

Caregiver burden and mood changes among unpaid caregivers of older adults living with dementia

Elen Andressa Berto Vaz

Federal University of São Carlos

Luana Rafaela Porcatti

Federal University of São Carlos

Gustavo Carrijo Barbosa

Federal University of São Carlos

Anna Clara Simon Landim Silveira

Federal University of São Carlos

Renan Silveira Giroto

Federal University of São Carlos

Ana Julia Souza Caparrol

Federal University of São Carlos

Kethelyn Izabella Almeida Silva

Federal University of São Carlos

Gabriela Martins-Cavichioli

Federal University of São Carlos

Alinne Suelma Santos Diniz

Federal University of São Carlos

Aline Cristina Martins Gratao

`alinegratao@ufscar.br`

Federal University of São Carlos

Research Article

Keywords: Anxiety, Unpaid caregiver, Dementia, Depression, Older adult, Burden

Posted Date: September 25th, 2026

DOI: <https://doi.org/10.21203/rs.3.rs-11145262/v1>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Population aging increases the prevalence of chronic and degenerative diseases, such as dementia, which impairs cognitive function and autonomy. Unpaid family caregivers frequently experience physical and emotional burden, especially when they live with the care recipient or provide care for long periods.

Objective: To assess caregiver burden and mood changes among unpaid caregivers of older adults with dementia.

Methods: A quantitative, observational, cross-sectional study was conducted from 2023 to 2024 with 50 unpaid caregivers of older adults diagnosed with dementia at the Gerontology Outpatient Clinic of the University Hospital of the Federal University of São Carlos (HU-UFSCar). The Hospital Anxiety and Depression Scale (HADS) and the 12-item Zarit Burden Interview (ZBI-12) were administered. Associations of caregiver burden, depression, and anxiety with sociodemographic variables were investigated using multivariable Poisson regression.

Results: Depressive and anxiety symptoms were more pronounced among caregivers with longer caregiving duration ($p = 0.01$; $p = 0.001$) and those living with the care recipient ($p = 0.04$; $p = 0.02$). Caregiver burden was associated with caregiver age ($p < 0.001$) and cohabitation ($p = 0.001$). Women predominated, and daily caregiving hours were long, indicating a high risk of physical and emotional exhaustion.

Conclusion: The findings reinforce the importance of recognizing unpaid caregivers as central to home care networks and promoting ongoing support strategies to ensure their health, well-being, and the sustainability of caregiving.

INTRODUCTION

Population aging is an unprecedented demographic phenomenon driven by advances in public health, sanitation, and medical technology. In Brazil, the proportion of individuals aged 60 years or older increased from 10.8% in 2010 to 15.6% in 2022 and is projected to reach 29.6% in 2050. This shift in the age structure contrasts with declining fertility and infant mortality rates, altering the epidemiological profile and increasing the prevalence of noncommunicable diseases [17].

The demographic transition has direct implications for health systems, which now face greater demand for long-term care, multidimensional care, and rehabilitation services. Chronic conditions such as cardiovascular diseases, diabetes, and dementia require continuous monitoring, multidisciplinary teams, and adaptations within the health care network to meet the specific needs of older adults [33].

Noncommunicable diseases (NCDs) are characterized by prolonged progression, multifactorial etiology, and a noninfectious clinical course and primarily include cardiovascular diseases, neoplasms, diabetes mellitus, and chronic respiratory diseases [23]. Among NCDs, dementia is becoming increasingly relevant and is characterized by insidious, progressive cognitive decline sufficient to impair memory,

language, attention, and the performance of instrumental activities of daily living, affecting the individual's autonomy [25]. WHO estimates that 55 million people worldwide were living with dementia in 2020, with approximately 10 million new cases per year; this number is projected to reach 78 million in 2030 and 139 million in 2050 because of global population aging [6].

In the Brazilian context, the *National Report on Dementia in Brazil* (Ministério da Saúde, 2024), based on the Delphi Consensus, reported an estimated prevalence of dementia of 8.5% among people aged 60 years or older in 2019, corresponding to approximately 2.46 million Brazilians. If current conditions persist, projections for the Brazilian population in two and four decades suggest that the number of dementia cases could rise to 5.05 million and 8.74 million in 2039 and 2059, respectively.

Among older adults, this group of diseases is one of the leading causes of disability and dependence, requiring comprehensive care, often for long periods. Accordingly, dementia affects not only those living with the condition but also society and the economy, with a substantial impact on caregivers [13].

Care for older adults with dementia, especially in home settings, is provided primarily by unpaid caregivers—family members or people close to the older adult—who assume this role without compensation and often without specific training [5]. According to the Brazilian Classification of Occupations (CBO), a caregiver is responsible for the well-being, health, hygiene, nutrition, leisure, and safety of the care recipient, serving as a liaison between the older adult and health services [5].

The literature indicates that unpaid caregiving is characterized by emotional ties and a lack of institutional support, which may result in physical, emotional, and social burden [13]. Recent studies indicate that caregivers' sociodemographic profile directly influences their caregiving experience. Women, especially daughters or wives, make up the majority of unpaid caregivers, reflecting sociocultural patterns that associate the caregiving role with women [33]. This feminization of caregiving leads to overlapping work, domestic, and caregiving responsibilities, increasing the risks to these caregivers' physical and mental health [28].

Unpaid caregiver burden refers to the accumulation of physical, emotional, and social strains resulting from the ongoing provision of care to people with functional limitations or chronic conditions. Among caregivers of older adults with dementia, this burden is associated with negative assessments of their own competence, impacts on family relationships, and changes in overall well-being; it may also substantially reduce caregivers' quality of life [31].

In this context, caregiver burden was associated with a higher prevalence of anxiety and depressive symptoms, an increased risk of cardiovascular disease, and reduced opportunities for self-care, especially in lower-middle-income countries where institutional support is limited [3] [15].

Mood changes, particularly depressive and anxiety symptoms, are among the most common psychological effects experienced by unpaid caregivers of older adults with dementia, compromising both the quality of care and caregiver well-being [14].

Studies show that caregivers of people with dementia experience high levels of stress, depressive and anxiety symptoms, as well as poorer physical health compared with the general population of non-caregivers. Estudy highlight that long-term home caregiving entails greater psychological strain than caregiving outside the home, underscoring the urgent need for specific support for this group [3]

In the Brazilian context, study emphasizes that support for unpaid caregivers remains insufficient, with gaps in the provision of psychosocial support, technical guidance, and public policies recognizing this unpaid work [22]. Moreover, authors have identified relationship to the care recipient, caregiving duration, and cohabitation as significant predictors of caregiver burden, but multivariable analyses integrating these variables with indicators of caregivers' mental and physical health are still lacking [31].

Therefore, there is both a social gap, related to insufficient support structures and recognition of family caregivers, and a scientific gap, related to the lack of studies that further examine the determinants of these caregivers' health in the context of dementia. Addressing this gap is essential to guide the development of public policies and clinical practices that promote caregivers' biopsychosocial well-being and ensure the sustainability of long-term care.

Considering this context, it is important to understand how sociodemographic, relational, and clinical factors are collectively associated with caregiver burden and emotional changes among family caregivers. The present study seeks to fill this gap by examining the interplay among caregiving duration, cohabitation, and caregiver age in relation to indicators of anxiety, depression, and caregiver burden.

OBJECTIVE

To assess caregiver burden and mood changes among unpaid caregivers of older adults living with dementia receiving care at the Gerontology Outpatient Clinic of the University Hospital of the Federal University of São Carlos (HU-UFSCar), as well as to examine the caregivers' sociodemographic and health profile and its relationship to burden and mood status.

METHOD

Study design and Setting

This was a quantitative, observational, cross-sectional study conducted from 2023 to 2024 with 50 unpaid caregivers of older adults with a clinical diagnosis of dementia receiving care at the Gerontology Outpatient Clinic of the University Hospital of the Federal University of São Carlos (HU-UFSCar). The study design followed the recommendations of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [20].

Sample and Eligibility criteria

Primary family caregivers aged 18 years or older who had been providing care for at least six months and who signed the informed consent form were included. Paid professional caregivers were excluded.

The sample size was determined by convenience based on the average patient flow at the outpatient clinic during the data collection period. This design was chosen because of the exploratory nature of the study and the logistical constraints imposed by the clinical setting.

Data collection procedure

Data were collected in person in a private room by a trained team. Participants completed a questionnaire developed by the researchers addressing sociodemographic characteristics, health conditions, and caregiving characteristics, as well as the 12-item Zarit Burden Interview (ZBI-12) and the Hospital Anxiety and Depression Scale (HADS).

The sociodemographic questionnaire included information such as name, sex, date of birth, marital status, years of education, ethnicity, whether the participant was the primary caregiver, relationship to the older adult, and whether they lived with the older adult. Information on medical history, medications in use, weight and height, and specific clinical conditions (such as HTN, DM, COPD, among others) was collected in the health conditions section. The caregiving characteristics section addressed years of caregiving and daily caregiving hours, as well as caregiving activities performed for the care recipient, such as personal and oral hygiene, assistance with toileting, feeding, medication administration, and accompanying the care recipient to health care appointments. Aspects related to the older adult's well-being and support network were also considered, such as participation in leisure activities, support from religious institutions, and follow-up by social services.

The 12-item Zarit Burden Interview (ZBI-12) [15] is a shortened version of the original instrument [35] and has been culturally adapted and validated for use in Brazil [30]. The ZBI-12, which is designed to assess caregiver burden, consists of 12 items with the following response options: never, rarely, sometimes, frequently, and always; for the final item, the response options are: not at all, a little, moderately, quite a bit, and extremely, represented on an ascending scale from 0 to 4 points. The total score is 44 points, with a cutoff score of ≥ 13 indicating caregiver burden.

The Hospital Anxiety and Depression Scale (HADS) assesses symptoms of anxiety and depression [36] and has been culturally adapted and validated for use in Brazil [4]. It consists of 14 items assessing anxiety and depression, with odd-numbered items addressing anxiety and even-numbered items addressing depression. Each item is scored from 0 to 3. Anxiety and depression scores can be classified as unlikely (0–7), possible (questionable or doubtful) (8–11), and probable (12–21).

Statistical analysis

Continuous variables were described as means $\pm$ standard deviations, and categorical variables as absolute and relative frequencies. Poisson regression models were used to assess scale scores according to caregiver characteristics. Analyses were performed using R version 4.0.3 with RStudio version 1.3.1093.

Ethical aspects

The study was approved by the Research Ethics Committee for Human Research at Federal University of São Carlos (CAAE: 24244519.3.0000.5504; under Opinion No. 3.825.117) and followed the ethical principles established in Resolution No. 466/2012 of the National Health Council, ensuring anonymity and informed consent from all participants.

RESULTS

Fifty-four caregivers of older adults living with dementia who were receiving care at the Gerontology Outpatient Clinic during this period were invited to participate in the study. Of these, 4 were excluded because they declined to participate; thus, 50 individuals were included in the study.

Of the 50 older adults diagnosed with dementia cared for by these caregivers, 30 (60%) had Alzheimer’s disease, 10 (20%) mixed dementia, 9 (18%) vascular dementia, and 1 (2%) alcohol-related dementia. The sample consisted predominantly of women (94%), with a mean age of 54.7 ± 15.1 years; 40% were married, and participants had a mean of 9.4 ± 4.7 years of education. The remaining sociodemographic and health characteristics of the study participants are presented in Table 1.

Table 1 - Sociodemographic characteristics and health profile of unpaid caregivers of older adults living with dementia receiving care at the HU-UFSCar Gerontology Outpatient Clinic. São Carlos, São Paulo, Brazil, 2024.

Variable	Sample (n = 50)
Sex	
Female	47 (94%)
Male	3 (7%)
Age group	
21–31 years	4 (8%)
32–42 years	7 (14%)
43–53 years	13 (26%)
54–64 years	12 (24%)
65–75 years	9 (18%)
76+ years	5 (10%)
Marital status	
Married	20 (40%)
Single	19 (38%)
Widowed	4 (8%)
Separated	5 (10%)
Other	2 (4%)
Years of education	
No formal education	2 (4%)
1–4 years	12 (24%)
5–8 years	7 (14%)
9 years or more	29 (58%)
Relationship to the older adult	
Spouse	10 (20%)
Child	28 (56%)
Son-in-law/Daughter-in-law	4 (8%)
Grandchild	4 (8%)
Sibling	3 (6%)
Nephew/Niece	1 (2%)

Non-relative	0 (0%)
Lives with the older adult	40 (80%)
Years of caregiving	8,7 ± 10.0
Hours of caregiving/day	17,5 ± 8.6
Comorbidities	
None	5 (10%)
1–4 medical conditions	43 (86%)
5 or more medical conditions	2 (4%)
Regularly used medications	
0–3 medications	42 (84%)
4 or more medications	8 (16%)
ZBI-12	
Score	17,3 ± 10.2
Caregiver burden	30 (60%)
HADS-D	
Score	5,7 ± 4.6
Depressive symptoms	
Unlikely	39 (78%)
Possible	3 (6%)
Probable	8 (16%)
HADS-A	
Score	6,3 ± 4.7
Depressive symptoms	
Unlikely	35 (70%)
Possible	8 (16%)
Probable	7 (14%)

ZBI-12: 12-item Zarit Burden Interview; HADS: Hospital Anxiety and Depression Scale.

Table 2 presents the types of care provided to older adults by caregivers. The most common caregiving activities were medication management (78%), feeding (60%), sleep/rest (54%), and personal hygiene

(52%).

Table 2 - Types of care provided to older adults by caregivers. São Carlos, São Paulo, Brazil, 2024.

Type of care	Sample n = 50)
Medication management	39 (78%)
Feeding	30 (60%)
Sleep/rest	27 (54%)
Personal hygiene	26 (52%)
Skin care	21 (42%)
Toileting	17 (34%)
Oral hygiene	16 (32%)

Poisson regression models were used to assess caregiver burden and depressive and anxiety symptoms according to caregiver age, cohabitation, and caregiving duration. Table 3 shows that cohabitation was significantly and positively associated with all three scores (ZBI-12, HADS-D, and HADS-A). Caregiver age was also significantly associated with burden and anxiety scores, but not with depression scores. Caregiving duration, however, showed a statistically significant positive association with anxiety and depression scores, but not with burden.

Table 3 - Poisson regression of ZBI-12 and HADS scores according to caregiver variables. São Carlos, São Paulo, Brazil, 2024.

Independent variable	Dependent variable					
	ZBI-12		HADS-D		HADS-A	
	PR (95% CI)	p	PR (95% CI)	p	PR (95% CI)	p
Caregiver age (years)	1.01 (1.01 - 1.02)	< 0.001	1.01 (0.99 - 1.01)	0.1	1.01 (1.00 - 1.01)	0.01
Lives with the older adult						
No	Reference	-	Reference	-	Reference	-
Yes	1.27 (1.05 - 1.54)	0.01	1.42 (1.00 - 2.00)	0.04	1.45 (1.04 - 2.03)	0.02
Years of caregiving	1.00 (0.99 - 1.01)	0.3	1.01 (1.00 - 1.02)	0.01	1.02 (1.00 - 1.02)	0.001

PR: Prevalence Ratio; CI: Confidence Interval; ZBI-12: 12-item Zarit Burden Interview; HADS: Hospital Anxiety and Depression Scale.

In summary, caregiver burden was associated with objective factors in the caregiving context—age and cohabitation—whereas mood changes were associated with caregiving duration and continuous cohabitation. These findings delineate a multidimensional vulnerability profile among unpaid caregivers.

DISCUSSION

The present study analyzed caregiver burden and mood changes among unpaid caregivers of older adults with dementia, identifying statistically significant associations between these outcomes and variables such as caregiver age, cohabitation, and caregiving duration.

These results are consistent with previous research highlighting the physical and emotional vulnerability of family caregivers facing continuous caregiving demands, often without adequate institutional support [18].

Analysis of the sociodemographic data showed that the sample consisted predominantly of women (94%), with a mean age of 54.7 years; 40% were married, and the mean number of years of education was 9.4. Daughters of the older adults were the predominant group of unpaid caregivers (56%), followed by spouses (20%) and other close relatives. These findings are consistent with literature identifying the feminization of caregiving as a persistent phenomenon attributed to sociocultural constructions that assign women the role of primary caregivers [9, 29]. Overlapping work, domestic, and caregiving responsibilities intensify the risks to these caregivers' physical and mental health, especially when adequate institutional support is unavailable [3].

Other findings point to a concerning situation: 86% of caregivers had comorbidities, which may further exacerbate the effects of caregiver burden and compromise the quality of care provided. The literature indicates that caregiver burden is associated with sleep disorders, muscle pain, and symptoms of anxiety and depression, negatively affecting both the caregiver and the care recipient [14, 24].

The relatively few years of education among a substantial proportion of the sample (42% had up to 8 years of education) may affect understanding of the older adult's clinical condition, coping strategies, and access to social and health care resources [21, 34]. This finding highlights the need for accessible educational materials, appropriate communication strategies, and ongoing caregiver training.

Moreover, the long daily caregiving hours (mean of 17.5 hours per day) severely limit caregivers' opportunities for self-care, leisure, or social participation. This finding is consistent with studies indicating that caregiving intensity is directly related to physical and psychological exhaustion [1, 10]. Regarding the type of care provided, the most frequent activities were medication management (78%), feeding (60%), sleep/rest (54%), and personal hygiene (52%). These tasks require continuous attention

and involve direct responsibility for the older adult's health and well-being, contributing to caregivers' physical and emotional strain.

Studies indicate that the intensity and complexity of caregiving activities are directly related to perceived burden and caregivers' risk of illness [13, 6]. Additionally, a literature review that analyzed Brazilian and U.S. studies over a five-year period found consensus regarding the needs of caregivers providing long-term care and the high level of caregiver burden, which needs to be monitored and shared through informal or formal sources of support [9].

Analysis of caregiver burden scores showed a mean score of 17.3 points, with 60% of participants experiencing caregiver burden. Poisson regression revealed a statistically significant association between caregiver burden and caregiver age, as well as cohabitation with the older adult. These findings reinforce evidence that older caregivers have lower resilience to stress and greater physical vulnerability, requiring specific interventions for this subgroup [15, 22]. This finding points to the need for specific interventions for this age group, including health education initiatives, psychosocial support, and strengthening community networks.

Regarding depressive symptoms, 16% of caregivers had scores consistent with probable depression, while 6% were classified as possible cases. Cohabitation with the older adult and caregiving duration were significantly associated with depression scores. These data suggest that prolonged cohabitation and a lack of boundaries between family and caregiving roles may contribute to social isolation and psychological distress among caregivers [3, 27]. Regarding anxiety, 14% of participants had scores consistent with probable anxiety, and 16% had scores indicating possible anxiety symptoms. Regression analysis showed significant associations with age, cohabitation, and caregiving duration, consistent with studies identifying anxiety as one of the main emotional consequences of unpaid caregiving, particularly in contexts of high caregiving demands and limited support networks [33, 26].

The identification of factors associated with caregiver burden and psychological distress reinforces the need to incorporate interdisciplinary strategies into primary and specialized care. Support groups, respite services, and caregiver training in behavioral management for people with dementia are recommended. Including standardized screening instruments for caregiver burden and mood changes in electronic health records may facilitate longitudinal follow-up and guide early interventions.

Given this scenario, there is an urgent need to implement public policies that recognize unpaid caregivers as central agents in the caregiving process. The recently enacted Law No. 14,878/2024, which establishes the National Policy for Comprehensive Care for People with Alzheimer's Disease and Other Dementias, proposes an interdisciplinary and integrated approach focused on professional training, support for families, and coordination of existing services to create a dementia care pathway. In addition, Law No. 15,069/2024, which establishes the National Care Policy, aims to guarantee the right to care, promote shared social responsibility, and recognize unpaid work, particularly that performed by women, by proposing support, training, and follow-up measures for family caregivers [6, 7].

Recognizing family caregivers as strategic agents requires the development of public policy guidelines that acknowledge their role, ensure the regular provision of support groups, practical workshops, and in-home respite services, and incorporate standardized tools for monitoring caregiver burden and mood into electronic health records. Only then will it be possible to ensure adequate conditions for maintaining caregivers' quality of life and, by extension, strengthen the autonomy and well-being of older adults receiving care at home [32]. Therefore, the findings of this study not only contribute to advancing knowledge of the factors associated with caregiver burden and psychological distress among unpaid caregivers of people with dementia but also point to concrete avenues for evidence-based intersectoral interventions aligned with care guidelines.

However, some limitations should be considered when interpreting the results. Because of the cross-sectional design, causal relationships cannot be established between the variables analyzed. The sample was selected by convenience and consisted exclusively of caregivers accompanying older adults with dementia at an outpatient clinic, which may limit the generalizability of the findings to other contexts. In addition, the small number of participants may compromise the statistical power of the analyses. Information was obtained using self-report instruments and may therefore be subject to social desirability bias. It should also be noted that potentially relevant contextual variables, such as the older adult's degree of dependence, dementia severity, the presence of a support network, and economic factors, were not controlled for in the models used. Finally, the absence of a control group precludes broader comparisons regarding the specific impact of dementia on caregiver burden and mood.

CONCLUSION

The study showed that older age, cohabitation, and longer caregiving duration were associated with greater caregiver burden, anxiety, and depression among unpaid caregivers of older adults with dementia. The predominance of women and long caregiving hours characterize a context of biopsychosocial vulnerability that calls for specific public policies and ongoing support measures.

The findings highlight the urgency of integrating individual, clinical, and contextual determinants into care strategies, recognizing informal caregivers as central to health care networks. In this regard, strengthening interdisciplinary actions, including training in managing cognitive behaviors, ongoing psychosocial support, and coordination between community and institutional services, is a cornerstone of efforts to mitigate the adverse effects of caregiving, promote the mental and physical health of these informal caregivers, and ensure the sustainability of long-term caregiving.

Declarations

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Funding

The study was supported by the Coordination for the Improvement of Higher Education Personnel (CAPES) (Grant No. 88887.831637/2023-00), which provided financial support through a doctoral scholarship for Gabriela Martins-Cavichioli.

Authors contributions

Elen Andressa Berto Vaz contributed to the conception or design of the study and to data analysis and/or interpretation.

Luana Rafaela Porcatti contributed to data analysis and/or interpretation and critically revised the manuscript for important intellectual content.

Gustavo Carrijo Barbosa critically revised the manuscript for important intellectual content.

Anna Clara Simon Landim Silveira critically revised the manuscript for important intellectual content.

Renan Silveira Giroto critically revised the manuscript for important intellectual content.

Ana Julia de Souza Caparrol critically revised the manuscript for important intellectual content.

Kethelyn Izabella Almeida Silva critically revised the manuscript for important intellectual content.

Gabriela Martins-Cavichioli critically revised the manuscript for important intellectual content.

Alinne Suelma dos Santos Diniz critically revised the manuscript for important intellectual content.

Aline Cristina Martins Gratão contributed to the conception or design of the study and to data analysis and/or interpretation and critically revised the manuscript for important intellectual content.

All authors read and approved the final manuscript.

Data availability

The datasets generated and analyzed during the current study are not publicly available due the restrictions related to participant confidentiality and ethical requirements but may be available from the corresponding author upon reasonable request, subject to applicable ethical and institutional restrictions.

References

1. Alves, L. C. D. S., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegrini, L. N. D. C., & Vale, F. A. C. (2019). Síndrome do esgotamento em cuidadores informais de idosos com demência: uma revisão

- sistemática. *Demência & neuropsiquiologia*, 13(4), 415-421. <https://doi.org/10.1590/1980-57642018dn13-040008>
2. Bianchi, M., Flesch, L. D., Alves, E. V. D. C., Batistoni, S. S. T., & Neri, A. L. (2016). Indicadores psicométricos de la Zarit Burden Interview aplican en ancianos cuidadores de otros ancianos. *Revista Latino-Americana de Enfermagem*, 24, e2835. <https://doi.org/10.1590/1518-8345.1379.2835>
 3. Brini, S., Hodkinson, A., Davies, A., Hirani, S., Gathercole, R., Howard, R., & Newman, S. P. (2022). O cuidado domiciliar para demência está associado a uma maior carga psicológica e uma saúde mental pior do que o cuidado fora do domicílio: um estudo transversal. *Envelhecimento & Saúde Mental*, 26(4), 709–715. <https://doi.org/10.1080/13607863.2021.1881758>
 4. Botega, N. J., Bio, M. R., Zomignani, M. A., Garcia Jr, C., & Pereira, W. A. (1995). Transtornos do humor em enfermaria de clínica médica e validação de escala de medida (HAD) de ansiedade e depressão. *Revista de saude publica*, 29(5), 359-363.
 5. Brasil. Ministério do Trabalho e Emprego. (2002). *Classificação Brasileira de Ocupações: CBO – Cuidador de pessoa idosa*. <https://cbo.mte.gov.br>
 6. Brasil. (2024a). *Lei nº 14.878, de 04 de junho de 2024: Institui a Política Nacional de Cuidado Integral às Pessoas com Doença de Alzheimer e Outras Demências*. Diário Oficial da União.
 7. Brasil. (2024b). *Lei nº 15.069, de 23 de dezembro de 2024: Institui a Política Nacional de Cuidados*. Diário Oficial da União.
 8. BRASIL. Ministério da Saúde. *Relatório Nacional sobre Demências – RENAME*. Brasília, DF: Ministério da Saúde, 2024.
 9. Dadalto, E. V., & Cavalcante, F. G. (2021). O lugar do cuidador familiar de idosos com doença de Alzheimer: uma revisão de literatura no Brasil e Estados Unidos. *Ciência & Saúde Coletiva*, 26, 147-157.
 10. de Souza Ahnerth, N. M., Dourado, D. M., Neuzilan, M. G., Rolim, J. A., & Batista, E. C. (2020). “A gente fica doente também”: percepção do cuidador familiar sobre o seu adoecimento. *Gerais: Revista Interinstitucional de Psicologia*, 13(1), 1.
 11. DSM, V., & AP Association. (2014). Manual diagnóstico e estatístico de transtornos mentais: DSM-5.
 12. Falcão, D., Braz, M., Garcia, C., Santos, G. D., Yassuda, M., Cachioni, M., ... & Forlenza, O. (2018). Atenção psicogerontológica aos cuidadores familiares de idosos com doença de Alzheimer. *Psicologia, Saúde & Doenças*, 19(2), 377-389.
 13. Falcão, H., Santos, I., Fonseca, I., & Coelho, R. (2020). Cuidadores formais e suas necessidades de educação para a saúde: conhecer no presente para atuar no futuro. *Cadernos de Saúde*, 12(Especial), 115-116.
 14. Gratao, A. C. M., Vendruscolo, T. R. P., Talmelli, L. F. D. S., Figueiredo, L. C., Santos, J. L. F., & Rodrigues, R. A. P. (2012). Burden and the emotional distress in caregivers of elderly individuals. *Texto & Contexto-Enfermagem*, 21, 304-312.

15. Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., ... & Pavarini, S. C. I. (2019). Versão breve da Entrevista Zarit Burden (ZBI) para avaliação de carga em cuidadores idosos. *Demência & neuropsiquia*, 13(1), 122-129. <https://doi.org/10.1590/1980-57642018dn13-010015>.
16. Gratao, A. C. M., Vendruscolo, T. R. P., Talmelli, L. F. D. S., Figueiredo, L. C., Santos, J. L. F., & Rodrigues, R. A. P. (2012). Sobrecarga e desconforto emocional em cuidadores de idosos. *Texto & Contexto-Enfermagem*, 21(2), 304-312.
17. Instituto Brasileiro de Geografia e Estatística (IBGE). (2022). *Censo Demográfico 2022*. IBGE. <https://www.ibge.gov.br/estatisticas/sociais/populacao/22827-censo-2022.html?=&t=resultados>
18. Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., ... & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The lancet*, 396(10248), 413-446.
19. Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A., ... Mukadam, N. (2020). Prevenção, intervenção e cuidado da demência: relatório de 2020 da Comissão Lancet. *The Lancet*, 396(10248), 413-446. [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)
20. Malta, M., Cardoso, L. O., Bastos, F. I., Magnanini, M. M. F., & Silva, C. M. F. P. D. (2010). Iniciativa STROBE: subsídios para a comunicação de estudos observacionais. *Revista de Saúde Pública*, 44, 559-565.
21. Mattos, E. B. T., Oliveira, J. P., & Novelli, M. M. P. C. (2020). As demandas de cuidado e autocuidado na perspectiva do cuidador familiar da pessoa idosa com demência. *Revista Brasileira de Geriatria e Gerontologia*, 23(3), e200189.
22. Minayo, M. C. D. S. (2021). Cuidar de quem cuida de idosos dependentes: por uma política necessária e urgente. *Ciência & Saúde Coletiva*, 26, 7-15.
23. World Health Organization. www.who.int/nmh/publications/ncd-status-report-2014/en.
24. Pavarini, S. C. I., Bregola, A. G., Luchesi, B. M., Oliveira, N. A. D., & Ottaviani, A. C. (2023). Fatores sociodemográficos, clínicos e psicossociais associados à sobrecarga de idosos cuidadores de idosos: um estudo transversal. *Demência & Neuropsiquia*, 17, e20220030. <https://doi.org/10.1590/1980-5764-DN-2022-0030>.
25. Perrotta, G. (2020). General overview of “human dementia diseases”: definitions, classifications, neurobiological profiles and clinical treatments. *Journal of Gerontology & Geriatrics Studies*, 6.
26. Queiroga, A. V. I., Pereira, O. C. L., Timoteo, M. L., & Pereira, O. C. L. (2025). Dificuldades e sobrecargas emocionais de cuidadores de idosos: Uma revisão de literatura. *Revista Interdisciplinar em Saúde*, 12(Único), 1355–1367.
27. Rebêlo, F. L., Jucá, M. J., Silva, C. M. de A., Santos, A. I. B., & Barbosa, J. V. P. (2021). FATORES ASSOCIADOS À SOBRECARGA E QUALIDADE DE VIDA DE CUIDADORES DE IDOSOS COM

DEMÊNCIA. *Estudos Interdisciplinares Sobre O Envelhecimento*, 26(2).

<https://doi.org/10.22456/2316-2171.107194>

28. Roland, B. B. S. (2020). Cuidador familiar: identificando a sobrecarga do cuidado.
29. Santos, R. L., Sousa, M. F. B. D., Brasil, D., & Dourado, M. (2011). Intervenções de grupo para sobrecarga de cuidadores de pacientes com demência: uma revisão sistemática. *Archives of Clinical Psychiatry (São Paulo)*, 38(4), 161-167.
30. Scazufca, M. (2002). Versão brasileira da escala Burden Interview para avaliação de sobrecarga em cuidadores de indivíduos com doenças mentais. *Brazilian Journal of Psychiatry*, 24, 12-17.
<https://doi.org/10.1590/S1516-44462002000100006>.
31. Silva, M., Sá, L., & Sousa, L. (2018). Eficácia dos programas psicoeducacionais na sobrecarga nos familiares cuidadores de pessoas com demência: Revisão integrativa. *Revista Portuguesa de Enfermagem de Saúde Mental*, (19), 54-60.
32. Sousa, G. S. D., Silva, R. M. D., Reinaldo, A. M. D. S., Soares, S. M., Gutierrez, D. M. D., & Figueiredo, M. D. L. F. (2021). "A gente não é de ferro": Vivências de cuidadores familiares sobre o cuidado com idosos dependentes no Brasil. *Ciência & Saúde Coletiva*, 26, 27-36. <https://doi.org/10.33448/rsd-v10i8.16990>
33. Souza, P. H., Rodrigues, P. F., Alcantara, R. S., de Carvalho, R. A., Santos, J. H. B., & Machado, M. M. P. (2021). Impactos físicos e emocionais na saúde do cuidador informal de pacientes com doença de Alzheimer. *Research, Society and Development*, 10(8), e1410816990-e1410816990.
34. Tristão, F. I. (2021). População idosa e letramento em saúde: reflexões acerca do acesso e da não utilização dos serviços de saúde. *Jornal de Investigação Médica (JIM)*, 2(2), 053-066.
<https://doi.org/10.29073/jim.v2i2.428>
35. Zarit, S. H., Reeve, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The gerontologist*, 20(6), 649-655.
36. Zigmond, A. S., & Snaith, R. P. (1983). A escala de ansiedade e depressão hospitalar. *Acta psychiatrica scandinavica*, 67(6), 361-370.