

Characterization of the informal caregiver of hospitalized elderly: a cross-sectional study

Caracterização do cuidador informal de idosos hospitalizados: um estudo transversal

Caracterización del cuidador informal de ancianos hospitalizados: un estudio transversal

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ABSTRACT

Objective: to describe the sociodemographic and clinical profile, life habits and workload of a family caregiver of elderly people admitted to a university hospital. **Method:** this is a cross-sectional, quantitative study carried out with 161 caregivers/relatives of the elderly during hospitalization at a university hospital. The Informal Caregiver Burden Assessment Questionnaire was applied to the participants, and the data were analyzed using the STATA 12.0® program. **Resultados:** we characterized the predominance of females, with a mean age of 63 years, sedentary, overweight, with systemic arterial hypertension as the main comorbidity, and severe (41.6%) and extremely severe (29.9%) overload was detected in the research participants. It was observed that the instrument used had good internal consistency, where the domains Emotional Burden, Implications for Personal Life, Financial Burden and Family Support had higher scores. **Conclusion:** the burden of informal caregivers of the elderly was detected as serious and extremely serious, directly impacting mental health, social and financial life. **Descriptors:** Caregivers; Caregiver's Burden; Elderly; Hospitalization.

RESUMO

Objetivo: descrever o perfil sociodemográfico e clínico, os hábitos de vida e a sobrecarga do trabalho de cuidador familiar de idosos internados em um hospital universitário. **Método:** trata-se de um estudo transversal, quantitativo, realizado com 161 cuidadores/familiares de idosos durante a hospitalização em um hospital universitário. Foi aplicado aos participantes o Questionário de Avaliação de Sobrecarga do Cuidador Informal, sendo os dados analisados no programa STATA 12.0®. **Resultados:** caracterizou-se a predominância do sexo feminino, com média de idade de 63 anos, sedentários, com sobrepeso, com hipertensão arterial sistêmica como principal comorbidade e detectou-se sobrecarga grave (41,6%) e extremamente grave (29,9%) nos participantes da pesquisa. Observou-se que o instrumento utilizado apresentou boa consistência interna, onde os domínios Sobrecarga Emocional, Implicações na Vida Pessoal, Sobrecarga Financeira e Suporte Familiar apresentaram maior pontuação. **Conclusão:** a sobrecarga dos cuidadores informais dos idosos foi detectada como grave e extremamente grave, repercutindo diretamente na saúde mental, vida social e financeira. **Descritores:** Cuidadores; Fardo do cuidador; Idoso; Hospitalização.

RESUMEN

Objetivo: describir el perfil sociodemográfico y clínico, los hábitos de vida y la sobrecarga de trabajo de cuidador familiar de ancianos internados en un hospital universitario. **Método:** trátase de un estudio transversal, cuantitativo, realizado con 161 cuidadores/familiares de ancianos durante la hospitalización en un hospital universitario. El Cuestionario de Evaluación de Sobrecarga del Cuidador Informal fue dado a los participantes y los datos fueron analizados en el programa STATA 12.0®. **Resultados:** quedó caracterizada la predominancia del sexo femenino, con promedio de edad de 63 años, sedentarios, con sobrepeso, con hipertensión arterial sistémica como principal comorbilidad y se detectó sobrecarga grave (41,6%) y extremadamente grave (29,9%) en los participantes de la investigación. Se observó que el instrumento utilizado presentó buena consistencia interna, donde los dominios Sobrecarga Emocional, Implicancias en la Vida Personal, Sobrecarga Financiera y Apoyo Familiar presentaron puntuación más elevada. **Conclusión:** la sobrecarga de los cuidadores informales de los ancianos fue detectada como grave y sumamente grave, repercutiendo directamente en la salud mental, vida social y financiera.

Descritores: Cuidadores; Fardo del cuidador; Anciano; Hospitalización.

INTRODUCTION

Brazil has more than 30 million elderly people and reached 14% of the total population, with a growing elderly population aged 80 years or more. With this panorama of population growth, a change in the epidemiological profile of the population is remarkable⁽¹⁾, thus, maintaining independence and autonomy is a challenge for this group, as they are more susceptible to chronic non-communicable diseases, disabling conditions, sensory decline, accidents and social isolation, requiring the help of caregivers for long periods⁽²⁾.

In this context, it is essential that the elderly have a comprehensive care support network, where the family is relevant to guarantee their well-being and care, represented by the role of the family caregiver or informal caregiver. The caregiver is the person who helps the other in their daily life activities⁽³⁾.

Thus, when a family member has a dependent elderly person, it is worrisome due to the demand for special care and excessive variation in tasks. The activities performed by the informal caregiver are complex and can generate physical and psychological burden and social isolation. Burden is conceptualized as a resistance to the provision of care, caused by the inclusion or increase of activities performed and is related to several reasons, linked to the characteristics of the elderly, such as the degree of dependence in daily activities, of the caregiver and the social support that these present⁽⁴⁾.

Knowing that most caregivers of the elderly are family members and play this role informally. It is important that these people have someone to turn to to resolve their concerns and doubts. Assisting the caregiver requires skill and knowledge, as well as knowing which individual interventions are appropriate, considering the different contexts of caregivers' lives. From this perspective, the present study sought to describe the socio-demographic and clinical profile, lifestyle habits and work burden of a family caregiver of elderly people admitted to a university hospital.

METHOD

This is a cross-sectional study with a quantitative approach. The sample consisted of informal caregivers of elderly people hospitalized in medical and surgical clinics at a university hospital in northeastern Brazil. Participants were selected

for convenience and included 161 caregivers of hospitalized elderly. The following inclusion criteria were adopted: being a caregiver of hospitalized elderly patients (over 60 years old); be of age ≥ 18 years old; having family ties of first and second degree of kinship or having a stable relationship/married couple; reside in the same household as the elderly; stay ≥ 6 hours daily as a companion/caregiver. Professional caregivers and those with an employment relationship with the elderly were excluded.

Data collection was carried out from January to April 2018, using two instruments, the application of which took place through self-completion. The first included a semi-structured questionnaire to obtain data on the sociodemographic and clinical profile and the lifestyle habits of the study participants. The second instrument already validated for the Brazilian population included the assessment of burden, using the Informal Caregiver Burden Assessment Questionnaire (QASCI)⁽⁵⁾, by Martins Martins, Ribeiro and Garret, includes 32 items, evaluated through an ordinal frequency scale ranging from 1 to 5. To complete this instrument, participants answered according to their degree of agreement, as follows: 1- no/never; 2- rarely; 3- sometimes; 4- almost always; and 5- always. The 32 items are further distributed into 7 subscales, namely: emotional overload (SE), four items; Implications for the caregiver's personal life (IVP), assessment of the repercussions of taking care of the family member, such as the reduction in available time, affected health and restrictions on the level of social life, eleven items; financial burden (SF), two items; reactions to demands (RE), five items. These are subscales that constitute the vulnerabilities or negative forces arising from the act of caring. And three in opposition, considered positive influencing forces or predictors of well-being in the informal caregiver, perception of the effectiveness and control mechanisms (PMEC), three items; Family support (SupF), two items; satisfaction with the role and with the family (SPF), five items⁽⁵⁾. These last factors (PMEC, SupF and SPF) of the instrument recommend inverted scores, so that higher values correspond to situations with greater weight or burden⁽⁵⁾.

So that the final scores of each subscale present homogeneous and comparable values for each dimension, the results of all items were added

and a formula was applied, obtaining values in comparable percentage (values 0 to 100). The higher the value, the greater the burden. All items were added for each factor to be measured. After analysis, the following data references were followed: value 0 - no burden; values between 1 and 25 - light burden; values between 25 and 50 - moderate burden; values between 50 and 75 - severe burden; above 75 - extremely severe burden⁽⁵⁾.

The collected data were stored in a specific database created in the Microsoft EXCEL®2019 program and analyzed in the STATA 12.0® program. Quantitative variables were described as mean and standard deviation (SD) (mean ± SD) and qualitative variables as frequencies and percentages. Quantitative variables were normal according to the Shapiro Wilk Test, and Cronbach's alpha index was used to analyze the internal consistency of the domains. This index ranges from 0 to 1 and the closer to 1, the greater the reliability of the instrument, with this reliability being categorized as: very good = greater than 0.9; good = between 0.8 and 0.9; reasonable = 0.7 and 0.8; weak = 0.6 and 0.7; inadmissible = less than 0.6⁽⁶⁾.

The study met the standards of Resolution No. 466 of December 12, 2012 involving human beings and was approved by the Research Ethics Committee of the University Hospital of the Federal University of Maranhão, as per opinion N°. 2.306.474.

RESULTS

Regarding sociodemographic data, there was a predominance of female caregivers (84.5%), with a prevalent age group of 60 to 70 years (69.0%), with a mean age of 63 years (±5.66),

brown and black (75.7%), with ≥5 years of education (69.0%), married (69.5%), wives (71.4%), housework (42.2%), with monthly income ≤ 1 minimum wage (63.3%) and living with family of 2 to 4 people (54.6%).

With regard to prevalent clinical conditions, the prevalent Body Mass Index (BMI) was overweight (62.1%), with the presence of associated comorbidities (83.8%), with arterial hypertension being the most prevalent (57.8%), with altered blood pressure and blood glucose levels during collection, respectively (68.4%) (41.7%). Still in relation to clinical data, it was observed that the majority used medications (96.9%), with only one medication being used (50%), followed by 2 to 4 medications (38.4%). Regarding the length of follow-up of the elderly during hospitalization, the prevalence was between 1 and 7 days (51%).

With regard to lifestyle, there was a predominance of non-smokers (93.8%), non-drinkers (92.5%) and sedentary (85.7%) informal caregivers.

As for the level of burden prevalent among informal caregivers of the elderly, there was Severe Burden (41.6%), followed by Extremely Severe Burden (29.9%), as shown in Table 1.

According to the data presented in Table 2, it was possible to observe that all domains had good internal consistency, with the exception of the P MEC domain, which presented a consistency of 0.6. Regarding the domains, they scored above 50, being classified as severe burden: Emotional Burden (56.3%), Personal Life Implications (56.8%), Financial Burden (67.8%) and Family Support (55.5%). Other domains presented Moderate Burden with scores lower than 50: P MEC (46.4%), Satisfaction with the Role and with the Family (42.7%) and Reactions to Demands (42.0%).

Table 1 - Type of burden of informal caregivers of elderly people admitted to a University Hospital (n=161). São Luís, MA, Brazil, 2018

Type of Burden- QASCI	n	%
Slight Burden	20	12.4
Moderate Burden	26	16.1
Severe Burden	67	41.6
Extremely Severe Burden	48	29.9

Source: Prepared by the authors, 2018.

Table 2 - Descriptive analysis and internal consistency of QASCI Domains of informal caregivers of elderly people admitted to a University Hospital (n=161). São Luis, MA, 2018

QASCI Domains	Crombach's α	Interval obtained	Mean (\pm dp)	Score (average)
Emotional burden (4 items, 4 to 20)	0.860	4-20	11.26 (\pm 4.56)	56.3%
Implications for personal life (11 items, 11 to 55)	0.859	11-54	30.70 (\pm 9.88)	56.8%
Financial burden (2 items, 2 to 10)	0.781	2-10	6.78 (\pm 2.16)	67.8%
Reactions to demands (5 items, 5 to 25)	0.758	5-24	10.08 (\pm 4.74)	42.0%
Perception of effectiveness and control mechanisms (3 items, 3 to 15)	0.674	3-13	6.04 (\pm 2.44)	46.4%
Family support (2 items, 2 to 10)	0.798	2-10	5.55 (\pm 2.09)	55.5%
Satisfaction with the role and with the family (5 items, 5 to 25)	0.703	5-23	9.83 (\pm 3.78)	42.7%
QASCI Total Burden (32 items, 32 to 160)	0.870	32-154	77.8 (\pm20.87)	50.1%

Source: Prepared by the authors, 2018.

DISCUSSION

The informal caregiver is a member of the family or community who provides any type of care to dependent people, especially the elderly, on a voluntary basis, whose task is to take care, with actions aimed at helping the elderly person who is physically or mentally impeded from performing tasks of activities of daily living and self-care⁽⁷⁾.

In this study, one of the highlighted points is the sociodemographic profile of informal caregivers who are married women, aged 60 to 70 years, self-declared brown, with low income, low education and living with more than 2 people in the same household, results similar to other studies⁽⁸⁻¹¹⁾. Thus, the prevalence of married women in this care practice reflects a change in the role of women in society, being an essential factor in the health paradigm. They ceased to be seen only as maids, at home and to be considered as traditional caregivers, starting to adopt a more active and participative role in society, generating the need to find answers to support people in a situation of dependency⁽¹²⁾. In the age group over 60 years old, the transition phase and several changes related to senescence, it can sometimes cause fragility in the act of caring, in view of the performance of physical efforts that compromise the quality of health of this caregiver^(8,11,13), however, bonding through marriage seems to facilitate the caregiver's adaptation process⁽¹⁰⁾, besides having an activity better executed and elaborated with optimistic feelings.

However, low education and low income are aspects that compromise the quality of care provided and burden the caregiver, as it reduces the possibilities of work to obtain resources, which will be necessary to maintain the needs of the dependent elderly⁽¹⁰⁾, consequently, it will generate a feeling of anxiety in caregivers who seek to offer a better quality of life for their family member under their responsibility, and having more education can contribute to reducing the burden, as caregivers can expand their development in providing care.

Two peculiarities in the profile of our study were: the prevalence of brown and black colors self-reported by the caregivers and the cohabitation with the elderly person and the caregiver with more than 2 people in the same household. Regarding the brown and black color of the participants, this phenomenon is related to miscegenation, common in this region and most of the time it sounds like a negative social aspect, always associated with low education and low income⁽¹⁴⁾. Cohabitation with more than two people in the same household presupposes more contingency for the provision of assistance. However, in the present study there was no such assumption, that is, larger family arrangements did not translate into a decrease in caregiver burden⁽¹⁰⁾.

Regarding the caregivers' life habits, non-alcoholism, non-smoking, sedentary lifestyle and overweight prevailed, a result similar to the study⁽¹³⁾, we emphasize that alcoholism, smoking, sedentary lifestyle and overweight are part of these conditions

that compromise the quality of life, worsening the health conditions of the elderly and caregivers.

In the validation and reliability of the instrument, the *Cronbach's* alpha obtained for the full version of the QASCI was 0.87, similar to the study by Monteiro et al.⁽⁹⁾ reinforcing that the questionnaire was well accepted by the respondents.

And regarding the burden of the informal family caregiver, this was seen as severe and extremely severe, especially in the physical, emotional and social aspects, corroborating other studies⁽¹⁵⁻¹⁷⁾, emphasizing harmful effects on the health of caregivers of elderly people with a high level of dependence, these effects are psychosomatic, psychiatric, chronic, are associated with greater burden, lack of time for caregivers for themselves, reflecting negative effects of interpersonal relationships and changes in the quality of social life^(4,12).

Physical dependence and disability on the part of the elderly gradually increases the condition of burden on the caregiver, and it is almost always an irreversible and continuous process, which further aggravates the level of burden. According to a study⁽¹⁸⁾ the awareness of degeneration, unpredictability, time limitations, affective relationship between the caregiver and the subject, the target of care, and the lack of alternative choices are crisis situations that are directly linked to this dysfunctional process of caring for an elderly and/or dependent family member.

Among the domains with the greatest severity of burden, SF was the indicative factor with 67.8, followed by IVP with 56.8, SE with 56.3. The results regarding the IVP and SE were similar to Loreiro's et al.⁽¹⁰⁾ and Monteiro's et al.⁽⁹⁾ in relation to the incidence of greater burden in these domains, however the SF domain presents a higher score in this study, which differs from other studies in which the financial factor was not a dimension with significant burden, moreover, this can be justified by the low income reported by the surveyed caregivers.

The characteristic of a mental or psychological balance goes beyond individual issues, but also basically due to socioeconomic circumstances as-

sociated with the environment in which they live, thus affecting the caregiver's social relationships and family dynamics. With this, the almost exclusive dedication to the elderly, they conceive a work burden that compromises health conditions, self-care and restricts the time for actions of good health practices of the caregiver⁽¹⁷⁾.

From this perspective, improving the caregiver's living and health conditions suggests providing them with knowledge to be able to recognize in themselves their physical, emotional and social capacities. In this way, the caregiver will be able to carry out their activities safely and ensure their biopsychosocial integrity, in addition to offering a service with better quality to the assisted elderly⁽¹⁹⁾.

CONCLUSION

There was the presence of a severe burden in most caregivers approached in the research. It was also possible to describe in more detail, within this general overload, which domains in the biopsychosocial sphere were the most affected, showing that financial and emotional issues were the most present weaknesses.

It demonstrates the importance of the QASCI instrument for the identification and assessment of situations in which caregivers are subject to face in this care process, which sometimes ends up being a difficult path to adapt, which may trigger a process of overload of different natures. However, the method used, as it has a cross-sectional design, did not allow the establishment of a cause-and-effect relationship, which is the main limitation of this study.

It is expected to contribute to the production of knowledge about the hospitalized elderly population and their informal caregivers, with an emphasis on burden in order to support the formulation of health promotion strategies for the elderly/caregiver binomial.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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