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ORIGINAL ARTICLE

Difficulties experienced by caregivers of patients with Alzheimer's Disease in relation to dietary care: integrative review

Dificuldades vivenciadas por cuidadores de pacientes com Doença de Alzheimer em relação ao cuidado dietético: revisão integrativa

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KEYWORDS
Alzheimer's Disease
Caregivers
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ABSTRACT

Objective: To analyze the problems experienced by caregivers of patients with Alzheimer's Disease (AD) in dietary care.
Methods: An integrative review was carried out, whose guiding question was "What are the experiences and difficulties reported by caregivers of people with Alzheimer's disease concerning dietary care?". The search occurred in April/2021 in the following databases: MEDLINE, Science Direct, SCOPUS, Web of Science, SciELO, and Lilacs. Publications fromthe last 10 years in English, Portuguese or Spanish were included.
Results: Of the 2,418 articles initially found, the titles of 39 seemed to fit the research objectives. Of these, 11 articles were selected for full reading, and 8 were evaluated to answer the research question. A gap in the approach to the problems experienced by caregivers of patients with AD concerning dietary care was observed. Difficulties dealing with reduced appetite, dysphagia, inability to remember eating, mealtime refusal, and food repulsion were reported. Allied to this, caregiver stress was reported.
Conclusion: The main problems experienced by caregivers of patients with AD involve reduced appetite, dysphagia, difficulty remembering what they have already eaten, refusal at mealtimes, and food repulsion. Thus, the theme deserves the attention and involvement of health professionals to focus on the most frequent difficulties and teach caregivers to overcome them.

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PALAVRAS-CHAVE

Doença de Alzheimer
Cuidadores
Dieta

RESUMO

Objetivo: Analisar os problemas vivenciados por cuidadores de pacientes com Doença de Alzheimer (DA) no cuidado dietético.
Métodos: Foi realizada uma revisão integrativa, cuja pergunta norteadora foi "Quais são as experiências e dificuldades relatadas por cuidadores de pessoas com doença de Alzheimer em relação ao cuidado dietético?". A pesquisa ocorreu em abril/2021, nas bases de dados: MEDLINE, Science Direct, SCOPUS, Web of Science, SciELO e Lilacs. Foram incluídas publicações dos últimos 10 anos, nos idiomas inglês, português ou espanhol.
Resultados: Dos 2.418 artigos inicialmente encontrados, os títulos de 39 pareciam se adequar aos objetivos da pesquisa. Desses, 11 artigos foram selecionados para leitura na íntegra e 8 artigos foram avaliados para responder à pergunta da pesquisa. Observou-se uma lacuna na abordagem dos problemas vivenciados por cuidadores de pacientes com DA em relação ao cuidado dietético. Foram relatadas dificuldades para lidar com a redução do apetite, disfagia, incapacidade de lembrar que realizou as refeições, recusa no momento das refeições e repulsa alimentar. Aliado a isto, foi relatado o estresse do cuidador.
Conclusão: Os principais problemas vivenciados por cuidadores de pacientes portadores de DA são aqueles que envolvem a redução do apetite, disfagia, dificuldade em lembrar que já se alimentou, recusa no momento das refeições e repulsa alimentar. Dessa forma, a temática merece preocupação e envolvimento dos profissionais de saúde no sentido de enfocar as dificuldades mais frequentes e ensinar os cuidadores a contorná-las.

INTRODUCTION

Population aging is a universal phenomenon that has been occurring throughout history but intensified significantly in the 20th century[1]. Studies show that aging is associated with nutritional status and nutrition due to physiological, gastrointestinal, hormonal, sensory, and musculoskeletal changes[2], which can be aggravated by chronic diseases and adverse socioeconomic and family conditions.

With aging, there is an increase in the number of people affected by dementia in general, particularly Alzheimer's disease (AD), considered its most common form in Western European and North American countries[3], representing more than 50% to 75% of dementia cases[4,5]. It is predicted that by 2050 the population of people with AD will reach 152 million people[6].

In Brazil, it is estimated that 77% of individuals with dementia have not been adequately diagnosed[7]. However, Feter et al.[8] reported that in 2016, Brazil had the second highest age-standardized prevalence of dementia in the world, with AD accounting for about 70% of cases.

The Clinical Protocol and Therapeutic Guidelines of the Ministry of Health state that AD is a progressive and fatal neurodegenerative disorder, which manifests itself by cognitive and memory deterioration, progressive impairment of daily living activities, and a variety of neuropsychiatric symptoms and behavioral changes[9]. Thus, the elderly reach total dependence in more advanced stages of the disease, demanding increasingly complex care[10]. AD usually begins insidiously and develops slowly and continuously over several years.

As AD evolves, the need for a caregiver arises. According to Lampert et al.[17], a caregiver is an individual who assists and promotes well-being, health, food, hygiene, education, culture, and leisure to the dependent person. Thus, there are two types of caregivers, the informal and the formal. Informal caregivers are family members, women (spouses or daughters) aged 50 or older, and physically and emotionally close to the elderly person. Formal caregivers, in turn, can be of two types: 1) people who, in addition to the domestic work performed at home, care for dependent elderly people, aiding in their primary activities and even in the administration of medications and specific nursing care, without, however, having any qualification or training for this specific function; and 2) health professionals, especially nursing technicians. Only those families with higher purchasing power, with private health insurance plans, ensure professional assistance with home care teams, which have health professionals as formal caregivers. In this study, when talking about caregivers, we are referring to the concept of greater amplitude, including informal and formal caregivers.

It is noteworthy that approximately 80% of the care of AD patients is performed by family members[11]. In general, these caregivers are women living in the same household as the elderly person, daughters, or spouses, with low education levels and performing daily activities voluntarily[10,12]. In the range of necessary care, nutritional attention stands out because, with increased dependence, the individual loses the ability to feed himself/herself[13].

From this perspective, the caregiver needs to be appropriately oriented to meet the nutritional demands of the individual with AD. A good strategy to design a program to prepare caregivers is to know they experience the most common difficulties. In this sense, this study aims to identify the difficulties reported by caregivers of people with Alzheimer's disease regarding dietary care through an integrative review on the subject.

METHODS

This integrative review discusses the knowledge already built up in previous research. The six stages proposed for this type of study were followed: 1) definition of the subject and selection of the research question; 2) establishment of inclusion and exclusion criteria; 3) identification of pre-selected and selected studies; 4) categorization of the selected studies; 5) analysis and interpretation of results; and 6) presentation of the review/synthesis of knowledge[14,15].

In the first step, the topic was chosen, and the guiding question was defined. Since the theme reports on the problems reported by caregivers in the dietary care of people with AD, the following question was formulated: "what are the difficulties reported by caregivers of people with AD regarding dietary care?"

The formulation of the question was based on the acronym PICO, where P corresponds to the patient or population, I is the intervention or interest, C is the comparison or control, and O is the outcome or result[16]. However, as the objective of the article was to identify the main difficulties reported, item C, referring to comparison and control, was excluded.

In the next step, we defined the descriptors and the databases to be searched. The MEDLINE, Science Direct, SCOPUS, Web of Science, SciELO, and Lilacs databases were used. The search for publications was carried out digitally in April 2021, including publications from the last ten years.

The search strategy was defined as: the combination of the primary descriptors "Alzheimer's", "Caregiver", and "Diet", using the Boolean connector "AND", and the secondary descriptors "Limitations", "Problems", and "Perspective" using the connector "OR". For the selection of descriptors, the search was done in the Descriptors in Health Sciences (DeCS), or its correlates in English language (Medical Subject Headings - MeSH), and its field of application was the title, the abstract, and the keywords or subject. The English language descriptors used for the search were: "(limitations or problems or perspectives) and Alzheimer and caregiver and diet" (Table 1). The search was carried out by two independent researchers who received previous training from the graduate program to which the authors are linked.

All articles that met the research question were included, regardless of the type of study, and that were published in English, Portuguese, and Spanish, in scientific article format, with full text, and available online for free reading and/or download, published in the last ten years. Repeated studies and review articles, regardless of type, were excluded.

The articles were initially selected by reading and sorting by titles and abstracts. A spreadsheet (MS Excel) was used to organize the search and select the articles by databases, aligned by authors' names.

The selected texts were read in full and presented in the form of an analytical chart, with the following items: authorship, journal, country, objective, types of study, sample, results, and conclusion.

RESULTS

Table 1 presents the results of the digital search. One repeated article was found in the MEDLINE database, which was subsequently excluded. Of the eight selected articles (Figure 1), three were published in 2013, one in 2021, one in 2019, one in 2017, one in 2015, and one in 2010. Table 2 summarizes the information regarding each selected article, including author/year of publication, journal, country, objective/type of study, sample, results, and conclusion.

The country that published the most on the topic was England, with four and the most recent publications (from 2017).

The journals with the most publications were Dementia and the American Journal of Alzheimer's Disease & Other Dementias, each with two publications.

It was observed that all articles were qualitative; only one used focus groups, and the others used semi-structured interviews. Regarding the type of caregiver evaluated, only the study by Mole et al.[18] evaluated professional caregivers. The other articles evaluated informal caregivers, usually family members. This is an important fact since the perceived difficulty is different.

The main difficulties reported by the professional caregivers were the restricted time to perform the activities that they believe help the patient to keep his or her mind active and to perform some recreational activity; the presence of pre-established care policies and models, which limits the possibility of initiatives that generate more expressive results; the little knowledge about food and nutritional care in general, which prevents them from making efficient decisions when necessary; and the lack of training to promote effective nutritional care.

Little knowledge and lack of training were also reported among informal caregivers, who, in addition to these, also reported concerns related to lack of experience in the kitchen and lack of time due to the accumulation of domestic activities.

Table 1 — Publications in databases regarding problems related to dietary care experienced by caregivers of people with Alzheimer's disease.

Database	Boolean operators	Total without filter	Filter last ten years	After reading the title and abstract
MEDLINE	(limitations or problems or perspectives) and 'Alzheimer's disease' and caregiver and diet	1,299	1,182	7
Science Direct		488	305	2
SCOPUS		1,142	925	28
Web of Science		8	6	2
SciELO		0	0	0
Lilacs		0	0	0
Total		2,941	2,418	39

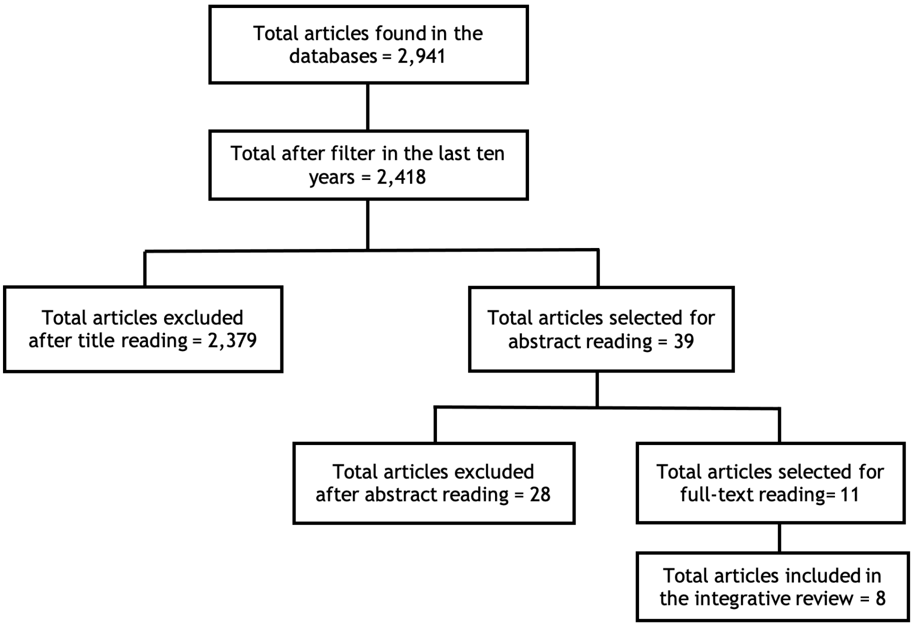

Figure 1 — Selection process of the publications on experiences and difficulties with dietary care experienced by caregivers of people with Alzheimer's disease.

Besides those, many informal caregivers also reported difficulties in the management of the feeding of factors related to the disease progression, such as the change in food preferences and appetite changes, the patients' interference in the act of buying food, change of behavior at the table, generating "socially inappropriate" situations, the difficulty of including the patient in meal-related activities, such as setting the table, reduction of autonomy, increasing the caregiver's dependence and sense of responsibility, and generating forgetfulness of meals in his absence.

Specifically, regarding knowledge, caregivers reported lacking information about an adequate diet for weight maintenance, food's effects on health and dementia, improving memory, for example, and food and nutritional care in general. This lack of knowledge hinders the decision-making process. Finally, they reported a lack of knowledge about written materials with information about dementia and dietary care available for reference.

DISCUSSION

This study allowed the perception of a literary gap in its approach. The eight studies showed that informal caregivers have difficulties in the dietary care of people with AD in aspects that involve, in general, a lack of knowledge, training, and difficulties generated with the progression of the disease.

Although little has been written about dietary care, it is already known that the progression of the disease generates difficulties in general care once the patient starts to resist hygiene care and medication, forget places and people, and develops aggressive aspects. Given this, family caregivers begin to develop strategies to manage the patient. However, daily handling generates physical, mental, and social stress for the caregivers[26].

A review published in 2021 shows that the field of research involving caregivers of patients with AD is still very much focused on describing the difficulties, with little focus on attempts to reduce such suffering[27]. These results suggest the lack of training programs for caregivers of this type of patient. However, there is a demand for caregiver training related to AD. Such demand can be met using information and communication technologies, specifically through the tools that enable voice and/or videos[28].

Regarding the difficulties pointed out by formal caregivers, we can highlight the difficulty in obtaining more expressive results from their care due to the existence of specific policies and guidelines for some approaches, such as pharmacological therapy, which can stiffen the adequacy of care to the reality of each patient. On the other hand, in other approaches, such as diet therapy, there is no guidance at all. This is what happens in Brazil with the Clinical Protocol and Therapeutic Guidelines for Alzheimer's Disease[9], which, for example, mainly mentions pharmacological therapy but does not mention dietary therapy.

Due to this lack of guidance and specific training in nutrition, one of the main problems is malnutrition, becoming a challenge for the caregiver when it comes to caring for the patient with AD. Thus, knowing the significant problems caregivers face will enable the creation of strategies to combat this scenario, to outline training directed to caregivers, maximizing the quality of care.

It is known that malnutrition occurs due to low food intake and that changes in appetite, preferences, and eating habits are also associated with malnutrition[29], as well as difficulties associated with eating and drinking, ranging from resistance to changes in taste to

Table 2 — Summary of publications on difficulties with dietary care experienced by caregivers of people with Alzheimer's disease.

Reference	Journal	Country	Objective/Type of study	Samples	Results/Conclusion
Mole et al., 2021[18]	BMC Geriatrics	England	Objective: To explore the experiences and perceptions of nutritional care for people living with dementia at home from the perspective of health care professionals and home care workers. Type of study: Interpretative Phenomenological Analysis	Health care professionals and home care workers	Difficulties reported: Restriction of time in care to perform the activities that they think help the patient to keep the mind active and perform some activity. The presence of pre-established policies and models of care, for many professionals, arouses tension and frustration, as they prevent these professionals from taking initiatives that generate more expressive results. Another major problem reported was little knowledge about food and nutritional care in general, which prevents them from making efficient decisions when necessary. Lack of training to promote effective nutritional care for their loved ones. In conclusion, it is perceived that healthcare professionals and home care workers need additional training to prepare them better to provide nutritional care for people living with dementia at home and that policies and models of care also need to be adapted to allow for a more flexible and personalized approach to incorporate nutritional care.
Mole et al., 2019[19]	Dementia	England	Objective: To explore and understand the experiences and concerns of family caregivers of people with dementia at home about nutritional care. Type of study: Interpretative Phenomenological Analysis	Family Caregivers	Caregivers expressed difficulty with mealtimes due to changes in the behavior of the family member with dementia, who presents changes in appetite, preferences, and eating habits.
Papachristou et al., 2013[20]	American Journal of Alzheimer's Disease & Other Dementias	England	Objective: To explore the impact of dementia progression on feeding-related processes from the perspective of informal caregivers. Type of study: Qualitative study	Informal Caregivers	Accumulation of activity with disease progression, in which they began to manage all aspects of shopping, including finances, travel, food selection, and payment. Regarding food purchasing, restless behavior and frequent questioning of the patient's choice of products in the market made it difficult for caregivers to perform such a food purchasing task. Lack of knowledge and experience about proper diet, so they maintained a diet like what the person had before dementia. For such caregivers, especially the men, eating ready-to-eat food became more practical and cheaper for the family's daily life. Difficulty in including the patient in activities involving eating, such as setting the table, generates increased responsibility and stress. Another difficulty is the change in food preferences, who start to refuse certain foods, such as carbohydrates, vegetables, and fruits, which worries the caregivers

Table 2 — Summary of publications on difficulties with dietary care experienced by caregivers of people with Alzheimer's disease (cont.).

Reference	Journal	Country	Objective/Type of study	Samples	Results/Conclusion
					about not offering a healthy diet and, consequently, directly affects the body weight of these individuals. Moreover, the problematic behaviors of care recipients during meals, such as misusing cutlery or holding food incorrectly, led to an even more significant increase in caregiver stress. In conclusion, it is perceived that family caregivers feel unsupported and uninformed regarding nutrition-related care for individuals with dementia.
Silva et al., 2013[21]	The Journal of Nutrition, Health & Aging	Canada	Objective: To identify the difficulties encountered by caregivers participating in the Nutrition Intervention Study (NIS) in the dietary management of a family member with Alzheimer's disease and to gather their opinions about the intervention. Type of study: qualitative intervention study Informal caregivers.	Informal Caregivers	The main dietary challenges reported by caregivers were modifications in food preferences and decreased food intake and appetite. In addition, specific problems related to eating practices described by caregivers were decreases in the family member's autonomy and the fact that meals are often forgotten when he is not present. Despite the great interest of some caregivers in participating in nutrition education programs to improve the quality of life of their spouses, lack of time to do so was the most cited limiting factor. Such findings provide important insights for developing nutrition interventions tailored to the needs of older adults with AD and maximizing caregiver satisfaction with nutrition interventions.
Papachristou et al., 2017[22]	Dementia	England	Objective: To investigate the experiences and views of informal caregivers about information related to food and support services in dementia. Type of study: Qualitative study	Informal Caregivers	Many caregivers reported little information about nutrition and diet related to this disease. They also reported a lack of knowledge about written materials available for their reference. Some participants also reported never receiving specific training on performing nutritional care in dementia. As a result, making decisions to avoid and prevent the consequences of dementia, such as memory loss, for example, was more difficult, as they did not know what kind of food was appropriate or how to administer it. Many still cannot concentrate on food-related activities because of the lack of support, which could be temporary services where the patient could go once a week or support with other everyday household tasks.
Fjellström et al., 2010[23]	American Journal of Alzheimer's Disease & Other Dementias	Sweden	Objective: To examine how people living with people with mild to moderate Alzheimer's disease perceive the everyday aspects of food choices, cooking, and work related to	Informal caregivers who live with patients	Most male caregivers were shown to be inexperienced in the kitchen, making it difficult for them to perform their role. Despite some caregivers' experience, working with their spouse in the kitchen or going shopping together became a difficult task.

Table 2 — Summary of publications on difficulties with dietary care experienced by caregivers of people with Alzheimer's disease (cont.).

Reference	Journal	Country	Objective/Type of study	Samples	Results/Conclusion
			food eating and nutritional concerns such as weight loss. Study Type: Qualitative Study		Planning menus and cooking foods that would be acceptable to the sick partner became a daily struggle due to changing food preferences and difficulty in communication. Another concern reported is about the effect of food on their spouses' health, as many knew the importance of healthy foods and weight management and health in this disease, but they could not always manage this correctly. Finally, it is observed that the level of concern is higher in those perceived to be inexperienced, which in this study were the men.
Ball et al., 2015[24]	Nutrition & Dietetics	Australia	Objective: To explore the perceptions of family caregivers of people with dementia, with an emphasis on feeding-related challenges, care burden attributable to nutritional support, and practical strategies developed to address these challenges Type of study: descriptive exploratory qualitative	Family Caregivers	Family caregivers described a range of eating and nutrition challenges they experienced, including physiological, cognitive, emotional, functional, and/or behavioral challenges, e.g., loss of appetite, difficulty swallowing, Aggression, Anger, Difficulty coordinating, and forgetfulness. Most family caregivers reported that they were initially uninformed about expected weight changes related to dementia and received little guidance from healthcare professionals about this and other eating problems associated with dementia. Family caregivers also perceived that there was no training available about nutrition, the needs of people with dementia, or methods to ensure adequate food intake. The cost of nutritional support, such as food supplements, is a significant difficulty. It is perceived that overall, family caregivers feel unsupported and uninformed about nutrition-related care for individuals with dementia and that healthcare professionals need to increase the support and education provided to family caregivers.
Vaingankar et al., 2013[25]	International Psychogeriatrics	Singapura	Objective: To elucidate the perceived unmet needs of informal caregivers of people with dementia in Singapore. Type of study: Qualitative study, using semi-structured interviews and focus group discussions as research tools.	Informal Caregivers	Caregivers reported a need for emotional and social support, diverse information about dementia, financial support and guidance, and accessibility. Specifically, caregivers reported the inability of care centers and nursing homes to cater to the patient's cultural specificities related to food.

reduced appetite[30]. The changes presented leave caregivers with limited food care options, which affect them emotionally, causing anxiety. To deal with these situations, the caregiver must make adaptations and strategies in routine food care situations[16].

For this reason, both people living with dementia and their caregivers, whether family members or not, need guidance, education, and support to assist in daily living activities, planning, and decision-making, which are essential to enable a better life. In addition, they need medical and social services to help organize and deliver care that ensures that both parties, caregivers, and people with dementia, can enjoy a safe, social, and engaged life and that neither suffers emotional, physical, or financial harm[31].

To this end, a sustainable support system must be generated over time that avoids overburdening the caregiver and, consequently, the emergence or worsening of health problems that may prevent them from continuing to care for their family member and, worse, making them a patient as well[12].

The study by de Li et al.[13] demonstrates that access to information or services related to food would help informal caregivers to provide better mealtime care to people living with dementia. However, many caregivers stated that they had not received this information, which can also generate an overload, negatively impacting the quality and ability to prepare meals, affecting the nutritional status of individuals with dementia.

Thus, promoting nutrition education and social support for informal caregivers and patients potentially reduces the pressure caused by eating difficulties and improves the nutritional status of the dementia patient[32].

One way to lessen this burden on the caregiver is to guide the difficulties experienced in caring for the person with AD. A valuable initiative was developed in the United Kingdom through free online courses for caregivers of people with dementia, a category that AD sufferers also fall into, allowing them to learn about the progression of the disease and exchange experiences with other caregivers from different countries. Although the tool was developed for informal caregivers, many professionals accessed the platform, including doctors, nurses, dementia specialists, and people diagnosed with dementia, which promoted a lot of experience exchange among the participants[33].

Initiatives like this can also be developed in Brazil since this study presents the topics that emerged and require educational actions, such as reduced appetite, dysphagia, inability to remember meals, caregiver stress, refusal at mealtimes, and food repulsion. With proper training and support from health professionals, it may be possible to ensure a good nutritional status and improve the quality of life of these patients and the caregiver himself.

Although the contributions of this study are relevant for the health promotion of AD patients, they are limited by the small number of studies. We intended to include publications from the last five years, but it was necessary to increase this period to 10 years to find an approach to the theme that would allow us to draw well-founded conclusions. Even so, the limited focus on the difficulties in dietary care faced by caregivers hinders a comprehensive and profound analysis of the theme, which characterizes the greatest weakness of this research.

CONCLUSION

This integrative review found that there is a gap in addressing the difficulties experienced by caregivers of patients with AD regarding dietary care. The few publications that met the inclusion criteria showed that the theme deserves concern and involvement of health professionals to focus on the most frequent difficulties and teach caregivers to overcome them. It is also evident the need for further research that portrays the caregivers' work routines.

REFERENCES

1. Miranda D, Morais G, Mendes G, Cruz A, Silva A, Lucia A. O envelhecimento populacional brasileiro: desafios e consequências sociais atuais e futuras. Rev Bras Geriatr Gerontol. 2016;19(3):507-19. https://doi.org/10.1590/1809-98232016019.150140
2. An R, Wilms E, Masclee AAM, Smidt H, Zoetendal EG, Jonkers D. Age-dependent changes in GI physiology and microbiota: Time to reconsider? Gut. 2018;67(12):2213-22. https://doi.org/10.1136/gutjnl-2017-315542
3. Rodríguez JL, Herrera RFG. Demencias y enfermedad de Alzheimer en América Latina y el Caribe. *Rev Cubana Salud Pública [Internet]*. 2014 [cited 2022 Aug 4];40(3):378-870. Available from: https://bit.ly/3QoeBTD
4. Nitzsche BO, Moraes HP de, Júnior ART. Alzheimer's disease: Guidelines for diagnosis. Consultant. 2015;38(2):295-6. https://doi.org/10.5935/2238-3182.20150043
5. International AD. Alzheimer's disease [Internet]. Alzheimer's Disease International. 2020 [cited 2020 Nov 30]. Available from: https://bit.ly/3PXMb2J
6. Organização Panamericana de Saúde. Demência: número de pessoas afetadas triplicará nos próximos 30 anos [Internet]. OMS. 2019 [cited 2020 Nov 30]. Available from: https://news.un.org/pt/story/2019/05/1672171
7. De Ferreira-Filho SF, Borelli WV, Sguario RM, Biscaia GF, Müller VS, Vicentini G, et al. Prevalence of dementia and cognitive impairment with no dementia in a primary care setting in southern Brazil. Arq Neuropsiquiatr. 2021;79(7):565-70. https://doi.org/10.1590/0004-282x-anp-2020-0410
8. Feter N, Leite JS, Caputo EL, Cardoso RK, Rombaldi AJ. Who are the people with Alzheimer's Disease in Brazil? Findings from the Brazilian longitudinal study of aging. Rev Bras Epidemiol. 2021;24:e210018. https://doi.org/10.1590/1980-549720210018
9. Brasil. Ministério da Saúde. Portaria conjunta no 13, de 28 novembro de 2017. Aprova o Protocolo Clínico e Diretrizes Terapêuticas da Doença de Alzheimer. Diário Oficial da União [Internet]. Brasília, DF: MS; 2017 [Internet]. Available from: https://bit.ly/3bBQCkS
10. Zabala-Gualtero JM, Cadena-Sanabria MO. Enfermedad de Alzheimer y Síndrome de Carga del Cuidador: la importancia de cuidar al cuidador. Médicas UIS [Internet]. 2018 [cited 2022 Aug 4];31(1):9-13. Available from: https://bit.ly/3vF2oSl
11. Cruz MN, Hamdan AC. Alzheimer Disease: Its impact on the health care nurse. Psicol Estud. 2008;13(2):223-9. https://doi.org/10.1590/S1413-73722008000200004

12. Acuña MR, Doren FM, Romero SC, Rojas CA. Adaptando mi vida: vivencias de cuidadores familiares de personas con enfermedad de Alzheimer. Gerokomos [Internet]. 2018 [cited 2022 Aug 04];29(2):54-8. Available from: https://bit.ly/3zrAeLQ
13. Li Y, Sun D, Zhang X, Li H, Zhao Y, Ma D, et al. Informal dementia caregivers' experiences and perceptions about mealtime care: A qualitative evidence synthesis. J Adv Nurs. 2020;76(12):3317-28. https://doi.org/10.1111/jan.14550
14. Souza MT, Silva MD, Carvalho R. Integrative review: what is it? How to do it? Einstein (São Paulo). 2010;8(1):102-6. https://doi.org/10.1590/s1679-45082010rw1134
15. Botelho LLR, Cunha CCA, Macedo M. O método da revisão integrativa nos estudos organizacionais. Gestão Soc. 2011;5(11):121. https://doi.org/10.21171/ges.v5i11.1220
16. Santos CMDC, Pimenta CADM, Nobre MRC. A estratégia PICO para a construção da pergunta de pesquisa e busca de evidências. Rev Lat Am Enfermagem. 2007;15(3):508-11. https://doi.org/10.1590/S0104-11692007000300023
17. Lampert CDT, Scortegagna SA, Grzybovski D. Dispositivos legais no trabalho de cuidadores: aplicação em instituições de longa permanência. Rev Eletrônica Adm (Porto Alegre). 2016;22(3):360-80. https://doi.org/10.1590/1413-2311.09515.57137
18. Mole L, Kent B, Abbott R, Hickson M. Family carers' experiences of nutritional care for people living with dementia at home: An interpretative phenomenological analysis. Dementia. 2021;20(1):231-46. https://doi.org/10.1177/1471301219872032
19. Mole L, Kent B, Hickson M, Abbott R. It's what you do that makes a difference' An interpretative phenomenological analysis of health care professionals and home care workers experiences of nutritional care for people living with dementia at home. BMC Geriatr. 2019;19(1):250. https://doi.org/10.1186/s12877-019-1270-4
20. Papachristou I, Giatras N, Ussher M. Impact of Dementia Progression on Food-Related Processes: A Qualitative Study of Caregivers’ Perspectives. Am J Alzheimer's Dis Other Dementias. 2013;28(6):568-74. https://doi.org/10.1177/1533317513494456
21. Silva P, Kergoat MJ, Shatenstein B. Challenges in managing the diet of older adults with early-stage Alzheimer dementia: A caregiver perspective. J Nutr Health Aging. 2013;17(2):142-7. https://doi.org/10.1007/s12603-012-0385-5
22. Papachristou I, Hickey G, Iliffe S. Dementia informal caregiver obtaining and engaging in food-related information and support services. Dementia. 2017;16(1):108-18. https://doi.org/10.1177/1471301215583148
23. Fjellström C, Starkenberg Å, Wesslén A, Licentiate MS, Tysén Bäckström A-C, Faxén-Irving G. To be a good food provider: an exploratory study among spouses of persons with Alzheimer's Disease. Am J Alzheimer's Dis Other Dementias. 2010;25(6):521-6. https://doi.org/10.1177/1533317510377171
24. Ball L, Jansen S, Desbrow B, Morgan K, Moyle W, Hughes R. Experiences and nutrition support strategies in dementia care: Lessons from family carers. Nutr Diet. 2015;72(1):22-9. https://doi.org/10.1111/1747-0080.12107
25. Vaingankar JA, Subramaniam M, Picco L, Eng GK, Shafie S, Sambasivam R, et al. Perceived unmet needs of informal caregivers of people with dementia in Singapore. Int Psychogeriatrics. 2013;25(10):1605-19. https://doi.org/10.1017/S1041610213001051
26. Ilha S, Backes DS, Santos SSC, Gautério-Abreu DP, Silva BT, Pelzer MT. Alzheimer's disease in elderly/family: Difficulties experienced and care strategies. Esc Anna Nery - Rev Enferm. 2016;20(1):138-46. https://doi.org/10.5935/1414-8145.20160019
27. 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. Cienc Saude Coletiva. 2021;26(1):147-57. https://doi.org/10.1590/1413-81232020261.38482020
28. Gomes CGS, Silveira AD, Estrela LPCB, Figueiredo ALB, Oliveira AQ, Oliveira IM. Efeitos do uso de tecnologias da informação e comunicação na capacitação de cuidadores de crianças com autismo. Rev Bras Educ Esp. 2021;27:285-300. https://doi.org/10.1590/1980-54702021v27e0085
29. Ball L, Jansen S, Desbrow B, Morgan K, Moyle W, Hughes R. Experiences and nutrition support strategies in dementia care: Lessons from family carers. Nutr Diet. 2015;72(1):22-9. https://doi.org/10.1111/1747-0080.12107
30. Cao L, Tan L, Wang HF, Jiang T, Zhu XC, Lu H, et al. Dietary patterns and risk of dementia: a systematic review and meta-analysis of cohort studies. Mol Neurobiol. 2016;53(9):6144-54. https://doi.org/10.1007/s12035-015-9516-4
31. Nacional Academies of Sciences, Engineering and Medicine. Larson EB, Stroud C, editors. Meeting the challenge of caring for persons living with dementia and their care partners and caregivers: a way forward. Washington, DC: The National Academies Press; 2021. https://doi.org/10.17226/26026
32. Molassiotis A, Roberts S, Cheng HL, To HKF, Ko PS, Lam W, et al. Partnering with families to promote nutrition in cancer care: Feasibility and acceptability of the PIcNIC intervention. BMC Palliat Care. 2018;17(1):50. https://doi.org/10.1186/s12904-018-0306-4
33. Poole M, Davis N, Robinson L. Massive open online courses: Enhancing caregiver education and support about dementia care towards and at end of life. Age Ageing. 2020;49(2):171-4. https://doi.org/10.1093/ageing/afz150

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