SAÚDE E PESQUISA
e-ISSN 2176-9206

ORIGINAL ARTICLE

https://doi.org/10.17765/2176-9206.2025v18e13135

THE CHALLENGE OF CARING FOR ANOTHER ELDERLY PERSON: EXPERIENCES OF ELDERLY CAREGIVERS

O DESAFIO DE CUIDAR DE OUTRO IDOSO: EXPERIÊNCIAS DE IDOSOS CUIDADORES

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ABSTRACT: **Objective**: To analyze the experience of elderly caregivers in caring for dependent elderly relatives. **Method**: This was a qualitative study with 10 elderly caregivers of dependent elderly relatives. A semi-structured interview was conducted and the reduced version of the Zarit Burden Scale was applied. The analysis was carried out using a thematic analysis. **Results**: Three categories emerged: 1) taking on the role of caregiver - offering and receiving care; 2) support network for caring and exercising self-care; 3) challenges of being elderly and caring for another elderly person - physical and emotional distress. With regard to burden, it was found that the majority were at the moderate to severe level. **Conclusion**: Despite the challenges faced by caregivers, many find satisfaction in caring and value the company of family members to cope with loneliness. The lack of a support network, financial difficulties, physical and emotional distress, and a lack of self-care were problems highlighted predominantly by women taking on the role of caregiver.

KEYWORDS: Elderly. Caregivers. Family. Caregiver's Burden.

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PALAVRAS-CHAVE: Elderly. Caregivers. Family. Caregiver's Burden.

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Received: 09 Sept. 2024
Accepted: 09 Nov. 2024

INTRODUCTION

In Brazil, according to the Brazilian Institute of Geography and Statistics (IBGE - *Instituto Brasileiro de Geografia e Estatística*), between 2012 and 2021 the number of people under 30 years of age fell by an average of 5.4%; on the other hand, there was an increase in the other groups above this age group, with emphasis on the elderly population.[1] This context of an increase in the number of elderly people along with the drop in fertility rates results in a society that is experiencing aging.[2]

The aging process can be seen as a natural and continuous phenomenon, which can also be linked to biological, economic and socio-cultural limitations and problems. The presence of functional decline reflects the need for a support network for elderly people who are dependent for basic or instrumental activities of daily living.[3]

Basic activities consist of the fundamental skills needed to fulfill essential physical needs, such as dressing, bathing, walking, feeding oneself, among others. Instrumental activities are those that support the basic activities of daily living, both at home and in the community, and therefore require more complex interactions, such as taking medication, driving and shopping. Loss of the ability to carry out these actions is known as frailty syndrome, which can result in increased health risks for the elderly, such as falls, hospitalization, disability, institutionalization, dependency, and death, requiring the support of a caregiver. [4]

Thus, caregivers of the elderly are family members or not who, whether paid (formal caregivers) or unpaid (informal caregivers), provide care to the elderly person, accompanying and helping them when they are unable to care for themselves due to illness, injury or incapacity.[5] Most caregivers belong to the family and face numerous challenges in providing care, as they experience physical limitations, burden, changes in their routine, and neglect of their own health in order to take on the role of caregiver. In this sense, given the demographic context described above, it has become increasingly common for caregivers of the elderly to be elderly people as well.[5]

Among the reasons why elderly people take on the role of main caregiver, the family bond stands out (which happens in more than 90% of cases), usually consisting of spouses, children or siblings who take on the position of main caregiver.[6] Although this responsibility of caring for the family member is supported by article 16, Law No. 10,741 of October 1, 2003 of the Statute of the Elderly, not all caregivers have the conditions, preparation and adequate knowledge or support to perform this role,[7] especially when it comes to elderly caregivers.

Elderly caregivers are exposed to greater health risks and a higher prevalence of chronic diseases due to the aging process, the demands of the role, and insufficient time for self-care. Thus, they need support in order to find a balance between fulfilling the role of caregiver effectively and taking care of their own health. Therefore, greater exploration of the particular vulnerabilities of this population is needed.[8]

Accordingly, it is important to shed light on the challenges of the aging process and the consequences that caring for the elderly can have on elderly caregivers. Based on the literature search, there is a need for research that can contribute to expanding knowledge and filling important scientific gaps for this public, as well as supporting the restructuring of public policies aimed at assisting their needs, since care for the elderly must be shared between the family, the State, and civil society.[6]

Given the importance of this issue, the general objective of this article is to analyze the experience of elderly caregivers in caring for dependent elderly relatives.

METHODOLOGY

This is a qualitative, descriptive and exploratory study designed in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines, carried out in three Primary Health Care (PHC) units in a medium-sized city in the interior of the state of Bahia.

For the study, 10 elderly family members who were available for direct and immediate contact were selected randomly, non-probabilistically and for convenience.

The inclusion criteria for the individuals in the study were field of study; being over 60 years old; living in the area covered by PHC services; having been the main family caregiver of another elderly person with some degree of dependency for at least six months; and not being paid. Exclusion criteria were caregivers with severe hearing and communication difficulties; and altered cognitive function assessed using the Mini-Mental State Examination (MMSE), a test used to quickly assess cognitive function, which is easy to apply and consists of 11 questions with a maximum score of 30 points. Based on these criteria, there was no exclusion.[9]

All 10 individuals interviewed met the stipulated criteria and agreed to take part in the study by signing the Informed Consent Form (ICF). Anonymity was guaranteed by the use of flower codenames. Data collection took place between February and April 2024, ending when data saturation was identified, characterized by the repetition of categories and statements, with no new topics emerging.

A Community Health Agent (CHA) accompanied the researcher to the home where the interviews were conducted, in a private place, without the presence of the elderly person being cared for, lasting approximately 25 minutes and using an audio recorder. At the end of the interviews, the statements were faithfully transcribed for later analysis.

For data collection, a questionnaire was used to characterize the sociodemographics of the elderly family caregiver, as well as a semi-structured interview with the following question to encourage narration: “Tell me about your experience caring for your elderly family member”. In addition, the burden of performing the role of caregiver was assessed by using the reduced version of the Zarit Burden Scale, made up of 7 questions with no right or wrong answers. Caregiver stress is indicated by high scores divided into three groups: up to 14 points - mild burden; 15 to 21 points - moderate burden; and above 22 points - severe burden.[10]

To analyze the data, the thematic analysis proposed by Minayo (2021),[11] which includes three stages, was used. In the pre-analysis stage, the material was explored and the results interpreted by means of a floating reading, in order to highlight the material that was congruent with the research objective. In the second stage, the material was explored and coded, helping to formulate categories. Finally, the results were processed and the information critically analyzed.

The study was developed in accordance with Resolution 466 of December 12, 2012, approved by the Human Research Ethics Committee of the Institute of Health Sciences of the Federal University of Bahia (IMS-UFBA) (opinion number: 5.937.167 and CAAE: 66914023.1.0000.5556).

RESULTS

Among the 10 elderly people who were interviewed, it was found that the average time they had been the main caregiver for their elderly relative was approximately 11 years. With regard to responsibility and kinship with the family member, 1 of the interviewees reported caring for two elderly

family members (spouse and sibling); the others cared for one family member; the majority of caregivers were spouses (n=05) or children (n=04); and only 1 interviewee cared for an elderly sibling (Table 1).

Table 1 - Characterization of the family caregiver of a dependent elderly person. Brazil, 2024 (N=10).

Variable	n	Mean (SD)	Min-Max*
Age of the caregiver (years)		70 (5,7)	62-81
60-69	5		
70-79	4		
80-89	1		
Age of the elderly cared for (years)**		82 (13,4)	64-102
60-69	3		
70-79	2		
80-89	2		
90-99	3		
100 and over	1		
Sex of the caregiver			
Male	3		
Female	7		
Marital status of the caregiver			
Married	6		
Single/Separated/Widow(er)	4		
Education of the caregiver			
Up to elementary school	6		
Illiterate	4		
Comorbidity of the caregiver			
Yes	6		
No	4		
Has care assistance			
Yes	3		
No	7		
Kinship with the elderly cared for **			
Spouse	5		
Sibling	1		
Child	4		
Caregiver burden level ***			
Mild	2		
Moderate	4		
Severe	4		

SD - Standard Deviation. * Minimum and maximum values. ** One family member cares for more than one elderly person. *** According to the reduced version of the Zarit Scale.

The average age of the caregivers was 70, ranging from 62 to 81; the majority were married (n=6), female (n=7), with up to elementary school education (n=6). Regarding the health conditions of the caregivers, 6 of them had some comorbidity, including hypertension, diabetes mellitus, erysipelas, and a brain tumor. The majority (n=7) did not receive regular help to care for their relative. The average age of the elderly being cared for was 82 years old, ranging from 64 to 102 years old.

When assessing the burden of elderly caregivers by applying the reduced version of the Zarit Scale,[10] it was found that the majority (n=8) fell into the moderate to severe range.

The analysis of the statements about the experience of elderly family members in caring for another elderly person in a condition of physical dependence made it possible to classify the results into three categories: 1) taking on the role of caregiver - offering and receiving care; 2) support network for caring and exercising self-care; 3) challenges of being elderly and caring for another elderly person - physical and emotional distress.

CATEGORY 1: TAKING ON THE ROLE OF CAREGIVER - OFFERING AND RECEIVING CARE

The motivational aspect of caring for dependent elderly family members was identified as being related to the need to return the care received over the course of their lives, which was mainly observed in bonds with parents. This characteristic stood out as a facilitating and motivating aspect for care.

> [...] We love our family, she is my mother, she has looked after us all our lives, so we look after her too. We have always lived together, always looking after each other, I have always been a caregiver; now that she is older, we have to look after her. (Rose)

> [...] My sister died and I came here to look after my mother. She was sad and it was difficult to look after her. My mother is nice, she keeps me company, she stays with me all day while I do things. She does not complain about anything. We watch TV together. I have always been a caregiver, and she is my mother, I take care of her with love, I have to. (Daisy)

The act of caring goes beyond practical tasks, it involves an emotional commitment to companionship and concern for well-being. There is resilience and love within family relationships, even with all the difficulties and challenges associated with caring for a dependent elderly member. Mutual care represents a vital bond that unites and strengthens family members' emotional ties.

> [...] That is how it is, we take care of each other, it has always been like that; but now that she is like this, I have to manage what she cannot do. She does her own things and I keep an eye on her, I have adapted the bathroom for her, [...] then I have to give her a shower. She goes to bed, eats. [...] There are people who, when this happens, throw their relative into a nursing home, but not us, we look after each other. It is difficult, but we do not do that. (Lavender)

> [...] There is just me and her, we have to take care of each other, I take care of her, but she helps me as much as she can. [...] I do the housework, I give her medicine, I help her with the chores, but she manages to take a shower, eat, go to bed; I do more of the housework, the market, and I accompany her, you know, you cannot leave her without doing things because of her head, she has to do what she can. (Orchid)

CATEGORY 2: SUPPORT NETWORK FOR CARING AND EXERCISING SELF-CARE

When caring for a dependent elderly person, the family plays a fundamental role. Collaboration and the division of tasks help to reduce the caregiver's burden, allowing them to attend to their own needs as well. However, only three caregivers reported the regular participation of family members in caring for the dependent elderly person when the main caregiver was unable to do so.

> [...] The family is united, and everyone is united, so we help each other with everything. If my sister is not available at the time, I go. There is my other sister too, who sometimes stays here, and I accompany her to the doctor. I sleep with her. So everyone does a bit, you know? [...] We are a family that has always taken care of each other. (Lily)

> [...] I am more in charge of the household, I make the food, I clean, I give her medicine, a shower, the food she can eat. My siblings help, they make some meals, they are with her when she eats, they go to the market, they help me with the medication when I need it, when I go out they stay with her. It is a rush all day, but

> when I need to do something, they stay with her for me. I take care of myself, I go to the doctor whenever I need to, I rest a bit in the afternoon. (Rose)

The role of the family caregiver is challenging, especially when faced with a lack of support and assistance from family members. The pressure to provide care alone becomes even bigger when advanced age and physical limitations become an additional factor. Another issue is the concern about disturbing another family member, especially the children who have already established another family, have jobs, projects and demands that, in the caregiver's perception, cannot be affected.

> [...] They (the children) help us when they can. But my children are all working, nobody is going to take away their freedom, you know? They are at the age to look after their children, to work. [...] They help, but we are already old and our children are not servants, you know, they have to look after their families. So there is no way they can help all the time, you know? [...] Then we have to look after each other and the house, just us. That is life... He is my husband and I have to take care of him, I love him, you know? Because our children grew up and had to live their own lives, they got married, they work, and it is just me and him. [...] We get old, but we cannot deprive them of their freedom. (Iris)

> [...] My daughter always helps with the shopping, paying the bills, taking him to the doctors, but the rest is all me, my husband cannot help me at all. My sister also helps, she lives nearby, I hardly leave the house because I have to look after him. [...] My children keep telling me that I have to look after myself because I am getting older. [...] The children left home to work, got married, so it is just me and him. (Dahlia)

> [...] Our children all got married, they all left; now I am the one who looks after him, now that he has had a stroke and has become very nervous. Everyone is married, have their jobs, everyone. (Tulip)

Financial difficulties are an additional and significant concern for family caregivers, affecting their ability to provide adequate care for dependent elderly people. Due to financial deprivation, caregivers even consider the possibility of looking for a job; however, they find it impossible because they are solely responsible for caring for the elderly family member.

> [...] She is 77, I am 62. I am the only one who takes care of her. I worked, I did not know she was going to be like this, I did not expect it, I did not expect it... If she was not like this, I would be working, but it happened, you know? [...] But thank God I am a pensioner, it is just a little, but it has been enough to pay for things in the house, except that I do not buy anything for myself, it is just to look after the house, pay for expenses, water, electricity, gas, everything is with my own money. (Lavender)

CATEGORY 3: CHALLENGES OF BEING ELDERLY AND CARING FOR ANOTHER ELDERLY PERSON - PHYSICAL AND EMOTIONAL DISTRESS

It was clear from the elderly family caregivers' comments that they were both physically and emotionally exhausted from caring. Constant worry, an overload of responsibilities, loneliness and sadness are some of the many challenges that caregivers face on a daily basis.

> [...] I am always fast-paced and worried, I am always doing something, I do not sleep properly, I am always worried about her, about the whole family. You see, it is a rush. [...] Sometimes when I put on two kilos, I lose three. When I put on three kilos, I lose it all again. [...] My health is affected, I feel tired too, my body feels tired. (Rose)

> [...] It is tiresome, we spend all day together, I do not leave the house for anything, but she is not so much work, I manage to do everything. But age makes you tired. (Daisy)

> [...] I get anxious, I do not sleep properly, I worry about his illness, I have no way of calling anyone in case something happens at night, I do not have a phone. And he does not want to take his medicine properly, so I get worried. He is my companion too, if he dies, I will be sad, I am afraid of him dying, I worry. (Azalea)

> [...] As well as looking after him, I also look after my sister, she is 87 and has hypertension. [...] But there are three of us and I do everything, it is very hard, I feel stressed. I still have to take him to and from dialysis, he gets dizzy. I feel anxious and sometimes I have insomnia, because I am the one who sorts everything out, and his stubbornness makes it difficult. (Dahlia)

Caring for an elderly person becomes even more challenging when the caregiver is also elderly and faces physical limitations and comorbidities. Many of the interviewees end up finding ways to adapt and cope with their limitations in order to continue providing the necessary care to their family member. This can lead to aggravation of their health condition and the emergence of new comorbidities.

> [...] I have a head problem, a head tumor and high blood pressure. I will have to have surgery now. [...] I try not to get stressed, because otherwise our life gets shorter, it robs us of well-being and companionship. Old age is a partner, old age changes everything, with high blood pressure, the head problem, then it changed, you know? We are only good up to the age of 50, after that we get old, problems that we did not even know we had start to appear. (Iris)

Providing care to an elderly loved one leads to significant deprivations in the life of the caregiver. The demands of caring often restrict their freedom and autonomy, preventing them from taking part in social activities and even looking after their own health and well-being. This deprivation can lead to feelings of loneliness, anxiety, depression, which negatively affects their physical and emotional state.

> [...] I feel very tired because of my legs, and sometimes I lie down to rest; he himself keeps asking me to lie down for a while because I am always going back and forth. [...] You have to do everything at the right time because of the medication, and he gets nervous. [...] Some days I do not go to church. I am afraid to go and leave him. [...] I do not do any more physical activity because he cannot be left alone; in the past I used to go out to my children's and grandchildren's houses, now I cannot even go to the neighbor's house, I am afraid. I go to the market and he stays here, I go quickly, [...] it has changed my life a lot. (Tulip).

DISCUSSION

A person's level of functional dependence makes them need continuous support from a caregiver, who is most often a family member who will provide assistance to the person who is unable to perform basic and/or instrumental activities of daily living.[12] In this sense, when it comes to caring for dependent elderly people, it is often another elderly family member who performs this task, with a higher proportion being female,[13] as can be seen in this study, in which 70% of the elderly caregivers were women.

In line with this survey, other studies have shown a predominance of women among caregivers, a reflection of the values that permeate the Western historical, cultural and social context, in which the

role of caring is attributed to women. From an early age, women are directed towards caring for the household and the family, and when a family member is ill, they are assigned the role of being the main caregiver. However, this role is added to all other demands, leading these women to burden and exhaustion.[7,14,13]

As for men, the circumstances that make them take on the role of caregiver are most often related to the exhaustion and illness of the woman who would take on this role, the lack of women in the family, or the financial difficulty to hire formal caregivers.[15] This situation reflects gender inequality in care, which leads to a greater chance of illness among female caregivers, especially when they are elderly themselves.[13]

Among the reasons why an elderly relative takes on the care of another elderly person are feelings of reciprocity, gratitude and love, as well as the emotional bonds established over the years of living together. However, there are those who take on this role due to a lack of choice, as they are the only family members who are touched by the need; based on personal values, morals and ethics, they do not abandon the elderly person, thus taking on the role of main caregiver.[15]

However, despite the strain related to the demands of caring, the caregiver feels personal satisfaction, a sense of purpose, gratitude for the opportunity to care, as well as a strengthened emotional bond,[7] as can also be seen in this study. In addition, most of the elderly people interviewed reported that caring for their loved ones helps them cope with loneliness, as they are each other's only companion.

In this context, the routine of an elderly caregiver is extremely exhausting, especially when he or she is also an elderly person and does not have a support network, since these activities require intense and continuous attention and care, generating a greater burden on the caregiver and more care time, with a direct impact on their quality of life.[14] The amount of time spent caring for the elderly and the lack of time to carry out activities of personal interest increase the burden. This is an inversely proportional relationship, in which the greater the dependence and the more time devoted to direct care of the elderly, the less time the caregiver has for self-care.[15]

In this sense, it can be seen that all these excessive demands make it difficult for elderly caregivers to prioritize self-care and activities that are pleasurable to them. As a result, they give up various aspects of their lives, such as their well-being, health care, financial resources, the exercise of spirituality and social interactions, with negative repercussions on their physical and mental health.[15,1]

This study found that 80% of elderly family caregivers had moderate and severe levels of care-related burden according to the Zarit Scale. Nevertheless, even in view of this high level of demand, some of the interviewees say they do not ask for help from other family members for fear of disrupting their routines. As a result, they end up taking on all duties, from caring for the dependent elderly person to household chores. This lack of emotional and practical support has a negative impact on the caregiver's health and well-being, increasing stress and exhaustion.[15-18]

In order to help with the demands arising from the health of the elderly, PHC services are a formal support network as they are an important support for the care of the elderly by managing and conducting a care plan through a multidimensional assessment, encouraging self-care, support from various professional specialties to the family, as well as directing the search for community resources.[4] Yet, there was no recognition or mention of this support network among the elderly people interviewed, which may be due to a lack of knowledge about the work of these units or failures in the service itself.

The support provided by the informal support network, made up of family members and friends, along with the formal support network are essential to prevent burden and damage to the physical and emotional health of the elderly caregiver.[15] According to the literature, any kind of support offered to

caregivers, even sporadically, benefits their quality of life.[12] In the present study, 70% of the elderly did not have any kind of support in the tasks they performed, which justifies the burden level they presented.

Moreover, many elderly caregivers also have limitations resulting from their own age and the presence of one or more chronic diseases that can affect their functional capacity, requiring attention and care.[17,19] A study showed that the majority of elderly caregivers who were frail had a poorer quality of life, concluding that elderly people who care for other elderly people suffer double vulnerability, as they have to deal with the health demands of the people they care for and manage their own frailty and care needs.[14] Among the caregivers interviewed in this study, 60% had one or more comorbidities, and the majority did not have support to take care of their own health.

Furthermore, another study of elderly female caregivers shows that one of their greatest concerns is related to the possibility of becoming ill or even dying and not knowing how and with whom the responsibility for caring for their elderly family member will lie,[20] a concern that is also present in some of the statements made by the elderly in this study.

Frequent reports show that most elderly caregivers suffer from insomnia and anxiety, reflecting their concerns about the illness of the elderly person they are caring for, as well as the financial difficulties they experience. The scarcity of resources and the lack of a family support network create a scenario of vulnerability that causes uncertainties and worries about the provision of care, generating stress and potentially causing numerous damages to the physical and emotional health of the caregiver.[21]

Elderly people who informally care for other elderly people are susceptible to two types of risk: the first is related to their role as caregivers, and the second stems from their own aging, which shows how much this group needs actions to support them, with a view to their well-being and to meeting their needs.[14]

The results of this study point to practical implications by revealing the need to create public policies with support strategies for elderly family caregivers in order to ease the burden of the double vulnerability they face. There is a clear need for a support and guidance network to promote the health of elderly family caregivers in order to guarantee the quality of life of this population through emotional, psychological and physical support strategies. These actions can significantly contribute to improvements in the quality of life of elderly caregivers, reducing the risk of burden and promoting healthier aging.[4]

Although the Brazilian legislation considers that caring for dependent elderly people is the responsibility of the family, of the State and of civil society, specific policies that support family caregivers are weak or non-existent, so it is also necessary to strengthen public policies to integrate them as part of the health system, valuing their demands and guaranteeing them rights and effective protection from the State.[15]

This study has limitations in that it describes the experiences of a group of elderly family caregivers from just one regional location and who have similar socio-economic backgrounds, which demonstrates the need to develop further studies that explore the subject from the reality of populations from other regions and socio-economic levels.

CONCLUSION

Despite the countless challenges faced by elderly caregivers, many feel satisfaction at being able to return the care they once received and emphasize the importance of the elderly being cared for to cope with loneliness. Most highlight the lack of a support network, financial difficulties, physical and emotional distress, limitations related to the aging process and the lack of self-care. In addition, it was found that it is mostly women who take on the role of main caregiver due to the socio-cultural context in which they are inserted.

It was clear that these elderly caregivers are overburdened. Many are unable to take a break or take care of their health, even though most of them have some form of comorbidity. The lack of a support network is a preponderant factor in the caregiver's distress, resulting in many of them losing social interaction with friends and in environments such as religious centers, generating isolation with direct damage to emotional health, perceived in reports of anxiety, insomnia and anguish.

In order to minimize these circumstances, it is necessary to strengthen a support network such as health services, social assistance, family and friends, as well as to build and strengthen public policies that meet the needs of this population. Furthermore, there is a need for further national and international research aimed at deepening our understanding of the challenges and ways of coping faced by elderly caregivers and that explores other issues such as spirituality/religiosity, financial costs of caring for elderly family members, care-related expenses, quality of life, level of anxiety, depression and psychological support.

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