

## ORIGINAL ARTICLE

**OVERLOAD AND SATISFACTION OF FAMILY MEMBERS OF PATIENTS WITH SCHIZOPHRENIA**

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**ABSTRACT**

**Objective:** To assess psychosocial care from the perspective of family members of schizophrenic patients.

**Method:** A correlational study with 40 family members at a Psychosocial Care Center III of Londrina, Paraná, was conducted in 2015 and 2016. Variables related to the sociodemographic characterization and evaluation scales of the overload and satisfaction of the family members were obtained. Data were analyzed with measures of central tendency and correlation.

**Results:** 24 caregivers were women, 23 were married, and the mean age was 46 years. The mean rate of satisfaction was 4.37, the overall mean value for objective overload was 2.26, and the overall mean value for subjective overload was 2.09.


**Conclusion:** Although the family members were very satisfied, differences in overload scores revealed that they received good psychoeducational support, but the overload generated by their concern for their family member was the aspect that generated the highest levels of suffering. Such results may guide nurses to give directions to family members, to support them and reduce their overload.


**DESCRIPTORS:** Family relations; Health services research; Caregivers; Schizophrenia; Psychiatric Nursing; Scales.


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
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## ARTIGO ORIGINAL / ARTÍCULO ORIGINAL

**SOBRECARGA E SATISFAÇÃO DOS FAMILIARES DE PACIENTES COM ESQUIZOFRENIA****RESUMO**

**Objetivo:** avaliar a atenção psicossocial pela ótica do familiar do paciente esquizofrênico.

**Metódo:** estudo correlacional com 40 familiares no Centro de Atenção Psicossocial III de Londrina-PR, entre 2015 e 2016. Foram obtidas variáveis relacionadas à caracterização sociodemográfica e das escalas de avaliação da sobrecarga e de satisfação de familiares. Os dados foram analisados com medidas de tendência central e de correlação.

**Resultados:** 24 cuidadores eram mulheres, 23 eram casados e a idade média foi 46 anos. A média de satisfação foi 4,37, a média global para a sobrecarga objetiva foi 2,26 e a sobrecarga subjetiva foi de 2,09.

**Conclusão:** Embora muito satisfeitos, diferenças nos escores de sobrecarga revelaram que os familiares recebem bom suporte psicoeducativo, mas a sobrecarga gerada pela preocupação com o ente familiar é o aspecto que mais gera sofrimento. Tais resultados podem nortear o enfermeiro no direcionamento das ações de suporte aos familiares, reduzindo a sobrecarga familiar.

**DESCRIPTORES:** Relações familiares; Pesquisa sobre serviços de saúde; Cuidadores; Esquizofrenia; Enfermagem psiquiátrica; Escalas.

**SOBRECARGA Y SATISFACCIÓN DE LOS FAMILIARES DE PACIENTES CON ESQUIZOFRENIA****RESUMEN**

**Objetivo:** Evaluar la atención psicossocial acorde la visión del familiar del paciente esquizofrénico. **Método:** Estudio correlacional con 40 familiares en el Centro de Atención Psicossocial III de Londrina-PR, entre 2015 y 2016. Fueron obtenidas variables de caracterización sociodemográfica, de escalas de evaluación de sobrecarga y de satisfacción de familiares. Datos analizados con medidas de tendencia central y de correlación.

**Resultados:** Veinticuatro cuidadores eran mujeres; 23 casadas; media etaria de 46 años. El promedio de satisfacción fue 4,37; el promedio global de sobrecarga objetiva fue 2,26; la sobrecarga subjetiva fue 2,09.

**Conclusión:** A pesar de la satisfacción, las diferencias en los puntajes de sobrecarga indican que los familiares reciben buen soporte psicoeducativo, pero la sobrecarga determinada por la preocupación por el familiar es el aspecto generador del mayor sufrimiento. Estos resultados pueden orientar al enfermero para que enfoque las acciones de soporte a los familiares, reduciendo la sobrecarga familiar.

**DESCRIPTORES:** Relaciones Familiares; Investigación en Servicios de Salud; Cuidadores; Enfermería Psiquiátrica; Escalas.

## INTRODUCTION

The presence of mental disorders in the family environment causes changes in the routines and habits of families. Some researchers have been concerned about the impact of deinstitutionalization on families and how they cope with this, calling this phenomenon family overload<sup>(1-2)</sup>.

Family overload may be defined as the impact caused in the family environment by coexistence with individuals with mental disorders, the economic, practical, and emotional aspects of which caregivers are subject, in objective and subjective dimensions<sup>(3)</sup>.

The Assessment Scale for Family Satisfaction with Mental Health Services (SATIS-BR) is a widely used instrument to assess services. A study conducted in Rio Branco-AC<sup>(3)</sup> suggested the need to improve the infrastructure, comfort, and appearance of the services, as well as to create strategies that favor a greater participation of family members in the treatment of the patient. Despite the satisfaction of patients and family members, 71.3% and 74.4%, respectively, considered that the service requires improvements. It also pointed out that the major factors that contributed to a high level of satisfaction of patients and family members were the following: the service provided by the team, the service scheduling system, and the delivery of drugs or medicines.

According to another study conducted with family members in 2012<sup>(4)</sup> in the same location as the present research, only 14% of family members reported being totally satisfied with the various aspects of the services, and 46% reported being totally satisfied with the outcomes of the treatment; the lowest level of satisfaction (54% of the participants) was found in relation to the physical structure of the service.

In Brazil, there are still only a small number of quantitative and/or psychometric studies<sup>(5)</sup> that assess the quality of psychosocial care, which makes further research a need, also assessing the overload of caregivers. Studies suggest that knowledge about overload enables mental health services, as well as nurses, to develop interventions that take into account the difficulties faced by these families<sup>(6)</sup>.

Therefore, the present study aims at assessing psychosocial care from the perspective of family members of patients with mental disorders, based on the measurement of the level of overload of the caregiver and their level of satisfaction with the service.

## METHOD

This was a correlational study conducted in Psychosocial Care Centers (CAPS), which are part of the mental health care network, and include children, adults, and drug-related CAPS, in addition to 52 basic health units, 3 support centers for family health, and the emergency services of Londrina, Paraná. The Brazilian Institute of Geography and Statistics (IBGE) estimates that the city of Londrina has a Human Development Index (HDI) of 0.778 and a population of approximately 485,822 inhabitants.

The study used a convenience sampling with 40 family members, representing the main caregivers of patients with a diagnosis of schizophrenia. The population of the study consists of approximately 170 family members on follow-up. All family members were invited, but only 40 agreed to participate in the study; the others demonstrated a sense of fear of being deceived or assaulted, or suffering retaliation, although the ethical precepts for research involving human beings were met. An integrative review study<sup>(7)</sup> suggested that the assessment processes, in general, use components such as user, professional, and family member satisfaction as indicators of the quality of the provided service.

The interviews were conducted in the CAPS-III and in previously scheduled home visits. Data were collected between October 2015 and September 2016 after a 12-hour

training for the interviewers so that they would become familiar with the data collection instruments.

The criterion for inclusion was that the interviewed caregiver was considered the person that lived with the patient the most, and that the patient received treatment in any modality (intensive, semi-intensive, or nonintensive) in a psychosocial care center (CAPS). The exclusion criterion was the presence of a diagnosis of mental disorder restricting their ability to understand and reason, perceived in the interview and/or at the beginning of the study.

This study was conducted using specific data collection instruments: (1) sociodemographic characterization; (2) the Family Overload Rating Scale (FBIS-BR); and (3) the Assessment Scale for Family Satisfaction with Mental Health Services (SATIS-BR)<sup>(8)</sup>. The FBIS-BR was validated in Brazil,<sup>(9-10)</sup> and it is intended to assess the experience of family members of psychiatric patients regarding the care provided to the patients and the impact of this experience on their lives in relation to the overload felt by them.

The objective overload was assessed by items such a Likert scale, ranging from 1=not even once to 5=every day. The subjective overload was also assessed by Likert-type items, where 1=not at all and 4=a lot for the level of discomfort when providing care, and also 1=never to 5=always or almost always for the frequency of concern about the patient. The scores were obtained based on an overall mean calculation (division of the total by the number of items). The higher the score, the greater the level of overload.

The SATIS-BR of family members was validated by Bandeira<sup>(8)</sup> and included 12 items assessing the satisfaction of patients, with answer options arranged on a five-point Likert scale assessing three dimensions or factors: (1) satisfaction in relation to the outcomes of the treatment; (2) satisfaction in relation to the embracement and competence of the team; and (3) satisfaction in relation to the privacy and confidentiality of the service. The interpretation of the scores was based on the overall mean calculation (total gross score divided by the number of items). The higher the score, the greater the level of satisfaction of the family member with the service.

A value of  $\alpha > 0.05$  was used in order to minimize the probability of a type 1 error. Central tendency measures were used to describe the data and nominal variables, and the correlation coefficient calculation was used for the correlational analysis between the scores of the scales used in the study. The calculations were performed using the statistical software Statistical Package for the Social Sciences (SPSS, v. 21).

The participants were invited verbally and individually (in person and via telephone), and were assured of their anonymity, the confidentiality of their information, and their right to refuse or abandon the study at any stage. The study was authorized by the human research ethics committee, CAAE number 18426114.7.0000.5231, by Ordinance 679.388 of June 10, 2014.

## RESULTS

The sociodemographic characteristics presented in Table 1 highlight that 24 caregivers (60%) were women, and 23 (57.5%) were married. The mean age of the family members was 46 years. Among the parents, 13 (32.5%) were identified as the main caregivers of the patients, and 21 (52.5%) had completed elementary education.

Table 1 - Sociodemographic characteristics of family members of psychiatric patients. Londrina, PR, 2016, Brazil

Variables	Categories	n	%
Marital status	Single	6	15
	Married or living with a partner	23	57.5
	Divorced or widower/widow	10	25
	Others	1	2.5
Relationship	Father/mother	13	32.5
	Spouse or partner	6	15
	Brother/sister	8	20
	Son/daughter	1	2.5
	Others	8	20
Education	No schooling	1	2.5
	Completed elementary education	10	25
	Elementary education not completed	21	52.5
	Completed middle school	1	2.5
	Middle school not completed	6	15
	Completed higher education	1	2.5
Main source of income	Formal employment	13	32.5
	Informal employment	3	7.5
	Income of the spouse/partner	1	2.5
	Retiring allowance/pension	15	37.5
	Sick pay	6	15
	Unknown	2	5
Family income	Up to 1 minimum wage	10	25
	1 to 2 minimum wages	23	57.5
	2 to 3 minimum wages	4	10
	3 to 5 minimum wages	7	17.5
	More than 5 minimum wages	1	2.5
Number of family members	No answer	3	7.5
	1 to 3 members	27	67.5
	4 to 6 members	13	32.5
Care division	0 to 2 individuals	36	90
	More than 3 individuals	4	10
Total		40	100%

The main source of family income was formal employment for 13 families (32.5%), and for 13 retired individuals (32.5%); 30 families (75%) reported having an income between one and two minimum wages. The size of the families was between one and three members, and for 36 families the care was divided between two individuals (90%). Table 2 presents the mean scores and standard deviations for satisfaction and changes perceived by family members.

Table 2 - Satisfaction of family members of patients with schizophrenia in the CAPS-III. Londrina, PR, 2016, Brazil

Items	M (dp)
Satisfaction with the service (SATIS)	
Outcome of the treatment	4.50 (0.659)
Embrace and competence of the team	4.42 (0.632)
Privacy and confidentiality	4.29 (0.617)
Overall score	4.37 (0.539)

The results in Table 2 point out that the mean rate of satisfaction of family members was 4.37. Table 3 presents scores that demonstrate the magnitude of the relationship between satisfaction and perceived change.

Table 3 - Scores of objective and subjective overload of family members of psychiatric patients. Londrina, PR, 2016, Brazil

Subscales	Overload dimensions	M (dp)
A - Support in daily life	Objective	3.15 (1.16)
	Subjective	1.34 (0.56)
B - Supervision of problematic behaviors	Objective	1.60 (0.67)
	Subjective	1.51 (0.60)
D - Impact on the daily life of the family	Objective	2.05 (1.11)
E - Concern of the family member for the patient	Subjective	3.42 (0.88)
Objective Overload Overall Score	Objective	2.26 (0.73)
Subjective Overload Overall Score	Subjective	2.09 (0.46)

Table 3 demonstrates that support in the daily life presented a mean score of 3.15. The subjective overload of support in daily life presented a mean score of 1.34, indicating a low subjective overload. Regarding subscale B, a mean score of 1.60 was observed for objective overload and 1.51 for subjective overload of family members, indicating that most of them were not supervising problematic behaviors with intense frequency. The analysis of subscale D, with mean score of 2.05, indicated that family members suffer a moderate impact on their daily routines. Analysis of subscale E, with a mean score of 3.42, indicated that a significant number of family members were intensely concerned with the patient, leading to a high overload.

Table 4 presents the magnitude of the relation between the subjective and objective overloads of family members in the sample.



Table 4 - Pearson correlation matrix (r) and coefficient of determination ( $r^2$ ) of the subscales of objective overload and subjective overload on the FBIS-BR scale. Londrina, PR, 2016, Brazil

ITEMS	Objective overload			Subjective overload		
	AVC	SCP	IRDF	AVC	SCP	PFCP
Objective overload (SO)						
Support in daily life (AVC)	-	-	-	-	-	-
Supervision of problematic behaviors (SCP)	$r$ 0.26 $r^2$ (6.5%)	-	-	-	-	-
Impact on the daily life of the family (IRDF)	$r$ 0.28 $r^2$ (7%)	$0.48^{**}$ (22.8%)	-	-	-	-
Subjective overload (SS)	-	-	-	-	-	-
Support in daily life (AVC)	$r$ 0.27 $r^2$ (7.3%)	$0.30^*$ (8.8%)	$0.26$ -7%	-	-	-
Supervision of problematic behaviors (SCP)	$r$ 0.25 $r^2$ (6.2%)	$0.82^{**}$ (66.7%)	$0.44^{**}$ (19.3%)	$0.33^*$ (10.9%)	-	-
Concern of the family member for the patient (PFCP)	$r$ $0.51^{**}$ $r^2$ (25.6%)	$0.31^*$ (9.3%)	$0.33^*$ (11.1%)	-0.03 (0.1%)	$0.24$ (5.5%)	

\* Statistically significant correlation for a level of 0.05 (2 extremities).

\*\* Statistically significant correlation for a level of 0.01 (2 extremities).

The data shown in Table 4 point out correlations between the scores of objective and subjective overload on the FBIS-BR scale and the respective coefficients of determination. The results indicate that the highest correlation was found in the domain "supervision of problematic behaviors," as the data variability was explained by the correlation between the subjective and objective overloads for 27 family members (66.7%) .

The lowest correlation coefficient was found between subjective overload (support in the daily life) and objective overload (supervision of problematic behaviors) ( $r=0.30$ ;  $p<0.05$ ). The correlation coefficient of 0.30 suggests that only for 8.8% of family members the data variability is explained by the correlation between these two domains, that is, 91.2% of the data variability can be attributed to variables that were not analyzed in the study.

## DISCUSSION

### Sociodemographic profile of the family members

Regarding the predominance of women (60%), this study found similarity with another study<sup>(3)</sup> conducted with family members of psychiatric patients, in which 72.5% of the caregivers were also women, with a mean age of 41.93 years. These studies pointed out that women feel a higher level of overload compared to men, with the existence of children sharing the house with the patient representing a triggering factor, a fact that is significantly associated with family overload.<sup>(11-12)</sup>

It is possible that economic and sociocultural differences are reflected in this profile, as a cross-sectional study with random sampling of 377 caregivers of psychiatric patients

hospitalized in Saudi Arabia<sup>(13)</sup> revealed that 55% of the caregivers were men, with mean age of 36.6 years, and 40.1% had completed middle school.

A review<sup>(12)</sup> found that 60.4% were family members that were married or lived with a partner and shared the care with up to three individuals, and the need to support these family members in the task of providing care for patients was also confirmed. More recent studies support the conclusions of previous studies, in which the generated overload affected caregivers in emotional, financial, and physical ways. According to these authors,<sup>(12)</sup> psychoeducational interventions with family members help to reduce the overload. A study with 201 family members conducted in Malaysia<sup>(14)</sup> using a regression analysis technique also identified that women feel a higher level of overload in comparison with male family members.

Most studies about family overload have been conducted with mothers and fathers of psychiatric patients. A study about the influence of the (male) gender of the caregiver identified that 36% consisted of fathers of patients and 34% were brothers; as for women, 42% consisted of spouses of patients and 28% were sisters.<sup>(15)</sup> The fact that fathers were in direct contact with the patient is corroborated in several studies, in which the number of interviewed fathers was higher. Another possible explanation is that the family of origin represents the strongest social contact of a significant number of the patients with mental disorders.<sup>(16-17)</sup>

The predominant level of education of the family members was incomplete elementary school (41.6%) and, of these, 47.9% presented a mean monthly income between one and two minimum wages. A study<sup>(16)</sup> conducted with 107 family members found, in relation to education, that 14.01% had a low educational level (0 to 4 years of schooling), 32.71% had a basic level of schooling (5 to 8 years of study), and 44.87% had 9 years or more of formal education, a fact that is confirmed in the present study.

A quasi-experimental study concluded that the relationship of family members represents an important factor in the responses of the caregivers to the intervention, ensuring more attention to the development and assessment of interventions with caregiver relatives.<sup>(12)</sup>

## Family member satisfaction

In relation to the subitems on the scale of satisfaction (Table 2), a higher level of satisfaction was observed in relation to the outcome of the treatment ( $M=4.50$ ), similar to results of another study,<sup>(3)</sup> which identified a higher mean score of satisfaction related to the outcome of the treatment ( $M=4.25$ ). In the same study, the lowest score was related to satisfaction ( $M=4.04$ ) in relation to the embracement and competence of the team, differing from the present study, in which the lowest score was related to privacy and confidentiality ( $M=4.29$ ), indicating that the participants had moderate to high satisfaction in the assessed aspects.<sup>(7-9,18)</sup>

Considering the variation of the scores between 1 and 5, it was concluded that there was a high level of satisfaction. Family members reported that the professionals fulfilled their role by offering safety and confidence in their relationship with family members when they needed to discuss personal matters.<sup>(19)</sup> These results, particularly in relation to family members, may indicate the presence of social acceptability, an important factor for the quality of the service and capable of influencing and intensifying the effects of the treatment.

A review highlighted that, despite their daily overload, caregivers feel satisfied with being able to provide care to their family members. Despite their satisfaction, a number of changes occurred in their daily lives, restricting them in terms of employment opportunities, leisure, and rest, in addition to emotional exhaustion resulting from overload, due to the lack of someone with whom to share the responsibility of providing care.<sup>(17-20)</sup>



## Objective overload and subjective overload

Table 4 suggests that support in daily life had a mean value of 3.15. In this sense, a strict medication administration schedule, difficulties faced by schizophrenic patients with hygiene tasks, and limitations on managing their own lives represent exhausting situations for caregivers, increasing the objective overload on the family members<sup>(20-22)</sup>.

The subjective overload of support in daily life had a mean value of 1.34, demonstrating that family members felt little discomfort when providing support in the daily life of the patient, indicating a low level of harm to their mental health.<sup>(22-23)</sup> In the present study, 30.2% of family members presented subjective overload when supervising problematic behaviors, corroborating the findings of another study<sup>(21)</sup> in which family members presented a higher level of discomfort when supervising the problematic behaviors of the patient (45.79%). The same study suggested that the aspects responsible for the highest levels of concern by family members were related to the physical safety of the patient (84.11%).

A study conducted with spouses of schizophrenic men<sup>(17)</sup> found that impacts on the daily routine of the caregiver were not responsible for high levels of objective overload. However, the evaluation of permanent impacts on the life of this family member showed a high level of changes in both social and professional respects, leading to a high subjective overload.<sup>(17)</sup> According to Table 3, the impact on the daily routine of the family had a mean score of 2.05, showing that the family members suffer a moderate impact on their daily routines, as they answered that they were hampered with moderate frequency, causing a moderate overload.

Therefore, families that live with patients with mental disorders experienced an overload in their daily routines, as they needed to take on the domestic tasks of the patient, which were hampered due to the complex symptomatology of the disease, which includes the disorganization of daily activities, leading the family member to be absent from work and social commitments and focusing their attention on the care for the patient with mental disorder.<sup>(12)</sup> Another study<sup>(17)</sup> presented data related to the items of the subscale "impact on the daily routine of the family member": women reported, at a higher frequency than men, that they were prevented from providing care to other family members due to the care they provided to a psychiatric patient.

The obtained score of 3.42 for the concern of the family member for the patient was the higher score, corroborated in a review study<sup>(22)</sup> in which the overload was often the result of the accumulation of tasks and the fact that few people were able to provide support in the care, supervision of problematic behaviors, daily life activities, financial impact, and costs.

Support in daily life and supervision of problematic behaviors (scores of 1.34 and 1.51, respectively) suggest that family members are informed and already familiar with the behavior of their family member, indicating that the educational character of the family support actions is seemingly appropriate. On the other hand, the concern of the family member for the patient was found to be the aspect that caused the highest level of emotional exhaustion, presenting the highest score (M=3.42).

The psychological distress of the caregiver was related to the overload associated with providing care to patients with mental disorders. The family of patients with mental disorders feel unsure about the quality of the treatment being provided and fear for the patient's physical safety, as in crisis episodes there is an exacerbation of body movements and they experience intense concern for the health and the future of the ill family member, particularly in relation to how their financial situation might be without the support of the caregiver.<sup>(24)</sup>

As for the limitations of this study, it is important to mention that each study on this theme used distinct statistical analysis resources, which did not always result in all scores being comparable; also, there are few recent studies on the theme.

## FINAL CONSIDERATIONS

In the present study, the interviewed family members were very satisfied with the outcome of the treatment, giving about 80–90% of the maximum score for satisfaction. Concern for the patient, which involves the health, housing, treatment, and social life of the family member, led to concerns and doubts in the life of the caregiver, while the lowest scores for overload were related to the supervision of the behaviors of the patient, suggesting a certain familiarity, as they receive a psychoeducational support in the CAPS-III.

Therefore, the insertion of the individual into the social environment, in psychosocial care centers (CAPS), and in workshops and joint activities would provide beneficial results to patients with mental disorders, alleviating caregivers' concerns.

The continuation and deepening of studies may help mental health managers and nurses, as the psychosocial rehabilitation process is continually developing, requiring a more accurate identification of the components causing the overload of the caregiver, so that mental health professionals may guide the caregivers' actions, as they suffer and become ill with their family member.

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