

The association between duration of untreated psychosis in first psychotic episode patients and help seeking behaviors in Jogjakarta, Indonesia

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ABSTRACT

Help seeking is predictor of prognosis in the first episode of psychotic disorders. Caregivers play a key role in deciding from whom to seek help. In Indonesia, caregivers often seek help from alternative healers first and health professionals later, which is believed to result in delayed psychiatric treatment and risk for poor prognosis. This study measured the duration of untreated psychosis (DUP) in a sample of 100 persons being treated for a first episode of psychosis in Yogyakarta, Indonesia. We attempted to measure and determine associations among caregivers' explanatory models, help seeking behaviors and DUP in this sample. The data were then statistically analyzed. The DUP for this population was very short. Most caregivers were parents or spouses (72 and 12%, respectively) and at the time of being interviewed described medical explanatory models for the psychotic symptoms (60%). A majority described having visited traditional/alternative healers prior to their visit to health professionals (67%). Despite this, the DUP was not significantly different for these two groups. Thus, first resort to traditional/alternative healers did not predict prolonged DUP. Further study with a larger sample is needed to better understand the relationship between care seeking, use of alternative healers and DUP in Indonesia.

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Introduction

Psychosis consists of a set of symptoms in which a person's mental capacity, affective responses and capacity to recognize reality, communicate and relate to others are impaired (Stahl, 2013). Without proper treatment, early phases of psychosis often develop into a more debilitating disorder with severe consequences.

Studies have shown knowledge discrepancies between common people and health professionals in term of psychotic disorders (Jorm, Angermeyer, & Katschnig, 2000; Riedel-Heller, Matschinger, & Angermeyer, 2005; Wright, Harris, & Wiggers, 2005). In contrast to professionals' beliefs that many persons suffering acute psychosis should be hospitalized and treated with antipsychotic medications, in some societies, common people tend to believe that psychotic illness can best be treated with a variety of alternative forms of care, including vitamins, diet or self-help treatments (e.g., Jorm et al., 1997). These discrepancies also affect family caregivers in their help seeking behaviors during the first episode of psychotic disorders of their family members.

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Care seeking processes for mental illness are mediated by culture. Family caregivers are often the first to know that an individual is beginning to experience psychotic symptoms. They interpret the illness, are usually the first to seek help and constitute the ‘therapy management group’ (Janzen, 1987). How family caregivers choose the first visit to a care provider during a first episode of psychosis may be important in determining the course of treatment a patient receives and thus the duration of untreated psychosis (DUP). The DUP is defined as the period between the onset of psychotic symptoms and establishment of effective medical treatment. Help seeking practices play a crucial role in determining DUP.

In Indonesia, family caregivers are particularly crucial in guiding the care seeking process. Indonesian caregivers often understand the underlying cause of a psychotic disorder to be supernatural, interpreting it as caused by spirits or spiritual forces, by intentional black magic or by a person engaging in meditation or religious practices without proper guidance (Good & Subandi, 2004; Kurihara, Kato, Reverger, & Tirta, 2006). Indonesian caregivers often seek help from alternative healers, such as *paranormal* or *dukun* (traditional Javanese healers) or *kyai*, *ustadz*, *ruqyah* (Islamic religious healers) before seeking care from medical specialists. Many Indonesian mental health specialists believe that this pattern leads to delay in finding appropriate medical treatment and thus lengthens DUP.

The analysis reported here is based on a study of the effectiveness of family psychoeducation in increasing caregivers’ knowledge of schizophrenia and the care they provide for a family member, conducted in Jogjakarta, Indonesia (Marchira, 2012). In this paper, we report on findings of DUP in this population and examine the influence of explanatory models and help seeking processes of caregivers on DUP in a first episode of psychotic disorder.

Methodology

Sample and study design

A total of 100 patients with early psychosis and their caregivers were recruited as part of an intervention study (Marchira, 2012). The inclusion criteria were that patients should: (1) be suffering the first episode of any psychotic disorder, with diagnosis established by at least two psychiatrists according to International Statistical Classification of Diseases and Related Health Problems-10th Revision (ICD-10) criteria, (2) be aged 15–30 years old, with caregiver’s aged 18–70 years old, (3) have given informed consent. Patients diagnosed as suffering affective disorders with psychotic symptoms and those for whom the DUP exceeded one year were excluded from the study to eliminate recall bias.

This study is a descriptive analytic study with cross-sectional design. The sample was assembled from hospitals in the Jogjakarta area that had at least one psychiatrist who agreed to participate in this study (Sardjito Hospital, Grhasia Mental Hospital, Jogjakarta District Hospital and Puri Nirmala Mental Hospital).

Instruments and definition of variables

A diagnosis of psychotic episode was established by at least two psychiatrists based on ICD-10 criteria. First episode was established if the episode was a first experience and duration had not exceeded one year. We used an in-depth interview of both the patients and caregivers to assess their beliefs and perspectives about the psychotic episode. Caregivers were relatives living together with the patients and having contact with them for more than 35 hours per week. We divided the caregiver’s explanatory models into supernatural/non-medical and medical, based on the presence or absence of biological, psychological or physical reasons in their explanatory models. We divided the caregivers’ help seeking into medical if they went directly for medical help, and supernatural/non-medical if they first visited some form of traditional healer after they recognized the behavioral changes. The DUP was measured as the period beginning when caregivers observed behavioral

changes representing psychotic symptoms until the patient received adequate medical treatment, in weeks.

Analysis

The data for the analyses reported here were collected from October 2010 to March 2012 during in-depth interviews with caregivers. Data from these interviews were analyzed and coded to allow quantitative analysis (Marchira, 2012). The protocol of this study was approved by the Ethical Committee of the Faculty of Medicine Gadjah Mada University, Jogjakarta.

Statistical analyses were performed using SPSS software (SPSS version 17 for windows, IL, USA). Statistical significances were defined at $p < 0.05$.

Results

We found that subjects were diagnosed as having acute and transient psychotic disorders (63%) or schizophrenia and schizoaffective disorders (31 and 6%, respectively). All subjects were confirmed by interview to be suffering the first episode of a psychotic disorder. Thirty-one percentage of the subjects were currently unemployed, but a large number were of school age and still attending school (mean age 22.4 ± 4.53 years). Subject age also accounted for marital status (Table 1).

The DUP was very low for this group of Indonesian patients suffering a first-episode psychosis. We divided our subjects into two groups, based on caregivers' explanatory model and first help seeking. Those who had supernatural/non-medical explanatory model had a longer DUP (3.8 ± 4.7 weeks versus 2.7 ± 3.9 weeks), although this was not statistically significant. Those whose first help seeking was alternative/traditional/religious also had a longer DUP compared to those who sought medical help (3.2 ± 4.3 weeks versus 3.0 ± 4.2 weeks) and this was also not statistically significant (Table 2).

Most of the identified caregivers were parents (72%) and all were family members of the patients (spouse, grandparent, brother/sister, child, nephew, cousin, etc.). In Javanese culture, children often live with their parents even when they are over 18 years old, and after marriage they join extended families. More than half of the caregivers were female (65%) and almost all were married (93%). Most of the caregivers had completed junior high school or less (Table 3).

Table 1. Demographic characteristics of subjects with first episode of psychotic disorders ($n = 100$).

Variable	Percentage
Sex	
Female	39
Male	61
Age (years)	22.4 ± 4.53
Marital status	
Single	86
Married	13
Divorced	1
Education	
Elementary school	13
Junior High School	22
Senior High School	52
Diploma/bachelor degree	13
Occupational status	
Employed	69
Unemployed	31
Diagnosis	
F 20 schizophrenia	31
F 23 acute and transient psychotic disorder	63
F 25 schizoaffective disorder	6

Table 2. Means of the duration of untreated psychosis in according to caregivers' explanatory model and help seeking behaviors.

Variable		Mean \pm SD (weeks)	T-test		
			<i>t</i>	<i>df</i>	<i>p</i>
Explanatory model	Supernatural/non-medical	3.8 \pm 4.7	0.215	98	0.831
	Medical	2.7 \pm 3.9			
First help seeking	Alternative/traditional/religious	3.2 \pm 4.3	1.304	98	0.195
	Medical	3.0 \pm 4.2			

Table 3. Characteristics of subjects' caregivers ($n = 100$).

Variable	Percentage
Caregiver	
Spouse	72
Parent(s)	12
Other	16
Age (years)	47.2 \pm 12.7
Sex	
Male	35
Female	65
Marital status	
Single	3
Married	93
Divorced	4
Education	
No formal education	1
Elementary school	33
Junior High School	18
Senior High School	33
Diploma/bachelor degree	15
Occupational status	
Employed	65
Unemployed	35

Many of the caregivers (60%) expressed medical explanatory models for the psychotic symptoms at the time of interview (that is, after entering medical treatment). More than half of the caregivers (64%) reported having sought help from alternative healers before entering treatment with health professionals. They visited religious healers (52%), traditional Javanese healers (19%), other alternative specialists (10%) or a combination of these (19%) before they went to health professionals (Table 4). There was no significant association between caregivers' explanatory model and their first help seeking behaviors (Chi square $\chi^2 = 1.93$; $df = 1$; $p = 0.165$) (Table 5).

The DUP for those who first visited traditional or religious healers was 3.2 weeks, while the DUP for those who first sought help from a medical specialist was 3.0 weeks. The difference between these

Table 4. Distribution of first contact for help of the caregivers of patients with first episode of psychotic disorders ($n = 100$).

Service provider	Percentage
General practitioner	4
Psychiatrist	2
General hospital	17
Mental hospital	11
Psychologist	1
Mental health nurse	1
Alternative healer	64
Religious healer	52
Shaman	19
Both	19
Other	10

Table 5. Explanatory model and first help seeking of the caregivers.

Variable		Caregiver's explanatory model		χ^2	df	p
		Supernatural/non-medical	Medical			
Help seeking	Alternative/traditional	30	37	1.93	1	0.165
	Medical	10	23			

Table 6. Medians of the duration of untreated psychosis in according to caregivers' explanatory model and help seeking behaviors.

Variable		Median		χ^2	df	p
		≤ Median	> Median			
Explanatory model	Supernatural/non-medical	24	16	0.133	1	0.737
	Medical	38	22			
First help seeking	Alternative/traditional/religious	40	27	0.605	1	0.437
	Medical	16	17			

groups was slightly in the predicted direction but was not statistically significant (Student's *t*-test [t] = 1.304; df = 98; p = 0.195). We also found that the caregivers' explanatory did not significantly affect DUP (t = 0.215; df = 98; p = 0.831). We did a median test to check for the possibility that the DUP of patients whose caregivers with medical explanatory model and help seeking have a higher proportion below median value, but found no significant differences (Table 6). There were no significant associations between caregivers' explanatory model and caregivers' education and social economic status (Table 7). Similar results were observed for help seeking behavior (Table 8).

Discussion

In this study, we investigated duration of untreated psychosis in a group of persons suffering a first episode of psychotic illness in Jogjakarta, Indonesia, a setting that includes both urban and rural areas. We asked whether traditional explanatory models and initial resort to traditional healers leads to delay in contact with psychiatric services in this population. This study fails to find evidence for delay in reaching medical services associated with an initial resort to a traditional healer.

There are several related findings of the research that deserve comment. First, a large number of the patients (63%) met ICD-10 criteria for Acute and Transient Psychotic Disorders. Although this is unusual in samples in Western countries, very rapid onset illnesses have been described as common in some countries (such as India: Susser & Wanderling, 1994; Susser, Varma, Malhotra, Conover, & Amador, 1995; cf. Marneros & Pillmann, 2004). Our previous studies have suggested that rapid onset psychoses are quite common in Jogjakarta (Good & Subandi, 2004; Good, Marchira, Hasanat, Utami, & Subandi, 2010; Marchira, Hasanat, Utami, & Good, 2006). Some of these remain single-episode psychoses, while others evolve into schizophrenia spectrum disorders.

Second, the mean DUP in this sample is extremely low. It is our experience that there is a direct relationship between speed of onset and DUP in Jogjakarta (Good et al., 2010; Marchira et al., 2006)

Table 7. Association between explanatory model and caregiver's education and social economy.

Variable		Explanatory model		Chi square		
		Supernatural	Medical	χ^2	df	p
Education	Low	18	34	1.309	1	0,253
	High	22	26			
Social economy	Low	29	44	0.008	1	0,927
	High	11	16			

Table 8. Association between help seeking and caregiver's education and social economy.

Variable		Help seeking		Chi square		
		Supernatural	Medical	χ^2	df	p
Education	Low	35	17	0.005	1	0.946
	High	32	16			
Social economy	Low	48	25	0.190	1	0.663
	High	19	8			

and that short DUP is consistent with a large number of persons meeting criteria for Acute and Transient Psychotic Disorder. It should also be noted that this is a treated sample and does not include persons who do not reach care during a first episode of psychosis, and that the inclusion criteria required cases of no longer than one year duration. These factors may have led to a lower mean DUP.

Third, a large number of caregivers expressed medical explanatory models, even though reporting initial resort to traditional healers as first contact. It should be remembered that interviews were carried out after these patients were already in medical treatment and caregivers had had the opportunity to discuss the illness with a psychiatrist. It seems likely that explanatory models of the illness having causes associated with spiritual forces, consonant with Javanese culture, were much more common as a first response to the illness, and these were linked to initial care-seeking practices. In addition, our work suggests that most caregivers maintain both traditional and medical explanatory models at the same time.

Fourth, the mean DUP in this sample is not significantly related to either the explanatory model or initial care-seeking. In part, this is a function of a short mean DUP in the sample, including both those with initial resort to healers and those with initial resort to medical specialists. However, it is consistent with our ethnographic studies, as well as clinical experience, that suggest initial resort to care is quite rapid, particularly when onset is rapid, and that the problem of sustaining care is often greater than the problem of long DUP (Good & Subandi, 2004; Good et al., 2010). Many persons with an initial psychosis enter medical treatment relatively quickly, but quickly drop out of medical treatment (in particular, stopping medications), both if the illness resolves and if it does not. Findings of this study, while not focused on long-term compliance, are consistent with this pattern. Our previous work also suggests that while caregivers of persons with an initial psychosis may seek answers from several traditional healers within days of the onset of the acute psychosis, this does not prevent them from seeking care from medical treatment if the religious therapies are not immediately effective. Again, findings of this study are consistent with this pattern.

While this study does not include persons who failed to seek treatment during the first episode of psychosis, the research does not support the view that resort to traditional healers leads to significant delay in initial care-seeking from medical sources in first-episode psychotic illness in Jogjakarta, Indonesia.

Proper and timely management of the early phases of psychotic disorders is important in reducing the social and medical consequences of untreated psychosis and in building a firm foundation for future management. Ineffective management may result in discontinuing treatment, relapse of symptoms, increase in the risk of treatment resistance and higher stigma (Birchwood, Todd, & Jackson, 1998; Edwards & McGorry, 2002). Our study shows that most persons with a first-episode psychosis in this cultural setting live with extended family members who are the primary caregivers and play a critical role in determining the course of treatment. Given the extremely limited mental health resources in Indonesia, families play the most important role in seeking treatment, monitoring medication use, observing relapse and supporting the social activities of the person with illness. Our study thus suggests that particular emphasis needs to be placed on building rapport with family caregivers during the initial contact with medical care and educating them about the nature of psychotic illness and the importance of adherence to medications.

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