

Relationship between the burden of informal caregivers and the level of independence of hospitalized older adults

Relação entre sobrecarga de cuidadores informais e nível de independência de idosos hospitalizados

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ABSTRACT: The objective of this study was to evaluate the burden upon informal caregivers, the level of independence of hospitalized older adults and to verify the relationship between them. It is a quantitative, cross sectional and descriptive study, conducted by individual interviews with the 40 caregivers of the older adults hospitalized in the Medical Clinic of a public hospital in Uberaba-MG. From the caregivers were collected sociodemographic data, relating to the care, and the burden level (Zarit Burden Interview) and from the older adults, gender, age, diagnosis and the level of independence (Barthel Index). Descriptive statistics and Pearson's Correlation Coefficient were used to verify the correlation between the caregivers' burden and level of independence of the older adults ($p < 0.05$). There was a predominance of female caregivers, with 1-4 years of study, with partners, children of the elders, who received help from other people to care for and spent more than 15 hours daily performing care activities. Moderate to light caregivers' burden (62.5%), older adults with total dependence (47.5%) and moderate and negative link was found between the caregivers' burden and the level of independence of the older adult ($r = -0.423$; $p = 0.007$). This investigation is expected to contribute for the development of actions for the caregiver in hospitals, aiming to prevent their burden and its consequences.

Keywords: Caregivers; Frail elderly; Hospitalization; Cost of illness.

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RESUMO: O objetivo do presente estudo foi avaliar a sobrecarga do cuidador informal, o nível de independência de idosos hospitalizados e verificar a relação entre eles. Trata-se de um estudo quantitativo, transversal e descritivo, realizado por meio de entrevistas individuais junto a 40 cuidadores de idosos internados no setor de Clínica Médica de um hospital público em Uberaba-MG. Dos cuidadores foram coletados dados sociodemográficos, referentes ao cuidado e nível de sobrecarga (Zarit Burden Interview) e dos idosos, sexo, idade, diagnóstico e nível de independência (Índice de Barthel). Foram utilizadas estatísticas descritivas e o Coeficiente de Correlação de Pearson para verificar a correlação entre sobrecarga do cuidador e nível de independência do idoso ($p < 0,05$). Predominaram cuidadores do sexo feminino, com 1-4 anos de estudo, com companheiro, filhos dos idosos, que recebiam ajuda de outras pessoas para cuidar e despendiam mais de 15 horas diárias ao cuidado. Foi identificada sobrecarga dos cuidadores de moderada a leve (62,5%), idosos com dependência total (47,5%) e relação moderada negativa entre a sobrecarga do cuidador e nível de independência do idoso ($r = -0,423$; $p = 0,007$). Espera-se que a investigação contribua para o desenvolvimento de ações para o cuidador nos hospitais, visando a prevenção da sobrecarga e suas repercussões.

Descritores: Cuidadores; Idoso fragilizado; Hospitalização; Efeitos psicossociais da doença.

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INTRODUCTION

Aging is a heterogeneous process that occurs differently for each individual¹. The combination of physical, environmental, socio-economic, genetic, and life habits factors can alter bodily functions and cause dependence on the family, community, and health care system, negatively influencing the social participation of part of the older adult population².

Loss or decrease of the functional capacity of older adults results in need of aid to perform basic daily tasks or of greater complexity, requiring the presence of a caregiver to take over these activities³. The caregiver is responsible for taking care of the older adult in situations of illness or dependence, performing daily activities. This function can be performed by a paid professional or by a family member⁴.

The literature emphasizes the role of caregivers in hospitals^{5,6}, an environment that concentrates a significant number of older adults with disabilities and complex or persistent diseases⁷. Ordinance No. 280, of April 7, 1999⁸, emphasizes the importance of caregivers by stating that it is the duty of hospitals to ensure the permanence of family members during the hospitalization, as their presence is associated with improvement of patients' quality of life⁸.

Studies show that, during the period of hospitalization of older adults, the care is usually assumed by informal caregivers, represented by a family member^{9,10}. This function implies responsibilities and time availability, in addition to condition economic, physical, and/or emotional changes in the caregivers' life, making them more vulnerable to burden and diseases¹.

Burden is characterized by mental and physical exhaustion due to the accumulation of stressor factors and occurs when the caregiver is devoid of adequate strategies to adapt to a new situation¹¹, for example, the hospitalization of an older adult.

The caregiver is exposed to multiple factors that favor burden¹², such as lack of preparation for the care^{13,14}, insufficient financial resources and support from the community⁹, difficulty to adapt to the new routine¹, and level of dependence of the person being cared for^{13,15}. We highlight that caring for an older adult in a situation of dependence requires from the caregiver resignation of their interpersonal relationships, as well as dedication and knowledge¹⁶, which vary according to the specificities of the disease or the cause of older adult's inability¹².

At the hospital, although care is provided by a technical team, the informal caregiver also ends up participating in the care routines¹, often without receiving training¹³, resulting in unsafe practices capable of

compromising the health of the older adult and generating, for the caregiver, negative feelings of guilt, worthlessness, and failure⁶.

The burden of the caretaker of dependent older adults is addressed in the literature, but in other contexts, such as at home^{13,14}. Studies on the relationship between burden and dependence of older adults in hospitals are still scarce. Therefore, further investigations are required to outline specific actions focused on caregivers.

In this perspective, the objective of this study was to evaluate the burden upon informal caregivers and the level of independence of hospitalized older adults, as well as to verify the relationship between them.

Methodological procedures

This is a quantitative, cross sectional, and descriptive study, conducted by individual interviews in the Medical Clinic of a public hospital in the city of Uberaba, state of Minas Gerais, Brazil. The participants were approached from July to October 2015, after meeting the following inclusion criteria: be an informal caregiver of an older adult patient (aged 60 years or more) hospitalized for at least 48 hours in the sector; be 18 years old or more; and have cognitive conditions evaluated by the Mini-Mental State Examination¹⁷ to reply the questionnaires. Caregivers who did not agree to answer all of the proposed instruments were excluded from the study.

The caregivers were interviewed during the hospitalization of the older adult, in a reserved room within the hospital. Initially, a script of the questions was applied to obtain the following data from the caregivers: sex, age, marital status, education level (in years of study), kinship with the older adult, presence or absence of help from other people to take care of him/her, and amount of daily hours dedicated to care during hospitalization.

The burden of caregivers was verified by the Zarit Burden Interview scale (ZBI), translated and validated to the Brazilian culture by Scazufca¹⁸. The score ranges from 0 to 88 points, with the higher scores referring to higher levels of burden¹⁸. The following cut points were used to classify the burden: between 61 and 88 points = intense; between 41 and 60 = moderate to severe; between 21 and 40 = moderate to light; and less than 21 points = absence of burden¹⁹.

The medical records of the older adults were consulted to obtain data on the patients' days of hospitalization, sex, age, and diagnosis. The level of independence of the older adult was evaluated by the Barthel index, validated in Brazil²⁰. The instrument evaluates daily activities related

to personal care, mobility, locomotion, and eliminations. The score ranges from 0 to 100, with five points intervals, with the highest scores referring to higher levels of independence²⁰. The following score was adopted to classify the level of independence: 0-20 = total dependence; 21-60 = severe dependence; 61-90 = moderate dependence; 91-99 = light dependence; and 100 = independence²¹.

The data were tabulated in the Microsoft Excel 2007 program and the analyses were aided by the Statistical Package for the Social Sciences (SPSS) software, version 20.0. The data were analyzed by descriptive statistics using absolute and relative frequencies, as well as measures of central tendency and variability.

After normality of the sample distribution was verified by the Kolmogorov-Smirnov test, the possible correlation between caregiver burden and level of independence for the older adult was assessed by Pearson's Correlation Coefficient. The interpretation of the magnitude of correlations considered the following classification of coefficients: weak (<0.3); moderate (0.3 to 0.59); strong (0.6 to 0.9); and perfect (1.0)²². A significance level of $p < 0.05$ was adopted.

The study was conducted after approval by the Ethics and Research with Human Beings Committee from the *Universidade Federal do Triângulo Mineiro*, under the opinion no. 1.121.346, CAAE no. 45858915.9.0000.5154. The caregivers and older adults were told about the objectives and agreed to participate in the research by signing an informed consent form.

RESULTS

A total of 52 individuals were approached in the study period, but twelve did not compose the final sample, since: two were under the age of 18 years; three did not agree to answer all questions; five were not caregivers (only visitors); and two did not achieve a satisfactory scores on the Mini-Mental State Examination. Therefore, the final sample was composed by 40 informal caregivers of 40 older adults hospitalized in the sector.

The caregivers were averagely aged 53.25 ± 11.89 years. According to Table 1, there was a predominance of women (87.5%), with education of 1-4 years of study (47.5%) and with companion (72.5%). Regarding kinship, sons or daughters of the older adults prevailed (60%). We found that 80% of caregivers received help from another person to take care of the older adult, and 57.5% dedicated over 15 hours daily to care during hospitalization.

Table 1 – Characteristics of informal caregivers of older adults hospitalized in the Medical Clinic sector, Uberaba-MG, Brazil, 2015

Characteristics of caregivers	n	%
Sex		
Male	5	12.5
Female	35	87.5
Marital status		
With partner	29	72.5
Without partner	11	27.5
Education level		
Illiterate	2	5
1-4 years	19	47.5
5-8 years	2	5
9-12 years	12	30
13 years or more	5	12.5
Kinship with the older adult		
Son/Daughter	24	60
Spouse	6	15
Son-in-law/Daughter-in-law	2	5
Brother/Sister	5	12.5
Other	3	7.5
Receive help from another person in care		
No	8	20
Yes	32	80
Daily hours dedicated to care		
Less than 5h	2	5
From 5h to 10h	9	22.5
From 11h to 15h	6	15
Over 15h	23	57.5

SOURCE: Developed by the author, 2015.

Regarding the characteristics of the older adults, there was a predominance of men (60%), with an average age of 74.8 ± 8.35 years, hospitalized due to diseases of the circulatory system (53%).

The average score of functional independence of the older adults according to the Barthel Index was

39.5±38.6. Concerning the classification, Table 2 shows the predominance of older adults with total dependence (47.5%). Considering all participants, 87.5% presented some level of dependence.

Table 2 – Classification of the level of independence of older adults, Uberaba-MG, Brazil, 2015

Classification of the independence of the older adult	n	%
Total dependence	19	47.5
Severe dependence	9	22.5
Moderate dependence	3	7.5
Light dependence	4	10
Independence	5	12.5

Source: Developed by the author, 2015.

Evaluating the level of burden of caregivers by ZBI, we found that the average was 23.37±10.35. According to the classification (Table 3), caregivers with moderate to light burden (62.5%) predominated. As for the relationship between caregiver burden and level of independence of the hospitalized older adult, a moderate negative correlation was found, statistically significant ($r = -0.423$ and $p = 0.007$); i.e., the lower the burden, the greater the level of independence of the older adult.

Table 3 – Classification of the level of burden of caregivers, Uberaba-MG, Brazil, 2015

Classification of the caregiver's burden	n	%
Severe to moderate burden (between 41 and 60 points)	2	5.0
Moderate to light burden (between 21 and 40 points)	25	62.5
Absence of burden (< 20 oints)	13	32.5

Source: Developed by the author, 2015.

DISCUSSION

Regarding the characteristics of the informal caregivers of hospitalized older adults, the predominance of women and sons/daughters supports another study conducted in the hospital context⁵. The findings confirm the socio-cultural role attributed to the female figure concerning the performance of household chores and attention to the family¹⁶, regarding the children, as a way to reciprocate the parents' care¹.

The average age (53.25±11.89 years) and the marital status of caregivers in this study were similar to those found in the literature^{10,23}. As for education level, we found lower ones, corroborating another study that indicates the tendency of individuals with less education assuming this care and domestic services, since the formal labor market demands higher education levels¹³.

Although 80% of caregivers have reported receiving help from another person, most of them still spend over 15 hours daily caring for the older adult at the hospital, which is consistent with findings on the literature⁵. Assigning care to a single family member is also common at homes, which can generate stress in the caregiver, since, most of the time, the relative is not prepared to take on this imposed function¹².

As for the older adults, although the women stand out in the literature as dependent of care in hospitals^{11,24}, in this study there was a predominance of the male sex, confirming some previous studies^{5,23}. This can be justified by the level of unsatisfactory care that men have with their own health, favoring the occurrence of hospitalizations²⁵.

The relatively high average age of the older adults (74.8±8.35 years) was also observed in other studies^{5,25} and can be justified by the increase in the life expectancy of the older population in Brazil, marked by contexts of disability, chronic illnesses, and hospitalizations⁷. In this study, the cause for hospitalization is consistent with a previous survey, in which circulatory diseases stood out between the years of 2003 and 2012²⁴.

According to the Barthel Index, the predominance of older people with some level of dependence corroborates another study conducted in the hospital context¹¹. Aging is marked by chronic diseases and their repercussions, such as the dependence, which represents a challenge to public health, since the projections indicate the continuity of this phenomenon in the next years⁷.

As for the burden of caregivers, the prevalence of the category "moderate to light" resembles the findings of a study that investigated the burden of family caregivers of older adults with stroke sequelae¹⁴, but at home. The relationship between caregiver burden and level of independence of older adults is consolidated in the literature^{13,15,16}, however, in hospitals, investigations are still scarce, which indicates the need for studies in them, in Brazil. As reported by an integrative review, the requirement and complexity of care are increased according to the dependence of the person being cared for, favoring the physical and mental stress of caregivers¹².

The classification of burden prevalent among caregivers and its moderate relationship with the level of independence of the older adult may be justified in this

study by the fact that 80% of caregivers receive help from another person. In addition to not providing care in a lonely way, at hospitals, caregivers receive supervision and/or training from the professional team, which provides greater security, reducing the level of burden when compared to the care they provide at home⁵. Also, Pavin and Carlos¹ claim that, although the act of caring can generate burden and negatively influence the quality of life of the caregiver, there are positive consequences of this act, such as the feelings of love and retribution, especially on the part of sons/daughters.

Although moderate to light burden is predominant among caregivers and there is a moderate relationship between the burden of these individuals and the level of independence of hospitalized older adults, 67.5% of respondents presented some level of burden, which may intensify in the long run. According to Nardi et al.¹⁵, care-related tasks are not stable, i.e.s, they can suffer modifications over time, with increasing weakness and dependence of the older person, demanding greater efforts from the caregiver.

It is worth noting that often the caregiver, without previous training and devoid of information, is faced with the function studied here, which forces him/her to assimilate knowledge with practice¹³. In this context, a good relationship with care facilitators is important, such as institutional support and health teams¹⁰, which should provide guidance during hospital stays so that caregivers are able to continue the care outside the hospital environment⁹.

The study presented some limitations, such as the cross sectional design, which did not allow us to establish cause and effect relations; limited number of caregivers participating; and restricted range of the research, whose findings refer to a single hospital. However, we highlight that the results can guide professionals in actions aimed at prevention of caregiver burden during the hospitalization of older adults.

We suggest that further studies on the subject are carried out, such as longitudinal design and with representative samples, to investigate other factors that can influence burden in this context and strategies to prevent it and cope with it.

CONCLUSION

This study found moderate to light burden level between caregivers; older adults with total dependence level; and moderate negative relationship between the informal caregiver burden and the level of independence of the hospitalized older adult. Considering that this association, in the hospital context, is still little explored in the literature, it is expected that the results of this study provide bases for conducting further research on the topic, contributing to the creation of specific programs and actions focused on the prevention of caregiver burden during the monitoring of older adults in hospitals.

Authors' contribution: Ikegami participated in all stages of development of the article (conception, design, collection, organization, and data analysis, writing and review). Almeida assisted in data collection and organization. Souza contributed to the writing of the article. Walsh contributed to data analysis and critical review of the article. Shimano and Patrizzi assisted in the critical review and adequacy of the article. All authors approved the final version of the text.

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