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Families' Experience With Seeking Treatment for Recent-Onset Psychosis

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Abstract

Objective—Qualitative research methods were used to understand the experiences of families seeking treatment for young people with recent-onset psychosis; such knowledge can inform services design.

Methods—The authors conducted open-ended interviews in 1999 through 2002 with family members of 13 patients with recent-onset nonaffective psychotic disorders in the New York metropolitan area, focusing on their experience in seeking treatment and engaging with mental health services.

Results—Family members described early lack of clarity of diagnosis and obstacles to obtaining treatment. Entry into the mental health system frequently occurred in the context of crisis, with African-American families specifically reporting police involvement. Inpatient hospitalization was depicted as traumatic yet offering relief. Aftercare was described as fragmented, and issues with third-party payers were paramount. Families expressed a desire for more education, information, and support and described their struggles with stigma. These data from families are presented in the context of more recent literature as to the efficacy of specialized treatment programs for early stages of psychotic disorder and their involvement of families.

Conclusions—These qualitative research data support the importance of involving and educating families about psychosis: its recognition, its treatment, and access to services. They also highlight the need to address stigma and implement structural changes in treatment that ensure continuity and coverage of care. Specialized first-episode psychosis services may address these issues, and they may minimize the traumatic experiences of involuntary hospitalization and police involvement early in treatment.

The onset of psychotic symptoms can be bewildering and stressful for patients and their families. Patients are confused by the changes that they are experiencing, and they often deny or are unable to articulate their symptoms, withdraw from others as a coping strategy, or do not recognize that symptoms are evidence of mental illness (1,2). New-onset psychosis usually strikes adolescents and young adults who live with their families and are emotionally and financially dependent on them. For this reason, it is often families who recognize symptoms as problematic and seek help (3–8). Recognizing symptoms and getting help can be difficult, and young people with psychotic symptoms go one to two years on average before accessing care (9). Reduction of this period or duration of untreated psychosis has important ramifications for long-term outcome (6,10). Given the crucial role families play in obtaining treatment, engaging them successfully may improve access to care and thus reduce the protracted period of untreated psychosis that many patients experience.

It has long been known how difficult the crisis of psychosis onset is for families. In retrospective studies, families of patients with chronic schizophrenia reported having felt scared and left in the dark during treatment for the initial psychosis of a family member (11–14). In response, there has been an increased effort to involve families in first-episode psychosis treatment. These programs, which generally involve psychoeducation and family support, are not universally available. Even when they are available, families frequently do not take advantage of them (15). One potential explanation is that families, having not been consulted in the design of these interventions, may not find them helpful. In one study, there was a trend toward more relapse among some families that received psychoeducation (16). It was hypothesized that these families' stress was increased by the focus on communication and problem-solving skills emphasized in the psychoeducation materials, which families interpreted as suggesting that they were currently doing something wrong (16,17).

When families are consulted as to what they would find helpful, participation improves. Focus groups have identified that families want more involvement, support, advice on managing symptoms, aid in navigating treatment systems, and contact with other families (18,19). Specifically, families requested multifamily psychoeducational groups in which patients are not present, rapid outreach after diagnosis, phone support from trained peers, and information on illness and treatment. Once implemented, these services have proved popular and are well utilized.

In the spirit of these focus groups, we conducted qualitative research with families of individuals with recent-onset psychosis to understand their experience and gain insight into how treatment services for first-episode psychosis could be improved.

Methods

Open-ended audiotaped interviews were conducted with families of inpatients with recentonset nonaffective psychosis who were diagnosed at the New York State Psychiatric Institute and Yale's Department of Psychiatry from 1999 through 2002. Because recentonset nonaffective psychotic disorders have a low prevalence, the sample size was determined by availability of eligible patients. Selection of patients and families was not random, and study participants represented a sample of convenience. This study had

approval from the institutional review boards at the Yale School of Medicine, the New York State Psychiatric Institute, and the Columbia Presbyterian Medical Center. The only exclusion criterion was an inability to speak English, on the part of either the patient or family member.

Patients were asked to identify the family member who they felt could best describe them. Patients provided consent for family members to be contacted, and family members also provided written informed consent to participate.

Most of the 13 inpatients were male (N=10, 77%). They were also ethnically diverse: five (38%) were Caucasian, four (31%) were Hispanic, three (23%) were African American, and one (8%) was East Asian. Inpatients ranged in age from 16 to 24 (mean \pm SD age, 20.7 \pm 3.0). Diagnoses included schizophrenia (N=6, 46%), schizoaffective disorder (N=1, 8%), and psychotic disorder not otherwise specified (N=6, 46%). All patients had first received treatment for psychosis within the previous year: six (46%) during their current hospitalization, five (38%) during a previous hospitalization, and two (15%) as out-patients within the prior year.

For 12 of the 13 patients, only one family member was interviewed. For one Korean-American patient, both parents were interviewed together, per their request (and with the patient's consent). Participating family members included nine mothers, three fathers, one brother (who was the primary caregiver for the patient for the several years since their parents had left the United States), and one aunt (who had raised the patient since his immigration to the United States as a young child).

The methods used have been detailed in a previous article (20). Family members were interviewed in an open-ended fashion, and they were encouraged to tell their story. Questions were asked for clarification of specific points or for elaboration. Interviewers were trained in and practiced techniques designed to minimize leading answers during interviews. Family members were queried about the following areas, if they did not discuss them spontaneously: What changes have you perceived in the patient? How have you and your family been affected? What has been helpful or not? What are your expectations for the future?

Data analysis followed established qualitative data analysis procedures (21–23). The four members of the research team separately and then jointly analyzed themes common across interviews. Themes that emerged from the narratives were remarkably similar, involving trajectories of symptoms, attributions, help seeking, interactions with the mental health system, and expectations for the future (20).

Herein, we present in greater detail themes specifically regarding families' encounters with the mental health system.

Results

Family members described a number of frustrations with the mental health system. If they first sought treatment from outpatient providers, they found it difficult to schedule appointments and to convince the patient to attend them. If a clinician was seen, families were often frustrated by the absence of a definitive diagnosis.

For most patients the diagnosis of psychotic disorder was made in the context of involuntary hospitalization, described by most families as traumatic yet necessary. One mother reported, "I will not forget when the door shut and we had to leave him in the psychiatric ward. It was a horrible feeling ... I was completely in shock ... my older son immediately said, 'Oh, I

should have been a better brother." Another family member said, "My putting him in the hospital was my cry for help too. I just felt I couldn't handle it anymore, and I saw that instead of getting better, he was just getting worse. So I said that's it." Another parent told doctors, "Do not take her out of the hospital ... because whatever's going on, I don't think I can handle it."

Of note, two of the three African-American families reported police involvement in hospitalization. One teenage African-American girl locked herself in the bathroom, threatening to hurt herself if anyone came in. Her family called 911, and as her family described, "You know it looked like 100 police was here. . . . They had like a SWAT thing or whatever. They had all these trucks and everything outside ... everybody was screaming and everything ... I thought they might shoot or something like that. Her sister was saying, 'Don't hurt my sister.' ... they broke the door down ... they handcuffed her ... and she was [crying], 'Why are you doing this to me?'" The other case of police involvement occurred when a young African-American woman became disoriented, wandering naked in the streets.

After the trauma of involuntary hospitalizations, families grappled with the stigma of psychotic illness, and they expressed anger toward hospital staff. As one mother said, "People tend to stigmatize people who are mentally ill ... I'm kind of ashamed, really, to tell somebody." The diagnosis of schizophrenia in particular was difficult for families. One family member said, "Now we have to deal with this 's' word ... it's like, oh, this is a dirty word. ... I almost had a breakdown myself, and I said, 'This is what I am dealing with, and I'm going to be dealing with it for the rest of my life, and I am angry.'" One mother said, "I talked to a social worker who was nice, but she said I should look at it as that I have three kids, two are good and one is not good." Another recalled a physician who "told my son to get used to it, and he would be like this for the rest of his life." One mother described waiting weeks before her son's inpatient psychiatrist spoke to her. She said, "the big cheese doctor came out and gave me the luxury of his presence for a few moments before my son was discharged."

Families' frustration continued after discharge. Families reported difficulty in finding outpatient doctors and struggles with third-party payers regarding coverage. One mother explained, "The doctor that was supposed to take care of him, [the one] that they got, she bailed out. She said she would treat him ... and then she decided he was too sick. She does not want to take care of him. So then I couldn't get anyone who takes his insurance." Insurance companies were also frustrating. One family member said, "I was told I had no more coverage." Another family member said, "It was clear that if I just went by my health insurance, it was going to be my son going to see someone for 15 minutes twice a month. And in that 15 minutes time she was supposed to be able to figure out how he was doing." Two of the five patients who required hospitalization for psychosis relapse were initially unable to access care because of insurance problems.

Additionally, families described wanting more information on how to manage the crisis of psychosis onset. As one mother said, "The psychiatrist and therapist are not going to know overnight what are the issues that your child will be dealing with. But three months into the process, is it reasonable for them to have some kind of conversation, provide some kind of information and education? Some therapy, something? ... What we can do in our health care system [to] support families better is to give more help in the beginning." Another said, "A little bit of advice or a chance to ask questions would have been nice." Although families recognized the importance of protecting the privacy and autonomy of their ill family member, they nonetheless expressed frustration with feeling kept in the dark. As one mother said, "There's the issue of patient confidentiality, which is so important, but then there's the

issue of the parents out there, who have no clue as to what is happening with their child. You could be walking around with a time bomb. . . . I recognize the need from a therapy standpoint for there to be exclusive keeping of confidentiality. On the other hand, is there not a way for families to be brought in sooner?"

Families who felt that they received useful information expressed gratitude toward doctors and staff for helping them understand psychosis and how to help their ill family member. As one father said, "You keep me informed, the way I gotta act towards him, the way I gotta be with him." And many families still held out hope. One family member said, "I want any parent who has to hear for the first time that their beloved son or daughter is developing this illness ... [to know,] yes, they can become well."

Discussion

These interviews with families of 13 individuals with recent-onset psychosis confirm what has long been known, which is that the onset of psychosis can be a terrible crisis and be frightening for patients and families. What is new in this article is a detailed indictment of the mental health system in the United States, as families describe their encounters with this system at different levels and how frustrating, enraging, and discouraging these interactions can be. Common points of entry into the system, through crisis services and hospitalization, are described as dangerous, traumatic, and guilt inducing. Aftercare in the context of discharge is described as difficult to access and inadequate. Throughout this process, families grapple with stigma, express frustration with clinicians, and wish for more information and support.

It is well known that families often find hospitalization for a first episode of psychosis frightening (11–14). Such negative experiences with hospitalization may lead to lasting fear and distrust of mental health services on the part of young people and their families (24). Families report that hospitalization occurs when psychosis escalates to the point that they can no longer handle it. This may be an important clue to understand and reduce the well-documented duration of untreated psychosis common at the onset of psychotic disorders.

The delay in treatment of psychotic symptoms until they reach crisis proportions may be due in part to families' misattribution of symptoms and behaviors to typical adolescence or to stress or drugs (20,25). Although evolving symptoms may be subtle and nonspecific, this misattribution of symptoms may be due in part to reluctance on the part of patients and families to deal with the stigma of the label of a mental illness (2,12). Families in this and other studies poignantly describe their experience of the stigma associated with mental illness and its associated shame and social isolation (12,26–28). In the United States, the President's New Freedom Commission on Mental Health (29) identified stigma as a primary obstacle to recovery in mental illness and called for implementation of campaigns that use television, the Internet, and print media to spread understanding through personal stories and education. One such campaign in Norway, the Treatment and Identification for Psychosis Project (TIPS), has led to use of services earlier and when individuals are less symptomatic (10) and to improved clinical outcomes (30).

The delay in treatment of psychotic symptoms may also be a consequence of structural problems in mental health care, as described by families in this and another study (25). The Institute of Medicine (IOM) endorses the development of an American mental health care system that anticipates needs, rather than simply reacts to events, to avoid coercion whenever possible (31). The IOM furthermore calls for a flexible and responsive system that offers assessments 24 hours per day in face-to-face interviews and through telecommunications (31). Such programs already exist in other countries, such as the Early

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Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Victoria, Australia, which has specialized mobile teams to perform rapid home-based assessments (32). Services in Australia are designed to be youth friendly, with peer counselors staffing phone and online support groups (33). Preliminary findings suggest that such early intervention services for young people with psychosis may significantly reduce police involvement in access to care (34), which is particularly common among African Americans (35–38). The fear expressed by one mother in the study presented here that "someone would be shot" has been echoed in other studies: for many African-American families, such fears are major obstacles to seeking treatment (39).

Beyond hospitalization, care is described by families as fragmented and expensive. The IOM has called for making collaboration, coordination of care, and integration of services the rule in mental health care (31). Some specialized first-episode programs in Europe and elsewhere offer integrated treatment, including assertive outreach, extended hours, vocational and social skills training, substance abuse treatment, and family services (40, 41). In the United States, the President's Commission recognized such services as critical to engage and retain in treatment young people with mental illness (29), and indeed, such programs have been associated with fewer rehospitalizations and better clinical outcomes (41–43). Some programs, like EPPIC, integrate first-episode psychosis services with primary care, community psychiatry, and addictions services for even better coordination of care (44).

The financial difficulties of underwriting psychiatric care were described not only by families of limited means but also by parents who were professionals—architects, teachers, and social workers. The President's Commission identified as problematic the lack of parity in third-party coverage of mental illness, with insufficient support for the treatment of early psychosis (29). This has been addressed in the United States with recent federal legislation. What remains is to develop a political consensus that early, coordinated, youth-friendly, and affordable treatment of psychosis for young people is a national priority.

What came across strongly in this study was a sense of outrage on the part of families. This can be channeled into political action through participation in family groups, such as the National Alliance on Mental Illness, which has played a strong role in obtaining legal parity of coverage for health care. As described in other studies (18,19), this study showed that families want information and support and more involvement in the care and recovery of their loved ones. Their wishes are consonant with calls by the President's Commission for more patient- and family-centered care (29) and calls by the IOM for involving patients and families in the design, administration, and delivery of treatment and recovery services (31). In general medical illness the benefit of involving and educating families has been recognized (45). And some specialized first-episode psychosis programs in other countries have successfully engaged families, such that both families and patients benefit (16,46).

The small sample of this study is typical of qualitative research studies, and it was able to provide rich and detailed information that could not be elicited otherwise with simple questionnaires. The results are consonant with findings in earlier retrospective studies of the impact of psychosis onset on family members (7, 11,12,14). However, because patients were drawn from academic centers, the generalizability of the findings may be limited.

Conclusions

Qualitative studies allow better understanding of subjective experience and the phenomenology of illness and treatment; here, we reveal the upheaval that a first episode of psychosis can cause in families, with its accompanying tragedy, grief, anger, and sense of

chaos. Our results underscore the need for broader implementation of specialized, accessible, affordable, and integrated treatment programs for patients with a first episode of psychosis—programs that involve families and are culturally sensitive. Implementing such programs is in line with the President's Commission on Mental Health, which has called for development of early detection services, improved access to treatment, better integration of services, and education campaigns to address stigma (29).

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