

Evaluation of the Overload of Care in Families of Psychiatric Patients in Psychosocial Care Center

ORIGINAL

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Abstract

Introduction: The burden of care in family refers to the weight caused by the primary caregiver role to psychiatric patients and the difficulties encountered in performing this function in daily life.

Objectives: Assessing the objective and subjective overload of family members who live with the reality of psychiatric disorder in a child day-care psychosocial care center.

Methods: Cross-sectional study, descriptive-exploratory, of quantitative approach, with non-probabilistic samples of accidental type with 80 families of psychiatric patients held in a Psychosocial Care Center. For overload evaluation, the subscales "B" and "D" of the Family Overload Rating Scale (FBIS-BR) were used.

Results: The study was conducted with 80 families of psychiatric patients. The average age of female caregivers was 39.6 years old, and

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40.7 years old for male caregivers, with female predominance (87.5%) compared to men (12.5%), with low education for both genres. Family caregivers presented high objective burden due to excessive demand attention ($p < 0.001$), heteroaggressiveness ($p < 0.001$) and perplexing behavior of psychiatric patients regarding the supervision of problematic behaviors ($p < 0.001$). The items on the impact on the family's daily routine have not helped to generate objective overload for the family members. On subjective overload, it was clear to observe familiar members with high degree of disturbance in all the dimensions assessed ($p < 0.001$).

Conclusion: The high degree of care overload observed in family members indicates the need to develop contacts with the family of the psychiatric patient to answer questions, offer support and assistance to the family caregiver.

Keywords

Caregivers; Patients; Mental Health Services.

Introduction

Until the mid-twentieth century, psychiatry offered the people suffering from mental disorders inhuman and inefficient care, which caused more damage than healing to mental health. Admissions were held for long periods with treatment similar to torture methods. In this context, the psychiatric patients could spend the rest of their lives in treatment in mental institutions [1].

The mental health care in these asylums was focused on practice and medical knowledge, whose assistance was restricted to admission and medication to combat the symptoms evidenced by psychiatric patients, excluding them of the bond, interactions and all that configured it as part and product of their knowledge [2].

The reality of asylums lasted until the process of deinstitutionalization of mental health, which took place in Brazil through the Psychiatric Reform which was characterized as a historical movement of political, social and economic character, which involved since breaking the practiced model to the nursing

care excluding the model based on admission of psychiatric patients in mental hospitals [3].

In the current model of mental health assistance, the family is entered as partner in the psychosocial rehabilitation process of person with psychiatric disorder, and can contribute to the effectiveness and efficaciousness of substitute services as also responsible for the treatment [4].

The process of change in the manner of treating the psychiatric patient, keeping the person with disorder within the family, is accompanied by the emergence of family burden factors, as we note that the family would not be prepared to accept mental disorders affected people [5]. Overloading of the family is defined as the feeling of weight caused by the constant provision of care to psychiatric patients and the difficulties encountered in the role of caregiver's performance in everyday [6].

Family members of mentally ill need care or assistance in relation to their own health and that of their hospitalized family member. This fact causes concern to the extent that the health system in

integrated network serves patients suffering from diseases or psychiatric problems, but for the most part, forget the people who are secondarily affected by these diseases.

Assistance is usually focused on the user, leaving the family on the margins of assistance, and they have to administer the various adversities related to assistance to psychiatric patients by themselves. In this reality, family members are exposed to the emergence of overload directly linked to the care provided.

The overload problem arises in the family while the role of primary caregiver to psychiatric patient is delegated to a family member, and this family caregiver feels so lost and helpless, making it susceptible to the development of distress feelings and suffering. These factors result in impacts in their lives directly related to psychiatric disorder, especially for times of crisis, illness reflections in the family group and living with the psychiatric family member, which is marked by a sense of insecurity and discomfort on the unpredictability of their actions [5].

Thus, this study aimed to evaluate the objective and subjective burden of family members who live with the reality of psychiatric disorder in a children's psychosocial care center. And, secondarily, to investigate the changes in the daily lives of the families of psychiatric patients, as well as understanding the burden of the family in the supervision of the psychiatric patients' behavior and analyze the use of the "B" and "D" subscales of FBIS-BR which can help evaluating the burden on the family member of the psychiatric patients.

Methods

A cross-sectional, descriptive and exploratory study was held with a quantitative approach, with families of psychiatric patients users of a Children's Psychosocial Care Center (CPSI) located in the city of Caxias, in the Mesoregion of East Maranhão, between July and August 2016.

The study included relatives of psychiatric patients considered primary caregivers and excluded from the sample subjects without family ties with the psychiatric patient or who were not legitimate officials of psychiatric patient, did not share the same residence, did not give daily assistance to the psychiatric patient and/or lived daily with him/her.

The family care overload was assessed using a standardized interview, being applied the (B) and (D) subscales of the Assessment Range of Family Members Overload (FBIS-BR) by treating supervision to problematic behaviors of psychiatric patients by family members and the impact on the daily routines of the family caused by the psychiatric disorder, respectively.

FBIS-BR assesses the objective and subjective burden of family in 52 items distributed in five subscales: assistance in everyday life; supervision to problematic behaviors; spending; impact on daily routines; concern for the patient. The objective burden is assessed at 5 points (1 = never to 5 = every day), the subjective burden assesses four-point scale (1 = not at all to 4 = a lot) and five-point scale (1 = never to 5 = always or almost always) [7].

The study was approved by the Research Ethics Committee of the Faculty of Sciences and Technology of Maranhão (FACEMA) under the CAAE n.: 57178415.1.0000.8007 and opinion n. 1.623.538. Survey respondents signed an Informed Consent (TFCC), according to Resolution No. 466 of 2012 of the National Commission of Ethics in Research (CONEP). The questionnaires were individually and privately applied to participants, and the purpose of the implementation of instruments and the destination of the data were clarified, making it clear to express any questions they could have during the interview.

Data were compiled and analyzed by means of the Statistical Package for the Social Sciences (SPSS) program, version 20.0. To characterize the overload, we used the percentage (frequency) of responses to the items of the B and D subscales of the FBIS-BR

and the variance of points, using the non-parametric test of Wilcoxon to identify items that led to greater burden on relatives. The items 'consumption of licit and illicit drugs (too much drink and drugs)' are not considered for the evaluation of subjective burden.

Results

Characterization of family caregivers

80 caregivers, being 87.5% female and 12.5% male, were sampled. Regarding their age, there was a higher prevalence of women between 30 and 39 years old (average of 39.6 years old) and higher prevalence of men among age groups from 30 to 39 years old, followed by 40 to 49 years old (average 40.7 years old) (**Table 1**).

The education of family caregivers is low, 25% literate; 23% illiterate; 16.3% with incomplete primary education; 17.5% completed elementary education; 5% had completed high school and 1.3% had incomplete higher education (**Table 1**). Regarding the degree of kinship caregiver, mothers of psychiatric patient stands out with 78.8%, followed by grandmothers with 11.3%, fathers with 8.8% father and brother/sister index of 1.3% (**Table 1**).

Distribution of Care Overload

Family caregivers have a high objective global burden with an average score of 2.77 (Standard Deviation: 1.61) and high subjective global burden with an average score of 2.85 (Standard Deviation: 1.10).

Objective overload

Table 2 shows the description of the objective burden of family members, evaluated by the percentage of responses 1 (no overload); 2 and 3 (moderate overload), 4 and 5 (high overload) of "B" and "D" subscales of FBIS-BR, and ranked by the average points earned. In supervising the problematic behaviors (B subscale), most families carry out supervision

Table 1. Distribution of family caregivers survey participants by age and gender, educational level and degree of kinship. Caxias, MA, Brazil. 2016.

Variables	N	%
Age		
20-29 years old	9	11.25
30-39 years old	39	48.75
40-49 years old	18	22.5
50-59 years old	13	16.25
60-69 years old	1	1.25
Maximum Age		
60 years old		
Minimum Age		
26 years old		
Gender		
Feminine	70	87.5
Masculine	10	12.5
Education		
Illiterate	19	23.8
Literate	20	25.0
Incomplete Elementary School	13	16.3
Complete Elementary School	14	17.5
Incomplete High School	9	11.3
Complete High School	4	5.0
Incomplete Higher Education	1	1.3
Complete Higher Education	-	-
Degree of Kinship		
Mother	63	78.8
Father	7	8.8
Grandmother (Grandfather)	9	11.3
Sister (brother)	1	1.3

Source: Direct Search, 2016

of patients from three times a week and every day, indicating the presence of high objective overload for caregivers in this dimension. As for the impact on daily routines (D subscale), no significance levels were found in the Wilcoxon test.

By analyzing specifically the supervision to the problematic behaviors (B subscale), some significantly high actions were observed. Excessive demand of

Table 2. Percentages of responses of family members to questions relating to objective overload in the B and D subscale, as items in the FBIS-BR. Caxiasm MA, Brazil. 2016.

Subscales Items	Answers %					Points Average	P **
	1*	2*	3*	4*	5*		
B: Supervision to the problematic behaviors							
Confusing behavior	17.5	13.8	21.3	25.0	22.5	3.21	<0.001
Excessive demand of attention	15.0	15.0	8.8	15.0	46.3	3.63	<0.001
Nocturnal disturbances	62.5	5.0	3.8	8.8	20.0	2.18	0.32
Heteroaggressiveness	28.7	8.8	7.5	18.8	36.3	3.25	<0.001
Self-harm	32.5	17.5	16.3	16.3	17.5	2.69	0.32
Drinking too much	-	-	-	-	-	-	-
Excessive consumption of food and non-alcoholic beverages or smoke	33.8	8.8	17.5	11.3	28.7	2.92	0.02
Use Drugs	-	-	-	-	-	-	-
D: Impact on caregiver's daily routine							
Tardiness or absences the commitments	42.5	12.5	15.0	16.3	13.8	2.46	0.77
Changes in social and leisure activities	45.0	25.0	7.5	10.0	12.5	2.20	0.51
Changes in the services or home routines	36.3	17.5	6.3	23.8	16.3	2.66	0.28
Changes in attention to other family members	51.2	3.8	11.3	18.8	15.0	2.43	0.76

*: 1 = Never; 2 = Less than once per week; 3 = 1 or 2 times per week; 4 = 3 to 4 times per week e 5 = every day.
**: "One-Sample Wilcoxon Signed Rank Test".
Source: Direct Search, 2016.

attention had an average score of 3.63 points which caused most objective burden to family members ($p < 0.001$); followed by heteroaggressiveness (average: 3.25) and confusing behaviors (average: 3.21) who also contributed to the high objective overload ($p < 0.001$). Excessive consumption of food and non-alcoholic beverages or smoke (average: 2.92) contributed less to the objective overload compared to the previous ($p = 0.02$). Nocturnal disturbances (average: 2.18) and self-harm (average: 2.69) showed no significance level (**Table 2**).

Considering the impact on the daily life of the caregiver (D subscale), none of the items evaluated were significant to generate objective overload in family caregivers (**Table 2**).

Subjective Overload

Table 3 shows a description of the high subjective burden of family members, indicated by 3 and

4 responses related to supervision of problematic behaviors (B subscale) and the impact on the daily routine of the caregiver (D subscale).

In the B subscale of FBIS-BR, items that contributed most to the increase in subjective burden on family caregivers were: Heteroaggressiveness (average: 3.25), followed by self-harm (average: 3.06), nocturnal disorders (average: 3.00), shameful /perplexing behavior of patients (average: 2.80), excessive demand of attention (average: 2.56) and excessive consumption of food, non-alcoholic beverages or smoke (average: 2.50), all were considered significant for generating subjective overload in family caregivers ($p < 0.001$), (**Table 3**).

Results showed that 65% of family members reported permanent impacts in their lives for being caregivers (item D2), which generated high subjective overload. As for the types of existing impacts, when becoming caregivers, it was shown that 70%

Table 3. Percentages of responses of family members to questions relating to subjective overload in the B and D subscale, as items in the FBIS-BR. Caxias, MA, Brazil. 2016.

Subscales Items	Answers %				Points Average	P **
	1*	2*	3*	4*		
B: Supervision to the problematic behaviors						
Confusing behavior	19.7	15.2	30.3	34.8	2.80	<0.001
Excessive demand of attention	23.5	22.1	29.4	25.0	2.56	<0.001
Nocturnal disturbances	10	20	30	40	3.00	<0.001
Heteroaggressiveness	10.5	10.5	22.8	56.1	3.25	<0.001
Self-harm	7.4	27.8	16.7	48.1	3.06	<0.001
Drinking too much	-	-	-	-	-	-
Excessive consumption of food and non-alcoholic beverages or smoke	18.9	28.3	22.3	30.2	2.50	<0.001
Use of Drugs	-	-	-	-	-	-
D: Impact on caregiver's daily routine***						
Permanent changes in the daily routine, work or social life.	1.3	10.0	23.8	65.0	3.53	<0.001
	Yes		No			
Work less or quit the job, or is working more	60		40		-	<0.001
Retired early	21.3		78.8		-	<0.001
Has less (or no) social life	70		30		-	<0.001
Lost friendships	33.8		66.3		-	<0.001
Did not take more vacation	50		50		-	<0.001
No longer receiving people at home (or less)	17.5		82.5		-	<0.001
*: 1 = not a little; 2 = very little; 3 = a little bit and 4 = a lot. ** "One-Sample Wilcoxon Signed Rank Test". ***: The question, which evaluates the permanent changes in family life, does not enter the calculation of the scores of this subscale, since all the scores that are included in overload calculations involve issues that refer only to the last 30 days. Source: Direct Search, 2016.						

of family members have left or reduced their social life; 60% decreased their working hours or left their jobs; 50% did not have or did not take a vacation; 39.3% reported losing friends; about 21.3% have retired to take care of the patient and 17.7% reduced the number of visits at home or did not receive them (Table 3).

Association between the Degree of Overload and Social-demographic Characteristics of the Subjects

As for the socio-demographic characteristics of the family and the items of the "B" subscale for the objective burden, it showed a strong positive and negative correlation for most items of the

subscale in relation to the degree of kinship, the family age and degree of instruction. Correlation between the variable gender and degree of objective overload of B subscale items was not observed (Table 4).

As for the objective burden of "D" subscale, it was obtained positive and negative correlation regarding the overload level with the age, level of education and kinship variables. There was no correlation between the variables gender to increase the objective burden in D subscale (Table 4).

When there was subjective overload on supervision of problematic behaviors (B Subscale), there were positive and negative interaction of the variables of age, level of education and degree

Table 4. Correlation of items of the objective burden of B and D subscales, with these variables: age, gender, level of education and degree of kinship. Caxias, MA, Brazil. 2016.

Subscales Items	Age (years)		Gender		Level of Education		Degree of kinship	
	C.C.#	P***	C.C.#	P***	C.C.#	P***	C.C.#	P***
Subscale B								
Confusing behavior	-0.18	0.06	-0.04	0.35	0.245*	0.01	-0.250*	0.01
Excessive demand of attention	-0.18	0.05	-0.03	0.38	0.229*	0.02	-0.216*	0.03
Nocturnal disturbances	-0.209*	0.03	-0.05	0.31	0.196*	0.04	-0.180	0.06
Heteroaggressiveness	-0.246*	0.01	-0.08	0.24	0.263**	<0.01	-0.261**	<0.01
Self-harm	-0.236*	0.02	-0.07	0.26	0.231*	0.02	-0.282**	<0.01
Excessive consumption of food and non-alcoholic beverages or smoke	-0.250*	0.01	-0.07	0.26	0.233*	0.02	-0.280**	<0.01
Tardiness or absences the commitments	-0.217*	0.03	-0.05	0.34	0.233*	0.02	-0.244*	0.01
Subscale D								
Changes in social and leisure activities	-0.197*	0.04	-0.09	0.22	0.258*	0.01	-0.278**	<0.01
Changes in the services or home routines	-0.234*	0.02	-0.03	0.38	0.241*	0.02	-0.231*	0.02
Changes in attention to other family members	-0.222*	0.02	-0.06	0.31	0.200*	0.04	-0.209*	0.03
*:(<0.05). ** (<0.01). ***: Spearman's Correlation. #C.C.: Correlation Coefficient. Source: Direct Search, 2016.								

Table 5 Correlation of items of the subjective burden of "supervision to problematic behaviors" (B subscale), with these variables: age, gender, level of education and degree of kinship. Caxias, MA, Brazil. 2016.

Subscale B	Age (years)		Gender		Level of Education		Degree of kinship	
	C.C.#	P***	C.C.#	P***	C.C.#	P***	C.C.#	P***
Confusing behavior	-0.212*	0.04	-0.05	0.34	0.207*	<0.05	-0.211*	0.04
Excessive demand of attention	-0.209*	0.04	-0.03	0.42	0.211*	0.04	-0.16	0.09
Nocturnal disturbances	0.420*	0.01	0.21	0.13	-0.06	0.38	0.09	0.33
Heteroaggressiveness	-0.05	0.35	0.00	0.49	0.19	0.08	-0.17	0.10
Self-harm	-0.05	0.37	0.06	0.32	0.275*	0.02	-0.17	0.11
Drinking too much	-0.03	0.43	-0.01	0.47	0.266*	0.03	-0.17	0.12
*:(<0.05). ** (<0.01). ***: Spearman's Correlation. #: C.C.: Correlation Coefficient. Source: Direct Search, 2016.								

of relatedness with respect to confusing behavior. Excessive demand of attention correlated positively with age and negatively with the familiar members' level of education. The nightly disturbances obtained positive correlation with the age of the familiar caregiver. The items of self-harm and drinking too much were positively correlated with the level of education. There was no correlation bet-

ween the genres of the subjects of the research with the items analyzed in B subjective subscale (Table 5).

Discussion

The socio-demographic profile of the participants of this study confirmed results of previous studies

[8, 9], and the study sample consisted of subjects with low education and aged between 30 and 60 years old. The primary family caregiver role reflected significantly in females, especially in mothers and grandmothers. This result corroborates the literature, which indicates women as the primary caregivers of patients [10].

Women's role as primary family caregiver has historical and cultural aspects that relate the caring to the female person, highlighting the mother as an icon of care. The woman in addition to internalize the function of mother as for the physiological, psychological and social aspects, suffers social pressures to assume the role of caregiver, even at the cost of compromising her individuality. Mothers, in particular, assume the function without much choice, assuming the role of caregiver and responsible for the children and close relatives [11].

There was no correlation between the degree of objective and/or subjective overload by familiar in relation to gender, for all items matching the B and D subscales. The data corroborate the studies where women caregivers, compared to men, possessed a high degree of overload. This is due to the already set role of women in society, still with patriarchal traits, such as main caregiver in the family context [6]. This precept justified the largest amount of women as household caregivers of relatives and, consequently, the one who presents a higher level of overload.

Cultural reasons delegate the role of caregiver to the female gender, being a wife, mother or grandmother. In this study, the results reaffirm the literature and reflects the tradition of caring for the woman being responsible for sick family members [4], where the task of caring sum other numerous tasks such as the care of grandchildren, work, other relatives diseased, in addition to the cleaning and organizing the home [8].

In the study, education is a determining factor of the increased burden for the family caregiver. It is noteworthy that caregivers with higher levels of

education have a higher burden of care. Corroborating studies that have realized that low educational level affects the degree of objective and subjective burden on family members [10].

The relationship with previous studies on the overload and low education of the caregiver is due to the difficulty in assimilating information and knowledge about the disease, which could help in the care. It can be assumed that less educated individuals often face problems of low income, which increases the daily concerns and affects directly on overload [9].

In this study, we assume that more educated families showed higher overload degree because of the needs and the desires and expectations of professional development/education of family members, which could not be held at the expense of being the main caregivers.

The data from this study showed the correlation between the degrees of overload felt in relation to the increased age of the family members. An international study [12] conducted with 40 primary caregivers showed that the absolute majority were mothers, older women and without entering the job market. The study also showed that as they get old, the ability of caregivers to effectively help psychiatric patients is limited, but concerns and demands to them (care overload) never decreases.

It was found the presence of overload at 100% of family caregivers in this study. With use of FBIS-BR, the absence of overload would be seen only in the situation where subjects responded with the "1" option (no time/not at all/never) in all matters of the B and D subscales, both the objective and the subjective overload, which did not occur to any familiar interviewed.

The global objective and subjective overload in the relatives of psychiatric patients in this study achieved average of 2.77 and 2.85 points, respectively, and such values confirm results of studies on the topic where the total overload ranged from 2.5 to 3.03 points in terms of average [9, 5].

Considering the objective burden of family caregivers, constant supervision of problem behaviors of patients was observed, resulting in high overload. In Brazil, this aspect had already been pointed out by other studies on the subject [13, 14]. The results of this study also showed the influence of occurrence (in terms of quantity) of the problematic behaviors of patients in the relatives' overload degree, confirming data from other national studies [8, 15].

The items of nocturnal disorders and self-aggression of the "B" subscale did not provide for the increase of the objective burden. This is due to low representativeness or the constant use of medication to aid sleep and repulse of patients.

Items related to licit and illicit drugs ("drinking too much" and "using drugs") did not receive statistical analysis, since it cannot be a matter that, according to criteria of the FBIS-BR, the subject of study answers only "1" (no time). In this situation, the individual may feel uncomfortable with a situation that he does not perform; so, the corresponding subjective question on FIBS-BR is not answered [13].

Regarding the changes in daily life by being a caregiver (D subscale), the results indicated that none of the evaluated items helped generating objective burden on the family members. Other authors, in a study held with 150 families of psychiatric patients in Belo Horizonte, MG, Brazil, also showed low contribution of the "D" subscale for the elevation of objective overload of the familiar [7].

The low representation of "D" subscale may be related to that influenced by the embarrassment and shame felt by the subjects studied, during the interview. They do not feel at ease while the interviewer questioned about the impacts on the daily routines because of the presence of the psychiatric patient in the home.

Lack of representativeness in size impact on the daily life of the caregiver (D subscale) does not justify the absence of overload, because the percentages of "less than once a week," "once or twice a week," "three to four times a week" and "every

day" answers show well represented by percentages. The hypothesis that there is no degree of overload in the family members would only be accepted if the families respond to "1" (no time/not at all/never) in all matters of "D" subscale [7].

In the study there was a high degree of discomfort in family members, in all the evaluated subjective dimensions (B subscale), even with low frequency [6]. The results corroborate previous studies, which identify the degree of nuisance (subjective) of the familiar to assist the psychiatric patient, which becomes the main source of overload of these caregivers [8, 14].

As for permanent changes in family life (D2 and D3 items of D subscale), it was obtained high number of family members who refer radical changes in daily routine, work or social life (65%), and although these items cannot be added to overload evaluation purposes, there is a marked nuisance of family members. In this study, it is clear that permanent changes in family life occurred mainly in relation to the daily routine, work, social life, holidays, leisure and early retirement. Similar data were reported with ten mentally ill family members in CAPS II in the city of Curitiba, PR, Brazil [16].

The highest degree of subjective overload of family members is related to the severity of the patient's symptoms, the aversive behaviors or the problems of the patients (mood swings, lack of motivation, insulation), the everyday tasks of monitoring their behavior, the limitation of the activities and the freedom of the family in the light of the liabilities with the patient [5].

The existence of physical exhaustion, the need for continuous and uninterrupted attention to the patient generate, in the family context, various feelings, including fear on attitudes of the individual, especially when he/she becomes aggressive, because, in these cases, his/her actions are unpredictable [17].

Conclusion

The high overload of care in families of psychiatric patients, as regards the supervision of problematic behavior of the patient, is due to the changes in the family routine that promote permanent changes in family's life in relation to the exercise of the caregiver role.

There is the need that healthcare services promote actions that help family caregivers, providing more guidance to families on how to deal with problems of patients and report the presence of change in behaviors such as agitation, self and hetero aggression, night disturbance, requiring patient reevaluation in various dimensions, as changes in medication and supporting treatments aimed at reducing the family burden.

The limitations in the study is due to a non-probabilistic sample of accidental type, which may have affected the results for the target population. It indicates new studies for the evaluation of family overload at different stages of treatment of the patient and health institutions through scales that investigate the severity of disorders and their relation to the burden of family caregivers.

The evaluation of psychiatric patients' caregiver burden appears to be necessary for enabling the family orientation in order to understand the pathology, the trials and mishaps present in patient-caregiver relationships. It is therefore important to know the caregiver's workload, the need for their inclusion in health care, and the importance of nurses for the effective inclusion of psychiatric patients within the family and in society.

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