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ORIGINAL PAPER

The Help-Seeking Experiences of Parents of Children with a First-Episode of Psychosis

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Abstract The objective was to understand the experiences of parents as they sought psychological and specialized medical services for a loved one having a first episode of psychosis. The research method was qualitative and the data gathering was done through semi-structured interviews. Eleven parents of eight adolescent or young adult children consented to be interviewed. Data from these interviews were coded and sorted. Parents reported that many of their encounters resulted in delays in accessing treatment. These encounters were characterized by misattributions of the child's behavior, poor advice, misdiagnosis, disbelief in the seriousness of the child's condition, and an unwillingness to share information. But parents also reported that encounters with other individuals were characterized by helpful advice, emotional support, and suggestions as to how to access early intervention services. Encounters with many professionals were generally not helpful to parents. These encounters served as roadblocks to accessing proper treatment for their child. More publicity, outreach, and education are recommended in the professional community.

Keywords First episode psychosis · Parents · Adolescents and young adults · Families · Pathways to treatment

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Introduction

Often, young people are not aware or cannot make sense of what is happening to them as they experience a first episode of psychosis (FEP; Keshavan et al. 2004; McEvoy et al. 2006; Norman et al. 2004; Tanskanen et al. 2011). Consequently, most do not immediately seek medical treatment. This means that, because most young people experiencing a first FEP reside with their family (Addington et al. 2001; American Psychiatric Association 1994; Compton and Broussard 2009; Corcoran et al. 2007), it is often up to their family to pursue psychiatric care for the loved one experiencing psychosis (Compton et al. 2009; Morgan et al. 2006; Wong et al. 2009).

Research shows that family involvement is associated with the timeliness and manner in which young individuals enter into mental health treatment systems for the first time (Compton et al. 2009; Morgan et al. 2006). Much of this literature on family involvement focuses on three topics: the point at which families decide to seek out professional help, the psychological experiences of families, and the characteristics and skills of families. First, research clearly indicates that families begin the help-seeking process when their family member begins to act strangely (Bergner et al. 2008; Compton et al. 2004; Corcoran et al. 2007), or when they exhibit disruptive and dangerous behaviors (Bergner et al. 2008; Compton et al. 2004; Franz et al. 2010). Second, families feel the stigma, fear, and burden of facing the reality that a family member is experiencing signs and symptoms of a serious mental disorder (Czuchta and McCay 2001; Franz et al. 2010; Gerson et al. 2009; Wong et al. 2009). Research has shown that fear of a stigmatizing label induces coping responses in families, such as secrecy, denial or enlisting informal help resources, each of which possibly delays formal help-seeking behavior (Boydell et al. 2006; Compton et al. 2009; Franz et al. 2010). Finally, characteristics of the family have been shown to influence treatment-seeking behavior. For example, Compton et al. (2009) and Goulding et al. (2008) have shown that greater coping capacity in families reduced the duration of untreated psychosis (DUP), suggesting that there was less of a delay in accessing treatment relative to those families who did not share these strengths. However, higher family strain was shown to increase DUP (Compton et al. 2009).

The literature reveals complex, social psychological factors that influence the help-seeking process that families go through once they begin to realize that their family member is in need of psychiatric treatment. Research is still needed to understand the complex manner in which family-related factors influence the time between the initial realization that a young adult child needs help and the actual receipt of help (Compton et al. 2008). One important factor that has been overlooked to date is the influence of the information received that may prevent or encourage treatment engagement.

Results of studies completed in Great Britain suggest that the social context in which families find themselves has an influence on how soon loved ones receive clinical treatment for psychosis (Cratsley et al. 2008; Morgan et al. 2005, 2006). No work that we know of has been produced in the United States that focuses solely on the social context in which families make decisions about how, when, and where to obtain proper medical services for a family member experiencing FEP. Thus, an information gap in the literature about pathways to treatment in FEP is how families seek input from others to help their loved one access psychiatric services in the most expeditious manner as possible.

Thus, we want to know what some families *do* to assist their family member to access treatment quickly when there is an emerging first FEP. Specifically, we want to document the pathway to treatment by examining the perceived impact of the advice, information, and support they receive as they seek professional help for their loved one. We want to understand what family members' interactions were like both inside and outside the medical milieu when seeking help for their child who was experiencing a first FEP. Our research questions are as follows: (1) what are the steps taken during the process of seeking treatment for a child who was, it was later learned, experiencing FEP? And (2) how do family members describe their interactions with others in the process of seeking treatment for a child experiencing FEP? Specifically, how do parents' encounters with others either delay or facilitate treatment engagement for their child experiencing FEP?

Methods

Setting

Respondents were recruited and data were collected at a child and family services agency in a northeastern Ohio county which operates a program designed for the early identification and treatment of those with a schizophrenia spectrum disorder. This early intervention service (EIS) is team-based and provides comprehensive, individualized, and developmentally appropriate interventions for individuals experiencing a first episode of a schizophrenia spectrum disorder (i.e., schizophrenia, schizophreniform disorder, schizoaffective disorder, and psychotic disorder not otherwise specified). The EIS program began enrolling clients in February 2010. Treatment components include: (1) individualized psychopharmacological and medication management, (2) individual counseling, (3) family psychoeducation, (4) supported employment and education, and (5) case management. Programmatic components are tailored to meet the needs of clients through regular collaborative treatment planning and follow-up.

Sampling and Recruitment

The criteria for inclusion into the study was that potential respondents needed to be a family member of a client currently enrolled in the first episode program. *Family member* was defined as any kin of the client, including parents, spouse of the client, or close friend of the client who has actively participated in seeking treatment on behalf of the client. In addition, clients needed to be at least 18 years old. Individuals who were not fluent in English and family members who were uninvolved, based on the information gathered from the client, in the effort of getting the client into medical treatment were excluded. At the time of recruitment for participation in this study, there were 35 families enrolled in the EIS program. All 35 families were made aware of the research study and its goals and objectives by the project coordinator. Of these 35 families, we determined that 23 were ineligible to participate in this study for the following reasons: clients had no family members involved in seeking treatment (5), clients were under the age of 18 (7), clients lived outside the county where early intervention services could be procured (4), clients could not provide informed consent because of the severity of their condition as determined by the FEP team psychiatrist (3), client was incarcerated (1), family was non-English speaking (1), client was in drug and alcohol rehabilitation (1), and client could not be located (1). Of the 12 eligible families, four clients declined participation in this study.

A researcher approached each client individually following an evaluation by the FEP team psychiatrist, when the team psychiatrist deemed that the client was able to provide informed consent. After describing the goals and procedures of the study, the researcher asked each client whether he or she would be willing to assent to having a family member participate in the study. Assent forms were distributed to eligible clients who agreed. After the client signed an assent form, one of the authors approached the parent about consenting to participate. If the parent was not immediately available to hear about the study, the interviewer telephoned the parent to determine whether he or she would be amenable to participating. If the parent agreed to be interviewed, the interviewer would provide a consent form for him or her to sign. A sample of 11 individuals from 8 families agreed to participate in the research study. The recruitment process lasted from April 2013 to May 2013.

Participants

Eight participants were female and three were male. Seven participants were white and four participants were black. Three couples were interviewed, while five individuals were interviewed separately. All participants were parents of the client in question. Parents were not asked about their marital status.

Research Design

In describing the pathway to treatment, our central research question was, “How did family members describe their interactions with others in the process of seeking treatment for a child experiencing FEP?” We determined that a qualitative method was the most appropriate approach to address our research question. This type of research involves “emerging questions and procedures, data typically collected in the participant’s setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data” (Creswell 2014:4). A phenomenological research design was used for this study because we sought a description of the “lived experiences of individuals about a phenomenon as described by participants” (Creswell 2014:14). Specifically, we wanted to describe, and then understand, the lived experiences of family members as they went through the process of accessing specialized treatment through interaction with others for their child experiencing psychosis for the first time. This type of approach usually involves conducting interviews (Creswell 2014).

Data Collection

Data were collected through the use of semi-structured interviews. There were eight interviews in all. Five interviews involved one parent, and three interviews involved both parents. Questions were developed under four main topics that were organized so that participants could describe the route they took to obtain specialized, medically-oriented intervention services for their child. These topics were: (1) “Experience of Initial Symptoms,” (2) “Initial Help-Seeking Action,” (3) “The Sequential Process of Help-Seeking,” and (4) “Going from Psychiatrist to EIS.” Interviews were held at the agency where the EIS program was located. Interviews lasted from 35 to 85 min. All interviews were audio-recorded and then transcribed verbatim. These interview transcripts served as the sole data for this research study. Interviews began in May 2013 and ended in July 2013.

Data Analysis

The central goal driving this research was to gain an understanding of the interactions that parents had during the course of accessing early specialized treatment for their child experiencing FEP. This report is intended to be a description of what has been learned from these parents about their encounters with individuals who may have been in a position to help them. Because we wanted to describe interactions as parents perceived them, we chose an issue-focused analysis as the most suitable manner in which to describe this process (Weiss 1994).

A summarization of the family’s experience from the time they believed they were seeing changes in their child’s behavior to the time specialized treatment was written for each interview. We did this because we wanted to document chronologically who parents sought out for advice about treatment for their child with FEP. By doing so, we hoped that we would be able to better see whether these interactions were of benefit in obtaining treatment, and also because we would be able to track and describe these parents’ pathway to treatment vis-à-vis these sequential interactions.

After coding all eight transcribed interviews, we sorted these codes into general themes. After much consideration and rereading of the transcripts and timelines, we found that nine discernible themes emerged as the coding material was sorted. Finally, we integrated these themes into two categories that we believed would be useful in describing and understanding the information that these parents provided to us. Participants’ encounters with others were categorized by how well these encounters helped parents find appropriate medical treatment for their child.

One group of encounters served to delay the accessing of appropriate medical treatment, and the other group of encounters served to facilitate the accessing of appropriate medical treatment.

Ethics

Both the clients and parents were given information about the research study. The clients provided written informed assent for their parents to be interviewed, and parents provided written informed consent to participate in the study. Participants in the study were informed about the option to withdraw at any time during the interview without stating a reason, and with the full understanding there would be no negative sanctions placed on them. Participants were guaranteed confidentiality, as all identifying information was deleted in the course of transcribing the recorded interviews. The research was approved by the Northeast Ohio Medical University Institutional Review Board (IRB). The authors know of no conflict of interest regarding the execution of this study, including the planning, sampling, data gathering, and data analysis performed as part of this research project, and all authors certify responsibility for the contents of this report.

Results

To better place our results in context, we found that the range of the DUP for the family members encountering a first FEP was 3–18 months, and the mean DUP was 7.87 months. For this paper, we defined DUP as the month that parents reported their son or daughter first experienced positive symptoms of psychosis (i.e., delusions, hallucinations, and/or disorganized thought processes) to the month that their child was officially enrolled in the local EIS program. We found no clear pattern of causes of longer durations of non-treatment relative to shorter durations of non-treatment. However, of the three cases in which the police were called in response to the child's first FEP, two were the longest DUP at 18 and 17 months respectively. Of the eight cases in our study, three began their pathway to treatment by contacting law enforcement officials, one was taken by campus security to the local hospital, and four began by taking their child to the local emergency room. Thus, for half of the participants, their path to treatment began with the involvement of law enforcement or security personnel. The other half were taken to the emergency room directly by the parents to begin their path to treatment. No parents reported seeking out advice from informal sources initially. It was only after their child was hospitalized did parents in our study seek out advice from family, friends, and other medical personnel such as nurses.

Delaying Access to Treatment

In examining the interview data around the interpersonal encounters that impacted treatment engagement, we found that parents interacted with other family members; friends; medical personnel (e.g., pediatricians, psychiatrists, paramedics, and nurses); counselors; law enforcement professionals (e.g., police officers, judges); and professional advocates. In analyzing the data, we found that six different themes characterized interactions that proved to be impediments to treatment. Encounters between parents and others were characterized by the following: (1) misattributions about the cause of the child's behavior, (2) lack of direction, (3) poor advice, (4) inappropriate diagnosis or non-diagnosis of the child's condition, (5) disbelief about the severity of the child's psychological state, and (6) unwillingness to share needed information.

Misattributions of Behaviors

Parents reported that they encountered various explanations as to why their child was beginning to act differently at the onset of his or her psychosis. Some family members and medical personnel thought their child's use of particular substances was at the root of his or her actions. One parent stated that her mother "…thought it was drugs. She was saying, 'That sounds like drugs or something. He's on something.'" Another parent reported that the staff at a family therapy session "…all thought that marijuana was the problem." Some family members of these parents believed that the child's new behaviors stemmed from their parents' lack of discipline. For example, one father stated, "My daughters…think that we kind of baby our son too much. I mean, they're the older ones and he's the youngest and sometimes they think that we shelter him too much, but that's their opinion."

Some parents also reported that doctors attributed their child's behavior to loneliness and normal conflicts between parents and adolescents. For example, one mother noted that her child's doctor "…thought it was probably due to some depression and not having friends and being lonely." Another mother stated, "The doctor just kind of blew me off…He just kind of chalked it up to, 'Oh, you guys are just not getting along. You're just having some difficulty. It happens with adolescents and parents. You'll get past it.'" In addition, one father reported that a nurse believed that demons may have been the root of her son's condition. He said, "One of the nurses on the floor said, 'I've been a nurse for over 20 years. I hope you won't be offended…but have you ever considered having your son prayed over for demonic possession? I've never been so afraid of anybody as I have been of your son…Do you think he might be possessed?'" In sum, many of these parents encountered individuals and professionals who attributed their child's behavior to drug use, general teenage problems, poor parenting, and demonic possession.

Lack of Direction

Some parents reported that the individuals whom they sought for help only had general recommendations for what do with their child. One mother recalled that her son's high school counselor said, "'I think he needs more help.' She didn't know where to send me. She didn't know what to do…" Another mother expressed her frustration about a lack of helpful direction for her sons who were having psychological difficulties.

> When our sons were in juvenile court, we would frequently say, 'Isn't there any help we can get?…we'd get stuff piecemeal here and there…but didn't know how to put it all together and didn't really know what resources were available in this community…it was like everybody had their own little niche, but nobody had the overall perspective.

Finally, one father described the family's experience at the hospital where their daughter was being treated.

> There was even no understanding that…'This is a new change for you and your family and here's some information for you. Here's some things that we recommend.' Nothing…so it was more of a frustrating experience. I can't say that they didn't try to do the best for her, but they certainly did nothing for us.

In summary, some parents reported that professionals who were perceived as experts provided little direction for them as they searched for how and where to find appropriate treatment for their child.

Poor Advice

Parents reported that some of the advice they received did little good. One mother stated,

> We had a lot of people telling us…'You just need to kick your son out of the house. If he won't obey…just kick him out,' and we'd always come back saying, 'We know he's creating havoc in the house, but he really has nowhere else to go.' We did not have anybody else that he could live with.

Another mother discussed two incidents with mental health professionals who offered little in the way of helpful advice. "The one psychiatrist that we could get into [see for an appointment]…I was very, very unhappy with him and my son was very unhappy with him. His idea was to turn the TV off at a certain time and not let my son watch TV at night." Of one counselor, this mother noted, "Yeah, the psychologist thought he had too much time and he needed to get a job. Well, I don't know how he could've worked during that time." Some parents, in summary, encountered advice by both friends and professionals that minimized their child's problem and encouraged tough love rather than actually help them obtain access to treatment for their child.

Misdiagnosis and Non-diagnosis

In encounters with pediatricians and psychiatrists, some parents reported that it was difficult, at least initially, to receive an accurate medical diagnosis for their child or to receive a diagnosis at all. One mother recalled a conversation she had with her son's pediatrician. "[The doctor] said, 'You know, I think he is showing signs of depression and he seems like he's stressed out. We could start him on some medication and see how that goes.' So he did start him on medication."

Some parents encountered medical personnel that could not or would not provide an initial diagnosis. When asked about their initial encounter with their daughter's psychiatrist, the mother stated, "[The psychiatrist] was very nice…[She] said that she wasn't quite sure of what the problem was…She really didn't…give us a diagnosis." Father: "She did not. She said, 'I will not give you a diagnosis. You've got to be hearing voices for six months. I'm not sure really what your diagnosis is.'"

Not receiving a diagnosis of psychosis was frustrating to parents as they recalled their experiences. One mother said, "No one ever mentioned psychosis or schizophrenia…I had no idea about any of that." Another mother shared the following about an encounter with a professional: "The psychologist that [my son] was seeing…that really surprises me because she never used the term *delusion*. She never used any of those terms with me." The same mother concluded, "When I heard about the…typical things for schizophrenia or psychosis, then I thought, well, why didn't anyone in the field see any of those things, or talk about those things?" Overall, many parents reported that psychiatrists and pediatricians whom they encountered could not (perhaps based on the uncertainty of the illness itself) or would not provide them with an accurate diagnosis, and that psychosis was rarely mentioned in the initial conversation.

Disbelief

A few parents reported that some professionals who were in a position to help them find medical treatment for their child did not believe the severity of their child's condition.

One mother related this story about her encounter with a paramedic unit:

> "…when the altercation broke out at my mom's house, I said, 'Call 9-1-1 now. The paramedics will come.' [But] they would not believe that anything was wrong with my son…" This same parent had a similar experience with the police. She said, "We called the police. My son left because he knew they were coming…[The police] said, 'Well, if he comes back, just give us a call. We'll be around.' I said…'No, you don't understand. My son needs to get medical attention. He's having a psychotic break.' They brushed me off…I couldn't get him to the emergency room. Nobody would believe me; the police would do nothing…Seven police visits in three days."

Another mother related a story of how she attempted to get her son into treatment, only to have the staff reject her son because they did not believe he was displaying severe enough symptoms. The mother said, "You know, for all the times I tried telling people how difficult things were at home, sometimes I felt like people thought I was crying wolf or something. Later on, when we ended up getting with a clustered program because my son was so severe…we didn't qualify because they thought my son wasn't severe enough." In sum, some parents reported that others' disbelief about the severity of their child's psychological condition restricted entry into treatment services.

Unwillingness to Share Information

Some parents reported an unwillingness on the part of various mental health professionals to share information about their child or other information which may have helped them to find appropriate treatment. For example, one mother told the story of why she ceased making appointments for her son to see his psychiatrist. She stated,

> I stopped taking my son to the doctor. For a whole year, my son and [the psychiatrist] became more buddies…I was never brought into the conversations of what they talked about…So I [thought]…'This is just a total waste of my co-pay,' and I stopped taking him.

A mother and father shared their annoyance with an out-of-state hospital treating their child. Father:

> "I don't remember them being very forthcoming at the hospital…In fact, every piece of information that we found out there was almost [a] tooth and nail pull…" Mother: "No one talked with us, the staff, doctor, social worker. It was terrible."

These parents reported an inability or unwillingness on the part of medical personnel to share information about either their child or about the illness in general, which may have hampered efforts to seek meaningful treatment.

Facilitating Access to Treatment

Not all encounters that parents had with other individuals as they sought medical solutions to their child's illness slowed progress toward accessing proper medical treatment. Some encounters were helpful to parents. They reported that they received emotional support and helpful recommendations from individuals such as nurses, family, friends, and advocates, and that these encounters actually accelerated the progress toward accessing specialized services.

Emotional Support

Friends and family members provided emotional support, some parents reported, as they sought advice and guidance. One father received support from a friend who lived out-of-state. He said, "I have a friend whose son suffers from psychosis, and I talked to him about it, and he was quite aware of what I was going through and he insisted that [my son] get some help…That was kind of tough to hear."

One mother reported that she had a variety of people who were willing to help her. "Well, my sister has depression and anxiety, so she was admitted [to the hospital] once, so she was helping me. The church…our pastor and his wife had a daughter that was admitted, so they kind of were trying to help me through that [time period]." Another mother had a close friend who provided emotional support for her and her husband. "My best friend…was a social worker. She was kind of at a loss, like, 'Wow, you know, you are dealing with such a difficult circumstance.' She just encouraged me, saying, 'Well, hold the line.' She had an adopted son who had his own mental illness when he was a teen, so she understood how deep the pain can be and how deep the struggles were, you know?" Parents in the present study reported that they found support from friends and family, especially from those who had similar experiences.

Helpful Advice

Many parents reported that they did eventually receive helpful advice from family members and medical personnel regarding the next steps in the process of caring for their child. For example, one mother stated of her conversation with a nurse as she and her family were experiencing a crisis stage regarding their son: "[The nurse] told me, 'I'm sorry about what happened to you, but this is what you need to do, if you ever experience this ever again.' She said, 'You need to get him downtown and have him probated…They will pick him up and put him in observation for 48 h…If that's the only way you can get him help, that's what you do.'"

One couple spoke of their experience trying to get their daughter out of the hospital to bring her home. They spoke with a nurse at the hospital where the child was being treated. The mother said about their conversation, "I'm telling [the nurse], 'We want to get her home. It's been over a week now and they won't let her home.' She hooks us up with the contact at the insurance on how to get her home." The father said later in the interview, "She really guided and gave suggestions to contact the insurer, you know, put us on paths and gave us reassuring information that, from a personal standpoint, she had experienced herself, and expressed concern and empathy."

Finally, the same mother who was advised to have her son probated had a sister who was a critical care nurse on the psychiatric floor of the local hospital. She provided this mother with some help via brochures from the National Alliance on Mental Illness (NAMI). "She said they were having a 'mental health week' or something and all this literature was on the table right outside…the psych ward, and she said she just started picking up everything she could find…Had I not called NAMI, I don't know what would've happened." In sum, some parents reported that those in the nursing profession provided much needed advice about how to get help for the child.

Finding Specialized Treatment

Parents spoke of the encounters they had with individuals who helped them get their child into the local EIS program. Some parents became aware of the local EIS program through staff members at the hospital where their child was being treated. One mother shared the following information from when her son was in the psychiatric unit of the local hospital: "They said that he was a good candidate for this program…While [my son] was still in the psych ward, they went over there and got him signed up and everything. [The hospital] knew about the [EIS] program."

Another mother became aware of the local EIS program through speaking with a resident who was familiar with her son's case. "I said to him…'Isn't there someone that we can see that can specialize in this area?' He said that he had heard a doctor speak to the residents shortly before that, so he told me about the program. And that was when I contacted the [EIS] program, and we came on board in February."

Other parents reported that NAMI was the link to accessing early intervention services for their child. One couple recalled that they met a Family-to-Family speaker at a NAMI meeting who urged the couple to contact the EIS program, which they did. The father stated, "That all seemed to go pretty quickly. Once [my daughter] went to the interview and then was accepted in the program, that seemed to transpire reasonably quickly." Another father, who had received some information about NAMI and mental illness from the pastoral care office of his church, was able to get his son into the EIS program quickly. "[The pastoral care office] gave me some numbers. I called somebody from NAMI and they told me about the [EIS] program." Interviewer: "So it sounds like it wasn't that long a time between the time your son was having problems to the time he went into the program." Father: "Right. It wasn't that long, maybe a week or two."

Finally, some parents reported that representatives of the EIS program were present at the hospital where their child was being treated, so that the parents did not need to contact them. For example, when asked how she contacted representatives of the program, one mother stated, "[The representative] was just there. I came to visit my son and…she introduced herself and said she was from the [EIS] program, and she explained everything about it…She had already talked to my son." In summary, most parents had to actively seek out early specialized services, but in a few cases, representatives of the local early intervention service had a presence in the hospital and were easily accessible.

Discussion

Our research questions were as follows: (1) what are the steps taken during the process of seeking treatment for a child who was, it was later learned, experiencing FEP? and (2) how do family members describe their interactions with others in the process of seeking treatment for a child experiencing FEP? Specifically, how do parents' encounters with others either delay or facilitate treatment engagement for their child experiencing FEP? We found few typical pathways to treatment, although all cases had reached a severe enough situation where the parents deemed emergency care was needed or in which law enforcement or security were involved.

With regards to the interactions that parents experienced, we found that certain experiences served to delay treatment engagement. Parents' descriptions of their encounters with others on the pathway to treatment involved some combination of misinformation, non-diagnosis, disbelief, and an unwillingness to share information about their child experiencing FEP. Specifically, our study reveals that many parents were faced with confusion about possible conditions, were given misinformation about the condition itself, as well as misinformation about available services and programs. Other barriers included poor communication and difficult interactions between parents and those in the mental health profession.

On the other hand, parents also described encounters that were supportive and helpful in accessing treatment. They reported that assistance and empathy from informal social support contacts, including friends, family members, and nurses were of great assistance. In addition, parents reported that local chapter of NAMI was a helpful resource because of the information shared via brochures, as well as through local family support groups. Furthermore, outreach efforts on the part of the EIS program staff were beneficial to families seeking a specialized care program for their children.

Some limitations to our study were that, first, our eligibility criteria for this study excluded some clients who may have reported different experiences on the pathway to treatment. This may have biased our results. Second, we did not collect information on the socioeconomic status of our participants, thus limiting our understanding of the role of social status in treatment-seeking behavior. Third, because we did not gather a random sample of parents of children with FEP, our findings cannot be generalized to the population of parents who are going through similar situations. Generalization is not a goal of qualitative research, which seeks to explore and describe social phenomena. However, we hope that further research will expand upon the results presented here by examining these issues in more representative samples. Fourth, we were unable to interview parents who did not obtain the benefits of early intervention services for their child, thereby excluding the experiences of those who were unable to find appropriate medical care for their loved one.

Nevertheless, our findings are consistent with much of the literature on parents of children experiencing FEP. For example, like Wong et al. (2009), we found that parents greatly desired to access information about the disorder and the treatment for it. In addition, similar to Corcoran et al. (2007), we found that individuals in parents' informal networks played a crucial role in helping parents obtain medical aid for their loved one. Finally, however, we found evidence that contradicts results of studies that examine the causes of long DUP. For example, while Morgan et al. (2006) found that DUP was associated with a lack of family involvement in the pathway to medical treatment, we found that adult family members (i.e., parents) were quite involved in the treatment-seeking process. Furthermore, we found that in many instances, it was lack of medical diagnosis and disbelief in the severity of child's illness on the part of pediatricians, psychiatrists, and counselors that prolonged the effort to obtain early intervention services. Of note is that these patterns emerged within a community that has an EIS program, illustrating that additional education about available programming is needed and may help mental health care providers connect parents to available services.

This study has some important implications for the mental health treatment community as well as for parents and family members who are seeking help for a loved one who is experiencing a FEP. First, members of the mental health community may better aid parents in dealing with FEP if they are honest about the child's condition. There is often a period of observation and uncertainty before a clinician will assign a diagnosis on the schizophrenia spectrum, and often a diagnosis is delayed until other conditions have been ruled out. Clinicians who are upfront about the nature of diagnosing and identifying psychosis may actually help to assuage parents' concerns or fears about the disorder. It must be noted that in our study, five of the eight adolescent or adult children experienced a first FEP after their 18th birthday. In such cases, privacy concerns may have prevented clinicians from entering into frank discussions with the parents about the child's condition. Furthermore, clinicians who seek out and contact parents and their children about possible treatment options may shorten the amount of time before the child engages with treatment. Future research is needed to explore this possibility.

In addition, training and information sharing about FEP among other responders, including EMS and police, would be helpful to parents to ensure that youth in crisis receive appropriate care, and may serve as an important referral source for programs, such as the EIS program described in this study. Finally, empathy and informal social support from close friends and family members can have a lasting, positive impact on family members seeking psychiatric treatment. Providing contact information for local resources and providing emotional support are invaluable resources for parents who are struggling to cope with FEP.

Our qualitative data speak to the importance of how parents use their social contacts in their quest for treatment for their loved one suffering from FEP. Understanding the avenues by which parents typically seek services after their child has developed symptoms may prove useful in developing strategies by which individuals can be referred to EIS-type services earlier in the FEP trajectory. This is important because early medical intervention in FEP often predicts a better prognosis.

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