

Correlation of family functionality and burden of informal caregivers of hospitalized older adults

Correlação da funcionalidade familiar e sobrecarga de cuidadores informais de idosos hospitalizados

Correlación de funcionalidad familiar y sobrecarga de cuidadores informales de ancianos hospitalizados

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ABSTRACT

Aim: to analyze the relationship between family functionality and burden of informal caregivers of hospitalized older people.

Methods: this is a cross-sectional study conducted with 98 informal caregivers of hospitalized older people in an inpatient unit of a large hospital in São Carlos, São Paulo. For data collection were used questionnaires to sociodemographic and care context characterization, to evaluate burden and family functionality. Descriptive analyzes and Spearman's correlation coefficient were used.

Results: female caregivers predominated, who took care of their parents and had no training. Approximately 59.8% of caregivers had good family functionality and 49.5% scored for mild to moderate burden. There was a negative correlation, moderate magnitude, between family functionality and burden ($p < 0.001$). The higher the burden score, the lower the family functionality score and vice versa.

Conclusion: caregivers with high burden had worse family functionality. Therefore, nurses need to identify such conditions early and implement assertive interventions so that the family functions as a therapeutic resource.

Keywords: Caregivers. Aged. Hospitalization. Family relations. Geriatric nursing.

RESUMO

Objetivo: analisar a relação entre funcionalidade familiar e sobrecarga de cuidadores informais de idosos hospitalizados.

Método: estudo transversal, quantitativo, realizado com 98 cuidadores informais de idosos hospitalizados em São Carlos, São Paulo. Para a coleta de dados, foram utilizados questionários para caracterização sociodemográfica e do contexto de cuidado, para avaliação da sobrecarga e da funcionalidade familiar. Foram usadas análises descritivas e coeficiente de correlação de Spearman.

Resultados: predominaram cuidadores do sexo feminino, que cuidavam de seus progenitores e não possuíam capacitação. Aproximadamente 59,8% deles apresentaram boa funcionalidade familiar, e 49,5%, sobrecarga leve a moderada. Houve correlação negativa, de moderada magnitude, entre funcionalidade familiar e sobrecarga ($p < 0,001$). Quanto maior o escore de sobrecarga, menor o escore de funcionalidade familiar e vice-versa.

Conclusão: cuidadores com alta sobrecarga apresentaram pior funcionalidade familiar. Diante disso, enfermeiros precisam identificar precocemente tais condições e implementar intervenções assertivas para que a família funcione como um recurso terapêutico.

Palavras-chave: Cuidadores. Idoso. Hospitalização. Relações familiares. Enfermagem geriátrica.

RESUMEN

Objetivo: analizar la relación entre la funcionalidad familiar y la sobrecarga de los cuidadores informales de ancianos hospitalizados.

Métodos: estudio transversal realizado con 98 cuidadores informales de ancianos hospitalizados en una unidad de internación de un gran hospital de São Carlos, São Paulo. Para la recolección de datos, se utilizaron cuestionarios para caracterizar sociodemográficos y contexto de atención, para evaluar la sobrecarga y funcionalidad familiar. Se realizaron análisis descriptivos y coeficiente de correlación de Spearman.

Resultados: predominaban las cuidadoras femeninas, que cuidaban a sus padres y carecían de formación. Acerca de 59,8% de los cuidadores mostró una buena funcionalidad familiar y 49,5% puntuó por sobrecarga leve a moderada. Hubo una correlación negativa, de magnitud moderada, entre funcionalidad familiar y sobrecarga ($p < 0,001$). Cuanto mayor puntuación de carga, menor puntuación de funcionalidad familiar y viceversa.

Conclusión: los cuidadores con alta carga tenían peor funcionalidad familiar. Por lo tanto, las enfermeras necesitan identificar estas condiciones de manera temprana e implementar intervenciones asertivas para que la familia pueda funcionar como un recurso terapéutico.

Palabras clave: Cuidadores. Anciano. Hospitalización. Relaciones familiares. Enfermería geriátrica.

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■ INTRODUCTION

Chronic noncommunicable diseases often affect the older adults, who live or will live with them for many years. Due to this context, the older people may present decompensations, functional dependence and frequent hospitalizations⁽¹⁾. In this sense, some older people may demand more direct care due to their reduced capacity to respond to different stressors, characterizing them as vulnerable individuals⁽²⁾.

Therefore, the chronicity of health problems and the population's longevity can contribute to the appearance of functional limitations, with the consequent need for a caregiver⁽²⁾. The Brazilian public policies consider that support for the older adult is the responsibility of the family, the State and society. However, the participation of the Brazilian State is punctual, providing basic health services with insufficient coverage and with reduced responsibilities, when compared to the burden of care, medicines and other expenses left to families⁽³⁾.

The literature points out to the existence of two types of caregivers: formal ones, who are paid for the offered service; the informal ones, who perform the act of caring voluntarily, which are usually relatives, friends, or neighbors of the older adult being cared for⁽⁴⁾. Most of the time, this caregiver suddenly assumes responsibility for care, either by a family agreement or the lack of options for other members. Moreover, they may find themselves unprepared both psychologically and technically for the performance of this new role and not receive the support of other people for the care of the older person⁽²⁾.

Factors such as high demands for informal care, insufficient social support, functional and cognitive impairment, unpreparedness for the act of caring, as well as intense changes in daily routine and social roles, can lead to family dysfunction and high levels of burden on these caregivers^(2,5). Thus, both family dysfunction and burden among caregivers of the older adult can interfere with the quality of care offered.

This research originated from the experience in an extension project entitled "Caregiver Guidance" (*Orienta Cuidador*), developed with caregivers of older adults hospitalized in a large institution in a city in the interior of São Paulo. With the objective of minimizing insecurity and anxiety due to unpreparedness/ignorance of this new scenario, the members of this project carry out health education and provide a moment to share experiences and anguish experienced. Most of these caregivers complained about the intense burden they were going through and the existing dysfunction among their family members. Based on this practical experience, the following research question was proposed:

is there a relationship between family functionality and the burden of informal caregivers of hospitalized older adults?

Previous studies described the relationship between burden and family functionality, indicating that caregivers with low levels of family functionality had high levels of burden and perceived stress⁽⁶⁻⁸⁾. A study conducted in Italy with the objective of examine caregiver burden and its relationship with family functioning in different neurological conditions. A total of 42 caregivers of the older adults participated in this study. The results showed high levels of burden among these caregivers. Cohesion, satisfaction and the quality of family communication were associated with reduced levels of caregiver burden⁽⁶⁾.

In Brazil, research with data from the Health, Welfare and Aging Study (SABE) was performed with 331 informal caregivers of the older adults. The results showed that the factors associated with burden were: age (OR = 1.04; p = 0.001), report of continuous care provision (OR = 2.78; p = 0.030) and family dysfunction (OR = 5.60; p < 0.001)⁽²⁾.

However, previous studies that explored the relationship between family functionality and burden of informal caregivers captured in the hospital context are scarce. It is worth mentioning the importance of evaluating the family functionality in order to identify it as a therapeutic resource or a possible stressor⁽⁹⁾. Furthermore, it is known that caregivers with high levels of burden can compromise their well-being and quality of life, in addition to resulting in a possible illness, also negatively impacting the quality of care offered⁽²⁾.

Given the above, the nurse can conduct an evaluation of these informal caregivers with the objective of early tracking the burden and family dysfunction. Then, together with the multiprofessional and interdisciplinary team, it will be able to outline assertive and individualized interventions, aimed at the needs of these caregivers, to minimize the negative impacts arising from these conditions and improve the quality of life of both the caregiver and the older people cared for. Therefore, in order to direct the assistance of health professionals, this study aimed to analyze the relationship between family functionality and burden of informal caregivers of hospitalized older people.

■ METHOD

This is an observational, cross-sectional study, based on quantitative research assumptions, following the guidelines present in the Declaration Strengthening the Reporting of Observational Studies in Epidemiology (STROBE).

It was conducted in an inpatient unit of a large hospital located in São Carlos, a city in the interior of São Paulo. It is a

philanthropic institution, founded 128 years ago. This hospital consists of 322 beds, being a reference in health care for an estimated population of 390,000 inhabitants, belonging to five municipalities that make up its microregion. The aforementioned clinical ward, the research scenario, has 24 beds and is not a specific unit for the older adults, although it is the unit of this hospital that admits the most older people.

The population consisted of individuals aged 18 years or older, who care for the older adults and who were accompanying the older adults during the hospitalization period. The convenience sample consisted of people who met the following inclusion criteria: being a relative of the older adults being cared for; being the main caregiver of this older adults; and not receive remuneration for exercising this care. The exclusion criterion used was: having severe hearing or vision deficits, perceived at the time of data collection, which could hinder communication during the application of the proposed instruments.

Through a survey conducted by the Nursing Management of this hospital, about 30 caregivers pass through the inpatient unit per month. 113 caregivers were approached during the data collection period. From these, five refused to participate and ten did not meet the inclusion criteria. There was no condition in relation to the older adults to make the caregiver eligible. Given these criteria, the convenience sample consisted of 98 informal caregivers of the older people. We emphasize that all the older adults hospitalized in this inpatient unit were checked daily, during the data collection period, to detect the presence of an informal caregiver to be invited to participate in the study.

Initially, contact was made with the Nursing Management of the hospital and with the coordinating nurse of the inpatient unit, to present the study. Then, it was performed the identification of hospitalized older adults people and their respective informal caregivers. In this first approach to the caregiver of the older people, the research objectives, the voluntary nature of participation, the confidentiality of the data collected and the way of returning the data to the participating caregivers were informed. Afterwards, they were invited to participate in the research. The caregivers who agreed to participate were directed to a reserved space within the inpatient unit itself so that the interview could be conducted. Data collection was carried out individually, in a single session, from January to March 2020. Each interview lasted approximately 30 minutes.

There was no need for software to record the interviews. Paper protocols were used for data recording. The approach to caregivers took place during business hours (8 am to 6 pm). The researchers went to that unit daily to collect the data.

The caregivers recruited for the research were all possible caregivers who were in the aforementioned inpatient unit during the data collection period. At the time of recruitment, the need to be the main caregiver of the older adults was highlighted. Those that were secondary or tertiary were excluded. During this period, there were no older adults people hospitalized for COVID-19 in this ward.

In order to avoid potential sources of bias in data collection, the interviews were conducted by trained nursing students, and participants were guaranteed privacy, the right to refuse to answer any questions and the confidential character of the answers. If any participant refused to answer any question, the interviewers were instructed to maintain an open and non-judgmental atmosphere. In addition, to avoid bias, the data collection instrument included previously validated scales to evaluate family functionality and caregiver burden.

To characterize the caregiver and the care context, a questionnaire previously constructed by the researchers was used, with 25 questions, containing the following information: gender, age, marital status, education, race/color, family arrangement, current occupation, personal and family income, number of people living in the house, use of medications, subjective health assessment, life satisfaction, multimorbidity (two or more self-reported diseases or conditions, namely: arterial hypertension, diabetes mellitus, heart disease, stroke, gastrointestinal disease, depression, peripheral vascular disease, neurological disease, impaired hearing and/or vision, anxiety, anemia, cancer, dyslipidemia, arthritis, lung problems, back problems and dizziness), physical activity (≥ 150 minutes per week), smoking, alcoholism, degree of kinship with the older adults being cared for, how many months have been caring, how many hours a day take care of the older people, how many days a week take care of the older people, participation in training to perform the task of caring, if receives help from someone to take care of the older people, what kind of help receives and if receives support from some entity.

There was no (semi)structured question so that the participant could expose something of their subjectivity about family functionality and care burden.

To the evaluation of family functionality, the family APGAR was adopted, an instrument developed by Smilkstein in 1978 and validated in Brazil⁽⁹⁾. It consists of five questions that allow the measurement of the satisfaction of family members in relation to five components considered basic in the unit and functionality of any family, that is, adaptation, partnership, growth, affection, and resolve. At the end, the sum of all answers is performed, whose result can range from

0 to 20 points. Therefore, family functioning can be classified as: high family dysfunction (0 – 8 points), moderate family dysfunction (9 – 12 points) and good family functioning (13 – 20 points)⁽⁹⁾.

To the evaluation of the burden, it was used the Zarit Burden Inventory, prepared by Zarit in 1987 and validated in Brazil⁽¹⁰⁾. The scale consists of 22 questions that assess the health, psychological and socioeconomic well-being of the family caregiver, as well as their relationship with the person being cared for. The points generated in the statements show the frequency with which they occur, namely: never = 0, almost never = 1, sometimes = 2, almost always = 3 and always = 4. The result obtained at the end of the questionnaire uses the sum of all the domains answered, ranging from 0 to 88. The higher the score obtained, the higher the burden perceived by the caregiver. It was used the cut-off point: "Absence of burden" (0 – 20), "Mild to moderate burden" (21 – 40), "Moderate to severe burden" (41 – 60) and "Intense burden" (61 – 88)⁽¹⁰⁻¹¹⁾.

The data obtained were coded and typed into a spreadsheet in Microsoft Office Excel, version 2019, with double data entry being performed by different typists, making it possible to correct possible typing errors. After, they were analyzed using the Stata statistical package, version 13.

The Kolmogorov-Smirnov test was used to test the normality of the variables. Considering the lack of normality in the distribution of all continuous variables, Spearman's correlation test was used to analyze the relationship between family functionality and caregiver burden. In the descriptive analysis of the data, proportions, frequency distributions,

medians and 25th and 75th percentiles were estimated. In the scatter diagram of the variables family functionality and caregiver burden, the line with the adjusted values was inserted. A significance level of 5% was adopted.

All ethical aspects ruling research involving human beings were respected according to Resolution 466/2012. This study was approved by the Research Ethics Committee of the *Universidade Federal de São Carlos*, under Opinion 3,480,461. The Free and Informed Consent Form (FICF) was provided for the research participants to read before starting the data collection, which was signed in two copies (one for the caregivers of the older adults and the other to file with the researchers).

■ RESULTS

The sample of this study consisted of 98 participants. Table 1 presents the sociodemographic and health characteristics of caregivers of the older people.

Most caregivers lived with their partner (74.5%), followed by those who lived with their children (49.0%) and with their parents (29.6%). On average, there were 3.1(±1.3) residents in the same household. There was a predominance of caregivers who did not work outside the home (60.2%) and who were not retired (66.3%). Caregivers rated life as good (52.0%), followed by those with a perception of a reasonable life (27.6%). They denied smoking (85.7%) and alcohol consumption (69.4%).

Table 2 presents the characteristics related to the care context of caregivers of the older people.

Table 1 – Distribution of informal caregivers of the older adults according to sociodemographic and health aspects. São Carlos, São Paulo, Brazil, 2020

Variables	n (%)
Gender (female)	87 (88.8)
Age (years)	57 (46-63)*
Age group (18 to 59 years old)	63 (64.3)
Race/color	
White	55 (56.1)
Black	13 (13.3)
Brown	29 (29.6)
Yellow	1 (1.0)
Years of study	8 (4-11)*
Marital status (married/with partner)	73 (74.5)

Table 1 – Cont.

Variables	n (%)
Personal income (in BRL)	975.00 (0-1,300.00)*
Family income (in BRL)	2,000.00 (1,500.0-3,000.00)*
Self-assessment of health	
Excellent	8 (8.2)
Very good	6 (6.1)
Good	40 (40.8)
Reasonable	36 (36.7)
Bad	8 (8.2)
Physical activity (<150 minutes per week)	70 (71.4)
Multimorbidity (yes)	90 (91.9)
Medications (yes)	73 (74.5)

Source: Research data, 2020.

*Median (p25-p75).

Regarding family functionality, most caregivers presented good functionality (59.8%), followed by high dysfunction (22.7%) and moderate family dysfunction (17.5%). The median score obtained in the family APGAR was 14 (9-18). As for burden, 49.5% scored for mild to moderate burden, followed by 25.8% moderate to severe, 17.5% absent and 7.2% severe

burden. The median score obtained on the Zarit Caregiver Burden Interview was 32 (24-44).

Figure 1 presents a moderate negative correlation between scores for family functionality and caregiver burden (Rho= -0.57; p<0.001), that is, the higher the burden score, the lower the family functionality score.

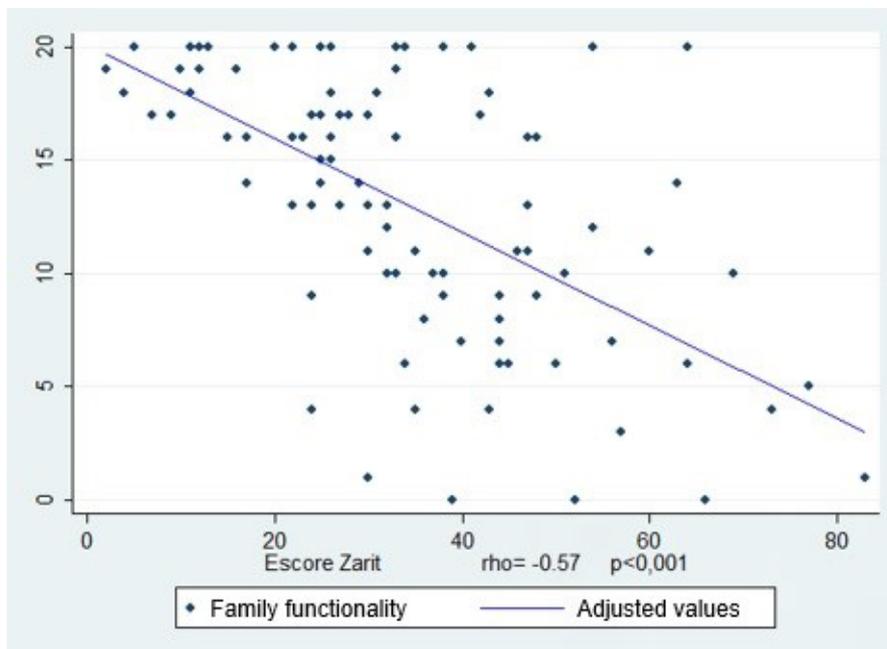


Figure 1 – Scatter diagram according to family functionality and burden of informal caregivers of the older people. Sao Carlos, Sao Paulo, Brazil, 2020

Source: Research data, 2020.

Table 2 – Distribution of informal caregivers of the older adults according to the care context. São Carlos, São Paulo, Brazil, 2020

Variables	n (%)
Older adults receiving care	
Spouse	31 (31.6)
Father/mother	45 (45.9)
Father-in-law/mother-in-law	8 (8.2)
Brother/Sister	5 (5.1)
Other	9 (9.2)
Care time (months)	24 (4-60)*
Daily hours of care	14.5 (8-24)*
Weekly days of care	7 (7-7)*
Provides care on the weekend (yes)	85 (87.6)
Previous training (no)	80 (81.6)
Receives help with care (yes)	75 (76.5)
Receives material/financial support (no)	82 (83.7)
Receives affective/emotional support (yes)	63 (64.3)
Receives support with ADL† (no)	50 (51.0)
Receives formal support from some entity (no)	84 (85.7)

Source: Research data, 2020.

*Median (p25-p75); †ADL – activities of daily living.

DISCUSSION

This study investigated the relationship between family functionality and the burden of informal caregivers of the older people. The sociodemographic characteristics of informal caregivers of the older adults are similar to those observed in national and international studies, which indicate a predominance of women, married, who provide care to their spouses or parents and who have low income and education⁽¹²⁻¹³⁾.

Education can influence the understanding of care to be implemented during hospitalization as well as the guidance for preparing for hospital discharge. Therefore, nurses must be aware of the resources adopted in view of the guidance

given to caregivers, so that possible mistakes are prevented. The low level of education is a worrying factor, as it can interfere, directly or indirectly, in the care provided to the older adults and bring negative repercussions to the quality of life of both the caregiver and the older adults receiving care⁽¹³⁾.

In addition, low income, often a consequence of low education, may reflect the social vulnerability to which these caregivers are subject. Faced with the impossibility of hiring a formal caregiver, many relatives leave the job market to perform the function of care and start to survive with resources from the older adults receiving care, which may not be sufficient to meet the needs of the entire family⁽¹³⁾.

Regarding the health of caregivers in the present study, most reported having two or more diseases, using two or

more medications and not practicing physical activities. The occurrence of multimorbidity in these informal caregivers can be explained by the deep involvement with the dependent older adults, which can be fraught with strenuous situations. When performing the task of caring in an uninterrupted way, the caregiver postpones the practice of self-care and neglects their own health, allowing the development of physical and psychological health problems⁽²⁾.

Associated with multimorbidity is the increased consumption of medications. Heavy medication use is a common practice among caregivers to relieve pain, stress, and insomnia. These drugs are often used without a medical prescription, which can cause worrying consequences, such as increased risk and severity of adverse reactions, drug interactions, cumulative toxicity, medication errors, in addition to reduced adherence to treatment and increased morbidity and mortality⁽¹⁴⁾.

Faced with the impossibility of leaving the role of caring under the responsibility of another person, the caregiver does not practice physical or leisure activities, which would help in their own well-being. The lack of these activities can be pointed out as one of the factors responsible for family dysfunction and for the increase in physical and emotional burden among informal caregivers of the older people⁽¹⁵⁾.

Regarding the context of care, most interviewees reported that the older adults receiving care was their parent or spouse, was of advanced age, had multimorbidity and was dependent for the performance of activities of daily living (ADL), which may be related to caregiver burden. Half of the caregivers performed the task of caring for more than two years, seven days a week, for more than 14.5 hours a day, without any type of previous training. Caregivers who reported receiving help in care predominantly had emotional and/or affective support. Socially, the family is the main support nucleus for the older people, with children and spouses responsible for caring. When the kinship relationship is one of filiation, the literature points out that caregiver children may be overburden due to the fact that they are often exposed to demands that go beyond the care context⁽¹⁵⁾.

Often, as they are the only caregiver option available within the family and do not have support from third parties, they dedicate much of their time to care for the older people. They have been caring for many years and for several hours a day, which can lead to burden and damage to the caregiver's quality of life⁽²⁾.

Concomitantly with the solitary exercise of the task of caring, most caregivers did not receive care training. The activities are performed empirically and the fact that these caregivers have not received previous training becomes an important triggering factor for the burden, given that many

are unaware of how to act in the face of the disease's evolution, especially during the hospitalization period. Therefore, it is worth emphasizing the importance of the nurse's role by establishing a bond with the informal caregiver to perform health education, an extremely important tool to reduce the existing tension in this context⁽¹⁶⁾.

Although most reported receiving affective/emotional support, many do not receive financial support or in relation to their own care and this can lead to intense burden and family dysfunction. Due to full dedication to the older people, there is no possibility for the caregiver to develop paid work outside the home. In this sense, the financial difficulty experienced in this context can generate burden, as the income of the older adults cared for is often not enough to meet their own needs. In addition, the literature points out that the lack of social support, whether from family members or health professionals, and the existence of family conflicts can also contribute in this sense⁽⁴⁾.

In this study, most caregivers presented good family functionality, although there are 40.2% of the sample with some dysfunction, in addition to an indication of mild to moderate burden. These findings are corroborated by similar studies conducted in Italy⁽⁶⁾, Brazil⁽¹⁷⁾, China⁽¹⁸⁾ and Taiwan⁽⁷⁾.

Satisfaction with family functioning is closely related to the emotional support existing among its members, especially when it is offered by people who are significant to the caregiver. This emotional support received by the caregiver can work as an important tool for coping with stressful situations arising from care and causing intense burden⁽¹⁷⁾. The intensity of affection, the ability to adapt to an unexpected situation and to try to resolve it and companionship are fundamental for good family functionality, which is related to a high quality of life⁽⁸⁾. In addition, factors such as living in the same household as the older adults upon approval and intergenerational coexistence also influence the positive perception of family relationships⁽¹⁷⁾.

As the older adults becomes weakened and dependent, the greater are the demands for care and, consequently, the efforts on the part of the caregiver to perform this task are greater. In this context, it is also worth mentioning that unpreparedness and sudden responsibility for care can result in high levels of burden. In addition, caregivers who live in the same house as the older adults cared for may present moderate to severe levels of burden due to frequent exposure to care demands in addition to other household tasks, such as taking care of the home and sharing care with other family members. In addition, it is common for the caregiver to become intensely involved with the older adults receiving care, making them forget about their own needs and well-being⁽⁴⁾.

In this sense, the importance of the development of interventions by nurses is highlighted, with assertive actions aimed at the prevention and/or reduction of the burden of informal caregivers of the older people, such as the creation of support groups or psychoeducational interventions. Such actions provide caregivers with the opportunity to exchange experiences and knowledge, guidelines that involve health promotion, support and social support and confrontations⁽¹⁹⁾.

A recent systematic review aimed to identify and analyze studies on non-pharmacological interventions for informal caregivers of the older people. Such studies performed psychoeducational, psychotherapeutic and psychosocial interventions, in addition to support groups, counseling and family meeting. Most of them showed that these interventions provided various benefits to caregivers, such as reducing the level of stress, pressure, physical and emotional burden, acquiring a feeling of support, increasing knowledge and skills, in addition to favoring an improvement in the caregiver's perception of health⁽¹⁹⁾.

In this research, a negative correlation of moderate magnitude was found between the scores of family functionality and caregiver burden, and the higher the levels of burden, the lower the levels of family functionality. Studies from Brazil⁽²⁰⁻²¹⁾, Japan⁽²²⁾ and Iran⁽²³⁾ also identified similar results.

Serious problems related to family functioning are identified as the main causes of increased burden, being a triggering factor for negative situations among family members⁽²⁰⁾. Some see family functionality as a mediator between burden and quality of life⁽²²⁾. When an older adults with physical and/or cognitive dependence needs care from a family member, there may be an imbalance in the dynamics of this family, generating psychosocial disorganization associated with negative feelings that affect family functionality⁽²¹⁾. It is noteworthy that family conflict can be both a consequence and the cause of burden, since the caregiver who lives in a dysfunctional family environment will likely be affected by emotional problems that will later trigger the burden⁽²⁰⁾.

Burden appears as a difficulty for family members who take care of the older adults, given that the context of care can cause physical, psychological, and social problems in the lives of caregivers. By restricting their leisure activities, caregivers may show signs of physical and emotional exhaustion. Such manifestations can impact affective relationships with other family members, causing issues to be poorly resolved and resulting in family conflicts⁽²¹⁾.

Unstable interpersonal and social relationships contribute to increased caregiver burden, given that, in this context, there will be no division of care among other family members, and, given the intense dedication to care, many caregivers abandon their recreational activities. In this sense, the

burden can be alleviated through the involvement of other family members in the division of care tasks with the main caregiver⁽²¹⁾. Considering the fundamental role of families in caring for the dependent older adults and the structuring of families in old age, strengthening family functionality and the support network can positively impact the health of caregivers and the quality of care offered.

It is believed that the hospital context can influence family functionality and the burden of informal caregivers of the older people, given that this environment has rules and routines to be followed and its fast-paced daily life can result in inadequate communication with these caregivers. Faced with not meeting their needs, such caregivers feel unprepared for continuity of care, anxious and overloaded, which can culminate in hospital readmission. In this sense, it is essential to approach relevant information and offer emotional support^(16,24).

The needs of caregivers of the older adults increase during hospitalization and this may be related to the time the older adults remains hospitalized⁽¹⁶⁾. It is known that the length of stay of an older adults in the service is longer than the length of stay of the other age groups. Such situation requires the need for reorganization from the family, as the continuous stay of a companion during this hospitalization period will become imperative⁽²⁵⁾.

Given the aging population, it is expected that there will be an increase in the number of hospitalizations in the coming years. This phenomenon reinforces the need for articulation between the three levels of health care, the removal of barriers to access the health system and a focus on health promotion and disease prevention actions. In order to reduce avoidable hospitalizations, there must be the implementation of Primary Health Care policies, in order to manage the most prevalent morbidities and avoid the occurrence of functional decline in the older adults people⁽²⁶⁾.

However, it is necessary to go further. Implementing policies to support the informal caregiver of the older adults is extremely important⁽³⁾, considering that the family is the main provider of care for the older people, whether out of necessity and/or obligation. The representation of the family as a caregiver for its older adults members is something traditional in our society⁽²⁷⁾. In European countries, family members who provide care to the older adults are valued because, in addition to being the most desired by the older people, it also reduces hospitalization expenses⁽³⁾.

The study presented limitations in data collection, which occurred through self-report and the reason and duration of hospitalization were not investigated. In addition, the results cannot be generalized, as they are related to a specific sample of caregivers of the older people. However, these

limitations do not extinguish the relevance of the findings. It is suggested that future investigations, of a longitudinal nature, to be carried out to deepen the subject and that considers the different contexts of the Health Care Network.

For the clinical practice of nurses, the results of the present study elucidate the need for early identification of both burden and family dysfunction, as both conditions can bring harm to the care offered and the well-being of caregivers and older adults receiving care. Therefore, it is essential to plan and implement individualized care in order to minimize the negative impact on the lives of those involved, alleviate the burden and favor more harmonious family relationships. The establishment of a bond between nurses, caregivers, family members and the older adults being cared for can contribute to the success of these interventions.

■ CONCLUSION

It is concluded that there is an inversely proportional correlation between burden and family functionality of the informal caregiver of hospitalized older adults people, and the higher the burden score, the lower the family functionality score and vice versa. In view of this, nurses need to identify such conditions early and implement assertive interventions so that the family works as a therapeutic resource.

In addition, the findings can support adequate therapeutic planning, in which there is integration between the multiprofessional team. In this sense, in order to minimize the wear on the informal caregiver, support groups and psychoeducational interventions can be developed in order to provide opportunities for sharing experiences and knowledge. In addition, health promotion actions, family meetings and social support can help these caregivers in coping with daily adversities.

■ REFERENCES

- Rosseto C, Soares JV, Brandão ML, Rosa NG, Rosset I. Causes of hospital admissions and deaths among Brazilian elders between 2005 and 2015. *Rev Gaúcha Enferm.* 2019;40:e20190201. doi: <https://doi.org/10.1590/1983-1447.2019.20190201>
- Nunes DP, Brito TRP, Duarte YAO, Lebrão ML. Caregivers of elderly and excessive tension associated to care: evidence of the SABE study. *Rev Bras Epidemiol.* 2018;21(supl 2):e180020. doi: <https://doi.org/10.1590/1980-549720180020.supl.2>
- Minayo MCS. Caring for those who care for dependent older adults: for a necessary and urgent policy. *Ciênc Saúde Colet.* 2021;26(1):7-15. doi: <https://doi.org/10.1590/1413-81232020261.30872020>
- Albuquerque FKO, Farias APEC, Montenegro CS, Lima NKF, Gerbasí HCLM. Quality of life of caregivers of the older people: an integrative review. *Rev Enferm Atual in Derme.* 2019;87:25. doi: <https://doi.org/10.31011/reaid-2019-v.87-n.25-art.189>
- Campos ACV, Rezende GP, Ferreira EF, Vargas AMD, Gonçalves LHT. Family functioning of Brazilian elderly living in community. *Acta Paul Enferm.* 2017;30(4):358-67. doi: <https://doi.org/10.1590/1982-0194201700053>
- Tramonti F, Bonfiglio L, Bongioanni P, Belviso C, Fanciullacci C, Rossi B, et al. Caregiver burden and family functioning in different neurological diseases. *Psychol Health Med.* 2019;24(1):27-34. doi: <https://doi.org/10.1080/13548506.2018.1510131>
- Liu HY, Huang LH. The relationship between family functioning and caregiving appraisal of dementia family caregivers: caregiving self-efficacy as a mediator. *Aging Ment Health.* 2018;22(4):558-67. doi: <https://doi.org/10.1080/13607863.2016.1269148>
- Pavarini SCI, Bregola AG, Luchesi BM, Oliveira D, Orlandi FS, Moura FG, et al. Social and health-related predictors of family function in older spousal caregivers: a cross-sectional study. *Dement Neuropsychol.* 2020;14(4):372-8. doi: <http://doi.org/10.1590/1980-57642020dn14-040007>
- Duarte YAO. Família: rede de suporte ou fator estressor: a ótica de idosos e cuidadores familiares [resumo]. São Paulo: Universidade de São Paulo; 2001 [cited 2021 Mar 25]. Available from: <https://pesquisa.bvsalud.org/portal/resource/pt/biblio-1036989>
- Sczufca M. Brazilian version of the Burden Interview scale for the assessment of care in carers of people with mental illnesses. *Rev Bras Psiquiatr.* 2002;24(1):12-7. doi: <https://doi.org/10.1590/S1516-44462002000100006>
- Ferreira F, Pinto A, Laranjeira A, Pinto AC, Lopes A, Viana A, et al. Validação da escala de Zarit: sobrecarga do cuidador em cuidados paliativos domiciliares, para população portuguesa. *Cad Saude.* 2010;3(2):13-9. doi: <https://doi.org/10.34632/cadernosdaude.2010.2806>
- Edwards VJ, Bouldin ED, Taylor CA, Olivari BS, McGuire LC. Characteristics and health status of informal unpaid caregivers – 44 states, District of Columbia, and Puerto Rico, 2015–2017. *Morb Mortal Wkly Rep.* 2020;69(7):183-8. doi: <http://doi.org/10.15585/mmwr.mm6907a2>
- Rangel RL, Santos LB, Santana ES, Marinho MS, Chaves RN, Reis LA. Avaliação da sobrecarga do cuidador familiar de idosos com dependência funcional. *Rev Aten Saude.* 2019;17(60):11-8. doi: <https://doi.org/10.13037/ras.vol17n60.5564>
- Leite BS, Camacho ACLF, Joaquim FL, Gurgel JL, Lima TR, Queiroz RL. Vulnerability of caregivers of the elderly with dementia: a cross-sectional descriptive study. *Rev Bras Enferm.* 2017 [cited 2021 Mar 25];70(4):682-8. Available from: <https://www.scielo.br/j/reben/a/chtJwWjyZCvDth9b8Tm9VBr/?format=pdf&lang=en>
- Sarpi MJY, Nogueira IS, Lourenço MP, Carreira L, Baldissera VDA. Context of life and health of informal caregivers of care-dependent elderly. *Rev Par Enferm.* 2019 [cited 2021 mar 25];2(1):51-8. Available from: <http://seer.fafiman.br/index.php/REPEN/article/view/554/532>
- Farahani MA, Bahloli S, JamshidiOrak R, Ghaffari F. Investigating the needs of family caregivers of older stroke patients: a longitudinal study in Iran. *BMC Geriatr.* 2020;20(1):313. doi: <https://doi.org/10.1186/s12877-020-01670-0>
- Lins AES, Rosas C, Neri AL. Satisfaction with family relations and support according to elderly persons caring for elderly relatives. *Rev Bras Geriatr Gerontol.* 2018;21(3):330-41. doi: <http://doi.org/10.1590/1981-22562018021.170177>
- Luo J, Zhou Y, Liu H, Hu J. Factors related to the burden of family caregivers of older adults patients with spinal tumours in Northwest China. *BMC Neurol.* 2020;20(1):69. doi: <https://doi.org/10.1186/s12883-020-01652-0>
- Reis E, Novelli MMPC, Guerra RLF. Intervenções realizadas com grupos de cuidadores de idosos com síndrome demencial: revisão sistemática. *Cad Bras Ter Ocup.* 2018;26(3):646-57. doi: <https://doi.org/10.4322/2526-8910.ctoAR0981>

20. Pedreira LC, Oliveira AMS. Cuidadores de idosos dependentes no domicílio: mudanças nas relações familiares. *Rev Bras Enferm.* 2012;65(5):730-6. doi: <http://doi.org/10.1590/S0034-71672012000500003>
21. Jesus FA, Aguiar ACSA, Santos ALS, Meneses KF, Santos JLP. Conviving and relating to the elderly person in the household: family perception. *J Nurs UFPE on line.* 2017 [cited 2021 Mar 25];11(suppl 10):4143-9. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/viewFile/231176/25148>
22. Kimura H, Nishio M, Kukihara H, Koga K, Inoue Y. The role of caregiver burden in the familial functioning, social support, and quality of family life of family caregivers of elders with dementia. *J Rural Med.* 2019;14(2):156-64. doi: <https://doi.org/10.2185/jrm.2999>
23. Ghasemi M, Arab M, Shahbabaki PM. Relationship between caregiver burden and family functioning in family caregivers of older adults with heart failure. *J Gerontol Nurs.* 2020;46(6):25-33. doi: <https://doi.org/10.3928/00989134-20200511-04>
24. McCusker J, Yaffe M, Lambert SD, Cole M, Raad M, Belzile E, et al. Unmet needs of family caregivers of hospitalized older adults preparing for discharge home. *Chronic Illn.* 2020;16(2):131-45. doi: <https://doi.org/10.1177/1742395318789467>
25. Pasini D, Pelzer MT, Gomes GC, Lange C, Szewczyk MSC, Severo DG. Ações, facilidades e dificuldades para o cuidado ao idoso no hospital: vivências do familiar cuidador. *Res Soc Dev.* 2020 [cited 2021 Jul 17];9(11):e5669119608. Available from: <https://rsdjournal.org/index.php/rsd/article/view/9608>
26. Melo-Silva AM, Mambrini JVM, Souza Junior PRB, Andrade FB, Lima-Costa MF. Hospitalizations among older adults: results from ELSI-Brazil. *Rev Saude Publica.* 2018;52(Suppl 2):3s. doi: <https://doi.org/10.11606/S1518-8787.2018052000639>
27. Cardoso AS, Leandro M, Silva MLB, Moré CLOO, Bousfield ABS. Representações sociais da família na contemporaneidade: uma revisão integrativa. *Pensando Fam.* 2020 [cited 2021 Jul 17];24(1):29-44. Available from: <http://pepsic.bvsalud.org/pdf/penf/v24n1/v24n1a04.pdf>

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