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# Family context and duration of untreated psychosis (DUP): Results from the Sao Paulo Study

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ABSTRACT

*Background:* Duration of untreated psychosis (DUP) depends on several factors, including socio-demographic, socioeconomic, clinical and contextual circumstances, such as availability of mental health services. Living arrangements may also play a role, especially in low- and middle-income countries, where most people who develop psychosis live with their relatives.
*Methods:* Population-based study of first-episode psychosis in São Paulo, Brazil. Participants were aged 18–64 years, lived in a defined geographic area of the city and had a first contact in life with mental health services due to a psychotic episode. Duration of untreated psychosis was defined as the period between onset of first psychotic symptom and first contact with health service due to psychosis. The median DUP was used to classify participants into short and long DUP. Psychopathology, social adjustment and psychiatric diagnoses were made with standardized assessments. Type of service sought and living arrangements were examined.
*Results:* Two hundred participants were included (52% women, 61% non-affective psychoses). The median DUP was 4.1 weeks (inter-quartile range: 1.9–11.4), and was shorter for affective psychoses. Most participants had their first contact with psychiatric emergency services. Those who did not live with a relative (children older than 18 years, parents, partner) were more likely to present long DUP (OR: 2.63; 95%CI: 0.98–7.04); $p = 0.05$).
*Conclusion:* The DUP in São Paulo was shorter than expected. Living arrangements may play an important role in shortening the DUP in urban centres of low- and middle income countries that have a network of mental health services.



## 1. Introduction

The period between the onset of psychotic symptoms and initiation of treatment, often called duration of untreated psychosis (DUP), can last days, months or even years (McGlashan, 2006; Loebel et al., 1992; Compton et al., 2008; Wunderink et al., 2006). Several studies have suggested that the longer the (DUP), the worse the prognosis of the illness (Larsen et al., 2000; Harrigan et al., 2003; Addington et al., 2004), and strategies aimed at reducing the DUP have been tested, especially in high-income countries (Black et al., 2001; Melle et al., 2004; Platz et al., 2006). The considerable variation in DUP across populations worldwide seems to be influenced by socio-demographic, socioeconomic and clinical dimensions, and by factors associated with the context individuals live in, such as social networks, living arrangements, organization of the health system and social stigma (Morgan et al., 2005, 2006a; Mbewe et al., 2006; Chen et al., 2005; Barnes et al., 2000). Cultural beliefs about mental illness seem to be important contextual determinants of DUP as well

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(Kalla et al., 2002; Bechard-Evans et al., 2007; Morgan et al., 2006b; Saravanan et al., 2005; Zafar et al., 2008; Yamazawa et al., 2004).

The large majority of studies about DUP were conducted in high-income countries, but there is some evidence that in low- and middle-income countries (LAMIC) the DUP is considerably longer than in high-income countries (Large et al., 2008). Brazil is a middle-income country with a population of almost 190 million people, with about two-thirds aged between 15 and 64 years, the age range at risk of developing psychosis (IBGE, 2006). In Brazil, most households include more than one person and about 65% of young Brazilians keep living with family members during their adult life (IBGE, 2006; Faleiros, 2008). Among individuals with severe mental illness this is even more pronounced, with approximately 85% of them living with close relatives (Menezes and Mann, 1993).

The present study aimed to investigate the DUP in a sample of first contact psychosis, using data from the "Schizophrenia and other Psychoses at unveiling and long-term outcome" study (SaoPaulo), a large population-based epidemiological investigation of first episode psychosis in São Paulo, Brazil (Menezes et al., 2007). We expected that the DUP in São Paulo would be longer than that observed in wealthy countries, given the relative scarcity of mental health services in São Paulo. Also, we hypothesized a shorted DUP for individuals living with family members than those living in other arrangements.

## 2. Method

### 2.1. Study design, setting and sample

Eligible participants were all those aged 18–64 years who lived in pre-defined areas of the city of São Paulo and had a first contact in their lives with mental health services due to a psychotic episode, according to DSM-IV criteria (American Psychiatric Association, 2004) (295.10–295.90; 297.1–298.8; 298.9; 296.0–296.4; 296.24), between July 2002 and February 2005. The area defined for the study comprised a population of 1,382,861 inhabitants in the year 2000 (Prefeitura do Município de São Paulo, 2006). Most Brazilians who need mental health care seek help in services provided by the Unified Health System (SUS), free of charge, and a small proportion of the population seeks care with private psychiatrists and private psychiatric hospitals. Participants were identified through systematic screening of medical notes of public and private health services in São Paulo, followed by direct contact. Full details about the study population, assessments and procedures of the SaoPaulo study have been previously reported (Menezes et al., 2007). The study received approval from the Brazilian National Committee for Ethics and Research (CONEP-Brazil) and from local Ethical Committees. Written informed consent was obtained from all participants.

### 2.2. Assessments

Assessments were carried out by trained mental health professionals and were performed preferably at participant's homes, as soon as possible after the identification of each case. Training of research assistants included sessions for discussion of all standardized assessments, followed by each research assistant interviewing patients with psychoses, under supervision of the study coordinators. Research assistants were supervised in their use of standardized assessments by the study coordinators throughout the field work. A standardized questionnaire was used to collect information on age, gender, educational level, income per capita, occupation and religion. We asked participants if they lived with other people and his/her relationship with them. When they lived with children we also asked their childrens' age. DSM-IV diagnoses were obtained with the Structured Clinical Interview (SCID-I) for the DSM-IV Axis I Disorders (First, 1995), using direct interview with participants and relatives, and review of medical records as sources of information. Social functioning was assessed with the Brazilian version of the "Disability Assessment Schedule" (DAS; WHO,1988; Menezes and Scazufca, 1993). Positive, negative and general symptoms were assessed with the Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987; Vessoni, 1993). Level of insight was assessed with the item 12 of the General Symptoms subscale of the PANSS.

DUP was defined as the period between the onset of the first psychotic symptom and the first contact with a mental health service due to psychosis (Morgan et al., 2006a). The psychotic symptoms included in this definition were any delusion, hallucination or thought disorder. For each participant, DUP was assessed using the information obtained with the SCID-I interview, collected with the "history of treatment" and "chronology of psychotic symptoms" sections The "history of treatment" section assesses the date of first contact with health services due to psychotic symptoms. The "chronology of psychotic symptoms" section is used to elicit the date of onset of each psychotic symptom assessed as present with the SCID. The interviewer establishes the date of onset of each symptom using the information gathered with the direct interview with study participants and their key informants, and the review of medical notes. A similar procedure has been used previously (Morgan et al., 2006a,b). The middle of the month was assigned as the date of onset of psychotic symptoms when it was difficult to reliably identify the exact day of the month when the symptoms started (Norman et al., 2004). In order to improve the consistency and reliability in the assessment of DUP, two members of the research team independently assigned the DUP for each study participant, using the information recorded in the study protocols. When they disagreed about the presence of symptoms, the date of onset of each symptoms or the date of first contact with health services, a final decision was made on the basis of a consensus meeting with the principal investigator, the two members of the research team that assigned the DUP and other members of the research team.

### 2.3. Data analysis

We classified living arrangements as "living with relatives" or "other living arrangements", according to the relationship between the study participants with those living in the same household. The category "living with relatives" included parents, children 18 years old or over, other first degree relatives and partners, whereas "other living arrangements" included living with friends or children younger than 18 years old, and those living alone. Participants were grouped in two diagnostic categories, according to the DSM-IV criteria: non-affective psychoses (codes 295.10–295.90; 297.1; 298.8; 298.9) and affective psychoses (codes 296.0; 296.4; 296.24). Insight was