

## 18 - QUALITY OF LIFE AND ALZHEIMER: A SYSTEMATIC REVIEW FROM 2016 TO 2018

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## INTRODUCTION

According to the Alzheimer's Association (2016), due to the progress of medicine, social conditions and environmental conditions, the number of Americans between 80 and 90 years tends to grow rapidly which consequently will increase the number of Alzheimer's Disease (AD) cases. By 2050, a new case of AD is expected for every 33 seconds, resulting in almost 1 million new cases per year. By 2025, the number of people aged 65 years or older with Alzheimer's disease is estimated to reach 7.1 million, an increase of almost 40%, compared to 5.2 million people aged 65 and over, 2016. By 2050, the number of people aged 65 years or older with Alzheimer's disease may almost triple from 5.2 million to 13.8 million.

Alzheimer's is a brain degenerative disease and the most common cause of dementia. Dementia is characterized by the decline (resulting from loss of neurons) in memory, language, problem solving, and other cognitive abilities that affect one's ability to perform everyday activities. The damage and destruction of neurons eventually affect other parts of the brain, including basic bodily functions, like walking and swallowing. (ALZHEIMER'S ASSOCIATION, 2016)

AD is responsible for 50% to 70% of dementia cases, being the most common form of dementia. Its main symptom is the difficulty of remembering recent events. After the initial phase other symptoms arise, such as disorientation, mood changes, confusion, behavioral changes, serious memory losses and still, difficulties in speech and swallowing and walking. (WINBLAD et al., 2016)

According to Pedroso et al. (2014), there is a growing concern with Quality of Life (QOL) in the last decades. QoL does not present a single concept, but presents three fundamental aspects: subjectivity, multidimensionality and the presence of positive and negative dimensions. Multidimensionality is divided into domains: physical domain, psychological domain, level of independence, social relations, environment and spirituality / religion / personal beliefs. (FLECK et al. 1999).

The concept of QOL is complex, subjective and difficult to conceptualize (Farquhar, 1995). According to Rocha and Felli (2004), quality of life depends on intrinsic factors, that is, physiological changes, extrinsic factors such as social aspects and still a different view of quality of life for each individual as a result of their insertion in society. The WHOQOL Group (1998, p. 552) brings the concept of QOL as the "individual's perception of their life expectancies, goals and concerns".

Regarding the number of publications in the field of QOL and Alzheimer's, a total of 638 articles were identified in the period from 2016 to 2018, which approached the issue directly or indirectly.

In the treatment for Alzheimer's disease there is pharmacological treatment and non-pharmacological therapy, aiming to maintain or improve cognitive function, ability to perform daily activities and increase QoL, using, for example, art therapy, and cognitive activities such as gardening, cooking and games (Alzheimer's Association, 2016).

From this brief context, the present study aims to identify factors that interfere in the quality of life of people with Alzheimer's disease in the period 2016-2018.

## METHODOLOGY

According to the research classifications proposed by Gil (2008), this research is bibliographical from the point of view of the object, basic from the point of view of its nature, with a qualitative approach from the point of view of the problem, exploratory about the objectives and finally, a research of the technical procedures.

A systematic review was developed using the Methodi Ordinatio methodology proposed by Pagani, Resende and Kovaleski, (2015). This methodology consists of eight steps, described below:

- Step 1 - Establishment of research intention;
- Step 2 - Preliminary exploratory research with keywords in databases;
- Step 3 - Definition and combinations of keywords and databases;
- Step 4 - Definitive research in databases;
- Step 5 - Filtering Procedures;
- Step 6 - Identification of impact factor, year and number of citations;
- Step 7 - Ordering of articles through InOrdinatio;
- Step 8 - Location of articles in full format;
- Step 9 - Reading and systematic analysis of articles.

Steps 1, 2, 3, 4 and 5 were performed as shown in Figure 1:

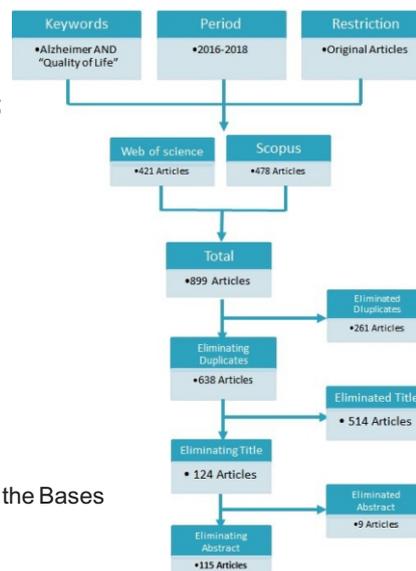


Figure 1 – Research stages for Articles in the Bases  
Source: Authors (2018)

For the application of the method, Mendeley®, Jabref® and Excel® softwares were used to select articles by title, in order to bibliometric analysis through the insertion of JCR data and citations, as described in step 6.

The next step regarding step 7 of Methodi Ordinatio, the articles were ordered based on the InOrdinatio equation, following the formula 1:

$$\text{InOrdinatio} = (Fi / 1000) + \alpha * [10 - (APe - APu)] + (\sum Ci) \tag{1}$$

At where:

Fi: Periodic impact factor;

α: Coefficient assigned by the researcher, usually 10;

APe: Year of the research;

APu: Year of article publication;

Ci: Citation number of the article in other studies.

After applying this equation, we selected the 20 articles (17% of the total) that were most relevant to the full readings.

**RESULTS AND DISCUSSIONS**

After the application of Methodi Ordinatio and the elimination of articles after reading the titles and abstracts, the first 20 articles (17% of the total) were selected and placed in decreasing order by InOrdinatio, as presented in Table 1.

Ranking	Authors	Article	Year	FI	Ci	InOrdinatio
1	Hoffmann et al.	Moderate-to-high intensity physical exercise in patients with Alzheimer's disease: A randomized controlled trial	2016	0,000	56	136,0
2	Laver et al.	Interventions to delay functional decline in people with dementia: A systematic review of systematic reviews	2016	2,413	50	130,0
3	Osman et al.	'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers	2016	0,000	47	127,0
4	Smit et al.	Activity involvement and quality of life of people at different stages of dementia in long term care facilities	2016	0,000	37	117,0
5	Hongisto et al.	Quality of Life in relation to neuropsychiatric symptoms in Alzheimer's disease: 5-year prospective ALSOVA cohort study	2018	2,940	10	110,0
6	Lamb et al.	Dementia And Physical Activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: randomised controlled trial	2018	23,259	8	108,0
7	Giebel, C.M., Challis, D.J. and Montaldi, D.	A revised interview for deterioration in daily living activities in dementia reveals the relationship between social activities and well-being	2016	0,000	28	108,0
8	Kenigsberg et al.	Dementia beyond 2025: Knowledge and uncertainties	2016	0,000	26	106,0
9	Adam, D., Ramil, A. and Shahar, S.	Effectiveness of a combined dance and relaxation intervention on reducing anxiety and depression and improving quality of life among the cognitively impaired elderly	2016	0,000	26	106,0
10	Conde-Sala et al.	Effects of anosognosia and neuropsychiatric symptoms on the quality of life of patients with Alzheimer's disease: A 24-month follow-up study	2016	2,940	24	104,0
11	Kallo et al.	Effects of Cognitive Training on Cognition and Quality of Life of Older Persons with Dementia	2018	4,155	2	102,0
12	Barbe et al.	Factors associated with quality of life in patients with Alzheimer's disease	2018	2,866	2	102,0
13	Belfort et al.	The Relationship Between Social Cognition and Awareness in Alzheimer Disease	2018	2,183	2	102,0
14	Guest et al.	Office for the Study of Aging at the University of South Carolina: Promoting Healthy Aging Through Program Development, Evaluation, Education/Training, and Research for South Carolina's Older Adults	2018	1,992	2	102,0
15	Lin et al.	Distinctive effects between cognitive stimulation and reminiscence therapy on cognitive function and quality of life for different types of behavioural problems in dementia	2018	1,318	2	102,0
16	Van Gennip et al.	How Dementia Affects Personal Dignity: A Qualitative Study on the Perspective of Individuals with Mild to Moderate Dementia	2016	0,000	22	102,0
17	Rapp et al.	The impact of institution use on the wellbeing of Alzheimer's disease patients and their caregivers	2018	3,007	1	101,0
18	Ballard et al.	Impact of antipsychotic review and non-pharmacological intervention on health-related quality of life in people with dementia living in care homes: WHELDA factorial cluster randomised controlled trial	2017	2,940	11	101,0
19	Sun et al.	The association between cognitive fluctuations and activities of daily living and quality of life among institutionalized patients with dementia	2018	2,940	1	101,0
20	Arrieta et al.	Physical activity and fitness are associated with verbal memory, quality of life and depression among nursing home residents: Preliminary data of a randomized controlled trial	2018	2,866	1	101,0

Quadro 1 – Resultado Final da Revisão sistemática  
Fonte: Autores (2018)

Of the 20 articles selected for the analysis of the research, ten articles were published in 2018, one was published in 2017 and nine were published in 2016. The countries where the studies were developed are identified in Figure 2:

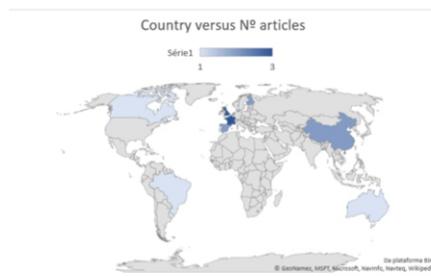


Figure 2 – Countries where research was conducted  
Source: Authors (2018)

It is verified that the largest number of articles, are concentrated in Europe with 65% of the total of 20 articles. The Table 2 presents the main findings in the articles selected through Methodi Ordinatio, which relate the themes of Quality of Life and Alzheimer's.

Order InOrdinatio	Authors	Quality of life e Alzheimer
1	Hoffmann et al. (2016)	Interventions that combine social interaction with specific physical training programs may be optimum, especially for diseases with complex symptomatology, such as AD.
2	Laver et al. (2016)	Interventions, daily living activities, and environmental adaptations for people living in private homes that perform cognitive stimulation therapy and for people in group homes have the greatest positive impact on quality of life.
3	Osman et al. (2016)	It was found that patients with Alzheimer's disease were more accurately reminiscent of sung lyrics, while healthy adults did not show significant difference. Musical activities have multiple health and wellness benefits for people with dementia and their caregivers. The group environment facilitates a sense of belonging and provides much needed social support. Like mood improvements that last longer than sessions and improved relationships, the activity has facilitated acceptance of the diagnosis of dementia, which can help promote long-term well-being for people with dementia and their caregivers and enable early access to adequate support.
4	Smit et al. (2016)	Involvement in activities (listening to music, watching television and talking) has a small but important contribution to promoting higher well-being in all stages of AD. Adjusting your preferences to individual preferences can broaden this result. Improvements were identified in the following aspects: decreased caregiver conflicts, good mood, social relationships and "having something to do".
5	Hongisto et al. (2016)	Patients reported a decline in QOL with greater age, lower level of schooling and functional loss in activities of daily living. We can't recommend using the patient's quality of life as a measure of success in the treatment of neuropsychiatric symptoms (NPS) or as a measure of the effect of NPS on the quality of life of patients with AD.
6	Lamb et al. (2016)	Physical training improved physical fitness in the short term, but this did not translate into notable improvements in daily activities, behavioral results, or health-related quality of life. It does not decrease cognitive decline in people with mild to moderate dementia.
7	Giebel, Challis, Montaldi, (2016)	Performance of daily instrumental activities and disabilities related to social activities are particularly related to well-being.
8	Kenigsberg et al. (2016)	Starting from care needs, a logical systems approach to the dementia care environment can be developed through organizational, architectural, and psychosocial interventions to help reduce symptoms in people with dementia and improve quality of life. Friendly environments for the dementia, culture and domesticity are key factors for such interventions.
9	Adam, Ramli, Shahar, (2016)	Dance as a form of exercise based in participation was found to reduce levels of anxiety and depression and to improve quality of life and cognitive function among the sample of elderly people with cognitive impairment in Malaysia. In the absence of a supportive environment, social stigma, depersonalization, sleep disorders, communication problems and diseases that affect their QOL and functional abilities.
10	Conde-Sala et al. (2016)	Neuropsychiatric symptoms associated with a more negative view of QOL-p were depression, self-assessment of patients, and apathy and agitation for caregiver evaluation.
11	Kallio et al. (2018)	Systematic cognitive training had no effect on global cognition or quality of life related to health in people living in the community with mild to moderate dementia.
12	Barbe et al. (2018)	Depression and polypharmacy (more than 3 medications per day) were two factors that influenced HRQOL in patients with AD, both by the patient's self-report and by the caregiver's report.
13	Belfort et al. (2018)	Recognition of Social and Emotional Functioning is important for social understanding and for the development and maintenance of social relationships. Besides the improving support for the person with AD and caregivers, strategies for social and emotional functioning can increase their autonomy and well-being.
14	Guest et al. (2018)	Programs, SCVAGAL (Volunteer Training), Dementia Dialogues Program (sessions of dialogue with the caregivers) and Placement Strength Training Program (to improve the strength and muscular endurance of the elderly) can have and influence health and well-being of aging adults with signs and symptoms associated with Alzheimer's disease or related dementias.
15	Lin et al. (2018)	Interventions for cognitive stimulation therapy and reminiscence therapy had positive effects on the cognition of participants and quality of life.
16	Van Gennip et al. (2016)	This study highlights the importance of living at home as long as possible for the sense of well-being and personal dignity of the individual with AD.
17	Rapp et al. (2018)	Permanent stays seem to improve some dimensions of patient well-being because they reduce the risk of agitation or irritability compared to temporary stays. Permanent stays are associated with a decrease of 18.8 percentage points in the likelihood of irritability. Its efficacy increases when patients experience more intense behavioral problems, they become functionally dependent when facing greater cognitive losses.
18	Ballard et al. (2017)	Social interaction has resulted in a significant benefit to quality of life in people with dementia.
19	Sun et al. (2018)	More severe cognitive losses in patients with dementia were significantly associated with impaired ability to engage in daily activities and poorer quality of life.
20	Arrieta et al. (2018)	Muscle strength and physical activity are positively associated with better performance in the Rey Verbal Hearing Test, QdV-D, and Goldberg Depression Scale in elderly with mild to moderate cognitive impairment in nursing homes.

Table 2 - Relationship between Quality of Life and Alzheimer's  
Source: Authors (2018)

It is possible to affirm that there is a relation between Quality of Life and Alzheimer's and to identify the main factors that interfere in the QoL of people with AD.

Eight of the twenty studies analyzed deal with the question of social interaction as a factor that directly interferes with the QoL of people with Alzheimer's disease (HOFFMANN et al., 2016; OSMAN et al., 2016; SMIT et al., 2016; GIEBEL, CHALLIS e MONTALDI, 2016; KENIGSBURG et al., 2016; ADAM, RAMLI, SHAHAR, 2016; BELFORT et al., 2018; BALLARD et al., 2017). Four studies point out that physical activities positively influence QoL (HOFFMANN et al., 2016; ADAM, RAMLI e SHAHAR, 2016; GUEST et al., 2018; ARRIETA et al., 2018). The study of Lamb et al. (2016), found that physical training improved physical fitness, but did not bring improvements in daily activities, behavioral results or QoL.

(SMIT et al., 2016; SUN et al., 2018, GIEBEL, CHALLIS e MONTALDI, 2018; HONGISTO et al., 2018). Another factor present in three of the studies analyzed is related to the environment. For Kenigsberg et al. (2016) to develop a logical approach to a dementia care environment through organizational, architectural, and psychosocial interventions, help reduce symptoms in people with dementia and improve QoL. Such interventions can make friendly environments for dementia, culture and domesticity. In this context, Van Gennip et al. (2016), points out that living at home most of the time, when possible, tends to improve the QoL of individuals with AD. Rapp et al. (2018), compares the permanent (nursing home) and temporary stays, both are associated with a decrease in the burden of informal caregivers, but only permanent stays lead to an improvement in the patients' QoL because they reduce the risk of agitation and irritability.

In only one study, but not less important, it is pointed out that music activity offers multiple health and wellness benefits to people with dementia and their caregivers. Group music activity facilitates a sense of belonging and promotes improvements in mood. The activity facilitated acceptance of the diagnosis of dementia, which may help promote long-term well-being (OSMAN et al., 2016). The AD patients are more accurate to remember sung lyrics, while healthy adults did not present significant difference. By observing these differences, it was suggested that brain processing areas of brain can be spared in AD and also that music increases excitement and therefore, better attention and better memory. (SIMMONS-STERN, BUDSON, ALLY, 2010)

Cognitive therapy was pointed out in two studies as a positive factor in QoL. (LAVER et al., 2016; LIN et al., 2018). Kallio et al. (2018), did not identify a significant influence of cognitive therapy on QoL in his studies.

Another factor related to QoL present in two articles analyzed is depression, characterized as a neuropsychiatric symptom. Conde-Sala et al. (2016) cites depression, apathy and agitation as negative factors to QoL. Barbe et al., (2018), points out that depression strongly influences QoL, however, depression may be difficult to identify, since certain depressive symptoms may be confused with symptoms of dementia, such as apathy or decreased energy. The same study identified in a lower score, that polypharmacy (intake of three or more medications per day), is linked to a lower QoL.

## CONCLUSION

This study aimed to identify factors that interfere in the QoL of people with AD. The study was carried out through a systematic review in the period of 2016 to 2018, in which it was possible to confirm the relation between QoL and AD in 20 articles mapped and analyzed. The results point out that the main factors that interfere positively, which tend to improve QoL measures: social interaction, daily activities, physical activities, a friendly and permanent environment, musical activities and therapy cognitive. The identified factors that negatively influence QoL are: depression, apathy, agitation, polypharmacy and increased cognitive impairment of the individual. It is important to emphasize that factors influencing QoL may present different results depending on the stages of AD cognitive impairment. According to Hongisto et al., (2018), when neuropsychiatric symptoms increase with the progression of AD, QoL decreases. Deficits in consciousness can interfere in the relationships and social interaction of individuals or interfere with daily activities.

It is worth mentioning that it is not possible to affirm that the factors identified in this study could reduce the progression of AD, such factors were analyzed in 20 studies related to their influence on the QoL of patients with AD only. According to Hongisto et al., (2018), it is not recommended that the use of QoL as a measure of success for the treatment of neuropsychiatric symptoms, since clinical treatment is indispensable. As a future study, it is proposed to perform systematic analyzes of each factor mentioned in this study, in order to obtain the deepening of the research.

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#### **QUALITY OF LIFE AND ALZHEIMER: A SYSTEMATIC REVIEW FROM 2016 TO 2018**

The present article aims to identify factors that interfere in the quality of life (QoL) of people with Alzheimer's disease (AD). A systematic bibliographical review was performed using the *Methodi Ordinatio* of 2016 to 2018. The keywords "Quality of Life" and "Alzheimer" were used. After the application of the *InOrdinatio* equation, the 20 relevant articles (17% of the total) were considered, which were read in their entirety. The results indicate as the main factors that interfere positively and that tend to improve QOL measures are: social interaction, daily activities, physical activities, a friendly and permanent environment, musical activities and therapy cognitive. The identified factors that negatively influence the QoL are: depression, apathy, agitation, polypharmacy and increased cognitive impairment of the individual, due to advances in AD.

**Key-words:** Alzheimer, Quality of life, Human resources.

#### **QUALITÉ DE VIE ET ALZHEIMER: REVUE SYSTÉMATIQUE ENTRE 2016 ET 2018**

Cet article vise à identifier les facteurs qui interfèrent dans la qualité de vie des personnes atteintes de la maladie d'Alzheimer. Une révision bibliographique systématique a été réalisée à l'aide de la *Methodi Ordinatio* de 2016 à 2018. Les mots-clés "Qualité de vie" et "Alzheimer" ont été utilisés. Après l'application de l'équation *InOrdinatio*, les 20 articles pertinents (17% du total) ont été examinés et lus dans leur intégralité. Les résultats indiquent que les principaux facteurs qui interfèrent positivement et qui tendent à améliorer les mesures de qualité de vie sont les suivants: interaction sociale, activités quotidiennes, activités physiques, environnement amical et permanent, activités musicales et thérapie cognitive. Les facteurs identifiés qui influencent négativement la qualité de vie sont: la dépression, l'apathie, l'agitation, la polypharmacie et une déficience cognitive accrue de l'individu, en raison des progrès de la maladie.

**Mots-clés:** maladie d'Alzheimer, qualité de vie, ressources humaines.

#### **CALIDAD DE VIDA Y ALZHEIMER: UNA REVISIÓN SISTEMÁTICA DE 2016 A 2018**

El presente artículo tiene como objetivo identificar factores que interfieren en la calidad de vida (CV) de personas portadoras de la enfermedad de Alzheimer (EA). Fue realizada una revisión sistemática de la bibliografía, por medio del *Methodi Ordinatio*, del periodo de 2016 a 2018. Fueron utilizadas las palabras clave "Calidad de vida" y "Alzheimer". Luego de la aplicación de la ecuación *InOrdinatio* fueron considerados 20 artículos (17% del total) potencialmente relevantes, los cuales fueron leídos íntegramente. Los resultados apuntan que los principales factores que interfieren positivamente y que tienden a mejorar las medidas de CV son: la interacción social, la realización de actividades diarias, la realización de actividades físicas, el ambiente amigable y permanente, la realización de actividades musicales y la terapia cognitiva. Los factores identificados que influyen negativamente a la CV son: depresión, apatía, agitación, polifarmacia y aumento de comprometimiento cognitivo del propio individuo, debido a los avances de la EA.

**Palabras clave:** Alzheimer, calidad de vida, recursos humanos.

#### **QUALIDADE DE VIDA E ALZHEIMER: UMA REVISÃO SISTEMÁTICA DE 2016 A 2018**

O presente artigo tem como objetivo identificar fatores que interferem na qualidade de vida (QV) de pessoas portadoras da doença de Alzheimer (DA). Foi realizada uma revisão sistemática bibliográfica por meio do *Methodi Ordinatio* no período de 2016 a 2018. Utilizou-se as palavras-chave "Qualidade de Vida" e "Alzheimer". Após a aplicação da equação *InOrdinatio* foram considerados os 20 artigos (17% do total) potencialmente relevantes, os quais foram lidos em sua íntegra. Os resultados apontam como os principais fatores que interferem positivamente e que tendem a melhorar as medidas de QV: a interação social, a realização de atividades diárias, a realização de atividades físicas, o ambiente amigável e permanente, a realização de atividades musicais e a terapia cognitiva. Os fatores identificados que influenciam negativamente a QV são: depressão, apatia, agitação, polifarmácia e aumento do comprometimento cognitivo do próprio indivíduo, devido os avanços da DA.

**Palavras-chave:** Alzheimer, Qualidade de vida, Recursos humanos.