanbe's central HIV clinic. The results of this qualitative study may not, therefore, represent regional variation in the experiences of migrants in Russia. Participants from remote regions (such as Gorno-Badakhshan) who were in Dushanbe for treatment, however, were purposively recruited, potentially mitigating this limitation. Finally, it was not possible to find migrant men who have sex with men (MSM) or recruit them into our sample. Gulov and colleagues have found a high level of stigma, including in the healthcare sector, towards MSM in Tajikistan which impacts their ability to seek testing and care [64]. It may have been for this reason that migrant MSM were reluctant to come to the HIV center at the call of staff.

Finally, 24% of participants in our sample were women (compared to 16% of all Tajikistani migrants with HIV [23], meaning women were oversampled relative to their share of migrants with HIV. The dominant attitudes toward HIV, sex, and drug use in both Tajikistan and Russia may have prevented many women, and more conservative men, from participating in our study. For the same reason, it is possible that participants withheld crucial information about their mechanisms of HIV transmission. At the same time, as this qualitative study did not aim to determine the prevalence of risk behavior, per se, but to explore barriers to testing, treatment, and care, it is unlikely that this limitation biased our results.

Conclusion

This is the first qualitative study to comprehensively examine the HIV treatment cascade among Tajikistani migrants with HIV to the Russian Federation. This paper found three main barriers to movement along the care cascade; these were: (1) Russia's migration ban on migrants with HIV, (2) general distrust of authority figures and health professionals, and (3) weak bridging social capital in the Russian Federation and altered bonding social capital upon their return. We propose several strategies that could ameliorate the cascade of care for this population, including abolishing Russia's HIV migration ban and investing in peer health workers in Tajikistan. A failure to introduce a treatment as prevention approach to HIV-positive migration in Russia will result in exacerbated HIV risk in the only region in the world where the HIV epidemic continues to grow.

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Table 1

Demographics

Demographic variable	Category	Frequency (%)
Gender	Female	8 (23.5)
	Male	26 (76.5)
Age	18–25	3 (8.8)
	26–30	1(2.9)
	31–40	16 (47.1)
	41–50	9 (26.5)
	Over 50	3 (8.8)
Education	Less than high school degree	9 (26.5)
	High school degree	15(44.1)
	Bachelor degree	5 (14.7)
	Technical college	3 (8.8)
Religion	Ismai'ili	1 (2.9)
	Sunni	27 (79.4)
	Other[a]	4 (11.8)
Employment status	Employed	8 (23.5)
	Part-time	4 (11.8)
	Unemployed	15 (55.6)
Marital status	Married	15 (44.1)
	Engaged	2 (5.9)
	Divorced	9 (26.5)
	Single	6 (17.6)
Risk behavior[b]	Formerly incarcerated	12 (35.3)
	MSM	0 (0)
	PWID	11 (32.4)
	Sex worker	2 (5.9)
	Using sex worker services	8 (23.5)
Time since return[c]	Less than six months	7 (20.6)
	Six months to a year	3 (8.8)
	One to three years	8 (23.5)
	Three to five years	4 (11.8)
	Five years to seven	4 (11.8)
	Seven years or more	4 (11.8)

Due to missing data, values may not necessarily sum to 100% (n = 34). As part of informed consent, participants were instructed to not answer any questions that they did not feel comfortable with, or that they did not want to answer. Therefore, we do not have complete information (e.g., year of birth) for all participants

[a]Other religions include Irreligious, non-denominational Muslim, Orthodox Christian, and Pentecostal Protestant Christian

[b]In some cases, interviewees exhibited more than one risky behavior and therefore were double counted for demographic purposes

[c]Time since return is calculated until the day of the interview (occurring between July–August 2019)