

# 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: I**dosos; 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 noncommunicable 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 <sup>(1-2)</sup>.

There are several types of dementias, which can be classified as reversible / nondegenerative 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, metabolic nervous system infection, and neurological diseases (primary brain tumors and normal pressure hydrocephalus), organic and metallic poisoning, thyroid and parathyroid disfunction, and nutritional deficiencies of vitamin B12, B6, thiamine and folic acid <sup>(3)</sup>.

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 <sup>(4-5)</sup>.

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 <sup>(7)</sup>.

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 <sup>(8)</sup>.

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 <sup>(9)</sup>.

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 <sup>(10)</sup>.

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 <sup>(10)</sup>.

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 5<sup>th</sup>, 2016 to December 10<sup>th</sup>, 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 <sup>(11)</sup>.

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 <sup>(11)</sup>.

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.

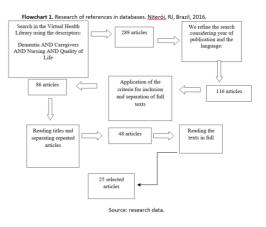
The research was performed in the database of the Virtual Health Library: Database of Nursing (BDENF), Latin American and Caribbean Literature in Health Sciences (LILACS) and PubMed, between the years 2011 and 2016.

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".

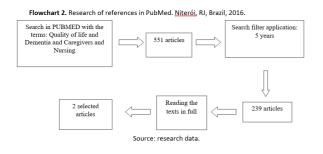
The third step consisted in defining the information to be extracted from the selected studies. In this stage, a table was elaborated containing the following information: year of publication, title of the article and type of study

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

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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	Ν.
Niterói, RJ, Brazil, 2017	

Title/Author/Year/Place	Objective of the study	Type of study	Conclusions
Changes in behavior in the	Identify major	Discriptive	Caregivers presented an
elderly with Alzheimer's	behavioral changes in		overload of functions.
disease and overload for	the elderly with		suffering and fear.
the caregiver / Marins,	Alzheimer's disease		surrening and rear.
AMF et al /2016/ Rio de	and distinctions in the		
Janeiro ()	burden placed on the		
Janeiro			
	caregiver.		
The Effect of a	To test the hypothesis	Randomized	The intervention was
Personalized Dementia	of the care provided		significant in the mental
Care Intervention for	to the caregivers by a		components of the quality of
Caregivers From Australian	specialized team		life of the citizens.
Minority Groups /Xiao, LD			
et al/2016/Austrália			
Transcendental Meditation	Verify that	Randomized	After meditating, the
for the improvement of	transcendental		participants presented
health and wellbeing in	meditation can		improvements in cognitive
community-dwelling	improve psychological		function, mood, quality of life
dementia caregivers/	stress, quality of life,		and stress
Leach, MJ/2015/Austrália	affect, and cognitive		
	performance in		
	caregivers of dementia		
Caregivers' quality of life in	Investigate quality of	Cross-	Overload and depressive
mild and moderate	life (QoL) of caregivers	sectional	symptoms were related to th
dementia/Santos, RL et	in mild and moderate		quality of life of caregivers i
al/2014/Rio de Janeiro	dementia and related		the two stages of dementia
	aspects.		
The impact of nurses'	To describe the view	Discriptive	Through the nurse-caregive
performance from the	of caregivers of elderly	Distriptive	relationship, the perspectiv
perspective of caregivers	people with dementia		of the caregiver's life and
of elderly people with	on the performance of		elderly person with dementi
dementia / Lindolpho, MC	the nurse in their		can change positively,
et al/2014/Rio de Janeiro			improving their quality of life
et al/2014/Kio de Jallello	benefit and analyse		improving their quality of in-
	and identify the results of this		
A study of the	assistance. To evaluate the effects	Discrimina	The use of MD2 of
A study of the		Discriptive	The use of MP3 players
effectiveness of MP3	of MP3 players use on		significantly reduced
players to support family	the mental health and		psychological distress,
carers of people living with	well-being of		improved mental health an
dementia at home/ Lewis,	caregivers, including		well-being of caregivers,
V et al/2015/Austrália	their self-care and		significantly increased the
	health promoting		caregiver's self-efficacy to de
	behavior.		with symptoms of dementia
Benefit-Finding	To describe an	Randomized	Approaches with a cognitive
Intervention for Alzheimer	intervention that		focus had effects in the
Caregivers: Conceptual	promotes the		alleviation of the caregivers
Framework.	achievement of		depression.



Implementation Issues,	benefits in Alzheimer's		
and Preliminary Efficacy/	caregivers.		
Cheng ST/2014/China			
Efficacy and experiences of	Produce a quantitative	Systematic	Phone counseling can reduce
telephone counselling for	review of the	review	the depressive symptoms of
informal carers of people	effectiveness of		caregivers of people with
with dementia/Lins, S et	telephone counseling		dementia.
al/2014/Alemanha	for informal caregivers		
	of people with		
	dementia.		
Feasibility of Central	Evaluate the pathway	Discriptive	The symptoms of anxiety,
Meditation and Imagery	of a meditation		depression and insomnia have
Therapy for Dementia	therapy program and		decreased.
Caregivers/ Jain, FA et	guided imagery group.		dereased.
al/2014/Estados Unidos da	Serece meger, groop.		
América			
Life enhancing activities		Randomized	Positive affect, negative
for family caregivers of		nanuomized	affection, overload, and stress
people with			scores improved in the
frontotemporal dementia/			intervention compared to the
Downling, GA et			
			control group.
al/2014/Estados Unidos da América			
America Program for caregivers of	Describe the	Experience	The guidelines offered to
elderly people with	experiences made	report	caregivers provide quality of
		report	life, well-being, and alleviate
dementia: report of	during the PRO- CUIDEM meetings.		the problems faced.
experience / Brum, AKR et	COIDEW meetings.		the problems faced.
al/2013/Rio de Janeiro A home-based training	To examine the effects	Bandomized	
program improves	of a home-based	Kandomized	The program improved caregiver QoL, especially the
Taiwanese family			role limitations due to
	training program for		
caregivers' quality of life	caregivers of elderly		emotional problems and
and decreases their risk for	people with dementia.		decreased the risk of
depression/ Kuo			depression.
LM/2013/Taiwan		Validation	
Improved Strain and	To examine the		There was a decrease in care-
Psychosocial Outcomes for	efficacy of an	study	related tension, lower
Caregivers of Individuals	educational and		emotional tension, tension in
with Dementia: Findings	cognitive ability		the dyadic relationship, and
from Project ANSWERS/	intervention to		greater mastery of care.
Judge, KS et	caregivers of elderly		
al/2013/Estados Unidos da	people with dementia		
América			
Psychosocial group	To examine the	Randomized	This is a sneak preview, which
intervention to enhance	effectiveness of the		will make it possible to
self-management skills of	self-management		provide data on the cost-
people with dementia and	support program on		effectiveness of the
their caregivers: study	QOL of patients with		intervention.
protocol for a randomized	dementia and their		
controlled trial/ Laakkonen, ML et	caregivers in the spouse.		

al/2012/Finlândia			
Positive effects of a	To analyze the effects	Cross-	There was a decrease in
cognitive-behavioral	of a Cognitive-	sectional	neuropsychiatric symptoms in
intervention program for	Behavioral Therapy		patients and an increase in
family caregivers of	(CBT) intervention		their quality of life, as well as a
demented elderly /Fialho,	program on family		significant decrease in the
PPA et al/2012/Minas	caregivers of patients		anxiety level of caregivers.
Gerais	with dementia.		anxiety level of caregivers.
The Experience of Quality	Explore the meaning	Phenomenolo	The topics covered were: unity
of Life for Caregivers of	of quality of life (QOL)		and cooperation in the family
	for Sardinian	gy	
People With Alzheimer's			freedom / independence;
Disease Living in Sardinia,	caregivers of people		have time for themselves;
Italy/ Vellone, E et	with Alzheimer's		serenity / tranquility; and
al/2012/Itália			well-being and health.
	To test the	Randomized	Caregivers who received the
Helping carers to care: the	effectiveness of the		intervention reported a
10/66 dementia research	intervention program		statistically significant
group's randomized	for people with		decrease in overload
control trial of a caregiver	dementia and their		measures when reassessed
intervention in Peru/	caregivers developed		after six months, compared to
Guerra, M et al/2011/Peru	by the group 10/66 in		caregivers in the control
	Lima, Peru.		group.
Quality of life and	Investigate quality of	Cross-	QoL was positive with
depression in carers of	life (QOL) and	sectional	increasing caregivers 'ages and
patients with early	depression in		patients' perception of their
onset dementia/ Rosness,	caregivers of patients		condition.
TA et al/2011/Noruega	with dementia of early		
	onset.		
Randomized controlled	To examine the	Randomized	Program participants reported
trial of a dementia care	effectiveness of a care		significantly greater
programme for families of	program for Chinese		improvements in the rates of
home-resided older people	families who live and		client symptoms and
with dementia/ Chien, WT	care for a relative with		institutionalization, and
et al/2011/China	dementia.		quality of life and caregiver
et el, 2022, ellis	demente,		overload.
Influence of personality on	To evaluate some	Cross-	The personality traits of a
depression, burden, and	personality traits for	sectional	family caregiver need to be
health-related guality of	health-related quality	sectional	evaluated to tailor support
life in family caregivers of	of life (HRQoL) among		programs to obtain the
persons with dementia/	family caregivers of		optimal benefits of caregiver
Kim, SK et al/2016/Coréia.	people with dementia		interventions.
KIII, SK EL BI/2010/00/018	(PKD) in relation to		incervencions.
	overload and		
	depression.		
Technological March		Randomized	The second second second second
Trajectories of health- related quality of life	To verify the effect	Kandomized	The caregivers who received
	under QOL of		the intervention presented
among family caregivers of	caregivers of elderly		better results in the
among family caregivers of individuals with dementia:	caregivers of elderly people with dementia		components of physical and
among family caregivers of individuals with dementia: A home-based caregiver-	caregivers of elderly people with dementia after one after the		
among family caregivers of individuals with dementia:	caregivers of elderly people with dementia		components of physical and

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#### 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 life of caregivers  $^{(12-13)}$ .

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 <sup>(14)</sup>.

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  $_{\scriptscriptstyle (1)}$ 

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 and evaluation of care management strategies for the elderly and their caregivers. caregiver <sup>(15)</sup>.

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 <sup>(15)</sup>.

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 <sup>(13)</sup>.

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 <sup>(9)</sup>.



#### 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 <sup>(15)</sup>.

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 <sup>(16)</sup>.

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 <sup>(15-17)</sup>.

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 <sup>(18)</sup>.

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 <sup>(18)</sup>.

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 <sup>(18)</sup>.

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 <sup>(7)</sup>.

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.

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