"If You Could Wave a Magic Wand": Treatment Barriers in the Rural Midwest

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ABSTRACT

INTRODUCTION: The multigenerational health considerations and negative economic impacts related to the opioid epidemic are many. Increasing numbers of opioid-related fatalities are bolstered by barriers related to access to evidence-based treatment. Ohio is ranked second in the country for number of opioid-related deaths, and for many their treatment needs remain unmet due to impaired access to effective treatment, in rural, medically underserved areas of the state.

PURPOSE: The goal of this study was to assess opioid use disorder treatment barriers in order to increase access to evidence-based treatment, wrap around services, and harm reduction efforts to support the reintegration of persons with substance use disorder back into society and subsequently reduce opioid fatalities in a rural, medically underserved region of Ohio.

METHODS: As part of a larger mixed-methods study design where a community health survey was randomly distributed to residents in a rural county in Ohio, this study used qualitative methods to triangulate findings. To supplement the data received from the surveys, 20persons with a diagnosed opioid use disorder (OUD) took part in focus group sessions guided by trained researchers. The sessions were transcribed, and the data was analyzed using Braun and Clarke's thematic analysis method.

RESULTS: Three major themes emerged from the data: epigenetics and exposure, management of disease including re-integration into society, and disease process. The participant data created insight regarding the need to recognize OUD as a chronic condition that must be addressed with integrated components of medical, behavioral, and mental health morbidities throughout the lifespan and across generations.

CONCLUSIONS: Findings from this study support the need for targeted interventions for integrated care and improved wrap around services such as transportation, sober living, and employment.

KEYWORDS: Substance abuse, substance misuse, opioid epidemic, harm reduction options, medication assisted treatment (MAT), opioid-related supports, addiction

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Introduction

The opioid epidemic has had devastating mortality and economic consequences across the United States for the last several decades. In 2017, 47 600 opioid-related fatalities occurred nationwide, continuing to increase from 33 091 in 2015 and 42 249 in 2016.[1,2] The Centers for Disease Control and Prevention (CDC) have noted these drug overdose deaths as a particular contributor to recent life expectancy losses. Unintentional injury deaths, mostly due to drug overdoses, have increased among people ages 15 to 64, and life expectancy across all races and sexes has dropped from 78.9 to 78.6 since 2014.[3] This crisis is also having a distinct impact on hospital and emergency services. In 2014, medical problems related to opioid use represented 1.27 million hospital visits. Hospitalizations related to opioid pain medications and heroin increased by 64% and emergency department visits doubled from 2005 to 2014, resulting in insurance costs of over $72 billion (not including substance use treatment programs).[4,5] A variety of further economic impacts have been noted, including those related to work productivity, the criminal justice system, and family and child services costs.

Ohio has been particularly affected by the opioid epidemic. In 2017, Ohio was ranked second in the nation for rate of opioid-related overdose deaths with 4293 fatalities reported, representing a rate of 39.2 deaths per 100 000, which is more than 2.5 times the national average of 14.6 per 100 000.[6-8] In Ohio, the number of opioid prescriptions is higher than the national average with 53.5 prescriptions per 100 persons, some counties reporting up to 89.2 opioid prescriptions per 100 persons.[8,9] Due to the multifactorial, multigenerational inheritance of addiction and substance use disorders, Ohio also reports higher rates of neonatal abstinence syndrome (NAS), HIV, and hepatitis C than respective national averages. Given the complex and far-reaching impact of OUD, it is imperative that integrative care models supporting evidence-based treatment and resources be supported to mitigate the fallout of the opioid crisis.

One region in highest need of attention for opioid-related considerations is Highland County, Ohio, a rural, medically

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underserved area (MUA) that suffers from a lack of much needed services including harm reduction options, medication assisted treatment (MAT), and other opioid-related supports and treatments that serve the client as well as the family. For example, harm reduction services such as needle-exchange and condom distribution have been slowed due to stakeholder buy-in and narcotics anonymous support group schedules and options are difficult to locate.

Located approximately an hour's driving distance from Portsmouth, Ohio, ranked by the CDC as #196 of the top 220 counties at highest risk of HIV and hepatitis C from injection drug use, Highland County is on the Appalachian frontline. Per the county health department, hepatitis C infections in particular increased by more than 100% from 2010 to 2015,[10] 400% in 2016, and 800% in 2017. Surrounding Appalachian counties also in the top 220, include Adams County (#51), Clinton County (#190), and Pike County (#72), and are served by critical access Highland District Hospital (HDH).

The overarching goal of this mixed methods study was to assess, plan and coordinate services that increase utilization of evidence-based treatment, wrap around services and harm reduction resources in rural, medically underserved Southern Ohio. Specifically, we aimed to:

1. Identify and bring entities together in partnership to ensure care coordination and optimization of resources.
2. Increase access to care including medication assisted treatment (MAT).
3. Prevent the spread of infectious disease in people who inject drugs (PWID).
4. Decrease bias through community education.

Methods

After obtaining Institutional Review Board approval from the University of Cincinnati quantitative data was captured through a community health survey that was completed by 173 community members. To elicit additional information about challenges and better understand community resources and needs, focus group data was integrated and interpreted providing a better understanding of treatment utilization and gaps.

Data collection

Focus groups are a form of qualitative data collection, often used when a researcher wants to receive insights into the experiences of a particular group or subgroup.[11,12] As a research method, focus groups encourage active conversation and exchange of viewpoints between participants; they also do not exclude those with literacy concerns as quantitative research often does.[12] Participants also may feel that they are able to speak more freely in the private space of a focus group than in other settings.[13]

Focus groups are particularly useful in research with prisoner and substance use populations. Because prisoners are considered a vulnerable research population, they may be at risk of coercion and researchers may not be able to ensure privacy or confidentiality.[14] However, by using focus groups, power is shifted away from the researcher, granting the participant a higher level of autonomy and control over how much information is shared; this is also why focus groups are valuable for research with marginalized populations in general.[15] Within the substance use population, individuals may be used to discussing thoughts and feelings within small group settings due to the common use of group therapy in substance use treatment,[16] as well as attendance at 12-step programs such as Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) where sharing personal experience is encouraged. Focus groups are extremely valuable in gathering data about these populations as members may not have other opportunities to voice their concerns and needs.

The first and second author have experience in research regarding substance abuse and worked with the research team to develop a semi-structured interview guide to be used in the focus group sessions. The guide consisted of 1 overarching question, and 3 follow up questions to be used if the conversation was not fluid. The first question was, "If you could wave a magic wand and create any treatment or support services, what would you need to support your recovery?" Participant data was rich and focus groups only utilized the first, so the additional questions on the focus group guide were not used.

A total of 20 participants, 14 males and 6 females, with a diagnosed opioid use disorder (OUD) were recruited from detention centers and treatment settings in Southwestern Ohio. Inclusion criteria included diagnosis of opioid use disorder or self-disclosed opioid use disorder. Informed consent process included self-identification of the research team, a discussion of anticipated uses of the results of the focus group data, and a statement that participation is completely voluntary and that at any point they could leave the discussion group, and their comments would not be included in the data. Participants were also informed that their participation would have no effect on their release date or parole eligibility if incarcerated or their treatment if receiving medical treatment.

A total of 4 focus groups were conducted. About 1 all male focus group at a detention center, 1 female focus group at a detention center, 1 focus group with males participating in sober living, and 1 mixed-sex focus group. Focus group discussions ranged from 60 to 90 minutes, until saturation occurred. Because the scope of the focus groups was to provide insight into general treatment barriers in the region, the research did not collect demographic data on the participants.

Data analysis

In order to determine viewpoints about services, needs, and OUD incidence in the region, researchers utilized Braun and Clarke's thematic analysis method. Thematic analysis is a process of actively identifying and reporting on themes within a

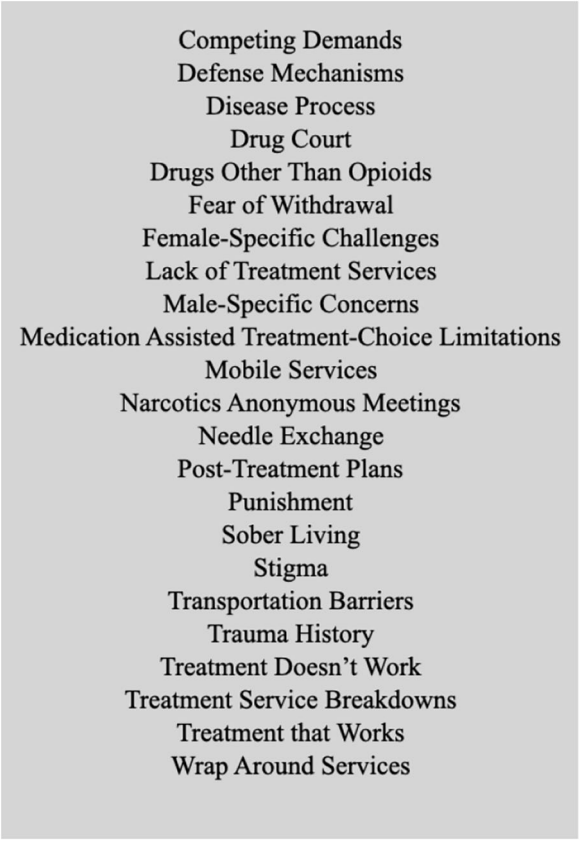

Figure 1. Focus group participant suggestions to decrease OUD treatment barriers.

qualitative data set. In thematic analysis, themes are identified in 1 of 2 ways: inductive ("bottom up") or deductive ("top down") way. In the former, identified themes are linked closely to the data itself, such as information gathered via focus group, and may not be closely related to the initial research question. In the latter, thematic analysis driven by more the researcher's interest and may result in a more focused look at specific components of the gathered data.[16] Because focus groups were conducted as a component of this project, an inductive thematic analysis was done to determine themes within the gathered data.

Focus groups were audio recorded and transcribed. Transcripts were uploaded to NVivo® for data analysis. The first and second author have expertise and experience in qualitative methodology and thematic analysis. The research team read each focus group transcript in its entirety, then convened inductive thematic analysis. The first, second, and third authors convened to Phase 2: *Generating Initial Codes*, which yielded 23 descriptive codes (Figure 1).

During Phase 3: *Searching for Themes*, the research team continued looking at patterned responses across transcripts, in addition to collapsing initial descriptive codes. Direct quotes were populated to support each of the identified themes. All potential themes were discussed among the data analysis group until recapitulation of the initial data had occurred (Phase 4). During Phase 5: *Defining and Naming Themes*, the team defined all themes and produced the report for the final phase of the thematic analysis. This process resulted in a federal implementation grant that utilized all findings to direct a response to the opioid epidemic in rural Ohio (Phase 6: *Producing a Report*).[17]

Results

Thematic analysis resulted in 3 major themes and 8 sub-themes after recapitulation of the initial data. Findings illustrate the complex, multigenerational, chronic nature of addiction and the need for an infrastructure that supports the client, the family unit, the community, and aligns the healthcare system and legislation. While individual responses varied when asked, "If you could wave a magic wand and create any treatment or support services, what would you need to support your recovery?" there was much overlap in the description of the current "revolving door" response to manage addiction. The majority of participants described multiple brief detox experiences while in detention centers but were released to the same community surrounded by the same experiences without long term linkage to evidence-based treatment for opioid use disorder. Patterns from transcripts revealed the 3 major themes and are described below.

Theme 1: Epigenetics and exposure: Interplay of genetics and the environment

Throughout all transcripts, participants described the familial linkage and home environments that contributed to emotional pain, anxiety, depression, and other vulnerabilities. Participants described using drugs as a means to self-medicate and cope with daily struggles. *"Pain killers, opiates, they take away your pain physically and emotionally."* Some began using opioids to treat chronic pain conditions. *"I have anxiety disorders, I have nervous ticks, when I use it takes them away."* Others described being exposed to opioids and other substances by parents and family members at an early age. *"I cannot be around my family. My mom uses, and my dad."*

Theme 2: Management of disease including re-integration into society

Participants described disease management problems including re-integration into society. For example, the longer they had been living with their addiction and functioning on the periphery of the community, difficulties and familiarity with how to function in society became greater. Data within theme 2 resulted in 8 sub-themes.

Sub-theme 1: Stigma. Participants discussed stigma and bias surrounding addiction and described the importance of educating the community to better understand addiction and treatment. "*Educating people in addiction is really important. They're not accepting of it. . .They don't have a problem. They'll never believe you do." "Until [it happens to] somebody they care about and then they begin to realize what it really is."*

Sub-theme 2: Medication assisted treatment service limitations. Participants spoke of the value of medication assisted treatment collectively and each tenet. *"That's what they should do. Medication and treatment." "I remember when I was on it [Vivitrol®], I didn't really think about using." "I just really didn't care about using drugs."* Others emphasized how important the counseling component of medication assisted treatment was to their recovery. Participants discussed the limitations in their community for MAT choices. Participants emphasized the need for more OUD treatment services. *"[This] county might need a wider range like a methadone clinic. . .and Subutex® injections."*

They talked about people who were forced to travel to other parts of the state for inpatient treatment and described a long wait time for these services. They discussed the limited access to medication assisted treatment (MAT) and "detox" facilities. *"I had them accept me over the phone, and my wife drive me [to another city], and when I got there, they denied me. I had my suitcase and everything." "Took forever."*

Conversely, some participants believed MAT was replacing 1 drug with another drug and reported getting "high" from suboxone. They also spoke of the abuse potential and the aftermarket sale of buprenorphine® tablets. *"They're giving you 30-50 Subutex®. You can sell them. You can trade them."*

According to participants, narcotics anonymous (NA) support group meetings are fewer than in urban areas and transportation to these meetings is often problematic. Some attend AA meetings, but again emphasized the lack of meetings compared to urban areas. Many preferred NA meetings to AA meetings because the perceived age of NA attendees in their area was younger than AA attendees. Most participants were unfamiliar with virtual NA meetings but were interested in this option. There was also concern that in such a small community, where there is a lack of anonymity, attending meetings threatens privacy. *"We need more NA."* and *"There are only 2-3 NA meetings per week." "Different age groups, different kinds of people [in AA vs NA]."*

Sub-theme 3: Post treatment plans. Participants discussed feeling unprepared for a life after treatment. *"We have no plan."* They expressed a need for help with high school diploma equivalencies, finding a job, finding a place to live, and help with learning how to budget and pay bills. *"A lot of us don't have GEDs." "[We need] somewhere that helps you get a job."* Participants reported that returning to their home environment was concerning with its concomitant triggers. Inpatient treatment group participants built strong, supportive relationships with each other and worried that returning home, instead of a sober living environment, would disrupt their support system. *"Sober living where you are in a safe, secure pace, right, and you have a chance to go out and work or go to college and learn a skill, that sort of thing." "The biggest help for me has been the 10, 12 guys in the house. We support each other. We got each other; we push each other to be clean." "If you could go into a house with four or five guys from your group and have clean and sober living that was supportive, would that be something!"* Participants also stated that a felony record can prevent placement in sober living, creating another barrier for receiving effective treatment.

Sub-theme 4: Competing demands. Participants described the difficulty in balancing normal daily activities such as employment and childcare with treatment requirements. *"Yeah, you got so much on your plate, trying to stay clean and then you put all that [on it]." "And they want me to go to treatment 3 times a week, see the judge every two weeks. That's too intense." "I didn't like counseling because it interfered with my job."* It was noted during female focus groups that women discussed loss of parental rights and managing children, but this was not brought up as a specific concern for males. *"How you gonna feed your kids?"* was a driving concern for mothers.

Sub-theme 5: Transportation barriers. Participants discussed difficulty in getting to work, treatment, and support group meetings because there is no public transportation in their rural community. *"You can't get a job because you don't have a car. You can't get a car because you don't have a job."* Transportation poses significant barriers that need to be considered when providing care for this population.

Sub-theme 6: Treatment service breakdowns. Participants described breakdowns in treatment services while navigating healthcare. For instance, when transitioning into a hospital, there may not be providers available to support MAT continuation. *"I was hospitalized, and I had a bad infection. I couldn't get Subutex® from the hospital.. . .sent to the extended care facility on pain killers."* There was discussion of opioids being prescribed—even after disclosing opioid use disorder without a pain management plan. Participants also noted a lack of communication between their primary care service providers and addiction treatment providers. The lack of continuity of care decreases patient outcomes.

Sub-theme 7: Treatment that works. Participants discussed the need for mental health counseling. *"We work on our thinking. Cognitive change all the time." "You practice situations with friendships. . .Different relationships. This prepares you for real life." "I work on my criminal thinking every day. . .I'm 25, I've been selling drugs since I was ten."* Some talked about using drugs to cope with traumatic events in their past and how counseling has helping them. *"I'm sure I have mental health issues, but I've never been [diagnosed]."* Treatment initiation and maintenance were discussed in the focus groups. For example, many participants were receiving services because of the County drug court. They felt they benefited from the structure in their lives and could find it in prison or inpatient treatment but could not maintain it without guidance. They expressed a need for developing coping skills and tools to deal with everyday struggles that would

help with the long-term recovery. Participants also identified the importance of sponsors.

Sub-theme 8: High-risk behaviors. Participants discussed the need for clean syringe exchange services and related testing and harm reduction measures in the county and reflected on the ongoing risks in their community. Several described groups passing the same syringe around in a manner analogous to sharing marijuana. *"They will pass a needle like a joint." "[syringe sharing occurs] all the time."* They also talked about the unprotected sex among those using methamphetamines. *"It's not just the needle, it's the sex too." "The sex with meth is crazy."* Participants described the complexities of managing sepsis, spinal abscesses, complications related to Hepatitis C, and heart valve replacement due to infections from re-using syringes.

Theme 3: Disease process

Participants described the desperation to feed their addiction, and their fears of being "dope-sick" with a lack of "detox," especially in the criminal justice system. They also spoke of fear of withdrawal from suboxone®. One participant shared how he melted snow and mixed dirty water with heroin in desperation to get "high." They described the need to stave off withdrawal as all-consuming. Several described criminal activities, especially stealing, in order to obtain drugs and prevent withdrawal symptoms. *"A lot of its hustling, selling drugs." "If you're going to go get dope. . .there ain't a barrier." "You gotta steal a car. Or a bike."* Many spoke of substituting methamphetamines for heroin if heroin was not readily available.

Discussion

Evidence supports that substance use disorder is attributed to both genes and environment and the interplay of the 2.[18] The goal of this study was to gain a better understanding of environmental considerations in the community that support evidence based treatment and resources, and identify barriers to services currently offered such as syringe programs to decrease the risk of diseases such as HIV.[19] The present study highlighted that the underlying thread of all of respondent discussion was the need to recognize and manage addiction and opioid use disorder (OUD) as a chronic disease. The ability to manage chronic disease has been linked with health literacy. Surprisingly, "only about 1 in 10 have the skills needed to successfully navigate the healthcare system."[20] The complex care associated with addiction treatment requires integrated components of medical, behavioral, and mental health aspects throughout the lifespan and into the next generation. Brief attempts supporting detox alone are not adequate.[21]

The thematic analysis of data collected in this study's focus group sessions with (N = 20) participants uncovered barriers at all levels of the client, community, healthcare system, and policy that must be addressed to meet the complex needs of individuals and communities suffering from addiction.[22] The lived experiences of those with OUD in prisons and inpatient care settings specifically provide insight into the problems and barriers regarding managing this chronic disease effectively-when treatment services are limited and support services such as transportation, sober living, and employment are inadequate. Interventions should exist at all levels so that informed communities can support integrative healthcare and support services that respond to the cyclic and chronic complexities of addiction and OUD.

A cost-effective approach that participants identified included the use of cell phones for services that are not offered in rural Ohio. Participants stated that regardless of their income they always had a cell phone in their possession and would benefit from services and interventions that utilized their phones. The only time participants describe not having their phone is while in jail. This finding is supported by the use of technology to manage other chronic diseases.[23] Participants also liked the anonymity of receiving services outside of their small community and felt that video conferencing could be a good way to improve service reach, such as attending virtual narcotics anonymous groups and working with peer mentors who didn't previously know about them in the community.

There are several limitations to this study. The first limitation is the risk for selection bias among participants, who agreed to participate in this study, given the protections of the study population, the research could not determine population characteristics. The next is the risk for reactivity; the phenomenon where respondents may have answered in a certain way because they were involved in a study and being observed. While a sample size of 20 participants has potential to be a limiting factor, the quality of information obtained and overlap of themes in relation to the quantitative survey supported saturation. Despite these limitations, there is support to believe that results are transferable to other populations in rural, medically underserved areas.

Conclusion

This study aimed to identify resources and barriers to recovery that persons living in rural, medically underserved areas experience. Results from the qualitative focus group interviews support the need to align services across the community and healthcare system, in partnership with government and legal entities to address the current "revolving door" response to the long-term treatment and management of addiction, mainly opioid use disorder. Policymakers, including healthcare stakeholders, should advocate for continued allocation of funds supporting more resources, and the integration of current resources, in medically underserved areas. An overall integrated healthcare approach for chronic disease management should serve as the framework for all initiatives, as evidence supports the clear need to manage comorbidities and multigenerational effects. A comprehensive treatment plan that addresses mental, behavioral, and medical

care for the family, within the context of the environment is critical to supporting recovery.

It is recommended that future interventions in rural Appalachia include more mobile services, including telehealth, and wrap around services like transportation and childcare assistance. Educational initiatives should address bias and stigma in the community and inform persons with OUD and providers about evidence-based treatment options for managing withdrawal symptoms, general information about the disease process, and how to navigate the healthcare system. Findings from this study support the recommendations to Appalachian county leaders from the Appalachian Regional Commission; (a) Create and Strengthen Preventative and Educational Initiatives, Expand Access to Addiction Treatments, and Implement a Criminal Justice Response to Illegal Opioid Sales and Provide Treatment and Services to Justice-Involved Individuals with Opioid Use Disorders.[24]

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Author Contributions

AC, JL-R, and JS equally contributed to the study, data analysis, and writing of the manuscript. All authors approved the final manuscript.

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