Scientific Evidence on the Quality of Life of Caregivers of Elderly People with Dementia

Evidências Científicas Acerca da Qualidade de Vida de Cuidadores de Idosos com Demência

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Abstract
The goal is to analyze the scientific production on quality of life of caregivers of elderly people with dementia in the last five years. This is an integrative review carried out in the databases of the Virtual Health Library (VHL) and PubMed, with the guiding question: What are the studies about the quality of life of caregivers of elderly people with dementia? The articles analyzed were published between 2011 and 2016, using the following descriptors: dementia; caregivers; nursing; quality of life. After applying the eligibility criteria, 27 scientific articles were selected and grouped into two categories: non-pharmacological interventions and symptoms and / or factors related to quality of life. It concludes that by providing strategies involving the elderly and caregivers can promote gains in both quality of life by providing a comprehensive and conscious attention.

Keywords: elderly; quality of life; dementia; nursing.

Resumo
Objetiva-se analisar a produção científica sobre a qualidade de vida de cuidadores de idosos com demência nos últimos cinco anos. Trata-se de uma revisão integrativa realizada nas bases de dados da Biblioteca Virtual de Saúde (BVS) e PubMed, com a questão norteadora: quais as evidências produzidas sobre a qualidade de vida de cuidadores de idosos com demência? Utilizou-se como recorte temporal artigos publicados entre 2011 e 2016, utilizando os seguintes descritores: demência; cuidadores; enfermagem; qualidade de vida. Após aplicação dos critérios de elegibilidade, foram selecionados 27 artigos, os quais foram agrupados em duas categorias: “Intervenções não farmacológicas” e “Sintomas e/ou fatores relacionados à qualidade de vida”. Conclui-se que ao fornecer estratégias que envolvem os idosos e cuidadores, é possível promover benefícios na qualidade de vida de ambos, proporcionar atenção integral e consciente.

Palavras-chave: Idosos; qualidade de vida; demência; cuidadores; enfermagem.
Introduction

The elderly correspond to the age group with the greatest growth in demographic structures. In 2009, there were more than 730 million people over the age of 60. By 2050, this group is estimated to increase to around 2 billion people \[1\].

The increase in life expectancy is accompanied by the occurrence of chronic non-communicable diseases and neurodegenerative diseases. Among the diseases typically related to the elderly, it is possible to highlight the dementias, which today affect part of the pre-senile and senile population of the whole world. In 2001, it was estimated that 24.4 million people aged 60 and over were suffering from the disease, which is expected to double every 20 years, that is, to 42.3 million in 2020 and 81.1 million in 2040 \[1-2\].

There are several types of dementias, which can be classified as reversible / non-degenerative and irreversible / degenerative. The irreversible ones are equivalent to 80% of dementias and are comprised of Alzheimer’s Disease, Vascular Dementia, Dementia with Lewy Corpuscles, and Frontotemporal Dementia, while reversible agents represent 10% of dementias, which can be caused by drug toxicity, depression, nervous system infection, metabolic and neurological diseases (primary brain tumors and normal pressure hydrocephalus), organic and metallic poisoning, thyroid and parathyroid dysfunction, and nutritional deficiencies of vitamin B12, B6, thiamine and folic acid \[3\].

Dementia is characterized by the progressive decline of memory that brings a series of consequences on cognitive functions, conducting motor commands deficiencies, and failures in planning. The elderly diagnosed with the disease are mostly women, aged between 60 and 100 years old, married or widowed, with low level of education and retired \[4-5\].

A North American study identified that people with severe dementia require 41.5 hours per week of additional care; in the moderate cases it takes 17.5 hours, and 8.5 in the mild cases \[6\].

In this scenario, the caregiver appears as a care option for the elderly, which has to deal with progressive changes in the manifestation of dementia. In many cases, the professional plays this role alone, without another person to share the tasks required \[7\].

Caregivers are mostly female, married, between the ages of 41 and 50, with incomplete primary education and with a monthly income of up to 1 (one) minimum wage. In general, they are members of the family and present some changes in their physical, social and emotional health patterns, which are intensified the higher the degree of the relationship between the elderly and the caregiver \[8\].

As part of the family care setting for the elderly, caregivers are responsible for the activities that were previously performed by the elderly, that is, daily care, home care, account management, and basic care activities \[9\].

In view of the limitations of the disease, caregivers begin to present stressful factors related to task overload, as well as forgetfulness of their own health and basic activities, directly affecting their quality of life \[10\].

By causing damage to the physical and emotional health of the caregiver, negative implications are generated for the care process of the elderly in the progression of the disease.

It is important that health teams understand the importance of caregivers and can develop strategies that promote their well-being, as well as favor improvements in their quality of life.

Quality of life is defined by the World Health Organization as the perception of the person regarding the their life’s considering the cultural values of the place where they live, in addition to their goals, expectations, standards and concerns \[10\].

In the elderly care setting, caregivers face a physical overload that ends up making it difficult to
perform certain tasks besides the existing chronic diseases, such as hypertension, diabetes, depression and osteoporosis (10).

The relevance of the study is to contribute to the updating of knowledge of the health team and to the improvement of the quality of assistance to caregivers of the elderly.

Considering the importance of caregivers in the care of the elderly with dementia and how this can affect the quality of life of the caregivers, the objective of this study is to analyze the scientific productions about the quality of life of caregivers of elderly people with dementia.

Method

It is an integrative review, with data collection period from November 5th, 2016 to December 10th, 2016. Integrative review is a method of research analysis that enables the synthesis of knowledge in a given subject. It includes studies with different methodological approaches, as well as identify knowledge gaps that need to be filled with new research (11).

The integrative review method is composed of six stages: (1) identification of the theme and the elaboration of the guiding question; (2) establishment of criteria for inclusion and exclusion of studies; (3) definition of the information to be extracted from the selected studies; (4) evaluation of studies included in the integrative review; (5) interpretation of results; and (6) presentation of knowledge review / synthesis (11).

The first stage is the identification of the theme and elaboration of the Questioning Question, which was as follows: "What is known about the quality of life of caregivers of elderly people with dementia?"

The second stage is the inclusion and exclusion criteria, being established as inclusion: adherence to the objective and the proposed theme, articles published in Portuguese, English and Spanish; articles in full that portrayed the issue of dementia and quality of life of caregivers published in the last five years. And the exclusion criteria was published articles that were repeated in the databases.

The research was performed in the database of the Virtual Health Library: Database of Nursing (BDENF), Latin American and Caribbean Literature in Health Sciences (LILACS) and PubMed, between the years 2011 and 2016.

The terms used, according to the descriptors in health sciences (DECS) and Medical Subject Headings (MESH), respectively, were: "Dementia" AND "Caregivers" AND "Nursing" AND "Quality of Life".

The third step consisted in defining the information to be extracted from the selected studies. In this stage, a table was elaborated containing the following information: year of publication, title of the article and type of study.

The articles found through this combination and the path traveled are shown below in Flowcharts 1 and 2.

In the fourth stage, the evaluation of the studies included in the integrative review and critical analysis is carried out, correlating them. In the fifth stage, we interpreted and discussed the results, highlighting the evidence of the quality of life of caregivers of elderly people diagnosed with dementia. In the last step, the review and synthesis of the acquired knowledge was presented.
Results

After a thorough reading of the references of the databases, 27 manuscripts were selected. MEDLINE quantified 79% (21 articles); LILACS was represented by 11% (3 articles) and 4% referring to BDENF (1 article). Therefore, PubMed accounted for 6% (2 articles).

For content analysis, the information was organized as follows: year of publication, language, methodological approach, content, database and authors’ recommendations.

Regarding the main characteristics of the selected articles, it is observed that regarding the publishing year, 2014 represented the largest quantitative, with 30% (8 articles); then the year 2012 with 18% (5 articles); the years 2013 and 2016 were represented by 15% (4 articles) and 2011 and 2015 quantified 11% each (4 articles / year).

The language that was most published in was English, represented by 85% (23 articles), articles in Portuguese obtained the percentage of 15% (4 articles).

The methodological approach of the studies was mostly of the randomized type, represented by 35% (9 articles); then cross-sectional articles, totaling 30% (8 articles); descriptive studies quantified 18% (5 articles), systematic / integrative reviews 7% with (2 articles); 3% refer to validation studies (1 article); report of experience and phenomenology with the same quantitative (1 article).

Regarding the substance of the content, the articles were grouped into categories for better understanding: non-pharmacological interventions (56%) and symptoms and / or factors related to quality of life (44%).

Table 1 shows the distribution of articles according to author, year of publication, location, purpose, type of study and main conclusions.

Table 1. Selected articles for the integrative review.

<table>
<thead>
<tr>
<th>Title/Author/Year/Place</th>
<th>Objective of the study</th>
<th>Type of study</th>
<th>Compliance</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Effect of a Personalized Dementia Care Intervention for Caregivers from Australian MCI Groups</td>
<td>To test the hypothesis of the care provided to the care recipient by the specialized team</td>
<td>Randomized</td>
<td>Cognitiva presented an overload of functions, reducing quality of life of the caregiver.</td>
</tr>
<tr>
<td>Transdisciplinary Care for the Improvement of Health and Well-being in Community-Dwelling Dementia Caregivers</td>
<td>To verify that transdisciplinary care can improve psychological areas, quality of life, and cognitive performance in caregivers of dementia patients</td>
<td>Randomized</td>
<td>Among the participants, there were no significant changes in the mental components of the quality of life of the caregivers.</td>
</tr>
<tr>
<td>Caregivers’ Quality of Life in Initial and Moderate Dementia Caregivers</td>
<td>To investigate quality of life in caregivers of people with dementia who live at home</td>
<td>Cross-sectional</td>
<td>Overload and depressive symptoms were related to the quality of life of caregivers in the two stages of dementia.</td>
</tr>
<tr>
<td>The Impact of Nurse Performance from the Perspective of Caregivers of Elderly People with Dementia</td>
<td>To describe the views of caregivers of elderly people with dementia about the performance of the nurse in their role and to identify the results of this assistance</td>
<td>Observational</td>
<td>Through the nurse-caregiver relationship, the perspective of the caregiver’s quality of life and well-being is altered.</td>
</tr>
<tr>
<td>A Study of the Effectiveness of NFL Players to Support Family Groups of People Living with Dementia at Home</td>
<td>To evaluate the effects of NFL players on the mental health and well-being of family members, including their self-care and health-promoting behavior</td>
<td>Observational</td>
<td>The use of NFL players significantly reduced psychological distress and depression in caregivers.</td>
</tr>
<tr>
<td>Benefit Finding Intervention for Alzheimer Caregivers: Cognitiva Organizacional</td>
<td>To describe an intervention that promotes the psychological well-being of individuals</td>
<td>Randomized</td>
<td>Approaches with cognitive and affective focus offer positive results in the alleviation of the caregiver’s depression.</td>
</tr>
<tr>
<td>Title</td>
<td>Design</td>
<td>Outcome Description</td>
<td></td>
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<tr>
<td>The Effects of a Cognitive-Behavioral Intervention Program for Family Caregivers of Demented Alzheimer's Patients (FRA)</td>
<td>Randomized</td>
<td>To analyze the effectiveness of a Cognitive-Behavioral Therapy (CBT) intervention</td>
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<td></td>
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<td>program for family caregivers of patients with dementia.</td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>Authors/Year</td>
<td>Design</td>
<td>Measures</td>
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<tr>
<td>The Role of Coping Strategies in Psychological Outcomes for Patients with Dementia</td>
<td>Costa et al. (2014)</td>
<td>Cross-sectional</td>
<td>Assessing depression, anxiety, and QOL of caregivers</td>
</tr>
<tr>
<td>Depression, Anxiety, and Quality of Life in Caregivers of Long-Term Hospitalized Patients</td>
<td>Patil et al. (2014)</td>
<td>Cross-sectional</td>
<td>Evaluating depression, anxiety, and QOL of caregivers</td>
</tr>
<tr>
<td>The differential impact of unique behaviors and psychological symptoms for the dementia caregiver: how and why do patients' behaviors and psychological symptoms influence caregivers' QOL</td>
<td>Vink et al. (2014)</td>
<td>Cross-sectional</td>
<td>Evaluating unique behaviors and psychological symptoms in the elderly care setting</td>
</tr>
<tr>
<td>Quality of Care for Dementia Caregivers: A Systematic Review</td>
<td>Ciccone et al. (2014)</td>
<td>Descriptive</td>
<td>Describing the characteristics and needs of caregivers</td>
</tr>
<tr>
<td>Factors Influencing the Quality of Life of the Family Caregiver of a Patient with Dementia</td>
<td>Pimenta et al. (2013)</td>
<td>Descriptive</td>
<td>Describing the available evidence on the factors that influence the QOL of family caregivers of the elderly with dementia</td>
</tr>
</tbody>
</table>

**Discussion**

**Non-pharmacological interventions**

This category, composed of 15 articles, addresses the use of strategies to promote an improvement in the quality of life of caregivers, such as support and guidance groups, training and information workshops, skills training and support. These measures are capable of improving levels of anxiety and depression, in addition to minimizing the impact of the disease on the quality of care provided to the patients. In the literature it is pointed out that caregivers lack information and support. They need adequate spaces to ask questions, and health professionals should offer support, guidance and information among the subjects. Corroborating, the support groups have an instructive character, provide psychological support and guidance in problems solving, as they exchange experience and value the knowledge of caregivers.

A descriptive study carried out in 2016 highlighted the importance of nurses working the elderly-caregiver binomial through meetings that provide listening, information, planning, monitoring, evaluation and care management strategies for the elderly and their caregivers. It is notorious that caregivers need a look from the health team, evidenced by an integrative review carried out in 2015 which noted that the interventions for the studied clientele have arisen in the last 15 years. In other words, there is still a shortage on this subject, which demonstrates the importance of interventional attitudes capable of impacting the life of caregivers and the elderly.

In this same study, the focus on family caregivers is highlighted, being considered one of the pillars in the health issues and in the care provided to the family. Care centered on the elderly and caregivers should begin in the confirmation of the diagnosis of dementia, in order to provide the caregivers understanding about the basic characteristics of the disease. Knowing the peculiarities of dementia, caregivers tend to understand and deal more easily with evolution, difficulties and challenges. Regardless of the level of care, it is fundamental to establish a harmony between the caregivers, since it becomes possible to offer well-being to them and, consequently, the quality of the care provided to the elderly with dementia.

Orientation and support to this group of caregivers allows for constructive involvement with the demented elderly and the promotion of both of their health. This strategy is valid in all settings, especially in the Family Health Program, where the caregiver should be seen as a health agent, receptive to specific guidelines and preventive measures to avoid early dependence on the elderly.
Factors related to quality of life

In order to offer intervention mechanisms to caregivers, it is necessary to know the symptoms / factors related to quality of life, corresponding to 12 articles in the category.

The literature indicates that caregivers of people with dementia present exhaustive demands on physical and mental health, as well as important changes in lifestyle based on the needs of the person being cared for \(^{15}\).

As an example of factors that can negatively influence the QoL: poor sleep quality; type of dementia and neuropsychiatric symptoms; support, social support and access to health services; leisure; pre-existing health problems; subsidized interventions with training for the caregiver and spirituality \(^{16}\).

The cited conditions are directly related to the occurrence of depressive symptoms, anxiety and overload, as well as psychological symptoms such as pain, anger, sadness and fear. These situations worsen as the disease progresses \(^{15-17}\).

The type of relationship between the elderly and the caregiver is also indicated as a cause of harm in the QoL, that is, the caregivers who are family members present feelings of grief, oppression and sadness, with a mixture of compassion and solidarity \(^{18}\).

A study conducted in 2016 with 296 caregivers of a Primary Health Care Unit identified that the participants’ overload was considered moderate, possibly associated with the level of dependence of the elderly. Regarding quality of life, the average score obtained through the SF-36 questionnaire was 58.04, and pain was considered the domain with the lowest score \(^{18}\).

In addition, the solitary care found in many families with elderly people with dementia is seen as a potential for overload, because in this case, the individual provides care individually, without any help in the execution of tasks. The mixture of sensations and conditions of care has repercussions on the quality of life, reflecting the importance of adequate support to these caregivers \(^{18}\).

As well as the lack of people to share the care, family income is also seen as a stressful factor for the maintenance of quality of life, since most caregivers do not exercise paid work due to the need for integral care for the demented elderly \(^{7}\).

The negative factors in the quality of life corroborate the need to carry out new studies on the subject, pointed out in 41% of the articles studied in the present review; 35% point to the importance of public policies aimed at the elderly and their caregivers, and 24% of the articles recommend the development of strategies for the care and management of caregivers.

Conclusion

With the increase of chronic neurodegenerative diseases, the elderly are increasingly dependent on aid and supervision to carry out their daily activities. In many cases, caregivers are responsible for this activity, which is defined as exhausting and impacting on their physical and emotional health.

The hours spent on care, the lack of recognition and information are capable of causing harm to the lives of caregivers. Overload, stress and anxieties are closely related to maladies in the quality of life.

It is evident that health professionals need to include in their practice measures not only care for the elderly with dementia, but also to articulate those involved in care.

Interventions should be tailored according to the specificity and need of caregivers, making them able to deal with the limitations that the disease causes in the elderly with dementia. By providing strategies involving the elderly and caregivers, it is possible to promote benefits in the quality of life of both, providing an integral and conscious care.
The study allowed the acquirement of knowledge about the relationship between quality of life and caregivers, evidencing the possible forms of nursing work that deals with the elderly and their caregivers, that is, the articulation between the analyzed categories.

As a limitation of the study, we highlight the low number of articles found and selected for the research, hence the need to develop current studies on the subject, in order to guide the planning of strategies aimed at the clientele studied.

References


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