Burden and participation of family in the care of Psychosocial Care Centers users

Sobrecarga e participação de familiares no cuidado de usuários de Centros de Atenção Psicossocial

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ABSTRACT 'Family burden' is the impact that may result in the family environment from the care devoted to a patient. The aim of this paper was to investigate the burden experienced by family caregivers of users assisted in Psychosocial Care Centers. For this purpose, we have applied the Family Burden Interview Scale for Relatives of Psychiatric Patients – BR and a socio-demographic questionnaire. The results indicate a relevant presence of burden in the analyzed families and the importance of the involvement of relatives in the care of people with mental disorders. It was also possible to register that cooperation with families in the work conducted by psychosocial care services is still incipient.

KEYWORDS Caregivers; Mental health services; Family health; Mental disorders; Community psychiatry.

RESUMO *'Sobrecarga familiar' é o impacto que o cuidado dedicado a um paciente pode provocar no ambiente familiar. O objetivo do presente estudo foi investigar a sobrecarga vivida por familiares cuidadores de usuários atendidos em Centros de Atenção Psicossocial. Para tanto, aplicaram-se a Escala de Sobrecarga dos Familiares de Pacientes Psiquiátricos e um questionário sociodemográfico. Os resultados indicam uma relevante presença de sobrecarga nas famílias analisadas e a importância do envolvimento de familiares no cuidado de pessoas com problemas mentais. Foi possível, também, registrar que ainda é incipiente o trabalho parceiro com as famílias realizado pelos serviços de atenção psicossocial.*

PALAVRAS-CHAVE *Cuidadores; Serviços de saúde mental; Saúde da família; Transtornos mentais; Psiquiatria comunitária.*

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Introduction

Psychiatric treatment in patients with severe and persistent mental disorders in Brazil was during a long time undertaken in large hospitals and based on long-term hospitalization, generating the separation of the individual from his family's home and from society. According to Koga and Furegato (2002), the only time the patient had contact with relatives was during the sporadic visits or when discharged from hospital, which rarely happened.

With the movement that led to the Brazilian Mental Health System Reform and the implementation of the National Mental Health Policy (NMHP), both long-term institutionalization and the isolation of the patient from his/her relatives and social environment were criticized. The response to overcome this became one of the objectives of interventions that aim to change the asylum model into a community model. The current emphasis of public mental health is the constitution of a community care network that results in the social inclusion of patients in the community, enhancing his/her care, and family and social bonds, thus sustaining the proposal of mental disorders treatment outside the psychiatric hospital institution.

This change made has presented extremely positive signs as to achieve humanized treatment, prioritizing psychosocial rehabilitation; nevertheless, it also revealed important challenges, especially regarding the position and role of relatives in the sustainability of the psychosocial project. The family that in the hospital centered model was placed in complete exteriority to the process of care, became directly involved in the daily care of the patient with mental disorder (DELGADO, 2014). The preparation, knowledge, and ability to give support to relatives, which are required from the community services, have not been sufficiently resolved to carry out the proposal of the new NMHP (BANDEIRA: BARROSO, 2005). According to the directive of the Ministry of Health that establishes the operation of Psychosocial Care Centers (PCC) – strategic services of the care network – the assistance provided to the user includes family assistance and the development of community activities, aiming at the user's integration in the community and his/hers familial and social insertion. Nevertheless, those actions have not been satisfactorily developed in most of the services. Bandeira *et al.* (2011) state that the cooperation between health professionals and the family can bring about benefits to the user's treatment, resulting in a decrease of hospitalization, reduction of family conflicts, and lessening of the burden felt by caregivers.

In the community care model, often the family is taken by a feeling of abandonment in face of the anxiety for not knowing how to deal with the patient's routine, problematic behavior, administration of medicaments, and their own daily impasses produced by the experience of becoming ill. Studies have found evidence that when the family caregiver lives with the patient there is greater burden because of the increased daily tasks and assistance to be provided (ALMEIDA *ET AL.*, 2010). The term 'family burden' is related to the impact that the presence of the patient with mental disorder may cause to the family environment, presenting economic, practical and emotional aspects, especially regarding the relatives directly in charge of the user's care (SOUZA FILHO *ET AL.*, 2010). Mental health services are apparently still little effective regarding the thorough follow-up prosed by the mental health policy; in a certain way, this contributes to the family burden, since the relatives are in charge of the major daily support to the patient, dealing with anxieties and worries intrinsic to the care.

The study of the concept of burden starts from the distinction between two complementary dimensions: the objective burden and the subjective burden. The first dimension refers to the changes that may occur in the daily family routine, such as restrictions to social and professional life, financial burden, supervision of problematic behavior, among others, which result in forcing the caregiver to give up some life projects and objectives. The second dimension is related to emotional aspects intrinsic to the patient's care, such as worries, perceptions, negative feelings and several troubles that this activity may cause (BARROSO; BANDEIRA; NASCIMENTO, 2007).

The aim of this study is to examine the burden component felt by family caregivers of patients with severe and persistent mental disorders and the socio-demographic data of a sample of relatives who care for users of PCCs in Rio de Janeiro state, seeking to contribute to the mental health assistance in the state, based on the proposals of the Mental Health System Reform. For the purpose of this research, a tool that considers the two dimensions of burden (objective and subjective) and a socio-demographic questionnaire were used. This article is inserted in a broader research and extension project that is still being undertaken with the purpose of promoting the enhancement of family autonomy in the role of caregivers.

Method

The study comprised 107 family caregivers of users under care in 19 PCCs of the public network of Rio de Janeiro state, including PCCs and Psychosocial Care Centers for Youth and Children (PCCYC), and not including Psychosocial Care Centers for Alcohol and Other Drugs (PCCAOD). The selection of family caregivers was based on their presence in gathering cycles, carried out after open calling at family meetings of the PCCs; therefore, recruitment was made by invitation to people present at the meetings of families of the services. The criteria for inclusion were: being a relative of a user under follow-up in PCCs; accepting to participate in the burden research; and being older than 18 years of age.

Data collection was made with the utilization of two instruments. First, a socio-demographic standardized form prepared by the research team. The other tool was the Family Burden Interview Scale for Relatives of Psychiatric Patients – BR (FBIS-BR), elaborated by Tessler and Gamache (1994), and adapted and validated in Brazil by Bandeira *et al.* (2005).

The purpose of FBIS-BR is to make an assessment of two types of burden (objective and subjective); the scale has a set of 52 items, distributed in five subscales: (A) assistance to the patient in daily life; (B) supervision of problematic behavior: (C) financial expenses; (D) impact on the routine; and (E) worries about the patient. The objective burden is assessed by means of a Likert-type scale (1 = Not once; to 5 = every day), in which the family caregiver answers in what frequency he/she performed some tasks related to the user's care, dealt with problematic behavior, and suffered changes in daily life. In the case of subjective burden, a Likert scale is also used, but with four points (1 = not at all; to 4 = very much), corresponding to the level of burden generated while providing assistance and to changes in his/her personal life; and also by scales of five points (1 = never; to 5 = always or almost always), for the frequency of worries and the weight of financial expenses with users. The tool also permits to measure the user's contribution to expenses and permanent changes occurred in the family caregiver's life. The questions are to be answered in relation to 30 days preceding the interview; there is only one item that assesses the past year.

Considering that the FBIS-BR scale has no established cut-off, the level of burden is estimated by considering the frequency (percentage) of answers in the two last points of the Likert scale for each of the subscales (BANDEIRA; CALZAVARA; VARELLA, 2005).

The application of FBIS-BR scale and the socio-demographic questionnaire were presential, during individual interviews carried out by previously trained researchers.

The analysis of the socio-demographic data and of the answers to FBIS-BR was not merely quantitative; the narrative collected during the application was also considered as illustrative regarding the context. The frequency of the answers to the items of FBIS-BR was analyzed, and the data found were confronted with the findings described in articles of the literature on the subject, to study the items that influenced the level of burden of family caregivers.

Those relatives were accordingly informed by Informed Consent Term on the research objectives and the guarantee of confidentiality and privacy of data. The project was submitted to the Research Ethics Committee of the institution and approved under number 15 – liv.4-11, CAAE 0044.0.249.000-11.

Results

Family characteristics

The PCCs that took part in the research are responsible for several regions of Rio de Janeiro state. The distribution was made as follows: 33 family caregivers from PCCs in the municipality of Rio de Janeiro; 14 from PCCs in the municipality of Niterói; and 61 from the other municipalities of Rio de Janeiro state. Among the family caregivers, 100 were connected to CPPs for adults and 8 to the CPPYC; one caregiver was connected to two PCCs due to being related to more than one user.

The majority of caregivers was female (80.00%) and married (46.73%). There was a prevalence of users' mothers (43.93%). Most caregivers were between 41 and 60 years old (62.62%). Regarding education, 14.01% had low education level (0 to 4 years of education); 32.71% had basic education (5 to 8 years of education); and 44.87% had 9 or more years of regular education.

Among the caregivers, 57.94% lived with the patient, mostly in owned residence (84.11%). Family income of the majority ranged from 01 to 04 minimum salaries (62.62%) and most families relied on the social benefit received by the patient (52.34%).

The presence of religious practice in the caregivers' life is significant, considering that only 6.54% declared having no religion: 58.88% declared being evangelic protestant/pentecostal; 27.10% catholic; 2.80% spiritualist; and 4.67% did not answer. Religion is considered 'very important' to 75.70%.

Regarding the current working condition, 21.50% were retired and 36.45% had a regular job. Although informal work was significant among the respondents, 37.38% declared themselves as unemployed.

The socio-demographic characteristics of the sample of family caregivers are described on *table 1* in terms of absolute numbers and percentages.

Table 1. Socio-demographic characteristics of family

Variables		**Frequency**	**%**
Gender	Female	86	80,00
	Male	21	20,00
Age range	21-40 years	8	7,48
	41-60 years	67	62,62
	61-80 years	31	28,97
	81-100 years	1	0,93
Kinship status	Mother	47	43,93
	Father	11	10,28
	Sister or brother	33	30,84
	Daughter or son	1	0,93
	Other	15	14,02
Civil status	Married/living with someone	50	46,73
	Widow/widower	21	19,63
	Single	20	18,69
	Separated or divorced	16	14,95
Education	Illiterate	3	2,80
	01 to 04 years	12	11,21
	05 to 08 years	35	32,71
	09 to 12 years	34	31,78
	13 to 16 years	10	9,35
	17 or over	4	3,74
	Doesn’t know	2	1,87
	Not answered	7	6,54
Living with patient	Yes	62	57,94
	No	28	26,17
	Not answered	17	15,89
Residence	Own	90	84,11
	Other kind	15	14,02
	Not answered	2	1,87
Family income	No income	1	0,93
	Less than 1 minimum salary	23	21,50

Table 1. (cont.)

Family income	01 to 02 minimum salaries	28	26,17
	02 to 04 minimum salaries	39	36,45
	Over 04 minimum salaries	14	13,08
	Not answered	1	0,93
	Not known	1	0,93
Patient's benefit	Receives	56	52,34
	Does not receive	44	41,12
	Not answered	7	6,54
Professional status	Retired	23	21,50
	Employed	39	36,45
	Unemployed	40	37,38
	Not answered	5	4,67
Religion	Catholic	29	27,10
	Evangelic protestant / Pentecostal	63	58,88
	Spiritualist	3	2,80
	No religion	7	6,54
	Not answered	5	4,67
Importance of religion	None	2	1,87
	Small	2	1,87
	Moderate	15	14,02
	Very important	81	75,70
	Not answered	7	6,54

Source: The authors.

Objective burden

Table 2 presents objective burden of family caregivers measured by the percentages of answers 1 and 2, considered low burden, and 4 and 5, considered high burden, in FBIS-BR subscales. The results indicate that the majority of family caregivers provide daily assistance to patients (the FBIS-BR tool uses the term 'patient' instead of 'user') from 3 times a week to every day, demonstrating a high level of objective burden for caregivers in this dimension (subscale A). Regarding the daily assistance provided to patients by caregivers, a higher weight of some tasks may be observed. Helping in preparing meals was the activity with greater objective burden to family caregivers (68.22%). The frequency of answers also indicated that the assistance to the patient with personal hygiene (54.21%), reminding them to take medication or give medication (58.88%), helping with housework (54.21%), and asking patients to use their free time (51.40%) contributed to the objective burden. Comparatively, being responsible for the patients shopping (31.78%), accompanying in the transport (31.78%), helping in the administration of his/her own money (40.19%), and reminding about medical consultation (29.91%) determined a lower level of burden felt by family caregivers.

When considering the supervision of the problematic behavior (subscale B), the results indicated that monitoring the patient's excessive smoking and/or drinking non-alcoholic beverage had the greatest responsibility for the objective burden (43.93%). The aspects that contributed less to the burden were the supervision of auto-aggressive behavior and suicidal ideation (3.74%) and the use of illicit drugs (2.80%). The lower frequencies in this subscale may be explained by the fact that all users were under regular follow-up by mental health community services.

Regarding impacts on the caregiver's daily routine (subscale D), none of the items indicated contribution to the increase on the level of objective burden of the family caregivers.

Table 2. Objective family burden

Subscales	Items	Answers 1 and 2*	Answer 3**	Answers 4 and 5***	Not answered
A. Assistance in daily life	Hygiene	37,38%	8,41%	54,21%	0,00%
	Medication	35,51%	4,67%	58,88%	0,93%
	Housework	29,91%	14,95%	54,21%	0,93%
	Shopping	47,66%	17,76%	31,78%	2,80%
	Meals	19,63%	8,41%	68,22%	3,74%
	Transport	40,19%	26,17%	31,78%	1,87%
	Money	52,34%	5,61%	40,19%	1,87%
	Time use	27,11%	21,50%	51,40%	0,00%
	Medical consultation	46,83%	23,36%	29,91%	0,00%
B. Supervision of problematic behavior	Problematic behavior	54,21%	19,62%	26,17%	0,00%
	Demand excessive attention	43,93%	18,89%	39,25%	0,93%
	Night disturbance	71,96%	5,61%	21,50%	0,93%
	Hetero-aggression	80,38%	6,54%	13,08%	0,00%
	Auto-aggression (suicidal ideation)	91,59%	4,67%	3,74%	0,00%
	Excessive drinking	90,65%	3,74%	2,80%	2,80%
	xcessive smoking or drinking (Non-alcoholic beverage)	33,64%	22,43%	43,93%	0,00%
	Drugs use	94,39%	1,87%	2,80%	0,93%

Table 2. (cont.)

	Being delayed or missing appointments	69,16%	18,69%	11,22%	0,93%
D. Impact on caregiver's daily routine	Changes in caregiver's leisure	67,29%	10,28%	22,43%	0,00%
	Changes in household work/routine	60,75%	14,95%	24,30%	0,00%
	Reduction of care to other family members	60,75%	12,15%	27,10%	0,00%

Source: The authors.

* 1 e 2: Never / less than once a week.

** 3: Once or twice a week.

*** 4 e 5: From three to six times a week.

Subjective burden

Table 3 registers the subjective burden experienced by the family caregivers. Subjective burden is considered high from the answers 3 and 4 to the items on daily assistance to the patient and supervision of problematic behavior. On items about the weight of expenses, impacts on caregiver's daily routines, and frequency of worries about the patient, the burden is considered high by answers 4 and 5.

It was possible to observe, as a very relevant fact, that the majority of family caregivers did not feel subjective burden when giving assistance on the patient's daily life (subscale A), despite the high frequency. The task that generated higher discomfort was housework assistance (45.80%); and the task that generated lesser discomfort was cooking for the patient or helping in the preparing meals (15.89%).

The analysis of results also demonstrated the high degree of subjective burden in the supervision of problematic behavior of patients (subscale B), although the frequency of this supervision was low. Monitoring the patient's excessive smoking and/or drinking non-alcoholic beverage (49.53%) and the problematic behavior (51.40%) were the items of higher discomfort to family caregivers. The generation of lesser discomfort came from monitoring the use of drugs and alcoholic drinking (no family caregiver demonstrated discomfort). It is necessary to remember that the PCCAODs were not included in the research.

When analyzing the perception that relatives have regarding the financial weight caused by the role of caregiver during the last year, the results show that the majority of relatives (46.73%) did not feel burdened in this aspect.

Regarding the permanent impact on the daily routine of the caregiver (item D2), the results indicate that the majority of relatives (80.37%) felt this impact on a high level, generating burden in their lives.

The worries with the patients (subscale E) were also items responsible for high subjective burden on relatives. The aspects that are responsible for the higher rates of worry to the relatives refer to the worries with the patient's physical safety (84.11%) and his/her future (85.98%); whereas the aspects that generate less worries were the quality of the treatment (42.99%) and the housing conditions (44.86%).

Table 3. Subjective family burden

Subscales	Items	Answers 1 and 2*	Answers 3 and 4 or 3**	Answers 4 and 5***	No changes	Not answered
A: Assistance in daily life	Hygiene	31,78%	36,45%	-	-	31,78%
	Medication	38,32%	31,78%	-	-	29,91%
	Housework	28,97%	45,80%	-	-	25,23%
	Shopping	37,38%	24,30%	-	-	38,32%
	Meals	63,55%	15,89%	-	-	20,56%
	Transport	47,66%	22,43%	-	-	29,91%
	Money	28,97%	25,23%	-	-	45,79%
	Time use	35,51%	42,99%	-	-	21,50%
	Medical consultation	34,58%	31,78%	-	-	33,64%
B: Supervision of problematic behavior	Problematic behavior	9,35%	28,04%	-	-	39,25%
	Demand excessive attention	21,50%	43,92%	-	-	34,58%
	Night disturbance	8,41%	37,78%	-	-	59,81%
	Hetero-aggression	8,41%	28,04%	-	-	63,55%
	Auto-aggression (suicidal ideation)	4,67%	16,82%	-	-	78,50%
	Excessive drinking	0	10,28%	-	-	89,72%
	Excessive smoking or drinking (Non-alcoholic beverage)	19,69%	49,53%	-	-	31,78%
	Drugs use	0	5,61%	-	-	94,39%
C: Expenses	Weight of expenses with patient	46,73%	21,50%	29,91%	-	1,87%
D: Impact on caregiver's daily routine	D2: Permanent impact on caregiver's life	8,41%	80,37%	-	9,35%	1,87%
E: Worries about the patient	Physical safety	9,35%	6,54%	84,11%	-	0,00%
	Quality of treatment	42,99%	18,69%	38,32%	-	0,00%
	Social life	22,43%	16,82%	60,75%	-	0,00%
	Health	11,21%	15,89%	71,96%	-	0,93%
	Residence	44,86%	10,28%	43,93%	-	0,93%
	Finances	23,36%	9,35%	67,29%	-	0,00%
	Future	5,61%	8,41%	85,89%	-	0,00%

Source: The authors.

*For subscales A and B: 1 – Not at all / 2 – very little; when answer 1 is marked on objective burden scale, the same item should not be answered on subjective burden scale. For subscales C and E: 1 – Never / 2 – Seldom. For subscale D: 1 – Not once / 2 – Less than once a week.

**For subscales A, B and D: 3 – A little / 4 – Very much. For subscale C: 3 – Sometimes.

*** For subscales C and E: 4 – Frequently / 5 – Always or almost always.

Discussion

In accordance with the literature on the subject, this study has identified that mothers are the main patients' caregivers, and they are the ones who experience greater burden comparing to other relatives (BARROSO; BANDEIRA; NASCIMENTO, 2007). Nolasco *et al.* (2014) observe that female relatives accumulate much housework, besides the care with the relative with mental disorder, thus increasing their burden. The authors also point out that those activities are commonly seen as women's work. According to Souza Filho *et al.* (2010), studies on the subject indicate that care relations have been historically constructed from gender division of labor, with social places being determined according to gender; therefore, care became a prevailing female role. The results of the present study corroborate the perception of that tendency, with the finding that the majority of caregivers are women, married, the kinship status being mainly of the patient's mother. Nolasco *et al.* (2014) also observe that this configuration is the result of a distribution of care by the members of families and it mirrors a typical pattern of obligation according to kinship, in which the parents and spouses would be the most involved in the tasks. Eloia *et al.* (2014) report in a survey on the subject how significant is the risk of becoming ill due to the burden in situations of unemployment, especially if the caregiver is a woman, who accumulates several roles (in long work hours) as mother, spouse, housewife, and caregiver, thus jeopardizing her self-care and leisure time.

The results show that the majority of caregivers lived with the user. According to Barroso, Bandeira and Nascimento (2007), this datum slightly differs from international studies with evidences that a large number of relatives does not live with the patient with mental disorder, when compared to the Brazilian context. Also to be stressed is the possibility that this aspect contributes to increase the objective burden regarding care in assisting daily tasks, as observed in this study. The comparison with available data from other countries suggests that in Brazil it is more frequent to have the configuration 'family caregiver living with the user', a fact that deserves more accurate analysis. This phenomenon, if confirmed in further studies in Brazil, may perhaps be attributed to a cultural characteristic (higher availability for the care in the residential environment) or to the capacity of the care network and existing resources (insufficient number of residential services or other devices), or to both factors.

With the results obtained from this research, it was possible to observe that the objective burden was higher regarding the activities of assistance to the patient's daily life than the other tasks. Schein and Boeckel (2012) observe that this characteristic may result from the little participation of patients in those activities, the time involved, and the daily repetition. Regarding the subjective burden, supervising problematic behavior was responsible for greater discomfort. These data coincide with those from Barroso, Bandeira and Nascimento (2007), Schein and Boeckel (2012) e Nolasco *et al.* (2014).

There was a high subjective burden in the majority of relatives regarding the supervision of patients' problematic behavior and the worries about their safety and future. These data can alert mental health services about the need of special support for those dimensions that generate higher burden to relatives, namely how to tackle patients' problematic behavior. It is necessary to make interventions to give orientation to relatives on dealing with those more difficult behaviors that produce uneasiness. According to Delgado (2014), international experience points to health education, training to deal with daily situations, and the elaboration of solidarity and 'mutual help' techniques as devices for the reduction of burden and intra-family crisis, better adhesion of patients to treatment, and greater autonomy of relatives in face of follow-up requirements.

Regarding the tasks of assistance to the patient's daily life, there was a high frequency, though not responsible for high discomfort. Some studies point out that this characteristic may be considered as typical in Brazilian culture: the acceptance of tasks in the care of a relative, whether or not with some kind of disorder (BARROSO; BANDEIRA; NASCIMENTO, 2007). In the survey carried out by Eloia *et al.* (2014) it is stressed that even in face of burden, caregivers take satisfaction in the care of their relatives.

The need to ask the patient to use his/her time was one of the tasks of assistance to daily life that generated a high degree of objective and subjective burden. This register may indicate not only the inactivity of many patients, but also the low efficacy of health services in proposing occupational and recreational activities to users, especially in the case of severe and persistent disorders. Those activities could expand the possibilities of improvement in the user's quality of life and contribute to lessen the burden felt by relatives.

It was also observed that the impacts on the caregiver's daily routine were not responsible for high rates of objective burden. Nevertheless, when observing the permanent impacts on that relative's life, there was a high degree of changes, both in social and professional aspects, leading to high subjective burden. According to Barroso, Bandeira and Nascimento (2007), the literature has been indicating this direction, underlying the fact that restrictions to leisure and social activities constitute the main permanent changes in the relatives' life. A study by Souza Filho *et al.* (2010) has also found permanent changes in the life of relatives, considering the professional, social or daily routine spheres, thus increasing the level of subjective burden. Eloia *et al.* (2014) point out other possible consequences of home care, such as the possibility of family disruption, caregiver's loneliness, and little opportunity for jobs, leisure and resting.

It was observed that worries causing greater discomfort to relatives are related to the patient's future and physical safety (BARROSO; BANDEIRA; NASCIMENTO, 2007; SOUZA FILHO *ET AL.*, 2010). There is a recurrent complaint related to the worry about how the patient's life would be in case of the family caregiver's death, and the data collected in the present study corroborate the registers available in the literature on the subject. Delgado (2014) refers to the presence, in the narrative of relatives, of the theme of fear, expressed by caregivers regarding their own aging and the possibility that they will no longer be alive to take care of the user.

The majority of relatives do not demonstrate a high degree of worry about the patient's housing. This may be related to the fact that the majority of relatives taking part in this research lives with the patient and owns the residence (despite the majority belonging to low-income families, as previously mentioned).

According to the results of this analysis, it is also noteworthy that the majority of relatives did not report worries about the quality of the treatment provided by the 19 PCCs that took part in the research. This fact suggests that the caregivers trust the mental health service and the team responsible for the patients' follow-up. Moreover, in the socio-demographic questionnaire, the majority of relatives reported on the easy physical access to the PCCs (less than 30 minutes away from the residence). In this aspect, the proposal of the mental health policy regarding the creation of care services territorially near the patients, thus facilitating the treatment, may be considered partially successful. The studies by Almeida *et al.* (2010) show evidences that the caregivers highlight the treatment at the PCCs as a possibility to reduce the burden, believing that the adequate treatment reduces the patient's dependency due to the improvement in the symptomatology. Brazilian studies (WAIDMAN;

JOUCLAS; STEFANELLI, 2002; BARROSO; BANDEIRA; NASCIMENTO, 2007), present accounts of relatives who wished that the patients would stay at home, receiving community treatment, even in situations of fragile economic structure and in cases of complex care.

The results of this research show that the majority of users receive some kind of financial support, which in many cases is used to complement the family income. Barroso, Bandeira and Nascimento (2009) report that, differently from international findings, the majority of Brazilian psychiatric patients have some kind of own income, and the main one is the invalidity pension. But there is still a high degree of worry from the caregiver regarding the patient's financial subsistence in his/her absence; other studies have pointed to this worry, especially when the patient has no financial means for subsistence (BARROSO; BANDEIRA; NASCIMENTO, 2009). Even when the patient receives his/her own money, there are still many cases in which the family is responsible for the management of this resource. There are also situations in which those financial benefits are not sufficient to cover all costs and, therefore, the patient is financially dependent on the family. It is noteworthy that, though being a minority (41.12%), a large parcel of patients receives no kind of financial benefit.

Studies on the subject of financial burden (KOGA; FUREGATO, 2002; ALMEIDA *ET AL.*, 2010) report situations in which the patient, after becoming ill, stopped contributing to the family income or reduced the contribution. There is also the aggravating situation of cases in which the family caregiver must stop working to take care of the patient. Koga and Furegato (2002), referring to schizophrenia, highlight that the mental disorder manifests in early age and is chronic, and therefore it produces an impact on the decrease or the loss of the patient's productive capacity, causing onus to the family.

The data collected in this study point to the strong presence of religiosity in the life of family caregivers of psychiatric patients (only 6.54% answered having no religion) and the importance of it (only 1.87% answered having no importance). Barroso, Bandeira and Nascimento (2009) found a lower degree of burden when the relative took part in religious activities and had leisure at home. The authors also observe that in empirical studies and literature surveys, religious practices are the main strategy adopted by relatives to face the situation in the Brazilian context. These items contribute to alleviate the subjective burden. These data also appear in the studies carried out by Bandeira and Barroso (2005), in which relatives mentioned religion as a source of support and one of the strategies adopted by those who help to feel better in the condition of caregivers. Eloia *et al.* (2014) also highlight religion and spirituality as factors of support to the family.

The results suggest the importance of dedicating attention and space to help the family in their difficulties, thus minimizing the burden and improving the quality of life. According to Falloon (2003), the sheer fact of convening regular family meetings in which the relatives are stimulated to talk openly about their tensions and strategies to deal with their most urgent problems, seems to have had a quite substantial therapeutic impact in a number of cases. Mielke *et al.* (2009) highlight that the family may also play an important role in the user's treatment, as a partner in the therapeutic follow-up, and in this sense facilitate social inclusion. The authors state that when the family is well received and informed, they become allies in the user's deinstitutionalization. The relationship of the family with the service helps the professionals' work and also favors the relatives in the work with the user. The relatives that were interviewed for this study were engaged in a project of health education and support to protagonism, and this participation seems to have had a positive influence in managing the burden. As previously pointed out, Delgado (2014) highlights that the family involvement in health education projects – that aim to clarify questions related to becoming ill and to promote the sharing of knowledge and experiences – presents positive results and helps in the strategies of care; nevertheless, there is a complaint about the lack of this kind of initiative in the services. The author also stresses that the PCCs must make a reflection about the relationship between the service professionals and the relatives, as clients or as partners in the care. According to Eloia *et al.* (2014), many phenomena related to the burden could be better managed if there would be an adequate guidance to family members. Olschowsky and Schrank (2008) highlight that the care should be a collective action shared between the health team and the family, to promote the user's autonomy, reconquering his/her citizenship and place in society.

The researches in the area highlight the importance of the relative's empowerment in face of the issues of the patient's treatment. According to Vasconcelos (2013), empowerment is the greater power and personal and collective autonomy of subjects and/or social groups, especially those submitted to relations of oppression, submission and social discrimination. In the sphere of mental health, the concept of empowerment is related to self-care, mutual help initiatives, changes in the culture regarding mental disorder in the society, and the defense of rights. Alves, Oliveira and Vasconcelos (2013) also highlight the participation and organization of relatives regarding users, in the sense of the care in the substitute services and also in the strategies of defense of rights and participation in social movements. The changes proposed by the mental health reform point to a condition of greater action of the family, that is convened to be co-responsible, together with the service professionals, for the patient's care and psycho-social rehabilitation (DIMENSTEIN *ET AL.*, 2010). In the 1960s, Franco Basaglia already defended the strengthening of the bonds between family and health professionals (DIMENSTEIN *ET AL.*, 2010; BASAGLIA, 1985). Bandeira *et al.* (2011) state that when assessing the treatment provided to the user of a health service it is crucial to include the family caregiver, because this generates a sense of empowerment and may produce a decrease in the level of burden. The family is, thus, called to act together with the health team, but also receives a place of its own, so it may expose all the difficulties and uncertainties faced in the role of caregiver.

Dimenstein *et al.* (2010) remind that the families have been, for many years, separated from the user and in some cases even made guilty for the disease; thus, bringing them back to the service deserves a specific care. The authors also reflect about an imperative of family participation in the activities previously defined by the service, which requires time availability from the subject; this results in burden increase, because some relatives report that they would like to have more participation, but there is lack of time and preparation. The incorporation of the family should be made confortable and welcoming, because there is the fear and uncertainty in face of the unknown, which is the mental disorder. The empowerment may be achieved, not thru the authoritarian convene to the participation of the family, but rather with the increase of self-esteem and autonomy, the stimulus to create projects with the family's protagonism, the elaboration of information booklets that clarify about the rights of people with mental disorders, and the strengthening of associations and cooperatives of families and users, among others (ALVES; OLIVEIRA; VASCONCELOS, 2013).

Final considerations

This study presents a number of limitations. It is an exploratory and descriptive study, which does not utilize stratified sample of family caregivers, thus not permitting the extrapolation of findings to all family caregivers of PCCs. Nevertheless, considering that the recruitment was made in all the PCCs of the region under study, thru the family meetings, it can be stated that the group of participants is, in some degree, representative of the entirety of family caregivers of those services under study. There is also the limitation of the instrument of data collection, which in some aspects is not sufficiently comprehensive or clear, though it certainly is a useful and objective questionnaire that has been validated in Brazil.

The results shown here may contribute to extending the study about the subject of burden experienced by family caregivers of patients with psychiatric disorders and, therefore, improve the model of assistance offered by the mental health services and expand the contribution to public policies that are solidary with the proposals of the Brazilian Mental Health System Reform. The study may contribute to the reflection about the user's psychosocial rehabilitation and the importance of the insertion of the family caregiver in the treatment in a broad, informed and participative way.

The bibliography survey demonstrates that the mental health services still lack regular actions that aim to inform the family caregivers, especially in regard to problematic behavior related to the disorders, to help with the management of those situations. It also demonstrates the importance of empowerment as a strategy to promote autonomy and to help in the social reinsertion. This approach could contribute to the daily issues of family caregivers, diminishing the experienced burden.

The strategies used by mental health do not as yet contemplate the family caregiver in a comprehensive way and do not adequately enhance the role of the caregiver. It is necessary to look at this segment, its contributions, the difficulties faced, and above all its importance in the process of the user's care. Therefore, there is an urgent need to develop public policies and practices of community care that are inclusive in the benefit of family caregivers, such as groups of health education, groups of mutual help, domiciliary visits, and assistance in the development of strategies to face the burden. ■

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