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Need for information in a representative sample of outpatients with schizophrenia disorders

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Abstract

Background: providing adequate information and involving patients in treatment has become an essential component of mental health care. Despite this, research regarding the extent to which this need has been met in clinical services is still scarce.

Aims: To investigate the need for information about psychiatric condition and treatment among outpatients with schizophrenia disorders and how this need is associated with service use, adjusting for sociodemographic and clinical characteristics.

Methods: Need for information for information about condition and treatment was assessed using the corresponding domain in the Camberwell Assessment of Need (CAN), in a representative sample of 401 schizophrenia outpatients in Santos, Brazil. Hierarchical logistic regression was used to investigate the association of information as a reported need and as an unmet need with service use variables, adjusting for sociodemographic and clinical characteristics.

Results: Need for information was reported by 214 (53.4%) patients, being met in 101 (25.2%) and unmet in 113 (28.2%). Hierarchical regression indicated a significant association of a reported need with higher age of onset, family monitoring medication use last year and lower education level, which was the only associated with an unmet need.

Conclusion: Information was a commonly reported need and which was often unmet, showing no significant association with service use. Greater attention should be given by mental health services to information provision.

Keywords: Schizophrenia; Service evaluation; Needs assessment; Information provision

Introduction

Patient-centred care for individuals with severe mental disorders has been increasingly promoted. Consequently, providing adequate information and involving patients in treatment has become an essential component of mental health care (Desplenter, Simoens, & Laekeman, 2006; Tlach et al., 2015). There is wide consensus that patients have the right to information about their own condition, benefits and risks of treatment (Hallett, Gupta, & Priebe, 2013). Beyond this ethical imperative, more than two-thirds of outpatients with severe mental disorders desire such information (Giacco et al., 2014; Hallett et al., 2013; Tlach et al., 2015).

Providing information has also a positive impact. Patient engagement and adherence to treatment can be promoted, enhancing treatment satisfaction and empowerment (Hasan & Musleh, 2017) towards shared decision making (Hamann et al., 2017; Slade, 2017; Tlach et al., 2015). In patients with schizophrenia, providing information is associated with reduced rehospitalisation and improved medication adherence, which are traditional challenges in this condition (Desplenter et al., 2006; Xia, Merinder, & Belgamwar, 2011).

Despite the importance of information provision, research regarding the extent to which this need has been met in clinical services is still scarce. Most studies have focused on structured interventions like psychoeducation (Xia et al., 2011), information seeking (Baup & Verdoux, 2017) and desire (Giacco et al., 2014) or the type of information patients feel is important (Hallett et al., 2013). Based on this gap, this study assessed (i) whether need for information was reported by outpatients with

schizophrenia disorders treated in community mental health services without structured educational programs, (ii) whether this reported need was unmet and (iii) the association of an unmet need with service use.

Methods

Design and sample

This cross-sectional study included an epidemiologically representative sample of outpatients with schizophrenia disorders from all community mental health services in the city of Santos, Brazil. These services provide outpatient care and have no structured educational programs. Sample calculation and procedures were described elsewhere (Andrade et al., 2016). The study included patients at least 18 years old, with a diagnosis of schizophrenia disorders and attending the service for the one-year period before the study. A random sample of 558 participants was calculated.

Measures and procedures

Need for information was assessed using the patient-reported Brazilian version of the Camberwell Assessment of Need (CAN) (Phelan et al., 1995; Schlithler, Scazufca, Busatto, Coutinho, & Menezes, 2007). The CAN evaluates 22 health and social need domains in patients with severe mental disorders, including Information on condition and treatment, the only domain used in this study. Responses are: No need (no information needs); Met need (information given and adequately understood); Unmet need (information not given or inadequately understood) or Not known (rated as no

need for analysis). Patients reporting a particular need (met or unmet) are also asked (i) whether they received formal help (e.g. health services) to meet this need and (ii) whether they received informal help (e.g. friends, family or self-help groups). Data analysis at the CAN domain level instead of summary scores, as we have done for information domain, has been considered a more useful and meaningful outcome criteria (Wennström & Wiesel, 2006).

Symptomatology was assessed with the Positive and Negative Syndrome Scale – PANSS (Higuchi et al., 2014; Kay, Opler, & Lindenmayer, 1988). Other clinical data were collected using an adapted version of the Life Chart Schedule (LCS) (Susser et al., 2000), including: diagnosis, age of onset, psychiatric hospitalization and lifetime suicide attempt. We also collected the following service use data: service attendance in the last month, satisfaction with medication, family monitoring medication use and family involvement in treatment in the last year, attendance at psychosocial rehabilitation and at psychotherapy in the last year. The following sociodemographic data were also collected: gender, age, marital status, having a child, years of education, occupation in the last six months, type of accommodation and living alone or with others. Informed consent was provided by all participants. Participants were interviewed by an independent and trained health professional. This study was approved by the Federal University of São Paulo (UNIFESP) institutional review board (reference: 2014/816.863).

Data Analysis

Statistical analyses were performed using SPSS for Windows version 20.0. First, for descriptive analyses, questions about the reception of formal and informal help were merged into the following algorithm: 0. No help; 1. Informal help only; 2. Formal help only or 3. Both kinds of help received. Covariates of information need were investigated through hierarchical logistic regression with stepwise modeling, containing two final models, one for each dependent variable: 1. information reported as a need (either met or unmet) versus not (No need); and 2. Unmet versus no/met need, given the primacy of unmet need as an outcome criteria to be approached by services in the literature on CAN (Wennström & Wiesel, 2006). The independent variables included in the multivariate models were selected using bivariate tests, with $p < 0.25$ (Hosmer & Lemeshow, 2004). Considering the aim of investigating the association between information need and service use, adjusted by sociodemographic and clinical characteristics, they were inserted into models through hierarchical steps, using $p < 0.05$ for the remaining variables. In this approach, distal or already known predictors (sociodemographic and clinical variables, respectively) are inserted in the first models and adjust for proximate or investigated predictors (service use), inserted in the final model.

Results

Please insert Figure 1 here

Figure 1. Flow chart of the participants

An eligible sample of 401 participants was included in the study. The numbers and reasons for exclusion are given in the flow chart presented in Figure 1.

Please insert Table 1 here

Table 1 describes sociodemographic, clinical and service use data. Mean age of participants was 45.61 (±12.30) years and education averaged 6.43 (± 4.01) years. Most were male (51.90%), single (56.60%), had no child (52.10%) and were unemployed in the past six months (85.50%). The most common accommodation was house (83.80%), followed by institution or therapeutic residential service (13.50%) and being homeless (2.70%). Most of them lived with someone else (89.00%). Age of onset averaged 26.80 (± 12.00) years. Most were diagnosed with schizophrenia (60.10%), compared with other psychosis (39.90%). The majority had a previous psychiatric hospitalization (64.30%) and did not attempt suicide in their lifetime (68.30%). PANSS general psychopathology, negative and positive symptoms scales, averaged 33.03 (± 10.41), 18.64 (± 7.82) and 13.95 (± 5.07), respectively. Regarding service use, most attended services during the last month (84.00%), but only a minority had attended psychotherapy (18.30%) and psychosocial rehabilitation (18.50%) in the last year. Most participants were satisfied with medication (77.70%), had its use monitored by family (69.10%) and had their family involved in treatment (68.80%).

Need for information was reported by 214 (53.4%) patients, being met in 101 (25.2%) and unmet in 113 (28.2%). Among those reporting the need, 87 (40.7%) received no help to meet this need, 47 (22.0%) only informal help, 30 (14.0%) only formal help, and 50 (23.4%) received both.

Please insert Table 2 here

Table 2 describes the results of the bivariate analyses for information as a reported need and for information as an unmet need, in terms of the *p* values obtained. Variables with $p < 0.25$ were retained, since they may show statistical significance ($p < 0.05$) in the multivariate analyses, according to Hosmer and Lemeshow (2004). When the dependent variable was information as a reported need, the retained independent variables were: higher age, lower education level, having children, higher age of onset, higher negative symptoms, medication use being monitored by family in the last year, family involvement in treatment in the last year and attendance to psychotherapy in the last year. For information as an unmet need, the following independent variables were retained to be included in the multivariate models: higher age, lower education, higher age of onset, having previous psychiatric hospitalization in life and non-attendance at psychosocial rehabilitation in the last year.

Please insert Table 3 here

Table 3 describes the factors associated with information as a reported need (met or unmet as opposed to no need). Three variables were significantly associated with the reported need ($X^2=30.105$; $p<0.001$): lower education level, later onset and family monitoring medication use in the last year. Psychotherapy attendance during the last year was also included in the model, but it was not significant.

Please insert Table 4 here

Table 4 presents the factors associated with whether need for information was unmet versus no/met need (X^2 = 11,991; p = 0,035). Only lower education level was significantly associated with unmet need. Attendance at a psychosocial rehabilitation in the last year was examined but not significant. Satisfaction with medication and service attendance during the last month were forced into the model as known covariates of information provision; however, neither showed significance.

Discussion

Our results showed that information on condition and treatment was a commonly reported need and unmet need among a sample of outpatients with schizophrenia disorders treated in community mental health services in Brazil, showing no significant association with service use. Information need was reported by more than half of the sample (53.4%). This is within the range found in international studies using the CAN in similar samples, with a maximum prevalence of 78% in outpatients with psychosis in England (Macpherson, Varah, Summerfield, Foy, & Slade, 2003). However, the rate of unmet need (28.2% of the whole sample or nearly 52% of those reporting the need) was higher than that reported in the English study (15%) and other sites, with no more than 22.7% of unmet needs in a Canadian sample (Fleury et al., 2010). This higher

proportion of unmet need is in line with the finding that most patients reporting the need received no help to meet it, followed by the receipt of informal help only.

The association of a reported need with lower education and medication use monitored by family in the last year (related to illness severity) could support the validity of this measure, as these variables are expected to be linked to lack of information. The later age of onset might indicate a shorter duration of illness and a shorter period of contact with services. For the second model, no service use variable was significantly associated with an unmet need, only lower education level again, reinforcing the role of this variable. However, this also raises the question about whether educational level is a marker for lower ability to navigate complex health and social care systems, which should be further investigated. The influence of psychosocial rehabilitation, the only non-forced service use variable included in the model, also requires further investigation as it was underused in this study (less than 20%). More than non-association with service use, this model could reflect a lack of information provision in the routine of these services.

The cross-sectional design and the few service use variables investigated are limitations of this study. Participants' attrition was not a problem, since it was less than 20% as included in the sample calculation, that is, 81% of the eligible participants were included in the final sample. However, one problem was the missing data in the final models of the multivariate analyses. On the other hand, missing were not higher than 5%, which seems to be an acceptable rate. Another problem was the exclusive use of statistical thresholds for including independent variables in the first models of multivariate tests. This may exclude important confounders, even using a standardized criteria as the *p*-value. Despite that, the descriptive and inferential findings are enough

to indicate that greater attention should be given by services to information provision. This is of major importance in Brazil, where reception of information by psychiatric patients is a right assured by law (Brasil, 2001). This study provides a basis for services without structured educational programs to implement or enhance information giving in routine clinical settings, including simple interventions that increase treatment adherence such as distributing pamphlets and leaflets or providing standardized oral and written information in sessions (Desplenter et al., 2006; Hasan & Musleh, 2017).

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Conflict of interest

The authors declare that they have no conflicts of interest. SEL has received consulting fees from Lundbeck unrelated to this work.

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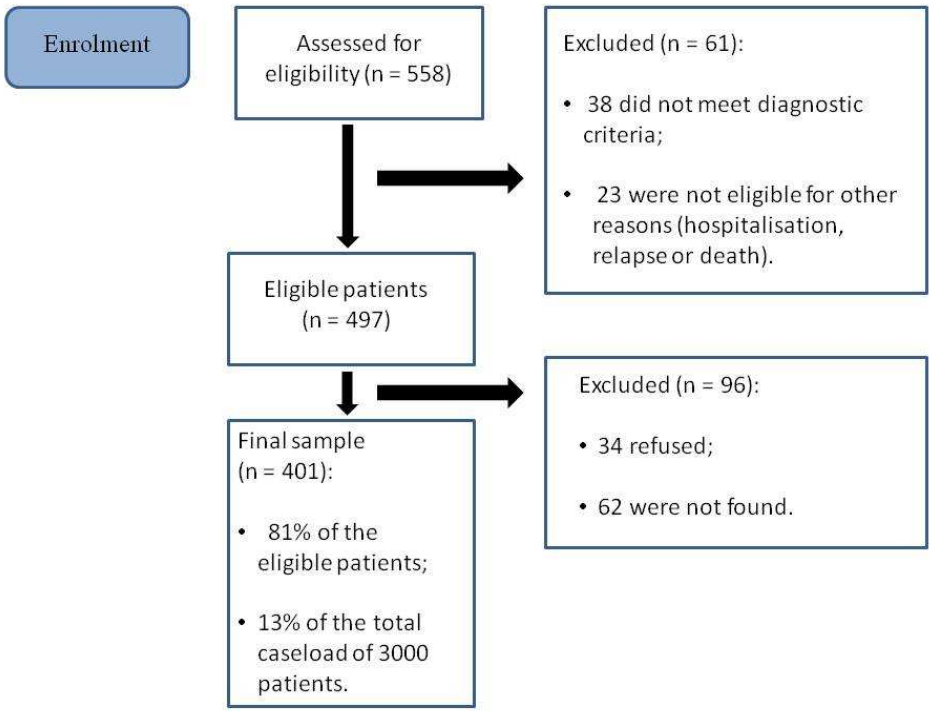

Figure 1. Flow chart of the participants

Table 1 Sociodemographic, clinical and service use data (N = 401).

Variables		Mean (S.D)	N (%)
Age		45.61 (12.30)	
Sex	Male		208 (51.90)
	Female		193 (48.10)
Marital Status	Single		227 (56.60)
	Others		174 (43.40)
Years of education		6.43 (4.01)	
Having a child	No		209 (52.10)
	Yes		192 (47.90)
Occupation in the last 6 months	No		343 (85.50)
	Yes		58 (14.50)
Accommodation	House		336 (83.80)
	Institution		54 (13.50)
	Homeless		11 (2.70)
Living with other people	No		38 (9.50)
	Yes		357 (89.00)
Diagnosis	Schizophrenia		241 (60.10)
	Other psychosis		160 (39.90)
Age of onset		26.80 (12.00)	
Lifetime Psychiatric Hospitalization	No		143 (35.70)
	Yes		258 (64.30)
Suicide attemption	No		127 (31.70)
	Yes		274 (68.30)
Positive symptoms (PANSS)		13.95 (5.07)	
Negative symptoms (PANSS)		18.64 (7.82)	
General Psychopathology (PANSS)		33.03 (10.41)	
Attendance to service in the last month	No		64 (16.00)
	Yes		337 (84.00)
Medication use	No		39 (9.70)
	Yes		362 (90.30)
Satisfaction with medication	No		84 (26.90)
	Yes		293 (73.10)
Medication use monitored by family	No		124 (30.90)
	Yes		277 (69.10)
Family involvement in treatment	No		125 (31.20)
	Yes		276 (68.80)
Attendance at psychotherapy	No		327 (81.70)
	Yes		73 (18.30)

Attendance at psychosocial rehabilitation	No	326 (81.50)
	Yes	74 (18.50)

Table 2 Bivariate analysis for information as reported need and for information as an unmet need

Variables	Information as a reported need (*p*-value)	Information as an unmet need (*p*-value)
Age	**0.08**	**0.08**
Sex	0.32	0.91
Marital Status	0.45	0.79
Years of education	**< 0.001**	**0.006**
Having children	**0.02**	0.32
Occupation in the last 6 months	0.48	0.64
Accommodation	0.92	0.37
Living with other people	0.73	1.00
Diagnosis	1.00	0.73
Age of onset	**0.01**	**0.03**
Lifetime Psychiatric Hospitalization	0.51	**0.04**
Suicide attempt in lifetime	0.28	0.90
Positive symptoms (PANSS)	0.73	0.68
Negative symptoms (PANSS)	**0.10**	0.70
General Psychopathology (PANSS)	0.55	0.92
Attendance to service in the last month	0.49	0.65
Medication use	0.40	1.00
Satisfaction with medication	0.46	0.41
Medication use monitored by family	**0.001**	0.47
Family involvement in treatment	**0.13**	0.63
Attendance to psychotherapy	**0.09**	0.39
Attendance to psychosocial rehabilitation	0.30	**0.20**

Table 3 Final model of hierarchical logistic regression for information as a reported need (met or unmet) (N = 393)[1]

Variable	*p*-value	OR (95% C.I.)
Years of education	**0.002**	**0.91 (0.87 – 0.97)**
Age of onset	**0.03**	**1.02 (1.00 – 1.04)**
Family monitoring medication use in the last year	**.001**	**2.15 (1.37 – 3.38)**
Attendance at psychotherapy in the last year	0.29	1.33 (0.78 – 2.29)

OR = odds ratio; C.I. = confidence interval.
[1]Model created using 393 (98%) of the original sample of 401 due to missing data in the predicting variables.

Table 4 Final model of hierarchical logistic regression for information as an unmet need (N = 205)[1]

Variable	*p*-value	OR (95% C.I.)
Years of education	**0 .01**	**0.93 (0.87 – 0.98)**
Age of onset	0.09	1.02 (0.99 – 1.03)
Non-attendance at service in the last month	0.46	1.28 (0.57 – 2.49)
Dissatisfaction with medication	0.48	1.21 (0.705 – 2.09)
Non-attendance at psychosocial rehabilitation in the last year	0.47	1.26 (0.67 – 2.34)

OR = odds ratio; C.I. = confidence interval

[1]Model created using 205 (95.80%) of the original sample of 214 outpatients reporting the need due to missing data in the predicting variables.