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ORIGINAL ARTICLE

Disclosure, Stigma, and Social Support Among Young People Receiving Treatment for Substance Use Disorders and Their Caregivers: a Qualitative Analysis

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Abstract Relational processes (i.e., disclosure, stigma, social support) experienced by youth with substance use disorders (SUDs) and their caregivers may act as barriers to, or facilitators of, recovery but are understudied. Single-session qualitative semi-structured interviews were conducted with 19 patients and 15 caregivers recruited by clinicians from a SUD program. There was variability in disclosure experiences, including how many people knew about patients' SUD diagnosis and treatment, whether patients or caregivers primarily disclosed to others, and feelings about others knowing about one's or one's child's SUD treatment. After disclosing, patients and caregivers experienced stigmatizing (e.g., social rejection) and supportive (e.g., understanding, advice) reactions from others. Disclosures may have important implications for relationship and recovery-related outcomes. Moreover, some child-caregiver pairs have significant disagreements regarding disclosure of SUD treatment. Addressing relational processes within treatment by encouraging patients and caregivers to share the disclosure decision-making process may support the recovery of youth with SUDs.

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Substance use disorders (SUDs; i.e., the recurrent use of alcohol and/or drugs that leads to clinically and/or functionally significant impairment) during adolescence and emerging adulthood set the stage for poor health outcomes throughout the lifespan, including chronic brain changes, escalating addiction, poor functional outcomes, overdose, and death (Brook et al. 2016; Gruber et al. 2012; McCabe et al. 2007; Meruelo et al. 2017; Moss et al. 2014; Squeglia et al. 2009; Truong et al. 2017). Successful treatment of SUDs among youth may reduce the risk of these outcomes. Caregivers (i.e., adult biological or adopted family members of youth, including parents) are often involved in treatment and evidence suggests that treatments that incorporate caregivers are the most efficacious (Waldron and Turner 2008).

Relational processes, including disclosure, stigma, and social support, experienced by both patients and their caregivers may play a powerful role in the recovery trajectories of youth with SUDs, acting as barriers to, or facilitators of, reduced substance use, treatment retention, and treatment adherence. Yet, these processes are understudied among youth with SUDs and their caregivers. The current study therefore explored relational processes experienced by youth with SUDs and their caregivers via qualitative interviews.

Disclosure

Disclosure involves the sharing of information by a patient or caregiver about SUD history, diagnosis, and/or treatment with others for the first time (Chaudoir and Fisher 2010). SUD treatment is often concealable, meaning it is not readily apparent to others, and so patients and caregivers must typically disclose their or their child's SUD diagnosis and treatment for others to become aware of it. Patients and their caregivers may disclose for a variety of reasons, such as to excuse absences from school or work during treatment or explain sobriety in settings where substance use is normative. The disclosure process model describes disclosure as a process wherein characteristics of disclosures shape others' reactions to those disclosures (Chaudoir and Fisher 2010). In turn, reactions to disclosures lead to long-term behavioral, psychological, and physical health outcomes, some of which may be relevant to recovery.

Much of the existing theory and research on disclosure focuses on how individuals disclose concealable information about themselves to others (Chaudoir and Fisher 2010; Derlega et al. 2004). There is far less research on how people in relationships disclose concealable information about one member of a relationship to others with whom they are mutually acquainted. Some research on couples in romantic relationships suggests that members may agree about to whom and how to disclose health-related information (Leiblum and Aviv 1997). Disclosure processes among youth with SUDs and their caregivers, however, may be quite different as these relationships may involve greater conflict and struggle for control over youth substance use and treatment decisions (Cornelius et al. 2017).

Stigma and Social Support

Others may react to disclosures of SUD treatment in stigmatizing and/or supportive ways. Perceived stigma (i.e., experiences of discrimination in the past or present) from others is associated with dropout from treatment and continued substance use among adults receiving SUD treatment (Brewer 2006; Simmonds and Coomber 2009). Anticipated stigma (i.e., expecting experiences of discrimination in the future) from others may further drive people to conceal their recovery, including by not engaging in treatment behaviors so that others do not learn about their SUD (Earnshaw et al. 2013). People receiving treatment for SUDs, who are often in early recovery, report being socially rejected by friends and family, are not hired by potential employers, and are distrusted by healthcare providers (Anstice et al. 2009; Earnshaw et al. 2013; Luoma et al. 2007). In contrast to perceived stigma, perceived social support (i.e., comfort, information, and/or assistance) from others is associated with outcomes that facilitate recovery, including decreases in SUD severity over time, greater retention in care, and lower psychological distress (Dobkin et al. 2002). Examples of social support support for people in recovery from SUDs may include emotional comfort, information about treatment options, and assistance with scheduling appointments.

Caregivers also experience stigma and social support from others, which may ultimately impact their children's SUD recovery. Caregivers may experience associative stigma due to their child's SUD, which is stigma that one personally experiences due to one's relationship with another person with a socially devalued characteristic (also called courtesy stigma; Goffman 1963). Evidence suggests that parents of children with SUDs are viewed as responsible for their child's SUD onset and relapses, likely to have substance use problems themselves, incompetent as parents, and pitiable (Corrigan et al. 2006). Associative stigma may undermine the capacity of caregivers to support their children's SUD treatment by harming caregivers' psychological wellbeing, leading to anxiety or depression, and/or preventing caregivers' from asking others for help or support. In contrast, caregivers who receive social support, including emotional and tangible support, from others may be better-equipped to support their children's SUD treatment.

Current Study

Evidence suggests that relational processes, including disclosure, stigma, and social support, play powerful roles in recovery from SUDs. Yet, little is known about these processes among youth with SUDs and their caregivers. Greater insight could inform treatment strategies to address relational processes and support youth recovery. To this end, the current study qualitatively explored relational processes experienced by youth with SUDs and their caregivers. The study focused on adolescents (12–18 year olds) and emerging adults (19–25 year olds; Arnett 2000) given evidence that trajectories of substance use and risk of SUDs show marked increases during these time periods in the USA (Flory et al. 2004; Kann et al. 2014; Maggs and Schulenberg 2004) and patients of these ages may seek treatment at programs focused on youth that often include caregivers (Waldron and Turner 2008).

Data and Methods

Participants were recruited from a SUD treatment program for youth in the Northeastern United States. Eligibility criteria for patients included being 12–25 years old and receiving SUD treatment. Eligibility criteria for caregivers included caring for a child aged 12–25 years old who was receiving SUD treatment. The study was introduced to patients and caregivers by program clinicians. When possible, patients and caregivers were recruited as a pair. Patients engaged in treatment without their caregivers were also recruited to gain insight into the experiences of youth with less engaged caregivers. Contact information of individuals who expressed interest in the study was given to the research team, who scheduled interviews to follow an upcoming appointment. After informed consent was obtained, patients and caregivers were taken to separate spaces where they were independently interviewed. Interviews were conducted in a single session that lasted approximately 45 min to an hour and were digitally recorded. Participants received $50 gift cards and parking validation. All study procedures received institutional review board approval.

Participants

Nineteen patients and 15 caregivers participated. Patients ranged in age from 13 to 25 years (mean = 18.63, SD = 2.95); 11 identified as boys or men and 8 as girls or women; and 14 identified as White, 2 as Black, 1 as Native American, 1 as White and Black, and 1 as White and Native American. Caregivers included biological parents, adoptive parents, and grandparents. Caregivers ranged in age from 36 to 67 years (mean = 54.20, SD = 8.80); 2 identified as men and 13 as women; and all 15 identified as White. Although patients and caregivers were not required to be related, all caregivers who participated were related to a patient who also participated. Four patients participated without their caregivers; these patients were older and their caregivers were not involved in their treatment.

Interview Protocol

Using a grounded theoretical approach, semi-structured interview protocols were followed to explore participants' experiences with SUD treatment, focusing on barriers to and facilitators of treatment success. Protocols for patients and caregivers were very similar, with patients reporting on their own experiences with treatment and caregivers reporting on their experiences with their child's treatment. The guide included 17 questions, focusing on experiences with SUD treatment, disclosure, stigma, and social support (see Table 1 for example questions). Participants were also asked questions about their goals for treatment, which have been reported elsewhere (Cornelius et al. 2017) and were not the focus of this analysis.

Analysis

Digital recordings of interviews were first transcribed for analysis. Following standard data analysis methods (Miles and Huberman 1994), two members of the study team read all of the transcripts to identify recurring themes across interviews. They then created a codebook listing each theme accompanied by a detailed description, inclusion/exclusion criteria, and example quotes. The current paper focuses on a subset of themes from the overall codebook, including (1) disclosure of SUD history, diagnosis, and/or treatment (i.e., descriptions of disclosures of SUD or SUD treatment to others, including how one feels about others knowing), (2) negative reactions from others (i.e., examples of poor treatment or stigma from others based on SUD or SUD treatment), and (3) positive reactions from others (i.e., examples of favorable treatment or support from others based on SUD or SUD treatment). Using *Dedoose*, a qualitative data management program, the two members of the team then coded areas of text relevant to each theme (Dedoose 2016). They first independently coded the same random sample of approximately 20% of transcript text. Their interrater reliability was strong (kappa = 0.89). One member of the team then coded the rest of the interviews.

Table 1 Example questions from interview protocol

Themes	Patient interview	Caregiver interview
Opening question	Please tell me about your experiences with substance abuse treatment, including when you first started, why you started, how it's gone so far, and whether you've had gaps in treatment.	Please tell me about your experiences with your child's substance abuse treatment, including when they first started, why they started, how it's gone so far, and whether they've had gaps in treatment. Also, please describe your involvement in your child's treatment.
Disclosure to others	Who knows that you're receiving treatment? You don't have to tell me their names, but describe who they are in your life, like a family member, friend, teacher, etc.	Who knows that your child is receiving treatment? You don't have to tell me their names, but describe who they are in your life, like a family member, friend, teacher, etc.
	(For each person discussed): How did he (/she) find out that you're receiving treatment? How do you feel about them knowing about your treatment?	(For each person discussed): How did he (/she) find out that your child is receiving treatment? How do you feel about them knowing about your child's treatment?
Stigma from others		How much has the stigma of your child's drug (/alcohol) use been a problem for them? In other words, do you feel that people treat your child differently or mistreat them because they know that your child uses (/has used) drugs (/alcohol)?
	How much has the stigma of using drugs (/alcohol) been a problem for you? In other words, do you feel that people treat you differently or mistreat you because they know that you use (/have used) drugs (/alcohol)?	How much has the stigma of your child's drug (/alcohol) use been a problem for you? In other words, do you feel that people treat you differently or mistreat you because they know that your child uses (/has used) drugs (/alcohol)?
Broad treatment from others	Do people treat you differently because they know that you are receiving substance abuse treatment?	Do people treat you differently because they know that your child is receiving substance abuse treatment?
	Do you talk to anyone about these experiences? If so, who do you talk to and what do you talk about?	Do you talk to anyone about these experiences? If so, who do you talk to and what do you talk about?

Interviews were categorized according to two characteristics related to disclosure. First, the proportion of people in the participants' social network who were aware of their or their child's involvement with SUD treatment was categorized as (a) very few people know (i.e., approximately 5 or fewer, often includes only family), (b) some people know (i.e., greater than 5 but not everyone in social network, often includes family as well as friends), or (c) almost everyone knows (i.e., everyone in social network; includes family, friends, school staff, coworkers, and others). Second, the family member who primarily disclosed to others about treatment was categorized as (a) caregivers as primary disclosers, (b) caregivers and patients both as disclosers, or (c) patients as primary disclosers. Characteristics were compared at the dyad level when both the patient and caregiver participated.

Results

Characteristics of disclosures of SUD treatment to others are described from the perspectives of patients and caregivers, including how many people know, who told, and how individuals feel about others knowing. Next, perceptions of reactions from others are described, including stigmatizing reactions, concerns about stigmatizing reactions, and supportive reactions.

Disclosure: How Many People Know

There was variability in the number of people who participants perceived to be aware of their or their child's SUD treatment. Among patients, 6 (31.6%) were coded as perceiving that *very few people know*, 6 (31.6%) as *some people know*, and 7 (36.8%) as *almost everyone knows*. Among caregivers, 3 (20.0%) were coded as perceiving that *very few people know*, 6 (40.0%) as *some people know*, and 6 (40.0%) as *almost everyone knows*. As shown in Table 2, 7 patient-caregiver dyads (46.7%) generally agreed about the extent to which others in their social network knew about their or their child's SUD treatment. A chi-square test comparing patient and caregiver responses was not statistically significant [$\chi^2(4) = 3.38, p = 0.50$]. Only 2 dyads (13.3%) held quite different perceptions, with patients perceiving that *very few people*

Table 2 Patient-caregiver comparisons of disclosure characteristics, $n = 15$ dyads

Caregiver interviewee	Patient interviewee		
How many people know	Very few people know	Some people know	Almost everyone knows
Very few people know	1 (6.7%)	2 (13.3%)	0 (0.0%)
Some people know	1 (6.7%)	3 (20.0%)	2 (13.3%)
Almost everyone knows	2 (13.3%)	1 (6.7%)	3 (20.0%)
Who told others	Caregivers as primary disclosers	Caregivers and patients both disclosers	Patients as primary disclosers
Caregivers as primary disclosers	2 (14.3%)	9 (64.3%)	0 (0.0%)
Caregivers and patients both as disclosers	0 (0.0%)	1 (7.1%)	1 (7.1%)
Patients as primary disclosers	0 (0.0%)	0 (0.0%)	1 (7.1%)

Chi-square tests comparing patient-caregiver responses: How many people know: $\chi^2(4) = 3.38, p = 0.50$; Who told others: $\chi^2(4) = 10.06, p = 0.04$. Dyad count totals to 14 for Who told others because one patient's response was not able to be coded into these categories *know* about their SUD treatment and caregivers perceiving that *almost everyone knows* about their child's SUD treatment. For example, a patient emphasized that only some people knew, including "my parents… the advisor at school, and then a couple of my friends." Their caregiver, however, listed many more people who knew, including "all of our family friends, his close friends and their parents… and at school, his advisor, the school counselor, his teachers from last year… everybody knows."

Participants disclosed their or their child's SUD treatment to several different kinds of people, including family members, friends, teachers and other school staff members (e.g., principals, guidance counselors), and coworkers. Patients and caregivers who were categorized as *very few people know* and *some people know* were able to list who knew about their or their child's SUD treatment, described telling others for a specific purpose, and identified stigma as a reason to not disclose to others. Patients in the *very few people know* category mostly reported that only their parents knew (see Table 3, quote 1). Some patients told their parents because they were concerned about their substance use and wanted help, and others reported that their parents found out through another means (e.g., finding substances among their belongings, observing them when intoxicated). Caregivers also reported that only members of their immediate family knew (see Table 3, quote 2). In contrast to participants in the *very few people know* category, participants in the *some people know* category described telling friends in addition to family (see Table 3, quotes 3 and 4), often to receive social support. Participants described relationship factors that helped them decide to whom they should disclose, including how well they knew others and whether others had experiences with SUDs. One patient noted that their decision to disclose depended "on the person," including "whether they know people who have gone through an experience like mine."

Participants in the *almost everyone knows* category perceived that most members of their social networks knew about their or their child's SUD treatment and so did not list specific others to whom they had disclosed (see Table 3, quotes 5 and 6). These participants discussed disclosing for a variety of reasons, including to receive advice, assistance, and social support. Many participants in this category also recognized that SUD stigma exists; however, they reported that they were not concerned about stigma or were resilient to stigma (see Table 3, quote 6). One patient regularly disclosed on job interviews, saying that "I always decided to tell them… honesty is always the best option" even though "they usually didn't call me back." Participants in this category tended to be living with their own or their child's SUDs for several years longer than those in the other categories.

Disclosure: Who Told Others

Patients generally perceived that caregivers and patients shared disclosures, whereas caregivers generally perceived that caregivers were the primary disclosers. Among patients, 2 (10.5%) were coded as *caregivers as primary disclosers*, 13 (68.4%) were coded as *caregivers and patients both as disclosers*, 3 (15.8%) were coded as *patients as primary disclosers*, and 1 (5.3%) could not be classified into these categories. Among caregivers, 11 (73.3%) were coded as *caregivers as primary disclosers*, 2 as *caregivers and patients both as disclosers* (13.3%), and 2 (13.3%) as *patient as primary disclosers*. As shown in Table 2, 4 patient-caregiver dyads (28.5%) generally agreed about who primarily disclosed to others. In the majority of dyads ($n = 9$, 64.3%), however, patients reported that *caregivers and patients were both disclosers* whereas caregivers reported that *caregivers were the primary disclosers*. For example, a patient reported that both they and their caregivers both disclosed to others, but emphasized the importance of their role in disclosures by noting that "the only way (others would) really find out is if I told them." Their caregiver, however,

Table 3 Patient and caregiver quotes about disclosure

Theme	Patient interviewee	Caregiver interviewee
How many people know		
Very few people know	1. My mom and dad are the only ones that I know for sure.	2. Family… her sisters, her grandparents.
Some people know	3. My whole family. That's sister, brother, sister, mom, dad. My girlfriend, and some of my friends.	4. My sister, a couple friends. But for the most part I have not been advertising it. There is somewhat of a stigma that goes on with it, for better or worse.
Almost everyone knows	5. I can't think of somebody who doesn't (know).	6. Pretty much everybody (knows)… I learned from early on mental health and substance abuse, they're not something to be ashamed of, they're something to get help for.
Who told others		
Caregivers as primary disclosers	7. My mom has a big mouth, she told all my family and before I knew it family members that I haven't been too close to growing up wrote me in rehab. I wasn't like mad or anything, I was just like, OMG, she told so many people… made me feel vulnerable and exposed.	8. We have sort of told people as they needed to know, because she was disappearing and she wasn't at family functions and we sort of told people.
Caregivers and patients both disclosers	9. I don't feel like my brother and sister need to know, and I think my parents are just kind of respecting that, and not telling my brother and sister…I think that it's just not the right time to tell them yet.	10. Periodically, like we have a party or something… she says, "I don't want to tell. What are (cousin)'s parents going to think?" I say, "They don't need to know anything."
Patients as primary disclosers	11. I told (my friends) when I got back from inpatient stuff.	12. He has told people.
Feelings about others knowing		
Negative	13. I felt kind of embarrassed, because it's not something a 17-, 18-year-old should be doing with their lives.	14. I think because I am so worried about the stigma impacting (patient), and us as a family that I kind of almost way overreact, and just don't tell a lot of people.
Neutral or ambivalent	15. It doesn't bother me. They can think what they want.	16. I kind of feel like "if you don't like it, too bad" feeling. I'm doing what's right. So, I try to live by that. But he is a fragile 15-year-old kid so obviously, other people matter a lot more at that point in your life.
Positive	17. I would feel happier because the name he called me ("addict") wouldn't be valid anymore and I could tell him that I'm getting better.	18. I feel good about it. I think it was important for us to have their support going through this… they were very helpful talking with them.

described telling family members and friends, noting that others learned about their child's treatment "from us" (i.e., the caregiver participant and spouse). A chi-square test comparing their responses was statistically significant [$\chi^2(4) = 10.06$, $p = 0.04$].

Patients who perceived their *caregivers to be the primary disclosers* described having little control over the disclosure process. One said that they felt "vulnerable and exposed" after their caregiver told their family members (see Table 3, quote 7). These patients were unsure of to whom their parents had disclosed, as evidenced by one who said that "whoever else my mom has told (knows about my SUD treatment)… probably her friends in AA, or Al-Anon, and maybe some of her relatives." Caregivers who described *caregivers as the primary disclosers* typically felt that others needed to know for a variety of reasons, including to explain their child's absences (see Table 3, quote 8) or due to medical or legal emergencies experienced by their child. Some caregivers described themselves as desperate and needing to talk to other people so that they could access advice and support.

Patients who perceived that *both patients and their caregivers were disclosers* felt that they had more control over the disclosure process. One patient noted that their caregivers were "respecting" their decision to not disclose to their siblings (see Table 3, quote 9). Disclosure was perceived to be a shared process among these participants, and patients and caregivers generally felt that they were aware of to whom their caregivers and children had disclosed. For example, a caregiver discussed talking with their child about their concerns regarding disclosure and then supporting their child's decision to not disclose (see Table 3, quote 10). *Patients who were the primary disclosers* were often older and/or had several more years of SUD treatment than patients in the other categories. Both patients and caregivers in this category described patients having control over disclosure (see Table 3, quotes 11 and 12), with caregivers sometimes not knowing precisely who knew about their child's SUD treatment.

Disclosure: Feelings About Others Knowing

Patients and caregivers expressed a range of feelings about others knowing about their or their child's SUD treatment. Participants who expressed negative feelings described embarrassment (see Table 3, quote 13) and concerns regarding experiencing stigma from others (see Table 3, quote 14). Participants who expressed neutral or ambivalent feelings described not caring about what others think (see Table 3, quotes 15 and 16). Caregivers emphasized that the well-being of their child was more important than what others thought of them. Several caregivers noted that although they were resilient to negative reactions from others, they were concerned that their child would be harmed by these reactions (see Table 3, quote 16). Patients who expressed positive feelings about others knowing thought that receiving treatment would reflect well on them (see Table 3, quote 17). Participants also reported positive feelings about disclosures when they received positive reactions from others, such as social support (see Table 3, quote 18). Some patients noted that their feelings about others knowing changed depending on the disclosure recipient or their recovery status. One said that "at the beginning, like the first time, I felt really embarrassed kind of. After it set in, like during when it was happening, I didn't care at all."

Reactions from Others: Perceived Stigma

Patients and caregivers discussed experiences of stigma after others became aware of their or their child's SUD treatment. Patients noted that family members treated them differently (see Table 4, quote 1) and that friends rejected them (see Table 4, quote 3). Several patients

Table 4 Patient and caregiver quotes about reactions from others

Theme	Patient interviewee	Caregiver interviewee
Perceived stigma	1. People who don't understand drugs, they really treat you differently. Like when I go to a family event, like during Christmas, it's the most awkward thing in the world because they don't understand that you're still a normal person, you just have a problem.	2. She was actually calling people and talking, like random friends of hers, and just for no other reason than to tell them that [my child] had gone to recovery. And sort of like the town crier.
	3. I have lost friends that way that are like… "you're a heroin addict. That's disgusting."	4. In that elementary school group of parents, an old friend of his who used to be very friendly in the dog park and talkative and stuff and now kind of walks quickly past. Maybe my dog offended him, but I don't think so.
Anticipated stigma	5. They would think less of me and I was weak and stuff, and that I couldn't be trusted. They think it's a moral failing… it's just like an embarrassment, I guess. Like one of the biggest things in my life is fear of embarrassment. I hate that feeling.	6. I am nervous that I'll be judged. Like I didn't do something, or did something wrong, to make him that way.
	7. I didn't want to get help because I was scared of what people were going to think in high school… because you're very scared about being judged and you know especially in high school that people are going to talk.	8. He is a passionate, committed fly fisherman who wants to be a fly fishing guide and does not want it to be common knowledge in his fly fishing network that he has been a drug user or in treatment, and is concerned about that.
Perceived social support	9. My friends completely changed their lifestyles, almost, to really benefit me and we haven't gone to parties this summer. We've been just hanging out at different friends' houses, going on adventures, hiking mountains, doing stuff like that.	10. My dad worked at a heroin rehab house, so he is, I feel very confident in enlisting them and knowing and as a resource as well.
	11. I kind of like getting treatment better now because people have encouraged me to go.	12. I think I told my friends so that they could comfort me, and tell me I'm doing a good job, because I feel like when [my child's] nervous, I'm nervous. I carry my own and then I carry his, so it feels good to talk to a friend, and they're very good to me like saying that I'm doing the right thing. Saying what I want to hear.

emphasized that people who treated them in stigmatizing ways did not understand SUDs (see Table 4, quote 1). Patients reported that stigma associated with certain substances, such as heroin, was worse than stigma associated with other substances, such as alcohol or marijuana. One stated that "A lot of people tend to get scared when they hear heroin. If I said I was an alcoholic everyone would be like, 'Oh, you're doing great... I'm glad you're staying away from alcohol'… If I say I was a heroin addict they, 'Oh…oh, really?' And they look at you differently." Patients described these experiences as hurtful and one noted that they coped with these experiences by engaging in further substance use.

Although caregivers reported experiencing stigmatizing reactions from others, these tended to be less frequent and extreme than those reported by patients. Caregivers noted that others gossiped about them and their children (see Table 4, quote 2) and that parents of other children rejected them (see Table 4, quote 4). Some caregivers described feeling anger and/or distress in response to stigmatizing reactions whereas others described not caring about stigmatizing reactions. Caregivers also discussed their perceptions of stigma experienced by their children, and some expressed greater concern regarding their children's experiences of stigma than their own experiences. One caregiver noted that her daughter was released from an emergency room with a discharge summary reading "STOP TAKING DRUGS BECAUSE THEY WILL KILL YOU OR HURT OTHERS." This caregiver said that she "burst into tears and laughter when I read that. There was no referral to other services... This was a long-term serious problem that had now almost killed her, and I was sent out with that piece of paper telling her to stop using drugs." The caregiver identified this as an example of enacted stigma that her daughter had experienced and was distressed by it. Caregivers noted that stigmatizing reactions from others made it more difficult for them to ask others for help and support.

Reactions from Others: Anticipated Stigma

In addition to discussing past experiences of stigmatizing reactions, patients and caregivers discussed their concerns regarding the possibility of stigmatizing reactions from others in the future. Patients worried that others would think less of them if they learned about their SUD history (see Table 4, quote 5). Some patients discussed concerns that others would not want to date them, including one who said that "I don't really date at all because I don't like to date other drug addicts and any sane person wouldn't date someone who is in treatment." Patients identified concerns about stigmatizing reactions from others as a barrier to accessing treatment. For example, a patient noted that they did not want to access treatment because they did not want other students at their high school to know that they had a SUD (see Table 4, quote 7). Caregivers expressed concerns that others would blame them for their child's SUD and/or perceive them to be poor parents (see Table 4, quote 6). They also worried about stigma that their children may experience in the future and how this may impact their careers (see Table 4, quote 8).

Reactions from Others: Perceived Support

Patients and caregivers reported receiving supportive reactions from family members, friends, coworkers, and others to whom they disclosed. Some patients noted that people who had rejected them while they were using substances later supported them when they were in treatment. One noted that "You're going to actually try and better yourself. You know what your problem is and I think a lot more people are accepting for that." Patients emphasized that they have encountered greater support as more people have learned about SUDs as a medical issue. Patients identified ways in which supportive reactions facilitated their treatment. One described that their friends engaged in sober activities and avoided parties with alcohol after learning of their treatment for an alcohol use disorder (see Table 4, quote 9). Another noted that they have developed positive attitudes toward treatment because they have received encouragement from others (see Table 4, quote 11).

Caregivers described receiving a range of social support from others. Several caregivers described receiving instrumental and informational support, including advice, from others with expertise in or experience with SUD treatment (see Table 4, quote 10). They noted that others who had experience with SUDs tended to be more supportive. One caregiver said that “I have other siblings who are very understanding, who actually have had issues around substance abuse themselves, and I think are kind of understanding and supportive and not stigmatizing it.” Caregivers also emphasized the importance of receiving emotional support from others (see Table 4, quote 12).

Discussion

The current study provides insight into characteristics of relational processes, including disclosure, stigma, and social support, experienced by young patients in SUD treatment and their caregivers. Disclosure experiences were diverse in regard to who knew about treatment, who primarily told others, and feelings about others knowing. The ways in which patients and caregivers navigated disclosures had implications for their relationships with each other. Tension was observed in relationships wherein caregivers disclosed information about their child’s SUD history or treatment without their child’s consent. Although caregivers and patients both acknowledged that this was necessary at times (e.g., during medical emergencies), patients described feeling vulnerable due to and angered by these disclosures. In contrast, several patients and caregivers described sharing the disclosure process by discussing and supporting each other’s preferences for disclosures. Similar to other decisions during adolescence (e.g., college selection), making shared decisions regarding disclosures may be an opportunity to facilitate growth and independence among young patients with SUDs (Chen et al. 2017).

This study extends previous work on disclosure to the context of child-caregiver relationships and SUD treatment. Results of the current work suggest that disclosure in the child-caregiver context may be quite different than disclosure in the romantic relationship context (Leiblum and Aviv 1997), with at least some child-caregiver pairs having significant disagreements regarding disclosure. This study further suggests that disclosures may have important implications for relationship and recovery-related outcomes. For example, youth felt distress and anger in response to caregivers who disclosed to others without their permission, and this distress and anger may affect their relationship with their caregiver and/or their SUD recovery.

The study further characterizes experiences of stigma and social support among young people with SUDs and their caregivers. Although some research has examined these processes among adults with SUDs (Conner and Rosen 2008; Dobkin et al. 2002; Earnshaw et al. 2013; Luoma et al. 2007), little research has examined them among this population. The current study highlights that young patients may worry about their peers at school learning about their SUD, and some may avoid treatment to hide their SUD from their peers. Caregivers may experience social rejection from the caregivers of their children’s peers. Patients and caregivers often face decisions regarding whether and to whom to disclose at school to excuse treatment-related absences. Similar to adults with SUDs (Earnshaw et al. 2013), young people report being hurt by family members who stigmatize them and some use substances to cope with this treatment. Caregivers experience a double-burden of stigma: they experience stigma themselves and worry that others will think that they are at fault for their child's SUD, and they also worry about their children's experiences of stigma.

Limitations and Future Directions

Findings from the study should be considered in light of some important limitations regarding sample size and selection, recruitment site, and study design. A relatively small number of participants in this study were recruited from a treatment setting, and results may not generalize to all youth with SUDs and their caregivers. Future work should include larger sample sizes recruited from other venues to better understand these processes among individuals who are not engaged in treatment, or have fewer healthcare-related resources. Additionally, some patient characteristics were underrepresented in this sample. For example, all but 2 of the 15 caregivers who participated identified as women. Future research should strive for more diverse samples of participants and explore how characteristics such as gender play roles in relational processes.

Future work should continue to explore these topics with quantitative and longitudinal methods to gain insight into whether relations processes affect SUD recovery outcomes over time, and whether these relational processes change with time in recovery. Quantitative methods can also contribute to understanding how characteristics such as age, gender, type of substance use, duration of SUD, diagnosis severity, and treatment intensity relate to disclosure processes. Dyadic analyses can continue to compare patients' and caregivers' perceptions of disclosure processes, including their perceptions of how many people know, who disclosed, and how they feel about others knowing. Guided by the disclosure processes model (Chaudoir and Fisher 2010), future work may also explore how these characteristics of disclosures within dyadic contexts affect relationship and recovery-related outcomes among youth with SUDs and their caregivers.

Conclusions

Addressing relational processes including disclosure among youth with SUDs and their caregivers within treatment settings may reduce patient-caregiver conflict, as well as distress and anger felt by youth, and ultimately support the recovery of youth. Patient-centered approaches to disclosure are recommended that acknowledge individual patients' and caregivers' values and preferences. Treatment providers may encourage patients and caregivers to share the disclosure decision-making process, including by discussing preferences for who should disclose to others and under what circumstances disclosures should occur. Providers may further promote understanding of patients' and caregivers' unique concerns regarding stigma and desire for support, and explore ways in which disclosures may be managed to reduce exposure to stigma and enhance access to social support.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients included in the study.

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