Relentless Stigma: A Qualitative Analysis of a Substance Use Recovery Needs Assessment

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ABSTRACT: Substance use disorders (SUD) pose emotional, mental, and physical threats to persons worldwide. There is a paucity of research focused on capturing individual perspectives on supports and barriers to recovery from a SUD. This need has been identified in areas of Minnesota where a gap in evidence-based substance use support exists. A team of interdisciplinary professionals distributed a qualitative survey assessing supports and barriers to SUD recovery within recovery circles in order to inform the efforts of local organizations. This paper and online access survey was adapted from an existing survey created by Faces and Voices of Recovery. The online survey was accessed by a link and distributed to persons in recovery across Minnesota over 7 months. Data from this survey were analyzed through a consensual qualitative research (CQR) coding method. Notable themes emerged in the following domains: healthcare, environment, individual, and community. Community-wide stigma was an overarching concern, and the study yielded unique insights into stigma within healthcare and the community at-large. Barriers and support to recovery were reported. Barriers included experiencing high levels of stigma and identifying a need for community education on SUDs and recovery. Support included local recovery groups, peer recovery support, and access to healthcare and medication. Our findings illuminate the needs of the recovery community from the perspective of individuals with lived experience and will inform local organizations in specifying resources to help meet the identified needs. This survey may also be adapted and used around the world to inform substance use prevention, treatment, and recovery programing.

KEYWORDS: Substance use disorder, stigma, recovery supports, community needs assessment, consensual qualitative research

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Introduction

Substance Use Disorders (SUDs) affect over 20 million Americans ages 12 and up,[1] resulting in nearly 91 800 overdose fatalities in 2020 alone[2] and an estimated 740 billion dollars in economic losses due to crime-related, health care, and other costs.[3] SUDs are especially prevalent during times of economic and social duress, and have wide-reaching implications for all of society.

SUDs and stigma

The loss of life and economic cost associated with SUD is significant.[4,5] However, the challenging personal experience of someone with SUD in society is often underappreciated. On a relational level, a large number of people suffering from SUD face the rejection of friends and family.[6] On a national level, reports show the majority of people in the United States hold critical views of people with a SUD due in large part to the war on drugs media campaigns, turning the issue into a moral failing rather than public health issue.[7] Stigma is also a problem when looking through a global lens. According to Room et al[8], in a World Health Organization survey of 14 countries, SUD and alcohol use disorder (AUD) are the number 1 and 4 most stigmatized conditions across countries when compared to other conditions such as mental illness, HIV-positive status, physical disability, and having a criminal record. In the same survey, the majority of respondents across countries reported that they believed someone habitually using heroin or alcohol would be, ". . .unlikely to keep things tidy, take on parenting roles, keep a full-time job, or hold a position in local government."[8]

SUD stigma can also negatively affect access to healthcare and treatment services, building and maintaining relationships, and seeking employment and financial independence.[9] Stigma can be subdivided into public, perceived, enacted, and self-stigma. These negative beliefs can range from public endorsement of negative attitudes toward a marginalized group, down to an individual's diminished self-image as a result of identification with that group.[6] Stigmatizing practices can impede SUD treatment progress, as the social isolation induced by being labeled an "addict" can lead to relapse. There are many biases regarding treatment options themselves; medication assisted therapy's validity has been challenged by communities previously studied in the boundaries of the current study region, and some view the medications as another substance one can get addicted to.[10] Stigma in accessing medication assisted therapy in this subregion, which consisted at the time of largely abstinence-only recovery communities, has also been reported.[10] Comprehensive access to care (including transportation, health insurance

Table 1. Qualitative questions and total number of responses.

QUESTION ASKED	NUMBER OF RESPONDENTS
What is one thing, if any, that could have helped you in your recovery during your experience of medical care?	n=222
Was the medication helpful for your recovery? Please explain.	n=83
If yes to [the previous question], what? [The previous question was: 'Is there something additional that could have helped you in your recovery during your experience of substance use disorder treatment that you did not have?]	n=54
What additional services, if any, could the ED have provided to be more helpful/supportive in recovery and substance use treatment?	n=69
What can the community do, if anything, to reduce the stigmatization (hurtful or disrespectful treatment/language) of people with substance use disorders?	n=229
Is there anything you would like to add about supports and barriers to recovery in your community? Please include additional thoughts below.	n=184

coverage, efficient response times, etc.) can enhance sustained involvement in treatment programs, which positively impacts treatment outcomes.[11] Barriers to this care can have deleterious effects on an individual's physical and mental health.[12]

Understanding substance use through community needs assessments

This study is an analysis of a community needs assessment surveying those recovering from SUD across Minnesota; with outcomes highlighting the stigma these individuals face. Community needs assessments (CNAs) are useful tools in understanding the unique and hidden health impacts that a community faces. CNAs are fundamental to understanding the needs of recovery communities in order to effect change and provide evidence-based assistance.[13] Needs of recovery communities can be segmented through an organizational framework such as the socio-ecological framework, which was adapted by Jalali et al[14] to accommodate specificities of the opioid crisis. It divides risk factors of opioid misuse into 4 categories: individual, interpersonal, community, and society. Individual factors include a person's being, past, existence, and perceptions. Some examples include socio-demographic factors, stress, trauma, genetics, pain perception, and self-empowerment. Interpersonal factors include the people and relationships surrounding the individual including family history, relationships with family and friends, professional relationships, and in some cases, substance access via these relationships. Community factors include access to care and treatment facilities, geographic variations, local prescribers, and access to drugs. Finally, societal factors encompass local culture, governing body regulations, social stigma and ideologies, economic conditions, and insurance payer policies. As outlined by Jalali et al[14] this framework emphasizes the complexity of SUD recovery influencers, which must be considered to fashion effective and sustainable treatments. Using this model as a guide, the supports and barriers indicated in this study have been segmented into healthcare, environment, individual, and social.

Studying SUDs in Minnesota

Individual-level views of addiction needs and services are scant in the literature. One of the most notable publications is a survey report titled "Life in Recovery" published by Faces and Voices of Recovery.[15] It detailed key findings from its survey distributed to persons in recovery across the nation and captured the individual perspective and humanistic complexity of SUD recovery. The survey captured both qualitative and quantitative data on individuals' history of substance use and recovery and how they affected their physical, financial, and mental well-being. Recovery was found to be beneficial for individuals in all metrics from an increase in employment to less experiences of domestic violence. The research team used this survey as an instrument in developing 6 open-ended questions (Table 1) as a part of a state-wide recovery needs assessment.

This study was conducted by a diverse team of academic partners, community stakeholders, and those with lived-experience with SUDs and recovery. The need for this study was sparked by a community desire to address the needs of the recovery community. The objective of this study was to explore the barriers and facilitators to recovery from a SUD by elucidating and maintaining the voices of individuals in recovery. These unique results frame a new perspective for understanding the diverse experiences of recovery with outcomes focusing on where and how stigma is experienced. The results seek to inform community and clinical approaches to substance use interventions.

Methods

Design

An interdisciplinary team of researchers and community members adapted the "Faces and Voices of Recovery" survey with permission from its creator Alexandre Laudet[15], Ph.D., Director of the Center for the Study of Addictions and Recovery at the National Development and Research Institutes, Inc, in order to capture the voices of individuals in recovery and their needs across Minnesota. Approval for this cross-sectional

survey was obtained prior to its distribution by the University of Minnesota Institutional Review Board (STUDY00006728). The adapted survey (Appendix A) was distributed in the study's area of interest within Minnesota to those who self-identified as a person in recovery from a SUD and were at least 18 years of age.

Recruitment and data collection

Recruitment was performed through convenience sampling methods. Distribution occurred through paper and electronic methods during various recovery events with the help of a local peer recovery group; paper entries were entered into an electronic system by research assistants. Participants took the survey electronically on a tablet, phone, or computer after scanning a QR code from an informational postcard. The survey link was also digitally distributed in collaboration with other local recovery organizations including a recovery organization partner, a peer-run tribal recovery group, social media outlets, and networking groups. The survey region, which was originally a more selective area, broadened to include state-wide data due to high adoption via online distribution channels. Online surveys were completed via Qualtrics (Qualtrics, Provo, UT). Participation was voluntary, and participants consented in writing at the beginning of the survey. They were informed that the results of the study "will be shared with the recovery community, public health community, and health care community in northeastern Minnesota so that the recovery experience for individuals living in this area can be improved." Responses were anonymous, and participants only had to give identifying information if they wished to be compensated (all were offered a $10 gift card for participation). This identifying information was kept confidential and separate from study results, keeping participant responses anonymous. The survey was available for approximately 7 months (October 8, 2019-April 26, 2020) and closed after funding limits were reached.

Analysis

The data were cleaned to remove any respondents reporting zip codes outside of Minnesota. Qualitative responses were analyzed using consensual qualitative research (CQR) methodology.[16] This methodology was selected due to its ability to explore detailed experiences and internal attitudes, aligning well with the data obtained through this study. Data analysis was conducted manually and the initial review of qualitative responses was led by 3 judges; 1 research assistant, 1 graduate student, and 1 AmeriCorps VISTA. These judges independently created codebooks of domains and core ideas based on emerging themes. The judges then cross-analyzed the individual codebooks by individually bringing possible categories to the group for discussion, and coming to consensus as a group on the wording of the categories and the placement of core ideas to create a single, master codebook (Table 2). The codebook was then updated by 2 university faculty auditors with extensive experience in CQR and a subject matter expert auditor who were familiar with the data. Six total qualitative questions were analyzed (Table 1). Each question had 2 judges assigned to it who determined, first individually, which core idea the particular statement applied to and coded it accordingly. The judges then consulted on their individual determinations and worked through the consensus process to decide the best thematic domain and core idea for each statement. Because the CQR method demands that any inconsistencies or disagreements between judges be discussed as a part of the consensus-building process, interrater reliability was not calculated. After all statements were reconciled, they were separated for each core idea and representative quotes were collected. Due to the anonymity of the study participants, survey results were not shared directly with participants. Instead, results were shared with coalitions and local prevention, treatment, and recovery organizations to inform their programing.

Results

The study included 497 respondents within Minnesota, but not all respondents chose to respond to qualitative questions. The largest response for a qualitative question was n = 229, or 46% (Table 1).

Synthesized demographic data represents all participants from Minnesota who completed the survey (Table 3). The majority of respondents identified as White (Non-Hispanic) (62.2%) with the next largest race/ethnicity groups being Black (Non-Hispanic) (13.9%), Hispanic (8.4%), and American Indian/Alaska Native (9.0%). The remaining 6.5% of participants identified their race or ethnicity among other racial or ethnic groups. Female-assigned at birth represented 58.8% of participants, while male-assigned at birth was 39.8%. A small number of responses represented intersex or no sex assigned at birth. While 76.3% of respondents identified as straight, 22.6% identified as Gay/Lesbian, Queer, Pansexual, Bisexual, or self-identified. A few respondents opted not to indicate their sexual orientation. Participants were also asked to report the primary substance they used while in active substance use. Nearly 27% of respondents reported cannabis, 20.2% reported alcohol, 16.7% reported methamphetamine, 13.2% reported heroin, 11.8% reported prescription opioids, 8% reported amphetamines, and 3.5% reported "other."

Responses to qualitative questions were segmented into 4 domains: healthcare, environmental, individual, social, and other.

Healthcare

Many participants commented on their experience with healthcare, both positive and negative. Most reports highlighted **stigma and misunderstanding** from healthcare providers as a barrier to recovery. For example, when asked if there was anything that could have helped during the recovery

Table 2. Master codebook.

DOMAIN	CORE IDEA	DEFINITION	EXAMPLE QUOTES
Healthcare	Lack of access	Areas identified by respondents as important ways that experiences with healthcare has impacted their recovery journey	"Need to be able to get into a psychiatrist faster"
	Lack of access - medication		"Medications would have helped such as Wellbutrin"
	Medication-related positive		"Yes it is. . .suboxone helps with my cravings. . .n helped function a lot better"
	Medication negative		"Not really. I was not ready to be done drinking, so I just drank on top of the vivitrol and ended up doing more damage"
	Medication neutral		"I was in methadone for 8 years. I can't say whether it was helpful or not. I abused it. But if I hadn't been using methadone, I might have been using other drugs. It kept me alive until I could get sober I guess."
	Stigma and misunderstanding		"Medical professionals being more educated on dealing with addicts. There were times I was made to feel 'less than' and not worth their time, even once I got clean"
	Comorbidities		"More focus on mental health because that is the root of my addiction"
	Clinical Therapies		"Referral services"
	Healthcare as a support		"I have received superb and genuine care thus far"
Social	Family/friend barrier	Themes that were identified by respondents related to how the community or social aspects of their life affected their recovery	"I know that in my experience, shame was a huge factor in my NOT asking for help. Whether it be from family, friends, or medical professionals. It is really hard to ask for help when the people you are asking or trying to ask have a preconceived opinion about what it means to be an addict."
	Peer recovery support		"Peer recovery support it really helps"
	Additional Community Supports		"More opportunity to be involved in the community learning how to live sober and mentally stable"
	Event barrier		"No sober activities or support"
	Culture		"Society as a whole looks for a 'band-aid' fix that is unavailable."
	Education/Stigma		"Education is vital. Though, education from addicts in recovery can relay the best information to people trying to understand the world of addiction."
Environmental	Transportation negative	Areas identified by respondents of aspects of external sources or their environment impacts their recovery journey	"Barriers to meetings are transportation and rural communities so far away. Low funding for mental health providers because it has to go hand in hand with SUD treatment"
	Housing negative		"More transitional housing for the homeless seeking recovery"
	Employment		"The biggest change for me was to. . . get a full time job."
	Finances negative		"Not having to worry about finances as a result of the high cost of medical care"
	Legal barrier		"It takes me a very very long time to gain myself back after a severe punishment such as jail. It does not help me, but rather extremely harms my recovery and self worth and chance at long term recovery."
Individual	Knowledge/belief	Identified themes where individual or internal factors influenced their experience with recovery	"Can help a person radically change the status quo, rediscover themselves and make a new life for themselves"
	Spirituality		"Staying connected to my higher power"
	Self-care		". . . More coping skills (art therapy, exercise)"
Other	Vague Response	Responses that were either unclear or were "No" or "I don't know"	
	No/I don't know		

Table 3. Demographic data.*

Race/ Ethnicity (%)	White (Non-Hispanic)	62.2
	Black (Non-Hispanic)	13.9
	American Indian/Alaska Native	9.0
	Hispanic	8.4
	Asian	1.6
	Middle Eastern or North African	0.8
	Native Hawaiian or Other Pacific Islander	0.2
	Multiple Native Hawaiian or Other Pacific Islander	0.4
	Multiple American Indian/Alaska Native	2.7
	Prefer not to answer	0.8
Sex (%)	Female-assigned at birth	58.9
	Male-assigned at birth	39.8
	Intersex	0.2
	No sex assigned at birth	0.2
	Other or no response	1
Sexual Orientation (%)	Straight	76.3
	Gay or Lesbian	11.6
	Bisexual	6.9
	Pansexual	2.5
	Queer	1.2
	Prefer not to say	0.8
	Prefer to self-identify	0.4
	No response	0.2
Primary substance of choice while in active substance use (%)	Cannabis	26.7
	Alcohol	20.2
	Methamphetamine	16.7
	Heroin	13.2
	Prescription Opioids	11.8
	Prescription Amphetamines	8.0
	Other	3.5

*Percentages are rounded to the nearest 10th.

process, 1 person noted, ". . . doctors actually listening and not just assuming that an alcoholic is going to be out 'pill shopping'." This perceived belittlement especially hurt participants who were already ashamed of their substance use. Many participants also mentioned, "Less judgment," specifically in reference to care in the emergency department. A few participants mentioned opportunities to, "Train employees on how to appropriately speak to individuals in addiction" or educate healthcare professionals as a way to improve experiences in the emergency department. Participants reported numerous missed opportunities where the healthcare system and staff could have had a positive influence on their recovery but failed due to a lack of education around treating individuals with a SUD. In the words of 1 participant, "It would of helped if doctors would of known about 12 step programing, and could of lead me in that direction." Other resources like "Rule 25" chemical dependency assessments were desired, but some reported never being offered this service.

Lack of access to healthcare and/or medication was also mentioned. A few participants mentioned that being offered medication to treat their SUD may have been helpful to them. Other participants noted wait times for treatment being a barrier. In the words of 1 participant, "The wait for a bed, or to be seen for mental health, and payment options for treatment took too long."

Many participants noted that **medication was helpful** in their recovery while some reported that **medication was a detriment**, and a few expressed a neutral or unsure attitude. Many participants reported medications were effective in reducing drug cravings. Some stated that certain medications were instrumental in taking back control of their lives. One participant stated, medication "stopped my withdrawals so I could start working and taking care of my daughter." One explanation for a negative experience was drinking alcohol while taking a prescribed medication. Another participant stated, "Vivitrol has been helpful for me [but] methadone was just another addiction I had to withdrawal from my methadone while in jail." Neutral comments asserted no change in cravings after taking prescribed medication.

Comorbidities and clinical therapies were mentioned by some participants as well. Co-occurring SUDs and mental health conditions were noted by a few participants as interconnected. A few mentioned it would be helpful to get treatment for both conditions in the same healthcare environment. Clinical therapies like psychotherapy were mentioned in reference to this. Finally, a few participants reported having **excellent experiences with healthcare providers** and appreciated the level of care they received.

Social

Participants consistently emphasized social factors influencing recovery. Overwhelmingly, **stigma** from the general community was described as detrimental to participants. To be seen as "criminals, junkies, whores, [or] bad parents" or a "plague in the neighborhood" compounded the shame those in recovery felt and drove some to avoid seeking assistance. A few participants experienced **stigma from friends and family**: ". . . shame was a huge factor in my NOT asking for help. Whether it be from family, friends, or medical professionals." In the words of another participant, "I felt and still feel fear of being stigmatized and so keep my past and my recovery a secret. . . But it's

my secret and I do not intend to share anytime soon because I fear the repercussions." To combat this, participants called for more education for healthcare workers, youth, and the general community to foster compassion and sensitivity in order to "humanize addicts" and normalize conversations about drug use and recovery.

A few participants noted **cultural barriers** or **event barriers** such as a culture of drinking alcohol. This was described as barriers to those in recovery. Solutions like, "More community events without alcohol" were offered. **Peer recovery support** was also desired by a few participants, whether they had utilized it for their recovery, or wished it had been offered to them. Finally, most participants suggested **additional community support** to assist with their recovery. Most participants referenced the importance of a supportive and caring community ranging from friends and family to the greater community; explaining the support of the community must be sustained long-term. As 1 participant commented,

> " . . .recovery doesn't just happen from a shot or a pill, it takes hard work and long-term supports. 30 days or 17 weeks is not comprehensive. . ..people need a supportive environment for longer periods of time, which managed care and legislative components have not realized that long-term care would be more effective."

Additionally, some participants cited the need for additional community support with readjusting into the community post-treatment. The readjustment process was defined by participants as comprehensive services for those pursuing recovery to rejoin the workforce, find stable housing, and form healthy social networks. Above all, finding "somebody to listen" was important to participants but this is made difficult by stigma, which was a common issue mentioned amongst participants.

Environmental

Another domain of participant responses was focused on environmental factors affecting recovery. Difficulties with **transportation** to treatment services, securing **housing**, and maintaining **employment** were noted by a few participants, especially in rural regions. As 1 participant notes, "Barriers to meetings are transportation [in] rural communities so far away." This transportation barrier impacted the financial well-being of some participants. While a few participants noted **financial issues** in regards to obtaining and maintaining employment or housing, other participants explained how the costs of care for their SUD impacted them. "Being able to pay for counseling services.. it's expensive."

Another environmental impact some participants disclosed were **legal barriers** like the negative perceptions of law enforcement held. Participants cited law enforcement to be prejudiced and aggressive toward people who use drugs. One participant stated "it's [law enforcement] making the recovery community worse." Some participants also suggested loosening the existing laws such as decriminalization of drug use and alternatives to jail for non-violent first offenses. Finally, a few participants requested further assistance with treatment, basic living, and housing expenses for financial stability.

Individual

Individual factors affecting recovery mentioned by participants centered around **self-care** and **knowledge/belief systems**. Participants stressed the need to take care of themselves mentally and physically, especially to control anxiety. A few participants mentioned exercise programs, meditation, art therapy, or alternative treatments such as chiropractic and acupuncture as facilitators to their recovery. Some participants also stressed the importance of self-belief in wanting to achieve recovery, noting the need to "stick with" treatment and to "not wait for others to reach out to you for help." Participants mentioned feeling empowered by the mental resiliency that was required to pursue their recovery. **Spirituality** was also mentioned by a few participants as a facilitator to their recovery, noting that, "Staying connected to my higher power," assisted in their journey.

Other

The final domain was a place to collect all responses that were vague, unclear, or those that responded "no" or "I don't know." Some examples of these responses include "This question doesn't make sense," and "N/A."

Discussion

Healthcare

Stigma was a central theme of this study, both in the way the questions were framed and how the respondents chose to focus on stigma. This was highlighted at the community, policy, and healthcare setting level (Table 4). While medical records will list SUDs as conditions in a patient's history, medical records often omit recovery, contributing to stigma in healthcare. This becomes important to a patient in recovery when their medical records do not indicate recovery, and providers assume (or are perceived to assume) "pill shopping" behavior is present. Additionally, while a patient may present with a SUD, it may or may not be their primary health concern at the time. This is especially true with mental health concerns, which many study participants emphasized as a comorbidity. Ensuring a holistic view of the health conditions at the time of visit is instrumental in reducing confusion or assumptions around the status of a patient's substance use. Provider education on what it means to be in recovery can assist in opening the conversation around SUDs, recovery, and how to treat health conditions when they co-occur with SUDs.

Based on this study, healthcare professionals should adapt new methods and tools in treating individuals with SUD.

Table 4. Stigma related to community, policy, and healthcare.

SETTING OF STIGMA	SURVEY QUESTION	RESPONDENT ANSWER
Stigma in the community	Is there something additional that could have helped you in your recovery during your experience of substance use disorder treatment that you did not have?	"the support of my community since they treated me like a plague in the neighborhood"
Stigma in policy	What can the community do, if anything, to reduce the stigmatization (hurtful or disrespectful treatment/language) of people with substance use disorders?	"Decriminalize the small amounts of drugs and get the people who are using the help they need rather than giving them a criminal record."
Stigma in healthcare	What is one thing, if any, that could have helped you in your recovery during your experience of medical care?	"The 1 time I did O.D. i went to the hospital an the doctor there was so judgmental that he said i did this to myself on purpose an it made me feel so mad and upset that I didnt even want to receive the help given from him. I just wanted to feel like everything was going to be ok an not be belittled by him when I already felt shameful about it in the 1st place."

Motivational interviewing is 1 method that opens the conversation regarding patient substance use.[17] Some respondents noted not being offered resources such as "Rule 25" chemical dependency assessments, which can lead to much needed funding for treatment. Some subject matter experts hypothesize this is due to discomfort in talking about substance use. If motivational interviewing can assist providers in having conversations on these topics, perhaps it would also lead to increased referrals to resources such as chemical dependency assessments. Additional research would be necessary to test this hypothesis. Another missing health resource that a few participants reported was medication for recovery while in jail. For example, 1 participant was forced to withdraw from Vivitrol, an evidence-based treatment,[18] in jail showing that unethical practices are still occurring. Courts around the U.S. have begun recognizing this unethical practice and ruling in favor of those pursuing medication access for their SUD while in jail.[19]

Language around addiction also plays a role in stigma. Research supports positive and negative affiliations to certain words which describe substance use. For example, the term "substance use disorder" asserts an unbiased medical approach surrounding these disorders and generally decreases stigma, while the terms "drug abusers," "dirty," and "clean" assert a sense of wrongness and punitive bias. Using non-stigmatizing language in exchange for medically-informed terminology helps to change the narrative around SUDs and create an atmosphere of respect.[20] Another study shows that the terms "alcoholic" and "addict" connotes strong negative associations and suggests removing them from conversational language.[21] In addition, this study supports the use of "pharmacotherapy" and "recurrence of use" instead of "medication-assisted therapy" and "relapse," both of which had negative associations.

Stigma in the healthcare setting can influence a person's trust in the system and influence their entire interaction with healthcare, both in their search for treatment and in treating other health needs.[22] Although SUD is a medically recognized pathology by the American Psychiatric Association,[23] it is 1 of the only disorders that is still commonly referred to by outdated language, such as referring to someone as an "substance abuser," a term carrying overwhelmingly negative connotations.[24,25] Repeated negative experiences with healthcare can leave individuals hesitant to seek treatment over fears of manipulation and prejudiced behavior, delaying vital care.[26] However, there has been much less effort and progress made to decrease this associated stigma when compared to the efforts behind the reduction of stigma associated with HIV and mental health.[24]

Social

Many of the stigmatizing experiences participants illustrated with the healthcare system were mirrored by similar stigmatizing experiences within the community. Many of the solutions participants desired to see in healthcare were similar to solutions in the community such as education and normalizing recovery. Community support has been shown to positively influence recovery[27] and was reported as desired by study participants. For example, while the culture of drinking can be deeply ingrained in many communities, participants offered that non-alcoholic options and supporting a person's decision not to drink could be simple ways to combat this.

Although stigma was a common theme throughout participant responses, many did not specifically name the term "stigma." Often, people in recovery need examples of stigma in order to relate to the term or know that a stigmatizing experience has happened to them. Participants spoke about stigma in terms of other individuals using discriminating language, exhibiting condescending and belittling behavior, and invoking an internal feeling of shame surrounding participants' SUDs. Many participants called on the community and organizations to provide education about SUDs and recovery to mitigate stigma. Utilizing familiar terminology to communities and providing examples of these situations may prove to be effective when providing education on these topics. Additional

analysis is needed to evaluate if or how stigma may have been experienced differently based on the primary substance of the participant while in active substance use.

Environmental

The environmental barriers to recovery reported by participants reaffirm the role that social determinants of health can have on SUD and recovery.[28] These types of barriers complicate providing accessible recovery services. While technology has enabled tele-health opportunities, online access to services isn't an option for everyone, especially for those in rural areas.[29] Since not all programing is reimbursable and not all insurance plans make treatment services affordable, peer recovery support can be a vital tool for those seeking or maintaining recovery.[30,31] Referrals to peer recovery support from drug courts or healthcare centers is 1 way to provide free recovery based services, when appropriate. Additional ways to ensure access to treatment are needed such as providing transportation or reducing the cost of treatment services. Collaboration between the criminal justice system and healthcare treatment centers can also be beneficial for those in recovery by exploring appropriate alternatives to incarceration for certain drug or alcohol-related charges.[32]

Individual

Knowledge and belief systems rely on an understanding of options for pursuing and maintaining recovery. Expanding the menu of options for a person to guide their own recovery can be incredibly important for the recovery pathway. A one-size-fits-all approach is not well suited for addressing SUDs. Additionally, there was a decreased focus surrounding knowledge and belief systems when compared to community supports, showing that individual mental fortitude alone is not what is most needed to support recovery; the support of the community is instrumental.

Lessons learned

Throughout the survey process, the research team learned the great importance of having those with lived experience and subject matter experts involved in the project. Subject matter experts from the community were consulted throughout the coding process to ensure core ideas were appropriately connected to responses. Some responses were difficult for individuals not actively engaged in recovery to determine. For example, when participants were asked if the community can do anything to reduce stigma surrounding SUDs, some respondents stated, "recovery-oriented care." Judges were unsure if this referred to a culture of recovery, stigma reduction within healthcare, or an additional community support. After consulting with a subject matter expert who was also a peer recovery specialist, the coders were able to confirm recovery-oriented care as an additional community support and defined it as a community ideology framing recovery support through the lens of health, empathy, and autonomy. This concept puts the onus for change on the community, instead of placing the entire responsibility on the individual.

Strengths and limitations

One strength of this study is that respondents self-identified as a person in recovery. When research teams do not limit what recovery looks like, participants are able to provide their own definitions and participate freely. Raising concerns about stigma was also a strength for these study results. While it is commonly known stigma impacts those in recovery,[33] this study illuminates the settings in which stigma is experienced, how stigma can impact recovery, and how those in recovery would like stigma to be addressed.

A limitation of this study is judge bias. This type of bias could have been introduced, but the research team was unable to measure this bias. For example, none of the judges themselves were persons in recovery. This type of bias was controlled through an auditing process, including both academics familiar with CQR and a subject matter expert, who is a person in recovery. The last limitation is that each qualitative question did not have the same number of respondents, potentially leading to response bias.

Future research

There is more work to be done in understanding the facilitators and barriers to recovery from SUDs. Findings from our study have documented a need for future studies such as investigating the impact of resource interventions that participants indicated were helpful to recovery, including transportation and funding for recovery supports. Providing transportation to participants in recovery, particularly in rural areas, and measuring outcomes could enhance the current understanding of transportation as a barrier. Providing specific recovery-directed funds and assessing effects in terms of group attendance, treatment goals, recurrence of use, and overall SUD prevalence would also be pertinent to the literature. In addition, research diving into nuanced family dynamics and specific social supports (or lack thereof) is a vital piece to recovery prognosis and would be useful as a future study. Finally, a measure that our research is unable to properly substantiate is the role of genetics and neurobiology in the development and continuation of SUDs which are pertinent in properly treating these conditions.[34,35]

Conclusion

This study was created and conducted by community stakeholders and academic partners who wished to expand and improve resources for individuals in recovery in a meaningful way to address the needs of the recovery community. Stakeholders and community members identified the need for local, first-hand data from individuals in recovery as to what their needs are, and the research team adapted a survey which

included several open-ended questions to identify these needs in the recovery community's own words. While the domains of healthcare, environment, individual, and social emerged, open-ended responses uniquely pointed to experiences of stigma in healthcare settings as well as in the community at large. The detriments of stigmatized language from friends, family, coworkers, and the very support services that cater to these individuals, was a main theme in responses. Community stakeholders were eager to use this data to inform local recovery efforts.

This study highlighted the need for future and directed research focused on several notable barriers and supports identified by study participants. While a surplus of helpful data was gathered from this study to aid recovery efforts, research into the specifics of supports or barriers will be needed to chip away at archaic ideologies (such as those relating to stigma) and logistics of physical needs such as transportation and healthcare access. The voices of individuals in recovery, by sharing their experiences of stigma and shame, articulate the power of kindness, unbiased attitudes, and fair treatment in achieving positive outcomes for individuals with SUD.

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Author Contributions

The analysis of the qualitative data was conducted by SJM, AVD, and RT; LP and KH supervised and audited this process. SJM led the revisions of this manuscript. All authors contributed substantially to the writing of this manuscript and provided critical feedback.

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Appendix A. Questions included in this study's survey

Q1.2 I consent to participate in this survey research project:

- ○ Yes, I consent to participate in this research study and would like to proceed with the survey
- ○ No, I do not consent and do not want to proceed

Q3.1 **Demographics:** These are questions about who you are, so we can better understand your unique needs/needs of your community. We are asking these questions to get to know you, and to better understand if different groups of people have different needs.

Q3.2 What is your age?

_____

Q3.3 What zip code do you live in?

_____

Q3.4 What sex were you assigned at birth?

- ○ Female (1)
- ○ Male (2)
- ○ Intersex (3)
- ○ No sex assigned at birth (4)
- ○ Prefer to self identify (5) _____
- ○ Prefer not to say (6)

Q3.5 With what gender do you currently identify?

- ○ Man/masculine (1)
- ○ Woman/feminine (2)
- ○ Genderqueer/non-conforming (3)
- ○ Non-Binary (4)
- ○ Agender (5)
- ○ Genderfluid (6)
- ○ 2 Spirit (7)
- ○ Prefer to self identify (8) _____
- ○ Prefer not to say (9)

Q3.6 How do you identify your sexual orientation currently?

- ○ Gay or lesbian (1)
- ○ Queer (2)
- ○ Pansexual (3)
- ○ Bisexual (4)
- ○ Straight/ heterosexual (5)
- ○ Asexual (6)
- ○ Demisexual (7)
- ○ Prefer to self identify (8) _____
- ○ I prefer not to say (9)

Q3.7 How would you best describe your racial/ethnic background?
Check all that apply.

- Black or African American (1)
- American Indian or Alaska Native (2)
- Asian (3)
- Middle Eastern or North African (4)
- Hispanic, Latino, or Spanish Origin (5)
- Native Hawaiian or Other Pacific Islander (6)
- White (7)
- Additional (8) _____
- I prefer not to say (9)

Q3.8 Current Employment (full time, part time, between jobs, unemployed)

- ○ Full Time (1)
- ○ Part Time (2)
- ○ Between Jobs (3)
- ○ Unemployed (4)
- ○ Retired (5)
- ○ Student (6)
- ○ Other (7) _____

Q3.9 What is your highest level of education?

- ○ Some high school or less (1)
- ○ High school graduate/GED (2)
- ○ Some College (3)
- ○ Vocational/Associate's degree (4)
- ○ Bachelor's degree (5)
- ○ Graduate degree (6)
- ○ Other (7) _____

Q3.10 What best describes your marital status?

- ○ Now married (1)
- ○ Living in a marriage-like relationship (2)
- ○ Divorced or separated (3)
- ○ Widowed (4)
- ○ Never married (5)
- ○ Other (6) _____

Q3.11 Have you ever served in the military (active or reserve)?

- ○ Yes (1)
- ○ No (2)

Q3.12 Do you identify as a military veteran?

- ○ Yes (1)
- ○ No (2)

Q3.13 How many children/dependents are in your care?

- ○ None (1)
- ○ 1-2 (2)
- ○ 3-4 (3)
- ○ More than 4 (4)
- ○ Other (5) _____

Q3.14 How many are under the age of 18?

- ○ None (1)
- ○ 1-2 (2)
- ○ 3-4 (3)
- ○ More than 4 (4)
- ○ Other (5) _____

Q3.15 This next section is going to ask you about your physical and emotional health.

Q3.16 Overall, how would you describe your **physical** health right now?

- ○ Poor (1)
- ○ Fair (2)
- ○ Good (3)
- ○ Very good (4)
- ○ Excellent (5)

Q3.17 Are you currently under a practitioner/health care provider's care for an ongoing "chronic" medical condition? (eg, high blood pressure, diabetes, high cholesterol, asthma, arthritis)

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.18 Do you use tobacco products (eg, smoking, snuff, chew, etc) or e-cigarettes (eg, vaping, juul)?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____
  _____

Q3.19 Overall, how would you describe your **mental** health right now?

- ○ Poor (1)
- ○ Fair (2)
- ○ Good (3)
- ○ Very good (4)
- ○ Excellent (5)
- ○ Other (6) _____

Q3.20 Are you currently receiving help or treatment for emotional or mental health problems (eg, therapy, counseling, medication, psychiatry)?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.21 Have you ever been treated for an emotional or mental health issue?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.22 What is one thing, if any, that could have helped you in your recovery during your experience of **medical care**?

_____

Q3.23 This next section is going to ask you about your first experiences with substance use.

Q3.24 At what age did you begin using substances?

- ○ Under 12 (1)
- ○ 12-17 (2)
- ○ 18-25 (3)
- ○ 26-36 (4)
- ○ Over 36 (5)
- ○ Other (6) _____

Q3.25 What circumstances best describe the environment of your first substance use?

- ○ Offered by family/friends (1)
- ○ In a school/school setting (2)
- ○ In a work setting (3)
- ○ Social event/community gathering (4)
- ○ Attempt to self-medicate (5)
- ○ Curiosity or experimentation (6)
- ○ Prescribed by medical provider for physical/mental health issue (7)
- ○ Other (8) _____

Q3.26 When you were in active substance use, which substance was your primary?

- ○ Alcohol (1)
- ○ Methamphetamine (2)

- ○ Heroin (3)
- ○ Prescription amphetamines (4)
- ○ Prescription opioids (5)
- ○ Cannabis (6)
- ○ Other (7) _____

Q3.27 For how long did you use drugs and/or alcohol?

- ○ Less than 6 months (1)
- ○ Between 6 months and 1 year (2)
- ○ Between 1 and 3 years (3)
- ○ Between 3 and 5 years (4)
- ○ Between 5 and 10 years (5)
- ○ Between 10 and 20 years (6)
- ○ More than 20 years (7)
- ○ Other (8) _____

Q3.28 The next series of questions will ask you about your experiences with substance abuse treatment programs.
Q3.29 Have you ever gone to a treatment program such as detox, methadone clinic, DWI program, in- or outpatient treatment to deal with substance use disorder?

- ○ Yes (1)
- ○ No (2)

Q3.30 How old were you when you entered treatment?

- ○ Under 12 (1)
- ○ 12-17 (2)
- ○ 18 to 25 (3)
- ○ 26-36 (4)
- ○ 37-50 (5)
- ○ 51-65 (6)
- ○ Older than 65 (7)
- ○ Other (8) _____

Q3.31 What circumstances brought you to seek treatment/ enter recovery?

- ○ Incarceration/arrest (1)
- ○ Physical/mental health issue (2)
- ○ Overdose (3)
- ○ Recommendation from friends/family (4)
- ○ Recommendation from health/treatment professional (5)
- ○ Other circumstance/personal choice (6)
- ○ Other (7) _____

Q3.32 How long have you been in recovery from substance use?

- ○ Less than 6 months (1)
- ○ Between 6 months - 1 year (2)
- ○ Between 1 and 3 years (3)
- ○ Between 3 and 5 years (4)
- ○ Between 5 and 10 years (5)
- ○ Between 10 and 20 years (6)
- ○ More than 20 years (7)

Q3.33 Have you ever used medications (eg, methadone, buprenorphine (Suboxone), or naltrexone (Vivitrol)) to assist you in your recovery?

- ○ No (1)
- ○ Yes (2)

Q3.34 Was the medication prescribed by a health care professional?

- ○ No (1)
- ○ Yes (2)

Q3.35 Was the medication helpful for your recovery? Please explain.

_____

_____

Q3.36 Were you offered support by anyone with a shared experience (peer recovery support) during your treatment/ recovery?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.37 Do you think that peer recovery support (anyone with a shared experience) would have been helpful in your recovery if you had been offered it?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.38 Have you ever attended recovery programs or meetings (other than in treatment)?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.39 Are you currently attending recovery programs or meetings regularly (other than in treatment)?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

Q3.40 Is there something additional that could have helped you in your recovery during your experience of **substance use disorder treatment** that you did not have?

○ Yes (1)
○ No (2)

Q3.41 What?

_____

Q3.42 Have you used the emergency department as a result of your substance use?

○ Yes (1)
○ No (2)
○ Other (3) _____

Q3.43 Please tell us how many times you used the emergency department as a result of your use.

○ Once (1)
○ 2-3 times (2)
○ 4-5 times (3)
○ More than 5 times (4)
○ Other (5) _____

Q3.44 Did you experience an overall supportive or non-judgemental response to your substance use during your visits to the emergency department (ED), as referenced in the previous question?

○ Yes (1)
○ No (2)

Q3.45 What were positive supports/services that the emergency department provided for you?
Select all that apply if applicable:

- Provided appropriate medical care (1)
- Treated you with autonomy and respect (2)
- Evaluated for substance use disorder/mental health services (3)
- Referred to appropriate mental health/treatment resources (4)
- Assisted with follow-up appointments and care (5)
- Contacted supports/loved ones as necessary (6)
- Provided non-judgmental care that was not offensive or shaming (7)
- I have never been to the ED For substance use (8)
- The ED provided no positive supports/services (9)
- Other (10) _____

Q3.46 What additional services, if any, could the ED have provided to be more helpful/supportive in recovery and substance use treatment?

_____

Q3.47 The next series of questions are about life events, both positive and negative, that occurred or did not occur when you were in active substance abuse and if they occurred and did not occur when you were in recovery. Please circle the appropriate "yes" or "no" response in the box provided.

	I EXPERIENCED/ ENGAGED IN THIS WHEN I WAS ACTIVELY USING		I EXPERIENCED/ ENGAGED IN THIS WHEN I WAS IN RECOVERY	
	NO (1)	YES (2)	NO (1)	YES (2)
Debts/poor credit/bankruptcy/unable to pay bills (1)	○	○	○	○
Had a bank account (2)	○	○	○	○
Had good credit/credit restored (3)	○	○	○	○
Had my own place to live (4)	○	○	○	○
○ wed back taxes (5)	○	○	○	○
Paid back personal debts (6)	○	○	○	○
Paid bills on time (7)	○	○	○	○
Paid taxes/paid back taxes (8)	○	○	○	○
Involvement of Child Protective Services or lost custody of children (other than through divorce) (9)	○	○	○	○
Participated in family activities (10)	○	○	○	○
Planned for the future (eg, saving for retirement, taking vacations) (11)	○	○	○	○
Regained child custody from protective services or foster care (12)	○	○	○	○

(Continued)

(Continued)

	I EXPERIENCED/ ENGAGED IN THIS WHEN I WAS ACTIVELY USING		I EXPERIENCED/ ENGAGED IN THIS WHEN I WAS IN RECOVERY	
	NO (1)	YES (2)	NO (1)	YES (2)
Was victim or perpetrator of domestic violence (13)	○	○	○	○
Volunteered in community and/or civic group (14)	○	○	○	○
Voted (15)	○	○	○	○
Contracted infectious disease (eg, Hep C or HIV/AIDS) (16)	○	○	○	○
Exercised regularly (17)	○	○	○	○
Experienced emotional/untreated health problems (18)	○	○	○	○
Frequent Emergency Room visits (other than for ongoing medical/mental condition) (19)	○	○	○	○
Frequent use of health care services (eg, hospitals, clinics, detox) (20)	○	○	○	○
Had regular dental checkups (21)	○	○	○	○
Had primary care provider (22)	○	○	○	○
Had healthy eating habits/good nutrition (23)	○	○	○	○
Took care of my health (eg, regular medical checkups, sought help if needed) (24)	○	○	○	○
Had no health insurance (25)	○	○	○	○
Lost health insurance/coverage (26)	○	○	○	○
Got arrested (27)	○	○	○	○
Damaged property (your own and/or others) eg, cars (28)	○	○	○	○
DWI (29)	○	○	○	○
Expunged my criminal record (30)	○	○	○	○
Got my driver's license back (31)	○	○	○	○
Lost right to vote (32)	○	○	○	○
Lost/suspended driver's license (33)	○	○	○	○
Had no involvement in criminal justice system (34)	○	○	○	○
Got off probation/parole (35)	○	○	○	○
Restored professional or occupational license (36)	○	○	○	○
Served jail/prison time (37)	○	○	○	○
Dropped out of school (38)	○	○	○	○
Got fired/suspended at work (39)	○	○	○	○
Frequently missed work or school (40)	○	○	○	○
Furthered my education and/or training (41)	○	○	○	○
Received positive job/performance evaluations (42)	○	○	○	○
Lost professional or occupational license (43)	○	○	○	○
Started my own business (44)	○	○	○	○
Steadily employed (45)	○	○	○	○

Q3.48 The next series of questions is going to ask you about your quality of life.

Q3.49 Overall, how would you rate your current **quality of life**?

- ○ Poor (1)
- ○ Fair (2)
- ○ Good (3)
- ○ Very Good (4)
- ○ Excellent (5)
- ○ Other (6) _____

Q3.50 What do you feel is **helpful** in your recovery?
Select all that apply

- Social supports (family/friends/peers) (1)
- Cultural community beliefs/activities (2)
- Personal achievements/initiative/mindfulness (3)
- Physical supports (food, housing, financial stability) (4)
- Community supports (support groups, recovery-positive organizations, de-stigmatized climate) (5)
- Recovery community (6)
- Social activities that do not involve substances (7)
- Other (8)
- None of the above (9)

Q3.51 What do you feel is **missing** from your recovery?
Select all that apply

- Social supports (family/friends/peers) (1)
- Cultural community beliefs/activities (2)
- Personal achievements/initiative/mindfulness (3)
- Physical supports (food, housing, financial stability) (4)
- Community supports (support groups, recovery-positive organizations, de-stigmatized climate) (5)
- Recovery community (6)
- Social activities that do not involve substances (7)
- Other (8) _____
- None of the above (9)

Q3.52 In what situations have you experienced stigmatization or discrimination (such as denied you services, treated you poorly, or disrespected you) based on having a substance use disorder?
Select all that apply

- Seeking medical treatment (1)
- Seeking mental health treatment (2)
- Seeking recovery services (3)
- Seeking housing (4)
- Applying for a job (5)
- Applying for government aid (6)
- Family/friend interactions (7)
- School/college applications (8)
- Social engagement/services (9)
- Public transportation (10)
- Going to church/faith-based activity (11)
- Other (12) _____
- None of the above (13)

Q3.53 What can the community do, if anything, to reduce the stigmatization (hurtful or disrespectful treatment/language) of people with substance use disorders?

_____

_____

Q3.54 Do you think that any of the following would be helpful to reduce stigmatization (hurtful or disrespectful treatment/language) of people with substance use disorders?
Select all that apply

- Substance use community forums/workshops (1)
- Educational presentations for family/friends (2)
- Health care provider education (3)
- Preventative education for youth (4)
- Over-the-counter access to naloxone (5)
- Removal of hurtful language (eg, junkie, addict, dirty, clean) (6)
- Active listening/concern from community members (7)
- Respectful and considerate physical/mental health care (8)
- Respectful and considerate substance use disorder treatment (9)
- Respectful and considerate law enforcement interactions (10)
- Community advocates for substance use disorder as a chronic treatable medical condition like diabetes or asthma (not a moral failing, or a personal choice) (11)
- Use of term "substance use disorder" rather than "addiction" (12)
- Other (13) _____
- None of the above (14)

Q3.55 **Is there anything you would like to add about** supports and barriers to recovery in your community? Please include additional thoughts below.

_____

_____

Q3.56 If you would like to receive a gift card for completing this survey, please include a valid email address below. The email address you provide will not be connected to the data you provided in the survey.

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