DOI: 10.1590/1413-81232018239.18252016

Family burden among caregivers of people with mental disorders: an analysis of health services

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Abstract *The objective of this study was to analyze the objective and subjective levels of burden felt by family caregivers of patients who were treated at three institutions: a General Psychosocial Care Center (known as 'CAPS Geral'), a CAPS center for Alcohol and Drugs ('CAPS AD') and the Psychiatric Admissions Unit of a General Hospital ('UIPHG') in the municipality of Sobral, Ceara State, Brazil. The study included 385 caregivers, 216 of whom were in the CAPS Geral, 86 in the CAPS AD and 83 in the UPHG, and applied the Family Burden Interview Scale (FBIS-BR). Excel and SPSS were used to organize and analyze the data, and a 5% significance level was applied. The results show that the general objective burden was greater for caregivers at the UIPHG. This group was also found to bear a greater objective burden with regard to caring in day-to-day life. The analysis of the subjective sub-scales showed that caregivers from the UIPHG group were most troubled by supervising problematic behaviors and also by the future and patient's type of care and medical treatment. Variables including sex and age were associated with burden.*

Key words *Mental health services, Family, Caregivers*

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Introduction

The possibility of providing care to people with mental disorders through substitute services is a recent phenomenon in Brazil. At the end of the 1970s, the Psychiatric Reform movement was established, after being influenced by manifestos declared across Europe. This movement called for a new approach to mental health services in Brazil, whereby the care system would no longer be based out of psychiatric hospitals, but would involve a network of extra-hospital services with increasing levels of complexity[1].

This move to 'de-institutionalize' had an impact not only on the people with mental disorders, but also on their families who took on more active roles as caregivers[2]. In this new context, most families did not possess the necessary conditions to support the plans for resocialization and rehabilitation that this news model of mental health care laid out and suffered negatively as a result[3].

On the one hand, this new care context promoted greater social inclusion for the person suffering from a mental disorder, but on the other, it led to greater burdening of the caregivers, who became active actors in the process without ever fully understanding its fundamentals or purpose[4].

Studies point to the burden faced by the family while living with a mentally ill person, although there is a need to investigate this issue further[2,5-7].

Family burden can be defined as the impact caused by the occurrence of a psychiatric disorder in the family environment, involving economic, practical and emotional elements that caregivers are faced with[8]. The burden can be considered to have an objective and a subjective dimension. Objective burden can be observed and involves the concrete costs arising from mental illness, such as the collapse of a structured family life and financial loss. Subjective burden is defined as the assessment that each individual makes of the situation and their perception of the burden caused by caring. These are discrete concepts relating to specific problems associated with the patient's mental illness[5].

Problematizing family burden is therefore relevant in this context in order to ensure advances in health promotion whereby the issue can be identified and addressed by the health team at the different moments that it arises[9]. Evaluating the impact of the role of the family caregiver can provide important information for the development of psychosocial and educational interventions that can effectively help these families and improve the quality of care in mental health services[10].

This study therefore aims to analyze the levels of objective and subjective burden felt by family caregivers of people with mental disorders who are treated by mental health services

Methods

Scope

This was a correlational study involving a static group in which the burden of family caregivers of patients with mental disorders was measured and compared across three different specialized services.

Study locations

The study was carried out in three mental health services in the city of Sobral in Ceara State of Brazil. These were the General Psychosocial Care Center (known as 'CAPS Geral'), a CAPS center for Alcohol and Drugs ('CAPS AD') and a Psychiatric Admissions Unit at a General Hospital ('UIPHG'). These services are part of the Network for Care in Mental Health in the municipality.

Participants

The family caregivers of people with mental disorders who were treated at one of the three institutions represented the study participants. The study sample was calculated on the basis of an infinite population and totaled 385 caregivers, distributed as follows: 216 of in the CAPS Geral, 86 in the CAPS AD and 83 in the UPHG.

The criteria used for selection of the study participants were: aged 18 or above; availability for interview, following the signing of free and informed consent forms and guarantee of anonymity; physical and mental capacity to understand the study instrument; be considered by the mental health service as the caregiver of the user; and residence in Sobral. Exclusion criterion was if the caregiver's family member was being treated at the health facility for the first time.

Analytical instruments

Two instruments were used for the analysis. The first was a form with information regarding demographics relating to the person with the mental disorder (sex, age and clinical diagnosis) and to the caregiver (sex, age and clinical diagnosis), as well as circumstantial information (relationship between the two).

Burden was assessed using the Family Burden Interview Scale (FBIS), which has been translated and adapted for Brazil: FBIS-BR[11]. The scale assesses the global, objective and subjective burden, based on independent scores. Elements of the individual's family life are assessed separately, enabling the assessor to identify the areas of greatest and least burden sustained by the family member in their role as caregiver. The level of burden is thus evaluated across five elements of the caregiver's life: A) care in the patient's daily life; B) supervision of the patient's problematic behaviors; C) financial onus borne by the family member due to the patient; D) impact on the family's daily routine; and E) family member's concerns with the patient. The questions for each one of the elements relates to the 30 days prior to the application of the scale. Objective burden is analyzed in relation to the frequency of care provided to the patient and includes subscales A, B and D. Subjective burden evaluated the level of inconvenience felt by the family member and relates to subscales A, B and E.

Data collection

Data was collected between July 2013 and August 2014. Upon first contact with the participants, the data collector presented himself or herself and explained the research and its objectives, methods and social importance. The interviewee was then invited to participate voluntarily and a structured interview was carried out, in a separate space without affecting the routine services provided by the health facility. Once the interview was completed, the clinical diagnosis in the patient's records was analyzed.

Pilot interviews were carried out beforehand, so that the data collector could be evaluated in real conditions and in order to understand the family members.

Data analysis

The data were compiled in Excel and the statistical analysis was processed using version 21.0 of SPSS (Statistical Package for the Social Sciences). Intergroup analysis was carried out in order to identify significant differences in the level of burden for the global scores, subscales and the specific items of the FBIS-BR among caregivers at the three health facilities.

The Kolmogorov-Smirnov test was applied to assess the normality of the quantitative data and since it did not have a normal distribution, the use of non-parametric techniques was chosen. To check for differences between the measures of burden, the Kruskal Wallis test was used. In cases of statistically significant differences, a post-hoc analysis was carried out using the least significant difference (LSD) method. A statistically significant difference between the assessments is considered to be when the value of the differences of the averages of data from the two groups is greater than the LSD.

The Mann-Whitney test was used to analyze the statistical associations of the measures of global objective and subjective burden with the sociodemographic characteristics of the caregivers and patients. For all the calculations, a level of 5% was adopted.

Ethical considerations

The study was approved by the Research Ethics Committee of the Universidade Estadual Vale do Acaraú (UVA).

Results

With regard to the sociodemographic characteristics of the patients, they were found to be predominantly male in the three facilities, with an average age of 33.63 (SD: 18.26), in the CAPS Geral; 36.76 (SD: 13.34) in the CAPS AD; and 34.93 (SD: 12.97) in the UIPHG.

The most prevalent diagnoses of patients in the CAPS Geral and in the UIPHG were from the group of schizophrenic disorders; in the CAPS AD, it was mental and behavioral disorders associated with the use of psychoactive drugs.

Table 1, presents the sociodemographic characteristics of the caregivers.

The measures for global burden and the subscales for each group of caregivers for each facility are presented in Table 2. Analysis of the frequency with which the family member of the person with a mental disorder participated in daily activities, the caregivers from the CAPS Geral were found to face greater objective burden (3.25/ SD:0.81), compared with caregivers of patients at the UIPHG (2.99/ SD:0.81). In relation to supervision of problem behaviors, the measures for both objective (2.62/ SD:0.93) and

Table 1. Sociodemographic characteristics of carers of patients treated at the CAPS Geral, CAPS AD and the UIPHG. Sobral, Brazil, 2015.

Characteristics	CAPS Geral (n = 216) n (%)	CAPS AD (n = 86) n (%)	UIPHG (n = 83) n (%)	Total (n= 385) n (%)
Sex				
Male	23 (10.6)	3 (3.5)	11 (13.3)	37 (9.6)
Female	193 (89.4)	83 (96.5)	72 (86.7)	348 (90.4)
Age				
18-20	5 (2.3)	2 (2.3)	3 (3.6)	10 (2.6)
21-30	27 (12.5)	6 (7.0)	12 (14.5)	45 (11.7)
31-40	37 (17.1)	19 (22.1)	18 (21.7)	74 (19.2)
41-50	41 (19.0)	17 (19.8)	21 (25.3)	79 (20.5)
51-60	59 (27.3)	27 (31.4)	14 (16.9)	100 (26.0)
61-70	38 (17.6)	6 (7.0)	10 (12.0)	54 (14.0)
70 a +	9 (4.2)	9 (10.5)	5 (6.0)	23 (6.0)
Relationship				
Mother	116 (53.7)	43 (50.0)	35 (42.2)	194 (50.4)
Father	4 (1.9)	2 (2.3)	5 (6.0)	11 (2.9)
Brother	3 (1.4)	-	4 (4.8)	7 (1.8)
Sister	26 (12.0)	12 (14.0)	9 (10.8)	47 (12.2)
Spouse	26 (12.0)	19 (22.1)	17 (20.5)	62 (16.1)
Son	3 (1.4)	-	-	3 (0.8)
Daughter	23 (10.6)	5 (5.8)	10 (12.0)	38 (9.9)
Grandfather	-	-	1 (1.2)	1 (0.3)
Grandmother	4 (1.9)	1 (1.2)	-	5 (1.3)
Other	11 (5.1)	4 (4.7)	2 (2.4)	17 (4.4)
Marital status				
Single	39 (18.1)	13 (15.1)	19 (22.9)	71 (18.4)
Married	100 (46.3)	40 (46.5)	33 (39.8)	173 (44.9)
Stable union	30 (13.9)	13 (15.1)	14 (16.9)	57 (14.8)
Separated	19 (8.8)	7 (8.1)	10 (12.0)	36 (9.4)
Widowed	28 (13.0)	13 (15.1)	7 (8.4)	48 (12.5)
Level of Schooling				
Illiterate	25 (11.6)	14 (16.3)	18 (21.7)	57 (14.8)
Incomplete primary education	98 (45.4)	34 (39.5)	32 (38.6)	164 (42.6)
Complete primary education	16 (7.4)	11 (12.8)	5 (6.0)	32 (8.3)
Incomplete secondary education	20 (9.3)	8 (9.3)	3 (3.6)	31 (8.1)
Complete secondary education	44 (20.4)	12 (14.0)	17 (20.5)	73 (19.0)
Incomplete higher education	6 (2.8)	2 (2.3)	5 (6.0)	13 (3.4)
Complete higher education	5 (2.3)	4 (4.7)	3 (3.6)	12 (3.1)
Postgraduate	2 (0.9)	1 (1.2)	-	3 (0.8)
Employment status				
Unemployed / at home	114 (52.8)	29 (33.7)	31 (37.3)	174 (45.2)
Employed (in formal or informal economy)	42 (19.4)	26 (30.2)	25 (30.1)	93 (24.2)
Retired	28 (13.0)	16 (18.6)	13 (15.7)	57 (14.8)
Self-employed	24 (11.1)	12 (14.0)	13 (15.7)	49 (12.7)
Student	3 (1.4)	3 (3.5)	1 (1.2)	7 (1.8)
Other	5 (2.3)	-	-	5 (1.3)

Table 2. Global burden averages and by scale for carers of patients with mental disorders, by health institution. Sobral, Brazil, 2015.

Burden	Subscale	Burden averages (SD)			p*
		CAPS Geral	CAPS AD	UIPHG	
Objective	Support in daily life (A)	3.25 (0.81)^{A}	3.03 (0.78)^{AB}	2.99 (0.81)^{B}	0.010
	Supervision of problematic behaviors (B)	2.26 (0.87)^{A}	2.35 (0.79)^{AB}	2.62 (0.93)^{B}	0.010
	Impact on daily routines (D)	2.13 (1.02$^{)A}$	1.92 (0.91$^{)A}$	2.64 (1.17$^{)B}$	<0.001
	Global objective burden	**2.55 (0.68)^{AB}**	**2.43 (0.60)^{A}**	**2.75 (0.70)^{B}**	**0.014**
Subjective	Support in daily life (A)	1.42 (0.53)	1.41 (0.55)	1.40 (0.54)	0.914
	Supervision of problematic behaviors (B)	1.94 (0.76)^{A}	2.12 (0.78)^{AB}	2.33 (0.79)^{B}	<0.001
	PConcerns about the patient (E)	3.88 (0.74)	3.77 (0.75)	3.94 (0.72)	0.386
	Global subjective burden	**2.41 (0.51)**	**2.43 (0.53)**	**2.56 (0.51)**	**0.082**

*Kruskal Wallis Test. Different letters relate to different measures.

subjective burden (2.33/ SD:0.79) for caregivers of patients at the UIPHG were greater than in the CAPS Geral at 2.26 (SD:0.87) and 1.94 (SD:0.76) respectively.

In relation to the impact on daily routines, the measures of burden were greater for carers at the UIPHG (2.64/ SD:1.17) than at the CAPS Geral (2.13/ SD:1.02) and the CAPS AD (1.92/ SD:0.91)

The global objective burden was also assessed and found to be greater among carers at the UIPHG (2.75/ SD:0.70) than at the CAPS AD (2.43/ SD:0.60). Nonetheless, the subjective global burden was not found to have a statistically significant difference between the groups of caregivers.

Analysis of items in the objective subscales

Table 3 presents items related to objective burden that have statistically significant differences.

Analysis of items in the subjective subscales

A comparison of the measures resulting from the subjective items of care in daily life (subscale A) showed that there was no difference found between the services (p > 0.05). For the subjective items of the other subscales, significant differences were found among the groups of carers (Table 4).

Association between the sociodemographic characteristics of caregivers and patients and burden

An analysis of the association between the variables sex, age, marital status, profession, level of schooling and family relationship for the caregivers with the variable burden, there was found to be a significant relationship between sex and the global measures for objective and subjective burden. Female caregivers were found to have a greater level of objective burden than their male counterparts (197.10 vs 154.43, p = 0.027); and greater subjective burden (197.85 vs 147.42, p = 0.009).

For the variables patient sex and age, sex was found to influence the level of global objective burden, indicating that the caregivers feel more objective burden when their family members are male as opposed to female (201.91 vs 174.91, p = 0.025). With regard to the variable age, the younger the patient, the greater the objective (p = 0.001) and subjective (p = 0.000) burdens.

Discussion

Consideration is given to the results about burden based on the specificities of the scale. For all three groups of caregivers, the highest averages were related to the frequency with which the caregivers support the patients in carrying out daily tasks; while the activities that cause them the greatest amount of inconvenience are supervision of problematic behaviors. These results are consistent with those found in other studies of family members of psychiatric patients[7,12].

A comparison between the groups of caregivers with regard to the global objective burden showed significant differences, and the UIPHG group was found to face greater burden than caregivers from CAPS AD. These results suggest that the symptomology of the illness may have an influence on the levels of care that are required,

Table 3. Average objective burden scores of the caregiver in relation to items from Subscale A – Support in daily life, Subscale B – Supervision of problematic behaviors and Subscale D – Impact on daily routines. Sobral, Brazil, 2015.

Subescales	Items	Burden averages			p*
		CAPS Geral	CAPS AD	UIPHG	
A	Hygiene and personal care**	3.26	2.72	2.83	0.017
	Administration of medication	4.04^{A}	3.58^{AB}	3.17^{B}	< 0.001
	Transport**	2,47	2,14	2,19	0.047
	Managing money	$2{,}93^{A}$	$2{,}13^{B}$	$2{,}14^{B}$	< 0.001
	Medical consultations or activities in the mental health services	$1{,}97^{A}$	$2{,}49^{B}$	$2{,}40^{B}$	< 0.001
B	Behaviors that cause embarrassment	2.57^{B}	3.06^{AB}	3.17^{A}	0.005
	Excessive demand for attention**	2.69	2.28	2.90	0.038
	Disruptions during the night	2.13^{B}	2.09^{AB}	2.67^{A}	0.009
	Suicide attempt or threatened attempt	1.58^{B}	1.60^{B}	2.28^{A}	< 0.001
	Excessive consumption of alcoholic beverages	1.10^{B}	2.71^{A}	2.31^{A}	< 0.001
	Use of illegal drugs	1.07^{B}	2.36^{A}	1.64^{B}	< 0.001
D	Tardiness or absences for commitments	1.80^{B}	1.65^{B}	2.37^{A}	< 0.001
	Changes to social and leisure activities **	2.09	1.95	2.49	0.045
	Changes to services or house routines	2.38^{B}	2.17^{B}	3.24^{A}	< 0.001

*Kruskal Wallis Test. **The minimum significant difference between the categories was not identified. Different letters relate to different measures.

Table 4. Subjective burden averages of carer relating to items from Subscale B – supervision of problematic behaviors and Subscale E – Concerns with the patient. Sobral, Brazil, 2015.

Subescales	Items	Burden averages			p*
		CAPS Geral	CAPS AD	UIPHG	
B	Behaviors that cause embarrassment	2.32^{B}	2.88^{A}	2.87^{A}	<0.001
	Disruptions during the night	1.89^{B}	2.12^{AB}	2.63^{A}	<0.001
	Suicide attempt or threatened attempt	1.75^{B}	1.90^{B}	2.52^{A}	<0.001
	Excessive consumption of alcoholic beverages	1.14^{B}	2.59^{A}	2.24^{A}	<0.001
	Use of illegal drugs	1.08^{B}	2.31^{A}	1.52^{B}	<0.001
E	Type of help and treatment of the illness	3.18^{A}	2.03^{B}	3.14^{A}	<0.001
	Future**	4.34	4.59	4.65	0.036

* Kruskal Wallis Test. **The minimum significant difference between the categories was not identified. Different letters relate to different measures.

since the family generally participates in the health-illness process of the patient with mental disorders and they seek alternatives to ensure improved care and/or admission, accompanying them throughout this process. Other studies also found that the clinical state of the patient was a relevant variable that influenced objective burden[2,6,7].

An analysis of the subscales of objective burden pointed to different results for each group. Caregivers from the CAPS Geral more commonly supported the patient in their daily activities, when compared with caregivers from the UIPHG. While the UIPHG group faced greater burden with regard to the frequency of supervision of problematic behaviors, compared with the CAPS Geral group, and also with regard to daily routines compared with the two other groups.

A more detailed analysis showed that the UIPHG carers faced greater burden in relation to a number of items. The objective items showed that they felt greater burden than caregivers from CAPS Geral in relation to the supervision of problematic behaviors including: avoiding or preventing the patient from behaviors that left them feeling embarrassed or troubled; when the patients spoke about dying or suicide attempts; when they woke people up during the night; and with excessive drug consumption. Another study also reported that the first two variables gave rise to the greatest objective burden. The reason for this finding is thus thought to be related to the fact that the UIPHG patients were in a state of crisis and their family member have recently passed through complex experiences with the patient[9].

Another study[13] reasoned that the factors that influence greater burden in this group include the greater seriousness of the disorder, a longer period of time passing before seeking treatment, unsatisfactory therapy, and resistance and refractiveness in relation to the available treatments. It is worth pointing out that only the family's awareness about possible suicide, substance abuse and the patient's positive or negative symptoms gave rise to burden. For this reason, social support and coping mechanisms must be buttressed by professionals in order to reduce the burden[14].

Another point that was raised was the greater frequency with which the UIPHG caregivers, compared with those from CAPS AD, sought to avoid or prevent their family member from demanding too much attention. Caregivers from the CAPS AD reported that the users who began to involve themselves with drugs distanced themselves from their families, spending less time at home and therefore demanding less attention.

The greater burden of UIPHG caregivers was also felt as a result of avoiding or preventing that their family members spoke about dying or attempted suicide. The family suffers a huge impact when faced with the imminent risk of losing their loved one and the accompanying barrage of emotions such as fear, tension and insecurity, whereby they recognize that the problem really does exist but they do not know how to deal with it, not knowing how to handle the family member nor what measures to take[15]. In light of this, support and guidance from health professionals is important as they can help caregivers to identify the signs of a suicide threat and what response can be taken.

In this study, the group of caregivers from the CAPS AD was found to endure greater burden than those from the CAPS Geral in relation to the frequency with which they had to supervise excessive consumption of alcohol by the patient and the use of illegal drugs. Two factors seem to have influenced these results: the first is the fact that the health facility provides daily clinical and psychosocial care for people who suffer from mental disorders that arise from alcohol and drug abuse; and secondly, the greater proportion of male patients who are treated at the CAPS AD, given the association between male sex and a greater degree of burden. Although the use of legal and illegal drugs is common in today's society, irrespective of gender, cultural questions involving prejudices particularly with regard to women were apparent in the activities involving care for drug users, and this may help to understand the significant numerical difference in the total number of users. However, it should not be forgotten that the male population is worse affected by drug dependence, leading to subsequent need for treatment tratamento[16].

Caregivers from the UIPHG were asked about the impact on daily routines and reported more delays or missing commitments and changes to services and routines in the home, compared with caregivers from the two other groups; they also were found to face greater burden than caregivers from CAPS AD in relation to changes to social and leisure activities. The fact that these items indicate greater burden among UIPHG carers points to the failure or non-existence of a social support and family network. Issues including the seriousness of the disorder, the level of commitment and the therapy proposed also influence the daily routines of the caregiver[13].

In addition, it is well known that the fact of a person with a mental disorder is admitted to a health facility can affect the caregiver's routine in a number of ways: they may be unable to establish other relationships because of a shortage of time; they place the ill person in the center of their lives and make demands on that person and on themselves; and they may withdraw themselves from society, including from their friends and families[17].

In this study, the frequency with which the CAPS Geral caregivers administered medication for their family member was greater than in comparison with the UIPHG group. They were also found to be more burdened than those from the CAPS AD group with regard to the frequency with which they dealt with the hygiene or personal care and transport needs of the patients. Caregivers from the CAPS Geral more commonly managed the finances of their family compared with the other two groups.

The statistically significant correlation of these results with patient age merits further discussion. The profile of patients at the CAPS Geral shows that this group has a lower average age and, unlike at other institutions studied, included children, who are treated there. Given this context, it is reasonable to assume that younger patients are more dependent on their carers, who may need to accompany them during their daily activities, including taking them somewhere and looking after money. Children with mental disorders have been found to be less autonomous and to give rise to a greater burden among their carers[12]. Another study also reported that children with more serious mental health disorders or with a reduced level of functioning probably need more help from the carer with regard to daily activities, and as such may elicit a greater care burden[18].

It is also believed that the fact that the majority of carers at the CAPS Geral were unemployed or responsible for carrying out activities in the home at the time of the study may have an influence on the greater amount of time spent in caring and attending the patient's needs. In a study carried out in Taiwan[19], there was found to be an association between burden and the number of hours of care spent daily with the patient, and it was related to a reduction in quality of life. The task of reminding patients about their medical consultations or even taking them to activities in mental health services contributed to greater objective burden among carers from the CAPS AD and UIPHG.

There were not found to be any significant differences between groups with regards to global subjective burden. Among the subscales for subjective burden, only supervision of problematic behaviors has a significant difference, whereby carers from UIPHG felt more troubled than carers from the CAPS Geral. Nonetheless, the feeling of being troubled because they had to look after a family member with a mental disorder in their daily activities and concern with the patient affected the carers in equal measure.

The distress caused by overseeing behaviors of the patient that caused shame, and the excessive consumption of alcohol were greater in the groups of carers from UIPHG and CAPS AD compared with CAPS Geral. With regard to the family of the person with mental disorders, the feelings of shame and embarrassment about the inappropriate behavior of the ill person were reported as making it difficult to live together, to have social interaction and, as a result, to accept the individual within the family. For the family members, living with the diagnosis of mental disorder of another member of that family could give rise to different feelings, including fear, sadness, pity and shame, which largely arise when certain behaviors that are considered beyond the norms of society occur in public[20].

It is interesting to take note of the results regarding the use of drugs, since they reflect the fact that family members are not yet fully informed about the patient's addiction. Families were often found to have an unclear understanding of the addiction and believed that the problem arose solely as a result of the free will of the patient to use alcohol and/or other psychoactive substances[21]. This is a reflection of a lack of a more general lack of understanding in society about this problem; as such, health professionals need to reflect about the place that drugs assume in a user's life and the interaction between the subject, drugs and society. In this way, professionals can bring together knowledge about the phenomenon and organize targeted prevention and treatment activities and the adaptation of other public policies.

In relation to other items, carers from UIPHG were more troubled by having to avoid or prevent a family member from disturbing people during the night, when compared with carers from CAPS Geral; the distress resulting from conversations, threats or suicide attempts were greater in UIPHG carers than in others; and from CAPS AD felt more troubled by the patient's use of illegal drugs, compared with the other two groups. As such, these results relating to the feeling of discomfort or being troubled are a consequence of spending more time with family members and, thus, having greater care needs.

Significant differences were found between groups with regard to two items relating to concerns with the patient: type of support / medical care and the patient's future. Carers from the CAPS Geral and UIPHG were found to be more concerned about the type of support and medical care of their relation with a mental disorder than was the case for carers from CAPS AD.

A study carried out in a public psychiatric hospital reported that the family felt impotent, desperate and worn out. This led to emotional burden on account of frustrated expectations about treatment and the commitment that the patient has taken on with regard to their treatment plan. For this reason, family members need the support of health professionals so that they might know about strategies to deal with the crisis and options for accessing resources outside of the hospital[22].

In the CAPS Geral, there were also carers who were concerned with the type of medical treatment that the patient received. These concerns may be the result of different factors including the chronicity of the illness, the more regular presence of family members during the consultations, interventions and in the process of the disease itself, even though they were users of more stable clinical manifestations.

Concerns about future perspectives with regard to the family member with a mental disorder are what score the highest average in this subscale. A comparison of the different carer groups shows that those from UIPHG were more worried about this issue than those from the CAPS Geral. It is possible that this result is caused by the uncertainty regarding the patient's clinical health, which causes great suffering in the family member, and the uncertainty about how relationships will be after leaving the hospital. In this context, a revision study identified that family members were not prepared for the admission to hospital of the patient, and upon discharge, they considered the patient's future pessimistically, full of concerns and uncertainties[2].

Given the difficulties faced by the family that looks after an addict after his or her discharge from the hospital, health professionals should include them as part of the treatment, which could reduce the feeling of impotence and encourage support in relation to the guidance and follow-up required for further services outside of the hospital. This can also help to reduce the crises that arise in the family and that can destabilize relationships[22]. In this way, there is greater concern placed upon the carers with regard to the patient's future[7,23-27]. It is therefore essential that health services focus, especially when they work with carers to address questions relating to concerns with the patient's future[2].

Studies have already pointed to a desire among carers for more interaction with healthcare professionals, and greater participation in the treatment and in the decisions about caring for their relation[28]. In addition to the management and treatment of the symptoms of the illness, interventions focused on how carers evaluate these symptoms can also help to reduce the burden and improve the emotional well-being of the carer[27].

The main limitations of this study relate to the sample type, given the different conditions of the carers at the three health services, the use of medical records for the diagnosis and the fact that it was only concerned with carers of patients who were in treatment, making it difficult to draw generalizations from the results, since family carers whose patients are not undergoing treatment may face even greater burdens.

Conclusion

Although the concept of 'de-institutionalization' is considered a recent policy for many authors, the relationship of care between the person who cares and his relation with a mental health disorder needs to be better understood, as does the resulting burden.

The results relating to burden meant that it was possible to identify similarities and differences among the three groups of carers, with suggestions for the planning of effective interventions that prioritize family needs in each mental health service. A comparative evaluation of the three groups of carers identified a greater burden among carers from the UIPHG group compared with those at other services.

A lack of other studies that have analyzed the burden of caregivers at the different mental health services makes it difficult to compare the results presented here. Nonetheless, the seriousness of the clinical state can be considered a predictive factor of objective and subjective burden felt by the caregivers.

The development of studies on this theme represents an attempt to contribute towards the practice of mental health professionals and managers, as well as to improve care to families, with a view to reducing the impact of the task of caring. For this reason, it is necessary to rethink strategies aimed at caring for and supporting family members, along with the necessary preparation of carers for the hospital discharge of the patient, taking into consideration his or her needs, knowledge and autonomy. A suggestion is to develop a therapeutic project targeting family members so that they can understand better the symptoms of the patient's disorder, the types of treatment and the importance of psychosocial support and that they give proper consideration to activities focused on their own comfort and well-being.

It is recommendable that there is on-going education for training health professionals to improve their skills in mental health, focused on integrated support to families and the use of technologies for the production of care.

Further studies would seem to be important in order to deepen an understanding of burden and its relationship with the family caregiver. Future themes should look at experiences relating to interactions and interventions and translate specific results and approaches to the needs of families.

Collaborations

SC Eloia and EN Oliveira worked on the design and writing of the article. MVO Lopes worked for the application of statistical data as well as analysis of these. JRF Relative in the critical and written analysis of the text. SMC Eloia and DS Lima in data collection.

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Article submitted 22/03/2016
Approved 16/09/2016
Final version submitted 18/09/2016