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Research paper

Impacts of stigma on HIV risk for women who inject drugs in Java: A qualitative study

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ABSTRACT

Background: People who inject drugs have experienced stigma around the world. Stigma has been found to have negative consequences for individuals in relation to health-service use, psychological wellbeing and physical health; and for populations in terms of health inequalities. Indonesia has experienced a rapid growth in injecting drug use and HIV and little is known about drivers of HIV risk among Indonesian women who inject drugs. The purpose of this paper is to describe and consider the multiple impacts of stigmatization of injecting drug use on injecting behaviors among women who inject drugs in Java.

Methods: In-depth interviews were conducted with 19 women who inject drugs in Java. Mean age was 25 years, all but one was employed or at college. The interviewers were Indonesian women.

Results: Significant stigma around women's drug use was reported from multiple sources in Java including family, friends and health services, resulting in feelings of shame. To avoid this stigma, most of the study participants hid their drug use. They lived away from family and had few friends outside their drug-injecting circle, resulting in isolation from mainstream society and harm-reduction services. Sharing of injecting equipment was restricted to a small, closed circle of trusted friends, thus limiting possible HIV transmission to a small number of injectors.

Conclusions: The stigmatization of drug use, particularly of drug use by women, in Indonesia appears to have contributed to significant shame, isolation from mainstream society and high rates of sharing injecting equipment with a small group of trusted friends (particularly the partner).

Background

Stigma has been defined as: "the co-occurrence of labeling, stereotyping, separation, status loss and discrimination in a context in which power is exercised" (Hatzenbuehler, Phelan, & Link, 2013). Phelan, Link, and Dovidio (2008) identified three functions of stigma. These are: exploitation and domination (keeping people down), norm enforcement (keeping people in) and disease avoidance (keeping people away). Hatzenbuehler et al. (2013) have described how stigma has negative consequences for individuals and populations due to its impacts in multiple domains including housing, employment, education, social relationships, mental and physical health. Specific impacts include diminished self-esteem, impacts upon the ability to marry and exclusion from social groups. Stigma has increasingly been conceptualized as more than an individual issue, but also as a social issue as it contributes to social inequalities (Hatzenbuehler et al., 2013; Parker, 2012).

International research has identified how stigma is attached to people who inject drugs (PWID) and to HIV and how the stigma attached to HIV has been uncritically bound to PWID (Chan, Stoove, Sringernyuang, & Reidpath, 2008; Chan, Yang, Zhang, & Reidpath, 2007; Chan et al., 2008; Parker & Aggleton, 2003). This stigma has resulted in negative outcomes for PWID in relation to HIV risk behaviors (Latkin et al., 2010), service use (Simmonds & Coomber, 2009), mental health (Ahern, Stuber, & Galea, 2007) and physical health (Tindal, Cook, & Foster, 2010). The experience of stigma can lead to "internalized stigma", characterized by feelings of shame, which can increase the likelihood of hiding ones drug use (Rivera, DeCuir, Crawford, Amesty, & Lewis, 2014). Accordingly, the World

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Health Organization (2014) has identified addressing stigma and discrimination as an essential strategy for creating an enabling environment for HIV prevention, diagnosis, treatment and care.

The experience of women who inject drugs is different to that of men who inject drugs, so gender-specific research is important for informing policy and program responses. For example, research has identified that women who inject drugs can experience a double stigma: firstly, because they are violating social norms against injecting drugs and secondly because their drug use is considered contrary to their traditional roles as mothers, wives and daughters (UNODC, 2006). Women who inject drugs are more likely than men who inject drugs to provide sex in exchange for drugs, money or other forms of sustenance; to suffer violence from their sexual partners; to experience rape and to be caring for children (Azim, Bontell, & Strathdee, 2015; Pinkham & Malinowska-Sempruch, 2008; Teets, 1997; UNODC, 2006). Women have less capacity than men to negotiate safe sex or injection practices (Nabila, Assel, & Sophie, 2010; UNODC, 2006). These gender differences have been attributed to the lower social status of women and their lack of power relative to men (Amaro & Raj, 2000; UNODC, 2006; Wingood & DiClemente, 2000).

Indonesia experienced an increase in injecting drug use during the mid 1990s, which fueled an increase in HIV through the sharing of needles and, indirectly, via sex work (Independent Commission on AIDS in Asia, 2008; Riono & Jazant, 2004). In 2007, HIV prevalence among PWID was 52% (HIV and AIDS Data Hub, 2010). While a small minority of the PWID in Indonesia are women, they are more likely than men who inject drugs to be HIV positive (57% compared with 52%) (HIV, 2010).

There have been few studies of HIV risk among Indonesian women who inject drugs. Indonesia is a culturally diverse country with over 300 ethnic groups so the experience of women in different parts of Indonesia is likely to be varied. The Javanese constitute the largest ethnic group (42% of the Indonesian population). As discussed in earlier publications relating to the study reported here, Javanese culture places gendered expectations on women to be considerate of others, to be polite and to behave in a manner that is 'proper' (Lazuardi et al., 2012; Saktiawati et al., 2013). Premarital sex and drug use are not considered acceptable behaviors for women. The Javanese notions such as *pekewuh* and *isin* amplify concerns about breaching traditional gender roles. *Pekewuh* refers to feeling reluctant and uncomfortable when dealing with people of higher rank and/or age (Collins & Bahar, 2000; Dardowidjojo, 2012; Suharno, 2013); *isin* is usually used to express shyness, shame, embarrassment or anxiety when one is a center of attention (Collins & Bahar, 2000; Keeler, 1983; Lindquist, 2004). Such concepts tend to be introduced during early childhood and to influence the importance placed on behaving appropriately.

Injecting drug use and HIV risk behaviours are influenced by multiple individual and environmental factors that are complexly inter-related and vary with geographic area as well as population groups (Poundstone, Strathdee, & Celentano, 2004; Rhodes, 2009; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005; Spooner & Hetherington, 2005). Harm reduction strategies need context-specific and population-specific information so that they can target their efforts effectively. A qualitative study of women who inject drugs in central Java was conducted with the aim of investigating HIV risk factors for this group. Earlier papers from this study have discussed the role of boyfriends in injecting behaviors (Lazuardi et al., 2012) and the notion of consideration as a barrier to condom use with boyfriends (Saktiawati et al., 2013). The purpose of this paper is to look outside the partner relationships and describe the impacts of stigmatization on injecting behaviors among women who inject drugs in central Java.

Methods

In-depth interviews were conducted with women who inject drugs in central Java to obtain qualitative data on their experiences relating to HIV risk behaviors. Some quantitative data on demographic background and HIV risk were collected for sample description purposes.

Study population and sample

The study population was women who inject drugs in three cities in Java: Yogyakarta, Salatiga and Solo. Consultations were conducted with local service providers as a part of the development of the study design. Service providers reported that it would be impossible to recruit study participants because women who inject drugs were a very hidden population in Java. Consequently, participants were recruited via outreach workers from three non-governmental organisations in two cities, and from the local branch of the National AIDS Commission in one city. Participants were reimbursed (approximately $AUD5) for expenses incurred in their participation in an interview.

To be included in the study, a woman needed to be aged 18 years or older, to have injected a drug within the previous month and to have been living or staying in a study site (Yogyakarta, Salatiga or Solo) during the data collection period. Over a 3 month data collection period (February to April, 2010) 19 women who inject drugs were interviewed in Yogyakarta ($n = 2$), Solo ($n = 10$) and Salatiga ($n = 7$).

The age of the study participants ranged from 19 to 36 years, mean = 25, SD = 5. Three quarters of the sample were educated up to senior high school level and one woman had tertiary education. A fifth of the sample had only completed junior high school. The women had lived in the city of interview for an average of 16 years (SD = 12 years). Most of the women were Muslim, two were Christian; most were Javanese, two had mixed ethnic background. Half of the women lived in a boarding house; three did so with their boyfriend and one with her husband. The others lived in their parent's home, with parents-in-law, or with their husband.

All of the study participants had injected an impure form of heroin called *putaw* or *etep* in the previous month. Injection of other drugs was rare. Less than half of the sample had drunk alcohol in the previous month and even fewer had used other drugs such as tranquillisers, cannabis and amphetamines. Among the 12 women who could access methadone, two were in a methadone program, and one had previously been on methadone. Thus, there was very little experience of methadone within the sample.

Most of the women had been initiated into injecting by another person, generally a male partner or male friend. They reported that they continued injecting because it helped them forget their problems and because it was now embedded within their social life as they were spending all their time with people who inject. To access drugs and injecting equipment, most of the women relied upon other people, particularly male partners and male friends. Injecting drug use was usually with friends or a partner, not with strangers.

Interviewers

The interviewers were Indonesian women with relevant university degrees (AMIS and EL). They were trained and supervised by senior academics from UNSW Australia (CS) and Universitas Gadjah Mada (UGM; YWS and RSP). Training was accompanied by a written protocol for data collection.