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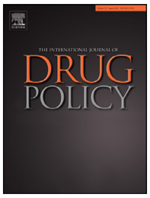

Research Paper

How the rural risk environment underpins hepatitis C risk: Qualitative findings from rural southern Illinois, United States

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ABSTRACT

Background: Hepatitis C virus (HCV) infection has increased among persons who inject drugs (PWID) in the United States with disproportionate burden in rural areas. We use the Risk Environment framework to explore potential economic, physical, social, and political determinants of hepatitis C in rural southern Illinois.

Methods: Nineteen in-depth semi-structured interviews were conducted with PWID from August 2019 through February 2020 (i.e., pre-COVID-19 pandemic) and four with key informants who professionally worked with PWID. Interviews were recorded, professionally transcribed, and coded using qualitative software. We followed a grounded theory approach for coding and analyses.

Results: We identify economic, physical, policy, and social factors that may influence HCV transmission risk and serve as barriers to HCV care. Economic instability and lack of economic opportunities, a lack of physically available HCV prevention and treatment services, structural stigma such as policies that criminalize drug use, and social stigma emerged in interviews as potential risks for transmission and barriers to care.

Conclusion: The rural risk environment framework acknowledges the importance of community and structural factors that influence HCV infection and other disease transmission and care. We find that larger structural factors produce vulnerabilities and reduce access to resources, which negatively impact hepatitis C disease outcomes.

Introduction

Hepatitis C virus (HCV) infections worldwide were estimated in 2020 to be approximately 56.8 million (Blach et al., 2022). It is estimated that approximately 10 million (60%) of current and former PWID have been infected by HCV (Grebely & Dore, 2014), and approximately 39% of people who recently injected drugs are living with HCV world-wide (Grebely et al., 2019).

The United States (US) has experienced increased incidence of HCV infection with a 63% increase in reported cases of acute HCV infection from 2015 to 2019 (Centers for Disease Control and Prevention, 2019). The burden of hepatitis C disease is disproportionate among persons who inject drugs (PWID) who have an estimated 46-80% prevalence (Havens et al., 2013; Jordan et al., 2015; Ozga et al., 2022; Wagner et al., 2021). Over time, chronic infection can lead to substantial morbidity and mortality, including end stage liver disease and hepatocellular carcinoma. Moreover, among PWID a temporal relationship exists between HCV and HIV outbreaks whereby HCV acquisition frequently precedes that of HIV. For instance, reports of HCV infection foreshadowed the 2015 HIV outbreaks in Indiana (Conrad et al., 2015) and, more recently,

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in West Virginia and Massachusetts (Centers for Disease Control & Prevention, 2011; Evans et al., 2018; Page et al., 2019; Zibbell et al., 2015). These outbreaks have disproportionately affected rural communities, where disparities in social determinants and structural barriers have given rise to syndemics (i.e., clustering of disease) of injection drug use, widespread nonmedical use of opioids and stimulants, and infectious diseases (Cloud et al., 2019; Cooper et al., 2020; Jenkins et al., 2022; Korthuis et al., 2022; Schranz et al., 2018).

Effective treatments for HCV can help reduce HCV infection (Fraser et al., 2018). Prior to 2014, HCV therapy required the use of interferon, which often had severe side effects and low rates of cure (Manns et al., 2006). Now, the availability of safe, effective oral direct-acting antiviral (DAA) agents has placed elimination of HCV infection as a public health target within reach (Falade-Nwulia et al., 2017) and the World Health Organization (WHO) has set goals for hepatitis C elimination by 2030 (World Health Organization, 2016). However, major implementation barriers have resulted in low awareness of HCV infection, testing, and treatment among PWID (Collier et al., 2015; Falade-Nwulia et al., 2020; Grebely et al., 2017; Kåberg et al., 2017) who comprise the core of HCV infections in the US (Hajarizadeh et al., 2013; Nelson et al., 2011; Shepard et al., 2005). Thus, it is unlikely that the WHO 2030 elimination goals will be reached in the US unless larger structural inequities driving HCV transmission are addressed (Pedrana et al., 2021).

Public health interventions to address hepatitis C prevention have typically focused on individual-based strategies of risk reduction. Examples include peer-education programs designed to reduce riskier injection practices (Garfein et al., 2007) and efforts aimed at increasing the scope of testing initiatives (Anderson et al., 2009; Sidlow & Msaouel, 2015). However, scholars who focus on structural forces of disease transmission have noted how such models are often reductive and can obscure the role of larger, contextual forces (LeBesco, 2011; Moore, 2008). For example, individuated accounts of risk can promote and reify a view of risk as generated through rational, and context-free, decision making. This view often fails to account for the complex and often contradictory pressures involved in decisions of risk and can obscure “power inequalities in risk negotiation (which may relate to gender, ethnicity or other material factors)” (Rhodes, 2002).

The Risk Environment framework – a conceptual model that identifies economic, physical, social, and political determinants of drug-related harms (Rhodes, 2002) – seeks to better understand how drug-related risks are generated within a social-ecological context. Specifically, it repositions analysis of risk away from a strict focus on individuals to one that better incorporates structural, contextual, and policy-based forces of harm in the lives of people who use drugs. As Tim Rhodes, who initially developed the concept, points out, “Shifting the unit of analysis and agent of change from individuals, and individual risk behaviour, to environments, shifts how we think about responsibility for harm—from constituting individuals alone as responsible for their behaviour to tackling the socio-political situations and structures in which individuals find themselves” (Rhodes, 2002).

This study examines perspectives of *how* and *why* the rural risk environment might affect hepatitis C risk and outcomes among PWID in rural southern Illinois. This line of research is particularly salient in non-urban areas where HCV incidence rates are double that of urban areas (Suryaprasad et al., 2014; Zibbell et al., 2015). Rural populations in the US generally have more limited access to resources compared to their urban counterparts, resulting in lower income and education levels, being under or uninsured, having more dispersed healthcare and thus having longer travel times to their usual source of medical care, and overall being less likely to access healthcare (Casey et al., 2001; Laditka et al., 2009; Meit et al., 2014; Ricketts et al., 1999; Schur & Franco, 1999). Compared with urban areas, far fewer physicians practice in rural areas of the US—a phenomenon driven primarily by a lack of specialty providers (Meit et al., 2014). Furthermore, rural communities often lack providers of medications for opioid use disorder (MOUD), harm reduction services including sterile syringe and equipment services, and overdose prevention (Schranz et al., 2018; Westergaard et al., 2015).

Accessing these services, when they are available, is also limited by rural experiences of community stigma (and the fear of discrimination) as well as a lack of privacy in areas with smaller populations (Bolinski et al., 2019; Browne et al., 2016; Ellis et al., 2020; Ezell et al., 2021; Walters et al., 2021). Together, geographic distance from harm reduction services, transportation barriers, and fears of being stigmatized may decrease accessibility of these service and likely increase risks for outbreaks of bloodborne infections, such as hepatitis C (Brown et al., 2018; Browne et al., 2016).

Environment

United States

The US is characterized by both public and private healthcare. Two programs are federally funded: Medicare for people over 65 years old and Medicaid for people with low incomes. In 2018, 92% of the population was estimated to have healthcare coverage, with 55% of the population having healthcare coverage under employer sponsored insurance. (Berchick et al., 2019). Thus, having employment is highly tied to accessing health services in the US, with individuals who are under or unemployed often left uninsured, underinsured, and/or beneficiaries of Medicaid. US Medicaid programs are administered by individual states and are characterized by marked heterogeneity in regards to coverage policies for hepatitis C treatment (Barua et al., 2015). Access to DAAs has been limited by states based on combinations of restrictive prior authorization criteria, including requirements for advanced fibrosis/cirrhosis, periods of sobriety, and/or consultation or prescribing by hepatologist/gastroenterologists or infectious diseases specialists (Barua et al., 2015; Do et al., 2015; Younossi et al., 2016). These restrictions have had an outsized impact on rural areas where Medicaid coverage is disproportionately higher than other settings, and where access to substance use treatment and medical specialists is limited (Benitez & Seiber, 2018; Foutz et al., 2020; Rosenblatt & Hart, 2000; Soni et al., 2017).

Another important structure in the US is the criminal legal system. Most drug use is illegal; thus, people who inject drugs often face criminal sanctions for their use. Criminal legal engagement is associated with increased burden of HCV and less engagement in HCV care (Hochstatter et al., 2017). For example, a recent study found 16.7% HCV positivity in a Dallas, Texas county jail (Hoff et al., 2022) and a Kentucky based study concluded that “incarceration is likely to be an important contributor to HCV transmission” (Stone et al., 2021).

Rural Southern Illinois

The area of interest for this study is the southern region of Illinois located within the US. This rural region is comprised of the 16 southernmost counties of the State. The area is characterized by widespread poverty with 45.4% of residents living below 200% of the poverty level (Zahnd, 2014). Residents also tend to be geographically isolated. For example, there are 56.7 residents per square mile in southern Illinois compared to 231.1 per square mile statewide. Most (89%) residents are white, the unemployment rate is 9.6% (Today’s Delta: A Research Tool for the Region, 2015; Zahnd, 2014), and there are high levels of food insecurity (Walters et al., 2022a).

In regard to HCV epidemiology, prevalence in the state increased by 43% from 6,887 in 2006 to 9,838 in 2017, with the predominance of the cases in persons less than 35 years of age and linked to injection drug use (Illinois Department of Public Health, 2018). A regression analysis using zip code level data that integrated social, economic, and physical environment covariates with HCV and overdose data as a proxy for injection drug use identified southern Illinois as a region of high vulnerability for HIV outbreak (Bergo et al., 2021). This area is characterized by high levels of environmental overdose risk as well (Kolak et al., 2020)

Many residents of this region lack access to healthcare as all counties are geographic and/or low income primary and mental health professional shortage areas (Health Resource and Services Administration; United States Department of Agriculture. Rural-Urban Continuum Codes). Furthermore, most health departments provide limited opioid use disorder related services (McLuckie et al., 2019). There is also a large amount of community stigma, which deters people who use drugs from accessing services (Ellis et al., 2020; Ezell et al., 2021; Ezell et al., 2020). Finally, research conducted with people who use drugs in this region has highlighted transportation as a barrier to health services (Walters et al., 2022a).

Methods

Participants were referred in collaboration with research staff conducting a study in the southern Illinois site of the Rural Opioid Initiative (ROI) cooperative agreement (Jenkins et al., 2022), funded by the National Institutes on Drug Abuse, the Centers of Disease Control and Prevention, and the Substance Abuse and Mental Health Service Administration (see https://ruralopioidinitiative.org). Both the ROI Illinois study site and this project partnered with a local, grassroots syringe service program (SSP) that serviced the 16 most southern counties in Illinois. Participants residing in the area and who had agreed to be approached for future research were contacted by study staff and SSP staff and offered the opportunity to participate in this study.

Semi-structured qualitative interviews

Nineteen semi-structured interviews were conducted with PWID from August 2019 through February 2020 (i.e., pre-COVID-19 pandemic) in-person by a staff member trained in qualitative data collection. Interviews took place in various locations depending on the comfort of the participants, with most done in the van or at the physical office space of the local SSP. In all cases, interviews were conducted in private by a research staff member. Eligibility requirements were to have injected drugs within the last 30 days (self-report), be age 18 or older, and be able to communicate in English. Written informed consent was obtained from all participants and each participant received $40 in a visa gift card as compensation for their time.

The qualitative guide focused broadly on drug use, healthcare, and HIV disease and prevention. We asked one general HCV knowledge question: *"Please tell me what you know and think about hepatitis C or HCV?"* Using a grounded theory approach and constant comparative methods (Charmaz, 2014), we noticed early on that hepatitis C was emerging as a theme throughout interviews and not only in responses to the one question we asked. Participants typically discussed people they knew having HCV infection and who had undergone treatment. Thus, we amended the interview guide to explore hepatitis C in more depth. Guided by the responses of the previous participants we added the following questions: *"How is HCV transmitted?"*, *"Is* hepatitis C *common among people you hang out with?"*, and *"Have you or someone you know been treated for* hepatitis C*?"* If participants responded yes to self or others for past HCV treatment, they were asked to describe the experience and give details on when it occurred. This information let us determine if treatment was after DAA became available. Participants were also asked a series of questions aimed at understanding HCV treatment experiences and knowledge, such as *"Can you describe what the treatment for HCV is like?"*, *"Are there any side effects to HCV treatment?"*, and *"Can you describe what the most current HCV treatment is like?"* Demographic characteristics including age, gender, sexual orientation, education, and employment were collected at the end of each interview. Interviews ranged in length from thirty minutes to two hours, with most interviews lasting about an hour and a half.

In addition to interviews with PWID, we conducted four interviews with key informants (KIs): a syringe service staff member, two pharmacists, and one emergency medical services (EMS) employee. The KI interview guides asked questions about drug use and the local area, the KI's professional jobs and how often they came into contact with PWID (and what those experiences were like), overdose, fentanyl test strips, naloxone, healthcare and SSP access for PWID, and HIV and HCV prevention and treatment. The HCV question for KIs was *"Please tell me about hepatitis C or HCV in the community?"* Given the timing of the KI interviews (they were conducted at the beginning of the project), the interview guide HCV questions were not adjusted as they were for PWID. Questions about stigma were not elicited by asking specifically about stigma, but rather we probed KI's perceptions about PWID, the local area, and how PWID were treated within the domains listed above. When key informants could not meet in person, we conducted interviews over the phone. Eligibility criteria for KIs was originally 18 years or older and spending over 30 hours per week working directly with drug-using populations. Since SSPs, pharmacy, and EMS were described by PWID as common places and people they engaged with who had a bearing on their ability to manage their health we modified the eligibility criteria to include people who interacted with PWID less than 30 hours a week. Of note, the SSP we partnered with had a limited number of staff members, so we were only able to conduct one SSP staff interview.

All interviews were audio recorded and professionally transcribed. After each interview, study staff immediately created a memo describing their observations and experiences which was analyzed in conjunction with the transcript (Miles et al., 2013). All protocols were approved by the New York University Institutional Review Board.

Data analysis

After reviewing an interview transcript for errors, it and the interviewer memo were independently coded by one of three research staff members. This process was done after every interview so we could appropriately adjust the study as needed (e.g., refining and adding to the guide to include more hepatitis C questions after it became clear that hepatitis C was a salient topic) (Charmaz, 2014). Data were processed and managed using Dedoose (Version 8.3.17). A qualitative codebook of themes was compiled as they emerged from the data, and the codebook continued to evolve throughout the coding process as new themes emerged (Charmaz, 2014; Orne & Bell, 2015). The three coders met weekly to discuss coding and emerging themes. During these meetings if discrepancies in coding arose a final consensus was reached through dialogue among the three coders. After all transcripts were coded, guided by our theoretical framework, and after using inductive coding where we began to see themes of the risk environment emerge, we went back and recoded the HCV, local area, healthcare, and stigma results into four environmental factors that influence hepatitis C risk on micro and macro levels: economic, physical, policy, and social. While these constructs overlap and interact with each other, they were disaggregated for analytical purposes. All participants have been given pseudonyms to protect their identities (Kaiser, 2009).

Results

We interviewed 19 PWID and 4 KIs. About half of the PWID interviewed were women, most identified as white and heterosexual, and most had a GED, high school diploma or higher (Table 1). We asked participants what their drug of choice was when injecting; 7 reported opioids and 12 reported methamphetamines. However, most participants reported using both, stating that they would use what they had access to. Table 2 provides a summary of the risk environment themes that emerged. Below we describe the proximal impact of these larger risk environment forces on individual health and behavior in four main themes: sharing syringes, low hepatitis C knowledge, mental health, and physical health.

Table 1
Demographics of people who inject drugs ($n = 19$).

Age	
18-30	6
31-40	7
41-50	5
51-60	1
Gender	
Male	10
Female	9
Race/Ethnicity	
White	17
Black	1
Black and Hispanic	0
Hispanic	0
Native American	1
Sexual Orientation	
Heterosexual	17
Bisexual	2
Education	
Less than High School	3
High School/GED	7
Some College	8
Bachelor's Degree	1
Drug of Choice	
Opioids	7
Methamphetamine	12

Economic

Economic instability

Participants linked many of the social problems in the area to pervasive economic distress. For example, Julia, a key informant who was a pharmacist, describes:

> *"I was born here and I love it here. [But] it's a very depressed region economically and psychologically. Um, I am a healthcare provider here, so….I've waited on people of all different backgrounds. Part of the reason why I love it here is because of the people…[who] are actually quite kind here. I think a lot of the misfortune that we see here is just a result of poverty. I think there's a lot of beauty in southern Illinois and along with that, there's also a lot of hardship that comes with it. And I think that's been that way forever."*

Stan, an EMT in the area said, *"Yeah, there's not a lot of opportunity, which I think adds to the poverty mentality."* Similarly, Vincent, a 30-year-old white male participant who injected drugs said, *"There's a lot of layoffs in down here. It's a pretty small town, and like I said it's a poverty-stricken area and the people here, it's been generational for generations, like the third generation now going on, where they've been brought up."*

Participants described how PWID's socio-economic status made accessing healthcare services difficult. PWID would often discuss access barriers while KIs noted service delivery issues. Specifically, participants noted that limited health insurance coverage can prevent PWID from obtaining the care and prescription medications needed to treat HCV infection and other medical problems. For example, John, a 26-year-old white man who injected drugs said, "*I had pneumonia in late December, went to the ER…It was horrible. It was $17.00 just for five pills. I couldn't even come up with $17.00 for the pills. I don't have healthcare, you know what I mean, public aid assistance, so I pretty [much] didn't even get the script."* Similarly, Alicia, a 44-year-old white woman who injected drugs said, "*I'm not employed. I'm searching for employment, but, um, right now I am unemployed, so I don't really have the means to pay for… any kind of medicine right now."*

Widespread poverty and a lack of access to resources also contributed to psychosocial distress. When asked to describe the biggest problem facing people who use drugs in the community, Julia, the pharmacist KI quoted above, answered that it was mental health issues:

> *"I feel like their mental health issues are not being adequately dealt with…They don't have resources, they look depressed. It's actually quite sad. I have pictures of people going through my mind as I'm talking, just their body language… reveals people who are broken down and I think it's because situations beyond their control…I feel like people are self-medicating because they're hopeless. I think the mental health issues surrounding drug abuse, that's the cause of a lot of the drug abuse. Actually, I think it's the primary cause."*

Mental health challenges rooted in structurally conditioned economic constraints shape the risk landscape in which people cope by using drugs, thus increasing vulnerability to HCV. Participants often attributed their drug use to its ability to numb emotional pain they felt daily. Melissa, a 36-year-old white woman who injected drugs said, "*I deal with [emotional pain] every day right now….I stay up one way or another, so (the drug) just blocks out the thought of it, but it's still there. I guess makes me go numb about it for a minute. I mean that's one of the reasons why I use multiple times daily."* Other participants who used drugs felt that drug use was one of the few sources of pleasure in their lives. Jessica, a 41-year-old white woman said, "*Oxycontin can mend a broken heart. And it's true. It's true because…when you're truly high, every leaf on every tree and every blade of grass is in his proper place. And it's there's contentment there. You're looking for relief. There's a way."*

The lack of economic opportunities created environments that were stressful and sometimes felt hopeless for participants. Widespread economic depression and lack of job opportunities, combined with systemic lack of access to medical and mental health care, engendered feelings of hopelessness. For some, small town living exacerbated the hopelessness, reflecting economic conditions that likely impact individual level mental health outcomes.

Physical landscape

The rural landscape: lack of services

In this section we discuss the physical environment and service provisions. Although we are discussing the rural landscape "we make no assumption that the physical environment is natural or given, since it is

Table 2
Interconnecting risk environment factors in rural Southern Illinois.

	Micro-environment	Macro-environment
Physical	• Drug use settings and behaviors (e.g., sharing or reusing equipment due to lacking access to new equipment)	• Healthcare and drug treatment shortages • Lack of access to prevention resources
Social	• Healthcare and drug treatment stigma experiences	• Societal stigma against people who use drugs
Economic	• Unaffordable costs for living and health related expenses • Lack of economic opportunities • Access to healthcare and harm reduction	• Poverty • Economic growth and development • Healthcare costs
Policy	• Access to new injecting equipment • Discrimination from police and pharmacy	• Criminalization of drug use

almost always socially constructed in two senses: human actions shape the physical environment, and human conceptions filer the experience of it" (Rhodes et al., 2005). Thus, social and structural conditions influence service provisions within the physical landscape (Collins et al., 2019). Policies and other factors also influence the landscape since risk environment factors are often intersectional (Collins et al., 2019). We cover policies in more depth in the next section.

Participants in this study made direct reference to their physical environments, which were often characterized by low accessibility of health care providers and resources, particularly specialty providers related to substance use disorder and HCV treatment. One reason healthcare providers were not accessible is that they physically were not present near participants. For example, Vincent, a 30-year-old white man who injected drugs, explained, *"They don't have a residential rehab here. Everybody here in this town is being shipped off to Indiana. At the moment, it's the only nine months residential program available, it's like the relocating all of us."* Physical distance is also described as a barrier to accessing drug treatment services such as daily methadone: "*It's hard [getting to the methadone program] because I don't have a full-time driver. It's wintertime is what [makes it hard]; I usually ride my bike there. So, it's a little chilly...I try to get other rides as well. Or take the transit bus or something like that."* (Alicia, age 44, white, injected drugs). To the limited extent public transportation is available in these areas, it typicallyis described as few and far between.

Christina, a 38-year-old white woman who injected drugs further described, *"[Getting to the doctor] is rough. I mean, whoever can give me a ride that day and most of the time they can't. I can't find a ride and I have to reschedule and go without my medication and it sucks."*

The healthcare shortage was also described as being particularly problematic for HCV treatment, where limited options for providers intersected with enacted stigma to challenge participants' ability to receive HCV-care in non-stigmatizing environments. Joshua, a syringe service staff member noted:

> *"I think there are four or five physicians in the area that are actually treating for hep C. We have two at the VA, which is great. We have another that is at Southern Illinois Healthcare which is the largest healthcare provider in Southern Illinois. They have three hospitals. I don't know how many doctors' offices...I won't say they're a monopoly, 'cause I think I'm not supposed to. But they...have cornered the market for sure...The providers that we do refer to, we, we actually dropped one of the providers, uh this last year, because um, he, he, although he was serving the participants*[1]*, he had some of those same issues that we were seeing at the blood draws: the staff was not receptive to the client base. And so for us, we don't want to refer to somebody that is going to further stigmatize that client. Make them think that healthcare doesn't care about them. They haven't a lot in their life. Many of them have lost their families. Many of them have lost their friends. Healthcare kind of seems like a place that should be neutral, and everybody should get the services that they need. But they don't have that sense. So, we had to drop one of our providers because of that. We don't refer to him anymore."*

Drug risk practices

Access to new injecting equipment was a challenge and participants often described a scarcity when discussing the physical landscape. Despite syringes being available without prescription at pharmacies and the presence of a SSP, people reported having to share or reuse syringes. For example, Christina, a 38-year-old white woman, described why she recently shared syringes with her boyfriend: "*Well, I just didn't have any [sterile syringes], I didn't have, we didn't have new ones and so... I'd share with my boyfriend it's what I'd do. And he would do the same with me. Sometimes we share needles."* Similarly, Sheila, a 39-year-old white woman, said,

> *"I share needles with people. I mean, not hundreds and hundreds of people but you know what I mean. A couple of people that I trust in my little tweaker family, or whatever. That I see every day, I run into, and the people I hang out with every day I would."*

Melissa, a 36-year-old white woman, further added, "*I probably use one of my needles like, more than once a few times. About 60 to 70% [of the time]*. Reusing syringes, which is associated with greater risk for other infections including skin and heart infections (Centers for Disease Control, 2019), was common and almost all participants who described reusing their syringes described preferring to not do so. Christina reported,

> *"I mean, there's been a couple times [I don't have sterile syringes]. And I'm just SOL [shit out of luck] until I do. Or I have to reuse one of mine which I don't, I, I hate using, I hate doing."*

Similarly, Justin, a 58-year-old white man elaborated, *"There's been times where I couldn't be able to get certain things that I needed and...I had to reuse the same things that I had, which was terrible...It's terrible to use the same supplies."*

As a result of reusing syringes, participants described physical pain, as John a 29-year-old white man described when he re-used a syringe that had become misshapen:

> *"Yesterday [I reused a syringe]. There was even a little hook (on it). It kept getting caught in my skin every time. Wouldn't, the syringe wouldn't pull back, it wouldn't draw. I had to guess if I was in or not. And you know, if you feel no burn, then you're in, and luckily, I got it on the seventh or eighth time."*

Similarly, Tawna, a 28-year-old white woman noted,

> *"Just a few days ago ...I had to use a- I mean it was mine still but it was old and jagged, and it took me forever to get it. It was, it was pretty bad actually. I sat there for like damn near an hour. It was to the point where I was like in tears cause I was having uh...just the thought of sitting there for over an hour. I mean, repeatedly poking and poking just to get it was really bad, actually."*

Participants reused syringes and other equipment due to a lack of access to new supplies. Part of the reason for the scarcity was the cost of buying syringes at a pharmacy, both in money and in stigma experiences (see following section focusing on policies). Thus, syringe access was in part a physical landscape issue, but it also overlapped with economic and policy issues.

Once participants were introduced to the SSP, where they could obtain free injecting equipment delivered to their preferred location, PWID typically found their situations improved. Even though the SSP was a small organization and covered the 19 most southern counties in rural Illinois (a vast area), the SSP was able to successfully deliver new injecting equipment to people's homes swiftly. Steve, a 30-year-old white man who told us in the past he had to re-use cottons *"I guess a lot of times"* explained how his access to new equipment has changed since he became a participant of the SSP. When asked how often he can get new injecting equipment he said:

> *"Basically as often as I want, it seems like. Every time I've texted them they've- they came either that day or the next day."*

In sum, the rural physical environment was described as having limited resources and service availability, with the exception of the SSP, which has been discussed in the authors' previous work (Bolinski et al., 2022; Walters et al., 2022a). Participants also feared being recognized

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[1] The SSP program has chosen to switch from referring to those who receive services from "clients" to "participants". The reasoning behind this change was a hope of being more relationship-driven and person-centered in their language. The "client" designation seemed to imply dependency, lack of autonomy, and incongruity with our core belief of "people first" when accessing the program's services. Essentially, the program doesn't exist without the people. The SSP recognizes that no label is perfect, but the hope is that participant better reflects (if only somewhat) the person/program relationship of the SSP.

and stigmatized while accessing care related to their drug use, which further challenged accessibility to services as we discuss below.

Policy issues

Stigmatizing policies structured the lives of people who injected drugs

Policies rooted in drug use stigma created conditions of constraint for participants that made access to hepatitis C prevention services and care more difficult. Particularly, the criminalization of drugs allowed for hyper-policing of PWID and fostered policies in some pharmacy settings that dissuade PWID from purchasing sterile syringes.

Policing persons who use drugs

Participants described the relationship between PWID and law enforcement as adversarial whereby law enforcement personnel employed heavy-handed measures aimed at eliminating drug use rather than providing resources or connecting PWID with help. For example, Stan, the EMS key informant, characterized the general attitude of law enforcement in the area: *"Police officers are more about enforcement and making it stop, period, and punishing."* Similarly, Justin, a 58-year-old white man who injected drugs described the reticence among PWID to see police as means to access care. He stated:

> *"There's a lot of good police in the world, but there's some that take their job too far…They treat users like they're dealers. Or I don't know. It's just, I, I just think the world's just getting too big or maybe they been in the job too long and they don't know what to do."*

Most participants described numerous interactions with the police and many had ongoing involvement with criminal justice institutions: "*I can't even count how many times [I've been arrested]…Probably at least 10 times*" said Sheila. Similarly, Melissa said *"[I've interacted with the police] plenty of times. 9, 10, 11. I don't know. I'm out on two bonds right now…I've been arrested for possession, aggravated battery, about six times of numerous trespassing on land."*

At the intersection of hyper-policing policies, the rural environment, and social stigma, participants described the impossibility of using drugs privately and that police knew they used drugs despite the general absence of the sort of public areas found in urban areas where people who use drugs congregate. Marked with the label of 'drug user' and 'criminal', participants felt constantly profiled and harassed. For example, Steve, a 30-year-old male who injected drugs reported having been arrested 20-30 times, said:

> *"I've had a lot of interaction with the police. They stop me for random reasons that is probably made up…they just know who the people are that uses needles. The police are always hassling me, always hassling me. I used to walk around a lot, uh, like to go to work or to go to whatever I needed to go. Yeah, I work in Applebee's. They would always like stop me and not even get out of their car half of the time, and just ask what- what I'm doing here, where I'm going. So I say, uh, "I'm going to work. Leave me alone, I'm not- I'm not doing anything. I'm not bothering anybody." I'm not robbing people and shit."*

Challenges accessing sterile syringes at pharmacies

Under Illinois statute 720 ILCS 635, persons 18 years of age or older are legally allowed to purchase up to 100 syringes from a pharmacy. Despite the law, pharmacies sometimes required study participants to sign a log sheet with their identification, show an identification card, and/or demand a prescription before selling them syringes. One participant, Steve described: "*They [pharmacists] say that you need a prescription. Which you don't need a prescription for. But they won't, they won't sell them to you without a prescription."*

Research has demonstrated how these kinds of informal barriers can significantly impact peoples' willingness and ability to obtain services (Chiarello, 2016). This may be particularly true in rural settings where participants are aware that their activities are likely to not remain private.

Participants reported that pharmacy policies made them feel stigmatized and embarrassed: *"It can be kind of humiliating. I don't like to ask [for sterile syringes]. I'm ashamed of it. It makes me feel this small to go there and ask. You need to show ID and they sometimes make you like sign your name…I mean it's just kinda awkward you know,"* Alex, a 26-year-old white man commented. Some participants reported being denied services altogether, as Frank, a 36-year-old white man who injected drugs explained: *"CVS, depending on the shift and the hour, they'll, supply [sterile syringes]… But if they believe that you're not diabetic, or they believe that you're gonna use 'em for anything other, they, uh, will refuse you service."* Similarly, Steve, a 30-year-old white man who injected drugs said, *"But they won't, they won't sell them to you without a prescription. Uh, I don't know, I went in there before and tried buy them and they literally would not sell them to me."*

After experiencing challenges at pharmacies, participants anticipated future conflict and as a result avoided purchasing sterile syringes at pharmacies. Sheila explained:

> *"You have to have ID. I usually don't have my ID. I tried a couple times at [pharmacy 1] but they said you have to have a prescription…[pharmacy 2] [pharmacy 2] you have to have ID, [pharmacy 3] you have to have ID. And it just depends who's workin' the pharmacy. It's you know, like the one in [pharmacy 3] at [location], they can be a dick if you don't have ID or prescription. I don't ever bother with it though because…people would just, ask me, "Hey do you have ID?" and I'm like, "For what?" And I'm like, "No, I don't""*

In addition to pharmacies refusing to sell syringes to participants, stigma combined with fear of arrest also resulted in participants avoiding pharmacies. Nick, a 44-year-old white man who injected drugs said:

> *"You could start buying them at [pharmacy]. But, but like I said, I mean, it just, people just don't want to do it. They don't, they don't want their face to be out there. And if somebody asks for their ID, they didn't want their name to be out there. Because you know, uh, you know, do-gooders or whatever, want to, you know, call the police and destroy somebody's life because they have a different opinion of how it should be lived, you know."*

The fear was well-founded, given past experiences of being arrested under paraphernalia laws (Criminal Offenses 720 ILCS 600), despite exceptions under the Illinois Hypodermic Syringes and Needle Act. Alicia, a 44-year-old white woman who injected drugs noted,

> *"[I've been arrested] several times…I've gotten in trouble for paraphernalia, which I didn't understand 'cause…I bought the paraphernalia at Walmart, but I told him that I use it for my (legal) suboxone. So it must've—you're not supposed to use the paraph [paraphernalia] —you know, needles—for that. But the equipment was clean…They just arrested me, and I got a paraphernalia charge."*

As a result, participants often relied on other sources for sterile syringe access, such as friends. However, this method could be unreliable. Melissa explained:

> *"I got a couple diabetic friends that help me out if I need [sterile syringes]. This past couple few weeks has been pretty rough honestly 'cause I got a lot going on…A normal weekly one's like…a ways down the road. He brings my supplies…I don't like gotta show my ID like at Walgreens to buy 'em. I don't want to show my ID to go buy them."*

Similarly, Vincent reported,

> *"With the, the syringes I, I would, like, get them from friends 'cause, I was too paranoid to go into CVS Pharmacy or something like that, you know, to go in and buy my own, so- I always had somebody else go in, or sent somebody with them."*

Since the provision of new syringes is among the most effective means of preventing hepatitis C in this population (CDC, 1998; Hagan et al., 2011), these barriers exposed participants to greater risk of

HCV infection and other harms associated with sharing and reusing injection equipment such as HBV and HIV transmission and skin and soft tissue infection. The negative experiences stemmed from policies criminalizing drugs and drug paraphernalia that were so entrenched that laws countermanding these policies were only partially successful. We also found that even at pharmacies that observed laws expanding access to syringes, new standards have been slow to form (or are non-existent) and practices preventing syringe access remain. This finding indicates the long-lasting effects of drug use stigma.

Social issues

Social stigma within healthcare

In conjunction with stigmatizing policies around drug use, participants also perceived stigma in healthcare settings, which impacted HCV prevention and treatment. Joshua, a syringe service staff member, described stigma in the healthcare system. He said, "*People who inject and use drugs do not wanna be in kind of a [healthcare] environment. They definitely have a sense that where they're at is, um, it's hostile towards them. And towards their life.*" Peter, a 36-year-old white man who injected drugs said, "*Ain't nobody like addicts. We're the most hated people in the fucking planet."* Similarly, Stan, a key informant who was an emergency medical technician explained,

> *"[People who use drugs] are treated like shit. I can sit in the back of the ambulance and let someone know that I'm not judging them and that whatever [drug use] is not a character defect of their own. Then I get this person calm and willing…I can get them to the point where they are willing to accept help, then they go into the emergency room and somebody doesn't want to put up with that stupid meth head. Even the healthcare workers who know the community, most of them are part of the community. So they…have dealt with the rotating door of the same people in and out of the emergency room. And what's going to be different this time? In my opinion, they are seen as more of a burden than anything."*

Like Stan, Nick, a 44-year-old white man who injected drugs explained how stigma due to drug use inhibits his ability to effectively communicate with health care professionals. He points out that once doctors become aware of an individual's history with substance use, all their interactions – and particularly any requests for medication – are seen through that lens. He stated:

> *"In my experience with doctors, anytime you bring [drug use] up you can just forget about anything that's really a problem. Anything that would need any medication…It's like, you're having a conversation and you mentioned [drug use] and all of a sudden everything else you say is womp, womp, womp, Charlie Brown's teacher. After you admit to drug use… they have really no use for you. You're pretty much wasting your time because they're not going to do anything for you. You're nothing but a drug seeker, and you can have some legitimate issues, concerns and they just don't care."*

Participants also described experiencing stigma while interacting with substance use disorder treatment providers: Melissa, a 36-year-old woman who injected drugs said, "*Where I've done my [SUD] treatments…I had the counselor that was a 23-year-old girl…I got up walked out of plenty of fucking appointments with her because… I felt like I was getting judged at times, more or less."*

For many participants, drug use stigma in healthcare settings created situations where they anticipated discriminatory treatment in the future. To avoid these experiences participants adapted strategies such as not disclosing their drug use to health care providers or avoided interacting with healthcare providers when possible. Frances, a 44-year-old woman who injected drugs explained,

> *"To tell you the truth, if I can avoid [disclosing drug use to a doctor], I will lie. Absolutely. Absolutely. I mean, I'll lie if I have to, just to not have to deal with it. But I have had experiences and I- it's not pleasant, it makes you not want to go back."*

Indeed, many participants described avoiding healthcare settings at all cost. Peter, a 36-year-old white man who injected drugs and had not seen a health care provider in two years said, "*I don't go to the doctors. I, if I'm sick, I, I'm just sick. If I hurt, I just hurt.*" Similarly, Paul, a 36-year-old white man who injected drugs told us, "*I really wouldn't go anywhere probably [if I was sick] unless it was like unless I could not function, move. I'd ride it out. Because it has to be a pretty much deadly."*

Stigma effects on hepatitis C awareness, knowledge, and care

Few participants were aware of recent advances in hepatitis C treatment and many cited the previous, more painful treatment regimens, as reasons for avoiding treatment. For example, when asked if she knew anyone treated for hepatitis C, Tawna, a 28-year-old white woman described a friend's experience with older treatments:

> *"He got it and he went through I want to say like chemotherapy…I haven't seen him in like two years, so I would say probably three years ago….He said like you killed him…He went through the chemo because his liver was in some trouble…That's the only treatment I… ever really [heard of]."*

Participants also described the need to abstain from drug use required by Medicaid, including in Illinois until late 2018 (Roundtable, 2021) as one of the reasons they had not received HCV treatment. For example, Sheila, a 39-year-old woman who injected drugs reported,

> *"I don't know much about it [hepatitis C]. I know now that- that the cure for it is, you have to stay clean which kinda' is like I have it, I have, I know I have Hep C and I've had it for about 10 to 15 years and, um, I never went through the program to- to, you know, get rid of it because when I was, they said that, I knew, like, I don't know, I guess I'm, I don't know, whatever. They said that I had to be off the drugs and I just never, you know, I'm an addict so…The person I- the first person I heard that from was my mother-in-law…And I've asked a couple times, like, when I was in the hospital for two or three days this arm thing if I could, if he could give me medicine for Hep C and he said no because I'm an addict or whatever and it's, one of their family doctor told me that. We couldn't do anything until I'm totally clean."*

Similarly, some participants referenced the need to be at the end-stage of liver disease to obtain treatment, another requirement of Illinois Medicaid until 2018 (Roundtable, 2021). For example, John, a 29-year-old white man who injected drugs said,

> *"I know it's expensive to do the [HCV] treatment and…in order to get the treatment, you had to be pretty much at the final stage of it. They couldn't do it when you're at the first stage, I guess there's stages in it. Like, they wouldn't do it if you just found out. You had to be, you know, your blood cell count had to be real low."*

Participants also expressed the belief that that treatment was not effective. Specifically, some referenced the fact that HCV relapses do occur even after achieving sustained virologic response (SVR) (Smith-Palmer et al., 2015) as evidence of its lack of utility. For example, Vincent, 30-year-old white man who injected drugs explained:

> *"My mother had [hepatitis C] and been cured twice…I know the first time… her body rejected the treatment, or something like that. Didn't take the treatment. And then the second time, she got rid of it. Well, not rid of it; I don't think you actually ever get rid of it."*

Moreover, in such cases, participants feared that the return of HCV would be assumed to be the result of drug use by the patient and thus, could negatively impact their relationship with their physician or even lead to police interactions. As such, they anticipated greater levels of stigma which oftentimes resulted in minimal engagement with healthcare providers. This in turn negatively affected their HCV awareness, knowledge, and treatment.

Discussion

This study demonstrates complex structural and community forces that produce risk for HCV infection among rural populations of PWID. Specifically, this study focuses on the risk environment of rural southern Illinois. In contrast to research that looks primarily to individual PWID as the source of risk and site of intervention, our data show how the production of hepatitis C risk operates at the economic, physical, policy, and social levels, and that individual risk is often directly related to vulnerabilities produced structurally.

We find that the rural landscape of southern Illinois is characterized by several conditions that impact the risk of HCV infection and treatment. In particular, participants discussed the lack of economic opportunities and widespread poverty that was coupled with a physical environment that made accessing healthcare difficult. A recent study sampling people who use drugs in rural Southern Illinois reported 49% of participants experienced homelessness in the past 6 months (Jenkins et al., 2022). Furthermore, the study area had limited healthcare options (*Health Resource and Services Administration*; *United States Department of Agriculture. Rural-Urban Continuum Codes*). Participants noted how the area was economically deprived, which echoes research on outmigration from this area and other midwestern towns where people move from this area to more urban spaces with more jobs and economic opportunities (Walzer, 2003). Economic disadvantages in both rural and urban areas can cause increased stress and other psychosocial issues associated with drug use (Carpenter et al., 2017; Nagelhout et al., 2017). This study adds to the limited research focusing on rural risk environments among drug using populations (Cloud et al., 2019; Ezell et al., 2021) and the dearth of research focusing specifically on hepatitis C in rural settings (Chan & Mangla, 2022; Kolak et al., 2020; Wagner et al., 2021).

Similar to other studies, we find that experiences with stigma due to both policies and personal interactions led participants to avoid drug treatment (Dew et al., 2007; Ezell et al., 2021) and healthcare (Muncan et al., 2021; Muncan et al., 2020; Surratt et al., 2021; Walters et al., 2021). Since HCV predominantly impacts people who inject drugs, drug use stigma likely directly affects HCV care continuum outcomes. Furthermore, given the intense amount of drug use stigma, particularly in southern Illinois, participants may internalize these negative beliefs (Walters et al., 2021). Past research focusing specifically on HCV stigma among people who inject drugs found that people can embody this “deviant label”, and thus, it drug use becomes a major part of their identity (Harris et al., 2021). This is one example of how people who use drugs can experience individual effects from structural forces (Harris et al., 2021). However, participants in this study focused their narratives on healthcare stigmatization.

Healthcare stigma is particularly concerning in this rural location given the already scant services available in the region. Stigma, along with the other risk environment factors mentioned above, also affected participants’ abilities to protect themselves due to lack of resources and trusted sources of current hepatitis C information. However, the SSP increased access to resources that provided participants with tools to protect themselves, as most participants in the SSP indicated having access to new injecting equipment most of the time when they were engaged with the SSP. The SSP in rural Illinois operated mainly as a mobile unit, which delivered to participants homes or other preferred location (Walters et al., 2022a). This type of service is likely missing in many other rural spaces.

Of particular importance was the lack of awareness of newer HCV therapies and recent changes in state Medicaid policies. Without access to updated information about therapies from providers or community members participants continued to avoid HCV treatment due to fear of harsh side effects and maintained the belief that sobriety and advanced fibrosis were required for insurance approval of medications. A 2013 study cited this former mistaken belief as a barrier to HCV care (Jordan et al., 2013). In this rural setting, almost a decade later, the barrier remains.

Our research demonstrates the importance of a more politically grounded approach to harm reduction. As harm reduction practices and philosophies have become more accepted in public health settings (and importantly, within the world of grant-funded research), they have also been become increasingly focused on biomedical models of risk that focus too much on the individual and not enough on the larger social and policy context (Albers, 2012; Castillo, 2019; Smith, 2012). We argue for a return to the movement’s more politically focused approach to understanding and challenging the harms linked to substance use (Friedman et al., 2020; Friedman et al., 2001; Solanki, 2019; Szott, 2016). This means greater efforts aimed at changing laws that criminalize and marginalize PWID as well as more focused resistance to economic inequality and poverty that make reliable and non-stigmatizing healthcare a luxury outside the reach of many PWID (and other marginalized populations). While such an approach requires greater effort on the part of activists since it involves a more complex assessment of the etiological nature of drug use harms, anything less will only serve as a band-aid for the many problems PWID face, or worse will lead to a reification of the ideologies that support prohibition, the War on Drugs, and the down-stream healthcare problems they create.

Our findings thus speak to the need for hepatitis C interventions that move beyond those based on individual behavioral modification. Interventions should focus more on addressing structural forces that influence access to harm reduction supplies, one’s power and agency to negotiate behaviors and situations that can protect them (Walters et al., 2017; Walters et al., 2018), access to health care, and even the extent to which the supply of illicit drugs can affect morbidity and mortality among people using drugs (Bolinski et al., 2022; Walters et al., 2022a). Although individual interventions are helpful for reducing injection-related HCV risk, community and structural approaches are needed to address elements that place PWID “at risk of risks” (Link & Phelan, 1995). Thus, HCV treatment needs to be socially situated and will require social and structural interventions (Harris & Rhodes, 2013). Structural interventions could target policing, housing and food insecurity, and gendered risk (Rhodes & Treloar, 2008).

Interventions could also target clinicians and healthcare workers by providing education and training about working with people who use drugs. Interventions such as Project ECHO® (Extension for Community Healthcare Outcomes), a tele-education strategy that uses collaborative learning and specialty training for non-specialists (Arora et al., 2010), could be used to educate and de-stigmatize drug use. Project ECHO may be particularly useful in resource-scarce rural settings (Arora et al., 2011; Walters et al., 2022b). With additional training and support healthcare workers could learn to build more positive trusting relationships with patients who use drugs (Marshall et al., 2020). Research has found that positive trusting relationships with healthcare workers is associated with healthcare utilization and reduced risk behaviors (Treloar et al., 2013). In addition to training healthcare workers, another intervention could focus on community healthcare and using nurse-led models of care to provide treatment in places where people who use drugs are comfortable and less stigmatized (Brener et al., 2013).

Despite these promising interventions, without larger structural changes that address the social, economic, political, and other structural drivers of inequities, HCV elimination will likely be unachievable (Seear et al., 2021). Stigma due to drug use, which often translates to HCV stigma, is structurally induced and supported by policies, such as policies that criminalize drug use as well as policies within healthcare (Harris et al., 2021).

Our study has several limitations. First, participants were recruited in collaboration with a SSP, and thus, most were SSP participants. It is likely that SSP participants have increased knowledge and access to information about hepatitis C. Second, our sample is limited in terms of racial and ethnic diversity, and circumstances likely differ between groups due to stigmas associated with race and ethnicity (Phelan & Link, 2015; Walters et al., 2020). The sample does, however, reflect local population demographics in rural southern Illinois. Third, the findings may not be generalizable to all rural PWID as treatment opportunities, neighborhood conditions, and other community and structural factors likely differ by geographic region. In fact, other areas may have less accessible SSP options than the population in rural southern Illinois (Pollini, 2019). Fourth, the sample size of 19 may not reflect all the rural population who inject drugs living in southern Illinois. However, we do believe we met theoretical saturation and therefore did not collect additional data (Charmaz, 2014; Saunders et al., 2018). Fifth, interviews were conducted prior to the COVID-19 pandemic and with SSP participants. Future research should look to engage people who use drugs who do not access harm reduction. The recent pandemic may have exacerbated risks for HCV infection and treatment, drug overdose, and exposure to other infectious diseases related to drug use among PWID (Bolinski et al., 2022; Jenkins et al., 2020; Walters et al., 2020).

Conclusion

This study explores the potential for using contextual and multifactorial models of risk to understand drug use issues. Specifically, we used the rural risk environment framework to understand the driving forces that have led to disproportionate hepatitis C burden among PWID residing in rural areas. We argue that such models, and the attention to economic, physical, policy, and social factors that they incorporate, are needed for a more in-depth understanding of hepatitis C in rural settings. As such, we recommend that the risk environment framework and other models that incorporate structural and contextual perspectives be utilized more often in substance use research, which has traditionally focused on individual-level data to explain the risks associated with substance use. Similarly, interventions must also account for the ways in which environmental factors shape the risk outcomes that drug using populations face.

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Declarations of Interest

The authors declared that they have no conflicts of interest.

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