



## HOME COGNITIVE INTERVENTION FOR ELDERLY WITH ALZHEIMER'S CAREGIVERS

### INTERVENÇÃO COGNITIVA DOMICILIAR PARA CUIDADORES DE IDOSOS COM ALZHEIMER INTERVENCIÓN COGNITIVA DOMICILIAR PARA CUIDADORES DE ANCIANOS CON ALZHEIMER

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#### ABSTRACT

**Objective:** to evaluate the effect of cognitive intervention on cognition, overload and stress in caregivers of elderly people with Alzheimer's disease. **Method:** this is a quasi-experimental quantitative study with 17 informal caregivers of elderly people with Alzheimer's disease. The Addenbrooke's Cognitive Examination-Revised (ACE-R), Perceived Stress Scale (PSS) and Zarit's Overload Scale were used for the evaluation before and after the intervention. The results were analyzed by the SPSS, applying the Student's t-test to evaluate the effect of the intervention. **Results:** women (88.2%) were identified, with a mean age of 52.5 years and mean schooling of 8.8 years. It was found a significant improvement in the general cognition by the MEEM ( $p = 0.008$ ) and ACE-R ( $p = 0.003$ ) and in the attention domains ( $p = 0.004$ ), memory ( $p = 0.017$ ) and verbal fluency ( $p = 0.023$ ). **Conclusion:** it was evaluated by the cognitive home improvement intervention in general cognition in caregivers of elderly people with Alzheimer's disease, and can be an important tool to promote health. **Descriptors:** Aged; Caregivers; Cognition; Stress, Psychological; Clinical Trial; Geriatrics.

#### RESUMO

**Objetivo:** avaliar o efeito de intervenção cognitiva domiciliar sobre a cognição, a sobrecarga e o estresse em cuidadores de idosos com Doença de Alzheimer. **Método:** trata-se de estudo quantitativo, tipo quase-experimental, com 17 cuidadores informais de idosos com Doença de Alzheimer. Utilizaram-se o Addenbrooke's Cognitive Examination-Revised (ACE-R), a Escala de Estresse Percebido (PSS) e a Escala de Sobrecarga de Zarit para a avaliação antes e depois da intervenção. Analisaram-se os resultados pelo SPSS, aplicando-se o test t de student para avaliar o efeito da intervenção. **Resultados:** identificaram-se mulheres (88,2%), com idade média de 52,5 anos e escolaridade média de 8,8 anos. Constatou-se melhora significativa na cognição geral pelo MEEM ( $p=0,008$ ) e ACE-R ( $p= 0,003$ ) e nos domínios atenção ( $p= 0,004$ ), memória ( $p= 0,017$ ) e fluência verbal ( $p= 0,023$ ). **Conclusão:** avaliou-se pela intervenção cognitiva domiciliar melhora na cognição geral em cuidadores de idosos com Doença de Alzheimer, podendo ser uma importante ferramenta de promoção a saúde. **Descritores:** Idoso; Cuidadores; Cognição; Estresse Psicológico; Estudo de Intervenção, Geriatria.

#### RESUMEN

**Objetivo:** evaluar el efecto de intervención cognitiva domiciliar sobre la cognición, la sobrecarga y el estrés en cuidadores de ancianos con enfermedad de Alzheimer. **Método:** se trata de un estudio cuantitativo, tipo casi-experimental, con 17 cuidadores informales de ancianos con enfermedad de Alzheimer. Se utilizaron el Addenbrooke's Cognitive Examination-Revised (ACE-R), la Escala de estrés percibido (PSS) y la escala de sobrecarga de Zarit para la evaluación antes y después de la intervención. Se analizaron los resultados por el SPSS, aplicándose el test t de student para evaluar el efecto de la intervención. **Resultados:** se identificaron mujeres (88,2%), con edad media de 52,5 años y escolaridad promedio de 8,8 años. Se observó una mejora significativa en la cognición general por el MEEM ( $p = 0,008$ ) y ACE-R ( $p = 0,003$ ) y en los dominios atención ( $p = 0,004$ ), memoria ( $p = 0,017$ ) y fluencia verbal ( $p = 0,023$ ). **Conclusión:** se evaluó por la intervención cognitiva domiciliar melhora en la cognición general en cuidadores de ancianos con Enfermedad de Alzheimer, pudiendo ser una importante herramienta de promoción a la salud. **Descriptores:** Anciano; Cuidadores; Cognición; Estrés Psicológico; Ensayo Clínico; Geriatria.

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INTRODUCTION

It is known that population aging is a worldwide phenomenon due to the fall in fertility and mortality rates, which leads to the prolongation of the population's life expectancy. The elderly were represented in Brazil in 2016 about 12.11% of Brazilians and projections indicate that, by the year 2050, this rate rises to 29.50%.<sup>1</sup>

It is known that, along with the aging process, the onset of chronic non-communicable diseases has been highlighted. It is considered that they may or may not compromise the functional capacity and quality of life of the elderly, implying the need for caregivers.<sup>2</sup> Dementias are characterized in this group of diseases due to the loss of autonomy in the individual, the most prevalent being Alzheimer's Disease (AD), which is considered a progressive brain disorder that affects the memory, reasoning and communication of the affected individual.<sup>3</sup> The role of the caregiver is essential because it entails total or partial dependence on care, especially home care.<sup>4-5</sup>

It is understood that caregivers care for those unable to perform tasks such as personal hygiene, food and financial management; is also called an informal caregiver because they do not receive any payment for the care provided and, as a family member, because they are a spouse, daughter, daughter-in-law or brother.<sup>6</sup>

It is shown in the literature that family caregivers of people with dementia experience high rates of stress and overload, with physical and mental impacts resulting from the demands of care provided.<sup>7-9</sup>

It is understood that stress is a response to excess demands, which leads to psychological and biological risks to health.<sup>10</sup> Psychologically, they are produced by excessive stress, mental exhaustion, loss of concentration, memory deficit, apathy, and emotional indifference.<sup>10</sup> As for the overload, one has to be objective or subjective. It is known that the objective overload is related as practical problems occurred in the daily life of caregivers such as financial difficulties, health problems and the neighborhood. On the other hand, subjective overload is related to the caregiver's sense of obligation to care and cares about the elderly.<sup>11</sup>

It is added that the literature shows that caregivers can also present cognitive alterations, which often arise as a consequence of the stress and the overload experienced, or even by genetic factors, since

they are family caregivers of the elderly with the AD.<sup>12</sup>

It is recognized that there is a shortage of studies at the national level that focus cognitive interventions for caregivers with the aim of preventing dementia and reducing stress and overload, since most of the research reports on psychoeducational interventions. Currently, it is known that cognitive interventions have shown important results in cognition, as well as depressive and anxious symptoms in the elderly.<sup>13-14</sup> It is also emphasized that such interventions can be used as forms of support (group or individual) psychoeducation, multicognition, specific knowledge or cognitive stimulation, in order to work with the caregiver aspects important for care, health promotion and disease prevention.<sup>8</sup>

It is noted that, unlike many other countries (including Latin American countries such as Argentina and Chile), Brazil still does not have any specific national public policy for the care of the person with dementia and their families, nor does it implement home-based cognitive interventions for these caregivers. Thus, it is considered that this study represents an initial step for the promotion of health, prevention of diseases and care for family caregivers of individuals with dementia at home.

OBJECTIVE

- To evaluate the effect of cognitive intervention on cognition, overload and stress in caregivers of elderly people with Alzheimer's disease.

METHOD

This is a quantitative, quasi-experimental study carried out in the city of São Carlos (SP). All the participants of the Department of Home Care (DHC), belonging to a private health care provider of São Carlos (health insurance), were created to provide the promotion and prevention of care with their family caregivers. A list of all the existing family caregivers (n = 54) was obtained through the coordination of the DHC, and from this, a telephone call was made to invite them to participate. After this step, 32 family caregivers accepted, however, only 17 were included respecting the inclusion criteria.

Informal caregivers of elderly people with AD diagnosis who have been caring for more than one year, agreed to the health care provider, and excluded caregivers or caregivers of the elderly with AD have been included in this study for less than one year, who have any physical or mental illness or

disorder or untreated systemic diseases and uncorrected auditory and visual deficits that make it impossible to participate and perform cognitive tests.

It is noteworthy that the elderly care recipients selected for the study were diagnosed with AD in the last 12 months, by physicians accredited at the health care provider of the Neurology and Geriatrics specialties. The list of the elderly with AD was also acquired, by the coordination of the DHC of the Health Operator.

This research was approved by the Research Ethics Committee of the Federal University of São Carlos under 2.069.671/2017 (CAAE 65119517.1.0000.5504).

A Free and Informed Consent Term (FICT) was presented prior to starting the evaluation, which was read together with the caregiver and had two ways signed by him and the evaluator; one was maintained with the caregiver and the other was attached to their evaluation.

### Collection instruments

#### ◆ Sociodemographic and clinical data

An instrument was used to characterize the caregiver with information such as sex, age, schooling, degree of kinship, knowledge about the disease, if he / she participates in / participates in a course to take care of, hours dedicated to caring and support.

#### ● Cognitive data

It is explained that the Addenbrooke's Cognitive Examination-Revised (ACE-R) is a battery of short cognitive evaluation developed by researchers of the Service of Cognitive Neurology of the University of Cambridge, United Kingdom, in 2000. It has been adapted into Brazilian Portuguese and validated.<sup>15</sup> This tool tests five cognitive domains separately. The maximum score is 100 points distributed as follows: orientation and attention (18 points); memory (35 points); verbal fluency (14 points); language (28 points) and visuospatial skills (five points). Scores for each of the six cognitive domains can be calculated separately, and their sum corresponds to the ACE-R participant's overall score. Within this total, 30 points refer to the Mini Mental State Examination (MMSE) score. A recent study confirmed that the Brazilian version of ACE-R maintains high accuracy in the identification of AD when the cutoff point is set at 78.<sup>16</sup>

#### ● Stress and overload data

The Perceived Stress Scale (PSS), developed in 1983, was translated and validated in Brazil.<sup>17</sup> The items were designed to verify how unpredictable, uncontrollable and overloaded the respondents evaluate

their lives and perceive the situations as stressful. It is a general scale that can be used in various age groups. PSS has 14 questions with answer options ranging from zero (never) to four (always). Some issues have a positive connotation and others, negative ones, being adjusted at the moment of the punctuation. The total of the scale is the sum of the scores of these 14 questions and the scores can vary from zero to 56, and the higher the score, the greater the level of stress perceived by the individual.<sup>18</sup>

The Zarit Overload Scale, elaborated in 1987<sup>19</sup>, was validated and translated for the Brazilian scope, in 2002.<sup>20</sup> It aims to assess the impact of care-related activities that the caregiver perceives about their physical and emotional health, financial conditions, and social relationships. It has 22 items where responses should be given according to a five-point scale: never (0), rarely (1), sometimes (2), often (3), and always (4), describing how each statement affects the person. The total scale is obtained by summing the statements and can range from zero to 88 points. The higher the score, the greater the overhead.

From the inclusion of the 17 selected caregivers, a first home visit was carried out to evaluate the participants. After this stage, in a second home visit, the activities of cognitive training in the caregivers' home began in the first half of 2017, comprising a period of 12 weeks (three months), through an individual primer<sup>13</sup> created by the group of research responsible for the research and validated by two medical reviewers in the area of cognition and aging. The primer comprised stimulus activities in the domains of cognition. There were 25 activities carried out, with the application of exercises like "what is different", "complete the sentence", "find the error", "tell a story", "amends history", "create categories", "sudoku", "Association game", "Tetra" and "complete the cross". Interspersed with the practice of these activities, the "Academy of Mind" games such as "What is different", "Face to face" and "Focus" were applied. We planned the exercises and games to be applied weekly with approximately 40 minutes. All the instructions about which exercises and games were to be performed each week were described in the handbook, as well as the guidelines that were set out in the four home visits: (1) evaluation of the subjects included in the research and orientations about the activities; (2-3) follow-ups / deliveries of activities and instructions and, finally, (4) revaluations and devolutions. Each visit took place within a 20-day break. The monitoring

was carried out through biweekly connections, with the clarification of doubts about the activities performed, about the physical and psychological state of caregivers and the elderly.

Statistical analysis was performed using specific applications including SPSS®, version 20.0, for Windows®. In the descriptive statistics of the group of subjects, the means and standard deviations for the quantitative variables and proportions or percentages for the categorical variables were calculated. All hypotheses were tested in a two-tailed way and the results were considered significant when  $p < 0.05$ . For the comparison of the pre and post intervention values of the cognition and mood variables, the t-Test for paired samples was used. Associations with values of  $p \leq 0.05$  were considered significant. The variables were treated as parametric given the normality tested.

RESULTS

It can be said, in a general way, that the majority of participants in this research were women (88.2%), with a mean age of 52.5 years and average schooling of 8.8 years. It was found that 29.4% of the sample are married and 11.8% are separated. Of these caregivers, 64.7% have individual income of one minimum wage and 17.6% of two salaries and 41.2% have family income of one minimum wage. Most caregivers (52.9%) are the child of the caregiver. Of these caregivers, 64.7% live with the elderly caregivers. On the health of caregivers, most of them do not have diabetes (82.7%) nor hypertension (70.6%).

It is reported, in relation to the care provided, that 88.2% say they are informed about the patients' illness and 94.1% consider themselves informed about how to take care of the patient.

Table 1. Distribution of the socio-demographic profile of elderly caregivers with AD (n = 17). São Carlos (SP), Brazil, 2017.

Variables	Caregivers group (n=17)
Mean age ± standard deviation	52.5 ± 15.3
Education (years)	8.8 ± 4.2
Caring Time ± standard deviation	7.2 ± 5.0
Hours of the day devoted to care ± standard deviation	15.4 ± 7.3
Sex	
Female (%)	15 (88.2%)
Male n (%)	2 (11.8%)
Marital status n (%)	
Married	9 (29.4%)
Widow	1 (5.9%)
Separated	2 (11.8%)
Single	5 (29.4%)
Lives with the elderly person	
Yes n (%)	11 (64.7%)
No n (%)	6 (35.3%)
Kinship n (%)	
Child	9 (52.9 %)
Husband	3 (17.6 %)
Grandchild	2 (11.8%)
Daughter-in-law/Son-in-law	3 (17.6%)
Family income n (%)	
Less than 1 salary	1 (5.9%)
1 salary	7 (41.2%)
2 salary	6 (35.3%)
3 salaries	3 (17.6%)
Individual Income n (%)	
Less than 1 salary	2 (11.8%)
1 salary	11 (64.7%)
2 salary	3 (17.6%)
3 salaries	1 (5.9%)
Informed about the disease	
Yes n (%)	15 (88.2%)
No n (%)	2 (11.8%)
Informed about Care	
Yes n (%)	16 (94.1%)
No n (%)	1 (5.9%)



About the cognitive profile, a significant improvement in the pre- and post-intervention moments in the general cognition indicated by the MMSE was observed, with the initial score from 24.47 ( $\pm$  2.32) to 26.05 ( $\pm$  1.43) and value of  $p = 0.008$ . And by ACE-R, with 82.82 ( $\pm$  10.95) for 89.88 ( $\pm$  7.09) and  $p = 0.003$ . In addition, the improvement in attention from 16.05 ( $\pm$  1.29) to 17.05 ( $\pm$  1.08) and the value of  $p = 0.004$ . The memory, with 19.29 ( $\pm$  5.57) for 22.11 ( $\pm$  2.99) and  $p = 0.017$  and the creep, from 9.23 ( $\pm$  3.17) to 11.47 ( $\pm$  2.09) and  $p = 0.023$ .

## DISCUSSION

This study evaluated the effectiveness of cognitive intervention on the effect on cognition, overload and stress in caregivers of elderly people with AD and showed a significant improvement in the general cognition of these individuals and in specific cognitive domains such as attention, memory and verbal fluency.

It can be observed that the majority of the caregivers are female, with an average age of 52 years and schooling of eight years, which is similar to findings of the recent literature,<sup>21-4</sup> as well as the degree of kinship, in which the majority represents the profile of children caring for their parents.<sup>23-4</sup>

An average of 8.8 years of schooling was found in relation to the schooling of caregivers, differing from other studies in this area, where caregivers with an average of four years of schooling are more commonly found.<sup>21-4</sup> Knowledge about the level of schooling of elderly caregivers is important, since the caregiver is assigned the functions of accompanying health services and understanding about treatment, health promotion and disease prevention.<sup>23-4</sup> It is considered that high schooling can facilitate the understanding of the caregiver in relation to what happens to the elderly and to the process of health education.

It is inferred that the time the caregiver performs the care function in this study was, on average, 7.2 years, in addition, the caregivers reported that they provide the care about 15.4 hours daily to the elderly with AD, corroborating the literature.<sup>21-3</sup> It is understood that, when dedicating much of the time to care, the caregiver often neglects his own health and, in this context, becomes a great challenge for professionals health care, dealing with the emergence of diseases in the elderly caregiver such as stress, overload and the susceptibility to develop dementia, which justifies the need for assistance from other members in the care of the elderly.<sup>21</sup>

It should be noted that a large number of caregivers reported living together with the elderly (64.7%), corroborated by the literature.<sup>21-5</sup> It can be seen that this fact may be favorable to elderly care, since their care demands may (25), but for the caregiver it can be seen as negative because of the great exposure to the effects of the caring process that he / she experiences daily, which can generate high levels of stress.<sup>10</sup>

It is mentioned, as far as income is concerned, that caregivers have, on average, the value of a minimum wage. Caregivers are often unable to engage in extra-household activity because there is no other available person to care for the elderly.<sup>25</sup> In this sense, retirement often becomes the only source of income for these families, the elderly being the main provider. The fact that living in a low income context can cause chronic stress during life and affect the physical and cognitive domains of both caregivers and the elderly care.<sup>25</sup>

In the literature, the scarcity of national works for the same purpose is noted. However, there are works with multicomponent and psychoeducational interventions that vary widely in the number of sessions applied to the public studied.<sup>8</sup> However, a study carried out in Spain and Portugal, whose objective was to identify different ways of training caregivers of people with dementia at home, showed that, in order to be effective, it is necessary to perform at least six to eight sessions, with weekly meetings and duration of approximately sixty minutes.<sup>26</sup> For this research, we worked with 12 sessions, and in ten of them the caregiver performed the activities without the presence of the researcher and in two sessions, through a home visit, the caregiver had the presence of the researcher respecting, in this way, the minimum of sessions recommended for the effectiveness of the findings.<sup>26</sup>

In a systematic review of 12 studies, non-pharmacological techniques such as stimulation, psychoeducation, cognitive training, and behavioral interventions were found to be more effective in caring for and increasing the quality of life. In addition, there are several studies that report the effectiveness of cognitive intervention for the elderly and, in general, the findings can be compared with this research.

A study was carried out,<sup>13</sup> in the city of São Carlos, SP, Brazil, in which the effects of a cognitive intervention on functional, cognitive performance and mood symptoms in the elderly were evaluated in an Open University for the Elderly (OUE).<sup>(13)</sup> Another

study <sup>(14)</sup>, which aimed to evaluate the effect of Health Education, carried out 12 sessions that evaluated the domains of cognition, cognition, humor and functional capacity also in participants of a OUE and found significant improvement in general cognition and especially in the memory domain after the intervention, which revealed the effectiveness of workshops for the prevention of cognitive disorders.<sup>14</sup>

It is pointed out that patients with AD also appear to have significant cognitive improvement expressed by the MMSE and, according to a study carried out with caregivers of elderly people with AD, whose objective was to know the influence of cognitive stimulation at home, performed by the caregiver, found that innovative didactic interventions at home collaborate to reduce stressors to the patient and the caregiver.<sup>27</sup> Healthy cognition has a positive impact on the quality of life of the individual, which ends up improving the service provided mainly in care.<sup>25</sup>

It should be emphasized that the challenges for the participation of caregivers in support activities in health facilities are many, such as the need to travel, the costs associated with travel to participate in face-to-face programs, inflexible time for them to attend on the dates and established schedules, lack of adequacy of support programs for the main needs, among others. Household intervention is therefore more cost effective and efficient.<sup>27</sup>

It is emphasized that, as levels of dependency and the symptoms of dementia increase, the demands and time spent on care also increase considerably, affecting the health of the caregiver.<sup>28</sup> Continual, individualized care aspects of health (of the caregiver), prevention of cognitive deficit and overload, is essential so that the care provided remains at home and with quality of life for the caregiver.

It is noticed that the overload and stress perceived in these caregivers, in this research, did not obtain significant improvement with the intervention, differing from another study that demonstrated that psychoeducational interventions can reduce the overload of caregivers. Although there were few participants, the improvement of the intervention group regarding overload and handling of care was observed.<sup>29</sup> The non-improvement of overload in this research may be related to the fact that the caregiver is involved in more than one activity in their daily life, that is, the performance of exercises and games. At the same time, it can

be attributed to the fact that a 12-week cognitive intervention, of which ten without the presence of the researcher, was not sufficient to reach the level of improvement of the overload which, perhaps, would have been more effective if added to this, also, psychoeducational strategies.

The limitations of this study should be overcome in future researches, such as the non-randomized and uncontrolled design for the reduction of biases, in addition to strategies with more sessions of more than 12, and with the presence of the researcher in all sessions.

It is emphasized that there are many studies about the effects of interventions in the elderly population, but caregivers of the elderly are still scarce in Brazil and, for the most part, focus only on psychoeducational strategies. Another important point is to approach the caregivers of this type of research because they tend to be overloaded people and, therefore, no longer accept an activity in their daily routine.<sup>29</sup>

CONCLUSION

It has been demonstrated that home-based cognitive intervention can be a viable strategy and an important tool for improving general cognition in caregivers of elderly people with AD, but for the improvement of overload and stress, it can not be concluded in the same way, necessitating other intervention alternatives.

We suggest future studies with a randomized controlled trial, with sessions greater than 12 and which include, in addition to cognitive activities to prevent cognitive decline, educational activities for the care of the elderly with dementia in order to reduce the overload and stress.

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