

Quality of life of caregivers of the elderly: an integrative review

Qualidade de vida em cuidadores de idosos: uma revisão integrativa

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RESUMO

O crescimento da população idosa é uma realidade atual e é consequência de um processo de transição demográfica e epidemiológica. O idoso com seu estado de saúde comprometido precisará da ajuda de um cuidador, geralmente alguém da família, na maioria das vezes em tempo integral, o que poderá gerar uma sobrecarga que comprometerá sua qualidade de vida. Objetiva-se analisar a produção científica à cerca da qualidade de vida dos cuidadores de idosos. Trata-se de uma revisão integrativa da literatura, cuja busca foi realizada nos indexadores LILACS, PubMed, CINAHL e Scopus. Foram analisados 18 artigos, nos quais a maioria dos estudos eram transversais. Quanto à população dos estudos, a maior parte dos artigos analisou cuidadores de idosos com Alzheimer. Os principais resultados para influenciadores na qualidade de vida dos cuidadores: depressão; má qualidade do sono; dificuldades de apoio, suporte social, financeiro, físico e na divisão de tarefas; falta de lazer e atividade física; problemas de saúde pré-existentes nos cuidadores; e características sócio demográficas. Através do conhecimento das variáveis que interferem na qualidade de vida dos cuidadores, pôde-se compreender como e o quanto essa qualidade de vida é afetada e assim projetar intervenções para melhorar a vivência dos cuidadores.

Palavras - chave: cuidadores; idoso; qualidade de vida.

ABSTRACT

The growth of the elderly population is a current reality and it is a consequence of an epidemiologic demographic transition process. The elderly with compromised health will need the help of a caregiver, generally someone who is part of the family, most of the time in integral time, and it could generate and overburden that will compromise his or her life quality. It aims to analyze the scientific production on the life quality of elderly caregivers. This is an integrative review of literature, in which the search was performed in the indexers LILACS, PubMed, CINAHL e Scopus. 18 articles were analyzed, in which most of the studies were cross-sectional. Regarding the population of the study, most of the articles analyzed caregivers of elderly people with Alzheimer. The main results for influencers in life quality of caregivers: depression; poor sleep quality; support difficulties, social, financial, physical and task division support; lack of physical activity and leisure; preexistent health problems in caregivers; and sociodemographic characteristics. Through knowing the variables that interfere in life quality of caregivers, it could be understood how and when this life quality is affected and thus plan interventions to improve caregivers' life experience.

Keywords: caregivers; elderly; quality of life.

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INTRODUCTION

One of the greatest cultural achievements of a people in its process of humanization is the aging of its population, reflecting an improvement in life conditions. According to United Nations Population Fund projections ⁽¹⁾, “one out of every 9 people in the world is 60 or older, and it’s estimated to grow up to 1 in 5 by 2050.” It is estimated that in 2050, for the first time, there will be more seniors than children under 15 years old.

The Brazilian Institute of Geography and Statistics (IBGE) ⁽²⁾ pointed out that the number of elderly people in Brazil is one of the largest in the world, with growth rates of more than 4% a year in the period 2012 to 2022, leading to a considerable change in its population pyramid. It is expected for the next 10 years, an average increase of more than 1 million elderly people every year.

The growth of the elderly population is a current reality and consequently a process of demographic and epidemiological transition. The tendency is to increase the number of individuals who will present chronic non-communicable diseases, and the increase in the prevalence of these diseases is directly related to the rates of dependent elderly people with functional, organic and / or psychological disabilities ⁽³⁻⁴⁻⁵⁻⁶⁾.

The more fragile elderly may have difficulty in balance and walking, which can lead to falls, dysphagia, difficulty in absorption, and urinary and fecal incontinence that are part of the reality of most elderly people, requiring at this stage of life the help of a caregiver ⁽⁷⁾. The caregiver can be formal or informal. The formal ones have acquired knowledge through specific training and have guaranteed remuneration, while the informal one is usually someone in the family, who does not have financial remuneration for the activities performed ⁽⁸⁾.

The elderly with their compromised health will need the help of someone to carry out the activities of life, however simple they may be, and most of the time those who assume this role are relatives. They assume the responsibility of support and assistance to the elderly, from their basic needs to other activities, such as going to the supermarket and conducting banking transactions. Most of the time, the care is performed by daughters or wives, full time, without relay with other relatives. This dependence can generate an overload on the caregiver and bring health risk factors, compromising their quality of life ⁽⁹⁻¹⁰⁾.

According to the World Health Organization, quality of life corresponds to the individual’s perception of their position in life in their cultural context and value systems in which they live and also in relation to their goals, expectations, standards and concerns. It also includes their physical, psychological health, levels of independence, social relationships, environmental characteristics and spiritual life ⁽¹¹⁾.

The repercussions on the life of the caregiver are unquestionable. The demand of time in the care demands a lot from them, causing their own personal life to not receive the necessary attention. This burden of exigency causes them to neglect their leisure, social and affective life, health, and in some cases, their paid work, which generates financial problems ⁽¹²⁾.

With the purpose of answering this question, we established as objective of the study: to analyze the scientific production about the quality of life of caregivers of the elderly.

METHOD

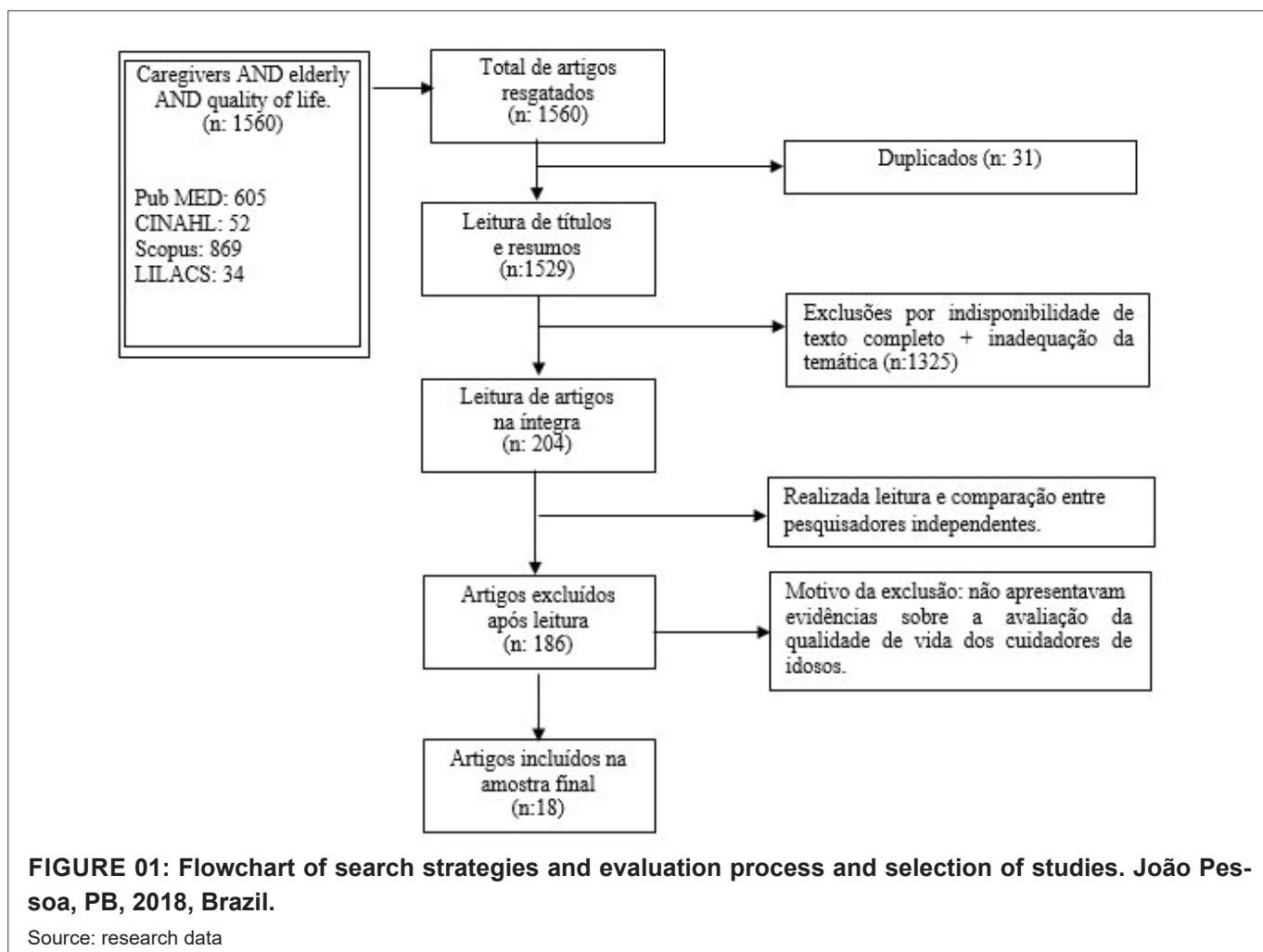
It is an integrative review of scientific literature, considered as a research method that allows the search, critical evaluation and synthesis of the available evidence of the subject investigated. It includes the analysis of relevant research in the scientific environment related to the researched topic, as well as to identify knowledge gaps that need to be filled through new research ⁽¹³⁾.

The construction of the integrative review had as stages: 1) formulation of the guiding question; 2) research in primary databases; 3) selection and categorization of studies; 4) evaluation of the selected studies; 5) discussion and interpretation of results; and 6) synthesis of knowledge with recommendation for practice.

To guide the study, the following guiding question was formulated: What are the scientific evidences about the quality of life of caregivers of the elderly? The research for the articles was carried out in the databases of Latin American and Caribbean Literature in Health Sciences (LILACS), American National Library of Medicine (PubMed), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Elsevier BV (Scopus). Crosses were performed with descriptors indexed in the MeSH Terms: ‘caregivers’, ‘elderly’ and ‘quality of life’ (Figure 01)

The inclusion criteria defined for selection of the articles were: primary studies developed with human beings; articles referring to the quality of life of caregivers of the elderly person measured by validated instruments; publications in Portuguese, English and Spanish in full and indexed in said databases from 2013 to 2018. The defined period is due to the fact that the studies of the health field have a constant evolution, making updating primordial. Articles that did not present evidence about the quality of life of caregivers of the elderly were excluded.

In order to organize the data obtained in the previous step, a table was elaborated (Table 1), in which variables related to selected articles were identified: publication identification (authors, periodical, year), objectives, type of study, sample and main results. The data were examined



through descriptive analysis, in order to answer the guiding question of the research and are presented in Table 1.

RESULTS

We initially found 1560 articles. After the withdrawal of the repeated ones and those that did not meet the inclusion criteria, 18 studies remained for review. In PubMed, 10; in CINAHL, no articles; in the Scopus database, 6; and in LILACS, 2.

As for the population of the studies, 4 of them investigated informal caregivers of the elderly comprehensively, 3 caregivers of elderly people with impaired functional capacity, 5 analyzed caregivers of elderly people with dementia or Alzheimer's disease, and 2 surveyed caregivers of elderly people with some type of disability. Other studied populations, appearing in 1 article each, were: informal caregivers of the elderly after rehabilitation; elders who suffer from cancer; carriers of chronic diseases; and who serve as caregivers of other elderly people.

Regarding the study methods, a qualitative study⁽²³⁾, a prospective study⁽²⁵⁾, an exploratory study⁽²⁸⁾, a sectional study⁽¹⁴⁾, two integrative models of literature review⁽⁹⁻¹⁵⁾, a systematic literature review model⁽²⁶⁾ and the others were cross-sectional.

The articles presented had the main results for influencers on the quality of life of the caregivers: depression⁽⁹⁻¹⁷⁻¹⁸⁻²⁷⁻²⁸⁻²⁹⁾; poor quality of sleep⁽⁹⁻²⁷⁻²⁹⁾; difficulties of social, financial, physical support and division of tasks⁽⁹⁻¹⁹⁻²³⁻²⁶⁻²⁷⁾; lack of leisure and physical activity⁽⁹⁻¹⁵⁾; pre-existing health problems in caregivers⁽⁹⁻²⁶⁾; and socio-demographic characteristics⁽¹⁴⁻²¹⁻²⁷⁻²⁸⁾.

DISCUSSION

Studies have shown that the role of caregivers is extremely stressful. The chronic stress situations are experienced by the family members, the psychological impact that prolonged care generates, difficulties in managing the disease, the degree of incapacity, adaptations to the changes and the characteristic itself⁽⁹⁻¹⁷⁻¹⁸⁻²⁷⁻²⁸⁻²⁹⁾, anxiety⁽⁹⁻¹⁸⁻²⁷⁻²⁸⁾, stress, and low life satisfaction may be triggered by progressive illnesses. Depressive symptoms appear as the most determinant factor of the physical health of caregivers compared to the general population worldwide⁽²⁸⁾.

Depression is often triggered by the fact that caregivers believe that nothing will change, no matter what they do⁽¹⁸⁾. The patient's depression has also been reported as a predictor of the caregiver's depression⁽¹⁷⁾, being difficult for them to deal with it, the difficulties it causes and the negative im-

TABLE 01 – Characterization of selected studies according to identification, objectives, type of study, sampling and main results. João Pessoa, PB, Brazil, 2018

	Authors, Periodical, Year / Country	Objective	Type of study	Sample	Main Results
E1 ⁽⁹⁾	Pereira LSM, Soares SM Ciência & Saúde Coletiva 2015 Brasil	To analyze the available evidence about the factors that influence the quality of life (QoL) of the family caregiver of the elderly with dementia.	Integrative model of literature review	11 articles	Factors influencing family caregiver QoL: depression; poor quality of sleep; type of dementia and neuropsychiatric symptoms; support, social support and access to health services; leisure; pre-existing health problems; subsidized interventions with training for caring and spirituality.
E2 ⁽¹⁴⁾	Reis LA et al Braz J Phys Ther 2013 Brasil	To evaluate the QOL and associated factors in caregivers of the elderly with impaired functional capacity.	Cross-sectional study	40 caregivers of elderly people with impaired functional capacity.	Most caregivers are women of low schooling; high distribution of health problems among caregivers; the Physical Domains and Environment were the most harmed, while the psychological was the least affected. The QoL of the caregivers of the elderly is very compromised, mainly in the Physical Domain in those who are the main caretaker. The presence of sequelae and diseases was related to the decrease of aspects of QoL.
E3 ⁽¹⁵⁾	Ferreira DC et al J Nurs UFPE on line 2014 Brasil	To analyze publications about the QOL of family caregivers of elderly people with Alzheimer's disease.	Descriptive study, integrative review of the literature.	12 articles	It is presented as a negative factor for the family caregiver's QOL, the capacity for leisure activity; as limiting the overload, communication in the binomial caregiver / elderly affected and the lack of physical activity. Caregiver QoL is worse when the functional capacity of the elderly is more compromised. Reinforced the importance of planning and nursing actions aimed at the family caregiver.
E4 ⁽¹⁶⁾	Rocha ACO et al J Nurs UFPE on line 2015 Brasil	To know the QoL of elderly people who play the role of caregivers of other elderly people, using the WHOQOL-bref instrument.	Descriptive, exploratory, cross-sectional study with a quantitative approach	151 elderly caregivers of other elderly people	The self-evaluation of the QoL of the elderly caregiver was satisfactory; the mean of the social relations domain brought greater contribution to the QoL; the physical domain presented higher values in the elderly who are caregivers when compared to the elderly who do not exercise this function; the environmental domain presented the lowest values in the evaluation of QoL, therefore, it is the domain that requires greater intervention.
E5 ⁽¹⁷⁾	Ornstein K et al Am J Geriatric Psychiatry 2013 EUA	Evaluating how distinct BPSD symptoms (behavioral and psychological symptoms associated with dementia) affect depressive symptoms for caregivers of patients with dementia.	Cross-sectional, longitudinal analysis	160 patients who had caregivers, recruited from memory disorder centers or private medical practices.	It was found that the patient's depressive symptoms had a greater magnitude of effect on the caregiver's depression; and that developing and testing more effective strategies for treating depression in patients with dementia can improve outcomes for the patient and caregiver.

E6 ⁽¹⁸⁾	Santos RL et al Arquivos de Neuro- Psiquiatria 2014 Brasil	To investigate the QoL of caregivers of patients with mild and moderate dementia; and aspects related to QoL.	Cross-sectional study.	88 primary patients (21 males) and patients with Alzheimer's disease (22 males).	The results showed that caregivers' burden and depressive symptoms were strongly related to the QoL of caregivers of both mild and moderate dementia groups.
E7 ⁽¹⁹⁾	Bagne BM, Gasparino RC Revista de Enfermagem UERJ 2014 Brasil	To evaluate the QOL of caregivers of Alzheimer's disease (AD) and its relationship with the level of functional independence of the patient.	Quantitative, descriptive and cross-sectional study	123 charts of patients with AD and 66 caregivers	The results demonstrate the relationship between the social relations domain and the support received by the caregiver; the importance of having the caregiver receive support from their families, since the burden of carrying out tasks, coupled with financial difficulties, management with the person with dementia, physical and mental fatigue contribute to the onset of stress and consequent worsening of QoL.
E8 ⁽²⁰⁾	Rosina NEF et al Rev.latino Americano de Enf 2013 Brasil	To identify the association between the functional capacity of the elderly and the caregiver's overload.	Descriptive, cross-sectional and quantitative study	178 elderly people with functional disabilities and their caregivers	Most caregivers reported moderate overload; men presented higher chances of less overload than women and the more independent the elderly, the greater the chances of a lower burden on the caregiver.
E9 ⁽²¹⁾	Du J et al Medicine 2017 China	To investigate QoL among Chinese caregivers of elderly people with disabilities in Beijing; and to explore the HRQoL predictors of caregivers.	Cross-sectional study	766 caregivers	The analysis showed that each block of independent variables (demographic characteristics of elderly adults with disabilities, demographic characteristics of caregivers, caring context and subjective caregiver load) contributed significantly to the physical and mental quality of the caregivers. The subjective caregiver factor explained the largest amount of total variance in all MH subscales and the 2nd largest variation in most of the physical subscales. Therefore, the subjective caregiver burden was the strongest predictor of QoL.
E10 ⁽²²⁾	Rodriguez-Perez M et al Health and Quality of life Outcomes 2017 Espanha	To analyze the relationship between coping strategies and QOL dimensions in primary caregivers of elderly dependent relatives.	Descriptive cross-sectional study	86 primary caregivers of dependent elderly people	Dysfunctional coping (passive or avoidant) was related to a worse QoL in the psychological dimension, while emotionally and socially supported coping strategies were associated with a higher quality of life in psychological and environmental dimensions, respectively. The physical and relational dimensions of the QOL were not related to the type of coping.
E11 ⁽²³⁾	Thai JN et al Am J Hosp Palliat Care 2016 EUA	Generate hypotheses about factors affecting QoL assessments for informal caregivers of the elderly (+65 years) with late disability.	Qualitative study	Caregivers of older relatives (+65 years) with disability.	The study showed that 52% of caregivers experienced a decline in QoL. The factors that affected the caregivers' quality of life were: social, emotional, physical and financial.
E12 ⁽²⁴⁾	Van Dam PH et al JAMDA 2017 Holanda	To describe the QOL of informal caregivers after geriatric rehabilitation and to identify the associated determinants.	Cross-sectional study with longitudinal follow-up	350 informal caregivers (66.2% female, 63 years of age) and their care recipients (63.4% female, age 78 years);	The study showed that the proportion of carers partners is large (50.4%). Most informal caregivers would feel less happy if they had to stop their caring tasks and turn over responsibility to another self-chosen person. Health, happiness and the burden before geriatric rehabilitation of the elderly are cited as determining factors associated with carers' QoL.

E13 ⁽²⁵⁾	Germain V et al Journal of Geriatric Oncology França 2016	To evaluate the perceived overload and QoL of the main caregiver of patients (≥70 years) who suffer from cancer and the predictors of QoL of this population.	A multicenter prospective study	98 patients (≥70 years) and 96 primary caregivers.	The patients' QoL scores showed a decrease in the dimensions "emotional role" and "body pain". Main determinants of quality of life: • Factors inherent to the primary caregiver (age and perceived overload); • Factors inherent to the patient (functional independence).
E14 ⁽²⁶⁾	Ge L, Mordiffi SZ Cancer Nursing 2017 China	To identify factors associated with the burden of family caregivers of elderly patients.	Systematic literature review	116 studies	Family caregivers who were at a younger age experienced greater psychological distress induced by the care given. Their activities were more restricted and their financial situation less secure than the older ones.
E15 ⁽²⁷⁾	Hui X et al BMC Geriatr. 2016 China	To examine the QOL in family caregivers of the elderly with chronic diseases; explore the demographic factors and characteristics of both the elderly and their caregivers.	Cross-sectional study	407 family caregivers who care for elderly people with chronic diseases.	Family caregivers of elderly people with chronic diseases showed lower mental well-being and better physical condition. Demographic characteristics of caregivers contributed to better QoL; younger age, marriage, and activity status of daily living were associated with a high physical component score. The study demonstrated the importance of addressing the mental health of family caregivers, and of economic and psychological support.
E16 ⁽²⁸⁾	Meiyan W et al PLoS One. 2016 China	To examine the prevalence and factors related to depression among female informal caregivers of the elderly with disabilities.	Exploratory study	444 Uyghur and Kazakh women, informal caretakers.	The findings suggest that the demographic characteristics of informal caregivers, the burden of caregivers, and the degree of disability and quality of life of people with disabilities have shown the most significant correlation with depressive symptoms among women's informal caregivers.
E17 ⁽²⁹⁾	Grun D et al J. Am. Med. Dir. Assoc Luxemburgo 2016	Investigate the patient and caregiver factors that contribute to the caregiver's burden.	Cross-sectional study	59 pairs of patients and their caregivers	The study demonstrated that sleep problems, autonomic dysfunction as well as motor impairment and night care strongly impacted the caregiver's burden and health-related QoL. It highlights the considerable time investment, including the night, and identifies the strong interaction with the mood of care. The severity of the disease only influences the caregiver's burden; the duration of the disease has no negative impact on the caregiver's burden and QoL. Concerns about patient safety directly increase the caregiver's mental stress. It was indirectly confirmed links such as anxiety and depression, present in 42% and 44%, respectively, of the caregivers investigated. Most caregivers in this study are female wives
E18 ⁽³⁰⁾	Vaingankar J A et al Int Psychogeriatr. 2016 Cingapura	Describe participation in care, care needs, and the burden of care among caregivers.	Cross-sectional study	693 pairs of older adults (60-100 years of age with care needs) and informal caregivers (21-88 years).	The participation of informal caregivers was greater in activities related to communication (35.1%), food (32%) and bath (21.1%). The need for care, assistance with activities of daily living and the presence of behavioral and psychological symptoms of dementia were significantly higher among elderly people with dementia, resulting in greater participation in the care of these patients.

Source: research data

pact it has on the quality of life, since the elderly patient is perceived as someone who is suffering. Feelings of helplessness and emotional distress are a thematic emphasized in some studies as a risk factor for caregiver depression.

In this theme, some studies have shown that poor sleep quality⁽⁹⁻²⁷⁻²⁹⁾ among caregivers of the elderly is related to the constant interruption of sleep in order to perform the tasks involved in providing adequate care, as well as safety concerns of the elderly. There is a strong link between night care and caregiver burden, impairing sleep quality and consequently quality of life⁽²⁹⁾.

The studies showed that lack of social support and insufficient financial support⁽⁹⁻¹⁹⁻²³⁻²⁶⁻²⁷⁾ were factors that contributed to a greater burden on the caregiver. The financial burden is a factor that generates stress and physical exhaustion, not only of the caregiver, but of the whole family, since the family caregiver usually has problems with lack of employment, due to them leaving or reducing their work flow. The impact on family relationships caused by elderly care is intense, as a result of the inevitable changes that affect affection, finances, power relationships and other variables. In this way, a process of family reorganization takes place, when one stops performing personal, domestic and social tasks for the other⁽⁹⁻¹⁹⁻²³⁾.

Among the studies analyzed, two of them talk about leisure activity and physical activity⁽⁹⁻¹⁵⁾, factors associated with the quality of life of the caregivers, since the overload experienced in their daily life limits them to include these programs in their daily routine. More hours of care per week and living with the patient negatively influence the quality of life of the caregiver. It is demonstrated that the greater number of caretakers are women and that they usually suffer more impact because of the exhausting tasks performed, such as patient hygiene. Thus, it requires a way to strengthen their body through physical activity, with the purpose of providing physical well-being, more disposition and health⁽⁹⁻¹⁶⁾.

This study detected a high prevalence of health problems in caregivers⁽⁹⁻²⁶⁾, such as musculoskeletal disorders, mental disorders, arterial hypertension and cardiovascular diseases. In addition, strenuous and repetitive activities, the burden of the tasks and the need to wake up at night, as well as the obstinacy of the elderly in performing their duties, contribute to the deterioration of their physical and mental well-being. This association is very worrying, especially considering that the pathologies presented are related to morbidity and mortality in the general population. The burden placed on caregivers directly affected their quality of life and health status⁽²⁶⁾.

The socio-demographic characteristics⁽¹⁴⁻²¹⁻²⁷⁻²⁸⁾ of the studies included age, sex, nationality, profession, family income, marital status, current employment and kinship with the elderly.

The studies showed that the older the caregiver, the worse their quality of life, because older people have more chance of having chronic diseases⁽²¹⁻²⁷⁾. Regarding nationality, it can be seen that in certain cultures, it is an obligation to care for elderly relatives⁽¹⁴⁻²¹⁻²⁷⁾. In these realities, the care is fulltime, exercised mainly by women, most often wives and daughters, without the help of the other family members. The time spent caring for the elderly limits these caregivers to providing this care, thus making it impossible for them to seek medical care and social interaction with others⁽²⁷⁻²⁸⁾.

Higher financial income positively influences the quality of life of caregivers, since there is a greater investment in their healthcare expenses and in health equipment for the elderly, which can reduce the effort during care⁽²¹⁾.

The burden and stress of fulfilling both family and professional commitments were severe enough to affect the psychological and social aspects of their personal quality of life, which often leads to the abandonment of the profession⁽²⁷⁾.

CONCLUSION

With the increase in the aging rate, it is clear that the number of caregivers will increase. And these characters, more and more common in the daily life of the elderly, need special attention.

Through the results and the discussion of this review, it was concluded that the variables that interfere in the quality of life of caregivers of the elderly are results of multiple factors. These variables are affected by simultaneous factors such as depression, poor sleep quality, type of dependence of the elderly, financial conditions, access to health services, leisure and pre-existing health problems. Through the score and knowledge of these, it was possible to understand how and how this quality of life is affected, and thus implement multidisciplinary interventions that aim to improve the caregivers' experience.

Among the samples found, most were caretakers of patients with neurodegenerative diseases, implying a greater dependence and, above all, greater dedication on the part of their caregivers.

A differentiated view by the health team that provides assistance to the elderly and their caregivers, whether at home or at hospital, will focus on a more humanized care, also focused on the psychosocial aspects linked to care and living with the elderly dependent on daily care.

In all the reviewed articles, the damage to the caregivers' health was clear, be it physical, emotional or financial. It is necessary to create health policies, which in a timely manner can prevent and treat the diseases characteristic of this emerging population that suffers from the neglect of the government.

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