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Analysis of the burden of caregivers of older adults with Alzheimer's disease – Cross-sectional study

Análise da sobrecarga de cuidadores de idosos com Doença de Alzheimer – Estudo transversal

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ABSTRACT
This cross-sectional study aimed to analyze the level of burden of 126 home caregivers of older adults with Alzheimer's disease, in addition to associating it with sociodemographic, health and professional performance variables. A questionnaire was used to assess the sociodemographic, health and care profile of the older adults, and also the Zarit Overload Inventory. Data collection took place between February and May 2023. Data analysis was performed using Pearson's Chi-square test ($p<0.05$). We found a higher frequency of intense burden in caregivers who care older adults for more than 12 hours a day ($p=0.015$), live with older adults ($p<0.001$), perform informal care ($p < 0.001$), care for older adults who were diagnosed no more than four years ago ($p=0.047$) and older adults who have a Chronic Non-Communicable Disease associated with Alzheimer ($p=0.006$). Caregivers who experience greater burden devote more time to care, live with the patient, and provide comprehensive informal care.

Keywords: Aging. Home care. Dementia.

RESUMO
Este estudo transversal teve o objetivo de analisar o nível de sobrecarga de 126 cuidadores domiciliares de idosos com Doença de Alzheimer, além de associá-lo com variáveis sociodemográficas, de saúde e atuação profissional. Foi utilizado um questionário de avaliação do perfil sociodemográfico, de saúde e de cuidado do idoso, e o Inventário de Sobrecarga de Zarit. A coleta de dados ocorreu entre fevereiro à maio de 2023. A análise dos dados foi realizada por meio do teste Qui-quadrado de Pearson ($p<0{,}05$). Encontrou-se maior frequência de cuidadores com sobrecarga intensa que cuidam do idoso por mais de 12 horas por dia ($p=0{,}015$), residem com o idoso ($p<0{,}001$), realizam cuidado informal ($p < 0{,}001$), atendem idosos que foram diagnosticados há no máximo quatro anos ($p=0{,}047$) e que possuem Doença Crônica não Transmissível associada ao Alzheimer ($p=0{,}006$). Cuidadores que experimentam maior sobrecarga, dedicam mais tempo aos cuidados, vivem com o paciente e oferecem cuidados informais abrangentes.

Palavras-chave: Envelhecimento. Cuidados domiciliares. Demência

INTRODUCTION

Alzheimer's Disease (AD) is a progressive and irreversible neurodegenerative condition that affects people in old age, mainly affecting memory, thinking and behavior1,2. It is a neurocognitive disorder that accounts for more than 60 to 80% of dementias in older adults2-4.

The main symptoms of AD include cognitive deterioration with memory loss, difficulty in learning new information and performing daily tasks, spatial and temporal disorientation, attention deficit, among others5,6. There are also mood changes, anxiety, sleep disorders, depressive symptoms and apathy6. As the disease progresses, these symptoms worsen and may include motor, swallowing and urinary continence changes, requiring singularized and sometimes intensive care, which leads to the need for a caregiver2,5. In this context, the caregiver (who may or may not be a family member), becomes fundamental in assisting activities of daily living, related to food, hygiene, locomotion, medication control, financial administration, among others7.

Most of the individuals who perform the task of caring are women and, in many cases, they are older adults themselves caring for another older adult. There are profiles of caregivers that vary according to generations, cultural, racial and ethnic differences5. Regardless of this caregiver's profile, his task is extremely important, challenging and demanding both physically and psychologically. The caregiver plays a key role in the well-being of the older adult, but also needs to take care of himself to avoid burnout and health problems7.

Caring for people with AD produces psychological, emotional and financial suffering for their caregivers due to the gradual loss of cognitive functions that can evolve into total dependence, causing burden to the family nucleus and especially to the main caregiver1,5.

The so-called caregiver burden is a very frequent condition and can lead to a reduction in the caregiver's quality of life and worsening of the older adult's behavioral symptoms. Several factors associated with caregivers' burden are known, related to the patients as disease severity and neuropsychiatric manifestations, and to the caregivers as time of care and their physical and mental health8.

Therefore, understanding the level of burden that caregivers face is essential to implement appropriate support measures. As well as, investigating sociodemographic, health and professional performance variables can help identify risk and protective factors for caregivers' burden. This makes it possible to implement specific strategies for more vulnerable groups of caregivers. However, this study aimed to analyze the level of burden of caregivers of older adults with AD, in addition to associating it with sociodemographic, health and professional performance variables.

METHODOLOGY

This is a quantitative, analytical, observational and cross-sectional research, approved by the Research Ethics Committee (REC) of Cesumar University (Unicesumar), through opinion number 6.001.701/2023, and which followed the guidelines of Strengthening the reporting of observational studies in epidemiology (STROBE).

PARTICIPANTS

The non-probabilistic sample was chosen intentionally and for convenience, and consisted of 126 formal (professional) or informal (family) caregivers of older adults with AD, living in different regions of the country. Only caregivers of older adults diagnosed with AD (reported by the caregiver), of both sexes, aged 18 years or older, residing in all regions of the country were included. Only those who cared for older adults with AD at home were included. Caregivers of institutionalized and hospitalized older adults were excluded.

INSTRUMENTS

To evaluate the sociodemographic, health and care profile of the older adults with AD, a questionnaire prepared by the authors was used, with questions related to age, age group, sex, family income, level of education, retirement, use of medications, associated diseases (comorbidities), and time of diagnosis of AD. For the evaluation of the caregivers of the older adults, another questionnaire was used containing questions of age, age group, sex, family income, level of education, use of medications, presence of diseases, time caring for the older adult with AD, daily time caring for the older adult with AD, whether or not they live in the same residence as the older adult.

The Zarit Caregiver Burden Interview9 was used to assess caregiver burden. This instrument aims to evaluate the perception of burden of caregivers of older adults focusing on the caregiver's perception of how his activity impacts his personal, social, financial, and physical and mental health. The instrument has 22 items that must be answered by the caregivers themselves from a 5-point Likert scale, ranging from 0 points (never), rarely (1 point), sometimes (2 points), very often (3 points) or always (4 points). The total score can vary between 0 and 88 points. The higher is the score, the greater is the burden of care for the caregiver9. Burden is considered mild up to 14 points; moderate, from 15 to 21 points; and severe, when above 22 points9.

DATA COLLECTION

The study followed the human research standards of resolution 466/12 of the National Health Council. Quantitative data collection took place through an online form made available by Survey Monkey. Subjects who were interested in participating in the research should first accept the informed consent form in an online form, indicating "I agree".

The link was created to host the electronic questionnaire developed for the study and circulated through the authors' social media (Facebook™, Instagram™ and WhatsApp™). The platform for completing the questionnaires was available to receive the subjects' answers for 90 days (February to May 2023). Before starting to complete the questionnaire, participants received a brief instruction containing information about the purpose of the research, the target audience and the estimated time to complete the questionnaire (approximately 15 minutes).

DATA ANALYSIS

Data analysis was performed using the SPSS 25.0 Software, using a descriptive and inferential statistics approach. Frequency and percentage were used as descriptive measures for categorical variables, and mean and standard deviation for numerical variables. Pearson's Chi-square test (X2) and Fisher's exact test (for cases with an expected frequency of less than 5 in any cell) were used to analyze the sociodemographic, health and professional performance factors associated with the level of burden of caregivers. Significance of $p < 0.05$ was adopted..

RESULTS

One hundred and twenty-six (126) caregivers participated in the research, female ($n = 118$) and male ($n = 8$), aged between 22 and 80 years ($M = 51.36$; $SD = 10.90$). The data in Table 1 reveal the predominance of caregivers aged 40 to 59 years (61.9%), with a partner (54.8%), with complete higher education (60.3%), white (64.2%%) and who had a monthly income of one to two minimum wages (42.1%). It is also noted that 42.8% of caregivers reported using one to two medications on a regular basis and 60.3% reported not having any chronic non-communicable disease (NCD).

Table 1. Sociodemographic profile of caregivers with Alzheimer's Disease. (n=126)

VARIABLES	*f*	%
Sex		
Female	118	93.7
Male	8	6.3
Age Group		
20 to 39 years	22	17.5
40 to 59 years	78	61.9
60 years or more	26	20.6
Marital Status		
With a partner	69	54.8
Without a partner	57	45.2
Education		
Incomplete/complete elementary school	10	7.9
Complete high school	40	31.7
Complete University education	76	60.4
Color		
White	81	64.2
Yellow	6	4.8
Black/Brown	39	31.0
Monthly Income		
1 to 2 MW	53	42.1
2.1 to 3 MW	25	19.8
More than 3 MW	48	38.1
Use of medication		
None	36	28.6
1 to 2	54	42.8
More than 2	36	28.6
Presence of NCDs		
Yes	50	39.7
No	76	60.3

Source: the authors. NCDs = Chronic non-communicable diseases MW = minimum wage (s).

According to the results in Table 2, most caregivers reported acting as a caregiver for a period of one to four years (50.8%), for more than 12 hours a day (53.2%) and caring for only one older person with AD (92.9%). It is also noted that most caregivers live with the older adult (65.9%) and perform informal care (78.6%). The mean age of the older adults reported by caregivers was 81.48 (SD = 7.91) years.

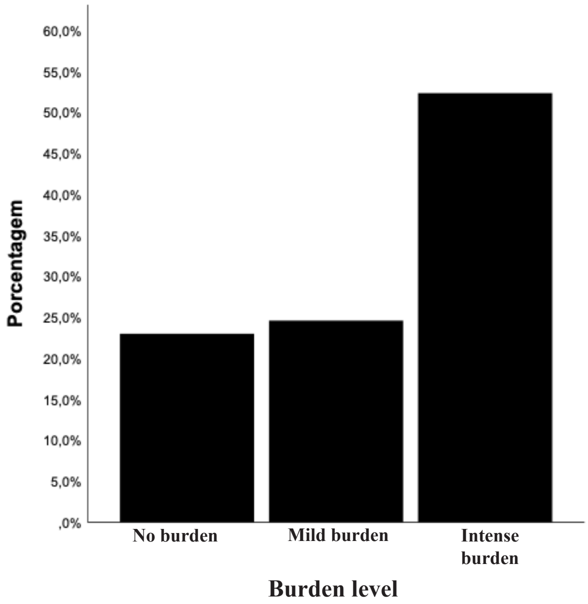
Table 2. Professional performance profile of caregivers of elderly people with Alzheimer's disease. (n=126)

VARIABLES	*f*	%
Time caring for the older adult		
Less than 1 year	11	8.7
1 to 4 years	64	50.8
More than 4 years	51	40.5
Number of older adults cared for		
Just 1	117	92.9
More than 1	9	7.1
Hours per day caring for the older adult		
Up to 8 hours	33	26.2
9-12 hours	26	20.6
More than 12 hours	67	53.2
Lives with the older adult		
Yes	83	65.9
No	43	34.1
Type of care		
Informal	99	78.6
Formal	27	21.4

Source: the authors.

According to caregivers, the older adults with AD treated are mostly female (80.2%), aged over 80 years (60.3%), using more than two medications (88.1%), who were diagnosed with AD less than four years ago (51.6%) and who have another NCD (68.3%). The older adults had a mean age of 81.48 (SD = 7.91) years.

When analyzing the level of burden of caregivers of older adults with AD (Figure 1), it is noted that 52.4% (n=66) had intense burden, 24.6% (n=31) had mild burden and 23.0% (n=29) had no burden.



Percentage

Figure 1. Level of burden on caregivers of older adults with Alzheimer disease.

No significant difference ($p > 0.05$) was found in the comparison of the proportions of sociodemographic and health variables of caregivers of older adults with AD according to the level of perceived burden. However, when comparing the proportions of the variables on the professional performance of caregivers of older adults with AD according to the level of burden (Table 3), there was a significant difference between the groups in the hours per day they care for older adults ($p = 0.015$), whether they live with the older adult ($p < 0.001$) and the type of care ($p < 0.001$). There is a higher frequency of caregivers with intense burden who care for older adults for more than 12 hours a day (68.2%), who live with older adults (81.8%) and who perform informal care (93.9%).

Table 3. Comparison of the proportions of variables on the professional performance of caregivers of older adults with Alzheimer disease according to the level of burden. (n=126)

(Continued)

VARIABLES	Burden level			X^2	p-value
	No burden (n=29)	Mild burden (n=31)	Intense burden (n=66)		
	f (%)	*f* (%)	*f* (%)		
Time caring for the older adult					
Less than 1 year	3 (10.4)	3 (9.7)	5 (7.6%)	0.017	0.897
1 to 4 years	13 (44.8)	16 (51.6)	35 (53.0%)		
More than 4 years	13 (44.8)	12 (38.7)	26 (39.4)		
Number of older adults cared for					
Just 1	25 (86.2%)	29 (93.5)	63 (95.5)	2.627	0.269
More than 1	4 (13.8)	2 (6.5)	3 (4.5)		

(Conclusion)

VARIABLES	Burden level			X^2	p-value
	No burden (n=29)	Mild burden (n=31)	Intense burden (n=66)		
	f (%)	*f* (%)	*f* (%)		
Hours per day caring for the older adult					
Up to 8 hours	8 (27.6)	14 (45.2)	11 (16.8)	5.915	0.015*
9-12 hours	8 (27.6)	8 (25.8)	10 (15.1)		
for more than 12 hours	13 (44.8)	9 (29.0)	45 (68.1)		
Lives with the older adult					
Yes	13 (44.8)	16 (51.6)	54 (81.8)	14.501	<0.001*
No	16 (55.2)	15 (48.4)	12 (18.2%)		
Type of care					
Informal	14 (48.3%)	23 (74.2)	62 (93.9)	25.092	<0.001*
Formal	15 (51.7%)	8 (25.8)	4 (6.1)		

* Significant difference –p<0.05: Chi-square test.
Source: the authors.

When comparing the proportions of the variables on the profile of older adults with AD treated by caregivers according to the level of burden (Table 4), there was a significant difference between the groups only in the time of diagnosis of the disease (p = 0.047) and in the presence of NCDs associated with AD (p = 0.006). There is a higher frequency of caregivers with intense burden who care for older adults who have been diagnosed with AD for a maximum of four years (59.1%) and who have NCDs associated with AD (77.3%).

Table 4. Comparison of the proportions of the variables on the profile of older adults cared for by caregivers according to the level of burden. (n=126)

(Continued)

VARIABLES	Burden level			X^2	p-value
	No burden (n=29)	Mild burden (n=31)	Intense burden (n=66)		
	f (%)	*f* (%)	*f* (%)		
Sex					
Female	22 (75.9)	25 (80.6)	54 (81.8)	0.406	0.524
Male	7 (24.1%)	6 (19.4)	12 (18.2%)		
Age group					
60 to 69 years	3 (10.3)	1 (3.2)	7 (10.6%)	0.023	0.879
70 to 79 years	9 (31.0)	12 (38.7)	18 (27.3%)		
80 years or more	17 (58.7)	18 (58.1)	41 (62.1)		
Use of medications					
0 to 2	4 (13.8)	5 (16.1)	6 (9.1%)	0.650	0.420

(Conclusion)

More than 2	25 (86.2%)	26 (83.9)	60 (90.9)		
Time since diagnosis					
Up to 4 years	12 (41.4)	14 (45.2)	39 (59.1%)		
More than 4 years	14 (48.3%)	15 (48.4)	25 (37.9)	3.945	0.047*
Does not know	3 (10.3)	2 (6.4)	2 (3.0%)		
Presence of NCDs					
Yes	14 (48.3%)	21 (67.7)	51 (77.3)	7.508	0.006*
No	15 (51.7%)	10 (32.3)	15 (22.7%)		

* Significant difference –$p < 0.05$: Chi-square test.
Source: the authors.

DISCUSSION

The main findings of this study indicate that most caregivers of older adults with AD present intense burden; no significant difference was found in the comparison of the proportions of sociodemographic and health variables of caregivers of older adults with AD according to the level of perceived burden; there is a higher frequency of caregivers with intense burden who care for the older adult for more than 12 hours a day, who live with the older adult, who perform informal care, who were diagnosed with AD for a maximum of four years and who have NCDs associated with AD.

The intense burden among caregivers can be explained due to the fact that AD is a neurodegenerative condition that worsens over time. As the disease progresses, patients often lose their cognitive and functional abilities, which makes them more dependent on care. This requires caregivers to devote more and more time and effort to meeting the patient's needs[10]. These patients often require constant assistance in daily activities such as feeding, personal hygiene, mobility, and medication management. This overwhelms caregivers, who usually need to be available 24 hours a day, seven days a week[5,11].

We must not forget that caring for a person with AD can be emotionally draining. Caregivers often witness deterioration of the patient's mental and emotional health, which can be distressing. The emotional stress associated with caring for an older person with AD can lead to exhaustion and depression[12,13]. Furthermore, caring for a person with AD often limits the caregiver's ability to participate in social activities and maintain relationships. Social isolation can aggravate burden, as caregivers may feel lonely and lack support[14,15].

This fact was also found in the study by Froelich et al.[16], which sought to evaluate the association of caregiver burden with the severity and progression of AD. The authors found increased burden and worsening in the quality of life of caregivers over time. In the research of Yin et al.[17], it is also notorious the high burden of the caregiver of the older person with AD.

In the present study, we found no significant difference in the comparison of the proportions of sociodemographic and health variables of caregivers of older adults with AD according to the level of perceived burden. Caregivers comprise a diverse population with a wide variety of experiences, needs, and sociodemographic characteristics. This heterogeneity may dilute the statistical differences that may exist between the groups[18,19]. Other variables not considered in the analysis may be playing a role in the relationship between sociodemographic and health variables and the level of perceived burden.

It is also worth noting that perceived burden is a subjective measure that depends on the individual perception of the caregiver. There may be caregivers who face significant challenges but do not perceive their situation as overwhelmed, while others may feel overwhelmed even in less challenging situations[19-22]. This can lead to a lack of significant difference in sociodemographic and health variables. Some caregivers may also develop effective coping strategies that allow them to deal with stress and burden more efficiently, regardless of their sociodemographic and health characteristics. These resilience factors can influence the perception of burden[23,24].

We found that there is a higher frequency of caregivers with intense burden who care for the older person for more than 12 hours a day, as in the study by Yin et al.[17], where the group of caregivers with a demand of 12 hours or more presented greater burden. We also found a higher frequency of caregivers with intense burden who live with the older person and perform informal care, as well as in the research by Ibrahim, Ibrahim and Zaghami[25] carried out with 550 informal caregivers. The authors found that the total burden among informal caregivers was relatively high.

It is worth noting that caring for an older person with AD is an intensive task that can consume a large part of the caregiver's time. Caring for long hours increases the likelihood of burden, as it leaves less time for self-care and other responsibilities, such as work and personal life[26,27].

Caregivers who live in the same house as the older adult face constant exposure to the demands of care, which can result in a continuous sense of responsibility and, consequently, a greater probability of burden[28,29]. And the provision of informal care (most, in the present study), without formal health training, can increase the stress load and the feeling of burden. Informal caregivers may feel less prepared to deal with the complex challenges associated with AD[30,31].

It is important to understand that in the early stages of the disease, patients may still be relatively independent and symptoms may be less pronounced. As the disease progresses, caregivers often have to face increasing challenges as patient capacities decline, which can lead to more intense burden[32,33].

Finally, the presence of other chronic health conditions, such as diabetes, hypertension or heart problems, can increase the complexity of care. The need to manage multiple health conditions, along with AD symptoms, can lead to increased caregiver burden[34,35,36].

Even in view of the important results presented, this study has limitations: participants were chosen in a way that is not representative of the target population, therefore, the results are not generalizable; participants may have provided socially desirable or distorted responses, which may compromise the accuracy of the results; there are other variables not considered in the study that also influence the burden of caregivers, such as social support, past experiences, among others; establishing causal relationships from observational studies can be challenging, as other unmeasured factors can influence the associations found; caregiver burden is a multifaceted and subjective concept.

CONCLUSION

It is concluded that most caregivers of older adults with AD present intense burden. Caregivers who reported intense burden tend to dedicate more than 12 hours a day to the care of the older person, live with the patient and provide informal care in a more expressive way. In addition, they tend to care for recently diagnosed older adults, up to four years since diagnosis, and deal with cases in which there is coexistence of NCDs associated with AD.

These findings suggest that the intensity of burden is directly related to the time of daily dedication, physical proximity to the older person and the informal nature of care and also point to the importance of specific support strategies, considering the time dedicated to care, the cohabitation arrangement and the nature of the care provided. Interventions targeting caregivers facing a more intense burden can be particularly effective, especially if tailored to the specific needs of older adults with newly diagnosed AD and coexisting health conditions.

Also noteworthy is the urgency of implementing public policies aimed at caregivers in the country, integrating them into the national health system, similar to what occurs in several nations globally. This implies the inclusion of formal care, conducted by health professionals, within the scope of the Unified Health System (SUS), in addition to the provision of salary, training and support for individuals who play the role of informal caregivers.

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