REVIEW ARTICLE

REVISTA ENFERMAGEM ATUAL IN DERME

THE IMPACT ON THE QUALITY OF LIFE OF THE CAREGIVER OF ELDERLY WITH ALZHEIMER'S DISEASE

EL IMPACTO EN LA CALIDAD DE VIDA DEL CUIDADOR DE ANCIANOS CON ENFERMEDAD DE ALZHEIMER

O IMPACTO NA QUALIDADE DE VIDA DO CUIDADOR DO IDOSO COM DOENÇA DE ALZHEIMER

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ABSTRACT

The quality of life of caregivers of elderly people with Alzheimer's dementia is influenced by several factors, corroborating to work overload, making them more prone to physical and mental complications arising from the care process. **Objective**: To identify how caring for elderly people with Alzheimer's disease impacted the quality of life of their caregivers. **Methods**: Integrative Literature Review, conducted in six steps. We followed the PRISMA protocol instructions to select the articles and the PICo strategy to construct the guiding question. DeCS and MeSH were used to select the descriptors, crossed with the Boolean operators AND and OR, as follows: Elderly, quality of life, caregivers, Alzheimer's disease/Aged, quality of life, caregivers, Alzheimer disease. The search was conducted between the months of September to November 2022, with studies in the period from 2016 to 2022, in the databases: LILACS, BDENF, MEDLINE and SciELO. The final sample was composed of 12 articles. **Results**: The caregiver's education influences the planning of actions aimed at the care of the elderly person, with a higher prevalence in women. It was observed that as the disease progresses, the caregiver's overload is greater, corroborating to the increase of anxiety level, favoring the increase of physical and emotional wear. **Final considerations:** It is expected that this research may favor the planning of health actions, decreasing the caregiver's burden, reducing the level of anxiety developed during the performance of their work activities and contributing to improve their quality of life.

Keywords: Aged; Quality of Life; Caregivers; Alzheimer's Disease.

RESUMEN

La calidad de vida de los cuidadores de pacientes ancianos con demencia tipo Alzheimer está influenciada por varios factores, que corroboran la sobrecarga de trabajo, haciéndolos propensos a complicaciones físicas y mentales derivadas del cuidado. **Objetivo**: Identificar cómo el cuidado de los enfermos de Alzheimer afecta la calidad de vida de sus cuidadores. **Métodos**: Revisión bibliográfica integradora, realizada en seis pasos. Se siguieron las instrucciones del protocolo PRISMA para la selección de artículos y la estrategia PICo para construir la pregunta guía. Se utilizaron DeCS y MeSH para seleccionar los descriptores, cruzados con los operadores booleanos AND y OR, de la siguiente manera: Ancianos, calidad de vida, cuidadores, enfermedad de Alzheimer/Ancianos, calidad de vida, cuidadores, enfermedad de Alzheimer. La búsqueda se realizó entre los meses de septiembre a noviembre de 2022, con estudios de 2016 a 2022, en las bases de datos: LILACS, BDENF, MEDLINE y SciELO. La muestra final estaba compuesta por 12 artículos. Resultados: La educación del cuidador influye en la planificación de las acciones dirigidas al cuidado de la persona mayor, con mayor prevalencia en las mujeres. Se observó que a medida que avanza la enfermedad, aumenta la sobrecarga del cuidador, corroborando al aumento de los niveles de ansiedad, favoreciendo aumento del desgaste físico y emocional. **Consideraciones finales:** Se espera que esta investigación pueda favorecer la planificación de acciones de salud, reduciendo la carga del cuidador, disminuyendo el nivel de ansiedad desarrollado durante el desempeño de sus actividades laborales y contribuyendo a mejorar su calidad de vida.

Palabras clave: Anciano; Calidad de Vida; Cuidadores; Enfermedad de Alzheimer.

RESUMO

A qualidade de vida dos cuidadores de idosos portadores de demência de Alzheimer sofre influência de diversos fatores, corroborando para a sobrecarga de trabalho, tornando-os mais favoráveis a complicações físicas e mentais decorrentes do processo de cuidar. **Objetivo**: Identificar como o cuidar de idoso com a Doença de Alzheimer impactou na qualidade de vida de seus cuidadores. **Métodos**: Revisão Integrativa da Literatura, conduzida em seis etapas. Seguiu-se as instruções do protocolo PRISMA para a seleção dos artigos e a estratégia PICo para construção da pergunta norteadora. Utilizou-se o DeCS e o MeSH para a seleção dos descritores, cruzados com os operadores booleanos AND e OR, sendo: Idoso, qualidade de vida, cuidadores, doença de Alzheimer/Aged, quality of life, caregivers, Alzheimer disease. A busca foi realizada entre os meses de setembro a novembro de 2022, com estudos no período de 2016 a 2022, nas bases de dados: LILACS, BDENF, MEDLINE e SciELO. A amostra final foi composta de 12 artigos. **Resultados**: A escolaridade do cuidador influencia no planejamento de ações destinadas ao cuidado da pessoa idosa, com maior prevalência nas mulheres. Foi observado que conforme o avanço da doença, maior é a sobrecarga do cuidador, corroborando para o aumento do nível de ansiedade, favorecendo o aumento do desgaste físico e emocional. **Considerações finais:** Espera-se que esta pesquisa possa favorecer o planejamento de ações em saúde, diminuindo a sobrecarga do cuidador, reduzindo o nível de ansiedade desenvolvido durante a realização de suas atividades laborais e contribuindo para melhora da sua qualidade de vida.

Palavras-chave: Idoso; Qualidade de Vida; Cuidadores; Doença de Alzheimer.

INTRODUCTION

In the last decades, population aging has shown a progressive increase. This process corresponds to changes of physiological nature (senescence) or pathological (senility) that occur over time in the body. Between 1950 and 2025, the World Health Organization (WHO) points out that the number of elderly people in Brazil is expected to grow 15 times, ranking sixth among the countries in terms of the number of elderly people, corresponding to approximately 32 million people over 60 years old (1).

With the growth of the elderly population, several physiological changes occur that corroborate to the vulnerability of the elderly individual, which may cause functional losses, increasing the rates of chronic degenerative diseases. These limitations demand more rehabilitation, financial, home care, and prolonged institutionalization resources, making the elderly frail. We recognize as frail elderly those aged over 75 years or over 65 years with some functional impairment(2).

In this context, concepts such as independence, dependence and autonomy are widely discussed in the health area, especially when it comes to frail elderly people. The functional decline occurs particularly after 30 to 40 years of age, being influenced by physical and/or organic factors, individual genetic constitution, environment, life habits, family, socioeconomic, and educational conditions(3).

Among the chronic degenerative diseases that affect the elderly population, dementia stands out. Dementia is a neurodegenerative disorder known for the progressive deterioration of cognitive functions, such as memory loss, significantly interfering with the patient's normal life activities. In view of this, Alzheimer's disease (AD) is the most common cause of dementia in the elderly, accounting for 50 to 60% of cases(4).

AD is a dementia that compromises the physical, mental, and social integrity of the elderly person, leading to total dependence when manifested in the advanced stage, requiring increasingly complex care. This situation demands specific care, influencing the caregiver's daily life, producing emotional, psychological, and financial stress, as the patient gradually loses his or her cognitive functions and evolves to total dependence(5).

The caregiver of elderly individuals with AD is the person directly responsible for the individual, usually the wife, children, relatives or even a person hired to perform this function. Additionally, the routine lived by the caregiver interferes significantly in his/her Quality of Life (QL), making him/her more favorable to several physical and mental complications resulting from the work overload(6).

According to the WHO, QL is defined as an “individual's self-perception of his life in various contexts, goals, expectations, standards, concerns and values in which he lives”. This concept interacts with the complexity of the environment, physical and psychological aspects, social relationships, level of independence, and personal beliefs(7).

In health, the use of QL measures is relevant, both in the individual and social aspects, especially in degenerative diseases, because the measurement regarding the effectiveness of treatment is an essential factor(8). In this context, knowing the QL of the caregiver of an elderly person with AD is essential, since it will help in the planning of integral health actions, aiming at minimizing the factors associated with the workload caused by the care.

Therefore, considering the importance of knowing the characteristics that influence the QL of caregivers of elderly people with AD, this paper aims to identify how caring for elderly people with Alzheimer's disease impacted the quality of life of their caregivers.

METHOD

This is an Integrative Literature Review (ILR), which contributes to the improvement of Evidence-Based Practice (EBP) and plays a key role in the development of scientific knowledge. It was conducted in six interconnected steps: identification of the topic and selection of the guiding question; inclusion and exclusion criteria; categorization of the studies; evaluation of the selected studies; analysis of the results; and a complete synthesis of knowledge.

The route used in the search, screening, and analysis of the articles to define the procedures followed the instructions of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) protocol.

The period elapsed from the planning of the study to its completion was from September to November 2022, based on the guiding question "How has caring for the elderly with Alzheimer's disease impacted the quality of life of the caregiver?" For the construction, the PICo strategy was used, so that P corresponds to the population (caregiver), I of interest (Impact on quality of life) and the context Co (Caring for the elderly with Alzheimer's disease).

To search for articles, the following databases were selected: Latin American and Caribbean Literature on Health Sciences Information (LILACS), Nursing Database (BDENF), Medical Literature Online (MEDLINE), and the electronic library Scientific Electronic Library Online (SciELO).

The Medical Subject Headings (MeSH) and Health Science Descriptors (DeCS) were used to select the descriptors, crossed with the Boolean operators AND and OR, according to the search strategy shown in Chart 1.

Chart 1 - Search strategies for product retrieval. São Paulo - SP, Brazil, 2022

Search	Strategy
LILACS	Idoso AND (Qualidade de vida OR Cuidadores) AND Doença de Alzheimer
BDENF	Cuidadores AND Doença de Alzheimer AND Qualidade de vida AND idoso
MEDLINE	Caregivers AND Alzheimer Disease AND Quality of Life AND Aged

SciELO	Caregivers AND (Alzheimer Disease OR Aged)

Source: The authors

The inclusion criteria were defined as being original research, focused on the guiding question, available in full online, free of charge, published in the last seven years, in Portuguese, English and/or Spanish. Theses, dissertations, monographs, editorials, event proceedings, duplicate articles, and other reviews and studies in which caregivers were not the target population were excluded. Chart 2 was constructed to present the final composition of the articles selected from the databases.

Chart 2 - Databases and number of selected articles. São Paulo - SP, Brazil, 2022

Databases	Totality	After Criteria	Final Sample	%
LILACS	105	63	4	33,3
BDENF	35	48	3	24,9
MEDLINE	1.494	34	3	24,9
SciELO	107	53	2	16,9
Total	1.667	198	12	100%

Source: The authors

The data were extracted independently by two authors to minimize possible errors of interpretation, analysis, and evaluation of the articles in the review process. There was no need in this research for a third reviewer to intervene due to conflicts in the selection.

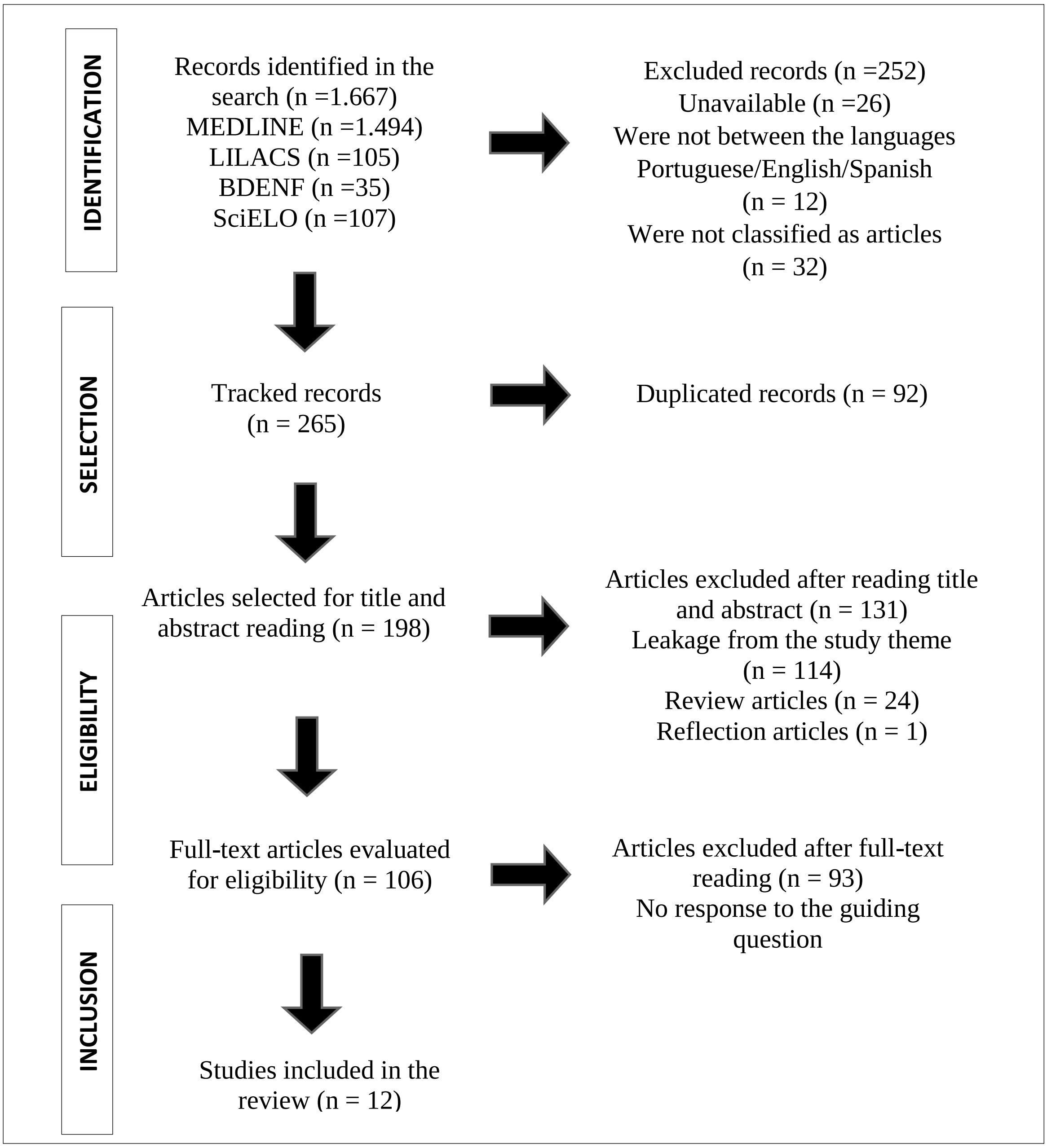
Melnyk and Fineout-Overholt's classification was used to classify the Level of Evidence (LE) of the studies: I: systematic review or meta-analysis; II: randomized controlled; III: controlled without randomization; IV: case-control or cohort study; V: systematic review of qualitative or descriptive studies; VI: qualitative or descriptive studies; and VII: opinion or consensus.

In the analysis phase, a summary table was prepared with the information from the selected studies, aiming to avoid erroneous information and inconsistencies in the search, namely: coding of the study, author(s), year of publication, language, objective, study, main results, and level of evidence. It is noteworthy that the copyright and precepts of Law number 9.610/1998 were respected.

RESULTS

In the present study, a total of 1,741 were found; after applying the previously established selection criteria, this was reduced to 265. Subsequently, the title and abstract were read to exclude publications that did not answer the guiding question, resulting in 106 publications. After reading, analysis, and interpretation of the studies, 12 articles were selected, as detailed in Figure 1.

Figure 1 - Flowchart of study selection, adapted from the PRISMA recommendation. São Paulo - SP, Brazil, 2022



Source: The authors

Among the studies analyzed, there was a greater number of publications in 2018, without exceeding the 10-year limit. Regarding the location of the studies, Brazil was the prominent country, but with greater flow in the English language. Chart 3 was constructed to present the synthesis of the studies included in the review.

Chart 3 - Characterization of the studies analyzed in the review. São Paulo - SP, Brazil, 2022

N	Authors Years/Idiom	Title	Study design	Main results	Journal	Level of Evidence
A1	Garzón et al. (2017) (9) Spanish	Health-related quality of life in caregivers of patients with Alzheimer's disease	Longitudinal analytical	The average age of the patients was 78.84 years, 64.9% were women, and 77.3% had not completed elementary school. The Short Form (SF-36) showed low scores in relation to the caregivers' quality of life	Journal of Neurology	VI
A2	Baldin et al. (2016) (10) Portuguese	Neuropsychiatric symptoms in the elderly with Alzheimer's disease and family caregiver attrition	Descriptive transversal	The age of the participants ranged from 66 to 96 years, and 68.7% were female. As for the care aspects, 70% of the caregivers reported caring for their father/mother. Anxiety being the neuropsychiatric symptom with the highest rate	Latin American Journal of Nursing	VI
A3	Queiroz et al. (2020) (11) Portuguese	Health literacy of informal caregivers of the elderly with Alzheimer's disease	Descriptive quanti-qualitative	The caregivers showed limitations in health literacy, compromising the quality of life and the assistance provided to the elderly person. This process corroborates the caregiver's overload through lack of knowledge about Alzheimer's disease	Brazilian Journal of Nursing	VI
A4	Silva et al. (2017) (12) Portuguese	Alzheimer's Disease: Experiencing the disease from the perspective of family caregivers	Qualitative descriptive	The degree of Alzheimer's dementia was severe, favoring emotional and physical manifestations. Most of the time, caregivers were so dedicated to caregiving that as a consequence they lost their jobs and quality of life	Journal of Psychology in Study	VI
A5	Rebêlo et al. (2021) (13) Portuguese	Factors associated with burden and quality of life of caregivers of older adults with dementia	Descriptive cross-sectional	It is noticed that the greater the degree of dependence of the elderly person, the more complex are the demands of the caregiver. This process contributes to physical and mental wear, leading to significant changes in lifestyle and personal time	Interdisciplinary Studies on Aging	VI
A6	Damásio et al. (2019) (14)	Factors associated with quality of life	Qualitative descriptive	Caregivers were informal or family members, mean age	Journal of Biosciences	VI

N	Authors Years/Idiom	Title	Study design	Main results	Journal	Level of Evidence
	English	from the perspective of the elderly caregiver with Alzheimer's disease		51, caregivers of the parent. The most common manifestations of caregiving were stress and decreased social support network in caregivers		
A7	Manzini et al. (2020) (15) English	Emotional disorders evidenced by family caregivers of older people with Alzheimer's disease	Descriptive cross-sectional	Most caregivers were female, married, with an average age of 56 years. Regarding the time spent on care, in the severe the average hours/day of care (11.5 h), i.e., the more advanced the stage of dementia, the greater the burden on the caregiver	Dement Neuropsychol	VI
A8	Marins et al. (2016) (16) Portuguese	Behavior Changes in the Elderly with Alzheimer's Disease and Caregiver Burden	Qualitative descriptive	The caregivers were mostly women 76%, in the age group between 50 and 60 years old, with a professional occupation with an average of 8 hours of daily work 52%. Caregivers face extensive demands, compromising their own physical and mental health	Anna Nery Journal	VI
A9	Cesário et al. (2017) (17) Portuguese	Stress and quality of life of the family caregiver of an elderly patient with Alzheimer's disease	Qualitative descriptive	The caregivers had a mean age of 56 years, working as caregivers for more than 3 years. Due to the workload, the caregivers presented high levels of anxiety	Debated Health Journal	VI
A10	Mattos et al. (2020) (18) Portuguese	Alzheimer's Disease: The Unique Experience of Family Caregivers	Qualitative descriptive	The caregiver's overload in the advanced stage of Alzheimer's disease triggers an accumulation of tasks, corroborating to physical and emotional exhaustion and a greater commitment of financial resources	Journal of Psychology USP	VI
A11	Rodriguez et al. (2018) (19) Spanish	Alzheimer's disease and the quality of life of the informal caregiver	Descriptive cross-sectional	The average age of the caregivers was 58 years old (70.8%). Regarding the stage of Alzheimer's dementia, 27% corresponded to the severe stage, generating pain/discomfort and anxiety/depression in caregivers	Spanish Journal of Geriatrics and Gerontology	VI

N	Authors Years/Idiom	Title	Study design	Main results	Journal	Level of Evidence
A12	Queiroz et al. (2018) (20) Portuguese	Sociodemographic profile and quality of life of caregivers of older adults with dementia	Descriptive cross-sectional	There was a predominance of female caregivers with a mean age of 57.51, with complete high school education. Caregivers tend to spend more time providing some tasks of caring for the elderly, causing the reduction of time for themselves, due to the demands of care	Brazilian Journal of Geriatrics and Gerontology	VI

Source: The authors

The studies were published in 2016, 2017, 2018, 2019, 2020, and 2021. As for the country of origin, it was evidenced that 66.6% of the studies come from Brazil, 16.7% from the United States of America (USA), and 16.7% from Spain. Regarding the methodological design, 41.6% of the studies are qualitative descriptive approach, 41.6% are cross-sectional descriptive, 8.4% longitudinal analytical, and 8.4% descriptive quanti-qualitative.

DISCUSSION

The QoL of caregivers of elderly patients with AD is influenced by several factors associated with physical, emotional, and financial conditions. Therefore, there are several manifestations presented by caregivers, significantly interfering in the care actions performed during care(9,13).

Impact on the quality of life of the caregiver of an elderly person with AD

The caregiver's education is a factor that facilitates access to information and understanding of the disease, which can promote QoL and health promotion(10). Caregivers' health literacy when inadequate influences care delivery and, as a result, health outcomes of the elderly person. The prevalence of inadequate caregiver health literacy corresponds to 52.2%(11).

In this context, raising the caregivers' level of health literacy conceives a necessary resource for the maintenance of therapeutic care at home. The care directed to the elderly person requires strategic, institutional, and adequate emotional support; in this way, the caregiver will be better prepared physically and mentally to follow his or her actions in daily life(21).

One notices in the analysis that most of the caregivers have a predominance of low education in approximately 35%.(12). Additionally, it was found that, on average, no caregiver had a college degree, studying less than 4 years. In some cases, the caregivers report that it is necessary to abandon the study and the family, aiming at greater dedication to work, corroborating the worsening of QoL through the workload exerted(14).

The level of education of caregivers of older adults with AD contributes directly to the understanding of the basics of the disease, favoring the promotion of health. The lack of knowledge of AD by the caregiver reflects directly in the difficulty in designing goals and efficient care strategies from the beginning of the disease. The limited knowledge of AD potentiates the work overload, tending to be exhausting, since they are exclusive and daily care, requiring much dedication(22).

The caregivers are mostly family members, with a higher prevalence of females, with an average age of 56 years(10,13). Historically, the literature shows that care is a deep-rooted issue of female attribution, with women being responsible for domestic actions in conjunction with childcare. This process accentuates the overload in relation to the caregiver's characteristics(17).

Corroborating the previous study, another factor that compromises the caregiver's QoL and can make care actions more difficult is when the caregiver is an elderly female. This process presents countless limitations inherent to the natural aging process, compromising the caregiver's physical and mental well-being(21).

In addition, when care is shared between spouses, it becomes necessary to perform other tasks besides caring, such as taking care of the children and domestic chores like preparing meals, which can contribute to work overload, interfering with their health, since the person does not have time to take care of him/herself(18,19).

In this context, regarding the degree of kinship, around 68% of caregivers are fathers or mothers. Therefore, exercising the role of caregiver is related to the fulfillment of social norms to the duties of filial obligation, together with the affective bond between the caregiver and the elderly. Some caregivers give themselves completely to caregiving, resulting in job losses and loss of QoL(22).

The presence of neuropsychiatric symptoms in elderly with AD is related to a higher degree of cognitive impairment, i.e., to the progression of dementia, increasing caregiver stress and reducing the QoL of the elderly. Nocturnal behavior was frequently mentioned, favoring a greater physical and emotional burden on the caregiver due to the constant supervision of the elderly(10,16).

When an elderly person presents more than one neuropsychiatric symptom, the caregiver will present greater functional wear and tear, generating greater burden in a linear fashion, i.e., increasing as the dementia progresses. The higher the levels of burden, the lower the QoL scores. Additionally, the time dedicated to care increases with the worsening of dementia, requiring almost an exclusive dedication, leaving aside their tasks to perform the care, renouncing their own lives to care for the elderly person(23).

Psychological and physical manifestations presented by caregivers of elderly Alzheimer's disease patients

Caregivers of elderly individuals with AD are more likely to develop psychological symptoms, such as depression and anxiety, together with several physical health problems, negatively affecting their QoL. When the elderly person has a higher degree of dependence, the physical stress associated with caregiving becomes greater, and the increase in the physical burden is attributed to the elderly person's age(13).

As the workload increases due to the severity of AD, it is common for caregivers to complain of pain, loss of a sense of freedom, stress, isolation, and a reduction in the social support network, and there are many complaints of chronic pain, insomnia, lack of financial resources, and other factors related to the elderly's behavior(24).

Caregiver attrition is also related to apathy, indifference, and inactivity due to feelings of frustration with the limitations the elderly individual may present. In relation to the delusions of theft and identification caused by the severity of dementia, the caregiver may present greater psychological stress due to the difficulty of being recognized by the elderly person(18).

With these statements, the emotional burden cannot be excluded in the severe phase, since the sadness generated by the severity of dementia is something frequently observed. As AD progresses, patients become physically more fragile, and the psychological and behavioral signs and symptoms presented by the caregiver worsen(25).

When the caregiver is able to recognize the changes and manifestations of AD presented in its stages, many problems can be avoided and the burden minimized(12,15). The caregiver's overload in the advanced stage triggers physical and emotional exhaustion, an accumulation of tasks and a greater commitment of financial resources, going from helping to some tasks of total dependence(18,19).

The burden generated by caregiving, often in the advanced stages of dementia, leads to social isolation, creating difficulties in maintaining social relationships and engaging in leisure activities with friends and family. This overload amplifies the level of stress and anxiety, compromising the QoL and impairing the self-care of the caregivers themselves(23).

Stress is often presented in research on this topic, since the role of caregiving is related to stressful actions, promoting impacts on the health and QoL balance of caregivers and family members. Stress has a direct reaction with the body, and it can generate physical and psychological compromises, affecting especially the caregivers who are in a situation of constant tension(17,20).

The impact generated during the years as a caregiver produces effects related to pain and discomfort, especially in relation to informal caregivers, in whom mental health problems, fear, worries about the future, and the tasks related to the act of caring are presented more frequently. Over time, as the elderly's dependence and the difficulties in the act of caring increase, psychosocial syndromes such as Burnout Syndrome, which arises because of the high level of stress and the high effort in the work actions(25).

FINAL CONSIDERATIONS

In view of the exposed information, it was found that several factors potentiate the growth of the workload performed by caregivers of elderly individuals with AD, favoring an increased predisposition to numerous health problems. It was observed that the more advanced the degree of dementia, the greater the burden of the caregiver, presenting several physical and emotional manifestations that interfere with their QoL.

Although most of the caregivers presented several problems arising from the work in relation to the body, anxiety was the main impact reported in the studies, corroborating the physical and mental wear of caregivers. In this context, some health actions are essential to minimize the damage presented by the overload, with emphasis on health education about AD, enabling adequate strategic and emotional support, preparing the caregiver for the actions developed in everyday life.

In view of this, this study identified the impact that caring for an elderly patient with AD causes on the caregiver's QoL, reaching the proposed objective. Therefore, it is expected that this research can contribute to the planning of health actions, aiming to reduce the caregiver's burden, focusing on the management of behavioral changes, enabling the improvement of the caregiver's QoL.

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