



THE VULNERABILITY OF CAREGIVERS OF ELDERLY PEOPLE WITH DEMENTIA: CROSS-SECTIONAL DESCRIPTIVE STUDY

A VULNERABILIDADE DOS CUIDADORES DE IDOSOS COM DEMÊNCIA: ESTUDO DESCRITIVO TRANSVERSAL

LA VULNERABILIDAD DE LOS CUIDADORES DE ANCIANOS CON DEMENCIA: ESTUDIO DESCRIPTIVO TRANSVERSAL

Bruna Silva Leite¹, Alessandra Conceição Leite Funchal Camacho²

ABSTRACT

Objectives: to evaluate the vulnerability of caregivers in the perspective of the overloading of elderly care in the dementia process; to identify the outcomes of the overload of elderly care in the dementia process; to describe the implications of caregiving overload on their life and health that may lead to their vulnerability; to verify the association between the vulnerability of elderly caregivers in the dementia process and the outcomes of care overload. **Method:** it is a quantitative cross-sectional descriptive study. Participants: Caregivers of elderly people who have dementia. The technique of data collection will be the structured interview with the application of two instruments. The Statistical Package for Social Science (SPSS®) version 21 will be used for data analysis. The project was approved by the Research Ethics Committee, CAAE: 48557115.1.0000.5243. **Expected results:** to identify the overload of care and its association with the vulnerability of caregivers of elderly people with dementia. **Descriptors:** Dementia; Caregivers; Family Nursing.

RESUMO

Objetivos: avaliar a vulnerabilidade dos cuidadores na perspectiva da sobrecarga proveniente do cuidado ao idoso em processo demencial; identificar os desfechos da sobrecarga do cuidado aos idosos em processo demencial; descrever as implicações da sobrecarga do cuidado na vida e saúde desse cuidador que podem levar a sua vulnerabilidade; verificar a associação entre a vulnerabilidade dos cuidadores de idosos em processo demencial e os desfechos da sobrecarga do cuidado. **Método:** estudo quantitativo do tipo descritivo transversal. Participantes: cuidadores de idosos que possuem demência; a técnica de coleta de dados será a entrevista estruturada com a aplicação de dois instrumentos; análise dos dados: será utilizado o Statistical Package for the Social Science (SPSS®) versão 21. O projeto foi aprovado pelo Comitê de Ética em Pesquisa, CAAE: 48557115.1.0000.5243. **Resultados esperados:** identificar a sobrecarga do cuidado e sua associação com a vulnerabilidade dos cuidadores de idosos com demência. **Descritores:** Demência; Cuidadores; Enfermagem Familiar.

RESUMEN

Objetivos: evaluar la vulnerabilidad de los cuidadores en la perspectiva de la sobrecarga proveniente del cuidado al anciano en proceso demencial; identificar los desenlaces de la sobrecarga del cuidado a los ancianos en proceso demencial; describir las implicaciones de la sobrecarga del cuidado en la vida y salud de ese cuidador que pueden llevar a sus vulnerabilidades; verificar la asociación entre la vulnerabilidad de los cuidadores de ancianos en proceso demencial y los desenlaces de la sobrecarga del cuidado. **Método:** estudio cuantitativo del tipo descriptivo transversal. Participantes: cuidadores de ancianos que poseen demencia; la técnica de recolección de datos será la entrevista estructurada con la aplicación de dos instrumentos; análisis de los datos: será utilizado el Statistical Package for the Social Science (SPSS®) versión 21. El proyecto fue aprobado por el Comité de Ética en Investigación, CAAE: 48557115.1.0000.5243. **Resultados esperados:** identificar la sobrecarga del cuidado y su asociación con la vulnerabilidad de los cuidadores de ancianos con demencia. **Descritores:** Demencia; Cuidadores; Ancianos Familiares.

¹Nurse, Master student, Program in Health Care Sciences, Fluminense Federal University/EEAAC/UFF. Niterói (RJ), Brazil. E-mail: bruna.silvaleite@gmail.com; ²Nurse, Ph.D. Professor in Nursing, Department of Foundations in Nursing and Administration, Nursing School Aurora de Afonso Costa/ Fluminense Federal University/EEAAC/UFF. Niterói (RJ), Brazil. E-mail: cicacamacho@uol.com.br

INTRODUCTION

The results of the census show a decrease in the index of population growth and an increase in the number of elderly people, who represent about 11.1% of the population. Therefore, the increase in the aging rate leads to growth in the number of age-related diseases, such as dementia. There are social, clinical, genetic, lifestyle-related factors that are related to the development of cognitive impairment considered as risk factors for the occurrence of dementia.¹

With the estimate of the life of the population more taken, it is also observed a significant increase of chronic-degenerative diseases related to the age. Among these dementias, Alzheimer's Disease (AD) stands out as the most common.²

The word dementia originates in the Latin *demens* (de-deprivation, mens-intelligence), it is a set of signs and symptoms, commonly presented in a chronic and progressive way, where the degradation of cognitive function occurs, of the capacity to organize the thought, above the common decrease of aging. Estimates show that dementias reach 2.0% to 8.0% of the population over 60 years old.³

Increasing the health care services for the elderly, with actions aimed at prevention in health, education of health professionals and raising awareness among those responsible for building health policies in Brazil and the world, can provide care directed to the elderly, as well as to their vulnerable caregivers, and ensure the universality of access, integrality, and equality of care.⁴

According to caregiver reports, the exercise of care and responsibility for dependent elderly is a highly stressful and exhausting occupation. This fact considers the affective relationship as an aggravating factor as well as the relation of dependence in the development of activities that encompass the physical and psychosocial well-being of the elderly person, who previously was reciprocal, interfering in his or her self-wellness.²

Care for the elderly with dementia causes innumerable and different repercussions on caregivers' lives. The nursing team's guidelines aim to clarify doubts and make care less regretful by understanding the factors involved in the development of dementia suggesting strategies that provide an improvement quality of life of caregivers and the elderly. Caregivers suffer from changes in sleep, affection, mood, and depression affecting the physical, emotional, psychological and social aspects due to the

progressive increase in the dependence of the elderly of their caregivers.⁵

Nursing should turn its attention to the health of caregivers of elderly people with dementia, considering the consequences of this work and the impact on their lives, seeking first to identify the aggravating and attenuating factors to devise appropriate intervention strategies.

Identifying the key needs of this people is essential for the provision of skilled nursing care. This study will identify diseases prevalent in caregivers of the elderly who attend the caregiver group of elderly people with dementia, facilitating intervention strategies for health promotion.

Explanation and relevance of the study

The maintenance of the quality of life of the caregiver acts in improving the quality of care provided, besides providing benefits for the same. Dementia disorder becomes a two-way street, where dementia impacts the quality of life of the caregiver and their quality of life can influence the delivery of care. Therefore, both the caregiver and the elderly with dementia need specialized attention focused on their needs.

Understanding caregiver vulnerability is the first step in building care prescriptions that address the needs of the caregiver.

It is imperative that nurses have human care as a foundation in their clinical practice. Moreover, this care must be specific to the caregiver's peculiarities. Before their orientation and prescription of care, attention should be paid to the most appropriate form of communication, taking into account the facilities and difficulties presented by the population involved.⁶

Understanding the theme makes it clearer that having an elderly person in the process of dementia, health professionals within their patients should think about the prescriptions of care and guidelines directed to the elderly and the caregivers involved.

The evaluation of the vulnerability of caregivers of elderly in the dementia process will help to improve the quality of nursing care and the promotion of their quality of life with interventions focused on the specific needs of the individuals.

From the scientific point of view, previous research in databases of scientific literature has observed the vulnerability of this person and the need for qualified nursing care. With this, this study seeks not only to enrich the notorious field of gerontological research in nursing but also to instigate research on this topic.

HYPOTHESIS

Does the caregiver overload of elderly people with dementia cause them vulnerability?

OBJECTIVES

- To evaluate the vulnerability of caregivers in the perspective of the overloading of elderly care in the dementia process;
- To identify the outcomes of the overload of care for the elderly in a dementia process;
- To describe the implications of caregiving overload on the caregiver's life and health that may lead to their vulnerability;
- To verify the association between the vulnerability of elderly caregivers in the dementia process and the outcomes of care overload.

METHOD

It is a quantitative research of the descriptive cross-sectional type.

Conducted according to the positivist paradigm, the quantitative research uses mechanisms designed to control the research situation with a focus on minimizing bias and enhancing accuracy and validity. They collect data that are grouped directly or indirectly, and the data collection is carried out in a systematic way, with formal instruments.⁷

The descriptive study is intended to describe, observe and document aspects of a given situation.⁷

Studies with a cross-sectional design are studies that look at the conditions of a population at a given moment; the data collection takes place in a certain temporal cut. These studies allow describing the state of the phenomena or the relation between them fixed moment. The main advantages are economy and ease of control.

The setting of the study will be the Mequinho, a geriatric outpatient clinic for elderly care at the Fluminense Federal University located in the municipality of Niterói in the State of Rio de Janeiro.

It will occur through nursing consultation activities carried out at the Health Care Center for the Elderly and Caregivers - CASIC/UFF linked to the Department of Fundamentals of Nursing and Administration of the Aurora Nursing School of Afonso Costa/UFF registered in the Extension Pro-Rectory Since 1997 held in Mequinho.

The CASIC has the following characteristics: to be a theoretical - practical teaching group

for nursing undergraduate classes; carrying out health promotion and disease prevention actions with the elderly and their caregivers; conducting Nursing Consultations with the elderly and their caregivers; home visits to the elderly with dementia are part of the program. On this occasion, assistance is provided from the Nursing Consultation to the elderly, family members and caregivers, guidance is given for care; meeting with caregivers of elderly people for dementia information; conducting cognitive stimulation workshops with elderly people with dementia belonging to the program; participating in interinstitutional surveys; and linked to the Interinstitutional Study Group on Health Care for the Elderly.⁸

Participants in this study will be caregivers of elderly people who have dementia. As eligibility inclusion criteria, there are: to be a formal and/or informal caregiver of elderly people with dementia; attending the CASIC; being the primary caregiver for at least six months. Exclusion criteria were: To have no practical experience as a caregiver for elderly people with dementia; three consecutive missed consultations without prior justification.

The research project was approved by the Research Ethics Committee, CAEE: 48557115.1.0000.5243.

The self-report method will be used for data collection. Self-reported responses are the participants' questions asked by the investigator, such as in an interview. This is the method most commonly used by nursing researchers.⁷

The technique used to collect data with caregivers of elderly people with dementia will be the structured interview conducted during the nursing consultation.

In the structured dimension, the same information is collected for all participants; structured approaches generate data that are more easily quantified.⁷

The face-to-face interview was chosen as the technique for this study because it represents high response rates. Respondents are less likely to refuse to respond to an interviewer than to a questionnaire. Also, the participant's chance to misinterpret the question is less, since the interviewer can determine whether the question was well understood or not.⁷

Two instruments were listed to make data collection viable.

The first instrument will aim to identify the profile of caregivers of elderly people with dementia through the following variables: I-

Leite BS, Camacho ACLF.

The vulnerability of caregivers of elderly...

Socio-Demographic Data, II- Physical Health Data and III- Emotional Health Data.⁹

The second relevant instrument, which will verify the caregivers' overload, will be the Zarit Burden Interview (ZBI) - Annex B, developed in 1987 (ZARIT and ZARIT, 1987), validated and adapted for the Portuguese language in 2002.¹⁰

This instrument has 22 items that assess the caregivers' overload, associated with the patients' functional capacity, their behavioral disorders and daily situations assessing health, social and personal life, financial situation, emotional well-being and interpersonal relationships and the the caregiver's environment. Each item is scored on a scale of 0 to 4, being: never = 0, rarely = 1, sometimes = 2, often = 3 and always = 4. The total score is calculated by adding all items and may vary from 0 to 88 points. Thus, the higher the score, the greater the overload. The level of caregiver overload is classified as follows: <21 = absence or low overload; between 21 and 40 = moderate overload; between 41 to 60 = moderate to severe overload and between 61 to 88 = severe overload.¹⁰

For the analysis of the data, a spreadsheet will be built in the program Excel®, where the data will be organized in double typing and validated for the comparison of the digits.

After validation, the spreadsheet will be imported into the Statistical Package for the Social Science (SPSS®) for Windows version 21, where the statistical analyses will be performed.

The description of the quantitative data will be carried out by graphs and tables, measures of central tendency and dispersion according to the normality of the data.

For the analysis of categorical variables, the Pearson correlation test will be used, with significance level $p \leq 0.05$.

EXPECTED RESULTS

Identifying the overload of care and its association with the vulnerability of caregivers of the elderly with dementia. Keywords: Dementia, Caregivers, Family nursing.

REFERENCES

1. Godinho C, Camozzato AL, Onyszko D, Chaves ML. Estimation of the risk of conversion of mild cognitive impairment of Alzheimer type to Alzheimer's disease in a south Brazilian population-based elderly cohort: the PALA study. In *Psychogeriatr*. 2011 Oct [cited 2014 Oct 1]; 24(4): 674-681.
2. Lenardt MH, Willig MH, Seima MD, Pereira LF. The condition of health and satisfaction

with life of family caregivers of elderly with Alzheimer. *Colomb Med* [Internet]. 2011 June [cited 2014 Oct 1]; 42(2):17-25. Available from:

<http://www.scielo.org.co/pdf/cm/v42n2s1/v42n2s1a3.pdf>

3. World Health Organization. Dementia. WHO Fact Sheets; 2012 [cited 2015 Sept 19]. Available from:

www.who.int/mediacentre/factsheets/fs362/en/

4. Camacho ACLF, Abreu LTA, Mata ACO, Leite BS, Santos RC. Bioethical issues of older adults and their aspects relevant to nursing: integrative review. *J Nurs UFPE on line* [Internet]. 2013 Mar [cited 2014 Dec 14];7(3):328-36. Available from:

http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/2544/pdf_2262

5. Camacho ACLF, Abreu LTA, Leite BS, Mata ACO, Marinho TF, Valente GSC. An integrative review about nursing care to people with alzheimer's and their caregivers. *Rev pesqui cuid fundam* (Online) [Internet]. 2013 July [cited 2014 Dec 14];5(3):186-93. Available from:

http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/1731/pdf_958

6. Leite BS, Silva EJS, Jorge FAF, Cavaleiro AJBG, Santos WA, Valente GSC. Risk assessment of falling in elderly. *Rev enferm UFPE on line* [Internet]. 2015 June [cited 2015 Nov 15];9(5):8346-53. Available from:

www.revista.ufpe.br/revistaenfermagem/index.php/revista/.../12492

7. Polit DF, Beck CT. *Fundamentos de Pesquisa em Enfermagem: avaliação de evidências a prática de enfermagem*. 7th ed. Porto Alegre: Artmed; 2011.

8. Camacho, ACLF. *Cuidados a pessoa com doença de Alzheimer e outros distúrbios demências* [Internet]. Rio de Janeiro: Escola de Enfermagem Aurora de Afonso Costa; c2011-2015 [up data 2015 Nov 10; cited 2014 Oct 3]. Available from:

<http://cicacamacho.blogspot.com.br/2011/04/programa-de-extensao-enfermagem-na.html>

9. Valente LE, Souza WF, Alves GS, Alves CEO, Sudo FK, Lanna MEO, et al. Health self-perception by dementia family caregivers: sociodemographic and clinical factors. *Arq Neuro-Psiquiatr* [Internet]. 2011 Oct [cited 2015 Nov 04];69(5):739-44. Available from:

http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0004-282X2011000600003&lng=en

10. Scazufca M. Brazilian version of the Burden Interview scale for the assessment of

Leite BS, Camacho ACLF.

The vulnerability of caregivers of elderly...

burden of care in careers of people with mental illnesses. Rev Bras Psiquiatr. 2002; 24(1):12-7.

Submission: 2015/12/04

Accepted: 2016/12/21

Publishing: 2017/01/15

Corresponding Address

Bruna Silva Leite
Rua Luiz Gonzaga Tavares, 175
Parque Luiz Gonzaga
CEP: 26460370 – Engenheiro Pedreira (RJ),
Brazil