

The place of family caregivers for older adults with Alzheimer's disease: a literature review in Brazil and the United States

Eliane Varanda Dadalto (<https://orcid.org/0000-0002-3873-7871>)¹

Fátima Gonçalves Cavalcante (<https://orcid.org/0000-0003-2680-1204>)²

Abstract *This is a review of the literature on family caregivers of patients with Alzheimer's disease from 2013 to 2017 available in the BVS, Scopus, and PubMed databases. The descriptors used (translated from Portuguese) were Alzheimer's disease, caregivers, elderly health, by combination. Of the 163 papers analyzed, after applying the relevance test, we selected 26 papers presented from five thematic units: 1- Literature reviews; 2- Prevalence profiles of AD caregivers; 3- Qualitative research that analyzes the feelings and sufferings of caregivers; 4- Comparative studies and objective tests; 5- Evaluation studies of intervention programs. The comprehensive and comparative analysis of the investigations highlighted differences and similarities, advantages, and disadvantages of the samples and methodologies adopted in Brazil and the US. The articles analyzed factors that influence family caregivers' impact with Alzheimer's disease, identifying the affective bonds involved, the expected reciprocity, the physical, emotional, and social costs associated with a prolonged chronic illness and requiring increasingly complex care. Family caregivers and older adults with AD require a broad, accessible, or articulated support network inside and outside the family.*

Key words *Alzheimer's disease, Caregivers, Elderly health*

¹ Centro de Ciências da Saúde, Universidade Federal do Espírito Santo. Av. Marechal Campos 1468, Maruípe. 29102-770 Vitória ES Brasil. elianedadalto@yahoo.com.br

² Universidade Veiga de Almeida. Rio de Janeiro RJ Brasil.

Introduction

Population aging is a worldwide event due to the increased life expectancy associated with sharp drops in mortality and fertility rates. For the first time in humankind's history, people aged 60 and over will outnumber children under 14, corresponding to 22.1% and 19.6% of the world population, respectively¹. In Brazil, statistics indicate that, currently, one in ten people in the country is 60 years of age or older^{2,3}.

The 2015 World Report on Aging and Health⁴ reveals that the percentage of people over 60 in Brazil grows above the world average. While the number of older adults will double in the world by 2050, it will almost triple in Brazil. According to the same report, Brazil will be the sixth country globally with the largest number of older adults by 2025. A projection estimates that older adults will increase from 24.4 million to almost 70 million in 2050. As the elderly population increases, chronic diseases of old age gain greater expression, with a significant increase in chronic disease incidence.

According to Pimenta et al.⁵, the aging process generates significant changes in patterns of morbimortality. According to WHO data⁴, "the main negative impact of population aging is the increased prevalence of NCDs, which are the main causes of mortality and disability worldwide"⁶. Older adults become frail and dependent due to chronic degenerative diseases, caused primarily by dementia syndromes.

NCDs are responsible for most diseases and deaths in many countries, whether of high, medium, or low socioeconomic status, and associated with advanced age, making the problem even more significant. In Brazil, it is now considered a real epidemic aggravated by the accelerated demographic transition that has occurred and is still occurring in the country, and changes that took a hundred years to happen in Europe are taking place in the country in two or three decades⁷.

According to the 2015 International Alzheimer's Association Report⁸, it is estimated that a new case of dementia is detected worldwide every 3.2 seconds, and a new case for every second is predicted for 2050. The number of Alzheimer's patients worldwide is expected to reach 65.7 million by 2030 and 115.4 million by 2050. Currently, 58% of the population with Alzheimer's is in developed countries, reaching 72% by 2050. There are indications that one in ten people over eighty years of age should have AD, and advancing age is the leading risk factor for the disease.

AD is already the third leading cause of death in developed countries, second only to cardiovascular disease and cancer⁹.

The World Health Organization⁴ estimates the global prevalence of dementia at 47.5 million, which is expected to increase substantially in the coming years, reaching 135 million by 2050. It also declares the need to make dementia a global public health priority. According to this WHO report⁴, the nine countries with the largest number of people with dementia in 2010 (one million or more) were China (5.4 million), the U.S. (3.9 million), India (3.7 million), Japan (2.5 million), Germany (1.5 million), Russia (1.2 million), France (1.1 million), Italy (1.1 million), and Brazil (1.0 million).

According to the Alzheimer's Association¹⁰, there are 500,000 Americans aged 65 and over with Alzheimer's and other types of dementia. Of these, approximately 40% are estimated to have Alzheimer's disease. More women than men are estimated to have dementia since the higher life expectancy of women increases the possibility of developing this or other types of dementia. In 2010, the US Congress approved the National Alzheimer's Bill (PL 111-375), establishing the Department of Health and Human Services to develop a specific disease plan, updated annually.

Brazil already has 1.2 million people with dementia. As the number of older adults has increased significantly over the past 20 years, the number of Alzheimer's cases will increase considerably. In our country, elderly care tends to be family-based or institutional, and families are primarily responsible for helping older adults with physical or cognitive dependence, and this care promoted by relatives has little State support¹¹.

Alzheimer's disease (AD) is one of the most frequent dementias. It is an irreversible and progressive brain disease. Advanced age increases the incidence of neurodegenerative diseases, including AD, significantly impairing memory and other cognitive functions, with sufficient intensity to produce functional loss, including, eventually, the loss of functions related to daily life or recognition of people and places.

As it is an irreversible, progressive deterioration process, AD requires full-time assistance from a family or formal caregiver. Several studies associate this task with the caregiver's physical and emotional exhaustion, showing an even more significant burden in the face of the demented older adult with cognitive symptoms¹².

There is a need to expand investigations on the impact of dementia on the family, especially

on the health of the family caregiver, who can become a “hidden patient”, given the predominance of older adults caring for their peers. Ximenes et al.¹³ affirm that “the burden of providing care makes relatives victims of the disease, plundering their reserves, uncertainties and unpredictability shakes their morals and belief that they are providing dignified care to their relatives”.

Increased dementia is a globally relevant issue. The rapid population aging associated with dependence emerges as a challenge for Brazilian public health because, despite national policies for older adults’ care, in practice, the existing resources to care for the dependent older adults have been scant and insufficient¹⁴.

This literature review study selected nine countries with the highest prevalence of dementia in 2010, two countries in the Americas, the US, and Brazil, the second and the ninth country⁴, respectively. This paper presents a comparative study on research productions related to the caregiver, emphasizing family caregivers.

Material and methods

The review started from the question: “How does Brazilian and American literature address the theme of caregivers of older adults with Alzheimer’s?” The bibliographic survey was carried out in national and international journals published from January 2013 to May 2017, available in the Virtual Health Library (BVS), Scopus, and PubMed databases. Descriptors *doença de Alzheimer/Alzheimer disease, cuidadores/caregivers, saúde do idoso/health of the elderly*, by combination, were used.

The inclusion criteria for selecting the papers were: a) is the study about caregivers of dependent Alzheimer’s patients? b) does it address the caregiver’s health? c) was it published from January 2013 to May 2017? d) was it performed in Brazil and the US? Papers that did not establish any relationship with the proposed theme did not meet the selection criteria, and those that were not found in full were excluded. The selected papers applied the relevance test initially in the titles, then in the abstracts, and, finally, in the full-text review. Chart 1 explains the selection process of the works included in the review.

A total of 163 papers were analyzed, and 135 texts were excluded after the relevance test, as they did not meet the established criteria. Then, 28 articles were selected and included in this literature review.

We performed a comprehensive and comparative analysis of the investigations, locating the objectives, methods, sample, results, and principal conclusions. Care was taken to locate national and international studies, and above all, to highlight differences and similarities and advantages and disadvantages of the samples and methods adopted, signaling the relevance and rigor of the results and the implications of the studies and recommendations.

Results and discussion

In a recent national research agenda by the Ministry of Health¹⁵, NCDs, particularly dementia, are among the fourteen most relevant research lines in the country. However, while the effectiveness of elderly care and health practices is the target of attention in the proposed investigations, nothing was mentioned about the caregiver issue. For this reason, it is urgent to highlight the place of family caregivers and the elderly care demand, which is expected to triple in the next thirty years.

The 28 selected papers were distributed in five thematic categories: 1- Literature reviews; 2- Prevalence profiles of AD caregivers; 3- Qualitative research analyzing the feelings and sufferings of caregivers; 4- Comparative studies and objective tests; 5- Intervention program evaluation surveys.

Literature reviews

Two national literature review papers open our analysis. Oliveira et al.¹⁶, from Rio Grande do Norte, analyzed 32 publications from 2006 to 2013, extracted from SciELO, PubMed and Bireme, highlighting the physical and pathological harm of stress to the caregiver, associated with care practices, along with anxiety, depression, severe heart disease, and immunological problems, recommending continued interventions and a professional support network. The authors point out that studies, in general, do not differentiate between family and formal caregivers.

Ximenes et al.¹³ studied the scientific production of books and theses, at the Virtual Health Libraries (BVS) in São Paulo, between August and October 2012, selecting 80 texts, of which some common topics were analyzed in an overview. Knowledge about the disease (AD) was highlighted from this scientific production, the care reciprocity expected by the family, with emphasis on the caregiver’s fatigue and lonely role and

Chart 1. Criteria for the inclusion and exclusion criteria of selected texts.

	PubMed	BVS	SCOPUS	Total
	1449	946	701	3096
Works from 2013 to 2017	369	165	285	819
Full-texts available analyzed	32	78	53	163
Works related to the theme and inclusion criteria	10	11	7	28

the mobilization of opposing feelings of love and anger, patience and intolerance, and fear and insecurity, requiring multiple supports.

In summary, on the one hand, studies emphasize stress, seen as the agglutinating element of symptoms, and its reduction would bring about an improvement in the caregiver's quality of life. On the other hand, the caregiver's diffuse malaise, fatigue, loneliness, and opposite feelings, were highlighted, whose improvement would come through interdisciplinary interventions.

Prevalence and profiles of AD caregivers

Three national surveys and one American survey found the prevalence and profile of caregivers. The American study by Wang et al.¹⁷ aimed to examine the prevalence and association of chronic disease among caregivers of people with dementia, in a sample of 124 informal caregivers, through thorough, descriptive, correlational, and cross-sectional research, based on individual interviews, sociodemographic data, and statistical analysis. In the sample, 54 caregivers were between 45 and 64 years old, and 70 were between 65 and 74 years old, predominantly wives ($n = 46$) and daughters ($n = 34$), and to a lesser extent, husbands ($n = 29$). The results reveal that 81.5% ($n = 101$) of the sample has at least one chronic disease, and this risk is three times more likely in people aged 65 and over and four times more likely in older women who are caregivers of husbands, compared to male caregivers. The high level of comorbidity in caregivers is noteworthy, regardless of age.

A cross-sectional, qualitative-descriptive study carried out in Brasília by Seima et al.¹⁸ aimed to interpret the care relationship between family caregivers and older adults with AD. They found that caregivers are women ($n = 178$; 86%), aged between 22 and 83 years, living with the older adults ($n = 169$; 81%), with more than eight years of schooling ($n = 147$; 71%), no professional occupation ($n = 121$; 58%) and a moderate

burden ($n = 96$; 46.2%). The study pointed out that most caregivers do not participate in social support groups, do not have the time to take care of themselves, and rely on faith as the main source of self-care in their daily lives.

Two other studies with smaller samples reached similar results. Marins et al.¹⁹ conducted a research in Rio de Janeiro, with 25 caregivers of older adults with AD, in the light of Symbolic Interactionism (SI), to identify behavioral changes in older adults with AD and distinctions in the burden imposed on the caregivers. Mendes and Santos²⁰ investigated the social representations of family caregivers in an empirical, exploratory, qualitative and quantitative study, carried out in São Paulo, using the Collective Subject Discourse as a method in which 21 family caregivers of older adults with AD participated. There are complementary conclusions. While the first points out that behavioral changes in older adults with AD have an emotional impact and result in stressful situations for family caregivers, the second highlights that the social representations of informal caregivers signal ideas of loss of freedom, moral duty, retribution, and inversion of social roles in the context of these caregivers and their older adults with AD.

Qualitative research analyzes caregivers' feelings and suffering

Seven qualitative investigations, distributed in six national and one American research, aimed to identify the impact of Alzheimer's disease according to the informal caregiver and his family. The first three Brazilian studies seek to shed light on the effects of a degenerative disease such as Alzheimer's disease on the family, reflecting on how the family system is reconfigured, how the informal caregiver perceives AD and family support and, finally, what is the social representation of the family caregiver about AD.

Brasil and Andrade²¹ conducted an in-depth qualitative study in Paraná with three family

caregivers of AD patients through semi-structured interviews, using a phenomenological approach and field theory, in order to describe and understand how the family caregiver's field re-configuration occurs. Four categories of analysis were identified: ways of taking responsibility for caring; main changes in the family of the family caregiver due to the intensification of the experience; support from the social network as an aid in coping with the act of caring; coping strategies that combine the care of AD with the care of one's own life. The authors concluded that when a serious illness affects a family, crises can happen, and it takes time for it to reorganize.

Andrade et al.²² conducted a study in São Paulo on AD patients' perception and the support received from their family for care in the phenomenological approach. Ten caregivers from the Mutual Aid Group participated in the study through individual semi-structured interviews and focus groups. The study notes that caregivers require recognition from their families, and, when incorporating care as a habit, caregivers start to deny the need for support and consider themselves self-sufficient.

Folle et al.²³ conducted a study with 26 relatives of AD patients through interviews, analyzed by the ALCESTE program. They aimed to know the Social Representation of the disease. The results pointed out two thematic axes: 1- daily routine and care; 2- the social representation of AD and its emotional, biological, and medical meanings. The authors conclude that given the patient's dependence and the repercussions of their illness, overload is the main content that requires attention in interventions aimed at caregivers.

Three national studies focus on the perception, impact, and difficulties experienced by the family caregiver. Valente et al.²⁴, researchers from Rio de Janeiro, carried out a cross-sectional investigation with pairs of patients with dementia and their primary family caregivers (n = 49) to examine the relationship between the type of dementia of the patient (VD: vascular dementia; AD: Alzheimer's disease; MD: mixed dementia) and self-perceived health in family caregivers. It was found that most patients were female, married, or widowed, with a mean age of 75 to 76 years. They also found that 45% of caregivers self-rated their physical health as "fair" or "poor", with a tendency for worse self-perceived health in caregivers of patients in the AD group compared to caregivers of patients in the VD and MD groups, although this difference is not statistically significant.

Santos and Gutierrez²⁵ aimed to know the quality of life of informal caregivers for the elderly (AD) in a study in Minas Gerais. Qualitative research was carried out with 50 caregivers, 25 adults, and 25 older adults. The following instruments were used for data collection: WHO-QOL-Brief, Geriatric Depression Scale and Depression Tracking Scale, and Anxiety Scale. A second study by Ilha et al.²⁶ developed exploratory, descriptive research with a qualitative approach in Rio de Janeiro, through a focus group, with six family caregivers of older adults with AD, to learn about the difficulties experienced by these caregivers. Both studies identified that family caregivers experience physical, mental, and social difficulties that impose challenges in living and caring for older adults with AD, including degrees of anxiety and depression. The first study recommended caregivers to relieve worry and burden, more opportunities to acquire new information and skills, participation, and opportunities for recreation and leisure. The second pointed out that overload can be minimized through the construction and socialization of collective care strategies.

Day et al.²⁷, from North Carolina, U.S., aimed to identify risk factors called "compassion fatigue" in adult caregiving daughters. They state that they can suffer fatigue from compassion, which they define as a combination of helplessness, hopelessness, inability to be empathetic, and a sense of isolation from prolonged exposure to perceived suffering. Twelve adult caregivers of a father with dementia participated in the randomized home training study. Content analysis was applied to interviews. Four themes were identified: uncertainty; concern; connection/affection; tension. The findings indicated that adult caregivers are at risk of long-term fatigue, supporting the need for a larger study to minimize this type of fatigue that weakens care.

As a whole, qualitative studies point out the challenges of caring, living, supporting, and facing AD and its deterioration in the face of dependence, the more significant burden of care associated with lack of hope, helplessness, and isolation of the caregiver, factors that when combined, increase the caregiver's suffering and health risks. They also point out that in cases where the caregiver denies support due to self-sufficiency or assuming too significant burdens, the family caregiver needs help to recognize possibilities, limits, and ways of taking care of themselves.

Comparative studies and objective tests

Four papers describe investigations through comparative studies between patients with AD and caregivers carried out through one international and three national evaluative scales.

Sousa et al.²⁸ compared the load levels in caregivers of patients with Alzheimer's disease in Brazil (n = 128) and Spain (n = 146) in an intercultural, observational, and cross-sectional study with outpatients with AD and their caregivers. Caregivers answered the Zarit Burden Interview (ZBI) and a sociodemographic questionnaire. Patients were evaluated in five tests, with the Mini-Mental State Examination (MMSE), the Functional Activities Questionnaire (FAQ), the Disability Assessment for Dementia (DAD), the Neuropsychiatric Inventory (NPI), and the Clinical Dementia Rating Scale (CDR). The authors concluded that a high level of stress was reported in Brazil by female caregivers, especially those who could not count on a Day Care Center.

In Spain, the highest stress levels were associated with younger caregivers living with older adults with AD and who participate in Daily Care Centers. High degrees of depression and anxiety were observed in Brazilian caregivers and high degrees of apathy and indifference, agitation, aggression, and irritability among Spanish caregivers. The authors highlight the importance of addressing neuropsychiatric symptoms in AD patients because they are an essential source of burden for caregivers.

Truzzi et al.²⁹ conducted a study in São Paulo with 150 family caregivers and patients to assess distress in the face of neuropsychiatric symptoms (NPS) of caregivers and patients with dementia. They analyzed which factors of patients and caregivers are strong predictors of caregivers' distress. Most patients had a diagnosis of AD (66.7%). Caregivers were assessed using a sociodemographic questionnaire, the Beck Anxiety and Depression Inventories, and the Neuropsychiatric Inventory – Distress. The patients were submitted to the Mini-Mental State Examination, Functional Activities Scale, and the Neuropsychiatric Inventory. The results showed alterations resulting from AD disorders most affecting caregivers, located in their M (measured by applied scales) and SD (standard deviation). Apathy (M = 1.9; SD = 1.8), agitation (M = 1.3; SD = 1.8) and aberrant motor behavior (AMB), (M = 1.2; SD = 1.7) were the most stressful NPS. The frequency/severity of the NPS was the factor most strongly associated with caregivers' distress ($\rho = 0.72$;

$p < 0.05$) and concluded that early recognition and management of apathy, agitation, and AMB in patients with dementia by relatives and health professionals possibly lead to a better quality of life and care for patients and caregivers.

In a study in São Paulo, Folquitto et al.³⁰ investigated the correlation between neuropsychiatric symptoms (NPS) and caregiver burden in 1,563 individuals randomly selected and assessed through the Mini-Mental State Examination, Fuld Object Memory Evaluation, Informant Questionnaire on Cognitive Decline in the Elderly, and the Bayer Scale – Activities of Daily Living. The Neuropsychiatric Inventory was applied to caregivers to assess NPS and the Zarit Caregiver Burden Scale to assess caregivers' burden.

Borghi et al.³¹ conducted research in Paraná to compare the burden of the primary family caregiver with that of the secondary caregiver of older adults with AD and identify which dimension generates the most significant impact with 20 primary caregivers of older adults with AD and 20 secondary ones. The Scale for the Evaluation of the Burden of Relatives of Psychiatric Patients was used. The results showed that the primary caregivers had a more significant burden than the secondary caregivers in daily care activities, and the concern with older adults was the dimension that most influenced the subjective burden of caregivers. That is, the greater the burden, the better the health planning actions should be.

Data indicate that the severity of AD is proportional to the caregiver's burden, and the greater the degree of daily burden, the more directly caregivers are affected in their health. Therefore, improved AD treatment ensures the quality of life of older adults with AD and their caregivers, and the degree of overload of caregivers, in turn, must be monitored.

Evaluation research for intervention programs

Nine publications on the evaluation of intervention programs are available, eight American and one Brazilian. Two studies evaluate intervention programs and their effects, three examine psychotherapeutic practices and a meditative technique, two examine strategies through the internet and the web, one analyzes a longitudinal investigation with caregivers. The last one addresses the impact of an educational program.

The Lykens et al.³² study examined the impact of the REACH II community-based pro-

gram on caregiver life and health in an American city. REACH II aims to reduce the burden and depression of caregivers of patients with AD and is provided by community agencies in the U.S. A total of 494 households were included in the program, of which 177 completed the six-month program. The median age for caregivers was 62 years. The domain scores for Depression and Caregiver Burden showed statistically significant improvements at the end of the investigation. The Program offered caregivers training and qualification, developed care skills, psychological support, and reception's ethnic and racial differences. Strategic information for caregivers, teaching instructions, stress management techniques, problem-solving strategies, and telephone support groups were added in the second phase. The results were positive for the caregivers who completed the program, especially blacks and Hispanics, compared to whites.

In the U.S., Moore et al.³³ evaluated the effectiveness of the "Pleasant Events Program" (PEP) through a six-week behavioral intervention designed to reduce the risk of cardiovascular diseases and depression symptoms in caregivers. Demographic characteristics, depressive symptoms, and social support scale were considered.

One hundred family caregivers were randomized to the PEP intervention (N = 49) or an information support (IS) control condition equivalent to time (N = 51). The results were favorable to the participants who received the PEP. The PEP program reduced depression and improved a measure of physiological health in elderly caregivers of dementia patients. Further studies are required to measure the effectiveness of PEP in preventing cardiovascular diseases. Abouafia-Brakha et al.³⁴ carried out a study in the U.S. to compare the effects of cognitive-behavioral group therapy (CBT) with a psychotherapy group from the EDUC Program, assessing cortisol secretion in caregivers of patients with moderate AD. The 26 participants were randomly assigned to one of the two intervention programs (CBT or EDUC). All responded to pre-intervention assessment, and questionnaires and saliva samples and blood samples were collected. The effects of the interventions were assessed with a self-report. The results showed that psychotherapy for caregivers could reduce neuropsychiatric symptoms in patients with AD, and cognitive behavioral therapy attenuates psychophysiological responses to stressful situations in caregivers, reducing cortisol levels, which can lead to a positive impact on the health of caregivers. Different psy-

chotherapeutic approaches bring specific contributions to caregivers.

Garand et al.³⁵ evaluated, in the US, the effects of Problem Resolution Therapy (PRT) on the mental health of caregivers of older adults with mild cognitive impairment (MCI; n = 43) or early dementia (ED; n = 30). They selected this group (N = 73) as they considered that caregivers with a high degree of distress with older adults with severe dementia would not respond well to this type of intervention. The results are positive for the mental health of caregivers of older adults with mild dementia (MCI), with a reduction of depressive symptoms and improved anxiety levels.

An American study of alternative medicine conducted by Danucalov et al.³⁶ aimed to investigate the effects of yoga practice in combination with compassion meditation on the quality of life, attention, vitality, and self-compassion of family caregivers of patients with AD (n = 46). A comparative study was carried out between the experimental group (n = 25) and the control group (n = 21). The results suggest that an eight-week yoga and compassion meditation program can improve the quality of life, vitality, attention, and self-compassion of family caregivers of patients with AD, reducing stress, anxiety, and depression.

Two American studies investigated actions using online or video-based resources. Kajiyama et al.³⁷ verified whether the American online training program *I Care Stress Management*, for three months, reduces stress, discomfort, depression, and poor quality of life for dementia family caregivers (n = 150). The results were promising, but there was a high level of abandonment of the program. Through a pilot study in the U.S., Austrom et al.³⁸ evaluated the feasibility and acceptability of a group of web-based video support (n = 5) by weekly video conferences over six months, offered in real-time for caregivers of people with dementia. The experience involved five caregivers of people with dementia who reported improved anxiety, depression, and physical health scores. The researchers concluded that the web-based support was a positive experience, although they cannot generalize it because it was a small group. This can be a tool that could reach larger populations, streamlining travel costs.

Mausbach et al.³⁹ carried out a consistent five-year longitudinal study with 126 caregivers of AD, all wives aged 55 years or older, to assess whether institutionalization of AD reduces caregiver depressive symptoms. The study starts from

the evidence that the long-term AD caregiver is affected by chronic stress and a high degree of depressive symptoms. The investigation aimed to identify psychological factors that make the caregiver vulnerable, especially the family caregiver, and how this group can be more effectively supported, even in the course of long-term chronic disease. Scales to assess depression, restricted activity (social and leisure), personal mastery (self-control), assessment of participation in psychotherapy, use of medication or group support, and analysis of the degree of social support in 44 wives who left their husbands in a daily care center, compared to the others who continued to provide comprehensive care were used. Annual evaluations were carried out using scales and quarterly monitoring, with the possibility of contacting the researchers, if necessary.

The impact of one or more hospitalizations of relatives with AD on caregivers was monitored. The results indicate that a reduction in depressive symptoms is observed when restrictive activity is reduced and caregivers' mastery increases. That is, caregivers who chose to hospitalize their beloved relatives had a better response in reducing depression, regaining more mobility, personal assertiveness, and well-being.

In a study carried out in São Paulo, Lopes and Cachioni⁴⁰ investigated the impact of a psycho-educational program aimed at family caregivers of older adults with AD ($n = 21$) concerning these caregivers' assessments of their subjective well-being. The program aimed to learn about the disease process and the various realities of care in the space of support and mutual learning, which worked through educating, instructing, and sharing five thematic axes: the dementia process, AD, treatment, physiological and behavioral changes, and care.

Four instruments were applied after the Program: The Overall Life Satisfaction Scale, Life Satisfaction Scale Linked to Domains, Positive and Negative Affect Schedule, and Geriatric Depression Scale. In the sample, the group of women over 60 years old, with higher education, income below five minimum wages, inactive, spouse, no task sharing, and living with the AD patient predominated. When comparing differences before and after the intervention, we observed a variance by gender, kinship, income, age, and care length. The results indicated that caregivers showed improved overall life satisfaction, social interaction, and positive affections.

Final considerations

The subjects addressed in the Brazilian and American literature on AD caregivers show that the two countries are at different research stages. Brazilian studies describe the caregivers' difficulties, and few studies assess attempts to intervene and alleviate caregivers' suffering. American studies highlight the need to care for the caregivers, investigating the effectiveness of programs and the results of different types of interventions or monitoring support in the short, medium, and long term, investing in improving the caregivers' health.

The studies included in this review reported that most individuals who perform the task of caring in the family context are female and generally daughters or wives of AD patients. While many emphasize that they are women over 60, that is, older adults caring for their peers, others point out that women of all ages, since adolescence, are already required to assume the role of caregivers, with profiles varying depending on generations, cultural, racial, and ethnic differences, as some comparative studies have pointed out.

There is a consensus that it is necessary to highlight the needs of caregivers undergoing long-term care in AD's severe phases and the extent to which this excessive burden should be monitored, shared, or offset with subjective and external, formal, or state support. The restriction of social and leisure activities, the lack of exercise of personal skills, and the management of problem situations by caregivers can tie them to dysfunctional and neuropsychiatric symptoms, at risk of becoming ill or not surviving. It is necessary to recognize possibilities and limits and expand self-care modes.

The papers analyzed factors that influence the impact on family caregivers with AD, identifying the affective bonds involved, the expected reciprocity, the physical, emotional, and social costs associated with prolonged chronic disease and increasingly complex care requirements. Family caregivers and older adults with AD required a vast support network, which is not always available, accessible or coordinated, within and outside the family, with the support of services, units, or networks of care, which public policies should support, as recommended.

Several American or Brazilian studies point out the importance of intervening and supporting inside and outside the family, in health institutions and units for older adults with AD and their families. Fatigued caregivers tend to have

reactions that can cause stress, guilt, and loss of patience. Emotional and affective suffering seems to be what weighs the most on family caregivers and starts to negatively influence their daily lives, transforming their life and family context. It is necessary to gather several therapeutic and pharmacological strategies, psychotherapies, educational, informational and didactic activities,

training of personal and social skills, meetings through focus groups, where systematic and longitudinal monitoring can occur. On a special note, it should be noted that the more severe the dementia, the more monitoring is required between the primary and secondary caregivers, triggering the support of health care, primary care, and service networks.

Collaborations

EV Dadalto participated in the design, writing, data collection, literature review and analysis from his doctoral research. FG Cavalcante participated in the design, writing and critical analysis as an advisor.

References

1. Organização Mundial de Saúde (OMS). *Global Health and Aging*. Geneva: National Institute on Aging, National Institutes of Health; 2011.
2. Brasil. Secretaria de Direitos Humanos (SDH). *Dados sobre o envelhecimento no Brasil, 2017*. [acessado 2018 Nov 13]. Disponível em: <http://www.sdh.gov.br/assuntos/pessoa-idosa/dados-estatisticos/DadosobreoenvelhecimentoBrasil.pdf>
3. Instituto Brasileiro de Geografia e Estatística (IBGE). *Síntese de Indicadores Sociais: Uma Análise das Condições de Vida da População Brasileira*. Rio de Janeiro: IBGE; 2016.
4. Organização Mundial da Saúde (OMS). *Relatório Mundial de Envelhecimento e Saúde. Resumo*. Geneva: OMS; 2015.
5. Pimenta FAP, Bicalho MAC, Romano-Silva MA, Moraes EN, Rezende NA. Chronic diseases, cognition, functional decline, and the Charlson index in elderly people with dementia. *Revista da Associação Médica Brasileira* 2013; 59(4):326-334.
6. Silva AR, Sgnaolin V, Nogueira EL, Loureiro F, Engroff P, Gomes I. Doenças crônicas não transmissíveis e fatores sociodemográficos associados a sintomas de depressão em idosos. *J Bras Psiquiatr* 2017; 66(1):45-51.
7. Barreto MS, Carreira I, Marcon SS. Envelhecimento populacional e doenças crônicas: Reflexões sobre os desafios para o Sistema de Saúde Pública. *Revista Kairós Gerontologia* 2015; 18(1):325-339.
8. Alzheimer's Disease International (ADI). *World Alzheimer Report 2015: the global impact of dementia - an analysis of prevalence, incidence, cost and trends*. London: ADI; 2015.
9. Basegio MC, Scherer S. Perspectivas atuais na prevenção da doença de Alzheimer. *Estudos Interdisciplinares Sobre Envelhecimento* 2012; 17(1):37-57.
10. Alzheimer's Association. Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2010; 6(2):158-194.
11. Mello JL. Introdução. In: Camarano AA, organizador. *Cuidados de Longa Duração para a População Idosa: um novo risco social a ser assumido?* Rio de Janeiro: IPEA; 2010.
12. Neri AL. *Cuidar de idosos no contexto da família: questões psicológicas*. São Paulo: Alínea; 2002.
13. Ximenes MA, Rico BLD, Pedreira RQ. Doença de Alzheimer: a dependência e o cuidado. *Revista Kairós Gerontologia* 2014; 17(2):121-140.
14. Bauab JP, Emmel MLG. Mudanças no cotidiano de cuidadores de idosos em processo demencial. *Rev Bras Geriatr Gerontol* 2014; 17(2):339-352.
15. Brasil. Ministério da Saúde (MS). *Guia prático do cuidador*. Brasília: MS; 2008.
16. Oliveira KSA, Lucena MCMD, Alchieri JC. Estresse em cuidadores de pacientes com Alzheimer: uma revisão de literatura. *Estudos e Pesquisa em Psicologia* 2014; 14(1):47-64.
17. Wang XR, Robinson KM, Carter-Harris L. Prevalence of chronic illnesses and characteristics of chronically ill informal caregivers of persons with dementia. *Age Aging* 2014; 43(1):137-141.
18. Seima MD, Lenardt MH, Caldas CP. Relação no cuidado entre o cuidador familiar e o idoso com Alzheimer. *Rev Bras Enferm* 2014; 67(2):233-240.
19. Marins AMF, Hansel CG, Silva J. Behavioral changes of elderly with Alzheimer's Disease and the burden of care for the caregiver. *Esc Anna Nery* 2016; 20(2):352-356.
20. Mendes CFM, Santos ALS. O cuidado na doença de Alzheimer: as representações sociais dos cuidadores familiares. *Saude Soc* 2016; 25(1):121-132.
21. Brasil MC, Andrade CC. Reconfiguração de campo do familiar cuidador do portador de Alzheimer. *Psicol Estud* 2013; 18(4):713-723.
22. Andrade LM, Sena ELS, Carvalho PAL, Matos ALP, Mercês MC, Oliveira DS. Suporte familiar ao cuidador da pessoa com Doença de Alzheimer. *Revista Kairós Gerontologia* 2014; 17(4):275-295.
23. Folle AD, Shimizu HE, Naves JOS. Social representation of Alzheimer's disease for family caregivers: stressful and rewarding. *Rev Esc Enferm USP* 2016; 50(1):79-85.
24. Valente LE, Truzzi A, Souza WF, Alves GS, Sudo FK, Alves CEO, Lanna MEO, Moreira DM, Engelhardt E, Laks J. Autopercepção de saúde em cuidadores familiares de pacientes com demência: fatores sociodemográficos e clínicos. *Arquivos de Neuro-Psiquiatria* 2011; 69(5):739-744.
25. Santos CF, Gutierrez BAO. Avaliação da qualidade de vida de cuidadores informais de idosos portadores da doença de Alzheimer. *REME* 2013; 17(4):792-798.
26. Ilha S, Backes DS, Santos SSC, Gautério-Abreu DP, Silva BT, Pelzer MT. Doença de alzheimer na pessoa idosa/família: Dificuldades vivenciadas e estratégias de cuidado. *Esc Anna Nery* 2016; 20(1):138-146.
27. Day JR, Anderson RA, Davis LL. Compassion fatigue in adult daughter caregivers of a parent with dementia. *Issues Ment Health Nurs* 2014; 35(10):796-804.
28. Sousa MF, Santos RL, Turró-Garriga O, Dias R, Dourado MC. Factors associated with caregiver burden: comparative study between Brazilian and Spanish caregivers of patients with Alzheimer's disease (AD). *Int Psicogeriatrics* 2016; 28(8):1363-1374.
29. Truzzi A, Valente L, Engelhardt L, Laks J. The association between caregiver distress and individual neuropsychiatric symptoms of dementia. *Dement Neuropsychol* 2013; 7(3):286-291.
30. Folquitto JC, Marques RCG, Tatsch MF, Bottino CMC. Correlation between neuropsychiatric symptoms and caregiver burden in a population-based sample from São Paulo, Brazil: A preliminary report. *Dement Neuropsychol* 2013; 7(3):258-262.
31. Borghi AC, Castro VC, Marcon SS, Carreira L. Sobrecarga de familiares cuidadores de idosos com doença de Alzheimer: um estudo comparativo. *Rev Latino-Am. Enfermagem* 2013; 21(4):876-883.
32. Lykens K, Moayad N, Biswas S, Reyes-Ortiz C, Singh KP. Impact of a community based implementation of REACH II program for caregivers of Alzheimer's patients. *PLoS One* 2014; 9(2):e89290.
33. Moore RC, Chattillion EA, Ceglowski J, Ho J, von Känel R, Mills PJ, Ziegler MG, Patterson TL, Grant I, Mautsach BT. A randomized clinical trial of Behavioral Activation (BA) therapy for improving psychological and physical health in dementia caregivers: Results of the Pleasant Events Program (PEP). *Behaviour Research and Therapy* 2013; 51(10):623-632.

34. Aboulafia-Brakha T, Suchecki D, Gouveia-Paulino F, Nitrini R, Ptak R. Cognitive-behavioural group therapy improves a psychophysiological marker of stress in caregivers of patients with Alzheimer's disease. *Aging Ment Health* 2014; 18(6):801-808.
35. Garand L, Rinaldo D, Alberth MM, Delany J, Beasock SL, Lopez OL, Reynolds 3rd CF, Dew MA. Effects of problem solving therapy on mental health outcomes in family caregivers of persons with a new diagnosis of mild cognitive impairment or early dementia: a randomized controlled trial. *Am J Geriatr Psychiatry* 2014; 22(8):771-781.
36. Danucalov MA, Kozasa EH, Ribas KT, Galduróz JCF, Garcia MC, Verreschi ITN, Oliveira KC, Oliveira LR, Leite JR. A yoga and compassion meditation program reduces stress in familial caregivers of Alzheimer's disease patients. *Evid Based Complement Alternat Med* 2013; 2013:513149.
37. Kajiyama B, Thompson LW, Eto-Iwase T, Yamashita M, Mario J, Tzuang YM, Gallagher-Thompson D. Exploring the Effectiveness of an Internet-Based Program for Reducing Caregiver Distress Using the iCare Stress Management E-Training Program. *Aging Ment Health* 2013; 17(5):544-554.
38. Austrom MG, Geros KN, Hemmerlein K, McGuire SM, Gao S, Brown SA, Callahan CM, Clark DO. Use of a Multiparty Web Based Videoconference Support Group for Family Caregivers. *Dementia* 2015; 14(5):682-690.
39. Mausbach BT, Chattillion EA, Ho J, Flynn LM, Tiznado D, von Känel R, Patterson TL, Grant I. Why does placement of persons with Alzheimer's disease into long-term care improve caregivers' well-being? Examination of psychological mediators. *Psychol Aging* 2014; 29(4):776-786.
40. Lopes LO, Cachioni M. Impacto de uma intervenção psicoeducacional sobre o bem-estar subjetivo de cuidadores de idosos com doença de Alzheimer. *Temas Psicol* 2013; 21(1):165-181.

Article submitted 14/10/2019

Approved 07/10/2020

Final version submitted 09/10/2020

Chief Editors: Maria Cecília de Souza Minayo, Romeu Gomes, Antônio Augusto Moura da Silva. Associate Editor, Elderly Health: Joselia Oliveira Araújo Firmo



