Original article

Stress and satisfaction of family members and independent living skills of psychiatric outpatients

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Abstract

Background: There are several parameters that must be included in the evaluation psychosocial rehabilitation. **Objectives:** To describe and correlate the degree of stress of family members who live with schizophrenic and bipolar disorder patients, their satisfaction with mental health services and the level of daily living skills of the patient. **Method:** Cross-sectional and correlational study, from 2012 to 2013, with a sample of 100 caregivers. The Family Satisfaction with Mental Health Services Rating Scale (SATIS-BR), the Independent Living Skills Survey (ILSS-BR), and the General Health Questionnaire (GHQ-12) were used. Data were analyzed using SPSS v.21, with the Mann-Whitney test, Jonckheere-Terpstra test, and Pearson's, Spearman's and Partial correlations, and a significance level α = 0.05. **Results:** The score for the SATIS-BR scale was 4.28, 1.59 for the ILSS, and 7.39 for the GHQ-12. The value of the Pearson correlation coefficient between the SATIS-BR and ILSS was r = -0.27, and r = -0.23 between the GHQ-12 and SATIS-BR. The Spearman's correlation coefficient between Education and the GHQ-12 was r = -0.24 and there was a negative linear trend between stress and the level of education (JT = -2.54, p < 0:01). **Discussion:** The caregivers presented a very high level of psychological distress, therefore, it is critical that mental health services perform more effective psychosocial rehabilitation actions.

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Keywords: Mental health, patient satisfaction, psychological stress, treatment outcome, daily living activities.

Introduction

According to the World Health Organization[1] there has been a considerable increase in the incidence of mental disorders throughout the entire world, affecting approximately 450 million people, with 75% to 85% of them not having access to any form of mental health treatment. In Brazil mental disorders affect approximately 18.8% to 29.2% of the Brazilian population per year[1]. For example, schizophrenia is a mental disorder that persists throughout life, affecting men and women of all social classes[2]. Another study[3] verified an annual incidence of 0.5% for bipolar disorder, very close to the annual prevalence of 0.6%, indicating that the average duration of a mood episode is generally longer than one year.

In accordance with the principles of the Brazilian psychiatric reform, the two disorders should be preferentially treated in outpatient mental health services, such as the Centers for Psychosocial Care (CAPS). The CAPS, among other objectives, aim to treat patients with mental disorders, to stimulate their social and family integration[4], to support them in their initiatives towards autonomy, and to offer them psychosocial care, which constitute the main strategy of the psychosocial rehabilitation process directed toward providing the individuals with a better quality of life[5-8].

Given the complexity of the psychosocial rehabilitation process, there are several other parameters to be included in an evaluation process of the quality or "degree" of psychosocial rehabilitation, such as user satisfaction with the mental health services, the burden of the family members in the care, and the satisfaction of the patient with the mental health services. Accordingly, the triad – users, family members, and services, should be considered in an interrelated way when proposing studies regarding the evaluation of the quality of the mental health services[9-11].

The daily care for the family member with a mental disorder unveils the burden on the caregiver. This can be caused either objectively, i.e., the negative consequences of the presence of a mental illness in the family, such as more financial expenditures, and changes in the routine, social and professional life of the family, or subjectively, this being the personal perception or assessment of the family regarding the situation, which involves emotional issues and feelings about suffering the burden[9].

Considering daily living skills as an indicator of the autonomy of patients with mental disorders, the satisfaction of the family with the mental health services, and the degree of stress caused by the burden upon the family members of psychiatric patients, justify the importance of performing this study, since these three variables indirectly indicate the quality of the actions of the community mental health services, including the CAPS[12].

Objective

To describe the degree of stress of family members that live with schizophrenia and bipolar affective disorder patients, their satisfaction with the mental health services, the daily living skills level of the patient, and the relationship between these variables.

Materials and methods

Correlational and cross-sectional study.

Sample

The sample consisted of 100 family members of patients with schizophrenia and bipolar disorder, undergoing treatment at a CAPS III of a city in Paraná state, the population of which was approximately 515,700 inhabitants, with a Human Development Index (HDI) of 0.824[13]. The municipality has a service network consisting of 3 CAPS, including one for children, one for alcohol and drug patients, and one for adults, and Primary Health Units, among others.

The sample of 100 family members represented approximately 10% of the total patients with these disorders registered in the service. An analysis power calculation was conducted using the IBM SPSS Sample Power 3.0 program, based on a sample of 100 subjects, α of 0.05, means and standard deviation. An analysis power of 100% was obtained for the GHQ-12 scale, 99% for the SATIS-BR scale and 8.5% for the ILSS scale. Studies with the ILSS scale with a larger number of

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subjects demonstrated the ability to detect the event, suggesting that the present study could consider the findings related to the ILSS scale, even with the low analysis power, and could accept the alternative hypothesis with more security[14,15].

The respondents were selected at the CAPS III, with a verbal invitation made during a home visit and/or after the consultation in the service and the data collection times adapted to suit the routine of the participants as well as the researcher. The criteria for inclusion in the sample were, to be a family member that lives with the patient and is responsible for the patient's care, to be participating in the care provided by the service, and to be over 18 years of age. The exclusion criterion was having a mental disorder. Following these criteria, no subject was excluded.

Instruments and data collection

Data collection took place from October 2012 to August 2013, with the relatives of 42 patients being approached through home visits and 58 approached after meetings or consultations in the CAPS itself. Information on the mental disorder diagnoses were obtained from the medical records of the patients, whose diagnosis was made by the mental health services of the city. Three data collection instruments were used:

Family Satisfaction with Mental Health Services Rating Scale (SATIS-BR)

This scale evaluates the degree of satisfaction of family members with the mental health services. It was developed by the World Health Organization in 1996 and validated for the Portuguese language (Brazil)[16] with a Cronbach alpha of 0.79. It contains 62 items, designed to evaluate the degree of satisfaction of family members in relation to the services. The short version, with 12 items, was used in this study to calculate the degree of overall satisfaction of the family members with the service, and the means of the responses obtained for the 8 quantitative items of the scale (questions 1 to 8) were calculated.

Independent Living Skills Survey (ILSS-BR)[8]

The original version of the scale was reported by Wallace[17]. The nine areas, represented by 84 items, are distributed as follows: 8 items that evaluate skills related to Eating, 13 items related to Personal Care, 12 items that concern Domestic Activities, 7 items that address the Food Preparation and Storage skills, 8 items regarding skills in the area of Health, 12 items that evaluate Money Management skills, 7 items related to Transportation, 9 items that evaluate the area of Leisure, and 8 items dealing with skills related to the search for and/or conservation of Employment. The original scale in the English language presented adequate psychometric properties of internal consistency (Cronbach's alpha of 0.67 to 0.84).

The ILSS evaluates, on a Likert 5-point scale, the frequency in the previous month with which the patient performed the daily activities necessary for their independent functioning in the community. When the patient had no opportunity to present the skill in question, the option NO (no opportunity) was marked.

In the Brazilian adaptation and validation study[8], the results indicated that the Cronbach's alpha values ranged from 0.75 to 0.96. To evaluate the level of functioning of the patients in relation to the nine areas of everyday independent living skills, the mean score of the responses was calculated for each of the nine sub-scales of the ILSS-BR. This mean, which can range from 0 to 4, indicates a higher level of independent living skills when it is nearer to the maximum value of 4.

General Health Questionnaire (GHQ-12)

This scale was created by Goldberg and Williams[18] for the purpose of detecting the individual's vulnerability to mild mental disorders and has been used in various studies. The questionnaire consists of 60 items, in its original form, with an internal consistency coefficient of 0.95. The author of the instrument formulated various abbreviated versions consisting of 30, 20 and 12 items. The 12 – item version, validated for the general population, was the version used in the present study. The GHQ-12 consists of 12 items and, regarding internal consistency, has a Cronbach's alpha of 0.87. It evaluates how much the person has experienced the symptoms described, with the answers provided through a four-point scale and lower scores indicative of a better level of psychological well-being[19]. This scale has been validated in many countries with diverse foci, such as that of one study[20] conducted in Austria, which validated the scale for the population of non-psychiatric patients, with a Cronbach's alpha of 0.75.

Ethical aspects

The research project was approved by the Research Ethics Committee of UEL (CAAE: 06394012.0.0000.5231).

Data analysis

After tabulation, the data were transferred to the Statistical Package for the Social Sciences (SPSS) v.21.0. The initial step was to perform the normality test, aiming to choose between parametric tests for normal distribution, and non-parametric for non-normal distribution, prior to starting the analysis itself. The Kolmogorov-Smirnov test was used to evaluate the normality of the sample. The data were analyzed using the Mann-Whitney test, Pearson's correlation, Spearman's Correlation, Partial Correlation, and the Jonckheere-Terpstra test. The significance level was set at $\alpha = 0.05$. For the interpretation of the correlation, the values adopted for this study were, up to 0.20 – very low, from 0.20 to 0.40 – low, 0.40 and 0.60 – moderate, 0.60 to 0.80 – high, and 0.80 to 1.0 – very high[21].

Results

The sample consisted of 100 family members of both sexes, 63% were female and 37% male, 60% married, with a mean age of 47 years (SD ± 1.6). Considering the family relationship, 27% of the family members were mothers, 17% were siblings, 15% children, and 41% another type of relation. Of these, 42% had completed high school and 21% had not studied. Regarding income and employment, the majority had an income (66%), with 40% being employed, 34% not working, and 26% retired.

In relation to the patients, 52% were female and 48% male, with 58% being single. A total of 72% of the patients had been diagnoses with schizophrenia and 28% bipolar disorder. The mean age of the patients was 40 years (SD ± 1.4), the minimum age being 18 years and maximum 69 years, and the mean age at which the diagnosis of the disease occurred was 24 years (SD ± 1.4), that is, as young adults. Considering the socioeconomic status, the majority of the patients had a total income of one minimum wage (57%), followed by those who had no income (33%), with the remainder receiving between 1 and 2 minimum wages (10%). With regard to education, the majority (56%) had attended elementary school.

The Kolmogorov-Smirnov normality test indicated a normal distribution in the SATIS scale factors. The ILSS scale also presented a normal distribution ($p > 0.05$) in the overall score and in the Personal Care and Health factors. The GHQ-12 scale and the other factors had a non-normal distribution ($p < 0.05$).

Using the Mann-Whitney test to compare the ILSS scale scores, in relation to gender the difference was statistically significant, indicating that males have a higher degree of independent living skills ($U = 895.500$, $p < 0.001$). The differences were also statistically significant when comparing the level of stress/psychological distress in relation to the type of patient diagnosis ($U = 330.000$, $p < 0.001$). However, no significant differences were identified when comparing the level of stress/psychological distress in relation to the gender of the family member ($U = 118.500$, $p = 0.629$).

Analyzing the relationship between the degree of stress, family satisfaction and the level of independent living skills, the partial correlation calculation was performed, using as a control variable the overall score of the GHQ-12, which provided a low value ($r = -0.298$; $p < 0.05$), thus measuring the magnitude of the relationship between the degree of satisfaction of the family members and the level of independent living skills, without the influence of the level of stress/mental suffering of the family. For the SATIS scale, the mean and standard deviation values for the Welcome and Competence of the Team subscale were 4.30 and 0.58 respectively, with 4.49 and 0.55 for the Results of Treatment in the Service subscale, and 4.06 and 0.93 for the Privacy and Confidentiality of the Service subscale.

Discussion

Stress of the family

The mean score of the GHQ-12 scale with the family members of the psychiatric patients was 7.39 (SD = 0.57), higher than that of another study[22], which applied this scale with adults and elderly people of the community, and found a mean of 2.06 (SD = 0.50), indicating that the burden generated by living with a psychiatric patient in the family context greatly increases the stress levels of the family caregiver, as the closer to the score is to zero the lower the stress of the respondent, and the closer to 12 the higher the stress. The score was also higher than another study[23] that tested the validity of the GHQ-12 to evaluate depressive phenomena, where the mean score obtained with depressed people was 5.92 and for the non-depressed population 1.7 for men and 1.9 for women. When evaluating the percentage of family members with stress, it was found that 81% of the family members in this study presented a degree of stress higher than 4, considered the cut-off point for this instrument[18], however, no data was available for comparison with other studies.

When correlating the level of education with the GHQ-12 scale, it was found that the Spearman's correlation coefficient was negative, indicating that the higher the educational level of the family member the lower the stress level and vice versa ($r = -0.237$; $p < 0.05$), however, only 5.6% of the variance was explained, i.e., a low correlation. When verifying the value of the Jonckheere-Terpstra test, a negative linear trend was found, confirming that the higher the level of education the lower the level of stress measured by the GHQ-12 scale, i.e., the linear relationship between these two variables occurs only in this sense ($JT = -2.54$; $p < 0.01$). However, no studies were found to compare the relationship between these variables.

Family satisfaction

According to the results, 74% of the family members reported being satisfied or very satisfied with the different aspects of the services, the other family members (26%) responded with the option "more or less", intermediate between satisfaction and dissatisfaction, with none of the family members reporting being dissatisfied or very dissatisfied with the mental health service. This differed from another study[9] that presented a higher percentage of satisfied or very satisfied family members (from 81.20% to 96.40%), with the other family members "more or less" satisfied (1.20% to 16.50%) and dissatisfied or very dissatisfied (1.20% to 5.90%). Despite both studies adopting similar data collection methodology, it was not possible to conclude the reason for this difference in the degree of satisfaction.

The mean overall satisfaction score was 4.28 (SD = 0.52), with a minimum score of 3.05 and a maximum of 5, with 14% of the sample attributing this higher score. In a study carried out using the same scale[10] a mean overall satisfaction score of 4.41 (SD = 0.56) was identified, similar to that identified in the present study, as well as in the subscales presented.

Independent living skills

Concerning the daily living skills of the psychiatric patients, it was identified that the scores encountered in this study were similar to those found in other larger studies. The mean overall score for the ILSS in this study was 1.59, median 1.50, and SD = 0.57, while another study[14], conducted in Rio de Janeiro, Brazil with hospitalized schizophrenic patients in a psychiatric hospital, found a mean score of 1.4 (SD = 0.8) and another study[15] performed in Minas Gerais, Brazil with patients in a psychiatric hospital in the process of deinstitutionalization, identified overall medians of 1.70 (SD = 0.62) (1st phase – in the hospital) and 2.29 (SD = 0.87) (2nd phase – in therapeutic housing). This demonstrates that the patients presented a limitation according to the daily living skills, requiring more training to develop these skills, as the scores obtained with the patients in the therapeutic housing phase was higher than those found in this study. This suggests that, in the daily living skills development process, therapeutic housing services provided better results than the CAPS of the city studied.

The relationship between stress, satisfaction and living skills

In the partial correlation, controlling for the influence of the stress level measured by the GHQ-12, a low negative correlation between family satisfaction and living skills was obtained ($r = -0.30$; $p < 0.05$), however, there was a variance of only 7.39%, i.e., only 7.39% of the variation in the degree of satisfaction of family members is explained by the level of independent living skills. After using Pearson's correlation, a low negative correlation (-0.27; $p < 0.01$) was identified between the caregiver satisfaction and daily living skills of the patient variables, indicating that the lower the skills of the patient the greater the satisfaction of the family caregiver. This relationship was an unexpected result and could be explained by the codependency* of the caregivers with their sick family members, mainly found in studies with relatives of drug dependent people[24].

Another correlation identified in this study is between the satisfaction of the family members with the mental health service and the their level of stress ($r = -0.23$; $p < 0.05$), indicating that the higher the level of satisfaction the lower the stress, which was empirically expected, although there is a limitation due to the fact that there are still no other studies on the same theme. Although not found, a negative correlation between the stress of the family caregiver and the daily living skills of the patients was expected. The limitations of this study include: the low analysis power of the ILSS scale (8.5%), the fact that the sample was by convenience, and the absence of studies that correlate the variables studied.

Conclusion

With this study, it was possible to identify that 81% of the family members of psychiatric patients presented psychological distress/stress and that 74% presented high satisfaction with the different aspects of the mental health services, i.e., despite this report in relation to the mental health service, the family members presented a very high degree of psychological distress. Regarding the level of independent living skills, it was perceived that the subjects studied presented similar scores to the population studied for the validation of the ILSS instrument, as well as hospitalized patients, although, lower than a study that measured these scores with patients living in therapeutic housing, suggesting that this service provides better conditions for social inclusion and relearning activities of daily living than the CAPS of the city studied.

With the results obtained, it can be concluded that it is essential that the mental health services perform more effective psychosocial rehabilitation actions, in order to facilitate better treatment outcomes in mental health, particularly in relation to the family members, due to their high degree of stress verified in this study. This study provides important results regarding the relationship between family satisfaction, the degree of independent living skills, and the level of stress, with the need for future studies related to this theme.

* Codependency can be defined as an emotional disorder characteristic of caregivers and family members who live with patients with mental disorders, drug dependants and pathological gamblers.

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