Original Article

Caregiver and burden health care of patients discharged from psychiatric hospitalization*

O cuidador e a sobrecarga do cuidado à saúde de pacientes egressos de internação psiquiátrica

El cuidador y la sobrecarga del cuidado a la salud de pacientes egresados de internamiento psiquiátrico

Lucilene Cardoso[1], Sueli Aparecida Frari Galera[2], Mariana Verderoce Vieira[3]

ABSTRACT

Objective: To identify the sociodemographic characteristics and the level of burden on family caregivers of patients discharged from psychiatric hospitalization. **Methods:** A quantitative exploratory study, performed in an outpatient mental health setting, using a questionnaire and the *Burden Assessment Scale for Families*. The sample was composed of 21 caregivers of patients discharged from psychiatric hospitalization. **Results:** All caregivers had a family relationship, the mean age was 46 years, of whom the majority were women. Mothers were the primary caregivers in 38% of the cases. All presented a level of burden, with the objective lens predominantly higher. The highest mean scores were related to concerns about physical security and the future of the patient. **Conclusion:** Considerable family burden was identified among caregivers, which highlights the importance of a collaborative relationship between mental health services, patients, their caregivers and their families for better maintenance of psychiatric treatments.

Keywords: Psychiatric nursing; Burden; Caregiver; Family; Mental health

RESUMO

Objetivo: Identificar as características sóciodemográficas e o grau de sobrecarga dos familiares cuidadores de pacientes egressos de internação psiquiátrica. **Métodos:** Estudo quantitativo exploratório realizado em um ambulatório de saúde mental utilizando um questionário e a Escala de Avaliação da Sobrecarga dos Familiares. A amostra compôs se de 21 cuidadores de pacientes egressos de internação psiquiátrica. **Resultados:** Todos os cuidadores tinham vínculo familiar, média de idade de 46 anos, sendo a maioria mulheres. As mães foram as principais cuidadoras em 38% dos casos. Todos apresentaram grau de sobrecarga, sendo a objetiva predominantemente maior. Os maiores escores médios relacionaram se às preocupações com a segurança física e futuro do paciente. **Conclusão:** foi identificada considerável sobrecarga familiar entre os cuidadores o que evidencia a importância de uma relação colaborativa entre os serviços de saúde mental, pacientes, seus cuidadores e suas famílias para melhor manutenção dos tratamentos psiquiátricos.

Descritores: Enfermagem psiquiátrica; Sobrecarga; Cuidador; Família; Saúde mental

RESUMEM

Objetivo: Identificar las características sociodemográficas y el grado de sobrecarga de los familiares cuidadores de pacientes egresados de internamiento psiquiátrico. **Métodos:** Estudio cuantitativo exploratorio realizado en un consultorio externo de salud mental utilizando un cuestionario y la Escala de Evaluación de la Sobrecarga de los Familiares. La muestra estuvo compuesta por 21 cuidadores de pacientes egresados de internamiento psiquiátrico. **Resultados:** Todos los cuidadores tenían vínculo familiar, con promedio de edad de 46 años, siendo la mayoría mujeres. Las madres fueron las principales cuidadoras en el 38% de los casos. Todos presentaron grado de sobrecarga, siendo la objetiva predominantemente mayor. Los mayores escores promedio se relacionaron a las preocupaciones con la seguridad física y el futuro del paciente. **Conclusión:** se identificó una considerable sobrecarga familiar entre los cuidadores lo que evidencia la importancia de una relación colaborativa entre los servicios de salud mental, pacientes, sus cuidadores y sus familias para el mejor mantenimiento de los tratamientos psiquiátricos.

Descriptores: Enfermería psiquiátrica; Carga; Cuidador; Familia; Salud mental

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**Study conducted at the University of São Paulo at Ribeirão Preto College of Nursing – EERP/USP.*

[1] *Professor. Department of Psychiatric Nursing and Human Sciences, University of São Paulo at Ribeirão Preto College of Nursing – EERP/USP – Ribeirão Preto (SP), Brazil.*

[2] *Free Docent. Department of Psychiatric Nursing and Human Sciences, University of São Paulo at Ribeirão Preto College of Nursing – EERP/USP – Ribeirão Preto (SP), Brazil.*

[3] *Post-graduate Student (Doctoral). Department of Psychiatric Nursing and Human Sciences, University of São Paulo at Ribeirão Preto College of Nursing – EERP/USP – Ribeirão Preto (SP), Brazil.*

Corresponding Author: **Lucilene Cardoso**
Avenida Bandeirantes, 3900, DEPCH/EERP/USP, sala 60, Ribeirão Preto
CEP: 14040-902. São Paulo – Brasil
E-mail: lucilene@eerp.usp.br

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INTRODUCTION

Psychiatric hospitalization is a resource used judiciously, for a short term, and at present is indicated for serious cases when extra-hospital resources for treatment have been exhausted, since the hospital of persons in institutions with characteristics of an asylum is prohibited(1,2). The maintenance of mental health care has moved from health institutions to the home of these patients, and consequently, to their families, showing increasing evidence of the role of family members as caregivers.

Because of the process of deinstitutionalization of psychiatric care and the severe and chronic nature of mental disease, the family and especially the family member/care-giver is submitted to constant stressor events during the course of these diseases, which may affect not only family relationships, the health of the family/care-giver itself, but always brings about some degree of burden, causing the constant need for adaptations(3,4).

For the first time, Hoenig and Hamilton defined family burden as a family burden carried by families the mentally ill(5). In the English language, the term *burden* is frequently used to describe the negative aspects associated with the care of sick individuals and is equivalent to expressions such as onus, impact, burden and interference.

The adverse consequences of mental disease in a family member, for families has been systematically documented and points towards the fact that all the areas of family functioning are affected by the presence of mental disease(5-7). It is important to note that burden related to care in mental health is an easily perceivable phenomenon, and that it persists even when the patient responds positively to innovative and effective treatments.

This burden has two aspects: objective and subjective(8). The objective aspect is related to the negative consequences of the presence of a mentally ill person in the family, such as: Accumulation of tasks, increase in financial costs, limitation on day-to-day activities, weakening of relationships between family members, among.

Subjective burden concerns the family's personal perception of the experience of living with the mentally ill patient, their feelings as regards the responsibility and concerns involved in caring for the patient's heath. From this angle, the mentally ill person's lack of autonomy is seen as a negative aspect that generates stress and worry, affecting the family member emotionally. Subjective burden is related to feels of lack of support, sadness and guilt(6,8,9).

As psychiatric hospital is a procedure directed towards situations of crisis for the patient and his/her family, the aim of this study is to broaden the knowledge of health professionals on the delicate situation that results after this hospitalization, exploring the question of burden of the care-giver of patients discharged from a psychiatric hospital. Considering that it is of great importance to health promotion, this burden felt by caregivers needs to be correctly identified and worked on by the health times at the different times in which it develops.

The aim of this study was to identify the sociodemographic characteristics and degree of burden on family members who provide care for persons with mental illness, who have been discharged from a psychiatric hospital.

METHODS

An exploratory, descriptive prospective study with a quantitative approach was conducted in a Mental Health Unit (MHU) attached to a School Health Center located in the interior of the State of São Paulo. The sample consisted of all the caregivers of patients discharged from a psychiatric hospital, over the age of 18 years, who agreed to participate in the research. In the routine of the mentioned service, discharged patients go through a medical consultation a few days after being discharged, and this was the time when the caregivers were identified. This was done according to the patient's opinion, and the caregivers was considered to be the person, whether or not he/she was a family member, who cares for the patient, helping him/her with daily life activities and the maintenance of treatment(2).

Data collection occurred at the mentioned service in 2008, with a duration of 4 months, by means of closed questions, with the following instruments being used: Questionnaire on sociodemographic data, which contemplated the following variables: *Diagnosis of the discharged patient, the Family caregivers tie with the patient; Family member's Gender; his/her Age; Degree of schooling; Marital status; Number of children; Job; Opinion about the importance of psychopharmalogical treatment*; Family Burden Interview Scale for Relatives of Psychiatric Patients – Brazilian version FBIS-BR – to evaluate burden on family members who care for psychiatric patients(10).

The FBIS-BR scale evaluates five dimensions of objective and subjective burden on family members of psychiatric patients. The following dimensions were assessed: Assistance with the patient's day-to-day life; supervision of the patient's problematic behaviors; family's financial expenses with the patient; impact on family's daily routine; and family's worries about the patient. The questions on the scale refer to the last 30 days.

The sociodemographic data were analyzed by means of descriptive statistics (measures of central tendency frequency, percentage, calculation of means) and for analysis of data with reference to burden, these were treated in accordance with the guidelines of the instrument, and analyzed by the percentage of responses to the items of the FBIS-BR scale and the (by Friedman's test) to identify the items that lead to the greatest burden on family members. The statistical program SPSS, version 10.0 was used. As the FBIS-BR does not have an established cut-off point, the indication of high burden is made considering the percentage of replies to the last two points on the Likert-type scales for each sub-scale**[8,10]**.

The research project was approved by the Research Ethics Committee of the mentioned service (Protocol No. 254/CEP-CSEFMRP-USP). The project was duly explained to all the participants, who signed the Term of Free and Informed Consent, and received a copy of it, guaranteeing them their rights and providing contact with the researchers whenever necessary.

RESULTS

Of the 48 patients identified on discharge from psychiatric hospital, only 21 affirmed that they had a care-giver (a person who helped them with the maintenance of their treatment). It was thus verified that the majority (56.2%) of the patients did not have a care-giver at the time of the research. All the patients who presented caregivers were diagnosed as having severe and persistent mental illness, with Schizophrenia being the most prevalent diagnosis among them (52.4%). The other diagnoses identified were: Mood Disorders (affective) (28.6%), Personality Disorders (14.4%) and Persistent Somatoform Pain Disorder (4.8%).

Caregivers of patients discharged from a psychiatric hospital

The caregivers had a mean age of 46 years; the majority were women (76.2%); married (61.9%), had children (95.2%), had first grade Primary Schooling; (71.4%), were unemployed, or had eventual jobs (43%). Among the 21 caregivers interviewed, there was the unanimous opinion that medication treatment of mentally ill patients is important.

Burden on caregivers of patients discharged from a psychiatric hospital

The care of patients who have recently been discharged from a psychiatric hospital brought about some degree of burden on the caregivers in all the cases. There was a mean total burden of 3.03. The mean objective burden was 2.41, with the highest burden being equal to 3.68 and the lowest being equal to 1. The mean subjective burden was 1.67, ranging between 2.59 and 0.91.

Objective burden was predominantly greater among these caregivers and they mentioned the concrete negative consequences involved in the process of caring. The activities of food preparation, administration of medications, administration of money and supervising problematic behaviors were the factors that most brought about burden on these caregivers. With regard to subjective burden, the activities that generated the highest degree of burden were: "a*sking the patients to occupy their time"* and, once again, *"supervising the problematic behaviors of patients*".

The data in Table 1 present the description of objective burden of caregivers by the percentage of replies 1 and 2 (which indicate low burden) and 4 and 5 (which indicate elevated burden in the item) in the sub-scales of the FBIS-BR, related to objective burden and the analysis of variance of statements.

Performing tasks in the day-to-day assistance provided to patients discharged prom psychiatric hospital caused significant objective burden on caregivers. As may be observed from the data shown in Table 1, "*preparing or helping patients to prepare meals"* (6.60) was the activity that resulted in the greatest objective burden on family members ($c2 = 35.213$; $p \leq 0.000$- Friedman's Test).

"Helping patients to administer their medications" (5.76), "*helping them with the administration of money"* (5.74), "*transporting them"* (5.38), "*doing shopping for them"* (4,93), *"asking patients to occupy their time"* (4.83), *"helping them to take care of cleaning the room and clothes"* (4.14) were tasks that also contributed to the objective burden of these family members. "*Remind patients about the doctor's appointments"* (4.10) and "*help them with hygiene and personal care*" (3.52) were the tasks that least contributed to the objective burden of family members.

Considering the supervision of problematic behaviors (sub-scale B), the results indicated that supervising "*problematic behaviors of patients*" (5.88) was the factor that generated the greatest objective burden on family members ($c2 = 33.298$; $p \leq 0.000$). The "*attempt or threat of suicide"* (5.21) was the second major question related to the objective burden on caregivers. The items that made the least contribution in this sub-scale were "*supervise drug abuse"* (3.62) "*alcoholic beverages"* (3.69) and "*foods, cigarettes and liquids"* (3.69).

The results relative to the items of *sub-scale D – Impact on routine*, alterations in daily life due to being a caregiver, did not indicate any item as being a generator of objective load in the sample of family member caregivers($c2 = 5.816$; $p = 0.121$).

The data in Table 2 present the description of subjective burden on the family member caregivers researched. Elevated burden is indicated by replies 3 and 4, to the items on the degree of inconvenience in day-to-day help provided; supervision of problematic behaviors and impact on the caregiver's routine, and by replies 4 and 5 to the items on the frequency of worries about patients.

Table 1. Replies in percentage of family member caregivers, to questions that evaluated objective burden, in each sub-scale A, B and D of the FBIS-BR-2008

Sub-scales and questions	Replies 1 and 2[a] %	Replies 4 and 5[b] %	Mean of statements/ (postos) %
Sub-scale A: Helping the patient in day-to-day life			
A1 – Hygiene and personal care	76.2	14.3	3.52
A2 – Administration of medications	47.6	47.6	5.76
A3 – Care and cleaning of the room and clothes	66.7	33.3	4.14
A4 – Various purchases	57.2	42.9	4.93
A5 – Preparing food	28.6	71.4	6.60**
A6 – Transport	42.9	38.1	5.38
A7 – Administration of money	42.9	57.1	5.74
A8 – Activities and occupying time	52	33.3	4.83
A9 – Frequency of doctor's appointment and treatment activities	66.	19.0	4.10
Sub-scale B: Supervision of problematic behaviors			
B1 – Problematic behaviors	57.1	28.6	5.88**
B2 – Excessive demand for attention	71.4	14.3	4.83
B3 – Disturbances during the night	71.4	14.3	4.81
B4 – Verbal and physical aggressiveness	90.4	4.8	4.26
B5 – Attempted or threat of suicide	76.2	14.3	5.21
B6 – Alcoholic beverages*	95.2	4.8	3.69
B7 – Excessive intake of foods, cigarettes and liquids.	95.2	4.8	3.69
B8 – Drug abuse *	95.2	4.8	3.62
Sub-scale D: Impact on routine*			
D1a – Non appearance at, being late for or cancellation of appointments.	52.4	19.0	2.15
D1b – Alteration in social and leisure activities	52.4	28.6	2.76
D1c – Disturbance in house work or routine	47.6	33.3	2.89
D1d – Alteration in care and attention to other members of the family	71.4	23.8	2.39

* Items that were not counted in the score calculations: Sub-scale C does not apply to score calculations, it concerns monetary values of the patient's expenses and contribution by the patient; items that evaluate permanent changes that have occurred in the family's life (within sub-scale D); items 6 and 8 of sub-scale B did not attain the minimum criterion of item-total correlation in validation of the scale. (** p ‹ ,000 ; [a] 1= Not even once and 2= less than once a week; [b] 4=three to six times a week and 5=every day). (n=21, n being = absolute number of caregivers researched).

The majority of family members did not manifest elevated subjective burden due to performing day-to-day task in helping discharged patients, as observed in the data in Table 2, replies 1 and 2. "*Ask patients to occupy their time*" (5.79) was the task that most caused inconvenience among the caregivers (c2 = 19.805; p ≤0.011). The tasks that caused the least inconvenience in helping the patient in day-to-day life were: "*taking care of cleaning the room and clothes*" (4.05), "*hygiene and personal care*" (4.19)

With regard to supervising "*problematic behaviors of patients*", the results indicated elevated subjective burden on the family members (5.90), item B1b (39.286; p ≤0.000). The item "*attempted or threat of suicide*" (5.38) was also related to elevated subjective burden. The items that generated the least inconvenience to family members were: "*supervising the behaviors of smoking or excessive drinking of non alcoholic beverages*" (5.55), "*supervising the use of drugs*" (3,45) and "*alcoholic beverages*" (3.67).

Among the worries about patients, sub-scale E, the aspects that generated the greatest worry to family members, according to Friedman's Test (c2 = 48.186; p ≤0.000), were with reference to "*worries about the future*" (5.79) and about "*the physical safety*" of the patients (5.05). The items occurring with the least frequency in this sub-scale were : "*the living conditions of the patients*" (2.24) and the "*quality of treatment*" (2.83).

Table 2. Replies of family member caregivers, to questions that evaluated subjective burden, in each sub-scale A, B and D of the FBIS-BR-2008

Sub-scales and questions	Replies 1 and 2[a]	Replies 3 and 4[b]	Replies 4 and 5[b]	Mean of statements/ (postos)
Sub-scale A: Helping the patient in day-to-day life				
A1 – Hygiene and personal care	20 (95.2)	1 (4.8)	-	4.19
A2 – Administration of medications	20 (95.2)	1 (4.8)	-	5.76
A3 – Care and cleaning of the room and clothes	21 (100.0)	0	-	4.05
A4 – Various purchases	20 (95.2)	1 (4.8)	-	4.43
A5 – Preparing food	17 (81.0)	4 (19.0)	-	5.52
A6 – Transport	16 (76.2)	5 (23.8)	-	5.64
A7 – Administration of money	18 (85.7)	3 (14.3)	-	4.90
A8 – Activities and occupying time	15 (71.4)	6 (28.6)	-	5.79**
A9 – Frequency of doctor's appointment and treatment activities	17 (81.0)	4 (19.0)	-	4.71
Sub-scale B: Supervision of problematic behaviors				
B1 – Problematic behaviors	14 (66.7)	7 (33.3)	-	5.90***
B2 – Excessive demand for attention	18 (85.7)	3 (14.3)	-	4.55
B3 – Disturbances during the night	17 (81.0)	4 (19.0)	-	4.88
B4 – Verbal and physical aggressiveness	18 (85.7)	3 (14.3)	-	4.50
B5 – Attempted or threat of suicide	15 (71.4)	6 (28.6)	-	5.38
B6 – Alcoholic beverages*	20 (95.2)	1 (4.8)	-	3.67
B7 – Excessive intake of foods, cigarettes and liquids.	20 (95.2)	1 (4.8)	-	3.67
B8 – Drug abuse *	21 (100.0)	0	-	3.45
Sub-scale E: Worries about the patient				
E1 – The patient's physical safety	2 (9.5)	-	17 (80.9)	5.05
E2 – Suitability of the medical treatment provided to the patient	13 (61.9)	-	5 (23.8)	2.83
E3 – The patient's social life	4 (19.0)	-	10 (47.6)	4.17
E4 – The patient's physical health	6 (28.6)	-	11 (52.4)	4.07
E5 – Living conditions for the patient	16 (76.2)	-	4 (19.0)	2.24
E6 – The patient's financial survival in the caregiver's absence	8 (38.1)	-	11 (52.4)	3.86
E7 – The patient's future	1 (4.8)	-	18 (85.7)	5.79***

* Items that were not counted in the score calculations: Sub-scale C does not apply to score calculations, it concerns monetary values of the patient's expenses and contribution by the patient; items that evaluate permanent changes that have occurred in the family's life (within sub-scale D); items 6 and 8 of sub-scale B did not attain the minimum criterion of item-total correlation in validation of the scale; ** p ‹ .01; *** p ‹.000 ; [a] 1= Not even a little or never; 2= very little or rarely; [b] 3=a little or sometimes; 4= a great deal or frequently and 5 =always or almost always. (n=21, n being = absolute number of caregivers researched).

DISCUSSION

In general, patients who have been discharged from hospital have *Mood Disorder* and *Schizophrenia* as the most frequent diagnoses; have previously been hospitalized, with risk of suicide (the idea and attempt), self- or hetero-aggression being among the main reasons for hospital(11,12). These are serious, frequently chronic conditions which, by reason of their nature and course, demand great dedication and care in: the maintenance of treatment, and making feasible the safety and comfort of the patient and his/her family. This care is primarily attributed to the caregiver, with the help and support of services, replacing the hospital-centric model, in accordance with the guidelines defined by the present mental health assistance policy in the Country(2).

It so happens that this articulation between mental health services, family and caregivers is still at the stage of development and presents innumerable weaknesses. This may be due to the lack of professional qualification, lack of resources, insufficient basic community mental health services, lack of qualified professional assistance to meet this demand, or due to social prejudice, by the family member's inability to deal with serious conditions experienced in day to day life.

The caregiver's inability is further aggravated by the absence of appreciation of the services and society with regard to the important role the caregiver plays in the maintenance of psychiatric treatment, which may be related to the difficulty the researchers experienced with identifying the caregivers of these patients. As occurred in the research, there was evidence of the patients' difficulty in recognizing and presenting those who were their caregivers, which was the main limitation imposed on the investigation.

This complex context related to mental health care favors the development of burden, particularly on the caregiver, commonly represented by a family member, in addition to the difficulty of the services to work on their potential action in the maintenance of psychiatric treatments.

Family members and the significant presence of women, essentially mothers, were outstanding in the role of caregivers of patients discharged from a psychiatric hospital. It is known that almost everywhere in the world, and it is no different in Brazil, the role of caregiver is attributed to women by cultural and social norms, so that young women must look of the children, and afterwards when they are older, they are also held responsible for the care of the husband, elderly and sick in the family nucleus(13). In some cases, this burden takes on a dimension that may contribute to the development of depressive conditions among caregivers(14).

When related to discharge from hospital, this burden was shown to be connected, above all with the caregiver's task of performing activities of food preparation, supervising problematic behaviors and provide the patient with him in occupying his/her time. It is especially related to caring for patients with severe mental illness, but in this case, patients with severe mental illness who have been discharged from hospital(5,8,10).

Often, the burden is related to compromise of the patients' capacity in performing daily life tasks causing strong impact on the burden felt by caregivers. This situation cannot always be overcome by the treatments available at present (15-17), showing the importance of developing interventions for the empowerment of patients and their caregivers to help in reducing this incapacity, and consequently, the burden on the caregiver.

However, the data with respect to burden show evidence of the need for more attention to be made available by the health team of the mental health services, in order to assist this caregiver, family member, who also lacks attention to her health.

On being considered the foundation of treatment, the families are closer to monitor the manifestations of the disease and efficacy of treatment. Being more active in the maintenance of this care, the family members of the mentally ill frequently live negatively together with the behavioral unpredictability of the patient, and with the costs of this dedication. In this context they become more susceptible to the innumerable day-to-day difficulties with the maintenance of treatment of these patients, which may cause the variations in family burden.

FINAL CONSIDERATIONS

The innovations generated by the change in paradigms in psychiatric assistance have cast families in the fundamental role of maintaining the care of mentally ill patients. In the case of caregivers of patients who have been discharged from a psychiatric hospital, this role has been assumed by women, with considerable burden related to metal health care, particularly as regards objective burden. As the subjective burden is not always assumed by these caregivers, this make it difficult to identify it clearly.

Moreover, in this study, the difficulty faced was that the patients themselves found it hard to recognize who their caregivers were in their social and family context, and who their allies were in the maintenance of psychiatric treatment, this being the main limitation of the study.

By means of research and improvement in the practices of care for the patient discharged from a psychiatric hospital and his/her caregiver, health professionals may share the responsibilities and roles with them, and cooperate with a better ability to face up to mental illness and the maintenance of psychiatric treatment. Conducting researches to achieve more effective interventions with these caregivers and the families of psychiatric patients constitutes one of the components of community treatment and may contribute to the development of the assistance offered.

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