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ORIGINAL ARTICLE

EVALUATION OF OVERLOAD ON FAMILY CAREGIVERS OF INDIVIDUALS WITH SCHIZOPHRENIA

AVALIAÇÃO DA SOBRECARGA DE FAMILIARES CUIDADORES DE INDIVÍDUOS COM ESQUIZOFRENIA

EVALUACIÓN DE LA SOBRECARGA DE LOS CUIDADORES FAMILIARES DE PERSONAS CON ESQUIZOFRENIA

Carla Rodrigues Pereira[1], *Raissa Caroline de Oliveira*[2], *Diego Dias de Araújo*[3], *Renê Ferreira da Silva Junior*[4], *Ricardo Otávio Maia Gusmão*[5]

ABSTRACT

Objective: to evaluate the overload (objective and subjective) experienced by family caregivers of individuals with schizophrenia. ***Method:*** this is a quantitative, descriptive study with 15 family members who directly or indirectly cared for the individual with schizophrenia in a Psychosocial Care Center. Data was analyzed using nonparametric statistics. ***Results:*** there was objective overload of family members in the preparation of meals (60%), patient follow-up in transportation (66.7%), administration of patient money (80%), follow-up at medical appointments (60%), supervision of problem behaviors (33.3%), suicidal behavior (33.3%) and excess cigarettes, food and liquids (33.3%). ***Conclusion:*** the main objective and subjective overloads experienced by caregivers of individuals with schizophrenia were evaluated, thus contributing to the reflection of the services on necessary interventions. ***Descriptors*:** Mental Health; Schizophrenia; Family Relationships; Caregivers; Mental Health Services; Psychosocial Impact.

RESUMO

***Objetivo*:** avaliar a sobrecarga (objetiva e subjetiva) vivenciada pelos familiares cuidadores de indivíduos com esquizofrenia. ***Método*:** trata-se de um estudo quantitativo, descritivo, com 15 familiares que cuidavam diretamente ou indiretamente do indivíduo com esquizofrenia em um Centro de Atenção Psicossocial. Analisaram-se os dados por meio da estatística não paramétrica. ***Resultados*:** evidenciou-se sobrecarga objetiva dos familiares no preparo das refeições (60%), acompanhamento do paciente no transporte (66,7%), administração do dinheiro do paciente (80%), acompanhamento nas consultas médicas (60%), em relação à supervisão de comportamentos problemáticos (33,3%), comportamento suicida (33,3%) e excesso de cigarros, alimentos e líquidos (33,3%). ***Conclusão*:** avaliaram-se as principais sobrecargas objetivas e subjetivas vivenciadas pelos cuidadores de indivíduos com esquizofrenia, possibilitando assim, contribuir para a reflexão dos serviços sobre intervenções necessárias. ***Descritores*:** Saúde Mental; Esquizofrenia; Relações Familiares; Cuidadores; Serviços de Saúde Mental; Impacto Psicossocial.

RESUMEN

Objetivo: evaluar la sobrecarga (objetiva y subjetiva) experimentada por los cuidadores familiares de personas con esquizofrenia. ***Método:*** este es un estudio cuantitativo y descriptivo con 15 miembros de la familia que cuidaron directa o indirectamente al individuo con esquizofrenia en un Centro de Atención Psicosocial. Los datos se analizaron mediante estadísticas no paramétricas. ***Resultados:*** hubo sobrecarga objetiva de miembros de la familia en la preparación de comidas (60%), seguimiento del paciente en transporte (66.7%), administración del dinero del paciente (80%), seguimiento en citas médicas (60%), supervisión de conductas problemáticas (33.3%), conductas suicidas (33.3%) y exceso de cigarrillos, alimentos y líquidos (33.3%). ***Conclusión:*** se evaluaron las principales sobrecargas objetivas y subjetivas experimentadas por los cuidadores de individuos con esquizofrenia, contribuyendo así a la reflexión de los servicios sobre las intervenciones necesarias. ***Descriptores*:** Salud mental; Esquizofrenia; Relaciones Familiares; Cuidadores; Servicios de Salud Mental; Impacto Psicosocial.

[1]Montes Claros University State/UNIMONTES. Montes Claros (MG), Brazil. [1]http://orcid.org/0000-0001-5961-5681 [2]http://orcid.org/0000-0001-6295-0499 [3]http://orcid.org/0000-0002-8927-6163 [4]http://orcid.org/0000-0002-3462-3930 [5]http://orcid.org/0000-0001-9941-1114

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INTRODUCTION

Schizophrenia is known to affect all peoples and cultures in an estimated prevalence of 1% of the population. It is the main form of psychosis due to its frequency and clinical importance and is characterized by the presence of typical symptoms, such as hallucinations and delusions; disorganized thinking; bizarre behavior and inappropriate or dull affects. It occupies a place among the most incapacitating diseases, producing a high cost for society and becoming an overload for the affected individual, family and community.[1,2]

It is considered that mental health care in Brazil has been undergoing several transformations resulting from the Brazilian Psychiatric Reform, initiated in the late 70's and legitimized by Law No. 10.216, of April 6, 2001. It stands out among its strategies the expanded conception of health, the focus of attention in the territory, the intersectoriality, the networking and the focus on the family. As a result, the responsibility for the care of people with mental disorders has also come from the family and at home.[3]

In this sense, the family is requested to be a partner of the new services and to reaffirm itself as one of the possible spaces for the provision of care, starting to be conceived as necessary and allied with their family member with mental disorder. It is known that the family lives and suffers intensely due to psychological distress, feelings of distress, isolation, depression, anguish, fear, guilt and chronic sadness that can lead to overload.[4,1]

It is considered that individuals with schizophrenia may present functional impairment, difficulties to perform activities of daily living (ADL) and instrumental activities of daily living (IADL) such as eating, grooming and taking care of personal hygiene, going to the toilets, transport, shopping, meal preparation and medication management, often requiring a caregiver who is often a family member to assist with their activities.[5,6]

It is reaffirmed that the presence of people with mental disorders in the family and home generates a heavy overload for all its members. This overload is seen in its objective and / or subjective extension.[4]

It is noteworthy that objective overload refers to changes that usually happen in the family member's routine due to the restriction of their social and family life, financial expenses and losses, supervision of problematic behaviors that hinder their life projects. Subjective overload includes concerns, discomforts in the task of caring and concerns arising from care.[7]

It is identified in clinical nursing practice, the caregiver overload through the nursing diagnosis "Tension of the caregiver role". It is defined by the difficulty to play the role of family caregiver. Becoming a caregiver, in some situations, means taking care of the other and neglecting yourself. This situation can be aggravated as the mental disorder is usually not transient and has a long duration requiring permanent adaptations.[8,9]

Considering the transfer of responsibility for mental health care, previously provided entirely by psychiatric institutions, to the family members, it is understood that this process has generated several changes in the dynamics of families, in their way of functioning, being very commonly accompanied by overload and suffering. It is believed that research on this reality can produce contributions to health services by facilitating the implementation of care for relatives of people with mental disorders.

OBJECTIVE

- To evaluate the overload (objective and subjective) experienced by family caregivers of individuals with schizophrenia.

METHOD

This is a quantitative, descriptive study at a Psychosocial Care Center (CAPS) II in a municipality in the northern region of Minas Gerais (MG), Brazil. CAPS is a service that is part of the Specialized Psychosocial Care component of the Psychosocial Care Network (RAPS), which aims to assist people with severe and persistent mental disorders and those with needs arising from the use of crack, alcohol and other drugs in its territorial area under intensive, semi-intensive and non-intensive treatment.[10]

The convenience sampling technique was used, thus, 15 family caregivers of patients diagnosed with schizophrenia participated. Family members of both sexes, aged over 18 years, who directly or indirectly cared for the patient and consented to participate in the study were included. The number of participants with the clinical staff of the service was defined, consisting of family members of patients who were admitted during the second semester of 2017.

Data was obtained through a family member description questionnaire that provided information from the caregiver and application of the Family Overload Rating Scale (FBIS-BR).

The FBIS-BR scale was used to assess the degree of objective and subjective overload of family members of psychiatric patients consisting of the following subscales: A) Assistance in the patient's daily life; B) Supervision of the patient's problematic behaviors; C) Financial expenses; D) Impact on daily family routines; E) Concerns with the patient. We evaluated the questions on the scale that referred to information arising from the last 30 days. The type and value of patient

expenses, their contribution and permanent changes in the caregiver's life were analyzed.

Objective overload was assessed through the frequency of care and supervision of the family member in daily care with the patient. It was indicated how consistently the family member performed tasks for the patient, dealt with problematic behaviors and obtained changes in the routine of his life. We used the likert model scale that has the following response alternatives: 1 = no time, 2 = less than once a week, 3 = once or twice a week, 4 = three to six times a week and 5 = every day.

In turn, subjective overload was used through the degree of discomfort felt by the family member when performing the role of caregiver and their concerns with the patient. The degree of discomfort was analyzed using the response options: 1 = not at all, 2 = very little, 3 = a little and 4 = a lot. For the assessment of concerns, the scale response alternatives also contain five points, where 1 = never; 2 = rarely, 3 = sometimes, 4 = often, 5 = always or almost always.

It is known that the FBIS-BR scale was applied by reading the questions to the family caregiver. The instrument was applied individually and without the patient's presence in a place determined by the caregiver: at home through home visits, at work in a private place provided by the caregiver or at CAPS, in a room provided by the institution.

Data was analyzed using the Statistical Package for the Social Science version Windows 20.0®. A descriptive analysis of the results regarding the family member description questionnaire was performed. It was analyzed the verification of family overload through the family members' overload scale of psychiatric patients, and the percentage of answers for each subscale item was analyzed, considering that: questions related to objective overload are high, whose answers are 4 and 5. Evidenciam-se sobrecarga elevada dos principais cuidadores referentes à sobrecarga subjetiva, as respostas 3 e 4, e na avaliação das preocupações do familiar com o paciente, as respostas 4 e 5 indicam sobrecarga elevada. Considera-se que na subescala C não se aplica aos cálculos de porcentagem. Obtiveram-se, a partir da mesma, dados referentes às despesas com o paciente e informações sobre as questões econômicas do grupo familiar.

This was followed by the research, which determines Resolution No. 466, of December 12, 2012, in all its aspects, and was approved by an independent Research Ethics Committee with opinion number 2.255.076.

RESULTS

Family caregivers of individuals with schizophrenia were found to be male and female, with the majority being male (73.3%). Their ages ranged from 39 to 70 years, with a predominance of 64 to 70 years. The siblings predominated in relation to the degree of kinship, representing 40% of respondents, followed by parents 26.7% and of these, the majority were the main caregivers (93.3%).

Regarding financial expenses, higher expenses with transportation, food, small amounts of money for small expenses and medication, lower expenses with mental health care and other expenses were identified, 73.3% of the patients contributed with the expenses, 66 % with the value of a minimum wage, while the average expense of family caregivers with the patient was $ 468.4. Questioning how often expenses were significant, 6.7% answered that rarely, 20% sometimes, 33.3% often and 40% answered that always or almost always.

Table 1 section A presents the objective overload of family members who provide assistance in daily life, and these tasks were performed more than three times a week by the caregiver. Caregivers were found to be responsible for preparing meals (60%), accompanying the patient in transportation (66.7%), administering the patient's money (80%), and following up on medical appointments (60%). In assessing subscale A (Table 2), there was a greater subjective overload on those who administered the patient's money (66.7%), those who followed the transportation (60%) and those who accompanied the patients in medical appointments (53.3%).

Objective overload was evidenced in relation to the supervision of problematic behaviors, starting from section B (Table 1) in which the majority occurred for the factors related to this type of behavior (33.3%), excessive demand for attention (33.3%), suicidal behavior (33.3%) and excess cigarettes, food and liquids (33.3%). Subjective overload was verified through subscale B (Table 2). Regarding the supervision of problem behaviors, it was higher for aspects related to problem behavior (80%), disturbing people at night and aggressive behaviors (53.3%), suicidal behavior (53.3%) and excessive attention demand (40%).

Section D (Table 1) identified the impact on daily care routines, with 40% of family caregivers having cancellations or delays in appointments, 46.7% having changes in social and leisure activities and 53.3% had to change the service and home routines to take care of the schizophrenic individual.

Table1 Objective overload of family caregivers of individuals with schizophrenia undergoing treatment in a Psychosocial Care Center. Montes Gerais (MG), Brazil. 2017.

Variables	Answers 1 and 2[a]		Answers 3, 4 and 5[b]	
	n	%	n	%
A: Assistance in everyday life				
Personal Hygiene	11	73.3	4	26.7
Medication	7	46.7	8	53.3
Household chores	9	60	6	40
Shopping	10	66.7	5	33.3
Food preparation	6	40	9	60
Transport	5	33.3	10	66.7
Care for finances	3	20	12	80
Time occupation	7	46.7	8	53.3
Medical appointments	6	40	9	60
B: Supervision of problem behaviors				
Problematic behaviors	10	66.7	5	33.3
Excessive Attention Demand	10	66.7	5	33.3
Bother people at night	11	73.3	4	26.7
Aggressive behaviour	11	73.3	4	26.7
Suicidal behavior	10	66.7	5	33.3
Drinking	13	86.7	2	13.3
Excess cigarettes, food and liquids	10	66.7	5	33.3
Use of Drugs	15	100	0	0
D: Impact on Daily Care Routines				
Delays or cancellation of appointment	9	60	6	40
Changes in social and leisure activities	8	53.3	7	46.7
Change of service / home routine	7	46.7	8	53.3
Reduced Attention to Other Family Members	13	86.7	2	13.3

Key: [a]1=never and 2= less than once a week; 3= 1 or 2 times a week; b 4= three to six times a week and 5= every day.

Table 2. Subjective overload of family caregivers of individuals with schizophrenia undergoing treatment at the Psychosocial Care Center. Montes Gerais (MG), Brazil. 2017.

Variables	Answers 1 and 2[a]		Answers 3, 4[b]	
	n	%	n	%
A: Assistance in everyday life				
Personal Hygiene	10	66.7	5	33.3
Medication	11	73.3	4	26.7
Household chores	10	66.7	5	33.3
Shopping	11	73.3	4	26.7
Food preparation	11	73.3	4	26.7
Transport	6	40	9	60
Care for finances	5	33.3	10	66.7
Time occupation	12	80	3	20
Medical appointments	7	46.7	8	53.3
B: Supervision of problem behaviors				
Problematic behaviors	3	20	12	80
Excessive Attention Demand	9	60	6	40
Bother people at night	7	46.7	8	53.3
Aggressive behaviour	7	46.7	8	53.3
Suicidal behavior	7	46.7	8	53.3
Drinking	10	66.7	5	33.3
Excess cigarettes, food and liquids	10	66.7	5	33.3
Use of Drugs	13	86.7	2	13.3

Key: [a] 1= not at all or never 2=little; [b] 3=a little 4=a lot

Table 3 shows the concerns of family caregivers with individuals with schizophrenia, according to the analysis of overload E, in which family members worried about the patient, which leads to greater overload. The biggest concerns were physical security 66.7%, the future 60% and finance 40%.

Table 3. Subjective overload related to patient concern in family caregivers of individuals with schizophrenia undergoing treatment in a Psychosocial Care Center. Montes Gerais (MG), Brazil. 2017.

	Answers 1,2 and 3[a]		Answers 4 and 5[b]	
	n	%	n	%
Patient Concerns				
Physical security	5	33.3	10	66.7
Quality of treatment received	15	100	0	0
Social life	12	80	3	20
Physical health	12	80	3	20
Adequate housing	13	86.7	2	13.3
Finances	9	60	6	40
Future	6	40	9	60

Key: [a]1=never 2=rarely 3=sometimes; [b] 4=frequently 5= always or almost always.

DISCUSSION

It is emphasized that schizophrenia is a serious mental disorder that usually develops in young adults causing changes in the structure of their lives and the individuals with whom they live prominently with their family. [11]

Most caregivers and family members of individuals with severe mental disorders are not prepared for care, especially schizophrenia. This phenomenon can be explained by the lack of knowledge about the disorder, few resources in the community and lack of knowledge to cope with crisis situations. Thus, there is both objective and subjective overload, which can also cause illness to caregivers.[12]

The results of the study showed that most caregivers were elderly and male. Thus, new roles are redefined with the presence of the male gender in the care, that is, in addition to his participation with the financial resources, the man begins to assume the role of caregiver that was previously put into female practice.[8] Thus, this data differs from other studies that obtained the predominance of females as caregivers.[13,14,7]

The number of elderly who are being responsible for the care of family members with schizophrenia were highlighted. It is known that the totality of patients with schizophrenia living with the family member, who is the main caregiver, contributes to the increased frequency of tasks and assistance provided to the sick individual. It is often the family who is the primary caregiver of schizophrenic patients and is responsible for ensuring their well-being. However, it should be noted that the family is also the one who commonly deals with crises and problem behaviors, and is also a source of social support and financial aid.[9]

According to family members, it is confirmed that most individuals with schizophrenia contributed to the expenses. Such fact is justified by the receipt of social benefit. It is noted that the minority who could not contribute to the expenses, had the tables funded by family members, with the largest expenses with transport and food. With regard to expenses, it was found that 40% of caregivers reported that they were always or almost always significant, ie, the individual with schizophrenia demands high financial resources and that the lowest expenses were with treatments with mental health care, possibly justified by the service offered by the network.

It was revealed that objective overload prevailed in the development of care activities of the patient's daily life, showing high objective overload compared to the supervision of problematic behaviors and impact on daily care routines that revealed mild overload. He stood out for high expenses in descending order to care provided with money, transportation, medical appointments, food preparation and medication. This data corroborates with a study by Reis et al [7].

It was evidenced that care with money, transportation, and medical appointments also showed high subjective overload. The precariousness inherent in the social and cognitive skills present in schizophrenia is known to produce poverty and joblessness creating a demand for the need for income support offered by social assistance. These benefits are generally managed by family members.[15] It is noted that most caregivers feel uncomfortable living with the judgment of others about the correct or inappropriate use of the individual's money with schizophrenia.[16]

It is noteworthy that the limitations often present in individuals with schizophrenia affect the need for constant supervision of these resources and routine care generating objective and subjective overload. Thus, the dependence to take medication, prepare meals, follow-up on transportation and consultations points to an objective and subjective overload on the caregiver, considering that they produce significant changes in their family context and way of life.[14]

Regarding the treatment, it is verified that the caregiver may refer to distress regarding the correct administration of the drugs, because it is common the fear that the individual with schizophrenia may make inappropriate use of the drugs, becoming a social risk.[17] It is noteworthy that non-adherence to medication may lead to crisis or worsening of symptoms, which may lead

to readmissions. About 50% of individuals with schizophrenia are known to not adhere to medication. This leads to worsening prognosis, increased hospitalization expenses, and increased risk of self or hetero-agressiveness.[18]

It was found in subscale analysis B, that the prevalence of objective overload was lower in relation to problem behaviors, however, in relation to subjective overload, there was high overload. The overload with problematic behaviors, bothering people at night, aggressive behaviors and suicidal behavior were highlighted. There was also evidence of subjective overload in relation to concerns about physical and future security. This data is corroborated with the study by Reis et al [7]. The relative is worried about the possibility that in his absence there is no one who can take care of the individual, forcing him to live in a situation of streets and without care.[12]

It is known that most people do not know how to act in the face of strange and bizarre behaviors common in schizophrenia. This shows concern, helplessness, fear, anxiety and anger, as well as doubts about how to act.[18-20]

It is emphasized that the family manifests difficulties in dealing with some behaviors such as hetero-aggressiveness, thus, living with the individual with schizophrenia is marked by feelings of insecurity and discomfort in the face of unforeseen actions.[21]

It is noteworthy that the data alert the mental health service network about the need to function as a support to the dimensions that cause greater overload to family members. It is therefore important to help family members cope with problem behaviors through interventions and management of these difficult behaviors.[7]

It is understood that behavioral changes presented by individuals with schizophrenia such as impulsive acts, strangeness, psychomotor agitation or slowness, bizarre behaviors, movement rigidity and depressive symptomatology, added to idleness, are directly related to the activation of caregivers hypervigilance affecting their quality of life and mental health.[15]

It is noticed that the care for individuals with schizophrenia can represent, besides a change in the family routine, changes in the family's plans and plans, thus, the diagnosis becomes the fundamental element that moves this family. It is known that the removal and sometimes the exclusion of the family from any social contact is very frequent and the unpredictability of behaviors present in schizophrenia is one of the factors that generates this condition in the family.[5] It is noteworthy that care for individuals with schizophrenia promotes changes in the daily lives of family caregivers, limiting them in relation to employment, leisure and rest opportunities, as well as producing emotional distress as a result of overload and because they have no one to share the activities with caution.[13]

It was found in this study that family members are satisfied with the quality of treatment received, individuals with schizophrenia enjoy attending CAPS, receive medication, and are welcomed thus favoring relief and satisfaction to the family caregiver. It is emphasized that this reported treatment was not mentioned to primary health care.

It is noted that the CAPS is made up of a multidisciplinary and interdisciplinary team, offers day care, has a welcoming environment, offers treatment to people in crisis situation, attends cases of severe mental disorders, aiming to avoid the hospitalization of the individual. It is noteworthy that some therapeutic activities developed in CAPS are: therapeutic workshops, group or individual psychotherapy, artistic activities, guidance and monitoring of medication use, as well as family care. It is noteworthy that the service has as one of its objectives to promote the reintegration of the person with mental disorder to the community and their family environment.[9]

This highlights the importance of the multidisciplinary team in preventing the caregiver's illness. It is up to the nurse to provide information about schizophrenia and its treatment, stimulate treatment and support families through listening, assisting in times of crisis and encouraging the family during the rehabilitation process. Thus, this action helps the patient and family member to identify and manage the demands regarding the disease.[17]

It is understood that among the multidisciplinary team, the nurse is the professional who maintains direct contact with the patient, for this reason, should know the disease process of schizophrenia, and support the family or the caregiver. Thus, the effectiveness of care for individuals with schizophrenia is guaranteed, being necessary for the quality of treatment with the mental health team.[17]

It is emphasized the need for nurses working in mental health care to be able to recognize the overload of the family member, thus providing satisfactory reception and developing strategies and interventions aimed at family caregivers. The role of the professional nurse and its importance in family approach in the context of mental health is highlighted. Thus, it is understood that the identification of the nursing diagnosis “Tension of the role of caregiver” subsidized by the use of instruments that assess objective and subjective overload allows the professional nurse to take care of those who care. Thus, it is envisaged interventions that favor the reduction of stress,

depression and fear, improving the caregiver's quality of life.[8]

It is emphasized that all staff should offer humanized assistance to users, providing comprehensive mental health care, ensuring rehabilitation and psychosocial reintegration of users into the service.[11] Thus, the importance of holistic care is emphasized, with a focus on integrality expressed through networking with the articulation between its devices; interdisciplinarity; intersectoriality; the contact and the welcome; therapeutic listening; psychosocial rehabilitation; the resources of therapeutic and educational workshops; the ambience and the incorporation of the subjective component and expansion of the clinic.[3]

CONCLUSION

Most caregivers of individuals with schizophrenia had objective and subjective overload due to several factors. The evaluation and characterization of the overload experienced by family caregivers of individuals with schizophrenia was revealed as essential, since the family is the main provider of continuous care and legally responsible for the individual with schizophrenia. It is evident that the family needs to be prepared and receive satisfactory support to adequately take care, must be instructed by professionals to know how to understand and deal with changes in the behavior of the family member. Thus, the role of health services in welcoming, accompanying and supporting these families is highlighted.

In view of this, the importance of seeking new mental health care strategies directed to the overload of family caregivers is highlighted. It is noteworthy that the welcoming, listening and guidance are fundamental so that family members can express their difficulties and be supported. It is important to work with a broad approach including family focus allowing the professional to realize the main overloads experienced by caregivers of individuals with schizophrenia, thus enabling the implementation of necessary interventions.

It was confirmed that the results found are similar to those reported in the literature and research on the subject. Thus, further qualitative studies are suggested, in order to value the discourses, singular experiences and feelings experienced by family caregivers of individuals with schizophrenia.

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Corresponding author
Renê Ferreira da Silva Junior
Email: renejunior_deny@hotmail.com

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