



Published in final edited form as:

*Compr Psychiatry*. 2008 ; 49(6): 530–536. doi:10.1016/j.comppsy.2008.02.010.

## The period of untreated psychosis prior to treatment initiation: A qualitative study of family members' perspectives

Erin Bergner<sup>1</sup>, Amy S. Leiner<sup>2</sup>, Tandra Carter<sup>2</sup>, Lauren Franz<sup>1</sup>, Nancy J. Thompson<sup>1</sup>, and Michael T. Compton<sup>1,2</sup>

<sup>1</sup>Department of Behavioral Sciences and Health Education, Rollins School of Public Health of Emory University, Atlanta, Georgia, U.S.A

<sup>2</sup>Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, Georgia, U.S.A

### Abstract

**Aim**—This study employed a qualitative research methodology to explore common themes pertaining to the period of untreated psychosis prior to treatment initiation in hospitalized, urban, African American, first-episode psychosis patients.

**Methods**—Twelve family members of 10 patients were interviewed at length to gather detailed narrative accounts of factors related untreated psychosis and treatment delay. Using qualitative analysis, verbatim transcripts were reviewed by two researchers to identify prominent themes useful for generating future research hypotheses.

**Results**—Four themes emerged as informative of the period of untreated psychosis prior to treatment initiation: (1) misattribution of symptoms or problem behaviors (e.g., depression, drug use, adolescent rebellion), (2) positive symptoms causing unusual or dangerous behaviors that served as a catalyst for initiating treatment, (3) views about personal autonomy of an adult or nearly adult patient, and (4) system-level factors (e.g., unaffordability of healthcare, inefficiency on the part of healthcare providers).

**Conclusions**—Family members encountered numerous barriers when seeking treatment, including their own misattributions, the nature of the patient's symptoms, financial issues, and system-level delays. The themes uncovered in this formative analysis merit further exploration with additional qualitative and quantitative research.

### Keywords

Duration of untreated psychosis; Psychosis; Schizophrenia

## INTRODUCTION

Schizophrenia is a major mental illness and is among the top ten causes of disability-adjusted life-years globally [1]. Recent years have witnessed a marked upsurge in research on the

---

Corresponding Author: Michael T. Compton, M.D., M.P.H., Emory University School of Medicine, Department of Psychiatry and Behavioral Sciences, 49 Jesse Hill Jr. Drive, S.E., Room #333, Atlanta, GA 30303, U.S.A., TEL: 404-778-1486, FAX: 404-616-3241, E-MAIL: Michael.Compton@emory.edu.

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

potential benefits of early intervention and the need to understand, and eventually reduce, the duration of untreated psychosis (DUP). DUP, generally defined as the time interval from the emergence of psychotic symptoms to the initiation of treatment [2], has been shown consistently to be a potentially modifiable predictor of early-course outcomes. Indeed, two seminal meta-analyses investigated the effect of DUP on a number of important outcome domains. Perkins and colleagues [3] demonstrated that long periods of psychosis prior to treatment may decrease symptomatic and functional recovery from the first episode of psychosis. Marshall and associates [4] also found significant associations between longer DUP and poorer outcomes in terms of positive symptoms, total symptoms, likelihood of achieving remission, overall functioning, and quality of life. These findings are consistent with the notion that antipsychotic medications, and perhaps psychosocial interventions, may protect against an early-course pathological and/or psychosocial deteriorative process.

There are at least two clinical reasons to emphasize early detection of schizophrenia: the growing evidence that by intervening in the early stages of psychosis, clinicians may be able to improve longer-term outcomes [3-5], and the equally important idea that early detection can result in an immediate reduction of suffering, regardless of any effects further downstream. Unfortunately, people experiencing early psychotic symptoms rarely seek treatment on their own. Family members often must play an important role in initiating treatment for individuals with first-episode psychosis [6]. In their recent study of potential clinical and social determinants of DUP from the *Aetiology and Ethnicity in Schizophrenia and Other Psychosis* (ÆSOP) study, Morgan and coworkers [6] found that an insidious mode of onset, unemployment, and lack of family involvement were independently associated with a longer DUP. De Haan and colleagues [7] reported that of 56 patients studied, many realized that something was wrong when psychotic symptoms initially developed, but they often underestimated the seriousness of the symptoms. These patients frequently acknowledged the need for others, particularly parents, to initiate treatment. These findings demonstrate that it is crucial that research exploring potential determinants of treatment delay and DUP include family members as a source of information.

Morgan and associates [8] emphasized that the process of help-seeking is situated within a larger social and cultural context whereby the pathway to care may be conceived as a dynamic social process. Pathways to care likely differ for various populations [9-13]. Given the importance of discovering determinants of DUP, some of which evolve during pathways to care, and in light of the fact that families commonly initiate evaluation and treatment, this study explored narrative accounts of family members who had been actively involved in initial treatment-seeking for their loved ones with first-episode psychosis. This study engaged an urban, African American sample, given that the African American population has been understudied with regard to early-course help-seeking for psychosis [10,14].

## METHODS

A qualitative research design, qualitative description, was employed in an attempt to uncover factors deserving of further research, particularly among urban African Americans. Qualitative description allows for a comprehensive summary of an event (in this case, initial help-seeking for psychotic symptoms) in the everyday terms of respondents. Furthermore, this method is useful in collecting responses that may not have yet been theorized [15]. Qualitative strategies do not aim to include a necessarily representative sample, do not test hypotheses based on statistical significance, and generally do not express results through relative frequencies, as this may be misleading [16]. Thus, qualitative description allows for rich narrative data to be collected, and may generate new hypotheses for further quantitative research.

Twelve family members who were instrumental in seeking treatment for 10 hospitalized first-episode patients were recruited for participation in this qualitative study. The study was initially designed and approved for twelve participants, as this was presumed to be a sufficient number of narratives. However, the *a priori* plan was that if after twelve interviews the researchers found that new information was continuing to be collected, the sample size would be increased and recruitment would continue. However, saturation of themes was reached at twelve participants. Patients and family members were participants in an ongoing research project, the *Atlanta Cohort on the Early course of Schizophrenia (ACES)*, which is being conducted at a large, public-sector, university-affiliated hospital in the southeastern United States.

Newly-admitted, first-episode, schizophrenia-spectrum disorder patients being assessed for the larger study gave consent for their family members to be contacted and invited to participate. Data on the clinical status of patients were obtained from a number of instruments, including the *Structured Clinical Interview for DSM-IV Axis I Disorders, Patient Version (SCID-I/P)*, the *Positive and Negative Syndrome Scale (PANSS)* and the *Global Assessment of Functioning (GAF)* scale. The SCID [17] is a semi-structured interview conducted to establish a research-based diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) [18]. The psychotic disorders and mood disorders modules of the SCID were used to confirm and specify schizophrenia-spectrum disorder diagnoses. The PANSS [19] measures the severity of psychopathology in adult patients with schizophrenia, schizoaffective disorder, and other psychotic disorders. The 30 PANSS items are grouped into three categories: positive symptoms, negative symptoms, and general psychopathology symptoms (such as depression and anxiety). The PANSS was rated with reference to symptoms in the month before hospitalization. The GAF [18] is a 100-point, single-item scale that rates overall psychosocial functioning on a hypothetical continuum from excellent mental health to severe mental illness.

The date of onset of psychotic symptoms, and thus DUP, was derived using a consensus-based, best-estimate approach that considered data from clinicians, the patient, and family members. The DUP endpoint was the date of hospital admission, which in each case could be considered the first adequate evaluation and treatment for nonaffective psychosis. Information on any prior contacts with professional help providers was collected, along with a description of the process of contacting help, specifically probing for any factors that may have influenced DUP.

Inclusion criteria for the family members required that they be aged 18 years or older and able to speak English. After giving written informed consent, family members participated in a semi-structured interview addressing their experiences of contacting professional services for the initial evaluation of the patient's psychosis. All interviews were audiotaped and transcribed verbatim. Each transcript was reviewed sentence-by-sentence by two independent raters. A list of recurring themes or common processes relevant to the period of untreated psychosis and potential determinants of DUP was compiled. The textual data were explored inductively using content analysis in order to generate categories [16]. This type of analysis is data-derived, in which codes are both systematically applied and also generated from the data itself [15]. The findings were discussed and compared between the raters to reach a consensus. There were no instances in which the two raters were unable to achieve consensus.

## RESULTS

Family-member participants' ages ranged from 32 to 62 years (mean,  $47.8 \pm 7.6$ ). Nine participants were female and three were male. The majority ( $n=10$ ) had graduated from high school and had attended trade or vocational school or college. All of the participants were African American, and most ( $n=7$ ) reported that their religious affiliation was Baptist. Seven

of the informants were mothers of patients, two were fathers, one was a sister, one was a grandmother, and one was an uncle. The majority ( $n=7$ ) were married or living with a partner.

The 10 patients for whom these 12 family members sought help were aged 18–28 years (mean,  $22.0\pm 3.5$ ). Seven of the patients were male and three were female. All of the patients were African American, and all were single/never married. The majority ( $n=6$ ) had not graduated from high school, though all were  $\geq 18$  years of age. Seven of the patients were diagnosed with schizophrenia, and three with schizophreniform disorder. Six of the 10 patients had been previously incarcerated. Three of the 10 patients had one or more children. The sample DUP ranged from 2.3 weeks to 204.4 weeks (median, 42.4 weeks). The larger ACES cohort had a median DUP of 23.1 weeks, which was not significantly different from the median DUP in this smaller subset based on a Mann-Whitney  $U$ -test. Mean scores for the PANSS positive, negative, and general psychopathology subscales were  $21.6\pm 4.6$ ,  $24.3\pm 8.0$ , and  $40.3\pm 9.2$ , respectively. The mean GAF scale score was  $34.4\pm 11.3$ .

As reported previously [20], in the larger study there was no evidence of significant differences in sociodemographic or clinical characteristics or in DUP between patients for whom information from a collateral informant (family member) was available and those for whom it was not. Additionally, there were no significant differences in gender, age, education, and having children among participants in this study and participants of the larger ACES study cohort, indicating that this sample was representative of the larger cohort.

With regard to family members' perspectives on the period of untreated psychosis and factors potentially associated with treatment delay or treatment initiation, and therefore DUP, four main themes emerged: (1) misattribution of symptoms or problem behaviors, (2) externalizing behaviors related to positive symptoms as a catalyst to treatment, (3) views about personal autonomy of the patient, and (4) system-level correlates of treatment delay. The ways in which labeling and stigma may impact treatment delay is the focus of another report from this same qualitative study [21], and therefore, is not discussed in-depth herein. Each theme was consistently described by participants as occurring during the period of untreated psychosis and potentially impacting DUP, and is illustrated below with direct quotes from the interviews.

### Misattribution of symptoms or problem behaviors

Most family members misattributed the patient's symptoms to either another mental disorder, most commonly depression, or a response to stress. This is exemplified by excerpts from the accounts of mothers of two separate patients:

“He used to say he was all stressed out, ya know. I was saying ‘Why are you so stressed out?’ I guess ‘cause he’s so, ya know, he says he’s so depressed, and I don’t know what he was so depressed about.”

“I think [she] just had a bad deal. There’s such a thing as postpartum [depression] after you have kids when you’re young, and back to back, being stressed.”

In addition to depression, family members tended to initially blame the possible use of illicit drugs for the patients' odd behaviors and declining role performance. Quotations from the mother of one patient and the sister of another patient illustrate this:

“Well I thought something had happened to him. Maybe he had gotten hooked to some bad drugs that flipped him out. That’s why, I said he needed some help ‘cause that wasn’t like him.”

“A lot of people would ask him what’s wrong, and they would ask me, ‘What’s wrong with your brother?’ and ‘Why is he acting like that?’ So, ya know, initially you’re

gonna think, okay, it has something to do with drugs or something, but that's not what it was."

This misattribution of symptoms—as either deriving from another condition, such as depression, or as an effect of street drugs—may be related to the fact that prodromal and early psychotic features of schizophrenia often overlap with depressive symptoms and may mimic behaviors induced by illicit drugs. Family members may have been witnessing the non-specific and highly variable symptoms that are characteristic of the schizophrenia prodrome.

Family members frequently viewed the changes they observed in their loved one as a passing developmental phase, or simply a function of growing up or rebelling against their family. For example, a mother of a patient stated the following:

"I thought it was, ya know, ...she was mad 'cause she didn't get to stay out as late as she wanted to. And since I was upset she stayed out late, we fought. I mean, I thought it was just, ya know, that...I thought she was going through an adolescent stage."

### Externalizing behaviors relate to positive symptoms as a catalyst to treatment

Another theme that emerged was related to the visibility and regularity of symptoms. Overt positive symptoms appeared to serve as a catalyst to initiating treatment, but it was only once such severe symptoms had developed that treatment was sought. A patient's sister describes this:

"I started noticing them more on a regular basis. Um, just like I said...ya know, I have small kids and he's uncle to them. So he's sitting there laughing at stuff and they're smaller and they're not laughing. So they're wondering what he is laughing at; it's not even funny. So, just being around him more, because he started coming around me more [helped me realize that he needed treatment]."

Regarding the severity of positive symptoms, it often took a dangerous incident involving either actual or potential harm to the patient or others for families to seek treatment. This theme is depicted by the following representative quotations from a father of one patient and a mother of another patient:

"We were just really trying to get [him] to a doctor or anybody, whoever we thought, such as the disability office. Until that happened, I hate to say it, but that's the only thing that helped him—when he came up with that gun."

"I was giving benedryl to put her to sleep, I'm serious. 'Here, take these benedryl. Go lie down. You need to lie down. Just lie down.' So, this time, it [became] dangerous. It was dangerous for her jumping out of the car when she was with her dad...while they were on the expressway, and that was last fall."

### Views about personal autonomy of the patient

In many instances, participants' responses indicated that treatment delay may have been partly driven by the notion that the patient was "of age" and capable of (and responsible for) independent decision-making. It should be noted, however, that in addition to the families' *perception* of what it means for patients to be adults, being  $\geq 18$  does convey legal rights and some autonomy, creating a barrier for family members to get help for a resistant person unless/ until the patient reaches threshold for involuntary evaluation/treatment. Family members expressed that they were not in the position to tell their loved ones that they needed help, or to get them treatment. This is exemplified by comments from two mothers:

“A lot of times unless they are showing suicidal signs or are gonna hurt someone else, there’s really nothing you can do. You know, it’s like that person is of age and they have to be the one, you know, to initiate [care].”

“I just kinda let him make his own decisions, ya know. I usually try to help him make decisions, but he says I treat him like a little boy.”

Similarly, patients’ functional decline and symptoms were sometimes viewed as personal or developmental experiences that they had to go through on their own, as shown by one mother’s quotation:

“I always felt from the beginning...that this is something she’s just gotta go through. Through her own experience, ya know, the bad with the good... ‘Cause my telling her, ya know, and saying, ‘You don’t need to do this’...the best lesson is your own experience. I knew she had to go through that and...I knew she had to hit rock bottom to open up her eyes to some changes that, ya know, that need to be made.”

### System-level factors related to treatment delay

DUP was impacted, both positively and negatively, by system-level factors. For example, treatment was sought sooner if family members utilized their friends as resources, especially if these friends had experience with the mental health field. As reported by an uncle of a patient:

“I called a friend of mine who was a psychiatrist...and she connected me with someone else who was, ya know, who deals with that. They kinda told me what I needed to do and they gave me, ya know, referrals and my wife and I went on the internet and we checked different places.”

Unfortunately, many system-level barriers were encountered during help-seeking, including lack of free or affordable services, inflexibility of appointments, and inefficient scheduling processes. A father gave the following account of perceived financial constraints, despite the fact that the patient was ultimately admitted to the unit that provides care to patients with no private or public-sector insurance:

“I mean we were just watching him deteriorate and couldn’t do anything about it... we just didn’t have the money...there’s just nothing we could do.”

The frustrations and difficulties encountered while trying to make appointments for their loved one to see a clinician is exemplified by this sister’s thoughts:

“It took a while because no one responded. No one was there, and I had to leave a message...I was told they would call me, and no one ever called back, or they weren’t in, so, that was the main thing. [They should] just call back. Ya know, if I’m calling, ya know, telling you something is going on with my brother, just call back.”

Family members described the long process they encountered after attempting to initiate treatment for their loved one. A patient’s grandmother recounts her experience:

“Even if you present at the mental health center stating, ‘I got a problem, I really need to see somebody,’ you have to go to the phone. You have to call over to their intake place. They give you an appointment, and then you have to come back. Then when you come back they do the paperwork. They do the intake, like your insurance and stuff like that, and you may see the worker then—the social worker—or whoever’s gonna be like working as your case manager, or then they may do some history stuff with you. Then you leave there with another appointment to come see the doctor, so with that, I think that’s just crazy.”

## DISCUSSION

This formative, hypothesis-generating study of the period of untreated psychosis and potential determinants of DUP among urban African Americans relied on interviews with family members of individuals experiencing a first episode of nonaffective psychosis. PANSS scores revealed high levels of positive and negative symptoms, signifying a relatively severe level of illness—mean PANSS subscale scores in this sample appear to have been greater than those reported in other first-episode samples, [22,23] although no direct comparison of means was calculated. Furthermore, the median DUP in this sample (42 weeks) was relatively consistent with those reported from other first-episode cohorts [24-28].

Study results showed that family members generally did not initially recognize that their loved ones needed medical assistance. Misattributions of symptoms or problem behaviors seem to have occurred because patients first displayed predominantly non-specific and negative symptoms, which were interpreted as signs of depression, drug use, or stress by family members, as also shown in other qualitative research [29-31]. Often, symptoms were seen as developmental characteristics, a view suggested in previous literature [29-33]. Only when positive symptoms presented as potentially dangerous or violent behaviors were family members moved to take action. In addition, early adulthood is a time of separation and individuation. Family members felt, and perhaps legally were, restricted in their role as caregivers because the patients were no longer children, but autonomous adults. Finally, system-level delays such as unreturned phone calls and being directed to a series of different providers within the mental health system also contributed to treatment delay. Czuchta and McCay [32] also found a lack of communication between service providers, with parents commenting on the amount of time it took to get their loved one in for proper psychiatric evaluation.

In a review article by Bhui and colleagues [9], inpatient admission rates were higher among Black patients than Whites in the United Kingdom, and Black patients had more complex pathways to care. Another study from the current setting revealed that urban African Americans have highly variable pathways to care [10]. These findings indicate various barriers to care which impact DUP, including factors within health services that are difficult to navigate. Snowden [11] hypothesized that help-seeking behaviors of African Americans may reflect specific coping styles, the influence of stigma, and a lack of resources and treatment opportunities. McLean and associates [12] found that cultural, institutional, and socioeconomic social exclusions were perceived by African Caribbean respondents in their interactions with health services, thereby perpetuating mental health inequalities.

The results of this study support previous findings that family members can influence the timeliness of a patient's entry into care [6,7]. This study also provides preliminary insight into the mechanisms through which patient-, family-, and system-level variables affect DUP. For example, it is not just the presence or absence of family members in a patient's life, but their perceptions and resources that matter. Some patients benefited from family members who were connected, knowledgeable, and persistent, while others did not have those advantages. Family members, however, do not solely determine DUP for their loved ones. This research suggests that the timeliness of treatment initiation reflects an intersection of several factors including family members' beliefs and resources, patients' clinical presentations and illness features, and the facilitating or impeding nature of the mental health system.

This study has several limitations that should be considered. Because the purpose of formative qualitative research is one of description and hypothesis-generation rather than generalization, the present findings are meant to be exploratory rather than representative. Although internal validity is supported given the relatively homogeneous sample of interest, these preliminary

findings may not generalize to dissimilar populations. Also, although two reviewers engaged in a consensus process to derive themes from the data, the use of more reviewers may have fostered a more thorough analysis.

Despite these limitations, the use of qualitative methods in an under-studied population allowed for rich and descriptive information to be collected. Such qualitative studies hold promise for generating further qualitative and quantitative research questions and hypotheses. It would be beneficial to reproduce this type of qualitative study in similar, and different, samples to determine whether the same themes would be generated. Of specific interest may be the finding pertaining to personal autonomy. Research may benefit from learning if this idea of personal autonomy and one's own decision-making capacity is socioculturally specific, and if it is found in other first-episode populations. Further, quantitative research would be essential in measuring the direction and strength of the associations between the themes obtained in this study and DUP. Researchers could develop specific scales to measure each of the themes detected in this study; alternatively, numerical coding of narrative interviews such as the ones employed in this study could be combined with measurement of symptoms and DUP to explore the relationships among these variables.

However, this will be challenging research given the complexity of sorting out true predictors of DUP from factors that are occurring during the period of untreated psychosis (e.g., misattribution of symptoms). Lack of clarity in determining the temporal order will make the direction of association difficult to specify, and will complicate implications for early intervention, though identifying the strength of association is more achievable. These interviews did not specifically capture information regarding how these themes affected the course of the illness or DUP. Future research may benefit from studying when family members first realized that their loved ones were ill, when they encouraged them to seek their own treatment, and when help was finally sought. Future research also may strive to capture information about the additional amount of time that system-level factors add to treatment delay. By gathering an estimate of these delays, researchers may be able to better quantify the impact of ameliorating these structural factors.

Public education about prodromal and early psychotic symptoms, along with more accessible services, may more broadly reduce DUP and its impact by offering both different explanatory models for behavioral changes for families and supplemental sources of help and support [31]. Understanding factors contributing to DUP, especially those that are potentially modifiable, will make early intervention efforts more feasible. This research illustrates specific barriers that may increase treatment delay. There is evidence that large-scale and multi-faceted community-based interventions can decrease DUP [23,34], though no such interventions have been documented in a population similar to the one involved in this study. Interventions designed to educate and facilitate earlier help-seeking must be accompanied by repair of barriers within the mental health system to decrease treatment delay and its associated morbidity.

## Acknowledgements

This study was funded by a grant to the last author from the National Institute of Mental Health (K23 MH067589 "Correlates of Duration of Initial Untreated Psychosis").

## References

1. Murray, CL.; Lopez, AD. The Global Burden of Disease: A Comprehensive Assessment of Mortality and Disability from Disease, Injuries, and Risk Factors in 1990 and Projected to 2020. Boston MA: Harvard University Press; 1996.



2. Compton MT, Carter T, Bergner E, Franz L, Stewart T, Trotman H, McGlashan TH, McGorry PD. Defining, operationalizing, and measuring the duration of untreated psychosis: Advances, limitations and future directions. *Early Intervention in Psychiatry* 2007;1:236–50.
3. Perkins DO, Gu H, Boteva K, Lieberman JA. Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: A critical review and meta-analysis. *Am J Psychiatry* 2005;162:1785–804. [PubMed: 16199825]
4. Marshall M, Lewis S, Lockwood A, Drake R, Jones P, Croudace T. Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: A systematic review. *Arch Gen Psychiatry* 2005;62:975–83. [PubMed: 16143729]
5. Norman RG, Malla AK. Duration of untreated psychosis: A critical examination of the concept and its importance. *Psycholog Med* 2001;31:381–400.
6. Morgan C, Abdul-Al R, Lappin JM, Jones P, Fearon P, Leese M, et al. Clinical and social determinants of duration of untreated psychosis in the ÆSOP first-episode psychosis study. *Br J Psychiatry* 2006;189:446–52. [PubMed: 17077436]
7. De Haan L, Peters B, Dingemans P, Wouter L, Linszen D. Attitudes of patients towards the first psychotic episode and the start of treatment. *Schizophr Bull* 2002;28:431–42. [PubMed: 12645675]
8. Morgan C, Mallett R, Hutchinson G, Leff J. Negative pathways to psychiatric care and ethnicity: The bridge between social science and psychiatry. *Soc Sci Medicine* 2004;58:739–52.
9. Bhui K, Stansfeld S, Hull S, Priebe S, Mole F, Feder G. Ethnic variations in pathways to and use of specialist mental health services in the UK. *Br J Psychiatry* 2003;182:105–16. [PubMed: 12562737]
10. Compton MT, Esterberg ML, Druss BG, Walker EF, Kaslow NJ. A descriptive study of pathways to care among hospitalized urban African American first-episode schizophrenia-spectrum patients. *Soc Psychiatry Psychiatr Epidemiol* 2006;41:566–73. [PubMed: 16604270]
11. Snowden LR. Barriers to effective mental health services for African Americans. *Ment Health Serv* 2001;3:181–87.
12. McLean C, Campbell C, Cornish F. African-Caribbean interactions with mental health services in the UK: Experiences and expectations of exclusion as (re)productive of health inequalities. *Soc Sci Med* 2003;56:657–69. [PubMed: 12570981]
13. Chien VH, Compton MT. In what ways does mode of onset (sudden/precipitous, subacute, or gradual/insidious) impact pathways to care in young adults with first-episode non-affective psychosis? *Early Intervention in Psychiatry*. in press
14. Merritt-Davis OB, Keshavan MS. Pathways to care for African Americans with early psychosis. *Psychiatr Serv* 2006;57:1043–4. [PubMed: 16816293]
15. Sandelowski M. Focus on research methods: What happened to qualitative description? *Res Nurs Health* 2000;23:334–40. [PubMed: 10940958]
16. Pope C, Ziebland S, Mays N. Qualitative research in health care: Analysing qualitative data. *BMJ* 2000;320:114–16. [PubMed: 10625273]
17. First, MB.; Spitzer, RL.; Gibbon, M.; Williams, JBW. *Structured Clinical Interview for DSM-IV Axis I Disorders*. New York, NY: New York State Psychiatric Institute; 1995.
18. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. Fourth Edition. Washington, DC: American Psychiatric Association; 2000.
19. Kay SR, Fiszbein A, Opler LA. The Positive and Negative Syndrome Scale (PANSS) for schizophrenia. *Schizophr Bull* 1987;12:261–76. [PubMed: 3616518]
20. Compton MT, Chien VH, Leiner AS, Goulding SM, Weiss PS. Mode of onset and family involvement in help-seeking as determinants of duration of untreated psychosis. submitted
21. Franz L, Carter T, Leiner AS, Bergner E, Thompson NJ, Compton MT. Stigma and treatment delay in first-episode psychosis: A grounded theory study informed by Link's Modified Labeling Theory. *Early Intervention in Psychiatry*. submitted
22. Emsley R, Rabinowitz J, Torremans M. The factor structure for the Positive and Negative Syndrome Scale (PANSS) in recent-onset psychosis. *Schizophr Res* 2003;61:47–57. [PubMed: 12648735]
23. Melle I, Larsen TK, Haahr U, Friis S, Johannessen JO, Opjordsmoen S, et al. Reducing the duration of first-episode psychosis. *Arch Gen Psychiatry* 2004;61:143–50. [PubMed: 14757590]

24. Keshavan MS, Haas G, Miewald J, Montrose DM, Reddy R, Schooler NR, et al. Prolonged untreated illness duration from prodromal onset predicts outcome in first episode psychosis. *Schizophr Bull* 2003;29:757–69. [PubMed: 14989413]
25. Addington J, Van Mastrigt S, Addington D. Duration of untreated psychosis: Impact on 2-year outcome. *Psycholog Med* 2004;34:277–84.
26. Perkins DO, Lieberman JA, Gu H, Tohen M, McEvoy J, Green AI, et al. Predictors of antipsychotic treatment response in patients with first-episode schizophrenia, schizoaffective and schizophreniform disorders. *Br J Psychiatry* 2004;185:18–24. [PubMed: 15231551]
27. Üçok A, Polat A, Genç A, Çakır S, Turan N. Duration of untreated psychosis may predict acute treatment response in first-episode schizophrenia. *J Psychiatr Res* 2004;38:163–68. [PubMed: 14757330]
28. Schmitz N, Malla A, Norman R, Archie S, Zipursky R. Inconsistency in the relationship between duration of untreated psychosis (DUP) and negative symptoms: Sorting out the problem of heterogeneity. *Schizophr Res* 2007;93:152–59. [PubMed: 17481857]
29. Corcoran C, Davidson L, Sills-Shahar R, Nickou C, Malaspina D, Miller T, et al. A qualitative research study of the evolution of symptoms in individuals identified as prodromal to psychosis. *Psychiatr Quart* 2003;74:313–32.
30. Monteiro VBM, Quirino dos Santos J, Martin D. Patients' relatives delayed help-seeking after a first psychotic episode. *Rev Bras Psiquiatr* 2006;28:104–10. [PubMed: 16810392]
31. Corcoran C, Gerson R, Sills-Shahar R, Nickou C, McGlashan T, Malaspina D, et al. Trajectory to a first episode of psychosis: A qualitative research study with families. *Early Intervention in Psychiatry* 2007;1:308–15.
32. Czuchta DM, McCay E. Help-seeking for parents of individuals experiencing a first episode of schizophrenia. *Arch Psychiatr Nurs* 2001;15:159–70. [PubMed: 11498809]
33. Wong DFK. Uncovering sociocultural factors influencing the pathway to care of Chinese caregivers with relatives suffering from early psychosis in Hong Kong. *Cult Med Psychiatry* 31:51–1. [PubMed: 17186381]
34. Johannessen JO, Friis S, Joa I, Haahr U, Larsen TK, Melle I, et al. First-episode psychosis patients recruited into treatment via early detection teams versus ordinary pathways: Course, outcome and health service use during first 2 years. *Early Intervention in Psychiatry* 2007;1:40–8.