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ORIGINAL PAPER

Living at the Confluence of Stigmas: PrEP Awareness and Feasibility Among People Who Inject Drugs in Two Predominantly Rural States

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Abstract

We explored knowledge, beliefs, and acceptability of pre-exposure prophylaxis (PrEP) for HIV prevention with reference to stigma among people who inject drugs (PWID) in two predominately rural U.S. states. We conducted interviews with 65 current or former PWID aged 18 years or older and living in Arizona or Indiana. Most (63%) of the interviewees were not aware of PrEP. They often confused PrEP with HIV treatment, and many believed that PrEP was only for sexual risk or gay sexual risk. Once they understood that PrEP was recommended for PWID, the participants held a positive view of PrEP and felt that a once-daily pill was feasible. Experiences of stigma about drug use remained a crucial barrier to accessing healthcare and PrEP. This was often linked with anticipated or expressed homophobia. PrEP interventions among PWID must focus on education and the confluence of stigmas in which PWID find themselves when considering PrEP.

Keywords PrEP · People who inject drugs · HIV prevention · Stigma · Healthcare access

Resumen

Exploramos el conocimiento, las creencias y la aceptabilidad de la profilaxis previa a la exposición (PrEP) para la prevención del VIH con referencia al estigma entre las personas que inyectan drogas (PWID) en dos Estados Unidos predominantemente rurales. estados. Realizamos entrevistas con 65 PWID actuales o anteriores de 18 años o más y viviendo en Arizona o Indiana. Más (63%) de los entrevistados no estaban al tanto de la PrEP. A menudo confundieron la PrEP con el tratamiento del VIH, y muchos creían que la PrEP era sólo por riesgo sexual o riesgo sexual gay. Una vez que entendieron que la PrEP se recomendaba para PWID, los participantes tenían una visión positiva de la PrEP y sentían que una vez-píldora diaria era factible. Las experiencias de estigma sobre el consumo de drogas siguieron siendo una barrera crucial para acceder a

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la atención médica y a la PrEP. Esto a menudo estaba relacionado con la homofobia anticipada o expresada. Las intervenciones de la PrEP entre PWID deben centrarse en la educación y la confluencia de estigmas en los que PWID se encuentra al considerar la PrEP.

Introduction

Pre-exposure prophylaxis for HIV prevention, also known as PrEP, is an important part of national and international HIV prevention efforts. It is proven to be both safe and effective [1–3] and is recommended by the U.S. Centers for Disease Control and Prevention (CDC) for all populations at high risk for HIV transmission, including people who inject drugs (PWID) [4]. The CDC released clinical guidelines in 2014 outlining best practices to improve the integration of PrEP into clinical practice; however, healthcare providers continue to be slow to educate their patients about PrEP and slow to prescribe it [5–7].

That PrEP should be offered to PWID reflects that this population is disproportionately infected by HIV globally [8, 9]. Since 2016, between 6 and 9% of new HIV infections in the United States have been attributed to PWID [10]. Recent dramatic increases in injection drug use in rural communities throughout the U.S. [11], including recent HIV outbreaks among PWID in rural Indiana [12], Arizona [13], and West Virginia [14], demonstrate that interventions to prevent HIV among PWID are particularly needed in rural communities. This is noteworthy for individuals at risk of acquiring HIV in Indiana and Arizona, as both states have been identified as part of the 48 counties and two jurisdictions in the United States that accounted for nearly half of all new HIV diagnosis in 2016 and 2017 [13]. The U.S. National Ending the HIV Epidemic Initiative has called for the eradication of HIV by 2030; however, if we are to meet this goal and reduce the number of new HIV infections by 90% within the next decade [15], we must understand how to improve awareness of PrEP and how to increase access among PWID in communities at risk.

Recent studies regarding PrEP among PWID have assessed awareness of PrEP [16–18], acceptability of PrEP [19, 20], cost-effectiveness [21], and ease of access and adherence [22]. These studies established varying but generally low levels of awareness among PWID, ranging from less than 5–30%, as well as a decreased willingness to initiate a PrEP treatment regimen [16–18]. Despite the reported suboptimal levels of awareness and willingness to take PrEP, previous studies have identified factors associated with PrEP interest, uptake, and adherence. One factor may be access to syringe service programs (SSP). Syringe service programs are community-based harm reduction services that provide a range of services, including access to sterile syringes and injection equipment, hepatitis C and HIV screening, and linkage to substance use disorder services. For example, a recent study by Sherman et al. [23] surveyed participants in a Baltimore SSP and reported that 24% of PWID who used an SSP were aware of PrEP, and those individuals who were eligible for PrEP were also more likely to report increased interest in initiating treatment, suggesting that SSPs may serve as a protective factor in HIV prevention work. Bazzi et al. [9] study among 33 PWID and other key informants in Boston, Massachusetts, and Providence, Rhode Island, found that perception of individual HIV susceptibility influenced PrEP interest, even among a sample that generally reported low levels of PrEP awareness. Shrestha et al. [22] study in a New Haven, Connecticut, methadone program testing acceptance of various PrEP access scenarios among those at high risk for HIV found that the scenario with the highest acceptance (86%) included having insurance, experiencing no adverse effects with daily dosing, and having access to HIV screening every 6 months at the methadone clinic. Although an increasing number of studies have been able to describe the intersection of PrEP and PWID, most have explored heavily populated states, excluding moderately rural areas of the country that continue to be disproportionately impacted by HIV.

Thus, despite the foundational nature of PrEP studies among PWID, a gap remains regarding PrEP knowledge, awareness, beliefs, and interest outside of large urban centers along coastal areas of the United States. Accordingly, the purpose of this study was to address this gap in the extant literature by exploring PrEP knowledge, beliefs, and acceptability among PWID in two rural U.S. states and to examine the continued relevance of the information-motivation-behavioral skills (IMB) model, which was the guiding framework for this study.

Theoretical Framework

The IMB model is a general social theoretical framework used to understand and promote health-related behaviors [24, 25]. This framework is beneficial for conceptualizing health behavior because of the mediating relationships among information, motivation to engage in health-related behavior, and behavioral skills to enact the behavior [26, 27]. Developed initially to explore HIV risk and prevention behaviors, the IMB model has been applied to various health domains, including infection control, diabetes management, and motor vehicle safety [28], further emphasizing the flexibility of its application. A previous study by Shrestha and colleagues [29] using the IMB model advanced understanding of the complexities associated with PrEP uptake among

PWID. Shrestha et al. empirically tested the IMB model for its application to PrEP use based on a cross-sectional survey among 400 HIV-negative people who used drugs and were enrolled in a New Haven, Connecticut, methadone maintenance program. They demonstrated that PrEP-related behavioral skills (e.g., self-efficacy, adherence, side effect management) are influenced by PrEP-related information such as knowledge of PrEP effectiveness and adverse effects and by social or personal motivation to use PrEP [29]. Their findings suggest that information and motivation-based interventions might influence PrEP-related behavioral skills and, presumably, increase PrEP uptake and adherence. Use of the IMB model has permitted clarification of complex elements of the health behavior of PrEP uptake and adherence. The IMB framework allows for a meaningful exploration of PrEP across the HIV prevention continuum, particularly among populations at the most significant risk of acquiring HIV, where information, motivation, and compliance behaviors are often interwoven with perceived and received stigma. However, important elements remain unaddressed.

Methods

We used semi-structured qualitative interviews to assess the current knowledge and experiences of PWID in Indiana and Arizona in an effort to explore their awareness of and beliefs about PrEP and its feasibility and their experiences with healthcare access. The study was fielded between August and December 2019. Participants were recruited using recruitment fliers posted on social media and within healthcare settings, including SSP's and community health clinics. A snowball sampling approach was also used where the interviewer would tell the participant they could refer peers who may qualify for the study. Study recruitment took place from August to December 2018.

The research team, which included six community members with previous injection drug use experience and three academic researchers, conducted one-on-one interviews with current or former PWID. Inclusion criteria were (1) at least 18 years of age, (2) current resident of Arizona or Indiana, and (3) current or previous injection drug use. Participants were excluded from the study if they were under 18 or did not have a history of injection drug use. Interviews lasted an average of 30–60 min. Each participant was read a summary of the study information sheet and given a physical copy that they could either take or leave in the interview space. This approach was used to offer an extra layer of protection to the study participants. Verbal consent was obtained from each participant before the start of the interview. Participants were given a $25.00 gift card for their participation.

Interviews were audio-recorded, transcribed, and checked for accuracy by the principal investigator. Any identifiable information was deleted from the transcript. Thematic analysis involved a priori and emergent coding, focusing on PrEP awareness, attitudes about PrEP acceptability, beliefs about PrEP, and feasibility of PrEP access and use. Healthcare access experiences were also coded as a component of the feasibility of PrEP access, as it was believed to contain elements of motivation and structural and behavioral capacities to access PrEP. A second researcher independently coded all interviews for an examination of inter-rater reliability. Theoretical saturation was assessed and determined independently by the coders as the point at which no new themes or concepts emerged. A coding conference was then held to identify and manage discrepancies using a consensus process. During this process, the authors discussed code definitions and rationales for interpretations, ultimately leading to agreement on final primary codes. The discrepancies identified during the code conference were determined to be minor; for example, one researcher used the term *homophobia,* and the other used *anti-gay stigma*. The subsequent recoding occurred with a collectively refined coding scheme. The study was deemed exempt by the Indiana University Institutional Review Board. Study measures were subsequently organized into overarching themes and classified during analysis using the IMB framework. Interview questions, concept organization, and IMB classification are shown in Table 1.

Results

Participants

The study sample included 65 participants: 37 (56.9%) from Arizona and 28 (43.1%) from Indiana. Over one-half (72.3%, n = 47) reported residing in an urban area, and 27.6% (n = 18) reported rural residency. Participants ranged in age from 22 to 69 years with a median age of 37 years. The number of years participants engaged in injection drug use was a median of 7 years with a range of 1–54 years. Most described a cyclical relationship with injecting involving recovery and relapse. At the time of the interviews, 61.5% (n = 40) reported they were currently injecting drugs. While participants were not explicitly asked about their hepatitis C virus (HCV) infection status, 33.8% (n = 22) of the sample stated they were living with HCV during interviews.

Table 1 Study measures classified by components of the IMB framework, Indiana and Arizona PWID PrEP study, 2018

IMB framework component	Study concept	Interview questions
Information about PrEP	PrEP-related awareness and knowledge	*What have you heard about PrEP?*
		How did you hear about it?
Motivation to use PrEP	Beliefs about PrEP	*What do you think about PrEP?*
		How helpful might PrEP be to prevent HIV among people who inject drugs?
		What are some of the challenges with getting and taking a daily pill to prevent HIV?
	Healthcare access experiences	*What kind of difficulties have you experienced getting healthcare because of your drug use?*
		What are your experiences with doctors?
		What are your experiences with clinics? *With emergency rooms?* *With addiction treatment?*
Behavioral skills to enact PrEP use	HIV and hepatitis C prevention approaches	*How do you protect yourself from HIV or hepatitis C?*
		What is your personal opinion about your own risk of getting and/or infecting others with HIV?
	Healthcare access	*Where do you usually go to get healthcare?*

Table 2 Characteristics of participants who participanted in interviews about PrEP knowledge and feasibility among people who inject drugs, Indiana and Arizona, 2018 (n = 65)

Variable	n (%)
Community characteristics	
Indiana participant	28 (43.1)
Arizona participant	37 (56.9)
Rural participant	18 (27.6)
Urban participant	47 (72.3)
Demographic characteristics	
Gender identity	
Cis female	26 (40.0)
Cis male	37 (56.9)
Trans male	1 (1.5)
No answer	1 (1.5)
Race and ethnicity	
Hispanic	8 (12.3)
White	41 (63)
African American	6 (9.2)
Native American	3 (4.6)
Multiple race	7 (10.7)
Age (years)	37 (22–69)[a]
Healthcare access	
Currently has a primary care provider (clinician, clinic relationship)	31 (47.6)
Currently has health insurance	38 (58.4)
Overdose was the only healthcare contact reported	16 (24.6)

[a]Median (range)

Characteristics of the interview sample are found in Table 2. Exemplars from interviews can be viewed in Table 3.

Information

PrEP Awareness

The majority (63%, n = 41) of interview participants were not aware of PrEP or even that there was a preventive medication for HIV. Of the 24 people (37%) who were previously aware of PrEP, the majority (n = 19, 79.1%) lived in Arizona. Of the 18 participants who lived in a rural area, most had never heard of PrEP prior to the interview (n = 13, 72.2%). Study participants reported they first learned about PrEP from their social networks, from SSPs providing HIV testing, and from advertisements on radio and television. Notably, PrEP awareness did not equate to an understanding of the purpose of PrEP or how to use it. Specifically, participants equated PrEP with HIV antiretroviral treatment (ARV) to suppress HIV—*This is what Magic Johnson is taking, correct?*—or confused it with emergency treatment immediately following HIV exposure (i.e., post-exposure prophylaxis).

> *Huh? I ain't gonna take a pill* (PrEP) *that, nah, I don't believe that. You give you a pill that you can't get it? Hell no.* (Interview 15, Rural, IN)
> *And it keeps you from getting HIV* (PrEP)*? What? That's crazy. No, I haven't heard anything about*

Table 3 Interview themes related to PrEP information, motivation, and behavioral skills among people who inject drugs in Indiana and Arizona, 2018 (n = 65)

Information about PrEP	
Not aware of PrEP, and not surprised about the lack of awareness	*Well I don't know. I've never heard about it. You're telling me that there's like a…pill….and this is obviously for people who are high risk in their behaviors? Hmm. I'll be damned. See, and I feel like information like that is hoarded. Keep this close to the vest. This would be something that everyone knows.* (Interview 69, Indianapolis, IN)
Confusing PrEP with HIV antiretroviral treatment (post-exposure, post-diagnosis)	*The only way I've heard about it was through some of my gay friends talking about their intimate experiences and saying, "Oh, yeah, I had unprotected sex with this guy. And he didn't tell me that he was HIV positive until afterwards, or I had unprotected sex. And I didn't ask the question." And so they've talked about going and getting like, the PREP pill to just…as an extra, kind of hindsight precaution to an experience.* (Interview 68, Indianapolis, IN)
Motivation to use PrEP	
I'm not at risk for HIV	*I don't share. Never. I don't have hepatitis C and I've been doing it* [injecting] *for a long time. I just got checked recently and I still don't have it.* (Interview 3, Kingman AZ)
	[I keep myself safe] *by using clean works. And that's everything. No cookers, nothing shared….My personal opinion is I think (my risk is) low. I think there's a low chance. I've been using for 12 years or more now, and I test negative for Hep and HIV.* (Interview 43, Bloomington, IN)
PrEP is only for sex risk, especially among men	*I think it might be more applicable probably to sex workers or people who are, not even just promiscuous, but massively promiscuous. I mean, I think one of the biggest problems with HIV today is that it's not stopped, but everybody believes that it has.* (Interview 60, Indianapolis, IN)
	It's obviously, okay for drug users but I think more at this point it's being used, or pushed, or seen as a way to prevent like I said two men or men who have sex with other men from getting HIV….I haven't heard about it from a medical professional, and even knowing that I'm an IV drug user….I don't think medical professionals are even thinking about using it for IV drug users, which is insane. (Interview 61, Indianapolis, IN)
Acceptability	
Positive view about PrEP's potential	(PrEP) *would be amazing….Especially for people who are even worried about it. Yeah, that would be, oh man, just a peace of mind. Just to know, all you gotta do is take a pill and you have to worry about it? Yeah that'd be great.* (Interview 4, Kingman, AZ)
Interest in using PrEP	*If it can prevent HIV? Fuck yeah, man* [I would take it]. *You know what I mean? Because we need our immune systems.* (Interview 56, Spencer, IN)
PrEP Feasibility	
Easy like birth control	*I would take it, because it's just a simple protective measure, like taking your birth control, or using condoms, or whatever. It's just, something like that to protect yourself a little bit more, for making life any harder than it already is, especially as an addict.* (Interview 34, Sierra Vista, AZ)
Disorganization of drug use	*I mean drug users have a very, very huge problem with structure whenever it comes to anything aside from getting that daily dose, so adding one more thing in there would be something that would be hard for them to remember to do or remember to take or keep track of.* (Interview 69, Indianapolis, IN)

Table 3 (continued)

Information about PrEP	
Stigma	
Social stigma about taking PrEP	*Okay, so I think again, stigma. People who* [say]*, "Why are you taking that?" "So and so is taking so and so." "I saw the commercial, it's for this and that. It's for gays." It's very much, like I said, this town is very stigmatized*. (Interview 1, Kingman, AZ)
Healthcare stigma about injection drug use	*You know what got me, is how the hospitals and the pharmacies, and everything, how they build themselves as places of healing, and health and everything, but the most basic of things they just didn't want anything to do with.* (Interview 51, South Bend, IN)
	I hear people talk about, "well I have hep C but I'm afraid to tell my doctor to get the PrEP." (Interview 6, Phoenix, AZ)
Behavioral skills to enact PrEP use	
HIV and HCV prevention approaches	*Just use alcohol pads and gloves, and just, rinse, effective as you can. I don't know, do that….the sex part, the same. You know you got to use a condom and everything now*. (Interview 7, Phoenix, AZ)
Structural barriers to healthcare access and PrEP	*The thing would be obviously cost, if it costs anything. But the other thing would be a lot of times people who are using don't always have stable living situations…or may move from place to place, may not be able to either have all their belongings on them or if they have it they might not be able to safely hold that medication, so getting it stolen, lost, this, that.* (Interview 61, Indianapolis, IN)
	Finding a way to get to wherever I could get it. Dealing with insurance and money—Yeah. And then dealing with whoever the person, the doctor or anyone at the medical place or the pharmacy, I would be afraid of them making judgments on me. For sure. (Interview 17, Prescott, AZ)

that. That's amazing. Do you get prescribed that? (Interview 32, Rural, AZ)

For those participants who were not aware of PrEP, the interviewer gave a brief educational summary about PrEP's use and efficacy. After receiving the brief educational summary, several participants expressed surprise that they did not know about PrEP, especially given PrEP's safety and effectiveness and the CDC recommendation that PrEP should be used to prevent HIV among PWID.

No, [I did not know about PrEP], *but that's amazing they have that. Why are they not shouting that from the rooftops?* (Interview 51, Urban, IN)
They need to get knowledge about that HIV pill out. Shoot, that's crazy that I haven't heard of that. How long has it been out? (Interview 14, Rural, AZ.)

Some participants expressed a sense of distrust and uncertainty about the scarcity of information about PrEP, deeming the lack of it as "normal" for communities of PWID because information was purposely kept from them or "*hoarded"* because of the stigma of drug use expressed by the general population, healthcare providers, or the pharmaceutical industry.

I've never heard of it before, but I think it's great…. But of course, why would I hear about it, because doctors and the medical world….They won't make any money off of [us]*, so of course they don't want us to know about it.* (Interview 70, Urban, IN)
I haven't heard about it from a medical professional, and even knowing that I'm an IV drug user….I don't think medical professionals are even thinking about using it for IV drug users, which is insane. (Interview 61, Urban, IN)

Motivation

Motivation to use PrEP

PrEP Beliefs and HIV Risk

Is it that fricking commercial? …I seen a commercial for, I think it's called Truvada? It's a commercial that's on, you'll see it on T.V… the commercial is targeting like homosexuals and shit with the commercials. I mean, I'm not, I'm not gay or anything, but

it's on T.V., like, all the time. (Interview 31, Urban, AZ)

Those who had heard about PrEP in the media conveyed a lack of representation and discussion of PWID, which ultimately led them to believe that PrEP was not for them. Participants exposed to these advertisements believed PrEP was primarily for gay men or sexual risk only: *for working girls or guys*. This opinion appeared to relate to a second belief about HIV in general: that HIV was solely a function of sexual risk. Many felt that HCV was the greatest risk to their health as a person who injects drugs.

We are more in fear of hep C [than HIV]*, especially if all you're around is heterosexuals….It's still, I think, a misconception, like* [sex] *is the only way you can get it. Or we know everybody around us and nobody has it.* (Interview 36, Urban, AZ)
I think it might be more applicable probably to sex workers or people who are, not even just promiscuous, but massively promiscuous. (Interview 60, Indianapolis, IN)

PrEP Acceptability

If people could take a pill a day, and prevent themselves from contracting HIV, why the hell wouldn't you? I know I would. (Interview 37, Urban, AZ)

Despite participants feeling PrEP was more targeted toward individuals with increased sexual risk, many participants continued to express positive views toward PrEP, whether they previously knew about it or learned about it from the interviewer. Conversely, several participants indicated that they and their peers might take PrEP, especially if PrEP would prevent HIV among PWID.

And it'll stop you from catching that?…I need that. I need some of that. Can I get those pills? How can I do that? (Interview 46, Urban, IN)
But then, I have a lot of friends that would be more than willing to (take PrEP)*, just to be safe. I think it might be a thriving thing.* (Interview 5, Rural, AZ)

Just as participants discussed positive views about PrEP and that they or their friends might be interested in it, participants also spoke clearly about social stigma acting as a barrier to PrEP use. Social stigma primarily centered around the belief that PrEP and HIV is *a gay thing;* because despite their opinions about gay people, or even knowledge about their own risk for HIV, the participants felt that socially, PrEP was associated with gay sex, and that was ultimately a barrier to uptake.

Okay, so, stigma. People who [say]*, "Why are you taking that?" "So and so is taking so and so." "I saw the commercial, it's for this and that. It's for gays." It's very much, like I said, this town is very stigmatized.* (Interview 1, Rural, AZ)
Some of them (might say)*, "I don't hang out with gays, and I'm not gay, so I don't need that."* (Interview 46, Urban, IN)
I think if people associate that with the gay community, there could be a degree of stigma around it. Particularly for heteronormative folks. (Interview 10, Urban, AZ)

PrEP Feasibility

When discussing the feasibility of taking PrEP, the ease of taking pills once daily appealed to most participants because it was *"like taking your birth control,"* or something that could be managed daily. Feasibility was initially discussed in terms of the once-daily pill requirement.

I've been always really good about just putting an alarm on my phone….So I just set an alarm daily….So I would just put one like 8:00 in the morning, "Pop the pill." You know what I mean? (Interview 38, Urban, IN)
I think the once daily thing is actually probably the best part of it. Once daily is one thing, three times a day is another. (Interview 1, Rural, AZ)

Even with the ease of a once-daily medication, participants recognized the disorganization that often comes with addiction and the way in which addiction causes a reprioritization. *"Adding one more thing"* might negatively influence PrEP compliance.

Okay so the challenges for an individual….is getting the information and the pill into their home while they're in active addiction. Because drug use is a full-time job. You wake up, you're on the hustle. You're on the grind until you go to bed. So to find time to do anything else, even eat. (Interview 45, Urban, IN)
Yeah, cost I think, would be the biggest one because... I imagine it's probably not too expensive, but fairly expensive. If I got 50 bucks in my pocket…am I gonna go buy 50 bucks worth of dope, or am I going to take the PREP…Dope's gonna win on that every time. (Interview 68, Urban, IN)

Another more significant issue around PrEP access and use was cost and healthcare access. As shown in Table 1, most of the sample did not utilize healthcare even though 47.6% of the sample had a primary care provider and 58.4% had health insurance. Further, healthcare access was unevenly distributed among participants, as 75% with a primary

care provider and 73.1% with insurance were from Arizona, compared to 25% of Indiana participants with a primary care provider and 26.9% with insurance. For 24.6% (n = 16) of participants, experiencing an overdose was the only healthcare contact reported.

> *Personally, I think that if it costs money and it takes insurance, then most people are not going to do it. Do I think it would be something I would be interested in? Yes.* (Interview 2, Rural, AZ)
> *The only* [barrier] *I can see is having to buy it. Having to pay for it. You know what I mean?* (Interview 53, Urban, IN)

Stigma

Yet even with a positive view of PrEP, healthcare access experiences were wrought with stigma. Participants generally believed that healthcare providers were fundamentally stigmatizing about drug use and enacted stigma toward PWID in the course of healthcare provision. Stigma was discussed in both direct and indirect ways, such as clinicians declining to mention PrEP —*I haven't heard about it from a medical professional, even knowing that I'm an IV drug user*—or anticipated judgment against them as a drug user based on experience—*I would be afraid of them making judgments on me*.

> *Once people go in….they're afraid to say anything because of the way they're treated. And then say, "Hey, I got HIV or I got hep C." A lot of drug users are scared to tell.* (Interview 6, Urban, AZ)
> *I have a lot of health issues due to* (addiction)….*so I got like seven doctors. They all know I'm in recovery from addiction….that the situation stemmed from IV drug use, and I can literally tell that the majority still have a stigma about drug addicts.* (Interview 45, Urban, IN)
> *Maybe somebody being ashamed of taking it. Other than that, I don't see why they wouldn't want to prevent it. (Interview 1, Rural, IN)*

Behavior

PrEP and Prevention

The concept of behavioral skills for PrEP use was closely related to motivation for PrEP use in terms of beliefs about once-daily use and challenges with structural issues such as healthcare access. Protective behavioral skills were identified as the participants discussed several ways they protect themselves against HIV and HCV. The primary behavior among them was not sharing syringes, cookers, cottons, or their "works." When they could not use a sterile syringe, they discussed how they approached sanitizing their works or minimizing risk by sharing with only one person. Regarding protective behaviors, participants also spoke about HIV and HCV testing.

> *Strap up* (wear a condom). *I'm real serious about that. I don't play with that. No no no. There's too much goin' on out here.* (Interview 47, Urban, IN)
> *My strategy was I shared needles with people, but I would only* [shoot behind] *my boyfriend. But he was sharing needles with other people. It was not the soundest strategy. I tried, generally, to limit the amount of times that I would share needles or use the same needle because obviously if it's used a whole bunch of times, it's harder to move and it's more likely to get you sick. But when we didn't have access to needles, I would use any needle that I could get my hands on.…I might have been tested. I don't think I was tested within the time that I was injecting drugs until after I got sober cause I didn't know where to do it for free.* (Interview 10, Urban, AZ)

Discussion

This study set out to explore the knowledge of and beliefs about PrEP and its acceptability among PWID by using the IMB model as the guiding framework. Our results highlight two key points: (1) PWID may be unaware of PrEP, and (2) PrEP interventions among PWID should focus on the confluence of stigmas in which PWID find themselves when considering PrEP. The latter point is put into sharp focus when considering the layering of both gay and drug use stigmas. In this study, participants surmised that the lack of knowledge about PrEP, its lack of representation in their social circles, media outlets, and healthcare interactions was not surprising given the systemic stigma against injection drug use expressed by media marketing and in healthcare settings. This finding alone suggests that experienced and anticipatory stigma is not only present in healthcare relationships, as noted by participants here, but is also characteristic of systems of information supporting any step toward PrEP acceptance and uptake for PWID. Notably, access to healthcare as measured by having a primary provider and/or insurance is not sufficient for PrEP access if the orientation of the healthcare system is centrally stigmatizing toward injection drug use and normalized healthcare access by PWID.

The study findings also indicated the presence of stigma at a social level, as illustrated by the participants' belief that HIV was primarily an issue concerning promiscuous sex *("working girls or guys")* and gay sex generally, and that taking PrEP would imply that someone was gay. This

emerged in conversations about self-perceptions of HIV risk and as the participants discussed the media and medical silence surrounding PrEP for PWID specifically. Further, some participants discussed anticipatory gay-related social stigma if they took PrEP, which could be an important barrier to adherence. Anti-drug use stigma has long been a fundamental part of social knowledge about HIV [30–32]. It should not be dismissed as something that has been overcome.

Findings from this study about PrEP knowledge among PWID reflect those conducted in urban or coastal areas of the U.S. As in previous studies, awareness of PrEP and correct knowledge about it was generally low among PWID. As Sherman and colleagues indicated [23], even PWID who are already engaged in HIV prevention activities through SSPs or other programs have low PrEP awareness. Our findings highlight the importance of reaching more deeply into communities of PWID to connect with those who do not have relationships with healthcare providers or services. The structural aspects of their environments limited the scope of opportunities for PrEP access available to study participants. Both Arizona and Indiana have SSPs; however, access is limited due to an absence of state law (AZ) and/or funding (AZ and IN). We also identified other barriers, such as lack of health insurance and usual source of healthcare. Over one-half of the study participants had health insurance, which was primarily found among participants from Arizona. Most of the study participants did not have a relationship with a healthcare provider, and anticipated stigma was identified as a limiting factor for healthcare access of any kind, PrEP notwithstanding.

Our finding that only 31 participants (47.6%) were previously aware of PrEP highlights an opportunity to engage in community-based education with PWID to promote information about the benefits of PrEP for PWID. The general lack of PrEP awareness in the Indiana subcohort is a concern, given that ten rural Indiana counties have been identified as vulnerable to an HIV or HCV outbreak [11]. Exploring the disparities regarding awareness in at-risk rural areas between these two states is important, as is understanding the unique social communication networks in Arizona that could inform future PrEP information and social marketing interventions in Indiana and other rural or moderately rural states.

Awareness of PrEP continues to be a significant barrier to improving the uptake of PrEP among those most likely to benefit and one of the most important differences between the participants who lived in rural vs. urban areas. The majority of the participants in rural areas (66.7%, n = 12) were not aware of PrEP before their interview, compared with 46.8% (n = 22) of those participants who live in an urban area. However, after providing a brief educational summary of PrEP to those rural participants, 100% expressed a positive attitude toward PrEP. These findings echo results from Allen et al., who reported a low level of PrEP awareness and a high level of willingness to use PrEP among rural PWID [33]. Rural areas of the United States are disproportionately impacted by the intravenous drug use crisis [34]. Despite the increased risk of HIV acquisition related to injection drug use, awareness of PrEP remains suboptimal [33]. Our results suggest it may be possible to address the rural HIV epidemic by linking PWID with a PrEP treatment plan using targeted community-based educational intervention.

Perhaps one of the most unexpected findings was the lack of information concerning PrEP and prevention behaviors among rural participants. There were numerous similarities between the attitudes expressed by the urban and rural participants throughout this study; however, results suggest that the most significant disparity faced by rural PWID may be a lower range of protective behavioral skills. This finding reflects those of Atav and Spencer [35], who reported elevated risk behaviors among rural PWID. Similarly, previous studies have reported that a higher proportion of rural individuals who misuse substances prefer injection drug use than their urban counterparts, placing them at increased risk of adverse health outcomes [36, 37]. Notably missing from these studies is the adaption of protective behaviors such as proactive HIV and HCV screening. These results may underscore the evolving nature of the injection drug use epidemic as it continues to move deeper into rural communities. Some of the issues emerging from the lack of protective behaviors may be related to the experience of stigma in smaller communities. Perceived and received stigma was discussed as a multilayered experience, describing cultural stigma toward injection drug use and stigma toward HIV and PrEP. Our findings are not able to describe whether or not rural PWID process stigma differently than urban PWID. However, identifying the variables that influence the lack of protective behaviors among rural PWID warrants further research.

Although the IMB framework has been helpful for conceptualizing relationships between PrEP knowledge, beliefs, motivation, and capacities, important aspects of these relationships must be more fully understood. Researchers have yet to sufficiently understand the influence of anti-gay and anti-drug-use stigma (experienced, expressed, and anticipated) in applications of the IMB framework to PrEP awareness and uptake among PWID. For example, what is the precise role that anticipatory healthcare stigma plays in motivation or capacity to access PrEP? What is the precise role of anticipated anti-gay social stigma in motivation to access PrEP and capacity and motivation to adhere to it? Still, the IMB framework provides explanatory value as a starting point for future explorations of social and healthcare-related stigma as it relates to PrEP beliefs, motivation, and capacities.

Initially, the study team envisioned that our study among PWID would be additive to studies about PrEP among people who use drugs generally because injection drug use may be differently experienced and constructed for participants when considering PrEP. Yet this may not be the case. Understanding PrEP awareness and interest among PWID alone may not be so different than doing so among people who use drugs, as Shrestha and colleagues have done. For example, in our sample of 65 PWID, 38.4% of the respondents (n = 25) were not injecting at the time of the interview, though they reported cyclical relationships with injecting.

Our study findings contribute to a greater understanding about PrEP awareness, beliefs, and feasibility among people in the PWID community who are not recruited or fundamentally linked with a service program or healthcare services such as addiction treatment. Understanding PrEP knowledge, beliefs, and access feasibility in populations recruited from the PWID community will be critical moving forward if systemic access to PrEP among PWID is to be realized because the healthcare component of the PrEP access model cannot be presumed. Complexities of access should be clarified, including but not limited to certain aspects of stigma, such as those closely related to social interactions and healthcare access. One can only hope that healthcare stigma and bias against drug users and drug use will be addressed, but PrEP access cannot wait for this unraveling of bias to occur. Other options for PrEP access will need to be explored. For example, California recently authorized pharmacy dispensing of PrEP without a prescription [38]. While such access does not mitigate the requirement for follow-up evaluation and medication counseling, perhaps if paired with harm reduction service providers or SSPs, such interventions might build a bridge to stable healthcare if also focused on stigmas.

Identifying the individuals most likely to benefit from PrEP and their barriers to PrEP access is a commonly reported concern among clinicians and researchers [39–41]. Because the study sample generally was unaware of PrEP, a frequently communicated barrier and concern was about the requirements for PrEP and the feasibility barrier of cost and insurance. This is likely due to the lack of knowledge about healthcare access and continued monitoring requirements and the absence of PrEP navigators throughout most communities. PrEP navigators, who are positioned to guide people at risk for HIV through the healthcare system, are essential for disseminating knowledge about PrEP and getting those at risk to start PrEP [42]. Often individuals can get on plans supported by state departments of health or a co-pay card sponsored by the drug manufacturer; however, access is not assured across states or in areas where geography prevents service availability. The discussion about PrEP and PrEP access is complicated because it is associated with a stigmatized illness (HIV) and stigmatized behaviors (men who have sex with men, PWID). As people become more aware of PrEP and the requirements of adhering to it, additional discussion should occur at the community level to understand healthcare stigma (experienced and anticipated) and the financial structures facilitating access to healthcare for PWID. Further research is also needed to explore the impact of strategically placed PrEP navigators to better understand interventions that may alleviate barriers to access and uptake.

Study Limitations

The present study has limitations that should be discussed. First, because we recruited participants from syringe exchange and HIV treatment settings, it is possible that PWID who are not affiliated with those services or programs may perceive PrEP and HIV prevention differently. Second, some eligible participants may have opted not to enroll in the study, may have been reluctant to share their lived experience, or may not have fully disclosed their thoughts and feelings because of the stigmatizing nature of injection drug use and HIV. Third, because the quality of qualitative research depends heavily on the individual skill and experience of the researcher, the participants' responses may have been influenced by interactions with the interviewer. Fourth, the nature of self-reported data is a potential source of bias as the interviews are subject to the participant's ability to recall thoughts and feelings surrounding previous events. Fifth, because this study was focused on describing the lived experience of the participants, the findings are not generalizable. Finally, participants were not asked about their sexual identity. As a result, this study may describe anti-gay stigma, but the authors are not able to situate the discussion through the lens of sexual identification.

Implications for Practice/Policy

The CDC recommends that people with an increased risk of acquiring HIV be screened at least annually for HIV and that those individuals with additional risk factors, including through sexual or injection drug use behaviors, receive HIV screening every 3–6 months. However, screening rates across healthcare settings continue to be suboptimal. One of the most significant clinical practice changes positioned to impact HIV screening rates is adherence to HIV "opt-out" screening policies. This approach states that HIV screening is a clinical practice standard and should be included as usual care for all individuals aged 15–65. This approach places the onus of screening avoidance on the patient and helps to reduce the stigma about HIV screening by signifying it is for all individuals, not only those who identify as gay or PWID.

Second, many participants described negative interactions with the healthcare system. This is a significant

concern because preventing the acquisition of HIV depends on trusting and transparent interactions between practitioners and patients. If disenfranchised individuals cannot view the health system as a source of support, then it may not be possible to address the HIV and drug use epidemic. It may also not be enough to address stigmatizing behaviors among healthcare providers once they are practicing. Advancing medical and nursing school curricula to encompass harm reduction education may be one step toward challenging future healthcare providers to reflect on their implicit bias and its impact in their patient/provider relationship. However, issues of implicit or explicit bias cannot be addressed by curricular changes alone. Embedding interprofessional, clinic-based training within the healthcare education structures may allow students to interact with disparate populations, including PWID, diverse racial/ethnic communities, and sexual minorities.

People who inject drugs continue to report decreased awareness and uptake of PrEP, and the lack of representation and visibility of PWID in PrEP advertisements may be partly to blame. Previous research has established that PrEP is an efficacious intervention to prevent HIV acquisition among PWID; however, PrEP continues to be associated with men who have sex with other men. This often-stigmatizing perception bars PWID, who may benefit from a PrEP regimen, and healthcare providers, who miss prescription and referral opportunities. Creating inclusive education and advertising campaigns aimed toward both patient and provider populations can change the conversation about PrEP. Just as we advertise antidepressants to individuals living with depression and statins to people living with high cholesterol, the cultural conversations about PrEP need to reflect those most likely to benefit from it.

Conclusion

PrEP interventions among PWID must centrally focus on education and the confluence of stigmas in which PWID find themselves when considering PrEP. Studies should be inclusive of community-based sampling and be conducted in both rural and urban settings.

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Declarations

Conflicts of interest The authors have no relevant financial or non-financial interests to disclose.

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Consent to Participate Informed consent was obtained from all individual participants included in the study.

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