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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

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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.

Keywords

Injection drug use; Stigma; Pharmacies; Syringe access; Healthcare disparities; Methadone

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 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 related to these services. Our study was prompted by a macro-level change, i.e., the passage of SB41; it examined pharmacy practices at the meso level, as well as micro-level factors that influence PWID engagement in pharmacy sales.

The first phase of our study involved a syringe purchase trial, followed by a pharmacy survey. Only 21 percent of purchase attempts at pharmacies across Fresno and Kern counties were successful (R. A. Pollini et al., 2015). In the subsequent survey, only 29 percent of pharmacists and other pharmacy staff were willing to sell nonprescription syringes to PWID compared to 79 percent for people with diabetes (R. A. Pollini, 2017). In the second phase of our study, we conducted semi-structured exploratory interviews with PWID. These interviews provide the basis of the current analysis and informed the development of a subsequent quantitative survey. Interviews covered local drug market characteristics; personal drug use histories; syringe access; injection-related risk behaviors and health harms; criminal justice involvement; interactions with healthcare providers; and drug treatment experiences.

Between March and December 2015, we conducted 46 in-depth interviews (22 in Fresno County, 24 in Kern County). We used targeted and snowball sampling (Schensul, LeCompte, Trotter II, Cromley, & Singer, 1999; Watters & Biernacki, 1989) to recruit participants who were at least 18 years old and reported injection in the past year. In Fresno, we worked with the SEP and local health service agencies to initiate recruitment. In Kern, we worked through local agencies and used street-based recruitment. We purposefully constructed our sample (Johnson, 1990) to achieve maximum variation in gender, age, drug use (opioids vs methamphetamine), and residence (urban vs. rural).

The study Principal Investigator and Co-Investigator conducted digitally recorded interviews in private office spaces. Interviews included open-ended questions related to topics in the interview guide (e.g., “What is healthcare like in Fresno for people who inject drugs?”; “Where do you normally get your syringes?”), as well as follow-up questions about topics of interest raised by participants (e.g., “Can you tell me more about [your experience]?”). Interviews typically lasted 60–90 minutes (range: 45 minutes to four hours). Participants were reimbursed \$50 for their time and were offered harm reduction materials (e.g., cottons, cookers, condoms) and referrals to local service providers. Interviews were transcribed verbatim and verified for accuracy by a research assistant using a structured protocol (McLellan, MacQueen, & Neidig, 2003). Participants provided informed consent and study protocols were approved by the Pacific Institute for Research and Evaluation’s Institutional Review Board.

The research team wrote summaries of each interview to begin identifying themes. Next, we independently read three interview transcripts and generated a preliminary coding scheme based on the primary areas of interest in the interview guide (deductive) and emergent themes (inductive) (Ryan & Bernard, 2003). The team met to discuss the coding schemes

and develop a codebook. Codes were arranged in a hierarchical structure by parent codes (e.g., health services) and sub-codes representing more specific themes (e.g., drug treatment, infectious disease, mental health). The first author coded all transcripts in consultation with the Co-Investigator, who checked the coding for consistency. The team discussed questions that arose during coding and refined the codebook as needed, which included creating additional parent codes and sub-codes. The first author wrote additional memos about important or unique findings in select transcripts to identify cross-cutting themes and generate a deeper understanding of the data.

Although we did not include specific questions about stigma in the interview guide, a majority of study participants provided unsolicited comments regarding how stigma affected their lives in a variety of contexts, including their interactions with the healthcare system. We therefore created a separate parent code for stigma, which we applied to any discussion of negative stereotyping or generalizations made by participants or others. We viewed the frequency with which stigma was raised by participants during the interviews as a testament to its importance in their lived experiences.

For the current analysis, we used a mixed inductive and deductive analytic approach to examine how stigma operates across health services contexts. The authors first read through all segments assigned to the “stigma” code. These segments broadly captured experiences of discrimination, stereotyping, rejection, and self-loathing related to a variety of identity factors including race, HIV status, and sexual orientation. Stigma related to PWID identity emerged as a theme across interviews (inductive), so we focused our analysis on injection-related stigma. With consideration of the study’s guiding framework and topics of interest (deductive), we then grouped the segments by the source of stigma and the context in which it was experienced (e.g., pharmacy, medical care, drug treatment) as well as by levels of the risk environment framework.

Here, we explore how stigma shapes injection-related health risk by influencing service access, service utilization, and related health risk behaviors. We consider SB41 and public stigma toward PWID as macro-level factors that may have influenced participants’ experiences of stigma, but our data primary speaks to meso-level enacted stigma by pharmacists, medical personnel, and drug treatment providers as well as micro-level perceived stigma, self-stigma, and health risk behaviors among PWID. We selected quotes to represent major themes, using pseudonyms to protect confidentiality.

Results

Among 46 PWID, the average age was 38.7 years (range: 20–65) and 37% were female (n=17). Sixty-three percent identified as white (n=29) and 37% as Latino (n=17). Past month injection drug use included heroin (67%, n=31), methamphetamine (50%, n=23), and powder cocaine (20%, n=9). Participants had injected an average of 16.7 years (range: 1 month – 54 years). We applied the stigma code in 28 out of 46 interview transcripts. Participants who cited stigma were similar to other participants on most demographic variables (e.g., age, sex, recruitment site) but more frequently reported past month heroin use (82% vs. 44%).

Participants raised the issue of stigma when discussing various health-related services, including syringe access, medical care, and methadone treatment. They primarily discussed meso-level stigma enacted by healthcare workers (e.g., pharmacists, nurses, drug treatment staff), as well as micro-level perceived stigma and related health risk behaviors. These experiences demonstrate some of the ways in which stigma manifested in PWIDs' everyday lives in the context of health services delivery.

Syringe Access

Participants repeatedly cited stigma when discussing syringe access, especially in the context of meso-level pharmacist interactions. Participants perceived that pharmacists made judgments based on appearance and refused to sell syringes to individuals they suspected were PWID. Some reported changing their appearance before attempting syringe purchase, including covering tattoos and injection stigmata (e.g., injection-related scars) and dressing conservatively. One participant said it was sometimes possible for PWID to purchase syringes from pharmacies if they did not "go in there looking like a sketchy drug addict." Alex, age 21 and from Fresno, described applying makeup to cover blemishes on their skin before attempting a pharmacy syringe purchase:

Interviewer: Is there anything you can point to that leads to... a successful purchase, versus a not-successful purchase?

Alex: Not looking like a drug addict. ... I typically wear make-up. Not-- just to make my skin look clear. And like, so that I look fine. ... But yeah, typically, if I know that I'm gonna be needing to go somewhere where I don't want them to suspect that I'm a drug user at all. Then I definitely will put a face on.

Interviewer: Yeah. Do you feel like that helps?

Alex: Yeah. ... One hundred percent. ... They're judging you on the way you look, for sure.

Because participants were often refused sales by pharmacists, some noted that these purchase attempts were embarrassing and stigmatizing and forced them to "out" themselves as drug users. Christopher, a 22-year-old from Kern, noted that others who inject drugs used to pay him to buy syringes for them because he "dressed nice." After being refused at a few pharmacies, however, he stopped trying:

Making \$2 going in and buying them for somebody else and getting shot down and kind of embarrassed in front of everybody, because you're getting turned down to buy needles, that's kind of embarrassing. It just basically tells everybody that's close, earshot away, that you're a junkie. I'd rather just not even try for fear of being shot down.

This concern with being identified as a PWID, combined with the high level of perceived stigma associated with injection drug use, acted as a significant barrier to ever attempting pharmacy syringe purchases for some participants. James, age 65 and from Fresno, said he never attempted to purchase syringes at a pharmacy because of the stigma he perceived toward PWID in his community, and his desire to protect his family's reputation:

James: I never have [attempted to buy syringes from a pharmacy]. I don't want the stigma attached to me...

Interviewer: What does that stigma look like to you?

James: To me, you know, it looks fairly bad for me, because my family and my family name is important to me. Although my mom's dead and gone, a lot of people in Fresno knew her. ... And, you know, they have great respect for her. And that respect is passed on to me. So, I have a reputation to live up to, you know? I don't want that passed on, I don't want anybody thinking, or knowing I should say, that I'm an IV drug user. So, I can't go into drug stores and buy syringes. I have to go to the exchange.

While for Christopher it was being publicly denied access to syringes and the resulting embarrassment that dissuaded him from making syringe purchase attempts, for James, the threat of being identified as a PWID was enough to prevent him from ever using pharmacies as a syringe source; in both cases, micro-level behaviors related to syringe procurement were influenced by stigma. Notably, in contrast to pharmacies, participants spoke very highly of the Fresno SEP and none reported any stigmatizing experiences there. The volunteers who run the SEP operate within a harm reduction framework which emphasizes the rights and dignity of people who use drugs and aims to destigmatize drug use; this may create a more welcoming and nonjudgmental environment for PWID than that of retail settings. However, one participant indicated that using the SEP could out him as a PWID and expose him to stigma from others because SEPs exclusively serve PWID. If PWID could consistently access syringes at a pharmacy without fear of discrimination, some might prefer this option because it offers a higher level of anonymity than SEPs.

Medical Care

Medical care was another area in which stigma was discussed repeatedly. Multiple participants indicated that first responders and hospital staff treat PWID poorly and with disdain. These experiences ranged from receiving "looks" from staff that participants perceived as stigmatizing to receiving medical care they believed was substandard due to their categorization as a drug user. Participants also gave glimpses into how these experiences influenced their micro-level health-related behaviors.

Multiple participants described a general sense of being "looked down on" by medical personnel. Lisa, age 42 and from Fresno, stated that hospital staff "look at [PWID] like we're garbage." David, 58 and from Kern, disliked accessing medical treatment because hospital staff "kind of look down on you. ... They give you dirty, snotty looks." Participants generally perceived that these attitudes were based solely on the knowledge of their injection drug use. Two participants mentioned that after identifying themselves as PWID, medical staff prioritized care for others, essentially putting them "at the back of the line." Robert, age 62 and from Kern, described the following:

Interviewer: What happens when people do know that you use drugs? What does that look like?

Robert: ... You're a nobody ... You're just on the back burner to them. For example, people get abscesses and stuff like that, and they go to the hospital, and once the doctors... realize that you're a drug user, they sit you on the back side and they'll take that person in front of you ... Yeah, you get treated a lot different.

Other participants indicated that treatment of PWID was worse at some hospitals than others. Maria, 56 and from Kern, described how she avoided a specific hospital after hearing about other drug users' experiences there, saying "They don't like heroin users." She continued:

I know people have been over there and they've got treated like shit. They don't care what race you are, as long as you are a dope fiend, they don't give a fuck. They don't care about you. They've never treated me.

Some participants also believed PWID receive sub-standard medical care. Bill, a 50-year-old from Kern, said that first responders sometimes reacted with a slow, uncaring response to potentially fatal opioid overdoses:

A lot of my friends have died, OD'd. ... When the ambulance gets there, they're just taking their sweet time. You tell them that they OD'd, they already know they're OD and they're heroin addicts, so the paramedics, they just walk in there all slow and they're just taking their sweet time, the fire department too. They tell you "Get out of the way and let us take care of the job," and you tell them, "They're not breathing." They're not going to listen to you. They go and they don't even try to help them breathe or nothing. That's really sad to see what happens. They just don't care.

In addition to the direct health impacts of substandard care, stigma against drug users in the medical system can negatively affect PWIDs' health by leading them to delay or refuse care. Maria, quoted above, said she would typically attempt to treat her injection-related abscesses herself, delaying medical care until it was absolutely necessary. This was a common approach; other participants indicated that they avoided hospitals or delayed care because of the stigma encountered in medical settings. Melissa, 38 years old and from Kern, knew multiple PWID who died from injection-related infections because they were afraid to go to a hospital:

Melissa: When you go to a hospital, and you're a drug addict – or an IV drug user, especially – you are treated horribly. ... Your life isn't as valuable, you're a second or third class citizen, and it's sad. ... [T]hey [PWID] don't want to go and have someone go and look down their nose, and tell them what a piece of crap you are. You already know. Most people using a needle know. They've hit rock bottom. They know that they're down there pretty far. A lot of people just won't go. They'd literally rather die than face that. It's sad. It's really sad, it happens. I get it. I never would have understood, I'm like, just go to the doctor, that's stupid, but I get it now. I understand.

As Melissa highlights, meso-level interactions with healthcare professionals clearly have important implications for PWIDs' health. Whether participants perceived stigma in the healthcare system, witnessed enacted stigma by medical professionals, or were themselves

discriminated against when seeking care, their experiences resulted in community-wide distrust and aversion toward medical systems. Melissa's narrative also points out that PWID enter into these interactions carrying the weight of self-stigma, which may be an important factor in how they interpret the behavior of care providers. Together, these examples demonstrate how the compounding effect of multiple types of stigma can influence PWID behavior, potentially leading to serious health consequences.

Methadone Treatment

Participants reported that stigma created barriers to engaging in drug treatment and recovery support. They described meso-level group norms among PWID in which participating in methadone treatment was more stigmatized than injecting drugs. They also described meso-level stigma within the context of other drug treatment and support programs that were hostile to or exclusive of individuals on methadone.

Multiple participants described the core beliefs that underlie macro-level public stigma toward methadone (i.e., equating methadone with illicit drug use) and indicated that this social stigma prevents PWID from enrolling in methadone treatment. Melissa summarized this perception:

[T]here is a huge stigma attached to [methadone]. A lot of people have been told that it's just as bad as being on heroin, you might as well stay on heroin. It's sad that that's how it is, but a lot of people are like, "Oh, no. I'll just get on heroin, methadone is just as bad."

Amanda, a 36-year-old from Kern, described how she and her husband delayed entering treatment due to methadone stigma. She said they "hated methadone," believing that it was "the same thing" as being addicted to heroin. Amanda's experience demonstrates how macro-level stigma against methadone affects meso-level group norms as well. She indicated that in her PWID community, being on methadone was stigmatized even in comparison to injecting heroin:

At that time, if you get on methadone, you are just as bad as any junkie heroin addict, so you might as well just do the heroin because then nobody knows you are at a methadone clinic, it is just trading one for another. We hated methadone, hated people who were on methadone and talked crap about them, because, for whatever reason, we thought we were so much better.

Amanda and her husband eventually enrolled in methadone treatment, but she wished that they had tried methadone sooner:

There is such a stigma, and I feel stupid because I was one of the people that talked crap, but now that I have been in all of those positions, that is how important all of this stuff is. If me and my fiancé would have known 5, 6, 7 years ago how easy this really could have been, we would have done it then instead of letting our daughter live with someone else because she had had heroin addicts her whole life as parents.

In addition to causing them to delay treatment, Amanda described how meso-level stigma created barriers to support once she and her husband started methadone. Many sober living

homes in her town refused to take individuals in methadone treatment, and Narcotics Anonymous groups she attended were hostile toward individuals who celebrated sobriety milestones while taking methadone. Amanda stated that sober living homes “look down on so many people who do methadone,” and “[n]o sober living wanted to take us if we were on methadone at the time.” Thus, Amanda’s experience demonstrates how stigma acts not only as a barrier to methadone, but also to accessing recovery support.

Discussion

Stigma played an undeniably important role in our participants’ experiences with health services, arising organically across interviews even though we did not ask about it directly. Our findings indicate that stigma has an impact on multiple aspects of life and health among PWID, including utilization of health-related services such as syringe access, medical care, and drug treatment. In each of these areas, stigma was linked directly by participants to micro-level health risk behaviors, lower health services utilization, and/or nonprofessional care.

Our participants’ discussions of syringe access provide a useful example of how stigma operates at multiple levels of the risk environment framework, acting as a barrier to optimal health. Macro-level public stigma against drug users (including negative views held by health professionals; van Boekel et al. 2013) has been well-documented in the literature (Barry et al., 2014; Link et al., 1999). Laws such as SB41 operate within the context of this public stigma against PWID; although SB41 was designed as a macro-level intervention to reduce HIV transmission by expanding syringe access, the law’s voluntary nature allows pharmacists to act as gatekeepers to this critical health service.

Macro-level stigma is often enacted at the meso level. The medical case for selling syringes to PWID is clear: access to sterile syringes reduces syringe sharing and HIV transmission (Wodak & Cooney, 2006) and may reduce transmission of other blood-borne viruses such as HCV (Fernandes et al., 2017). Nonetheless, U.S. studies suggest that some pharmacists decide whether to provide services like syringe sales based on their perception of a patient as morally deserving rather than medical need (Chiarello, 2011, 2016). This is borne out in findings from Phase I of this study; only 21 percent of our purchase trial pharmacies sold nonprescription syringes, and many pharmacy employees reported via survey that they were willing to sell syringes to persons with diabetes but not those who inject drugs (R. A. Pollini et al., 2015; R. A. Pollini, 2017). Our study did not directly examine the role of stigma in pharmacists’ decision-making. However, the PWID in our sample strongly believed that stigma influenced pharmacists’ decisions.

Regardless of pharmacists’ rationale for denying syringe sales, the end effect of these interactions was to perpetuate stigma. To our participants, refusing syringe sales represented a form of enacted stigma and exacerbated the already-existing perceived stigma associated with pharmacy syringe purchase. It is notable that perceived stigma was the primary form of stigma assessed in Latkin et al.’s (2010) study of stigma and HIV injection risk behaviors, in which the authors found that higher levels of PWID-reported stigma were associated with risky injection practices. Our findings suggest one possible causal pathway for this finding,

in which perceived stigma reduces the likelihood that PWID will attempt syringe purchase, thus increasing the likelihood of syringe sharing.

Our study echoes previous research from Tijuana, Mexico, in which members of our research team described how PWID engage in “Goffmanian impression management” by taking measures to conceal their drug using identities when attempting pharmacy syringe purchases (Davidson et al., 2012; p.14). Specifically, Goffman (1963) theorized that people attempt to mitigate the practical consequences of their stigmatized or “spoiled” identities through efforts designed to influence their perception by others. Our participants, like those in Davidson et al.’s (2012) study, described trying to increase their chances of successful syringe purchase by undertaking efforts to appear less like “sketchy drug addict[s].” However, these attempts had varying success, and some participants who “dressed nice” were often enough identified as PWID and refused syringe sales that they eventually stopped attempting syringe purchases altogether.

Enacted and perceived stigma were also important in the context of medical care. Our participants believed that PWID received poor care from medical professionals who cared little about their lives due to their stigmatized status as drug users. Indeed, past research has suggested that people with substance use disorders may receive suboptimal medical care because healthcare workers are less involved and have less empathy for these patients (Peckover & Chidlaw, 2007) – a form of meso-level enacted stigma. Additionally, in support of findings from previous research (Neale, Tompkins, & Sheard, 2008), we found that stigma acted as a significant barrier to medical services utilization for injection-related health issues among our participants. Given high rates of morbidity and mortality related to overdose and injection-related infections in the U.S., these data suggest that stigma toward PWID among medical professionals may have life or death consequences.

Even when PWID are motivated to stop using drugs, stigma may act as a barrier to accessing evidence-based treatments such as methadone. Our study supports the theory that methadone-related stigma is, at its core, the same stigma that surrounds drug addiction. This stigma is rooted in the belief that methadone treatment “merely substitutes one drug for another” (Joseph et al., 2000, p. 358) or “one addiction for another” (Gordis, 1991, p. 106). Our participants indicated that this belief is pervasive among PWID in the Central Valley and clearly identified it as a deterrent to engaging in methadone treatment. They also reported that methadone-related stigma prevented people who use methadone from receiving equal access to recovery supports in the form of sober living houses and Narcotics Anonymous. Previous research has demonstrated that stigma acts as a barrier to treatment engagement (Browne et al., 2016; Keyes et al., 2010; Radcliffe & Stevens, 2008; Semple et al., 2005). Our study supports these findings, suggesting that stigma contributes to negative health outcomes among PWID not only by increasing HIV risk and decreasing medical care utilization, but by preventing PWID from engaging in evidence-based drug treatment modalities and other recovery programs.

In summary, our study suggests that combating stigma is an essential component of efforts designed to improve PWID health. Specifically, there is a need for interventions that reduce stigma at multiple levels of influence, with particular emphasis on meso-level service

delivery and related micro-level PWID decision-making. Structural interventions may be particularly useful; for example, legislators could consider mandatory rather than voluntary syringe sales legislation. Where this is unfeasible, laws allowing voluntary participation should be accompanied by anti-stigma interventions targeting meso-level gatekeepers, such as pharmacists. Within healthcare settings like hospitals and clinics, administrators should consider policies and educational strategies for combatting stigma in their organizational culture. Similarly, drug treatment and recovery programs should institute policies that are inclusive of individuals taking methadone, recognizing that opioid replacement therapies are an integral, evidence-based component of successful treatment for many opioid users.

Our study has limitations. First, our sample may not be representative of all PWID in the region and therefore may not be generalizable; however, our results are consistent with prior literature on drug-related stigma, particularly regarding its role as a barrier to health services access and utilization. This lends confidence that the insights gained here can contribute to appropriate anti-stigma interventions. Second, we did not directly ask about stigma and thus only have data for those in our sample who raised the topic independently. Nonetheless, the fact that more than half of our participants independently raised stigma as a concern highlights its importance for PWID and the need to include its exploration in future research. Our qualitative research design and inductive analytic approach enabled us to identify stigma as a key theme that cut across our core topics of interest. Last, we do not have information about participants' stigmatizing experiences from the perspective of others involved in those interactions (e.g., pharmacists) or independent observers. Thus, we cannot determine to what extent stigma actually influenced the behavior perceived by PWID as stigmatizing or whether the interactions would be perceived similarly by non-PWID. However, in the pharmacy surveys we conducted during the first phase of our study, only one in four participants said their pharmacy would sell syringes to "known or suspected" injection drug users (R.A. Pollini, 2017). While the current study only included the perspectives of PWID in the Central Valley, our related pharmacy-based research supports their perceptions.

Conclusions

PWID in our study reported pervasive perceptions and experiences of stigma in the context of health services in California's Central Valley. This stigma was linked by participants to decreased health services access and utilization in the areas of sterile syringe access, medical care, and drug treatment. Our study illustrates the need to develop and test interventions that target drug use stigma at all levels of influence.

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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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