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Voices From the Field: A Qualitative Study of the Challenges and Promising Practices of Rural Public Health in Addressing HIV and Hepatitis C

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Voices from the Field: A Qualitative Study of the Challenges and Promising Practices of Rural Public Health in Addressing HIV and Hepatitis C

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Abstract

Rural areas of the United States may be vulnerable to an HIV or hepatitis C (HCV) outbreak among persons who inject drugs. We conducted semi-structured interviews with 36 state and local public health professionals from six rural states to gain an understanding of the challenges rural communities face and strategies they are using to prepare for, identify, and respond to HIV and/or HCV outbreaks due to intravenous drug use. Key informants described inadequate funding, insufficient staffing, limited health care infrastructure, and other factors as limiting the public health capacity of rural areas. Promising prevention, surveillance, and treatment strategies in rural areas included the use of mobile treatment units, telemedicine approaches, and community education initiatives to overcome resistance to evidence-based harm reduction programs.

Key Words: Rural communities; Hepatitis C; HIV; Public health; Injection drug use

Points for Practitioners:

- Health and human service organizations, particularly those serving rural jurisdictions, faced challenges in preparing for, detecting, and responding to HIV and/or HCV outbreaks that may accompany injection drug use. Most faced funding and staffing limitations that compromised surveillance, testing, and treatment functions, as well as stakeholder and/or community resistance to evidence-based public health approaches.
- Practitioners at the state and community levels engaged in developing and implementing strategies to address these limitations and build rural public health capacity. To address limited access to testing and treatment for HIV, HCV, and substance use disorder in rural areas, some public health agencies developed mobile units that could deliver services where they were otherwise not available. Some organizations used telehealth to expand the capacity of rural health care providers and connect rural patients with specialty services for treatment of HIV or HCV.
- Health and human service practitioners in rural communities promoted evidence-based harm reduction programs through education initiatives, technical assistance, and community coalitions.
- Although challenges and promising practices varied by public health governance structure and other factors, rural

HIV and hepatitis C (HCV) are major public health issues associated with high-risk drug injection practices (e.g., sharing needles or other drug injection equipment). Prior research identified 220 predominantly rural counties in the United States as being potentially vulnerable to an HIV or HCV outbreak among persons who inject drugs (PWID) (Van Handel et al., 2016). Growing prevalence of high-risk behaviors in rural areas and challenges associated with limited public health capacity place some rural counties at risk of HIV and/

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or HCV outbreaks.

HIV and HCV Prevalence Estimates and Injection Drug Use in Rural Areas

Nationally, HIV diagnoses have remained stable in recent years (CDC, 2018a). The Centers for Disease Control and Prevention (CDC) attributes this lack of improvement in HIV rates to limited availability of prevention and treatment services, especially in rural areas (HIV.gov, 2020). Across nine southern states, HIV diagnosis, prevalence, and mortality rates were higher among rural and suburban residents compared with urban residents (Reif et al., 2015).

Acute HCV infections increased significantly in the United States between 2004 and 2017, with injection drug use (IDU) cited as the most common risk factor (Zibbell et al., 2018). Rural areas reported greater increases in HCV infection rates than urban areas (CDC, 2018c; Schranz et al., 2018). According to state surveillance data from 2006-2012, the incidence of acute HCV infections increased by 13% per year in rural counties, compared with 5% in urban counties (Suryaprasad et al., 2014). The CDC reported an increase of 364% in acute HCV infections in four states most affected by the opioid epidemic—Kentucky, Tennessee, Virginia, and West Virginia (Office of Infectious Disease and HIV/AIDS Policy, 2016). Additionally, in these four states, HCV incidence among rural adults younger than 30 was more than twice the rate of their urban counterparts (Zibbell et al., 2015).

IDU is a risk factor for both HIV and HCV transmission, and PWID in rural areas report injection behaviors that place them at high risk for acquiring HIV or HCV (Paquette & Pollini, 2018). In a small sample of PWID in rural upstate New York, persons who reported sharing injection equipment were more likely to test positive for HCV antibodies (Zibbell et al., 2014).

Public Health Capacity

Given the increasing prevalence of IDU in rural communities (Paquette & Pollini, 2018; Schranz et al., 2018), state and local health departments (LHDs) may benefit from an exploration of their vulnerability to a potential HIV or HCV outbreak and their capacity to provide an effective response. Ensuring comprehensive surveillance, case finding, access to treatment services, and harm reduction interventions could reduce the occurrence and severity of outbreaks (Gonsalves & Crawford, 2018). The CDC provides guidance (CDC, 2018b) and a capability-based framework (CDC, 2019) to aid public health agencies planning, preparing, and coordinating across a wide variety of community partners in the event of outbreaks of HIV or HCV among PWID.

In recent years, public health budgets have been cut at the federal, state, and local levels (Trust for America's Health, 2017, 2020), reducing public health capacity to prepare for infectious disease outbreaks. Following significant funding support after 9/11, budgets for the Public Health Emergency Preparedness (PHEP) and the Hospital Preparedness Program decreased by 31% and 50%, respectively (Watson et al., 2017). Several studies have identified attendant decreases in surveillance and investigation, two key activities for

infectious disease detection and control at the LHD level (Davis et al., 2014; NACCHO, 2016). For example, between 2010 and 2012, preparedness capacity among LHDs declined or did not improve in domains representing activities related to plans and protocols, communication, and incident command systems (Davis et al., 2014).

Rural local public health department capacity. Rural public health departments have fewer staff, smaller budgets, and provide fewer health services than their urban counterparts (Beatty et al., 2010). Furthermore, they have fewer partnerships with local non-governmental organizations, a potential means of increasing service provision (Beatty et al., 2010). As of 2016, only five percent of all full-time public health employees worked in rural areas (NACCHO, 2017). Due to this smaller workforce, rural public health departments are less likely to have specialized public health professionals (e.g., epidemiologists) (Meit et al., 2012). Recruitment and retention of staff are challenged by a shortage of funding and lack of support from elected officials (Meit et al., 2012). As a result of this lack of funding and support, many rural health departments may not meet the recommended infrastructure guidelines to be well-equipped in the event of an outbreak (Meit et al., 2008). Small LHDs are also less likely to have an emergency plan or public health staff trained in emergency preparedness (NACCHO, 2017).

Limited rural public health capacity to respond to potential outbreaks is evidenced by a scarcity of testing facilities and laboratory diagnostics, especially for HCV (Easterbrook et al., 2017). LHDs serving small populations are significantly less likely to offer HCV testing than those serving larger populations (19.8% in rural compared with 30.1% in urban) (Fraser et al., 2002). Rural persons are less likely to report lifetime HIV testing compared with urban persons (32.2% compared with 43.6%, respectively) (Ohl & Perencevich, 2011). A recent study analyzing data from the Behavioral Risk Factor Surveillance System found rural residents had 15% lower odds of lifetime HIV testing than urban residents (Henderson, Subramaniam, & Chenet, 2018), which may contribute to later HIV diagnosis in rural areas (Ohl & Perencevich, 2011; Henderson et al., 2018).

Access to HIV and HCV Treatment

Access to HIV and HCV testing and treatment services may be limited for rural residents. Among rural Appalachian PWID who tested positive for HCV, only eight percent received treatment (Stephens et al., 2017). Barriers to HIV and HCV care in rural areas include limited availability of treatment services, lack of awareness of HIV and/or HCV at the community level, perceived lack of confidentiality, and lack of substance use disorder (SUD) treatment facilities willing to work with persons with HIV (Reif et al., 2005; Schafer et al., 2017). Restrictions on HCV treatment imposed by private and public insurers, and reluctance of providers to treat patients who are actively injecting drugs are additional challenges (Kapadia et al., 2019; Schranz et al., 2018). Health system barriers include complicated navigation, mistrust between PWID and the medical community, high cost of HCV treatment, and stigmatization in health care settings (Zeremski et al., 2013).

Stigma is a substantial barrier to accessing care among people living with HIV in rural

areas (Reif et al., 2017) and can impact health outcomes. In the Deep South, where nearly 30% of persons living with HIV reside in rural areas and small towns, persons with higher internalized stigma were more likely to miss medical appointments, report poorer medication adherence, and have detectable viral load, all of which have implications for the spread of HIV (McAllaster & Goodrow, 2018).

Harm Reduction

Harm reduction strategies seek to decrease the negative outcomes associated with certain behaviors without necessarily eliminating the behaviors. These approaches stand in contrast to the abstinence-based approach to drug policy that has been dominant in the United States for most of the last century (MacMaster, 2004). Harm reduction strategies that aim to decrease HIV and/or HCV transmission include syringe service programs (SSPs); supervised injection facilities; condom distribution; and pre- and post-exposure prophylaxis. We focus here on SSPs given their growing use in preventing the spread of HIV and HCV.

Syringe service programs. SSPs dispose of used needles and syringes and supply PWID with sterile needles and syringes to help prevent the transmission of HCV and HIV (CDC, 2018b). They may also provide alcohol prep pads, sterile water, clean cotton or other filter devices; wound care material such as bandages and pain relievers; and condoms, dental dams, and lubricants (CDC, 2018b). SSPs often provide referrals to SUD treatment programs; education on safer injection practices and wound care; HIV and HCV counseling and testing; and naloxone distribution.

SSPs vary in design, and can be in a fixed location or operate as a mobile unit. Injection materials may be distributed based on one-for-one exchange (i.e., individuals can only receive a syringe if they turn one in) or need (i.e., individuals can receive as many syringes as they think will be needed between visits). While federal funds cannot be used to purchase sterile injection equipment, jurisdictions that consult with the CDC can use federal funds to support salaries of SSP staff, rent, syringe disposal, naloxone, outreach, planning, and evaluation activities (CDC, 2018b).

Though they are illegal in 12 states, there were 363 SSPs operating in the United States as of July 2020 (amfAR, 2019, 2020). In the 12 states where SSPs are illegal there are restrictions on SSP funding and/or state laws criminalizing the sale, distribution, and possession of syringes for use with illicit drugs (Cloud et al., 2018). Although some states have restrictions such as requiring identification at pharmacies, which may limit access (Bramson et al, 2015), syringes can be purchased at pharmacies in most states without a prescription (CDC, 2018b).

Proximity to SSPs varies by rurality. SSPs are located primarily in urban or metropolitan areas (Des Jarlais et al., 2015). A study of young persons with HCV in the United States found that their median distance to an SSP was 37 miles, and the proportion of young persons with HCV who lived more than 10 miles from an SSP increased with rurality (Canary et al., 2017). Forty-seven percent of study participants in large metropolitan

areas lived more than 10 miles from an SSP, compared with 98% of those in non-metropolitan areas (Canary et al., 2017).

Study Design

The present qualitative study aims to build an understanding of the capacity of rural counties to prepare for, identify, and respond to an HIV or HCV outbreak, the challenges rural communities face in addressing a potential outbreak, and the strategies used to address those challenges. This qualitative analysis is a companion study to a quantitative analysis that categorized 20 states as potentially at risk for an HIV or HCV outbreak based on a composite burden of opioid use, and HIV and HCV indicators (Lendardson et al., 2021). Specifically, high-risk states were identified using data from the National Institute on Drug Abuse's *Opioid Summaries by State* (NIDA, 2018); CDC's *Surveillance for Viral Hepatitis* (CDC, 2018c); and AIDS-Vu data (Emory University, 2018).

From this group of 20 at-risk states identified in the quantitative study, we selected six rural states for qualitative interviews. County-level rural-urban status was based on the 2013 Office of Management and Budget metropolitan and micropolitan area designation (Office of Management and Budget, 2013). We classified states as rural if a larger proportion of their population resided in a rural area than the national average (19.3 percent) (Economic Research Service, 2018). The selected states represented all four United States Census regions. Because challenges rural counties face may vary by public health governance structure, our sample of states included at least one state from each governance classification. These governance structures are: centralized, in which state employees lead LHDs and retain fiscal authority; decentralized, often called "home rule" in which the LHD retains authority over key decisions; shared, where the LHD is led either by state or local government employees; and mixed, in which no single state or local governance structure predominates (ASTHO and NORC, 2012).

Data Collection

Between May and August 2019 the research team conducted semi-structured interviews with 36 key informants. Thirty-five key informants were interviewed by phone, either alone or in small groups, and one key informant provided written responses to interview questions. Interviewees included state and local public health officials, harm reduction professionals, epidemiologists, and public health surveillance staff. Key informants were identified through purposive and snowball sampling. We reviewed state and LHD websites and publicly available reports (e.g., epidemiological reports, strategic plans, and community health needs assessments) related to HIV, HCV, and/or PWID to identify subject matter experts for initial interviews in the targeted states. Interviewees were recruited via email and by phone. Local-level informants were recruited exclusively from rural areas. The University of Southern Maine Institutional Review Board approved this study. Informed consent was obtained from all participants. To protect participant anonymity, location and job titles are not reported.

The research team developed a semi-structured interview guide. The guide focused on

rural challenges; promising practices; the relationship between state and local public health organizations; and strategies related to outbreak preparedness and detection, outbreak investigation, and outbreak response in rural areas, as outlined in the CDC's 2018 report, *Managing HIV and Hepatitis C Outbreaks Among People Who Inject Drugs: A Guide for State and Local Health Departments* (CDC, 2018b). The interview guide was piloted with a surveillance professional from a state not selected for the study. At least two researchers conducted each interview, which lasted approximately one hour. The interviews were audio recorded, transcribed verbatim, and imported into NVivo version 12 software (QSR International) for coding and thematic analysis.

Data Analysis

Three researchers separately hand coded one of the interview transcripts using a provisional coding structure derived from the interview guide. The researchers compared their coding, clarified concepts, and revised the coding structure based on consensus. They then conducted an additional round of transcript coding and review to further refine the coding structure before developing the final codebook and individually coding the remaining transcripts.

Limitations

The study has several limitations related to key informant recruitment and generalizability of study results. The 36 key informants were spread across six states, with the number of interviewees in each state ranging from 3-12. Because our study focused on six rural states at higher risk of an HIV or HCV outbreak, our findings may not be generalizable at the national level. Additionally, although state- and local-level key informants were interviewed in each state, snowball sampling resulted in a different mix of the types of key informants for each state. Variation in the number and type of key informants in each state may have affected the depth of our understanding of activities underway in selected states. Finally, data are based solely on perceptions of key informants.

Results

Our analysis of key informant interviews identified a number of challenges health and human service practitioners face in rural communities preparing for and responding to possible HIV and/or HCV outbreaks due to IDU. These challenges limited the capacity of rural communities to respond to a potential outbreak and included funding and staffing limitations; inadequate surveillance, testing, and treatment; and resistance to evidence-based harm reduction initiatives. However, key informants also described strategies and promising practices that health, human service, and community-based practitioners were developing and implementing to address these challenges.

Funding and Funding Allocation

Many public health organizations, particularly in rural areas, lacked adequate funding to prepare for and respond to a potential HIV and/or HCV outbreak. Key informants described three subthemes related to funding: funding favoring population centers, declining public health funding, and inadequate funding for viral hepatitis initiatives as compared to HIV.

Funding favoring population centers. Key informants attributed the lack of funding in rural areas to federal funding formulas and state funding decisions that favor population centers. Federal funds, often allocated to areas with higher population density, left rural communities with fewer resources to address public health needs. As one state-level key informant noted, “Most of our services, because they're federally funded, are based on funding formulas that focus on the populated areas. That can be really challenging for us.” In addition, needed funding and other resources, such as rapid HIV tests, were not available in some rural areas because state resource allocations were targeted to more populous communities: “Prevention dollars have been siphoned away from agencies in smaller, more rural communities and those dollars have been sent to more urban areas.”

Declining public health funding. Key informants described decreased funding for public health as having eroded their capacity to respond, particularly in rural areas. Reduced funding resulted in fewer public health staff, low salaries, and limited resources:

In the rural areas...you see really a significant decrease in...the areas of expertise as it relates to public health or health care, as it relates to the amount of resources, the amount of people and funding, etcetera, available to tackle any problems that should arise.

Funding cuts from the state affected LHD infrastructure and their ability to provide testing and treatment for HIV, HCV, and/or IDU: “The state chose to, in balancing the budget, take [more than 20%] of the income from all the local health departments. So to take that much of the cut and still try to provide services has been very challenging.”

Funding disparity between HCV and HIV. In addition to rural-urban public health funding disparities, several key informants noted that rural counties had fewer funds and resources to address HCV than HIV—even in areas that were particularly burdened by HCV. Several key informants pointed out the relative lack of federal and state funding to support HCV surveillance and prevention staff compared with HIV-related public health activities; and that HCV resource limitations challenged rural jurisdictions' ability to prepare for, detect, and respond to a potential HCV outbreak. A community-based key informant stated: “Hepatitis doesn't have the federal programs associated with HIV that can help pay for treatment.” Aside from funding challenges, informants noted that community members and other stakeholders expressed less political will for addressing HCV than HIV.

Strategies to address funding limitations. Despite public health funding challenges in many rural communities, several key informants described efforts to address funding limitations. For example, when funding for a recovery center in a rural community was eliminated, members of the community quickly organized to identify funding, resources, and an administrative structure to maintain the center. One local key informant shared about the effort: “As much as we’re challenged with some of our rurality, I do think that some of the community that comes with the rurality can be a powerful part of the solution.” Another community-based informant described soliciting funds from community organizations to pay for treatment: “Because sometimes for a lack of \$65 somebody may lose their access to the MAT [medication-assisted therapy] program, relapse and then they’re back off and running again.” Other key informants described organizations integrating their HCV response into existing, more robust HIV programs and infrastructure. For example, one state sought funding to incorporate HCV screening into its HIV screening outreach programs.

Staffing

Human capital was identified as a critical element of outbreak preparedness, detection, and response. Key informants from every state cited state-, LHD-, and community-level shortages of public health and clinical staff as a barrier to preparing for and detecting HIV and/or HCV outbreaks, managing outbreak response, and providing health care and harm reduction services to rural PWID. The public health-focused positions identified as being in short supply included epidemiologists, surveillance staff, disease intervention specialists (DIS), and staff trained to provide HIV testing services. Key informants also noted workforce shortages among clinical providers, including infectious disease specialists, gastroenterologists, mental health providers, MAT providers, and primary care providers with experience treating PWID and/or individuals living with HIV or HCV.

Public health workforce capacity. Factors that made it difficult for key informants to recruit and retain staff included low salaries and a lack of funding to support hiring; bureaucratic hiring processes that prevented quick scale up of services; reluctance of prospective employees to move to rural areas; and turnover due to staff burnout. The most commonly identified staffing-related challenges were lack of funding and low salaries. Regarding pay, one state-level key informant shared: “One of the main reasons for our vacancy rate is salary range. It’s hard for public health—with the fewer dollars we have—to compete with the private and/or for-profit company.” The leader of an LHD provided an illustrative example of recruitment difficulties related to low salaries: “My staff—especially the position I’m trying to hire in nursing—they can go to Wal-Mart or McDonald’s or Chick-fil-A and earn more than a nurse.”

Consequences of staffing shortages included losing patients to care and attendant risk of outbreaks, staff burnout, and limited hours and outreach for SSPs and clinics. DIS, characterized as being “at the heart of getting an outbreak under control,” and other surveillance staff were routinely identified as being stretched thin. A state-level key informant described DIS who covered large territories that spanned dozens of counties and took hours

to cross: “You cannot track down people who are newly diagnosed and interview them when you’re trying to cover that much territory. It’s just not possible. And there’s a lot of frustration among those workers.” This lack of capacity affected patient enrollment in treatment; the same state-level key informant continued:

[People who are HIV positive] just don’t even get into care because they don’t get interviewed. You lose their contacts, but not only that, they feel like they’ve been dropped. They’re told these people will come talk to them and they’ll interview them, and they never show up. Or if they do, it’s much later and the person’s moved or whatever, and they’re like, “Well if they don’t care then I don’t care.”

Interviewees who worked in harm reduction described limiting clinic or SSP hours and testing outreach due to lack of staff capacity. These limited hours were identified as a barrier to care: “I can’t do evening hours because I don’t have staff, and I know it’s difficult for people working to come in and get testing during the workday.”

Clinical workforce capacity. Many key informants noted that their LHDs have shifted away from direct clinical service provision and depend on local clinicians to provide medical care and treatment services. Key informants identified shortages of clinical providers in rural areas as a barrier to HIV and HCV treatment. Requirements that primary care providers consult with specialists to treat HCV exacerbated provider shortages: “Even finding a PCP who interfaces with the telehealth specialist—it’s just hard to help people. There isn’t a good infrastructure in place to help individuals navigate that process yet.” Even in areas where providers were available, key informants noted challenges accessing treatment due to the unwillingness of providers to treat PWID and/or persons living with HIV or HCV. Almost all key informants shared concerns about patient confidentiality and stigma. One state-level key informant shared that these concerns are particularly prevalent in rural areas:

In terms of access, it is access or is it accessible? They might have a provider in their community but might not feel comfortable accessing that provider. Therefore, it’s not accessible to them and they need to travel to the next provider. There are far fewer [providers] in the [rural] part of the state.

Strategies for addressing staffing shortages. The primary strategy for addressing staffing shortages identified by key informants was shifting staff to areas of high need. Key informants identified “surge capacity” as coming from state-level agencies, neighboring states and counties, community-based organizations (CBOs), the Medical Reserve Corps, and the CDC. A centralized public health governance structure and funding to support travel-related expenses of public health staff were facilitators for shifting human resources to areas of high need. A state-level informant from a state with a centralized public health structure noted: “[The state doesn’t] hold back when it comes to funding people and getting hotels for folks. Because when it comes down to it, that’s a smaller expense compared to the potential consequences of not responding to an outbreak.”

Key informants from two states described using contractual arrangements with public health nurses to circumvent bureaucratic hiring processes during recent hepatitis A outbreaks, and noted that a similar strategy could be employed for HIV/HCV outbreaks. Another capacity extender described by key informants was training surveillance staff in phlebotomy so they can collect samples for testing.

Regarding treatment of HIV and HCV, key informants identified several facilitators to providing treatment in rural areas. These facilitators included the use of telehealth to deliver care and to train providers to treat HIV and HCV in primary care settings; and Ryan White funding to support access to HIV treatment services, case management, and medication.

Surveillance

Key informants identified surveillance as essential to outbreak detection, investigation, and control. However, several challenges emerged as common impediments to surveillance efforts and fell into three main subthemes: delays in detection, limited testing and investigation capacity, and lack of connection to affected populations.

Outbreak detection. Key informants in many of the study states expressed concern that HIV or HCV outbreaks may be occurring without timely detection. Informants indicated that rural areas with disproportionate rates of IDU were particularly vulnerable. Timely outbreak detection was challenged by several factors, including a lack of testing in some rural areas and among some populations, and varied jurisdiction over surveillance for HIV and HCV.

Key informants described a lack of PH capacity, particularly in rural areas, as an impediment to timely infection detection, and as one state-level informant noted:

Because resources vary widely in local jurisdictions, some of the most isolated and rural areas of the state have limited testing services for some high-risk populations and [limited] capacity to interview cases and trace contacts. This could create delays in detection of new infections.

In addition to limited local testing services and contact tracing, delays in receiving HIV data from the state impeded timely detection of new clusters. Some informants from LHDs facing such delays implied that communities could be “sitting on clusters” of undiagnosed infectious disease. One state-level epidemiologist concurred: “There’s always a delay in testing and [results] showing up...in our database. And that’s inherent to the system of how most of the states across the nation collect their HIV data.” Furthermore, key informants noted that suboptimal reporting of test results by testing entities and/or providers could lead to delays in detection.

Testing and investigation capacity. LHD key informants reported that a lack of tests, and training on how to administer them, hampered their efforts to prevent and control outbreaks among PWID in rural areas. As one leader from an LHD shared:

It is important that we be allowed to be trained on how to do rapid HIV testing so that we're not having to do a blood draw and wait a week and a half for results, because after a week and a half, I'm lucky if I can find them.

One LHD staff member described training as a barrier to administering free rapid point-of-service tests supplied by the state. Because the state was slow in providing the required training, the LHD was not able to use rapid tests, their preferred testing method. Additionally, some rural communities had no HIV and/or HCV testing capacity, so individuals needed to travel long distances to venues offering no- or low-cost testing. A state-level key informant stated:

If I have a person on my staff who identifies a contact to [test for] HIV, for example, it can be difficult to find a location in that [rural] part of the state for them to be able to get no-cost HIV testing even though they potentially have been exposed.

Many key informants viewed disease investigation as critical to minimizing the spread of disease and limiting potential outbreaks, but investigation challenges, particularly in rural areas and among PWID, were described by several key informants. One reported challenge was inadequate capacity at the state and local level to investigate each reported new case of HIV and HCV. While describing HCV surveillance activities, a state-level official noted limited capacity to conduct investigations for positive cases: "We don't have the staffing right now to create investigations for every new laboratory report we get." In one state, HIV investigations were not conducted in a timely fashion, if at all, risking further transmission. A medical provider specializing in infectious disease shared:

There's a lack of funding to these small counties for this, and to me it is extremely important. For a person to have HIV and never been asked, "Who are your partners?" is sad. And yet if they had had syphilis there would have been somebody pounding on their door, showing up at their work, the very next day. But we do not have that same robust response with HIV as we do with a positive syphilis test.

Many key informants expressed concern about rising cases of HCV, but few communities had the capacity to conduct investigations. In most of the interview states, key informants described the adverse effects of DIS shortages on their capacity to interview and conduct contact tracing among newly diagnosed cases, especially in rural areas. A state-level public health professional reported:

We would have to rely on state and federal partners to do real outbreak investigations....What I'm seeing with hepatitis C in our opioid-using population is so alarming that it's just hard to understand why there's not been a bigger response to it.

Connection to affected populations. According to key informants in all states,

investigations among the population at risk for spread of HIV and HCV due to IDU may be complicated by homelessness, transient housing situations, lack of insurance, lack of phones, lack of reliable transportation, and rurality. An epidemiologist in one state commented:

So with any disease investigation it's really easy to talk to people with a stable address, and phone bill they can pay regularly, and with insurance, and it's harder to talk to people dealing with things that make their lives more complicated than that.

Investigation among PWID may be hampered if those conducting the investigation do not have relationships with this population. As one local-level key informant stated: "If you're not really partnering with them and you're just case-counting and telling them what to do... you're not going to get very far."

Strategies for addressing surveillance challenges. Key informant interviews yielded several strategies to respond to surveillance challenges. To overcome delays in disease reporting, a key informant from a state health department educated providers about case reporting. Another state-level strategy involved cultivating relationships and enhancing communication with multiple sources, including providers, DIS, and social service agencies, to obtain information about increases in positive HIV and/or HCV tests earlier than they might otherwise.

Other key informants described the development of more timely surveillance systems. For example, one key informant praised the use of syndromic surveillance, which provides alerts in near real-time for earlier detection of clusters, before diagnoses are confirmed, in order to mobilize rapid investigative response. This state-level informant stated: "It provides us with ED [emergency department] admission diagnoses and presentation of symptoms and those types of things...it's our first line of defense."

Key informants described building surveillance staff capacity through cross-training and support from the CDC. One state cross-trained public health professionals in their infectious disease departments to be able to assist in HCV investigation interviews. LHD key informants that had received Epi-Aid from the federal CDC noted that this assistance had boosted surveillance and response meaningfully by increasing surveillance capacity as well as bringing about positive changes in local disease reporting. For example, as a result of Epi-Aid assistance in one jurisdiction, the local health care system began testing for HCV in the emergency room: "so having the oomph of the CDC is very helpful with community partners and with elected officials."

Collaboration with community organizations during surveillance activities was identified as a key strategy to more successfully reach and interview PWID. For example, in one state, when conducting contact tracing interviews, a state-level epidemiologist partnered with a staff member from a local CBO familiar with the population and geography: "What we found is that [partnership] will actually help with the individual. It helps ease the mind of that particular patient. It also helps establish a little additional rapport with them because they're talking to someone that they already know."

Access to Testing and Treatment

Key informants identified access to screening and treatment as essential to HIV and/or HCV outbreak detection and control, and described challenges to ensuring access for those at risk and affected, particularly in rural counties. Challenges to testing and treatment access included limited health infrastructure, provider shortages, stigma, and HCV treatment restrictions in state Medicaid policies. These factors contributed to low treatment uptake.

Limited health infrastructure and provider shortages. Lack of clinics and hospitals in rural areas created challenges for both LHDs and those seeking testing and treatment. One state-level health professional commented:

The rural areas that have hospitals and/or FQHCs [federally qualified health centers] are in a much better situation if they've got good working relationships to be able to draw on those assets so they can be testing for hepatitis C, they can be testing for HIV, they can be vaccinating for hepatitis A. Unfortunately, in many rural areas they have neither.

Provider shortages and limited staffing were identified as barriers to testing and treatment. One local informant noted that their local primary care provider: "will try to link folks to care if they find out they're hepatitis C positive, but they don't have the capacity to care for their patients." In some rural communities, personnel from LHDs and CBOs were unable to conduct comprehensive screening because of limited staffing:

Testing is time-consuming and we only have two testers....Since we do a lot of other things as well, it's hard; we don't prioritize general testing. If someone calls our agency to be tested, we do test because we feel it's important to do that, but we're not out there offering testing days.

Access to treatment varied between HIV and HCV with a number of key informants reporting that access to HCV treatment was more limited than HIV treatment. One key informant from a CBO noted:

HIV care is great...but hepatitis is not as easy. There are physicians that still won't treat active injection drug users for hepatitis C, so that has been hard trying to find somebody that will work with our clients. The expense of hepatitis C treatment is difficult....I want to stress how hard it is to get people with hepatitis C to get follow-up care and treatment.

Many rural areas did not have treatment facilities, requiring patients to travel long distances for their care. One key informant spoke to this issue: "Quite frankly a lot of people simply do not have the gas money or a vehicle capable of driving them 60 miles and sometimes more to the nearest place where they can get HIV or hepatitis C treatment."

Stigma. Key informants in all six study states described challenges reaching rural PWID so they can be tested and, if needed, treated for HIV and/or HCV. The most commonly identified barrier was stigma, which contributed to the reluctance of PWID to get tested locally for fear of a lack of anonymity, which was particularly difficult in rural areas with limited access to testing services. One key informant from an LHD shared: “[People] feel like if they can go over to [a different] county nobody’s going to know them and they can get a test. Remember, we are a very, very small community.”

Although mobile clinics and SSPs were described as expanding access to testing services, some key informants noted that mobile units might not provide the same anonymity as brick and mortar clinics and SSPs. While discussing the advantages of having both brick and mortar and mobile testing sites, a state-level public health professional shared:

Mobile seems like it’s a convenience for people—but it may not be that long a distance to travel and a fixed site has more hours, and you’re not seen going in and out of a mobile unit and everyone knows what it’s for.

Medicaid and provider barriers to treatment. Key informants from several states noted state Medicaid and provider-specific policies that posed significant barriers to treating patients with HCV. Specifically, key informants mentioned sobriety requirements for both rehabilitation and HCV treatment, and fibrosis staging requirements for HCV treatment as barriers to treatment: “The biggest challenge was the fact that somebody had to be sober for seven days before they could get into the program.” In states that did not have these requirements, patients faced fewer barriers to testing and treatment.

Strategies to improve access to testing and treatment. Key informants described a mix of strategies to improve access to testing as well as uptake of testing and treatment among affected populations. These included telehealth, community outreach (including mobile units), service integration, and patient navigation. Many viewed increased access to testing and treatment as key to outbreak prevention and control, and as one local-level key informant noted, “We have better access to care, which is in turn treating people for hepatitis C and HIV so they’re non-transmittable.”

Telehealth was used to train or support providers so they could deliver specialty care needed for HCV, HIV and MAT. A state-level key informant shared that use of telehealth meant: “those folks in more rural areas can still get access to specialty or primary care without needing to physically travel two or three hours to see them.” Key informants also described new federal funding in support of telehealth-enabled MAT services as a facilitator to increased treatment uptake among PWID.

Key informants in many states mentioned outreach to affected populations—via CBOs, Community Health Workers (CHWs), or mobile units—as an essential part of ensuring access to testing and treatment. Community outreach workers were deployed to areas where affected populations could be reached and where IDU was more prevalent: “It’s basically meeting the people where they really are, literally and figuratively.” Several key informants emphasized the importance of CHWs or community organizations that may have

relationships with PWID to build trust and encourage testing and treatment. Others mentioned testing in other settings such as EDs. For example, in one state, recovery coaches were positioned in hospital EDs to help navigate patients to testing and treatment.

Key informants in several states viewed mobile units as a promising strategy, particularly in rural areas. Some mobile units were full-service health centers, while others focused on syringe exchange or other harm reduction services. Key informants also identified several strategies for lessening stigma, including harm reduction trainings for individuals serving affected populations. In some communities, CBO staff accompanied clients to provider appointments to facilitate communication between provider and patient to ensure that patients receive needed care.

Some key informants identified service integration, co-location of services, and patient navigation as means of improving access among at-risk, rural populations. For example, local organizations integrated education and counseling about SUD services, HIV and HCV testing, and treatment into their clinics (including mobile clinics) and helplines: “Because we know that hepatitis C is often intersecting with mental health and substance use disorder. They have resources in there for that.” In another example of service integration, key informants described SSPs providing a range of services that at-risk populations may need:

Making sure that they're integrated so they're not doing just syringe services as a silo—most of those programs also do work with regard to testing or navigation into hepatitis C testing and treatment...overdose prevention and naloxone distribution, [and] HIV testing.

Resistance to Harm Reduction Services

Although key informants from every state described SSPs as a promising strategy for strengthening efforts around HIV and HCV prevention and testing, several interviewees shared that some community members, elected officials, and law enforcement professionals key to the establishment and sustainment of SSPs were resistant to harm reduction services. Key informants identified several factors driving resistance to harm reduction services in rural areas: stigma surrounding IDU, HIV, and HCV; the belief that drug use is a criminal issue, rather than a medical or public health issue; and the opinion that SSPs enable drug use.

Establishing SSPs. Several key informants commented on the difficulty of establishing harm reduction programs, including SSPs. Approval processes varied depending on location and state public health governance structure; among states with decentralized public health governance structures, it often involved working with local boards of health, and state, city, and county governments. There was variation across states, counties, and municipalities in the policies regulating the items SSPs can distribute (i.e., needles, syringes, cookers, sterile water, fentanyl testing strips), where they could be located, hours of operation, and other aspects of program design (i.e., needs-based versus one-for-one exchange models, caps on the number of syringes that can be distributed, and residency requirements for SSP clients). Key informants shared that in many instances the government officials approving SSPs and

developing SSP regulations did not have a public health background. A key informant from an LHD shared: “Our county commissioners—they’re not experts in health, or rural health, or disease intervention, so...a lot of education has to be done and sometimes you’re just not going to change people’s mind.” Another LHD interviewee described removing needles from harm reduction kits to conform to county regulations about needle distribution. Others described limits on SSP hours of operation as short as three hours per week.

Law enforcement professionals. Key informants described law enforcement resistance to harm reduction services both during the SSP approval process and after SSPs were established. While discussing the efforts of Sheriff’s departments to curtail the establishment of SSPs, a state-level key informant shared, “In some counties they’ve been successful in preventing the establishment of a syringe exchange program....They see it as a drug problem, not a public health problem.” Two local-level key informants identified the presence of law enforcement outside SSPs as a deterrent to service use: “If you don’t have a good relationship with local law enforcement, they sit outside a syringe exchange site and no one comes.”

Strategies to increase acceptance of harm reduction services. Many key informants described efforts to increase acceptance of harm reduction practices by educating stakeholders and community members about services provided by SSPs and the impact of stigma related to HIV, HCV, IDU, and MAT. One LHD key informant shared:

We’re going to take [a presentation about harm reduction] to the Board [of Health] and hopefully get their buy-in, because they are not real supportive of doing a whole lot of this. But it’s because they don’t understand [that] it’s more than handing out needles.

Harm reduction trainings for police officers, particularly ones led by retired law enforcement professionals, were identified as a promising practice; “you pretty much have to have buy-in with law enforcement....We work with a lot of retired police officers that help with the promotion of harm reduction in the state.”

One key informant stressed the importance of cultivating a champion with political clout to support and lobby for the establishment of an SSP, including advocating for changes in laws and regulations when they hamper the establishment of an SSP. Several key informants emphasized the importance of including community stakeholders from different sectors in the planning process. A key informant from an LHD shared their experience:

Before we started our harm reduction program one of things we did is we pulled together all the key players. So I had ministers there. I had my EMS director there. I had as many law enforcement officials as I could get there. I had county commissioners, mayors, anybody that I thought would be a mover and a shaker with this particular program I had in the room. I showed them what our hepatitis C rates were. We discussed what that meant for us and how that happened—how everything

took place in Scott County, Indiana—and gave some examples of what harm reduction programs looks like, what type of information they collect.

Key informants from states with centralized public health governance structures described centralization as a facilitator of SSP establishment:

There's a different political environment in a lot of places so in more conservative communities it's a little harder to get a lot of support for harm reduction. Given that we, though, can provide those services in our health offices, we can operate regardless of [a location's political] environment.

Discussion

Findings from key informant interviews in six rural states identified as potentially at risk of an HIV or HCV outbreak among PWID suggest that because of funding, health care infrastructure, staffing, and other factors, rural communities may have limited capacity to prepare for, identify, control, and respond to a potential HIV and/or HCV outbreak associated with IDU. Capacity deficits in some rural communities were attenuated by centralized public health systems that equalized response capacity across their rural jurisdictions. Key informants from states with more decentralized public health systems, noted that local control over the public health agenda, programs, and services resulted in substantial variation in the capacity of their rural communities to respond.

This research describes challenges encountered in rural areas as well as strategies and promising practices underway to prepare for or respond to infectious disease outbreaks accelerated by increased IDU. For example, because of inadequate public health and health system capacity, some states deploy staff temporarily to other areas to assist with the response. States and LHDs are addressing surveillance and investigation challenges through cross-training staff and implementing strategies to improve timeliness of data reporting. Some states noted the success of collaborating with community partners to reach PWID for contact tracing. To address limited access to testing and treatment for HIV, HCV, and SUD in more remote rural areas, public health agencies have deployed mobile units that can deliver services where they are otherwise not available. Others have used telemedicine to provide rural patients with specialty services and support primary care doctors treating patients in need of more specialized care. Rural communities have also used education initiatives, technical assistance, and community coalitions to overcome resistance to evidence-based harm reduction programs.

Key informants working in health and human services noted that funding challenges and public health infrastructure inadequacy are impediments to building the needed capacity to meaningfully counter public health vulnerability in rural communities, particularly where IDU is prevalent. Despite these challenges, a variety of innovative approaches were being used by rural communities to prepare for and address the threat of infectious disease outbreak due to IDU.

Conclusion

Key informants with knowledge of rural LHDs in areas that may be at risk for an HIV and/or HCV outbreak reported insufficient public health capacity to prepare for, detect, and respond to potential outbreaks given declining budgets, reduced staff, and few resources devoted to the health needs of PWID. Despite these limitations, many rural counties demonstrate creativity, resilience, and perseverance. Rural and state health departments can learn from each other through the sharing of promising practices and strategies to overcome these challenges.

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