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Short communication

## Subjective distress in a representative sample of outpatients with psychotic disorders

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## ABSTRACT

**Background:** The affective burden of psychotic disorder has been increasingly recognised. However, subjective reports of distress and its covariates, especially those related to service use, remain under-investigated in patients with psychosis.

**Methods:** This study investigated subjective distress and its covariates in a representative sample of 401 outpatients with a confirmed diagnosis of psychotic disorders in Brazil. Distress was assessed using the corresponding domain of a standardised measure of need – the Camberwell Assessment of Need.

**Results:** Distress was reported as a need by 165 (41%) patients, being met in 78 (20%) and unmet in 87 (22%). Hierarchical logistic regression showed that the presence of distress as a need was predicted by attendance at psychotherapy (OR=3.49, CI=1.62–7.53), presence of suicidal ideation (OR=2.89, CI=1.75–4.79), non-attendance at psychosocial rehabilitation (OR=2.84, CI=1.31–6.19), and higher psychopathology (OR=1.09, CI=1.06–1.12). An unmet need was predicted by family not accompanying patients to treatment (OR=2.60, CI=1.05–6.44) and higher psychopathology (OR=1.05, CI=1.02–1.09).

**Limitation:** The use of a cross-sectional design and a single questionnaire domain to evaluate distress are the main limitations.

**Conclusions:** Subjective distress is a common unmet need in psychosis, and can be treated. The main clinical implication is that subjective distress in psychosis may be impacted on by family engagement and psychosocial interventions.

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## 1. Introduction

Outcome measures in psychotic or schizophrenia spectrum disorders have evolved in the last decades. Despite being traditionally somewhat neglected, the affective impact of these conditions has been increasingly recognised (Sandhu et al., 2013; Uptegrove et al., 2014). Consequently, the focus on psychotic symptoms has moved towards their personal and emotional burden, given their negative influence on quality of life (Millier et al., 2014; Ritsner et al., 2012). In this context, patients' distress has emerged as a core target of psychosis treatment (Birchwood, 2003; Sönmez et al., 2014).

Psychological or emotional distress following psychosis has been defined as an individual response to illness, experienced as a traumatic life event which disrupts everyday life and requires some adaptation (Birchwood, 2003; Tarrier et al., 2007). It is expressed in terms of non-specific affective manifestations, but often only indirectly assessed through measures of depression and/or anxiety symptomatology. These symptoms constitute a highly prevalent comorbidity in non-affective psychosis, associated with poorer prognosis (Hartley et al., 2013; Lako et al., 2012; Michail and Birchwood, 2014). However, the distress, though highly correlated with anxiety and depression, is a distinct affective feature, being more comprehensive and transient (Ritsner et al., 2012). Few studies have assessed subjective reports of patients' distress, despite the growing focus on patient-reported outcomes (McCabe et al., 2007; Thornicroft and Slade, 2014) and on patient narratives about illness in the context of personal recovery in psychotic disorders (Lysaker et al., 2010; Roe and Lachman, 2005).

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The few studies assessing subjective distress identify it as one of the most prevalent needs, present in 50% or more of patients with psychotic disorders, and among the most common unmet needs (Bengtsson-Tops and Hansson, 1999; Grover et al., 2015; Landolt et al., 2012; Thornicroft et al., 2004). It is a predictor of worse quality of life (Ritsner et al., 2006; Ritsner et al., 2012), and has been associated with more severe psychopathology (Bradshaw and Brekke, 1999; Hartley et al., 2013) and increased insight (Cooke et al., 2007; Selten et al., 2000). Even so, the variables associated with subjective distress remain under-investigated in the context of psychosis treatment, especially those related to service use. This study aimed (1) to assess subjective reports of distress in a representative sample of outpatients with psychosis; and (2) to investigate the sociodemographic, clinical and service use covariates of whether it was reported as a need and whether the need was met or unmet.

## 2. Methods

### 2.1. Design and setting

This was a cross-sectional study with a representative sample of patients from all five community mental health services of Santos, Brazil. It included patients aged at least 18 years, with a confirmed diagnosis of psychosis, and attending the service for the one-year period before the study.

### 2.2. Measures

Subjective distress was assessed using the corresponding domain of the Brazilian version (Schlithler et al., 2007) of the Camberwell Assessment of Need (CAN) (Phelan et al., 1995). The CAN is used to assess 22 domains of needs of patients with severe mental disorders, including psychological distress. The patient-rated version was administered through an interview. Patients are asked whether psychological distress is considered a need or not and, if so, whether it is met or unmet. Ratings are No need, Met need (no serious problem due to continuing intervention) or Unmet need (current serious problem). Additional questions regarding the degree of informal (from friends and family) and formal (from services) help received to meet the need were also included for patients who reported it. The answers to these questions were grouped in this study in terms of whether they received or not each kind of help.

A standardised questionnaire adapted from the Life Chart Schedule (LCS) (Susser et al., 2000) was used to collect information regarding clinical characteristics, history of illness and treatment. General psychopathology, positive and negative symptoms were assessed with the Positive and Negative Syndrome Scale (PANSS) (Kay et al., 1988).

### 2.3. Procedures

Participants were randomly recruited from each of the five services in proportion to the overall number of people with a diagnosis of psychosis on each caseload. This sampling strategy maximised representativeness. Diagnosis was then confirmed through interview with independent trained health professionals, using the section for schizophrenia, schizotypal and delusional disorders from the Composite International Diagnostic Interview (CIDI) 2.1 (Quintana et al., 2007; Wittchen et al., 1998).

A previous study found that 8000 people were treated per year on the caseload of the participating teams, of whom 38% had a diagnosis of psychotic disorders (Andreoli et al., 2004). On the basis of approximately 3000 people with psychotic disorders on

the caseload, and assuming a prevalence of 5 unmet needs assessed using CAN (ranging from 2 to 7 unmet needs with a two-tailed distribution) and alpha of 0.95, a sample size of 465 people was calculated. Allowing for 20% attrition, a sample of 558 people was sought. From this sample, 38 were excluded for not meeting the diagnostic criteria and 23 were not eligible for other reasons (hospitalisation, relapse or death). From the pool of 497 eligible patients, 96 refused or were not contactable, resulting in a final sample of 401 (81%) patients, i.e. 13% of the total caseload of 3000 patients. The study was approved by the ethics committee of Universidade Federal de São Paulo (approval 816.863). All participants provided informed consent.

### 2.4. Analysis

Bivariate analyses investigated covariates associated with subjective distress. Sociodemographic covariates comprised gender, age, marital status, having a child, years of education, occupation in the last six months, accommodation and living alone. Clinical variables comprised diagnosis (schizophrenia vs. other psychosis), illness duration, previous psychiatric hospitalisation, suicidal ideation in life and PANSS subscales scores. Service use variables comprised service attendance currently and in the last month, current use of antipsychotics, satisfaction with medication, family accompanying patients in treatment, and attendance in psychosocial rehabilitation and psychotherapy in the last year.

All variables reaching  $p < 0.25$  in the bivariate analyses (Hosmer and Lemeshow, 2004) were included in hierarchical logistic regression. A significance level of  $p < 0.05$  was used for the regression models and two final models were obtained: dependent variable of subjective distress reported as a need (either Met or Unmet) versus not (No need) and the reported need rated as Met versus Unmet. Independent variables were introduced through the following hierarchical steps, keeping those which were significant for the next step, until obtaining the final model: sociodemographic variables; history of illness and clinical characteristics; service use. The variables regarding service attendance in the last month and psychotherapy attendance in the last year were forced into the last model for subjective distress as a met or unmet need. This was done due to the relevance of the former as an index of service use in this study and the recognised importance of the latter in addressing psychosis distress (Dickerson and Lehman, 2011).

## 3. Results

Most of the patients were men (51.9%), single (56.6%), with a mean age of 45.6 (SD=12.3), 6.4 (SD=4.0) years of formal education, 52.0% had a child and only 14.5% of them were employed in the past six months. The majority (83.8%) had a house as accommodation, 13.5% lived in an institution and 2.7% were homeless. Most did not live alone (89.0%). For diagnosis, 60% were diagnosed with schizophrenia and 40% with other psychotic disorders. The mean duration of illness in lifetime was 18.83 (SD=12.57) years. Two-thirds (67%) had been hospitalised in their lifetime, 91% were in current treatment in the service and 84% had attended service last month. Mean scores of PANSS positive, negative and general psychopathology scales were 13.9 (SD=5.1), 18.5 (SD=7.8) and 33.0 (SD=10.4), respectively. Almost all patients were receiving pharmacological treatment in the past year (90.3%) and most (73.1%) were satisfied with this treatment. Only 18.5% and 18.3% received psychosocial rehabilitation and psychotherapy, respectively. Most (76.1%) were accompanied by family during treatment.

Subjective distress was reported as a need (met or unmet) by 165 (41.2%) patients, with 78 (19.5%) rating it as a met need and 87

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