



Feelings and family burden in the care of older adults with Alzheimer's: integrative literature review

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ABSTRACT

OBJECTIVE

Identify in the national scientific literature the difficulties faced by the family when caring for older adults with Alzheimer's Disease (AD).

METHODS

Integrative literature review carried out between March and September 2020 in the Regional Portal of the Virtual Health Library (VHL) and in the journal directory *Scientific Electronic Library Online* (SciELO) using DECS descriptors and keywords, respecting the characteristics of the portal and the directory.

RESULTS

Fifteen studies were selected and read in their entirety, and two categories were created according to similarity of content, namely: (1) Strain on family caregivers - from the feeling of imprisonment to the burden generated by the care; (2) Family relationships and feelings related to care.

CONCLUSIONS

Care is based on love, affection, recognition, and retribution. Creating a care network for the entire family is necessary in order to alleviate the suffering of the entire family.

DESCRIPTORS

Older adults, Alzheimer's Disease, Family care, Family relationships, Emotions.

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INTRODUCTION

The increase in life expectancy is a reflection of cultural changes and advances related to health conditions. The demographic transition is mainly a result of the reduction in the fertility rate, decrease in child mortality, and increase in the quality of eating habits, and care for the body¹.

On the other hand, the possibility of older adults being affected by chronic degenerative diseases is greater, making them dependent on someone else's care and distancing them from their own autonomy, meaning that the work of caring is gaining more space in Brazilian society^{1,2}.

The drop in the mortality and birth rates has caused significant changes in the age structure in Brazil, leading to large-scale growth of the older population, in a process called demographic transition. In 1920, life expectancy was low in Brazil at 35.2 years and the older population represented 4.0% of Brazilian citizens, that is, 11 older people for every 100 children³.

In 2010 the life expectancy of Brazilian citizens was almost double, that is, 74 years and 10.8% of them were 60 years old or more, which changed the composition of the age pyramid. Brazil is starting to grow and with this it is estimated that there will be an inversion between the young population and the older population, with 153 older people for every 100 children under 15 years old^{3,4}.

For 2020, the projections indicate that the older population will reach approximately 30.9 million people, being 14% of the Brazilian population, which is eight times larger compared to the growth of the young population. For 2030 it is estimated that the total older population in Brazil will exceed the number of young people between 15 and 29 years old^{1,4}.

With the country's demographic transition, the epidemiological profile experienced by the population has changed, as despite significant numbers for morbidity in Brazil, hospitalizations for circulatory, respiratory, endocrine, nutritional, and metabolic diseases have decreased significantly. This decrease may be a reflection of the quality and expansion of health services provided by the country's primary health care. On the other hand, it is possible to identify increasing and significant hospitalizations for neoplasms and external causes, which reinforces the epidemiological situation in Brazil³.

With this change in the epidemiological scenario, great challenges are arising, as studies show that in the third stage of the epidemiological transition, the main causes of mortality will be chronic non-communicable diseases, such as: heart diseases, cerebrovascular diseases, and neoplasms. These represent the main demands for health care in Brazil, and, despite the increase in important prevention actions, the challenge of carrying out health care for these older adults continues^{3,5}.

The aging process brings with it pathologies that are characteristic of age, such as Alzheimer's Disease (AD). First described in 1906 by neuropathologist Alois Alzheimer, AD was defined as an unrecognized neurological disease, being a dementia that leads to memory deficits, behavioral alterations, and the inability to perform daily activities.^{4,5}

"In 1910 it received the name 'Alzheimer's Disease' from the physician Emil Kraepelin, when describing the findings of Alois Alzheimer in his 'Manual of Psychiatry'"⁴.

AD is defined as a degenerative and insidious disease that causes a progressive decline in cognitive functions, related to perception, learning, memory, reasoning, psychomotor functioning, and neuropsychiatric conditions with severe manifestations⁴.

Its etiology is still unknown, however, there is a close relationship with predisposing factors such as: family history, age over 60 years, low educational level, head

trauma, and late-onset depression. The definitive diagnosis of this pathology can only be made through the histopathological analysis of the post-mortem brain tissue. Thus, the diagnosis has been made by evaluating the patient's clinical history associated with tests such as CT, MRI, and laboratory tests, used to support the diagnostic hypothesis⁴.

AD has an insidious onset, in addition to being a progressive and irreversible pathology. AD affects about 10% of older people over 65 years of age, and is among the most common causes of senile dementia, being, therefore, a chronic-degenerative disease⁵.

Statistics referring to the AD index in Brazil are imprecise. However, it is estimated that approximately 500 thousand people are affected by this pathology, causing a social impact, due to the direct costs involved in caring for older adults with AD. It is believed that AD costs reach 200 billion reais and that in 2050 the expenses will reach 1.1 trillion reais/year (3). These factors place AD as an important public health problem worldwide⁴.

The family routine undergoes significant alterations with the arrival of AD, the behavior of the older carrier changes completely and this has a very strong repercussion in the environment in which they are inserted, requiring greater physical, emotional, and social demands from caregivers, which can make them more depressed and stressed. These factors mainly affect the primary caregiver, who takes on the care routine with greater intensity, which may compromise their physical and mental health^{2,6}.

The care is mostly provided by family caregivers, unassisted and unprotected by government support and without social support. For the most part they are forced to resign from their employment and daily activities and sometimes absent themselves from family relationships. These unexpected changes can lead to physical, emotional, and financial burdens⁶.

The lack of preparation of caregivers to deal with the responsibility and burden that care brings is notable, seeing that there is a lack of knowledge about dementia, about how to act, how to understand the older carrier and their feelings, which places strain on the person responsible for care and for the family. This is mainly due to the long duration of the treatment and the loss of cognitive functions in the older adult, causing greater dependence and requiring greater care and dedication on the part of those who provide this care⁶.

Even when referring to the caregiver, most of the time this care is provided by people who are not in good health, by people with some family ties to the carrier, most often women, being in greater demand; wives, daughters, daughters-in-law, and sisters, women present themselves as the main actors of care, and largely without any kind of support. Care also presents the scenario that most caregivers are over 50 years old, that is, older people caring for older people, whose functional capacity is insufficient, and have health problems such as: back pain, depression, high blood pressure, arthritis and rheumatism, heart problems, and diabetes. Older people with AD need 24-hour care, which demands work, time, energy, financial resources, affection, effort, goodwill, and patience, tasks that require a division of labor and should not be performed by just one person. It is necessary that the caregiver's work be reflected on and reorganized, thinking about more efficient division of the tasks in order to better meet the needs as a whole of both this older person with AD and the caregivers^{1,3,5}.

The objective of this work was to identify in the national

scientific literature the difficulties faced by the family when caring for older people with AD.

METHODS

An Integrative Literature Review, with a broader methodological approach referring to reviews that provide a more comprehensive conception of the phenomenon or health problem that one wishes to research. In addition, it includes analysis of relevant research that will support decision-making and improve clinical practice^{7,8,9,10}.

Therefore, five methodological steps¹⁰ were used in the structuring of this study, as follows:

Step 1: Problem identification.

From the moment an older individual is diagnosed with Alzheimer’s Disease (AD), the routine and family environment undergo significant changes that impact family caregivers, in the physical, emotional, and social fields, making them more vulnerable to depression and stress due to the intensity of daily care. In this context, the research question emerges: What are the difficulties faced by the family when caring for an older adult with AD?

Step 2: Literature search.

The bibliographic survey was carried out between March and September 2020 in the Regional Portal of the Virtual Health Library (VHL) and in the journal directory *Scientific Electronic Library Online* (SciELO) using DECS descriptors and keywords, respecting the characteristics of the portal and the directory, summarized in the table below.

Table 1. Search strategy according to the characteristics of the databases. São Paulo, 2020.

Electronic Resource	Search strategy
BVS	tw:((mh:(idoso)) AND (mh:(“doença de Alzheimer”)) AND (tw:(“cuidado familiar”)) OR (tw:(“relações familiares”)) OR (tw:(emoções)) OR (tw:(“Efeitos psicossociais”))) AND (full-text:(“1”) AND la:(“pt”)) AND (year_cluster:[2010 TO 2020])
SciELO	“cuidado familiar” [All indexes] and idoso [All indexes]

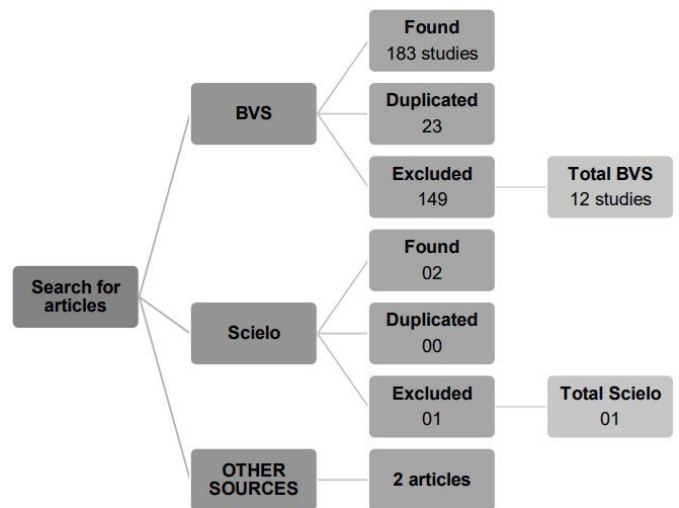
In total, 183 articles were found in the BVS and two studies in SciELO, totaling 16,499 documents.

Step 3: Data evaluation.

The articles were selected by titles and abstracts and were required to meet the following criteria: published in the last 10 years, in Portuguese, with free access and addressing the care of the older adults with AD in the family context. Duplicated studies, those which addressed dementia syndromes without specifying AD, and those that analyzed the care of older people with AD in Long-stay Institutions for Older Adults were excluded.

After applying the inclusion and exclusion criteria, 12 articles from the BVS and two from SciELO were considered for full reading. The study evaluation flow is shown in the figure below:

Figure 1. Evaluation flow of studies searched in electronic resources. São Paulo, 2020.



Finally, 15 studies were read in full and information was extracted on author and year of publication, objectives, method used in the study, studied population, main results, and final considerations.

Step 4: Data analysis.

After reading, the articles were analyzed and organized into tables containing the main information, in order to characterize the available literature on the subject of this study.

Furthermore, two categories were created according to content similarity, namely: (1) Strain on family caregivers - from the feeling of imprisonment to the burden generated by the care; (2) Family relationships and feelings related to care.

Step 5: Presentation.

The synthesis of the findings is presented in a table, and the analysis was performed from the established categories.

RESULTS AND DISCUSSION

The 15 studies analyzed are summarized in Table 1. The period of publication varied between 2011 and 2020, with a predominance of publications in 2016 (26.7%). Most studies (93.4%) are empirical research with a qualitative approach.

Table 2. Characterization of studies according to author, year of publication, type of study and objectives. São Paulo. 2020.

Autor	Ano de publicação	Tipo de estudo	Objetivos do estudo
Ilha, S. et al.	2018	Empirical	Identify gerontotechnologies developed by family members/caregivers as complex care strategies for the older person/family with Alzheimer’s disease.
Engel, C.L	2017	Empirical	Ethnographically deepen what is meant by suffering when talking about Alzheimer’s and how it is treated and cared for.
Souza, I.P et al.	2017	Empirical	Understand the modeling of family care over time for the older adult with Alzheimer’s, entering it in the donation circuit.
Pizolotto, A.L.Z et al.	2015	Empirical	Analyze how the family organizes itself to provide care to the older adult with Alzheimer’s disease in the home space.
Souza, I.P et al.	2016	Empirical	Understanding the arborescence of care in the family experience of Alzheimer’s disease, which, generated and maintained over time, needs to meet diversified needs.
Mendes, C.F.M et al.	2016	Empirical	Observe and identify the representations of family caregivers about care and analyze how this influences their care practices.
Souza, T.E.C et al.	2016	Empirical	To understand the care produced by the man-husband to the elderly woman who experiences illness due to Alzheimer’s, apprehending the care potentials in this relationship

Andrade, L.M et al.	2014	Empirical	The perception of family caregivers of people with Alzheimer's disease about the family support received for care, in light of the phenomenology of Maurice Merleau-Ponty
Seima, M.D et al.	2014	Empirical	Interpret the relationship in care between family caregivers and older people with Alzheimer's, based on the concrete dialectic of participation according to the four precepts of Gabriel Marcel.
Ilha, S. et al.	2014	Theoretical	Reflect on the difficulties generated by Alzheimer's disease in the family context of the older person.
Seima, M.D et al.	2011	Empirical	Identify the level of burden of the family caregiver of the older adult with Alzheimer in a community.
Oliveira, A.P.P et al.	2012	Empirical	To investigate the repercussions of care in the life of family caregivers of older people with Alzheimer's disease.
Oliveira, T.I et al.	2020	Empirical	To analyze the quality of life of family members/caregivers of older people with Alzheimer's disease and the influence of the Multi-disciplinary Care group for caregivers of people with Alzheimer's disease in this process.
Kucmanski, L.S et. al	2016	Empirical	To analyze the challenges faced by family members in the daily care of patients with Alzheimer's disease in the city of Chapecó, Santa Catarina.
Almeida, L.G.R.S et. al	2014	Empirical	To apprehend the caregiver's perception in relation to the experience of caring for the older adult with dementia of the Alzheimer type.

Strain on family caregivers: Strain on family caregivers: from the feeling of imprisonment to the burden generated by care

In this category, it is possible to see that AD not only affects the older carrier, but also the family structure and especially the life of the main caregiver. Over the years, due to the progression of the disease, the care routine becomes more intense, causing significant changes to occur in the routine of the family caregiver, who changes their way of life to dedicate themselves to caring^{2,4,11,12}.

In these circumstances, most of the time, this caregiver abandons their routine, work, which is their source of income, personal, social, and affective life, and their moments of self-care and leisure, and is constantly dedicated to the older person, which contributes to the decrease in their quality of life. These changes do not always occur of their own volition, but because of need, their commitment, loyalty to their family member, and love for the older person^{4,6,13,14,15}.

We feel as if the caregiver was imprisoned and couldn't get out of there, because they have to be controlling that other person all the time. This means that sometimes we don't have a life of our own. Alzheimer's will affect the life of the whole family, especially the life of that person who will be directly connected¹³.

As they are responsible for the life of the affected older adult, the demand for attention, time, and dedication weighs heavily, and means the effort, in addition to being physical, is also mental, making the routine exhausting, in addition to having a constant concern for the life of the other, making them feel trapped to live for caring and, consequently, overloaded, physically, emotionally, socially, and financially^{2,4,14,16}.

The daily life of the family caregiver is exhausting due to the intense care required by older adults with AD and that, because it is routine, the caregiver feels exhausted with this responsibility. The routine was characterized as "blinding" due to the impossibility of seeing changes in the following days, the feeling of imprisonment in the face of care, and the sadness of living life in the shadow of another¹⁴.

Thus, it is possible to see that the caregiver lives to care,

is totally dedicated to the older adult and their priorities are all focused on the AD patient. With their activities completely modified, the loss of their autonomy and independence, without government financial support, and without their daily activities, the feeling of imprisonment and overload is increasingly present^{2,14}.

"Living to care" is a reality demonstrated between the lines of the caregivers' statements, in which their life became the life of the older person under care. Giving through care, in the caregiver's view, prevents them from meeting their psychosocial needs².

Care in most circumstances is provided by only one person, the main caregiver, who is usually a family member, who is responsible for the life of this older person as a whole, making them unable to dedicate themselves to their personal needs. This care without rotation, in addition to causing loneliness and overload, often leads to physical and mental illness of the caregiver^{2,4,6}.

The disease imposes on the family caregiver a break from their way of life, making them feel like a stranger in their world, a situation that is not chosen by them. This change brings about a distressing and fragile state, as they watch their daily life collapse⁴.

It is difficult to find situations in which care is evenly divided between family members. In some situations, we see people who have greater purchasing power who manage to hire people to help provide care, or who do maintenance of household chores, but this situation does not cover much of the population. The purchasing power is something that directly interferes in this process, affecting the quality of life of these people, who assume the care without any financial or family governmental support, which has a lot of repercussions in their life and in their family relationships^{6,16}.

It is observed that in most cases, care is provided by a single family member, while the others 'pretend' that everything is fine, that the disease does not exist. However, if there is no person in the family who can take turns with the primary caregiver, the task of caring becomes much more exhausting⁴.

Family relationships and feelings related to care

In this category, it is possible to see that family relationships are not always the best, the main caregivers feel overwhelmed by the care, the difficulties in providing the care, and for depriving themselves of their daily activities, while other family members do not sympathize with them^{11,17,18}.

With the lack of equal division between family members, the ties are weakened, either by conflicts generated by the strain, or by other family members simply not making themselves responsible for the life of that older person, without offering to help. When caregivers feel alone and responsible for these older people, they become increasingly self-sufficient in this role assigned to them^{16,17}.

Caregivers not only no longer need the help of family members, but also do not ask for it, not because they are already tired of waiting for family support for care, but because they discovered that, deep down, there was a hope of rescuing negative experiences and, in this way, presenting themselves as on top of the situation, as a heroic member and no longer needy and alone¹⁷.

We can also see how much good and bad feelings are linked to care. The love, gratitude, reciprocity, and affection that the older person had with their families, and the way they were cared for influences the way in which this care is provided, this care often appears as retribution, making the family members feel responsible for providing care at the onset of the disease, as a way of thanking the older person and paying back everything that they were previously willing to do for the family member who is now their caregiver^{3,13,14,17,19,20}.

The love of the family caregiver for the older person is unconditional, and this allows the choice for donation, dedication, and abdication. The caregiver's sacrifice is quite noticeable, as they choose to experience care with the older person with Alzheimer's, while being aware that there is no possibility of recognition and affective return on the part of the patient, it is a disinterested compassion. They believe that the supreme feeling is love, but that it is essential to develop the ability to be patient with the other person¹⁴.

Family members also share the suffering of this older person, they suffer when they see the loss of their autonomy, the way they are now dependent on the care of the other. Behavioral alterations, cognitive losses, and the way they behave now make feelings such as fear, sadness, compassion, and guilt also present in the daily life of this family, thus forming a set of feelings^{13,14,17,21}.

“Caregivers report feeling fear and despair, due to changes in the behavior and personality of the older adults with AD”¹⁴.

By living this reality so closely, and knowing how the entire illness and aging process works, these caregivers also demonstrate the fear of going through this same situation, of needing care, of being dependent on others. They also report feeling afraid of not being able to provide care^{2,14}.

Fear is a constant in the lives of some caregivers. Each demonstration of dependence on care provided by the sick older person brings to the caregiver the immense desire not to be in this same situation, the fear of one day being affected by any disease that makes them lose functional capacity; that makes them eternally dependent on the care of others².

FINAL CONSIDERATIONS

Alzheimer's disease affects the entire family nucleus and especially the life of the main caregiver, therefore, it is essential to see care as a sharing of suffering and feelings. Care is based on love, affection, recognition, and retribution. It is necessary to create a care network that encompasses the whole family, thus trying to alleviate the suffering of all parties, not letting just one person be responsible for all the physical, psychological, and emotional needs of this older person.

It is important that Nurses study about family care in order to better guide and support the family about the pathology itself, advising on AD and its changes in the older person's life and on the care for the patient. It is essential that caregivers have a network of physical, psychological, financial, and governmental support, and even if they cannot live their routines as before, care is divided so that they can have the same moments of leisure and rest in their daily lives, in order to reduce the various problems caused by overload.

The caregiver must be properly assisted by the health team, with a kind of support network. There is a need for this caregiver to be assisted, guided, and cared for, possibly participating in care plans that are created and aimed at these family caregivers. Offering comprehensive and individualized care is

essential so that these caregivers feel welcomed, supported, and more prepared to deal with the daily situations they face.

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