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ORIGINAL PAPER

The Role of Internalized Stigma in the Disclosure of Injecting Drug Use Among People Who Inject Drugs and Self-Report as HIV-Positive in Kohtla-Järve, Estonia

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Abstract Disclosure of injecting drug use and its associations with stigma have received very little research attention. This cross-sectional study examined the role of internalized HIV and drug stigma (i.e., self-stigmatization) in the disclosure of injecting drug use among people who inject drugs (PWID) self-reporting as HIV-positive (n = 312) in Kohtla-Järve, Estonia. The internalization of both stigmas was relatively high. On average, PWID disclosed to three disclosure targets out of seven. Disclosure was highest to close friends and health care workers and lowest to employers and casual sex partners. Internalized drug stigma was negatively associated with disclosure to other family members (AOR = 0.48; 95% CI 0.30–0.77) and health care workers (AOR = 0.46; 95% CI 0.25–0.87). Internalized HIV stigma was positively associated with disclosure to health care workers (AOR = 2.26; 95% CI 1.27–4.00). No interaction effect of internalized stigmas on disclosures emerged. We concluded that effects of internalized stigmas on disclosures are few and not uniform.

Keywords Injecting drug use · Disclosure · Internalized stigma · HIV · Estonia

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Introduction

Estonia is among the countries with the highest prevalence of people who inject drugs (PWID) [1, 2]. Injecting drug use has been the driving force behind the HIV epidemic in Estonia [2, 3]. It is estimated that PWID constitute around one percent of Estonia's population [4] and approximately 45–65% of PWID are infected with HIV [5–9]. Particularly in regions where the spread of HIV is primarily concentrated among PWID, better understanding of self-disclosure of injecting drug use and the potential role of stigmas in that process could be valuable in designing and implementing interventions for curbing the spread of HIV. Among HIV-positive PWID, failure to disclose injecting drug use could, for example, leave their non-injecting sex partners unaware of the heightened risk of infection, deprive PWID of social support, and hinder drug and/or HIV treatment utilization. But since disclosure of injecting drug use and also drug-related stigma have received little attention in previous research the former statements are mostly speculative at this point. Although there is adequate evidence of the influence of HIV-related stigma on the lives of people living with HIV/AIDS (PLWHA), there has been little research on how drug-related stigma might affect PWID [10, 11] and how it might facilitate the spread of HIV [12]. Also, in Estonia, the stigma related to HIV has received more attention [13–15] whilst the problem of the stigma related to injecting drugs has been raised [16] but not thoroughly addressed. Likewise, HIV serostatus disclosure has been studied widely [13–15, 17–21] but disclosure of injecting drug use has received considerably less attention. Moreover, there has been little research exploring the relationships between stigma and the failure to disclose injecting drug use. More research is thus needed to

better understand the role of stigma in the disclosure of injecting drug use.

Stigma and discrimination are inseparable parts of the lives of PWID [10, 22, 23] and PLWHA [13–15, 23–25]. Generally a stigmatized person or group is considered to possess a characteristic that is regarded as undesirable and discrediting (i.e., stigma) by the society in which they live, and therefore the person or group is labeled, considered inferior, condemned socially, rejected and excluded [26–28]. Individuals are stigmatized particularly strongly for possessing stigmas which they are perceived to be responsible for acquiring [25]. Stigmas associated with drug users and PLWHA are highly negative, and discrimination against such groups is socially accepted and expressed openly [29]. Stigma can have multiple negative impacts on the lives of stigmatized people [22–24, 27, 28, 30] through several distinct mechanisms (e.g., enacted stigma or discrimination, anticipated stigma, internalized stigma) [31–34]. The need to distinguish between these different mechanisms has been emphasized [31, 34]. In the present study we concentrated on the subjective experiences of internalized HIV and drug stigma. Internalized stigma (or self-stigma) is the personal acceptance and often justification of negative judgments directed towards a stigmatized group one belongs to, resulting in a range of negative effects, including low self-esteem, self-blame and isolation [32, 34]. Luoma et al. suggest that, because of its more significant effect on substance abusers (quality of life, mental health), internalized stigma should perhaps be the preferred target in stigma reduction interventions rather than other types of stigma [32]. The stigma experienced by HIV-positive PWID can be very complex because different coexisting stigmatizing statuses need to be considered. For instance, HIV-related stigma cannot be viewed independently from stigmas associated with the mode of HIV transmission (e.g., injecting drug use) [35, 36] and, as a result, PWID are (in specific settings) often regarded as being HIV-positive and vice versa [35]. Recent studies have indicated not only a separate effect of internalized drug and HIV stigmas [23] but also an interaction effect of both stigmas on health outcomes among HIV-positive PWID [37]. The coexistence of multiple stigmas has been referred to as layering of stigma [36] or as co-stigmas [38]. It is important to determine if and how different stigmas overlap and interact [35, 36, 38] and take this into account when studying the effect of stigmas.

Non-disclosure of injecting drug use may be one way in which PWID cope with stigmas linked to this illicit behavior. PWID have reported fear of being socially excluded and the strong need to conceal their drug use from others [12]. PWID have also been found to use secrecy as a means of avoiding stigma more frequently than non-injecting substance users [32]. Not only possessing a concealable stigmatized identity, but also the constant efforts to hide that identity and the fear of being found out, can have detrimental psychological effects on the stigmatized [39]. On the other hand, possessing a concealable stigmatized identity and being in a position to choose whether to disclose and to whom (to ensure a more positive response) may be less harmful than possessing a visible stigmatized identity (i.e., involuntary disclosure) [17]. Layering of HIV and drug stigmas could also have a significant impact on disclosure decisions. It has been found that PLWHA infected through injecting drugs are less likely to disclose their HIV status than those infected through sexual contact [21, 40], which reveals the intention to conceal the more highly stigmatized status of an injecting drug user. Rudolph et al., in addition, found that PWID experienced more stigmatization from the community after their HIV-positive serostatus was revealed; disclosure to family members, however, had the opposite effect [41]. Therefore, it can be assumed that the subjectively experienced levels of internalized HIV and drug stigma can individually (main effects) as well as jointly (interaction effect) contribute to a person's decision about disclosing their injecting drug use, which we expected to be reflected in the results of our study.

The aim of the present study was to explore the experienced levels of internalized HIV and internalized drug stigma and the disclosure of injecting drug use among PWID self reporting as HIV-positive, and to investigate the independent relationships of these internalized stigmas with the disclosure of injecting drug use (main effects). The second objective was to analyze whether internalized HIV stigma and internalized drug stigma have an interaction effect (i.e., combined effect) on the disclosure of injecting drug use. We thus sought to add novel information to a research topic which has not received much attention until now.

Methods

Study Population and Data Collection

We used data from a cross-sectional study conducted among PWID in Kohtla-Järve, Estonia in 2012. By using respondent-driven sampling (RDS), which is suitable for hidden and stigmatized populations such as PWID [42], 600 PWID were recruited in Kohtla-Järve and its neighborhood from May to July 2012. Participants eligible for the study were at least 18 years old, reported injecting drugs in the past four weeks, spoke Estonian or Russian, were able to give informed consent and agreed to give a blood sample. The first six participants ("seeds") were

recruited non-randomly to represent various PWID types (by gender, age, ethnicity, drug primarily used, and HIV status). After completing the study the participants were provided with coupons to recruit up to three of their peers. For participation in the study, subjects received a primary incentive (a 10 euro grocery store voucher) and a secondary incentive (a 5 euro grocery store voucher) for every peer recruited.

Face-to-face interviews were conducted in private by trained study staff (n = 5) using a structured questionnaire based on the World Health Organization Drug Injecting Study Phase II survey (version 2b (rev.2)) [43]. The study questionnaire covered the following subject areas: recruitment information; sociodemographic characteristics; contact with drug treatment and incarceration facilities; use of alcohol, tobacco and drugs; sexual behavior; knowledge of HIV, AIDS and tuberculosis; physical and mental state; utilization of harm reduction, health care and social services; HIV and injecting drug use stigma and disclosure; experiences with overdose. While similar studies using the same questionnaire (with some variations) are conducted regularly (since 2005) this was the first time that questions about stigma and disclosure were included in the survey. On average, it took 45 min (SD = 11) to complete the survey.

Participation in the study was voluntary and anonymous. The study was approved by the human research ethics boards at the University of Tartu in Estonia and Yale University in the United States. Additional information on the study can be found elsewhere [7, 23].

Measures

Sociodemographic Characteristics, Drug Use and HIV-Related Variables

Participants were asked to report their date of birth (age was calculated using date of birth and date of the conducted interview), gender and ethnicity (Russian, Estonian, other). Time since first injection was calculated from the age of the participant and the self-reported age when they first injected illegal drugs. Time since HIV diagnosis was calculated from the self-reported year when the participant was first told they had HIV and the date of the conducted interview. Participants reported if they had ever received treatment for drug abuse and if they were currently in such treatment (all medical and non-medical treatments were included, e.g., opioid substitution therapy, counseling, psychotherapy, support groups, etc.). Participants were also asked if they were visiting an infectious diseases specialist regularly (at least once a year), i.e., receiving regular HIV care.

Disclosure

The participants were asked to what extent they had disclosed their injecting drug use and to whom. Disclosure information was collected in relation to the following targets: main and casual sex partners, close friends, parents, other family members, current or potential future employers, and health care workers. Extent of disclosure was graded from 1 to 5 (where 1 = have not discussed at all, and 5 = have discussed fully and completely).

Internalized Stigma

Internalized HIV stigma was measured using the Internalized AIDS-Related Stigma Scale (previously validated in the USA, South Africa and Swaziland [44]), which consists of six items which focus on the concealment of stigmatized identity and self-blame (e.g., "I am ashamed that I am HIV-positive", "I sometimes feel worthless because I am HIV-positive") [44]. The internal consistency of the scale (Cronbach's alpha) was 0.87. For measuring internalized drug stigma the Internalized AIDS-Related Stigma Scale items were reworded to address drug stigma rather than HIV stigma (e.g., "I am ashamed that I am a drug user"). The adapted scale for measuring internalized drug stigma was field-tested in Russia and found to be well suited for its purposes [37]. The internal consistency of the drug stigma scale (Cronbach's alpha) was 0.83. For both stigma scales the possible responses to items ranged from 1 = strongly agree to 5 = strongly disagree (midpoint being 3 = undecided), while the original measure used a dichotomous response scale (agree, disagree). For data analysis the coding of both stigma scale items was reversed so that the highest values would correspond to higher levels of internalized stigma. Mean scores for the two scales were computed to describe internalized HIV stigma and internalized drug stigma, with higher scores representing higher levels of internalized stigma.

Data Analysis

Descriptive statistics (absolute (n) and relative (%) frequencies for categorical variables and median, mean, standard deviation (SD), minimum, maximum and range for continuous variables) were calculated. Each disclosure variable (the act of disclosing the injecting drug user status to a disclosure target) was recoded into a binary variable with 0 indicating no disclosure (previously coded as 1) and 1 indicating disclosure (answers previously coded from 2 to 5). The drug disclosure total score was computed by summing the number of disclosure targets to whom the injecting drug user status had been disclosed. A higher disclosure total score therefore reflected disclosure to a

larger number of target groups. To assess the relationships between internalized drug stigma, internalized HIV stigma and the drug disclosure total score a correlation analysis was performed using Kendall's τ correlation coefficient.

Two sets of multivariable logistic regression analyses were performed with the disclosure of injecting drug use as the dependent variable (analyzed separately for each disclosure target; n = 6). The first set of multivariable logistic regression analyses (model I) examined the main effects of internalized drug and HIV stigmas on disclosure, adjusting for age, gender, ethnicity, time since first injection, receiving treatment for drug abuse, time since HIV diagnosis and receiving regular HIV care. The second set of 6 multivariable logistic regression analyses (model II) examined the interaction effect of internalized drug and HIV stigmas on different disclosure acts, adjusting for the same variables as in the first model. Adjusted odds ratios (AOR) were reported with 95% confidence intervals (CI). The independent variables included in the logistic regression models for adjustment were associated significantly (at an alpha level of 5%) with one or more disclosure acts in the bivariate analysis. Disclosure to current or potential future employer was not included in the logistic regression models as there were only a few disclosure acts in that category.

The data were analyzed using STATA 12 software.

Results

From the total of 600 recruited participants, 312 had self-reported being HIV-positive and formed the sample for the current study. Sample characteristics (sociodemographic characteristics, drug use and treatment, HIV infection and care) are presented in Table 1. Participants had a mean age of 30 years, most were men (72%) and of Russian ethnicity (82%). The mean time since first injection was 12 years and the mean time since HIV diagnosis was 7 years. The majority of participants (72%) were receiving regular HIV care and were currently or had previously received treatment for drug abuse (68%).

Disclosure of injecting drug use to disclosure target categories is presented in Table 2. More than half of the participants had disclosed to close friends, health care workers, main sex partners, and parents, but only a few disclosed to current or potential future employers and to casual sex partners.

Table 3 presents the drug disclosure total score, internalized HIV stigma and internalized drug stigma scores and the correlations between these variables. On average, participants disclosed their injecting drug use to three disclosure targets out of a possible seven. Six participants (2%) disclosed to nobody and one (0.3%) disclosed to all seven disclosure targets presented (data not shown). On a scale of 1–5, the average scores of internalized HIV stigma (mean = 3.68) and internalized drug stigma (mean = 3.54), as well as the corresponding medians, exceeded the midpoints of the scales (Table 3). The former indicates that the participants experienced on average relatively high levels of internalized HIV and drug stigmas, although no unified standards are established for determining if the experienced levels of stigma are low or high. There was a moderate positive correlation ($\tau = 0.53$; $p < 0.001$) between internalized HIV and internalized drug stigma but no association was detected between the drug disclosure total score and either internalized stigma variable.

Results from the first logistic regression model, assessing the relationships between disclosures of injecting drug use and internalized stigma variables, are presented in Table 4. The first model revealed that internalized drug stigma was significantly and negatively associated with the disclosure of injecting drug use to family members other than parents (AOR = 0.48; 95% CI 0.30–0.77; p = 0.002) and health care workers (AOR = 0.46; 95% CI 0.25–0.87; p = 0.016). Internalized HIV stigma was positively associated with the disclosure of injecting drug use to health care workers (AOR = 2.26; 95% CI 1.27–4.00; p = 0.005). No interaction effect of internalized drug and internalized HIV stigmas on the disclosure of injecting drug use to any of the different disclosure targets was present (the second model; data not shown). In neither of the regression models did any consistent relationships between different disclosure acts and other independent variables (besides internalized stigma variables) become evident (data not shown).

Discussion

The disclosure of concealable stigmatized identities is an ongoing and complex process, since stigmatized people need to consider carefully what to reveal and to whom over their lifetime [45]. We found that, although 98% of the study participants had disclosed to someone (a finding in concordance with HIV disclosure practices [46]), the disclosure of injecting drug use was not prevalent among the participants, i.e., on average current PWID disclosed their status to less than half of the possible disclosure targets presented. Our study showed that very few of the participants (1%) disclosed or would disclose to an employer or potential employer; this could be due to the fear of not being hired or being dismissed [47], as has also been reported in relation to HIV disclosure [25, 41]. A large proportion of participants (86%) reported disclosing to close friends but the way the question was presented did

Table 1 Sample characteristics of HIV-positive people who inject drugs in Kohtla-Järve, Estonia in 2012 (n = 312)

Characteristic	Value[b]
Sociodemographics	
Age (in years) [mean (SD); range]	30 (4.1); 20–49
Gender [n (%)]	
Male	224 (72.3)
Female	86 (27.7)
Ethnicity [n (%)]	
Russian	256 (82.3)
Estonian	30 (9.7)
Other	25 (8.0)
Drug use and treatment	
Time since first injection (in years) [mean (SD); range]	12 (4.4); 1–27
Treatment for drug abuse [n (%)]	
Has never received treatment	100 (32.0)
Has received treatment before	134 (43.0)
Is receiving treatment now	78 (25.0)
HIV infection and care	
Time since HIV diagnosis (in years) [mean (SD); range]	7 (3.6); 0–14
Receiving regular HIV care[a] [n (%)]	
Yes	224 (71.8)
No	88 (28.2)

HIV status defined from respondents' self report

SD standard deviation

[a] Visiting an infectious disease specialist at least once a year

[b] The numbers may not always add up to 312 because some questions were not answered by some participants

Table 2 Disclosure of injecting drug use among HIV-positive people who inject drugs in Kohtla-Järve, Estonia in 2012 (n = 312)

Variable	Value n (%)
Disclosure of injecting drug use to	
Main sex partner	204 (65.4)
Casual sex partners	34 (10.9)
Close friends	269 (86.2)
Parents	200 (64.1)
Other family members	98 (31.4)
Current or potential future employer	4 (1.3)
Health care workers	239 (76.6)

HIV status defined from respondents' self report

not allow for the distinction between friends who were or were not themselves injecting drug users and/or HIV infected. Although the fear of stigma and exclusion by family members can impede disclosure, the need for social support may prove to be stronger and, on the contrary, motivate disclosure [41]. This may be the reason why over half (64%) of the participants reported disclosing to their parents. Further, disclosing injecting drug use as the route of HIV infection, after the disclosure of HIV serostatus, may prove unavoidable for many PWID [40]. One reason for the small proportion of participants disclosing to other family members (31%) and why 36% did not disclose to parents may be the wish to protect them from secondary stigma (courtesy stigma [26]) and from social isolation [35, 48]. Also, it is unknown if and how much the participants still had contact with different family members (i.e., opportunities to disclose).

The disclosure of injecting drug user status and also the disclosure of risky injecting practices to sex partners may play an important part in preventing the transmission of HIV into the general population (i.e., non-injecting partners of PWID). Go et al. found that PWID tend not to disclose their risky injecting practices to partners [49]. We could speculate that without knowing their partner's history of injecting drug use the sex partners of PWID may underestimate the risks of HIV infection and more easily stray from safer sex practices. This is especially troubling because a substantial proportion of the sex partners of PWID in Estonia are not themselves injecting drug users [8, 9]. Our study showed that the disclosure of injecting

Table 3 Bivariate (Kendall's τ) correlations and descriptive statistics of internalized drug stigma, internalized HIV stigma and drug disclosure total score among HIV-positive people who inject drugs in Kohtla-Järve, Estonia in 2012

Variable	Internalized drug stigma score	Internalized HIV stigma score	Drug disclosure total score	N	Mdn	Mean	SD	Min	Max
Internalized drug stigma score[a]	–			311	3.67	3.54	0.76	1.83	5.00
Internalized HIV stigma score[a]	0.5278[c]	–		311	3.83	3.68	0.83	1.17	5.00
Drug disclosure total score[b]	−0.0594	0.0092	–	312	3.00	3.36	1.32	0.00	7.00

HIV status defined from respondents' self report

Mdn median, *SD* standard deviation

[a] Score ranging from 1 to 5; higher score corresponding to higher levels of stigma

[b] Score ranging from 0 to 7; higher score reflecting disclosure to a larger number of target groups

[c] $p < 0.001$

Table 4 Logistic regression analysis of main effects of internalized stigmas on disclosure of injecting drug use among HIV-positive people who inject drugs in Kohtla-Järve, Estonia in 2012

Stigma score	Disclosure of injecting drug use to AOR (95% CI)[a]					
	Main sex partner	Casual sex partners	Close friends	Parents	Other family members	Health care workers
Model I						
Internalized drug stigma	0.99 (0.63–1.56)	0.62 (0.32–1.22)	0.80 (0.44–1.46)	0.99 (0.63–1.54)	0.48 (0.30–0.77)[b]	0.46 (0.25–0.87)[c]
Internalized HIV stigma	0.93 (0.61–1.42)	1.18 (0.64–2.15)	1.16 (0.66–2.05)	1.19 (0.79–1.79)	1.36 (0.89–2.08)	2.26 (1.27–4.00)[b]

HIV status defined from respondents' self report

AOR adjusted odds ratio, *CI* confidence interval

[a] Adjusted for age, gender, ethnicity, time since first injection, time since HIV diagnosis, receiving treatment for drug abuse, receiving regular HIV care

[b] $p < 0.01$

[c] $p < 0.05$

drug use to the participants' main sex partner was more prevalent than disclosure to casual sex partners; this is similar to the findings of Rosengard et al. [50]. A similar pattern of conduct has also been observed in the disclosure of HIV serostatus to main and casual sex partners [21]. A reason for such a pattern may be the lack of concern for the welfare of casual sex partners compared with that for the main sex partner [51]. It is important to note that previous studies (examining HIV disclosure) have found that disclosure by itself does not necessarily induce safer sex practices [20, 52, 53]. According to Crepaz et al., disclosure accompanied by a comprehensive discussion about safer sex could be a means for increasing the prevalence of safer sex practices [53]. In addition, disclosing a concealable stigma to sex partners could have psychological benefits for the discloser (i.e., experiencing less emotional distress) [54].

Discrimination against substance users by health care workers is widespread [47, 55] and is also a problem in Estonia [16] therefore fears of poor treatment may discourage PWID from disclosing their status to health care workers. However, disclosure of injecting drug use history to health care workers may facilitate getting proper care, counseling, or treatment and thereby minimize or prevent the greater harm to PWID themselves and to society. A study from Australia found that 31% of injecting drug users had not revealed their drug use to their last medical service provider [56]. Although most (77%) of the PWID in the current study reported disclosing to health care workers, it was not possible to differentiate how many of them disclosed to health care workers who were not involved with drug or HIV treatment services. Considering that 68% of the participants were currently receiving or had previously received treatment for drug abuse (requiring the disclosure

of injecting drug use) and 72% were in HIV care (involving possible disclosure of injecting drug use as the route of infection), it is conceivable that disclosure to health care workers outside the drug or HIV treatment services was, in fact, considerably lower.

Our findings showed that HIV-positive PWID in Kohtla-Järve, Estonia, experience relatively high levels of internalized HIV and internalized drug stigma. In other studies, drug users have also reported high levels of internalized drug stigma [37, 57] and HIV-positive PWID report high levels of internalized HIV stigma [37]. It needs to be pointed out that since different authors use different methods for measuring stigma it is difficult to compare study findings directly, nevertheless, one direct comparison can be made. Using the same methodology as in the current study, relatively similar levels of internalized HIV and internalized drug stigma were detected among HIV-positive PWID in Russia [23, 37]. The positive correlation found in the present study between internalized HIV and internalized drug stigma is in accordance with the findings of Earnshaw et al. [58] and Calabrese et al. [37]. This implies that if a person has internalized drug stigma at higher levels it can predict the internalization of HIV stigma at higher levels.

It has been shown that stigma and disclosure are weakly negatively correlated [59]. Studies of substance abusers in treatment have also found a weak positive association between self-stigma and keeping substance use a secret [32, 57]. Studies among PLWHA have also linked internalized stigma and disclosure [19, 60, 61]. In the present study neither of the internalized stigmas was significantly correlated with the drug disclosure total score and the logistic regression analysis revealed that internalized stigmas were associated with only a few disclosure acts. Disclosure to health care workers was the only disclosure act associated with both of the internalized stigmas; however, internalized HIV stigma was positively and internalized drug stigma was negatively associated with the disclosure of injecting drug use. This is an indication that although different types of internalized stigmas are positively correlated, their associations with disclosure acts can be very distinct. Contrary to what was expected, no interaction effect of the two internalized stigmas on different disclosure acts became evident in our analyses. We hope that future research will explore these associations further and may confirm if these results are true for other populations of HIV-positive PWID. Based on our results, the main effects of internalized HIV and drug stigma on disclosures are not uniform and vary by disclosure target and there is no interaction effect of internalized HIV and drug stigmas on disclosures. Although high levels of internalized HIV and drug stigma are substantial problems among HIV-positive PWID, other factors may be playing a more significant role in the disclosure of injecting drug use and this warrants further investigation.

In addition to a few aforementioned considerations our study has some other limitations that should be kept in mind when interpreting the results. Due to the cross-sectional design of the study the direction of associations cannot be verified. Although the study examined the role of stigma on disclosure it is possible that stigma may also be the outcome of disclosure. The possibility of information bias must be taken into account, in particular considering the relatively high stigmatization of the participants and the use of face-to-face interviews. The participants could have been giving socially acceptable answers and there may have been differences in interpreting the questions and inaccuracies in remembering events. The possible prior contact between interviewers and participants (through the needle and syringe exchange program) could have influenced the participants to be more open or, on the contrary, more reserved in answering the questions. The possibility of selection bias must be considered due to the sampling method used (RDS). PWID who were concealing their drug use could have had a smaller circle of drug injecting friends and therefore a smaller chance of getting an invitation to participate in the study. In addition, the PWID who decided not to participate in the study may have had higher levels of internalized stigma. It could also be that some participants experienced high levels of internalized stigma but had become so accustomed to this that they considered it normal and therefore scored lower on the stigma scales.

Other limiting factors to the study are the rather general questions about disclosure/non-disclosure. It was not possible to determine whether participants reported actual disclosure acts to currently existing disclosure targets or revealed the intent to disclose or not to disclose. Further, the questions did not specify time periods for disclosure. Also, we cannot tell whether participants who reported disclosing their injecting drug use at an intermediate level (i.e., those who disclosed but did not discuss it fully and completely) did it in a manner that clearly conveyed the message, and if the disclosure of high risk injecting practices also followed. In interpreting the results it needs to be considered that no distinction was made between voluntary and involuntary disclosure. Also, disclosure to various people may result from different processes of reasoning, which makes different disclosure acts not necessarily comparable with each other nor combinable into a total score [62]. It should also be taken into account that since equivalent levels of HIV and drug stigma can have substantially different associations with health outcomes in different countries [23], associations between internalized stigmas and disclosure acts could possibly vary by region/country as well.

Despite these limitations, our study provides new information on the disclosure of injecting drug use and on its associations with internalized HIV and drug stigma among PWID self reporting as HIV-positive, which so far has been scarce.

Conclusions

The results of the present study showed that PWID self-reporting as HIV-positive experienced relatively high levels of internalized HIV and drug stigmas and that the disclosure of injecting drug use varied significantly by the disclosure target. The effects of internalized stigmas on the disclosure of injecting drug use were few and not uniform and an interaction effect of internalized HIV and internalized drug stigmas was not detected in this sample. Future studies should investigate the role of stigma resilience and other factors that might influence the disclosure of injecting drug use. Measures are also needed to combat the stigmatization of PWID and PLWHA and to educate PWID to manage disclosures.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval The study was approved by the human research ethics boards at the University of Tartu in Estonia and Yale University in the United States. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committees and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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