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Health literacy of family caregivers of older adults with dementia due to Alzheimer's

Alfabetização em saúde de cuidadores familiares de idosos com demência devido ao Alzheimer

Alfabetización en salud de los cuidadores familiares de personas mayores con demencia debida a la enfermedad de Alzheimer

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ABSTRACT

Objective: to evaluate, in a population sample, the level of health literacy of family Portuguese caregivers of the older adults with AD-d. **Method:** cross-sectional, exploratory, non-interventional, descriptive and analytical study with a non-random sample of 107 family caregivers of elderly people diagnosed with AD-d followed at the Neurology Service of the Centro Hospitalar e Universitário de Coimbra, Portugal. The research was approved by the Research Ethics Committee. The following were used: a sociodemographic questionnaire and The Alzheimer's Disease Knowledge Scale. The Mann-Whitney, Kruskal-Wallis and Spearman correlation tests were applied, at a significance level of 5%. **Results:** the level of knowledge of caregivers family members about Alzheimer's disease is between 63.3% and 70%. The highest score was found in the "Symptoms" domain (80.6±21.0), and the lowest in the "Being a caregiver" domain (53.8±19.3). **Conclusions:** the study highlighted the health literacy gap in the domain of being a caregiver, pointing to the need related to education and training in this domain.
Descriptors: Alzheimer disease; Caregivers; Health Literacy; Elderly People.

RESUMO

Objetivo: avaliar, em uma amostra populacional, o nível de alfabetização em saúde dos cuidadores familiares portugueses de idosos com DA-d. **Método:** estudo transversal, exploratório, não intervencionista, descritivo e analítico com uma amostra não aleatória de 107 cuidadores familiares de idosos diagnosticados com DA-d acompanhados no Serviço de Neurologia do Centro Hospitalar e Universitário de Coimbra, Portugal. A pesquisa foi aprovada pelo Comitê de Ética em Pesquisa. Foram utilizados: um questionário sociodemográfico e a Escala de Conhecimento sobre a Doença de Alzheimer. Os testes de correlação Mann-Whitney, Kruskal-Wallis e Spearman foram aplicados, com um nível de significância de 5%. **Resultados:** o nível de conhecimento dos familiares dos cuidadores sobre a doença de Alzheimer variou entre 63,3% e 70%. A maior pontuação foi encontrada no domínio "Sintomas" (80,6±21,0) e a menor no domínio "Ser cuidador" (53,8±19,3). **Conclusões:** o estudo destacou a lacuna em alfabetização em saúde no domínio de ser cuidador, apontando a necessidade relacionada à educação e treinamento nesse domínio.
Descritores: Doença de Alzheimer; Cuidadores; Alfabetização em Saúde; Pessoas Idosas.

RESUMEN

Objetivo: evaluar, en una muestra poblacional, el nivel de alfabetización en salud de los cuidadores familiares portugueses de personas mayores con EA-d. **Método:** estudio transversal, exploratorio, no intervencionista, descriptivo y analítico, con una muestra no aleatoria de 107 cuidadores familiares de personas mayores diagnosticadas con EA-d, seguidas en el Servicio de Neurología del Centro Hospitalar y Universitario de Coímbra, Portugal. El Comité de Ética en Investigación aprobó la investigación. Se utilizaron un cuestionario sociodemográfico y la *Alzheimer's Disease Knowledge Scale*. Se aplicaron las pruebas de Mann-Whitney, Kruskal-Wallis y la correlación de Spearman, con un nivel de significación del 5%. **Resultados:** el nivel de conocimiento de los cuidadores familiares sobre la enfermedad de Alzheimer se sitúa entre el 63,3% y el 70%. La puntuación más alta se encontró en el dominio "Síntomas" (80,6±21,0) y la más baja en el dominio "Ser cuidador" (53,8±19,3). **Conclusiones:** el estudio puso de relieve una brecha en la alfabetización en salud en el dominio de ser cuidador, lo que señala la necesidad de educación y formación en este ámbito.
Descriptores: Enfermedad de Alzheimer; Cuidadores; Alfabetización en Salud; Personas Mayores.

INTRODUCTION

The World Health Organization (WHO)[1] defines health literacy as "the degree to which individuals possess the ability to obtain, process, and understand basic health information to use services and make appropriate health decisions". Thus, literacy is important for health promotion and disease prevention, providing appropriate knowledge to exercise greater control over their health and, consequently, the personal, social, and environmental factors of health. This knowledge also impacts on the perceived satisfaction with health services, particularly in what concerns effectiveness and efficiency related to their specific needs[1,2].

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It is estimated that 5 out of 10 Portuguese have low levels of health literacy requiring the expert contribution of all health professionals, namely through outreach campaigns to the public[1].

With advancing age, an increase in neurodegenerative diseases is expected, of which some forms of dementias are the most prevalent. The WHO projects that by the year 2050 there will be 139 million people with dementia worldwide, with Dementia due to Alzheimer's disease (AD-d) being the most frequent cause[2]. AD-d and other neurodegenerative dementias are still incurable, but symptomatic treatment is available[3].

It is estimated that in Portugal, currently, there are 194 thousand people with dementia, 60 to 80% have Alzheimer's, increasing to 351.504 by 2050. Most of them are old or very old and in great need of care[3]. According to previous studies, the cost per patient/year is around 5.500 euros, with most of the expenses associated with informal caregiving and social support. The same studies indicate that the family is the major provider of care in Portugal[2,3].

In its clinical phenomenology, AD-d presents as a progressive decline of cognitive functions in which memory loss is almost always the initial and dominant symptom, followed by the loss of other abilities, leading to functional loss and eventually behavioral symptoms. In later stages of progression, autonomy in activities of daily living (ADLs) is compromised - feeding, hygiene, urinary and fecal continence, medication management, among others, implying an increase in the demand for care and constant supervision. This care is, to a large extent, provided by people from the elderly's relational network, usually family members, known as family caregivers[4].

Worldwide, the Alzheimer's disease dementia is a highly prevalent situation, which impacts on healthcare systems and the family. Considering the estimate that the number of people with dementia will double in the next 20 years, an increasing number of families are expected to care for a relative with dementia[4].

According to the European Association Working for Carers (*Eurocarers*), in Portugal, in October 2020, there were approximately 1.1 million family caregivers[5]. They are people who provide care to someone with a long-term illness or need, like dementia, usually a family member or close person, with no remuneration, schedule and/or professional training to provide this care. Family caregivers of dementia face dramatic challenges that may be mitigated by specific-training and health literacy[6,7].

In the past few years, there has been a growing interest in studies addressing health literacy. However, investigations on the subject relating to family caregiving of the elderly with AD are still scarce. Considering the huge numbers and social impact of AD-d as well as the recognition that care for these patients is mostly provided by the family as caregivers, it is our conviction that health literacy is determinant in health care and quality of life of those families. In this sense, analyzing the level of knowledge of family caregivers of older adults with Alzheimer's disease is important as it allows planning and developing interventions focused on the knowledge of these caregivers, either about the disease or about the ways of acting, and on the ability to perform certain activities inherent to the care provided.

Promoting health literacy for family caregivers aligns directly with the goals of Sustainable Development Goal (SDG) 3 – Good Health and Well-being, which aims to ensure healthy lives and promote well-being for all at all ages. In the specific context of caregivers of elderly people with Alzheimer's disease, SDG 3 emphasizes the importance of empowerment with health information and skills. This preparation is fundamental not only to improve the quality of care offered to the elderly person, but also to preserve the physical and mental health of the family caregiver themselves.

The present study aims to evaluate, in a population sample, the level of health literacy of family Portuguese caregivers of the older adults with AD-d.

METHOD

This is a cross-sectional, exploratory, non-interventional, descriptive, and analytical study[8], following the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist.

The study was carried out at the Centro Hospitalar e Universitário de Coimbra, Portugal which provides specialized care in all health areas, acting simultaneously as a proximity center for the population of the district of Coimbra and as a tertiary referral unit for the Central Region, with about two million inhabitants[9].

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The choice of this hospital is also justified because it is one of the nine health units that the Portuguese Ministry of Health has designated to participate in the national project "Health Care Safety Literacy", coordinated by the Directorate General of Health (DGS in Portuguese), which aims to increase patient literacy around health care safety and increase the participation of patients, their families and/or caregivers in the improvement, quality, and safety of health care delivery[1]. It is noteworthy that the choice of location does not present any bias to the inclusion/exclusion criteria, since there is an advantage of having accuracy in the biological diagnosis of dementia due to Alzheimer's disease (AD-d), which is beneficial in terms of differential diagnosis.

The target of the study were the family caregivers of the older adults diagnosed with AD-d at any stage and/or time of diagnosis followed at the Neurology Service of the CHUC in the period between February 1st to April 30th 2023.

It is noteworthy that according to the Statute of the Elderly[10] in force in Portugal, a) *family caregiver or primary informal caregiver* is defined as the spouse or unmarried partner, relative or kin up to the 4th degree in direct or collateral lineage of the person cared for, living with him/her in a communal dwelling, not receiving any remuneration, and having the person cared for in need of permanent care; and, b) *non-main family caregiver*, the spouse or unmarried partner, relative or kin up to the 4th degree in direct or collateral lineage of the person being cared for, but who only accompanies the person being cared for on a regular and non-permanent basis, and may receive remuneration either for the care provided or for any other type of professional activity. While the formal caregiver is the professional prepared in an educational institution to provide paid care to the person cared for.

To obtain the population sample, the non-random sampling technique of the intentional and convenience type was used[11]. Thus, doctors of the Neurology Service who performed outpatient consultations (General Neurology Consultation and Dementia Consultation) were asked to identify all the elderly with AD diagnosis accompanied by family caregivers, to conduct interviews.

Regarding the elderly flagged for the initial sampling, the inclusion criteria were defined as having age 65 years or older; probable diagnosis of AD-d according to McKhann[12] at any stage of the disease and/or time of diagnosis; having regular follow-up at the Neurology Service. Conversely, suffering from another form of dementia (not AD) as well as nonattendance of a partner or being acompanied by a formal caregiver, were criteria of exclusion. All the patients included in this study were investigated in the baseline eventually with biomarkers of AD-d and have follow up in the center. According to the defined criteria (inclusion/exclusion criteria), they were all were classified as probable Alzheimer' disease with biomarkers support in 80% of the cases.

Regarding the interviewees, inclusion criteria were: to be over 18 years old and have formal schooling; not receiving any kind of remuneration for the care provided and to be family caregiver of the older adults diagnosed with AD-d (the restringent criteria of being the main caregiver was not considered).

A total of 120 older adults diagnosed with AD-d were flagged, constituting the initial sample. From these, 13 further were excluded for several reasons, such as older adults who attended alone and/or with a formal caregiver (n=6), patients under 65 years old (n=4), older adults couples both diagnosed with AD-d (n=2) and giving up for not being able to completely answer the study instruments (n=1), resulting in a final sample of 107 interviewees.

Initially, the researcher was inserted in the assistencial field to be familiarized with the routine and dynamics of the Neurology Service. For data-collection, the family caregiver accompanying the older adults patient with AD-d was invited to participate in the study before or after medical consultation, in any shift of care, except holidays, following the routine of medical care of the Neurology Service. The interview was collected in a specific room in order to provide data confidentiality and the questionnaire was self-applied by the family caregiver, lasting an average of 5 to 10 minutes. In case of doubts, the interviewee received help from the researcher.

Two instruments were applied:

i) a **sociodemographic questionnaire** prepared by the researcher, was divided into two parts: the first focusing on the caregiver: demographics (age, sex, marital status, education), caregiver context (relationship with the person they care for, quantification of time as caregiver, prior knowledge of the disease and search for information about the disease) and health (health status of the caregiver, perception about the stage of AD-d of the older adults they care for); the second regarding the patient: demographic (sex and age) and health (diagnosis and stage of AD-d confirmed by medical information).

ii) **"The Alzheimer's Disease Knowledge Scale"** (ADKS) is an instrument developed by the University of Washington to assess the level of knowledge about AD[13], envisaging the general population, patients, health professionals and

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caregivers. The English version was adapted into Portuguese using the translation/back-translation method, maintaining the structure and meaning of the original questions and being designated as the *"Escala de conhecimento sobre Doença de Alzheimer"* (ECDA).

This scale can be used in various circumstances to assess what people know about AD by identifying education needs or indicating the success of education efforts. It is a scale consisting of 30 "true (value 1) or false (value 0)" questions about AD-d, with scores ranging from 0 (worst) to 30 (best) and, calculated by summing the number of correct answers, being restricted to assessing respondents' uncertainties. "True" is the correct answer for 18 items, while the rest -12 items-are scored as "False". There is no cut-off score, and a high score indicates that respondents have better knowledge about the disease.

The ADKS can be divided into seven domains: impact on the patient's life (questions 1, 11 and 28), risk factors (questions 2, 13, 18, 25, 26 and 27), symptoms (questions 19, 22, 23 and 30), treatment (questions 9, 12, 24 and 29), being a caregiver (questions 5, 6, 7, 15 and 16), assessment and diagnosis (questions 4, 10, 20 and 21), disease development and progression (questions 3, 8, 14 and 17).

Initially, the data was recorded in a Microsoft Excel® spreadsheet and domain and overall scores were computed according to the total number of correct answers. These scores were converted to percentages in order to be comparable to each other.

The description of qualitative data was made using absolute and relative frequencies, while quantitative variables were described using the mean (standard deviation) and median [quartile 1; quartile 3]. The total values for each dimension and the total scale, which constitute the total number of correct answers in each dimension and in total, were converted to percentages in order to be comparable to each other. The distribution of each of the dimensions and the total scale was evaluated using the Shapiro-Wilk test, concluding that there were large deviations from normality, which is why the Mann-Whitney test was applied to compare those scores in relation to binary variables, the Kruskal-Wallis test when there were 3 or more categories and the Spearman correlation to assess the relationship between those and the age of caregivers and patients. The analysis was carried out in SPSS, version 27, and analyzed at a significance level of 5%.

The study followed the standards of the 2013 Declaration of Helsinki, ensuring confidentiality and anonymity of data of all participants, with a aproved opinion N°. 161/CES of the Ethics Committee of the CHUC. The interviewees were informed about the purpose of the study and the voluntary nature of their participation, as well as the guarantee of access to the results if they wished so, and informed consent was obtained.

RESULTS

The characteristics of the 107 participants are presented in Tables 1 and 2.

Table 1: Sociodemographic characterization of the family caregivers (n=107). Coimbra, Portugal, 2023

Variables	n	f(%)
Age (years)		
37 ⊣ 49	31	29.0
50 ⊣ 64	33	30.8
≥ 65	43	40.2
Gender		
Female	72	67.3
Male	35	32.7
Marital status		
Married/stable union	90	84.1
Single	9	8.4
Divorced/Separated	7	6.5
Widowed	1	0.9
Education		
1st cycle (1st – 4th grade)	27	25.2
2nd cycle (5th – 6th grade)	15	14.0
3rd cycle (7th – 9th grade)	20	18.7
Secondary (High School)	35	32.7
College or University	10	9.3

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Table 2: Health and context relationships characterization of the family caregivers (n=107). Coimbra, Portugal, 2023

Variables	n	f(%)
Self-assessment of health status		
Good	50	46.7
Neither good nor bad	45	42.1
Excellent	7	6.5
Bad	5	4.7
Relationship to the person for whom you are the primary caregiver		
Parent	47	43.9
Spouse/partner	47	43.9
Son or daughter-in-law	7	6.5
Uncle/uncle	3	2.8
Brother or sister-in-law	1	0.9
Friend/Neighbor	2	1.9
Previous knowledge about Alzheimer disease		
No	80	74.8
Yes	27	25.2
Where do you look for information about Alzheimer disease		
Health care professionals	78	72.9
Internet	40	37.4
Others (books)	5	4.7

The results showed a predominance of female family caregivers (n=72, 67.3%), with the highest percentage of caregivers over 65 years old (n=43, 40.2%). The mean age of the sample was 60.8 years (SD±14.0). Most were married (n=90, 84.1%) and had a high school education (n=35, 32.7%). In addition, most of the respondents considered their health status as "good" (n=50, 46.7%). As for the relationship with the person for whom they are the primary caregiver, they were caregivers of their father/mother and/or spouse (n=94, 43.9%), reported having no previous knowledge about AD (n=80, 74.8%) and seek information with health professionals (n=78, 72.9%).

Regarding the characterization of the older adults that are being cared, there was a predominance of females (n= 74, 69.2%), age ranging from 65 to 93 years (mean 78.3 years SD±6.4) with a considered predominance of septuagenarians (n=53, 49.5%) with a diagnosis of AD-d between 1 and 5 years (n=69, 64.5%). As for the agreement between the classification of the stages of AD-d by the caregiver and the confirmed medical stage diagnosis, there was no variation/disagreement, both in the moderate stage (n=50, 46.7% and n=48, 44.9%)

As for the analysis of the ADKS results with the values (in percentages) of correct answers for each of the questions of the instrument, question 6 obtained the lowest percentage of correct answers, followed by question 16, as opposed to questions 8 and 29 in Figure 1.

In Table 3, as for knowledge about AD, it seems to be more accurate in relation to ‘Symptoms’, ‘Development and progression’, and ‘Treatment’. In the remaining domains, variability is high, and there are some caregivers with little knowledge, particularly with regard to ‘Impact on the patient’s life’, ‘Risk factors’, ‘Being a caregiver’, and ‘Assessment and diagnosis’. Caregivers had a total score of at least 60% in knowledge about the disease. The maximum value for the total is 86.7%, and the confidence interval for the median varies between 63.3% and 70%, that is, we can assume, with 95% confidence, that the level of knowledge of caregivers' family members about Alzheimer's disease is between 63.3% and 70%.

Regarding the association between the independent variables and the ADKS scale, it is clear that the domains “Treatment” (*P*=0.002), “Being a caregiver” (*P* =0.007), “Assessment and diagnosis” (*P* =0.002), “Development and progression” (*P* =0.025) present a statistically significant difference with the level of education of the informal caregiver, that is, higher education can influence the care provided to elderly people with AD-d. The domains “Assessment and diagnosis” (*P* =0.007) and “Risk factors” (of elderly care) showed a statistically significant difference with sex, the latter specifically associated with the male sex (*P* =0.001), suggesting that family caregivers with more knowledge about elderly people with AD-d are male.

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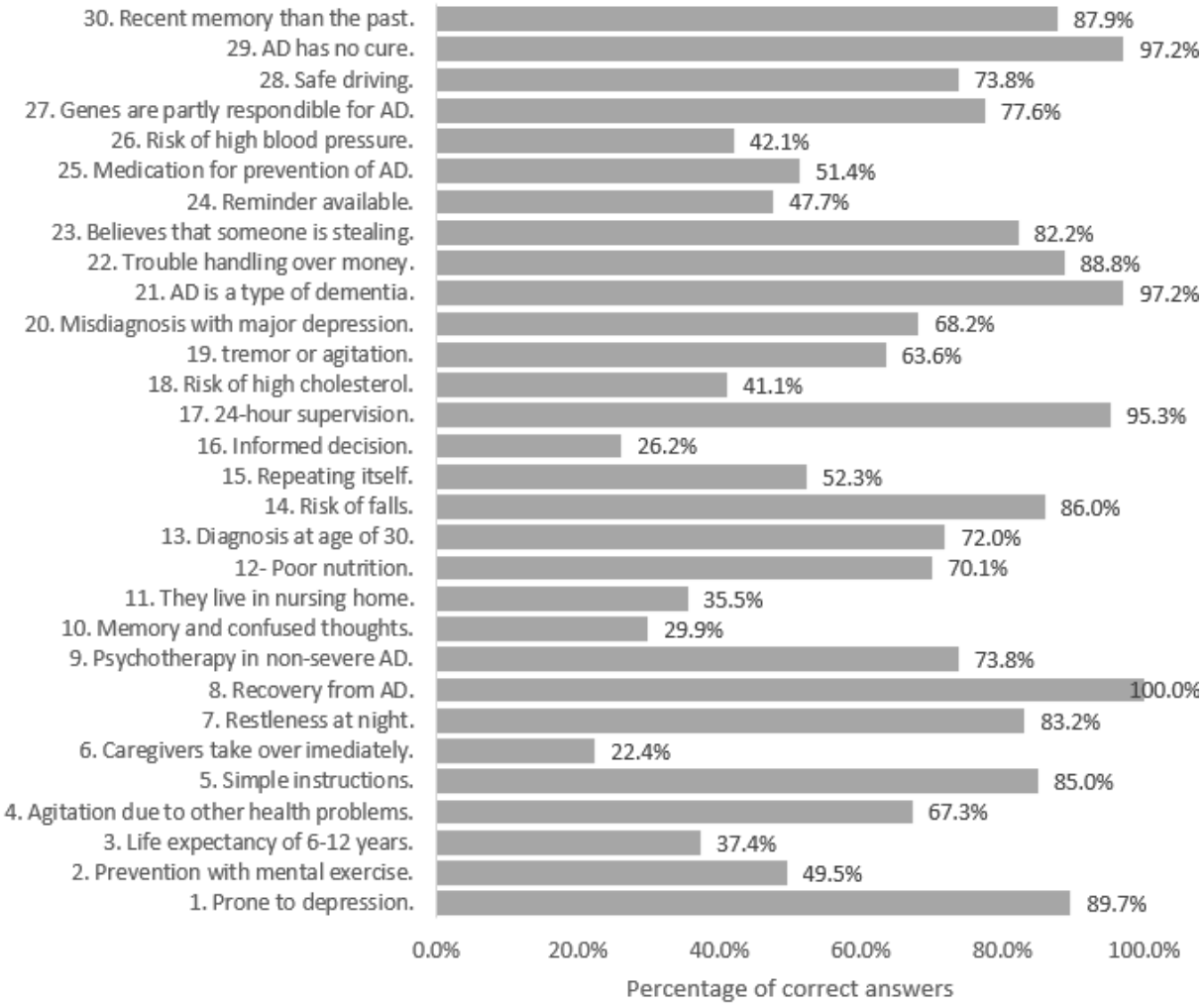

Figure 1: ADKS scale with percentage of correct answers per question*.
Abbreviations: AD- Alzheimer disease. ADKS- The Alzheimer's Disease Knowledge Scale**.**
Notes*: Domain Impact on the patient's life (questions 1, 11 and 28); Domain Risk factors (questions 2, 13, 18, 25, 26 and 27); Domain Symptoms (questions 19, 22, 23 and 30); Domain Treatment (questions 9,12, 24 and 29); Domain Being a caregiver (questions 5,6,7, 15 and 16); Domain assessment and diagnosis (questions 4, 10, 20 and 21); Domain disease development and progression (questions 3, 8, 14 and 17).

Table 3: Descriptive analysis and percentage referring to the ADKS domains of correct answers (n=107). Coimbra, Portugal, 2023.

Domains	n	Min – Max	*95,0% Lower-Upper CL for Mean*	Average(±SD)	Median [Q1; Q3]	*95,0% Lower-Upper CL for Median*
Impact on life	107	0 – 100	61.3 – 71.4	66.4(±26.5)	66.67 [33.3; 100]	66.7-100.0
Risk Factors	107	0 – 100	51.0 -60.2	55.6(±24.1)	50 [33.3; 66.7]	50.0-66.7
Symptoms	107	25 – 100	76.6 – 84.6	80.6(±21.0)	75 [75.0; 100]	75.0-100.0
Treatment	107	25 – 100	68.7- 75.7	72.2(±18.3)	75 [50.0; 75]	75.0-100.0
Being a Caregiver	107	20 – 100	50.1 – 57.5	53.8(±19.3)	60 [40.0; 60.0]	60.0-80.0
Assessment and Diagnosis	107	25 – 100	61.4 – 69.9	65.7(±22.1)	75 [50.0; 75.0]	75.0-100.0
Development and Progression	107	25 – 100	76.6 – 82.7	79.7(±15.8)	75 [75.0; 100]	75.0-100.0
Total	**107**	**43.3 - 86.6**	**64.6 – 68.4**	**66.5(±9.8)**	**66.67 [60.0; 73.3]**	**63.3-70.0**

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Regarding the length of time working as a caregiver, there is a statistically significant difference in the domains "Risk factors" (*P* <0.001), "Symptoms" (*P*=0.034), "Being a caregiver" (*P*=0.051) and "Development and progression of disease" (*P* =0.013), that is, during the course of AD the family caregiver seeks to know about AD and its care. Regarding the relationship between the caregiver and the elderly person being cared for, there was a statistically significant difference with the domains "Treatment" (*P* =0.007), "Being a caregiver" (*P* =0.046) and "Evaluation and diagnosis" (*P* = 0.008), this result It may reflect that the close relationship helps in providing care. Having prior knowledge about AD presents a statistically significant difference with the domains "Impact on the patient's life" (*P*=0.022), "Assessment and diagnosis (*P*=0.041) and "Development and progression of the disease" (*P* =0.038), this the latter was also significant in relation to the search for information from health professionals (*P* =0.002).

The time since diagnosis of AD showed a statistically significant difference with the domains "Symptoms" (*P* =0.014), "Development and progression of the disease" (*P*=0.002) and "Risk factors" (*P*=0.001), the latter being also significant in relation to the medical diagnosis phase of AD (*P*=0.003). Such findings may indicate that knowledge about AD can improve information about the disease (treatment and prognosis) in order to improve the daily life management of the elderly in Supplementary material.

DISCUSSION

The sociodemographic profile of family caregivers and the association between variables of interest and the ADKS scale are in line with other international investigations [14,15].

First of all, gender - the majority were female (wives and daughters) -evidencing that, also in Portugal, the care is predominantly provided by women. Probably due to the sociocultural construction inherited from the past, women were not employers, being the most responsible for the family and home care. Therefore, a hierarchy of the support network and the caregiving task is observed: in first place comes the wife, and then come the daughters, especially the eldest [16].

Regarding the age of the respondents, the majority was over 65 years old, is in line with other research conducted in the USA[17] , Brazil[18] and Portugal[19]. In this sense, there is a need to expand investigations on the impact of dementias on the family nucleus, especially on the health of the family caregiver, who may become a "hidden patient", considering the predominance of elderly caregivers.

Regarding education, we evidenced that most have secondary education, corroborating a national study conducted with Portuguese family caregivers[20]. Study points out that the level of education is related to literacy level; thus, it is expected that higher levels of education, will reflect on higher health literacy. As one of the factors that most contributes to health literacy, researchers and/or professionals advocate the urgency of developing educational interventions[19] .

As for self-assessment of health status, most respondents considered it as "neither bad nor good" or "good", a similar result found in another study[21]. Studies point out that self-assessment of health status are indicators of quality of life and well-being[22,23]. The results found in this study may be indicative of the resolutive nature and benefits of health monitoring of the older adults with AD-d by the hospital team.

One of the difficulties reported by most of the caregivers in this study was the lack of previous knowledge about AD-d, which is in line with a former investigation made in Brazil with family caregivers of older adults with AD-d[24]. These results show that caregiver's perception is that caring in this specific clinical setting requires knowledge and skills development. This is also the perception of health services: first, an informed caregiver has more confidence and ability to perform this task; second, caregiver's understanding about the appropriate care to be provided to the older adults patient will directly interfere in his/her quality of life[25]. In this context, Portugal promotes the Literacy and Care Integration Program, through educational campaigns in the media, equipped with digital repositories with appropriate information, accessible to different population groups and literacy levels[26].

As for the search for information on AD-d, most of them mentioned health professionals as the major providers of this information. The access to the health service as the main source of information to clarify doubts is an important aspect for the caregiver, but the accessibility will not be the most effective through the existing channels, being mostly during the consultation period. It is considered important to stimulate the dialogue between health professionals and caregivers, as this will allow the creation of a climate of trust to express doubts, seek information, problematize, and reflect on the care provided. In this way, it is shown to be relevant to reinforce the relationship between caregivers and health services, as this is a reliable source to search for information, being able to provide support to the caregiver in the assistance given and, thus, to positively interfere in the care of the older adults. Additionally, it is worth mentioning the importance of the nurse in the attention and support to this caregiver, informing him/her about AD-d and its

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evolution, informing the appropriate way of the aids and the social support networks, to contribute to the resoluteness of the care plans and to strengthen the empowerment of this caregiver[27,28].

Regarding the older adults patients cared for, there was a predominance of septuagenarian women, a phenomenon already known as the feminization process of aging[21]. It is estimated that more women than men have dementia, since the longer life expectancy of women increases the possibility of developing this or other dementias[29]; furthermore, evidence is growing that women also have a higher risk due to hormonal factors that play a significant role in the development and progression of AD[30,31] .Thus, it is essential that health professionals who follow patients with AD-d and/or other dementias consider, in their interventions, particularities of elderly women's health care[32].

This study revealed, regarding the time of diagnosis and stage of AD-d, that most of the older adults had between 1 and 5 years of confirmed diagnosis and were in the moderate stage of AD-d. A similar result was found among the older adults in Brazil[33] and in the USA[34], showing that, as the disease progresses, there is a worsening in the cognitive and functional performance of the older adults. In this sense, it is essential to provide an adequate and individualized care, as the losses in the moderate and severe stages are not homogeneous and their needs differ. It is necessary to understand the evolution of the disease to determine the necessary care, since it is usually provided by family members who have no knowledge of the disease and its consequences.

Regarding the application of the ADKS, for comparative purposes with the original study, in our study, 19 questions presented above 60% correct answers obtained among family caregivers, suggesting a satisfactory level of health literacy. A similar result was found in family caregivers of older adults with dementia in Portugal[19] and Spain[35].

There was good understanding of the domains "Symptoms", "Treatment" and "Development and progression of the disease", considering the percentage of right answers. Regarding the questions, we evidenced that question 8 (“In rare cases, have people recovered from Alzheimer’s disease?” referring to the domain “Development and progression of the disease”) was answered correctly by all respondents and other 25 questions were mostly correct, which reveals a satisfactory level of health literacy about this disease.

It is noteworthy that most family caregivers answered incorrectly predominantly to items related to: questions 3 (domain “Disease development and progression”: "After the onset of Alzheimer's disease symptoms, the average life expectancy is 6 to 12 years?") which was incorrectly answered considering that studies point out that the average life expectancy of the person with AD is on average 8.5 years[36].

The questions 6 and 16 (which refer to the “Caregiver” domain, respectively: "When people with Alzheimer's disease begin to have difficulty caring for themselves, should caregivers immediately assume these responsibilities? and "Once people have Alzheimer's Disease, are they no longer able to make informed decisions about their own care?"). It is important to highlight that the diagnosis of the disease does not automatically eliminate the right to autonomy. However, with the progression of the disease, the capacity may deteriorate, and it is likely that the person loses his or her legal capacity to make decisions[37] .

Finally, regarding question 11 (related to the “Impact on the life of the patient” domain: "Do most people with Alzheimer's Disease live in nursing homes?"), the international literature shows that older adults with AD tend remain at home with family members[38]. In this sense, it is noteworthy that, until the 1960s, the aging process was not only a "biological and psychological problem", but also a social issue "useless according to society" (i.e., changes in the family nucleus reflected in the lives of the elderly, determining the increase in their institutionalization). From the 70s on, there were social changes such as the development of specialized professionals and new support systems, such as the hospital and social assistance, in which the support provided to the elderly started to produce a fundamental role in the Portuguese society[39].

Considering that literacy in the crucial domain of being a caregiver is still lacking, one of the ways to achieve this goal, is to prepare informative leaflets and/or encourage the caregiver to participate in campaigns and support programs, educational meetings organized by health services or associations of patients and relatives, such as the Portugal Alzheimer Association[19].

Regarding the demographic variables of the family caregiver associated with the level of knowledge, we found that age is an independent variable that does not correlate with any domain of the ADKS, a result similar to the study carried out with caregivers in the United Kingdom[40] and Denmark[41].

Education presented a significant association with the domains “Treatment” and “Being a caregiver” and “Assessment and diagnosis” and “Development and progression of the disease.” A study carried out with informal caregivers in Saudi Arabia[42] showed that higher education was associated with the “Being a caregiver” and “Assessment and diagnosis” domains. In this context, having higher education is associated with better awareness and greater

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knowledge regarding the diagnosis, management and therapeutic intervention of AD-d, as well as the care process. Health literacy also has a strong connection with the level of education, as the knowledge, skills and assessments that an individual is or are not able to make in light of all health information are at stake[43].

The gender of the older adults being cared for was associated with the domains “Assessment and diagnosis” and “Risk factors”, the latter being specifically associated with the male gender. A similar result with a study carried out in China[44] showed that the male gender was associated with greater knowledge about the assessment and diagnosis of the disease, possibly influenced by advanced age, leading to better awareness regarding diagnosis, management and therapeutic interventions.

The relationship between caregiver time showed a significant association with the domains “Being a caregiver”, “Risk factors”, “Symptoms” and “Development and progression of the disease”; the time since diagnosis of AD-d was also associated with the domains “Symptoms”, “Development and progression of the disease” and “Risk factors”, the latter also being significant in terms of the stage of medical diagnosis of AD, a similar result found in a study with informal caregivers in the United Kingdom[45] . The WHO and Alzheimer's Disease International[46] in the report “Dementia: A public health priority” warn of low levels of understanding about AD, symptoms and risk factors that may contribute to some misconceptions about the disease, resulting in a perpetuation of stigma. Therefore, it is necessary for the caregiver to understand the nature of AD and its implications, in order to recognize the symptoms for early diagnosis and intervention.

Regarding the relationship between the caregiver and the older adults being cared for, it was associated with the domains “Treatment”, “Being a caregiver” and “Assessment and diagnosis”. These results reveal that having relatives diagnosed with AD increases the need for better awareness and knowledge of family caregivers of older adults with AD. The study carried out in Saudi Arabia[42] points out that the lack of knowledge about the practice of care increases the delay in disease management and interventions for elderly people with AD, affecting their quality of life. Furthermore, better understanding the disease allows early identification and the search for an ideal treatment as soon as possible[45].

In the item prior knowledge about AD there was a significant association with the domains “Impact on the patient's life”, “Assessment and diagnosis and “Development and progression of the disease”, the latter also significant in relation to the search for information from health professionals. This result suggests the need to increase family caregivers knowledge about AD. In this context, healthcare professionals continue to be an important source of reliable information for this specific population[42] .

The major strength of this study is the potential contribution for increasing the health literacy of family caregivers in the future and analyse in a sample population what they knowledge about the disease. In addition, it reduces the stigma and fear for the caregiver, promoting the improvement of the quality-of-care assistance to the older adults with AD-d, since studies[47,48] point out that the increase in health literacy [26] is an important factor for the reduction of stigma and prejudice, and consequently, increase the capacity of understanding the information related to AD-d.

Study limitations

One limitation of this study may be inherent in the self-report of the family caregivers, who may not be cautious enough in providing the answers. Another point is the cross-sectional nature of this study, which means that longitudinal studies may produce different or more accurate results and may examine the impact and/or influence of health literacy throughout the progression of the disease. On the other hand, being a study carried out in a central hospital and partly in a reference consultation, it may not reproduce the reality in other contexts, namely at primary care level and in other environments.

CONCLUSION

In this study, family caregivers presented a satisfactory level of health literacy in relation to AD-d, allowing them to optimize and maximize the care provided to this population. There was a significant association between the variables (demographic, context and health) and the ADKS scale.

The literacy in the crucial domain of being a caregiver is still scarce, pointing to an unmet need related to education and training, highlighting the existence of knowledge gaps that healthcare professionals must be aware of to increase health literacy about AD-d.

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Health literacy made it possible to reveal the needs of family caregivers, highlighting the lack of health education interventions on the care provided to older adults with dementia, thus being a tool capable of achieving better health results. It is suggested that intervention studies be carried out to promote knowledge and skills about caring for older adults with AD-d, to guarantee empowerment and support for family caregivers.

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Authors contributions

Conceptualization, F.J.D.S., C.R.O. and A.M.P; methodology, S.V.P. and B.O.; software, B.O.; validation, A.M.P., C.R.O, S.V.P. and I.S.; formal analysis, C.R.O. and A.M.P.; investigation, F.J.D.S.and I.C.; resources, F.J.D.S.; data curation, B.O.; manuscript writing, F.J.D.S, C.R.O., S.V.P, A.M.P, B.O. and I.S.; review and editing, M.T.P. and J.D; visualization, B.A.; supervision, C.R.O., S.V.P, A.M.P, B.O. and I.S; project administration, F.J.D.S. All authors read and agreed with the published version of the manuscript.

Preprint Publication

The authors declare that research data have been published in preprint format in the repository https://preprints.jmir.org/preprint/59303, electronic address/DOI: 10.2196/preprints.59303. The research database is available from the corresponding author and can be accessed upon request

Use of artificial intelligence tools

Authors declare that no artificial intelligence tools were used in the composition of the manuscript "*Health literacy of family caregivers of older adults with dementia due to Alzheimer's*".