


LITERACIA EM SAÚDE DOS CUIDADORES INFORMAIS SOBRE A DOENÇA DE ALZHEIMER
HEALTH LITERACY OF INFORMAL CAREGIVERS ON ALZHEIMER'S DISEASE
ALFABETIZACIÓN EN SALUD DE CUIDADORES INFORMALES SOBRE LA ENFERMEDAD DE ALZHEIMER

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RESUMO

Introdução: Considerando o envelhecimento populacional e as projeções demográficas para Portugal é esperado um aumento do desenvolvimento de doenças crónicas e degenerativas, como é o caso da doença de Alzheimer (DA). Deste modo os Cuidadores Informais (CI) têm um papel fundamental na prestação de cuidados, sendo este influenciado pelo nível de literacia desta população.

Objetivo: Explorar o nível de literacia dos Cuidadores Informais sobre a doença de Alzheimer.

Métodos: Estudo descritivo, exploratório e quantitativo, com uma amostra de 28 participantes. A recolha de dados decorreu através de um questionário e da Escala do Conhecimento sobre a Doença de Alzheimer, no *Google Forms*, após o consentimento informado.

Resultados: A maioria dos CI era do sexo feminino (75%), com uma média de 54,04 anos de idade ($\pm 12,46$), um elevado nível de habilitações literárias e uma relação próxima com a pessoa cuidada. Prestam cuidados em média 4,18 anos ($\pm 2,41$), aproximadamente 12 horas por dia, sete dias por semana. Sobre as dificuldades sentidas, a maioria referiu alterações neurocomportamentais na DA, gestão da vida pessoal e profissional, falta de apoio e incertezas de capacitação pessoal para cuidar. Considera-se que 57,14% dos CI têm um nível intermédio (3 numa escala de 1-5) na forma como prestam cuidados.

Conclusão: Devido às dificuldades e necessidades referidas pelos CI revela-se essencial a criação de novos programas de literacia em saúde na comunidade. Em estudos futuros importa avaliar a eficácia destes programas a fim de promover estratégias de cuidados para os CI de pessoas com DA.

Palavras-chave: doença de Alzheimer; cuidador informal; demência; literacia em saúde

ABSTRACT

Introduction: Considering population aging and the demographic projections for Portugal, is expected an increase in the development of chronic degenerative diseases, as is the case of Alzheimer's Disease (AD). Thus, Informal Caregivers (IC) have a fundamental role in the provision of care, which is influenced by the literacy level of such population.

Objective: To explore the level of literacy of Informal Caregivers on Alzheimer's Disease.

Methods: Descriptive, exploratory and quantitative study, with a sample of 28 participants. The data collection took place through a questionnaire and the Alzheimer's Disease Knowledge Scale, on *Google Forms*, after informed consent.

Results: Most IC were female (75%), with an average of 54,04 years of age (12,46), a high level of educational qualifications and a close relationship with the person cared for. They provide care on average 4,18 years ($\pm 2,41$), approximately 12 hours a day, seven days a week. Regarding the difficulties felt, the majority reported neurobehavioral changes in AD, management of personal and professional life, lack of support and uncertainties of personal training to care. It is considered that 57,14% of IC have an intermediate level (3 on a scale of 1-5) in the way they provide care.

Conclusion: Due to the difficulties and needs mentioned by IC, the creation of new health literacy programs in the community is essential. In future studies it is important to evaluate the effectiveness of these programs in order to promote care strategies for IC of people with AD.

Keywords: Alzheimer's disease; informal caregiver; dementia; health literacy

RESUMEN

Introducción: Teniendo en cuenta el envejecimiento de la población y las proyecciones demográficas para Portugal, se espera un aumento en el desarrollo de enfermedades crónicas y degenerativas, como la Enfermedad de Alzheimer (EA). Así, los Cuidadores Informales (CI) juegan un papel fundamental en la prestación de cuidados, lo que está influenciado por el nivel de alfabetización de esta población.

Objetivos: Explorar el nivel de alfabetización de Cuidadores Informales en Enfermedad de Alzheimer.

Métodos: Estudio descriptivo, exploratorio y cuantitativo, con una muestra de 28 participantes. La recolección de datos se llevó a cabo a través de un cuestionario y la Escala de Conocimiento de la Enfermedad de Alzheimer, no *Google Forms*, posterior al consentimiento informado.

Resultados: La mayoría de los CI fueron mujeres (75%), con un promedio de 54,04 años (12,46), un alto nivel de calificación educativa y una estrecha relación con la persona atendida. Brindan atención en promedio 4,18 años ($\pm 2,41$), aproximadamente 12 horas al día, siete días a la semana. En cuanto a las dificultades sentidas, la mayoría reportó cambios neuroconductuales en la DE, manejo de la vida personal y profesional, falta de apoyo e incertidumbres de entrenamiento personal para el cuidado. Se considera que el 57,14% de los CI tienen un nivel intermedio (3 en una escala de 1-5) en la forma en que brindan atención.

Conclusión: Debido a las dificultades y necesidades mencionadas por los CI es esencial crear nuevos programas de alfabetización en salud en la comunidad. En estudios futuros es importante evaluar la efectividad de estos programas con el fin de promover estrategias de atención para las personas con EA.

Palabras clave: enfermedad de Alzheimer; cuidador informal; demencia; alfabetización en salud

INTRODUCTION

European countries experience one of the most striking phenomena of contemporary societies: the demographic revolution with fewer births and increased longevity (Quaresma, 2008). Portugal is the fourth country in the world with the highest number of elderly people and is predicted that one in three residents will be elderly and thus will occupy third place as the country with the oldest population in the world, after Japan and Spain (INE, 2017). This demographic trend entails new challenges in a multidimensional sphere, with economic, social, political and health impact.

With advancing age, a rapid increase in the development of chronic degenerative diseases is expected, often accompanied by multiple conditions of comorbidity that require greater attention and care (Teixeira et al., 2017). Of chronic and degenerative diseases, the neurocognitive disorders that represent the highest prevalence are dementias. Of these, Alzheimer's disease (AD) is the most common, presenting a rate between 50 and 75%, being characterized by several psychological symptoms, including anxiety, depression, delusions and hallucinations; and behavioral symptoms such as agitation, aggression, screams, sleep disorders, ambulation and apathy (Prince et al., 2015).

Considering the demographic projections for Portugal and the complexity of care for a person with dementia, informal caregivers (IC) play a key role in providing care to the elderly with AD. The level of literacy of this population can influence the effectiveness of the commitment to care. Therefore, a good understanding of the main components of IC health literacy can contribute to the development of measures and interventions to support them in the care of the elderly (Jiang, Sereika, Lingler, Tamres & Erlen, 2018).

Despite the increase in studies aimed at the physical and emotional well-being of IC, preparation has been a widely used strategy to meet the demands of care delivery, however there are still some gaps in the knowledge of IC regarding AD, this being a possible factor that contributes to the increase in the level of anxiety, depression and overload (Costa, Paúl, Azevedo & Gomes, 2019). Considering these factors, the present study aims to explore the literacy of IC regarding AD.

1. THEORETICAL FRAMEWORK

According to Eurocares, in Portugal, in October 2020 there were approximately 1.1 million IC (Eurocarers, 2020). These are persons who provide care to someone with a prolonged illness or need, usually family or close person, and there is no remuneration, a schedule and/or vocational training for the provision of such care (Konerding et al., 2019).

The IC performs a set of tasks in its routine that requires knowledge and training, such as management of care of Activities of Daily Living (ADL's), problem solving, decision making, activities that require communicative and organizational skills, among other anticipatory and surveillance care (Costa, Paúl, Azevedo & Gomes, 2019).

Caring for a person with dementia, taking into account that their average life expectancy is 8.5 years after the onset of symptoms, involves important requirements that can lead to exhaustion, frustration and other adverse reactions to IC when the situation is maintained over time (Lane, Hardy & Schott, 2018; Ruisoto, Contador, Fernández-Calvo, Palenzuela & Ramos, 2018). These consequences can negatively interfere with the quality of life of IC in the personal, psychological, physical, social and economic domains where they often feel stressed and overwhelmed (Costa, Paúl, Azevedo & Gomes, 2019).

Caregivers are increasingly required to have a greater knowledge and abilities, in order to face, as best as possible, the challenges that are posed to them while playing a fundamental role in the care of the elderly, especially with a diagnosis of AD. To this end, it is important to assess their level of literacy, which potentially influences the effectiveness with which IC's are committed to caring for (Jiang, Sereika, Lingler, Tamres & Erlen, 2018).

Therefore, health literacy, according to the World Health Organization, is defined as the set of "cognitive and social skills and the person's ability to access, understand and use information in order to promote and maintain good health". It is also the ability to make informed health decisions during the day-to-day in various contexts. It enables people to increase their control over their health, their ability to seek information and to take responsibility. (World Health Organization, 1998)

This concept has been revised over time, however the *European Health Literacy Consortium* added that it involves people's knowledge, motivation and skills to access, understand, assess and apply health information in order to promote it and prevent disease (World Health Organization, 2013; Almeida et al., 2019).

It is verified that the concept was evolving from an individual perspective to a complementary and integrative perspective of the social component, empowering the individual to an informed and responsible decision-making process of their choices and decisions. It is also an indispensable tool for the individual's ability to exploit health systems and their health care provision (Rodrigues, 2018).

In Portugal, the Action Plan for Health Literacy (2019-2021) aims to keep the person at the center of the intervention, continuously, consciously and with sustainability the level of Health Literacy of the population. However, it is important to improve it in the context of navigation in the National Health Service and the Health System (Arriaga et al., 2019).

Improving the level of health literacy is expected to result in the acquisition of new knowledge, more positive attitudes, greater self-efficacy and positive health behaviours (Despacho nº 5988/2018 de 19 de junho do Gabinete do Secretário de Estado Adjunto e da Saúde. 2018). Thus, it is intended to avoid the low level of literacy of the Portuguese population, since it entails individual

and social costs, and is associated with low educational levels and access to information that cause the decrease of the autonomy of the person (Espanha, Ávila, & Mendes, 2016).

Briefly, to what has already been mentioned, it should be noted that it is essential to train IC, due to the high psychological, physical and social overload. To this end, it is necessary to develop measures that promote empowerment, which support the decrease in the above levels and identify the needs of IC (Konerding et al., 2019). Thus, in the present study, we intend to explore the level of health literacy of these caregivers in the provision of care to a person with AD.

2. METHODS

In order to explore, the level of health literacy of the IC of the person with AD was initiated, an exploratory, descriptive and cross-sectional study was initiated, with a quantitative approach.

2.1 Sample

Of the 28 IC that make up the sample, 75% were female (n=21) and 25% male (n=7), with an average age of 54,04 years ($\pm 12,46$), with a minimum of 24 and maximum 79 years. Regarding the place of residence, 57,1% of the sample resided in the Central Region, 21,4% in Lisbon and Vale do Tejo area and 21,4% in the Northern Region of Portugal. In relation to educational qualifications, 39,3% have higher education, 25% have secondary education and 17,9% the 4th grade. Regarding the professional situation, 46,4% of the caregivers surveyed were employed full-time, 17,9% retired and 17,9% unemployed.

Regarding the degree of kinship, 64,3% were sons, 25% spouses, 3,6% grandchildren, 3,6% nephews and 3,6% had no relationship with the person with AD. In relation to the years to provide care, on average the IC had been there for 4,18 years ($\pm 2,41$) to provide care (minimum 1 year and maximum 10 years) and on average, devote 12 hours ($\pm 8h:09$) during the day and the vast majority (82,1%) assumed this care for 7 days a week.

Of the present sample, 67,9% of the IC reported that they had someone to turn to if they needed help (of which IC, 78,9%, refer to being family) and the remaining 32,1% said they had no one to turn to. It should be noted that 60,7% of caregivers said they did not benefit from any kind of help, however, 39,4% were supported by the home services, day care centre and religious associations.

2.2 Data collection tools

For data collection, we used to complete an *online* questionnaire in *Google Forms* that remained available in the period from January to March 2021. The questionnaire consisted of four parts, the first consisted of the presentation of the study as well as its objectives including free participation in the study, the second part addressed questions about the sociodemographic profile of the IC the third on health literacy and the fourth comprised the Alzheimer's Disease Knowledge Scale (Carpenter, Balsis, Otilingam, Hanson & Gatz, 2009), translated for the Portuguese population by José Monteiro and Tiago Coelho, in 2011. The scale scores were interpreted based on the document made available by the authors.

The dissemination of the questionnaires was made through social networks and various associations in Portugal, such as Alzheimer Portugal and its various delegations.

2.3 Procedures

In order to carry out the study, a favorable decision was obtained from the Ethics Committee of the Polytechnic of Leiria, according to Opinion No. CE/IPLEIRIA/02/2021. The IC was asked to confirm the reading of the informed, free and informed consent. Anonymity, confidentiality of data and the possibility of giving up at any time of the study were guaranteed, and the data collected were only used in the present investigation and were subsequently destroyed at its end.

The use of the Alzheimer's Disease Knowledge Scale (ADKS) was preceded by the authorization by the authors of the Portuguese translation, José Monteiro and Tiago Coelho, in 2011. The statistical treatment of the data was processed in the *software Statistical Package for the Social Sciences*® version 27, emerging the analysis of the use of descriptive statistical measures. It is added the use of *WebQDA software* for counting references and content analysis of the question related to the main difficulties identified by IC, later segmented by four categories, selected by three researchers.

3. RESULTS

The study focused on the application of an electronic questionnaire to the IC of the person with AD, resulting in a sample of 28 participants. The sociodemographic characterization of IC revealed that the majority were female, with an average of 54,04 years ($\pm 12,46$), presenting mostly a degree of kinship with the person cared for. Thus, the motivations that are most evident for the care of the person with AD are affective motivation (78,6%), the traditional family model (35,7%), the individual history, relationship with the dependent person (32,1%) and the willingness to help (14,3%).

Regarding the need to obtain information, 35,7% of the IC mentioned that they resort "many times" to the neurologist; "sometimes", 50% to the family doctor and 35,7% to the Internet, "never", 46,4% to the nurse, 75% to the psychologist, 82,1% to the psychiatrist and 50% to friends.

The IC referred to having difficulties in several areas, which are grouped into 4 categories, as can be seen in the following table:

Table 1 - Difficulties of IC

Categories	Tree Codes	% (n)
Neurobehavioral interactions	Aggressiveness	6,3% (n=2)
	Feeding	3,1% (n=1)
	Personality Changes	3,1% (n=1)
	Cognitive decline	21,9% (n=7)
	Dependency	12,5% (n=4)
Gare of personal and professional life	Personal Organization	15,6% (n=5)
	Time Management	3,1% (n=1)
Uncertainties of personal training	Knowledge of DA	15,6% (n=5)
	Dealing with the DA	9,4% (n=3)
Lack of biopsychosocial support	Medical Follow-up	6,3% (n=2)
	Social Support	6,3% (n=2)

Regarding the needs felt, 67,9% of the IC identified that they had a deficit at the emotional level, 64,3% financial and 35,7% social. Regarding the characterization of the literacy of IC, with regard to the knowledge of the Statute of the Informal Caregiver (Lei 100/2019, 6 de setembro de 2019 - Diário da República), it is possible to observe that 28,6% reported having a very low knowledge, 21,4% low, 25% reasonable, 17,9% high and 7,1% very high. The IC, regarding the assessment of the level of knowledge of the way of providing care, 3,6% identified having a very low level, 7,1% low, 57,1% reasonable, 28,6% high and 3,6% very high.

With regard to the importance of acquiring more information, 92,9% of respondents classified it as very important to deepen their knowledge about the evolution of the disease; 92,9% on how to communicate with the family member; 85,7% learn new ways to deal with difficult behaviors; 82,1% know the limitations of the family member; 71,4% know the support resources that exist; 67,9% know how to adapt the house; and 78,6% know how to manage stress.

When asked about "who they consider useful to obtain information", 89,3% of the IC reported turning to health professionals to acquire information about an accurate diagnosis, 67,9% alternative treatments and 96,4% medication. In the same way that 50% turn to other sources (friends and family) to get emotional support to deal with the situation. Therefore, about practical advice to deal with day-to-day care, 57,1% of IC reported turning to health professionals and other sources.

Table 2. Results of the Alzheimer's Disease Knowledge Scale

Issues	True (% , n)	False (% , n)
1. People with AD are particularly prone to depression.	82,1% (n=23)	17,9% (n=5)
2. Mental exercise can prevent a person from contracting AD.	35,7% (n=10)	64,3% (n=18)
3. After the onset of symptoms of AD, the average life expectancy is 6 to 12 years.	50% (n=14)	50% (n=14)
4. When a person with AD becomes agitated, medical examinations may reveal other health problems as a cause of this agitation.	78,6% (n=22)	21,4% (n=6)
5. People with AD respond better to simple instructions, given one at a time.	100% (n=28)	0% (n=0)
6. When people with AD begin to have difficulty taking care of themselves, caregivers should immediately assume these responsibilities.	50% (n=14)	50% (n=14)
7. If a person with AD starts to get alert and agitated at night, a good strategy is to try to make sure that this person has a lot of physical activity during the day.	50% (n=14)	50% (n=14)
8. In rare cases, there have been people who have recovered from AD.	3,6% (n=1)	96,4% (n=27)
9. People whose AD is not yet in an advanced state may benefit from psychotherapy to treat depression and anxiety.	100% (n=28)	0% (n=0)
10. If memory problems and confused thoughts suddenly arise, this is probably due to.	42,9% (n=12)	57,1% (n=16)
11. Most people with AD live in nursing homes.	60,7% (n=17)	39,3% (n=11)
12. Malnutrition can lead to worsening symptoms of AD.	82,1% (n=23)	17,9% (n=5)
13. People in their 30s may have AD.	67,9% (n=19)	32,1% (n=9)
14. The risk of a person with AD with AD tends to increase with worsening disease.	96,4% (n=27)	3,6% (n=1)
15. When people with AD repeat a question or story multiple times, it is helpful to remind them that they are repeating themselves.	21,4% (n=6)	78,6% (n=22)
16. As soon as people have AD, they are no longer able to make informed decisions about their own care.	39,3% (n=11)	60,7% (n=17)
17. Eventually, a person with AD will need 24-hour surveillance.	92,9% (n=26)	7,1% (n=2)
18. Having high cholesterol can increase a person's risk of contracting AD.	21,4% (n=6)	78,6% (n=22)
19. Shaking or shaking of the hands or arms is a common symptom in people with AD.	42,9% (n=12)	57,1% (n=16)
20. Symptoms of severe depression may be confused with symptoms of AD.	60,7% (n=17)	39,3% (n=11)
21. AD is a type of dementia.	96,4% (n=27)	3,6% (n=1)
22. Difficulties in dealing with money or paying bills is a common initial symptom of AD.	82,1% (n=23)	17,9% (n=5)

Issues	True (% , n)	False (% , n)
23. One symptom that can occur with AD is to think that other people are stealing our stuff.	92,9% (n=26)	7,1% (n=2)
24. When a person has AD, the use of written reminders is a support that can contribute to their decline.	35,7% (n=10)	64,3% (n=18)
25. There are medicines, available on a medical prescription, that prevent AD.	25% (n=7)	75% (n=21)
26. Having high blood pressure can increase the risk of developing AD.	46,4% (n=13)	53,6% (n=15)
27. Genes contribute only partially to the development of AD.	82,1% (n=23)	17,9% (n=5)
28. It is safe for a person with AD to drive, if there is always a companion in the car.	0% (n=0)	100% (n=28)
29. The DA is incurable.	100% (n=28)	0% (n=0)
30. Most people with AD more easily recall recent events than things that have happened in the past.	7,1% (n=2)	92,9% (n=26)

4. DISCUSSION

Considering the results obtained in the present study, it is verified that the sociodemographic profile of IC is in line with that mentioned by Ruiz-Adame Reina, et al., 2017 cit por Costa et al., 2019, since most are women (wives, daughters, granddaughters or nieces), with a variable level of education, employment and socio-economic status. The high number of hours to be cared for provides negligence in self-care, leisure and/or social activities that are in the background, making IC vulnerable to the development of depression, stress and lower quality of life (Bauab & Emmel, 2014).

The main motivations identified by IC are the "affective motivations" and the "traditional family model", since they provide care due to a personal and non-financial relationship (Stall et al., 2019). However, these motivations can influence the caregiver's well-being and the relationship of care, since they are closely linked to the quality of the relationship. Thus, the motivations for care have been associated with the positive meaning that caregivers find in care (Quinn et al., 2019).

It is also important to consider the main difficulties mentioned by the IC, described in Table 1. The "*neurobehavioral changes*" in particular the "*cognitive decline*" and the "*dependence*" stand out; "*management of personal and professional life*" in particular "*personal organisation*"; and in the category "*uncertainties of personal training*", the "*knowledge of the DA*". These difficulties are often narrated in the literature, since with the evolution of the pathology there is a deterioration of the residual capacities of the elderly that lead to the needs of IC strain, learning new ways of dealing with the person cared for, managing time and obtaining new information about AD (Lin, Shih & Ku, 2019).

It is said that 57,14% of IC have an intermediate level, i.e., 3 in the way they provide care, through the analysis of the *Likert* scale. It can be seen that there is a high number of IC that considers the acquisition of more information on the provision of care "*very important*". This is in line with what is based on the Despacho nº 5988/2018, de 19 de junho, which promotes the Literacy and Care Integration Program, through pedagogical campaigns in the media, endorsed with digital repositories with adequate information, accessible to different population groups and literacy levels.

Regarding the sources of information (family doctor, nurse, neurologist, psychologist, psychiatrist, friends and internet), the results suggest that IC consider that the most reliable information is obtained through health professionals. Therefore, and taking into account the state of the art, it is concluded that caregivers are abandoning the role of passive beneficiaries of technical instructions, having an active participation in the learning process and in the establishment of objectives (Almeida et al., 2019).

The application of ADKS in IC is translated into the analysis of their health literacy, which allows the identification of disparities in knowledge about AD, promoting the creation of new health literacy programs.

As can be seen in Table 2, there are four questions answered correctly by all respondents and 18 mostly correct, which suggests a satisfactory level of health literacy in relation to AD. It is added that there are five questions in which respondents have shown to be subdivided on the correct answer.

With regard to the average life expectancy of the person with AD, as mentioned above, it is concluded that it is 8,5 years, on average (Lane, Hardy & Schott, 2018). With regard to IC immediately assuming responsibility for these people, it is important to explain that the diagnosis of the disease does not automatically eliminate the right to autonomy. However, as the disease progresses, the ability may deteriorate and the person is likely to lose his legal capacity to make decisions (Griffiths, Mustasaari & Mäki-Petäjä-Leinonen, 2017).

Regarding the practice of physical exercise, as a strategy to regulate wandering, the literature reports that it can relieve depression and sleep disorders in people with AD. Therefore, physical activity may be an additional treatment to pharmacological treatment to reduce or prevent these symptoms (Veronese, Solmi, Basso, Smith & Soysal, 2019).

Finally, with regard to the symptoms of AD, it is considered that initially there is a progressive deterioration of episodic memory, leading to mild amnesic cognitive impairment, followed by a state of agitation, aggression and psychosis (in advanced stages of the disease)(Lane et al., 2018).

It should be noted that the IC answered predominantly incorrectly 3 questions, which is the number question: 11 "Most people with AD live in nursing homes"; 18 "Having high cholesterol can increase a person's risk of contracting AD"; and 26 "Having hypertension may increase the risk of developing AD". With regard to the first question, it can be noted that it is false, since Struckmeyer & Pickens (2016) claim that the majority of people with AD remain in their homes accompanied by an IC. In relation to the other issues, these address the risk factors of AD, as advocated by Lane et al. (2018) which states that the risk factors of this pathology are also vascular disorders that include hypertension and cholesterol metabolism.

Taking into account the above results it is possible to affirm that a good understanding of the main components of IC health literacy can contribute to the development, evaluation of measures and interventions to provide support in the care of the elderly (Jiang et al., 2018).

Health Literacy should preferably be promoted in the different contexts of people's daily lives, and it is increasingly important to provide tools that facilitate the interpretation of information so that they can make decisions and options consciously (Almeida et al., 2019).

According to the Manual of Good Practices Health Literacy, there are several recommendations for the promotion of health literacy in Portugal, such as reducing the complexity of the health and social care system; and the support of initiatives that improve health literacy, in particular aimed at the most vulnerable groups in Portuguese society (Almeida et al., 2019).

CONCLUSION

Following the importance of exploring the health literacy of the people with AD in Portugal, the need arose to identify the existing difficulties of this population and, consequently, to create literacy programs.

Through the results obtained in the present study, it is concluded that the IC of the person with AD present satisfactory knowledge in relation to AD. Since it was possible to verify that these dominated the knowledge about care, however, they reveal that they have a greater difficulty in understanding about AD, namely risk factors, symptomatology and facilitating strategies to care for the person with AD, as is the case of physical exercise to prevent perambulation.

It should also be noted that the limitations of this study are based on the fact that the dissemination occurred in online format, which substantially reduced the sample, since the dissemination depended on associations in Portugal, such as Alzheimer Portugal and its various delegations. Thus, it is assumed that respondents have a high level of digital literacy or have obtained the support of third parties to complete the questionnaire.

In a few respects, it was possible to see that it is relevant to develop new health literacy programs, which meet the difficulties identified by the IC. Therefore, it is also suggested to carry out further studies in this area, in order to evaluate the impact that the new programs may have on the level of literacy of IC on AD.

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