Assessing Needs for Mental Health and Other Services Among Transition-Age Youths, Parents, and Providers

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Objectives: **This qualitative study assessed the needs for mental health and other services among transition-age youths who were receiving services in youth-specific programs.** ***Methods:*** **Thirteen focus groups were conducted between June 2008 and January 2009. The purposefully sampled participants included transition-age youths age 18 to 24 who were receiving services in youth-specific programs (N=75, eight groups), parents of transition-age youths (N=14, two groups), and providers in the youth-specific programs (N=14, three groups). The qualitative analysis used an inductive approach in which investigators focused on generating themes and identifying relationships between themes. Through a process of repeated comparisons, the categories were further condensed into broad themes illustrating service needs.** ***Results:*** **Youths expressed needs for improved scheduling of services, stronger patient-provider relationships, and group therapies that address past experiences of violence, loss, and sexual abuse and that provide skills for developing and nurturing healthy relationships. Parents and providers expressed needs for increased community-based and peer-led services. Youths, parents, and providers all expressed needs for more housing options and for mentors with similar life experiences who could serve as role models, information brokers, and sources of social support for youths who were pursuing education and employment goals.** ***Conclusions:*** **Findings from the focus groups suggest that there is room for improvement in the provision of services that are relevant to the current needs and life experiences of transition-age youths. Even within age-specific programs, improvements in services are needed to foster transitions to independence. (*Psychiatric Services* 63:338–342, 2012; doi: 10.1176/appi.ps.201000545)**

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The transition from adolescence to adulthood is especially challenging for youths with mental illness, who have lower rates of education and employment than their peers without mental illness and higher rates of poverty, unplanned pregnancy, sexually transmitted disease, substance use disorders, homelessness, and involvement in the criminal justice system (1–3). The challenges inherent in the transition to adulthood among transition-age youths (generally, youths age 16 to 25) are often complicated by emancipation among foster care youths, a lack of mentors, and a need for services related to life transitions that is not adequately met by the mental health service system (4–6). As a result, transition-age youths are more likely than adults to drop out of mental health treatment; predictors of dropout include practical barriers to accessing care, the perceived relevance of treatment, and the quality of the therapeutic relationship (7–12).

This disconnect between service needs and service provision for youths with mental illness has been conceptualized as a discordance between developmental and institutional transitions (3,13). The developmental transition includes natural cognitive, moral, social, and sexual development and the formation of identity. The developmental transition is mediated by cultural norms and celebrated by rites of passage. In contrast, the institutional tran-

sition is governed by bureaucratic and legal guidelines and is in part determined by a bifurcated mental health system that is geared toward either children or adults but not necessarily toward individuals transitioning between developmental periods. Common themes related to barriers encountered in the institutional transition include deficits in continuity of care and transition planning and a lack of age-specific institutional supports (3,13).

Mentorship has been identified as both a predictor of success and a potential target of intervention among transition-age youths with serious mental illness (14). Mentoring relationships have been defined as connections built on mutuality, empathy, and trust that have an impact on youths through social, emotional, cognitive, and modeling processes (6). Quantitative studies of nonkin or nonparental natural mentors have found that mentorship is associated with improved self-reported health status; reduced symptoms of depression, suicidal ideation, and perceived stress; less fighting; and fewer sexually transmitted infections (5,15). Qualitative studies have identified the importance of similarities in life experiences between mentors and youths; trust, consistency, empathy, and authenticity are key qualities of the mentoring relationship (16). Interventions to improve mentorship of youths with mental illness focus on supporting natural mentors or employing professional mentors who work in youth-specific programs. The Transition to Independence Process model employs mentors in the form of transitional facilitators (also described as life coaches) who use specific core processes (for example, social problem solving, in-vivo teaching, and planning to prevent high-risk behaviors) to help youths to make better decisions and to improve their progress and outcomes (17).

California's Mental Health Services Act (MHSA) provided new sources of funding for services for transition-age youths. The California Council on Youth Relations concurrently issued a set of policy recommendations that include promoting involvement of youths in decision making, identifying the family as the unit of service, providing age-appropriate clinical services, improving communication about medication, preparing adults to support and respect youths, providing a safe environment and sense of purpose, and reducing stigma (4). However, there has been little effort to determine whether youths receiving services in these programs perceive barriers to accessing mental health services and other services.

In the general population, common perceived barriers to mental health service use include financial costs, the inconvenience of receiving services, stigma, and the belief that mental health problems will resolve themselves (18). Studies of special populations, such as veterans, immigrants, and older adults, have emphasized the need for age-appropriate and culturally appropriate services and providers with specific training or expertise (19–21). This study assessed the needs of transition-age youths receiving services in youth-specific programs in San Diego County, California, to learn about their perceived needs for services and barriers to receiving services as a way to inform strategies to reduce these barriers.

Methods

Participants and setting

This qualitative study is based on 13 focus groups, conducted between June 2008 and January 2009. The study purposefully sampled transition-age youths age 18 to 24 who were receiving services in youth-specific programs (75 youths in eight groups), along with parents (14 parents in two groups) and providers (14 providers in three groups). Youths were sampled from geographically diverse programs to obtain a broad range of perspectives from San Diego County. All focus groups were conducted on site at youth-specific programs. Four groups were gender specific (two were for males and two for females). Gender-specific focus groups were conducted in order to elicit responses that might not be provided in a mixed-gender group. Participants were recruited by program staff and by flyers posted in communal areas.

Two focus groups were conducted with parents of transition-age youths. Participants were recruited through two organizations focused on parents of children with mental illness. One parent group consisted primarily of well-educated, middle-class professionals. A second group consisted of parents whose children had been legally removed from their homes. Three focus groups were conducted with providers of services to youths. Most were clinical therapists and social workers; child and adolescent psychiatrists declined to participate because of their busy schedules. Participants were recruited by word of mouth by a provider who assumed responsibility for recruitment at each site.

All participants provided written informed consent before participating in the groups. Participants were compensated for their time with refreshments and $25 gift cards. This study was approved by the Human Research Protections Program of the University of California, San Diego.

Procedures

Focus groups were conducted with semistructured questionnaires that were designed to elicit information about needs for mental health services, including mental health, general medical health, and substance abuse services, and the need for services promoting independent living, including housing, education, employment, and transportation services and social and financial support. Examples of questions posed included: Are mental health services easy or difficult to get? Do you think that the mental health system does a good job of meeting your needs (are your needs being met)? Do you have any suggestions about how those needs could be met? Before the start of the focus groups, the facilitators were trained by the authors in conducting such groups, including training on using the interview guide, establishing rapport with participants, collecting sensitive data, and maintaining confidentiality (22).

Analysis

Focus group discussions were recorded, transcribed, and analyzed with a methodology of "coding consensus, co-occurrence, and comparison" outlined by Willms and colleagues (23) and rooted in grounded theory (24). The qualitative data analysis software Atlas.ti was used (25). An initial coding

scheme of key concepts and categories was created after review of several cross-sections of transcripts (26,27). These codes were then independently applied to five interviews in order to refine and create more nuanced coding. To ensure intercoder reliability of the coding scheme, multiple sections of five additional interviews were coded, and discrepancies in coding between the multiple coders were discussed and resolved among all members of the research team (28,29). If new codes emerged, the coding scheme was changed and the transcripts were reread and recoded according to the new structure. The qualitative analysis followed an inductive approach in which investigators focused on generating themes and identifying relationships between themes (30). Through the process of repeatedly comparing these categories with each other, the categories were further condensed into broad themes illustrating the needs of transition-age youths (23,24).

Results

The focus group discussions yielded several themes. The themes are organized below by whether they are related to clinical services or to services that promote independence. [A table presenting sample quotes from group participants by theme is available online as a data supplement to this article.]

Mental health and substance abuse services

Youths identified several barriers to their use of mental health and substance abuse services, including needs for improved scheduling of services and reduced wait times, stronger patient-provider relationships, and more relevant content for group therapy. Parents and providers described a need for increased access to community-based services.

Among youths' more frequently mentioned concerns were the inconvenient scheduling of services and substantial wait times. Early morning meetings were considered difficult to attend by youths who had to rely on time-consuming public transportation and by those with medication-related side effects that affected morning wakefulness. Once youths arrived at their providers' offices, wait times proved to be a concern, particularly for working youths who might be penalized or lose their job because of a delay. Youths' comments indicated that expectations and standards of conduct vis-à-vis appointment timeliness differed for providers and clients, resulting in a double standard of punctuality: "To some degree I find it funny that if we show up late, we get chewed out, but if the doctor's an hour late, it's like, deal with it."

Weak patient-provider relationships also emerged as a significant concern. Both the duration and frequency of appointments were deemed insufficient for providers to review their cases, reestablish rapport, and discuss progress made or challenges experienced by clients. Youths demonstrated awareness that program funding was limited and that providers were under pressure as a result of large caseloads and related time constraints. Youths recognized the resulting frustrations among both providers and clients and even offered suggestions for increasing the efficiency of the office visits—for example, by having nurses prepare providers by eliciting information from clients in advance and by improving health literacy among clients. Provider turnover was viewed as having a negative impact on continuity of care.

Youths also voiced dissatisfaction with the content of group therapy. Suggested topics of interest for group therapy included coping with effects of violence against family members and with intimate partner violence, addressing the aftermath of sexual abuse, grieving, acquiring skills for establishing and maintaining healthy relationships, problem solving related to couples issues, and parenting skills. One youth commented, "They have music appreciation, they have yoga, they have fitness training, three days a week they have [dual disorders] recovery. And stuff like that. And they have cooking classes, and they have car washes, they have stuff like that. But they don't have the groups that will actually help us along the way. Say like someone lost someone they really love? They don't have a group where we'll be able to talk about our feelings about it and help us like, you know, help us through the feelings we're feeling about that loss."

Some youths mentioned that services were unavailable at an appropriate level of intensity: "We can talk about anything but [the fact is that] you need more support. But me, I need a lot more support for what happened in my past." Another youth in the focus group responded to this statement by saying, "Watching your mom get beat to death, it's not a good thing for a ten-year-old."

Parents and providers identified a need for additional community-based services. Parents expressed a need for services that were closer to home and for peer services: "I would like to see rehabilitation services in the communities again, you know, for my son to go to that are peer to peer." Some providers emphasized delivering services in the community, outside traditional clinics—essentially mobile services. One said, "Our most effective services are services that . . . get pushed out into the community and [are] flexible in how they engage."

Services that foster a transition to independence

Youths, parents, and providers identified needs for additional services to help them succeed in living independently in the community, and all agreed on the need for housing and mentorship. Parents and providers also identified a need for employment support.

Several youths expressed a desire for affordable, age-specific housing: "It would be really cool if they had a place like this that was . . . a transitional living program just for people in a certain age group." Parents and providers also felt strongly that more age-specific housing was needed; the current lack of housing was thought to increase youths' vulnerability. Emergency housing was deemed critical, particularly for youths transitioning from inpatient care and for those who may need additional medication management support. It was suggested that housing combined with an independent living skills program would help facilitate youths' transitions to adulthood while encouraging socialization. Provision of mental health services at housing sites was also suggested; it was felt that such on-site services would be attractive to youths and might be less stigmatizing because

they would not be situated in a mental health facility.

Youths also identified a need for mentorship, either from within the service system or by someone familiar with it (for example, a peer). As one youth stated, "It would be nice to have like a CASA [Court Appointed Special Advocate, an advocacy and support service offered to children who are abused or neglected] again, just so you know that somebody who is familiar with the systems [and who works] with the systems can help you with what you need, that they're willing to be a friend if you need, you know in the middle of the night to call and say, I'm freaking out."

Youths expressed a need for mentorship, which was related to their having limited social support from family or friends. They also expressed a desire for help in multiple domains, including assistance with maintaining finances, pursuing academic goals, and obtaining employment. Several youths reported needing assistance opening bank accounts and establishing and staying within a budget. Another participant who was interested in attending junior college felt that a mentor could help facilitate her transition to higher education, including preparing for classes, since she perceived that the activities required to continue schooling were overwhelming.

Parents and providers also remarked upon the need for mentorship services, noting that peer mentors who had experienced mental illness are potentially best suited for this role. They believed that relationships with peer mentors would increase youths' receptivity to and engagement in services and assist in the development of their independent living skills. Parents in particular believed that it was important for youths to have support from nonparental mentors with similar life experiences: "If they had somebody that they could talk to that's their own age that is going through some of the issues that they're going through, you know, I think that'd be really powerful."

Parents and providers raised concerns regarding a lack of employment opportunities. They felt that additional services, such as vocational interest tests and educational and vocational training, would enable youths to define a work path. Programs that provide employment support were viewed as critically important. Such programs would help participants develop resumes and complete applications, teach them how to perform well in a job interview, and place them in jobs. As one provider stated, "[It would be good to have] job developers, who could develop relationships with employers willing to hire these kids. [It would be good for kids to know] that they have a job coach who will work through the issues with them. It would be kind of a two-part thing—people to develop jobs specifically that will help kids work toward their goals and also a job coach to help them along."

Discussion

This study sought to determine the service needs of transition-age youths who were receiving age-specific services in San Diego County. Results showed that even in these specialized programs, youths expressed needs for mental health services, housing, employment, and mentorship. This study provides new findings with respect to the content of group therapy and insights into the importance of having mentoring relationships—a need that youths described differently compared with parents and providers.

Youths expressed needs for better scheduling of services, shorter wait times, and stronger patient-provider relationships. These elements are not unique to the experience of transition-age youths. For example, high provider turnover is common in public mental health systems (31). However, these common concerns are particularly problematic for transition-age youths, who have high rates of dropout from mental health treatment (8). The barriers of long wait times and provider turnover may have an outsized impact on transition-age youths. Directing more resources toward improving these common deficiencies may lead to better retention of youths in treatment.

Youths also expressed a need for more relevant group therapies. They indicated that existing wellness-focused groups, and even dual-diagnosis groups, were not meeting their needs. Suggested topics included building healthy relationships and dealing with current and past experiences of violence and sexual abuse. The lack of concordance between current offerings and service needs highlights the importance of including the input of youths in the development and provision of services.

Youths, parents, and providers all expressed needs for increased housing options and for mentors who could serve as role models, information brokers, and sources of social support for youths pursuing education and employment goals. We found it interesting that the recovery-oriented goals of education and employment were raised in this context, suggesting that mentors may be crucial in facilitating recovery and independence (17). We also found it interesting that although parents emphasized peer mentoring, youths emphasized professional mentoring by adult personnel in youth-specific programs. Youths indicated that they would like someone whom they could trust and who would help them negotiate the challenges of the mental health system and their lives; parents and providers suggested that these mentors should be peers. The limited literature on mentoring of youths with mental illness and the broader literature on various vulnerable youth populations provide little guidance about effective approaches. Additional research in the field of mentoring is greatly needed, particularly research to specify models of mentoring and to discover which types of mentoring are best for which populations.

The supported employment model, in which specialists help clients obtain competitive employment and provide ongoing support when the client is employed, speaks directly to the need raised by parents and providers for increased employment opportunities among transition-age youths (32). Recent research has shown that individual placement and support programs are effective in helping clients obtain and maintain long-term employment (33).

The study had several limitations. This study purposefully sampled transition-age youths receiving mental health services in youth-specific outpatient programs. We were interested in hearing the voices of youths who were receiving services in programs that

were explicitly designed for this population and in identifying unmet needs. We did not provide specific instructions to program staff other than to recruit youths who would be willing to share their experiences with the program. However, we found that youths who participated described a wide range of mental health service needs and experiences. Although both mixed-gender and single-gender groups participated in the study, the analysis did not find obvious themes related to group composition. Another limitation is that the parents of transition-age youths who participated in the focus groups were not necessarily parents of the youths who were enrolled in the youth-specific programs. Thus the comments of these parents were not necessarily informed by their experiences with the youth-specific programs. Also, the provider focus groups did not include psychiatrists, who might have provided additional insight into issues related to pharmacotherapy and medication adherence.

Conclusions

Findings from this study suggest that there is room for improvement in the provision of services that are relevant to the current needs and life experiences of transition-age youths. The findings illustrate the challenges that youths face in accessing and benefitting from mental health services while simultaneously transitioning to independence.

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