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Health conditions and workload burden among informal caregivers of elderly individuals with dementia syndromes

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Abstract

Objective: To estimate the prevalence of caregiver burden and identify associated factors among informal caregivers of elderly individuals with dementia. *Method:* Cross-sectional and analytical study with a sample of caregivers of elderly individuals receiving care at a reference center for elderly health. Caregiver burden was assessed using the Zarit scale. Sociodemographic characteristics and factors related to the health and care of the elderly person were investigated. Data analysis was performed using Poisson regression with robust variance, based on a hierarchical model, with a significance level of 5%. *Results:* A total of 436 caregivers participated in the study, the majority of whom were female (88.1%). The prevalence of caregiver burden was 32.8%. In the multiple model, the following factors were associated with a higher prevalence of caregiver burden: age between 40 and 59 years (PR=1.20; 95% CI=1.02-1.39), being in a marital relationship (PR=1.18; 95% CI=1.02-1.36), being a child or spouse of the elderly person (PR=1.16; 95% CI=1.01-1.33), having a negative self-perception of health (PR=1.30; 95% CI=1.10-1.52), using medication (PR=1.24; 95% CI=1.06-1.45), not practicing self-care measures (PR=1.49; 95% CI=1.17-1.89), providing support to the elderly person in family integration activities (PR=1.41; 95% CI=1.05-1.89), cultural activities (PR=1.36; 95% CI=1.08-1.72), and medication administration (PR=1.13; 95% CI=1.01-1.25). *Conclusion:* The high prevalence of caregiver burden among caregivers of elderly individuals highlights the need for specific policies for this group and represents an aspect to be regularly evaluated by healthcare professionals who work directly with people with dementia and their families.

Keywords: Workload. Caregivers. Aged. Dementia.

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INTRODUCTION

Dementia syndromes (DS) are characterized by impairment in memory, intellect, behavior, and the ability to perform activities of daily living, and have shown a growing prevalence in recent years, paralleling the rapid aging of the population[1]. After being neglected for several decades, DS have come to be recognized as the primary cause of disability and functional dependence among elderly individuals worldwide, and should be considered a public health priority[2].

The chronic, progressive, and unpredictable nature of DS has a significant physical, emotional, psychological, and social impact on the affected elderly individual and their families[3]. It is in this context that families seek to identify an elderly caregiver, an essential figure in providing support to patients with DS who, whether paid or unpaid, undertake the care of the elderly person in their daily activities. This is by no means a simple task. Caring for someone is a complex endeavor, as it demands numerous adjustments and profound changes in the family dynamics, both for the caregiver and the care recipient[4]. In most cases, care is provided by family members or individuals with a close relationship to the patient, known as a family or informal caregiver. This individual, due to familial ties, directly or indirectly assumes responsibility for the unpaid care of a sick or dependent family member[5].

The provision of care often arises more from circumstantial necessity than from the individual's choice. Whether due to a family agreement or a lack of alternatives, the caregiver assumes their role, almost always in a sudden manner, without prior consultation or consent, and without psychological preparation or technical training for this new responsibility[6]. The caregiver, typically the sole person responsible for the care of elderly individuals, often reduces their own activities and may compromise their social life to dedicate themselves exclusively to the dependent individual. Consequently, the constant and uninterrupted care of individuals with DS and the moments of tension experienced by the caregiver can lead to detrimental effects on their health and result in high levels of caregiver burden[6,7].

Caregiver burden can be defined as a complex and multidimensional construct that encompasses the perceived and experienced physical, psychological or emotional, social, and financial consequences faced by individuals, whether they are family members or not, who provide care to patients with DS[8,9]. This excessive strain arising from prolonged stress can lead to caregiver self-neglect, as they may disregard their own needs, result in the onset of illnesses, and even lead to death among caregivers, ultimately resulting in inadequate care for the person being cared for[4].

It is essential to have a clear understanding of the triggering conditions of excessive stress among caregivers in order to develop an appropriate therapeutic plan that includes the elderly person, the caregiver, and the family. This approach enables the prevention of health complications and an improvement in the quality of life for all involved parties[4]. There are still gaps in the literature concerning the factors associated with caregivers' health conditions and workload when caring for individuals with DS. Recognizing these conditions will facilitate the implementation of public policies within healthcare services that provide support to caregivers of individuals with DS, promote self-care among them, and enhance the quality of care they provide.

This study aims to estimate the prevalence of caregiver burden and identify associated factors among informal caregivers of elderly individuals with DS.

METHOD

This was a cross-sectional, analytical study conducted in Montes Claros, located in the northern region of the state of Minas Gerais, Brazil. The municipality has a population of approximately 413,000 inhabitants and serves as a regional reference for the provision of services, including healthcare. The target population for this research consisted of informal caregivers of elderly individuals with dementia syndromes (DS) who were being assisted at the Center for Elderly Healthcare Reference (*Centro de Referência em Assistência à saúde do Idoso* - CRASI). This outpatient unit is affiliated with the State

University of Montes Claros (*Universidade Estadual de Montes Claros* - Unimontes) and the Clemente de Faria University Hospital (*Hospital Universitário Clemente de Faria* - HUCF). It is staffed by a multi- and interdisciplinary team, and all procedures are exclusively provided through the Unified Health System (*Sistema Único de Saúde* - SUS). This Center is considered a reference point for the entire frail elderly population in the northern macro-region of the state, including those with dementia.

The sample size was obtained proportionally to the number of elderly individuals with dementia who had undergone medical consultation at the aforementioned service in the previous year. An estimated prevalence of 50% was assumed for the studied event (as it provides the largest sample size and considering the investigation of other variables for the study), with a confidence level of 95% and a margin of error of 5%. The minimum number of elderly individuals to be selected for the study based on these parameters was 434, including a 20% addition for potential losses. The selection of participants was carried out by physicians at CRASI, who, after consulting with the elderly individuals, identified and referred those who met the inclusion criteria. Subsequently, the caregivers were approached by the researchers and invited to participate in the study, with data collection conducted consecutively until the predetermined sample size was achieved.

Inclusion criteria for the study were as follows: being a family caregiver of an elderly person with a medical diagnosis (recorded in medical records) of irreversible dementia (Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, and Mixed Dementia) of mild, moderate, or severe severity, who had been under care within the last 12 months; being at least 18 years old; having a caregiving duration of at least six months; and being an informal caregiver responsible for the direct care of the elderly individual. Exclusion criteria included being a caregiver for more than one elderly person and being on Sick Leave (*Licença para Tratamento de Saúde* - LTS) at the time of data collection.

Data collection was carried out by a team composed of nurses and undergraduate students in Scientific Initiation (IC), who received specialized training through meetings with the research coordination and a pilot project aimed at equipping the team with the skills required to administer the questionnaire. Calibration was achieved through repetitions of data collection in the pilot project until a consensus was reached among the interviewers. Data were collected in both morning and afternoon shifts, in the reception area of the CRASI outpatient clinic, from August to December 2019, while elderly individuals, accompanied by their caregivers, awaited various assessments or procedures.

As a data collection instrument, a questionnaire was developed by the researchers, comprising three sections: caregiver socio-economic variables, clinical variables and caregiver self-care, and variables related to caregiving. The socio-economic variables included age, gender, marital status, education level, relationship with the elderly person, and family income. The clinical and self-care variables encompassed self-perceived health, medication usage, self-care practices (defined as any actions the individual undertakes to promote their physical and mental well-being and enhance their quality of life, such as accessing healthcare, leisure, physical activity, or health-promotion procedures), nutritional status (derived from self-reported weight and height), and self-reported morbidities, which included depression, hypertension, diabetes, arthritis/osteoarthritis, and insomnia.

Regarding the variables related to caregiving: time spent working as a caregiver for the elderly person, daily hours dedicated to caregiving, assistance from someone else in caregiving activities for the elderly, provision of support to the elderly person in activities such as feeding, hygiene, ambulation, physical activities, cultural activities (civic, cultural, or religious celebrations), family integration activities (family celebrations or gatherings), and medication administration (defined as either supervision or direct provision of medications).

The outcome variable was caregiver burden, assessed using the Zarit Burden Interview (ZBI), which has been adapted and validated in Brazil[10]. This scale evaluates the burden reported by informal caregivers across various domains, including health, social life, economic situation, mood, and the nature of the relationship with the elderly person. It consists of 22 items, each categorized from zero (never) to four (always) points, yielding a total score of 88 points that reflects the level of caregiver stress or burden. A higher score indicates a greater perceived burden[10].

As there is no established cutoff point for the Brazilian population that has been validated, terciles were used for classification, following a previous study[4]. Initially, the normality of the burden variable distribution was tested, and no normal distribution was detected (*p<0,001*) by the Kolmogorov-Smirnov test. Subsequently, caregiver burden among family caregivers was divided into terciles: 1st tercile: up to 9 points; 2nd tercile: between 10 and 17 points; and 3rd tercile: >18 points. Participants classified in the third tercile (presence of burden) were considered to have associated caregiving burden, while those in the first two terciles were considered to have no burden[7]. The association between caregiver burden and caregiver socio-economic, clinical, self-care, and caregiving-related variables was investigated.

Initially, descriptive analyses of all investigated variables were conducted using simple and relative frequencies. The association between the presence of burden and the independent variables was assessed through the chi-square test. Variables that were associated at a significance level of up to 20% (*p≤0,20*) were selected for multiple analysis using a hierarchical Poisson regression model. The model followed a scheme composed of blocks of variables at distal, intermediate, and proximal levels (Figure 1).

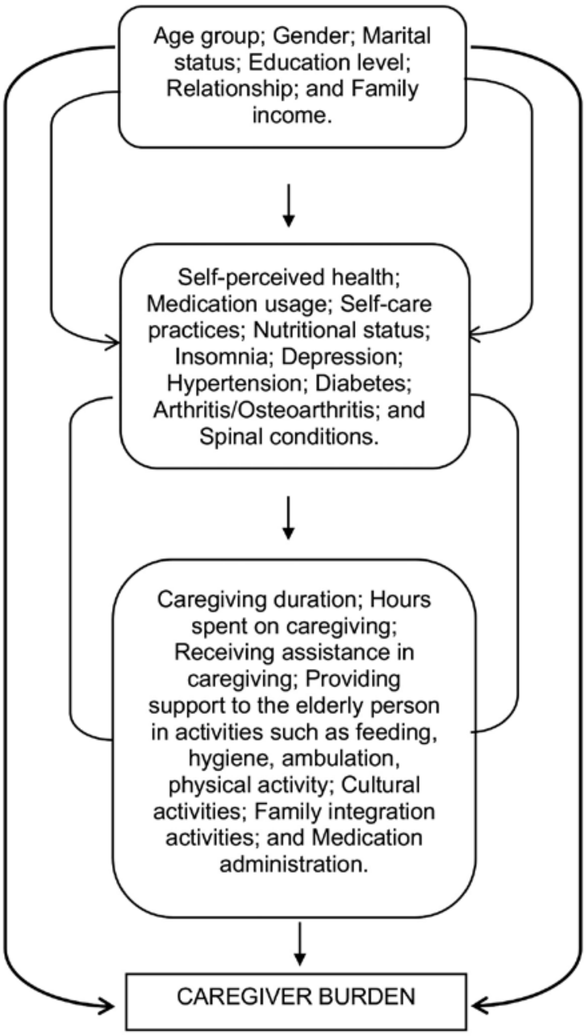

Figure 1. Hierarchical theoretical model of potential factors associated with caregiver burden among elderly individuals with dementia. Montes Claros, MG, 2019.

The hierarchical modeling began with the inclusion of distal-level variables. Variables in this model that exhibited a significance level of up to 5% ($p<0.05$) were included in the subsequent model along with intermediate-level variables. The same methodological approach was followed for the final model, which included proximal-level variables. In the final model, only variables with a significance level of up to 5% ($p<0.05$) were retained. The quality of the model fit was assessed using the Deviance test.

The study project was approved by the Research Ethics Committee of the State University of Montes Claros (*Parecer* Nº. 3.377.246). The Informed Consent Form was signed by all participants as a prerequisite for data collection. The Informed Consent Form was signed by all participants, as a prerequisite for data collection. The research is in accordance with Resolution No. 466/2012 and Resolution No. 510/2016.

RESULTS

A total of 436 caregivers of elderly individuals participated in the study, with the majority being female (88.1%), aged between 40 and 59 years (55.2%), and either a child or spouse of the elderly person (79.6%). Other demographic, socioeconomic, and clinical characteristics of caregivers of elderly individuals with dementia are presented in Table 1.

Table 1. Socioeconomic and Clinical Characteristics of Caregivers of Elderly Individuals with Dementia (N=436). Montes Claros, MG, 2019.

Variables	n (%)
Age Group (years)	
<40	119 (27.4)
40 a 59	240 (55.2)
≥60	76 (17.5)
Gender	
Female	384 (88.1)
Male	52 (11.9)
Marial status	
With a partner	271 (62.2)
Without a partner	165 (37.8)
Education (years of study)	
>12	79 (18.1)
5 a 12	285 (65.4)
≤4	72 (16.5)
Relationship	
Child/Spouse	347 (79.6)
Other (son-in-law, daughter-in-law, grandchild)	89 (20.4)
Family Income (in minimum wages)	
>1	244 (56.0)
≤1	165 (37.8)
No information	27 (6.2)
Perceived Health	
Good/Excellent	271 (62.3)
Regular/Poor/Bad	164 (37.7)

to be continued

Continuation of Table 1

Variables	n (%)
Medication Usage	
No	229 (52.5)
Yes	207 (47.5)
Nutritional Status	
Normal	177 (40.6)
Overweight	163 (37.4)
Obesity	86 (19.7)
No Information	10 (2.3)
Depression	
No	375 (86.0)
Yes	61 (14.0)
Hypertension	
No	303 (69.5)
Yes	133 (30.5)
Diabetes mellitus	
No	405 (92.9)
Yes	31 (7.1)
Arthritis/Osteoarthritis	
No	397 (91.1)
Yes	39 (8.9)
Insomnia	
No	320 (73.4)
Yes	116 (26.6)

Table 2 presents the characteristics of self-care and caregiving among caregivers of elderly individuals with dementia. It is noteworthy that the majority had been engaged in this activity for more than two years (68.8%) and received assistance in providing care (69.0%). Nearly half of them dedicated more than 8 hours per day to caring for the elderly individual (49.5%).

Regarding the prevalence of caregiver burden according to the ZBI scale, 143 (32.8%) of the caregivers scored higher than 18 points, thus indicating a higher level of burden. The absence of burden was observed among 153 (35.1%) and 140 (32.1%) participants in the 1st and 2nd terciles, respectively.

Table 3 shows the association between caregiver burden and the studied variables in a bivariate analysis, recording the crude prevalence ratio and the respective level of significance. Variables with a significance level of up to 20% ($p\text{-value} \leq 0.20$) were selected for multivariate analysis.

Table 4 presents the results of the hierarchical multiple analysis. A higher prevalence of caregiver burden was associated with individuals aged 40 to 59, those in a conjugal situation with a partner, being a child or spouse, having a negative self-perception of health, using medications, not engaging in self-care measures, and providing support to the elderly individual in cultural activities, family integration, and medication administration tasks.

Table 2. Characteristics related to self-care and caregiving among caregivers of elderly individuals with dementia (N=436). Montes Claros, MG, 2019.

Variables	n (%)
Self-Care	
Yes	356 (81.7)
No	80 (18.3)
Care time for the elderly	
Up to 2 years	136 (31.2)
More than 2 years	300 (68.8)
Daily hours spent on caregiving	
≤8	220 (50.5)
>8	216 (49.5)
Receives assistance in caregiving	
Yes	301 (69.0)
No	135 (31.0)
Supports the elderly in feeding	
No	228 (52.3)
Yes	208 (47.7)
Supports the elderly in hygiene	
No	247 (56.7)
Yes	189 (43.3)
Supports the elderly in ambulation	
No	275 (63.1)
Yes	161 (36.9)
Supports the elderly in physical activities	
No	308 (70.6)
Yes	128 (29.4)
Supports the elderly in cultural activities	
No	327 (75.0)
Yes	109 (25.0)
Supports the elderly in Family integration activities	
No	318 (72.9)
Yes	118 (27.1)
Supports the elderly in medication administration	
Yes	359 (82.3)
No	77 (17.7)

Table 3. Bivariate association between caregiver burden and characteristics of caregivers of elderly people with dementia (N = 436). Montes Claros, MG, 2019.

Independent variables	Burden		PR_{crude}	p-value
	No n (%)	Yes n (%)		
Distal level				
Age group				
60 years or older	51 (67.1)	25 (32.9)	1.59	0.008
40 a 59 years	151 (62.9)	89 (37.1)	1.91	0.010
< 40 years	91 (76.5)	28 (23.5)	1.00	
Gender				
Female	253 (65.9)	131 (34.1)	1.48	
Male	40 (76.9)	12 (23.1)	1.00	0.112
Marital Status				
Without a partner	102 (61.8)	63 (38.2)	1.29	
With partner	191 (70.5)	80 (29.5)	1.00	0.062
Education				
Up 4 years of study	39 (54.2)	33 (45.8)	2.50	0.008
5 a 12 years of study	195 (68.4)	90 (31.6)	1.36	0.284
Over 12 years of study	59 (74.7)	20 (25.3)	1.00	
Relationship				
Child/Spouse	224 (64.6)	123 (35.4)	1.58	0.020
Other	69 (77.5)	20 (22.5)	1.00	
Family income (n=409)				
Up to 1 minimum wage	107 (64.8)	58 (35.2)	1.19	0.229
More than 1 minimum wage	172 (70.5)	72 (29.5)	1.00	
Intermediate level				
Perception of Health				
Regular/poor/bad	86 (52.4)	78 (47.6)	2.01	<0.001
Good/excellent	207 (76.4)	64 (23.6)	1.00	
Medication Use				
Yes	120 (58.0)	87 (42.0)	1.72	<0.001
No	173 (75.5)	56 (24.5)	1.00	
Self-care				
No	35 (43.8)	45 (56.3)	2.04	<0.001
Yes	258 (72.5)	98 (27.5)	1.00	
Nutritional status				
Obesisity	51 (59.3)	35 (40.7)	1.65	0.092
Overweight	113 (69.3)	50 (30.7)	1.06	0.794
Normal	125 (70.6)	52 (29.4)	1.00	
Depression				
Yes	29 (47.5)	32 (52.5)	1.77	< 0.001
No	264 (70.4)	111 (29.6)	1.00	
Hypertenssion				
Yes	79 (59.4)	54 (40.6)	1.38	0.021
No	214 (70.6)	89 (29.4)	1.00	

to be continued

Continuation of Table 3

Independent variables	Burden No n (%)	 Yes n (%)	PR_{crude}	p-value
Diabetes mellitus				
Yes	14 (45.2)	17 (54.8)	1.76	0.007
No	279 (68.9)	126 (31.1)	1.00	
Arthritis/Osteoarthritis				
Yes	20 (51.3)	19 (48.7)	1.59	0.026
No	273 (68.8)	124 (31.2)	1.00	
Insomnia				
Yes	62 (53.4)	54 (46.6)	1.67	< 0.001
No	231 (72.2)	89 (27.8)	1.00	
Proximal level				
Time spent caring for the elderly (years)				
>2	193 (64.3)	107 (35.7)	1.35	0.058
≤2	100 (73.5)	36 (26.5)	1.00	
Daily hours spent caregiving				
More than 8 hours	127 (58.8)	89 (41.2)	1.68	< 0.001
Up to 8 hours	166 (75,5)	54 (24.5)	1.00	
Receives help in caring for the elderly				
No	81 (60.0)	54 (40.0)	1.35	0.032
Yes	212 (70.4)	89 (29.6)	1.00	
Support for the elderly in feeding activities				
Yes	142 (68.3)	66 (31.7)	0.94	0.650
No	151 (66.2)	77 (33.8)	1.00	
Support for the elderly in hygiene activities				
Yes	110 (58.2)	79 (41.8)	1.61	< 0.001
No	183 (74.1)	64 (25.9)	1.00	
Support for the elderly in ambulation				
Yes	96 (59.6)	65 (40.4)	1.42	0.010
No	197 (71.6)	78 (28.4)	1.00	
Support for the elderly in physical activities				
Yes	63 (49.2)	65 (50.8)	2.01	< 0.001
No	230 (74.7)	78 (25.3)	1.00	
Support for the elderly in cultural activities				
Yes	38 (34.9)	71 (65.1)	2.96	< 0.001
No	255 (78.0)	72 (22.0)	1.00	
Support for the elderly in family integration activities				
Yes	43 (36.4)	75 (63.6)	2.97	< 0.001
No	250 (78.6)	68 (21.4)	1.00	
Support for the elderly in medication administration				
Yes	228 (63.5)	131 (36.5)	2.34	< 0.001
No	65 (84.4)	12 (15.6)	1.00	

PR_{crude}: Crude prevalence ratio

Table 4. Factors associated with caregiver burden in family caregivers of elderly individuals with dementia. Hierarchical Poisson regression model (N=436). Montes Claros, MG, 2019.

Variables	$PR_{Ajusted}$	C.I 95%	p-value
Distal level			
Caregiver's Age (years)			
60 years or older	1.16	0.96-1.25	0.122
40 to 59 years	1.20	1.02-1.39	0.013
<40 years	1.00		
Marital Status			
With partner	1.18	1.02-1.36	0.025
Without partner	1.00		
Relationship			
Child/Spouse	1.16	1.01-1.33	0.040
Other	1.00	1.06-1.28	
Intermediate level			
Self-Perceived Health			
Regular/poor/bad	1.30	1.10-1.52	0.001
Good/excellent	1.00		
Medication Use			
Yes	1.24	1.06-1.45	0.008
No	1.00		
Proximal level			
Self-Care			
No	1.49	1.17-1.89	0.001
Yes	1.00		
Support for cultural activities			
Yes	1.36	1.08-1.72	0.012
No	1.00		
Support for family integration			
Yes	1.41	1.05-1.89	0.023
No	1.00		
Supports the elderly in medication administration			
Yes	1.13	1.01-1.25	0.027
No	1.00		

$PR_{Ajusted}$: Adjusted prevalence ratio; IC: confidence interval; Deviance:188; 759 p= 0.446

DISCUSSIONS

Among caregivers, a high prevalence of work overload was observed. This finding is similar when compared to the results of a nationwide study involving caregivers of elderly individuals with dementia, which used the same ZBI classification[4], and it differs only slightly from an international investigation involving 340 caregivers that also utilized the same instrument[11].

Considering that cases of dementia have been increasing worldwide, a high prevalence of caregiver burden becomes a significant and concerning issue that deserves attention for this population, as they are at risk of developing health issues. Prolonged stress caused by the continuous provision of care leads caregivers to devalue their own needs and neglect self-care, resulting in illnesses and ultimately in neglect in providing care[4,12,13] and early institutionalization of the care recipient[14].

In this study, various factors were associated with caregiver burden, ranging from demographic characteristics and the caregiver's health conditions to the support provided to the elderly person. Regarding health conditions, it was observed that caregivers who reported not engaging in self-care, those with a perception of regular or poor health, and those who used medications had a significantly higher prevalence of caregiver burden compared to those in better health. Other studies also demonstrate a close relationship between the caregiver's health and caregiver burden. Family caregivers with a more negative self-perception of health showed a high caregiver burden[3,15]. Another study that assessed caregiving associated with caregiver burden found that the caregiver's perception of their health was strongly associated with burden, being higher in individuals who reported a poor perception of their health compared to those who reported good or fair health[11].

To provide proper care for the elderly person, it is expected that the caregiver is in good health. However, more than one-third of the caregivers reported an unsatisfactory self-perception of their health, which can compromise their ability to perform their caregiving duties. An investigation involving family caregivers of Alzheimer's patients in Andalusia, Spain, also showed that perceived health is poor and caregiver burden is high among family caregivers[3].

The caregiving activity can bring benefits and positive outcomes, but there is a high rate of burden resulting from emotional stress, physical strain, and health issues, as well as restrictions on social and leisure activities[16]. A national study revealed that chronic stress caused by the role of caring for elderly individuals with dementia exacerbates deficits in attention, working memory, and executive function, compared to non-caregivers[17].

Participants in this study who reported not engaging in self-care had a higher prevalence of burden compared to those who reported engaging in self-care. In a study conducted in Colombia, caregivers who gave up some of their sports, cultural, leisure, and even work activities had five times the burden of those who did not give up their activities to take on the caregiving role[11].

Caregivers who reported using medications had a higher prevalence of burden when compared to those who did not use medications[7]. This result also reinforces the influence of health conditions on caregiving-related burden, as it can be inferred that caregivers who use medications have compromised health, which, in turn, impacts their ability to perform work-related activities[18,19].

The association between caregiver burden and the age group of caregivers, which represents a transition from adulthood to old age, has been reported in other studies discussing the fact that individuals who should be recipients of care end up becoming caregivers for their family members[11,20]. Considering that aging comes with increased limitations and reduced functional capacity, the involvement of individuals closer to old age may hinder their ability to perform their caregiving role or make it more challenging for these caregivers[21]. The presence of caregivers in this transitional stage can negatively impact their ability to perform their duties and compromise the quality of care provided to more dependent elderly individuals4. Since caregivers of elderly people are often exposed to stressful situations, are also rights holders, and require attention in risk prevention programs related to caregiving[4], it is expected that caregivers of older elderly individuals face greater challenges in performing their caregiving role[22].

It was observed that the prevalence of caregiver burden among individuals aged 40 to 59 years was significantly higher compared to caregivers below the age of 40. However, this was not observed among caregivers aged 60 and above. A national study revealed a high level of caregiver burden among informal caregivers who were young adults caring for dependent elderly individuals[23]. Higher caregiver burden associated with a younger age of the caregiver has also been demonstrated in international studies[8,24]. This can be justified by the accumulation of roles. Caregiver burden was higher among younger family caregivers, especially those who lived with the elderly person with dementia and had other family obligations[14].

As indicated by the results of this study, caregivers with a partner exhibited a higher caregiver burden when compared to caregivers without a partner. This finding is consistent with previous studies[16,24]. While the marital situation "with a partner" can be positive for the caregiver by representing support for their activities, on the other hand, it can have negative consequences as it overburdens the caregiver due to the accumulation of tasks[25,26]. A national study with informal caregivers of dependent elderly individuals revealed that caregiver burden was higher among spouses[15]. A population-based study conducted in Singapore with informal caregivers of elderly individuals with dementia found a 2.4 times higher risk of caregiver burden among married caregivers compared to those who were single. According to the authors, a possible explanation for the association of caregiver burden among married individuals is that spouses often express more distress and feelings of burden when they are solely responsible for caregiving[16].

Another finding of this study was the association between the caregiver's degree of kinship (spouse, child) and the presence of higher caregiver burden. One possible explanation for this result is that both spouses and children may perceive caregiving as an "obligation," a responsibility, which in turn makes caregiving more exhausting. In a similar manner to this study, previous research has demonstrated this association, which also included elderly individuals with dementia[16,27,28].

While not the focus of this study, it is relevant to highlight that the literature records differences in caregiver burden between children and spouses. Spouses and adult children experience dementia caregiving differently, which can be explained by the younger age of adult caregivers, the frequency of contact with the care recipient, differences in the characteristics of the care recipient, the frequency of neuropsychiatric symptoms, and the severity of the disease[29]. Research on differences between spouse caregivers and adult children has shown that spouse caregivers are more likely to report more depressive symptoms, overall health deficits, greater financial burden, and physical difficulty managing their responsibilities. This difference can be attributed to the older age and reduced physical health of spouse caregivers (who may be more affected by health problems), as well as the possibility of a spouse residing in the same household as the person with dementia and the greater burden of continuous caregiving that another adult caregiver would typically not experience[30].

Adult child caregivers and spouses also respond differently to the presence of various types of social support[31]. Support for adult children caregivers should aim to provide psychoeducation for complicated neuropsychiatric symptoms in the care recipient. Spouses may benefit from interventions that focus on increasing social support, while adult child caregivers may benefit from interventions aimed at alleviating caregiver burden and improving quality of life[29]. Adult child caregivers reported more rewards from their caregiving role than spouse caregivers[30].

Regarding the finding of caregiver burden and their support for the dementia patient in family integration and cultural activities, no studies addressing such associations were identified. One important aspect to consider is the family bonds with the elderly person. It's essential to recognize that these bonds are developed over years of living together, and the way these relationships have evolved throughout life can have an impact on how the support network is established when the individual becomes dependent[32]. Providing support for them in cultural and family integration activities can be challenging and very draining for the caregiver because they not only have to provide care for the person under their responsibility but also manage the complex interactions of family and social bonds for that individual, along with other more practical aspects like transportation, among others. Additionally, these activities can cause discomfort and disrupt the caregiving routine[33]. In this regard, offering support in family integration and cultural activities are complex caregiving tasks that require more mental effort from the caregiver as they involve planning and constant supervision.

Further related to this situation, often hidden within families, there are other factors that may be associated with caregiver burden in supporting the elderly person with dementia in family and cultural integration activities. The following considerations can be outlined: the absence of shared responsibility among family members in caregiving, lack of financial support from other relatives, and the presence of illness and/or comorbidities among other family members. Since these considerations were not addressed in this study, they should be the subject of future investigations.

The caregiver burden associated with support in medication administration for the elderly person with dementia can be explained by the fact that medication administration is one of the caregiver's ongoing responsibilities, meaning it's another task they cannot delegate and one that requires a lot of attention and precision. Elderly individuals often have multiple chronic diseases, require various medications, have more difficulty adhering to therapeutic regimens, and are more vulnerable to the adverse effects of drugs. Therefore, managing these patients is much more complex[34]. The caregiver's high demand, coupled with a limited support network, can lead to difficulties in adequately supporting the caregiver in medication administration, potentially leading to forgetting to administer the medication, confusion, and overmedication of the elderly person.

Some limitations of this study should be considered. It is a cross-sectional investigation, which does not allow for causal inferences between caregiver burden and the evaluated independent variables. Some aspects related to caregivers were not assessed but may be relevant in the context of burden, such as their functionality. Similarly, there was no distinct evaluation considering the types of dementia or its severity (mild, moderate, and severe) because the classification of dementia severity was not a systematic practice for all medical professionals in the institution. Additionally, the selection of the evaluated group was made based on the elderly care service, utilizing the appointments for medical consultations, which could represent a significant difference compared to caregivers randomly allocated in their own homes.

Despite these limitations, this study has the merit of assessing a large sample thoroughly, considering socioeconomic, clinical, self-care, and caregiving aspects and their implications for burden among caregivers of elderly individuals with dementia. There are few national studies on this topic. All instruments used for data collection were validated and adapted to Brazilian culture and administered by a specially trained team.

CONCLUSION

This study revealed a significant prevalence of workload burden among caregivers of elderly individuals with dementia. The factors associated with burden were age, marital status, the degree of kinship with the elderly individuals, self-perceived health, medication use, self-care, and support for cultural activities, family integration, and medication administration in the elderly individuals.

This high prevalence of burden among caregivers of elderly individuals highlights the need for specific policies for this group and represents an aspect that should be regularly assessed by healthcare professionals who work directly with people with dementia and their families.

It is essential to recognize that the importance of caring for elderly individuals with dementia should not be limited to the family environment but should extend to society as a whole. Society should encourage the government to implement specific public policies that operate in a coordinated, integrated, and intersectoral manner, including informal caregivers as key players in the care assistance model. This model should primarily ensure human dignity for those providing care.

AUTHORSHIP

- Mariza Alves Barbosa Teles – Conception and design, data analysis and interpretation, article writing, critical review, and approval of the final version to be published.

- Mirna Rossi Barbosa-Medeiros – Data analysis and interpretation, article writing, critical review, and approval of the final version to be published.

- Lucineia de Pinho – Conception and design, data analysis and interpretation, critical review, and approval of the final version to be published.
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