

A família não é de ferro: ela cuida de pessoas com transtorno mental

Family needs a break: it takes care of people with mental disorder

Familia no es de hierro: ella se encarga de las personas con trastorno mental

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ABSTRACT

Objective: To analyze the workload of family caregivers members of people with mental disorders assisted by a Psychosocial Care Center in Northern Ceara. **Method:** The sample consisted of 120 family members, using the Scale for Evaluation of Family Workload for data collection. **Results:** The majority of caregiver members were female, mother, and married, aged over 40 years, primary education not completed and was unemployed or housewife. The assistance to users in their everyday life was the domain that contributed most to the objective workload of these caregivers, while concerns about the patient, financial expenses and supervision of confusing behavior constituted the most subjective workload. **Conclusion:** The family became a partner in treatment and it needs special attention from professionals and health management aiming the physical privation and mental illness.

Descriptors: Mental health, Mental disorders, Caregivers.

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RESUMO

Objetivo: Analisar a sobrecarga de cuidadores familiares de pessoas com transtorno mental assistidas por um Centro de Atenção Psicossocial no Norte do Ceará. **Método:** A amostra se constituiu por 120 familiares, utilizando-se a Escala de Avaliação da Sobrecarga dos Familiares para coleta de dados. **Resultados:** O perfil dos cuidadores caracterizou-se pelo gênero feminino, mãe, casada, com faixa etária entre 51 a 60 anos, ensino fundamental incompleto e encontrava-se desempregada ou do lar. A assistência prestada aos usuários em sua vida cotidiana foi o domínio que mais contribuiu para a sobrecarga objetiva destes cuidadores, enquanto preocupações com o paciente, peso dos gastos financeiros e supervisão dos comportamentos desconcertantes se constituíram os de maior sobrecarga subjetiva. **Conclusão:** A família se tornou parceira no tratamento e necessita uma atenção especial dos profissionais e gestão da saúde que vise prevenir o seu adoecimento físico e mental.

Descritores: Saúde mental, Transtornos mentais, Cuidadores.

RESUMEN

Objetivo: Analizar la sobrecarga de los cuidadores familiares de personas con trastornos mentales con la asistencia de un Centro de Atención Psicossocial en el norte de Ceará. **Método:** La muestra estuvo conformada por 120 familiares, utilizando la Escala de Evaluación de Sobrecarga de los Familiares para la recolección de datos. **Resultados:** La mayoría de los cuidadores son mujeres, madres, casadas, mayores de 40 años, educación primaria incompleta y estaba en paro o en el hogar. Asistencia a los usuarios en su vida cotidiana era el dominio que más contribuyó a la carga objetiva de estos cuidadores, mientras que las preocupaciones sobre el paciente, el peso de los gastos financieros y la supervisión de la conducta confusa constituían la carga más subjetiva. **Conclusión:** La familia se convirtió en un socio en el tratamiento y las necesidades de los profesionales y la gestión sanitaria especial atención dirigidas a prevenir enfermedades físicas y mentales.

Descritores: Salud mental, Trastornos mentales, Cuidadores.

INTRODUCTION

For many years, prolonged hospitalization was the only alternative offered by psychiatry and society for people with mental disorders. However, the recognition of iatrogenic effects and the development of psychopharmacology, psychotherapy and social treatments collaborated intensely for deinstitutionalization and the emergence of community care approaches in health mental.¹⁻²

In view of the reformulation of psychiatric care, the family unit plays an important role in the care and rehabilitation of people with mental disorders,³ because they need care due to impairment of organic conditions of psychological, mental or cognitive order.

In this context, the new form of care in mental health ends up generating overload, causing the family to put their needs and background interests in second place, causing a decrease in leisure time, the loss of social ties and causing them to absorb the suffering entering, thus in a social process of deterioration.⁴

As we understand the importance of family in the rehabilitation job, the limitations recognized by family members in the process of care at home and the difficulty of

understanding the behavioral changes affected by the disease were verified.⁵

It rests to Psychosocial Care Centers (CAPS) to support family members to maintain and strengthen those ties,⁶ demonstrating the relevance of the presence of family members in the service, informing them that they are partners and co-responsible for user treatment. It is from the bond and mutual accountability that they intend to achieve adherence to treatment.⁷

Some scholars have called attention to the impact of deinstitutionalization in families. The way they are organized, the strategies used in the care as well as weaknesses and potentials, require a broader view of mental health services and workers to form ideas about the needs facing the overload of daily life.⁸

In light of this, by the diversified approach that sets the overload, studies Maurin and Boyd⁹ differed in two dimensions, an objective overload and other subjective. The objective aspect of overload refers to the observable negative consequences generated by the caregiver role, such as changes in routine, decrease of social and professional life of the caregivers, financial losses, the performance of tasks and supervision of problematic behaviors. The subjective overload refers to the perceptions, concerns, negative feelings and discomfort generated by the care.

Therefore, health professionals must recognize the physical, economic and emotional aspects of the overload care to help the family in the interaction and the management of everyday life of people with mental disorders in order to alleviate the burden of costs, facilitate the process of building cooperation, reduce stress factors, stimulate the development of participative opportunities and improve the quality of life of all people involved.¹⁰

This study demonstrated that the main signs of overload care involve fatigue, body aches, insomnia, anxiety and depression, and most caregivers have more than one of these signs. The study also argues that this overload is related to the involvement in daily tasks and daily problems faced in performing care.¹¹

Given this context, it is relevant to ask: to what extent the family members of people with mental disorders are experiencing an overload related to home care?

It is known that identifying the determinants of overload becomes fundamental to health professionals and researchers in for a more assertive pursuit of appropriate forms of attention to family.⁵

Thus, the objective of this research is to analyze the overload, objective and subjective ones, of family caregivers of people with mental disorders, assisted by a General CAPS.

METHOD

This article was an excerpt of a project funded by Cearense Foundation of Support for Scientific and Technological Development, which analyzes overload of family caregivers of people with mental disorders assisted in the network care to mental health in the city of Sobral - Ceará.

The study included 120 family caregivers of people with mental disorders attended by CAPS General II Damião Ximenes Lopes, located in the municipality. As inclusion criteria, these families should be identified by the service as the main caregivers, ie those who experienced the daily care of the patient. These families were approached randomly in CAPS, when waiting for service. It attempted to clarify the families about the social and academic importance of the study, requesting voluntary participation from the informed consent, in accordance with Resolution 466/2012 of the National Health Council, which regulates the conduct of research involving beings humans.

The data collection was conducted from July 2013 to January 2014 and it was used as an instrument a sociodemographic questionnaire with questions related to the context of mental patients (gender, age and clinical diagnosis), the socio-demographic context of caregiver (gender, age, marital status, occupation and education) and the situational context (kinship). Consecutively, it was applied to the Family Overload Rating Scale (FBIS-BR).

Tessler and Gamache initially developed this scale, and it was adapted and validated to Brazil by Flag, Calzavara and Varela¹². The FBIS-BR scale assesses both the objective and subjective overload care of family members. The domains related to objective overload include the frequency of assistance and supervision of the family member in everyday patient care and the frequency of changes in the routine of his life; and the subjective overload, the evaluated areas refer to the degree of discomfort felt by the family member when perform the role of caregiver and their concerns with the patient.

It is highlighted that, for the correct application of the scale and the greater reliability of the information, the researchers were trained to approach and interview individuals.

The data were organized and processed by Excel 2010 software for statistical analysis. It is noteworthy that the study was submitted to the Ethics Committee of the State University of Vale do Acaraú (UVA), opinion n° 19765.

RESULTS PRESENTATION

Most users were male (55.8%) with average age of 32.3 years. The ICD 10 diagnostics most prevalent were mood disorders and affective (34.2%), followed by schizophrenic disorders, schizotypal and delusional (32.5%).

The sociodemographic characteristics of the caregivers are presented in Table 1. The profile was characterized by females (87.5%), mother (55%), married (48.3%) and aged between 51-60 years (27,5%). Regarding education, it was

identified more often caregivers with incomplete primary education (45%) and unemployed or housewives (58.3%).

Table 1 - Profile of user caregivers assisted by CAPS General. Sobral, Ceará, 2014

Characteristics	N	%
Gender		
Male	15	12.5
Female	105	87.5
Age		
18-20	5	4.2
21-30	13	10.8
31-40	22	18.3
41-50	24	20.0
51-60	33	27.5
61-70	21	17.5
70 a +	2	1.7
Kinship		
Mother	66	55.0
Father	2	1.7
Brother		
Sister	15	12.5
Spouse	15	12.5
Son	2	1.7
Daughter	12	10.0
Grandmother	2	1.7
Other	6	5.0
Estado civil		
Single	24	20.0
Married	58	48.3
Stable Union	17	14.2
Divorced	9	7.5
Widow	12	10.0
Education		
Illiterate	15	12.5
Incomplete primary education	54	45.0
Complete primary education	10	8.3
Incomplete High School	8	6.7
Complete High School	26	21.7
Incomplete higher education	4	3.3
Complete higher education	2	1.7
Profession		
Unemployed/household	70	58.3
Employee with/without formal contract	21	17.5
Retired	11	9.2
Self employed	13	10.8
Student	3	2,5
Others	2	1,7

Objective overload

Regarding the presentation of the objective overload, the data answers 1 and 2 represent low overload and 4 and 5 represent high overload (Table 2). In this context, it was noticed that among the objectives domains FBIS-BR scale, items relating to assistance in daily life (subscale A) were those who contributed to the high overload care of the caregivers, claiming that they help in the daily care of your family member with mental disorder between three times per week every day. The items that stood out in this area were meal preparation, medication administration and performing household chores. Remember or lead to medical appointments and activities in mental health services, transportation and money management were the least overload care generated.

Regarding the supervision domains of problematic behaviors (subscale B) and impact on daily routines (subscale D) none of the evaluated items helped generate more objective overload on caregivers.

Table 2 - Percentages of responses to each item of FBIS-BR scale indicating objective overload. Sobral, Ceará, 2014

Subscales	Items of objective scale	Answers 1 e 2	Answers 4 e 5
Subscale A	Assistance in everyday life		
	Hygiene and personal care	37.5%	53.3%
	Medication administration	22.5%	74.2%
	Performing house chores	23.3%	70.8%
	Go shopping	34.2%	48.3%
	Meal preparation	14.2%	81.7%
	Transportation	58.3%	15.8%
	Money Management	50.8%	46.7%
	Time Management	36.7%	48.3%
	Medical appointments and activities in mental health services	71.7%	6.7%
Subscale B	Problematic Behavior Supervision		
	Confusing behavior	51.7%	33.3%
	Ask for excessive attention	47.5%	36.7%
	Nocturnal disturbances	60.8%	26.7%
	Heteroagression	70.0%	21.7%
	Attempt or suicide threat	81.7%	11.7%
	Excessive consumption of alcohol	96.7%	1.7%
	Excessive consumption of food, non-alcoholic beverages or smoke	59.2%	35.0%
	Use of illegal drugs	97.5%	1.7%

(To be continued)

(Continuation)

Subscales	Items of objective scale	Answers 1 e 2	Answers 4 e 5
Subscale D	Impact on daily routines		
	Delays or absences in appointments	75.0%	10.8%
	Changes in social and leisure activities	65.8%	20.8%
	Changes in chores and home routines	59.2%	30.0%
	Changes in the care of other family members	56.7%	35.8%

Table legend: 1 = never once, 2 = less than one per week, 4 = three to six times per week e 5 = every day.

Subjective overload

Table 3 shows the subjective overload. The results showed that the financial burden domains (subscale C) and the concern for the patient (subscale E) led to greater overload than assistance in everyday life (subscale A) and supervision of problematic behaviors (subscale B).

Presenting the items of subscale B, there is the fact of dealing with perplexing behavior, which is the largest in overload.

All items of the subscale E led to high overload. Security and physical health concerns, financial survival and future with the family member with were the items that most contributed to this finding.

Table 3 - Percentages of responses to each item of FBIS-BR scale indicating subjective overload care. Sobral, Ceará, 2014

Subscales	Items of subjective scale	Answers 1 e 2*	Answers 3 e 4	Answers 4 e 5
Subscale A	Assistance in daily life			
	Hygiene and personal care	68.3%	31.7%	
	Medication administration	78.3%	21.7%	
	Performing house chores	75.8%	24.2%	
	Go shopping	85.8%	14.2%	
	Meal preparation	90.8%	9.2%	
	Transportation	81.7%	18.3%	
	Money Managment	94.2%	5.8%	
	Time Managment	79.2%	20.8%	
	Medical appointments and activities in mental health services	85.0%	15.0%	
Subscale B	Problematic Behavior Supervision			
	Confusing behavior	49.2%	50.8%	
	Ask for excessive attention	65.8%	34.2%	
	Nocturnal disturbances	60.8%	39.2%	
	Heteroagression	69.2%	30.8%	
	Attempt or suicide threat	67.5%	32.5%	
	Excessive consumption of alcohol	94.2%	5.8%	
	Excessive consumption of food, non-alcoholic beverages or smoke	70.0%	30.0%	
	Use of illegal drugs	96.7%	3.3%	
Subscale C	Financial Burden			
	Weight of expenses with patient	35.8%		41.7%
Subscale E	Concern for the patient			
	Physical security	3.3%		80.0%
	Aid type and treatment	32.5%		49.2%
	Social life	35.0%		48.3%
	Physical helath	4.2%		80.0%
	Conditions of current housing	30.8%		59.2%
	Financial survival	5.8%		77.5%
	Future	9.2%		78.3%

Table legend: 1 = not at all or never, 2 = very little or rarely, 3 = little or sometimes, 4 = a lot or often e 5 = always.

DISCUSSIONS

The results of this study about gender and diagnosis of users assisted in the General CAPS resemble other Brazilian researches.¹³⁻¹⁶

Regarding the socio-demographic profile of the caregivers, the results support the Barroso's research,¹³ in which women, married and mothers of users constituted the representative sample. Estevam and other authors¹⁷ point the female figure in the role of primary caregiveras it is incorporated in the woman the task of providing care to family and needy.

In this context, it is believed that due to the care demand at home caregivers are mostly in the situation of unemployed or housewives. These data are related to the responsibility of the woman on the historical and social constructions

determined by the sexual division of labor and perpetuated by the mode of production and society accumulation.¹⁸

The prevalence of caregivers aged 51 to 60 years also allowed us to understand that in most cases, these people assume a role that was imposed on them by circumstance and not by choice, though they also consider a mission of responsibility.¹⁷

Regarding the education profile, the results were similar to the study of Barroso, Flag and Nascimento,¹³ which shows that more often caregivers have incomplete primary education. It is important to know the education of the caregivers because they are they who receive the information and health team guidelines. Laham¹⁹ raises the hypothesis that the level of education can influence the feelings of the caregivers, and the little education make the understanding

of what happens to the patient difficult. However, the same author agrees that the feelings of the caregivers are the result of a complex interaction of factors, which goes beyond the information. About the type of occupation the caregivers have, it was found that, in most cases, they were unemployed or housewives. These data relate to the responsibility of the woman on the historical and social constructions determined by the sexual division of labor and perpetuated by the mode of production and society accumulation.¹⁸

With the research, it became clear that all caregivers lived with overload and the identified data showed no significant differences when compared to other studies of the same object.^{13,20}

According to table 2, the objective overload was more related to assistance in activities of daily life, especially in the preparation of meals, help to take medication and household chores due to the high frequency that these activities fall on women, who characterized as public profile studied¹³. Other possibilities for this finding are due to the time spent in daily repetition of activities, the amount of years that the family member takes care of the person with mental disorder and the presence or absence of some assistance in providing this assistance.²¹

Regarding the supervision of problematic behaviors and the impact on the daily routine of the family member, it was noticed low objective overload. It is assumed that this data is related to the active participation of the family in the treatment and clinical stability of the person with mental disorder who is being accompanied by CAPS, as the treatment results reflect both the user with the improvement or remission of some symptoms of the disorder as the family that breaks the stigma of uselessness and inability to mental disorder patient to socially live.²²

However it is emphasized that, even with good adherence to treatment and positive response to the interventions overload will continue to exist, because the caregiver tends to assume alone the responsibility to assist and supervise the demands of family member with with a mental disorder as well as dealing with complaints and demands of other family members about the care provided. Therefore, the importance of special attention from health professionals in identifying signs of overload care and emotional aspects problems in these caregivers in order to strengthen them in emotional vulnerability.²³

Among the domains that indicated higher subjective overload there is the finances and the concern for the patient. In this context, it is believed that financial difficulty is associated with several factors from the inability of the person with mental illness return to the labor market and thus contribute to home expenses,²³ or even the caregiver difficulty working outside the home. When the patient receives some kind of benefit, there may be the need for this feature to be applied not only the costs of the patient but also in domestic demand and the caregiver who is unable to work and so, this benefit may become insufficient.²⁴

The financial burden when analyzed in the daily context gains even greater proportions when it identifies that in addition to concern in meeting the needs of the house and of the treatment, other family members may suffer hardship due to the tight control of the budget.²³

When investigating the frequency with which the family member was concerned about the safety, physical health, treatment, social life, housing conditions, financial survival and the future of the sickened family member, it found a high degree of overload care because most of the caregivers said that are always or almost always concerned with the patient. This concern can affect the mental health of these caregivers, as it was reported during the interviews that treatment in this service or primary care was conducted.

A study focused in the overload of caregivers of people with bipolar disorder showed that the level of family overload is related to an increased demand for specialized care in mental health services.²⁵ Therefore, to value these data, to analyze them and to place a professional conscience in the face of these caregivers is urgent in order to develop effective strategies and interventions.

It is interesting to note that the domain assistance in activities of daily life did not cause severe subjective overload, differing the objective aspect. In this context, the study corroborates the results of Schein and Boeckel,²⁴ justifying the sense of obligation that individuals have to perform household chores and the care of family. This discourse is characterized as a gender issue, in which the woman does not realize the right to express feeling uncomfortable on these activities because she thinks she is doing her duty.

Therefore, it is important to identify the degree of overload on family caregivers of people with mental disorder by the need to assess the care provided by mental health services and to rethink strategies that meet the family/caregiver to not get sick mentally.

Regular home visits and family groups that seek help for the development of overload confronting strategies are important aspects to be integrated into mental health programs in order to contribute to a better quality of life for these family members and for better social reintegration of the patients. The recognition of its importance, contribution and difficulty facing are a decisive step in the development of public policies and sensitive community care practices to the needs of this population.¹³

In this context, the General CAPS of Sobral conducts activities for family members weekly. It was identified the need to strengthen these spaces conversations and reorganization of the assistance directed to caregivers so that they take hold of knowledge about mental illness, as well as promote their quality of life.

CONCLUSION

It is known that the psychiatric reform came not only as a human model of care for people with mental disorders, but it

has principles aiming to promote health and prevent illness. With the speech of social reinsertion, it favors autonomy and citizenship of mental patients and reduces their dependence on health institutions.

In this context, the family became a partner in the treatment and needs of professionals and management health attention aiming to prevent physical and mental illness and that effectively contribute in monitoring and rehabilitation. It is about being committed to the caregiver. The strengthening of programs and activities that include their welfare should be inserted in the daily schedule of the multidisciplinary team.

These data suggest the formation of community groups that provide moments of participation and communication with other caregivers in similar profiles, helping to raise their self-esteem and better placement of professionals, as they would be closer and understand the conditions of the caregivers' life.

The results of this study also allow the reflection that the evaluation of public health programs is incomplete until they consider the participation of family members as caregivers of the patients and the resulting overload of this paper.¹³

For these reasons, it is believed that other studies will be important to deepen the theme, particularly because health care, when living with this reality, must be equipped and qualified to assist the family members.

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