



OVERLOAD FOR FAMILY MEMBER CAREGIVERS OF PEOPLE WITH MENTAL DISORDERS

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ABSTRACT

Objective: to evaluate the overload for family caregivers of people with mental disorders, through the Familial Overload Assessment Scale (FOAS-BR).

Method: descriptive and quantitative study. Participants were 42 family members from two hospitals in the northwest region of Rio Grande do Sul, in the year 2014. The sociodemographic Scale and Questionnaire was used to collect data. Ethical aspects have been respected.

Results: of the caregivers, 78.57% are female, from 51 to 60 years old, mothers. They presented a high objective load in the daily changes in the routine and in the aid to the patients in the daily tasks. High subjective overload, referring to patient concerns, perceptions of permanent changes in caregivers' social and professional life, and discomfort in supervising problem behaviors.

Conclusion: the need for actions and support programs, inform and help family caregivers was identified for a better quality of life.

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INTRODUCTION

According to the World Health Organization (WHO) (2001), mental disorders have reached about 700 million people worldwide, this represents about 13% of all diseases.

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Among these is the depression that is considered the fourth leading cause of disability worldwide, in the year 2012. In 2020, there will be the second largest cause, and in 2030 it will be a prevalent evil. Another important finding in this WHO review, is related to the high user index of psychoactive, licit and illicit substances, contributing to the increase in the number of people with mental disorders. A study pointed out that approximately 26 million people worldwide are chemical dependents, about 0.6% of the world's adult population

(Fontana *et al.*, 2011). In addition, tobacco kills five million people a year, alcohol about 2.5 million and illicit drugs about 200 thousand people a year, around the world. Brazil is the second country with the largest number of users of cocaine, with approximately 870 thousand users (Fontana *et al.*, 2011). For several decades the psychiatric treatment was carried out in asylums with long periods of hospitalization, which entailed the removal of the person with a mental disorder from the family. With the Psychiatric Reform, which began in the 1980s, new ways of caring for the person with a mental disorder were instituted, shifting attention to this population from the asylum to other services, preferably at the local level (Amarante, 2015). This context began to demand new profiles of professionals to meet the demands of this population stratum, in line with the assumptions of the Brazilian psychiatric reform.

In this scenario, the family began to be included in the therapeutic project of the person with mental disorder and to assume an important role in the care of this individual, as protagonist and co-responsible. However, the family also requires care, since the process of caring for a mentally ill person is sometimes painful and difficult (Martins and Guanaes-Lorenzi, 2016). Being a caregiver and patient supporter often generates an overload for the family. It sometimes leaves some needs or desires in the background and reorganizes their life or their daily activities, according to the demands of the patient (Schein and Boeckel, 2012). It is worth mentioning that overloading refers to the negative impact that the role of caregiver causes in the family's life (Batista *et al.*, 2013). Despite the possible overload generated, the family became a valuable ally for the recovery process, with positive results during the treatment (Martins and Guanaes-Lorenzi, 2016).

Continuous overloading of the caregiver can cause physical and psychological health burnout, resulting in psychological distress, especially anxiety and depression. This overload can be objective, which refers to the observable negative consequences generated by the role of caregiver, such as; changes in the routine of social and professional life of caregivers, financial loss, overlapping of tasks and supervision of problematic behaviors. Still, the overload can be subjective and refers to the perceptions, concerns, negative feelings and annoyances generated by becoming caregiver of a psychiatric patient (Gomes and Melo, 2015). Assessing the impact of the caregiver role in families can provide important information for the development of psychosocial and educational interventions, capable of effectively helping these families and improving the quality of care in mental health services (Bandeira, Calzavara and Castro, 2008). The success of the social reintegration of people with mental disorders is related to the contributions of family members in this process, as well as the attention given to the family group, in order to strengthen the interrelations with the sick individual. The assessment of family burden will allow you to identify your needs. In this scenario, the importance of Nursing is reinforced in intervening with the patient and the family, providing support, helping them in their difficulties. Therefore, the general objective of this research is to evaluate the overload of family caregivers of patients with mental disorders, through the Familial Overload Assessment Scale (FOAS-BR). The specific objectives are: to describe the sociodemographic and health characteristics of the family caregivers, and to identify

the objective and subjective overload in some domains of their lives.

METHODS

Quantitative and descriptive research, developed in two general hospitals, one of them considered Porte I¹, reference for mental health, and the other of Porte IV². Both located in the northwest region of the State of Rio Grande do Sul, characterized for this study as hospitals 1 and 2, consecutively. Participating in the study were 42 family caregivers of hospitalized mental disorder patients, distributed as follows: nine in the hospital 1, and 33 in the hospital 2. The sample size was determined by convenience, and data collection was performed in September and October 2014, shortly after the approval of the research project by the Research Ethics Committee of the Regional University of the Northwest of the State of Rio Grande do Sul (Unijuí), under Opinion Consubstanciado n° 775.145. The instruments of data collection used were: Sociodemographic questionnaire of the family caregiver, containing characterization data such as: gender, date of birth, age, schooling, origin, marital status, occupational situation, income, the number of hours spent for daily care, third-party assistance and, if so, who, how often and in what situations. The other instrument is the Family Overload Assessment Scale FOAS-BR, it was developed by Tessler and Gamache (1995) and adapted and validated for Brazil by Bandeira, Calzavara and Varella (2005). The FOAS-BR evaluates the objective and subjective overload of the family members in 52 items, distributed in five subscales: (a) assistance in daily life; (b) supervision of problem behaviors; (c) expenditures; (d) impact on daily routines; (e) concern with the patient.

The subjects were, initially, contacted by the researcher and invited to participate in the study, after explaining the objectives of the study. Those who agreed to join the study population were provided with the Free and Informed Consent Form (FICT) in two copies and communicated about the secrecy and anonymity of their identities and responses. The inclusion criteria to participate in the research were: to be familiar to a person with mental disorder, over the age of 18 years, to have cognitive and emotional conditions to respond to the instrument, and to be the primary caregiver of the patient for at least three months. Minor relatives were excluded, those who were not in cognitive and emotional conditions, caregivers who were not primary caregivers and who cared for less than three months the patient, and, also those who did not accept to participate in the research. FOAS-BR was applied orally, in individual interviews performed by the previously trained team. They were carried out inside the proper hospitals in appropriate rooms, reserved and with privacy, space that was only the familiar and the researcher. The data were entered into Excel spreadsheets after being stored and analyzed using the *Statistical Package for the Social Sciences* (SPSS), version 18.0, and data presented in absolute and relative frequencies, mean and standard deviation.

¹ Hospital Porte I: It has 20 to 49 beds, low complexity and up to 2 operating rooms. Reaching from 01 to 05 points according to Administrative Rule No. 2,224 / GM of December 5, 2002.

² Hospital of size IV: It has 150 to 299 beds, high complexity, high risk gestation. It reaches from 20 to 27 points according to Administrative Rule No. 2,224 / GM of December 5, 2002

For the evaluation of the normality of the variables, the Kolmogorov-Smirnov test was applied. For the correlation of variables, the Pearson test was used for the parametric variables and the Spearman test for the non-parametric variables, being statistically significant $p \leq 0.05$. The results were calculated by means of objective or subjective overloads, to identify the items with the greatest overload.

RESULTS

In both hospitals, of 42 primary caregivers, the majority were female (78.57%), aged between 18 and 70 years, with a predominant age range of 51-60 years (30.95%). Regarding the marital status, in hospital 1, most caregivers were married (55.5%), and in hospital 2 the majority of caregivers were single (39.9%),

In relation to schooling, the majority had incomplete primary education (42.85%). In hospital 1, most caregivers were professionals (66.6%), whereas in the hospital 2 the majority were unemployed (45.4%). In hospital 1, the origin of patients with mental disorder came from several municipalities in the region, whereas in hospital 2, the majority came from the municipality where the hospital is located. The sociodemographic characteristics of the sample of relatives are shown in table 1. Table 2 shows the characteristics of living conditions of the family caregivers. Most of them reside with the individual care (78.57%), and the period spent on care was all day (61.90%). Mothers were identified as the main caregivers of the patients (42.85%), and most of them did not receive help from third parties (59.52%). The income of the interviewees was on average a salary and a half, and the variable does not present a statistically significant difference.

Table 1. Sociodemographic characteristics of family caregivers, in terms of frequency and percentage of the sample, Brazil, 2014

Variables		Hospital 1 N (%) n=9	Hospital 2 N (%) n=33	Total Sample n=42
Sex	Female	8 (88.88)	25 (75.75)	33 (78.57)
	Male	1 (11.11)	8 (24.24)	9 (21.42)
Age (years)	18 - 25	1 (11.11)	5 (15.15)	6 (14.28)
	26 - 30	1 (11.11)	2 (6.06)	3 (7.14)
	31 - 40	-	5 (15.15)	5 (11.90)
	41 - 50	3 (33.33)	8 (24.24)	11 (26.19)
	51 - 60	4 (44.44)	9 (27.27)	13 (30.95)
	61 - 70	-	4 (12.12)	4 (9.52)
Education	Incomplete Elementary School	3 (33.33)	15 (45.45)	18 (42.86)
	Complete Elementary School	-	3 (9.09)	3 (7.14)
	Complete Highschool	3 (33.33)	4 (12.12)	4 (9.52)
	Incomplete Highschool	-	8 (24.24)	11 (26.2)
	Incomplete Higher Education	1 (11.11)	2 (6.06)	3 (7.14)
	Complete Higher Education	2 (22.22)	1 (3.03)	3 (7.14)
Profession	Student	-	1 (3.03)	1 (2.38)
	Clerk	-	6 (18.18)	6 (14.28)
	Retired	1 (11.11)	2 (6.06)	3 (7.14)
	Liberal Professional	6 (66.66)	8 (24.24)	14 (33.33)
	Unemployed	1 (11.11)	15 (45.45)	16 (38.09)
Marital Status	Single	1 (11.11)	13 (39.39)	14 (33.33)
	Separated/Divorced	2 (22.22)	3 (9.09)	5 (11.92)
	Married	5 (55.55)	10 (30.30)	15 (35.71)
	Stable Union	1 (11.11)	5 (15.15)	6 (14.28)
	Widow	-	2 (6.06)	2 (4.76)

Table 2. Characteristics of living conditions of the family caregivers, in terms of frequency and percentage of the sample, Brazil, 2014

Variables		Hospital 1 N (%)	Hospital 2 N (%)	Total	p
Lives with the individual who required care	Yes	6 (66.66)	27 (81.81)	33 (78.57)	
	No	3 (33.33)	6 (18.18)	9 (21.42)	
Period spent in care	All day	4 (44.44)	22 (66.66)	26 (61.90)	
	Morning or afternoon	2 (22.22)	8 (24.24)	10 (23.80)	
	Night	3 (33.33)	3 (9.09)	6 (14.28)	
Relationship with the person who requires care	Spouse	-	6 (18.18)	6 (14.28)	
	Child	3 (33.33)	7 (21.21)	10 (23.80)	
	Father	-	2 (6.06)	2 (4.76)	
	Mother	5 (55.55)	13 (39.39)	18 (42.85)	
	Brother	1 (11.11)	2 (6.06)	3 (7.14)	
	Uncle	-	1 (3.03)	1 (2.38)	
	Cousin	-	1 (3.03)	1 (2.38)	
Help from third parties	No	5 (55.55)	20 (60.60)	25 (59.52)	
	Yes	4 (44.44)	13 (39.39)	17 (40.47)	
Income (average± SD) R\$		1.531.56±1.147.87	1.229.65±1.195.10	1.380.61±213.48	0.53
Time giving care (average± SD) months		43.11±38.51	26.39±55.27	34.75±11.82	0.13
Number of hours needed for care (average± SD) hours		15.11±7.90	14.79±8.70	14.95±0.23	0.91

*P < 0.05

Table 3. Mean and Standard Deviation of the responses of the familiar caregivers to the questions that evaluate the Objective Overload, Brazil, 2014

Subscales	Hospital 1 (Average±SD)	Hospital 2 (Average±SD)	Total (Average±SD)	p
A – Daily life care	3.37 ± 0.81	2.50 ± 0.96	2.94 ± 0.62	0.018*
B – Supervision of Problematic behaviours	2.56 ± 0.72	2.14 ± 0.79	2.35 ± 0.30	0.167
D – Impact of daily routines	3.75 ± 0.83	2.70 ± 1.21	3.23 ± 0.74	0.023*
Global Score	3.23 ± 0.61	2.45 ± 0.28	2.84 ± 0.55	

Table 4. Results of the responses of the family caregivers to the questions that evaluate the subjective overload, Brazil, 2014

Variables	Hospital 1 (Average±SD)	Hospital 2 (Average±SD)	Total (Average±SD)	p
A – Daily life care	2.48 ± 0.77	1.68 ± 0.74	2.08 ± 0.57	0.007*
B – Supervision of Problematic behaviours	3.35 ± 0.77	2.78 ± 1.06	3.07 ± 0.40	0.189
D – Permanent impact on the life of the caregiver (D2)	3.56 ± 0.69	3.17 ± 1.02	3.37 ± 0.28	0.15
E – Preoccupation with the patient	3.97 ± 0.47	3.45 ± 0.77	3.71 ± 0.37	0.062
GLOBAL SCORE	3.34 ± 0.63	2.77 ± 0.78	3.06 ± 0.40	

*p < 0.05

Table 5. Results of family caregiver responses to issues assessing financial expenses, Brazil, 2014

Variables	Hospital 1		Hospital 2		p
	N (%)	Average ±SD	N (%)	Average ±SD	
C1 – Personal expense to cover patient expenses.					
Yes	4(44.45)		13(43.34)		
No	5(55.55)		17(56.66)		
C2 – Gastos do paciente					
a. Transportation	4 (44.44)	125.00 ± 64.50	14 (42.42)	112.50 ± 98.11	0.815
b. Clothers/Shoes	3 (33.33)	154.00 ± 56.11	11 (33.33)	189.09 ± 84.08	0.514
c. Changes	6(66.66)	58.30 ± 20.41	15 (45.45)	47.00 ± 48.54	0.591
d. Food	8(88.88)	125.00 ± 53.45	26 (78.78)	403.85 ± 368.27	0.023*
e. Living	-	-	5 (15.15)	406.00 ± 266.61	-
f. Medication	5(55.55)	108.00 ± 13.04	7 (21.21)	130.57 ± 118.22	0.684
g. Health Treatment	3(33.33)	222.50 ± 74.25	5 (15.15)	130.08 ± 50.68	0.627
h. Cigarettes	4(44.44)	87.50 ± 47.87	9 (27.27)	172.22 ± 188.53	0.405
i. Personal Objects	-	-	8 (24.24)	33.63 ± 23.53	-
j. Telephone	6(66.66)	19.17 ± 7.47	16 (48.48)	127.06 ± 149.58	0.097
l. Health plan	1(11.11)	150.00 ± 0.00	2 (6.06)	71.00 ± 57.98	-
m. Others	1(11.11)	70.00 ± 0.00	7 (21.21)	187.14 ± 139.01	-
C2 – Total		464.11±350.36		787.84±475.63	0.067
C3 – contribution of the patient to the expenses	4(44.44)	525.00±718.22	20 (60.60)	493.15±377.66	0.51
C4 – Family expenses with the patient		513.89±458.73		490.65±611.63	0.60
C5 – Weight of the patient's expenses		1.78±0.97		2.41±1.64	0.38

*P < 0.05

The average time the patient cared for the patient was 34.75 months, being higher in the hospital 1 (43.11 months), but did not present statistically significant difference. The number of hours needed or spent for care was on average 14.95 hours, the variable does not present a statistically significant difference. Table 3 presents the descriptive results of the objective overload presented by the relatives. The results showed that the overall mean of the overall score was 2.84 ± 0.55 being higher in hospital 1 (3.23 ± 0.61). The mean scores obtained on the subscales vary between 2.14 and 3.75. The subscale that presented the highest mean score was the one that evaluates the impact on the daily routines (3.23 ± 0.74), being higher in hospital 1 (3.75 ± 0.83), the variable presents a statistically significant difference. These data indicate that there was this type of disturbance in the family's life on average one or two times a week. The subscale that presented the lowest mean score in both hospitals was the one that evaluated the supervision of problematic behaviors (2.35 ± 0.30), this difference being not statistically significant, indicating that there was a low frequency of supervision of problematic behaviors of patients, less than once a week, on average. Table 4 presents the description of the subjective overload of the family caregivers. The overall score was 3.06 ± 0.40 , being higher in hospital 1 (3.34 ± 0.63).

The mean score was between 1.68 and 3.97. The subscale that presented the highest mean score in both hospitals was the one that evaluated the family member's concerns with the patient (3.71 ± 0.37); this variable did not present a statistically significant difference, which was sometimes and frequently. The subscale with the lowest mean score in both hospitals is about care in daily life (2.08 ± 0.57), being higher in hospital 1 ($p = 0.007$), and showing that family members do not care about performing daily tasks to assist patients. The degree of discomfort felt by caregivers to provide assistance in everyday life is between little and very little. Table 5 represents the financial expenses of the caregiver with the patient. Most family members did not lend money to cover the patients' personal expenses. Regarding the patients' expenses, in the last 30 days, the mean value was R \$ 464.11 in hospital 1 and R \$ 787.84 in hospital 2, the variable did not present a statistically significant difference. Patients at hospital 1 contributed more with their expenditures (525.00 ± 718.22) than those at hospital 2 (493.15 ± 377.66), this difference being not statistically significant. The family's perception of financial weight in the last year indicates that most did not feel overwhelmed. This variable does not present a statistically significant difference between hospitals. It also shows that patient spending is between never and sometimes.

DISCUSSION

Regarding the characterization of the respondents, in both hospitals, it is evident that the great majority was female and the mothers as the main caregivers. The analysis was performed between two hospitals, but, without significant statistical difference in most of the analyzed variables; which shows that the presented reality has no influence of the type of institution analyzed and presents the general context of a population. The high prevalence of women as caregivers can be seen in other studies showing that they assume a greater burden of activities leading to greater overload (Barroso, Bandeira and Nascimento, 2007; Cosentino *et al.*, 2017). The results of this study also confirm this trend, since the majority of caregivers were women, mothers of people with mental disorders hospitalized.

Caregivers, for the most part, live with the patient, a situation evidenced in other studies (Barroso, Bandeira and Nascimento, 2007, Schein and Boeckel 2012). This factor may contribute to the overload of family members, since, there is an increase in care tasks that require care and attention. In addition, this study shows that 24 hours a day, most of their time, on average 15 hours, are expended for patient care. Some studies have described low schooling and the older age of caregivers (Bandeira and Barroso, 2005; Nolasco *et al.*, 2014; Cosentino *et al.*, 2017), which can also be seen in the research under analysis. These conditions may represent factors that contribute to the overload of the family group, especially, in situations of hospitalization of one of its members. Also, it can be observed that the highest percentage of caregivers was unemployed, which in many cases occurs due to the illness of a person in the family group and requires the removal of formal activities to exercise the role of caregiver, (Nolasco *et al.*, 2007).

In this research, a high subjective overload regarding patient concerns, permanent changes in the daily routine and supervising problematic behaviors was highlighted. Already, in relation to objective overload, the impact on daily routines and on the daily tasks of patient care are highlighted. These results may contribute to help health services adapt their care, providing support for the dimensions that generate greater burden to family members (Barroso, Bandeira and Nascimento, 2007). Subjective overload involves issues related to the provision of care, refers to the personal feelings experienced by the family members about the act of caring (Soares and Munardi, 2007). The subscale regarding patient concerns was the one that obtained the highest subjective overload, also confirmed in national studies (Barroso, Bandeira and Nascimento, 2007, Bandeira, Calzavara and Castro, 2008, Schein and Boeckel, 2012), in which it was observed that family members cared about the patients' future. It can be noticed that women caregivers do not always assume the subjective overload, because, in their view it is their responsibility to care, thus hindering the clear investigation of the overload. Objective overload refers to problems or difficulties faced by family members, caused by the behavior of the individual with mental disorder and the frequency of care provided (Soares and Munardi, 2007). In this study, a high objective overload was observed with regard to the impact on the social and professional life of the caregiver, a result confirmed in some studies (Schein and Boeckel, 2012; Souza Filho *et al.*, 2010), from the moment, in which family members take responsibility for care occur to changes in their

normal social activities. A study comparing the burden of caregivers in relation to gender identified that the objective burden was higher in the group of women caregivers, especially in relation to everyday assistance to the subject with a mental disorder and the impact on their social and professional life (Batista *et al.*, 2013). There was also a high subjective overload with regard to permanent changes in the daily routine, work and / or social life of the caregivers participating in the study. These findings were confirmed by the literature (Barroso, Bandeira and Nascimento, 2007; Souza Filho *et al.*, 2010), where it was found that leisure and social restrictions on caring for a person with mental disorder cause permanent changes and generate high overload.

The care in the daily life of the patient had a high score in the objective overload and the lowest score in the subjective overload of the research participants. Studies show that performing daily tasks of care raises objective overload (Batista *et al.*, 2013, Barroso, Bandeira and Nascimento, 2007, Schein and Boeckel, 2012), and the obligation to perform these tasks is an explanation for the low rate of subjective overload. Regarding the supervision of problematic behaviors, a higher subjective overload was observed, and, on the other hand, the lower objective overload score. The results showed a high degree of discomfort, even in the behaviors that occurred with low frequency (Barroso, Bandeira and Nascimento, 2007). These results corroborate previous studies that identify problematic behaviors as the main sources of subjective overload of caregivers of patients with mental disorders (Campos and Soares, 2005; Schein and Boeckel, 2012; Soares Neto, Teles and Rosa, 2010; Demarco *et al.* 2014). From these data, it can be observed that the subjective overload is characterized, mainly by the lack of information about mental disorders and how to deal with the user. In this sense, mental health services must develop interventions aimed at guiding families about how to deal with patients' problematic behaviors (Barroso, Bandeira and Nascimento, 2007). Regarding the financial aspects, it can be observed that the expenses with the patient did not represent weight in the budget of the caregiver. Even if, according to the sociodemographic questionnaire, the average income is a minimum and a half salary, most of the caregivers are unemployed and the expenses are high, a large portion of the patients help in some way with expenses. However, in many situations, they represent weight and may contribute to subjective overload (Scheme and Boeckel, 2012; Koga and Furegato, 2002; Borba *et al.*, 2002) Schwartz and Kantorski, 2008, Albuquerque, Cintra and Bandeira, 2010, Batista *et al.*, 2013, Barroso, Bandeira and Nascimento, 2007). Family overload can be generated by family unpreparedness, lack of support and knowledge in developing patient care, and, also, by the frustration of not producing physically and mentally healthy individuals (Barroso, Bandeira and Nascimento, 2007). Health service teams are poorly prepared to work with the family, focusing on care for the person with the disorder (Cavalheri, 2010). In this context, Nursing has the attributions and competencies to act with caregivers, it is essential to assess the level of overload of these people, which will enable the professional to identify more appropriate strategies of care.

FINAL CONSIDERATIONS

The main objective of this research was to describe and evaluate the overload of family caregivers of psychiatric patients in the hospital setting.

Data were obtained through the Overload Assessment Scale (FOAS-BR), and allowed to verify differences in objective and subjective overload. The results pointed to the need for more research, because if one realizes the lack of Brazilian studies that involve this subject, it is known that this shortage may be related to the lack of measurement instruments to assess the family surcharges that are validated for Brazil. The presence of both objective and subjective overload of the family caregivers points to an important aspect, the intervention with this family member, since it is necessary to offer information regarding the doubts and difficulties of coping, to help a better quality of life, to recognize the fundamental importance of their role, so that they feel valued, respected, have someone as a reference whenever they need protection. It is necessary to devise strategies to intervene with these families, considering the particularities of each one.

It was also evidenced that the female figure continues with the cultural inheritance of being responsible for the care of family members who become ill, and can produce overloads, since the woman historically develops more exhausting activities in the care; besides managing household chores. This shows the need for programs with the family caregiver, because these people can also develop psychiatric conditions. In addition, to the extent that you take care of the family, it will have greater support to care for the sick person.

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