

## **Pathways to care in first episode psychosis: A pilot study on help-seeking precipitants and barriers to care**

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### **Abstract**

*Background:* It is well documented that individuals experiencing first episode (FE) psychosis encounter significant delays in obtaining appropriate treatment, but why this occurs remains poorly understood.

*Aims:* To examine the duration of untreated psychosis in a FE population, to describe precipitants of help-seeking attempts, and to identify barriers to obtaining appropriate treatment.

*Methods:* Twenty individuals who recently received antipsychotic treatment for a FE of psychosis were interviewed about help-seeking behaviors.

*Results:* A total of 75 help-seeking attempts were reported. Fifty percent of the sample reported aggressive behaviors toward the self or others prior to obtaining treatment. Patients and their families experienced significant delays in linking with appropriate psychiatric care. The most common barrier to treatment was a failure to recognize the seriousness of behavioral changes as part of a mental illness.

*Conclusions:* Further investigations on treatment delay that highlight barriers to care and emphasize the patient's perspective are warranted.

*Declaration of interest:* None.

**Keywords:** *First episode, psychosis, treatment, help-seeking*

### **Introduction**

Research suggests that delays in treatment for first onset schizophrenia aggravate the course of illness. A prolonged duration of untreated psychosis (DUP) is associated with multiple adverse consequences, including worse outcome (Norman & Malla, 2001; Addington et al., 2004), increased risk for violence toward the self or others (Lincoln & McGorry, 1999), and elevated treatment costs (Moscarelli et al., 1991). Delays may also contribute to extensive damage to social networks before treatment commences, and increase the likelihood of compulsory hospitalization. Emerging evidence furthermore suggests that the earlier antipsychotic medication is administered after the onset of psychosis, the better the response (Norman & Malla, 2001; Ücok et al.,

2004). Such findings underscore the “critical hypothesis period” in which the first five years of psychosis represent a crucial period for treatment initiation (Birchwood et al., 1998).

Despite these findings, individuals encounter significant delays between the onset of psychotic symptoms and linkage with appropriate care. Delays average 1 and 2 years (Johnstone et al., 1986; Beiser et al., 1993; Helgason, 1997) and are associated with multiple service contacts (Lincoln et al., 1998). Contributions to treatment delay include lack of caregiver involvement in the help-seeking process (Cole et al., 1995), poor community knowledge, and underestimation of the importance of early intervention among general practitioners and lay public (Addington et al., 2002; Etheridge et al., 2004). Extant research on pathways to care (PTC) has occurred mostly outside of the United States (US), and given the differences in health care infrastructure, it is conceivable that help-seeking patterns and barriers to care vary across countries.

The purpose of this study was to examine barriers of care and identification of behaviors and symptoms among first episode patients in the United States; a group who’s PTC has hitherto not been investigated. PTC was assessed using a “topographical approach” which emphasizes the perspective of clients, an emerging methodology in this area (Lincoln et al., 1998; Lincoln & McGorry, 1999).

## Method

We recruited 20 individuals through the Schizophrenia Treatment and Evaluation Program (STEP) at the University of North Carolina at Chapel Hill, the only specialized psychotic disorders clinic in this catchment area, which ranges from suburban to rural. Study staff approached individuals, who had been stabilized on antipsychotic medication for the first time within the previous year, about participation. Written consent was obtained from all 20 participants. All met DSM-IV criteria for schizophrenia, schizophreniform, or schizoaffective disorder, based on the Structured Clinical Interview for DSM-IV, by raters trained to a gold standard criterion. Mean age was 19.8 years, and 15 were male and 5 were female. Ethnic backgrounds comprised Caucasian ( $n = 14$ ), African American ( $n = 5$ ), and Hispanic ( $n = 1$ ). We determined the onset of prodromal and psychotic symptoms using the Schizophrenia Onset Symptom (SOS) Inventory (Perkins et al., 2000), and defined DUP as the time between onset of psychosis and administration of antipsychotic medication.

A social worker used a structured interview, the Pathways to Care Interview, developed by two of the authors (DOP & JN) to collect data on help-seeking (Perkins et al., 1999). The Pathways to Care interview enquires about each help seeking attempt, its symptomatic or behavioral precipitant, to whom participants turned for help, the outcome of attempts, and perceived barriers to care. The definition of help-seeking behavior or response includes two components: (i) the recognition that “something was wrong,” and (ii) determination of an action to impact on symptoms (e.g., seeking advice from lay individuals or professionals, prayer, or a “watch and wait” approach). We conducted a second interview with the patient’s relative or significant other to supplement the patient’s account and fill in missing information. From this interview, we coded help-seeking *precipitants*, defined as behaviors or symptoms that led to administration of antipsychotic medication, and help-seeking *barriers*, which are factors that dissuaded the patient and/or family from seeking help despite the presence of anomalous behaviors or symptoms.

## Results

Less than half of the participants were the first to notice changes in their thinking or behavior, with caregivers more likely to be the first to recognize a change in their loved one ( $n = 13$ ). The majority of successful help-seeking attempts were facilitated directly by caregivers ( $n = 15$ ), and most remaining individuals ( $n = 4$ ) were linked with treatment via emergency services (e.g., police).

The duration of time from onset of prodromal symptoms to the patient or family recognizing that a problem existed averaged 7.8 months ( $SD = 8.5$  months), from first recognizing a problem and to obtaining appropriate treatment averaged 14.4 months ( $SD = 16.9$ ), and DUP ranged from 2 to 72 months, with a mean of 19.2 months ( $SD = 17.8$ ) (Figure 1).

A total of 75 help-seeking attempts were made by our sample, with a range of 1–15 attempts (mean = 5.1,  $SD = 3.2$ ). The most common precipitant was the presence or exacerbation of psychotic symptoms, followed by suicidal ideation. Neither prodromal symptoms nor negative symptoms resulted in initiation of treatment. Aggressive behavior toward the self (e.g., suicide attempt) or others (e.g., assault, destruction of property) occurred 15 times (mean = 1.5;  $SD = 0.53$ ), among 50% of the sample.

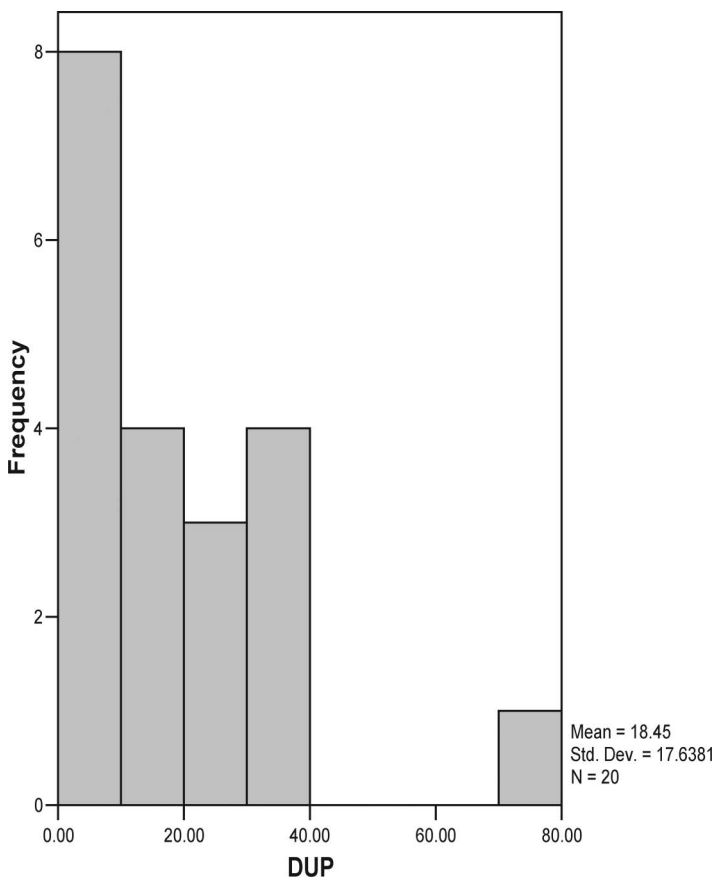


Figure 1. Histogram depicting the distribution of DUP across the 20 participants.

The most frequently reported barrier to care was a failure among patients, families, law enforcement officials, and mental health providers to recognize the presence of and/or seriousness of active symptoms ( $n = 16$ ). The second most frequent barrier was uncertainty regarding where to seek help ( $n = 11$ ), and the third was a lack of financial resources, insurance, or transportation to the hospital ( $n = 6$ ). A lack of insight in patients, embarrassment around seeking psychiatric care, and cultural and language barriers were less frequently reported barriers to seeking care.

## **Discussion**

Consistent with previous research (Lincoln & McGorry, 1995; Addington et al., 2002), our sample experienced significant delays in obtaining appropriate antipsychotic treatment. Average DUP was 19.2 months, the most successful precipitant to antipsychotic treatment was a worsening in psychotic symptoms, and the most common barrier to care was a failure to recognize symptoms as part of a serious mental illness. These findings from a US sample are consistent with research conducted in Canada (Addington et al., 2002), the UK (Cole et al., 1995; Etheridge et al., 2004), Australia (Lincoln & McGorry, 1995; 1999), and Japan (Yamazawa et al., 2004).

Relatives and friends were more likely than individuals themselves to notice changes in behavior, and such others were involved in all but five successful help-seeking attempts. This is consistent with past research that has associated support during help seeking with less adverse PTC (Cole et al., 1995). Although individuals and families noticed prodromal and negative symptoms prior to the onset of psychosis, these symptoms alone were not salient precipitants of treatment. Previous research in other countries has yielded similar findings (Lincoln & McGorry, 1995, 1999; Lincoln et al., 1998; Addington et al., 2002), suggesting that improved education about the early stages of psychotic illness is an international concern. It is striking that the most common barrier to care cited here was a lack of understanding about psychosis rather than a paucity of community resources, underscoring the high levels of uncertainty surrounding early psychosis (Czuchta & McCay, 2001).

Prominent barriers, such as not realising the seriousness of symptoms and where to seek help, may also be addressed by education of community members in general, and of those in gatekeeper roles in particular. Indeed, a history of regular contact with general practitioners was among the most important factors in avoiding an adverse PTC in the UK (Cole et al., 1995). Importantly, countries with more developed infrastructures for the recognition and management of early psychosis such as Australia, the UK, Canada, and Denmark, have shown that community education can reduce DUP (reviewed in Edwards & McGorry, 2002), and that reduction of DUP through an early detection program was associated with better clinical status at baseline and 3-month follow-up (Melle et al., 2004). Comparative efforts in the US are only now underway.

Potentially violent and dangerous behaviors were relatively common in this sample, and are of great concern, particularly when even their occurrence did not necessarily facilitate linkage with appropriate treatment. These data along with previous reports provide a sound justification for early intervention (Lincoln & McGorry, 1995).

Our findings underscore a discrepancy between what is known about the possible risks of a prolonged DUP and the stark delays and related barriers that individuals and their families regularly confront. Further research is indicated to clarify perceived barriers to care and better conceptualize the most common one cited here, namely a failure to recognize serious mental illness.

Our study has limitations, notably its small sample size and use of retrospective self-report, but it nevertheless directs work in this area toward understanding of what specifically

prevents individuals from recognizing the need for care and then actively seeking it. This study represents a pilot phase of a larger ongoing project undertaken first, to identify barriers to care and causes of treatment delay among a FE sample and second, to assess the consequences of delay over time.

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