



## Research paper

## Stigma at every turn: Health services experiences among people who inject drugs

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## ABSTRACT

**Background:** People who inject drugs (PWID) encounter varying forms of stigma in health services contexts, which can contribute to adverse outcomes. We explored the lived experience of stigma among PWID to elucidate pathways by which stigma influences health care access and utilization.

**Methods:** We conducted 46 qualitative interviews with PWID in California's Central Valley between March and December 2015, as part of a multi-phase, multi-method study examining implementation of a new pharmacy syringe access law. A "risk environment" framework guided our data collection and we used a deductive/inductive approach to analyze the qualitative data.

**Results:** Participants repeatedly cited the impact of stigma on syringe access, particularly in the context of meso-level pharmacist interactions. They described being denied syringe purchase as stigmatizing and embarrassing, and these experiences discouraged them from attempting to purchase syringes under the new pharmacy access law. Participants described feeling similarly stigmatized in their meso-level interactions with first responders and hospital staff, and associated this stigmatization with delayed and substandard medical care for overdoses and injection-related infections. Drug treatment was another area where stigma operated against PWID's health interests; participants described macro-level public stigma towards methadone (e.g., equating methadone treatment with illicit drug use) as discouraging participation in this evidence-based treatment modality and justifying exclusion of methadone patients from recovery support services like sober living and Narcotics Anonymous.

**Conclusion:** Stigma played an undeniably important role in PWID's experiences with health services access and utilization in the Central Valley. Our study illustrates the need to develop and test interventions that target drug use stigma at both structural and individual levels to minimize adverse effects on PWID health.

## Introduction

Stigmatization of people who use drugs is increasingly recognized as a serious public health issue. In the United States, substance use problems carry more stigma than other mental health problems (Barry, McGinty, Pescosolido, & Goldman, 2014; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999), and manifest in pervasive stereotypes, prejudice, and discrimination. Many Americans indicate that they desire social distance from individuals who use drugs (Barry et al., 2014; Corrigan, Kuwabara, & O'Shaughnessy, 2009; Link et al., 1999), and are afraid of those with drug use problems, viewing them as dangerous

(Corrigan et al., 2009; Link et al., 1999). People who use drugs are seen as unworthy of receiving assistance (e.g., finding jobs or housing), and public policies designed to help them are widely opposed (Barry et al., 2014; Corrigan et al., 2009). Stigma against drug users is reinforced structurally by laws that criminalize people struggling with drug addiction and permit discrimination against them (Leis & Rosenbloom, 2009). People who use drugs report that such discrimination affects them more than discrimination related to race, sex, sexual orientation, poverty, incarceration history, or mental illness (Minior, Galea, Stuber, Ahern, & Ompad, 2003; Young, Stuber, Ahern, & Galea, 2005).

Many conceptualizations of stigma have been proposed since Erving

Abbreviations: HCV, hepatitis C virus; MSA, metropolitan statistical area; PWID, people who inject drugs; SB41, California Senate Bill 41; SEP, syringe exchange program

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Goffman established it as a sociological construct, defining stigma as “an attribute that is deeply discrediting” (1963, p. 3). Subsequent scientific literature on substance use and mental illness suggests that multiple types of stigma operate at both the structural and individual levels (Kulesza, Larimer, & Rao, 2013). At the structural level, public stigma describes cultural norms that negatively affect stigmatized groups, including widely-held stereotypes and prejudices (Corrigan & Watson, 2002). Perceived stigma (or felt stigma) is a belief on the part of a person with a stigmatized identity that the general population ascribes to negative stereotypes about people with that identity (Livingston & Boyd, 2010). For example, a person who uses drugs may endorse the statement that “most people believe that drug addicts cannot be trusted” (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Enacted stigma, which operates at both structural and individual levels, is the experience of discrimination or rejection related to a stigmatized identity (Luoma et al., 2007). Finally, individual-level self-stigma (or internalized stigma) results when members of a stigmatized group accept stigmatizing attributions about themselves and believe them to be true (Corrigan & Watson, 2002).

Literature on stigma and drug use suggests that drug users experience multiple types of stigma, and these experiences are associated with adverse health outcomes. Studies of people who use drugs and alcohol have found that enacted stigma, perceived stigma, and self-stigma are associated with mental health problems, including increased depressive symptoms (Ahern, Stuber, & Galea, 2007; Latkin, Davey-Rothwell, Yang, & Crawford, 2013; Link et al., 1997; Luoma et al., 2007; Young et al., 2005). Enacted stigma is also associated with poor physical health among drug users (Ahern et al., 2007; Young et al., 2005).

Stigma may play a role in maintaining substance use disorders and increasing the likelihood of relapse. Studies have identified stigma as a barrier to engaging in substance use treatment (Browne et al., 2016; Keyes et al., 2010; Radcliffe & Stevens, 2008; Semple, Grant, & Patterson, 2005) and associated it with continued drug use after treatment (Kulesza, Ramsey, Brown, & Larimer, 2014). People who use drugs may also experience stigma from participating in drug treatment, particularly opioid substitution therapy. For example, although methadone maintenance is an evidence-based treatment for opioid use disorders (Amato et al., 2005; Connery, 2015; Veilleux, Colvin, Anderson, York, & Heinz, 2010), it is widely viewed as an alternative form of addiction. As a result, methadone patients experience many of the same forms of stigma as people who use illicit drugs (Conner & Rosen, 2008; Earnshaw, Smith, & Copenhaver, 2013; Etesam, Assarian, Hosseini, & Ghoreishi, 2014; Vigilant, 2004). This stigma around methadone has long been a barrier to its implementation and use (Joseph, Stancliff, & Langrod, 2000).

People who inject drugs (PWID) experience greater levels of stigma than those who use drugs through non-injection routes like smoking or snorting (Etesam et al., 2014; Luoma et al., 2007), and this stigma has unique implications for health. PWID are at high risk of HIV, hepatitis C virus (HCV), and bacterial infections from sharing and/or reusing syringes, and stigma may play a role in increasing risk. For example, one study found that self-stigma among PWID was associated with lower utilization of pharmacies and syringe exchange programs (SEPs) to obtain sterile syringes (Rivera, De Cuir, Crawford, Amesty, & Lewis, 2014). Additionally, drug use stigma is associated with risky injection behaviors, including sharing syringes and other injection supplies, among PWID (Latkin et al., 2010).

Given the growing body of literature associating stigma with negative health outcomes, it is important to understand how PWID experience stigma and the processes by which stigma affects their health. Healthcare settings are an especially important context in which to study stigma's impact, as there are a variety of health complications associated with injection that require medical intervention. Previous research indicates that health professionals often have negative attitudes toward people with substance use disorders (for a review, see van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). These attitudes are

associated with serious consequences for PWID, such as lower rates of exposure to life-saving medications like highly active antiretroviral therapy (Ding et al., 2005).

Nonetheless, there is still very little research assessing the impact of stigma on PWID health behaviors. Lloyd (2013) identified a small number of studies from Europe and Canada that examined PWID experiences of stigma in pharmacies and other healthcare settings. Most related literature from the U.S. has examined the attitudes of healthcare workers rather than the experiences of drug users themselves (see Lloyd, 2013 and van Boekel et al., 2013). We are aware of at least one U.S. study that examined drug user experiences in healthcare settings (Weiss, McCoy, Kluger, & Finkelstein, 2004), but none have specifically addressed the experiences of PWID across such settings. Additionally, we identified only two international studies examining PWID experiences of stigma in retail pharmacies (excluding pharmacy-based SEPs; Davidson et al., 2012; Matheson, 1998), and none that have done so in the U.S. It is notable, then, that stigma emerged as a key factor influencing access to and utilization of a variety of health-related services (including nonprescription syringe sales) in our interviews with PWID in the Central Valley of California. Herein, we explore how stigma is experienced by PWID within the health services system and its impact on health behaviors.

### Study setting

Injection drug use is a prominent health concern in California's Central Valley. In a study of 96 U.S. metropolitan statistical areas (MSAs), the Fresno and Bakersfield MSAs both ranked in the top four in prevalence of injection drug use (2.95% and 2.40%, respectively) (Brady et al., 2008). Fresno (population ~510,000) in Fresno County and Bakersfield (population ~364,000) in Kern County are the main urban hubs in this predominantly rural and agricultural region.

Many Central Valley communities have limited access to health services, including drug treatment and harm reduction programs. Social and political opposition have presented significant barriers to implementing SEPs in the region. As of 2017, the only regularly operating SEP in the Central Valley is in Fresno and operates only two hours per week; the program has been consistently opposed by the County Board of Supervisors and consequently has operated mostly illegally since 1994. Bakersfield, which ranks 8th among the most politically conservative cities in the United States (Alderman et al., 2005), has never had a SEP. California Senate Bill 41 (SB41), which went into effect in 2012, was designed to expand sterile syringe access across the state by allowing pharmacies to sell syringes without a prescription. Under this law, any pharmacy in California may voluntarily, and without any prior registration or authorization, sell syringes to customers at least 18 years old without a prescription. In addition, the law allows possession of syringes for personal use if acquired from a physician, pharmacist, SEP, or other legally authorized sterile syringe distribution source.

### Methods

The overarching purpose of our study was to examine SB41 implementation from the perspectives of both pharmacy staff and PWID. To this end, we used a multi-phase, sequential mixed methods research design (Creswell & Clark, 2010; Ivankova, Creswell, & Stick, 2006) to characterize impacts on implementation at multiple levels. Our inquiry was guided by a “risk environment” framework, which views drug use and associated harms as a product of social and environmental interactions at macro, meso and micro levels (Rhodes, 2002). “Macro”-level factors are distal to the individual and affect health via structural influences (e.g., laws and policies). “Meso”-level factors are more proximal to the individual and encompass social and group interactions, as well as decision making in the context of the healthcare delivery system. “Micro”-level factors are most proximal to the individual, and include factors like attitudes toward health services and experiences

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