



Stress and coping strategies of caregivers of older adults with Alzheimer's Disease

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Abstract

Objective: To compare stress symptoms and coping strategies among caregivers of older adults with Alzheimer's disease according to sociodemographic, health, and professional variables. **Method:** A cross-sectional study was conducted of 126 caregivers of older adults with Alzheimer's disease. A questionnaire assessing caregiver sociodemographic and health profiles, the Perceived Stress Scale, and the Ways of Coping Scale were applied. Data analysis was performed using the independent *t*-test, one-way ANOVA, and Tukey's post-hoc test ($p < 0.05$). **Results:** Women made greater use of the coping strategy of seeking social support ($p = 0.013$). Caregivers with more than one care recipient made greater use of problem-focused coping strategies ($p = 0.020$). Caregivers engaged in formal care exhibited higher levels of stress ($p = 0.015$) and made less use of problem-focused coping strategies ($p = 0.020$). **Conclusion:** Sociodemographic, health, and professional profiles are factors mediating the stress coping strategies employed by caregivers of older adults with Alzheimer's disease.

Keywords: Caregivers. Aged. Coping. Dementia.

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INTRODUCTION

Alzheimer's Disease (AD) is characterized by progressive degenerative effects of the brain, leading to cognitive decline and functional impairment, with consequent dependence¹. The disease has several stages: early, intermediate and advanced. With disease progression through these stages, patients require increasing levels of care². Due to the degenerative multifactorial process of AD, patients exhibit impairments which negatively impact their ability to carry out activities of daily living (ADLs)³, increasing the burden on caregivers².

Evidence shows that carers of AD patients can develop physical and emotional problems⁴. Neuropsychological and psychological symptoms, agitation and *delirium* induced by AD are directly associated with caregiver burden⁵.

These caregivers act as intermediaries between the older adult, family and health services, with care involving assistance with hygiene, medication, accompaniment, ADLs, among others⁶. Key factors such as the socioeconomic profile of caregivers, coping mechanisms and social support, plus primary stressors of care provision and secondary factors such as self-esteem and burden of professionals, contribute to caregiver stress and emotional impact on their quality of life (QoL)⁷.

Emotional and physical support offered by families to caregivers can be an important coping strategy, with such engagement serving to reduce caregiver stress. Moreover, engaging in physical exercises as part of self-care of professionals is another useful strategy for coping with stress^{4,8}. Additionally, caregiver experience is not a determining factor for the development of stress events. Also, frequent tiredness and fatigue renders professionals more vulnerable to stress episodes⁹.

A Brazilian study found that 85.7% of caregivers presented chronic health problems, most commonly back issues, and 65.7% were in use of medications. Caregivers were predominantly female, educated to secondary level and had low QoL⁶. In another study, the profile of caregivers of older adults with AD was female, aged 22-83 years, mostly wives or daughters of the patient, with 81% harboring

a chronic disease¹⁰. Thus, this profile showed that caregivers were generally women, explained by their greater willingness to accept more intensive tasks, and also influenced by cultural, racial, ethnic and generational aspects. This tendency, however, may vary according to cultural, racial, ethnic and generational differences.⁸

Given the high level of care needed by people with AD provided by formal (paid hired professionals) or informal (unpaid family members, friends or acquaintances) caregivers, these individuals are typically exposed to stressing situations during the care process. Therefore, it is important to analyze sociodemographic, health, and professional variables of these caregivers in order to inform professionals and help them devise coping strategies to tackle the problems faced. Ultimately, this knowledge can promote the delivery of more effective and supportive care to patients with AD.

Thus, the objective of the present study was to compare stress symptoms and coping strategies of caregivers of older adults with Alzheimer's Disease according to sociodemographic, health and professional variables.

METHOD

A quantitative, analytical, observational, cross-sectional study was conducted. The study was approved by the Research Ethics committee of the Cesumar University (Unicesumar) under permit no. 6.001.701/2023 and complied with Resolution nos. 466/2012 and 510/2016.

Non-probability convenience sampling was employed for intentional selection of 126 caregivers, comprising 27 formal (professional) and 99 informal (family/friends) carers, of older adults with AD from different regions of Brazil. Only caregivers of older adults diagnosed with AD (as reported by carer), of both genders, aged ≥ 18 years, and from different regions of Brazil, were included. Caregivers of institutionalized or hospitalized patients were excluded.

Data on sociodemographic profile, health variables and aspects of care of the older adult with

AD were assessed using a questionnaire devised by the authors collecting information on age, age group, sex, family income, educational level, retirement status, use of medications, associated diseases (comorbidities) and time since AD diagnosis.

Perceived stress was analyzed using the Brazilian version of the Perceived Stress Scale containing 14 items scored on a 5-point Likert-type scale from 0 to 4 (0=never; 1=almost never; 2=sometimes; 3=fairly often; and 4=very often). The scores for positive questions (4, 5, 6, 7, 9, 10 and 13) were reversed as follows: 0=4; 1=3; 2=2; 3=1; and 4=0. The negative questions were summed directly. Summing of these 14 questions yields a total score of 0 (indicating lower perceived stress) to 56 (higher perceived stress)¹¹.

The Brazilian version of the Ways of Coping Scale (EMEP) was used to identify the way the subject dealt with the stressful encounter, in this case, caring for the older adult(s) with AD. The questionnaire is scored on a 5-point Likert-type scale. The scale is a 45-item questionnaire containing a wide range of thoughts and acts that people use to deal with the internal and/or external demands of specific stressful encounters. Response options were: 1= I never do this; 2= I rarely do this; 3= I sometimes do this; 4= I often do this; and 5= I always do this¹².

Data collection was performed using the on-line form provided by Survey Monkey. All participants wishing to take part in the study agreed by selecting "I agree" on the online free and informed consent form.

A link to the electronic questionnaire developed for the study was created and disseminated via the authors' social media accounts (FacebookTM, InstagramTM and WhatsAppTM). The platform for completing the questionnaires remained available for respondents to answer for 90 days (February-May 2023). Prior to filling out the questionnaire, participants were provided with brief instructions containing information on the aim of the study, the target audience and estimated completion time (around 15 mins). The older adults were recruited during the data collection period, i.e., February-May 2023.

Data analysis was performed using descriptive and inferential statistics. Categorical variables were expressed as frequency and percent, whereas Numerical variables were checked for normality using Kolmogorov-Smirnov's test and coefficients of skewness and kurtosis. Bootstrapping procedures (1000 resamples; 95% CI BCa) were employed to obtain greater confidence in results, correct potential deviations of normality of the sample and group size differences, and to provide a 95% confidence interval for the means.

Student's *t*-test for independent samples (2 groups) and One-Way ANOVA with Tukey Post-Hoc correction (>2 groups) were employed to compare perceived stress and coping strategies in relation to sociodemographic, health and professional variables. A significance level of $p < 0.05$ was adopted.

DATA AVAILABILITY

The full dataset underpinning the results of this study are available from the corresponding author Daniel Vicentini de Oliveira upon request.

RESULTS

A total of 126 caregivers (118 female; 8 male) aged 22-80 ($M=51.36$; $SD\pm 10.90$) years took part in the study. Of the caregivers assessed, most were aged 40-59 years (61.9%), living with a partner (54.8%), white (64.2%), had higher educational level (60.3%), and a monthly income of 1-2 minimum wages (42.1%). Among the caregivers evaluated, 42.9% reported regular use of 1-2 medications and 60.3% reported having no chronic Non-Communicable Diseases (NCDs). Mean stress score of the caregivers was 29.58.

Comparing perceived stress and coping strategies of caregivers by gender (Table 1), women had higher scores ($M=16.60$) than men ($M=14.62$) for use of the strategy of seeking social support.

Table 1. Perceived stress and coping strategies of caregivers according to gender Brazil, 2023.

Variables	Sex		p-value
	Female (n=118)	Male (n=8)	
	M (SD)	M (SD)	
Stress	29.58 (10.08)	23.63 (8.09)	0.105
Coping strategies			
Problem-focused	64.30 (11.47)	68.75 (7.87)	0.284
Emotion-focused	40.54 (6.41)	37.62 (3.85)	0.208
Religious practices / fantasy thoughts	23.97 (4.62)	22.12 (4.12)	0.275
Seeking social support	16.60 (3.52)	14.62 (1.68)	0.013*

*Significant difference; $p < 0.05$; Student's *t*-test for independent samples; M: mean; SD: standard deviation.

Comparing perceived stress and coping strategies of caregivers according to age group, no significant ($p > 0.05$) group difference was found for any of the variables investigated. Similarly, no significant difference ($p > 0.05$) in perceived stress or coping strategies of the caregivers was found according to marital status (living with or without partner).

Comparing perceived stress and coping strategies of caregivers according to educational level (Table 2), a significant group difference was found only for the emotion-focused coping strategy ($p = 0.008$), where caregivers with higher education had lower score ($M = 38.96$) on this strategy than those with secondary ($M = 41.90$) or primary (incomplete/Complete) ($M = 44.70$) levels.

Perceived stress and coping strategies of caregivers according to medication use are presented in Table 3. The results reveal a significant group difference only for the problem-focused coping strategy, showing that caregivers using no medications ($M = 68.47$) scored higher on this strategy compared to those in use of > 2 medications ($M = 61.75$).

A comparison of perceived stress and coping strategies of caregivers according to monthly income revealed no significant group difference ($p > 0.05$) for any of the variables investigated. Also, no significant difference ($p > 0.05$) in perceived stress or coping strategies of the caregivers was found according to presence or absence of chronic NCDs. Moreover, no significant difference ($p > 0.05$) in perceived stress

or coping strategies of the caregivers was found according to length of time caring for the older adult(s) with AD.

A comparison of perceived stress and coping strategies of caregivers according to number of care recipients with AD is presented in Table 4. The results reveal a significant group difference only for the problem-focused coping strategy ($p = 0.020$), showing that caregivers with more than one care recipient ($M = 73.00$) scored higher on this strategy compared to those caring for only one AD patient ($M = 63.94$).

No significant difference ($p > 0.05$) in perceived stress or coping strategies of the caregivers was found according to number of hours daily dedicated to caring for the older adult(s) with AD.

Comparison of perceived stress and coping strategies of caregivers who lived with the AD patient (s) to those who did not, showed no significant ($p > 0.05$) group difference for any of the variables investigated.

Comparison of perceived stress and coping strategies of caregivers according to type of care delivered to the older adult(s) with AD (Table 5) revealed a significant group difference only for stress score ($p = 0.015$) and the problem-focused strategy ($p = 0.020$). Formal caregivers scored higher for stress and lower for the problem-focused strategy use compared to informal carers.

Table 2. Perceived stress and coping strategies of caregivers according to education. Brazil, 2023.

Variables	Education			p-value
	Primary Inc./ Comp. (n=10)	Secondary Complete (n=40)	Higher Complete (n=76)	
	M (SD)	M (SD)	M (SD)	
Stress	29.80 (14.23)	30.52 (9.98)	28.42 (9.52)	0.556
Coping strategies				
Problem-focused	64.50 (14.92)	63.20 (11.10)	65.33 (10.98)	0.632
Emotion-focused	44.70 (6.54)	41.90 (6.51)	38.96 (5.89)	0.008*
Religious practices / fantasy thoughts	25.70 (4.05)	23.95 (4.44)	23.55 (4.74)	0.379
Seeking social support	17.70 (4.67)	16.12 (3.69)	16.50 (3.18)	0.440

*Significant difference; $p < 0.05$; ANOVA followed by Tukey's Post-Hoc correction comparing: a) Higher with Secondary complete and Primary; M: mean; SD: standard deviation.

Table 3. Perceived stress and coping strategies of caregivers according to use of medications. Brazil, 2023.

Variables	Use of medications			p-value
	None (n=53)	1-2 (n=25)	> 2 (n=48)	
	M (SD)	M (SD)	M (SD)	
Stress	28.14 (9.75)	28.77 (9.58)	30.86 (11.05)	0.483
Coping strategies				
Problem-focused	68.47 (9.96) ^a	63.89 (11.27)	61.75 (11.86)	0.033*
Emotion-focused	40.58 (6.55)	39.98 (5.65)	40.67 (7.11)	0.853
Religious practices / fantasy thoughts	24.42 (4.47)	23.98 (4.90)	23.08 (4.26)	0.455
Seeking social support	16.39 (3.77)	16.22 (3.31)	16.94 (3.45)	0.620

*Significant difference; $p < 0.05$; ANOVA followed by Tukey's Post-Hoc correction comparing: a) None with > 2; M: mean; SD: standard deviation.

Table 4. Perceived stress and coping strategies of caregivers according to number of care recipients with Alzheimer's disease. Brazil, 2023.

Variables	Number of care recipients		p-value
	1 (n=117)	> 1 (n=9)	
	M (SD)	M (SD)	
Stress	29.56 (9.91)	24.44 (11.20)	0.141
Coping strategies			
Problem-focused	63.94 (11.22)	73.00 (9.25)	0.020*
Emotion-focused	40.41 (6.49)	39.55 (3.24)	0.697
Religious practices / fantasy thoughts	23.91 (4.67)	23.00 (3.60)	0.567
Seeking social support	16.38 (3.51)	17.67 (2.78)	0.287

*Significant difference; $p < 0.05$; Student's *t*-test for independent samples; M: mean; SD: standard deviation.

Table 5. Perceived stress and coping strategies of caregivers according to type of care provided to older adults with Alzheimer's Disease. Brazil, 2023.

Variables	Type of care		p-value
	Formal (n=27)	Informal (n=99)	
	M (SD)	M (SD)	
Stress	30.33 (9.98)	25.04 (9.34)	0.015*
Coping strategies			
Problem-focused	63.37 (11.45)	69.04 (9.18)	0.020*
Emotion-focused	40.25 (6.32)	40.70 (6.38)	0.743
Religious practices / fantasy thoughts	23.81 (4.51)	24.00 (5.00)	0.848
Seeking social support	16.45 (3.49)	16.56 (3.46)	0.894

*Significant difference; $p < 0.05$; Student's *t*-test for independent samples; M: mean; SD: standard deviation.

DISCUSSION

The main findings of this study revealed that women made greater use of coping strategies based on social support and that carers not using medications, with more than one care recipient, and engaged in informal caregiving tended to make greater use of problem-focused strategies. Caregivers with higher education tended to make less use of emotion-focused strategies. Furthermore, caregivers providing formal care had higher levels of perceived stress and made less use of the problem-focused strategy.

The gender difference in use of social support-based coping strategies among caregivers of older adults with AD might be explained by social and cultural factors, and also by differences in gender-based experiences and expectations. For example, in many cultures, women are socialized from an early age to perform roles of caring and promote emotional wellbeing in the family. This may lead to women seeking social support more naturally when encountering stressor events, such as caring for older adults with AD^{6,15}. Society often expects women to perform the role of informal caregiver, where this may extend to caring for family members. This expectation may influence women's readiness to seek social help, given they feel it is their duty to provide care¹⁴⁻¹⁶.

Coping strategies that encompass social skills and social support help in administering care to older individuals, positively influencing interpersonal

aspects and favoring quality of life of carers⁷. The need for social support among family members has been identified in previous studies¹⁷, where caregiving is predominantly performed by daughters, wives or daughter-in-laws.

Brito et al.¹⁸ noted that social support seeking by caregivers of older adults occurs to cope with the stress associated with the burden of care, and that this behavior helps promote the health, QoL and wellbeing of caregivers. Hernández-Padilla et al.¹⁹, in a study involving 255 caregivers of AD patients, reported that, although caregiver burden was high, so was social support, whereas perceived health was poor, outcomes that proved more accentuated in women than in men.

It is also noteworthy that women may have more prior experience with caring and social support, whether from traditional domestic responsibilities or the roles of carer in other family situations. This previous experience may render them more prone to seeking social support^{15,20}. In addition, this group may have more developed social support networks that encompass family members, friends and support groups. These networks might be more accessible to women, favoring the use of social support-based coping strategies^{21,22}.

The present results showed that caregivers using no medications made greater use of problem-focused coping strategies. It is likely that this group of caregivers uses non-pharmacological

alternatives to deal with the challenges of caregiving, such as changing the environment, implementing behavioral therapies and promoting more effective communication with patients.

Caregivers of more than one person with AD and that employ problem-focused strategies, as seen in the present study, may do so for a number of reasons. Caring for more than one older adult with AD can be extremely challenging due to the multiple physical, emotional and practical demands involved. The use of problem-based coping strategies allows caregivers to deal with the many needs and challenges posed by older adults in a more effective manner²³. This group of caregivers can seek to maximize their available resources, such as time, energy and support. Problem-based coping strategies help allocate resources more effectively to meet the needs of the older adult²⁴.

Studies show that²⁵ the use of problem-focused strategies reduces the burden on caregivers as well as the family stigma of emotional anguish. Balbim et al.²⁶ found that problem-focused strategies help reduce caregiver anxiety, leading to improved outcomes. Durán-Gomez et al.²⁷, in a study of caregivers of AD patients, showed that greater use of problem-focused coping strategies was associated with better caregiver QoL, who also exhibited less depressive, anxious and somatic symptoms. This association may explain the lower use of medications among the caregivers assessed in the present study.

In another study¹⁸, caregivers enrolled on a program addressing education, stress management, problem solving and support had greater capacity to deal with the stresses of caring effectively, improving self-control, management of patient needs and personal QoL.

Moreover, it is clear that caring for several older adults with AD calls for the implementation of practical effective solutions to preserve the QoL of all involved¹⁰. Problem-centered strategies often entail seeking practical solutions to deal with daily demands, ensure safety and deliver satisfactory medical care. Caregivers can adopt problem-focused approaches to coordinate and organize care in an effective fashion, ensuring that all needs are catered for²⁸.

The present study results confirmed that informal caregivers of older adults with AD tended to resort to problem-focused coping strategies. Caregiving often involves dealing with challenging behaviors, assisting with ADLs, managing safety and administering medications²⁹. Informal care often requires the caregiver to devise a comprehensive care plan, establishing routines, safety strategies and management of daily tasks. Problem-focused strategies help the carer more effectively organize and plan care³⁰.

Regarding the use of problem-focused strategies by informal caregivers, the study of Monteiro et al.²³, providing a systematic review of different coping strategies employed by caregivers of AD patients, found that the most used coping strategy was emotion-based as opposed to problem-based. However, the authors of the study noted that the problem-focused strategy was used to reduce the impact of psychological stressors based on active coping. Family caregivers use problem-focused strategies to modify their behaviors with the older adult(s)³¹. Male caregivers used these strategies more often than their female counterparts³¹.

Also, in the present study, caregivers with higher education tended to make less use of emotion-focused strategies when caring for the older adults with AD. Higher-educated caregivers generally hold greater knowledge on AD and about the challenges associated with caring for people with the condition. This group may also be more familiar with evidence-based strategies, such as problem-based strategies, recommended by health professionals^{27,31}. Higher education often promotes greater critical analysis and application of problem-solving skills. Carers with higher education may also be more inclined to address the practical challenges of caring for older adults with AD rather than pursuing emotional responses to the challenges faced.

According to Thompson et al.³¹, caregivers with higher education, given their greater ease of access to educational information and greater understanding of facts, tend to display better decision-making regarding which strategies to employ. Balbim et al.²⁶ conducted a study involving caregivers with 12-13

years of formal education and found that emotion-focused strategies were often used. Conversely, in the study by Durán-Gómez et al.²⁷, around 19.2% of participants had higher education and made less use of the emotion-focused strategy and greater use of the problem-focused approach.

Lastly, caregivers providing formal care had higher levels of perceived stress and made less use of the problem-focused strategy. Typically, formal carers face professional pressures such as fixed working schedules, performance expectations and specific duties. These pressures can increase stress levels, in turn, hampering engagement in problem-focused strategies, given they are more concerned about meeting institutional requirements³². Furthermore, formal caregivers often work in an institutional setting where resources are scarce. Lack of trained staff and insufficient resources to deal with multiple patients with AD can also increase stress and limit the ability to consistently implement problem-focused strategies³².

It is also important to bear in mind that informal caregivers often have closer ties with care recipients, possibly facilitating the adoption of more adaptive person-centered strategies. Formal carers, on the other hand, may lack the same level of closeness, hindering effective implementation of problem-focused strategies. Despite the strength of its findings, this study has some limitations, such as the fact that caregivers may have introduced reporting bias, albeit stemming from social concerns, pressure to provide socially acceptable responses, or poor memory recall. These factors may have impacted the validity of results. Also, AD severity can vary widely across patients, a disparity which may have influenced the experiences of caregivers. Moreover, the perception of stress is subjective and differs among individuals, where caregivers can have different levels of tolerance to stress, influencing their responses. The study analyzed the coping strategies reported by caregivers but was unable to gauge how effectively these strategies were implemented in practice. This disparity between reported and actual behaviors may represent a limitation.

Another limitation lies in the higher educational level of the sample studied compared with that of similar investigations available in the literature. This disparity might be attributed to the method of data collection via an online form, an approach which may have excluded potential participants with lower educational level or difficulties accessing the internet.

CONCLUSION

Taken together, the study results confirm that sociodemographic, health and professional profiles are factors mediating the stress coping strategies used by caregivers of older adults with Alzheimer's Disease. More specifically, factors including sex, educational level, use of medications, number of care recipients and type of care can influence the coping strategies adopted. Formal caregivers exhibited higher perceived stress compared to informal caregivers.

The practical implication of these findings is that this group of caregivers requires a tailored individualized approach. Implementing focused intervention support programs can yield better results for caregivers and, consequently, for care recipients.

Thus, the study paves the way for future investigations to further understanding of stress in this group of caregivers and help devise effective targeted interventions supporting this vulnerable population. Elucidating the factors which impact the wellbeing of caregivers can allow the promotion of significant improvements in their QoL, directly enhancing the quality of care delivered to older adults with AD.

AUTHOR CONTRIBUTIONS

- Izabela Vitória P. Marques – conception, design, data analysis and interpretation, writing of article and critical review.
- Chia Chen Lin – conception, design, data analysis and interpretation, writing of article and critical review.

- Eduardo Q. Silva – data analysis and interpretation, writing of article and critical review.
- José Roberto A. Nascimento Júnior – data analysis and interpretation.
- Daniel Vicentini de Oliveira – responsible for all aspects of the research, vouching for all issues related to the accuracy or integrity of any part of the study. Approval of final draft for publication.

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