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Qualitative Brief: Perspectives on Opioid Use Disorder Treatment Access and Engagement from Rural Family Members and People in Treatment

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Background

The mission of the University of Vermont Center on Rural Addiction (UVM CORA) is to expand substance use disorder treatment capacity in rural areas by providing consultation, resources, training, and evidence-based technical assistance to rural healthcare practitioners and community organizations. Our Vermont baseline needs assessment aims to identify current and future addiction treatment needs and barriers in Vermont with direct input from practitioners, community partners, and people impacted personally by opioid use.

In the qualitative phase of our Vermont baseline needs assessment, in collaboration with the University of Southern Maine's Substance Use Research and Evaluation (USM SURE) Unit, we interviewed two groups of people living in rural Vermont: First, people who were receiving medications for opioid use disorder (MOUD; "people in treatment") and second, family members of people who were receiving MOUD and family members of people who were actively using illicit opioids and not receiving MOUD ("family members"). Family member interviewees were not related to the people in treatment who were interviewed.

There was substantial overlap in the feedback we received from people in treatment¹ and family members, as well as some important nuances and differences in perceptions. This Data Brief focuses primarily on the feedback related to treatment access and engagement received from family members noting overlap with, and key differences from, the feedback received from people in treatment. The exemplar quotes included are only from family members.

Methodology

We conducted semi-structured qualitative interviews using a guide based on previous qualitative work done by USM SURE with similar populations, our quantitative baseline needs assessment survey, ² input from UVM CORA faculty, staff, and clinicians, and

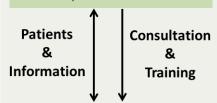
Vermont uses a Hub and Spoke model
to provide treatment with medications for
opioid use disorder (MOUD).

This system of care emphasizes coordination between **Hub** sites, which generally offer more comprehensive and intensive services in *clinic settings*, and **Spoke** sites, which offer lower-intensity MOUD treatment in *office-based settings*.

See: https://blueprintforhealth.vermont.gov/about-blueprint/hub-and-spoke

Hub I

- Outpatient clinic settings (Opioid Treatment Programs)
- MOUD initiation, intensive treatment
- Offer methadone, buprenorphine, and naltrexone
- Regional locations throughout VT
- All staff specialize in OUD treatment





- Office-based settings (primary care)
- MOUD maintenance, lower-intensity treatment
- Offer buprenorphine, naltrexone
- Lead provider, nurse, SUD counselor

feedback from community partners. Family member interviews focused on interviewee perspectives regarding their loved one's OUD treatment plan, challenges related to accessing and engaging with MOUD treatment, and potential gaps in OUD treatment or recovery services within the community. Interviews were conducted via Zoom by experienced staff from UVM CORA and USM SURE (September 2021 – December 2022). The average family member interview length was 40 minutes. Interviews were transcribed verbatim using a HIPAA-compliant transcription service and analyzed using NVivo 20[©]. The study team conducted

¹ See: University of Vermont Center on Rural Addiction (2023). Vermont Baseline Needs Assessment Qualitative Report: Opioid Use Disorder Treatment Experiences in Rural Vermont; available at: uvmcora.org/data-reports.

² See: University of Vermont Center on Rural Addiction (2021). Vermont Baseline Needs Assessment: Rural Practitioners and Stakeholders; available at: uvmcora.org/data-reports.



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thematic analysis using traditional qualitative methods based on a grounded theory approach. Transcribed interviews were coded through an iterative process with codes drawn from the text and frequent comparative analysis.³

Respondent Characteristics

Family member interviewees (n=20) identified as white (100%), non-Hispanic (100%), and female (95%), with a mean age of 51 years, and reported living in 8 of the 13 rural Vermont counties. Most family members were parents discussing their adult child or children, although a few described their relationship to their loved one as sibling, partner, or adult child discussing a parent. Approximately one fourth of interviewees reported having more than one loved one with OUD. At the time of screening, 12 interviewees identified as a family member of a person receiving MOUD while 8 identified as a family member of a person actively using illicit opioids and not receiving MOUD.⁴

Access to Opioid Use Disorder Treatment

Facilitators to OUD Treatment Access

Interviewees in the family member and in-treatment groups agreed on several factors that facilitate access to treatment for OUD. For example, both groups agreed on the importance of quick and easy access to OUD treatment services (e.g., MOUD, residential) and supports, and shared how access barriers can prevent individuals from initiating treatment when they feel most ready.

Family member and in-treatment interviewees also agreed on the importance of reliable transportation (particularly a personal vehicle); easier and more available access to contact information to request treatment or counseling; childcare assistance; stable housing; access to technology (e.g., phone, tablet); peer and family support; health insurance coverage; and substance-free environments.

"We have some resources out here where a lot of times, if people want to get on [MOUD], they can have a prescription almost by the end of the day."

"I was driving her at first, and then she started to get the Medicaid ride because I couldn't do it every seven days a week."

"I think being with probation, it can give you a good start to a decent support team, like a support network if needed." There were also differences between interviewee groups. Regarding insurance, family members focused on access to insurance coverage for residential services while people in treatment focused on insurance coverage for MOUD services. Additionally, while both groups described the justice system as an access point to receive MOUD, and noted barriers to treatment within the correctional system, some family members remarked that the correctional system is a missed opportunity to provide an array of SUD services.

Barriers to OUD Treatment Access

There was widespread agreement among family members and people in treatment that lack of reliable transportation or transportation costs and long wait periods or lack of immediate access to preferred treatment sites (e.g., residential, primary care) are barriers to treatment access.

³ Corbin, J., & Strauss, A. (2014). Basics of quality research: techniques and procedures for developing grounded theory. Thousand Oaks, CA: Sage Publications.

⁴ The treatment status of the family member with OUD was sometimes described differently at the time of interview, i.e., some who reported family members as not in treatment at screening were later described as receiving MOUD during the interview.



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People in treatment also discussed lack of childcare services, the complicated administrative processes associated with entering treatment (e.g., application, paperwork, multiple interviews), and the clinic's time requirements as barriers to treatment access. While these concerns were discussed less often by family member interviewees as barriers to treatment access, some family members described taking on childcare or guardian roles and assisting their loved ones with transportation to appointments. Some family members described the lack of available residential treatment beds as a major access barrier.

"Transportation,
homelessness, availability
[of] communication
devices, could all block
someone from being able
to access treatment."

Family members and people in treatment focused on different aspects of health insurance and cost concerns. Family members generally placed more focus on lack of health insurance or inability to pay for treatment services as well as difficulty using Medicaid insurance to cover out of state services. People in treatment tended to focus on the steps involved in obtaining Medicaid insurance or the cost-sharing associated with commercial health plans and fear of losing Medicaid coverage.

Some family members noted the isolating nature of OUD for their loved one, as well as their own isolation related to this experience. Family member interviewees described lack of community support and difficulty finding resources as barriers to treatment access and expressed need for community-level support (e.g., counseling, family services) for their loved one and the entire family.

Finally, both people in treatment and family members described the stigma experienced by people with OUD and its impact on access to and quality of health care services. Both groups described concerns about a lack of anonymity when trying to find help or access services in rural areas.

"There was not a whole lot of support for family members. We're trying to support our family person and you don't know where to go for resources.

Since then, I have done my own research and I have a boatload of information and resources at my fingertips, but when you start off and your family member, your son, your daughter, your husband, your spouse, whatever—it is overwhelming."

Opioid Use Disorder Treatment Experiences

Facilitators to Treatment Engagement

Both people in treatment and family members identified insurance, stable housing without exposure to illicit substances or others in active substance use, access to safe and reliable transportation, awareness of available resources in their community, and welcoming and supportive providers as facilitators to ongoing treatment engagement.

"Stability is how you stay sober. I mean, housing is a big part of recovery— if you're not sober and you're not—if you don't have a stable home— then you're not gonna be stable in your recovery."

Family members emphasized the benefit of having private insurance coverage for out-of-state treatment services (i.e., residential treatment not covered by Vermont Medicaid) as a facilitator to

"[People] going into treatment are— They're okay with having a little team to be able to talk to each other and work with each other, and— So just remembering that, kind of like the old saying, 'it takes a village.'" "I think that being able to meet someone's basic needs and then allow them that safety and comfort to work on themselves and those challenges that they are experiencing right along with their substance use disorder is really, really life changing to me. I think that would be a huge help."



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their loved ones' treatment engagement. Family members also discussed stable employment, childcare assistance from family members (e.g., grandparent caring for a grandchild), transitional housing, continued treatment upon release from incarceration, and strong social and family support as facilitators to continued treatment engagement.

Barriers to Treatment Engagement

Family members and people in treatment described similar barriers to maintaining engagement in treatment, including lack of stable housing, lack of transportation, and their perception that people and places can greatly impact experiences within the treatment environment.

Both groups also shared barriers related to the treatment setting including stringent policies, unwelcoming treatment environments, exposure to other people in active use, and high patient volume in clinic settings. Several interviewees described clinic treatment policies that required people to "jump through hoops," and some described penalties for non-adherence to policies including treatment discontinuation or revocation of take-home medication. Family members also expressed concern about lack of adequate outpatient treatment options for people with complex health and psychosocial needs and some described their loved ones experiencing treatment discontinuation due to complex care needs or involvement in the correctional system.

Additionally, family members discussed their loved ones' co-occurring mental illness and limited availability of counseling services as barriers to treatment engagement. Some described lack of high quality, consistent, patient-centered counseling services across service settings and several identified staff turnover, specifically, as a cause of poor access to and quality of counseling services in clinic settings, including inability to form a long-term therapeutic relationship with a counselor.

"It's always just been, 'Oh, here's the Suboxone,' and not working to see if there's anything else that she needs medication for to help deal with things, [to ensure] the drugs weren't her answer to feeling the way she does."

Perceived Benefits and Drawbacks of MOUD

People in treatment and family members discussed their perceptions of MOUD; however, most family members focused less on this area than those in treatment, and some family members provided their loved ones' perceived views on MOUD rather than their own opinions.

Some family members described MOUD as "a necessity" or "essential," with one stating that their loved one "needed it to be able to survive" and others noting that it allowed their loved ones to live "a normal life." Some family members discussed the value of MOUD for regulation of cravings and elimination of the effects of other opioids, thus precluding their use. Like people in treatment, some family members cited perceived drawbacks of MOUD including concern that MOUD treatment could lead to dependence or that MOUD could be abused.

"I think that he likes [buprenorphine] because he knows when he does take it, he can't do anything else—It just wouldn't do any good if he did."



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In comparing types of MOUD, some family members noted distinct benefits of buprenorphine (e.g., more accessible) while others described benefits of methadone (e.g., preferable for pain management). Additionally, some family members described their loved one's concern that transitioning from methadone to buprenorphine would be physically and emotionally challenging. Family members expressed concern that continued methadone treatment required their loved one to continue receiving services in a clinic setting that may have stringent or less flexible policies.

"He has in the past preferred methadone because it has a painkiller to it and he has chronic pain... The suboxone doesn't touch that at all... There is nothing on the market today for him for pain other than opioids or the methadone." "Buprenorphine is pretty widely available... At least in our county, it's much easier to make that connection. You can connect through the emergency department; you can connect through your primary care provider."

Recovery Success, Unmet Needs, and Recommendations for Improved Care

Recovery Success

Family members shared their views on what is needed for successful long-term recovery, many of which were aligned with sentiments expressed by people in treatment. Both groups discussed the importance of a positive social environment characterized by opportunities to build community with like-minded peers who share common goals, such as bettering themselves and helping others.

"[There is a need] to get involved with people that have the same goal in mind, to better their lives... Instead of just sitting in the same old apartment building surrounded by the same old people who are just as unhealthy as they are."

Family support was also frequently mentioned by both groups as a facilitator to long-term recovery success. Further, both groups discussed the importance of people in treatment receiving assistance with securing essential needs like housing (or recovery housing), employment, a driver's license, and transportation.

"They don't know to manage money, they don't know how to clean their house, they don't -- you know, they need basic life skills in addition to treatment." Family members highlighted some additional unique needs for long term recovery success that were not discussed by people in treatment, including access to a primary care physician for MOUD, continued substance use and mental health counseling, and maintained engagement with other recovery services and supports. Lastly, family members discussed the need for their loved ones to develop independence and confidence executing tasks of daily living (e.g., home chores, money management). Some family members also expressed personal convictions that it could be crucial for their loved ones to cut ties from friends and environments (including treatment sites) associated with illicit drug use.



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Unmet Needs

Family members and people in treatment shared unmet needs or gaps in the continuum of OUD care that they felt were critical for long-term recovery. Both groups discussed the need for residential treatment options and enhanced outreach and follow-up by providers and support staff between outpatient appointments. Family members also expressed a need for trauma-informed care, behavioral health services, comprehensive care for co-occurring disorders, and expanded infrastructure to support care transitions for those leaving carceral settings.

"I would say residential treatment [is needed]... Just a program that is intense, it's every day, you live it for a few months... Or however long you have to be there."

"[It's important that] patients... Know that they're getting checked up on, and that they feel important to someone."

Family Member Perspectives on Unmet Needs in the Opioid Use Disorder Continuum of Care



Infrastructure to support care transitions for individuals leaving carceral settings



Comprehensive care for co-occurring disorders



Behavioral health counseling for individuals receiving MOUD



Trauma-informed care across healthcare settings



Capacity for active provider outreach, follow-up, and longterm recovery planning

Recommendations for Improved Care

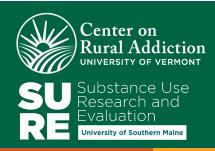
While people in MOUD treatment largely expressed satisfaction with their providers and the care they were receiving for OUD, several family members shared ways in which their loved ones' OUD treatment providers could enhance patient centered care.

"Honestly, I don't think that [providers] work hard enough at previously underlying issues might've been [present] prior to using drugs."

For example, family members recommended that providers, especially primary care providers, be more aware of OUD treatment and recovery options to effectively provide support and guidance for people with OUD and their families. Several family members also expressed that there should be greater focus on anxiety, depression, and other co-occurring or underlying mental health concerns.

Family members and people in treatment also discussed the need for people with OUD to be treated without judgement and with respect and dignity. The desire for health care providers, particularly those less familiar with OUD, to be more sensitive to the whole person was raised by both groups, with a focus on the stigma and shame surrounding OUD. There was also agreement

"He would go back because they were kind, they didn't judge him, and they let him make up his mind about what his medical care would look like."



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about continuity of care and consistency for the persons receiving treatment. People in treatment talked about the importance of consolidated or coordinated care so they weren't seeing multiple providers for services; some also mentioned turnover as an issue and made recommendations for assistance with aftercare planning (e.g., residential to community). Family members stressed the importance of transitional services, the need for coordinated care from one setting to another and maintaining consistent providers.

Family members also expressed their desire for their loved one's providers to assess and treat OUD like other chronic diseases, and for their loved one to have access to long-term continuity of care across the healthcare service continuum that is patient-centered and designed to meet their unique needs.

"When a new person goes in there to get help at the clinic, I think they need to be assigned a physician and a counselor that sticks with them through this... And they go with you through your whole treatment program."

Summary

Interviewing both people in treatment and family members offered a chance to compare the two groups' perceptions of OUD and the treatment continuum in rural Vermont. The following infographic summarizes overlapping and unique themes from interviews with people in treatment and family members.



Strong thematic agreement between people in treatment & family members

Lack of transportation, insurance, stable housing, and financial stability were identified as barriers to initiating and maintaining treatment engagement.

Clinic settings were described as often having inflexible policies and treatment environments not conducive to patientcentered care.

Continuity of care was identified as vital for high quality treatment (e.g., meeting regularly with the same health provider).

Stigma associated with OUD was perceived to increase the need for compassionate, patient-centered care.

Positive social connections were identified as a need, particularly with peers who share common goals.

Some people in treatment and family members viewed MOUD as a continuing tie to opioid dependence.



Nuanced thematic agreement between people in treatment & family members

Family members highlighted the importance of residential treatment.

While people in treatment and family members viewed treatment services in primary care settings favorably, family members also discussed a need for primary care providers to become more educated on treatment options and involved in care for people with OUD, particularly prior to treatment initiation.

While people in treatment shared that exposure to individuals in active use made recovery more challenging, family members articulated a need for their loved ones to cut ties from friends and all environments (including treatment sites) associated with illicit drug use.

Both groups emphasized the need for childcare, and family members discussed their role in providing childcare support.



Perspectives unique to family members

Family members discussed access to a primary care physician as critical to starting MOUD treatment.

Family members expressed that providers should screen and treat OUD like other chronic diseases.

Family members discussed treatment for co-occurring disorders, with an emphasis on the need for treatment to address mental health conditions and trauma that may underlie OUD.

Family members identified life skills education and support as necessary components of OUD treatment.

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