Original Article

Factors associated with unmet needs in individuals with schizophrenia in Chile

Fatores associados com as necessidades não satisfeitas em indivíduos com esquizofrenia no Chile

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Abstract

Objective: To evaluate the possible associations between different sociodemographic, clinical, and healthcare factors and the number of unmet needs among people being treated for schizophrenia. **Methods:** The sample was made up of 141 subjects who were being treated at eight mental health service networks throughout Chile. Unmet need was assessed with the Camberwell Assessment of Need, which was specifically created for people with severe mental disorders. A multiple linear regression analysis was also applied. **Results:** It was found a direct association with clinical variables: score in the Positive and Negative Syndrome Scale, global functioning at diagnosis, and change in global functioning at diagnosis from diagnosis to interview. However, sociodemographic (ethnicity, education level, and number of people who live with subject) and other clinical variables (age at diagnosis, and annual rate of relapse) were indirectly associated with unmet needs. **Conclusions:** Our results can be applied in order to coordinate and improve the effectiveness of mental health services in Chile.

Keywords: schizophrenia; needs assessment; mental health services.

Resumo

Objetivo: Avaliar as possíveis associações entre diversos fatores sociodemográficos, clínicos e de cuidado à saúde e o número de necessidades não atendidas entre pessoas que estão sendo tratadas devido à esquizofrenia. **Métodos:** A amostra foi composta por 141 indivíduos que estavam sendo tratados em oito redes de serviço de saúde mental por todo o Chile. A necessidade não atendida foi avaliada pela *Camberwell Assessment of Need*, que foi especificamente criada para pessoas com distúrbios mentais graves. Também foi aplicada uma análise de regressão linear múltipla. **Resultados:** Encontrou-se associação direta com variáveis clínicas: escore na *Positive and Negative Syndrome Scale*, funcionamento global ao diagnóstico e mudança no funcionamento global ao diagnóstico desde o diagnóstico à entrevista. Entretanto, variáveis sociodemográficas (etnia, nível educacional e número de pessoas que moram com o indivíduo) e clínicas (idade no momento do diagnóstico e taxa anual de recidiva) foram indiretamente associadas com as necessidades não atendidas. **Conclusões:** Os presentes resultados podem ser aplicados para coordenar e aprimorar a eficácia dos serviços de saúde mental no Chile.

Palavras-chave: esquizofrenia; determinação de necessidades de cuidados de saúde; serviços de saúde mental.

INTRODUCTION

Assessment of need has become an important indicator, both to evaluate healthcare systems, and to measure the results of clinical investigations. It has special relevance in the process of psychiatric treatment reform, since the move from hospital-centered care to a system focused on the community has changed the criteria used to evaluate care. The goal is to move beyond simple clinical results in order to achieve a greater number of satisfied needs, successful social reinsertion, and improved quality of life.

Torres Gonzalez et al.[1] stated that planning treatment and services for individuals with severe mental illnesses should begin with the identification of patients' needs and clear definition of the desired outcomes, in order to coordinate patient-specific care. Wing et al.[2] wrote that the optimal outcome is the minimization of the individuals' social disability, in which social disability is defined as the decline of physical, psychological, and social abilities in the context of a society or particular group of people.

During the 1990s, more research began to evaluate needs by focusing on their existence, and the degree to which they were met.

Studies performed in several countries with severe mental disorders individuals (the majority with schizophrenia) showed that the number of needs varies between 4 and 10, and that between a half and a quarter of those needs are unmet. Categories that most often become needs are psychotic symptoms, psychological distress, daytime activities, company, food, looking after home, and information on condition and treatment[3-8].

The majority of the studies did not find differences based on sex or age[8]. While there were no differences in the number of needs based on gender, there was one in type of need (women had more unmet clinical needs, and men had more unmet social needs)[8,9]. The results regarding educational level have been inconsistent, with some studies reporting that there is an association and others stating that there were not.

The relationship between satisfaction of needs and other outcome variables in patients and caregivers has been explored in multiple studies[10,11]. There are associations between variables related to clinical presentation and number of unmet needs, such as duration and chronicity of the illness, global functioning level, and psychopathological severity[8,9].

Many studies demonstrate a strong inverse relationship between the number of unmet needs and quality of life[8,12,13]. Evidence tends to show that satisfaction of needs is relatively stable over time and only partially depends on the reduction of psychotic symptoms[8,12]. Improvement of unmet needs is closely related to the individual's quality of life[13].

Similarly, assessment of need has been used to evaluate the effectiveness of health services. The PRISM Psychosis Study, for example, compared two forms of community-based services (one standard and one intensive) using several parameters, one of which was the assessment of need[14]. The investigators found that patients in both types of services had a reduced number of needs (from 77 to 70% in Nunhead, London, and from 74 to 67% in Norwood, London). There was a relationship between unmet needs and satisfaction with services, as well as between the type of needs and that of services[15,16].

Another study, performed in Sweden[17], compared the change in number of needs (total and unmet) in a group of individuals with severe mental disorders, who were being treated in health services, which had undergone psychiatric care reform. The results showed a decrease in these two indicators of needs (total and unmet), between the initial and the second assessment, which had occurred five years earlier[17].

The aforementioned studies motivated us to investigate the factors associated with the number of unmet needs in individuals undergoing treatment for schizophrenia in Chile, a middle-income country that has been developing psychiatric care reform for more than ten years.

MATERIALS AND METHODS

This was an observational and analytical study, which used a sample of people who were being treated in mental health services in Chile diagnosed with schizophrenia or a related disorder.

The sample was selected from a pool of individuals who were being treated in eight mental health networks in Chile diagnosed with schizophrenia or a related psychotic disorder (codes F20 – F29 in the International Classification of Diseases – ICD-10). Their initial diagnosis was given between April 1, 2001 and March 31, 2003 and did not change in the entire period leading up to this study. The interviews were performed in 2005, i.e., around two or three years after the initial diagnosis. The reference population for the eight service networks was equivalent to 23.7% of the total Chilean population that is treated under the country's public health system.

There were 178 individuals who fit the inclusion criteria for the study. Of those, 33 refused to be interviewed (corresponding to 18.5% of the total identified cases), and 4 were unable to fully complete the questionnaires. The final sample was composed of 141 people, who signed an informed consent form before entering the study.

Next, the considered pieces of information are shown.

Sociodemographic data: sex, age, identification with a minority group, number of people living with the patient, number of years of study (highest education level), and work condition (if she/he had a stable job or not) were considered in this study.

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Clinical history and received care: age at first diagnosis of schizophrenia, level of global functioning at diagnosis (GAF)[18], annual rate of relapse, number of hospitalizations since diagnosis, change in GAF between diagnosis and interview, and number of psychosocial interventions (psychotherapy, psychoeducation, etc.) that the patient has received since diagnosis.

Social support was measured with the Scale of Social Support of the Mental Health Department of California, which is made up of six items that explore the number of people whom the subject can go to in various salutations (to share problems, to receive help, to interact socially, etc.)[19]. In Chile, the discriminate validity of the scale has been studied to contrast results of individuals with common mental disorders with a control, and there were significant differences in the current support score[20]. Likewise, the convergent validity was tested with the Affective Balance Scale, and a significant correlation was found[21].

Clinical status at the time of interview was measured with the Positive and Negative Syndrome Scale (PANSS), an instrument that evaluates negative and positive symptoms seen in schizophrenia, along with other general psychopathological elements. It was developed by Kay et al.[22] and was validated in Spanish[23], with 30 items.

The number of unmet needs was evaluated with the Camberwell Assessment of Need (CAN)[24-26]. The instrument is based on the conceptual framework that views needs in conjunction with the interventions used to meet them and, therefore, is useful to evaluate health services. "Needs" are designated when a patient's level of functioning in an area is below an established standard, and when there is also an effective intervention to correct the discrepancy. A need is considered met, or covered, when it has undergone the most effective intervention known to date; conversely, it is unmet when no intervention has been put in place, or when there was an intervention but other more effective interventions exist, and so the need was not satisfied[27]. The CAN evaluates 22 areas of need: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information on condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child care, basic education, telephone, transportation, money, and benefits.

The validity and reliability data of CAN were originally published by the authors of the assessment[25], who reported that the instrument has good face and content validity. The inter-judge reliability for professionals was a kappa of 0.90, and for patients it was 0.87. The test-retest reliability was lower, with a kappa of 0.51 for patients and 0.61 for professionals. The instrument was translated into Spanish by the Mental Health Research Group of the University of Granada, following the protocol of simultaneous translation and back-translation. The group reported preliminary data from a Spanish sample with similar values: a kappa of 0.91 for the inter-judge reliability of both professionals and patients, and with test-retest reliability, a kappa of 0.60 for professionals, and 0.62 for patients[26].

Data analysis began with an overview of the variables and then proceeded with a multivariate analysis based on the construction of several multiple linear regression models, with the number of unmet needs (based on the 22 areas evaluated in CAN) as the dependent variable. Since the variables under investigation corresponded to different times, more multiple linear regression models were created for the significant variables, based on what had been included in the final models from the previous analysis. Analysis ended with a proposal for a model of variables that are associated directly and indirectly with the quality of life of the subjects.

Ethical considerations

The project was approved by the Ethical Committee of Sótero del Río Hospital, in Southeast Santiago. The study aims and instruments were explained to potential participants, and written informed consent was obtained.

■ RESULTS

Sociodemographic characteristics

Sociodemographic data are presented in Table 1.

The final sample included 141 people, with 96 men (68.1%) and 45 women (31.9%). The mean age was 27.2±7.6 years-old, and the age range was from 17 to 55 years-old. With respect to civil status, 131 of the individuals were single (92.9%), 6 were married at the time of the interview (4.3%), and 4 were divorced (2.8%).

The mean number of people who lived with the subject (including subject) was five, and the range was from 1 to ten individuals.

Regarding ethnic identity, the large majority of the subjects (in 136 of 141 cases, or 96.5%) identified themselves as Chilean. Only five individuals (3.5%) identified themselves as belonging to an ethnic minority group (*Mapuche* or *Aymara*).

With respect to educational level, the average number of years spent in school was 9.9±2.8 years; the median number was 10, and the range was between 1 and 17.

With regards to the subjects' occupational situation at the time of the interview, 9.9% were studying, 19.1% had occasional work, 9.2% had a stable job, and 45.4% of the subjects were unemployed.

Clinical history and received care

Clinical history and received care data are shown in Table 2.

The mean age of the individuals at first diagnosis was 23.7±7.5 years-old, with a range from 13 to 51.

The mean GAF score at time of diagnosis was 36.8±11.3 points; the median was 35, and the range of the scores was from 15 to 91. With respect to the change in GAF score between initial diagnosis and interview, it was found that there was an average increase of 31.7 points in global functioning. In 138 cases (97.9%), there was an increase in GAF score; only in one case there was a decrease in the GAF score (0.7%), and in the two other ones there were no changes (1.4%).

Regarding the subjects' clinical evolution, it was found that only in 18.4% of the cases there was not a relapse after the first psychotic episode. In the entire studied group, there was a mean of 2.1±1.6 relapse episodes during the illness' evolution (the period from diagnosis until the study's interview). The average annual rate of relapse episodes was 0.6±0.5 episodes; the median was 0.5, with a range between 0 and 2.7 per year.

There was an average of 1.4±1.4 episodes of hospitalizations per subject, with a median of one hospitalization and a range between zero and eight. Only in 27.7% of the cases, there was no hospitalization during the evolution of the disorder.

With respect to psychosocial interventions, the most used one was psychoeducation for the patient (in 61.7% of the cases), followed by other psychological interventions (in 60.3% of cases). The third most frequently ones were family interventions (in 54.6% of cases), and finally, in fourth, there were psychosocial rehabilitation programs (used in 42.6% of cases). Table 2 presents the distribution of patients according to the number of types of psychosocial interventions they underwent. One can see that 22.0% of the patients did not undergo any type of psychosocial education, and 22.5% participated in all four types of interventions that were examined.

Table 1. Sociodemographic characteristics of people diagnosed with schizophrenia who were treated in eight mental health service networks in Chile (n=141)

Sex	
Male	96 (68.1%)
Female	45 (31.9%)
Age	
mean	27.2±7.6 years-old
median	25 years-old
range	between 17 and 55 years-old
Civil status	
single	131 (92.9%)
married	6 (4.3%)
separated	4 (2.8%)
Number of people in the family group	
median	5
range	between 1 and 10
Ethnic identity	
considers self Chilean	136 (96.5%)
considers self part of ethnic minority group	5 (3.5%)
Education level (years of study)	
mean	9.9±2.8 years
median	10 years
range	between 1 and 17 years
Occupational situation	
student	14 (9.9%)
with a stable job	13 (9.2%)
with occasional work	27 (19.1%)
unemployed	64 (45.4%)
other	23 (16.3%)
Social support	
mean	10.7±6.6 points
median	10 points
range	between 0 and 27 points

Table 2. Characteristics of clinical evolution and received treatment in people diagnosed with schizophrenia who were treated at eight mental health service networks in Chile (n=141)

Age at diagnosis	
mean	23.7±7.5 years-old
median	21.5 years-old
range	between 13 and 51 years-old
GAF at diagnosis	
mean	36.8±11.3 points
median	35 points
range	between 15 and 91 points
Annual rate of relapse	
mean	0.6±0.5
median	0.5
range	between 0 and 2.7
Number of hospitalizations	
mean	1.4±1.4
median	1
range	between 0 and 8
Change in GAF score	
increase	138 (97.9%)
no change	2 (1.4%)
decrease	1 (0.7%)
Number of psychosocial interventions	
none	31 (22.0%)
one	17 (12.1%)
two	23 (16.3%)
three	34 (24.1%)
four	36 (25.5%)
Score on PANSS	
mean	45.3±15.7 points
median	40 points
range	between 30 and 123 points

GAF: global functioning at diagnosis; PANSS: Positive and Negative Syndrome Scale

Social support

The average score from the Scale of Social Support of the Mental Health Department of California was 10.7±6.6 points; the median was 10, and the range was between 0 and 27 points.

Clinical status at time of intervention

Table 2 also shows the results of the different sub-scales of the PANSS, along with the total value. For the latter, one can see that the group obtained an average score of 45.3±15.7 points, with an average of 40 and a range between 30 and 123 points.

Unmet needs

There was an average number of 1.2 areas of unmet need per person, with a standard deviation of 1.5; the median was 1, and the number of unmet needs ranged from 0 to 8. In the group, 45.4% had no unmet needs. Of the 54.6% of subjects that had at least one area of unmet need, the majority had between one and two types of unmet need (39.7% of cases).

Multivariate analysis for the number of unmet needs

The construction of multiple linear regression models involved: creation of an initial model with all key variables and their possible interactions; identification of the preliminary parsimonious model; analysis of multicollinearity (variance inflation factor – VIF indicator); evaluation of the model; study of the possible existence of influential variables; and obtainment of the final parsimonious model.

The final model for the number of unmet needs had a R^2 of 0.3580 (with p<0.001) and incorporated three principal variables: the score on the PANSS, the GAF score at diagnosis, and the change in GAF score between diagnosis and the study's interview, as well as a variable of interaction between the last two variables.

The final model for the PANSS score had a R^2 of 0.3582 (with p<0.001) and was made up of five key variables: the number of people who lived with the patient, the number of years of schooling at diagnosis, the GAF score at the moment of diagnosis, the change in GAF score between diagnosis and the interview, and the annual rate of relapse.

The final model for the annual rate of relapse, in turn, had a R^2 of 0.0795 (with p=0.033), and it was composed of two main variables: the age of the patient at the time of diagnosis and his or her GAF score at that moment.

In the case of the GAF score at diagnosis, the final model had a R^2 of 0.0983 (with p=0.001) and it was made up of two main variables: age of the subject at diagnosis and number of people who lived with the subject.

With respect to the change in GAF between diagnosis and interview, the final model had a R^2 of 0.3221 (with p<0.001), and it was composed of three key variables: ethnic identity, GAF score at diagnosis, and annual rate of relapse.

Finally, the model for the age of the patient at diagnosis had a R^2 of 0.3582 (with p<0.001), and it was composed of two main variables: number of years of schooling at diagnosis and number of people who lived with the patient.

In summary, we were able to identify various variables corresponding to the socioeconomic environment, moment of diagnosis, evolution of the disorder, and clinical status at interview, which are associated with the number of unmet needs. Some of those variables are directly associated, and others are associated indirectly (through other variables). Figure 1 shows these associations in a graphic representation.
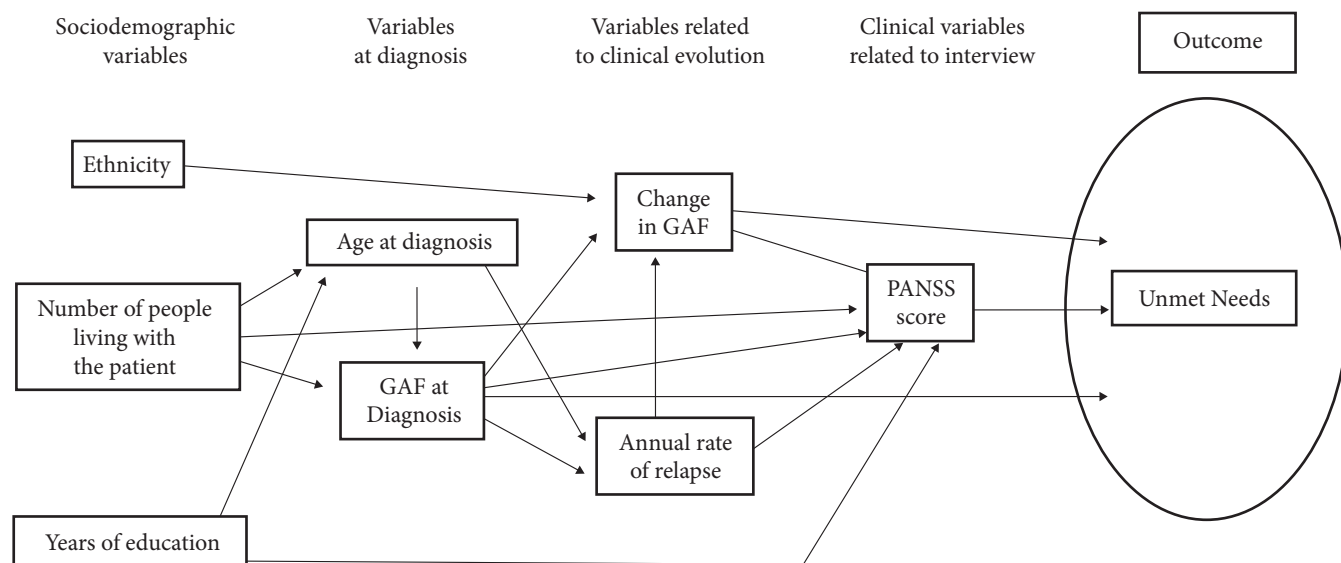
GAF: global functioning at diagnosis; PANSS: Positive and Negative Syndrome Scale.

Figure 1. Factors associated with number of unmet needs in people diagnosed with schizophrenia (n=141)

DISCUSSION

The present results show that the number of unmet needs is only significant associated with a few variables related to the evolution of the illness and clinical status: GAF at diagnosis, change in GAF between diagnosis and interview, and PANSS score. We found an indirect association of patients' identification with an ethnic minority group, and the number of people who lived with the patient, with the number of years of schooling, the age of the patient at diagnosis, and the annual rate of relapse.

These results tend to be consistent with those reported in the majority of studies, which found that there is little association between the number of unmet needs and sociodemographic characteristics and a greater association with clinical variables.

Rosales Varo et al.[4] reported that there is no association between the total number of needs and sex, age, residential zone (urban *versus* rural), civil status, or if the patient lives with his or her nuclear family. There is, however, one with educational level and work situation: patients with lower level of education and those with a disability pension had a greater number of needs. The authors of that study only reported a bivariate analysis; therefore, it was not possible to identify the indirect actions of variables.

Furthermore, Ochoa et al.[9,28] reported a strong association between psychopathological severity (measured by PANSS) and number of total and unmet needs, which is consistent with our results.

Korkeila et al.[29] similarly found a significant correlation between the number of needs and level of functioning (measured by GAF), as well as between the number of needs and clinical severity. They did not find an association with age of the patient, nor with age at diagnosis or duration of the illness. All of these results are consistent with the ones in the present study.

In this work, we chose to construct a multivariate model to identify the variables that are directly associated with the number of unmet needs in order to later generate various multiple linear regression models with intermediate variables. This enabled us to understand, with great detail, the mechanism through which all of the variables interact. We were able to identify which variables and how (directly or indirectly) they are associated with unmet need, as well as the different moments at which the variables act (in the two or three-year period from diagnosis until the interview).

Thus, we conclude that only clinical variables were directly associated with unmet needs (global functioning at diagnosis, change in GAF, and the severity of clinical symptoms at time of interview), and that the rest of the variables acted indirectly through them. Figure 1 shows a diagram of all of the associations (direct and indirect) that were found.

Interestingly, we did not find an association between receiving a greater number of psychosocial interventions and the number of unmet needs. These results could explain why patients treated in community-based service networks, which generally offer more psychosocial interventions, are more adherent to treatment than those treated in hospital-centered services, despite having worse social conditions and more severe psychopathology[30]. However, another possible explanation is that the psychosocial interventions were not of sufficient quality, due to a lack of resources or of training[30]. This should be explored in future studies, since it is important to ensure the effectiveness of mental health services.

We believe that the application of this type of model, with directly – and indirectly-associated variables, is valuable for it represents the complexity of psychosocial phenomenon and allows one to better understand the processes and mechanisms influencing the number of unmet needs. In the future, this model should serve as a hypothesis to be empirically tested through a longitudinal study.

Finally, we believe that the results reflect the reality of what is happening with individuals who have been diagnosed with schizophrenia in the nation's current health system, and they are useful to generate and implement mental health policies. Considering that this is the first time patients' needs have been evaluated in this way, and that mental health policy in Chile is moving towards a more community-centered model, our findings are significant for the continued development of mental health services in Chile.

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