

Quality of life, stress, coping and burden of caregivers of older people with Alzheimer's

Qualidade de vida, estresse, enfrentamento e sobrecarga de cuidadores de pessoas idosas com Alzheimer

Chia Chen Lin ¹
Izabela Vitória Pereira Marques ¹
Grazieli Covre da Silva ¹
Eduardo Quadros da Silva ¹
Agnes Vitória Colombari ¹
José Roberto Andrade do Nascimento Junior ²
Daniel Vicentini de Oliveira ^{1*}

¹ Universidade Cesumar (Unicesumar), Maringá, PR, Brazil

² Universidade Federal do Vale do São Francisco (UNIVASF), Petrolina, PE, Brazil

Date of first submission: October 16, 2023

Last received: May 15, 2024

Accepted: August 2, 2024

Associate editor: Mariana Asmar Alencar Collares

*Correspondence: d.vicentini@hotmail.com

Abstract

Introduction: Caring for older people with Alzheimer's disease can generate a state of prolonged stress, especially when the overload is intense, which impacts the caregiver's quality of life. **Objective:** To compare the quality of life, perception of stress, and coping strategies depending on the level of overload of caregivers of older people with Alzheimer's. **Methods:** Quantitative and cross-sectional study carried out with 126 caregivers of older people with Alzheimer's. The World Health Organization Quality of Life Bref (WHOQOL-Bref), Perceived Stress Scale, Zarit Overload Inventory, and the Problem Coping Scale were used. Data analysis was performed using the Kolmogorov-Smirnov test, bootstrapping procedures, and one-way ANOVA, followed by Tukey's posthoc. A significance of $p < 0.05$ was adopted. **Results:** Caregivers with intense burden had worse quality of life ($p < 0.001$). Caregivers without overload had less stress ($p < 0.001$) and used a problem-focused coping strategy ($p < 0.001$). **Conclusion:** The level of overload is an intervening factor in the quality of life, stress symptoms, and coping strategies of caregivers of older people with Alzheimer's Disease.

Keywords: Aging. Home Care Services. Psychological stress. Psychological adaptation.

Resumo

Introdução: O cuidado à pessoa idosa com doença de Alzheimer pode gerar um estado de estresse prolongado, principalmente quando a sobrecarga é intensa, o que impacta a qualidade de vida do cuidador. **Objetivo:** Comparar a qualidade de vida, percepção de estresse e estratégias de enfrentamento em função do nível de sobrecarga de cuidadores de pessoas idosas com Alzheimer. **Métodos:** Trata-se de um estudo quantitativo e transversal realizado com 126 cuidadores de pessoas idosas com Alzheimer. O World Health Organization Quality of Life Bref (WHOQOL-Bref), a Escala de Estresse Percebido, o Inventário de Sobrecarga de Zarit e a Escala de Modos de Enfrentamento de Problemas foram utilizados. A análise dos dados foi realizada por meio do teste de Kolmogorov-Smirnov, procedimentos de bootstrapping e Anova one-way seguida por post-hoc de Tukey. Adotou-se significância de $p < 0,05$. **Resultados:** Cuidadores com sobrecarga intensa apresentaram pior qualidade de vida ($p < 0,001$). Cuidadores sem sobrecarga apresentaram menor estresse ($p < 0,001$) e utilizavam estratégia de enfrentamento focada no problema ($p < 0,001$). **Conclusão:** O nível de sobrecarga é um fator interveniente na qualidade de vida, sintomas de estresse e estratégias de enfrentamento de cuidadores de pessoas idosas com Alzheimer.

Palavras-chave: Envelhecimento. Cuidado domiciliar. Estresse psicológico. Adaptação psicológica.

Introduction

With the aging population, an increase in age-associated chronic-degenerative diseases is anticipated, including dementia. Dementia is generally present in a neurodegenerative disease characterized by a decline in cognitive functions, such as memory loss.¹ Alzheimer's disease (AD) is the most common cause of dementia in the elderly. As it progresses, there is an increased demand for caregivers to provide the necessary support to elderly individuals with the disease.² AD, which is incurable, involves damage to neurocerebral functions such as memory and language loss, with an estimated latent phase lifespan of eight to ten years. The need for care becomes more crucial as the disease progresses.^{3,4}

As AD progresses, caregivers encounter various situations, including learning about the disease, dealing with the physical and psychological suffering of the older

adult, and experiencing feelings of guilt. These situations require caregivers to set aside their pain and needs.⁵ The caregiver is the person who assumes responsibility for primary care on a continuous or regular basis, and this individual may or may not be a family member.⁶ Furthermore, the caregiver takes on all or most care responsibilities. The reality faced by the caregiver can lead to mental and physical overload. Additionally, the lack of time for leisure and self-care directly impacts their quality of life and self-esteem, affecting the care provided to older adults.⁷ Such circumstances can result in prolonged stress, causing the caregiver to neglect their own needs and self-care, potentially leading to illness or even premature death. On the other hand, evidence suggests that caregiver overload may ultimately lead to neglect of the person being cared for.⁸

Research highlights that caregiving is a stressful task. Caregivers commonly experience feelings of "entrapment" and fatigue.⁹ Such overload can lead to the development of health issues and, consequently, the use of psychotropic medications. It is crucial to assess the overload level to make caregiving guidelines more effective.¹⁰

For caregivers, a valuable alternative to assist them in supporting elderly individuals with AD, organizing activities, and modifying relationships to prevent or reduce problems, as well as to enhance their well-being, is providing psychoeducational support.¹⁰ Similarly, prioritizing problem-solving strategies can serve as a coping mechanism. Cognitive stimulation and daily activities for older people contribute to maintaining mental health, as the caregiver manages the environment and encourages appropriate behaviors to prevent problematic behaviors. This approach tends to reduce negative perceptions related to caregiving, decrease both physical and mental overload on the caregiver, and address other stress-related issues. Consequently, it improves their quality of life, habits, social relationships, and caregiving excellence.^{1,10}

Although there is research on caregiver overload,^{11,12} a deeper understanding of how it impacts various aspects of quality of life, such as physical health, mental health, social relationships, and emotional well-being, is needed. Similarly, while research exists on coping strategies caregivers use,¹³⁻¹⁵ it is essential to identify which methods are most effective in reducing stress and improving their quality of life and understanding how these strategies can be adapted to different contexts and individuals.

Thus, it is essential to assess the quality of life, stress perception, and coping strategies of caregivers for elderly individuals with AD. Such data can support intersectoral actions, ongoing education strategies, and the formulation of public policies. Adopting a holistic and person-centered approach to care is vital, considering both the patient and the caregiver at all levels of health care. Additionally, addressing the urgent and multifaceted need for public policies focused on caregivers of elderly individuals with AD is critical. Policies that recognize and address the specific needs of caregivers, such as emotional support programs, training, and financial assistance, are essential to ensure they receive the necessary support to continue their role effectively and sustainably.

Understanding how caregivers manage stress and overload is crucial for developing effective support strategies. Given this, the aim of this study was to compare the quality of life, stress perception, and coping strategies of caregivers of elderly individuals with AD based on the level of overload experienced.

Methods

This quantitative, analytical, observational, and cross-sectional study was approved by the Research Ethics Committee of Cesumar University under the approval number 6.001.701/2023.

The non-probabilistic sample was intentionally and conveniently selected, comprising 126 formal (professional) or informal (family) caregivers of elderly individuals with AD residing in various regions of the country. Only caregivers of elderly individuals with a diagnosis of AD (reported by the caregiver) were included, regardless of gender, and aged 18 or older. Caregivers of institutionalized or hospitalized elderly individuals were excluded.

Instruments

The authors developed a questionnaire to assess the sociodemographic, health, and caregiving profiles of elderly individuals with AD. This questionnaire covered age, age group, sex, family income, educational level, retirement status, medication use, associated diseases (comorbidities), and duration of AD diagnosis. For evaluating the caregivers of these elderly individuals,

another questionnaire was employed, addressing age, age group, sex, family income, educational level, medication use, presence of diseases, duration of caregiving, daily caregiving time, and whether they live with the elderly individual or not.

The World Health Organization Quality of Life Bref (WHOQOL-Bref) was used to evaluate the caregivers' quality of life. This abbreviated version of the WHO quality of life assessment questionnaire consists of 26 questions, two addressing individual perceptions of quality of life and health, and the remaining questions divided into physical, psychological, social relationships, and environmental domains. Each domain has a score ranging from four to 20 points, with higher scores indicating better quality of life in that domain.¹⁶

The Perceived Stress Scale, with 14 questions offering responses ranging from zero to four (0 = never; 1 = rarely; 2 = sometimes; 3 = almost always; 4 = always), was used for assessing perceived stress. Positive-connotation questions (4, 5, 6, 7, 9, 10, and 13) have their scores inverted (0 = 4; 1 = 3; 2 = 2; 3 = 1; 4 = 0), while negative-connotation questions are summed directly. The total scale score ranges from zero to 56.¹⁷

The Zarit Caregiver Burden Inventory was used to assess caregiver burden. This tool evaluates caregivers' perceptions of burden, focusing on how caregiving impacts their personal, social, and financial lives and physical and mental health. It contains 22 items answered by the caregiver using a five-point Likert scale: 0 (never), 1 (rarely), 2 (sometimes), 3 (very frequently), and 4 (always). The total score can range from 0 to 88, with higher scores indicating a more significant caregiver burden.¹⁸

The Problem Coping Scale was used to identify how caregivers cope with the stressor of caregiving for an elderly individual with AD. This Likert-type questionnaire consists of 45 items reflecting thoughts and actions used to manage specific stressors, with response options: 1 = I never do this, 2 = I do this a little, 3 = I do this sometimes, 4 = I do this a lot, and 5 = I always do this.¹⁹

Data collection procedures

Quantitative data collection was conducted via an online form provided by Survey Monkey platform. Interested participants had to first agree to the online informed consent form by selecting "I agree."

The link, created to host the study questionnaires, was shared through the authors' social media channels (Facebook, Instagram, and WhatsApp). The platform for completing the questionnaires was open for responses for 90 days (from February to May 2023). Before starting the questionnaire, participants received brief instructions with information about the study's purpose, target audience, and estimated completion time (approximately 15 minutes).

Data analysis

Data analysis was conducted using SPSS 25.0 software, employing descriptive and inferential statistics. Frequency and percentage were used as descriptive measures for categorical variables. For numerical variables, data normality was assessed using the Kolmogorov-Smirnov test and skewness and kurtosis coefficients. Bootstrapping procedures (1000 resamplings; 95% BCa confidence intervals) were also performed to enhance the reliability of the results, correct for potential deviations from normality in the sample distribution, address differences in group sizes, and provide a 95% confidence interval for the means.²⁰

To compare quality of life domains, stress perception, and coping strategies based on the level of caregiver burden, one-way ANOVA followed by Tukey's post-hoc test was used. A significance level of $p < 0.05$ was adopted.

Results

The study involved 126 caregivers, both male (8) and female (118), aged between 22 and 80 years [mean (M) = 51.36; standard deviation (SD) = 10.90]. Caregivers were predominantly in the 40 to 59 age range (61.9%), had a partner (54.8%), held a bachelor's degree (60.3%), were of white ethnicity (64.2%), and had a monthly income of one to two minimum wages (42.1%). Analysis of the caregiver burden level for individuals with Alzheimer's disease (Figure 1) revealed that 52.4% (n = 66) experienced high burden, 24.6% (n = 31) experienced light burden, and 23.0% (n = 29) reported no burden.

Table 1 shows the M and SD for quality of life domains, stress perception, and coping strategies among caregivers of elderly individuals with Alzheimer's.

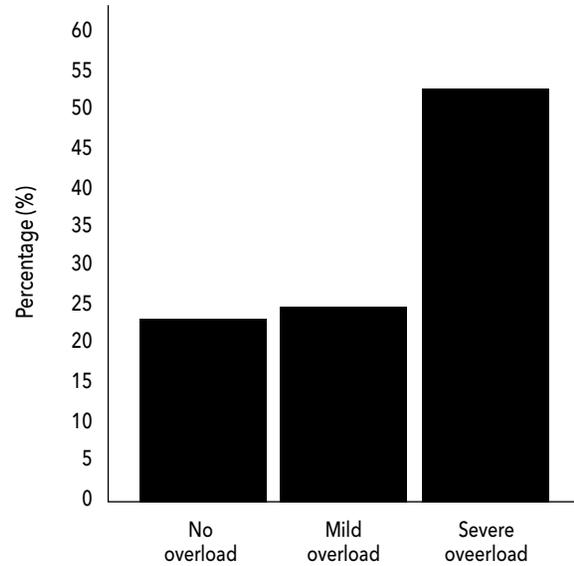


Figure 1 - Level of caregiver overload for elderly individuals with Alzheimer's disease. Brazil, 2023.

Table 1 - Descriptive analysis of quality of life domains, stress perception, and coping strategies among caregivers of older adults with Alzheimer's disease. Brazil, 2023

Variables	Mean (standard deviation)
Quality of life domains	
Physical	12.92 (3.39)
Psychological	12.37 (3.27)
Social relationships	11.89 (3.90)
Environment	12.73 (2.50)
Self-assessment	12.50 (3.42)
Stress	29.20 (10.05)
Coping strategies	
Problem-focused	64.59 (11.31)
Emotion-focused	40.35 (6.31)
Religious/Fantasy practices	23.85 (4.60)
Seeking social support	16.48 (3.47)

Regarding the quality of life, the highest score was observed in the physical domain (M = 12.92; SD = 3.39), followed by the environment domain (M = 12.73; SD = 2.50), self-assessment domain (M = 12.50; SD = 3.42), psychological domain (M = 12.37; SD = 3.27), and social relations domain (M = 11.89; SD = 3.90). The mean stress perception score was 29.20 (SD = 10.05).

Lastly, the highest average in coping strategies was found in problem-focused strategies (M = 64.59; SD = 11.31), followed by emotion-focused strategies (M = 40.35; SD = 6.31), religious practices/fantasy thinking (M = 23.85; SD = 4.60), and seeking social support (M = 16.48; SD = 3.47).

Table 2 compares caregivers' perception of quality of life based on perceived burden. Significant differences ($p < 0.001$) between groups across all quality-of-life domains were found. Notably, caregivers with intense burden reported lower mean scores in all quality of life domains than those with slight or no burden.

Table 2 - Comparison of quality of life perception among caregivers of older adults with Alzheimer's disease based on perceived level of burden. Brazil, 2023

Quality of life domains	Level of burden			p-value*
	No burden (n = 29)	Mild burden (n = 31)	Intense burden (n = 66)	
Physical	15.41 (2.48)	13.81 (2.64)	11.40 (3.28) ^a	<0.001
Psychological	15.01 (2.67)	13.29 (2.11)	10.79 (3.06) ^a	<0.001
Social relationships	14.76 (3.04)	13.46 (2.65)	9.90 (3.63) ^a	<0.001
Environment	14.34 (2.23)	13.27 (2.37)	11.77 (2.25) ^a	<0.001
Self-assessment	14.41 (2.23)	13.81 (2.60)	11.06 (3.56) ^a	<0.001

Note: Data expressed as mean (standard deviation). ^aOne-way ANOVA followed by Tukey's post-hoc test between intense burden with mild burden and no burden. *Significant difference ($p < 0.05$).

When comparing the perception of stress and coping strategies among caregivers of elderly individuals with Alzheimer's disease based on the level of perceived burden (Table 3), significant differences were found between the groups in stress perception ($p < 0.001$), problem-focused coping strategies ($p < 0.001$), emotion-focused strategies ($p = 0.003$), and religious/fantasy

thinking practices ($p = 0.021$). Notably, caregivers with no burden reported lower stress levels and higher scores in problem-focused coping strategies than those with slight or intense burdens. Additionally, caregivers with slight burdens had higher scores in emotion-focused strategies and religious/fantasy thinking practices compared to those with intense burdens.

Table 3 - Comparison of stress perception and coping strategies among caregivers of older adults with Alzheimer's disease based on perceived level of burden. Brazil, 2023.

Quality of life domains	Level of burden			p-value
	No burden (n = 29)	Mild burden (n = 31)	Intense burden (n = 66)	
Stress	20.76 (8.87) ^a	27.16 (7.41)	33.86 (8,89)	<0.001*
Coping Strategies				
Problem-focused	72.24 (10.09) ^a	64.13 (10.90)	61.44 (10,53)	<0.001*
Emotion-focused	38.97 (6.01)	37.87 (4.57) ^b	42.12 (6,67)	0.003*
Religious/Fantasy practices	22.97 (4.92)	22.42 (5.17) ^b	24.90 (3,93)	0.021*
Seeking social support	16.03 (3.04)	15.77 (3.37)	17.00 (3,65)	0.199

Note: Data expressed as mean (standard deviation). ^aOne-way ANOVA followed by Tukey's post-hoc test between burden with mild burden and intense burden; ^bOne-way ANOVA followed by Tukey's post-hoc test between mild burden with intense burden. *Significant difference ($p < 0.05$).

Discussion

The main results of the present study revealed that caregivers with an intense burden reported lower quality of life, while caregivers with no burden reported lower stress and used problem-focused coping strategies more frequently. Caregivers with a mild burden used emotion-focused coping strategies and religious/fantasy practices more often compared to caregivers with an intense burden.

Caregivers of elderly individuals with AD who experience intense overload may have a worse quality of life due to several physical, emotional, and social factors. Caring for an older adult with AD can be physically exhausting. Constant monitoring, help with daily activities, and the need to lift or move the patient can lead to physical exhaustion, resulting in a lower quality of life for the caregiver.²¹ The intense demand of caring for an older adult with AD often limits the caregiver's time and ability to maintain social relationships. Social isolation can lead to loneliness, depression, and a sense of disconnection, negatively affecting quality of life.²² It is worth noting that managing behavior changes, confusion, and forgetfulness associated with AD can be emotionally draining. Constant worry about the safety and well-being of the older adult can lead to high levels of stress and anxiety, affecting the caregiver's emotional health.

Caregivers often neglect self-care due to the demands of caring for older adults. A lack of time for exercise, proper nutrition, and rest can result in physical and mental health problems for the caregiver.^{1,23,24} Additionally, long-term care for a person with AD can be costly, and caregivers may face financial difficulties due to extra medical expenses, reduced work hours, or even complete cessation of employment.²

Many caregivers devote themselves entirely to the caregiving role, losing their identity and personal goals. This loss of autonomy and purpose outside of patient care can significantly impact the quality of life. The lack of access to support resources, such as support groups, respite services, and home help, can further overwhelm caregivers. This can result in feelings of helplessness and isolation.²⁵

We cannot forget that the older adult's ability to communicate diminishes as AD progresses, making interaction more challenging. This can cause frustration and sadness for the caregiver. Additionally, caregivers

often experience anticipatory grief as they witness the progression of AD in their loved ones. This prolonged emotional process can negatively impact the caregiver's quality of life.²⁶

According to Rebêlo et al.,²⁷ there is a correlation between overload levels and quality of life. Generally, higher overload levels are associated with lower quality of life and vice versa. This means that when someone experiences high-stress levels, excessive responsibilities, or pressures, their quality of life tends to decrease. Balancing these factors can play an essential role in the overall sense of well-being for caregivers of elderly individuals with AD.

Caring for someone, especially when it involves constant care and under stress, can lead to significant stress levels. This can affect both the physical and mental health of caregivers and impact family balance and their quality of life. Recognizing these challenges is crucial for providing the necessary support to caregivers and minimizing the adverse effects of stress.²⁸ Zhang et al.,²⁶ in an international review, pointed out that considering the quality of life of caregivers and care recipients together can potentially improve the understanding of care needs, service provision, and positive outcomes for quality of life. Queiroz et al.²⁹ reveal that the care provided to an older adult with dementia, such as in AD, affects the caregiver's quality of life, and similarly to the present study, the highest average was found in the physical domain and the lowest in social relationships.

On the other hand, this study found that caregivers without overload experienced lower stress. Caring for an older adult with AD, even without intense overload, can still be a challenging task. Still, caregivers who manage the situation in a balanced way may experience less stress than those who are overwhelmed.²⁸ This result can be explained by the fact that caregivers with access to adequate support, such as help from family, friends, or professional home care services, can share the caregiving responsibilities, reducing the pressure on a single caregiver. This reduces the stress associated with overload. Additionally, caregivers who can effectively organize and manage caregiving tasks can reduce stress. This includes establishing routines, using effective communication strategies, and ensuring the older adult can access appropriate medical services.³⁰⁻³²

Cesário et al.²⁸ found that caregivers of elderly individuals have their health conditions significantly affected, leading to a state of stress. Thus, those who do

not perceive high overload generally experience less stress. It is noted that caregivers of elderly individuals with AD who prioritize their self-care, including finding time for rest, leisure activities, and psychological support, have a better ability to cope with stress; this may include participating in support groups or counseling sessions. Similarly, those who are well-informed about AD and its implications may be better prepared to handle behavioral changes and caregiving demands. Knowledge can reduce anxiety and stress related to uncertainty.^{33,34}

Caregivers who report an absence of overload and consequently lower stress levels use problem-focused coping strategies. These strategies are employed when the consequences of a stressful situation are perceived as alterable or removable. This involves directly addressing the problem to find solutions and reduce stress.³⁵ Likely, these caregivers experience significant benefits from this approach. Problem-focused coping involves the active identification and resolution of specific challenges and difficulties related to caring for an older adult with AD. This may include establishing routines, developing effective communication strategies, and managing practical issues such as environmental safety. This pragmatic approach allows caregivers to tackle problems head-on. By actively confronting the challenges and issues associated with caring for an older adult with AD, caregivers may experience stress reduction. This happens because having some control over the situation and the ability to take concrete steps to improve the quality of life for both the older adult and the caregiver can be empowering and reassuring.^{14,36,37}

Problem-focused coping generally leads to greater effectiveness in caregiving. Identifying and addressing specific issues can improve the quality of care for older adults, offering them more comfort and safety. This, in turn, can reduce conflicts and crises, enhancing the quality of life for both the caregiver and the older adult.³⁸

It is important to emphasize that dealing with problems proactively can help prevent additional complications and difficulties in the future. By creating a safe environment and implementing behavior management strategies, for example, caregivers can avoid accidents and stressful situations. Similarly, finding solutions to caregiving challenges can provide a sense of personal achievement and competence. Caregivers who see themselves making progress and improving the situation for the older adult may experience increased personal

satisfaction and self-esteem.^{10,11} Furthermore, by addressing problems directly and effectively, caregivers can reduce conflicts with other family members, colleagues, or healthcare professionals. A solution-oriented approach can promote more effective and collaborative communication.^{39,40}

When caregivers can address issues related to the safety, communication, and well-being of the older adult with AD, the quality of life of the elderly individual can improve. This benefits both the older adult and the caregiver, resulting in fewer stress and conflict situations.⁴¹ Emotion-focused coping is commonly used when the caregiver perceives the situation as unchangeable, i.e. when they understand that the dementia condition will not reverse.^{14,38} Literature shows that caregivers of individuals with AD tend to use emotion-focused coping strategies, which are associated with reductions in anxiety, depression, and behavioral and psychological symptoms, such as stress and overload, for the caregiver.^{13,14} Abojabel et al.,³⁹ in their study with caregivers of elderly individuals with AD, concluded that neither problem-focused coping nor emotion-focused coping significantly affected caregiving overload.

In the present study, it was found that caregivers with mild overload use more emotion-focused coping strategies and religious practices/fantasy thinking compared to caregivers with intense overload. This may occur for several reasons. Caregivers with mild overload might be in the early stages of the caregiving experience when AD has not yet progressed significantly. This could mean they face fewer practical and emotional challenges than caregivers in a more advanced stage of the disease, which may reduce the need for problem-focused coping strategies. These caregivers may be able to handle the current caregiving demands without resorting to a problem-focused strategy. This might involve dealing with early symptoms of the disease, such as mild memory lapses, without needing to solve more complex problems.^{36,42}

When the overload is mild, caregivers may feel more capable of managing emotional stress through emotion-focused coping strategies. This may involve sharing their feelings with friends or family, practicing emotional expression, or seeking psychological support. Caregivers facing mild overload may use emotional coping strategies to prevent intense overload in the future, focusing on maintaining their emotional well-being to avoid burnout that can occur over time.⁷

Religious practices or fantasy thinking can provide comfort and emotional support for some caregivers. Faith and spirituality can help alleviate the stress and anxiety associated with caring for an older adult with AD, providing a sense of purpose and hope. Additionally, caring for an older adult with AD can be challenging and often requires finding meaning to cope with difficulties. Religious practices or fantasy thinking can offer a way to find a greater purpose in caregiving. In the early stages of the disease, interpersonal relationships may be less complicated and conflictual than in advanced stages. This may allow caregivers to focus more on emotional and religious strategies to cope with the situation.⁴³⁻⁴⁵

According to Barreto et al.,⁴⁶ there is a lack of studies regarding coping strategies involving religious practice and social support, as understanding the relationship between spirituality, quality of life, and depression in family caregivers of elderly individuals with dementia could help provide more comprehensive and appropriate support for these caregivers. Recognizing the risk of emotional and physical overload in this context highlights the importance of directing healthcare professionals' attention to this specific group of caregivers.

Expanding attention to caregivers of elderly individuals with AD, especially regarding spirituality, quality of life, and depression, is crucial for providing more comprehensive and practical support. Healthcare professionals should receive training on the challenges faced by caregivers of elderly individuals with AD, including awareness of spiritual and religious issues and their role in caregivers' mental health and well-being. Through workshops, seminars, and educational materials, healthcare professionals can learn strategies to address these issues sensitively and empathetically, integrating them into personalized care plans for caregivers.

Despite the significant findings, this research has limitations that must be considered when interpreting its results. One of the main limitations is selection bias, as the sample does not adequately represent the population of caregivers of elderly individuals with AD. Additionally, the nature of the study may involve subjective reports from caregivers about their quality of life, stress levels, coping strategies, and overload. This may introduce self-report bias, as participants' perceptions may influence responses and desire to present themselves favorably. Another potential limitation is the lack of control over external variables that may affect the

results. Factors such as social support, the caregivers' health conditions, financial resources, and access to healthcare services, for example, may play an essential role in caregivers' quality of life and stress but were not controlled for in the study. It is necessary to consider these limitations when interpreting and applying the study results to ensure an accurate understanding of the impact of caregiving for elderly individuals with AD on caregivers' quality of life and well-being.

Conclusion

It can be concluded that the level of overload is an intervening factor in the quality of life, stress symptoms, and coping strategies of caregivers of elderly individuals with AD. It is noted that higher overload appears to impair quality of life and trigger more stress symptoms, as well as favor the use of more emotion-focused strategies and religious practices. From a practical standpoint, healthcare professionals working with caregivers of elderly individuals with AD must be aware of the possibility of overload. Regular assessments of caregivers' overload levels are essential to identify those at risk of experiencing high levels of stress and reduced quality of life.

The results have significant practical implications. For society, it is crucial to recognize that the overload of caregivers of elderly individuals with AD negatively impacts their quality of life and increases stress symptoms. This highlights the need for community support and respite care programs to alleviate the burden on these caregivers. For healthcare professionals, it is essential to be vigilant about the possibility of caregiver overload, conduct regular assessments, and provide emotional support and access to support services. For the healthcare system, it is necessary to develop policies and programs that address the specific needs of caregivers, including respite care services and training programs. Investing in research on the impact of caregiver overload can inform resource allocation and the implementation of effective interventions.

Acknowledgments

The authors thank the Araucária Foundation for the funding received.

Authors' contributions

CCL, IVPM, GCVS, and EQS participated in the conception, design, analysis, and interpretation of the data. AVC, JRANJ, and DVO contributed to the manuscript's writing and revision. DVO supervised the work and reviewed the manuscript. All authors approved the final version.

References

1. Costa GD, Santos OG, Oliveira MAC. Conhecimento, atitudes e necessidades de qualificação de profissionais da atenção básica no atendimento às demências. *Rev Bras Enferm.* 2020; 73(Suppl 3):e20200330. [DOI](#)
2. Costa EMDMC, Lucena MM, Estrela YCA, Oliveira Neto HT, Maranhão Neto T, Brito EPR, et al. Impactos na qualidade de vida de cuidadores de idosos portadores de Alzheimer. *Braz J Hea Rev.* 2021;4(2):7726-41. [DOI](#)
3. Soria Lopez JA, González HM, Léger GC. Alzheimer's disease. *Handb Clin Neurol.* 2019;167:231-55. [DOI](#)
4. Tobbin IA, Gonçalves GHP, Costa KM, Kucmanski D, Costa JPG, Nunes PLP, et al. Doença de Alzheimer: uma revisão de literatura. *Braz J Hea Rev.* 2021;4(3):14232-44. [DOI](#)
5. Hernández-Padilla JM, Ruiz-Fernández MD, Granero-Molina J, Ortiz-Amo R, Rodríguez MML, Fernández-Sola C. Perceived health, caregiver overload and perceived social support in family caregivers of patients with Alzheimer's: Gender differences. *Health Soc Care Community.* 2021;29(4):1001-9. [DOI](#)
6. Martins G, Corrêa L, Caparrol AJS, Santos PTA, Brugnera LM, Gratão ACM. Características sociodemográficas e de saúde de cuidadores formais e informais de idosos com Doença de Alzheimer. *Esc Anna Nery.* 2019;23(2):e20180327. [DOI](#)
7. Kobayasi DY, Rodrigues RAP, Fhon JRS, Silva LM, Souza AC, Chayamiti EMPC. Sobrecarga, rede de apoio social e estresse emocional do cuidador do idoso. *Av Enferm.* 2019;37(2):140-8. [DOI](#)
8. Casal Rodríguez B, Rivera Castiñeira B, Currais Nunes L. Alzheimer's disease and the quality of life of the informal caregiver. *Rev Esp Geriatr Gerontol.* 2019;54(2):81-7. [DOI](#)
9. Mattos EBT, Kovács MJ. Doença de Alzheimer: a experiência única de cuidadores familiares. *Psicol USP.* 2020;31:e180023. [DOI](#)
10. Campos CRF, Carvalho TR, Barham EJ, Andrade LRF, Giannini AS. Entender e envolver: avaliando dois objetivos de um programa para cuidadores de idosos com Alzheimer. *Rev Psico.* 2019;50(1):e29444. [Link](#)
11. Pudelewicz A, Talarska D, Bączyk G. Burden of caregivers of patients with Alzheimer's disease. *Scand J Caring Sci.* 2019; 33(2):336-41. [DOI](#)
12. Manzini CSS, Vale FAC. Emotional disorders evidenced by Family caregivers of people with Alzheimer's disease. *Dement Neuropsychol.* 2020;14(1):56-61. [DOI](#)
13. Lloyd J, Muers J, Patterson TG, Marczak M. Self-compassion, coping strategies, and caregiver burden in caregivers of people with dementia. *Cin Gerontol.* 2019;42(1):47-59. [DOI](#)
14. Monteiro AMF, Santos RL, Kimura N, Baptista MAT, Dou-rado MCN. Coping strategies among caregivers of people with Alzheimer disease: a systematic review. *Trends Psychiatry Psychother.* 2018;40(3):258-68. [DOI](#)
15. Oliveira NA, Souza EM, Luchesi BM, Alexandre TS, Inouye K, Pavarini SCI. Elderly caregivers of other elderly living with and without children: burden, optimism and coping strategies. *Cien Saude Colet.* 2020;25(2):473-81. [DOI](#)
16. Fleck MPA, Louzada S, Xavier M, Chachamovich E, Vieira G, Santos L, et al. Aplicação da versão em português do instrumento abreviado de avaliação da qualidade de vida "WHOQOL-bref". *Rev Saude Publica.* 2000;34(2):178-83. [DOI](#)
17. Luft CDB, Sanches SO, Mazo GZ, Andrade A. Versão brasileira da Escala de Estresse Percebido: tradução e validação para idosos. *Rev Saude Publica.* 2007;41(4):606-15. [DOI](#)
18. Bianchi M, Flesch LD, Alves EVC, Batistoni SST, Neri AL. Indicadores psicométricos da Zarit Burden Interview aplicada a idosos cuidadores de outros idosos. *Rev Latino-Am Enfermagem.* 2016;24:e2835. [DOI](#)
19. Morero JAP, Bragagnollo GR, Santos MTS. Estratégias de enfrentamento: uma revisão sistemática sobre instrumentos de avaliação no contexto brasileiro. *Rev Cuid.* 2018;9(2):2257-68. [DOI](#)

20. Haukoos JS, Lewis RJ. Advanced statistics: bootstrapping confidence intervals for statistics with "difficult" distributions. *Acad Emerg Med*. 2005;12(4):360-5. DOI
21. Pinto MF, Barbosa DA, Ferreti CEL, Souza LF, Fram DS, Belasco AGS. Qualidade de vida de cuidadores de idosos com doença de Alzheimer. *Acta Paul Enferm*. 2009;22(5):652-7. DOI
22. Albuquerque FKO, Farias APEC, Montenegro CS, Lima NKF, Gerbasi HCLM. Qualidade de vida em cuidadores de idosos: uma revisão integrativa. *Rev Enferm Atual In Derme*. 2019;87(25). DOI
23. Costa AF, Lopes MCBT, Companharo CRV, Batista REA, Okuno MFP. Qualidade de vida e sobrecarga de cuidadores de idosos. *Texto Contexto Enferm*. 2020;29:e20190043. DOI
24. Costa EMDMC, Lucena MM, Estrela YCA, Oliveira Neto HT, Maranhão Neto T, Brito EPR, et al. Impactos na qualidade de vida de cuidadores de idosos portadores de Alzheimer. *Braz J Hea Rev*. 2021;4(2):7726-41. DOI
25. Andrade SMB, Marinho MS, Santana ES, Chaves RN, Oliveira AS, Reis LA. Associação entre os aspectos sociodemográficos, condições de saúde e qualidade de vida dos cuidadores de idosos dependentes. *Fisioter Bras*. 2019;20(5):603-9. DOI
26. Zhang W, Rand S, Milne A, Collins G, Silarova B. The quality of life of older carers and the people they support: An international scoping review. *Health Soc Care Community*. 2022;30(6):e3342-53. DOI
27. Rebêlo FL, Jucá MJ, Silva CMA, Santos AIB, Barbosa JVP. Fatores associados à sobrecarga e qualidade de vida de cuidadores de idosos com demência. *Estud Interdiscipl Envelhec*. 2021;26(2):275-92. DOI
28. Cesário VAC, Leal MCC, Marques APO, Claudino KA. Stress and quality of life of the family caregivers of elderly with Alzheimer's disease. *Saude Debate*. 2017;41(112):171-82. DOI
29. Queiroz RS, Camacho ACLF, Gurgel JL, Assis CRC, Santos LM, Santos MLSC. Sociodemographic profile and quality of life of caregivers of elderly people with dementia. *Rev Bras Geriatr Gerontol*. 2018;21(2):205-14. DOI
30. Cerutti P, Pauli J, Rissi V, Gomes P. O trabalho dos cuidadores de idosos na perspectiva da economia do care. *R Katal*. 2019;22(2):393-403. DOI
31. Mollica MA, Smith AW, Kent EE. Caregiving tasks and unmet supportive care needs of family caregivers: A U.S. population-based study. *Patient Educ Couns*. 2020;103(3):626-34. DOI
32. Pérez V, Manéndez-Crispín EJ, Sarabia-Cobo C, Lorena P, Fernández-Rodríguez A, González-Vaca J. Mindfulness-based intervention for the reduction of compassion fatigue and burnout in nurse caregivers of institutionalized older persons with dementia: a randomized controlled trial. *Int J Environ Res Public Health*. 2022;19(18):11441. DOI
33. Hellis E, Mukaetova-Ladinska EB. Informal caregiving and Alzheimer's disease: the psychological effect. *Medicina (Kaunas)*. 2022;59(1):48. DOI
34. Koufacos NS, Gottesman EM, Dorisca E, Howe JL. Supporting caregivers of veterans with dementia. *J Soc Work End Life Palliat Care*. 2023;19(1):12-22. DOI
35. Pinto FNFR, Barham EJ. Habilidades sociais e estratégias de enfrentamento de estresse: relação com indicadores de bem-estar psicológico em cuidadores de idosos de alta dependência. *Rev Bras Geriatr Gerontol*. 2014;17(3):525-39. DOI
36. Balbim GM, Marques IG, Cortez C, Magallanes M, Rocha J, Marquez DX. Coping strategies utilized by middle-aged and older Latino caregivers of loved ones with Alzheimer's disease and related dementia. *J Cross Cult Gerontol*. 2019;34(4):355-71. DOI
37. Siqueira FD, Girardon-Perlini NMO, Andolhe R, Zanini RR, Santos EB, Dapper SN. Habilidade de cuidado de cuidadores familiares urbanos e rurais: relação com a sobrecarga, estresse e coping. *Rev Esc Enferm USP*. 2021;55:e03672. DOI
38. Coppetti LC, Girardon-Perlini NMO, Andolhe R, Silva LMC, Dapper SN, Noro E. Habilidade de cuidado, sobrecarga, estresse e coping de cuidadores familiares de pessoas em tratamento oncológico. *Rev Bras Enferm*. 2019;72(6):1618-24. DOI
39. Abojabel H, Werner P. The mediating effect of social support and coping strategies on the relation between family stigma and caregiver burden among Israeli Arab family caregivers of people with Alzheimer's disease (AD). *Aging Ment Health*. 2022;26(8):1597-1603. DOI
40. Jeong JS, Kim SY, Kim JN. Ashamed caregivers: self-stigma, information, and coping among dementia patient families. *J Health Commun*. 2020;25(11):870-8. DOI

-
41. Morero JAP, Bragagnollo GR, Santos MTS. Coping strategies: a systematic review on evaluation tools in the Brazilian context. *Rev Cuid.* 2018;9(2):2257-68. [DOI](#)
42. Nordtug B, Malmedal WK, Alnes RE, Blindheim K, Steinheim G, Moe A. Informal Caregivers and persons with dementia's everyday life coping. *Health Psychol Open.* 2021;8(1):20551029211000954. [DOI](#)
43. Farinha FT, Bom GC, Manso MMFG, Razera APR, Mondini CCSD, Trettene AS. Fatores relacionados ao uso do coping religioso por cuidadores informais: revisão integrativa. *Rev Bras Enferm.* 2021;74(3):e20201227. [DOI](#)
44. Britt KC, Richards KC, Radhakrishnan K, Vanags-Louredo A, Eunice P, Gooneratne NS, et al. Religion, spirituality, and coping during the pandemic: perspectives of dementia caregivers. *Clin Nurs Res.* 2023;32(1):94-104. [DOI](#)
45. Owokuhaisa J, Kamoga R, Musinguzi P, Muwanguzi M, Natukunda S, Mubangizi V, et al. Burden of care and coping strategies among informal caregivers of people with behavioral and psychological symptoms of dementia in rural southwestern Uganda. *BMC Geriatr.* 2023;23(1):475. [DOI](#)
46. Barreto LV, Cruz MGS, Okuno MFP, Horta ALM. Associação da espiritualidade, qualidade de vida e depressão em familiares de idosos com demências. *Acta Paul Enferm.* 2023;36:eAPE03061. [DOI](#)