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Mental Health Services for Children of Substance Abusing Parents: Voices from the Community

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Abstract This qualitative study explores how to improve services for children of parents with Substance Use Disorders (SUD) with unmet mental health needs. Focus groups were conducted with parents and caregivers to identify perceived barriers to services, including: (1) attitudes and beliefs about mental health care, (2) inadequacies in mental health services, (3) children's ambivalence about treatment, and (4) parental disagreement and lack of involvement. Peer support, afterschool activities, and family counseling were identified as potential improvements. This information can serve as a foundation and guide to develop services for the underserved population of children and adolescents of substance abusing parents.

Introduction

Seven and a half million children and adolescents in the United States have at least one parent dependent on alcohol and/or illicit drugs, and are at significantly greater risk for mental health disorders than children whose parents do not have such disorders (Substance Abuse and Mental Health Services Administration Office of Applied Studies 1997). Boys whose fathers have a substance use disorder (SUD) and the offspring of mothers with alcohol problems have substantially greater prevalence of Axis I disorders than those whose fathers do not have SUD or mothers who do not have alcohol problems (Clark et al. 1997; Hill and Muka 1996). In households where both parents have SUD, offspring have much higher rates of conduct disorder and other lifetime psychiatric disorders, such as anxiety disorders and SUDs (Dierker et al. 1999; Schuckit and Smith 1996). Parental substance misuse also affects children's emotional and psychological development, commonly resulting in challenges with attachment and family functioning, increasing the risk of violence and abuse, and often resulting in role reversal with the child acting as the caregiver for the parent (Kroll 2004).

Despite these challenges and higher rates of psychiatric disorders than other children, children of parents with SUD commonly do not receive interventions for emotional and behavioral problems. Several barriers to treatment exist for these children to receive appropriate care, including the reluctance of parents to engage their child in treatment (Fals-Stewart et al. 2004) and the lack of integration between adult substance use treatment services and

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children's services (McKeganey et al. 2002). These barriers to care can be more prominent in urban, socioeconomically disadvantaged racial/ethnic minority youth and families, as accessing mental health services is already difficult for these youths with non-SUD parents (Gonzalez 2005). In response to system-level barriers to treatment, there have been efforts to develop programs that provide treatment to children of substance abusing parents (Shulman et al. 2000). Often designed by program managers and health care administrators, these programs frequently do not incorporate the views and opinions of patients and their families (Milstein and Wetterhall 1999), individuals who are considered key to effective implementation. Additionally, existing services may not be applicable or sensitive to the different needs and cultural mores of minority populations.

As part of an effort to develop services and identify interventions for the underserved youth of parents with SUD, we conducted focus groups with parents with SUD and caregivers of children and adolescents of individuals with SUD. Through collecting and analyzing such qualitative data, (Bernard 2000) we sought to develop a richer understanding of the important issues by capturing the range of views and opinions about barriers to care from parents and caretakers of children with SUD parents, and identify the type and range of services desired for youth with SUD parents.

Methods

We recruited participants from a community mental health center (CMHC) located in a community center in the Hill District of Pittsburgh, Pennsylvania. In addition to mental health and substance abuse treatment services for Medicaid enrolled adults offered through the CMHC, the community center offers a variety of social and physical health services for adults, but offers no mental health services or programs for children or adolescents. The population of the Hill District is primarily (approximately 90%) African American with high rates of unemployment and crime, approximately a quarter of the population is under the age of 19, and the population has a median annual income of less than $15,000 (Pittsburgh Department of City Planning 2000; SquirrelHill.com 2010).

Parent focus group participants were recruited from individuals receiving treatment for SUD at the CMHC, and primary caregiver focus group participants were individuals caring for children of parents with SUDs. Fliers at the clinic were used to recruit interested individuals, and clinicians also informed their clients about the project and asked if their clients would be interested in participating in a focus group. We sought to recruit participants from this

area who could provide a broad range of perspectives to address the specific aims of this study, and participants were comparable to other individuals being served in the clinic. Once identified as interested in the study, the principal investigator met with each participant individually and discussed the study and the consent form.

From February through November 2007, we conducted a total of four focus groups: parents with SUD with children ages 5–11; parents with SUD with children ages 12–17; family members who are primary care givers for 5–11 year old children of parents with SUD; and family members who are primary care givers for 12–17 year old children of parents with SUD. Each focus group met once and there were a total of twenty-two participants, including twelve parents and ten primary caregivers. Twenty participants identified themselves as African American and two as white on questionnaires that were completed at the start of the focus groups.

The focus groups, conducted by the principal investigator and an experienced facilitator (MC), lasted approximately 2 h. The focus groups were designed to elicit a broad range of views and opinions regarding access barriers to services for children whose parents have SUD, as well as what type of services participants would identify as most useful and appropriate for the children of parents with SUD. The University of Pittsburgh Institutional Review Board approved all study procedures, and there are no conflicts of interest to report.

The focus groups were digitally recorded, transcribed, and reviewed by research team members to identify and explore general themes that arose (Glaser and Strauss 1967; Strauss and Corbin 1990). Field notes were also taken during focus groups. Two research team members (LC and KC) independently coded focus group transcripts for major themes based on an initial transcript review (Ryan and Bernard 2003). If coders assigned different categories to the same statements, the field notes were consulted and the statement was discussed in a research team meeting until a consensus about coding was reached (MacQueen et al. 1998). Provisional themes and subthemes were finalized after a process of consensus and constant comparison in which each statement was checked against similar data and again a more inclusive category that described statements in a class. Subsequently, the research team discussed the content of each domain and refined the coding schemes by expanding, collapsing or eliminating codes until there was consensus.

Results

Six major themes emerged during the focus groups. Four themes related to barriers to care; i.e., parents/caregivers'

attitudes and beliefs about mental health care, perceived inadequacies in available mental health services, child ambivalence and reluctance to engage in treatment, and parent resistance toward child treatment. Two themes emerged regarding optimal services: integrated treatment and availability of non-mental health services. More detailed descriptions and exemplars from the focus groups for each theme are provided below.
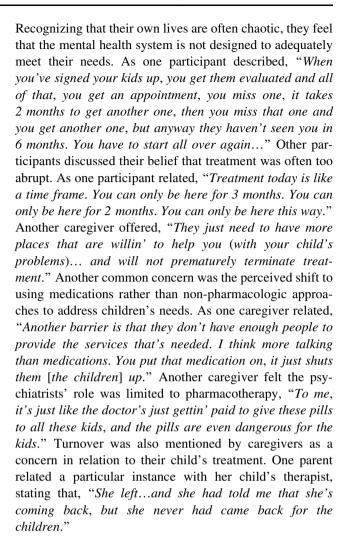
Attitudes and Beliefs About Mental Health Care

A commonly discussed theme in all focus groups, participants discussed the stigma associated with taking a child to a mental health provider, and several parents with SUD discussed the stigma and possible judgments associated with drug use. As one parent described, "*The first thing that got in my way. Embarrassment. Shame. And guilt. I mean it's hard to admit that you don't have control over your child.*" Another described a provider's reaction, "*They knew that I was a strugglin' mother with an addiction, and I just felt labeled. It was an insult.*" Other parents with SUD felt providers discounted their reports of their child's problems, as did this parent who related, "*The thing that I run into, all my suggestions are button-holed into the fact that you are a druggie, you're a convict, and what the hell do you know?*"

Many parents and caregivers expressed skepticism about and distrust of mental health providers and the mental health system. As one caregiver said, "*Sometimes even though things are supposed to be confidential, they have a way of 'leaking out'.*" This same distrust deters caregivers and parents from seeking care, as a parent described, "*We'll stay sick before we let somebody come in and help us. Because if they help us they'll separate us, or they'll degrade us, or they'll say things that's not true, or they'll think it's a certain way. That would be a barrier, you might say.*" Caregivers were also wary of what would happen once they took children to see a mental health professional. As one caregiver related, "*A lot of parents, that don't want to take their children to see someone because they fear that they're gonna be taken, or they fear the child is gonna be institutionalized.*" Many other parents and caregivers also related that they felt many clinicians were distant and removed, reflected by one who said that, "*There are some therapists that are compassionate, or will work with you and say well, I don't think she (my daughter) is there yet, or I don't think she's right. And we need more of those (therapists).*"

Perceived Inadequacies in the Mental Health Services System

A theme extensively discussed was participants' frustration with how care is delivered in the mental health system.

Recognizing that their own lives are often chaotic, they feel that the mental health system is not designed to adequately meet their needs. As one participant described, "*When you've signed your kids up, you get them evaluated and all of that, you get an appointment, you miss one, it takes 2 months to get another one, then you miss that one and you get another one, but anyway they haven't seen you in 6 months. You have to start all over again…*" Other participants discussed their belief that treatment was often too abrupt. As one participant related, "*Treatment today is like a time frame. You can only be here for 3 months. You can only be here for 2 months. You can only be here this way.*" Another caregiver offered, "*They just need to have more places that are willin' to help you (with your child's problems)… and will not prematurely terminate treatment.*" Another common concern was the perceived shift to using medications rather than non-pharmacologic approaches to address children's needs. As one caregiver related, "*Another barrier is that they don't have enough people to provide the services that's needed. I think more talking than medications. You put that medication on, it just shuts them [the children] up.*" Another caregiver felt the psychiatrists' role was limited to pharmacotherapy, "*To me, it's just like the doctor's just gettin' paid to give these pills to all these kids, and the pills are even dangerous for the kids.*" Turnover was also mentioned by caregivers as a concern in relation to their child's treatment. One parent related a particular instance with her child's therapist, stating that, "*She left…and she had told me that she's coming back, but she never had came back for the children.*"

Child Ambivalence/Reluctance to Engage in Treatment

Discussed extensively in parent and caregiver focus groups, a range of stakeholders identified child ambivalence and reluctance to engage in treatment as an important issue. Participants often described the child's behavior as being a barrier to treatment, either refusing to be taken to see a mental health professional and/or being uncooperative once there. As one caregiver related, "*The problem is her [the granddaughter]. She don't take the medicine. I got to almost fight her to get her to go to an appointment, and then when she get there she don't wanna talk.*" Another caregiver reported that she had never even attempted to get services, relating, "*A reason why I wouldn't take my granddaughter? 'Cause she don't wanna go.*"

Parental Ambivalence and Lack of Involvement

Both parent and caregiver focus group participants described challenges resulting from disagreements with and between parents. One caregiver who was prevented by

the child's mother from getting help for the child described, "*It's up to her* [the mother] *because I do anything, but she (the mother) was like this (the daughter), and she didn't want to (let the girl get treatment).*" "*The parents say there's nothing wrong with the child,*" was a situation commonly described by non-parental caregivers. Other participants reported the lack of the other parent's involvement in the child's life was another barrier, as did the mother who related, "*(I) know* [their child] *needs to see somebody, but his Dad doesn't have insurance for him and his Dad is not going to take the time to take him to appointments.*"

Integrated Treatment

Focus group participants had many suggestions to address the barriers they identified above. When describing the services they would like to see available, many wanted services involving both the parents with SUD and their children, as did the caregivers who wanted treatment, "*Half (with the child), and then parents with the children. With counselors, half alone and then with the children.*" Other participants also wanted family therapy, as did one parent who requested having, "*Just one place you go, and just get help for the whole family.*" The availability of family therapy was important to another parent, who said, "*I want family counseling. So then that way they (the therapist) can look at me and give me their input and I can sit right there in front of (the child) with the therapist.*"

Ancillary and Community Support Services

Many participants spoke at length about the importance of other services as being vital for the emotional and behavioral health of their children. Most frequently mentioned were peer support groups for children and teenagers, as did the caregiver who said, "*(My granddaughter) is reaching a certain age where I think she would benefit from talking to other kids her age that are going through the same thing.*" Another caregiver described the importance of children, "*Needing a support group for each other.*" Other caregivers described wanting non-clinical services for their children to attend, such as, "*A walk-in program where these kids can come to this room and sit, whether they just do some arts and crafts together, and then they can make something.*"

Discussion

Children of parents with SUDs often suffer from a range of emotional and behavioral problems, yet commonly do not receive services to address those problems. This qualitative study of parents and caregivers of children of SUD parents enhances our knowledge of the barriers faced by these families, identifying those commonly reported among parents of children requiring services (Fals-Stewart et al. 2004; McKeganey et al. 2002). In addition, focus group participants identified a number of factors that would make services for children with emotional and behavioral disorders more appropriate and accessible.

Skepticism of treatment and stigma are two well-established barriers to seeking care for mental health disorders (Leaf et al. 1987; Meltzer et al. 2003; Sirey et al. 2001). Parents and caregivers discussed these issues with respect to the treatment of children of parents with SUD. Stigma, lack of confidence in available treatment options, and help-seeking are interrelated. Stigma predicts attitudes towards treatment services, which influences willingness to obtain treatment (Vogel et al. 2007). Particularly for African-Americans individuals, such as the majority of the focus group participants, reticence towards seeking treatment and concerns about stigma are well-documented with respect to seeking mental health services (Cooper-Patrick et al. 1995).

These deeply entrenched problems are challenging to address, but programs such as the Acceptance and Commitment Training (ACT) program are designed to reduce self-stigma of patients and stigmatizing beliefs among substance abuse treatment providers (Hayes et al. 2004; Luoma et al. 2008). Modifications of such programs could potentially be useful in attenuating stigma-related barriers to seeking mental health treatment for children of adults with SUD. Other promising approaches for increasing treatment among underserved population are social marketing campaigns designed to attenuate stigma on a broader, public scope (Lavack 2007), and psychoeducational (Copello et al. 2005) approaches that educate families that addiction is a "family disease" and a "chronic medical condition."

The public mental health system is often described as providing disorganized and inefficient services to those in need, often resulting in ineffective services (Regier et al. 1993; U.S. Department of Health and Human Services 1999). Focus group participants discussed their frustrations with these aspects of the mental health system as a major deterrent from seeking care for their children. The lack of coordination between service providers (Institute of Medicine Committee on Crossing the Quality Chasm 2006) and the high levels of staff turnover (Ben-Dror 1994; Gallon et al. 2003) are commonly recognized challenges. Parents and caregivers were particularly troubled by the long wait times for appointments and the perception of relatively brief and often uncoordinated treatment. While some of these challenges are associated with a limited number of providers of child mental health services for publicly

insured individuals (Thomas and Holzer 2006), targeted efforts have been shown to significantly decrease waiting times, no-show rates, and the need for psychiatric hospitalization while enhancing engagement, participation in treatment, staff morale and teamwork (McKay et al. 1996, 2004; Szapocznik et al. 1988; Williams et al. 2008).

There has been increasing public attention and scrutiny in recent years regarding the use of psychotropic medication in youth (Duncan et al. 2007; Koelch et al. 2008). Many of the parents and caregivers were concerned about children receiving psychotropic medications, particularly in cases in which they felt there were insufficient non-pharmacologic interventions. Enhanced dialogue about clients' preferred treatment options and the risks and benefits of psychotropic medications (Sparks and Duncan 2008) is an important response to the concerns expressed by parents and caregivers. Equally important is educating parents and caregivers about the appropriate use of effective non-pharmacologic interventions to address the emotional and behavioral problems in children (Birmaher et al. 2000; Kazdin 2003). Establishing strong therapeutic relationships with patients and emphasizing the patient's autonomy can also help decrease patient and familial perception of psychiatrists just "pushing medication" while improving engagement (Daley and Zuckoff 1999).

Parents and caregivers frequently discussed the challenge of getting children and adolescents to initiate and engage in treatment. This is a challenge for many families, but may be exacerbated in families of adults requiring treatment for SUDs due to the additional family chaos that often accompanies such disorders. In such situations, providing more information beforehand about therapy and the process may allay children's fears and hesitations about participating in treatment (Day et al. 2006). Such conversations at the beginning of treatment may also be an effective way to engage children and adolescents in their mental health care (Day 2008) as well as the whole family. Many caregivers and parents without SUD disorders also described opposition to services for children from the parent with SUD. This is consistent with others findings that parents with SUD are often opposed to mental health services for their children (Fals-Stewart et al. 2004). Motivational Interviewing is effective in engaging substance-abusing parents in their own treatment (Carroll et al. 2001), and such motivational approaches with both children and parents might also be useful in increasing initiation and engagement of children in treatment.

The family treatment approach described by participants as an ideal mental health service is another viable solution consistent with recent recommendations (Substance Abuse and Mental Health Services Administration 2004). Family therapy involving the substance abusing parent and their children helps deter children from using drugs themselves (Catalano et al. 1999), while having better psychosocial outcomes (Kelley and Fals-Stewart 2002). Similarly, peer support groups for children with a substance-abusing family member can impart numerous benefits upon children. These range from reducing a sense of isolation, feeling more informed about their family member's illness (Gregg and Toumbourou 2003), and improving school performance and social relationships (Gance-Cleveland 2004). Clinicians and policymakers should consider interventions that would enhance the use of more integrated family treatment models and peer support for children of individuals with substance use disorders.

The consistent desire for non-clinical services in every focus group is also important to note, and raises the question about a much wider public health concern. This suggestion for an "ideal service" highlights the lack of constructive, meaningful activities in which the youth can participate, as participants repeatedly discussed the lack of after-school and recreational activities for children. Participation in organized activities, including after school activities are associated with academic success, improved mental health, positive social relationships and behaviors, identity development, and civic engagement and facilitate normal adolescent development (Mahoney et al. 2005). As these services relate specifically to children of substance abusing parents, there is evidence to suggest a protective effect associated with more community-oriented supports and services for these children (Bancroft et al. 2004).

Our findings must be considered within the context of the limitations of the study. The focus groups were held at a single community mental health center in a socioeconomically disadvantaged racial/ethnic minority urban community where participants or their family members were receiving treatment or other services. We do not know how themes might be different in other communities, populations or regions. Nor do we know in what way the themes identified would differ among individuals for whom the adult with a substance use disorder was not receiving any services or had previously received services. Focus group participants were also not specifically asked if they felt the child needed treatment for emotional or behavioral problems. We note, however, that many focus group participants spontaneously discussed their concern about the child's mental health.

Despite these limitations, the present study adds important information regarding the opinions and perceptions of adults caring for children of substance using parents and serves as a catalyst to exploring and addressing the mental health service needs of children of substance using parents. While participants discussed challenges and concerns about participating in the current mental health system, they also provided a number of suggestions regarding changes that would be perceived as being more responsive

to their needs, including the increased use of family-focused interventions. Our findings can inform those seeking to enhance existing services and/or develop new services for this underserved population, and highlight the importance of seeking input from those who seek mental health services for children of parents with SUD to ensure developed programs are accessible and relevant to the target population.

Considering the paucity of research on children with emotional and behavioral problems of substance using parents, further research is needed to better understand how to improve access to and quality of mental health care. Qualitative and quantitative studies in different populations are required to better understand the issues. At the same time, consideration should be given to examining the impact on this population of interventions that have been demonstrated to be effective in similar populations. Only through better understanding of the issues, and the development and implementation of effective interventions will these youth receive the care they need.

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