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Provider–patient experiences and HIV care utilization among people living with HIV who inject drugs in St. Petersburg, Russia

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Abstract

Providers' disrespect and abuse of patients is a recognized but understudied issue affecting quality of care and likely affecting healthcare utilization. Little research has examined this issue among people living with HIV (PWH) who inject drugs, despite high stigmatization of this population. No research has examined this issue in the context of Russia. This study assesses patients' reports of disrespect and abuse from providers as a barrier to healthcare and examines the association between these reports and HIV care outcomes. We conducted a cross-sectional analysis of the associations between disrespect/abuse from health providers as a barrier to care and the following HIV care outcomes: (i) anti-retroviral treatment (ART) uptake ever, (ii) past 6-month visit to HIV provider, and (iii) CD4 count. Participants ($N = 221$) were people living with HIV who injected drugs and were not on ART at enrollment. Two in five participants (42%) reported a history disrespect/abuse from a healthcare provider that they cited as a barrier to care. Those reporting this concern had lower odds of ever use of ART (adjusted odds ratio 0.46 [95% CI 0.22, 0.95]); we found no significant associations for the other HIV outcomes. We additionally found higher representation of women among those reporting prevalence of disrespect/abuse from provider as a barrier to care compared to those not reporting this barrier (58.1% versus 27.3%). Almost half of this sample of PWH who inject drugs report disrespect/abuse from a provider as a barrier to healthcare, and this is associated with lower odds of receipt of ART but not with other HIV outcomes studied. There is need for improved focus on quality of respectful and dignified care from providers for PWH who inject drugs, and such focus may improve ART uptake in Russia.

Keywords: HIV; Russia; provider disrespect; PWID

Introduction

HIV incidence globally is declining, but HIV infections over the past decade have increased in Eastern Europe and Central Asia, largely driven by unsafe injection drug use [1]. Global Fast Track 2030 targets, established in 2014, seek to end the AIDS epidemic by 2030 [2]. They envision a goal 95–95–95 by 2030—95% of people living with HIV know their HIV status, 95% of people who know their status are receiving treatment, and 95% of people on HIV treatment have a suppressed viral load. A target of zero discrimination by 2020 was set, and an end to discriminatory laws and discrimination in healthcare settings. There is little research on provider discrimination against people living with HIV (PWH) and

people who inject drugs (PWID) in Russia, despite some qualitative evidence on patient concerns regarding providers' stigma and abuses against them being a barrier to care [3]. This paper focuses on experiences with disrespect or abuse from a provider reported by PWH as a barrier to healthcare and its association with receipt HIV care. Findings from this work can inform efforts for Fast Track 2030 targets in Russia, by providing insight into negative experiences in healthcare settings and factors affecting HIV treatment for those who know they are HIV-infected.

Studies on HIV stigma—i.e. negative attitudes that reinforce discrimination against and deny full social acceptance of PWH—receive more attention than those on direct

experiences of disrespect and abuse from providers faced by PWH [4]. Qualitative research from Russia indicates that HIV stigma, including pervasive social views that those infected with HIV through injection drug use or sex trade involvement are immoral, leads to delayed receipt of HIV care among those at risk, due to anticipation of disrespect or abuse from providers [5, 6]. However, quantitative examination of HIV stigma in the country has focused on patient self-stigma rather than providers' stigma of patients [7], impeding understanding of whether and how providers affect patients' HIV care utilization in the Russian context. Nonetheless, findings on patient HIV and substance use stigma, which include patient fears of discrimination and abuse more broadly than just in clinical care, provide important insights [4]. Research from Russia shows that among PWH who inject drugs, there are no significant associations between HIV stigma and HIV care outcomes, including receipt of HIV care and use of ART [8–10]. However, a combination of high HIV stigma and high substance abuse stigma, compared with low stigma on both, is associated with lower odds of healthcare in this population [9].

These studies demonstrate that patients' HIV stigma, a variable related to patient beliefs, can affect HIV care, but no studies examine the role of provider beliefs and behavior in Russia. While there are measures of providers' stigma of HIV patients, largely from research in North America, these require reports from providers rather than patients [11–14]. Patients cannot know the beliefs of the provider, but they can speak of the negative experiences they have faced from providers, knowing that these negative experiences may stem from provider HIV stigma as well as provider substance abuse stigma [15]. Unfortunately, there has been little study on PWH reports on provider discrimination and abuse, despite academic commentaries calling out this concern for more than a decade [16, 17]. There is some growing work examining provider mistreatment of patients as part of quality of care, but most of this work centers on patients' experiences during childbirth, mostly in sub-Saharan Africa and South Asia. This research does reveal that these experiences disproportionately affect marginalized populations and impede healthcare utilization [18–20]. There is some cross-national evidence on providers' disrespect and physical or verbal abuse of PWH PWID [21], but it did not examine associations between these abuses and HIV care.

Russia offers an important and interesting context in which to understand provider disrespect and abuse, because Russia ensures healthcare via their public health system, facilitating universal access to care but at the same time leaving patients concerns with provider disrespect and abuse with little recourse [22]. We are aware of no literature examining disrespect and abuse of patients by providers in the Russian context, and consequently no study examining the association of this with healthcare use. Experiences of disrespect or abuse from healthcare providers may reinforce this self-stigma and may affect patients' comfort or willingness to utilize care. This can be a particular concern for PWH where care offers access to anti-retroviral treatment (ART), medication that is both lifesaving (for the PWH) and of public health benefit (by reducing risk of transmission via lower viral loads) [23]. Focus on disrespect and abuse from providers, a behavioral experience measure, rather than on stigma, an attitudinal measure, allows us to assess patient experiences with the

healthcare system as a potential barrier to care. As discussed above, recent research on provider disrespect and abuse measurement comes from the field of maternal health; disrespect and abuse measures cover provider perpetration of physical abuse, sexual abuse, psychological or verbal abuse, humiliation, discrimination, and improper care (specifically, denial of care, provision of non-consensual care, and use of contraindicated or improper procedures) [18, 19]. Disentangling of disrespect and abuse in these behaviors is difficult; hence, the term 'disrespect and abuse' is used in tandem to allow for more comprehensive coverage of these types of behaviors from providers [18]. Disrespect and abuse from providers are directly counter to quality healthcare which should offer care that is dignified, respectful, and free of violence and discrimination [24]. However, too often, health systems inadequately conceptualize and monitor quality of care, which can leave patients vulnerable to disrespect and abuse by providers [22]. The Russian Federation has sought to improve quality of care over the past decade, though here too with limited monitoring of quality of care [22, 25]. Patient assessments may be a useful means of monitoring quality of care, and this work can offer insight into whether patients will disclose negative clinical experiences in the context of a research survey.

In this study, we examine the prevalence of disrespect and abuse as a barrier to care, reported by PWH who inject drugs recruited from an in-patient narcology hospital in St. Petersburg, Russia. Secondly we evaluate whether those participants reporting a history of disrespect and abuse from a health provider have lower odds of engaging in HIV care. We include in our definition of HIV care the following outcomes: ART ever (primary), recent HIV clinical visit (secondary), and lower CD4 count (secondary). Given the low rates of ART in Russia and the utility of CD4 counts offering a more objective clinical indicator rather than self-report data, we focused on this as our secondary outcome rather than ART adherence. Findings from this work can offer important insight to guide programs on improvements in quality of care for PWH and PWID with the goal of improved healthcare utilization and better health outcomes. Such findings can be of particular importance in Russia, given the capacity of the state to address care in its large public health system. These findings can be particularly important to support HIV care for PWH who inject drugs, given that new HIV infections in Russia increased by 72% over the past decade, and half of all new infections in Russia are among PWID [26].

Methods

Study design and participants

We performed secondary cross-sectional analyses of baseline data from the Linking Infectious and Narcology Care—Part II (LINC-II) study [27]. LINC-II is a two-armed randomized controlled trial evaluating an intervention combining rapid initiation of ART, receipt of naltrexone for opioid use disorder (OUD), and 12 months of strengths-based case management among PWH with OUD in St. Petersburg, Russia. LINC-II participants ($N = 221$) were recruited from a government-funded City Addiction Hospital (CAH) from September 2018 to December 2020. Key eligibility criteria included: (i) ≥ 18 years; (ii) HIV-positive; (iii) history of injection drug use (ever); (iv) current OUD (diagnosed by psy-

chiatrist as part of intake); (v) no ART use in 30 days prior to hospitalization. Further details on study recruitment are available elsewhere [27].

CAH offers inpatient narcology treatment at no cost to St. Petersburg residents with a drug or alcohol use disorder. Individuals must register with the government as having a drug or alcohol use disorder. Services include detoxification and inpatient rehabilitation for a period of 1–4 weeks [27]. Rapid HIV testing is standard procedure for all patients at entry, unless they already registered as a patient with HIV. An HIV physician makes weekly visits to the narcology hospital, and eligible patients can receive ART at no cost.

Data collection

Trained research staff collected survey data via electronic tablets. Participants self-administered all sensitive items, including disrespect/abuse from a medical provider as a barrier to care. All participants completed CD4 count testing at baseline. The Institutional Review Boards of Boston University Medical Campus and Pavlov University approved this study, and we registered our trial on clinicaltrials.gov (NCT03290391).

Measures

Our primary outcome of interest was self-reported ART use ever, and secondary outcomes were recent HIV care, defined as meeting an HIV provider in the past 6 months and CD4 count.

The primary independent variable was self-report of disrespect/abuse by a provider as a barrier to care, created for this survey based on prior research identifying this issue as a concern [18, 21], as well as expert input. We asked the following question: ‘People can have many different types of problems getting their medical care. Please indicate “NO, I disagree” or “YES, I agree” if you have not gotten needed medical care in the past six months... (because you) have been disrespected or abused by a healthcare provider in the past.’ We did not specify definitions of disrespect and abuse in this study.

We included the following covariates: age, sex, income, history of incarceration, years since first positive HIV diagnosis, depressive symptoms (Community Epidemiology Scale-Depression (CES-D)) [28], alcohol use (AUDIT) [29], social support (Duke-UNC Functional Social Support) [30], and general health. For income, we defined lower income as $\leq 20\,000$ rubles (equivalent to US\$271–296 in the period of data collection, 2018–2020) based on our prior studies from St. Petersburg and with this value corresponding to the sample median. Based on the Purchasing Power Parity (PPP) between Russia and United States (28.804), 20 000 rubles would roughly correspond to around US\$693.94 (using the following for PPP: <https://data.oecd.org/conversion/purchasing-power-parities-ppp.htm>). This value may fluctuate in the 2023 economy and political context. We selected these covariates based on prior research demonstrating their associations with uptake of HIV care in Russia [27]. Further details on measures with citations are available in our protocol paper [27].

Statistical analysis

We conducted descriptive statistics to characterize study participants overall and by whether participants reported disrespect/abuse by a provider as a barrier to care. We had no

missing data, and thus we were able to include all participants in analyses. We then used multiple regression models to evaluate the association between our independent variable and HIV care outcomes. We used logistic regression for binary outcomes, ever ART use and recent HIV care, and we used linear regression for CD4 count. We conducted confirmatory analyses using log transformed CD4 count, and the results were consistent with the untransformed CD4 count. We present findings with the untransformed variable to simplify interpretation. We report odds ratios (OR) and 95% confidence intervals (CIs) from the logistic regression models and betas (representing mean differences between exposure groups) and 95% CIs from the linear regression model. We used two-tailed tests and a significance level of 0.05 for all analyses, and we conducted all analyses using SAS 9.4.

Results

Participants ($N = 221$) had a mean age of 37 years (range 25–47); the majority were male (59.7%), married (55.2%), and completed higher level secondary education or greater (11 years; 78.7%) (Table 1). On average, participants were diagnosed with HIV 10 years prior to the survey; 30.8% met with an HIV provider in the past 6 months. Mean CD4 count was 415 (range 13–1482); and 33.9% had ever been on ART. Half of the participants (48.1%) reported some level of harmful alcohol use (AUDIT score of 8 or higher); 43.6% reported low social support; 76.9% reported depressive symptoms (CES-D scores of 16 or higher), and 20.8% reported poor health.

Two in five participants (42.1%, 95% CI 0.35, 0.49) reported experiences of disrespect/abuse from a provider as a barrier to care. In bivariate analyses, we found that those reporting yes on our disrespect/abuse measure compared to those reporting no on this measure were more likely to be female (58.1% vs 27.3%), lower income (39.8% vs 24.2%), depressed (87.1 vs 69.5%), and have lower social support (54.7 vs 35.3%), but less likely to report a history of incarceration (58.7% vs 75.6%). We found no notable differences between disrespect/abuse from a provider as a barrier to care for our HIV outcomes in bivariate analyses (Table 1). However, in adjusted models, participants reporting these experiences as a barrier to care had lower odds of ever having been on ART (adjusted odds ratio (aOR) 0.46 [95% CI 0.22, 0.95]; $P = 0.04$) (Table 2). For the secondary HIV outcomes, we found no statistically significant associations in adjusted analyses.

Discussion

Statement of principal findings

We conducted this study to assess the prevalence of disrespect and abuse by healthcare providers to care for PWH who inject drugs in St. Petersburg, Russia, and to examine the association between this exposure as an identified barrier of care and the following HIV outcomes: ART use ever (primary), recent HIV care, and CD4 count. We found that a large minority of participants (42%) reported a history of disrespect/abuse from a healthcare provider and noted it as a barrier to care, offering a first-time demonstration of how common this disrespect/abuse experience is for PWH who inject drugs in St. Petersburg, Russia. We found a

Table 1. Characteristics of PWH who inject drugs in St. Petersburg, Russia stratified by history of disrespect/abuse from health provider as a barrier to care ($N = 221$).

	Overall ($N = 221$)	Disre- spect/Abuse from provider as barrier to care ($n = 93$)	No disre- spect/abuse from provider as barrier to care ($n = 128$)
Mean age (years) (SD)	37 (5)	36 (5)	37 (5)
Sex ^{***}			
Male	132 (59.7%)	39 (41.9%)	93 (72.7%)
Female	89 (40.3%)	54 (58.1%)	35 (27.3%)
Income [*]			
0–20 000 rubles	68 (30.8%)	37 (39.8%)	31 (24.2%)
20 001+ rubles	153 (69.2%)	56 (60.2%)	97 (75.8%)
Ever incarcerated ^{**}	147 (68.4%)	54 (58.7%)	93 (75.6%)
Mean years since HIV diagnosis (SD)	10 (6)	10 (6)	10 (6)
Health			
Poor	46 (20.8%)	22 (23.7%)	24 (18.8%)
Excellent to fair	175 (79.2%)	71 (76.3%)	104 (81.3%)
Depression ^{**}			
Yes	170 (76.9)	81 (87.1%)	89 (69.5%)
No	51 (23.1%)	12 (12.9%)	39 (30.5%)
Alcohol use			
Possible depen- dence	49 (22.7%)	21 (22.8%)	28 (22.6%)
Harmful use	21 (9.7%)	6 (6.5%)	15 (12.1%)
Hazardous use	34 (15.7%)	15 (16.3%)	19 (15.3%)
Abstinent/Low risk	112 (51.9)	50 (54.3%)	62 (50.0%)
Social support ^{**}			
High	114 (56.4%)	39 (45.3%)	75 (64.7%)
Low	88 (43.6%)	47 (54.7%)	41 (35.3%)
Ever on ART	75 (33.9%)	28 (30.1%)	47 (36.7%)
Met with HIV provider, past 6 months	68 (30.8%)	29 (31.2%)	39 (30.5%)
CD4 count mean (SD)	415 (286)	397 (281)	429 (290)

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.0001$.

statistically significant association between this barrier and ever ART use, with participants reporting provider disrespect/abuse as a barrier to care having only about half the odds of ever having received ART, compared to those not reporting this experience. Interestingly, this association was seen in the adjusted but not the simple regression model. Possibly this is because gender, which was associated with both reports of providers' disrespect/abuse and ART, served as a negative confounder for our disrespect/abuse variable. These findings indicate that, while female gender is a key driver for ART uptake in Russia, disrespect/abuse from a provider is also meaningful after accounting for this strong gender effect.

Findings also suggest such experiences may be more common among those from more socially marginalized groups or vulnerable circumstances, such as women and those with depressive symptoms. Previous studies examining provider disrespect and abuse in maternal care in other national settings have yielded similar findings concerning greater vulnerability for such abuse among socially vulnerable women [18]. Our data suggesting higher prevalence of disrespect/abuse from a provider for females compared with male participants correspond with prior research which found stigmatization

from providers to be a significant barrier to care for women in the sex trade [31], a more common behavior for female than male PWID in St. Petersburg [32]. Those with a history of incarceration history are less likely to report disrespect/abuse from a provider as a barrier to care in crude analyses. Healthcare in prison may affect perceptions of treatment by providers or views of provider disrespect/abuse as a barrier to care, but that does not mean incarceration is linked to better HIV outcomes. Prior research documents that prior incarceration is significantly and positively associated with patient HIV stigma [33–35]. These more descriptive findings from the current study warrant higher-level analysis in future research.

We found no statistically significant associations between history of disrespect/abuse from a healthcare provider as a barrier to care and recent receipt of HIV care or CD4 count. Our use of a lifetime assessment of the main independent variable may have yielded insufficient specificity to show an association with recent or current HIV outcomes. In addition, our study may have been underpowered as LINC-II was not designed to evaluate the current research questions. To assess this, we conducted a post-hoc power calculation for the recent receipt of HIV care variable. Assuming 30% of those who did not self-report disrespect/abuse by healthcare provider as a barrier to care received HIV care in the past 6 months (as observed in our sample), our study would have 80% power to detect an OR as small as 0.34. Our study was therefore likely underpowered to detect associations of the observed magnitude. We also note that the apparent lack of association may indicate that other barriers to care or health for this population in Russia are more dominant determinants of HIV outcomes. Prior research indicates that active substance use and desire to avoid abusive policing prevent PWID from obtaining HIV care and narcology treatment [32]. Abusive policing practices continue to be a concern in this context, particularly among PWID, with indications that women PWID are particularly vulnerable to abuses from police [32]. In such a context, the relative severity of disrespect/abuse by providers may seem less consequential to decision-making for care, and the prioritization of care may be a greater concern. Less than one-third of our sample met with an HIV care provider in the past 6 months, and only one-third of participants had ever been on ART despite the sample reporting an average of 10 years since initial HIV diagnosis.

Strengths and limitations

While this paper offers important insight into patient treatment by providers and the roles this may have in affecting healthcare utilization, the study should be considered in light of certain study limitations. With regard to our measure, which we developed as a single item for this study, we do not know when the disrespect/abuse happened, by what type of provider, what form it took, or how often it occurred; nor are we able to distinguish between exposure to provider disrespect/abuse and viewing such an exposure as a barrier to care. We do not know if this disrespect/abuse is tied to providers' stigma and discriminatory practices against PWH who inject drugs, or is typical practice regardless of the patient population. Understanding this would be valuable to guide the development of potential interventions for providers. Previous studies have found that addressing stigma among health providers can improve healthcare use and health outcomes,

Table 2. Regression models to assess the association between history of disrespect/abuse from health provider as a barrier to care and HIV health outcomes among PWLH who inject drugs in St. Petersburg, Russia ($N = 221$).

	ART ever aOR (95% CI)	HIV care provider in past 6 months aOR (95% CI)	CD4 count adjusted mean difference (95% CI)
History of disrespect/abuse from health provider as a barrier to care	0.46 (0.22, 0.95)*	1.12 (0.55, 2.25)	-15.51 (-109.73, 78.72)
Age (continuous)	1.01 (0.94, 1.09)	0.99 (0.92, 1.06)	-10.64 (-20.40, -0.88)*
Female (ref male)	2.91 (1.33, 6.38)**	0.77 (0.36, 1.64)	-112.04 (-214.09, -9.99)*
Income 20 001+ (ref 0–20 000)	0.80 (0.38, 1.67)	1.01 (0.49, 2.10)	-32.64 (-129.46, 64.17)
Ever incarcerated (ref No)	1.35 (0.64, 2.87)	1.16 (0.55, 2.45)	-108.79 (-207.57, -10.00)*
Number of years since HIV diagnosis (continuous)	1.11 (1.05, 1.17)**	1.05 (1.00, 1.11)	-5.85 (-12.75, 1.06)
Poor health (vs excellent to fair health)	0.76 (0.33, 1.75)	1.59 (0.72, 3.49)	51.93 (-57.73, 161.58)
High depressive symptoms (higher score ≥ 16 vs lower score <16)	0.60 (0.27, 1.35)	0.62 (0.28, 1.37)	16.82 (-92.32, 125.96)
Alcohol use (ref abstinent/lower risk use)			
Hazardous use	0.50 (0.19, 1.34)	0.45 (0.17, 1.22)	103.93 (-22.29, 230.16)
Harmful use	0.79 (0.27, 2.35)	0.67 (0.23, 1.98)	95.67 (-48.68, 240.03)
Possible dependence	0.65 (0.29, 1.48)	0.69 (0.31, 1.54)	-4.96 (-111.28, 101.36)
Low social support (ref high social support)	1.71 (0.86, 3.40)	0.93 (0.48, 1.83)	-35.98 (-125.12, 53.17)

* $P < 0.05$, ** $P < 0.01$.

particularly for socially marginalized groups, such as PWH who have lower income or have low social support [36], groups also more likely to report disrespect/abuse from a provider as a barrier to care in our study. We also rely on self-report. This may yield recall bias and under-reporting—or possibly over-reporting—of provider disrespect/abuse and recent use of HIV care. The study sample from a narcology hospital and not on ART may limit generalizability, although findings likely hold value for PWH who inject drugs in Russia. Finally, this study involves cross-sectional analysis with patients, and longitudinal analyses inclusive of triangulated data from providers, including providers' stigma of PWH, may offer additional insight.

Interpretation within the context of the wider literature

Study findings offer first time insight into the pervasiveness (reported by two in five participants) of PWH's experiences with disrespect/abuse from a healthcare provider, and that such experiences were associated with lower odds of ART utilization. While this is the first study focusing on direct disrespect and abuse of PWH patients, it corresponds with growing qualitative research from Africa, Asia, and North America highlighting PWH's experiences of disrespect and abuse from providers and its role in impeding healthcare utilization [37–39]. Our research extends this work by showing its potential effects on ART uptake quantitatively, and with PWH who inject drugs.

Implications for policy, practice, and research

Findings document the need to focus on health system change, training providers in respectful care, monitoring provider treatment of PWH and other vulnerable groups, and holding accountable providers who are abusive to patients. While these findings highlight the importance of assessing provider abuse/mistreatment as a barrier to care, the limitations of our measure also point to the need for understanding these issues distinctly—provider abuse/mistreatment occurrence and separately assessing the issue as a barrier to care. Future research should also include an additional question to determine

whether the abuse experiences are attributable to patients' use of injection drugs, HIV infection, or the combination. Longitudinal research examining changes in provider disrespect/abuse over time as well as its influences on patients over time would also offer important insight.

Conclusions

In sum, this study observed that more than two in five participants in this sample of PWH who inject drugs view past disrespect/abuse by a health provider as a barrier to care, and those reporting this have significantly lower odds of ever having been on ART. We need further research to clarify the nature of the disrespect/abuse, the cases where history of disrespect/abuse from a provider is and is not viewed as a barrier to care, and how this type of barrier affects ART uptake. Simultaneously, improved quality and respectful healthcare should be a monitored and made a priority for PWID and PWH.

Supplementary data

Supplementary data is available at *INTQHC* online

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Data sharing statement

Data collected for the LINC-II study are available to interested investigators in the URBAN ARCH Repository: www.urbanarch.org.

Author contributions

JHS, KL, AR, and EK designed the study and secured funding. AR wrote the first draft of the manuscript. DMC participated

in study design and led statistical analyses. LR carried out statistical analyses. NG and VT participated in study design and study implementation. EB and EK led study implementation in the field. All authors critically reviewed and provided feedback on the article. AR finalized the manuscript based on all inputs from co-authors.

Ethics and other permissions

The Institutional Review Boards of Boston University Medical Campus and Pavlov University approved this study, and we registered our trial on clinicaltrials.gov (NCT03290391).

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