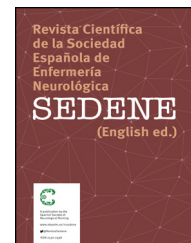




Enfermería Neurológica (English ed.)

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ORIGINAL ARTICLE

Perception of quality of life in caregivers of patients with dementia[☆]



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Received 9 September 2016; accepted 13 September 2017

Available online 26 November 2017

KEYWORDS

Caregivers;
Dementia;
Quality of life;
Nursing

Abstract

Introduction: Individuals with dementia suffer from changes at a cognitive, emotional, and behavioural level. These changes can also affect the quality of life of their caregivers in a physical, psychological, social and spiritual dimension.

Objective: Determine the perception of life quality, taking into account the burden of caregivers of patients with dementia.

Method: A descriptive, correlational and cross-sectional study was conducted on an intentional sample of 50 caregivers of patients diagnosed with dementia. The information was collected using three tools: socio-demographic variables, quality of life, and dimension of caregiver's burden.

Results: The sample consisted of 80% women, with an age range of 36–59 years, of whom 54% were married. More than three-quarters (78%) of them had been a caregiver for more than 37 months, and 66% dedicated 24h to the work of caring. The main caregivers experience a low care burden and low effect on their quality of life.

Conclusions: The study shows the presence of women in the role of caregivers, the relationship between the quality life and burden, and how they are influenced by the physical and psychological dimensions. Similarly, a low social well-being negatively influences the quality life.

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PII of original article: S2013-5246(17)30015-6

[☆] Please cite this article as: Perdomo-Romero AY, Ramírez-Perdomo CA. Percepción de calidad de vida en cuidadores de pacientes con demencia. Rev Cient Soc Esp Enferm Neurol. 2017;46:26–31.

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PALABRAS CLAVE

Cuidadores;
Demencia;
Calidad de vida;
Enfermería

Percepción de calidad de vida en cuidadores de pacientes con demencia**Resumen**

Introducción: La demencia es una enfermedad que produce en la persona que la presenta cambios a nivel cognitivo, afectivo y comportamental, estas alteraciones pueden afectar la calidad de vida del cuidador en sus dimensiones físicas, psicológicas, sociales y espirituales.

Objetivo: Determinar la percepción de la calidad de vida, teniendo en cuenta la sobrecarga en cuidadores de pacientes con demencia.

Método: Estudio descriptivo, correlacional, transversal, muestra intencional con 50 cuidadores de pacientes diagnosticados con demencia; se recolectó la información mediante 3 instrumentos: caracterización sociodemográfica, calidad de vida y sobrecarga del cuidador.

Resultados: Mujeres en un 80%, con rango de edad de 36 a 59 años, 54% casados, 78% llevaba más de 37 meses como cuidador y 66% dedican 24 h a la labor de cuidado; los cuidadores principales experimentan baja sobrecarga y baja afectación en su calidad de vida.

Conclusiones: El estudio muestra la presencia de las mujeres en el rol de cuidador, así como la relación entre la calidad de vida y la sobrecarga e influidos estos directamente por las dimensiones física y psicológica. De igual forma, un bajo bienestar social influye de manera negativa en la calidad de vida.

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Introduction

Dementia is a worldwide public health challenge facing our generation. The number of people with dementia throughout the world today is estimated to be 44 million, and it is calculated to rise to almost double this by 2030 and more than triple the number by 2050.¹

When an elderly adult begins to suffer from dementia, functional impairment is progressive, and requires care to preserve minimal quality of life conditions, which in the majority of cases are provided by a family member. Over time the burden upheld by the caregiver may affect their everyday lives and is detrimental to their quality of life. Ersek et al.'s model (1997) accepts the concept the caregivers' quality of life, as the result of a subjective assessment of positive or negative attributes characterising their own lives and which consist of 4 dimensions: physical, psychological, social and spiritual wellbeing.²

When faced with a chronic degenerative disease, the family or some of its members feel seriously affected, suffer changes and adjustments to their daily activities and functions and if these are not favourable, become ill themselves (stress, depression, hypertension, gastritis, colitis, anaemia, lung conditions, etc.).³

The family generally offer the main support, but it is usually one member who takes on the highest responsibility and this person may therefore end up being physically and emotionally overburdened with caring for the patient.⁴

That person accepts the job of caring and attending to the needs of the person with dementia, overstraining themselves in their family and social roles, with repercussions on their physical, mental, financial, employment, family, social and free time areas.^{5,6} This may affect their health in a negative way and bring about a loss in their quality of life,⁷⁻¹³ as they adapt to new conditions for the

improvement in the health and wellbeing of the person they are taking care of. In this regard, Zambrano and Ceballos identified the presence of overburden in the majority of dementia patient caregivers.¹⁴

Given the above, we decided that the objective of our study was to determine the quality of life related to health and the degree of overburden in dementia patient caregivers.

Materials and methods

Quantitative, descriptive, correlational, transversal and intentional sample design study. The participants (n=50) who were the main caregivers of patients with moderate and severe dementia, recorded in the data base of the Neiva memory clinic.

Selection criteria: resident in the city of Neiva, caregiver for a period over 3 h, male or female over 18 years of age, a caregiver of a patient with dementia for a minimum period of one year. The participants were informed of the objectives and procedures to follow and were required to sign an informed consent form. Information was collected by nurses and psychologists, in the caregiver's home.

Research was approved by the Ethics and Bioethics Committee of the Faculty of Health of the South Colombian University. The bioethical principles were taken into account: respect for human dignity, privacy, freedom of expression and feelings, confidentiality and reciprocity.

Instruments

Socio-demographic characterisation of caregivers (created by the Care Group to the chronic patient and their family of the Faculty of Nursing, National University of

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