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# An Exploration of Young Adults With Opioid Use Disorder and How Their Perceptions of Family Members' Beliefs Affects Medication Treatment

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**Background:** Young adults with opioid use disorder (OUD) have low engagement and retention in medication treatment. Families are uniquely situated to play an important role in treatment decisions. This qualitative study explored how young adults with OUD perceive their families' beliefs about OUD and medication treatment, and how those beliefs impacted young adults' beliefs about their own treatment decisions.

**Methods:** We conducted a qualitative study of a convenience sample of 20 English-speaking young adults with OUD receiving care from

an urban safety net hospital in Massachusetts. We explored young adults' perceptions of how families viewed medication treatment. We conducted semi-structured interviews that were recorded and transcribed. We analyzed interviews using hybrid inductive and deductive categorization to support thematic analysis.

**Results:** We identified 3 themes. First, family history of substance use disorder and treatment negatively impacted how young adults perceive their OUD and medication treatment. Second, young adults shared that many families held negative or stigmatizing views of medication treatment. Finally, acceptance by family was important but young adults acknowledged that keeping treatment decisions from family was sometimes necessary.

**Conclusions:** In this qualitative exploration of young adults with OUD, we found that young adults felt that their families held important beliefs about the kind of treatment family members found most appropriate, and these perceived family beliefs impacted their treatment choices. Future research to improve engagement and retention of youth adults with OUD could target the beliefs of family members.

**Key Words:** family, gender, medication for opioid use disorder, nonfatal overdose, opioid-related disorders, stigma, young adult

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Young adults (ages 18–25) have the highest prevalence of opioid use disorder (OUD) of all age groups,<sup>1</sup> and the fatal opioid overdose rate among young adults has significantly increased since 1999.<sup>2,3</sup> Despite this, young adults have higher relapse rates and lower treatment retention rates than older adults in medication treatment<sup>4,5</sup> and use of buprenorphine among young adults has decreased in recent years.<sup>6</sup> The reasons for low engagement in medication treatment among young adults are multifactorial and include lack of availability of age appropriate addiction treatment programs.<sup>7</sup> There is also a need to better understand how young adults make decisions about OUD and treatment, and who or what may influence their decision-making process, including their families. Young adulthood is a distinct development stage, when an individual may rely more on families to make decisions, including health care related decisions.<sup>8,9</sup> Families are therefore uniquely situated to play an important role as they often continue to influence young adults' lives.<sup>9</sup>

Family beliefs about treatment, including positive or negative beliefs about medication treatment, may have an impact on young adults' decisions to engage in care. Families also have the potential to encourage engagement in care and provide ongoing support outside of the treatment system. Family involvement in the treatment of adolescents with substance use disorder (SUD) has been shown to improve outcomes, including retention. In a pilot study of adults with OUD, the primary outcome of retention in care was improved when the family was trained in a family-focused intervention called Community Reinforcement and Family Training for Treatment Retention.<sup>10</sup> There are limited data, however, exploring how families' beliefs about OUD and treatment may affect young adults' treatment decisions.

The objective of this qualitative study was to explore how young adults with OUD perceive their families' beliefs about OUD and medication treatment, and how those beliefs impacted young adult treatment decisions. The results of this investigation can inform interventions to improve engagement in treatment of young adults with OUD by targeting the family.

## METHODS

### Study Design and Population

We conducted a qualitative study of young adults with OUD who received care at outpatient SUD programs at Boston Medical Center, an urban safety-net hospital in Boston, Massachusetts. The institutional review board of Boston University Medical Campus approved all study protocols.

### Eligibility and Sampling

We used convenience sampling to recruit eligible participants who were between 18 and 29 years old, able to speak and understand English, and provide informed consent. We did not restrict eligibility to having had previous experience with medication treatment; however, 19 of 20 young adults recruited for this study had current and/or previous experience with medication treatment. We considered young adults through age 29 years based on clinical experience and data that suggest that young adulthood can extend through the 20s.<sup>11</sup>

### Recruitment

Two trained research assistants completed interviews from June 2019 to February 2020. We used a warm hand-off approach for study recruitment, with clinical providers introducing the research study and research staff. Research staff completed a 2-question eligibility screener with interested participants, and if eligible, obtained verbal informed consent in a confidential study room. Participants received a \$25 debit card as compensation for interview completion.

### Data Collection

We created 3 guides with open-ended questions for our semi-structured interviews (see Supplemental Interview Guide 1, <http://links.lww.com/JAM/A395>; Supplemental Interview Guide 2, <http://links.lww.com/JAM/A396>; and Supplemental Interview Guide 3, <http://links.lww.com/JAM/A397>). These guides covered the same domains of interest, but questions were tailored to participants' previous experience with MOUD. The guides are available as an appendix.

The guide included the following domains: experience with MOUD, sources, and impact of stigma, addiction and recovery supports, and interactions with family, healthcare professionals, and social networks. The analysis and results related to young adult definitions of addiction and recovery have been previously published.<sup>12</sup> The length of interviews ranged from 40 and 70 minutes. We recorded interviews and used Audacity (version 2.4.2, 2020) software to change pitch and tone of audio recordings before sending them to a third-party vendor for verbatim transcription. Research staff reviewed transcriptions against audio files for fidelity and removed any remaining identifiers from transcripts. All names used in this paper are pseudonyms and the ages are not the actual ages of the participants.

### Data Analysis

We used a hybrid inductive and deductive approach to conduct a thematic analysis of the data.<sup>13,14</sup> As a first step, 4 members of the research team created a deductive codebook based on the domains assessed in the interview guide. Once these broad codes were established, the interviews were coded using NVivo (QSR International Pty Ltd., version 11, 2017) software to apply finalized codes to transcripts. During consensus meetings among the 2 coders (SMB and SFS), additional codes and modifications to the code book were made. Each transcript was coded independently by 2 coders and examined for agreement. Coding pairs met to discuss discrepancies to reach consensus.<sup>15</sup> Regular discussions between the larger research team resolved any outstanding disagreement.

Authors (SMB and SFS) led a close analysis of codes related to family systems, treatment decision making, and experiences of stigma, drawing iterative categorization approaches (Neale, 2016). During this phase, we explored transcripts line by line to identify themes, categories, and concepts. We then contextualized our findings in relation to existing research.

## RESULTS

Participants ranged from 21 to 29 years old, average age was 26 years, and median age of 25 years. Fifteen identified as non-Hispanic White, 2 participants identified as Hispanic/Latino, 2 participants identified as mixed race, and 1 participant identified as Asian American. Twelve participants identified as male, 7 identified as female, and 1 identified as nonbinary. We identified 3 themes related to families, described below.

### **Theme 1: Family history of SUD and treatment negatively impacts how young adults perceived their substance use and treatment.**

About half of the young adults described a history of alcohol and other SUDs in immediate and extended families and recalled experiences from childhood that impacted their goals for themselves in addition to their treatment decisions. They talked about the desire to not turn out like their parents because resulting feeling of failure and inevitability. Dakota (non-binary, 23) shared significant shame that they would have developed a SUD given their family history:

“And, I think, particularly like as someone who was the child of someone who had a substance use disorder, that was very difficult, because growing up it's sort of like the

thing that will never happen. The thing that you say will never happen to you and so I think there's a unique sense of failure and shame that comes from that inter-generational aspect, as well."

Other participants who grew up with parents with SUD in treatment expressed their parents' treatment impacted their current treatment decision-making related to MOUD. For example, 2 young adults held negative views about methadone because they believed it had negatively affected their parents' ability to function and to be parents. Methadone treatment was directly associated with adverse aspects of their childhood. Jeremiah (male, 28) said,

"I'll tell you the reason I don't like methadone. Just because it's like, my mom was on methadone for 9 years and she was basically asleep those 9 years. And, she was on Klonopins [clonazepam], also. So, every blanket had burn holes in the sheets. And, I had to learn how to cook at a young age because of that."

In the case of Robert (male, 29), whose father and mother were in recovery from opioids and had been treated with methadone, he described being "judgmental" about methadone treatment and the length of time that his parents had been on it. His feelings were consistent with how he understood others in his family viewed methadone. He shared:

"Like I said, my father and my mother were on it when I was little and. . . I never want to be like them. And something in the back of my mind has always [been] judgmental. . . They're junkies, they're on methadone. All my cousins, anybody that mentions suboxone or methadone to them [cousins] they're like that's for junkies, that's for junkies."

Robert also viewed his mother as a success and someone with goals because she had stopped methadone, "He [father] said if he gets off of methadone he's just going to go back to drugs. My mom on the other hand, she had a different. . . She had goals. She's doing real well now." In Robert's view, although both of his parents were in recovery from opioids, his mother was the success because she was no longer in treatment with methadone and doing well. This is despite his father feeling that he would relapse without treatment with methadone.

One young adult described their parents' ongoing substance use as a challenge, but they also wanted to find ways to be supportive. When discussing their father's cocaine use, Dakota (non-binary, 23) said:

"I called him [my father] and offered to teach him how to use fentanyl testing strips and give him a box of them and so I went down and did that. It was very triggering for me. . . He's reached out for my help on a couple of occasions now. Which has been really wonderful and like beyond anything I could have expected and also really hard on me."

## **Theme 2: Many families held negative or stigmatizing views of medication treatment.**

More than half of young adults described perceptions that family members held stigmatizing views about both SUD and MOUD. For them, family involvement in or awareness of treatment often led to complications and more to "worry about." They recognized that families' concerns came from a place of care and lack of understanding but nonetheless felt it was easier to manage their treatment on their own. Louis (male, 29) said,

"I didn't want them [my parents] to know that I was taking the Suboxone. If I went and made an appointment and the rule is when I'm at home, my mother has to give me the medications. . . Anyway it just would have been something to worry about. They wouldn't have liked it and it would have created an issue because they're not a fan of MAT. . . But now that I live on my own I'm able to take it."

One participant reported how her parents were very focused on the duration of medication treatment and she felt pressure about tapering off MOUD. This was despite her being clear that this could lead to relapse. Maria (female, 29) shared:

"The other day my mom was like, 'Are you getting off of it yet? How long till you get off it' and I'm like, 'Mom, we just talked about this. If I get off it too quick, I'm just going to relapse. Let me do it in my own time.' She's like, 'It's been long enough.'"

Even when a family was not explicitly asking about duration or expectations of treatment, the participant perceived implicit or explicit disapproval with ongoing treatment decisions. Maria (female, 29) described her interactions with her father, who was in recovery himself:

"I think for him [my father], he's old school, he knows the person I was when I was on nothing, when I was in high school, when I was in middle school. He wants me on nothing but I have to explain to him that it's so bad out in these areas. If I get off it too quick, I'm just going to relapse. . . He's been really understanding even though I know what he's really thinking"

Brett (male, 25) specifically talked about the stigma related to treatment with buprenorphine that he experienced during interactions with his father who had an active alcohol use disorder. He was able to have some perspective about the disconnect between his father's active alcohol use and calling Brett a "junkie" (implication of not being in treatment or recovery) because he was taking buprenorphine.

"My father, who is an alcoholic. . . he would get drunk and he would call me a junkie. Regardless of whether I was doing Suboxone or blah, blah, blah, the stigma was still there. Even a man that's drunk as a skunk, drunk on bourbon, a musician, he's been around drug addicts his whole life, the stigma is still there. . . I found that to be very interesting. I mean, this man is an alcoholic and actively

drinking and the stigma is still there. It hasn't gone anywhere"

Participants described family members asking questions or making comments about MOUD that highlighted stigmatizing views of both having a SUD and MOUD. They expressed feeling as though they had to defend to their family members how they were treated within healthcare systems. Elliot (male, 24) said:

"Well, my stepdad, he's the one that actually said. . . 'I'm surprised [hospital name] treats you like a patient, especially with you being on that stuff.' I'm just like how are they supposed to treat me? Because I'm on the Suboxone clinic are they supposed to treat me any less?"

Yet family views about MOUD were not all negative. About 1/3 of young adults shared that they received support from parents and siblings regarding their medication treatment. As Glen (male, 28) said,

I've got 2 sisters. One of them is younger. She is very supportive and understanding of me being on Suboxone. As for my older sister, she's on it as well. My parents are understanding. My mother has gone to meetings, Al-Anon meetings and stuff and understands about it, and has seen throughout the years first-hand with me and my sister how it has helped us.

Support for MOUD was not always driven by confidence in the efficacy of the treatment. In Colin's (male, 26) case, he felt that their family's enthusiasm for MOUD was driven by a fear of relapse.

"They took care of me growing up. They would always ask, 'Oh, did you go get your shot again? How's that going? All right, cool.' Then when the day comes that I explain, 'Oh, I didn't go back and get my shot.' They'll freak out a little, they'll be like, 'But it was helping so much.' I'll be like, 'No, it helps to a degree, but I'm the only person that can help myself. I need to learn to help myself.' Very supportive, but almost like concerned that I could never live without it or something because they're just so afraid of me going back to using."

### **Theme 3: Acceptance by family was important to young adults but they acknowledged that keeping treatment decisions from family was sometimes necessary.**

A few participants felt that they could eventually share that they were taking medications because they were currently doing well in their recovery. These participants identified that their parents' goal was for them to stop using substances and hoped that parents could eventually recognize that medication treatment was an important part of their recovery. Still, there was something that was preventing Brett from sharing his treatment decisions with his mother. As he (male, 25) said,

"I pretty much get support all round from people, besides my mom. But I'm sure if I told her, at some point, she'll end up supporting me anyway because she

supports me in my recovery. If I tell her like, 'Look, I've been on Suboxone this whole time, and you never seen me high.'"

Other participants felt that they could be open with certain people in their lives about treatment, but that they needed to keep MOUD hidden from parents because of lack of understanding. The same participant, Brett (male, 25) described how his mother was trying to learn but still had stigma about medication treatment that prevented him from sharing he was on Suboxone.

"My mother doesn't know I'm on Suboxone because she doesn't really know much about addiction. She's trying to learn. I haven't told her I'm on it because there's the stigma around it. Like methadone, she believes people who use it are just still getting high off the medication, but I don't get high off of it. I never got high off of it. It helped me get off the drugs."

One young adult expressed a concern that sharing with others about treatment with medications would also signal the extent of their drug use. The hiding of treatment did not specifically have to do with MOUD but the stigma related to OUD. Shaun (male, 25) said:

"I haven't told my mother I'm on Suboxone. She didn't know. . . much about my drug use anyway but if she knew I was on Suboxone then she would know the other stuff. That's the reason I don't like it all over the place"

## **DISCUSSION**

In this qualitative study of young adults with OUD we found that family history of SUD and experiences with treatment affect the perceptions that young adults have about their own treatment. Furthermore, some family members held stigmatizing views of MOUD that led to young adults not sharing decisions about treatment. These findings highlight a potential missed opportunity to engage with families in the treatment of young adults with OUD.

This study adds to the existing literature about parental influence on decision-making in young adults. One of the key developmental tasks of young adulthood is to establish autonomy, which may include making independent decisions about health and medical care. However, to date, the existing literature has been limited in describing how young adults make decisions about addiction treatment. In 1 experimental study unrelated to substance use, young adults were more likely to prioritize relationships with parents compared to peers when making decisions. Interestingly, in that study, relationship quality moderated the effect although age did not.<sup>16</sup> The importance of the family has also been found in studies examining parental attitudes toward alcohol use and subsequent risky alcohol use in adolescence.<sup>17,18</sup> Given this influence that the family has on decision-making in general and use of alcohol, it is reasonable to expect that family beliefs about treatment would also impact young adults.

In this study, many young adults described family histories of both alcohol use disorder and SUD. In many cases, their experiences in childhood led to beliefs that medication treatment, and specifically methadone, negatively impacted their parents' ability to provide care for them. Those beliefs, which developed over years, seemed to be internalized and contributed to more fixed ideas and doubts about the benefits of methadone. For example, the young adult whose father had been abstinent from opioids but had remained on methadone treatment viewed his mother as successful for tapering off and being able to achieve her goals. As we have learned in our other studies of this age group, young adults have diverse experiences and some define recovery as more than abstinence. They want to return to normalcy.<sup>12</sup> Ideas or perceptions that they develop during childhood may have an impact on how they decide to engage in treatment or in treatment choices. Family history is an important risk factor for developing an alcohol use disorder or SUD. Family history of addiction is often collected as part of an OUD history in clinical settings. Collecting additional information related to family history of treatment may provide an opportunity to address stigma or misconceptions about treatment that may affect young adult treatment decisions. Studies of family-based interventions to address MOUD-related stigma should consider including family history of substance use and treatment experiences.

Some young adults shared that their families have stigmatizing views of medication treatment and were focused on the duration of treatment. For some young adults, that informed their decision to not share details of treatment with parents or other family members. Despite this, young adults expressed that, overall, families wanted them to be in recovery and be well. Young adults perceived that for most family members, resistance to medication treatment originated from a place of concern, lack of understanding, or prior negative experiences. There is an opportunity in young adult SUD treatment to provide families with information to ensure they are familiar with the potential benefits of treatment, including both improved survival and also reduction in other health-related risks. Such information may lead to greater support of medication treatment. However, research has also shown that knowledge alone is not enough to change beliefs or behaviors. There may be opportunities for intervention development to provide families with knowledge about medication treatment, including addressing misconceptions and stigma. Recent reviews of stigma and discrimination related to mental illness show some positive impacts of interventions to reduce stigma in mental health.<sup>19,20</sup> However, authors highlighted the limitations of the current literature and need for additional rigorous research to develop and implement effective interventions to reduce stigma. This study contributes by highlighting the need for interventions to address stigma related to medication treatment and the important, and often overlooked, opportunity to include families as intervention targets.

There are limitations to this study. The participants were all treatment-seeking or treatment involved young adults with experience taking medication treatment. It would be important to also include the perspectives of young adults who have

not been on medication treatment to explore whether their experiences with families are different. It may be that the impact of the family may be even greater in this population. Although the objective of this study was to understand how young adults perceive their family beliefs, we did not interview family members themselves. Other work could include family members as participants and ideally include them in intervention development. Finally, although the sample size was appropriate for a qualitative study, it is a small sample. Qualitative studies can often be important in generating new hypotheses and areas of future research as described in the conclusions.

## CONCLUSIONS

Families can be powerful allies in working with young adults with OUD. They also may have strong beliefs about what kind of treatment may be most appropriate for their family member. In the context of poor engagement and retention in care of young adults with OUD, there is a critical need to explore new ways to improve care and a need for evidence-based approaches that include families.<sup>21</sup> Interventions that consider family relationships may be an important strategy to engage and retain young adults in care for OUD.

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