ORIGINAL ARTICLE

Impact of cognition, function and strength of individuals with Alzheimer's disease on the caregiver's quality of life

Impacto da cognição, funcionalidade e força de indivíduos com doença de Alzheimer sobre a qualidade de vida do cuidador

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ABSTRACT

The Alzheimer's disease demands can influence the caregiver's daily life. **Objective:** The objective of this study was to assess the impact of cognitive, functional, and motor impairment of patients with Alzheimer's disease on the caregiver's quality of life. **Method:** This study included 27 participants with Alzheimer and their caregivers in a cross-sectional design. The Quality of Life-AD questionnaire assessed the caregiver's quality of life. The patient's cognition was rated by the Clinical Dementia Rating, the functionality by the Functional Independence Measure, mobility by the Timed Up and Go, and the muscle strength by the handgrip strength. The variables were analyzed in association by Kruskal-Wallis and Fisher's exact tests or by the Pearson or Spearman correlation tests, and the results were considered significant if $p \leq 0.05$. **Result:** An association was found between the cognition of the patient with Alzheimer and the caregiver's quality of life ($p = 0.026$) and a correlation was observed between the patient's functionality and the caregiver's quality of life ($p = 0.031$). **Conclusion:** The aspects of quality of life affected by cognition, function, and mobility are willingness, ability to do leisure activities and life in general. We conclude that developing strategies that provide the caregivers with professional support for proper training and care performance is essential.

Keywords: Alzheimer Disease, Quality of Life, Caregivers

RESUMO

As demandas de cuidados na Doença de Alzheimer podem influenciar no cotidiano do cuidador. **Objetivo:** Avaliar se o comprometimento cognitivo, funcional e motor do indivíduo com a doença influenciam na qualidade de vida do cuidador. **Método:** Estudo transversal, do qual participaram 27 indivíduos com Doença de Alzheimer e seus cuidadores. A qualidade de vida do cuidador foi avaliada pelo questionário Quality of Life-AD, a cognição do paciente foi verificada pela Clinical Dementia Rating, a funcionalidade pela Medida de Independência Funcional, mobilidade pelo Timed Up and Go e a força muscular pela força de preensão manual. A associação entre as variáveis foi realizada pelos testes Kruskal-Wallis e exato de Fisher ou pelos testes de correlação de Pearson ou Spearman, considerando $p \leq 0{,}05$. **Resultado:** Observou-se associação entre a cognição do indivíduo com Doença de Alzheimer e qualidade de vida do cuidador ($p = 0{,}026$) e correlação entre a funcionalidade do paciente e qualidade de vida do cuidador ($p = 0{,}031$). **Conclusão:** Os aspectos de qualidade de vida afetados pela cognição, função e mobilidade, são: disposição, capacidade para fazer atividades de lazer e a vida em geral. Percebe-se a necessidade de se pensar em estratégias que representem suporte profissional para a capacitação e desempenho de cuidados.

Palavras-chaves: Doença de Alzheimer, Qualidade de Vida, Cuidadores

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INTRODUCTION

Population aging is a worldwide phenomenon that affects developed as well as developing countries, such as Brazil.[1] The increase in life expectancy is concomitant with a higher incidence of neurodegenerative diseases, including dementia, and Alzheimer's Disease (AD) is the most frequently observed.[2]

Histopathologically, AD is characterized by an intense synaptic degeneration, neuronal death, a significant increase in the deposition of senile plaques and neurofibrillary tangles in the cerebral cortex.[3] Cognitive decline and deterioration of intellectual abilities are common marks of AD. Most AD cases start after 65 years of age (late-onset), but it can also affect younger individuals (early-onset). The onset of the disease is subtle, prolonging for months or even years, with the first symptoms often being perceived as the decline in episodic memory and spatial disorientation, which are cognitive aspects subordinate to the hippocampal formation, most of the time.[2]

The patient with AD also presents a non-amnestic aspect, that is, in addition to the previous characteristics, at least one affected domain, such as language (word memories), visual-spatial (spatial cognition, agnosia for objects or faces, simultanagnosia, and alexia), or executive functions, such as altered reasoning, judgment, and problem solving.[2,4]

Alzheimer’s disease is a progressive and irreversible pathology whose manifestations are slow, but its evolution is deteriorating. In addition to cognitive impairments, the individual may have motor and functional alterations as well. Such impairments may interfere with social life, activities of daily living (ADLs) and consequently, generate dependence.[5]

Regarding dependence, a caregiver, who may be a family member, is the person who assists the individual with AD.[5] The caregiver pays attention to the patient, assists in all health care needs, and is dedicated to multiple practical tasks. Also, housing, use of public transportation, and economic-related issues, among others, are tasks of the caregiver, which are burdensome and challenging. Thus, stress and physical and psychological overloads often accompany the responsibilities of caregivers of patients with AD, influencing and jeopardizing the caregiver's daily life quality of life (QOL), which can negatively impact the QoL of patients the patient.[6,7]

The World Health Organization (WHO) defines QoL as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.[8] Nursing or caring for a patient with AD can worsen physical health, cause social problems, and generate emotional, psychological, and financial stress for the caregiver, compromising their QoL in different aspects.[7,9,10] Therefore, different studies assess the impacts of AD over the QoL of caregivers, and the possible aggravating factors are becoming prominent.[11] Understanding the QoL of caregivers and the influencing factors is decisive for developing comprehensive health strategies to minimize the damaging effects of care overload.[12]

The WHO Global action plan on the public health response to dementia 2017-2025 aims to improve the lives of people with dementia, their caregivers, and family members and reduce the impact of dementia on communities and countries.

The document provides a comprehensive plan of action in awareness of dementia, reducing risk factors of developing dementia, diagnosis, treatment and care, support for caregivers, research and innovation, and evidence-based practices.[13]

It is clear then the importance of specific and in-depth studies, still scarce in Brazil, regarding the effects of care and the QoL of caregivers. Such studies could be a resource to improve the QoL of both the caregiver and the patient with AD, consequently. Identifying the profile of caregivers and their particularities may allow interventions to improve their QoL and that of the patient with AD, leading to a reduction in public costs on healthcare.[10,11,13]

Studying in detail the QoL of caregivers of patients with AD and the influencing factors can lead to the definition of guidelines and strategies for QoL improvements.

OBJECTIVE

This study aims to establish the influence of cognitive, functional, and motor skills impairments of patients with Alzheimer's Disease over their caregiver's QoL.

METHOD

This is a cross-sectional study conducted at the outpatient facility of the Complexo Hospital de Clínicas da Universidade Federal do Paraná (CHC-UFPR) from 2018 to 2019. It was approved by the Independent Review Board Comitê de Ética e Pesquisa com Seres Humanos of the CHC-UFPR with registration number 57901016.0.0000.0096.

A non-probabilistic sample of twenty-seven participants with Alzheimer’s Disease diagnosis and their caregivers were included. The patients with AD were requested to be regular patients of the CHC, with the medical diagnosis of AD, and without any functional limitations. The caregivers could be a professional or a patient’s relative. They were requested to be the patient's primary caregiver and be 18 years of age or older.

All subjects, either caregiver or patient, signed the Informed Consent Form before any evaluations. The caregiver was identified regarding age, gender, education, profession, type of caregiver (family or professional), and degree of kinship, if familiar. Then, the caregiver's QoL assessment questionnaire was applied. The assessment was conducted with an interview by the researcher.

The QoL Assessment instrument (Quality of Life-AD) was adapted, translated, and validated for the Brazilian culture.[14]

This scale assesses the QoL of caregivers and elderly with AD in three versions: one to assess the patient’s QoL (PQoL-DA), one for the caregiver to assess the patient’s QoL (CQoL-DA), and another one as a caregiver self-assessment (CsaQoL-DA). Each one contains 13 items: physical health, energy, mood, housing, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do leisure activities, money, and life as a whole.

The answer options are scored from 1 to 4, where 1= “poor”, 2= “fair”, 3= “good” and 4= “excellent”. The score ranges from 13 to 52 points, and higher scores predict better QoL.[14] In our study, the version for the caregiver was the only one used.

To assess the patients and to identify their demands for care, which are considered factors that may interfere with the caregiver's QoL, cognitive, functional, and motor assessments of the patients with AD were conducted. The patients were investigated for the presence and classification of dementia. The independence was assessed with Functional Independence Measure (FIM), the functional mobility with Timed Up and Go (TUG), and strength with handgrip strength (HGS).

A physician conducted the dementia evaluation based on the Clinical Dementia Rating (CDR). This scale assesses cognition, behavior, and the influence of cognitive losses on the ability to perform activities of daily living adequately. This assessment is divided into six cognitive-behavioral categories: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. Each category is rated 0- no cognitive impairment; 0.5- questionable or very mild dementia; 1- mild dementia; 2- moderate dementia; and 3- severe dementia. The main category is memory, and the others are considered secondary categories.

The overall classification is obtained by analyzing the categories, following a set of rules elaborated and validated by Morris.[15]

The FIM quantitatively assesses the burden of care required by a person to perform a series of motor and cognitive tasks of daily living. This assessment can be applied to individuals with functional restrictions of various origins. Among the domains evaluated, there is personal care, sphincter control, transference, locomotion, communication, and social cognition.

The complete FIM can be classified into four sub-scores, according to the total score obtained: a- 18 points: complete dependence (patient needs full assistance); b- 19 to 60 points: modified dependency (the patient requires the assistance of up to 50% of the tasks); c- 61 to 103 points: modified dependency (the patient demands assistance of up to 25% of tasks); and d- 104 to 126 points: complete independence.

The partial scores range from 1 (total dependence) to 7 (complete independence), and the total score ranges from 18 to 126. Therefore, the lower the score, the greater the degree of dependence of the individual.[16]

The TUG was used as an indication of functional mobility. This assessment covers essential daily activities that are considered to have a high risk of falls. The test consists of standing up from a chair, walking 3 meters, turning 180°, walking back to the chair, and sitting down again.[17] A patient that performs this test within 10 seconds is considered normal or healthy, without risk of falls. Values between 11 and 20 seconds are expected for frail or elderly people with disabilities, partial independence, and low risk of falls. Those with results above 20 seconds suggest a significant deficit in physical mobility and risk of falls.[18]

A Jamar dynamometer was used to measure handgrip strength (HGS). This instrument has two parallel handles, one fixed and one mobile, that can be adjusted to the size of the patient's hand. This device contains a closed hydraulic system that measures the amount of force produced by an isometric contraction applied to the handles.

In this test, the participant must remain seated in a chair without arm support, with the shoulder in adduction, neutral rotation, elbow flexed at 90º, forearm in a neutral position, and wrist in slight extension (between 0 and 30º). Then, the patient is requested to contract the hand muscles pressing the parallel handles three times, with an interval of 60 seconds.[19] The handgrip strength was recorded in kilograms of force (kgf). It reflects the maximum force from the contraction of the hand muscles and has a good association with other muscle groups, being an independent predictor of decline in functional capacity.[20]

Categorical variables were described as frequency and percentage, while numerical variables were presented as mean and standard deviation. The Shapiro-Wilk normality was conducted and, the correlation between the variables was tested with the Pearson or Spearman tests, depending on the results of the normality test.

The Kruskal-Wallis test was used to compare the value of continuous variables between groups of categorical variables, followed by post-hoc tests when necessary. To assess the association between categorical variables, Fisher's exact test was implemented. A significance level of 5% was considered in all statistical analyses.

RESULTS

Twenty-seven caregivers of patients with AD were included in this study. Their mean age was 52.9 (±14.2) years, 24 (88.89%) were female, and three (11.11%) were male. In general, these caregivers had a low educational background, with incomplete elementary school.

Among the caregivers, 25 (92.6%) were members of the patients' families, and only 2 (7.4%) were professional caregivers. Considering the whole sample, 11 participants (40.7%) were sons or daughters of the AD patients, 9 participants (33.3%) were spouses, 11 participants (40.7) shared the care activities with other professions, 6 participants (22.2%) were retired, and 8 participants (29.6%) were exclusive caregivers of the respective patient, who was a member of the family.

As for the caregivers' QoL, 22.48 was the total mean score. Considering that 52 is the maximum score for this questionnaire, it is clear that there is an interference in the caregiver's QoL. The items best evaluated by the participants were: "ability to do chores around the house," "housing," and "family." The items with the worst ratings were: "energy," "mood," and "ability to do leisure activities."

The sample of patients with AD was also composed of 27 participants, with 13 females and 14 males, and their mean age was 74.8 (±10.4). Their symptoms and diagnosis were onset 5 (±3.5) and 3.4 (±2.6) years before inclusion, respectively. Their educational level mainly was incomplete elementary school (70.4%) with mild dementia (59.3%). The cognitive, motor, and cognitive characteristics of the included patients are presented in Table 1.

An association between the caregiver's QoL and the individual's cognitive impairment with AD (p= 0.026) was found, shown in Table 2. It was also shown a difference in the caregiver's QoL when comparing "Mild Dementia" with "Severe Dementia" (p= 0.03) and "Mild dementia" with "Moderate dementia" (p= 003) of patients with AD included in our study.

The aspects of QoL with clear changes were "energy" (p= 0.025), "friends" (p= 0.050), "ability to do chores around the house" (p= 0.049), "ability to do leisure activities" (p= 0.001) and "life in general" (p= 0.042).

Table 1. Cognitive, motor, and functional characteristics of patients with AD

		F (n= 13)	M (n= 14)	Total (n= 27) (100%)
CDR (Clinical Dementia Rating)	Healthy	-	-	-
	Dementia questionable	-	-	-
	Mild dementia	8 (61.5%)	8 (57.1%)	16 (59.3%)
	Moderate dementia	3 (23.1%)	4 (28.6%)	7 (25.9%)
	Severe dementia	2 (15.4%)	2 (14.3%)	4 (14.8%)
FIM (Categorized)	Complete dependence (total assistance)	0 (0%)	0 (0%)	0 (0%)
	Modified dependence (assistance of up to 50% of the tasks)	2 (15.4%)	3 (21.4%)	5 (18.5%)
	Modified Dependence (assistance of up to 25% of the tasks)	6 (46.2%)	5 (35.7%)	11 (40.7%)
	Complete Independence	5 (38.5%)	6 (42.9%)	11 (40.7%)
Handgrip Strength (Results – for sex and age)	Adequate	2 (15.4%)	5 (35.7%)	7 (25.9%)
	Inadequate	11 (84.6%)	9 (64.3%)	20 (74.1%)
TUG (Categorized)	Independent and without risk of falls	1 (7.7%)	1 (7.1%)	2 (7.4%)
	Partially independente – low risk of falls	7 (53.8%)	7 (50%)	14 (51.9%)
	Significant physical mobility deficit and risk of falls	5 (38.5%)	6 (42.9%)	11 (40.7%)

Table 2. Association between caregiver’s QoL and cognitive impairment of patients with AD

QV TOTAL	Mild dementia	Moderate dementia	Severe dementia	Total score	Test	P-value
	25.1 (±6.5)	19.3 (±6.5)	17.5 (±4.2)	22,5 (±6.9)	Kruskal-Wallis	0.026*

*p<0,05**

There was a moderate correlation (r= 0.416) between the total FIM values and the caregiver's QoL (p= 0.031). The analysis evidenced that worse functionality of patients with AD in the domains of “personal care,” “transferences,” and “social cognition” is associated with worsened caregiver's QoL. These correlations are shown in Table 3.

The aspects of the caregiver's QoL affected mainly by the functionality of the individual under their care are “energy” (p= 0.004), “self as a whole” (p= 0.035), “ability to do leisure activities” (p= 0.002), and “life in general” (p= 0.027).

Considering the handgrip strength (HGS), no association was found with the QoL of their caregivers (p= 0.394) in any of the domains. Also, there was no association between the TUG results of the patients with AD and their caregiver's QoL (p= 0.090). Nonetheless, TUG influenced some aspects of the caregiver's QoL, such as: “energy” (p= 0.016), “mood” (p= 0.030), “self as a whole” (p= 0.017), “ability to do leisure activities” (p= 0.036), and “life in general” (p= 0.016).

DISCUSSION

Caregivers are those who take care of a dependent or sick person in the exercise of their daily activities, such as food, personal hygiene, and other issues required in daily living activities, being a family member or a professional hired for this purpose.[7] The primary caregivers assume the full responsibility of supervising, guiding, monitoring and directly taking care of a sick person.[21]

The caregivers of individuals with AD, all of the principal caregivers, who participated in this study had a profile which is commonly described in the literature: women, usually daughters or wives, with a mean age of about 50 years, living in the same household, with about eight years of schooling. This finding may be due to cultural norms in which women are responsible for organizing family life.[9,11,22,23]

Table 3. Association between caregiver’s QoL and functional impairment of patients with AD

FIM items	Spearman rho (ρ)	P-value
Eating	**0.412**	**0.033***
Grooming	0.370	0.058
Bathing	**0.385**	**0.047***
Dressing (Upper body)	0.323	0.100
Dressing (lower body)	0.364	0.062
Toileting	**0.410**	**0.034***
SELF-CARE TOTAL SCORE	**0.415**	**0.031***
Bladder management	0.327	0.096
Bowel management	0.207	0.299
SPHINCTER CONTROL TOTAL SCORE	0.304	0.123
Bed / Chair / Wheelchair	**0.455**	**0.017***
Toilet	**0.410**	**0.034***
Tub / Shower	**0.447**	**0.019***
TRANSFERS TOTAL SCORE	**0.433**	**0.024***
Walk / Wheelchair	0.330	0.093
Stairs	0.312	0.113
LOCOMOTION TOTAL SCORE	0.306	0.120
Comprehension	0.269	0.175
Expression	0.268	0.176
COMMUNICATION TOTAL SCORE	0.264	0.184
Social interaction	0.279	0.158
Problem solving	**0.410**	**0.034***
Memory	**0.476**	**0.012***
SOCIAL COGNITION TOTAL SCORE	**0.422**	**0.028***
MOTOR DOMAIN SCORE	**0.384**	**0.048***
COGNITIVE DOMAIN SCORE	0.365	0.061

*p<0,05**

Cachioni et al.[24] reported that this female responsibility is increased because, in most Western countries, women have a longer life expectancy than men, being also often younger than their husbands. Moreover, when the wives are unable, such tasks tend to be conducted by their daughters.

According to Falcão et al.[23] this could be a cultural pattern result, in which caregiving is still seen as a female role. Most caregivers are family members due to the financial difficulty in maintaining specialized or professional care or because it is still imposed as a family responsibility, another social norm.[25]

In this study, the average QoL of caregivers was low, compared to the maximum value of the questionnaire Quality of Life-AD. Inouye et al.[10] compared, with the same questionnaire, the QoL of caregivers of individuals with AD with a group of non-caregivers, matched on sociodemographic variables. As for the total QoL scores, the average obtained was 38.83 points for caregivers and 41.81 for non-caregivers. These data suggest that living with individuals with AD diminishes the total score and some QoL dimensions of the family caregiver, such as: "physical health," "energy," "mood," "memory," "self as a whole," and "ability to do leisure activities".[10] In another study, carried out by Cesário et al.[26] the QoL of the caregivers of patients with AD is affected, mainly in the physical, social and emotional domains.

Caregiver's QoL, as found in the specialized literature, can be physically and emotionally jeopardized once caring for individuals with dementia, especially when they are family members, is challenging due to the lack of proper training or to the burden and stress this responsibility generates.[5]

Cesário et al.[26] showed that the QoL of family members who are caregivers is related to stress, directly influencing the care they provide. Most caregivers had another profession, a paid activity, in addition to taking care of the patient with AD.

For Lenardt et al.[27] continuous care for the elderly associated with the other tasks, which may be a daily chore or a job, is a common characteristic in the life of a family caregiver, causing more significant burden and worsening QoL.

The average age of patients with AD included in our study was 74.8 years. Similar results were found, as the literature states that AD is more frequent in older age groups, concluding that age is the leading risk factor for this disease.[28,29,30] In our study, 13 participants were female and 14 were male. Nonetheless, studies show that females are predominant among patients with AD, which can occur because women live longer than men, increasing the chances of being affected by AD.[12,31,32] Also, most individuals with AD included in our study did complete elementary school. This data agrees with other studies, suggesting that low education is also a risk factor for dementia.[32,33]

Once this is a progressive and variable disease, AD is classified according to its degenerative stages as mild, moderate, and severe, even considering possible individual differences.[29] In the initial stage (about 2 to 3 years since first symptoms), patients can lose recent memory, temporal and spatial disorientation, and loss of interest in daily activities.

Between 2 to 10 years, the intermediate phase, there is the forgetting of names, difficulty living alone due to the inability to perform daily or more complex activities, such as shopping, cooking, and doing chores, speech difficulties, and extrapyramidal symptoms such as alterations in posture, increased muscle tone, impaired gait, and imbalance. In the severe phase (8 to 15 years), brain functions are widely affected, with marked changes in the sleep-wake cycle, behavioral changes, irritability, aggressiveness, memory impairment, dysphasia, urinary and fecal incontinence, and gait impairment.[29,32,34,35]

In this study, most participants with AD had mild dementia, measured by the medical CDR. The mean time of symptom onset (5 years) and diagnosis (3.4 years) show that the patients were mainly in the early or moderate stage of the disease. The difference between the first symptoms onset and the actual diagnosis can be explained by the fact that, in the initial phase, patients usually present clinical signs that hinders the accurate diagnosis of AD.[35]

Caring for the individual with AD, especially when the caregiver is a family member, poses several challenges due to the progressive cognition decline, which may affect the performance and the QoL of the caregiver.[5,26] The different manifestations of AD impose several demands, causing the caring activity to become a difficult task to perform, as the affected individual will need constant and increasingly complex care.[29] As was found in our study, there is a significant correlation between the caregiver's QoL and the cognitive impairment of the individual with AD, that is, the greater the cognitive impairment of the individual with AD, the worse the caregiver's QoL.

According to the systematic review results by de Paula et al.[7] the QoL of caregivers of patients with AD, in most studies, is negatively affected. Several factors interfere with the caregiver's QoL, especially the severity of the disease, cognitive and behavioral changes that patients with QoL may present.

The aspects of the caregiver's QoL that are mainly influenced by the cognitive impairment of patients with AD are energy, ability to make friends, ability to perform tasks, ability to perform leisure activities, and life in general. Inouye et al.[10] also evaluated caregivers of individuals with AD. They found that caregivers had greater chances to negatively rate their physical health, mood, mood, memory, life in general, and the ability to do leisure activities when compared to a control group of non-caregivers.

Dementia progression time variates according to the individual's characteristics. In addition to cognitive impairment, loss of functional capacity is another marker of AD progression.[36] In our study, most participants had complete independence or modified dependence, requiring the assistance of caregivers in about 25% of their tasks. As cognitive impairment advances in AD, patients gradually require more significant assistance to perform their ADLs.[32,36]

The continuous care of the individual with AD is associated with the performance of other tasks, such as paid work, chores, and activities related to the caregiver's personal life. These tasks can cause more significant burden and stress in the lives of these caregivers, since activities of daily living (ADLs) such as bathing, intimate hygiene, feeding, in addition to instrumental activities of daily living (IADLs), may be altered by the disability of patients with AD.[27]

At the beginning of the disease, caregivers are mainly responsible for the IADLs. As the disease progresses, they need to assist in more primary care, such as personal hygiene, bathing, and feeding, in basic daily living activities (ADLs).[32]

Therefore, it seems that diminished functionality of patients with AD demands increasing care lowering the caregiver’s QoL. In our study, in which most patients had mild dementia and were in the early or moderate stages of AD, there was a significant correlation between the caregiver's QoL and the general functionality of their patients as well as the activities such as "personal care, “transfers” and “social cognition.” The domains “sphincter control” and “locomotion” did not significantly interfere in the caregiver's QoL, as most patients, due to the stage of the disease, were independent or demanded little assistance. As AD progresses, the degree of dependence and the ADL-related demands increase.[32]

Activities such as bathing, dressing, hygiene, and the management of behavioral disorders can be some of the most stressful tasks for the caregiver.[29] Individuals with dementia may resist these activities due to functional impairment and their behavioral disorders or lack of memory, which usually lead them to believe that such activities are inadequate or expendable, or even mere repressive impositions of their caregivers.[27] The functional impairment of individuals with AD affects the caregiver's QoL in the aspects: "energy," "self as a whole," "life in general,” and “leisure activities.”

For Bagne & Gasparino[37] as dementia evolves, patients present difficulties in performing ADLs. Therefore, greater dependence of the patient is associated with greater demand for care, which contributes to psychological burden and worsening of the caregiver's QoL, especially in the psychological domain.

Most participants with AD had inadequate HGS, which is expected for individuals of the same sex and age, in individual analysis. According to Silva & Menezes[20] HGS has a good relationship with other muscle groups. Thus, one can infer that individuals with AD can present global muscle weakness, a characteristic that may be onset even in the initial phase of the disease. This matter was also observed in a cross-sectional study by Rogers & Jarrott, conducted with 38 participants with AD. They reported that dementia is associated with loss of strength, one of the main contributors to functional disability.[38]

This loss of strength is related to the deleterious effects of AD jeopardizing the performance of motor tasks. Muscle weakness may also be a consequence of the difficulty or inability to complete the movements. Other factors, including older age or internal and external factors, such as apathy or ineffective assistance, can also influence the disability and decrease muscle strength in patients with AD.[38]

In our results, no correlation was found between the HGS of the individual with AD and the caregiver's total score of QoL. Also, there was no influence of HGS over any aspect of QoL separately. This lack of correlation may be related to the fact that most of the participants had inadequate HGS previously, even in the initial phase of the disease, hindering comparison. It may also be associated with the small sample size, which is a limitation of the study.

In our study, according to the TUG assessment, most participants with AD showed partial independence and a low risk of falls. Kato-Narita et al.[39] reported that, during the initial stages, the risk of falls in individuals with AD is equal to the risk of falls in healthy elderly. However, they also show that motor processing, such as sitting and standing up, can be affected, even in the mild and moderate stages of AD, changing functional mobility, which may induce the risk of falls. The increase in the risk of falls is commonly found during the advanced stages of AD, which may be due to the probable visual impairment and cognitive alterations.[39]

In our study, most participants were partially independent with a low risk of falls due to the phases of AD in which they were. Hence, no correlation was found between the TUG results and the caregiver's total QoL. Nonetheless, functional mobility, assessed by the TUG, influenced some aspects of the caregiver's QoL, such as "energy," "mood," "self as a whole," "ability to do leisure activities," and "life in general."

For Luzardo et al.[27] the concentration of care in only one family member hinders the care procedures themselves as the stages of the disease progress towards the total dependence of the patient with AD. The increased dependence on functional mobility increases the demands for care, worsening the caregivers’ QoL of the.

In general, factors such as cognition, functionality, and functional mobility of individuals with AD interfere with the caregiver's QoL. The aspects of QoL that were influenced with the worst scores, and associated with the degree of dependence, were "energy," "friends," "ability to perform tasks," "ability to do leisure activities," and “life as a whole,” “self as a whole,” and “mood.” Likewise, as the patient's dependence increases, "energy," "life as a whole," and "ability to do leisure activities" are the aspects that had significant changes, except in measures of muscle strength.

For Luzardo et al.[29] the task of caring for individuals with AD usually requires the caregivers’ exclusive dedication, causing them to abdicate from their activities of daily living. Individual aspects associated with the perception of general QoL or energy, or willingness, are affected, given the family context in which the person who plays the role of the caregiver is subject to demands and burdens that risks their physical and mental health health. The caregiver’s QoL aspects that are undermined may be associated with the burden that limits the family daily life, including the caregiver’s self-care, well-being, and health.[10]

CONCLUSION

The increasing demands for care resulting from the progression of Alzheimer’s Disease (AD) change the caregiver's daily life and influence the QoL. The cognitive impairment and functional changes also reduce the caregiver's QoL, especially regarding aspects of energy, ability to perform leisure activities, and life as a whole. Acknowledging that the items that influence this result are functional mobility and risk of falls and activities related to personal care, transfers, social cognition, and the degree of dementia, it is possible to develop strategies for professional support and training of the caregiver.

Support and programs for caregivers may provide them with resources to prevent a decline in physical and mental health and social well-being. Accessible and evidence-based information, training programs, temporary services, and other resources designed to their needs should be provided to improve their knowledge and skills for care activities. We expect this study to guide professionals or family members towards the proper conduct towards the patient and the caregivers themselves to improve their QoL and their performance in caring for individuals with AD.

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