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Subjective distress in a representative sample of outpatients with psychotic disorders

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Abstract

Background: The affective burden of psychotic disorders 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.

Key-words: psychotic disorders; outcome; distress; psychological stress; needs assessment.

Highlights

- Subjective distress was a common reported unmet need in outpatients with psychosis.
- It was mostly predicted by clinical and service use variables.
- It may be impacted on by family engagement and psychosocial interventions.

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; Upthegrove 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).

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 8 000 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 3 000 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 3 000 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 Jr 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 subjective distress reported 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 (21.7%) as an unmet need. Among the 165 patients who reported the need, 78 (47.3%) were receiving formal help (e.g. from mental health services), 84 (50.9%) were not and 3 (1.8%) did not know. Similarly, 110 (66.7%) were receiving informal help (e.g. from family), 54 (32.7%) were not and 1 (0.6%) did not know.

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Table 1 shows the regression analysis of predictors of subjective distress reported as a need (met or unmet as opposed to no need).

Insert Table 1 here

Four predictor variables were positively associated with psychological distress being reported as a need (X^2 =63.123, p<0.001): attendance at psychotherapy in the last year (OR = 3.49), presence of lifetime suicidal ideation (OR = 2.89), not attending psychosocial rehabilitation in the last year (OR = 2.84), and higher general psychopathology according to PANSS (OR = 1.09). The final model also included the variables non-attendance at service currently and in the last month, current non-use of medication and dissatisfaction with medication, but they were not significant.

Table 2 shows the regression analysis for subjective distress being reported as an unmet need for patients who stated the presence of need (met or unmet).

Insert Table 2 here

Two predictor variables were positively associated with the reported distress being rated as an unmet need (X^2 =7.586, p<0.01): family not accompanying patient to treatment (OR = 2.60) and higher psychopathology (OR = 1.05). The variables dissatisfaction with medication, non-attendance at psychotherapy in the last year and non-attendance at the service in the last month were also included in the final model, though not significant.

4. Discussion

Our results showed that subjective distress was reported as a need by less than half (41.2%) of the sample. This proportion is smaller than the prevalence of over 50% found in other studies using the CAN with psychosis patients (Bengtsson-Tops and Hansson, 1999; Grover et al., 2015; McCrone et al., 2001). This might be explained by the higher chronicity in the sample (with a mean duration of psychosis of 18 years), which is recognised to be more distressing in the early stages, given the traumatic disruption caused in life (Birchwood, 2003; Tarrier et al., 2007). However, reports of subjective distress as an unmet need (21.7%) were inside the range found in the other studies and higher than most of them. For example, another study assessing the personal impact of schizophrenia in Europe with the CAN found 17% of unmet need (Thornicroft et al., 2004). The finding that less than half of patients experiencing distress reported help from services indicates that greater attention should be given by services to subjective distress in the treatment of psychotic disorders.

More patients reported help from friends and family than from services. This coincides with the lack of family attendance at treatment predicting an unmet need. These findings reinforce the importance of family engagement, which is a positive aspect of Brazilian culture and has been recognised as a key component of treatment (Boyd et al., 1981; Harvey and O'Hanlon, 2013).

One limitation is the cross-sectional design, which makes it difficult to examine causation. The use of a single questionnaire domain to assess subjective distress is another limitation. Even so, this domain seems to be a valid measure, given the significant association in the first model with suicidal ideation, which is highly distressing itself and associated with components of distress in psychosis (Tarrier et al., 2007). Subjective distress was also predicted by higher psychopathology as measured by PANSS in both models. This PANSS dimension includes some symptoms highly associated with increased subjective distress, such as depression / anxiety (Hartley et al., 2013; Selten et al., 2000), and insight (Belvederi Murri et al., 2015; Cooke et al., 2007), and has showed a negative correlation with quality of life in other studies (Eack and Newhill, 2007).

Finally, subjective distress as a reported need was strongly predicted by psychotherapy attendance and psychosocial rehabilitation non-attendance. This might also reinforce the importance of these interventions, although they were not received by the majority of the patients. This should be viewed with caution, given the cross-sectional design, but if confirmed the clinical implications are that subjective distress may be reduced by supporting psychosocial interventions attendance by the patient, focusing on general symptoms instead of only psychotic symptoms, and by facilitating family engagement in the patient's treatment.

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Contributors

Sérgio Baxter Andreoli designed, conducted the study and collaborated with data analysis and manuscript preparation. Mário César Rezende Andrade did the analysis, interpreted data, and prepared the whole manuscript. Denise Martin and Jair de Jesus Mari collaborated on study design and Denise Martin also collaborated on study conduct. Marina Bandeira collaborated with data analysis and gave major contribution to the first draft of the manuscript. Mike Slade collaborated on data analysis, interpretation and gave major contribution to manuscript preparation. Sara Evans-Lacko and Janina Komaroff contributed to data analysis, interpretation and manuscript preparation. All authors contributed to the final version and have approved the final manuscript.

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Conflict of interest

The authors have no conflict of interest.

Table 1

Hierarchical logistic regression of subjective distress as a reported need (met or unmet) (N = 362).

Variable	Estimate	S.E.	Wald X^2	OR (95% C.I.)	p-value
Psychotherapy attendance in the					•
last year	1.25	0.39	10.21	3.49 (1.62 - 7.53)	0.001**
Non-attendance at service					
currently	1.13	0.67	2.88	3.11 (0.84 - 11.53)	0.090
Suicidal ideation in lifetime	1.06	0.26	17.00	2.89 (1.75 – 4.79)	< 0.001**
Non-attendance at psychosocial					
rehabilitation in the last year	1.04	0.40	6.96	2.84 (1.31 - 6.19)	0.008**
Dissatisfaction with medication	0.58	0.31	3.49	1.79 (0.97 – 3.29)	0.062
Level of general					
psychopathology (PANSS)	0.09	0.01	42.07	1.09 (1.06 – 1.12)	< 0.001**
Current non-use of medication	- 0.02	0.64	0.001	0.98 (0.28 - 3.45)	0.976
Non-attendance at service in the					
last month	- 0.13	0.46	0.08	0.88 (0.35 - 2.18)	0.782

S.E. = standard error; OR = odds ratio; C.I. = confidence interval; ** p < 0.01

Note. Model created using 362 (90.3%) of the original sample of 401 due to missing data in the predicting variables.

Table 2

Hierarchical logistic regression of subjective distress as an unmet need (N = 145).

	·	·					
Variable	Estimate	S.E.	Wald X^2	OR (95% C.I.)	p-value		
Family not accompanying							
patient to treatment	0.96	0.46	4.27	2.60(1.05 - 6.44)	0.039*		
Dissatisfaction with medication	0.46	0.40	1.36	1.59 (0.73 – 3.47)	0.244		
Non-attendance at							
psychotherapy in the last year	0.06	0.42	0.02	1.07 (0.46 – 2.45)	0.877		
Higher general							
psychopathology (PANSS)	0.05	0.19	7.87	1.05 (1.02 - 1.09)	0.005**		
Non-attendance at service in							
the last month	- 0.19	0.49	0.15	0.83 (0.31 - 2.16)	0.693		

S.E. = standard error; OR = odds ratio; C.I. = confidence interval; * p < 0.05; ** p < 0.01Note. Model created using 145 (88.9%) of the whole sample of 165 due to missing data in the predicting variables.