

Title: *I don't even want to go to the doctor when I get sick now: Healthcare experiences and discrimination reported by People who Use Drugs, Arizona 2019*

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Key Words

Stigma

Healthcare access

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Community based participatory research

Highlights

- 40% of people using drugs avoided healthcare due to anticipated mistreatment.
- Those seeking healthcare reported mistreatment and abuse by healthcare providers.
- Social mistreatment by clinicians included disapproval, embarrassment and shaming.
- Medical providers ignored health complaints and provided inappropriate treatment.
- Healthcare providers abused patients verbally and physically to convey disapproval.

Abstract

Background. People who use drugs experience severe health inequities created by structural and social barriers related to healthcare access including stigma.

Objective. To characterize the experience of healthcare access among people who use drugs in Maricopa County, Arizona USA.

Methods. A 20-item guided survey with quantitative and qualitative items was fielded between October 23-November 5, 2019 among people who use drugs in community locations (public spaces, trap houses, drug copping areas). Surveys were administered face-to-face by community researchers with lived experiences. Survey recruitment included convenience sampling and social referral among respondents. Quantitative items were described and qualitative data were independently coded using an *a priori* coding scheme including reasons for healthcare seeking and healthcare seeking stigma (anticipated, experienced, enacted).

Results. Over one-third (39.5%) of the 185 person sample did not seek medical care in the past year. Of this group, 34.2% reported that they did not seek needed healthcare because they were afraid of being treated badly by medical providers for using drugs. The three major experiences reported by those seeking healthcare in the past year included 1) medical mistreatment (not addressing the primary medical complaint, providing wrong or inadequate treatment), 2) social mistreatment (disapproval, embarrassment, shaming) and 3) abusive behavior (verbal and physical) by healthcare providers.

Conclusions. Efforts should create healthcare social and practice environments that assure appropriate and competent medical care and prohibit healthcare provider mistreatment of people who use drugs. Structural incentives such as healthcare finance, hospital accreditation and medical complaint registration should be considered.

Introduction

People who use drugs (PWUD) in the U.S. experience disproportionate adverse health outcomes and mortality as compared with the population as a whole (Reisinger et al., 2017; Lake and Kennedy, 2016). Similar health outcomes have been reported elsewhere, for example in the UK (Neale, 2004), and across 8 other European countries (Bargagli et al., 2006). In the U.S. health outcomes among PWUD are intensified by the overdose pandemic, epidemic rates of HIV, hepatitis A and C and skin and soft tissue infections (CDC, 2020; Scholl et al., 2019; Hagen et al., 2005), and by structural barriers thwarting health access and utilization. For example, even with confidentiality protections for U.S. healthcare patients who use illicit substances (42 CFR Part 2), there exist exemptions that work against those protections (U.S. Commission on Civil Rights, 1998). Further, stigma is increasingly recognized in several countries as a healthcare barrier for PWUD and therefore a significant public health issue (Kiriazova et al., 2017; Barry et al., 2014; Tindal et al., 2010; Ronzani et al., 2009); but it has yet to become a focus of healthcare policy in the U.S. Laws that criminalize drug use continue to reinforce social stigma and cultural norms against drug use; serving to deter PWUD from accessing healthcare of any kind (Lopez and Reid, 2017; Link et al., 1997).

It is well documented that healthcare stigma around drug use results in healthcare access delay or avoidance by PWUD (Biancarelli et al., 2019; Kiriazova et al., 2017; Neal et al., 2008); thus creating poorer health outcomes as compared with non-drug users (Paquette et al., 2018; Latkin et al., 2013; Ahern et al., 2007). One would have hoped that by 2019, healthcare provider stigma and discrimination against drug users seeking healthcare would have reduced. This, however, does not appear to be the

case. A review of studies between 2000-2011 documented the pervasiveness of negative attitudes among health professionals toward patients who use drugs in several western countries (Van Boekel, et al., 2013). Medical education interventions to reduce ambivalence and bias toward PWUD have been few and with unimpressive results (Crapanzano et al., 2014; Knaak et al, 2014. Oliveira et al., 2013), yet calls continue for improved medical education to reduce stigma as the overdose epidemic emerged worldwide (Pearlman, 2016; National Academies of Sciences, 2016). The literature suggests, however, that PWUD continue to experience stigma while accessing healthcare (McKnight et al., 2017; Merrill et al., 2002). Further characterization of healthcare access experiences by PWUD may help to advance our understanding of how to intervene to improve medical interactions for PWUD beyond educational interventions among clinicians. Knowing that health care providers (HCPs) have stigmatizing or negative views about PWUD is not sufficient to developing interventions to reduce it. Instead, studies characterizing the expression and experience of stigma may be more helpful to inform interventions that focus on health care provider behavior and social expression of stigma. This study therefore seeks to characterize the experience of healthcare access among people who use drugs in Maricopa County, Arizona, U.S.A. with particular focus on experiences and expressions of stigma. This county is home to the city of Phoenix, the 5th largest U.S. city. To our knowledge, not only would this study be one of the first of its kind in a Southwestern U.S. community, but it also has a community-based participatory research orientation (Balazs and Morello-Frosch, 2013; Scharff et al., 2010). For this study, stigma refers to biases that are socially or institutionally expressed as discrimination. Our conceptualization of

stigma was informed by Pescosolido and Martin, 2015; Link and Phelan, 2001; and Goffman, 1963.

Methods

The community-based participatory research orientation for this study involved the fact that study goals, methods, and the interpretation of results were directed by the Maricopa County, Arizona drug users' union (also called the community health advisory committee (CHAC)). The CHAC is convened by a statewide harm reduction organization (Sonoran Prevention Works). CHAC Members and facilitators are active drug users, and supportive members are former drug users and allies. The premise under which the CHAC operates is similar to many labor unions, such that people who are impacted by the same structural oppression have more power to affect positive change by working together and supporting each other (Hagedorn et al., 2016). Members of drug user unions work together to promote or oppose policies that impact PWUD, share knowledge and build leadership among drug-using community members, and to confront and combat stigma that is harmful to PWUD (Madden et al., 2021; Frank et al., 2012; Mold and Berridge, 2009).

For this study, CHAC members developed capacity to conduct community-based survey research with assistance from co-author (BEM) of the University of Arizona Southwest Institute for Research on Women. All participating CHAC members learned about survey development and how to interpret findings (Balazs and Morello-Frosch, 2013).

This cross-sectional study collected data through an anonymous survey containing 20 qualitative and quantitative items developed and vetted by the CHAC to measure service experiences, including healthcare, as well as needs related to housing, healthcare, social services, police and courts. The survey also collected demographic data (race/ethnicity and gender identity but not age), and drug use experience with the exception of drugs used. Survey eligibility included being 18 years of age or older, self-identifying as a person who uses drugs, and living in Maricopa County, Arizona U.S.A.

Here, we report findings related to healthcare access and experiences of stigma. Our approach to characterizing health care access experiences in the last year (12 months) included measuring whether people sought health care (yes/no), why they did not seek it (if no), and exploring experiences with healthcare providers when care was sought. In this exploratory study, health care provider (HCP) refers to doctors, nurses, administrative staff and other health professionals to which patients were exposed during their healthcare seeking experiences in the past year.

CHAC members opting to be surveyors were trained in research ethics and human subjects protection in a “Community Partnered Research Training” approved by the University of Arizona Institutional Review Board (1910062779) and provided by co-author BEM. Surveyors recruited survey participants and administered face-to-face guided surveys in community and private venues during three time periods: evening (6pm-midnight), daytime (noon-5pm) and morning (6am-noon) between October 23-November 5, 2019. Surveyors recorded survey responses by hand with pen or pencil directly on to the survey instrument. Completed surveys were returned to coauthor (DMR) for verbatim database input. Convenience sampling guided recruitment in

community venues (trap houses, drug copping and use areas) and also involved social referral by interview participants. Survey participants gave verbal informed consent for participation. A \$10 (USD) cash incentive was offered for survey completion.

Quantitative data were described with frequencies using SPSS (version 26). Qualitative data were organized using QSR Nvivo (version 12) and coded using an *a priori* coding scheme including reasons for healthcare seeking and healthcare seeking stigma (anticipated, experienced, socially enacted). Open coding was then conducted with thematic emergence. Data were first independently coded by two researchers (BEM and DMR). A coding conference identified few discrepancies, and all data were recoded using the finalized coding scheme. The CHAC met to discuss and interpret survey outcomes and to make recommendations for data translation to practice and policy.

Results

The sample included 185 persons identifying as a person who uses drugs. Table 1 displays participant demographics. We sampled active drug users, including people with injection drug use experience. The majority of the sample (73.0%) reported drug use the day of or before the survey. Most (78.4%) reported having injection drug use experience, with over half of this group (54.6%) indicating they had injected the day of the survey. Almost everyone in the sample (79.5%) wanted a safe, clean place to use drugs (such as a safe consumption site), because 65.4% reported a history of having to use drugs in places that were unsafe (dirty or dangerous).

Table 1 about here

Over one-third (39.5%) of people surveyed did not seek medical care in the past year. Of this group, 34.2% reported that they did not seek needed healthcare because they were afraid of being treated badly by medical providers for using drugs; and 21.0% said that they couldn't pay for the needed healthcare. For the 109 people (58.9%) who sought medical care in the past year, the vast majority (81.7%) reported using a hospital, emergency room, or urgent care at least once (see Table 2). This paper reports experiences with healthcare providers in the past year as detailed by the 109 people who accessed medical care in the past year.

Table 2 about here

Medical Mistreatment

For the majority of survey participants, the healthcare experience in the past year was one of discrimination and outward, socially expressed stigma, which appeared to reinforce the anticipation of mistreatment and stigma. Participants described medical mistreatment, social mistreatment and abusive behavior by healthcare providers (HCPs).

Almost all participants reported medical mistreatment by HCPs in the past year. Reported medical mistreatment included not addressing the primary medical complaint, providing wrong or inadequate treatment, and refusal of appropriate medication. Participants reported perceived HCP fixation on their substance use, which in turn

appeared to dictate whether and how their health was addressed and managed by the HCP. Participants listed several examples of medical needs presented for treatment unrelated to substance use; however, substance use became the primary if not the exclusive lens through which HCPs interpreted patient medical need. In many cases, participants reported that the HCP ignored the presenting issue and focused only on substance use.

They seemed to think I just wanted drugs. But I can get drugs on my own without their help. I needed help with my chest being infected, but they couldn't even do that without judging me and treating me like a junkie.
(Participant 78, White, non-Hispanic, Cisgender male)

Several participants indicated that pain associated with their presenting injury was ignored and that often medical treatment was not provided. They believed that HCPs assumed they were seeking drugs instead of healthcare. Participants reported that this assumption completely derailed patient-provider communication and trust building.

Treated me like I was a piece of shit. They felt I was a junkie so I needed no pain meds even though I had to have multiple surgeries and stayed in hospital and rehabilitation for weeks. My foot was crushed, (I had a) concussion. They talked to me like I was stupid.
(Participant 1, White, non-Hispanic, Cisgender male)

I (came in for treatment of a urinary tract infection), but instead they stigmatized me for drugs, didn't help me with the problem I went in for, just shamed me..... (They) made me feel unwelcome, alone and alienated as a user....They speak about drug use like it makes you a different breed, unworthy. When I admitted to using, I was only monitored and now (when I return) it is assumed I am high even when I am not... (Participant 12, Asian, Cisgender female).

Participants reported that once the HCP knew or assumed there to be substance use history, they witnessed their treatment being augmented; often involving a reduction of

medical care. Participants felt this was because their HCPs assumed they were drug seeking.

I was at Urgent Care for a chest infection and the doctor still seemed to think I was there to get drugs. At the emergency room the same thing happened: they looked at me like I am a junkie and just wanted drugs. But I care about my health they just make it hard because I don't even want to go to the doctor when I get sick now. (Participant 155, White, non-Hispanic, Cisgender male)

(I went for) an abscess, wound. The doctor only gave me one Percocet even though my arm was flayed right open and they scraped it while I was awake. He handed me one single Percocet like he thought it was such a great gift and he was so generous, but really didn't care about me being in pain at all. (Participant 31, White, non-Hispanic, Cisgender female)

In some cases, reported medical mistreatment involved providing partial medical treatment such as treatment but no pain management, inappropriate treatment such as laxatives when they were not required, or no treatment at all. (The doctor) was supposed to fix my knee after the accident. Broken ribs. Doctor didn't do shit (Participant 6, White, non-Hispanic, Cisgender male). Participants felt that the mistreatment by HCPs was to teach a lesson to or punish drug using patients.

Doctor told me he wouldn't provide me any medical care unless I could prove I had no drugs in my system and could pass a UA (urine analysis). My lungs were so filled with fluid, they had to break my ribs to scrape out my lungs and they still didn't provide me any pain meds or relief, so my friend was bringing me in heroin to help with the pain I was in. (It was clear that) the doctor was mad that I wasn't detoxing and sick, so he said he knew I had to be getting drugs somehow and called police in to search my room while I was sick. They wouldn't provide me any methadone or pain management even though I was in so much pain. (Participant 5, White, non-Hispanic, Cisgender male)

They didn't listen to me when I told them I was in pain and kept giving me laxatives even though I said I didn't need them. They

said that because I was addicted to opiates, I had to take laxatives, but it was more to punish me.... and I was already hurting from being hit by the truck. But to have all the laxatives too was awful. (Participant 32, Hispanic, Cisgender female)

Social Mistreatment by Health Care Providers

Participants reported HCP-expressed social disapproval about their current or past substance use during medical examinations. Experienced social disapproval was direct or implied; yet always clear to patients. More than one participant reported HCPs expressing *exhaustion* or *frustration* over drug using patients; or that providing medical care to them was a *waste of time*.

The doctor said they didn't want to waste their time treating anymore junkies. (Participant 7, White non-Hispanic, Cisgender female)

Participants reported HCP discrimination, even when it was known by the HCP that they were in recovery with medication for opioid use disorder. Discrimination was experienced socially and immediately in response to learning that the patient was on this treatment.

They helped the wound, but as soon as they found out I was on methadone, they totally got cold. (Participant 66, Black, Cisgender female)

They searched my clothes when I took them off in the room and said they were looking for drugs. They treated all my visitors like they were bringing drugs to me, and wouldn't even give me methadone to help when I got sick. I had to have friends bring in stuff to keep me well. (Participant 83, White, non-Hispanic, Cisgender female)

At times participants reported HCP mistreatment of them; seemingly trying to *embarrass* or *shame* them. Participants were themselves completely aware of this social mistreatment, and reported knowing that the HCPs were also aware of patient mistreatment.

The nurses treated me like a freak show; even brought the office workers through my room to gawk at my wounds. (Participant 7, White non-Hispanic, Cisgender female)

They wouldn't give me a hair brush the entire time I was there, so my hair was so tangled by the time I got out of hospital I had to cut it all off and they just talked down to me the whole time. (Participant 32, Hispanic, Cisgender female)

Participants reported that HCPs expressed their negative views of drug using patients and their drug use during patient interviewing to learn about the primary medical complaint and health history. Several participants spoke of HCPs *not listening to me*, *talking down to me*, or treating them *like a child* once it was learned that the patient was a drug user.

Once they found out that I was a drug user they started treating me very badly. (Participant 70, White, non-Hispanic, Cisgender female)

I was treated like some animal. Like cattle, and they were really judgmental and I saw lots of fucked up shit happen to others, like they turned a guy away cause they thought he was high and I think they just discriminated against him. (Participant 64, White, non-Hispanic, gender nonbinary)

Several participants reported experiencing direct and active rudeness, as well as verbal abuse expressed as *lectures*.

They seemed to think that yelling in my face and being cruel to me would make me somehow not addicted to drugs anymore. (Participant 7, White non-Hispanic, Cisgender female)

The nurses seemed scared of me. I got lectured about using drugs and told I did this to myself. (Participant 143, Hispanic, Cisgender male)

Physical Abuse

In addition to emotional and verbal abuse, some participants reported physical abuse by HCPs. Participants believed that these behaviors were meant to be noticed by them and to somehow be of benefit to them. As with the verbal abuse, participants felt that the physical abuse was designed to *teach a lesson or make a point*.

The doctor stabbed me in the wrist with a giant needle and jerked it around to get fluid out of my arm, he didn't even use any numbing. They treated me like a piece of shit. (Participant 30, Hispanic, Cisgender female)

Because I was in there for abscesses due to my drug use the doctors (left) an outrageous scar to make a point or use me as an example. (Participant 36, White, non-Hispanic, Cisgender female)

Discussion

Findings from this study are evidence of healthcare provider mistreatment of and discrimination against people who use drugs in Maricopa County, Arizona, U.S.A. One might suggest that stigma and discrimination against PWUD is concentrated in Arizona, given similar study findings of mistreatment and stigmatizing behaviors by pharmacy staff in three Arizona counties (Maricopa included) (Meyerson et al., 2019). That study, however, occurred in Arizona and a second state (Indiana), and findings of health care related stigma against people who use drugs continues to be observed globally (Lopez

and Reid, 2017; Kiriazova et al., 2017; Barry et al., 2014; Tindal et al., 2010; Ronzani et al., 2009 Link et al., 1997). Further, to our knowledge, there are no studies documenting the reduction of stigma and discrimination against PWUD in healthcare settings in Arizona or elsewhere. Thus, it is likely that our study findings indicate the persistence of widespread healthcare provider bias against drug users and drug use; suggesting the need for continued research to inform policy that will improve healthcare practice and HCP behavior toward patients. Our study found evidence of socially expressed stigma, medical maltreatment, and abuse in physical and verbal forms. Suboptimal medical care associated with HCP stigma about patients that use drugs was also observed in a review of studies conducted in several Western countries (Van Boekel et al., 2013). If patients with other health conditions (such as diabetes or heart disease) were to report these experiences, it would be deemed highly unacceptable and tantamount to medical malpractice. With PWUD, however, persistent evidence of these behaviors indicates either social acceptance of drug user mistreatment in healthcare settings, or a need for structural interventions (such as law or policy) to prevent such behaviors.

In our study, participants reported that healthcare providers prioritized substance use as the primary and sometimes singular medical issue to address, even though none of the participants sought medical care to address their substance use. Reported HCP behavior may be an artifact of recent U.S. emphases to increase patient screening for substance use in primary care settings in preparation for brief intervention to reduce it through patient counseling (Saunders et al., 2019; Albright et al., 2017; Muhrer, 2010). Primary care clinics or physician offices may be good places for such screening when relationships of trust are built with patients; however, in this sample, 81.7% of

participants (Table 2) sought health care in a hospital, emergency room or urgent care setting. Further, reported HCP behavior indicated a paucity of evidence-based interventions in response to provider knowledge of patient drug use. In settings reported for this study, feelings of trust and behaviors to build patient-provider trust were not reported by any of the 109 participants reporting healthcare access in the past year. Thus, provider fixation on patient substance use might well be grounded in negative attitudes and social constructions of substance use and/or people who use drugs.

At issue is whether patients who use drugs can autonomously prioritize their medical needs, and whether HCPs can provide adequate medical treatment to patients who use drugs without judging their desire to use them. Respect for patient decisions to use drugs was not reported by any participant in this sample. Instead, participants reported that once drug use was suspected or reported, HCPs exhibited a negative change in demeanor. The moniker of “junkie” used by HCPs against participants was a totalizing ‘master status’ (Goffman, 1963). So instead of a desire to screen for and address patient substance use, we found that HCPs used a stigmatized master status of “junkie;” which in turn allowed other harmful HCP behaviors such as minimizing the primary medical complaint, not listening to patients, and infantilizing patients. All medical issues appeared to become subsumed under the primary HCP-determined “problem” of drug use. Thus, a urinary tract infection, pneumonia, and injuries from a car accident became bases for stigmatizing treatment and medical disregard.

The central question is whether the U.S. healthcare system is truly ready to treat the medical needs of PWUD without focusing on substance use. Susan Boyd’s comparison of U.S., Canadian and British HCP treatment of PWUD is illustrative (Boyd, 2004). Boyd

theorizes that U.S. healthcare and drug treatment providers suffer from pathological, compulsive, and addictive behaviors in their treatment of and conduct toward PWUD. Specifically, she argues, they are addicted to punishing drug users. Our findings substantiate this observation. Participants reported their HCPs yelling, socially expressing disapprobation, and the causing of physical harm *to make a point*.

Larger healthcare stigma characterization studies among PWUD are necessary to measure the extent and expression of stigma and discrimination against PWUD in healthcare settings. Such studies will inform needed policy changes to improve patient health and safety. It may also be that local studies will be most powerful to policy makers. This too should be empirically tested. Examples of policy changes that could normalize medical care for PWUD include malpractice reform or publicly reported healthcare performance and quality outcomes specific to populations such as PWUD. In both cases, healthcare systems would need to be penalized financially to create the environment for improved HCP behavior toward PWUD.

The as yet unsolved debate about substance use in our cultures continues to stall with thinking that some substances are acceptable (caffeine, alcohol, marijuana (near future)), while others are pathologies that must be solved and treated. This is a variation of the dichotomous construction of substance use as a health issue or a moral and therefore criminal issue (Howard and Chung, 2000). The U.S. faces a major overdose crisis, with over 46% of people reporting that a family member or close friend is or was addicted to drugs (Gramlich, 2017). In Arizona, where this study was conducted, the rates of overdose exceed the national average (Hafajee et al, 2019). This suggests the need to review our social views about drug use and drug users, and to openly discuss

our social constructions. Studies have documented healthcare provider belief that substance use is a moral issue and not a medical issue. For example, Corrigan et al.'s study of causal attribution found that having a belief that people could control their substance use disorders increased intolerant judgements toward people who used drugs and toward substance use (Corrigan et al., 2003). This again raises a central question of whether PWUD should be 'reformed' or changed in some way to accommodate societal expectations before they will be provided with appropriate and competent medical care. Our findings suggest that in order to receive proper medical treatment without social mistreatment and physical harm, PWUD would need to either entirely hide their substance use histories or delay healthcare generally. These findings do not reflect those from a small study in Sydney Australia finding that HCP contact with people who inject drugs predicted positive attitudes toward them irrespective of conservatism (Brenner L et al., 2007). Thus, it appears the task at hand is not to stop at educating our medical colleagues, but to create social and practice environments through policy changes which prohibit mistreatment of PWUD. Structural incentives such as healthcare finance, hospital accreditation and medical complaint registration should be considered.

This study was limited by the size of the sample, its location (only U.S.), and the lack of gender and race/ethnic diversity of the study sample. The age of participants was also not gathered, though all participants were at least 18 years of age. As an exploratory study, findings were not intended for inference to a larger population. Further, the survey did not collect information about drugs used by participants. This is not a limitation, however, because the issue is not what type of drugs people use but

the mistreatment they experience whilst attempting to access healthcare as a person who uses drugs. We recognize that certain drugs have been socially constructed to be more harmful than others and are more stigmatized than others.

In conclusion, this study reveals the persistence of HCP enacted stigma against drug using patients in a major U.S. city. The deleterious outcomes included reinforced anticipated stigma when accessing healthcare, and decisions to forego or delay future healthcare. It is time for more structural approaches to assure equitable and appropriate medical care for patients, irrespective of drug use.

References

- 42 CFR Part 2: Confidentiality of substance use disorder patient records.
- Ahern, J., Stuber, J., Galea, S., 2007. Stigma, discrimination and the health of illicit drug users. *Drug Alcohol Depend.* 88,188-196.
- Albright, G., Bryan, C., Adam, C., McMillan, J., Shockley, K., 2017. Using virtual patient simulations to prepare primary health care professionals to conduct substance use and mental health screening and brief intervention. *J Am Psych Nurse Assoc.* 24(3),247-259.
- Balazs, C.L., Morello-Frosch, R., 2013. The three R's: How community-based participatory research strengthens the rigor, relevance and reach of science. *Environ Just.* 6(1):9-16.
- Bargagli, A.M., Hickman, M., Davoli, M., Peruccii, C.A., Schifano, P., Buster, M., Brugal, T., Vincente, J., 2006. Drug-related mortality and its impact on adult mortality in eight European countries. *Euro J Pub Health.* 16(2), 198-202.
- Barry, C.L., McGinty, E.E., Pescosolido, B.A., Goldman, H.H., 2014. Stigma, discrimination, treatment effectiveness and policy: Public views about drug addiction and mental illness. *Psych Serv.* 65(10),1269-1272.
- Biancarelli, D.L., Biello, K.B., Childs, E., Drainoni, M., Salhaney, P., Edeza, A., Mimiaga, M.J., Saitz, R., Bazzi, A.R., 2019. Strategies used by people who inject drugs to avoid stigma in healthcare settings. *Drug Alcohol Depend.* 198(1),80-86.
- Boyd, S.C., 2004. *From witches to crack moms: Women, drug law and policy.* Durham, NC.: Carolina Academic Press.

- Brenner, L., Von Hippel, W., Kippax, S., 2007. Prejudice among health care workers toward injecting drug users with hepatitis C: Does greater contact lead to less prejudice? *Int J Drug Pol* 2007; 18(5):381-387.
- CDC (Centers for Disease Control and Prevention), 2020. Persons who inject drugs and viral hepatitis. [online]: <https://tinyurl.com/yaw67kun>; Accessed 1/7/2020.
- Corrigan, P., Markowitz, F.E., Watson, A., Rowan, D., Kubiak, M.A., 2003. An attribution model of public discrimination towards persons with mental illness. *J Health Soc Beh.* 44,162-179.
- Crapanzano, K., Vath, R.J., Fisher, D., 2014. Reducing stigma toward substance users through an educational intervention: Harder than it looks. *Acad Psych.* 38,420-425.
- Frank, V.A., Anker, J., Tammi, T., 2012. Drug user organizations in the Nordic countries- local, national, and international dimensions. *Sub Use Misuse.* 47(5):462-473.
- Goffman, E., 1963. *Stigma: Notes on the management of spoiled identity.* Englewood Cliffs, NJ.: Prentice Hall.
- Gramlich, J., 2017. Nearly half of Americans have a family member or close friend who's been addicted to drugs. Pew Research Center Fact Tank. October 26. [online]: <https://www.pewresearch.org/fact-tank/2017/10/26/nearly-half-of-americans-have-a-family-member-or-close-friend-whos-been-addicted-to-drugs/> Accessed July 7, 2020.
- Haffajee, R.L., Lin, L.A., Bohnert, A.S.B., Goldstick, J.E., 2019. Characteristics of US Counties With High Opioid Overdose Mortality and Low Capacity to Deliver Medications for Opioid Use Disorder. *JAMA Netw Open.* 2(6),e196373.
- Hagedorn, J., Paras, C.A., Greenwich, H., Hagopian, A., 2016. The role of labor unions in creating conditions that promote public health. *Am J Pub Health.* 106(6),989-995.
- Hagen, H., Thiede, H., Des Jarlais, D.C., 2005. HIV/Hepatitis C virus coinfection in drug users: risk behavior and prevention. *AIDS.* 19(supp 3),S199-S207.
- Howard, M.O., Chung, S.S., 2000. Nurses' attitudes toward substance misusers. I. Surveys. *Subst Use Misuse.* 35(3),347-365.
- Knaak, S., Modgill, G., Patten, S.B., 2014. Key ingredients of anti-stigma programs for health care providers: A data synthesis of evaluative studies. *Canadian Journal of Psychiatry.* 59(10 Suppl 1),S19-S26.
- Kiriazova, T., Karsten, L., Raj, A., Bushara, N., Blokhina, E., Krupinsky, E., Briden, C., Lioznov, D., Samet, J.H., Gifford, A.L., 2017. *It's easier for me to shoot up: stigma, abandonment, and why HIV-positive drug users in Russia fail to link to HIV care.* *AIDS Care,* 29(5), 559-563.
- Lake, S., Kennedy, M.C., 2016. Health outcomes associated with illicit prescription opioid injection: A systematic review. *J Addict Dis.* 35(2),73-91.
- Latkin, C., Davey-Rothwell, M., Yang, J.Y., Crawford, N., 2013. The relationship between drug user stigma and depression among inner-city drug users, Baltimore, MD. *J Urban Health* 2013; 90(1):147-156.
- Link, B.G., Phelan, J.C., 2001. Conceptualizing stigma. *Annu Rev Social.* 27,363-385.
- Link, B.G., Struening, E.L., Rahav, M., Phelan, J.C., Nuttbrock, L., 1997. On stigma and its consequences: evidence from a longitudinal study of men with dual

- diagnoses of mental illness and substance abuse. *J Health Soc Behav.* 38,177-190.
- Lopez, K., Reid, D., 2017. Discrimination against patients with substance use disorders remains prevalent and harmful: The case for 42 CFR Part 2. *Health Affairs Blog*, April 13. [online]: <https://www.healthaffairs.org/doi/10.1377/hblog20170413.059618/full/> Accessed June 16, 2020.
- Madden, A., Lancaster, K., Ritter, A., Treloar, C., 2021. Making legitimacy: Drug user representation in United Nations drug policy settings. *Int J Drug Pol.* 80:103014. <https://doi.org/10.1016/j.drugpo.2020.103014>
- McKnight, C., Shumway, M., Masson, C.L., Pouget, E.R., Jordan, A.E., Des Jarlais, D.C., Sorenson, J.L., Perlman, D.C., 2017. Perceived discrimination among racial and ethnic minority drug users and the association with health care utilization. *J Ethnic Subst Abuse.* 4,404-419.
- Merrill, J.O., Rhodes, L.A., Deyo, R.A., Marlatt, G.A., Bradley, K.A., 2002. Mutual mistrust in the medical care of drug users: The keys to the “narc” cabinet. *J Gen Intern Med.* 17,327-333.
- Meyerson, B.E., Lawrence, C.A., Cope, S.D., Levin, S., Thomas, C., Eldridge, L.A., Coles, H.B., Vadie, N., Kennedy, A., 2019 *I could take the judgement if you could just provide the service: non-prescription syringe purchase experience in Arizona pharmacies.* *BMC Harm Reduction.* 16(57):1-9.
- Mold, A., Berridge, V., 2008. ‘The rise of the drug user’? Voluntary organizations, the state and illegal drugs in England since the 1960s. *Drugs: Education, Prevention and Policy.* 15(5):451-461.
- Muhrer, J.C., 2010. Detecting and dealing with substance abuse disorders in primary care. *J Nurse Pract.* 6,597-605
- National Academies of Sciences, Engineering, and Medicine, 2016. *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change.* Washington, DC: The National Academies Press. [online]: <https://doi.org/10.17226/23442>. Accessed July 6, 2020.
- Neal, J., 2004. Measuring the health of Scottish drug users. *Health Soc Care Comm.* 12(3),202-211.
- Neal, J., Tompkins, C., Sheard, L., 2008. Barriers to accessing generic health and social care services: a qualitative study of injecting drug users. *Health Soc Care Comm.* 16,147-154.
- Oliveira, M.C., Martins, L.F., Richter, K., Ronzani T.M., 2013. Evaluation of an intervention to reduce health professional stigma towards drug users: a pilot study. *J Nurs Educ Pract.* 3(5),138–48.
- Paquette, C., Syvertsen, J.L., Pollini, R.A., 2018. Stigma at every turn: Health services experiences among people who inject drugs. *Int J Drug Pol.* 57,104-110.
- Pearlman, J., 2016. Combatting Massachusetts opioid epidemic: Reducing the social stigma of addiction through increased access to voluntary treatment services and expansion of mandatory clinician education programs. *Am J Law & Med.* 42, 835-857.
- Pescosolido, B.A., Martin, J.K., 2015. The stigma complex. *Annu Rev Sociol.* 41,87-116.

- Reisinger, W.E., Pratt, L.A., Shoenborn, C.A., Druss, B.G., 2017. Excess mortality among people who report lifetime use of illegal drugs in the United States: A 20-year follow-up of a nationally representative survey. *Drug Alcohol Depend.* 171,31-38.
- Ronzani, T.M., Higgins-Biddle, J., Erikson, F.F., 2009. Stigmatization of alcohol and other drug users by primary care providers in Southeast Brazil. *Soc Sci Med*, 69(7), 1080-1084.
- Saunders, E.C., Moore, S.K., Gardner, T., Farkas, S., Marsch, L.A., McLeman, B., Meier, A., Nesin, N., Retrosen, J., Walsch, O., McNeely, J., 2019. Screening for substance use in rural primary care: a qualitative study of providers and patients. *J Gen Int Med.* 34,2824-2832.
- Scharff, D.P., Mathews, K.J., Jackson, P., Hoffseummer, J., Martin, E., Edwards, D., 2010. More than Tuskegee: Understanding mistrust about research participation. *J Poor Underserved.* 21(3):879-897.
- Scholl, L., Seth, P., Kariisa, M., Wilson, N., Baldwin, G., 2019. Drug and Opioid-Involved Overdose Deaths – United States, 2013-2017. *Morb Mortal Wkly Rep.* 67(5152),1419-1427.
- Sonoran Prevention Works. [online]: <https://spwaz.org/> Accessed November 18, 2020.
- Tindal, C., Cook, K., Foster, N., 2010. Theorising stigma and the experiences of injecting drug users in Australia. *Aust J Prim Health*, 16(2),119-125.
- U.S. Commission on Civil Rights, 1998. Sharing the dream: Is the ADA accommodating all? Chapter 4: Substance Abuse under the ADA. November. [online]: <https://www.usccr.gov/pubs/ada/ch4.htm> Accessed: June 16, 2020.
- Van Boekel, L.C., Brouwers, E.P.M., van Weeghel, J., Garretsen, H.F.L., 2013. Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug Alcohol Depend.* 131(1-2),23-35.

Table 1. Sample Characteristics, Maricopa County Arizona Drug User Health Care Experience - 2019 (N=185)

	N(%)
Gender	
Cisgender male	105 (58.8%)
Cisgender female	71 (38.4%)
Gender nonbinary	5 (2.7%)
Preferred not to share	4 (2.2%)
Race/ethnicity	
White, non-Hispanic	101 (55.1%)
Black, non-Hispanic	22 (11.9%)
Native American	8 (4.3%)
Asian or Pacific Islander	6 (3.2%)
Multi-race, non-Hispanic	10 (5.4%)
Hispanic/Latinx	25 (13.5%)
Multi-race, Hispanic/Latinx	7 (3.8%)
Unstable housing in the past year	53 (28.6%)
Drug Experiences	
Injects or has injected drugs	145 (78.4%)
Used drugs the day of or the day before the survey	147 (79.5%)
Had to use drugs in an unsafe or unclean place	121 (65.4%)

Table 2. Medical Services Accessed in the past year by people who use drugs in Maricopa County, Arizona- 2019 (N=109)

	N(%)
Hospital, ER or Urgent Care	89 (81.7%)
Health Clinics	11 (10.1%)
Doctor	7 (6.4%)
Correctional Health Care (jail and prison)	4 (3.7%)