

# Caregiver burden and stress in psychiatric hospital admission

*A sobrecarga do cuidador e o estresse na admissão de um hospital psiquiátrico*

*La sobrecarga del cuidador y el estrés en la admisión de un hospital psiquiátrico*

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## ABSTRACT

**Objective:** to evaluate the relation between sociodemographics factors, stress and burden of care of family caregivers of patients at a psychiatric hospital admission. **Method:** quantitative study, with a cross-sectional correlation design. A total of 112 family caregivers participated, older than 18, in a Brazilian psychiatric hospital. A sociodemographic questionnaire was used to collect data, the Zarit Burden Interview and LIPP Adult Stress Symptom Inventory. **Results:** burden of care in family caregivers at a psychiatric hospital admission was significantly associated with stress ( $p=0.000$ ). The psychological symptoms of stress predicted severe burden. Most caregivers presented a moderate or severe burden, with 52.7% in the resistance phase of stress; 66.1% presented psychological symptoms. **Conclusion:** results show the alarming situation of caregivers of patients from a psychiatric hospital, evidencing their own vulnerability to illness. Indeed, the during admission in a psychiatric hospital, not only patients need care, but also their caregivers.

**Descriptors:** Caregiver; Psychological Stress; Mental Health; Psychiatric Nursing; Psychiatric Hospitals.

## RESUMO

**Objetivo:** avaliar a relação entre fatores sociodemográficos, estresse e sobrecarga de cuidado de cuidadores familiares na internação de pacientes em um hospital psiquiátrico. **Método:** estudo quantitativo, com desenho de correlação transversal. Um total de 112 cuidadores familiares participaram do estudo, maiores de 18 anos, em um hospital psiquiátrico brasileiro. Um questionário sociodemográfico, o *Zarit Burden Interview* e o *LIPP Adult Stress Symptom Inventory* foram usados para a coleta de dados. **Resultados:** a carga de cuidado dos familiares cuidadores em internação no hospital psiquiátrico foi significativamente associada ao estresse ( $p=0,000$ ). Os sintomas psicológicos do estresse previam uma sobrecarga. A maioria dos cuidadores apresentava sobrecarga moderada ou grave, com 52,7% na fase de resistência ao estresse, e 66,1% apresentavam sintomas psicológicos. **Conclusão:** os resultados mostram a situação alarmante dos cuidadores de pacientes na admissão ao hospital psiquiátrico, evidenciando sua própria vulnerabilidade à doença. De fato, a internação em um hospital psiquiátrico não requer cuidados apenas para o paciente, mas também para os cuidadores familiares.

**Descritores:** Cuidadores; Estresse Psicológico; Saúde Mental; Enfermagem Psiquiátrica; Hospitais Psiquiátricos.

## RESUMEN

**Objetivo:** evaluar la relación entre los factores sociodemográficos, el estrés y la carga de atención de los cuidadores familiares en el ingreso de pacientes en un hospital psiquiátrico. **Método:** estudio cuantitativo, con diseño de correlación transversal. Participaron 112 cuidadores familiares, mayores de 18 años, en un hospital psiquiátrico brasileño. Para la recolección de datos se utilizó un cuestionario sociodemográfico, el *Zarit Burden Interview* y el *LIPP Adult Stress Symptom Inventory*. **Resultados:** la carga de atención de los cuidadores familiares en el ingreso al hospital psiquiátrico se asoció significativamente con el estrés ( $p=0,000$ ). Los síntomas psicológicos del estrés predijeron una carga severa. La gran parte de los cuidadores presentaron una carga moderada o grave, con un 52,7% en la fase de resistencia del estrés, y el 66,1% presentó síntomas psicológicos. **Conclusión:** los resultados muestran la situación alarmante de los cuidadores de pacientes en el ingreso al hospital psiquiátrico, evidenciando su propia vulnerabilidad a la enfermedad. De hecho, el ingreso al hospital psiquiátrico no requiere cuidado solamente al paciente, sino también a los cuidadores familiares.

**Descriptorios:** Cuidadores; Estrés Psicológico; Salud Mental; Enfermería Psiquiátrica; Hospitales Psiquiátricos.

## INTRODUCTION

Family caregivers play a key role in caring for people with mental illness, but living with it can have a significant cost for family members. The chronic nature of mental illnesses, the gravity of symptoms, and the occurrence of relapses requiring hospital admissions cause significant changes in family dynamics and routine, expression of emotions, finances, quality of life, and interpersonal and social relationships of each family member. This situation can cause prolonged stress that may affect family caregivers and their own health<sup>(1-3)</sup>. Literature defines the perception of caregivers about the extra demand for care required by a family member with chronic illness and the attending negative changes in social, financial, physical, and emotional aspects of life as a variable defined as burden of care<sup>(4-5)</sup>. Many studies show that the burden of care makes family caregivers vulnerable to stress and to developing diseases such as anxiety and depression<sup>(6-7)</sup>. In this study, stress was based on The General Adaptation Syndrome<sup>(8)</sup>, that defines it as the organic response to any stimulus that threatens the body's internal balance, causing a set of reactions to adapt to the "threatening" situation. The General Adaptation Syndrome identifies three phases of stress: alert, resistance, and exhaustion, to which Lipp (1994) added a fourth phase, called almost-exhaustion, in between the resistance and exhaustion phases<sup>(9)</sup>.

The high level of caregiver stress associated with medical conditions and quality of life is recognized for some time<sup>(10-12)</sup>. In this context, the psychiatric hospital admission is a relevant moment for the care of patients experiencing a crisis and also for family caregivers. Since the 1980s, changes in Brazilian public policies for mental health have been encouraging the treatment of patients with mental disorders in the community<sup>(13)</sup>, and psychiatry hospitalization is only used to contain crisis situations. Family caregivers are those who are closest to patients at this time, accompanying and assisting the treatment, creating expectations of the patients' rehabilitation and facing mental imbalance of their relatives. This causes distress, emotional distress and many demands on family caregivers.

## OBJECTIVE

To evaluate the relation between sociodemographic factors, stress and burden of care of family caregivers of patients at a psychiatric hospital admission.

## METHOD

### Ethical aspects

Ethical approval for this study was obtained from the Research and Ethical Committee in accordance with Resolution CNS No. 466/2012<sup>(14)</sup>. Family caregivers gave formal informed consent after the objectives and procedures of the study had been explained to them.

### Study design, location, and period

The study used a cross-sectional correlation design and was performed in a Brazilian psychiatric hospital, between May and

August 2015. This hospital has 101 beds for care of patients in acute psychiatric crisis and 89 beds for care of long-stay patients.

### Sample, inclusion and exclusion criteria

A functional definition of family caregiver was adopted, considering them co-resident family members who assume the major responsibility for assisting another disabled family member. In the family caregiver situation, one family member helps another on a regular (daily, or almost daily) basis with tasks that are necessary for independent living, if not all of the patient's daily care needs<sup>(1,5)</sup>. All family caregivers of patients admitted to the psychiatric hospital during the data collection period (4 months), over 18, were invited to participate in the study. On average, this hospital has 50 psychiatric admissions per month and the family caregivers were invited to participate in the study at the moment of patient admission or during visits to patients, in the first 15 days of patient admission.

### Study protocol

Data collection was performed individually, in a reserved room at the hospital, in a single meeting. The instruments were applied through the researcher's reading, followed by the choice of response by the participant subject. A questionnaire was used to collect data on baseline demographics, the Zarit Burden Interview (ZBI) was used to assess burden of care and the LIPP Stress Symptom Inventory for adults to assess stress.

A sociodemographic questionnaire was used to collect data on baseline demographics (age, gender, and educational level), marital status, level of kinship, religion, physical activity, and related health problems. Regarding patients, their caregivers were asked how long the patient had had the given psychiatric illness, and the number of previous admissions.

The Zarit Burden Interview (ZBI) has been used to assess caregiver burden in different countries and across many languages, with good reliability and internal consistency. Developed by Zarit, Orr, Zarit (1985)<sup>(4)</sup> and validated in Brazil by Scazufca (2002)<sup>(15)</sup>, ZBI presents a satisfactory internal consistency ( $\alpha=0.92$  and  $\alpha=0.88$ ). In this study, Cronbach's alpha to internal consistency for the 22 items was  $\alpha=0.86$ . Each item of the ZBI was scored on a 5-point Likert scale, ranging from 0= "never" to 4= "nearly always". The scale's total score is obtained by adding all items and may vary from 0 to 88. The greater the total score, the greater the burden. In this study, the scores used were: less than 21= little or no burden; 21 to 40= ranging from mild to moderate burden; 41 to 60= from moderate to severe burden; and 61 to 88= severe burden<sup>(16)</sup>.

LIPP Stress Symptom Inventory for adults developed and validated by Lipp, Guevara (1994)<sup>(9)</sup>, presents a satisfactory internal consistency ( $\alpha=0.88$ ). It evaluates the presence or absence of stress; the phase of stress; and the predominant type of symptom (physical and/or psychological). It has three frames that refer to the phases of stress, consisting of symptoms with possible responses (yes/no), subdivided into "a" and "b", corresponding to physical and psychological symptoms, respectively. To perform the calculations for each possible analysis, the Lipp Adult Stress Symptom Inventory Manual must be consulted<sup>(12)</sup>.

For the present study, the internal consistency was considered adequate ( $\alpha=0.93$ ).

### Analysis of results and statistics

The data collected were coded and organized in a Microsoft Windows Excel spreadsheet, double-typed. After statistical validation, the statistical analyses were performed in the programs R 3.1.2 and Statistical Package for the Social Sciences (SPSS, version 22), with the support of a statistician. The level of significance adopted in all analyses was 5% ( $\alpha=0.05$ ).

Descriptive statistics of sociodemographic variables and scales were calculated using means and SD for quantitative data, and frequencies and percentages for categorical variables. Cronbach's alpha coefficient was used to assess the internal consistency of the scales used, and alpha coefficients equal to or greater than 0.70 were considered satisfactory.

The tests of association between sociodemographic factors, stress and burden were performed through Pearson's Chi-Square test and Fisher's exact test. The Ordinal Multinomial Logistic Regression Model was adopted and the burden of care was considered as the dependent variable and classified into four levels: "little or no burden"; "Mild to moderate burden"; "Moderate to severe burden"; and "Severe burden". In the first stage of the regression analysis, the variables related to stress were inserted (presence of stress, stress phase, and predominant symptom of stress). The second stage consisted of adding sociodemographic variables to the model chosen in the first stage. They were inserted simultaneously and the removal of non-significant variables was performed manually, always removing the one with the highest p value, to the point where only statistically significant variables remained. In the third stage, the same was done regarding variables for health problems of caregivers, using the model chosen in the first stage. The variables that presented significance in the 2<sup>nd</sup> or 3<sup>rd</sup> stages were added and a final model was adjusted with these variables, to the point where only significant variables remained. From the final model obtained, the odds ratio and the predicted probabilities of burden classification were calculated.

### RESULTS

During the data collection period, 193 patients were admitted to the hospital, and 21 had no family caregivers. Thus, 172 caregivers were invited to participate and 112 family caregivers accepted the invitation.

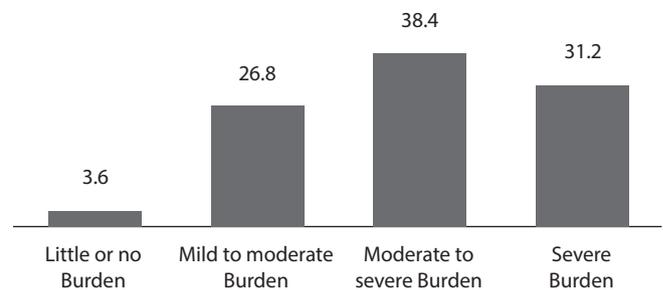
Among family caregivers, most were women (82.0%) and most were married or had a steady partner (59.0%). The mean age of caregivers was 49 ( $\pm$  SD 12.8, range 23–77 years old). According to the level of kinship, mothers were 54.0% of the caregivers, followed by siblings (12.5%), spouses (9.0%), and children (8.0%).

Most caregivers (83.9%) reported having a religion (46.4% were Evangelical and 33.4% Catholic), 57.1% had not finished primary education (with only 4.5% having attended higher education institutions, with or without obtaining a degree). Regarding their lifestyle and health, 77.0% of caregivers did not practice any type of physical activity and 68.0% reported having health problems, such as cardiovascular and endocrine diseases (19.0% with only one

health problem; 17.0% with two health problems; 12.5% with three health problems; and 19.5% with four or more health problems).

As for patients, 16.9% were in their first psychiatric hospitalization, 16.9% in the second and 61.6% in the third or more. The time since the diagnosis of mental disorder averaged 13.5 years ( $\pm$  SD 10.0, range 0.25–40 years), with 35.3% between 11 to 40 years, and 20.4% 5 years or less. Thus, the sample studied comprised mostly family caregivers of chronic patients.

The subjects in this study presented high levels of burden, as described in Figure 1 below. Burden mean score was 50.2 ( $\pm$  SD 16.6, range 13–81 points). Most family caregivers presented "moderate to severe burden" and "severe burden".



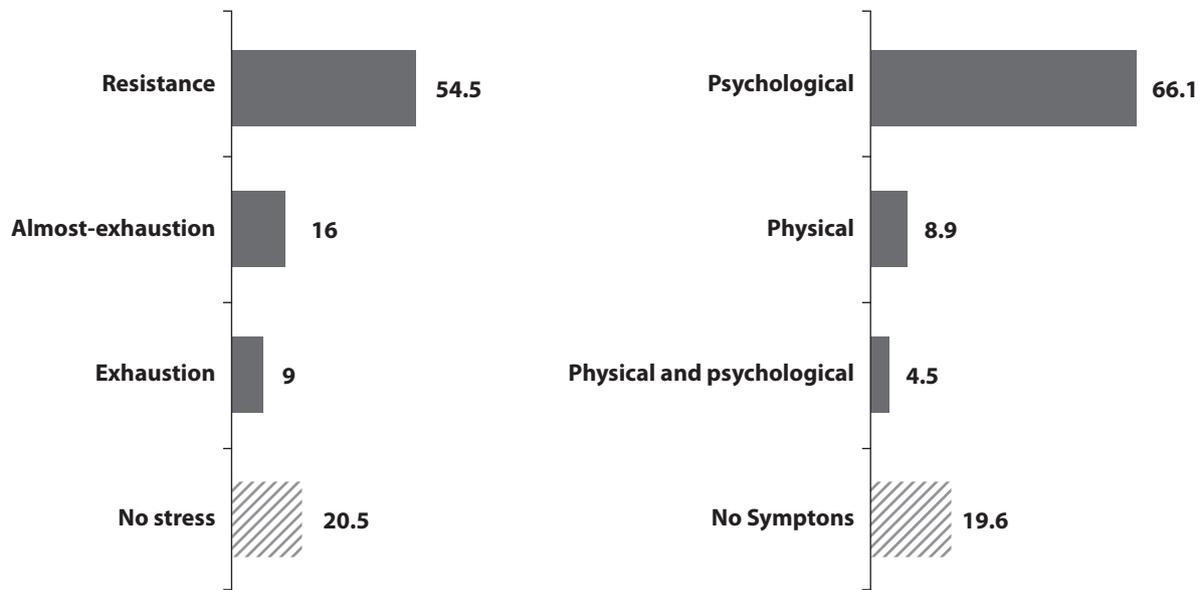
**Figure 1** - Percentage of family caregivers in each burden of care classification according to the Zarit Burden Interview, Ribeirão Preto, São Paulo, Brazil, 2015, N=112

Considering the nature of the burden, most family caregivers reported always feeling that their relatives depend on them (73.2%); being always afraid of what the future holds for their relatives (58.0%); always feeling that their relatives expect them to take care of them, as if they were the only ones they could depend on (58.0%); and always feeling that they do not have enough money to take care of their relatives, added to other expenses (55.4%). On the other hand, most of these caregivers (53.6%) would not like to simply let someone else take care of their relatives.

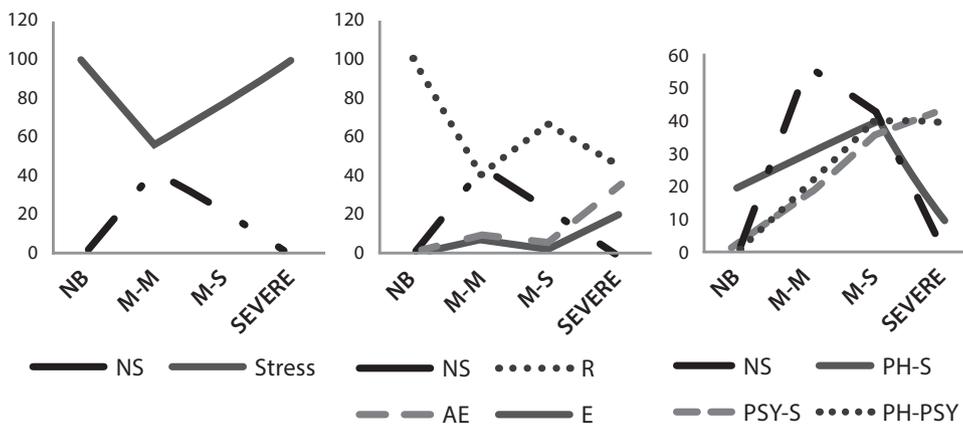
According to the LIPP scale, 79.5% of family caregivers suffered from stress, with 52.7% suffering from the resistance phase of stress, and 66.1% presenting psychological symptoms (Figure 2).

Regarding the resistance and almost-exhaustion phases of stress, considering the manifestations of stress in the last week, most family caregivers reported feeling constant physical exhaustion (65.2%) and constant fatigue (63.4%). As for the psychological symptoms related to this phase, most caregivers reported excessive emotional sensitivity (70.5%) and irritability (55.4%). Moreover, they reported feeling self-doubt (53.6%) and constantly thinking about a single issue (78.6%).

The results of stress symptoms, corresponding to the phase of exhaustion (that is, the phase related to the symptoms of stress manifested in the last month), showed that 61.6% of caregivers had difficulties with sleeping or insomnia, as physical symptoms. Regarding the psychological symptoms, they reported loss of their sense of humor (50.9%); apathy, depression, or prolonged anger (53.6%); emotive hypersensitivity (59.8%); feeling excessive fatigue (64.3%); thinking and/or speaking constantly on a single subject (65.2%); willingness to evade everything (68.8%); feeling distress and/or daily anxiety (73.2%).

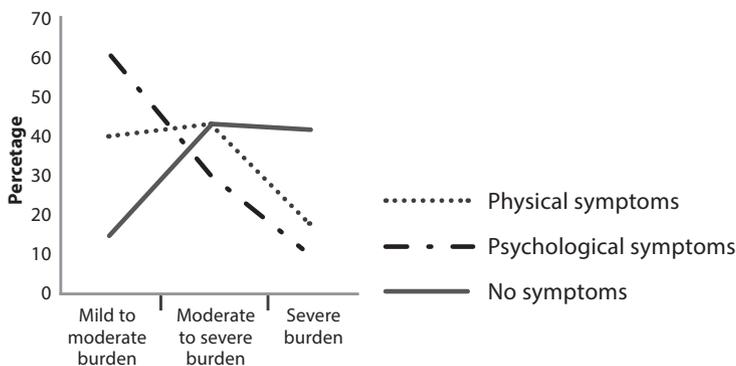


**Figure 2** - Stress phase (A) and Symptoms of family caregiver (B) according to the LIPP Stress Symptoms Inventory for adults, Ribeirão Preto, São Paulo, Brazil, 2015, N=112



*Note: NB=no burden, M-M=mild to moderate burden, M-S= moderate to severe burden; Severe= severe burden; NS=no stress; S= stress; R= resistance; AE= almost-exhaustion; E= exhaustion; PH-S= physical symptoms of stress, PSY-S= psychological symptoms of stress, PHPY-S= physical and psychological symptoms of stress. LIPP Stress Symptom Inventory for adults. For "A", "B", "C"; Chi-square Pearson test, p value ≤ 0.001.*

**Figure 3** - Association between the levels of burden in family caregivers of patients at psychiatric hospital admission with stress (A), phases of stress (B), and type of predominant symptoms (C), Ribeirão Preto, São Paulo, Brazil, 2015



**Figure 4** - Probability of occurrence of high burden among caregivers considering the independent variables found statistically significant in the regression model, Ribeirão Preto, São Paulo, Brazil, 2015

The alert phase of stress is related to symptoms manifested in the last 24 hours. In this phase, physical stress symptoms predominant in the caregivers were: muscle tension (55.4%), insomnia (48.2%), dry mouth (44.6%), and change in appetite (40.2%). As for the psychological symptoms of this phase, a sudden desire to start new projects was highlighted (38.4%).

As shown in Figure 3, burden of care and stress showed a strong association ( $p=0.000$ ) among family caregivers, with stressed caregivers mostly reporting "moderate to severe burden" and "severe burden" (80%). There

were no reports of "severe burden" among family caregivers who did not present stress. Family caregivers with "moderate to severe burden" and "severe burden" were also at the highest stress phases ( $p=0.000$ ) (Figure 3 (B)).

The association between burden levels and stress symptoms types showed that "moderate to severe burden" and "severe burden" were observed among caregivers with a predominance of psychological stress symptoms, with an association with high statistical significance ( $p=0.000$ ).

There were no statistically significant associations between burden of care and sociodemographics factors among family caregivers.

Psychological symptoms of stress were evidenced as predictors of severe burden among family caregivers of patients in psychiatric hospital admissions.

The logistic regression showed that caregivers who presented psychological symptoms of stress are 8.37 times more likely to have “moderate to severe burden” or “severe burden” care burden than caregivers who did not have symptoms.

Figure 4 shows that the more psychological symptoms of stress the caregiver presents, the greater the probability that the latter presents a “severe burden”. In addition, a predominance of psychological symptoms of stress indicate a higher probability of “severe burden”.

## DISCUSSION

The aim of this study was to evaluate the burden of care and the stress of family caregivers at patient admission to a psychiatric hospital. The findings indicate that caregiver burden was significantly associated to stress, and that psychological stress symptoms were predictors of severe burden. These results provide evidence that burden of care and stress are correlated in the context of mental health-care.

Burden of care is related, objectively, with perception of negative consequences of care tasks, and subjectively, with feelings and concerns that involve the health-care<sup>(17-18)</sup>. Almost all participants (96.4%) presented burden of care, with severe burden levels predominating, indicating that the transfer of care of patients to professionals failed to alleviate the burden of family caregivers. This is probably because, in this study, caregivers were evaluated in psychiatric hospital admissions. In Brazil, psychiatric hospital admission is recommended for severe cases when extra-hospital resources have been exhausted for the treatment or management of the problem, making it a moment of crisis for patients and of great impact to their families<sup>(19-21)</sup>. Indeed, other studies which reported only a mild burden of care, evaluated more clinically stable patients, at the time when the care was carried out at home or in outpatient care<sup>(22-23)</sup>.

In this study, 79.5% of the family caregivers displayed stress, with the majority in the resistance phase of stress and with a predominance of psychological symptoms, such as excessive irritability, apathy, depression, prolonged anger, excessive tiredness, and anxiety. This result is consistent with other studies on the same area, which indicate that the psychological symptoms of stress are the most frequent<sup>(24)</sup>. The predominance of the resistance phase is particularly relevant because it is marked by feelings of weariness and fatigue, as well as by psychological, physiological, and biochemical changes that overload the organism<sup>(8,25-26)</sup>.

Family caregivers play multiple roles in care for people with mental illnesses, including supervising medications, looking after financial needs, missing important social obligations or days at work, feeling trapped by the caregiver role and having excessive concerns about future<sup>(11,18)</sup>. This study has brought to light the alarming situation of these caregivers. In this context, rethinking the role of mental health services, concerning caregiver's health, is essential.

Several studies have investigated health care attention for caregivers. Regarding these interventions, the study by Caqueo-Urizar *et al.* (2014)<sup>(27)</sup> identified that psychosocial interventions with family caregivers can help manage the caregiver's burden and decrease the number of patients who experience relapse

and hospitalization. As for intervention time, scientific literature indicates that the best results were obtained after three months of intervention; however, these improvements may disappear after a few months, if maintenance therapy is not performed<sup>(28-30)</sup>.

In contrast, Martín-Carrasco *et al.* (2016)<sup>(11)</sup> implemented a psychoeducational intervention program for family caregivers of individual with schizophrenia diagnoses, called EDUCA-III trial, that reduced caregiver burden during post-intervention (4 months), and follow-up (8 months). This intervention program was developed by a group of psychiatric, psychologist and mental health experts and it is a behavioural-cognitive approach to provide caregivers with education, problem management skills, social support, cognitive strategies for reframing negative emotional responses, and control stress.

The efficacy of such interventions is demonstrated by, for example, McCann *et al.* (2013)<sup>(31)</sup>, who showed a large and significant decrease in symptoms of psychological stress among a group of caregivers of young people in the first psychotic episode, after interventions such as problem-solving therapy.

A review of Yesufu-Udechuku *et al.* (2015)<sup>(3)</sup>, aimed to determine whether interventions provided to caregivers of people with severe mental illnesses improve caregiving experience and help reduce caregiver burden. This review included studies with interventions focused on family caregiver of individuals with bipolar affective disorders and schizophrenia spectrum disorders. About the interventions, review shows treatment of control groups when compared to psychoeducation groups, a support group, a combined psychoeducation and support group, problem-solving bibliotherapy, and self-management. This review concluded that psychosocial interventions specifically aimed at helping carers can decrease burden and psychological distress.

Nonetheless, Manami and Suro (2016)<sup>(18)</sup> implemented a program called Culturally informed intervention for caregivers of patient with schizophrenia (CIT-S). This program aims to reduce the levels of burden of care, shame and guilt among the family caregivers, using cognitive and behavioral techniques such as thinking monitoring, cognitive restructuring and behavioral activations to access participants beliefs, behaviors and practices of ethnic and cultural origin. The results of this study suggest that caregivers may respond well to this type of treatment and help them cope with schizophrenia.

Therefore, psychiatric nurses should encourage the development and implementation of intervention programs, both individually and in group, with family members of patients with mental disorders. The family caregiver must also be included in the planning of treatment, besides participating as a co-responsible for care.

Concerning the profile of family caregivers, the results indicate that they were predominantly women, similar to what is reported for family caregivers in a number of countries<sup>(6,22,32)</sup>. Throughout human history, women, usually mothers, have usually borne the responsibility for health-care<sup>(27)</sup>.

There were no statistically significant associations between burden of care, stress and sociodemographics factors among family caregivers. However, Kumar and Gupta (2014)<sup>(24)</sup> found that wives of people undergoing treatment for depression had a higher mean of burden score than other caregivers, which infers

that level of burden may be related to the type of care and relationship between caregivers and patients. Another study showed that caregivers with lower ages, single and who spent more time with patients, experienced higher levels of tension than older and married caregivers<sup>(6)</sup>.

### Study limitations

The cross-sectional design of this study limits the understanding of the processes of developing burden and stress, given that participants were not representative of the general population of family caregivers. As all caregivers were interviewed at the time of hospital admission, the results cannot be generalized to stable patients. Furthermore, only the main caregiver was interviewed, which precluded understanding the impact of the burden of care in other family members. On the other hand, present work is innovative in being the first to address the important moment of psychiatric treatment (hospital admission). Moreover, the instrument used, an internationally validated questionnaire with adequate reliability and validity in this setting (data to be presented elsewhere), makes the findings comparable with reports in different cultural contexts.

Several researchers have reported that primary and secondary stressors related to the severity of the illness, caring activities, family context, and financial problems affect the burden of care<sup>(21)</sup>. In contrast, our findings show that stressors, including some unrelated to the illness, that occur in the lives of family caregivers, can increase their perception of severe burden by multiplying their stress levels. Regarding the patients' diagnoses, this separation was not made and cannot be compared with other studies.

The restructuring of the Brazilian model of mental health care presents some challenges for a safe transition from hospital treatment to community treatment, such as the lack of educational interventions that help family caregivers to better understand the therapeutic treatment and to deal with mental disorders<sup>(33)</sup>.

### Contributions to the Nursing and Health field

Psychiatric hospitalization is a time of great tension for those with mental disorders and for their family caregiver. The results of this study show high levels of burden associated with stress. The lack of care programs for family caregivers, considering these two phenomena, can cause higher financial costs to public health

services. High levels of stress and burden are also related to higher risk of illness. In this sense, the role of nurses in the creation of long-term intervention protocols and programs for higher quality care for family caregivers of patients in psychiatric hospitalization is highlighted.

Further studies must be conducted to investigate aspects of caregivers of patients who are experiencing episodes of psychiatric crisis. In this study, the caregivers of all hospitalized patients were assessed for burden of care and stress, regardless of the patient's previous admission. An assessment of whether the caregivers' burden of care and stress change according to the number of hospitalizations is also suggested. Finally, it is important that future research can implement and evaluate intervention programs directed to caregivers of patients admitted for psychiatric hospitalization.

### CONCLUSIONS

Research addressed current and relevant themes related to the situation of family caregivers of psychiatric patients, more specifically regarding the burden of care and stress that they face daily. This is a fundamental issue in health-care planning, which works in cooperation with the other subjects of this complex context, but is still with no due recognition and care.

The results obtained confirm the traditional and ongoing role of women as the main health caregivers. They also confirm the presence of care burden for almost all caregivers, as well as the presence of stress symptoms. The psychological symptoms of stress, such as worry, anxiety, irritability, and depression, among others, were identified as a risk factor for "severe" burden.

Thus, the results of this study show the alarming situation of caregivers of patients in psychiatric hospitalization admission, demonstrating their vulnerability to illnesses. The results evidenced that, in the psychiatric hospital admission, not only patients need care, but also their family caregivers. There is a consequent need for interventions and studies aimed at expanding and qualifying the health-care of these caregivers.

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