

Original article

Silva MMAF, Lopes RF, Almeida TG, Silva AF, Silva VN, Leite LKT, et al.

Health Literacy of caregivers of older adults with Alzheimer's disease: a qualitative study.

Rev Gaúcha Enferm. 2026;47:e20260018.

<https://doi.org/10.1590/1983-1447.2026.20260018.en>

Health Literacy of caregivers of older adults with Alzheimer's disease: a qualitative study

Letramento em Saúde de cuidadores de pessoas idosas com doença de Alzheimer:
pesquisa qualitativa

Alfabetización en salud de cuidadores de personas mayores con enfermedad de Alzheimer:
investigación cualitativa

Millena Maria Araújo Feitoza Silva^{a,b} <https://orcid.org/0000-0003-1349-6917>

Raquel Ferreira Lopes^c <https://orcid.org/0000-0002-2061-7038>

Thayse Gomes de Almeida^a <https://orcid.org/0000-0001-8747-023X>

Andrey Ferreira da Silva^a <https://orcid.org/0000-0002-1038-7443>

Vanessa Nunes da Silva^d <https://orcid.org/0009-0009-0757-7367>

Luzia Karoline Teixeira Leite^a <https://orcid.org/0000-0003-0296-7226>

Andreivna Kharenine Serbimm^a <https://orcid.org/0000-0003-4369-9635>

^a Universidade Federal de Alagoas (UFAL), Campus Arapiraca, Arapiraca, Alagoas, Brasil.

^b Universidade Estadual de Ciências da Saúde de Alagoas, Maceió, Alagoas, Brasil.

^c Universidade Federal da Bahia (UFBA), Escola de Enfermagem, Salvador, Bahia, Brasil.

^d Secretaria Municipal de Saúde, Arapiraca, Alagoas, Brasil.

How to cite this article:

Silva MMAF, Lopes RF, Almeida TG, Silva AF, Silva VN, Leite LKT, et al. Health Literacy of caregivers of older adults with Alzheimer's disease: a qualitative study. Rev Gaúcha Enferm. 2026;47:e20260018. <https://doi.org/10.1590/1983-1447.2026.20260018.en>

ABSTRACT

Objective: to understand the health literacy skills experienced by family caregivers of older adults with Alzheimer's disease.

Method: qualitative, exploratory-descriptive study, conducted with 12 family caregivers of older adults with Alzheimer's disease, participants of a support group on social media, in the municipality of Arapiraca, Alagoas. Data collection occurred through semi-structured interviews about seeking, understanding, communicating, and assessing information about the disease. Data were analyzed using thematic analysis.

Results: the caregivers' health literacy was built through autonomous search for information, use of digital sources, and difficulties in translating received guidelines into safe care practices. Communication of information occurred predominantly in family and community networks, while the evaluation of content reliability was found to be fragile

Final considerations: caregivers' health literacy goes beyond access to information and involves the ability to understand, communicate, and critically evaluate it in daily caregiving. The findings support the development of nurse-led educational interventions, the strengthening of digital health literacy, and the implementation of institutional actions to support family caregivers.

Descriptors: Health Literacy; Alzheimer Disease; Aged; Caregivers.

RESUMO

Objetivo: compreender as habilidades de letramento em saúde vivenciadas por cuidadores familiares de pessoas idosas com Doença de Alzheimer.

Método: estudo qualitativo, exploratório-descritivo, realizado com 12 cuidadores familiares de pessoas idosas com Doença de Alzheimer, participantes de um grupo de apoio em mídia social, no município de Arapiraca, Alagoas. A coleta de dados ocorreu por meio de entrevistas semiestruturadas, sobre busca, compreensão, comunicação e avaliação de informações sobre a doença. Os dados foram analisados segundo a Análise Temática.

Resultados: o letramento em saúde dos cuidadores foi construído em meio à busca autônoma por informações, ao uso de fontes digitais e às dificuldades de transformar orientações recebidas em práticas seguras de cuidado. A comunicação das informações ocorreu predominantemente em redes familiares e comunitárias, enquanto a avaliação da confiabilidade dos conteúdos se mostrou fragilizada.

Considerações finais: o letramento em saúde dos cuidadores ultrapassa o acesso à informação e envolve a capacidade de compreendê-la, comunicá-la e avaliá-la criticamente no cotidiano do cuidado. Os achados contribuem para orientar intervenções educativas conduzidas por enfermeiros, fortalecer a alfabetização digital em saúde e subsidiar ações institucionais de apoio aos cuidadores.

Descritores: Letramento em saúde; Doença de Alzheimer; Idoso; Cuidadores.

RESUMEN

Objetivo: comprender las habilidades de alfabetización en salud vivenciadas por cuidadores familiares de personas mayores con enfermedad de Alzheimer.

Método: estudio cualitativo, exploratorio-descriptivo, realizado con 12 cuidadores familiares de personas mayores con enfermedad de Alzheimer, participantes de un grupo de apoyo en redes sociales, en el municipio de Arapiraca, Alagoas. La recolección de datos ocurrió por medio de entrevistas semiestructuradas sobre búsqueda, comprensión, comunicación y evaluación de informaciones sobre la enfermedad. Los datos fueron analizados según el análisis temático.

Resultados: la alfabetización en salud de los cuidadores fue construida en medio de la búsqueda autónoma de informaciones, del uso de fuentes digitales y de las dificultades para transformar orientaciones recibidas en prácticas seguras de cuidado. La comunicación de las informaciones ocurrió predominantemente en redes familiares y comunitarias, mientras que la evaluación de la confiabilidad de los contenidos se mostró fragilizada.

Consideraciones finales: la alfabetización en salud de los cuidadores ultrapasa el acceso a la información e involucra la capacidad de comprenderla, comunicarla y evaluarla críticamente en el cotidiano del cuidado. Los hallazgos respaldan el desarrollo de

intervenciones educativas lideradas por enfermeros, el fortalecimiento de la alfabetización digital en salud y la implementación de acciones institucionales de apoyo a los cuidadores.

Descriptores: Alfabetización en Salud; Enfermedad de Alzheimer; Anciano; Cuidadores.

INTRODUCTION

In Brazil, Noncommunicable Diseases (NCDs) represent the main burden of disease and mortality among the older population and are associated with vulnerabilities arising from the aging process, illness, and dependence. These conditions are significantly related to the loss of functionality, constituting one of the main causes of functional impairment among older adults in most South American countries⁽¹⁾.

Among NCDs, Alzheimer's disease (AD) stands out as one of the main conditions causing disability in later life. It is a progressive neurodegenerative disorder characterized by memory loss and cognitive impairments affecting language, reasoning, visuospatial skills, and behavior, progressively compromising the performance of activities of daily living⁽²⁾. AD is the most common form of dementia, accounting for approximately two-thirds of cases among individuals aged 65 years or older⁽³⁾.

In this context, Health Literacy (HL) emerges as a central element of health care, particularly given the complexity of NCDs and AD. There is a consensus that addressing the HL needs and demands of patients and caregivers is essential to improving adherence, knowledge, understanding, and health-related decision-making⁽⁴⁾. The term, translated from the English "health literacy", refers to the set of cognitive and social skills that enable individuals to access, understand, communicate, and evaluate health-related information, thereby facilitating appropriate decisions and the adoption of behaviors that promote well-being⁽⁵⁾.

Among HL skills, access to information stands out and is defined as the ability to find/search for relevant health information. Understanding health information reflects the ability to comprehend the meaning of health-related information. Communicating health information represents the ability to inform other people (friends, neighbors, and family members) about health-related information. Finally, assessing health information refers to the ability to assess the credibility of health information sources and the merit of the information itself⁽⁵⁾. From this perspective, HL goes beyond the concept of functional literacy, as it incorporates fundamental skills for the management of chronic and degenerative conditions⁽⁶⁾.

In the context of caring for older adults with AD, these skills become even more relevant, considering that progressive cognitive impairment transfers caregiving responsibility to the caregiver, who assumes the role of mediator of health information and therapeutic decisions⁽⁷⁾. Thus, caregivers' HL directly influences their ability to seek appropriate information, interpret professional guidance, assess the reliability of information, and apply it in everyday caregiving.

HL levels in adult populations, particularly in developing countries such as Brazil, is associated with social determinants such as age, education, income, and race, which may intensify health vulnerabilities. Evidence indicates that low levels of HL are associated with poorer outcomes, such as higher mortality, lower treatment adherence, inappropriate use of health services, and more frequent hospitalizations⁽⁸⁾. When these limitations affect caregivers of people with AD, they may result in difficulties in understanding the disease and professional guidance, compromising the quality of care and increasing the risk of inappropriate caregiving practices for older adults.

Despite the importance of the topic, there is a scarcity of national studies specifically addressing the HL of caregivers of older adults with AD. National research have indicated that informal caregivers frequently experience limitations related to accessing and understanding health information, influenced by factors such as low education, low income, and difficulties in using information sources^(9,10). Internationally, studies have also demonstrated unsatisfactory levels of HL among family caregivers of people with dementia, highlighting similar challenges, particularly among older individuals and those with lower levels of education^(11,12).

The relevance of this investigation aligns with the "Health of Older Adults" axis of the National Agenda for Health Research Priorities in Brazil, as well as with the Sustainable Development Goals (SDGs), particularly those related to the promotion of health and well-being⁽¹³⁾. By addressing aspects related to home care, aging, and the strengthening of health literacy of family caregivers, this research considers the strategic role of caregivers in the home setting. Understanding HL skills may contribute to the planning of more effective and equitable interventions, as well as support the development of knowledge and skills that benefit individuals, communities, and society as a whole⁽¹⁴⁾.

Given this context, and recognizing the essential role of caregivers in caring for older adults with AD and the importance of developing HL, the following research question was formulated: how are HL skills (seeking, understanding, communicating, and assessing health information) experienced by family caregivers of older adults with Alzheimer's disease?

Thus, this study aimed to understand the HL skills experienced by family caregivers of older adults with AD.

METHOD

This is an exploratory study with a qualitative approach, conducted in compliance with the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁽¹⁵⁾. The study was conducted in the municipality of Arapiraca, Alagoas, Brazil, with family caregivers of older adults diagnosed with AD who participated in an independent support group mediated through the instant messaging application WhatsApp, called “Alzheimer x Care” (*Alzheimer x Cuidado*).

The group, associated with a nonprofit social project, was established by a health professional with the aim of promoting the sharing of information and experiences related to AD. At the time of the study, the group had approximately 50 caregivers, whether family members or not, and 17 health professionals who provided guidance regarding caregiving.

The main researcher joined the virtual group after authorization from the health professionals responsible for managing the virtual space. Individuals over 18 years of age who served as the primary caregiver of older adults diagnosed with AD in the home care context and who had a family relationship with the older adult were eligible for inclusion. Individuals who received financial compensation for the care provided were excluded. All family caregivers affiliated with the group were invited to participate in the study; however, only 12 met the inclusion criteria and expressed an interest in participating. The number of participants was determined by theoretical saturation of the data, reached when the interviews began to present recurring content and patterns of meaning, without adding new relevant elements to the understanding of the phenomenon under investigation⁽¹⁶⁾. This assessment was conducted by the two researchers responsible for data analysis through successive readings of the transcripts and consensus-based discussion regarding the sufficiency of the empirical material.

Initial contact with the participants was made by telephone, at which time information about the research objectives was provided and the interviews were scheduled. Data collection took place between April and May 2024 through individual interviews conducted at the participants' homes. The interviews were conducted by two researchers: a nurse with a doctoral degree in Nursing and previous experience in qualitative research, and an undergraduate nursing student who had been previously trained for the activity. Although the principal researcher had previously joined the virtual group for purposes of institutional

engagement and access to the field, there was no prior personal, professional, or care-related relationship between the researchers and the participants before data collection began. Throughout the interview process, an empathetic and non-directive listening approach was adopted, minimizing interference in the participants' statements and encouraging the free expression of their experiences.

Before the interviews began, the Informed Consent Form (ICF) was read and signed by the participants. The interviews were guided by a semi-structured interview script comprising sociodemographic questions (age, sex, marital status, education level, family income, occupation, relationship with the older adult, internet access, and use of social media), health-related information (self-reported health status), and aspects related to caring for the older adult with AD (activities performed, difficulties encountered, and type of health care received by the older adult).

Considering the skills related to HL, guiding questions addressing caregivers' experiences in managing information related to AD were used. The following questions were asked: "Have you ever needed or sought information about AD, and the care required older adult?" "Have you ever received guidance about AD?" "Have you ever received guidance about AD that you did not understand?" "Have you shared any information about AD?" "Have you come across any fake news about AD?"

The interviews lasted an average of 30 minutes, were audio-recorded with the participants' authorization, and were subsequently fully transcribed with the assistance of word-processing software. Data analysis was performed according to the Thematic Analysis proposed by Minayo⁽¹⁷⁾, comprising three interdependent stages: pre-analysis, material exploration, and treatment and interpretation of the results.

During the pre-analysis stage, the transcripts were subjected to a floating reading aimed at becoming familiar with the content and constructing the research corpus. Subsequently, during the material exploration stage, the data were coded by identifying significant excerpts related to the study objectives and guiding questions. These excerpts were grouped according to similarities in meaning, allowing the identification of thematic cores related to the caregivers' experiences. This stage involved successive analytical readings to ensure the interpretive fidelity of the data⁽¹⁷⁾.

During the treatment and interpretation of the results stage, the data were analyzed considering the theoretical framework of HL^(5,14) and the care for older adults with AD. Initially, open thematic coding was performed, with the identification of units of meaning related to caregivers' experiences in managing health information.

Subsequently, the codes were grouped according to thematic proximity and discussed between the researchers until interpretive consensus was reached. Although the analysis was theoretically guided by HL skills, interpretive openness was maintained to identify meanings, contradictions, and particularities present in the participants' statements.

The results were organized into four analytical axes related to the skills of seeking, understanding, communicating, and assessing health information, understood as constitutive dimensions of HL in the context of home care for older adults with AD.

The analysis was conducted by two researchers, involving ongoing discussion of codes and interpretations until analytical consensus was achieved. No formal feedback was provided to the participants, nor was methodological triangulation performed, which were considered limitations of the study. Nevertheless, analytical rigor was sought through successive readings of the empirical material, interpretive discussion between the researchers, and continuous integration of the data with the adopted theoretical framework.

The study complied with the ethical principles established in Resolutions No. 466/12 and No. 510/16 of the National Health Council (*Conselho Nacional de Saúde* - CNS). It was approved by the Research Ethics Committee (REC) of the *Universidade Federal de Alagoas* (UFAL), under Opinion No. 6,678,358, CAAE No. 76648423.7.0000.5013. To ensure anonymity and confidentiality of the information, participants were identified by flower names.

RESULTS AND DISCUSSION

Characterization of participants

Twelve family caregivers of older adults with AD, residing in the municipality of Arapiraca, Alagoas, participated in the study. There was a predominance of women (n=10), aged between 23 and 56 years old, with the age group of 51 to 56 years being the most frequent (n=5). This profile reinforces the trend described in the literature that caregiving falls predominantly on middle-aged women, who assume the role of primary caregivers for older family members⁽¹⁸⁾.

Regarding education, most participants had completed higher education (n=9), with an average monthly income of up to BRL 5,000. Despite this socioeconomic profile, the participants' accounts indicated that educational attainment and income do not necessarily guarantee better HL conditions, as access to and understanding of health information remained challenging⁽¹¹⁾.

Regarding marital status, five caregivers were married, five were single, and two were widowed. All lived with the older adult under their care and with at least one other family member, usually children or spouses. The predominant family relationship was that of adult children caring for their older parents (n=8), which represents a typical pattern of intrafamilial caregiving in dementia contexts.

Regarding health conditions, most caregivers (n=7) reported having no comorbidities. However, five reported one or more chronic conditions, such as systemic arterial hypertension (SAH), depression, asthma, generalized anxiety disorder (GAD), and panic disorder. Some participants reported the onset of anxiety and depressive symptoms after beginning continuous caregiving, indicating emotional and physical burden. Nevertheless, self-perceived health status was predominantly positive, being rated as “very good” by eight caregivers and “good” by four.

Daily activities primarily involved assistance with feeding, medication administration, and personal hygiene care. Other activities mentioned included transportation to medical appointments, emotional support, and nighttime supervision, particularly among caregivers who lived with older adults. Only two participants reported previous experience with AD, having previously cared for another family member with a similar diagnosis. All older adults receiving care exclusively used private health services.

The analysis of the statements was organized into four analytical axes corresponding to the HL skills mobilized by caregivers in daily home care: seeking information about AD; understanding information about AD; communicating information about AD; and assessing information about AD.

Seeking information about AD

The statements revealed that the seeking information about AD occurred largely in an autonomous manner and was motivated by practical caregiving needs. However, some caregivers reported that they had not sought information from formal sources about AD because they considered the illness to be a “natural” process of aging.

I never researched it. I take care of my mother, but I first took care of my aunt, who had the same symptoms before my mother did, but I didn't know what it was. I thought it was normal because of her age. People in the old days used to say that someone was becoming senile, right? [...] and so I never researched it. I only noticed the similarity because she started forgetting things, right? Then she didn't remember the house, didn't recognize people, and even called me mother [crying] [...] I only really found out what it was because of the medication. The doctor said it was for

Alzheimer's, and that's when I understood what she had, and that what my aunt had was Alzheimer's too. (Dália)

The statement shows that the lack of accessible information may delay disease recognition and favor interpretations based on common knowledge. In the context of HL, this difficulty involves not only access to information but also the ability to recognize situations that require professional guidance and systematic follow-up.

Conversely, most participants (n=10) reported having sought information about the disease at some point, mainly through the internet and social media, such as YouTube, Instagram, and WhatsApp. The internet was identified as the main source of information, particularly for managing behavioral changes in older adults with Alzheimer's disease.

[...] I am always making an effort to seek information, especially on Instagram. On Instagram, I found a lot of information that I couldn't find anywhere else, including a gentler way of caring for a patient with Alzheimer's. (Tulip)

Yes, I am always looking, because when my mother received the medical diagnosis, I was not given any explanation about the disease. So, I started searching on the internet. (Orchid)

[...] through the internet. When I took my mother to the doctor, the doctor performed the tests and said it was Alzheimer's [...], put me in a group of people who have family members and are caregivers of people with this condition, and from time to time we get some information, which helps a little to understand what the disease does. I also like watching videos on YouTube about the symptoms of the disease and how to deal with them. I like searching and learning something. [...] accessing this information makes me feel more at ease about caring for my mother. (Lily)

I searched online, on Google, for interviews and things like that [...]. (Bromeliad)

The statements indicated that the internet played an important role in building caregivers' knowledge about AD. In this case, the search for digital information is not merely an individual preference but a response to the need to understand concrete caregiving situations, particularly when professional guidance is perceived as insufficient.

This trend of independently seeking information in digital environments was also identified in a study on access to and use of online information related to dementia, in which caregivers reported difficulties associated with inaccessible language, inaccurate content, and limitations in identifying reliable sources⁽¹⁹⁾.

Although the older adults receiving care were followed up in private health services, caregivers reported difficulties related to guidance and educational follow-up regarding AD management, particularly concerning the understanding of symptoms, disease progression, and everyday caregiving strategies.

The search for, understanding, and use of health information constitute core skills for informal caregivers, particularly in the context of dementia. In the absence of continuous professional support, these caregivers assume an active role in caregiving-related decisions, frequently turning to the internet as a source of guidance. However, digital navigation for informational purposes presents important barriers, such as irrelevant content, inappropriate formats, oversimplified or inaccurate information, and the absence of reliable sources, generating uncertainty and hesitation regarding the adoption of the guidance found⁽¹⁹⁾.

Similar results were observed in a study that identified low levels of HL among informal caregivers of older adults with dementia, particularly among spouses and individuals with lower educational attainment, which may compromise communication with health services and increase the risk of inappropriate decisions⁽¹²⁾.

In this study, it was notable that caregivers did not mention seeking guidance from nurses or from reference services in their local area, such as Basic Health Units (BHU). References to health services focused mainly on medical consultations, during which participants reported gaps in explanations about the disease and its management.

Initially, I sought information from the geriatrician and neuropsychiatrist who care for us. They provided some information, but I obtained more information about what I needed to know to care for her through specialized Instagram pages, where they sometimes held lectures, and on YouTube. (Hibiscus)

[...] the doctors themselves, even the geriatrician, they don't have the ability to explain these things, right? So I don't think so. (Orchid)

Although the data do not allow us to conclude that Nursing was absent, they indicate that caregivers did not recognize nurses as a direct source of information in the caregiving process investigated. This finding suggests the need to expand educational and communication strategies in health services, involving the multidisciplinary team and promoting greater access to information that is understandable, contextualized, and useful for home care. Multidisciplinary care, particularly nursing care, is essential for promoting HL, providing effective guidance, coordinating care, and fostering shared responsibility throughout the care process⁽²⁰⁾.

Understanding information about AD

Understanding information proved to be a fragile skill among the participants. Most reported difficulties in understanding the guidance they received, which was considered

nonspecific, confusing, or limited to medication use, thereby restricting their overall understanding of the disease and its everyday management.

Well, I received some information when I first went to the doctor, when we took the MRI scans. It was as if she didn't really tell me that it was Alzheimer's. She said: "Look, can you see this? There are some abnormalities in the brain, as if there were several tiny strokes, and that's it." I was left wondering, not knowing how to ask, because my mother was still oriented. Then, later, I came to understand what it was. I was a little confused; she wasn't direct, and only later did I notice some things related to the symptoms. In addition, information regarding the medications was often confusing. There is the patch that they say doesn't cause as many side effects, but my sister has a friend who used the patch and got worse [...] so we switched the patch to other medications, and many of them really did cause harm [...]. Medication was prescribed for depression and to help her sleep. My mother isn't depressed; I don't know if she really needs it. We who live with her know what she actually needs. (Tulip)

I never received any kind of guidance other than information related to medication. Regarding the medication, I was able to understand things related to the timing of administration, whether it should be taken with food or not, and the importance of giving it every day. But I was not told about the reactions the medication could cause or exactly what it was for. My grandmother becomes very agitated, somewhat aggressive, and it is very difficult to deal with her behavior. Guidance about not contradicting her, which I know makes things worse, for example, I only learned through everyday experience. (Sunflower)

Specifically, no. Only during medical consultations, regarding the medications she needs to take. (Daisy)

Regarding the guidance I received, the geriatrician explained a little about the disease, and some information was easy to understand, while other information was more difficult. Because we don't really have the knowledge of what Alzheimer's is. At first, I thought it would be just a mild form of dementia, that it wouldn't make her lose all the abilities she is losing. But later, through the lectures I watch on YouTube, we began to understand it better.. (Hibiscus)

I used to watch the live streams. When she experienced that "sundowning" issue, I already knew how to respond because I had seen information on the internet about what to do at that time, when the person keeps asking to go home [...] the person comes over, hugs, laughs, kisses, and you should never contradict the person,, [...]. If you don't have knowledge, you can't deal with this disease. You have to look for new things, learn new things, do crossword puzzles, listen to music, read, dance; you must involve many things, everything. It's not just medication. (Orchid)

For me, it was always very confusing, not in terms of the medication, but rather what the disease brings: to be afraid to take a shower or forget that she has already eaten, even when her stomach is full, and I didn't know this, much less how to deal with it. It was always a great frustration for me. (Gerbera)

The statements showed that caregivers' understanding depends not only on the transmission of technical information but also on the possibility of relating such information to situations experienced in everyday care. When guidance is limited to pharmacological

treatment, essential aspects of disease management, such as behavioral changes, communication with the older adult, and the organization of daily routines, remain poorly understood.

Some caregivers reported receiving information from other family members, whereas others reported having received no formal guidance on caregiving.

I did receive guidance, yes. Because of her memory loss, she is afraid to do some basic things, and you need to know how to care for her. So, my sister is always sharing some guidance with me. She searches for information and passes on what the doctor told her during her appointments, and I am able to understand what she tells me and put it into practice in our daily lives. (Bromeliad)

They [mother and sister] were always sharing the information they obtained from YouTube and from the doctor herself, but I never went looking for information about Alzheimer's. (Gardenia)

I was never given guidance on how to care for my mother. And it's not an easy task. She says so many things, gets very stressed and agitated, she hides things in different places and then forgets, and keeps claiming I took them [crying]. (Carnation)

Family mediation emerges in this axis as an important resource for making information more understandable and applicable. However, when such mediation occurs without systematic professional support, there is a risk that incomplete guidance, subjective interpretations, or isolated experiences may become the primary basis for caregiving decisions.

The absence of adequate guidance exposes caregivers to physical and emotional burden, with negative repercussions for their quality of life and the care provided to older adults with Alzheimer's disease. Evidence associates caregiver burden with poorer caregiving outcomes and increased psychological symptoms^(21,22).

These findings align with studies^(23,24) that identified gaps in communication among health professionals, people with dementia, and caregivers, particularly regarding the provision of therapeutic guidance and care coordination, reinforcing the need for patient-centered communication strategies. In this context, nurses play an important role in providing qualified listening, facilitating the understanding of information, and supporting shared decision-making⁽²⁴⁾.

Communicating information about AD

Communication of information about AD was experienced by caregivers primarily within family and community settings. All participants reported sharing information about

AD with other people, mainly family members, coworkers, church members, neighbors, and, to a lesser extent, through social media.

Yes. I've shared it with my siblings. Especially about this care, this greater attention, trying to understand that she is no longer the mother we used to have, right? And that probably she won't be—we can't expect her to be the same as before. [crying] We realize that the tendency is for her to forget, right? (Daisy)

[...] sharing it personally, directly with people, in conversations. Whenever this disease comes up, we always explain what it is, what it involves, how it works, and how to care for the person, with my friends, people from church, and some cousins as well. (Gardenia)

At work, you know? I always make a point of making observations, just commenting on symptoms and certain medications. (Rose)

I share a bit of my daily life with my grandmother among friends and at church, and I also talk a little about dealing with Alzheimer's on social media [...], on Instagram, for example, I sometimes post something or other about her. [...]. (Sunflower)

I shared everything I knew with a family member who also had a problem, like her sister, and with some older people who live near my home as well. I shared information with those who were caregivers, particularly the idea that we should not contradict them. (Hibiscus)

The statements showed that caregivers assume the role of mediators of information about the disease, translating experiences and guidance for other people in their social circles. This communication, however, is not limited to transmitting content; it also involves interpretation, negotiation of meanings, practical guidance, and emotional support among family members and close social networks.

The shared knowledge was limited and acquired empirically through everyday caregiving experiences, although caregivers developed strategies to cope with the difficulties of home care⁽²⁵⁾. The burden associated with prolonged caregiving requires the development of formal and informal support networks capable of mitigating the physical and emotional impacts of continuous caregiving⁽²⁶⁾.

In this specific WhatsApp group for caregivers, right? We share information and our feelings there and talk with people at work or at church who are going through the same situation, and sometimes we exchange information about it. (Lily)

A lot of things about the treatment have improved because I seek a lot of information about the disease and share it with those who care for her with me, so we are already able to manage things better. (Tulip)

Social media have become established as spaces for informational and emotional support, facilitating the exchange of experiences and the development of support communities among caregivers, which may strengthen autonomy and self-efficacy in health-related decisions⁽²⁷⁾. However, communication mediated through these spaces requires critical skills to distinguish personal accounts, professional guidance, and content lacking scientific support.

Assessing information about AD

Assessing information was the most fragile skill demonstrated in the caregivers' statements. Although participants recognized the existence of questionable information about AD, few demonstrated clear criteria for assessing the reliability, quality, and applicability of the content accessed, particularly in digital environments.

It became evident that none of the participants reported clearly identifying fake news related to AD. However, caregivers mentioned receiving questionable information, particularly in digital environments, without necessarily recognizing it as false or misleading.

The statements revealed that content presented as miraculous solutions aroused curiosity and hope, although accompanied by uncertainty and skepticism:

On Instagram, one time, I didn't quite understand it, but I saw an advertisement showing a miraculous food that gets rid of Alzheimer's, even for people who already had Alzheimer's. I realized that, because I search a lot about the subject, a lot of good information comes up, but so does this kind of news. It was a very long video, and I even showed it to my sister, who said: "That's a lie, that doesn't exist" [...], but it was like a miracle, a food that gets rid of Alzheimer's. (Tulip)

Other participants reported mixed feelings toward information widely disseminated on social media, such as alternative therapies, including the use of medical cannabis:

Well, we get all sorts of news, right? Take cannabis, for example. We get our hopes up, but at the same time, we feel frustrated because we can't actually pursue the treatment, it's very expensive, and there's no guarantee it will work. Some people say it's harmful in the long run, while others post only about the benefits. Doctors haven't really explained much about this treatment. (Lily)

On the other hand, some caregivers demonstrated a more skeptical attitude, although without clear criteria for assessing the reliability of the information received:

No, no, they say there are many different treatments and things like that, but I don't really believe it. (Carnation)

Even when they did not explicitly identify fake news, participants recognized the presence of misinformation in everyday caregiving, particularly regarding disease progression and symptom management:

I never actually explicitly identify fake news, but I saw a lot of misinformation from people, caregivers, and family members regarding the symptoms and progression of the disease. Those kinds of things. But I was never aware of any fake news specifically about Alzheimer's. (Hibiscus)

Given the difficulty in assessing the veracity of information, some caregivers relied on empirical observation of the older adult's behavior as their main criterion for validation:

I don't think I have enough in-depth knowledge to say whether it is false or not, but when we receive information, we try to observe the older adult I care for, and then we see whether or not it applies to her, right? (Gardenia)

This finding highlights an important weakness in this HL skill, which involves the ability to assess the quality, reliability, and applicability of health information. Although social media play an increasingly important role in supporting families by enabling the sharing of experiences, information, and resources relevant to health-related decision-making, these same environments also facilitate the dissemination of inaccurate or false content^(5,28).

The circulation of incorrect or incomplete information may directly influence health behaviors, generate false expectations and uncertainty, and lead to inappropriate decisions in the care of older adults with AD⁽²⁹⁾. In this context, the role of health professionals is essential in supporting caregivers in the critical evaluation of health information. Educational strategies should consider individual specificities and employ multiple tools to promote communication, understanding, and the ability to evaluate information received in both digital and in-person settings⁽⁷⁾. Strengthening the capacity for critical analysis of information contributes to safer decision-making, a reduction in risks associated with misinformation, and improved quality of care for both older adults and family caregivers^(30,31).

A limitation of this study is the scarcity and heterogeneity of the available literature on HL among caregivers of older adults with AD, which restricts the diversity of theoretical approaches and may influence the dialogue between the findings with those of other studies. Furthermore, the participant profile, predominantly comprising women with higher

education and access to private health services, may not represent the diversity of family caregivers of older adults with AD.

Furthermore, during the fieldwork, some interviews had to be rescheduled due to unforeseen circumstances involving the caregivers, requiring adjustments to the data collection schedule. This aspect should be considered when interpreting the findings, although it did not compromise an in-depth understanding of the phenomenon investigated.

Despite these limitations, the study demonstrates how family caregivers experience, in the context of everyday home care, the skills of seeking, understanding, communicating, and assessing information about AD, thereby highlighting their specific educational and communication support needs.

FINAL CONSIDERATIONS

The results of this study showed that HL among family caregivers of older adults with AD is developed amid gaps in guidance, autonomous searches for information, recurrent use of digital environments, and family mediation of care. This process reveals that the skills of seeking, understanding, communicating, and assessing information do not occur in isolation but are interconnected in everyday home care and influence caregivers' safety, confidence, and decision-making.

The main contribution of this study is to highlight that the HL challenge faced by these caregivers is not limited to access to information but also involves the ability to interpret guidance, translate information into caregiving practices, and critically assess content available from different sources. In this regard, the findings point to the need for continuous educational strategies using accessible language, contextualized guidance, and spaces for dialogue that consider caregivers' concrete experiences.

For Nursing and health services, the results underscore the importance of strengthening communication and educational practices aimed at family caregivers, particularly in the management of chronic and progressive conditions such as AD. Such practices may contribute to safer use of health information and to the development of more qualified support for home care.

As a limitation, the participant profile may not represent the diversity of family caregivers of older adults with AD. It is recommended that future studies explore different care settings and educational strategies aimed at strengthening HL among family caregivers.

REFERENCES

1. Figueiredo AEB, Ceccon RF, Figueiredo JHC. Chronic non-communicable diseases and their implications in the life of dependente elderly people. *Cien Saúde Colet*. 2021;26(1):77–88. <https://doi.org/10.1590/1413-81232020261.33882020>
2. Kamatham PT, Shukla R, Khatri DK, Vora LK. Pathogenesis, diagnostics, and therapeutics for Alzheimer's disease: breaking the memory barrier. *Ageing Res Rev*. 2024;101:102481. <https://doi.org/10.1016/j.arr.2024.102481>
3. Safiri S, Jolfayi AG, Fazlollahi A, Morsali S, Sarkesh A, Sorkhabi AD, et al. Alzheimer's disease: a comprehensive review of epidemiology, risk factors, symptoms diagnosis, management, caregiving, advanced treatments and associated challenges. *Front Med*. 2024;11:1474043. <https://doi.org/10.3389/fmed.2024.1474043>
4. Nock AM, Metzging S, Jürgensen IN, Petersen-Ewert C. Health literacy in adults with chronic diseases in the context of community health nursing: a scoping review. *Nurs Rep*. 2023;13(2):823-834. <https://doi.org/10.3390/nursrep13020072>
5. Begoray DL, Kwan B. A Canadian exploratory study to define a measure of health literacy. *Health Promot Int*. 2012;27(1):23-32. <https://doi.org/10.1093/heapro/dar015>
6. Peres F. The emancipatory perspective of health literacy in Brazil: contributions from the Freirean thought to knowledge translation regarding a global concept. *Cad Saúde Pública*. 2024;40(11):e00089824. <https://doi.org/10.1590/0102-311XPT089824>
7. Soares TAM, Brasil VV, Moraes KL, Santos LTZ, Vila VDSC, Borges Júnior LH. Health literacy of home caregivers in a Brazilian capital. 2021;34:eAPE002255. <https://doi.org/10.37689/acta-ape/2021AO002255>
8. Shahid R, Shoker M, Chu LM, Frehlick R, Ward H, Pahwa P. Impact of low health literacy on patients' health outcomes: a multicenter cohort study. *BMC Health Serv Res*. 2022;22(1):1148. <https://doi.org/10.1186/s12913-022-08527-9>
9. Serbim AK, Santos NO, Paskulin LMG. Effects of the Alpha-Health intervention on elderly's health literacy in primary health care. *Rev Bras Enferm*. 2022;75(Suppl 4):e20200978. <https://doi.org/10.1590/0034-7167-2020-0978>
10. Ribas KH, Araújo AHIM. [The importance of Health Literacy in Primary Care: integrative literature review]. *Res Soc Dev*. 2021;10(16):e493101624063. <https://doi.org/10.33448/rsd-v10i16.24063> Portuguese
11. Kimzey M, Howe CJ, Martin C, McLarty J, Baucham R. Development of health literacy in persons and caregivers living with dementia: a qualitative directed content analysis. *Dementia*. 2022;21(2):540-555. <https://doi.org/10.1177/14713012211049691>
12. Lorini C, Buscemi P, Mossello E, Schirripa A, Giammarco B, Rigon L, et al. Health literacy of informal caregivers of older adults with dementia: results from a cross-sectional study conducted in Florence (Italy). *Aging Clin Exp Res*. 2022;35(1):61-71. <https://doi.org/10.1007/s40520-022-02271-0>

13. United Nations (UN). Transforming our world: the 2030 agenda for sustainable development[Internet]. 2015 [cited 2026 May 27]. Available from: <https://sdgs.un.org/2030agenda>.
14. Nutbeam D. Health literacy as a public health goal: 25 years on. *Health Promot Int*. 2025;40(4):daaf119. <https://doi.org/10.1093/heapro/daaf119>
15. Souza VRS, Marziale MHP, Silva GTR, Nascimento PL. Translation and validation into Brazilian Portuguese and assessment of the COREQ checklist. *Acta Paul Enferm*. 2021;34:eAPE02631. <https://doi.org/10.37689/acta-ape/2021AO02631>
16. Duarte R. Pesquisa Qualitativa: reflexões sobre o trabalho de campo. *Cad Pesqui*. 2002;115:139-154. <https://doi.org/10.1590/S0100-15742002000100005>.
17. Minayo MCS. Pesquisa Social. Teoria, método e criatividade. Petrópolis: Vozes; 2001. 128p
18. Duangjina T, Jeamjitvibool T, Park C, Raszewski R, Gruss V, Fritschi C. Gender differences in caregiver burden among family caregivers of persons with dementia: a systematic review. *Innov Aging*. 2023;7(Suppl 1):419-420. <https://doi.org/10.1093/geroni/igad104.1386>.
19. Dixon E, Anderson J, Blackwelder DL, Radnofsky M, Lazar A. Barriers to online dementia information and mitigation. In: *Proceedings of the 2022 CHI Conference on human factors in computing systems*. 2022;513:1-14. <https://doi.org/10.1145/3491102.3517554>
20. Costa LSAD, Santos CRID. Challenges faced by the Family Health Team in caring for older adults with Alzheimer's disease and their caregivers. *Rev Bras Geriatr Gerontol*. 2025;28:e240137. <https://doi.org/10.1590/1981-22562025028.240137.pt>
21. Souza MS, Teles MAB, Pinho LD, Rocha JSB, Maia LC, Caldeira AP. Factors associated with impaired quality of life of family caregivers of older adults with dementia. *Rev Bras Geriatr Gerontol*. 2025;28:e240218. <https://doi.org/10.1590/1981-22562025028.240218.pt>
22. Hermes-Pereira A, Goulart M, Kochhann R, Schumacher-Schuh AF. Fatores associados à sobrecarga do cuidador familiar de pacientes com demência. *Dement Neuropsychol*. 2025;19:e20240190. <https://doi.org/10.1590/1980-5764-DN-2024-0190>
23. De Poli C. Explaining the unmet information needs of family carers of people with dementia: a theoretical model of information behaviour. *BMC Geriatrics*. 2025;25:219. <https://doi.org/10.1186/s12877-024-05626-6>
24. Sunjaya AM, Schreiber T, Kantilal K, Davies N, Griffiths S. Communication strategies for delivering personalised dementia care and support: a mixed-methods systematic review and narrative synthesis. *Age Ageing*. 2025;54(5):afaf120. <https://doi.org/10.1093/ageing/afaf120>

25. Silva PVC, Silva CMP, Silveira EAA. Family and the care of older adults with Alzheimer disease: a scoping review. *Esc Anna Nery Rev Enferm.* 2023;27:e20220313. <https://doi.org/10.1590/2177-9465-EAN-2022-0313pt>
26. Dadalto EV, Cavalcante FG. The place of family caregivers for older adults with Alzheimer's disease: a literature review in Brazil and the United States. *Ciênc Saúde Colet.* 2021;26(1):147-157. <https://doi.org/10.1590/1413-81232020261.38482020>
27. Daynes-Kearney R, Gallagher S. Online Support Groups for family caregivers: scoping review. *J Med Internet Res.* 2023;25:e46858. <https://doi.org/10.2196/46858>
28. Maia LFS, Vaz EM. Consequências negativas das notícias falsas na saúde da população. *Rev Recien.* 2023;13(41):949-956. <https://doi.org/10.24276/rrecien2023.13.41.949-956>
29. Korukonda S, Pantula H. The media's influence on the validity of medical information regarding Alzheimer's disease. *J Stud Res [Internet].* 2021[cited 2025 Dec 20];10(2). Available from: https://www.researchgate.net/publication/352907373_The_Media%27s_influence_on_the_validity_of_medical_information_regarding_Alzheimer%27s_Disease
30. Ogbadu-Oladapo, L, Bissadu K, Kim H, Smith DL. Information and health literacy: could there be any impact on health decision-making among adults? evidence from North America. *J Public Health (Berl.).* 2026;34:151-181. <https://doi.org/10.1007/s10389-024-02260-9>
31. Xie L, Zhang S, Xin M, Zhu M, Lu W, Mo PKH. Electronic health literacy and health-related outcomes among older adults: a systematic review. *Prev Med.* 2022;157:106997. <https://doi.org/10.1016/j.ypmed.2022.106997>.

Data and material availability

“Access to the dataset is available upon request from the corresponding author”.

Authorship contribution

Conceptualization - Millena Maria Araújo Feitoza Silva, Andreivna Kharenine Serbimm.

Data curation - Millena Maria Araújo Feitoza Silva, Andreivna Kharenine Serbimm.

Formal analysis - Millena Maria Araújo Feitoza Silva, Andreivna Kharenine Serbimm.

Investigation - Millena Maria Araújo Feitoza Silva, Andreivna Kharenine Serbimm.

Methodology - Millena Maria Araújo Feitoza Silva, Raquel Ferreira Lopes. Thayse Gomes de Almeida. Andrey Ferreira da Silva. Vanessa Nunes da Silva. Luzia Karoline Teixeira Leite. Andreivna Kharenine Serbimm.

Project administration - Andreivna Kharenine Serbimm.

Supervision - Andreivna Kharenine Serbimm.

Writing-original draft - Millena Maria Araújo Feitoza Silva, Raquel Ferreira Lopes. Thayse Gomes de Almeida. Andrey Ferreira da Silva. Vanessa Nunes da Silva. Luzia Karoline Teixeira Leite. Andreivna Kharenine Serbimm.

Writing-review & editing - Millena Maria Araújo Feitoza Silva, Raquel Ferreira Lopes. Thayse Gomes de Almeida. Andrey Ferreira da Silva. Vanessa Nunes da Silva. Luzia Karoline Teixeira Leite. Andreivna Kharenine Serbimm.

Conflict of interest

The authors declare that there is no conflict of interest.

Corresponding author

Raquel Ferreira Lopes

E-mail: raquelloppes@gmail.com

Received: 01.22.2026

Approved: 07.15.2026

Associate editor:

Elen Ferraz Teston

Editor-in-chief:

João Lucas Campos de Oliveira