Original Article

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Assessment of burden on caregivers of elderly people in a home environment

Avaliação da sobrecarga de cuidadores de pessoas idosas em ambiente domiciliar

Joicielly França Bispo[1]
ORCID: https://orcid.org/0000-0001-9701-8968

Andrezza Marques Duque[2]
ORCID: https://orcid.org/0000-0002-8775-1565

Resumo
Introdução: Cuidar de alguém sem nenhum tipo de apoio pode gerar sobrecarga, sobretudo pelo cuidado realizado de maneira intensa. **Objetivo:** Investigar a sobrecarga de cuidadores de pessoas idosas em ambiente domiciliar. **Materiais e métodos:** Trata-se de um estudo quantitativo descritivo com corte transversal realizado com cuidadores de pessoas idosas em domicílio vinculados a uma unidade de saúde da família localizada num bairro de Aracaju, Sergipe. Os instrumentos utilizados para a coleta de dados foram: Formulário Sociodemográfico; Escala de Katz - Avaliação das Atividades Básicas de Vida Diária e Inventário de Sobrecarga do Cuidador (ISC). Os dados foram tabulados e digitados em planilhas do Microsoft Excel® e analisados mediante uma estatística descritiva por meio do software BioEstat® versão 5.3. **Resultados:** Os resultados indicaram um perfil de cuidadores composto majoritariamente por mulheres (88,46%), casadas ou em união estável (53,85%), autodeclaradas pretas ou pardas (73,08%), com algum grau de parentesco (80,77%) e que residiam com a pessoa idosa (73,08%). Foi evidenciada uma fragilidade no perfil de saúde física e mental dos cuidadores, bem como uma maior sobrecarga nas médias referentes ao domínio tempo dependente (16,3±2,8), vida pessoal (9,0±5,7) e sobrecarga física (9,0±5,7). **Conclusão:** A sobrecarga estava presente e pode estar relacionada com o processo de cuidar que repercute na saúde dos cuidadores. Ressalta-se a necessidade de se discutir acerca da formação de uma atenção à saúde do cuidador que promova uma melhor qualidade de vida para os cuidadores, em essencial, os familiares.
Palavras-chave: Cuidador. Exaustão do cuidador. Pessoa idosa.

Abstract
Introduction: Caring for someone without any type of support can lead to burden, especially due to the intensity of the care provided. **Objective:** To investigate the burden on caregivers of elderly people in a home environment. **Materials and methods:** This is a quantitative, descriptive cross-sectional study carried out with caregivers of elderly people at home linked to a family health unit located in a neighborhood of Aracaju, Sergipe. The instruments used for data collection were: a) Sociodemographic Form; b) Katz Index of Independence in Activities of Daily Living and c) Caregiver Burden Inventory (CBI). The data were tabulated and entered into Microsoft Excel® spreadsheets and analyzed using descriptive statistics using the BioEstat® software version 5.3. **Results:** The results indicated a caregiver profile composed mainly of women (88.46%), married or in a stable relationship (53.85%), self-declared black or mixed race (73.08%), with some degree of kinship (80.77%) and living with the elderly person (73.08%). A fragility in the physical and mental health profile of caregivers was evidenced, as well as a higher burden in the averages related to the time-dependent domain (16.3±2.8), personal life (9.0±5.7) and physical burden (9.0±5.7). **Conclusion:** Burden was present and may be related to the caregiving process, which affects the caregivers' health. It is noteworthy the need to discuss the development of caregiver health care that promotes a better quality of life for caregivers, especially family members.
Keywords: Caregiver. Caregiver exhaustion. Elderly.

Introduction

The number and proportion of people aged 60 and over has been steadily

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[1] Enfermeira graduada pelo Centro Universitário de Maceió - UNIMA. Especialista em Saúde da Família pela Universidade Federal de Sergipe - UFS, São Cristóvão, SE, Brasil. E-mail: joiciellyfbispo@gmail.com

[2]. Professora Associada do Departamento de Terapia Ocupacional e do Programa de Pós – Graduação em Gerontologia - Universidade Federal de Pernambuco - UFPE, Recife, PE, Brasil. E-mail: andrezza.duque@ufpe.br

increasing. According to the Pan American Health Organization (PAHO), by the end of 2030, the number of people over 60 will be 34% higher, reaching 1.4 billion compared to 1 billion recorded in 2019. By 2050, this figure will have more than doubled, with 2.1 billion older adults[1]. The results of the most recent 2022 Demographic Census show that, in Brazil, the elderly population represents 15.8% of the total population, corresponding to 32,113,490 individuals, with an increase of 56% compared to the 2010 census[2].

As a consequence of this rapid aging process, and concomitantly, there has been an increase in various health conditions in this population, especially chronic diseases. In Brazil, demographic transition is still occurring simultaneously with an epidemiological transition. That is, in addition to the aging of the Brazilian population, there is a decrease in acute conditions and a relative increase in chronic conditions. This situation leads to rising healthcare service costs due to the need for high-cost technologies[3].

Thus, it is very common that, after stabilization of a pathological condition, chronic-degenerative diseases can be continuously treated at home. Home Care (HC) aims to restructure the work process of teams that provide home assistance within primary care, outpatient care, emergency and urgent care services, and hospitals. HC seeks to reduce the demand for hospital care as well as the length of hospital stays, thereby increasing the humanization of care, deinstitutionalization, and user autonomy[4].

HC is organized into three modalities: HC1, HC2, and HC3. The type of modality is defined according to the specific care needs of each case, the frequency of home visits, the intensity of multiprofessional care, and the use of equipment. Within the scope of primary care, teams carry out actions under the HC1 modality, through periodic home follow-up according to the specific needs of each case, and must rely on support from the Family Health Support Centers (*Núcleos de Apoio à Saúde da Família*, or NASF), specialty outpatient clinics, and rehabilitation centers[5].

For HC to take place, the presence of a caregiver at home is essential. According to Ordinance No. 963 of May 27, 2013, a caregiver can be defined as a person with or without a family relationship to the patient, who is trained and prepared to assist them with their needs and activities of daily living[4]. This caregiver can also be classified as formal or informal.

The formal caregiver is a professional who provides care at home for payment. The informal caregiver, considered the most common, is a family or community member who often, without preparation, provides care voluntarily and without any remuneration. The choice of an informal caregiver may be related to the degree of kinship, gender, and physical and emotional closeness. In most cases, care is provided by a single family member, who is regarded as the primary caregiver[6].

Often, without any type of support to assist them in their tasks, the primary caregiver ends up experiencing intense burden, since they perform their role in an accentuated and continuous way. This is evidenced in studies that highlight how caring for someone uninterruptedly can affect psychological and physical functions, social aspects, and even finances[7,8].

In this context, this study aimed to identify the level of dependence of older adults in the home environment and the burden of their caregivers. The hypothesis was that caregivers of these older adults would present some burden in physical, mental, and social aspects that could affect both their own health and the quality of the care provided to the person being cared for.

Materials and Methods

This is a quantitative, descriptive, cross-sectional study carried out in households linked to a Primary Health Care Unit (*Unidade Básica de Saúde*, or UBS) in

Aracaju, state of Sergipe. Formal or informal caregivers aged 18 years or older, of both sexes, of older adults living at home with some mobility difficulties and/or bedridden in a home environment were included. Those not considered the primary caregiver were excluded. In this study, the primary caregiver was defined as the person solely responsible for providing care, regarded as the reference caregiver[6]. The final sample consisted of 26 primary caregivers of 27 older adult participants.

Data collection was carried out in a single stage between January and March 2023, in which the researcher visited the homes of older adults, accompanied by a community health worker (CHW), to apply three instruments. The instruments used for data collection were: a) Sociodemographic and Health Conditions Form, developed by the researchers themselves; b) Katz Index of Independence in Activities of Daily Living[9]; and c) Caregiver Burden Inventory (CBI), which consists of 24 closed-ended questions assessing caregiver burden. The questions are divided into five domains: time-dependent burden; personal life burden; physical burden; social burden; and emotional burden[10].

It is important to emphasize that participants' privacy was respected through the confidentiality of the research by not identifying the caregiver, conducting the interview in a safe location, and providing the opportunity to withdraw at any time if they deemed necessary.

The study data were tabulated and entered into Microsoft Excel® spreadsheets, version 2016. For data analysis, descriptive statistics were performed using BioEstat® software version 5.3, with frequencies and percentages for qualitative variables and means as a measure of central tendency for quantitative variables.

This research followed all ethical principles with approval from the Research Ethics Committee under opinion no. 5.807.295, and consent and authorization of participants through the signing of the Informed Consent Form. All guidelines and regulatory standards for research involving human beings of the National Health Council were respected, according to Resolution no. 466 of December 12, 2012[11].

Results

Among the 27 older adults living at home, 70.37% were female, 48.15% were between 75 and 89 years old, with a mean age of 83.3 (±10.0) years, ranging from 64 to 99 years. Almost all (96.30%) were classified as highly dependent in basic activities of daily living (Table 1).

Table 1 – Profile of older adults in a home environment linked to a Primary Health Care Unit in Aracaju, Sergipe, 2023.

Variables	n (%)
Age group	
60 to 74 years	5 (18.52)
75 to 89 years	13 (48.15)
90 years or older	9 (33.33)
Sex	
Male	8 (29.63)
Female	19 (70.37)
Independence in activities of daily living	
Independent	1 (3.70)
Moderate dependence	0 (0.0)
Highly dependent	26 (96.30)
Total	27 (100)

Source: Prepared by the researchers based on the study database.

Regarding the 26 caregivers interviewed, 42.31% were between 40 and 59 years old, with a mean age of 53.3 (±14.3) years, ranging from 27 to 78 years. Female participants represented 88.46%, 53.85% were married or in a stable relationship, 73.08% self-identified as black or mixed-race, and 84.62% followed the Catholic religion. As for education, 73.08% had completed high school, and 50.0% had a monthly family income between one and three minimum wages (Table 2).

About 80% had some degree of kinship with the older adult, of which 63.64% were sons/daughters, and 73.08% lived with them. A total of 19.23% had no kinship, characterizing them as formal caregivers. Regarding their role, only 23.08% had another job besides caregiving. All caregivers worked an average of 21 (±6.3) hours per day and had been caring for the older adult for an average of 5.10 (±4.80) years. It was also found that almost all (96.15%) received home care through the Family Health Strategy (*Estratégia da Saúde da Família*, or ESF). Nevertheless, 61.54% reported not having received guidance on how to care for the older adult (Table 2).

Table 2 – Profile of caregivers of older adults in a home environment linked to a Primary Health Care Unit in Aracaju, Sergipe, 2023.

Variables	n (%)
Age group	
18 to 39 years	5 (19.23)
40 to 59 years	11 (42.31)
60 years or older	10 (38.46)
Sex	
Male	3 (11.54)
Female	23 (88.46)
Marital status	
Single	7 (26.92)
Married/Stable relationship	14 (53.85)
Widowed	1 (3.85)
Divorced/separated	4 (15.38)
Self-declared race/color	
Black/mixed-race	19 (73.08)
Asian/white	7 (26.92)
Religion	
Catholic	22 (84.62)
Evangelical	1 (3.85)
Spiritist	1 (3.85)
Other	1 (3.85)
No religion	1 (3.85)
Education level	
Incomplete elementary school	6 (23.08)
Complete high school	19 (73.08)
Incomplete high school	1 (3.85)
Monthly family income in minimum wages	
Between 1 and 3	13 (50.0)
4 or more	12 (46.15)
No response	1 (3.85)
Kinship with older adult	
Yes	21 (80.77)
No	5 (19.23)
Degree of kinship with older adult[1]	
Son/daughter	14 (63.64)
Husband/wife	5 (22.73)
Son-in-law/daughter-in-law	1 (4.55)
Nephew/niece	2 (9.09)
Lives with older adult	
Yes	19 (73.08)
No	7 (26.92)
Has another job besides caregiving	

Variables	**n (%)**
Yes	6 (23.08)
No	20 (76.92)
Receives home care from ESF	
Yes	25 (96.15)
No	1 (3.85)
Received caregiving guidance	
From ESF	2 (7.69)
No	16 (61.54)
Other	8 (30.77)
Total	26 (100)

Source: Prepared by the researchers based on the study database.
[1]For this variable, the total number of caregiver responses was considered.

Regarding mental health, 23.08% had previously undergone some type of mental health treatment, 71.43% of them with psychological follow-up, with a mean treatment duration of 13.7 (±8.6) months. At the time of the interview, 50% reported having mental health complaints. Among these, 81.25% reported symptoms suggestive of anxiety and 12.50% of depression, and all had presented such complaints for more than one year. Despite this, only 15.38% had a history of or were currently using psychotropic medications, among them antidepressants (54.55%) followed by anxiolytics (27.27%), with predominant use lasting between one and four years (50%) (Table 3).

Regarding physical health, 70.37% of caregivers reported having some clinical condition, the most prevalent being related to the circulatory and cardiovascular system (42.42%), followed by hormonal and endocrine (24.24%), and musculoskeletal (15.15%). It was also found that 42.31% of respondents practiced some type of physical activity, averaging 3.3 (±1.4) days per week. Only 38.46% engaged in leisure activities (Table 3).

Table 3 – Health profile of caregivers of older adults in a home environment linked to a Primary Health Care Unit in Aracaju, Sergipe, 2023.

Variables	**n (%)**
Previous mental health treatment	
Yes	6 (23.08)
No	20 (76.92)
Type of previous mental health treatment[1]	
Psychological follow-up	5 (71.43)
Psychiatric follow-up	2 (28.57)
Current mental health complaint	
Yes	13 (50.0)
No	13 (50.0)
Type of current mental health complaint[1]	
Anxiety	13 (81.25)
Depression	2 (12.50)
Insomnia	1 (6.25)
Duration of current mental health complaint[1]	
Between 1 and 4 years	5 (50.0)
5 years or more	5 (50.0)
Current use of psychotropic medication	
Yes	4 (15.38)
No	22 (84.62)
Type of psychotropic medication (previous and/or current)[1]	
Anxiolytics - benzodiazepines	3 (27.27)
Antidepressants	6 (54.55)

Variables	**n (%)**
Anticonvulsants	1 (9.09)
Mood stabilizers	1 (9.09)
Duration of psychotropic use (previous and/or current)¹	
Less than 1 year	3 (37.50)
Between 1 and 4 years	4 (50.0)
5 years or more	1 (12.50)
Clinical condition	
Yes	19 (70.37)
No	8 (29.63)
Self-reported clinical conditions¹	
Circulatory and cardiovascular	14 (42.42)
Gastrointestinal	2 (6.06)
Genitourinary	3 (9.09)
Hormonal and endocrine	8 (24.24)
Musculoskeletal	5 (15.15)
Ophthalmologic	1 (3.03)
Practices physical activity	
Yes	11 (42.31)
No	15 (57.69)
Engages in leisure activities	
Yes	10 (38.46)
No	16 (61.54)
Total	26 (100)

Source: Prepared by the researchers based on the study database.

¹For these variables, only the total number of responses provided by caregivers was considered.

Regarding caregiver burden, higher burden was observed in the time-dependent domain, with a mean of 16.3 (±2.8), followed by the personal life and physical burden domains, both with a mean of 9.0 (±5.7).

Table 4 – Burden of older adults caregivers in a home environment of a Primary Health Care Unit in Aracaju, Sergipe, 2023.

Domains	**Total score**
Domain 1: Time-dependent burden M±SD¹ (16.3±2.8) Min–Max² (8–20)	
The person I care for needs my help to perform many daily activities	96
The person I care for is dependent on me	96
I have to be constantly attentive to the person dult I care for	96
I have to help the person I care for in many basic functions	97
I do not have a minute of rest in my caregiving work	38
Domain 2: Burden on personal life M±SD (9.0±5.7) Min–Max (0–17)	
I feel that I am no longer living my own life	54
I would like to be able to get out of this situation	45
My social life has been impaired	46
I feel emotionally exhausted from caring for this person	36
I expected things to be different at this point in my life	53
Domain 3: Physical burden M±SD (9.0±5.7) Min–Max (0–20)	
I am not getting enough sleep	50
My health has been impaired	46
Caring for this person has made me physically ill	43
I am physically tired	52
Domain 4: Social burden M±SD (6.1±4.8) Min–Max (0–16)	
I do not get along with other family members as well as I used to	27
My caregiving actions are not valued by other family members	32
I have had problems in my relationship with my partner	16
I have not been working as well as I used to (outside or inside the home)	33
I feel resentful toward other relatives who could help but do not	50
Domain 5: Emotional burden M±SD (1.8±2.0) Min–Max (0–7)	

I feel embarrassed/uncomfortable about the behavior of the person I care for	10
I feel ashamed of the person I care for	4
I feel resentful toward the person I care for	8
I feel uncomfortable when I receive friends	15
I get irritated in my interaction with the person I care for	9

Source: Prepared by the researchers based on the study database.

[1] Mean ± Standard Deviation

[2] Minimum and Maximum values

Discussion

This study investigated the burden of caregivers of older adults in the home environment and found that burden was present and may be related to the caregiving process, which affects caregivers' health. In the sociodemographic profile of the caregivers, the mean age was 53.3 years, and approximately 40% of the caregivers were 60 years or older, which can be explained by the increased life expectancy, occasionally allowing caregivers of different age groups, mainly older and middle-aged adults[12]. The profile of older adults was characterized mainly by females, aged between 75 and 89 years, and highly dependent in basic activities of daily living.

Other sociodemographic characteristics of the caregivers were similar to those described in previous studies, such as being predominantly women, married or in a stable relationship, self-declared black or mixed race, practicing the Catholic religion, and having a secondary level of education[13,14,15]. On the other hand, in some of these same studies, caregiver income was considered inadequate[16,17], differing from the current research, in which the majority reported a family income between one and three minimum wages. This may be explained by the diverse socioeconomic characteristics present in the neighborhood where the study was conducted, as some areas have a higher-income population compared to others with lower-income residents.

A significant number of caregivers had some degree of kinship and lived with the older adult, with more than half being the children of the older adult. This aligns with findings from other studies, which reported a higher prevalence of caregivers being the children of older adults, and predominantly female[16,17].

It is common for family members to assume the caregiving role, including children, spouses, nephews, and siblings. However, in most cases, this responsibility falls on women, which can be explained by caregiving being considered a gendered role imposed by society, requiring women to accept it as an obligation[18].

Globally, it is estimated that three-quarters of unpaid care work is the responsibility of women[19]. This societal responsibility negatively impacts women's quality of life, particularly because they sacrifice self-care to care for others, foregoing their personal and/or professional growth and life expectations[18].

It should be noted that the proportion of male caregivers is still very low compared to female caregivers. The presence of male caregivers may occur due to the unavailability of a woman or a trained person, as most men consider women the "ideal" caregivers, often resulting in a burden on a single individual performing the role[18].

This demand was observed in the present study, in which the mean daily working hours as caregivers reflected continuous dedication to caring for older adults. Worldwide, women spend on average 3.2 times more hours on this type of work than men. Furthermore, in no country do men and women perform unpaid caregiving work equally[20].

In addition to the exhaustive caregiving hours, these individuals often lack an adequate support network, and when it exists, it is usually sporadic, potentially affecting the quality of care provided to older adults. Caregivers commonly experience insecurities when facing a new context, often without proper guidance, as they need to learn about aging and the condition that made their family member dependent to provide timely care[21]. This situation was observed in this study, since, although nearly all participants reported receiving home care from the family health team, not all received professional guidance on how to care for the older adult.

Regarding mental health, a higher percentage of symptoms suggestive of anxiety, followed by depression, was observed, self-reported by caregivers, similar to findings in other studies[14,16,22]. Despite this symptomatology, only a small proportion had a history of mental health treatment, and slightly over 15% were currently using some type of psychotropic medication, with anxiolytics and antidepressants being the most prevalent.

The initiation of psychotropic medication use among caregivers may occur due to the emergence of symptoms in daily life, often seeking help only when problems have already worsened. Another factor leading caregivers to seek this treatment is the perceived benefits of the medication as a solution for sleep issues, anxiety, and depression symptoms, as well as improving caregiving conditions[23].

However, such expectations tend to decrease over time due to negative aspects, including side effects, which are the main reason for self-discontinuation. In addition, many caregivers start psychotropic medication use without any prescription and/or proper professional guidance, alternating between continuous and occasional use, depending on the presence of symptoms[23]. These factors were also reported by caregivers in the present study.

Considering that common mental suffering can result from emotional impact, social conditions, temperament, life history, and support networks, it is essential for health professionals to understand that promoting health requires acknowledging each individual's unique context[24].

Primary care teams must understand that, depending on the type of suffering or mental health impairment, medication alone is insufficient as a care strategy. When causative factors involve family, work, and/or interpersonal contexts, it is necessary to develop a therapeutic plan including other interventions[24].

Participants in this study also reported physical health conditions, with the most prevalent problems related to the circulatory and cardiovascular systems, followed by hormonal/endocrine and musculoskeletal systems, consistent with other studies[25,26].

It was also observed that just over 40% of caregivers practiced some physical activity, averaging 3.3 days per week, which aligns with the Ministry of Health recommendation of at least 150 minutes of physical activity per week[27]. This contrasts with a study of informal caregivers of frail older adults, where 78.4% did not engage in any physical activity[25].

This result may be related to the burden present in caregivers' routines, as the need to perform more tasks reduces opportunities for leisure and physical activity, potentially leading to social isolation[25]. This was observed in the current study, where less than 40% of caregivers reported engaging in leisure activities.

Studies have shown a strong association between caregiving burden and caregivers' overall health and quality of life, particularly physical and mental domains[16,28–30]. Another study found a significant association between psychotropic medication use and caregiver burden[31].

The presence of burden associated with lower caregiver quality of life has been evidenced in other studies[32,33]. Research with caregivers of older adults with dementia found that caregiver burden increased the risk of physical and psychological morbidity by 4.5 times[32]. Another study with dependent older adults reported that loss of quality of life was related to caregiving burden, highlighting the importance of assessing caregivers' health to prevent the emergence or worsening of physical and mental disorders[33].

In this study, burden associated with caregiving was also observed, mainly in the domains of time-dependent burden, personal life, and physical burden. Other studies found that physical and psychological burden were the most prevalent among caregivers[32,34–36].

The sample size and the exclusion of older adults without a primary caregiver may have limited this study. Additionally, the small number of formal caregivers prevented analysis of associations between different caregiver profiles. Nevertheless, the study contributed to identifying the profile and presence of burden among caregivers in the study area. Future research should expand to different socioeconomic contexts and regions, particularly to develop and test strategies in primary care aimed at ensuring caregivers' health.

Conclusion

Based on the data obtained in this study, it was found that the majority of caregivers were women, married or in a stable union, self-declared black or mixed race, had some degree of kinship, and lived with the older adult. In addition, the older adults were predominantly female and highly dependent in basic activities of daily living.

A fragility in the physical and mental health profile of caregivers was evident. The presence of caregiver burden was also identified across several domains, with the highest levels observed in time-dependent, personal life, and physical domains. The presence of burden may be related to the caregiving process, which impacts the sociodemographic and health profile characterized in this study, particularly regarding gender aspects, mental health, and daily caregiving hours, vulnerabilities that may facilitate or exacerbate the emergence of burden in these individuals.

Therefore, the results of this study indicate the need for a better approach to strategies related to caregivers of older adults, not only in the health sphere but also in the social context, considering factors such as economic and social conditions. In primary care, this study was essential for characterizing the profile of caregivers within the Family Health Strategy (ESF) area where the research was conducted. It is expected that understanding the sociodemographic and health specifics of this group will better sensitize health professionals regarding the importance of developing effective local strategies for this population. The lack of qualified guidance on caring for older adults was noted, despite nearly all caregivers reporting home visits from the ESF.

Finally, it is hoped that the results can guide the proposal of targeted actions for caregivers and future research addressing interventions and raising community awareness to enhance discussion about the effective development of caregiver-focused health care. Such efforts may improve knowledge about the caregiving process and promote a better quality of life for caregivers, particularly family members.

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