**Frequency of care mediates the effect of older adults’ cognitive performance on the perceived strain of their informal caregivers in a Middle-Income Country**

**Abstract:**

**Background and Objectives:** As low and middle-income countries face a rapid increase in their older adult populations, the demand for informal caregiving is expected to rise. Understanding caregiving dynamics in these settings is crucial for developing effective support systems. **Aims:** To investigate whether the frequency and duration of care provided to older adults mediate the relationship between cognitive performance and caregiver strain. **Methods:** A cross-sectional study that evaluated informal caregivers of cognitively unimpaired (n=78) older adults and people living with Alzheimer’s dementia (n=39). We controlled for variables including age, current medications, functional status, cognitive decline, and cognitive functioning. We analyzed whether caregiving frequency and duration mediated the effect of older adults’ cognitive performance on caregiver strain. **Results:** Frequency of care, rather than its duration, significantly mediates the association between older adults’ cognitive performance and caregiver strain. Specifically, more days of care are associated with increased caregiver strain, compared to the total number of caregiving hours. **Conclusion:** Addressing the frequency of caregiving days rather than just the duration in hours offers a more effective approach to reducing caregiver strain. Policies should aim to reduce the number of caregiving days, potentially through expanded respite care programs and full days off for caregivers.

**Keywords:** Alzheimer’s Disease; Caregiver; Burden; Cognition; Under-Represented Groups; Frequency of Care

**Introduction**

Low and middle-income countries are experiencing a rapid increase in their older adult populations. Over the next 15 years, the population of individuals over 60 is expected to increase by 71% in Latin America and the Caribbean, 66% in Asia, 64% in Africa, and 47% in Oceania (Fam et al. 2019; Patterson 2018). Consequently, a substantial portion of the population in low and middle-income countries is likely to either develop dementia and/or require informal care, leading to an increased need for caregivers (Brazil, 2024; Lambert et al., 2017). Accordingly, there is likely to be a growing demand for informal caregiving, particularly in low and middle-income countries, where resources for care are often limited (Kalaria et al. 2024; World Health Organization, 2021). Critically, most of the expenses associated with dementia are linked to informal care, accounting for 50% globally and around 65% in low and middle-income countries (Wimo et al., 2023).

People with dementia experience behavioral, cognitive, and functional impairments that are associated with high levels of strain and distress for their caregivers (Chiari et al. 2021, Tay et al. 2022). Consequently, informal caregivers, who are typically family members or close friends, can face more significant challenges when caring for individuals with dementia compared to other disorders (Teahan et al. 2020). Despite providing essential support, these caregivers often bear a substantial personal cost, particularly socially and emotionally (Lindeza et al. 2020). The challenging impacts on caregivers’ psychological and physical health are considerable, manifesting as emotional, physical, and financial stress, affecting their overall well-being and the quality of care they can provide (Allen et al. 2019).

Previous research has established a connection between the magnitude of older adults’ cognitive decline and the increased strain on their caregivers (Cousins et al. 2023; Pilon et al. 2016; Sorensen et al. 2006). Evidence indicates that carers of people with dementia often experience elevated levels of psychological distress, depressive symptoms, social isolation, and reduced quality of life as a result of their caregiving responsibilities (Lee et al., 2023; Nemcikova et al., 2023; Zhang et al., 2023). However, the impact of caregiving frequency, measured by the number of care days, and caregiving duration, measured by the number of daily care hours, on this relationship has yet to be thoroughly investigated. This issue is particularly pertinent in low and middle-income countries, where socioeconomic and healthcare factors differ significantly from high-income settings (Durgante et al. 2020; Lambert et al. 2017).

This study addresses this research gap by examining how the frequency or duration of care provided affects the relationship between older adults’ cognitive performance and the strain on their informal caregivers in Brazil, a middle-income country. By focusing on a middle-income country, this research seeks to gather data that can inform policy and practice in similar socioeconomic settings, thereby contributing to a better understanding of caregiving dynamics on a global scale. Understanding this relationship is crucial for developing interventions and support systems that can reduce caregiver strain and improve the quality of life for both caregivers and care recipients. The hypothesis is that the time of care provided (i.e. frequency and duration) by informal caregivers mediates the association between older adults’ cognitive performance and the caregiver’s strain.

Finally, it is important to note that compared to high-income countries, low- and middle-income countries often face similar structural and systemic challenges related to the diagnosis, management, and research of dementia and caregiving (ADI, 2021; Durgante et al. 2020; Tan, 2022). In Latin America—where both low- and middle-income countries coexist—these challenges are frequently addressed collectively in the literature (Durgante et al. 2020; Mukadam et al., 2019). Although Brazil is officially classified as a middle-income country, it is marked by significant economic and cultural heterogeneity, with several regions experiencing pronounced social inequalities and vulnerability (Brazil, 2024). For this reason, throughout the manuscript, we occasionally refer to low- and middle-income countries rather than exclusively to middle-income settings, to more accurately reflect the Brazilian context and remain consistent with the international literature.

**Methods**

*Ethics*

This research was conducted following the principles outlined in the Declaration of Helsinki and the guidelines outlined in Resolution 466/12 of the Brazilian National Health Council, which address the ethical considerations of human research. Approval for the study was granted by the Ethics Committee of the Federal University of Sao Carlos (UFSCar), registration number 64200522.5.0000.5504. Data collection commenced only after obtaining signed Informed Consent from participants.

*Design and participants*

 This is a cross-sectional, observational, analytical, and quantitative study. Participants (n=117) were informal caregivers of cognitively unimpaired (CU, n=78) older adults and people living with Alzheimer’s dementia (n=39) residing in the urban area of Sao Carlos, São Paulo – Brazil. The city of São Carlos has 245,448 inhabitants, of whom 17.9% are aged 60 years or older. The municipality is located in the central-eastern region of the state, approximately 228 km from the state capital (Municipality of São Carlos, 2022).

Since the primary independent variable in this study was the cognitive performance of older adults, the inclusion/exclusion criteria were structured based on the cognitive status of the older adults. The following criteria were applied for the inclusion of cognitively unimpaired older adults: (1) being a resident of São Carlos, São Paulo - Brazil; (2) being registered in the primary healthcare system; (3) not presenting cognitive impairment, according to the Clinical Dementia Rating (CDR=0); (4) being 60 years of age or older. For participants in the people living with Alzheimer’s dementia group, the inclusion criteria were: (1) being registered in the outpatient clinics of Internal Medicine, Geriatrics, Gerontology, and/or Neurology at the Federal University of São Carlos Hospital (HU-UFSCar); (2) being under the care of the outpatient clinic teams at HU-UFSCar; (3) having a diagnosis of probable AD (mild, moderate, or advanced) according to the Clinical Dementia Rating (CDR=1; CDR=2 or CDR=3); (4) using medications for Alzheimer's dementia (Donepezil, Rivastigmine, Galantamine, and/or Memantine); (5) having an informal caregiver.

The inclusion criterion for the caregivers was (1) self-identifying as supporting and/or caring for the older adult. To ensure that caregiver participants met the inclusion criterion, the protocol included items assessing whether they provided any form of support to older adults, whether they received assistance with caregiving tasks, the number of days per week they engaged in caregiving, and the number of hours per day dedicated to these responsibilities.

The exclusion criteria for both cognitively unimpaired and people living with Alzheimer’s dementia groups were: having a diagnosis of major depressive disorder, bipolar disorder, schizophrenia, intellectual disability, substance use disorder, hydrocephalus, intracranial mass, significant cerebrovascular dementia as an etiology of dementia, clinically significant alterations in vitamin B12 levels, clinically significant alterations in syphilis serology, history of clinically significant brain injury, other clinically significant neurological conditions, clinically significant auditory and visual deficits (without correction). No exclusion criteria were applied to the caregivers.

*Recruitment and procedures*

Initially, the municipality’s primary and specialized care services provided a list from which potential participants were contacted. If the participant had a diagnosis of dementia due to Alzheimer’s Disease, initial contact was made with the informal caregiver. During the first contact, they were invited to participate in the study, and an initial screening was conducted to confirm their eligibility. If the criteria were met, data collection appointments were scheduled. Participants visited the Department of Gerontology at UFSCaron scheduled dates and times for evaluation. The interview assessed both the caregiver/family member and the older adult individual and started only after the participants signed the informed consent form. In compliance with Brazilian legislation, if an older adult participant had a dementia diagnosis, informed consent was obtained from the participant and a family member or legal guardian. This additional consent confirmed that the older participants would likely have wished to participate if they had full decision-making capacity.

The evaluation process was conducted by staff members who had received prior training from a gerontological and neuropsychological assessment researcher. Initially, caregivers were assessed, followed by the evaluation of the older adult participant. Overall, the caregiver evaluation process lasted approximately 1 hour, while the evaluation of the older adults lasted approximately 1 hour and 30 minutes. Data acquisition occurred between June 2023 and March 2024.

*Instruments*

*Sociodemographic Questionnaire*: Two versions of this instrument were created by the research group: one for the caregiver and the other for the older adult participant. Both contained questions concerning sex (male/female), age (in years), years of education, income (measured in minimum wages), morbidities (quantity of diagnosed health issues), and medication (number of prescribed medications currently taken), marital status (single, married, divorced, widowed), and employment status (employed; retired; inactive - the participant is employed but not working due to sick leave; retirement age but without income - the participant has the legal retirement age but lacks income due to a lack of contribution to a retirement account).

Specifically in the caregiver’s version, additional questions were included regarding the duration of care (in years, days per week, and hours per day), degree of kinship to the care recipient, and whether they received any training to perform caregiving activities. Furthermore, it was also investigated whether informal caregivers received assistance from another person for caregiving duties, as well as whether they received any financial compensation.

*Zarit Burden Interview*: ZBI assesses caregiver strain in individuals providing care to older adults (Zarit et al., 1985). The Brazilian version of the ZBI was adapted and validated for use in the Brazilian context and shows great internal consistency (α=0,87) (Scazufca, 2002). It has 22 questions, whose answers vary from 0 to 4 points each. Final scores range from 0 to 88, and the higher the score, the higher the strain experienced by the caregiver.

*Memory Complaint Scale – Version B*: developed by Vale, Balieiro-Jr, and Silva Filho (2012), this questionnaire has two versions: MCS-A and MCS-B, tailored for use by older adults and family members/caregivers, respectively. Scores span from 0 to 14 points, with the final score categorized as follows: absence of memory complaint (0-2 points), mild memory complaint (3-5 points), moderate memory complaint (7-10 points), and severe memory complaint (11-14 points). In this study, only MCS-B was employed.

*Pfeffer Functional Assessment Questionnaire (P-FAQ)*: it is a 10-item questionnaire that aims to verify the presence and severity of cognitive decline by assessing functionality and, consequently, the assistance required (Pfeffer et al., 1982). Final scores range from 0 to 30 and the higher the score, the higher the dependence level. Its Brazilian version is reliable to use and shows a sensitivity of 75,68%, specificity of 97,26%, and intraclass correlation coefficient exceeding 0.95, which suggests excellent agreement (Dutra et al., 2015).

*Informant Questionnaire on Cognitive Decline in the Elderly – Brazilian Version*: IQCODE is a 26-item questionnaire that assesses the changes in older adults’ cognitive performance in the last 10 years. Each answer varies from 1 to 5 points and final scores are obtained by summing the point of each question and dividing by the total number of items (26). Final scores ≤3 indicate no change, a score of 4 indicates significant changes, and a score of 5 indicates severe changes. IQCODE’s Brazilian version demonstrates good psychometric properties (α=0.94; interclass correlation coefficient=0.92; sensitivity=89%; specificity=72%) (Jansen et al., 2008; Lourenço et al., 2008; Sanchez et al., 2009).

*Addenbrooke’s Cognitive Examination-Revised*: ACE-R evaluates the overall cognitive functioning of participants (Mioshi et al., 2006), and offers insights into five cognitive domains: attention and orientation, memory, verbal fluency, language, and visuospatial abilities. Scores on this battery range from 0 to 100, with higher scores indicating better cognitive performance (Carvalho & Caramelli, 2007). The Brazilian version of this battery demonstrates notable accuracy in discriminating between cognitively unimpaired older adults and those with dementia, with a cutoff of 64 (sensitivity= 91%; specificity= 76%) (César et al., 2017).

*Mini-Mental State Examination* (MMSE): MMSE is a cognitive assessment battery whose scores vary from 0 to 30, and higher scores reflect better cognitive performance (Folstein et al., 1975). Its Brazilian version was adapted and validated by Brucki et al. (2003). A cut-off threshold of 20 distinguishes between CU older adults with lower education levels and those with dementia (sensitivity= 80%; specificity= 71%) (Almeida, 1998). In this study, we employed Mini-Mental State Examination scores extracted from the ACE-R battery.

*Clinical Dementia Rating*: CDR was developed in 1979 as part of the "Memory and Aging" project at Washington University in St. Louis, Missouri, USA, and aims to classify dementia stages, particularly Alzheimer's (Hughes et al., 1982). Adapted and validated for Brazil by Montaño and Ramos (2005), it integrates information from family members/caregivers with patient responses during the interview. Scores range from 0 to 3, with higher scores indicating greater severity of dementia.

*Consortium to Establish a Registry for Alzheimer’s Disease Battery- word list*: CERAD is a cognitive assessment battery (Morris et al., 1989), which has been adapted and validated to the Brazilian population by Bertolucci et al. (1998). The word list from the CERAD battery is an episodic memory task (Morris et al., 1989) and evaluates the retention of ten words presented three times consecutively. For immediate memory scoring, the sum of words recalled across the three trials is used, ranging from 0 to 30 points. For delayed recall (after ten minutes) and recognition, scoring ranges from 0 to 10 points, with higher scores indicating better memory ability.

*Geriatric Anxiety Inventory – 5-item version*: its original version was created by Pachana et al. (2007), has 20 items, and evaluates older adults’ anxiety symptoms. Recently, a short form was developed (Byrne & Pachana, 2011) using 5 of the original items. The presence of three or more symptoms on this short form indicates the likely presence of Generalized Anxiety Disorder, according to the authors’ recommendations. GAI-5 shows good internal consistency and appropriate convergent and divergent validity. In its Brazilian version, GAI-5 shows adequate internal consistency (0,62) and time stability (0,97) (Silva et al., 2016).

*Geriatric Depression Scale – 15 items*: GDS-15 assesses depressive symptoms among older adults using a series of 15 questions (Sheikh & Yesavage, 1986). The scoring system classifies symptoms into three categories: <5 points mean an absence of depressive symptoms; 5 to 10 points indicate mild depressive symptoms; and scores exceeding 11 points suggest severe depressive symptoms. In its Brazilian version, the instrument exhibits great reliability (α=0.81) (Almeida & Almeida, 1999).

*Data analysis*

A priori sample size was calculated considering a significance level of α=0.05, power of 0.8, and effect size (f2) of 0.15. One hundred and two participants were required for the regression analysis with five predictors. G Power (version 3.1) was used to calculate the sample size (Faul, Erdfelder et al. 2009).

Categorical variables were presented as percentages, while continuous variables were represented using means and standard deviations. Informal caregiver participants were categorized based on the diagnosis status of the older adult to whom they provided care (i.e., cognitively unimpaired or with Alzheimer’s dementia). For group comparison analyses, the Student’s T-test and the Chi-Square test were used for continuous and categorical variables, respectively. For correlation analysis, Pearson’s correlation was employed.

We conducted a mediation analysis to test the hypothesis that the time dedicated to care (i.e. frequency and duration) mediates the association between the cognitive performance of the person cared for and the perceived strain of their informal caregivers. First, we performed a bivariate regression analysis between the independent variable (cognitive performance, as per ACE-R scores) and the dependent variable (perceived strain, as per ZBI scores) to determine the total effect. After that, we regressed the independent variable on the potential mediator. The last analysis consisted of multiple regression of older adults’ cognitive performance and time dedicated to care on the perceived strain. Such analysis provided both the direct effect of cognitive performance on the perceived strain and the impact of the potential mediator on the independent variable. Bias-Corrected and Accelerated Confidence Intervals (BCa CI) were used to verify the significance of the mediation effect.

Analyses were conducted in SPSS, version 29.0.0, and PROCESS v.4.1 (Hayes, 2022). Images were created on GraphPad Prism, version 9.2.0. Statistical significance was met when p≤0.05, specifically for the indirect effect if the CI did not include 0.

**Results**

*Participants’ characteristics and group comparison*

Table 1 shows caregiver participants’ sociodemographic and clinical characteristics. Informal caregivers were primarily female (72.6%), whose mean age and years of education were, respectively, 55 (±13.8) and 13.5 (±6.1). Regarding occupational status, most participants were either active in the labor market (47%) or retired (31.6%). Considering the degree of kinship between the caregiver and the older person who received care, participants were frequently son/daughter (47.9%) or spouse (38.5%). The sample’s mean Zarit Burden Interview score was 18.7 (±17.7). Caregivers of individuals with dementia experienced a significantly higher strain, with a mean score of 33.2 (±16.5), compared to those caring for cognitively unimpaired individuals, who had a mean score of 11.5 (±13.3) (T=-7.7; p=<0.001).

Table 2 demonstrates the characteristics of care provided by the participants in this study. Regarding the time of care, 68.9% of the informal caregivers had been caring for the older person for three years or more, with a mean time of 9.4 (±9.7) hours per day and 5.4 (±2.5) days per week. Group comparison analyses revealed that, compared to caregivers of CU, more caregivers of people living with Alzheimer’s dementia received training (20.5%; χ2=9.2; p=0.002) and help/support in care duties (47.4%; χ2=10.62; p=0.001). People caring for persons living with Alzheimer’s dementia had also been taking care for more extended periods (χ2=10.87; p=0.012), during more days per week (T=-3.73; p<0.001) and more hours per day (T=-4.97; p<0.001) than those caring for CU individuals. Because all participants were informal caregivers, none received financial compensation. Also, 9.3% of our sample had received training and 28.3% help/support in care duties.

 Table 3 shows the characteristics of the older adults who received care. Older adults were primarily female (66.7%) with a mean age of 73.1 (±8.8). On average, older adults had 10.5 (±6.5) years of education, 2.3 (±1.6) diagnosed health problems, and were taking 4 (±3.5) prescribed medicines. Group comparison analyses showed that people living with Alzheimer’s dementia were older (T=-9.17; p<0.001), had less years of education (T=4.75; p<0.001), and more diagnosed health problems (T=-3.32; p=0.001), as well as were taking more medicines (T=-4.07; p<0.001). As expected, people with Alzheimer’s dementia had poor cognitive performance on ACE-R (T=12.05; p<0.001), MMSE (T=11.26; p<0.001), and on CERAD’s word list (Immediate Recall – T=9; p<0.001 / Evocation – T=7.32; p<0.001 / Recollection – T=4.74; p<0.001). Also, as expected, persons living with AD had higher scores on P-FAQ (T=-14.66; p<0.001), MCS-B (T=-17.47; p<0.001), and IQCODE-BR (Total – T= -14.11; p<0.001 / Mean – T=-14.16; p<0.001). No differences were observed in anxiety (T=-0.79; p=0.432) or depressive symptoms (T=-1.7; p=0.092).

*Correlation analysis*

Pearson’s correlation analyses were performed to verify the variables related to the cognitive performance of older adults. Scores on ACE-R, MMSE, and CERAD’s word list (Immediate Recall; Evocation; Recollection) had a negative correlation with older adults age (ACE-R: r= -0.673; p≤0.001 / MMSE: r= -0.593; p≤0.001 / Immediate Recall: r: -0.557; p≤0.001 / Evocation: r= -0.314; p≤0.001 / Recollection: r= -0.426; p≤0.001) and the number of medicines in current use (ACE-R: r= -0.345; p≤0.001 / MMSE: r= -0.399; p≤0.001 / Immediate Recall: r: -0.349; p≤0.001 / Evocation: r= -0.191; p=0.049 / Recollection: r= -0.289; p=0.003). Cognitive performance was also correlated with older adults’ years of education (ACE-R: r= 0.624; p≤0.001 / MMSE: r= 0.505; p≤0.001 / Immediate Recall: r: 0.502; p≤0.001 / Evocation: r=0.226; p=0.019 / Recollection: r= 0.343; p≤0.001). Except for scores on the CERAD word list for evocation task, cognitive assessment scores were significantly correlated with depressive symptoms, as per GDS-15 scores (ACE-R: r= -0.222; p=0.018 / MMSE: r= -0.246; p=0.009 / Immediate Recall: r: -0.276; p=0.003 / Evocation: r=0.002; p=0.986 / Recollection: r= -0.264; p=0.005). Finally, a correlation between GAI-5 scores and ACE-R / MEEM was also observed (ACE-R: r= -0.257; p=0.006 / MMSE: r= -0.193; p=0.043).

Regarding the informal caregivers’ perceived strain, Zarit scale total scores were correlated with P-FAQ (r= 0.629; p≤0.001), MCS-B (r= 0.634; p≤0.001), IQCODE-BR (r= 0.584; p≤0.001), but not with caregivers age (r=-0.011; p=0.908) or caregivers’ years of education (r= -0.003; p=972). Caregivers’ strain was also correlated with older adults’ age (r=0.567; p≤0.001), years of schooling (r= -0.218; p=0.021), number of medicines in current use (r=0.298; p=0.001), depressive symptoms (r=0.287; p=0.002), and cognitive performance (ACE-R: r= -0.530; p≤0.001 / MMSE: r= -0.552; p≤0.001 / Immediate Recall: r: -0.529; p≤0.001 / Ev.: r= -0.362; p≤0.001 / Rec.: r= -0.500; p≤0.001) and time dedicated to care in days (r=0.405; p≤0.001) and hours (r=0.401; p≤0.001) demonstrated positive correlation with strain. Figure 1 illustrates the heatmap for this correlation analysis.

*Mediation analysis*

A mediation analysis was performed to investigate whether the time dedicated to care (i.e. frequency and duration) mediated the relationship between older adults’ cognitive performance and their caregivers’ perceived strain. Initially, a linear regression indicated a significant total effect (c) of older adult’s cognitive performance on the caregivers’ perceived strain (b = -0.358, 95% CI [-0.465 to -0.251], t = -6.65, p < 0.001, R² = 0.281). Additionally, older adult’s cognitive performance was significantly associated with both duration (in hours, b = -0.149, 95% CI [-0.216 to -0.081], t = 4.35, p < 0.001, R² = 0.168) and frequency (in days, b = -0.029, 95% CI [-0.047 to -0.011], t = -3.24, p = 0.002, R² = 0.099) of care provided by their informal caregivers. When controlling for duration of care in hours, the cognitive performance had a significant direct effect (c’) on the caregiver’s perceived strain (b = -0.258, 95% CI [-0.383 to -0.134], t = -4.12, p < 0.001).

A direct effect was also observed when cognitive performance was regressed on strain scores controlling for frequency of care (b = -0.285, 95% CI [-0.403 to -0.168], t = -4.83, p < 0.001). Finally, both duration (b = 0.728, 95% CI [0.391 to 1.066], t = 4.29, p < 0.001, R² = 0.161) and frequency of care (b = 2.898, 95% CI [1.578 to 4.217], t = 4.35, p < 0.001, R² = 0.164) had significant effects on caregiver’s strain.

Because of our sample’s characteristics and correlation analysis results, we conducted multivariate regression analyses to verify whether the time dedicated to care remained associated with caregivers’ perceived strain after controlling for older adults’ age, medicines in current use, P-FAQ, IQCODE-BR, and ACE-R mean scores. The effect of frequency (b = 1.449, 95% CI [0.220 to 2.678], t = 2.34, p = 0.021, R² = 0.475), but not duration (b = 0.269, 95% CI [-0.073 to 0.611], t = 1.563, p = 0.121, R² = 0.434), was still significant. The association between the mediator and the dependent variable is a key assumption for conducting mediation analysis. In the multivariate analysis, caregiving duration (i.e., the potential mediator) showed no significant impact on caregiver strain (i.e. the dependent variable) after adjusting for covariates. Consequently, the evidence was insufficient to justify proceeding with mediation analysis for the duration of care. However, caregiving frequency continued to exert a significant effect on perceived caregiver strain, even after accounting for covariates. Thus, the assumptions for mediation analysis were met, and the analysis was performed to explore the potential mediating role of caregiving frequency.

The final model suggested a mediation effect (indirect effect) of frequency of care (b = -0.055; 95% BCa CI [-0.100 to -0.013]) on caregiver strain. Figure 2 illustrates the mediation model.

**Discussion**

In this study, we aimed to explore whether the frequency of care (in days) or duration (in hours) would mediate the connection between older adults’ cognitive performance and the perceived strain of their informal caregivers in a middle-income country after controlling for age, medicines in current use, function (P-FAQ), cognitive decline (IQCODE-BR), and cognitive functioning (ACE-R). Our findings indicate that the frequency of care, rather than the duration, mediates this association. Therefore, more days of care is related to a higher caregiver-perceived strain compared to more hours of care.

Caring for older adults with dementia is linked to well-documented rises in strain, distress, and declines in carers’ mental health and overall well-being (Lindeza et al. 2020). Moreover, the severity of behavioral, cognitive, and functional impairments in persons living with dementia correlates with heightened levels of strain and distress for their caregivers (Chiari et al. 2021, Tay et al. 2022).

Our findings suggest that the cognitive performance of older adults, their age, and their level of functionality were associated with caregiver strain, as also reported in the literature (Allen et al., 2019; Lee et al., 2023; van den Kieboom et al., 2020). Interestingly, although available evidence demonstrates that caregiver age is associated with the perceived level of strain (Lee et al., 2023; van den Kieboom et al., 2020), our results did not suggest such a relationship. Considering that the data analyzed were from a Latin American country, the association between caregiver age and caregiver strain may not be straightforward due to cultural norms that place the responsibility of caring for older family members on relatives, a concept known as familism (Villa-Castelar et al., 2022). These sociocultural expectations can shape the caregiving dynamic, assigning this role to family members (Martinez & Gonzales, 2022), regardless of the caregiver's age.

To our knowledge, no studies have separately evaluated the mediating effects of the frequency and duration of care on these aspects. It has been reported that caregiver strain tends to escalate with the number of care hours, the volume of tasks, and diminishing coping mechanisms and support resources (Sorensen et al. 2006). Specifically in the context of caregiving frequency, measured in days per week, one study identified an association between this variable and the perceived strain among caregivers of older adults (Yan et al., 2019). On the same hand, our study corroborates with such evidence and advances in the sense that it shows evidence that more days of caring, rather than the number of care hours, increases the caregiver’s perceived strain.

More studies need to assess the mediating effects of the relationship between cognitive performance in older adults and the perceived strain of their caregivers, especially in low and middle-income countries. A previous multi-country analysis examining the effect of caregiver age on care strain and psychological morbidity across many low and middle-income countries indicated lower psychological morbidity among older caregivers compared to younger ones (Phetsitong et al. 2022). However, the authors did not investigate any mediating variables or the caring frequency, preventing meaningful comparisons. In our study, we observed that the cognitive performance of older adults is associated with caregiver strain, and this relationship is mediated by the frequency of care rather than its duration.

Our study’s findings have important implications for creating new dementia care models and providing insight into shaping public policies to aid caregivers in low and middle-income countries. Our results suggest that policies to reduce caregiving duration time may not effectively alleviate caregiver stress (Acton & Kang 2001). Understanding that the frequency of care (days caring) is more impactful on caregiver strain, at least in Brazil, suggests that policymakers could focus on reducing the number of days caregivers are required to provide care rather than the total daily hours. Interventions could be developed and expanded to offer caregivers full days off, allowing them to engage in other activities, rest, or manage their personal affairs, ultimately reducing their perceived strain. For example, a systematic review showed that daycare delivered in specialized settings for older adults can reduce caregiver strain (Vandepitte et al. 2016). Similarly, respite care programs that provide caregivers full days of relief rather than just a few hours could be more effective in mitigating caregiver stress (Beach et al. 2022).

Assessing the feasibility and practicality of implementing such changes within the country’s existing healthcare and social support infrastructure is essential. The proposed changes must be sustainable and supported by the current system. Moreover, policies should be flexible enough to accommodate caregiver and patient circumstances and wishes, recognizing that caregiving needs and situations vary widely.

However, while suggesting that days of care should be fewer, it is essential to ensure that the care needs of individuals with dementia are adequately met. Longer hours of care on fewer days must still meet the patient’s needs for care and attention. It is also crucial to consider the preferences and capacities of caregivers. Some caregivers might prefer spreading out their caregiving responsibilities rather than having intense caregiving days.

Strengthening support networks, such as caregiver support through in-person or virtual groups, is another effective strategy that has been tested in the context of low and middle-income countries (Ferretti et al. 2021; Monteiro et al. 2023). These networks can step in on certain days to provide necessary care, ensuring that caregivers do not have to provide care every day.

Educational programs that teach efficient caregiving techniques and stress management strategies are essential (Pihet et al. 2024). Such programs should focus on handling cognitive impairments effectively within consolidated caregiving periods. Social support services, such as counseling and peer support groups, could also mitigate the psychological strain associated with frequent caregiving.

It is also important to mention that the frequency of care is a key indicator of caregiving demands and impacts the potential for caregiver empowerment (Kraun et al., 2022). Sufficient engagement in caregiving activities may facilitate skill acquisition, strengthen the caregiver-care recipient relationship, and enhance self-efficacy (Kraun et al., 2022; Meyer et al., 2022). However, without adequate support, higher caregiving frequency may exacerbate strain, as evidenced by the literature and our results. Future research should explore how the frequency of care intersects with positive caregiving outcomes, including carer empowerment.

This study has limitations, we did not examine what caregiving activities consisted of, for example, those providing more personal care assistance such as washing, dressing, and going to the toilet may have experienced more strain than those assisting with activities such as shopping and finances. Furthermore, we did not assess whether financial compensation or previous caregiving training influenced caregivers' perceptions of burden, which should be considered when interpreting our findings. Additionally, we did not comprehensively evaluate social support and specific measures of participants’ socioeconomic conditions. These aspects are crucial for caregivers in managing their roles, especially when considering the disparities within these populations in low and middle-income countries (Ibanez et al. 2021, Nemcikova et al. 2023). Particularly when policies that provide financial support or subsidies for caregivers who reduce their work hours to provide care can significantly alleviate any financial strain (Bainbridge & Townsend 2020).

In conclusion, our results underscore the importance of focusing on the frequency of care (days caring) in reducing caregiver strain. This study contributes to advancing the understanding of caregiver strain within the middle-income Latin American context. The findings offer evidence of factors influencing caregiving in this region and highlight the importance of tailoring interventions to these unique dynamics. Moreover, the results can support the development of targeted public policies that address caregiver needs, improve support systems, and ultimately enhance the quality of care for older adults. These contributions are crucial for guiding future research and promoting effective, culturally sensitive strategies to alleviate caregiver strain, which is a public health concern.

 It will be necessary for low and middle-income countries to customize solutions to fit their specific circumstances. This involves identifying the most suitable programs or services within their limitations and using information about local contexts. Services should be designed based on an understanding of local resources to enable the evaluation of their impact and the provision of adequate and sustainable programs.

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**Table 1.** Sociodemographic characteristics and clinical variables of informal caregivers stratified by diagnosis group. Values are expressed as means and SD in brackets or percentages.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Total****(n=117)** | **Cognitively Unimpaired****(n=78)** | **People with Alzheimer’s dementia****(n=39)** | **T** | **p** |
| Gender, % female | 72.6 | 66.7 | 84.6 | 4.22\* | 0.040 |
| Age, in years | 55.0 (±13.8) | 54.3 (±14.6) | 56.3 (±12.1) | -0.76 | 0.452 |
| Education, in years | 13.5 (±6.1) | 14 (±6.0) | 12.6 (±6.2) | 1.06 | 0.293 |
| Occupation | - | - | - | 9.20\* | 0.056 |
| Unemployed, % | 17.1 | 10.3 | 30.8 | - | - |
| Active, % | 47.0 | 50.0 | 41.0 | - | - |
| Retired, % | 31.6 | 35.9 | 23.1 | - | - |
| Paid leave, % | 0.9 | 1.3 | 0.0 | - | - |
| Other, % | 3.4 | 2.6 | 5.1 | - | - |
| Degree of kinship | - | - | - | 21.68\* | <0.001 |
| Son/Daughter, % | 47.9 | 34.6 | 74.4 | - | - |
| Wife/Husband, % | 38.5 | 50.0 | 15.4 | - | - |
| Sibling, % | 6.8 | 10.3 | 0 | - | - |
| Other, % | 6.8 | 5.1 | 10.2 | - | - |
| Zarit scores | 18.7 (±17.7) | 11.5 (±13.3) | 33.2 (±16.5) | -7.70 | <0.001 |

\*= Pearson’s Chi-Square (χ2).

**Table 2.** Characteristics of care provided by informal caregivers according to the diagnosis group. Values are expressed as means and SD in brackets or percentages.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Total** **(n=117)** | **Cognitively Unimpaired****(n=78)** | **People with Alzheimer’s dementia****(n=39)** | **T** | **p** |
| Years as a caregiver | - | - | - | 10.87\* | 0.012 |
| < 1 year, % | 14.6 | 18.5 | 7.9 | - | - |
| 1 year, % | 7.8 | 3.1 | 15.8 | - | - |
| 2 years, % | 8.7 | 4.6 | 15.8 | - | - |
| ≥ 3 years, % | 68.9 | 73.8 | 60.5 | - | - |
| Time of care provided | - | - | - | - | - |
| Hours per day | 9.4 (±9.7) | 6.1 (±8.5) | 15.4 (±9.1) | -4.97 | <0.001 |
| Days per week | 5.4 (±2.5) | 4.8 (±2.8) | 6.4 (±1.5) | -3.73 | <0.001 |
| Receive help/support, % yes | 28.3 | 17.6 | 47.4 | 10.62\* | 0.001 |
| Received training, % yes | 9.3 | 2.9 | 20.5 | 9.20\* | 0.002 |
| Receive payment, % yes | 0 | 0 | 0 | - | - |

\*= Pearson’s Chi-Square (χ2).

**Table 3.** Demographic characteristics and clinical variables of the older adults who received care stratified by diagnosis group. Values are expressed as means and SD in brackets or percentages.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Total** **(n=117)** | **Cognitively Unimpaired****(n=78)** | **People with Alzheimer’s dementia****(n=39)** | **T** | **p** |
| Gender, % female | 66.7 | 62.8 | 74.4 | 1.56\* | 0.212 |
| Age, in years | 73.1 (±8.8) | 69.1 (±6.5) | 81.1 (±7) | -9.17 | <0.001 |
| Education, in years | 10.5 (±6.5) | 12.4 (±6.4) | 6.7 (±5.1) | 4.75 | <0.001 |
| Diagnosed health problems | 2.3 (±1.6) | 1.9 (±1.5) | 2.9 (±1.6) | -3.32 | 0.001 |
| Medicines in use | 4 (±3.5) | 2.9 (±2.6) | 5.9 (±4.1) | -4.07 | <0.001 |
| ACE-R | 69.9 (±26.2) | 84.1 (±13.7) | 39.9 (±20.3) | 12.05 | <0.001 |
| MMSE | 24.1 (±6.5) | 27.4 (±3.5) | 16.5 (±5.2) | 11.26 | <0.001 |
| CERAD | - | - | - | - | - |
| Immediate Recall | 14.3 (±6.9) | 17.2 (±5.6) | 7.6 (±4.3) | 9 | <0.001 |
| Evocation | 4.4 (±6.2) | 6.1 (±6.7) | 0.5 (±1.1) | 7.32 | <0.001 |
| Recollection | 8 (±2.5) | 8.9 (±1.6) | 6.2 (±3.1) | 4.74 | <0.001 |
| P-FAQ | 7.9 (±11) | 1.2 (±3.2) | 21.5 (±8.3) | -14.66 | <0.001 |
| MCS-B | 6.3 (±5.4) | 3.2 (±3.4) | 12.5 (±2.3) | -17.47 | <0.001 |
| IQCODE-BR | - | - | - |  |  |
| Total score | 88.9 (±24.8) | 74.8 (±16.2) | 116.4 (±12.2) | -14.11 | <0.001 |
| Mean score | 3.4 (±1) | 2.9 (±0.6) | 4.5 (±0.5) | -14.16 | <0.001 |
| GAI-5 | 3 (±1.8) | 2.9 (±1.8) | 3.2 (±1.9) | -0.79 | 0.432 |
| GDS-15 | 3.5 (±3.1) | 3.2 (±3) | 4.2 (±3.1) | -1.7 | 0.092 |

\*= Pearson’s Chi-Square (χ2); ACE-R= Addenbrooke’s Cognitive Examination – Revised version; MMSE – Mini-Mental State Examination from ACE-R; CERAD= Consortium to Establish a Registry for Alzheimer’s Disease; P-FAQ= Pfeffer Functional Assessment Questionnaire; MCS-B= Memory Complaint Scale – version B; IQCODE-BR= Informant Questionnaire on Cognitive Decline in the Elderly – Brazilian Version; GAI-5= Geriatric Anxiety Inventory – 5 items; GDS-15= Geriatric Depression Scale – 15 items.



**Figure 1.** Heatmap of Person’s correlation analysis. OA = Older adult; CGV = Caregiver; ACE-R = Addenbrooke’s Cognitive Examination – Revised; MMSE= Mini-Mental State Examination; IR = CERAD’s word list – Immediate Recall; Evocation = CERAD’s word list – Evocation; Recollection = CERAD’s word list – Recollection; GAI-5. Geriatric Anxiety Inventory – 5 items; GDS-15 = Geriatric Depression Scale – 15 items; YOE = Years of Education; P-FAQ = Pfeffer Functional Activities Questionnaire; MCS-B = Memory Complaint Scale – B; IQCODE-BR = Informant Questionnaire on Cognitive Decline in the Elderly – Brazilian Version.



**Figure 2.** Model illustrating the effect of older adults’ cognitive performance on their caregivers’ perceived strain, mediated by the frequency of care (in days). 95% Bias-Corrected and Accelerated Confidence Interval (BCa CI) was obtained through Bootstrapping analysis (5.000 samples).