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Opening up the HIV epidemic: a review of HIV seropositive status disclosure among people who inject drugs

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ABSTRACT
HIV status disclosure plays a crucial role in reducing risk behaviors of drug and sexual partners and thereby limiting HIV transmission. As people who inject drugs (PWID) bear a significant HIV burden and disclosure research among PWID is relatively few, we reviewed the literature to highlight what is known about disclosure among HIV-positive PWID. Searches of articles published from 2000 to 2015 yielded 17 studies addressing different aspects of disclosure, and results are presented by major themes. Our results suggest that despite the difficulties, most PWID (64–86%) disclose their HIV-positive status to trusted individuals (family members and intimate sexual partners) and to those who are known to be HIV-positive. Disclosure to non-intimate sexual partners and fellow drug users is relatively lower. Disclosure decision-making is primarily driven by the perceived positive and negative consequences of disclosure. Subsequent risk reduction practices following disclosure are influenced by the feeling of responsibility, as well as partners’ willingness to accept risk. Cultural family values, ethnicity, and different localities were several contextual factors that affect patterns of disclosure and risk behaviors of PWID. Areas for future research are recommended.

Disclosure of HIV status plays a vital role in managing the HIV epidemic, due to its complex relationship with various factors associated with HIV prevention and treatment. It is also a critical component in reducing risk behaviors with drug and sexual partners as it can facilitate communication and assist in making shared decision regarding safer injecting and sexual practices. Disclosure allows the opportunity to reduce the risk of becoming infected with HIV, serves as a cue for the partners to seek HIV testing, and prevents mother-to-child transmission (Chakrapani, Newman, Shunmugam, & Dubrow, 2011; Jasseron et al., 2013; Noar, Carlyle, & Cole, 2006).

However, as disclosure is a private decision, some individuals choose not to disclose due to possible negative outcomes such as abandonment, blame, stigma, discrimination, loss of income, and physical and emotional harm (Anglewicz & Chintsan, 2011; Bird & Voisin, 2013; Hardon et al., 2013; Stockman et al., 2014). These negative consequences may hinder disclosure and put uninfected partners or unborn children at risk of HIV transmission.

Given its implications in individual and public health outcomes, researchers have reviewed disclosure literature in various perspectives and affected populations. However, to the best of our knowledge, there is no review specifically focusing on people who inject drugs (PWID). Disclosure research involving PWID is limited, and we know little about disclosure among PWID since previous disclosure research was largely from studies that sampled heterosexuals, women, and men who have sex with men (MSM).

As disclosure patterns may vary not just by demographics but also by mode of transmission (Obermeyer, Baijal, & Pegurri, 2011), this paper aims to complement existing reviews by highlighting what is known about HIV disclosure specifically among PWID, identify gaps, and suggest future directions for disclosure researchers.

Method
We conducted electronic searches for journal articles in Web of Science, PUBMED, ScienceDirect, and PsychARTICLES databases using these keywords: (a) disclosure, (b) truth disclosure (MeSH term), (c) HIV (d) seropositive, and (e) drug or drug use. Published sources between 2000 and 2015 yielded 423 articles. After further
scanning and hand-searching, we retained 17 articles based on these criteria: (a) original studies related to disclosure (b) studies exclusively involved PWID as sampled population, or PWID as a distinguished group among other populations (c) PWID were HIV-positive, and (d) Disclosure is defined as the act of revealing a person's HIV-positive status to someone.

The studies’ characteristics are shown in Table 1. As previous studies were limited and covered a range of topics related to disclosure among PWID, we piece together information and present this review with three major themes: (1) rates and predictors of disclosure, (2) disclosure decision-making, and (3) disclosure and sexual behavior.

Rates and predictors of HIV disclosure

Compared to MSM and heterosexuals, PWID were the least likely and had the most difficulties to disclose. This might be due to lack of social support and isolation from others, because of their drug use or criminal history (Ko et al., 2007; O’Brien et al., 2003). Despite that, the majority of PWID (64–86%) did disclose to someone they knew (see Table 2). Generally, they are more likely to disclose to emotionally closer and trusted network members, specifically family members and intimate sexual partners. In contrast, they are less likely to disclose to drug and non-intimate sexual partners, friends, and other community members.

HIV disclosure to drug partners

Overall, disclosure to drug partners was less likely compared to other network members, with rates around 33–49% (Go et al., 2015; Gyarmathy et al., 2011; Latkin et al., 2002). This is due to the potential loss of drug resources following disclosure and the need to satisfy an addiction, which, for some PWID, is more important than exposing HIV risks (Parsons, VanOra, Missildine, Purcell, & Gómez, 2004). Moreover, there are few perceived benefits from disclosure, and drug partners are not seen as a source of social support. There were also PWID who somehow felt responsible to prevent HIV transmission to their peers despite avoiding disclosure. These PWID used some strategies to self-manage the risk, such as being the last receiver of a syringe, asking others to wash used equipment, limiting the number of injecting partners, and telling others that they are infected with Hepatitis C – something normalized among the injectors – instead of HIV (Chakrapani et al., 2011; Higgs, Yohannes, Hellard, & Maher, 2009).

On the other hand, among those who opted to disclose, disclosure was associated with a greater awareness of anti-retroviral therapy (ART), and was more likely to occur when the drug partners were also HIV-positive, as well as when they had good ties with them (Go et al., 2015; Gyarmathy et al., 2011; Latkin et al., 2002). This explains the practice of serosorting by some PWID, where they shared injecting equipment only with other HIV-positive drug partners based on the assumption that this is not harmful and as a strategy to prevent infecting other HIV-negative injectors (Chakrapani et al., 2011).

The tendency toward non-disclosure to fellow drug partners is worrying, given the high risk of transmitting HIV through contaminated equipment. Although this particular risk is being countered effectively by harm reduction measures, substantial numbers of PWID in this review (Chakrapani et al., 2011; Go et al., 2015; Grau et al., 2011; Latka et al., 2007) and other settings (Luo et al., 2015; Tassioopoulos, Bernstein, & Bernstein, 2013; Zhou et al., 2012) still shared injecting paraphernalia and were non-attendees of harm reduction programs. Additionally, even if disclosure did occur, serosorting could expose PWID to other co-infections. These findings indicate that counseling and harm reduction messages to PWID should emphasize not only the benefits of disclosure, but also the importance of using clean needles and syringes at all times, regardless of one’s HIV status.

HIV disclosure to sexual partners

Disclosure to sexual partners varied by partnership types. Disclosure toward intimate partners was generally high (86–93.8%), compared to non-intimate partners (Hammett et al., 2014; Latka et al., 2007; Latkin et al., 2002). Parsons, Missildine, VanOra, Purcell, and Gómez (2004) found a slightly lower rate (60.6%), but disclosure in this study was measured prior to first sexual contact. The general tendency toward non-disclosure to non-intimate partners may be due to the assumption that sex workers are more likely to be HIV-infected, not considering them as someone to be concerned about, or the risk of sexual rejection (Knight, Purcell, Dawson-Rose, Halkitis, & Gomez, 2005; Parsons, Missildine, et al., 2004).

Parsons, Missildine, et al. (2004) also demonstrated ranges of disclosure behaviors and categorized study participants into four types: (a) consistent disclosers – who consistently disclose to sexual partners and are more likely to believe that it is important to protect partners from HIV, (b) conditional disclosers – who only disclose in certain situations, (c) eventual disclosers – who did not disclose early in the sexual relationship, and (d) non-disclosers. This study indicates the need to
understand different contexts and issues underlying disclosure behaviors, as well as how interventions involving PWID should acknowledge their unique circumstances and be individualized when it comes to disclosure to sexual partners.

With regard to predictors of disclosure, perceived HIV-positive status of a sexual partner is a significant factor (Grau et al., 2011; Latkin et al., 2002). In fact, one study found that disclosure occurred to 100% of the respondents’ non-intimate and 67.3% of intimate HIV-positive partners (Parsons, Missildine, et al., 2004). This indicates that PWID are less likely to disclose to potentially at-risk sexual partners who are HIV-negative or of unknown status.

Several studies found that disclosure was less likely when the sexual partners were also drug users (Latkin et al., 2002; Parsons, Missildine, et al., 2004). While this is seen in several U.S. settings, in Russia, disclosure was independently associated with the perception that their sexual partners were also PWID. Perhaps the assumption that PWID are more likely to be infected leads to disclosure (Grau et al., 2011).

### HIV disclosure decision-making

Studies exploring disclosure decision-making were mostly guided by Serovich’s consequence theory, which postulated that disclosure will occur when the benefits outweigh the costs (2001).

Studies in U.S demonstrated that PWID evaluate their personal gains and losses from disclosure to rationalize disclosure decisions. Perceived costs include stigma, blame, rejection by sexual partners, loss of income, loss of privacy, fear of causing emotional harm, as well as threats to safety. Perceived benefits are emotional catharsis, increased social support and connection with partners or family members, and the opportunity to form a relationship when the disclosure recipient is also HIV-positive. Despite potential income loss, those who disclosed their status might gain advantages from social

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**Table 1. Study characteristics.**

<table>
<thead>
<tr>
<th>Topic addressed</th>
<th>First author (year)</th>
<th>Location</th>
<th>Sample</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsibility and disclosure</td>
<td>Latka</td>
<td>U.S.</td>
<td>N = 1114 Male, female Majority African American and Hispanics</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Perceived outcome of disclosure</td>
<td>Valle</td>
<td>U.S.</td>
<td>N = 80 Male, female African American</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Perceived outcome of disclosure, and role of</td>
<td>Parsons</td>
<td>U.S.</td>
<td>N = 158 Male, female Diverse ethnicity</td>
<td>Qualitative</td>
</tr>
<tr>
<td>responsibility in disclosure</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Predictors of disclosure</td>
<td>Latkin</td>
<td>U.S.</td>
<td>N = 161 index Male, female</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Predictors of disclosure</td>
<td>Go</td>
<td>Vietnam</td>
<td>N = 336 Male</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Predictors of disclosure</td>
<td>Gyarmathy</td>
<td>Lithuania</td>
<td>N = 27 138 injecting dyads Male, female</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Disclosure patterns in different groups of populations</td>
<td>O’ Brien</td>
<td>U.S.</td>
<td>N = 31 Male, female Majority African American</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Disclosure patterns in different groups of populations</td>
<td>Ko</td>
<td>Taiwan</td>
<td>N = 59 Male, female</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Disclosure and contexts of sexual encounters</td>
<td>Knight</td>
<td>U.S.</td>
<td>N = 161 Male, female, transgender Diverse ethnicity</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Disclosure and condom use</td>
<td>Grau</td>
<td>Russia</td>
<td>N = 70 Male, female</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Disclosure and sexual behavior</td>
<td>Parsons</td>
<td>U.S.</td>
<td>N = 158 Male, female</td>
<td>Mixed</td>
</tr>
<tr>
<td>Impact of disclosure/ non-disclosure</td>
<td>Salter</td>
<td>Vietnam</td>
<td>N = 25 Male</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Disclosure to wives</td>
<td>Solomon</td>
<td>India</td>
<td>Number of male PWID not mentioned 400 wives of male PWID</td>
<td>Mixed</td>
</tr>
<tr>
<td>Disclosure and stigma</td>
<td>Rudolph</td>
<td>Vietnam</td>
<td>N = 25 Male</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Disclosure accuracy</td>
<td>Hammet</td>
<td>Vietnam</td>
<td>N = 749 couples of male PWID and female sexual partners</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Disclosure and risk reduction strategies</td>
<td>Higgins</td>
<td>Australia</td>
<td>N = 9 Vietnamese PWID residing in Melbourne Male, female</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Disclosure and risk reduction strategies</td>
<td>Chakrapani</td>
<td>India</td>
<td>N = 75 Male, female</td>
<td>Mixed</td>
</tr>
</tbody>
</table>
service programs (Parsons, VanOra, et al., 2004; Valle & Levy, 2009). Valle & Levy (2009) further explained the tipping factors that directed toward disclosure or non-disclosure: The need to disclose, personal values on privacy, anticipated reactions of confidants, and the person’s self-perceived ability to contain information were the said tipping factors.

The role of responsibility in disclosure decision-making was also explored, and it was reported that responsibility did motivate disclosure in some participants, especially those who disclosed consistently (Parsons, Missildine, et al., 2004; Parsons, VanOra, et al., 2004). Latka et al. (2007) confirmed this, but its association with disclosure depended on partner type; those who felt greater responsibility were more likely to have disclosed their status to intimate partners.

Studies in Asian countries demonstrated family concern as a central subject matter in decision-making. This even applies to Vietnamese PWID in Melbourne. Apart from perceived stigma from families, narratives about emotional, physical, and psychological effects of HIV diagnosis toward family members dominated the discussion of disclosure. Some PWID expressed the need for help to disclose (Solomon, Mehta, Latimore, Srikrishnan, & Celentano, 2010). In addition, perceived double stigma from the community due to both injecting behavior and HIV infection also played a big role in making decision. HIV diagnosis could further stigmatize PWID, making them not just worried about stigma from the community toward themselves, but also the secondary stigma being directed to their family members. Nevertheless, the desire for support and love from family members was the major reason that drove the PWID to disclose (Higgs et al., 2009; Ko et al., 2007; Rudolph et al., 2011; Salter et al., 2010).

These findings suggest that counseling and programs to facilitate safe disclosure should emphasize components that are meaningful to the PWID. In western settings, interventions should highlight individual benefits, such as gaining social support and resources, which would minimize the anxiety of perceived negative consequences of disclosure. Instilling the feeling of responsibility in protecting others from HIV infection or reinfection also is noteworthy, both to intimate and non-intimate partners.

Besides these, in Asian countries, interventions must recognize the central role of family in managing the epidemic. This involves family counseling, primary and secondary community stigma reduction, and providing support for PWID to play a positive family role despite the HIV diagnosis.

### HIV disclosure and sexual behavior

The most-researched disclosure outcome among PWID is sexual behavior. Two quantitative studies investigated the correlation between disclosure and sexual behavior among PWID. Parsons, Missildine, et al. (2004) found that consistent disclosers were more likely to not use condoms. However, consistent disclosers in the sample were having sex more frequently with HIV-positive casual partners. Knowing that both partners were positive possibly lead to a shared decision for unprotected sex.

Meanwhile, Grau et al. (2011) found no correlation between disclosure and condom use. Instead, condom use was more likely with partners perceived as HIV-negative, implying that some PWID do take protective measures for susceptible partners, but not through the act of disclosure. This could be explained by another study, which stated that some PWID felt responsible for ensuring safer sex despite the lack of the same feeling for disclosure (Parsons, VanOra, et al., 2004), and that those with greater perceived responsibility were less...
likely to report unprotected sex with at-risk partners, and better condom use self-efficacy (Latka et al., 2007).

Nevertheless, sexual practice differs in different partnerships. A partner’s HIV-negative status does not necessarily lead to condom use, especially when it involved intimate partners (Grau et al., 2011; Knight et al., 2005). Knight et al. (2005) discovered that within intimate serodiscordant relationships, disclosure created and revitalized love relationships. However, the intention to preserve intimacy often serves as a barrier to safer sex. Some PWID felt the burden of responsibility to ensure safer sex, but committed partners tend to have a fatalistic orientation toward infection, making the decision for unprotected sex to be mutual. Yet, a study in Vietnam found that most participants reported condom use with their wives with the intention to protect them from HIV, regardless of disclosure or non-disclosure. However, one couple who was aware of the HIV status did not use condoms in order to conceive, and another did not use condoms to avoid suspicion from his wife (Salter et al., 2010).

Within non-intimate sexual partnerships where assumptions about positive HIV status are prevalent and occurrence of disclosure is relatively low, perceived responsibility seems to determine whether condoms are used or not. Even without disclosure, some PWID believed that everyone should be aware of the risk of casual sex and insisted on safer sex (Parsons, VanOra, et al., 2004). In fact, driven by the feeling of responsibility, there were PWID who reported stopping sex work altogether, rather than dealing with the decision to disclose (Knight et al., 2005). There were PWID who never disclosed and did not use condoms in their casual sexual encounters, and further probes clearly showed a lack of responsibility in preventing transmission (Parsons, VanOra, et al., 2004). These observations show that the relationship between disclosure and sexual behavior among PWID is complex. Similar to previous studies involving other HIV-positive populations (Relf et al., 2009; Simoni & Pantalone, 2004), the pattern of results between disclosure and safer sex are inconsistent.

Nevertheless, the challenge of preventing sexual transmission among PWID remains significant. This is because it has been repeatedly shown that although PWID are accessing harm reduction programs and have reduced injection equipment sharing, many of them still engage in unsafe sex (Armstrong et al., 2015; Mazhnaya et al., 2014; Mishra et al., 2014; UNAIDS, 2013). Furthermore, evidence suggests that HIV transmissions among PWID are magnified by high-risk sexual activities more than drug-related risks, when injection risks are lowered through structural, behavioral, or educational interventions (Kral et al., 2001; Strathdee et al., 2001).

Despite the need to improve the integration of safe sex education in harm reduction programs, interventions should emphasize the responsibility to protect others with or without disclosure, and safer sex should be practiced regardless of the partner’s HIV status and gender. In the context of intimate partnerships, couple-based interventions are important in informing both partners of the risks involved, and guiding couples to practice safe sex without jeopardizing intimacy.

Conclusion

The studies on disclosure that we reviewed showed that although disclosure is difficult for PWID, most of them disclose their status to trusted individuals (e.g., intimate sexual partners, emotionally close drug partners, and family members), and to those who are HIV-positive. Disclosure to non-intimate sexual partners and fellow drug users was relatively lower. Disclosure decision-making is primarily driven by the perceived consequences of disclosure. Disclosure however does not necessarily lead to safer sexual and injecting practices. Conversely, non-disclosure does not necessarily indicate unsafe sexual and injecting practices. Rather, the decision to disclose and subsequent risk reduction practices were clearly influenced by the feeling of responsibility and partners’ willingness to accept risk. Cultural family values, ethnicity, and different localities were several contextual factors that affected patterns of disclosure and risk behaviors of PWID.

A number of important limitations need to be considered. Because PWID are hard-to-reach populations, most of the studies used non-probability sampling strategies which compromised the respondents’ representativeness and thus the findings’ generalizability. Some quantitative studies have low sample size, as low as 27 respondents. In view of the quite small number of studies and some methodological weak points, analyses in this review need to be interpreted with caution. More research on disclosure among PWID should be done in diverse settings to understand the priorities needed in designing tailored interventions and policies. Quantitative studies should consider using other sampling strategies such as respondent-driven sampling for better representative sample, and more qualitative studies are warranted to obtain rich data in understanding contextual issues.

Most of the partner disclosure surveys were single perspective self-reports, without supporting data from partners. Because the topics explored are personal, they are subject to social desirability bias. It was shown that
HIV disclosure self-reports could be unreliable and the proportion of disclosure could be more accurate with confirmatory reports from partners (Anglewicz & Chintsanya, 2011; Conroy & Wong, 2015). In this review, only Hammett et al. (2014) employed validation measures to verify disclosure rates, where a significant number of sexual partners were either uninformed or misinformed about their PWID partners’ status. This also applies to condom use self-reports.

Most of the quantitative studies were cross-sectional, which hinder determination of causality. Due to the lack of a time element in cross-sectional studies, study contexts need to be understood, and comparisons of disclosure levels need to be made while keeping in mind that participants’ duration of HIV diagnosis varies, and the likelihood of disclosure increases with time. The relationship between disclosure and other antecedents or outcomes of interest, thus, is better to be investigated with longitudinal studies.

Most studies asked participants whether they had ever disclosed and did not specify whether the disclosure took place before or after first sexual encounters. Knowing this is important, as it reflects the accuracy of rates of disclosure in relation to decision-making process and sexual partners’ vulnerability toward HIV risk.

Although most studies involved both genders, exploration through gender perspectives is lacking. This is relevant given that women and men who inject drugs have different needs, behaviors, and risk factors (Magnus et al., 2013). In this review, only one study reported on gender differences in disclosure behavior on the responsibility for condom use; female disclosers were more likely than female non-disclosers to believe that the responsibility for safer sex fell mainly on their partners, while for men there was no difference observed (Parsons, Missildine, et al., 2004). How gender roles, expectations, as well as masculinity and femininity shape disclosure process among PWID should be carefully examined. This gender-specific exploration is needed not just for PWID, but also for the disclosure confidants, as interpersonal dynamics and reactions of confidants may affect disclosure outcome.

Given that disclosure decision-making can be more nuanced than weighing costs and benefits, other models such as the disclosure process model (Chaudoir, Fisher, & Simoni, 2011) may be considered.

Although ART is increasingly available for HIV-positive individuals, few studies have investigated how disclosure or non-disclosure affects ART initiation or adherence among PWID. Furthermore, in the advent of treatment as prevention where HIV transmission risk can be significantly reduced, the relationship between perceived infectivity, disclosure, and sexual and injecting behavior during viral suppression should be explored in this population.

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