

## Physical, emotional and social burden of elderly patients' informal caregivers

Sobrecargas física, emocional e social dos cuidadores informais de idosos  
Sobrecargas física, emocional y social de los cuidadores informales de ancianosPolyana Norberta Mendes<sup>1</sup>Maria do Livramento Fortes Figueiredo<sup>1</sup>Ana Maria Ribeiro dos Santos<sup>1</sup>Marcia Astres Fernandes<sup>1</sup>Ruth Suelle Barros Fonseca<sup>1</sup>**Keywords**

Aged; Caregivers/psychology; Geriatric nursing

**Descritores**

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**Abstract****Objective:** Assess the burden and identify the burden-related factors in home-based informal caregivers of bedridden elderly attended by the Family Health Strategy.**Methods:** Analytical, cross-sectional study involving 208 informal caregivers. The data were collected between February and July 2017 by applying the characterization script and the Informal Caregiver Burden Assessment Questionnaire. For analysis purposes, the *Statistical Package for the Social Science*, version 20.0 was used. Descriptive (central trend and dispersion, absolute and relative frequency measures) and inferential (Mann-Whitney and Kruskal-Wallis tests; Spearman correlation test) statistics were applied.**Results:** The mean total burden score was 71.1 ( $\pm 26.3$ ). A statistically significant difference was observed in the total burden and domain scores according to the variables: marital status of caregiver, degree of kinship with the elderly and all clinical variables of the caregivers. A positive correlation was registered between the burden and the caregiver's age and between the burden and number of daily hours spent on care.**Conclusion:** The burden was higher for the partners, caregivers with comorbidities, pain related to the activity performed and caregivers who considered their health as regular.**Resumo****Objetivo:** Avaliar a sobrecarga e identificar os fatores relacionados a sobrecarga em cuidadores informais de idosos acamados em domicílio assistidos pela Estratégia Saúde da Família.**Métodos:** Estudo analítico, transversal, desenvolvido com 208 cuidadores informais. A coleta de dados ocorreu no período de fevereiro a julho de 2017, por meio da aplicação do roteiro de caracterização e do Questionário de Avaliação da Sobrecarga do Cuidador Informal. Para análise utilizou-se o *software Statistical Package for the Social Science*, versão 20.0. Foram realizadas estatísticas descritivas (medidas de tendência central e dispersão, frequência absoluta e relativa) e inferenciais (teste de Mann-Whitney e Kruskal-Wallis; teste de correlação de Spearman).**Resultados:** A média total da sobrecarga foi de 71,1 ( $\pm 26,3$ ). Observou-se diferença estatística do escore total de sobrecarga e dos domínios que a compõe e as variáveis: estado civil do cuidador; grau de parentesco com o idoso e em todas as variáveis clínicas do cuidador. Registrou-se correlação positiva entre a sobrecarga e a idade do cuidador e entre a sobrecarga e horas do dia dedicadas ao cuidado.**Conclusão:** A sobrecarga foi maior para os cônjuges, os que apresentavam comorbidades, dores relacionadas à atividade desempenhada e para os que consideraram sua saúde regular.**Resumen****Objetivo:** Evaluar la sobrecarga e identificar los factores relacionados con la sobrecarga en cuidadores informales de ancianos acamados en domicilio, asistidos por la Estrategia Salud de la Familia.**Métodos:** Estudio analítico, transversal, desarrollado con 208 cuidadores informales. La recolección de datos ocurrió en el período de febrero a julio de 2017, por medio de la aplicación del guión de caracterización y del Cuestionario de Evaluación de la Sobrecarga del Cuidador Informal. Para el análisis se utilizó el software *Statistical Package for the Social Science*, versión 20.0. Se realizaron estadísticas descriptivas (medidas de tendencia central y dispersión, frecuencia absoluta y relativa) e inferenciales (prueba de Mann-Whitney y Kruskal-Wallis, prueba de correlación de Spearman).**Resultados:** El promedio total de la sobrecarga fue de 71,1 ( $\pm 26,3$ ). Se observó diferencia estadística de la puntuación total de sobrecarga y de los dominios que la componen y las variables: estado civil del cuidador; el grado de parentesco con el anciano y en todas las variables clínicas del cuidador. Se registró correlación positiva entre la sobrecarga y la edad del cuidador y entre la sobrecarga y horas del día dedicadas al cuidado.**Conclusión:** La sobrecarga fue mayor para los cónyuges, los que presentaban comorbidades, dolores relacionados con la actividad desempeñada y para los que consideraron su salud regular.**Corresponding author**Polyana Norberta Mendes  
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E-mail: [polyananorberta@hotmail.com](mailto:polyananorberta@hotmail.com)**DOI**<http://dx.doi.org/10.1590/1982-0194201900012>**How to cite:**Mendes PN, Figueiredo ML, Santos AM, Fernandes MA, Fonseca RS. Physical, emotional and social burden of elderly patients' informal caregivers. *Acta Paul Enferm.* 2019;32(1):87-94.<sup>1</sup>Universidade Federal do Piauí, Teresina, PI, Brazil.**Conflicts of interest:** paper resulting from Master's thesis, presented to the Graduate Nursing Program at the Federal University of Piauí – *Universidade Federal do Piauí*, titled: "Physical, emotional and social burden of bedridden elderly patients' informal caregivers at home".

## Introduction

The increase in human longevity has fostered diverse challenges for the government and community in ensuring the physical, social and legal well-being of the elderly and their family. These challenges include the physical, emotional and social burden caregivers of dependent elderly experience. This state of dependence, whether due to the appearance of non-transmissible chronic diseases and their consequences or due to the cognitive and functional losses of advancing age demand home care and changes in the daily lives of many families.<sup>(1-4)</sup>

The family is assigned the responsibility of assisting its aging members. The family caregivers are part of the informal support network, consisting of family members, friends, acquaintances, and neighbors, who work without pay. This fact marks the difference from the formal network of caregivers, composed of professionals, whether at home, in hospital or outpatient institutions.<sup>(2)</sup>

Informal care is the most frequent model of care for the elderly identified in the literature, but there is no clear description of the geographical areas where this care takes place.<sup>(3)</sup> Many relatives prefer this, possibly because of their cultural values, lack of formal care services or lack of financial resources to hire a caregiver.<sup>(3,4)</sup>

It is a contemporary reality to say that the family is responsible for meeting the social and health demands of the elderly and, therefore, the need for qualified and constant support, and the Family Health Strategy (FHS) team plays a fundamental role in this respect.<sup>(5)</sup>

The reality a family member faces when he or she has a dependent elderly person at home is worrisome due to the demand for special care, with a considerable variation of tasks. The activities the home-based informal caregiver carries out are complex and can generate physical, psychological, and social isolation. A burden is defined as resistance to care provoked by the inclusion or expansion of activities performed and is related to several factors, linked to the characteristics of the elderly, such as the degree of dependence in daily activities, of the caregiver and of the social support of both.<sup>(6)</sup>

Besides the burden, taking care of a dependent elderly can trigger other health problems for the caregiver who performs this activity full time and without assistance. The caregivers face greater chances of depressive disorders and anxiety, worse health conditions, besides substance abuse, including hypnotics and anxiolytics, and smoking.<sup>(7,8)</sup>

Because of the importance of knowing the various facets of home-based care for the elderly, concerning the informal caregiver/elderly patient, the study objective was to evaluate the burden and to identify the burden-related factors in home-based informal caregivers to bedridden elderly at home attended by the Family Health Strategy.

## Methods

An analytical study with a cross-sectional design was developed in the capital of the State of Piauí (PI). Due to the urbanization process in the city of Teresina, the largest number of elderly people live in the Central and North regions of Barra do Rio Poti. Thus, it was decided to carry out the research in the urban area assigned to all 22 Primary Health Care Services Units (BHU), within the Central and North regions.

The reference population of the study consisted of the home-based informal caregivers of bedridden elderly people assisted by the Family Health Strategy (ESF) teams. The teams active in the research scenario attend to 433 bedridden elderly people. The inclusion criteria were: 18 years or older; intact cognitive skills according to the parameters of the Mini-Mental State Examination (MMSE);<sup>(9)</sup> the bedridden elderly live in the area covered by the study; the bedridden elderly are enrolled in the FHS; the caregiver does not receive remuneration to take care of the bedridden elderly; be the primary caregiver because (s)he provides most of the care to the elderly most of the time; taking care of the bedridden elderly for four weeks or more.<sup>(10)</sup>

For the interpretation of the MMSE results, the cut-off points are determined according to the ed-

education level, considering the cut-off point 13 for illiterates, 18 for those with low (one to four incomplete years) and medium education level (four to eight incomplete years) and 26 for participants with high education level (eight or more years). These cohort values were used in this study to decide on the caregiver's participation.<sup>(9)</sup>

The sample was calculated by means of proportional stratified sampling of the number of bedridden elderly and, consequently, of their caregivers. To do so, we used the following formula:

Formula 1:

$$n_0 = \frac{1}{E_0^2}$$

Formula 2:

$$n = \frac{N \cdot n_0}{N + n_0}$$

Where  $n_0$  is the first approximation of the sample size;  $E_0$  is the tolerable sampling error, set here at 5%;  $N$  is the number of population elements;  $n$  is the final sample size, with 208 participants. Subsequently, the sample was divided into subgroups proportional to the number of bedridden elderly of each UBS, being 188 from the North and 20 from the Central region.

For the data collection, all instruments were then applied to the caregivers. The first, structured script to characterize the informal caregivers was used to obtain the data related to the demographic, economic, clinical and care profile of the bedridden elderly people's caregivers. The script has already been used in Brazil<sup>(10)</sup> and the researcher adapted it for the sake of this study. The second, the Informal Caregiver Burden Assessment Questionnaire (QASCI), was developed in Portugal and previously adapted and validated in Brazil.<sup>(11)</sup>

The QASCI consists of seven dimensions and 32 items, evaluated by means of an ordinal frequency scale ranging from 1 to 5 points. These are: Implications in personal life (11 items - 11 to 55 points); Satisfaction with role and relative (5 items - 5 to 25 points); Reactions to requirements (5 items - 5 to 25 points); Emotional bur-

den (4 items - 4 to 20 points); Family support (2 items - 2 to 10 points); Financial burden (2 items - 2 to 10 points) and Perception of effectiveness and control mechanisms (3 items - 3 to 15 points). For each participant, the total score is calculated by adding up the scores of the 32 items, after reversing the values of the items that make up the three positive dimensions, ranging from 32 to 160 points.<sup>(11)</sup> It is inferred that the highest scores correspond to situations with higher weight or greater burden. The score of the participant group is adopted as the mean total score.<sup>(11,12)</sup>

Data were collected from February to July 2017. After contact with the caregiver at home, the place where that person takes care of the elderly, the necessary procedures to carry out the research were explained and, after the participant had voluntarily accepted to participate, by means of the caregiver's consent and the signing of the Informed Consent Form, the interview was initiated.

Data were entered into Excel® 2013 and analyzed using the Statistical Package for Social Science (SPSS®) version 20.0. Subsequently, descriptive analyses were performed, such as central trend measures for numerical variables (mean and median), absolute and relative frequency for qualitative variables, and measures of dispersion or variability (standard deviation).

In the bivariate analysis, after proving a non-normal distribution of the variables, the non-parametric Mann-Whitney tests were used when they were dichotomous and the Kruskal-Wallis test when the variables presented three or more classes. These tests permit comparing differences between medians or ranks.

To analyze the association between independent quantitative variables and the study-dependent variable (total QASCI score), we chose to use the Spearman Correlation Coefficient. In the interpretation of the strength of the correlations (values of "ρ"), values from 0.00 to 0.20 were considered very low; 0.21 to 0.39 low; 0.40 to 0.69 moderate; 0.70 to 0.89 high; 0.90 to 1.00 very high and equal to 1 as a perfect correlation.<sup>(13)</sup> For all statistical tests used,  $p < 0.05$  was set to reject the null hypothesis.

The research took into consideration the ethical and legal aspects of research involving human beings, with the approval of the Ethics Committee at the Federal University of Piauí – *Universidade Federal do Piauí* (1.971.805).

## Results

It was identified that 40.4% of the informal caregivers participating were between 40 and less than 60 years old, with a mean age of 53 years (SD 15.1); 91.3% were female; 89.9% literate, with 8.9 years of study on average (SD 3.2) and 55.3% did not maintain a stable union. As for the degree of relationship with the elderly, it was verified that 56.3% of the caregivers were the children, 13.0% the spouses and 10.1% friends, neighbors, close people, and people the elderly had contact with. 85.1% of the participants lived with the bedridden elderly person.

Most caregivers reported one or more diseases, most notably those of the circulatory system (57.2%) and musculoskeletal and connective tissue conditions (40.6%). Of the total, 77.9% answered affirmatively about the presence of pain in the body. Of these, 66.7% complained of back pain; 56.2% stated that the pain started after the elderly had become bedridden and 69.1% said that the pain remained after the care was performed. Of the total, 59.6% felt changes in their body and health after

assuming the role of caregiver and 53.8% considered their health regular.

The average number of years spent on the care for the bedridden elderly was 6.4 (SD 6.2), ranging from 0.33 to 40 years. The journey of more than eight hours of care stands out, both during the week and at weekends.

The caregivers' mean total burden score, assessed using QASCI, was 71.1 (SD 26.3). In order to investigate the possible differences in the burden, according to the sociodemographic characteristics of the informal caregivers, the domain and total QASCI scores were compared between the groups (Table 1). And the difference in the burden according to the clinical characteristics of the informal caregiver is described in table 2.

It is added that the age of the caregiver is positively and significantly correlated with the domains of efficacy and control ( $\rho = 0.139$ ) and satisfaction with the role and family ( $\rho = 0.182$ ). There was a positive correlation between the number of weekly hours and the emotional burden ( $\rho = 0.172$ ), personal life implications ( $\rho = 0.227$ ), financial burden ( $\rho = 0.161$ ), reactions and demands ( $\rho = 0.156$ ) domains and the total QASCI score ( $\rho = 0.222$ ). We also identified a positive correlation between the amount of hours at weekends and the emotional burden ( $\rho = 0.176$ ), personal life implications ( $\rho = 0.232$ ), financial burden ( $\rho = 0.164$ ), reactions and requirements ( $\rho = 0.137$ ) domains and the total QASCI score ( $\rho = 0.215$ ).

**Table 1.** Distribution of total burden score in the caregivers' sociodemographic categorical variables marital status and degree of parenthood with the elderly

Variables	EB	IPL	FB	RR	MEC	FS	SRR	Total QASCI
	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)
Marital status								
Single/ No fixed partner	8.9 $\pm$ 4.47	27.7 $\pm$ 12.32	4.9 $\pm$ 3.02	9.1 $\pm$ 4.33	5.1 $\pm$ 2.35	4.5 $\pm$ 2.94	7.2 $\pm$ 2.89	67.4 $\pm$ 23.88
Married/ Fixed partner	10.2 $\pm$ 4.73 (0.037)	30.9 $\pm$ 13.29 (0.081)	5.38 $\pm$ 3.24 (0.407)	10.0 $\pm$ 5.08 (0.232)	5.9 $\pm$ 3.12 (0.079)	4.8 $\pm$ 3.19 (0.501)	8.4 $\pm$ 4.07 (0.044)	75.6 $\pm$ 28.42 (0.046)
Degree of parenthood with elderly								
Partner	11.5 $\pm$ 4.73	34.0 $\pm$ 12.85	6.3 $\pm$ 3.49	10.8 $\pm$ 5.13	6.8 $\pm$ 3.83	4.8 $\pm$ 3.37	9.4 $\pm$ 4.33	83.7 $\pm$ 28.29
Son/Daughter	9.4 $\pm$ 4.44	29.9 $\pm$ 11.78	5.4 $\pm$ 3.15	9.5 $\pm$ 4.41	5.4 $\pm$ 2.62	5.0 $\pm$ 3.07	7.5 $\pm$ 3.33	72.1 $\pm$ 24.67
Sibling	11.1 $\pm$ 5.17	34.6 $\pm$ 15.55	4.5 $\pm$ 2.74	11.9 $\pm$ 5.29	5.4 $\pm$ 2.41	4.7 $\pm$ 3.25	9.4 $\pm$ 4.29	81.7 $\pm$ 28.42
Grandchild	8.4 $\pm$ 4.87	20.6 $\pm$ 11.04	4.5 $\pm$ 3.06	7.4 $\pm$ 2.93	4.3 $\pm$ 1.54	4.3 $\pm$ 3.12	6.1 $\pm$ 2.23	55.5 $\pm$ 22.70
Son/Daughter-in-law	8.5 $\pm$ 5.62	25.5 $\pm$ 14.52	4.0 $\pm$ 2.98	9.8 $\pm$ 7.61	6.2 $\pm$ 2.89	3.1 $\pm$ 1.66	7.5 $\pm$ 3.03	64.6 $\pm$ 29.59
Other	7.2 $\pm$ 3.03 (0.014)	20.9 $\pm$ 9.99 (<0.001)	3.7 $\pm$ 2.10 (0.081)	6.9 $\pm$ 2.31 (0.002)	4.5 $\pm$ 1.94 (0.108)	3.2 $\pm$ 2.29 (0.109)	6.5 $\pm$ 2.11 (0.011)	52.8 $\pm$ 15.64 (<0.001)

QASCI – Informal Caregiver Burden Assessment Questionnaire; EB – Emotional Burden; IPL – Implications in personal life; FB – Financial Burden; RR – Reactions and requirements; MEC – Efficacy and control mechanisms; FS – Family support; SRR – Satisfaction with role and relative; SD – Standard deviation. The p-value was calculated by means of the non-parametric Mann-Whitney and Kruskal-Wallis tests. Statistical significance was set at  $p < 0.05$ .

**Table 2.** Distribution of total burden score among the caregivers' categorical clinical variables

Variables	EB	IPL	FB	RR	MEC	FS	SRR	Total QASCI
	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)	Mean $\pm$ SD (p-value)
Referred diseases								
Yes	10.0 $\pm$ 4.80	31.7 $\pm$ 12.7	6.6 $\pm$ 3.2	9.6 $\pm$ 4.69	5.6 $\pm$ 2.87	4.6 $\pm$ 3.05	8.2 $\pm$ 3.71	75.3 $\pm$ 26.1
No	8.4 $\pm$ 4.08 (0.025)	24.1 $\pm$ 11.7 (<0.001)	4.4 $\pm$ 2.85 (0.012)	9.2 $\pm$ 4.72 (0.413)	5.0 $\pm$ 2.46 (0.194)	4.6 $\pm$ 3.0 (0.663)	6.9 $\pm$ 2.92 (0.006)	62.6 $\pm$ 24.67 (<0.001)
The caregiver feels bodily pain								
Yes	10.2 $\pm$ 4.70	31.1 $\pm$ 12.59	5.5 $\pm$ 3.17	10.1 $\pm$ 4.97	5.6 $\pm$ 2.81	4.8 $\pm$ 3.08	8.0 $\pm$ 3.49	75.4 $\pm$ 25.92
No	6.9 $\pm$ 3.27 (<0.001)	22.2 $\pm$ 11.29 (<0.001)	3.7 $\pm$ 2.46 (<0.001)	7.1 $\pm$ 2.32 (<0.001)	4.8 $\pm$ 2.42 (0.069)	4.1 $\pm$ 2.87 (0.120)	6.8 $\pm$ 3.45 (0.005)	55.6 $\pm$ 21.39 (<0.001)
The pain emerged after the elderly became bedridden								
Yes	11.2 $\pm$ 4.74	33.1 $\pm$ 11.80	6.0 $\pm$ 3.24	10.4 $\pm$ 5.07	6.0 $\pm$ 3.05	5.0 $\pm$ 3.18	8.2 $\pm$ 3.72	80.1 $\pm$ 25.93
No	8.9 $\pm$ 4.36 (0.002)	28.5 $\pm$ 13.16 (0.019)	4.9 $\pm$ 2.99 (0.037)	9.8 $\pm$ 4.86 (0.394)	5.1 $\pm$ 2.39 (0.042)	4.4 $\pm$ 2.93 (0.321)	7.8 $\pm$ 3.19 (0.790)	69.5 $\pm$ 25.93 (0.009)
The pain continues after providing care								
Yes	11.1 $\pm$ 4.73	33.5 $\pm$ 12.01	6.1 $\pm$ 3.28	10.7 $\pm$ 5.16	6.0 $\pm$ 3.01	5.1 $\pm$ 3.15	8.5 $\pm$ 3.66	80.9 $\pm$ 25.33
No	8.3 $\pm$ 4.05 (0.001)	25.6 $\pm$ 12.22 (<0.001)	4.4 $\pm$ 2.56 (0.003)	9.0 $\pm$ 4.36 (0.039)	4.7 $\pm$ 2.09 (0.010)	3.9 $\pm$ 2.78 (0.029)	7.0 $\pm$ 2.86 (0.008)	63.0 $\pm$ 22.93 (<0.001)
Felt modifications in the body and in health after the caregiver role								
Yes	11.1 $\pm$ 4.58	33.8 $\pm$ 12.05	6.1 $\pm$ 3.22	10.2 $\pm$ 4.69	5.9 $\pm$ 2.94	5.0 $\pm$ 3.11	8.4 $\pm$ 3.86	80.6 $\pm$ 25.28
No	7.1 $\pm$ 3.54 (<0.001)	22.1 $\pm$ 10.58 (<0.001)	3.7 $\pm$ 2.31 (<0.001)	8.5 $\pm$ 4.53 (0.001)	4.7 $\pm$ 2.26 (0.002)	4.0 $\pm$ 2.87 (0.026)	6.9 $\pm$ 2.68 (0.004)	56.9 $\pm$ 20.91 (<0.001)
How do you consider your health?								
Good	7.9 $\pm$ 3.99	24.1 $\pm$ 11.92	4.0 $\pm$ 2.56	8.3 $\pm$ 3.93	4.9 $\pm$ 2.01	4.3 $\pm$ 3.05	7.1 $\pm$ 2.79	60.7 $\pm$ 22.45
Regular	10.0 $\pm$ 4.53	30.4 $\pm$ 12.15	5.4 $\pm$ 3.15	9.8 $\pm$ 4.74	5.4 $\pm$ 2.71	4.6 $\pm$ 2.92	7.8 $\pm$ 3.42	73.5 $\pm$ 24.79
Bad	12.3 $\pm$ 5.54 (<0.001)	41.0 $\pm$ 10.54 (<0.001)	7.9 $\pm$ 2.86 (<0.001)	12.1 $\pm$ 5.78 (0.004)	7.5 $\pm$ 4.22 (0.055)	6.0 $\pm$ 3.48 (0.107)	9.8 $\pm$ 5.34 (0.052)	96.8 $\pm$ 27.89 (<0.001)

QASCI – Informal Caregiver Burden Assessment Questionnaire; EB – Emotional Burden; IPL – Implications in personal life; FB – Financial Burden; RR – Reactions and requirements; MEC – Efficacy and control mechanisms; FS – Family support; SRR – Satisfaction with role and relative; SD – Standard deviation. The p-value was calculated by means of the non-parametric Mann-Whitney and Kruskal-Wallis tests. Statistical significance was set at  $p \leq 0.05$

## Discussion

In the descriptive analysis of the QASCI, it was observed that the caregivers demonstrated high levels of burden when confronted with the results of other studies with dependent elderly people developed in Brazil (elderly with functional dependency) and internationally (elderly with Alzheimer's disease) in which the same tool was used.<sup>(11,14)</sup>

When comparing which sociodemographic characteristics were related to the greater burden of the caregivers, the differences in the degree of kinship and in the fact of having a fixed partner were identified as significant, with a higher burden for the spouses. Marriage brings about a relationship of obligation to care because there is a common life project assumed by marriage and the commitment to be together in sickness and health.<sup>(15)</sup> A study carried out in Spain pointed out a similar result.<sup>(6)</sup>

In Brazil, the family taking responsibility for the care of its members represents a cultural value. Family members who take care of the elderly, even though they are satisfied with this role, are subject to countless sources of stress, resulting from the task definitions of a role for which they are often not prepared, as well as the repercussions in their daily lives.<sup>(16,17)</sup>

The fact that caregivers need to respond to the elderly people's care demands and the requests of other family members entails negative implications, and the relationship with the elderly who receives care may be ambiguous and may lead to stressful situations. Having a kinship relationship is a predictor of burden due to the accumulation of roles.<sup>(18,19)</sup>

The age of the caregiver is positively correlated with the domains of efficacy and control and satisfaction with the role and family, i.e., the older the caregiver, the greater the perceived burden in these

aspects. Thus, older caregivers find fewer facilitators to cope with the difficulties resulting from this role and less satisfaction in caring for their relatives.<sup>(12)</sup>

Another factor that influenced the caregivers' perceived burden is their health condition. Whether the caregiver presents diseases or not differs in the scores obtained for four of the seven domains: emotional burden, personal life implications, financial burden, role and family satisfaction, and total burden score. For all, the highest average burden is found in the group that reported having diseases. The impact of chronic stress can manifest itself in the caregiver through physical and psychological problems, which influence the type of care the dependent family member receives.<sup>(20)</sup>

When evaluating the mental health of 636 informal caregivers of post-stroke dependent elderly in Portugal, the researchers observed that the perceived mental health was poor. Poor mental health is influenced by the emotional burden, personal life implications, and the satisfaction with caregiving, as well as by the demands of the care receiver.<sup>(21)</sup>

The work burden, the complicated coexistence with the care receiver, and the limitation of the caregiver's time to invest in health promotion actions often end up influencing the caregiver's illness.<sup>(22)</sup>

In terms of pain, the average burden of the participants who started to experience pain after the elderly had become bedridden, was significant for the domains emotional burden, personal life implications, financial burden, mechanism of effectiveness and control, and total burden score. For those caregivers who continue experiencing pain after they provide care, the mean burden is higher, significantly affecting all the domains evaluated. This study is in line with another study developed in Brazil, which included family caregivers of individuals with stroke sequelae, in which the presence of pain resulted in a poorer health-related quality of life in the domains 'functional capacity', 'physical aspects', 'emotional aspects' and 'pain'.<sup>(23)</sup>

This fact is justified by the physical effort and varied care demand of a bedridden patient. As the patients' degree of dependence increases, so does the difficulty the caregiver faces, due to a lack of technical knowledge, skill, and physical conditioning.<sup>(24)</sup>

The participating caregivers' burden is significantly higher for those who have felt changes in their body and their health after taking on the role of caregiver. Another study ratifies the result when observing that those caregivers who reported some change obtained higher burden scores.<sup>(25)</sup>

The caregivers with the greatest burden are those who have manifested worse subjective health, which is confirmed in the research presented here. The burden is significant in the emotional burden, personal life implications, financial burden, reactions and demands domains, and in the total QASCI score.

In this sense, in a survey carried out in Peru, informal caregivers showed deficiencies in physical, psychological and social performance, with poor perceived health and development of various clinical problems and comorbidities.<sup>(26)</sup>

Manifesting worse subjective health, as well as worse objective health, is associated with a greater caregiver burden. Thus, having several conditions, being treated for some chronic illness and suffering from a psychological/psychiatric illness are associated with a greater burden.<sup>(6)</sup>

With regard to the characteristics of care, the more daily hours are spent on the care activities for the elderly bedridden, the greater the caregiver's perceived burden. This finding supports other studies in different contexts in Brazil<sup>(27,28)</sup> and internationally.<sup>(19)</sup>

In Canada, the evaluation of the caregiver burden of stroke survivors revealed that the burden of caring for a dependent person is greater for the perceived time spent than for difficulties in carrying out care activities for the relative. The caregivers perceived most of the tasks as being of mild to moderate difficulty, however, the amount of time spent performing these tasks was perceived as more burdensome.<sup>(29)</sup>

Caregivers do not have time for themselves and for the development of social and cultural activities. Some caregivers maintain their job, while others have to give it up, as the care receivers need assistance for most of their basic activities and most of the time.<sup>(19,30)</sup>

Caregivers dedicate themselves full-time to activities with the elderly and the time, including,

their absence from the home, is timed, but usually to meet the needs of the dependent family member. There is a correct time for medication, bath time, mealtime, and thus the caregiver is restricted to the home, with much of his time spent on the activities with the elderly, being mostly a solitary activity.<sup>(27)</sup>

The informal caregiver burden assessment questionnaire (QASCI), the instrument used, was easy to apply and permitted analyzing the physical, emotional and social aspects of the research construct. The method used, however, due to the cross-sectional design, did not allow for the establishment of the cause-and-effect relationships, which is the main limitation of this study.

We hope to contribute to the production of knowledge about the bedridden elderly and their informal caregivers, with emphasis on the burden, in order to support the formulation of health promotion strategies for the elderly/caregiver pair, as well as to support professional training and capacity building in order to take care of individuals and families in a holistic and humanistic way, with emphasis on the nursing team.

## Conclusion

A significant relationship exists between the burden perceived by the informal caregiver and the caregivers' sociodemographic and clinical characteristics and the characteristics of the activity. The average burden was high, and the domain "personal life implications" contributed the most to the physical, emotional and social burden of informal caregivers. The burden was greater for the spouses, and for those who experienced comorbidities, pain related to the activity performed and for those who considered their health as regular.

## Collaborations

Mendes PN, Figueiredo MLF, Santos AM, Fernandes MA, Fonseca RSB declare that they contributed to the writing of the article, relevant critical review of the intellectual content and final approval

of the version for publication and collaborated in the study design, data analysis and interpretation, writing of the article, relevant critical review of the intellectual content and final approval of the version for publication.

## References

1. Debert GG. Migrações e o cuidado do idoso. *Cad Pagu*. 2016;(46):129-49.
2. Sousa ÁF, Queiroz AA, Oliveira LB, Moura LK, Andrade D, Watanabe E, et al. Deaths among the elderly with ICU infections. *Rev Bras Enferm*. 2017 Jul-Aug;70(4):733-9.
3. Mosquera I, Vergara I, Larrañaga I, Machón M, del Río M, Calderón C. Measuring the impact of informal elderly caregiving: a systematic review of tools. *Qual Life Res*. 2016 May;25(5):1059-92.
4. Anjos KF, Boery RN, Pereira R, Santos VC, Boery EN, Casotti CA. Profile of family caregivers of elderly at home. *Rev Online Pesqui Cuid Fundam*. 2014;6(2):450-61.
5. Wendt CJ, Aires M, Paz AA, Fengler FL, Paskulin LM. Elderly families of south of Brazil in the Hhealth strategy. *Rev Bras Enferm*. 2015;68(3):350-7.
6. Rodríguez-González AM, Rodríguez-Míguez E, Duarte-Pérez A, Díaz-Sanisidro E, Barbosa-Álvarez A, Clavería A, et al. [Cross-sectional study of informal caregiver burden and the determinants related to the care of dependent persons]. *Aten Primaria*. 2017;49(3):156-65. Spanish.
7. Delalibera M, Presa J, Barbosa A, Leal I. Sobrecarga no cuidar e suas repercussões nos cuidadores de pacientes em fim de vida: revisão sistemática da literatura. *Ciênc Saúde Coletiva*. 2015;20(9):2731-47.
8. Valle-Alonso MJ, Hernández-López IE, Zúñiga-Vargas ML, Martínez-Aguilera P. Overload and burnout among aged informal caregivers. *Enferm Univ*. 2015;12(1):19-27.
9. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975 Nov;12(3):189-98.
10. Monteiro EA. Validação do questionário de avaliação da sobrecarga do cuidador informal em uma amostra de cuidadores brasileiros [tese]. Ribeirão Preto, Escola de Enfermagem de Ribeirão Preto; 2014.
11. Monteiro EA, Mazin SC, Dantas RA. The Informal Caregiver Burden Assessment Questionnaire: validation for Brazil. *Rev Bras Enferm*. 2015;68(3):364-70.
12. Martins T, Ribeiro JP, Garret C. Questionário de avaliação da sobrecarga do cuidador informal (QASCI): reavaliação das propriedades psicométricas. *Rev Referência*. 2004;(11):17-31.
13. Pestana MH, Gageiro JN. Análise de dados para ciências sociais: a complementariedade do SPSS. 3rd ed. Lisboa: Sílabo; 2003.
14. Pereira MF. Cuidadores informais de doentes de alzheimer: sobrecarga física, emocional e social e psicopatologia [dissertação]. Porto: Instituto de Ciências Biomédicas de Abel de Salazar, Universidade do Porto; 2011.
15. Rico-Blázquez M, Escortell-Mayor E, Del-Cura-González I, Sanz-Cuesta T, Gallego-Berciano P, de Las Casas-Cámara G, et al. CuidaCare: effectiveness of a nursing intervention on the quality of life's caregiver: cluster-randomized clinical trial. *BMC Nurs*. 2014 Jan 27;13(1):2.

16. Faller JW, Zilly A, Alvarez AM, Marcon SS. Filial care and the relationship with the elderly in families of different nationalities. *Rev Bras Enferm.* 2017;70(1):22-30.
17. Folle AD, Shimizu HE, Naves, JO. Representação social da doença de Alzheimer para familiares cuidadores: desgastante e gratificante. *Rev Esc Enferm USP.* 2016;50(1):81-7
18. Pereira RA, dos Santos EB, Fhon JR, Marques S, Rodrigues RA. [Burden on caregivers of elderly victims of cerebrovascular accident]. *Rev Esc Enferm USP.* 2013;47(1):185-92. Portuguese.
19. Pocinho R, Belo P, Melo C, Navarro-Pardo E, Muñoz JF. Relação entre o estado psicossocial do cuidador informal e o tempo de cuidado dos idosos da região centro de Portugal. *Educ Humanismo.* 2017;19(32):88-101.
20. Souza LR, Hanus JS, Libera LB, Silva VM, Mangilli EM, Simões PW, et al. Overload in care, stress and impact on the quality of life of surveyed caregivers assisted in primary care. *Cad Saúde Colet.* 2015;23(2):140-9.
21. André SM, Nunes MM, Martins MM, Rodrigues VM. Mental health of informal caregivers of dependent elderly patients after cerebrovascular accident. *Referência.* 2013;3(11):85-94.
22. Ae-Ngibise KA, Doku VC, Owusu-Agyei S. The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. *Glob Health Action.* 2015; 8:26957.
23. Costa TF, Costa KN, Fernandes M, Martins KP, Brito SS. Quality of life of caregivers for patients of cerebrovascular accidents: association of (socio-demographic) characteristics and burden. *Rev Esc Enferm USP.* 2015;49(2):245-52.
24. Yamashita CH, Amendola F, Gaspar JC, Alvarenga MR, Oliveira MM. Association between social support and the profiles of family caregivers of patients with disability and dependence. *Rev Esc Enferm USP.* 2013;47(6):1359-66.
25. Brigola AG, Luchesi BM, Rossetti ES, Mioshi E, Inouye K, Pavarine SCL. Perfil de saúde de cuidadores familiares de idosos e sua relação com variáveis do cuidado: um estudo no contexto rural. *Rev Bras Geriatr Gerontol.* 2017; 20(3):410-22.
26. Custodio N, Lira D, Herrera-Perez E, Del Prado LN, Parodi J, Guevara-Silva E, et al. Informal caregiver burden in middle-income countries Results from Memory Centers in Lima - Peru. *Dement Neuropsychol.* 2014;8(4):376-83.
27. Carvalho DP, Toso BR, Viera CS, Garanhani ML, Rodrigues RM, Ribeiro LF. Caregivers and implications for home care. *Texto Contexto Enferm.* 2015;24(2):450-8.
28. Aires M, Mocellin D, Fengler FL, Rosset I, Santos NO, Machado DO, et al. Association between filial responsibility when caring for parents and the caregivers overload. *Rev Bras Enferm.* 2017;70(4):767-74.
29. Ganapathy V, Graham GD, DiBonaventura MD, Gillard PJ, Goren A, Zorowitz RD. Caregiver burden, productivity loss, and indirect costs associated with caring for patients with poststroke spasticity. *Clin Interv Aging.* 2015;6(10):1793-802.
30. Sakakibara K, Kabayama M, Ito M. Experiences of "endless" caregiving of impaired elderly at home by family caregivers: a qualitative study. *BMC Res Notes.* 2015;8:827.