

## “There are too many steps before you get to where you need to be”: Help-seeking by patients with first-episode psychosis

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### Abstract

*Background:* There has been substantial research on pathways to care in first-episode psychosis (FEP); however, few studies have used a qualitative research paradigm or have been done from the perspective of the person experiencing the psychotic episode.

*Objective:* We sought to describe the experiences of patients with FEP on their pathway to care and to identify factors that help or hinder help-seeking efforts.

*Methods:* Using a qualitative descriptive approach, we conducted semi-structured interviews with 16 patients recruited from an early intervention program. Data were analyzed using content analysis to organize the findings into themes.

*Findings:* Self-stigma and a pervasive lack of knowledge regarding the symptoms of psychosis and availability of services were barriers to help-seeking. Participants highlighted the crucial role of significant others in initiating the help-seeking process. Participants typically described a complex series of contacts along the pathway to care which resulted in feelings of being misunderstood and losing control, but many individuals identified unexpected benefits of their experience.

*Conclusions:* Our findings suggest a shift in the philosophy and orientation of service delivery towards the creation of services that address these concerns and are relevant to the young people who utilize them.

**Keywords:** *first-episode psychosis, pathways to care, health services, qualitative research*

### Background

The patterns of health services use by patients experiencing a first episode of psychosis (FEP) are complex and often involve a diverse range of service providers. There is evidence to suggest that these pathways to care can have an impact on the length of time that psychotic symptoms go untreated (Anderson et al., 2010), known as the duration of untreated psychosis (DUP), which is an important determinant of clinical and functional outcomes (Marshall et al., 2005; Perkins et al., 2005). Gaining an in-depth understanding of the pathways to care for patients with FEP is crucial for informing the provision of early intervention services, which focus on case detection, attempts to shorten the DUP and comprehensive care during the initial stages of illness (McGorry et al., 2007).

Although there have been numerous studies on pathways to care in FEP, the bulk of prior research has been done using a quantitative research paradigm (Anderson et al., 2010). It is important to also consider the subjective experiences of patients, family members and service providers. A recent review of qualitative research in FEP identified eight studies that looked at the help-seeking experiences of individuals suffering from the symptoms of early psychosis (Boydell et al., 2010). Of those, only two examined help-seeking from the perspective of the patients themselves (Boydell et al., 2006; Judge et al., 2008), and two additional studies published since the review examined the experiences of patients and caregivers (Cadario et al., 2012; Tanskanen et al., 2011). The remaining qualitative studies on pathways to care in FEP have been done from the perspectives of family members (Boydell et al., 2010). It is well established that family members play a pivotal role in the pathway to care for many patients (Lincoln et al., 1998); however, the personal narratives of those experiencing psychotic symptoms should also contribute to the discourse for a deeper understanding of the dynamic processes that impact help-seeking attempts.

In the current study, we sought to describe the experiences of patients with FEP on the pathway to care and to identify factors that may help or hinder the help-seeking process.

## Methods

We used a qualitative descriptive approach, which is defined as “...a distinct method of naturalistic inquiry that uses low inference interpretation to present the facts using everyday language” (Sullivan-Bolyai et al., 2005, p. 128). It is used when the objective is to produce a comprehensive summary of the phenomenon that is recognizable to those who experienced it (Sandelowski, 2000). The description produced is a low inference interpretation of events, such that the research remains at the “surface” of the data, while still capturing relevant aspects of the experience (Milne & Oberle, 2005). This approach was chosen because it is useful for research involving vulnerable populations and it is relevant in health services research for improving the utility and uptake of the findings (Sandelowski, 2000; Sullivan-Bolyai et al., 2005).

We recruited participants from the Prevention and Early Intervention for Psychoses Program (PEPP) at the Douglas Mental Health University Institute in Montréal, which specializes in the early assessment and treatment of FEP. Eligible patients include those between 14 and 30 years with a primary diagnosis of an affective or non-affective psychotic disorder. The PEPP uses an open referral system, and referrals come from a variety of medical and non-medical sources.

Qualitative research uses purposive sampling strategies that aim to select “information-rich cases” (Patton, 1990, p. 169). We employed a criterion sampling strategy to recruit patients in months 3–12 of the PEPP program who were deemed to be clinically stable and sufficiently talkative for an interview. No additional exclusion criteria were imposed. The study was presented to the patient by a staff member following a regularly scheduled session. For all interested patients, we followed-up within 1 week to confirm participation and schedule an interview.

Recruitment continued until the data had reached saturation, which is the point at which new data support existing findings but do not add any additional insights (Sandelowski, 1995). Saturation is often difficult to achieve in a qualitative descriptive design, as the objective of the research is to capture individual experiences and explore commonalities and differences across them (Milne & Oberle, 2005). Thus, data collection was concluded when no new primary themes were apparent, and the data on the primary themes had sufficient

depth and breadth to allow for a comprehensive understanding of the phenomenon (Sandelowski, 1995).

We used a combination of unstructured and semi-structured in-depth interviews, which involved an open-ended, conversational technique that focused on the participants' help-seeking experience. The unstructured portion of the interview involved asking each participant to describe their experiences seeking help for their psychotic symptoms. The semi-structured portion of the interview involved questions developed *a priori* based on a separate qualitative study on help-seeking in early psychosis (Boydell et al., 2012). The topics probed in this portion of the interview are presented in Table I, although these were often mentioned spontaneously during the unstructured narrative. The interview guide remained flexible to allow the data to be participant-driven.

Ethics approval was obtained from the Douglas Mental Health University Institute, a healthcare facility within the McGill Academic Health Network, and all participants provided written consent. Interviews were held at a time and location that was convenient for participants, and the interviews were audio-taped with the permission of the participant; however, if he/she refused ( $n = 1$ ), the interviewer made detailed notes on responses. All participants were given \$20 as compensation for their time and contribution.

Content analysis is the recommended technique for qualitative descriptive studies, as it is less-interpretive relative to other types of qualitative analyses (Sandelowski, 2000). It is focused on summarizing interview content using data-derived codes or themes (Hsieh & Shannon, 2005). We transcribed all interviews verbatim, and excerpts of the French interviews relevant to our study objectives were translated into English. We used the software program NVivo 8.0 (QSR International<sup>®</sup>, Victoria, Australia) to facilitate data management and analysis.

Two members of the research team reviewed the transcripts independently to gain a sense of the content and recurring themes. This initial coding scheme was used to identify the segments of text pertaining to each code, the segment of text was highlighted in NVivo, and the most relevant code was applied to the text segment. As this process continued, new insights were gained that were added to the emerging coding scheme. Upon completion of this first level of coding, the segments were sorted to consolidate all of the data related to a specific code, which allowed for the data to be organized into themes (Hsieh & Shannon, 2005). Each of the main themes was based on numerous excerpts described by the majority of participants, and we present several quotations that are representative of these excerpts.

Table I. Topics probed by the semi-structured questions in the qualitative interview.

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Topics

- People you told about symptoms
  - Individuals involved in the help-seeking process
  - How the involvement of others impacted the process
  - One word to describe your help-seeking experience
  - Things that made help-seeking easier
  - Factors that made help-seeking more difficult
  - How the experience has had an impact on you
  - Suggestions or advice to make the help-seeking process easier
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Table II. Socio-demographic characteristics of the participants.

Variable	n (%)
Sex	
Male	12 (75)
Female	4 (25)
Education	
>High school	8 (50)
≤High school	8 (50)
Born in Canada	
Yes	12 (75)
No	4 (25)
Visible minority	
Yes	5 (31)
No	11 (69)
Language	
English	6 (38)
French	3 (18)
Bilingual	7 (44)
	Median (IQR)
Age	22.5 (20–24)
Months since program entry	5.5 (4–11)

## Findings

### *Description of the sample*

Twenty-seven individuals were approached with information on our study and six refused. We contacted the remaining 21 individuals: 1 had disengaged from PEPP, 1 had entered a residential detoxification program, and 3 could not be reached. Sixteen interviews were conducted, 10 in English and 6 in French. The interviews ranged from 15 to 75 min (median = 20 min) depending on the loquacity of the participant. The socio-demographic characteristics of the sample are presented in Table II.

Participants typically described a complex series of contacts that eventually culminated in admission to the PEPP program. Family members were involved in the pathway to care for 10 individuals. Participants had a median of two contacts (maximum five) prior to PEPP. Thirteen participants had contact with the emergency department and five had contact with police or ambulance. Seven participants were admitted to inpatient care at the time of entry to the PEPP program.

### *Primary themes*

When describing their experiences seeking help for their symptoms of psychosis, five primary themes were evident from participants' responses: (A) Lack of knowledge regarding the symptoms of psychosis and availability of services; (B) Self-stigma as a barrier to help-seeking; (C) The importance of significant others for initiating service contact; (D) Feelings of misunderstanding and loss of control throughout the help-seeking process, and (E) Unexpected benefits of the experience. We also asked all participants for advice on how to make it easier for people who are experiencing psychotic symptoms to access help. Their responses are summarized in Table III.

Table III. Advice provided by interview participants on how to make it easier for people with first-episode psychosis to access help.

## Education

- Inform the public about the symptoms of psychosis
- Integrate information about mental illness into the education system
- Reduce the shame and stigma associated with psychosis
- Continue research on first-episode psychosis to identify people at highest risk

## Delivery of services

- Reduce wait times
- Crowded waiting rooms are challenging for those with paranoia or social anxiety
- Improve communication between providers so patients aren't forced to continually recount their stories
- Reduce length of inpatient stay
- Limit the use of force or coercion
- Provide diversions and activities during time in hospital
- Make an effort to validate the patient's experiences and not be dismissive of delusions or hallucinations

## Early intervention services

- Increase the visibility of early intervention services
- Emphasize the non-medication aspects of early intervention services and the interdisciplinary approach
- Provide individualized treatment
- Create opportunities for patients to connect with other people going through the same thing

## Personal strategies

- Keep busy
- Pray
- Talk to others about the symptoms you are experiencing
- Share your experiences with others
- Listen to your doctor

*Lack of Knowledge.* Eleven participants made reference to their lack of knowledge about psychosis prior to initiating the help-seeking process. Participants typically described experiencing the symptoms of early psychosis, but not knowing that it was part of a mental illness or something for which they could receive medical treatment. Participants also made reference to this lack of knowledge regarding the symptoms of early psychosis when making suggestions on how to improve the help-seeking experiences of patients with FEP (Table III).

I guess the biggest thing would be to get more information out about what psychotic symptoms are ... I was having symptoms for eight months before I sought any help ... I didn't know that this was a condition that you could seek medical treatment for. For me it was just, you know, a state of facts.

*Participant #5*

Well, I was hearing voices, but I didn't know that it was a disease ... And I realized that this is something that started years ago ... So then, I didn't hear voices, but I was still quite depressed at the time. So, bit by bit, it added up, and then I started hearing voices. But I didn't know that I had such a big problem that I needed help.

*Participant #7 (Translated)*

When the psychotic symptoms did begin to impair functioning and the need for help was recognized, participants were often unaware of the services that were available or how to access them.

For people, really, to know that it exists, people who are there for them ... that they be able to talk to people who will listen to them and give them solutions. So it's important that we really draw attention to that. For those who have problems. Especially us, in fact, we come from [foreign country]. We haven't lived in this system, like you ... We don't necessarily know that there are people there, who are even paid by the government for this.

*Participant #7 (Translated)*

It's because there's not, you know, there's the Douglas in Verdun [Hospital with PEPP program], but not every city has one, and you have to know where it is. That's it with psychiatrist hospitals, there aren't many.

*Participant #14 (Translated)*

Many participants were also not aware of the availability of non-pharmacological treatment options within the context of early intervention services, such as case management and vocational services, and felt that these should be emphasized when promoting the program to other young people with early psychosis.

*Self-stigma.* Twelve participants made comments related to the shame and stigma surrounding mental illness when discussing their experiences with seeking help for their psychotic symptoms. Although none of the participants described a situation where they were directly stigmatized, many used words and descriptions that indicated they had internalized society's stigma against individuals with mental illnesses.

I wasn't in denial that I was sick, but I was kind of angry that I was sick, and I wasn't comfortable being in the office, well being in the little area the first time I was seeing the psychiatrist, you know. I wasn't in denial, but there were times I wanted to say 'F\*\*k man, I'm a normal person I'm not sick.'

*Participant #3*

And she was like 'I'm going to make a phone call to the Douglas Hospital and I'm going to get you help because I can't give you the help that you need.' So I said, I was like oh s\*\*t, the Douglas Hospital ... that's for retards, you know? It's for people who are like really sick, you know?

*Participant #8*

These preconceptions about mental illness sometimes resulted in a fear of seeking help for their symptoms and acted as a barrier to obtaining services.

I don't know if I should do this ... I'm scared, I'm petrified of that place. Of going into the asylum.

*Participant #8*

I could have gone to detox, but I let it drop. And I continued taking drugs, and I was scared, and I continued to be scared. I was afraid to go and do ... how can I say this? Telling my story. I was afraid of that. I don't know. And then, I said 'No, I'm just going to drop it.'

*Participant #10 (Translated)*

*Role of significant others.* All participants highlighted the important role of a significant other in initiating the help-seeking process on their behalf. For most, this significant other was a family member, usually a parent.

...If I was alone I don't know what to do and like ... I really don't know what to do and it really, like f\*\*\*d up my life. But the good thing is have the support from them, 'cause uh, like the care-ness

[sic] that I have from them, because I have people who care for me, and they want me to have a better life.

*Participant #2*

Whatever, the care was there and it was given when needed. But as far as seeking it out as an individual, I likely wouldn't have. So I think the important thing for me was that I had people around me to stimulate that...

*Participant #4*

For individuals who did not have family involvement on the pathway to care, there was still an important individual who was the impetus to the help-seeking process.

...the human resource manager. She gave me the list of numbers for this type of problem.

*Participant #6*

If there was no psychoeducator in my school, I don't know where I might have ended up.

*Participant #13*

Most participants acknowledged that they would not have obtained help for their symptoms of psychosis had they not had a significant other to initiate the process.

*Feeling misunderstood and loss of control.* When describing their experiences seeking help for their symptoms of psychosis, more than half of the participants ( $n = 10$ ) described feeling misunderstood by service providers. Individuals often felt that the fear and paranoia they felt as a result of their psychotic symptoms were dismissed or not taken seriously and would have appreciated a more empathic response from service providers.

It was difficult, and I felt misunderstood throughout the whole process... I think the biggest thing was the idea of misunderstanding between myself 'the patient' and those trying to treat me... And sadly in the long run of it, I may have started to curb my responses to what I knew was wanted to be heard of me. Or, you know, what was an expected or desired answer, as opposed to the intimate truth...

*Participant #4*

Yeah, even at the hospital, no one really listened to me ...they diagnosed me with a disease and everything, but no one said 'Ah okay, yeah, it's true, it's possible.' ...They listen and they judge you.

*Participant #10 (Translated)*

Many participants ( $n = 9$ ) also described the loss of control that came along with the help-seeking experience, especially with respect to treatment decisions such as medication and inpatient admissions.

It was almost the release of any self-will. And just doing what I was asked to do, instead of doing what I felt I'd prefer, you know? ... I almost felt like I was a young kid again, being broken, like a dog, being trained to pee outside or something.

*Participant #4*

From a legal standpoint, I didn't know my rights. I didn't know ... how they could have the right to keep me like that. You know, if I wanted to leave, did I have the right? At one point, they took away my privileges. I thought about calling a lawyer, but didn't, you know...

*Participant #14 (Translated)*

*Unexpected benefits of help-seeking.* Although there were many challenges throughout the help-seeking process, more than half of the participants ( $n = 9$ ) described unexpected benefits of the experience. For some, it brought them closer to their family and friends.

I have a fortunate situation of having a pretty caring, loving family on all ends, immediate and external. So I'm sure it strengthened it in some sense, but for the most part, it maintained our love and support of each other in whatever situation we may be in.

*Participant #4*

I guess there's still the baseline where they're still my parents or my family and they'll do, you know, whatever they can so far as they're able to, you know, make sure that I'm healthy. And they'll support me and all the rest of it. I guess what is a little bit more clear to me are partly the limits of that. I mean, as much as they're willing to do, you know, they can't do everything ... On the other hand, you know, it is much more clear to me that there's a lot that they would do. A lot more than I probably know.

*Participant #5*

Others described the sense of community that they found by meeting other people who were going through similar experiences.

Then I put myself in the Douglas Hospital. That's when I got to meet the whole staff and everybody, and I stayed for a month. And that was the best time of my life ... I was with the patients, you know? ... And they were dealing with problems that were real. In the real life, outside, people hide it. They pretend like it doesn't exist, you know? ... And like, they [the other patients] knew what loneliness was.

*Participant #8*

I was talking about this with another girl, who was there with me, and we've kept in touch ... it's something that stays with you. You know, you meet all kinds of people who are also psychotic.

*Participant #14 (Translated)*

Participants valued opportunities to connect with other people who were going through a similar experience, and this was mentioned as a recommendation for improving services for people with FEP (Table III).

## Discussion

Our qualitative description of help-seeking for FEP focused on the experiences as reported by the patients themselves, a perspective which has been lacking in qualitative research on pathways to care (Boydell et al., 2010). Self-stigma and a lack of knowledge regarding the symptoms of psychosis and availability of services were barriers to help-seeking, and participants highlighted the crucial role of significant others in initiating the help-seeking process. Participants typically described a complex series of contacts along the pathway to care, which resulted in feelings of being misunderstood and losing control, but many individuals identified unexpected benefits of their experience.

Nearly all participants mentioned a key individual who initiated or facilitated help-seeking on their behalf, which is consistent with quantitative research on pathways to care in FEP (Singh & Grange, 2006). For most individuals in our study, this help-seeker was a family member, usually a parent. Prior qualitative studies have also found that family members play a pivotal role in seeking help and maintaining contact with services (Boydell et al., 2006; Lester et al., 2011; Wong, 2007). Although important, this involvement takes its toll

on family members, and the process is fraught with frustration (Corcoran et al., 2007) and emotional distress (Cadario et al., 2012). The involvement of parents, in particular, often results in a return to more dependent forms of the parent–child relationship, such as young-people returning to the parental home and parents resuming care-giving tasks that had been previously relinquished (Lester et al., 2011; McCann et al., 2011b; Sin et al., 2005). This may have been reflected in our findings when participants described feelings of “losing control.” Family members do report tensions in their ability to assume this care giving role, given that many patients with FEP have reached the age of majority and are autonomous adults (Bergner et al., 2008). Despite these challenges, many participants in our study mentioned that the help-seeking experience brought them closer to their families and emphasized the lengths that their loved ones will go to for them. This sentiment has been previously reported in the qualitative literature (Lester et al., 2011) and is echoed in interviews with family members who are involved in the pathway to care (McCann et al., 2011b).

Although family members were the primary help-seekers for many participants, it is important to also acknowledge the essential role that non-related help-seekers played in the pathway to care of some individuals. When lacking in social support or unable to turn to family for help, patients turned to other individuals, such as school counselors and work colleagues. These individuals were pivotal in directing patients to services, sometimes even accompanying them. It is important to identify and support these key contact points in the care pathway, as patients who lack family involvement have an increased likelihood of involuntary and negative pathways to care (Burnett et al., 1999).

Prior qualitative research on help-seeking in FEP found that patients often ignored the signs and symptoms of psychosis and engaged in strategies to hide the symptoms from others in their social network (Boydell et al., 2006). Although this was not described by the participants in our study, there was a pervasive lack of recognition that these symptoms were associated with a mental disorder that could be treated. This finding was also reported by both Judge et al. (2008) and Tanskanen et al. (2011), who found that patients were usually the first to notice changes in themselves but did not necessarily associate them with a need for care or services. This lack of knowledge of the signs of early psychosis is echoed in the literature on help-seeking by family members, who often misattribute the symptoms to emotional issues, behavior problems, or substance use, and believe the problem will resolve on its own (Boydell et al., 2010). The failure to recognize early psychotic symptoms as manifestations of a mental illness is a common barrier to accessing treatment (Judge et al., 2008) and may contribute to treatment delay (Cadario et al., 2012). Among participants in our study, there was also uncertainty about which services to turn to and how to access them once the symptoms were recognized as a mental health problem. This finding is again consistent with studies on help-seeking by patients (Tanskanen et al., 2011) and their family members (Etheridge et al., 2004; McCann et al., 2011a). Participants in our study emphasized the importance of educating people about the signs of psychosis and availability of services, and used examples of local public awareness campaigns for other mental health conditions.

The words and phrases participants used to describe their psychotic disorder indicate that many have internalized society's stigmatizing attitudes toward people with mental illness, and this may have acted as a barrier to help-seeking. This type of self-stigma has been reported previously among adolescents taking psychotropic medication, as reflected in the terms used to describe their illness, in their self-image, and in their secrecy among peers for fear of being ostracized or teased for taking medication (Kranke et al., 2011). The labels that young people use when describing mental health problems are also predictive of a preference

for specific types of care pathway contacts (Wright et al., 2012), and a fear of stigma is a barrier to help-seeking by FEP patients (Judge et al., 2008) and their family members (Cadario et al., 2012; Etheridge et al., 2004; Franz et al., 2010).

Participants in our study had several recommendations for facilitating help-seeking for patients who are experiencing psychotic symptoms. They emphasized the importance of public education and stigma reduction campaigns. The visibility of services could be increased, and the non-physician and non-pharmacological aspects of the program should be emphasized to avoid deterring people who may be averse to seeking “psychiatric” treatment. They also identified several aspects of service delivery that were barriers to help-seeking, such as being forced to wait in a crowded room with strangers for long periods of time while experiencing symptoms of social anxiety or paranoia, and having to continually recount intimate or embarrassing details to strangers over the course of multiple service contacts to access help. Finally, participants mentioned the importance of being able to talk to others about what they were experiencing, and meeting others who were in a similar situation was one of the unexpected benefits of the help-seeking process. Taken together, our findings suggest a shift in the philosophy and orientation of service delivery towards the creation of services that address these concerns and are relevant to the young people who utilize them. They also highlight the need for improved mental health literacy and stigma reduction campaigns for both the general public and mental health service providers.

The findings from our study are limited by several factors. Patients at PEPP have been successful at obtaining specialized services, and the experiences they described may differ from individuals who do not obtain treatment or who are currently under the care of routine health and social service providers. We also limited our sample to patients who are engaged with services, and the experiences of non-engaged individuals may differ. The median duration of our interviews was only 20 minutes which has the potential to limit the depth and breadth of the data obtained, although it is likely sufficient to achieve the objectives of a qualitative descriptive design. Finally, we asked participants to give a retrospective account of events from a highly distressing period in their lives, which may lead to inaccuracies in their descriptions.

Studies using qualitative methods make an essential contribution to the burgeoning body of literature on FEP, as it “...allows us to pursue essential questions regarding the subjective experience of psychosis and the complex social settings in which young people and their families live their lives.” (Boydell et al., 2010, p. 8). The discourse on pathways to care would benefit from further qualitative inquiry on such topics as the socio-cultural processes underlying help-seeking and the impact of the pathway to care on engagement with services and future help-seeking. It would also be beneficial to include the perspective of service providers to gain insights into difficulties they face in identifying and responding to the signs of early psychosis and the supports that are needed to facilitate prompt referral to specialized care. This in-depth knowledge afforded by a qualitative approach is an important component to our overall understanding of pathways to care in FEP.

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