

# The burden of caregivers: how the characteristics of the elderly and their caregivers articulate

*A sobrecarga de cuidadores: como as características de idosos e seus cuidadores se articulam*

*La sobrecarga de los cuidadores: cómo se articulan las características de los ancianos y sus cuidadores*

Gabriela Martins<sup>1</sup>, Luana Aparecida da Rocha<sup>1</sup>, Diana Quirino Monteiro<sup>1</sup>, Gustavo Carrijo Barbosa<sup>1</sup>,  
Anabel Machado Cardoso<sup>1</sup>, Giuliana Duarte de Oliveira da Silva<sup>1</sup>, Henrique Pott Junior<sup>1</sup>, Aline Cristina Martins Gratão<sup>1</sup>

<sup>1</sup>Universidade Federal de São Carlos. São Carlos, Brazil

## ABSTRACT

**Objective:** to analyze the association between the characteristics of elderly people and caregivers and their impact on caregiver burden. **Method:** in 2021, 50 pairs of informal caregivers and their elderly were evaluated through the sociodemographic and health profile, Hospital Anxiety and Depression Scale (HADS), Zarit-Brief Burden Interview (ZBI-12), and information on the degree of dependence of the elderly for basic and instrumental activities (ABVD and IADL). Regression models evaluated ZBI-12 and HADS scores as a function of characteristics of caregivers and assisted elderly. The research protocol was approved by the Research Ethics Committee. **Results:** high morbidity and BADL dependence were significantly associated with higher levels of caregiver burden. These characteristics lost significance when we adjusted the model for the caregiver's age, time that provides care, and living with the elderly. **Conclusion:** these results reveal the need for interventions to guarantee support for caregivers in terms of reducing the burden related to the care.

**Descriptors:** Aged; Caregivers; Burnout, Professional; Depression; Anxiety.

## RESUMO

**Objetivo:** analisar a associação entre as características de idosos e cuidadores e seus impactos na sobrecarga dos cuidadores. **Método:** em 2021, foram avaliados 50 pares de cuidadores informais e idosos pelo perfil sociodemográfico, de saúde, Escala Hospitalar de Ansiedade e Depressão (HADS), Entrevista de Sobrecarga de Zarit-Brief (ZBI-12) e informações sobre grau de dependência dos idosos para atividades básicas e instrumentais (ABVD e AIVD). Modelos de regressão avaliaram os escores ZBI-12 e HADS em função das características dos cuidadores e idosos assistidos. O protocolo de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa. **Resultados:** alta morbidade e dependência para ABVD foram significativamente associadas a maiores níveis de sobrecarga do cuidador. Essas características perderam significância quando ajustado o modelo por idade do cuidador, tempo que presta o cuidado e convivência com o idoso. **Conclusão:** esses resultados revelam a necessidade de intervenções para garantir suporte aos cuidadores quanto a diminuição da sobrecarga relacionada ao cuidado.

**Descritores:** Idoso; Cuidadores; Esgotamento Profissional; Depressão; Ansiedade.

## RESUMEN

**Objetivo:** analizar la asociación entre las características de ancianos y sus cuidadores y el correspondiente impacto en la sobrecarga de los cuidadores. **Método:** en 2021, se evaluaron 50 pares de cuidadores informales y sus ancianos a través del perfil sociodemográfico, de salud, Escala de Ansiedad y Depresión Hospitalaria (HADS), Escala de Zarit Reducida para la Sobrecarga (ZBI-12) e información sobre el grado de dependencia de los ancianos respecto a actividades básicas e instrumentales (ABVD y AIVD). Modelos de regresión evaluaron las puntuaciones de ZBI-12 y HADS en función de las características de los cuidadores y ancianos asistidos. El Comité de Ética en Investigación aprobó protocolo de investigación.

**Resultados:** la alta morbilidad y la dependencia de BADL se asociaron significativamente con niveles más altos de sobrecarga del cuidador. Estas características perdieron su importancia cuando ajustamos el modelo por la edad del cuidador, tiempo que proporciona cuidados y convivencia con los ancianos. **Conclusión:** estos resultados revelan la necesidad de intervenciones para garantizar apoyo a los cuidadores para reducir la sobrecarga relacionada con el cuidado.

**Descriptores:** Anciano; Cuidadores; Agotamiento Profesional; Depresión; Ansiedad.

## INTRODUCTION

Functional and cognitive losses caused by aging, associated with chronic non-communicable diseases (CNCDs), can impair older adults' autonomy and independence and, therefore, the need for periodic care in charge of a caregiver emerges<sup>1</sup>. According to the Brazilian Classification of Occupations (*Classificação Brasileira de Ocupações*, CBO), caregivers of older adults are responsible for ensuring the care recipients' well-being, health, nutrition, personal hygiene and leisure<sup>2</sup>.

Informal caregivers are the most prevalent type of support for older adults, that is, people aged at least 60 years old<sup>3</sup>. Thus, they are represented by family members, friends or community members who do not have any type of training, act on a voluntary basis and do not receive any remuneration for the care provided to the older adults<sup>1</sup>.

This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brazil (CAPES) - Process No.: 88887.497734/2020-00.

Corresponding author: Gabriela Martins. E-mail: gabrielamartins93@gmail.com

Editor in chief: Cristiane Helena Gallasch; Associate Editor: Magda Guimarães de Araujo Faria

Received: Dec 12<sup>th</sup> 2022 – Accepted: Jul 14<sup>th</sup> 2023

Rev enferm UERJ, Rio de Janeiro, 2023; 31:e71739

p.1



Historically, it is known that the main role of the family is to assist the needs of its members; however, due to unpreparedness and to the immediate need to provide care for a dependent aged person, the tendency is for them to disregard their own needs<sup>4</sup>. In addition to that, caregivers who provide care for many hours a day are more likely to develop negative repercussions on their lives and health, such as care burden<sup>5</sup>.

Burden is a psychological indicator related to the caregivers' emotional responses to the care demands and, when added to physical and emotional wear out, it can be manifested as constant fatigue, sleep disorders, muscle pain, anxiety and depression<sup>6,7</sup>.

The literature more commonly signals the causes of caregivers' burden as associated with the older adults being cared for, such as the increased demand for specialized care, the dependence degree presented by the older adults in daily activities and the lack of social support received<sup>7-9</sup>; however, there are few studies that consider aspects inherent to the caregivers in association with burden<sup>6,10,11</sup>. Hence the importance of developing studies that consider caregivers in addition to older adults in this context.

In view of this, the objective of the current study was to analyze the association between the characteristics of aged people and caregivers and their impact on the caregivers' burden.

## METHOD

This is a quantitative, cross-sectional, and correlational study. The research was carried out through teleconsultations with caregivers of older adults who had already been treated in a Gerontology Outpatient Service in 2019, located in a city in the inland of the state of São Paulo. The study was conducted following the requirements set forth in the *Strengthening the Reporting of Observational Studies in Epidemiology* (STROBE) protocol.

The team consists of the professor in charge of the service and a nurse and professor of the Gerontology course, in addition to undergraduate Gerontology students and Graduate Gerontology and Nursing students, who are responsible for caring for the older adults and the caregivers.

The sample was non-probabilistic and intentional. All informal caregivers of aged patients treated at the Outpatient Service were invited. In 2019, 54 aged individuals were assisted, and contact with their caregivers was resumed in the first half of 2021, in order to invite them to undergo an evaluation, as well as to provide diverse information about the older adults receiving care.

The inclusion criteria for the caregivers were as follows: acting as the main caregiver of the aged person who was monitored by the Outpatient Service in 2019; being over 18 years old; being able to read and write; having prior knowledge in technology; and showing an interest in participating in the study, agreeing to the Informed Consent Form (ICF). The exclusions corresponded to the cases when it was not possible to contact the person and to those who were unable to participate in the teleconsultations due to difficulties with technology were excluded. The inclusion criteria for the older adults were the following: individuals aged at least 60 years old; of both genders; who were treated by the Gerontology Outpatient Service in 2019; who have a family member/caregiver to assist in care; and who showed an interest in participating in the study, agreeing to the ICF. Patients who did not have informal caregivers were excluded.

The participants were asked about their interest in participating in the study and, after their acceptance, the informed consent form was sent via *Google Forms* and the teleconsultations were scheduled after the due signature. Thus, during the teleconsultations, the evaluation protocol was applied, which was also completed by the researcher using the *Google Forms* form, as the questions were asked during the teleconsultations.

For the caregivers, a questionnaire was applied with sociodemographic characterization data, in addition to data on health, on knowledge about the older adults' diseases and types of activities performed in the care provided.

The Zarit Burden Inventory was used to assess the objective and subjective perceptions of the burden underwent by the caregivers of older adults<sup>12</sup>, translated and validated to the Brazilian version<sup>13</sup>, in its abbreviated version, the Zarit-Brief Burden Interview (ZBI-12)<sup>14</sup>. ZBI-12 has 12 items, for a total score of 44 points. Burden can be identified by the cutoff score of 13 points<sup>14</sup>.

The manifestation of the caregivers' depression and anxiety symptoms was evaluated using the Hospital Anxiety and Depression Scale (HADS)<sup>15</sup>, validated in Brazil<sup>16</sup>. Initially, the scale was designed with the objective of assessing anxiety and depression in patients from non-psychiatric hospitals, but it has also been used in general populations (general practitioners, outpatients with unexplained somatic symptoms and psychiatric outpatients)<sup>17</sup>. The scale has 14 items with specific questions that assess depression and anxiety. The answers vary from 0 to 3 and sums from 0 to 7 indicate unlikely depression and anxiety symptoms, from 8 to 11, possible presence of symptoms and from 12 to 21, probable presence of symptoms<sup>15,16</sup>.

Regarding to the older adults' evaluation, it was decided to use an assessment protocol developed by the researchers, in which sociodemographic data were required, in addition to health data, including medication use, presence of diseases, falls and lifestyle habits.

Regarding the presence of diseases, the Charlson Comorbidity Index (CCI) was calculated. The CCI consists of 17 clinical conditions that take weights from 1 to 6 based on the relative risk; these weights are added to a total score. Thus, patients with CCI  $\geq 5$  points have an 85% mortality risk in one year<sup>18</sup>.

To measure the dependence degree for performing Basic Activities of Daily Living (BADLs), the Katz Scale<sup>19</sup> was used, adapted to the Brazilian context<sup>20</sup>, which addresses issues related to self-care. Patients who score between 5 and 6 points are considered independent, partially dependent between 3 and 4 points, and highly dependent if they score between 0 and 2<sup>21</sup>.

Finally, the dependence degree for Instrumental Activities of Daily Living (IADLs) was verified through the Lawton and Brody scale<sup>22</sup>, adapted for Brazil<sup>23</sup>. The score varies between 7 and 21 points, with individuals who score 7 being considered dependent, partially dependent between 8 and 20 and independent with 21 points<sup>23</sup>.

The data were tabulated in *Microsoft Excel*® 2016 and normality was analyzed using the Shapiro-Wilk test. The numerical variables were presented as mean and standard deviation or median, based on the test result. The continuous data referred to mean and standard deviation. The categorical variables were presented through absolute and relative frequencies.

*Poisson* multivariate regression models were used to analyze the ZBI-12 and HAD scores (depression and anxiety separately) as a function of a set of characteristics of the participating caregivers. Statistical significance was assessed with a two-tailed  $p$ -value $<0.05$ .

The analyses were performed using the R software, version 4.0.3 (*The R Foundation for Statistical Computing*, Vienna, Austria), in *R-Studio* 1.3.1093 (*RStudio Inc.*, Boston, USA). The Charlson Comorbidity Index (CCI) was used in the analyses to consider secondary clinical conditions and link their repercussions on the prognosis of the older adults included in the sample<sup>18</sup>.

The ethical aspects were respected in accordance with Resolution No. 466/2012 of the National Health Council. The study objectives and method were presented to the participants, who, upon agreeing to take part in the research, signed the ICF. The research protocol was approved by the local Research Ethics Committee.

## RESULTS

In total, 100 evaluations were carried out via teleconsultation, 50 of which were informal caregivers and 50 were aged people assisted by the Gerontology Outpatient Service in 2019, assessed through the self-report of their caregivers.

First, it was decided to present the older adults' profile. The sample was predominantly female (72%), with a mean age of 75.9 ( $\pm 9.3$ ) years old and mostly corresponded (44%) to aged individuals who self-declared as widowed. With regard to schooling, the older adults had a mean of 4.2 ( $\pm 3.6$ ) years of study, that is, the majority had from one to four years of study (48%).

As for the health profile, the mean of the total number of diseases presented by the older adults was 3.0 ( $\pm 1.6$ ). The most frequent disease was Systemic Arterial Hypertension (62%).

The mean CCI was 4.2 ( $\pm 1.5$ ) points, with 32% of the older adults having an 85% mortality risk in one year and 64% making continuous use of four or more medications. After evaluating the older adults' dependence level for BADLs, the mean result among the aged individuals was 4.6 ( $\pm 1.7$ ) points, with half of the sample classified as independent (50%). In the assessment of the dependence level for IADLs, the mean was 15.2 ( $\pm 5.3$ ) points, that is, most of the aged people were considered partially dependent (48%).

In relation to the informal caregivers, there was predominance of women (94%), with a mean age of 54.7 ( $\pm 15.1$ ) years old. Most of the caregivers identified themselves as married (40%), with a mean of 9.4 ( $\pm 4.7$ ) years of study, and with 58% indicating nine or more years of study.

Regarding the degree of kinship with the older adults, most of the caregivers are their children (56%). Most caregivers reported living in the same house as the aged person (80%) and, therefore, had provided care for a mean of 8.7 ( $\pm 10.0$ ) years and 17.5 ( $\pm 8.6$ ) hours per day.

As for the caregivers' health, most of them (86%) had clinical diagnoses of one to four different diseases, and made continuous use of one to three medications a day (72%).

In relation to burden, the mean result among the caregivers was 17.3 ( $\pm 10.2$ ) points, noticing burden in 60% of these caregivers.

The mean value as obtained for depression symptoms was 5.7 ( $\pm 4.6$ ) points, whereas it was 6.3 ( $\pm 4.7$ ) points for anxiety, indicating unlikely depression and anxiety symptoms, with 78% and 70%, respectively.

Models 1 to 3 show the results of the analysis corresponding to the ZBI-12 and HAD scores as a function of the older adults' variables (Table 1).

**Table 1:** Distribution of the *Poisson* Regression models for the ZBI-12 and HAD scores according to the older adults' variables. São Carlos, SP, Brazil, 2021.

Independent variable	Dependent variable					
	Model 1: Burden		Model 2: Depression		Model 3: Anxiety	
	PR (95% CI)	p-value	PR (95% CI)	p-value	PR (95% CI)	p-value
Age, years old	1.0 (0.9 – 1.0)	0.5	1.0 (1.0 – 1.0)	0.1	1.0 (0.9 – 1.0)	0.3
Charlson Comorbidity Index	1.0 (1.0 – 1.1)	<b>0.01</b>	0.9 (0.8 – 1.0)	0.3	0.9 (0.9 – 1.0)	0.8
Katz scale	0.9 (0.8 – 1.0)	<b>0.03</b>	0.9 (0.8 – 1.1)	0.8	0.8 (0.8 – 0.9)	<b>0.01</b>
Lawton scale	1.0 (0.9 – 1.0)	0.1	0.9 (0.9 – 1.0)	0.3	1.0 (0.9 – 1.0)	0.8

**Notes:** Model 1 – Zarit Burden Inventory (ZBI-12); Models 2 and 3 – Hospital Anxiety and Depression Scale (HADS), with Model 2 for Depression and Model 3 for Anxiety; PR: *Poisson* Regression; CI: Confidence Interval; p: p-value.

The CCI showed a statistically significant and positive association with the ZBI-12 score, but not with the HAD scores for depression and anxiety. In addition, it was noticed that the functional capacity for BADLs assessed by the Katz Scale also presented a statistically significant and negative association with the ZBI-12 and HAD - Anxiety scores, but not with the HAD - Depression score.

Models 4 to 6 show the results of the analysis corresponding to the ZBI-12 and HAD scores as a function of the caregivers' variables (Table 2).

**TABLE 2:** Distribution of the *Poisson* Regression models for the ZBI-12 and HAD scores as a function of the caregivers' variables. São Carlos, SP, Brazil, 2021.

Independent variable	Dependent variable					
	Model 4: Burden		Model 5: Depression		Model 6: Anxiety	
	PR (95% CI)	p-value	PR (95% CI)	p-value	PR (95% CI)	p-value
Caregiver's age, years old	1.0 (1.0 – 1.0)	<b>&lt;0.001</b>	1.0 (0.9 – 1.0)	0.1	1.0 (1.0 – 1.0)	<b>0.01</b>
Lives with the older adult						
No	Reference	-	Reference	-	Reference	-
Yes	1.2 (1.0 – 1.5)	<b>0.01</b>	1.4 (1.0 – 2.0)	<b>0.04</b>	1.4 (1.0 – 2.0)	<b>0.02</b>
Time spent caring for the older adult, years	1.0 (0.9 – 1.0)	0.3	1.0 (1.0 – 1.0)	<b>0.01</b>	1.0 (1.0 – 1.0)	<b>0.001</b>

**Notes:** Model 4 – Zarit Burden Inventory (ZBI-12); Models 5 and 6 – Hospital Anxiety and Depression Scale (HADS), with Model 5 for Depression and Model 6 for Anxiety; PR: *Poisson* Regression; CI: Confidence Interval; p: p-value.

Living in the same environment as the aged people presented a statistically significant and positive association with all scores. The caregivers' age showed a statistically significant and positive association with the ZBI-12 and HAD - Anxiety scores, but not with the HAD - Depression score. On the other hand, the time in years caring for the older adults presented a statistically significant and positive association with the HAD scores for depression and anxiety separately, but not for the ZBI-12 score.

Finally, in Table 3, models 7 to 9 present the results of the analysis corresponding to the ZBI-12 and HAD scores as a function of the union of the variables regarding the older adults and the caregivers.

**TABLE 3:** Distribution of the *Poisson* Regression models for the ZBI-12 and HAD scores as a function of combining the older adults' and the caregivers' variables. São Carlos, SP, Brazil, 2021.

Independent variable	Dependent variable					
	Model 7: Burden		Model 8: Depression		Model 9: Anxiety	
	PR (95% CI)	p-value	PR (95% CI)	p-value	PR (95% CI)	p-value
Age, years old	0.9 (0.9 – 1.0)	0.08	1.0 (0.9 – 1.0)	0.07	1.0 (0.9 – 1.0)	0.2
Charlson Comorbidity Index	1.0 (0.9 – 1.0)	0.9	0.9 (0.8 – 1.0)	0.1	0.9 (0.8 – 1.0)	0.4
Katz scale	0.9 (0.9 – 1.0)	0.7	1.0 (0.9 – 1.1)	0.6	0.9 (0.8 – 1.0)	0.07
Lawton scale	1.0 (0.9 – 1.0)	0.3	0.9 (0.9 – 1.0)	0.1	0.9 (0.9 – 1.0)	0.6
Caregiver's age, years old	1.0 (1.0 – 1.0)	<b>&lt;0.001</b>	1.0 (0.9 – 1.0)	0.3	1.0 (0.9 – 1.0)	0.1
Lives with the older adult						
No	Reference	-	Reference	-	Reference	-
Yes	1.2 (1.0 – 1.5)	<b>0.01</b>	1.4 (0.9 – 2.0)	0.06	1.3 (0.9 – 1.9)	0.06
Time spent caring for the older adult, years	1.0 (0.9 – 1.0)	0.5	1.0 (1.0 – 1.0)	<b>0.008</b>	1.0 (1.0 – 1.0)	<b>&lt;0.001</b>

**Notes:** Model 7 – Zarit Burden Inventory (ZBI-12); Models 8 and 9 – Hospital Anxiety and Depression Scale (HADS), with Model 8 for Depression and Model 9 for Anxiety; PR: *Poisson* Regression; CI: Confidence Interval; p: p-value.

It is possible to verify that, when combining the independent variables, the caregivers' and living in the same environment as the aged people presented statistically significant and positive associations with the ZBI-12 scores, but not for HAD. It is also observed that the time the caregivers have devoted to caring for the older adults in years was statistically, significantly and positively associated with HAD for anxiety and depression, but not for burden. Thus, the older adults' variables lost their impact significance for burden when we included the care time, the caregivers' age and whether the caregivers live with the aged people.

## DISCUSSION

The results showed that there was predominance of females in the sample, similarly to other studies<sup>24,25</sup>. In the current research, the older adults had an overall mean age of 75.9 ( $\pm 9.3$ ) years old. According to Almeida<sup>26</sup>, aged people use health services more when compared to the adult population. This can be related to longer-lived older adults presenting a higher frequency of involvement with chronic health conditions and disabilities<sup>26</sup>.

As for marital status, most of the aged individuals self-declared as widowed (44%). Widowhood is the most common marital status among older adults and is more frequently linked to females, due to the greater life expectancy inherent to this gender<sup>25</sup>.

The CCI analysis showed that 32% of the older adults had an 85% mortality risk in one year. According to Bahlis<sup>27</sup>, as it has already gone through the validation process and due to the results achieved so far, the CCI is considered a good predictor of mortality.

The functional capacity of the sample comprised by the aged people assessed showed that half (50%) of them were classified as independent for BADLs and 48% as partially dependent for IADLs. Functional limitation has multidimensional characteristics and a health problem related to a physical limitation may turn into a functional limitation. Therefore, it is indispensable to identify which activities older adults find more difficult to carry out, in order to develop activities to promote health, prevent injuries and treat such declines<sup>28</sup>.

Most of the caregivers were female (94%), married (40%) and had children (56%), corroborating several studies in the area<sup>1,10,29-31</sup> and with the participation of caregivers aged at least 60 years old, revealing a warning, as aging makes people more susceptible to developing diseases and disabilities, which can harm their own condition and the quality of the care provided to older adults<sup>1,31</sup>.

Most of the caregivers (80%) reported living with the aged people cared for, in addition to having shown an extended period of time in years and hours in this function. These factors can generate stress and burden on caregivers, especially when care is assumed without the support of other family members, as they perform the function full-time, making them have to maintain constant surveillance<sup>10,32</sup>. This is why it is extremely important to involve other family members in the care of older adults in the elaboration of guidelines for caregivers, allowing the main caregivers time to take care of themselves.

The caregivers reported making continuous use of a mean of 1.8 medications. The presence of comorbidities can be a consequence of the caregivers' role and is linked to mental wear out, which can be manifested by psychological disorders such as anxiety and depression, causing caregivers to use medications continuously<sup>33</sup>.



Regarding the caregivers' burden levels, 60% of them had care-related burden. As already mentioned, the time spent exclusively caring for the aged people, together with the postponement or interruption of personal activities, can lead to caregiver burden, as it is possible to find a relationship between the care recipients' greater dependence degree, the time spent on the act of caring and less time available for themselves<sup>34</sup>.

The caregivers presented unlikely depression and anxiety symptoms, which can be explained by the method adopted for the study, that is, a prevalence survey. A later prospective cohort study, for example, might measure from which moment there is anxiety and depression incidence in the caregivers evaluated. However, it is important to emphasize that such symptoms can emerge based on high burden levels. According to Manzini and Vale<sup>8</sup>, caregivers of aged people with higher burden levels become susceptible to onset of these symptoms. It is fundamental to have a support network to provide guidelines regarding the act of caring, in addition to proposing coping techniques to reduce the physical, psychological and social repercussions in these individuals<sup>30</sup>.

In the current study, to assess the association of variables in relation to burden levels, the following analytical sequence was adopted: the older adults were focused on; the caregivers were focused on; both were focused on. It was observed that the older adults' characteristics are no longer relevant for the burden score when analyzed in conjunction with the caregivers; therefore, we searched for the caregivers' variables that were associated with burden.

Consequently, significant associations were found between higher burden levels and dependence of the older adults, burden of comorbidities, caregivers' age in years old and living in the same home environment. It is evidenced that these factors are interconnected in a certain way, as more comorbidities lead to more dependence and, when within the same home environment, the caregivers' burden significantly increases, especially if they are older. If for every 1-unit increase in age, there is an increase of up to 1.0 times in the burden scale score, and can reach up to 1.5 for living in the same house, it is implied that, for age to exert the same impact as living in the same house, the caregiver has to be 55 years old. From this perspective, whether physical, emotional and/or financial, care-related burden occurs mainly when the aged person requires prolonged and complex care; in addition, this factor intensifies in the case of caregivers belonging to an older age group<sup>11</sup>.

The burden of the disease assessed by the CCI can be configured as an indicator of greater severity, as well as the probability of developing complications, given that the patients' recovery can become more difficult, especially if they are aged<sup>35</sup>. It is known that caring for a dependent older adult requires greater attention to help with the performance of ADLs and, as a consequence, can generate burden in the caregiver<sup>9</sup>.

Another significant finding is related to the time in years devoted to caring for the older adults. In the statistical analyses, it was found that older adults' dependence is only relevant for burden when the care time is not considered. Previous studies highlight that, after the impact caused by the duty of helping a dependent aged person, caregivers seek to adapt to the current circumstance and, therefore, it is possible to verify that there is a relationship between this attitude and a greater state of resilience, that is, the higher the burden degree perceived by the caregiver, the lower the resilience<sup>36,37</sup>.

Therefore, the research contributions are in line with showing relevant fundamentals in the scope of conveying scientific knowledge and progress in health and nursing practices, due to the presentation of a care model directed to the health of caregivers of aged people.

### Study limitations

The results presented by the study must be considered taking some limitations into account, that is, the sample defined by the study had greater knowledge about technology and communication resources. Thus, caregivers who did not have an Internet connection and/or support to access the teleconsultations were not able to participate in the research. In addition, the study population corresponds to a small part of caregivers of aged people from a health service at a hospital in the municipality, which denotes certain possibility that the findings are biased. It is necessary to develop new research studies based on a more expressive sample in order to allow data generalization.

### CONCLUSION

Results showed that the dependence degree and the burden of comorbidities of the older adults cared for were associated with greater burden on the caregivers. When considering the caregivers' characteristics, such as their age, if they live with the aged people and how long they have provided care to them, it is evidenced that the impact of the burden of comorbidities and the dependence of the aged person on the burden levels ceased to be relevant. In addition to that, the older the caregivers and whether they live with the aged people, the greater the burden levels. Such findings show interconnectivity of the factors where, in a way, when there are more comorbidities, higher dependence levels will be found and, if this condition occurs within the same home environment, it significantly increases burden on the caregivers, especially if they are older.

In view of this, it is indispensable that health systems identify the demands and develop an action plan that integrates preventive and treatment strategies to the impairments presented by the older adults. This may make it possible to prevent future limitations in BADLs, exerting positive impacts both on older adults and on their caregivers.

The data obtained showed relevant fundamentals in the scope of conveying knowledge and progressing in health and nursing practices, due to the presentation of a care model aimed at the health of caregivers of aged people. However, the suggestion is to develop new research studies based on a more expressive sample of caregivers in order to allow data generalization.

It is necessary to focus on informal caregivers of older adults through public policies to assist this population segment. In addition to that, it is recommended to devise a care plan that includes assessments and referrals with the multidisciplinary team, as well as guidelines for caregivers regarding the available support resources that indicate ways to reduce burden while performing their role.

## REFERENCES

1. Conceição HN, Jesus MLRS, Gomes IMN, Luz KRG, Conceição HN, Costa Filho JGD et al. Profile and overload of informal caregivers of dependent elderly people. *Res Soc Dev*. 2021 [cited 2021 Jul 22]; 10(6):e47210616061. DOI: <http://dx.doi.org/10.33448/rsd-v10i6.16061>.
2. Classificação Brasileira de Ocupações – CBO. Cuidador de idosos. CBO 5162-10 [Internet]. CBO TEM; 2002 [cited 2021 Jul 22]. Available from: <https://bit.ly/3DCqNej>.
3. Ministério da Saúde (Br). Estatuto do idoso. Brasília: Ministério da Saúde; 2013. [cited 2023 Apr 26]. Available from: [https://bvsms.saude.gov.br/bvs/publicacoes/estatuto\\_idoso\\_3edicao.pdf](https://bvsms.saude.gov.br/bvs/publicacoes/estatuto_idoso_3edicao.pdf).
4. Wangler J, Jansky M. Support, needs and expectations of family caregivers regarding general practitioners – results from an online survey. *BMC Fam Pract*. 2021 [cited 2021 Jul 23]; 22(47):1-12. DOI: <https://doi.org/10.1186/s12875-021-01381-4>.
5. Jawahir S, Tan EH, Tan YR, Noh SNM, Rahim IA. The impacts of caregiving intensity on informal caregivers in Malaysia: findings from a national survey. *BMC Health Serv Res*. 2021 [cited 2021 Jul 30]; 21(391):1-16. DOI: <https://doi.org/10.1186/s12913-021-06412-5>.
6. Jesus ITM, Orlandi AAS, Zazzetta MS. Burden, profile and care: caregivers of socially vulnerable elderly persons. *Rev Bras Geriatr Gerontol*. 2018 [cited 2021 Jul 30]; 21(2):194-204. DOI: <https://doi.org/10.1590/1981-22562018021.170155>.
7. Mendes PN, Figueiredo MLF, Santos AMR, Fernandes MA, Fonseca RSB. Physical, emotional and social burden of elderly patients' informal caregivers. *Acta Paul Enferm*. 2019 [cited 2021 Jul 30]; 32(1):87-94. DOI: <https://doi.org/10.1590/1982-0194201900012>.
8. Manzini CSS, Vale FAC. Emotional disorders evidenced by family caregivers of older people with Alzheimer's disease. *Dement Neuropsychol*. 2020 [cited 2022 Jan 05]; 14(1):56-61. DOI: <https://doi.org/10.1590/1980-57642020dn14-010009>.
9. Lopes CC, Oliveira GA, Stigger FS, Lemos AT. Association between the occurrence of pain and caregivers overload on main and the elderly Independence level in daily life activities: cross sectional study. *Cad Saúde Colet*. 2020 [cited 2021 Dec 17]; 28(1):98-106. DOI: <https://doi.org/10.1590/1414-462X202028010184>.
10. Silva JK, Boery RNSO. Family caregivers of stroke survivors: burden and related factors. *Ciencia y Enfermeira*. 2021 [cited 2021 Dec 16]; 27(11):1-10. DOI: <https://doi.org/10.29393/CE27-11CFJR20011>.
11. Sousa GS, Silva RM, Reinaldo AMS, Brasil CCP, Pereira MO, Minayo MCS. Metamorfosis in the lives of elderly people caring for dependente elderly in Brazil. *Texto Contexto Enferm*. 2021 [cited 2022 Jan 06]; 30:1-14. DOI: <https://doi.org/10.1590/1980-265X-TCE-2020-0608>.
12. Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980 [cited 2021 Jul 05]; 20:649-655. DOI: <https://doi.org/10.1093/geront/20.6.649>.
13. Scazufca M. Brazilian version of the Burden Interview scale for the assessment of burden of care in carers of people with mental illnesses. *Rev Bras de Psiquiatr*. 2002 [cited 2021 Jul 05]; 24(1):12-17. DOI: <https://doi.org/10.1590/S1516-44462002000100006>.
14. Gratão ACM, Brigola AG, Ottaviani AC, Luchesi BM, Souza EM, Rossetti ES et al. Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dement Neuropsychol*. 2019 [cited 2021 Jul 05]; 13(1):122-129. DOI: <https://doi.org/10.1590/1980-57642018dn13-010015>.
15. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983 [cited 2021 Jul 06]; 67(6):361-370. DOI: <https://doi.org/10.1111/j.1600-0447.1983.tb09716.x>.
16. Botega NJ, Bio MR, Zomignani MA, Garcia Júnior C, Pereira WAB. Mood disorders among medical in-patients: a validation study of the hospital anxiety and depression scale (HAD). *Rev Saúde Pública*. 1995 [cited 2021 Jul 06]; 29(5):359-363. DOI: <https://doi.org/10.1590/S0034-89101995000500004>.
17. Delai M, Hohl A, Marques EL, Pincelli MP, Ronsoni MF, Sande-Lee SV. Prevalence of anxiety and depression symptoms in patients with different degrees of obesity. *Arq Catarin Med*. 2020 [cited 2023 Apr 26]; 49(4):86-97. Available from: <https://revista.acm.org.br/index.php/arquivos/article/view/877/475>.
18. Dal Ponte AL, Schwingel FL, Schmidt HSS, Baum G. Depression and anxiety as the potential causes of exacerbation in patients with COPD. *ACM Arq Catarin Med*. 2021 [cited 2022 Jan 06]; 50(2):190-202. Available from: <https://revista.acm.org.br/index.php/arquivos/article/view/707>.

19. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *JAMA*. 1963 [cited 2021 Jul 15]; 185(12):914-919. DOI: <https://doi.org/10.1001/jama.1963.03060120024016>.
20. Lino VTS, Pereira SEM, Camacho LAB, Ribeiro Filho ST, Buksman S. Cross-cultural adaptation of the Independence in Activities of Daily Living Index (Katz Index). *Cad Saúde Pública*. 2008 [cited 2021 Jul 15]; 24(1):103-112. DOI: <https://doi.org/10.1001/jama.1963.03060120024016>.
21. Carvalho TC, Valle AP, Jacinto AF, Mayoral VFS, Villas Boas PJF. Impact of hospitalization on the functional capacity of the elderly: a cohort study. *Rev Bras Geriatr Gerontol*. 2018 [cited 2021 Aug 01]; 21(2):136-144. DOI: <http://dx.doi.org/10.1590/1981-22562018021.170143>.
22. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*. 1969 [cited 2021 Jul 05]; 9:179-186. Available from: <https://pubmed.ncbi.nlm.nih.gov/5349366/>.
23. Santos RL, Virtuoso Júnior JS. Reliability of the Brazilian version of the Scale of Instrumental Activities of Daily Living. *Rev Bras Promoç Saúde*. 2008 [cited 2021 Jul 05]; 21(4):290-296. Available from: [https://www.researchgate.net/publication/26609262\\_Reliability\\_of\\_the\\_Brazilian\\_version\\_of\\_the\\_Scale\\_of\\_Instrumental\\_Activities\\_of\\_Daily\\_Living](https://www.researchgate.net/publication/26609262_Reliability_of_the_Brazilian_version_of_the_Scale_of_Instrumental_Activities_of_Daily_Living).
24. Brasil CHG, Maia LC, Caldeira AP, Brito MFSF, Pinho L. Positive self-perception of health among non-long-lived older adults and associated factors. *Cien Saude Colet*. 2021 [cited 2021 Dec 13]; 26(3):5157-5170. DOI: <https://doi.org/10.1590/1413-812320212611.3.06352020>.
25. Lobato TCI, Souza AD, Reis DA, Xavier FR, Siqueira GG. Functional capacity of the amazonian long-lived elderly people. *Rev Nursing*. 2021 [cited 2021 Dec 13]; 24(281):6528-6534. DOI: <https://doi.org/10.36489/nursing.2021v24i282p6528-6534>.
26. Almeida APSC, Nunes BP, Duro SMS, Lima RCD, Facchini LA. Lack of access and the trajectory of healthcare use by elderly Brazilians. *Cien Saude Colet*. 2020 [cited 2021 Dec 13]; 25(6):2213-2226. DOI: <https://doi.org/10.1590/1413-81232020256.27792018>.
27. Bahlis LF, Diogo LP, Fuchs SC. Charlson Comorbidity Index and other predictors of in-hospital mortality among adults with community-acquired pneumonia. *J Bras Pneumol*. 2021 [cited 2022 Jan 14]; 47(1):e20200257. DOI: <https://dx.doi.org/10.36416/1806-3756/e20200257>.
28. Santos RG, Lima MRS. Functional capacity of elderly care in familia's health strategy. *Revista Interdisciplinar*. 2021 [cited 2021 Dec 13]; 14(21):1-10. Available from: <https://dialnet.unirioja.es/servlet/articulo?codigo=7973388>.
29. Caparrol AJS, Martins G, Barbosa GC, Gratão ACM. Effects of a psychoeducational intervention focusing on cognitive training in caregivers of older adults with Alzheimer's disease. *Cad Bras Ter Ocup*. 2021 [cited 2021 Dec 15]; 29: e2886. DOI: <https://doi.org/10.1590/2526-8910.ctoAO2181>.
30. Santos MI, Leite CD, Barbosa VFB, Alves ANO, Silva Filho MC, Inojosa SMT et al. Care-educational gerontotechnology: thematic workshops with family caregivers of elderly people with Alzheimer's dementia. *Enfermagem Brasil*. 2021 [cited 2021 Dec 15]; 20(5):614-626. DOI: <https://doi.org/10.33233/eb.v20i5.4720>.
31. Souza BG, Silva JG, Figueira TG. Profile evaluation of elderly caregivers: preliminar study. *Longeviver*. 2021 [cited 2021 Dec 15]; 10:25-34. Available from: <https://revistalongeviver.com.br/index.php/revistaportal/article/view/889/952>.
32. Aires M, Fuhrmann AC, Mocellin D, Dal Pizzol FLF, Sponchiado LF, Marchezan CR et al. Burden of informal caregivers of dependent elderlies in the community in small cities. *Rev Gaúcha Enferm*. 2020 [cited 2021 Aug 01]; 41(esp):e20190156. DOI: <https://doi.org/10.1590/1983-1447.2020.20190156>.
33. Felipe SGB, Oliveira CES, Silva CRDT, Mendes PN, Carvalho KM, Silva-Júnior FL et al. Anxiety and depression in informal caregivers of dependent elderly people: an analytical study. *Rev Bras Enferm*. 2020 [cited 2020 Aug 01]; 73(Suppl 1):e20190851. DOI: <https://doi.org/10.1590/0034-7167-2019-0851>.
34. Sousa GS, Silva RM, Reinaldo AMS, Soares SM, Gutierrez DMD, Figueiredo MLF. "We are humans after all": Family caregivers' experience of caring for dependent older adults in Brazil. *Cien Saude Colet*. 2021 [cited 2022 Jan 05]; 26(1). DOI: <https://doi.org/10.1590/1413-81232020261.30172020>.
35. Santos APA, Carvalho TA, Soares JPR, Coelho PRLF, Santos ES. Comparison of nursing workload between clinical and surgical intensive care patients. *Cogit Enferm*. 2021 [cited 2022 Jan 07]; 26:e73689. DOI: <https://doi.org/10.5380/ce.v26i0.73689>.
36. Martins G, Corrêa L, Caparrol AJS, Santos PTA, Brugnera LM, Gratão ACM. Sociodemographic and health characteristics of formal and informal caregivers of elderly people with Alzheimer's Disease. *Esc Anna Nery Rev Enferm*. 2019 [cited 2022 Jan 06]; 23(2):e20180327. DOI: <https://doi.org/10.1590/2177-9465-EAN-2018-0327>.
37. Navarro-Abal Y, López-López MJ, Climent-Rodríguez JÁ, Gómez-Salgado J. Burden, empathy, and resilience in dependent people caregivers. *Gaceta Sanitaria*. 2019 [cited 2022 Jan 06]; 33(3):268-271. DOI: <https://dx.doi.org/10.1016/j.gaceta.2017.11.009>.

#### Authors' contributions:

Conceptualization, G.M. and A.C.M.G.; methodology, G.M. and A.C.M.G.; software, H.P.J.; validation, G.M., H.P.J. and A.C.M.G.; investigation, G.M. and A.C.M.G.; formal analysis, A.C.M.G.; resources, A.C.M.G.; data curation, G.M., H.P.J. and A.C.M.G.; manuscript writing, G.M., L.A.R., D.Q.M., G.C.B., A.M.C. G.D.O.S., H.P.J. and A.C.M.G.; writing—review and editing, G.M., L.A.R., D.Q.M., G.C.B., A.M.C. and G.D.O.S.; visualization, G.M., L.A.R., D.Q.M., G.C.B., A.M.C. and G.D.O.S.; supervision, A.C.M.G.; project administration, G.M. and A.C.M.G.; funding acquisition, G.M. All authors have read and agreed to the published version of the manuscript.