

A vulnerabilidade dos cuidadores de idosos com demência: revisão integrativa

Vulnerability of caregivers for the elderly with dementia: integrative review

Vulnerabilidad de los cuidadores de personas mayores con demencia: revisión integradora

Bruna Silva Leite¹; Alessandra Conceição Leite Funchal Camacho²; Raquel dos Santos de Queiroz³; Gláucio Diré Feliciano⁴

How to quote this article:

Leite BS; Camacho ACLF; Queiroz RS; et al. Vulnerability of caregivers for the elderly with dementia: integrative review. Rev Fund Care Online. 2017 jul/sep; 9(3):888-892. DOI: <http://dx.doi.org/10.9789/2175-5361.2017.v9i3.888-892>

ABSTRACT

Objective: To analyze the vulnerability of caregivers of elderly with dementia. **Method:** This is an integrative review of quantitative and qualitative nature. The data collection period was from 01/09/14 to 10/30/14. **Results:** Of the articles analyzed, 26% point interventions to relieve overload; 20% analyze the depression load; 16% of studies address caregiver burden; 14% guided their discussions in physical and spiritual well-being, psychological and social well-being and damage to quality of life; 12% address stress. **Conclusion:** Researchers from several countries show the care impact on the life of the caregiver, highlighting: the emotional overload, routine stress, and depressive symptoms. However, there are mitigation measures identified through the research that can contribute to the everyday stress relief, such as the daily practice of yoga meditation, religion, the positive relationship between the family, the elderly and the caregiver.

Descriptors: Dementia; Caregivers; Family Nursing.

¹ Nurse. Specialist in Infection Control Related to Health Care. Student at the Aurora Afonso Costa (EEAAC) Nursing School of the Fluminense Federal University (UFF) at the MSc in Health Care Sciences (MACCS). Graduated in Nursing by EEAAC of UFF, in 2014. Email: bruna.silvaleite@gmail.com.

² Adjunct Professor at Aurora School of Nursing Afonso Costa, Department of Fundamentals of Nursing and Administration (MFE), Fluminense Federal University - Niterói (RJ).

³ Nurse. Masters Student in the Aurora Afonso Costa (EEAAC) Nursing School of the Fluminense Federal University (UFF) in Academic Master in Health Care Sciences (MACCS).

⁴ Biologist. Research Professor at the State University of the West Zone. PhD in Biology from the State University of Rio de Janeiro.

RESUMO

Objetivo: Analisar a vulnerabilidade dos cuidadores de idosos com demência. **Método:** Trata-se de uma revisão integrativa de natureza quanti-qualitativa. O período de coleta de dados ocorreu de 01/09/14 a 30/10/14.

Resultados: Do total de artigos analisados, 26% apontam intervenções para alívio da sobrecarga; 20% analisam a carga de depressão; 16% dos estudos abordam a sobrecarga do cuidador; 14 % pautaram suas discussões no bem-estar físico e espiritual, bem-estar psicológico e social e nos prejuízos à qualidade de vida; e 12% abordaram o estresse. **Conclusão:** Pesquisadores de diversos países apontam os impactos do cuidado na vida do cuidador destacando a sobrecarga emocional, estresse rotineiro e sintomas depressivos. Entretanto, existem medidas atenuantes, identificadas através das pesquisas, que podem contribuir para alívio do estresse cotidiano, por exemplo, a prática diária de meditação yogue, a religiosidade, o relacionamento positivo entre a família, o idoso e o cuidador.

Descritores: Demência; Cuidadores; Enfermagem Familiar.

RESUMEN

Objetivo: Analizar la vulnerabilidad de los cuidadores de ancianos con demencia. **Método:** Se trata de una revisión integradora de la naturaleza cuantitativa y cualitativa. El período de recolección de datos fue de 09/01/14 a 30/10/14. **Resultados:** De los artículos analizados, 26% puntuaron intervenciones para aliviar la sobrecarga; 20% analizaron la carga de la depresión; 16% de los estudios abordaron la carga del cuidador; 14% guió sus discusiones en buena salud física y espiritual, psicológico y social y dañar la calidad de vida; 12% se refirió al estrés. **Conclusión:** Investigadores de varios países apuntan los impactos del cuidado en la vida del cuidador, destacando: la sobrecarga emocional, el estrés y la rutina de los síntomas depresivos. Sin embargo, hay medidas de mitigación identificadas a través de la investigación que pueden contribuir al alivio de la tensión diaria, tales como: la práctica diaria de la meditación del yoga, la religión, la relación positiva entre la familia, los ancianos y el cuidador.

Descriptor: Demencia; Los Cuidadores; Enfermería de la Familia.

INTRODUCTION

With the higher life expectancy of the population, it is observed, in concomitance, a significant increase of chronic-degenerative diseases related to the age. Among these, Alzheimer's Disease (AD) is the highlighted dementia.¹

Today, aging is no longer only features of developed countries, but also in developing and underdeveloped countries. This fact is explained due to the significant decrease in mortality from infectious and chronic diseases at all ages, a result of medical advances and the population's access to health services generating, consequently, improvements in quality of life.²

The Brazilian Ministry of Health needs to implement actions that benefit the elderly because of its significant increase. The focus cannot be only in children, young and adult, but encompass all citizens of the current society.³

With the increase in the rate of population aging, there is the need for health attention on the more likely the emergence of chronic, disabling and involution afflicting the autonomy of the individual. For example, dementia, when people reached the age of sixty years old, the citizens

have the prevalence of dementia doubled every five years, resulting in an exponential increase with age. There are numerous causes, of which the specific diagnosis is subject to the discernment of different clinical manifestations and a specific and mandatory follow-up laboratory tests.⁴

Dementia can be defined as a syndrome that affects the normal functioning of the brain and has chronic and progressive nature producing multiple deficits in memory, language, reasoning, judgment, orientation and learning with enough intensity to meddle in citizen's social performance and/or professional. There are primary degenerative dementias, progressive and irreversible, and dementias that result in a progressive but potentially reversible process of secondary origin. In most cases, changes occur in the emotional, behavioral and motivational control before the onset of multiple deficits. Currently, the most commonplace cause of dementia is Alzheimer's Disease (AD) accounting for 60% to 70% of cases, followed by vascular dementia, dementia with Lewy bodies and frontotemporal dementia.⁴

Exercise care and responsibility for dependent elderly people, according to reports of caregivers, is a highly stressful and exhausting occupation. This fact considers the emotional relationship as an aggravating factor as well as the dependency ratio in the development of activities that include physical and psychosocial well-being of the elderly, formerly reciprocal, shall interfere with their self-well-being.¹

Care for the elderly with dementia causes numerous and distinct impact in the lives of caregivers; the nursing team's guidelines aim to clarify doubts and make the caregiver less regretful by understanding the factors involved in the development of dementia suggesting strategies that provide an improvement in the quality of life of caregivers and the elderly. Caregivers suffer from sleep disorders, affection, mood swings and depression. Echoing the physical, emotional, psychological and social aspect due to the progressive increase in the elderly dependency of their caregivers.⁵

Because, for the most part, not being trained to exercise care, the caregiver suffers from overload and is vulnerable to the emergence of diseases that can be acute and chronic, which leads to a loss in quality of life. The preparation and appropriate follow-up to the tasks must be performed by the health team thus offering all necessary support for the caregiver.⁶

Research shows that caregivers develop complications in their health such as high blood pressure, depression, digestive disorders, also including psychiatric symptoms and family conflicts due to stress.⁷

Occupational chronic stress associated with the care burden, which involves an intense interpersonal contact, makes caregivers more likely to develop Burnout Syndrome. This includes three important factors: emotional exhaustion - lack of energy with exhaustion; depersonalization - emotionally callousness; and finally the lack of involvement in the workplace. This syndrome is seen as a significant psychosocial problem that can cause serious consequences.⁸

Thus, the purpose of this article is to analyze the vulnerability of caregivers of elderly with dementia.

It is necessary an analysis of the scientific content published, national and international, on the subject afflicting an increasing number of people in our society.

Its relevance is highlighted to contribute in updating health team knowledge and improving the quality of care for elderly's caregivers.

METHODS

It was chosen an integrative review of quantitative and qualitative nature to enable the development of this study. The data collection period was from 09/01/14 to 10/30/14 in the following databases: LILACS (Latin American and Caribbean Health Sciences), MEDLINE (Medical Literature Analysis and Retrieval System Online) and PUBMED (NLM).

The inclusion criteria of the references were as follows: possessing adherence to the proposed objective; contain conjunction with caregivers of elderly with dementia; available full texts in languages: English, Portuguese and Spanish. As exclusion criteria, there were repeated texts. The analysis of the references was based on publications of the last five years (2010-2014).

The data collection instrument used for organizing the content obtained in the references was a table containing the following items: year; database; publication type and methods/techniques; the essence of the content; and production of knowledge.

After reading accurate references to three databases, there were 42 (100%) manuscripts selected. In LILACS, from 12 references found after adjustment with the predefined criteria, five articles were selected (12%). In the MEDLINE, 70 manuscripts were initially found and after further reading only 6 (14.2%) were elected. Therefore, in 99 references of PUBMED found, 31 (73.8%) were adopted.

RESULTS AND DISCUSSION

For content analysis, the information has been organized as follows: year of publication, type of publication, the essence of content and production of knowledge, database, the authors' recommendations.

Thus, related to the quantity per year, we found 13 (31%) references in 2010, 12 (29%) references in 2011; 11 (26%) references in 2012; 6 (14%) references in 2013; there were no references found in 2014. By observing the data, it was noted that the highest number of publications was in 2010, and there was a decline in the percentage of publications related to the vulnerability of elderly caregivers with dementia in later years.

By analyzing the type of publication in the method and employed research techniques, we found: 14 (33%) bring the randomized controlled trial longitudinal, where: 5 were published in 2010, 4 in 2011, 2 in 2012 and 3 in 2013; 10 (24%) manuscripts work the cross-sectional study in its content, as

follows: 2 in 2010, 3 in 2011, 4 in 2012 and 1 in 2013; 5 (12%) were descriptive studies, among these references: 1 in 2010, 1 in 2011, 2 in 2012, 1 in 2013; 3 (7%) developed a literature review where: 2 were published in 2011 and 1 in 2013; 2 (4.8%) were descriptive exploratory studies in which 1 was published in 2010, and another one in 2013; 2 (4.8%) were case studies, as follows: 1 in 2011 and the other in 2013.

Still on the type of publication in the method and techniques used research we have: 2 (4.8%) comparative studies respectively in 2010 and 2013; 1 (2.4%) observational cross-sectional study in 2010; 1 (2.4%) study of an oral history in 2011; 1 (2.4%) in the case of a theory founded in 2011; 1 (2.4%) mixed cross-sectional study also in 2011. At that time cut, publications brought mostly the randomized controlled clinical trial longitudinal.

Regarding the approach, we obtained 17 (40%) qualitative studies, as follows: 4 in 2010, 5 in 2011, 5 in 2012 and 3 in 2013. Quantitative approach were 25 (60%), where: 9 were published in 2010, 7 in 2011, 6 in 2012 and 3 in 2013.

On the essence of the analyzed content and the production of knowledge 26% point interventions to relieve overload; 20% analyze the depression load.

The conservation of outside interests, dedicating time for them and the occupation of the mind with other activities are some strategies that caregivers find it helpful in relieving care burden. Coping strategies focused on emotion suggesting to protect elderly caregivers with Alzheimer's Disease develop higher levels of anxiety.⁹

The repercussions on the life of the caregiver are evident, the demand of time required by the care causes that the life of the caregiver does not receive the necessary attention. This is true also for the intense involvement with the patient's life, thus neglecting the leisure, social, family and emotional life and, in some cases, economic difficulties that creates a loss in quality of life. One of the biggest risks for caregivers is getting sick because of care. This audience has the highest rates of insomnia and depression, are at risk of serious illness and are less likely to engage in preventive measures to health.¹⁰

We verified that 16% of the studies deal with the caregiver's overload; 14% guided their discussions on physical and spiritual well-being, psychological and social well-being, and impairments to quality of life; and 12% addressed stress.

The stress of caregivers is increasing when perceiving their burden, the performance of the functions is impaired, which leads to an unbalanced care frame, usually accompanied by unsatisfactory results. A epidemiological, descriptive and cross-sectional study aimed at estimating the prevalence of overload among family caregivers of dependent elderly people in the city of João Pessoa, Paraíba, and also to identify their relationship with health conditions, functionality and demand for elderly care, identified In 84.6% of the caregivers of the research the overload, measured through the Burden Interview Scale. Related to overload levels, with mild to moderate overload, it was evidenced on 61.5% of caregivers, 12% moderate and severe and 15.4% had no burden.¹¹

Only 2% of manuscripts discuss coping skills; 2% abusive behavior of the caregiver; 2% care styles; 2% low immunity, cardiovascular problems and hypertension; 2% sleep dissatisfaction; and 2% of the rewards of caring.

By analyzing the stress experienced by the caregiver of a patient with dementia, it can be said that this is intense which leads to, according to the studies found, low immunity, cardiovascular problems such as hypertension and difficulty in healing mechanisms. This fact also reflects the caregiver's sleep quality, interrupting their natural cyclic.¹²

On the recommendations of the authors, 19% suggest new studies about the theme for further findings and further evidence favoring the promotion of health of caregivers indicating that it should be given greater attention from researchers in this area; 16.68% defend and recommend the creation and implementation of measures for stress relief, which would provide improved quality of life acting as a preventive factor in diseases; 16.6% approach and encourage the creation of support networks to develop joint interventions with comprehensive health care models for caregivers, Since with the development of care they become vulnerable to becoming ill.

It is important to address not only the symptoms of neuropsychiatric patients but also the caregivers with depression, as it is an important and significant source of emotional distress. It is believed that early identification of caregivers more likely to develop Burnout Syndrome is necessary to improve their involvement in dementia care and, therefore, the quality of life of caregivers and elderly with dementia.¹³

Among the recommendations of the manuscripts to improve deficits in caregiver quality of life, 11.9% advocate planning social programs that meet the needs of caregivers; other 7,14% recommended exercise a focused management in the elderly and their caregivers; 7.4% raised the need to facilitate the development of families of screening (elderly with dementia and their caregivers) to identify risk situations. We observed that 7.4% guided the creation of education programs on the dementing process to facilitate the completion of care.

It is evident the impact of caring for people with dementia and the need to expand support for caregivers, education and training interventions. The lack of compensatory benefits to the caregiver and limited access to benefits should be a concern of policymakers.¹⁴

Only 2.4% of authors recommended daily practice of yoga meditation, claiming that it can reduce the routine stress; as a way to mitigate the burden experienced by caregivers, 2.4% of the findings concluded that religious coping is a facilitating factor to overcome and/or live with the problems arising from care; other studies (2.4%) underscore the importance of maintaining relationships and connection between family members, caregivers and the elderly. We found 2.4% of the studies advocate and encourage the use of interventions by telephone to fill gaps in customer service to the caregiver of

people with dementia; 2.4% say that daily stressors increase inflammation markers; some researchers indicate a larger more comprehensive understanding of how the program Tailored Caregiver Assessment, and Referral (TCARE) affects the life of the caregiver, program developed to analyze and support the caregivers of elderly with dementia.

Study limitations as some authors state that participants caregivers of the research should be followed for a longer period with a broader analysis of the factors involved in the care process linking them and correlating the consequences and benefits.

CONCLUSION

It is evident that the number of caregivers grows over the years due to the increase in population aging rate. The dependence of the elderly with dementia and the burden of care put the caregiver in physical and emotional risk conditions. Researchers from several countries study the impacts of care in the caregiver's life, highlighting as major losses: the emotional overload, routine stress, and depressive symptoms.

However, there are mitigating measures of overload that can contribute to daily stress relief, such as the daily practice of yoga meditation, religion and positive relationship between the family, the elderly and the caregiver.

Health professionals need to return their gaze not only to the elderly with dementia, but perform an expanded service comprehensively analyzing the risks arising from the dementing process for both the caregiver as the individuals involved in the care. Through focused interventions in the elderly with dementia and their caregivers, it is possible to conquer benefits in quality of life of both.

Providing educational measures to the caregiver, talking about dementia, its development and staging contribute to the development of the conscious and qualified care.

Strategies to identify vulnerable caregivers are extremely important to set appropriate measures promptly to be carried out aimed at preventing disease and maintaining the quality of life.

REFERENCES

1. Lenardt MH, Willig MH, Seima MD, Pereira LF. A condição de saúde e satisfação com a vida do cuidador familiar de idoso com Alzheimer. *Colomb Med [periódico da internet]*. 2011 Jun [citado 2014 Nov 14]; 42 (2): 17-25. Disponível em: <http://www.scielo.org.co/pdf/cm/v42n2s1/v42n2s1a3.pdf>.
2. Burlal C, Camarano AA, Kanso S, Fernandes D, Nunes R. Panorama prospectivo das demências no Brasil: um enfoque demográfico. *Ciênc saúde coletiva [periódico da internet]*. 2013 Out [citado 2014 Dec 14]; 18(10): 2949-56. Disponível em: http://www.scielo.org/scielo.php?script=sci_arttext&pid=S14131232013001800019&lng=en. <http://dx.doi.org/10.1590/S1413-81232013001000019>.
3. Souza EM, Cunha AP, Melo R, Moreira A. Cuidado do enfermeiro aos portadores desíndromes demenciais: um levantamento bibliográfico. *Rev pesqui cuid fundam (Online) [periódico da internet]*. 2014 Jul/Set [citado 2014 Dec 14]; 6(3):1268-75. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/2743/pdf_1391.

4. Farlow MR. Alzheimer disease. In: Fillit HM, Rockwood K, Woodhouse K, organizadores. *Brocklehurst's Textbook of geriatric medicine and gerontology*. 7th Edition. Philadelphia: Saunders, Elsevier; 2010. p.411-20.
5. Camacho ACLF, Abreu LTA, Leite BS, Mata ACO, Marinho TF, Valente GSC. REVISÃO INTEGRATIVA SOBRE OS CUIDADOS DE ENFERMAGEM À PESSOA COM DOENÇA DE ALZHEIMER E SEUS CUIDADORES. *Rev pesqui cuid fundam (Online)* [periódico da internet]. 2013 Jul/Set [citado 2014 Dec 14]; 5(3):186-93. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1731/pdf_958.
6. Nogueira PC, Rabeh SAN, Caliri MHL, Dantas RAS, Haas VJ. Sobrecarga do cuidador e impacto na qualidade de vida relacionada à saúde de cuidadores de indivíduos com lesão medular. *Rev Latino-Am Enfermagem* [periódico da internet]. 2012 [citado 2014 Dec 14]; 20(6):1048-56. Disponível em: http://www.scielo.br/pdf/rlae/v20n6/pt_06.pdf.
7. Albuquerque EPT, Cintra AMO, Bandeira M. Sobrecarga de familiares de pacientes psiquiátricos: comparação entre diferentes tipos de cuidadores. *J Bras Psiquiatr* [periódico da internet]. 2010 [citado 2014 Dec 14]; 59(4):308-16. Disponível em: <http://www.scielo.br/pdf/jbpsiq/v59n4/07.pdf>.
8. Marques AKMC, Landim FLP, Collares PM, Mesquita RB. Apoio social na experiência do familiar cuidador. *Ciênc Saúde Coletiva* [periódico da internet]. 2011 [citado 2014 Dec 14]; 16(1):945-55. Disponível em: <http://www.scielo.org/pdf/csc/v16s1/a26v16s1.pdf>.
9. Benjumea, CC. Strategies for the relief of burden in advanced dementia care-giving. *J ADV NURS* [periódico da internet]. 2011 Ago [citado 2014 Dec 14]; 67(8): 1790-9. Disponível em: <http://onlinelibrary.wiley.com/doi/10.1111/j.13652648.2010.05607.x/abstract>.
10. Seima MD, Lenardt MH. A sobrecarga do cuidador familiar de idoso com Alzheimer. *Texto Contexto Enferm* [periódico da internet]. 2011 [citado 2014 Dec 14]; 10(2):388-98. Disponível em: <http://www.scielo.br/pdf/reben/v67n2/0034-7167-reben-67-02-0227.pdf>.
11. LOUREIRO LSN, FERNANDES MGM, NOBREGA MML, RODRIGUES RAP. Sobrecarga em cuidadores familiares de idosos: associação com características do idoso e demanda de cuidado. *Rev bras Enferm* [periódico da internet]. 2014 [citado 2014 Dec 14]; 67(2): 227-32. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672014000200227&lng=en&nrn=iso.
12. Varela G, Varona L, Anderson K, Sansoni J. Alzheimer's care at home: a focus on caregivers strain. *Prof Inferm*. [periódico da internet]. 2011 [citado 2014 Dec 14]; 64(2):113-7. Disponível em: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3662364/pdf/nihms447986.pdf>.
13. Truzzi A, Valente L, Ulstein i, Engelhardt E, Laks J, Engedal K. Burnout in familial caregivers of patients with dementia. *Rev Bras Psiquiatr* [periódico da internet]. 2012 [citado 2014 Dec 14]; 34:405-12. Disponível em: <http://www.scielo.br/pdf/rbp/v34n4/v34n4a07.pdf>.
14. Prince M, Brodaty H, Uwakwe R, Acosta D, Ferri CP, Guerra M, et al. Strain and its correlates among carers of people with dementia in low-income and middle-income countries. *Int J Geriatr Psychiatry* [periódico da internet]. 2012 [citado 2014 Dec 14]; 27:670-82. Disponível em: <http://onlinelibrary.wiley.com/doi/10.1002/gps.2727/pdf>.

Received on: 23/02/2016

Reviews required: No

Approved on: 08/03/2016

Published on: 10/07/2017

Author responsible for correspondence:

Bruna Silva Leite

Rua Luiz Gonzaga Tavares, n°175

Parque Luiz Gonzaga

Engenheiro Pedreira/RJ

ZIP-code: 26460-370

E-mail: bruna.silvaleite@gmail.com