



# Family and the care of older adults with Alzheimer disease: a scoping review

*A família e o cuidado de pessoas idosas com doença de Alzheimer: revisão de escopo*

*A familia e o cuidado del anciano con enfermedad de Alzheimer: revisión de escopo*

Pedro Victor de Carvalho Silva<sup>1</sup>

Caléo Moisés Pinto da Silva<sup>1</sup>

Edilene Aparecida Araujo da Silveira<sup>1</sup>

1. Universidade Federal de São João del-Rei.

Divinópolis, MG, Brasil.

## ABSTRACT

**Objective:** to identify scientific evidence, in the context of the home, available on family care to elderly people with Alzheimer's disease. **Method:** this is a scoping review according to JBI®, through a search strategy in the PubMed, Embase, Cochrane, CINAHL, Web of Science, LILACS and BDNF databases. The analysis of the identified material was performed by three independent reviewers. The extracted data were analyzed and synthesized in a narrative way. **Results:** of the 1,546 studies found, 17 were kept for review and their content was summarized and divided into ten types of care: 1) Protection and supervision; 2) Hygiene and comfort; 3) Food and hydration; 4) Social and leisure; 5) Oral hygiene; 6) Drug treatment; 7) Communication; 8) Independence; 9) Cognitive exercises; and 10) Pressure injury prevention. **Conclusion and implications for practice:** there is a lack of studies on the actions carried out by family caregivers and, especially, research on interventions. Care is performed empirically and without professional guidance. It is necessary to invest in research and training for family caregivers.

**Keywords:** Family; Caregivers; Housing; Alzheimer Disease; Aged.

## RESUMO

**Objetivo:** identificar e mapear evidências científicas, no contexto do domicílio, disponíveis sobre cuidado familiar de pessoas idosas com doença de Alzheimer. **Método:** trata-se de uma revisão de escopo, conforme JBI®, por meio de uma estratégia de busca nas bases de dados PubMed, Embase, Cochrane, CINAHL, *Web of Science*, LILACS e BDNF. A análise do material identificado foi realizada por três revisores independentes. Os dados extraídos foram analisados e sintetizados de forma narrativa. **Resultados:** dos 1.546 estudos encontrados, 17 foram mantidos para revisão e seu conteúdo foi resumido e dividido em dez tipos de cuidados: 1) Proteção e supervisão; 2) Higiene e conforto; 3) Alimentação e hidratação; 4) Social e lazer; 5) Higiene bucal; 6) Tratamento medicamentoso; 7) Comunicação; 8) Independência; 9) Exercícios cognitivos; e 10) Prevenção de lesões por pressão. **Conclusão e implicações para a prática:** há carência de estudos sobre as ações realizadas pelos cuidadores familiares e, principalmente, faltam pesquisas com intervenções. Os cuidados são realizados de maneira empírica e sem orientação profissional. É preciso investir em pesquisas e suporte para os cuidadores familiares.

**Palavras-chave:** Família; Cuidadores; Habitação; Doença de Alzheimer; Idoso.

## RESUMEN

**Objetivo:** identificar y mapear evidencias científicas, en el contexto del hogar, disponibles sobre el cuidado familiar de los ancianos con Alzheimer. **Método:** se trata de una revisión de alcance según el JBI®, a través de una estrategia de búsqueda en las bases de datos PubMed, Embase, Cochrane, CINAHL, *Web of Science*, LILACS y BDNF. El análisis del material identificado fue realizado por tres revisores independientes. Los datos extraídos fueron analizados y sintetizados de forma narrativa. **Resultados:** de los 1.546 estudios encontrados, 17 fueron guardados para revisión y su contenido fue resumido y dividido en diez tipos de cuidado: 1) Protección y supervisión; 2) Higiene y comodidad; 3) Alimentación e hidratación; 4) Social y ocio; 5) Higiene bucal; 6) Tratamiento de drogas; 7) Comunicación; 8) Independencia; 9) Ejercicios cognitivos; y 10) Prevención de lesiones por presión. **Conclusión e implicaciones para la práctica:** faltan estudios sobre las acciones realizadas por los cuidadores familiares e, especialmente, investigaciones sobre intervenciones. La atención se realiza de forma empírica y sin orientación profesional. Es necesario invertir en investigación y formación para los cuidadores familiares.

**Palabras clave:** Familia; Cuidadores; Vivienda; Enfermedad de Alzheimer; Anciano.

### Corresponding author:

Edilene Aparecida Araujo da Silveira.

E-mail: edileneap@ufsj.edu.br

Submitted on 08/24/2022.

Accepted on 03/22/2023.

DOI: <https://doi.org/10.1590/2177-9465-EAN-2022-0313en>

## INTRODUCTION

The growth of the older adult population is a worldwide phenomenon and in Brazil this process happens at a vertiginous and accelerated pace. The inversion in the age pyramid occurs due to the increase in life expectancy and the decrease in the birth rate, which causes the number of older adults to increase proportionally. In 1950, 8% of people living in the world were over 60 years old. This percentage increases in 2020 to 13%. The Brazilian population in 1950 consisted of 2.6 million people and, of these, 4.9% were over 60 years old. There was an increase to 14% in 2020.<sup>1,2</sup>

The increase in the older adult population brings several challenges to public health, as it requires services not only to control disease, but also to prevent and promote active and healthy aging. In this age group, there is a higher incidence of cases of chronic non-communicable diseases (NCDs) as well as the consequent increase in the number of hospitalizations and institutionalization that can result in a decrease in functional capacity. Among the NCDs related to aging, there are dementias, which stand out as the main causes of functional impairment and quality of life of older adults.<sup>3</sup>

Currently, it is estimated that there are about 46.8 million people with dementia in the world, according to data provided by the 2015 Report of the International Alzheimer Association. Alzheimer's disease (AD) is the most common etiology among dementias and tends to intensify with population aging.<sup>4</sup>

AD is a progressive neurodegenerative disorder characterized by cognitive and memory deterioration, behavioral changes and a variety of neuropsychiatric symptoms, which cause changes in behavior in older people. Because it affects memory and cognitive functions, this neurodegenerative disease implies the need for individuals affected by the disease to include caregivers to assist them in activities of daily living (ADL) and instrumental activities of daily living (IADL), in addition to performing supervision constant.<sup>5</sup>

Informal caregivers are people close to patients (family, friends or neighbors), who most often provide care voluntarily, motivated by feelings of obligation, retribution, dependence, love or for not being able to pay a formal caregiver.<sup>6</sup> Studies reveal that care is mostly performed by female spouses, who are also older adults and claim to be overloaded with activities.<sup>7,8</sup>

The lack of discernment on the part of caregivers in relation to the real level of assistance needed is also a barrier to carrying out care, since sometimes older adults is able to perform some tasks alone; however, the fear and feeling of neglect of care make caregivers perform the task with older adults or do it for them.<sup>9</sup> A study carried out in Maranhão shows that caregivers do not receive any kind of formal guidance to perform care and that the necessary skills are acquired in practice while living with older adults.<sup>10</sup>

Considering the complexity of home care, it is necessary to carry out actions aimed at caregivers, such as providing information about dementia, managing its symptoms and

consequences and, especially, the specific care needed in all stages of the disease.<sup>2</sup> Therefore, the question emerged: what scientific evidence, in the context of housing, is available on family care related to older adults with AD? When we previously performed a PubMed search, we did not find any reviews related to the types of care that caregivers perform. The relevance of this study lies in providing a mapping of the main care provided by family caregivers, in the home environment, to older adults with AD in order to provide subsidies to assist professionals in the development of educational activities that help caregivers during living with the consequences of pathology.

Thus, this study aimed to identify and map scientific evidence, in the home context, available on family care for older adults with AD.

## METHOD

This is a scoping review with a research protocol registered in the Open Science Framework (<https://osf.io/5FJUM>), developed based on the recommendations of PRISMA-ScR<sup>11</sup> and the method proposed by the JBI<sup>®</sup> Manual 2020,<sup>12</sup> which establishes five stages, namely: 1) research question identification; 2) identification of relevant studies; 3) study selection; 4) data analysis; and 5) data grouping, synthesis and presentation.

This modality of review is a type of knowledge synthesis that follows a systematic approach to map evidence on a topic and identify key concepts, theories, sources and knowledge gaps.<sup>12</sup> The phases of identifying the research question and relevant studies were supported by a librarian and Rayyan software.

The Participants, Concept and Context (PCC) strategy was used to construct the research question, in which P (participants) – Caregivers, C (concept) – AD and C (context) – Housing. Thus, the established research question was: what scientific evidence, in the context of housing, is available on family care for older adults with AD? Initially, a search was carried out in the PubMed database in order to identify the most frequent descriptors and keywords in studies that addressed the topic of interest.

The strategy adopted was the search for studies using Boolean operators and is described in Chart 1.

The search strategy was adapted according to the specificities of each database, and the similar combination of descriptors was maintained.

Articles published with full texts or abstracts available online in selected databases, in Portuguese, Spanish and/or English, with no time limit and that addressed home care provided by family caregivers related to older adults with AD were included. Articles that did not contemplate the guiding question, editorials, experience reports, scientific communication, reviews, letters, theoretical essays and single case studies were excluded. In this scoping review, we will not consider the gray literature, although we recognize its importance. Registered literature, such as the DOI, undergoes expert evaluators and is governed by systematic methodological rigor.

**Chart 1.** Distribution of search strategies according to databases.

Database	Search
<b>PubMed</b>	(("Alzheimer Disease"[Mesh]) OR ("Alzheimer Disease"[Title/Abstract] OR "Alzheimer Dementia"[Title/Abstract] OR "Alzheimer Dementias"[Title/Abstract] OR "Alzheimer Diseases"[Title/Abstract] OR "Alzheimer Syndrome"[Title/Abstract] OR "Alzheimer Type Dementia"[Title/Abstract] OR "Alzheimer Type Dementia"[Title/Abstract] OR "Alzheimer Type Senile Dementia"[Title/Abstract] OR "Alzheimer's Disease"[Title/Abstract] OR "Alzheimer's Diseases"[Title/Abstract] OR "Alzheimer-Type Dementia"[Title/Abstract] OR "Alzheimers Diseases"[Title/Abstract] OR "Early Onset Alzheimer Disease"[Title/Abstract] OR "Familial Alzheimer Disease"[Title/Abstract] OR "Familial Alzheimer Diseases"[Title/Abstract] OR "Late Onset Alzheimer Disease"[Title/Abstract] OR "Presenile Alzheimer Dementia"[Title/Abstract] OR "Presenile Dementia"[Title/Abstract])) AND ((((((("Home Nursing"[Mesh]) OR ("Home Nursing"[Title/Abstract] OR "Nonprofessional Home Care"[Title/Abstract] OR "Non-Professional Home Care"[Title/Abstract])) OR ("Health Services for the Aged"[Mesh])) OR ("Geriatric Health Services"[Title/Abstract] OR "Health Services for the Elderly"[Title/Abstract] OR "Geriatric Health Service"[Title/Abstract] OR "Health Services for Aged"[Title/Abstract])) OR ("Health Knowledge, Attitudes, Practice"[Mesh])) OR ("Health Knowledge, Attitudes, Practice"[Title/Abstract])) OR ("Home Health"[Title/Abstract] OR "Home care"[Title/Abstract] OR "Patient Care"[Title/Abstract]))
<b>Cochrane</b>	("Doença de Alzheimer" OR "Alzheimer de Início Tardio" OR "Alzheimer Precoce" OR "Alzheimer Tardio" OR "Demência de Alzheimer" OR "Demência Pré-Senil" OR "Demência Pré-Senil Tipo Alzheimer" OR "Demência Senil" OR "Demência Senil com Estado Confusional Agudo" OR "Demência Senil Tipo Alzheimer" OR "Demência Tipo Alzheimer" OR "Doença de Alzheimer de Início Focal" OR "Doença de Alzheimer de Início Precoce" OR "Doença de Alzheimer de Início Tardio" OR "Doença de Alzheimer Familiar" OR "Doenças de Alzheimer" OR "Mal de Alzheimer" OR "Alzheimer Disease" OR "Acute Confusional Senile Dementia" OR "Alzheimer Dementia" OR "Alzheimer Dementias" OR "Alzheimer Diseases" OR "Alzheimer Sclerosis" OR "Alzheimer Syndrome" OR "Alzheimer Type Dementia" OR "Alzheimer Type Dementia" OR "Alzheimer Type Senile Dementia" OR "Alzheimer's Disease" OR "Alzheimer's Diseases" OR "Alzheimer-Type Dementia" OR "Alzheimers Diseases" OR "Early Onset Alzheimer Disease" OR "Familial Alzheimer Disease" OR "Familial Alzheimer Diseases" OR "Focal Onset Alzheimer's Disease" OR "Late Onset Alzheimer Disease" OR "Presenile Alzheimer Dementia" OR "Presenile Dementia" OR "Primary Senile Degenerative Dementia" OR "Enfermedad de Alzheimer" OR "Demencia de Alzheimer" OR "Demencia Presenil de Alzheimer" OR "Demencia Senil" OR "Demencia Senil Aguda Confusa" OR "Demencia Senil Tipo Alzheimer" OR "Demencia Tipo Alzheimer" OR "Enfermedades de Alzheimer" OR "Mal de Alzheimer") AND (Cuidadores OR "Cônjuges Cuidadores" OR Cuidador OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores Cônjuges" OR "Cuidadores de Família" OR "Cuidadores Familiares" OR "Familiar Cuidador" OR "Familiares Cuidadores" OR "Family Caregiver" OR "Family Caregivers" OR "Spouse Caregiver" OR "Spouse Caregivers" OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores de Esposos" OR "Cuidadores de Família" OR "Cuidadores Familiares" OR "Familiar Cuidador" OR "Familiares Cuidadores") AND ("Assistência Domiciliar" OR "Assistência Domiciliar aos Idosos" OR "Assistência Domiciliar por não Profissionais de Saúde" OR "Assistência Domiciliária" OR "Cuidados Domiciliares de Saúde" OR "Home Nursing" OR "Non-Professional Home Care" OR "Nonprofessional Home Care" OR "Atención Domiciliaria de Salud" OR "Asistencia Domiciliaria de Salud" OR "Atención no Profesional en Domicilio" OR "Cuidados Domiciliarios de Salud" OR "Informal care" OR "Informal cares" OR "Atención al Paciente" OR "Saúde do Idoso" OR "Saúde da Pessoa Idosa" OR "Saúde da Terceira Idade" OR "Health of the Elderly" OR "Aging Health" OR "Elderly Health" OR "Health of Aged Persons" OR "Health of Elders" OR "Health of the Aged" OR "Salud del Anciano" OR "Salud de la Persona Anciana" OR "Salud de la Persona Mayor" OR "Salud de la Tercera Edad" OR "Home Health" OR "Saúde domiciliar" OR "Home care" OR "Cuidados domiciliares" OR "Conhecimentos, Atitudes e Prática em Saúde" OR "Atitudes e Prática em Saúde" OR "Atitudes e Práticas em Saúde" OR "Conhecimentos, Atitudes e Práticas em Saúde" OR "Health Knowledge, Attitudes, Practice" OR "Knowledge, Attitudes, Practice" OR "Conocimientos, Actitudes y Práctica en Salud" OR "Conocimientos, Actitudes y Práctica Sanitarias" OR "Conocimientos, Actitudes y Práticas en Salud")

Source: Scoping Consultancy Librarian in health, 2022.

Chart 1. Continued...

Database	Search
<p><b>Web of Science, EMBASE</b></p>	<p>("Doença de Alzheimer" OR "Doenças de Alzheimer" OR "Mal de Alzheimer" OR "Alzheimer Disease" OR "Alzheimer-Type Dementia" OR "Demencia Tipo Alzheimer" OR "Enfermedades de Alzheimer" OR "Mal de Alzheimer") AND (Cuidadores OR "Cônjuges Cuidadores" OR Cuidador OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores Cônjuges" OR "Cuidadores de Família" OR "Cuidadores Familiares" OR "Familiar Cuidador" OR "Familiares Cuidadores" OR "Family Caregiver" OR "Family Caregivers" OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores de Esposos" OR "Cuidadores de Família" OR "Cuidadores Familiares" OR "Familiar Cuidador" OR "Familiares Cuidadores") AND ("Assistência Domiciliar" OR "Assistência Domiciliar aos Idosos" OR "Assistência Domiciliar por não Profissionais de Saúde" OR "Assistência Domiciliária" OR "Cuidados Domiciliares de Saúde" OR "Home Nursing" OR "Non-Professional Home Care" OR "Nonprofessional Home Care" OR "Atención Domiciliaria de Salud" OR "Asistencia Domiciliaria de Salud" OR "Atención no Profesional en Domicilio" OR "Cuidados Domiciliarios de Salud" OR "Informal care" OR "Informal cares" OR "Atención al Paciente" OR "Saúde do Idoso" OR "Saúde da Pessoa Idosa" OR "Saúde da Terceira Idade" OR "Health of the Elderly" OR "Aging Health" OR "Elderly Health" OR "Health of Aged Persons" OR "Health of Elders" OR "Health of the Aged" OR "Salud del Anciano" OR "Salud de la Persona Anciana" OR "Salud de la Persona Mayor" OR "Salud de la Tercera Edad" OR "Home Health" OR "Saúde domiciliar" OR "Home care" OR "Cuidados domiciliares" OR "Conhecimentos, Atitudes e Prática em Saúde" OR "Atitudes e Prática em Saúde" OR "Atitudes e Práticas em Saúde" OR "Conhecimentos, Atitudes e Práticas em Saúde" OR "Health Knowledge, Attitudes, Practice" OR "Knowledge, Attitudes, Practice" OR "Conocimientos, Actitudes y Práctica en Salud" OR "Conocimientos, Actitudes y Práctica Sanitarias" OR "Conocimientos, Actitudes y Prácticas en Salud")</p>
<p><b>CINAHL</b></p>	<p>("Doença de Alzheimer" OR "Alzheimer de Início Tardio" OR "Alzheimer Precoce" OR "Alzheimer Tardio" OR "Demência de Alzheimer" OR "Demência Pré-Senil" OR "Demência Pré-Senil Tipo Alzheimer" OR "Demência Senil" OR "Demência Senil com Estado Confusional Agudo" OR "Demência Senil Tipo Alzheimer" OR "Demência Tipo Alzheimer" OR "Doença de Alzheimer de Início Focal" OR "Doença de Alzheimer de Início Precoce" OR "Doença de Alzheimer de Início Tardio" OR "Doença de Alzheimer Familiar" OR "Doenças de Alzheimer" OR "Mal de Alzheimer" OR "Alzheimer Disease" OR "Acute Confusional Senile Dementia" OR "Alzheimer Dementia" OR "Alzheimer Dementias" OR "Alzheimer Diseases" OR "Alzheimer Sclerosis" OR "Alzheimer Syndrome" OR "Alzheimer Type Dementia" OR "Alzheimer Type Dementia" OR "Alzheimer Type Senile Dementia" OR "Alzheimer's Disease" OR "Alzheimer's Diseases" OR "Alzheimer-Type Dementia" OR "Alzheimers Diseases" OR "Early Onset Alzheimer Disease" OR "Familial Alzheimer Disease" OR "Familial Alzheimer Diseases" OR "Focal Onset Alzheimer's Disease" OR "Late Onset Alzheimer Disease" OR "Presenile Alzheimer Dementia" OR "Presenile Dementia" OR "Primary Senile Degenerative Dementia" OR "Enfermedad de Alzheimer" OR "Demencia de Alzheimer" OR "Demencia Presenil de Alzheimer" OR "Demencia Senil" OR "Demencia Senil Aguda Confusa" OR "Demencia Senil Tipo Alzheimer" OR "Demencia Tipo Alzheimer" OR "Enfermedades de Alzheimer" OR "Mal de Alzheimer") AND (Cuidadores OR "Cônjuges Cuidadores" OR Cuidador OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores Cônjuges" OR "Cuidadores de Família" OR "Cuidadores Familiares" OR "Familiar Cuidador" OR "Familiares Cuidadores" OR "Family Caregiver" OR "Family Caregivers" OR "Spouse Caregiver" OR "Spouse Caregivers" OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores de Esposos" OR "Cuidadores de Família" OR "Cuidadores Familiares" OR "Familiar Cuidador" OR "Familiares Cuidadores") AND ("Assistência Domiciliar" OR "Assistência Domiciliar aos Idosos" OR "Assistência Domiciliar por não Profissionais de Saúde" OR "Assistência Domiciliária" OR "Cuidados Domiciliares de Saúde" OR "Home Nursing" OR "Non-Professional Home Care" OR "Nonprofessional Home Care" OR "Atención Domiciliaria de Salud" OR "Asistencia Domiciliaria de Salud" OR "Atención no Profesional en Domicilio" OR "Cuidados Domiciliarios de Salud" OR "Informal care" OR "Informal cares" OR "Atención al Paciente" OR "Saúde do Idoso" OR "Saúde da Pessoa Idosa" OR "Saúde da Terceira Idade" OR "Health of the Elderly" OR "Aging Health" OR "Elderly Health" OR "Health of Aged Persons" OR "Health of Elders" OR "Health of the Aged" OR "Salud del Anciano" OR "Salud de la Persona Anciana" OR "Salud de la Persona Mayor" OR "Salud de la Tercera Edad" OR "Home Health" OR "Saúde domiciliar" OR "Home care" OR "Cuidados domiciliares" OR "Conhecimentos, Atitudes e Prática em Saúde" OR "Atitudes e Prática em Saúde" OR "Atitudes e Práticas em Saúde" OR "Conhecimentos, Atitudes e Práticas em Saúde" OR "Health Knowledge, Attitudes, Practice" OR "Knowledge, Attitudes, Practice" OR "Conocimientos, Actitudes y Práctica en Salud" OR "Conocimientos, Actitudes y Práctica Sanitarias" OR "Conocimientos, Actitudes y Prácticas en Salud")</p>

Source: Scoping Consultancy Librarian in health, 2022.

Chart 1. Continued...

Database	Search
LILACS, BDEFN	<p>(“Doença de Alzheimer” OR “Alzheimer de Início Tardio” OR “Alzheimer Precoce” OR “Alzheimer Tardio” OR “Demência de Alzheimer” OR “Demência Pré-Senil” OR “Demência Pré-Senil Tipo Alzheimer” OR “Demência Senil” OR “Demência Senil com Estado Confusional Agudo” OR “Demência Senil Tipo Alzheimer” OR “Demência Tipo Alzheimer” OR “Doença de Alzheimer de Início Focal” OR “Doença de Alzheimer de Início Precoce” OR “Doença de Alzheimer de Início Tardio” OR “Doença de Alzheimer Familiar” OR “Doenças de Alzheimer” OR “Mal de Alzheimer” OR “Alzheimer Disease” OR “Acute Confusional Senile Dementia” OR “Alzheimer Dementia” OR “Alzheimer Dementias” OR “Alzheimer Diseases” OR “Alzheimer Sclerosis” OR “Alzheimer Syndrome” OR “Alzheimer Type Dementia” OR “Alzheimer Type Dementia” OR “Alzheimer Type Senile Dementia” OR “Alzheimer’s Disease” OR “Alzheimer’s Diseases” OR “Alzheimer-Type Dementia” OR “Alzheimers Diseases” OR “Early Onset Alzheimer Disease” OR “Familial Alzheimer Disease” OR “Familial Alzheimer Diseases” OR “Focal Onset Alzheimer’s Disease” OR “Late Onset Alzheimer Disease” OR “Presenile Alzheimer Dementia” OR “Presenile Dementia” OR “Primary Senile Degenerative Dementia” OR “Enfermedad de Alzheimer” OR “Demencia de Alzheimer” OR “Demencia Presenil de Alzheimer” OR “Demencia Senil” OR “Demencia Senil Aguda Confusa” OR “Demencia Senil Tipo Alzheimer” OR “Demencia Tipo Alzheimer” OR “Enfermedades de Alzheimer” OR “Mal de Alzheimer”) AND (cuidadores OR “Cônjuges Cuidadores” OR cuidador OR “Cuidador de Família” OR “Cuidador Familiar” OR “Cuidadores Cônjuges” OR “Cuidadores de Família” OR “Cuidadores Familiares” OR “Familiar Cuidador” OR “Familiares Cuidadores” OR “Outro Apoiador” OR caregivers OR “Care Giver” OR “Care Givers” OR caregiver OR carer OR carers OR “Family Caregiver” OR “Family Caregivers” OR “Spouse Caregiver” OR “Spouse Caregivers” OR “Cuidador de Família” OR “Cuidador Familiar” OR “Cuidadores de Esposos” OR “Cuidadores de Família” OR “Cuidadores Familiares” OR “Familiar Cuidador” OR “Familiares Cuidadores”) AND (“Assistência Domiciliar” OR “Assistência Domiciliar aos Idosos” OR “Assistência Domiciliar por não Profissionais de Saúde” OR “Assistência Domiciliária” OR “Cuidados Domiciliares de Saúde” OR “Home Nursing” OR “Non-Professional Home Care” OR “Nonprofessional Home Care” OR “Atención Domiciliaria de Salud” OR “Asistencia Domiciliaria de Salud” OR “Atención no Profesional en Domicilio” OR “Cuidados Domiciliarios de Salud” OR “Assistência ao Paciente” OR “Assistência Prestada ao Paciente” OR “Cuidados Prestados ao Paciente” OR “Patient Care” OR “Informal care” OR “Informal cares” OR “Atención al Paciente” OR “Administração dos Cuidados ao Paciente” OR “Patient Care Management” OR “Manejo de Atención al Paciente” OR “Saúde do Idoso” OR “Caderneta de Saúde da Pessoa Idosa” OR “Caderneta de Saúde do Idoso” OR “Saúde da Pessoa Idosa” OR “Saúde da Terceira Idade” OR “Health of the Elderly” OR “Aging Health” OR “Elderly Health” OR “Health of Aged Persons” OR “Health of Elders” OR “Health of the Aged” OR “Salud del Anciano” OR “Salud de la Persona Anciana” OR “Salud de la Persona Mayor” OR “Salud de la Tercera Edad” OR “Home Health” OR “Saúde domiciliar” OR “Home care” OR “Cuidados domiciliares” OR “Conhecimentos, Atitudes e Prática em Saúde” OR “Atitudes e Prática em Saúde” OR “Atitudes e Práticas em Saúde” OR “Conhecimentos, Atitudes e Práticas em Saúde” OR “Health Knowledge, Attitudes, Practice” OR “Knowledge, Attitudes, Practice” OR “Conocimientos, Actitudes y Práctica en Salud” OR “Conocimientos, Actitudes y Práctica Sanitarias” OR “Conocimientos, Actitudes y Prácticas en Salud”) AND ( db:(“LILACS” OR “IBECs” OR “BDEFN” OR “CUMED” OR “LIS” OR “INDEXPSI” OR “WHOLIS” OR “BINACIS” OR “coleccionaSUS”))</p>

Source: Scoping Consultancy Librarian in health, 2022.

The search was carried out in August 2021 with the help of a librarian, in the following databases: PubMed (National Library of Medicine and National Institutes of Health), Embase, Cochrane, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Web of Science, LILACS (Latin American and Caribbean Health Sciences Literature) and BDEFN (Nursing Database). It is worth noting that for all the databases listed above, search standardization

took place through using the Coordination for the Improvement of Higher Education Personnel (CAPES - *Coordenação de Aperfeiçoamento de Pessoal do Nível Superior*) Journal Portal, through the Federated Academic Community (CAFe - *Comunidade Acadêmica Federada*), with access selection from the higher education institution *Universidade Federal de São João del-Rei* (UFSJ) and its Online Catalog of the SIGAA Library Module.

Titles and abstracts of articles retrieved in the search, when available, were read and analyzed by three independent reviewers to identify those potentially eligible for the study. In situations of doubt, the articles remained for the next phase, which involved the full reading of each of the articles selected by three independent reviewers in order to confirm the pertinence to the review question and, if so, to extract the data of interest. Inconsistencies or doubts were resolved by consensus between the authors.

For the stage of dividing, summarizing and reporting the essential elements found in each study, an instrument was used. This instrument allowed data synthesis, interpretation and the basic numerical analysis of the extension, nature and distribution of studies incorporated in the review. Items such as title, authors, year of publication, journal, country of study, objectives, method, database, main findings and description of home care related to AD in older adults were grouped together.

Data mapping through using a structured instrument proposed by JBI<sup>®</sup> allowed identifying the studies' essential elements, data synthesis and interpretation. The fundamental nuclei were analyzed, turning to the full texts when necessary.

Analysis categories were identified that allowed synthesizing the findings in a narrative way. Finally, the stage of synthesis and presentation of results took place.

## RESULTS

The initial search generated a total of 1,567 studies distributed in the databases as described in Figure 1. 338 articles that were duplicated were excluded, leaving 1,229 articles for reading the title and abstracts. A total of 100 studies were selected for full reading. After this new screening, 85 papers that did not respond to the research objective were excluded. The final sample consisted of 15 studies, of which four had only available abstracts. At the time of collection, these were accessed in full through the Journal Portal via CAFE.

Figure 1 shows the process of search, exclusion and selection of studies found.

In Chart 2, the studies were presented showing the following data: title; authors; year of publication; journal; country where the study was carried out; and main home care performed by caregivers.

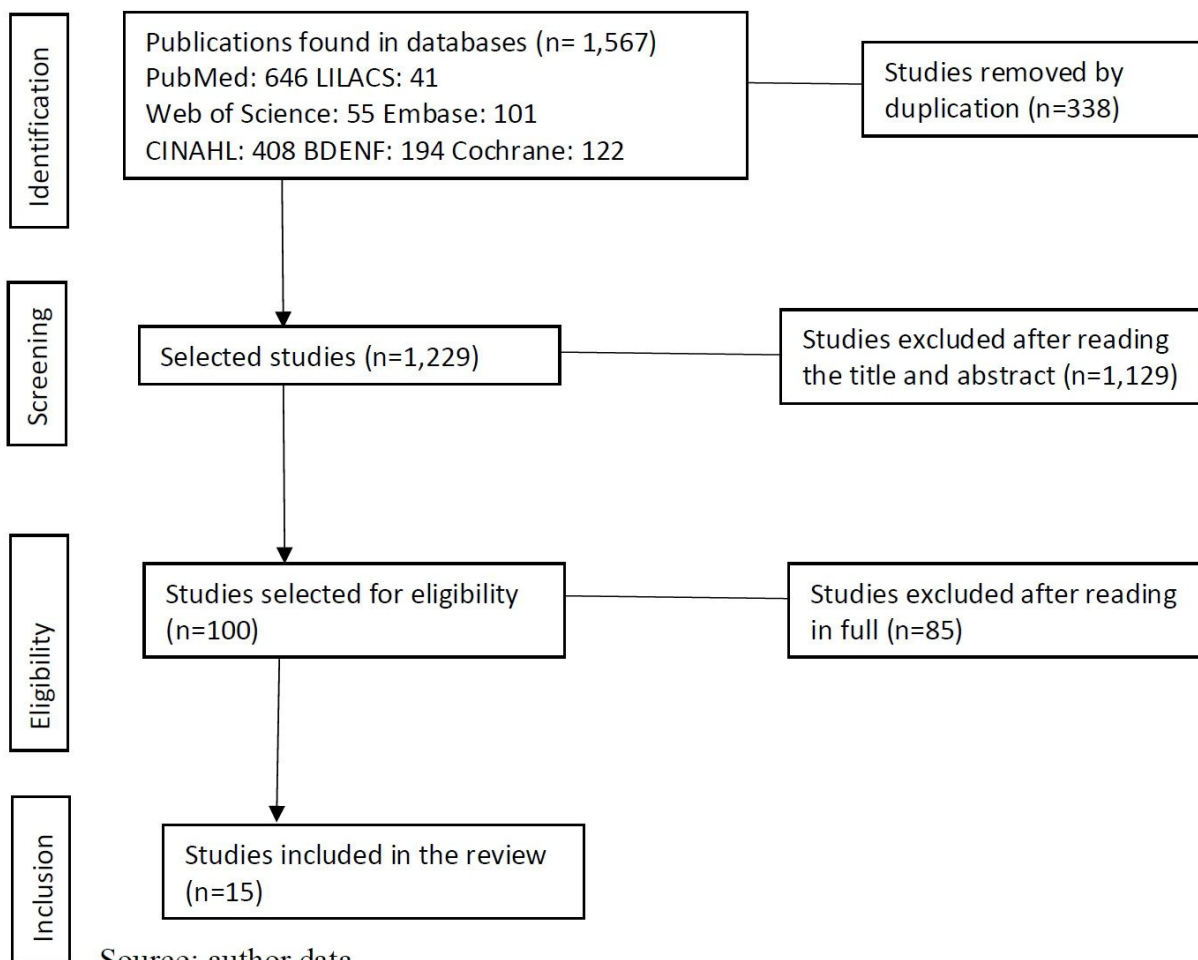


Figure 1. Article selection flowchart, adapted from PRISMA ScR<sup>11</sup>.

**Chart 2.** Scientific production of the main home care provided to older adults with Alzheimer's disease and carried out by family caregivers, according to authors, year of publication, journal, care and place of study.

Title, author	Year, journal and country	Family care
Management Decisions Made by Caregiver Spouses of Persons With Alzheimer's Disease Corcoran MA. <sup>13</sup>	The American Journal of Occupational Therapy, 1994, USA	The study describes the activities carried out by 26 caregivers' wives in five categories of work, describing the types of care according to the purpose. They are defined as anticipatory, preventive, supervisory, instrumental and protective care.
Communicating With Persons With Alzheimer's Disease: Experiences of Family and Formal Caregivers Richter JM, Roberto KA, Bottenberg DJ. <sup>14</sup>	Archives of psychiatric nursing, 1995, USA	The study addressed strategies carried out by 23 family caregivers (spouses and children) to deal with behavioral problems of older adults with Alzheimer's, such as fear, agitation, wandering and difficulty communicating. Two themes emerged as care strategies: environmental adjustments and comfort.
The experience of caring for a family member with Alzheimer's disease Butcher HK, Holkup PA, Buckwalter KC. <sup>15</sup>	Western journal of nursing research, 2001, USA	Study carried out with 103 family caregivers. Caregivers are fully immersed in care, respecting older adults' dignity and trying to keep their daily lives as normal as possible. Caregivers is concerned with safety, avoiding dangerous situations in the domestic environment and with older adults' autonomy, thus allowing them to continue performing some domestic tasks that they still manage, respecting their limitations.
<i>Dinâmica familiar, as fases do idoso com alzheimer e os estágios vivenciados pela família na relação do cuidado no espaço domiciliar</i> Coelho GS, Alvil NAT. <sup>16</sup>	<i>Revista Brasileira de Enfermagem</i> , 2004, Brazil	The study addresses the care provided by eight family caregivers and the family modification resulting from caring for an older adult with Alzheimer's at home according to the evolution of the disease. Maintaining family care during the course of the illness depends on how well the family is able to implement effective strategies in caring for older adults with dementia. The study selects care according to the evolution of the disease, which is divided into three phases: initial, intermediate and advanced.
<i>Atenção ao familiar cuidador do idoso com doença de Alzheimer</i> Luzardo A, Waldman BF. <sup>17</sup>	<i>Acta sci</i> , 2004, Brazil	The activities carried out by the four caregivers (a wife and three children) are described as continuous and uninterrupted care and characterized by hygiene care, care with food and elimination, emotional support, care with transporting older adults, financial administration, environment maintenance, environmental modifications and control of drug treatment accompanying older adults in appointments and supplying the drugs at the correct times.
Female Alzheimer's Patient Caregivers Share Their Strength Pauan O. <sup>18</sup>	Holistic Nursing Practice, 2004, USA	The article brings the concern of 14 family caregivers to maintain older adults' social and religious side through efforts to preserve customs, for instance, participating in masses, social events and leisure activities.
<i>La artesanía del cuidado: cuidar en la casa a un familiar con demencia avanzada</i> Cuesta-Benjumea C. <sup>19</sup>	<i>Enfermagem Clínica</i> , 2005, Spain	The author identifies strategies that 18 family caregivers and two professionals create to help older adults in the home environment, such as using "tricks" and non-verbal communication. In addition, they also adapt the environment and create "work tools" that facilitate care.
Caregiver Perspectives on Safety in Home Dementia Care Lach HW Chang YP. <sup>20</sup>	Western journal of nursing research, 2007, USA	Caregivers report a lot of concern about older adults' safety, mainly due to the risk of falling and being lost if they leave the house. In general, the author identified four approaches taken by caregivers to help older adults: environment supervision, modification, encouragement of social and recreational activities, and moving to older adults' residence.

Source: author data.

Chart 2. Continued...

Title, author	Year, journal and country	Family care
<i>O cuidador e os cuidados ao portador de doença de Alzheimer: contribuições à enfermagem</i> Fonseca AM, Soares E. <sup>21</sup>	<i>Revista Mineira de Enfermagem</i> , 2008, Brazil	Study carried out with eight family caregivers. The authors found several activities carried out by caregivers in the home environment, such as body hygiene, oral hygiene, food and hydration, help with basic activities such as dressing and combing hair, constant supervision and concern for maintaining communication.
The demands of family caregivers of elderly individuals with dementia Gratao ACM, Vale FAC, Roriz-Cruz et al. <sup>22</sup>	<i>Revista da Escola de Enfermagem da USP</i> , 2010, Brazil	The study had the participation of 104 family caregivers and demonstrated that they help older adults in practically all activities of daily living (ADLs), and those that were assessed were body hygiene, oral hygiene, bowel movements, skin care, food, medication, sleep/rest, physical activity, leisure and return appointments.
<i>O idoso portador da doença de alzheimer: o cuidado e o conhecimento do cuidador familiar</i> Lenardt MH, Silva SC, Willig MH, Seima MD <sup>23</sup>	<i>Revista Mineira de Enfermagem</i> , 2010, Brazil	The study included the participation of 14 family caregivers. Most care is related to concern for physical integrity, protection and constant observation, but it also extends to basic care such as body hygiene. There is also a report of concern with maintaining, at the very least, cognitive capacity through simple memory exercises, such as spelling words and doing math.
<i>Cuidar de idosos com doença de alzheimer: um enfoque na teoria do cuidado cultural</i> Ramos JLC, Menezes MR. <sup>24</sup>	<i>Revista RENE</i> , 2012, Brazil	In this study, the authors report care for older adults with a ritual of constant activities, which are repeated daily, during the day and at night, due to older adults' dependence. Daily activities are usually based on helping with bathing, changing diapers, putting on clothes, providing meals, administering medications at the correct times, and mentioning watching television as a leisure activity. A total of 20 family caregivers participated in the study.
<i>A perspectiva do cuidador frente ao idoso com a doença de Alzheimer</i> Silva SPN, Aquino CAG, Barbosa TLA, Silva CSO, Xavier-Gomes LM. <sup>25</sup>	<i>Rev. Pesquisa</i> , 2013, Brazil	The study brings, through the speeches of the ten family caregivers, the constant concern and care they provide in relation to older adults' physical integrity, focusing mainly on falls. Therefore, they organize the home environment and always accompany older adults, even inside the home. Vigil is always constant and they try to keep older adults away from dangerous places and objects. Caregivers also have a routine of daily activities, which consists of helping with bathing, taking care of hair, brushing teeth, performing oral hygiene, dressing, feeding and hydration, changing chairs, taking to the bathroom, offering medications on time correct and take for walks. In cases where older adults are bedridden, caregivers are concerned with skin hydration and the acquisition of suitable mattresses to avoid injuries.
<i>Estratégias de cuidado bucal para idosos com Doença de Alzheimer no domicílio</i> Warmling AMF Santos SMA, Mello ALSF. <sup>26</sup>	<i>Revista brasileira de Geriatria Gerontologia</i> , 2016, Brazil	The study brings oral health care performed at home by 30 caregivers, 26 family members, 1 friend and 3 professionals. The author identified the necessary care according to the dependency of older adults, showing the difference in care according to the evolution of the disease.
Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services Häikiö K, Sagbakken M, Rugkåsa J. <sup>27</sup>	BMC health services research, 2019, Norway	The 23 family caregivers participating in the study act to prevent physical harm through preventive presence, keeping company with older adults routinely or constantly to prevent falls or accidents at home. They help older adults to deal with their finances, helping with trips to banks or with electronic devices and controlling unnecessary expenses. Family caregivers also sought to prevent negative emotions for the person with dementia by providing leisure activities.

Source: author data.



In study selection, the American journal “Western journal of nursing research” stands out for containing two selected studies. The countries with included studies were Brazil, Spain, United States and Norway, as Brazil was the country with the highest number of retrieved studies with eight studies (52.9%), followed by the United States with five studies (29.4%), Norway and Spain with one study (5.8%).

After critical reading, the data reduction method was used to conceptually classify the results.<sup>28</sup> The activities described in the studies were classified into ten types of care according to the purpose. The type most addressed by the authors was “Protection and supervision”, mentioned in twelve studies (70%), followed by “Hygiene and comfort”, present in ten studies (58.8%) and “Food and hydration” in nine studies (52.9%). The least mentioned care were those related to “Communication”, “Cognitive exercises” and “Independence”, present in three studies (17.6%), and “Pressure injury prevention”, mentioned in a study.

## DISCUSSION

The analysis of publications found revealed that they are qualitative and descriptive. No studies were found that derived from interventions, revealing that professionals have difficulties in locating evidence of better care that can be performed by caregivers at home.

During the reading phase of abstracts, titles and full texts, we excluded many articles about the difficulties, obstacles and potential to develop care. However, only 15 described the care provided by family caregivers. Cultural and socioeconomic aspects can influence researchers in the way they deal with the subject. Thus, we did not find studies from the East or from other Latin American countries, although we included the LILACS database that brings together literature from the Caribbean and Latin America.

It is noticed that knowledge about the disease and the necessary care are limited and acquired in quick meetings with professionals or empirically in routine care. However, although caregivers receive limited information that allows them to understand AD, they have created strategies to direct care in the home environment and face the difficulties experienced.<sup>10</sup> Analyzing the evidence found in the literature on the care provided by family members, it is clear that they are very similar in the different realities presented, thus making it possible to group them according to the purpose of the activities described by the studies.

The type of care most cited by the review articles was “Protection and supervision”, characterized by the great concern of caregivers with older adults’ physical integrity.<sup>20</sup> As there are multiple factors, it is important that accident prevention strategies involve several articulated dimensions, such as muscle strengthening, maintaining a safe space and also assessing medication.<sup>29</sup>

Supervision and protection care is present from the early stages of the disease, when there is loss of recent memory,

difficulty retaining new information, language disorders and progressive difficulty in activities of daily living.<sup>16,21</sup> Caregivers define supervision as always being close to help with basic tasks, preventing accidents and health risks.<sup>13,23</sup>

Actions involving the maintenance of physical integrity, protection and observation are constant. Caregivers report not feeling safe leaving older adults alone, not even at home, due to the risks that may arise from the consequences of the disease.<sup>14,15</sup> For this reason, caregivers hide dangerous objects and restrict activities they consider dangerous, for instance, handling the stove and sharp objects.<sup>17</sup> A strategy used is restricting access to some areas of the house to facilitate supervision and reduce risks.<sup>13</sup>

This care also extends to the constant concern about falls, given that the incidence of falls in older adults with dementia is twice as high compared to older adults who have normal cognitive functions.<sup>29</sup> Considering all the risks that the home itself provides, environmental changes are inevitable to guarantee older adults’ safety in the face of the repercussions of the disease.<sup>20</sup> Caregivers organize the home environment according to the family’s possibilities.<sup>25,27</sup> House adaptation is done, such as through modifications to the floors, installation of railings and security bars and other various changes to promote safety and facilitate care.<sup>19,20</sup> The safe environment facilitates walking indoors, thus ensuring safety and greater comfort, since older adults with dementia feel the need to walk due to the neuropsychiatric symptoms of AD.<sup>14</sup>

The second most cited type of care in the review was “Hygiene and comfort”, which is related to help with basic day-to-day tasks, such as bathing, changing diapers, dressing, combing hair and cutting nails. This care is normally carried out during the second phase of the disease, when there is an increase in cognitive and motor decline and caregivers begin to perform tasks with older adults.<sup>16</sup> This type of care is imbued with symbolic values and is seen by many as an obligation.<sup>24,25</sup>

Body hygiene was often referred to as the most difficult and exhausting task because it invades privacy and older adults refuse to perform it.<sup>17,21-23</sup> Strategies observed to facilitate such activity were reconciling the best time for a bath, assessing the frequency of bathing, installing grab bars in the bathrooms for greater safety and encouraging independence whenever possible.<sup>21</sup>

Another type of care highlighted by caregivers was “Food and hydration”, which was present in nine of the assessed studies. Regarding the nutrition of older adults with dementia, an increased risk of malnutrition was observed in relation to older adults without cognitive problems. A cohort carried out in Goiás shows that 18.4% of assessed older adults with Alzheimer’s were in a state of malnutrition and 63.2% had a high risk of developing it, thus demonstrating the importance of dietary surveillance.<sup>30</sup>

Through the studies, it is noted that caregivers are concerned with maintaining older adults’ good nutritional status and, for this, they prepare food and control the times, quantity and consistency of meals, in addition to the frequent liquid supply.<sup>13,16,21,25</sup>

Cognitive impairment makes older adults believe that they have eaten, thus causing refusal of meals and opposing behaviors.<sup>24</sup> Along with body hygiene, helping with food was reported as one of the most exhausting tasks in one of the studies.<sup>16</sup> However, another study mentioned this as being the care that generates less fatigue and emotional stress.<sup>20</sup>

The next most cited type of care was “Social and leisure”, present in six studies. Investigations indicate a wide variety of activities that caregivers encourage older people to perform, such as gym, hiking, water aerobics, playing sports, going to the cinema, listening to the radio, watching television, using the computer, reading books and handicrafts.<sup>23,28</sup> Family caregivers seek to prevent negative emotions for the person with dementia, providing pleasant practices.<sup>27</sup>

Although the main AD treatments still involve the pharmacological aspect, many non-pharmacological alternatives have shown good results in the treatment of dementia. The practice of different leisure activities delays the evolution of the disease, reduces behavioral and psychological symptoms and, consequently, increases the quality of life of older adults.<sup>31</sup>

Caregivers seek to maintain the independence and social and leisure ties of individuals with AD through participation in social events such as birthdays and family gatherings.<sup>20,24</sup> One of the studies analyzed addresses religious faith as an effective strategy to guarantee distraction, leisure, comfort and quality of life for older adults, making it a tool for maintaining social ties through participation in masses and services. In cases where dementia is already very advanced and socialization becomes very difficult, the study brings reports from caregivers who seek strategies such as receiving communion at home and following masses on television.<sup>18</sup>

The type of care “Oral hygiene” was present in four articles. The studies identified the necessary care according to older adults’ dependence, showing the difference in care according to the evolution of the disease. Thus, in early-stage dementia, caregivers participate little in the oral health of older people. Due to a greater degree of independence, they follow the moment of brushing, but do not assess whether it is correct.

Caregivers remind older adults to perform hygiene, refer them to the bathroom, help with movements such as putting toothpaste on the brush, removing and replacing removable prostheses, showing the movements that must be performed to perform oral hygiene by means of imitation in front of the mirror, but it is older adults alone who actually perform the hygiene. In advanced dementia, caregivers need to brush their teeth and removable prostheses using a toothbrush and toothpaste or using gauze or a diaper with an antiseptic solution to apply to the teeth and mucosa, ensuring comfort and preserving the palate.<sup>21,22,25,26</sup>

In the type of care “Drug treatment”, caregivers take on tasks related to drug treatment control, such as reminding older adults to take the medications at the correct times, seeking the health system when necessary, accompanying older adults to medical appointments and assist in administering insulin.<sup>14,17,22,24</sup>

Regarding the type of care “Communication”, caregivers seek non-verbal communication strategies to meet older adults’ demands and needs.<sup>22</sup> They need to act intelligently and use strategies to overcome resistance without using force so that patients accept care. When communication becomes difficult through words, caregivers reinvent themselves and create styles with which to overcome obstacles. Living with AD on a daily basis provides a greater understanding of needs through the signs they present. Older adults understand, collaborate and are reassured not by what is said, but by the way it is said.<sup>18</sup> Affectionate communication with older adults is presented as a strategy to generate comfort and reduce the symptoms of agitation and aggressiveness.<sup>14</sup>

The type of care “Independence” was considered by caregivers as difficult to implement and little cited in assessed studies. Independence appears associated with emotional well-being, maintenance of self-esteem and dignity helps to guarantee older adults’ autonomy in order to provide feelings of usefulness and purpose. The review studies cite the following strategies: involving older adults in simple and productive activities; and facilitate some tasks so that they can perform with less dependence, such as washing dishes, sweeping the floor and making the bed.<sup>13,15</sup>

Less frequently, some caregivers also use mental exercises to prevent/reduce cognitive decline, care that is present in the type of care “Cognitive exercises”. Stimuli are done through simple memory exercises, such as spelling words, doing math and reinforcement to remember everyday facts.<sup>13,23</sup>

Finally, the last type of care presented was “Pressure injury prevention”. In some cases, when the dementia is advanced and older adults are more restricted to the chair or bed, caregivers are also concerned about skin integrity due to appearance of pressure injuries. In the study, it was found that caregivers are careful with skin hydration and acquisition of suitable mattresses to avoid such injuries.<sup>25</sup>

Although the studies in this review are mostly observational, they were developed in four different nationalities and published in sixteen different journals. In this way, a broad view was built on the care provided in the home environment by family caregivers.

## **FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE**

This study synthesized the main home care provided by family caregivers to older adults with AD. This care was grouped according to the activities mentioned in the studies that were part of the review. Most studies were observational and qualitative, in which the majority of the sample consisted of family members and women who provided daily care. Through this scoping review, a lack of studies is perceived, especially those that bring a more consistent theoretical-practical basis for the actions to be developed by family caregivers.

Literature mapping and stratification into types of care allow professionals to know the main difficulties of caregivers when performing the care and the actions that are indicated or developed.

In this context, the information can support nurses and other professionals in the development of educational activities and the elaboration of educational materials aimed at this public.

The consideration of three languages and the inclusion of articles only in online form, which may have excluded old articles existing only in printed form, is a study limitation. However, it is believed that the results would not be substantially altered, since a time limit was not established and many studies are published in the original language and in English.

Based on the results, there was a need for investments in research that explore in depth the nature of the care provided at home as well as build instruments with the purpose of assessing the quality of care provided. This knowledge is fundamental to guide professionals during the support to be provided to family caregivers in the process of caring for older adults with AD.

## AUTHORS' CONTRIBUTIONS

Review study design. Pedro Victor de Carvalho Silva. Edilene Aparecida Araujo da Silveira.

Text acquisition. Pedro Victor de Carvalho Silva. Edilene Aparecida Araujo da Silveira. Caléo Moisés Pinto da Silva.

Data analysis. Pedro Victor de Carvalho Silva. Edilene Aparecida Araujo da Silveira. Caléo Moisés Pinto da Silva.

Interpretation of results. Pedro Victor de Carvalho Silva. Edilene Aparecida Araujo da Silveira. Caléo Moisés Pinto da Silva.

Manuscript writing and critical review. Pedro Victor de Carvalho Silva. Caléo Moisés Pinto da Silva. Edilene Aparecida Araujo da Silveira.

Approval of the final version of the article. Pedro Victor de Carvalho Silva. Caléo Moisés Pinto da Silva. Edilene Aparecida Araujo da Silveira.

Responsibility for all aspects of content and integrity of the published article. Pedro Victor de Carvalho Silva. Caléo Moisés Pinto da Silva. Edilene Aparecida Araujo da Silveira.

## ASSOCIATED EDITOR

Fabio da Costa Carbogim 

## SCIENTIFIC EDITOR

Ivone Evangelista Cabral 

## REFERENCES

- Alves JED. Envelhecimento populacional no Brasil e no mundo: novas projeções da ONU. *Rev Longevidad*. [Internet]. 2019; [cited 2022 Oct 12];5-9. Available from: <https://revistalongevidad.com.br/index.php/revistaportal/article/viewFile/787/842>
- United Nations. Department of Economic and Social Affairs. Population Division. *World Population Prospects 2022: summary of results* [Internet]. New York: United Nations; 2022 [cited 2022 Oct 12]. Available from: <https://static.poder360.com.br/2022/07/Relatorio-ONU-populacao-2022.pdf>
- Silva ILC, Lima GS, Storti LB, Aniceto P, Formighieri PF, Marques S. Sintomas neuropsiquiátricos de idosos com demência: repercussões para o cuidador Familiar. *Texto Contexto Enferm*. 2018;27(3):1-11. <http://dx.doi.org/10.1590/0104-07072018003530017>.
- Alzheimer's Association Report. 2020 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2020;16(3):391-460. <http://dx.doi.org/10.1002/alz.12068>.
- Gonçalves FCA, Lima ICS. Alzheimer e os desafios dos cuidados de enfermagem ao idoso e ao seu cuidador familiar. *R Pesq Cuid Fundam*. 2020;12:1474-82. <http://dx.doi.org/10.9789/2175-5361.rpco.v12.7971>.
- Anjos KF, Boery RNSO, Santos VC, Boery EN, Rosa DOS. Homem cuidador familiar de idosa com doença de Alzheimer. *Saúde Pesqui*. 2017;10(2):317. <http://dx.doi.org/10.17765/1983-1870.2017v10n2p317-324>.
- Cesário LMS, Chariglione IPFS. A percepção de familiares cuidadores frente às mudanças ocorridas após um diagnóstico de demência. *Rev Bras Geriatr Gerontol*. 2018;21(06):768-80. <http://dx.doi.org/10.1590/1981-22562018021.180123>.
- Taranrod LB, Eriksen S, Pedersen I, Kirkevold O. Características, carga de cuidado e qualidade de vida de parentes próximos de pessoas com demência que frequentam creches em fazendas na Noruega: um estudo transversal descritivo. *J Multidiscip Healthc*. 2020;13:1363-73. <http://dx.doi.org/10.2147/JMDH.S268818>. PMID:33173299.
- Leite BS, Camacho ACLF, Joaquim FL, Gurgel JL, Lima TR, Queiroz RS. A vulnerabilidade dos cuidadores de idosos com demência: estudo descritivo transversal. *Rev Bras Enferm*. 2017;70(4):714-20. <https://doi.org/10.1590/0034-7167-2016-0579>.
- Chaves ASC, Jesus LM, Lopes DA, Rosa CM, Abrão RK. Práticas e saberes dos cuidadores de idosos com alzheimer: a invisibilidade do enfermeiro. *Rev UNIABEU*. [Internet]. 2019; [cited 2022 Mar 4];12(30):400-21. Available from: <https://core.ac.uk/download/pdf/268395875.pdf>
- Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D et al. PRISMA extension for *Scoping Reviews* (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018;169(7):467-73. <http://dx.doi.org/10.7326/M18-0850>. PMID:30178033.
- Peters MDJ, Godfrey C, Mclnerney P, Munn Z, Tricco AC, Khalil H. Revisões do escopo (versão 2020). In: Aromataris E, Munn Z, editors. *JBIM Manual for Evidence Synthesis*. Australia: JBI; 2020. Cap. 11. <http://dx.doi.org/10.46658/JBIMES-20-12>.
- Corcoran MA. Management decisions made by caregiver. *Am J Occup Ther*. 1994;48(1):38-45. <http://dx.doi.org/10.5014/ajot.48.1.38>. PMID:8116782.
- Richter JM, Roberto KA, Bottenberg DJ. Communicating with persons with Alzheimer's disease: experiences of family and formal caregivers. *Arch Psychiatr Nurs*. 1995;9(5):279-85. [http://dx.doi.org/10.1016/S0883-9417\(95\)80047-6](http://dx.doi.org/10.1016/S0883-9417(95)80047-6). PMID:7487169.
- Butcher HK, Holkup PA, Buckwalter KC. The experience of caring for a family member with Alzheimer's disease. *West J Nurs Res*. 2001;23(1):33-55. <http://dx.doi.org/10.1177/019394590102300104>. PMID:11216023.
- Coelho GS, Alvim NAT. A dinâmica familiar, as fases do idoso com alzheimer e os estágios vivenciados pela família na relação do cuidado no espaço domiciliar. *Rev Bras Enferm*. 2004;57(5):541-4. <http://dx.doi.org/10.1590/S0034-71672004000500005>. PMID:15997795.
- Luzardo AR, Waldman BF. Atenção ao familiar cuidador do idoso com doença de Alzheimer. *Acta Sci Heal Sci*. 2004;26(1):135-45. <http://dx.doi.org/10.4025/actascihealthsci.v26i1.1640>.
- Paun O. Female Alzheimer's Patient Caregivers. *Holist Nurs Pract*. 2004;18(1):11-7. <http://dx.doi.org/10.1097/00004650-200401000-00003>. PMID:14765687.
- Cuesta-Benjumea C. La artesanía del cuidado: cuidar en la casa a un familiar con demencia avanzada. *Enferm Clin*. 2005;15(6):335-42. [http://dx.doi.org/10.1016/S1130-8621\(05\)71140-2](http://dx.doi.org/10.1016/S1130-8621(05)71140-2).
- Lach HW, Chang YP. Perspectivas do cuidador sobre segurança no atendimento domiciliar à demência. *West J Nurs Res*. 2007;29(8):993-1014. <http://dx.doi.org/10.1177/0193945907303098>. PMID:17630389.
- Fonseca AM, Soares E. O cuidador e os cuidados ao portador de doença de alzheimer: contribuições à enfermagem. *Rev Min Enferm*. [Internet]. 2008; [cited 2022 Mar 4];12(4):501-7. Available from: <https://pesquisa.bvsalud.org/portal/resource/pt/bde-17883>
- Gratao ACM, Vale FAC, Roriz-Cruz M, Haas VJ, Lange C, Talmelli LFS et al. The demands of family caregivers of elderly individuals with dementia. *Rev Esc Enferm USP*. 2010;44(4):873-80. <http://dx.doi.org/10.1590/S0080-62342010000400003>. PMID:21329110.

23. Lenardt MH, Silva SC, Willig MH, Seima MD. O idoso portador da doença de Alzheimer: o cuidado e o conhecimento do cuidador familiar. *Rev Min Enferm.* [Internet]. 2010; [cited 2022 Mar 4]; 14(3):301-7. Available from: <https://pesquisa.bvsalud.org/portal/resource/pt/bde-19549>
24. Ramos JLC, Menezes MR. Cuidar de idosos com doença de Alzheimer: um enfoque na teoria do cuidado cultural. *Rev Rene.* [Internet]. 2012; [cited 2022 Mar 4]; 13(4):805-15. Available from: <http://www.periodicos.ufc.br/rene/article/view/4037>
25. Silva SPN, Aquino CAG, Barbosa TLA, Silva CSO, Xavier-Gomes LM. The perspective of caregiver front to the elderly people with Alzheimer Disease. *Rev Pesqui Cuid Fundam Online.* 2013;5(1):3333-42. <http://dx.doi.org/10.9789/2175-5361.2013.v5i1.3333-3342>.
26. Warmling AMF, Santos SMA, Mello ALSF. Estratégias de cuidado bucal para idosos com Doença de Alzheimer no domicílio. *Rev Bras Geriatr Gerontol.* 2016;19(5):851-60. <http://dx.doi.org/10.1590/1809-98232016019.160026>.
27. Häikiö K, Sagbakken M, Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res.* 2019;19(1):635. <http://dx.doi.org/10.1186/s12913-019-4478-2>. PMID:31488131.
28. Whittemore R, Knaf K. The integrative review: updated methodology. *J Adv Nurs.* 2005;52(5):546-53. <http://dx.doi.org/10.1111/j.1365-2648.2005.03621.x>. PMID:16268861.
29. Goldup H. Falls prevention in dementia: literature review. *J Dement.* [Internet]. 2017; [cited 2022 Mar 4];2(1):1000105. Available from: <https://www.omicsonline.org/open-access/falls-prevention-in-dementia-literature-review.pdf>
30. Graciano AR, Cozer AM, Santana VML, Oliveira JMR. Avaliação nutricional e risco de desnutrição em idosos com demências. *Saúde Pesqui.* 2018;11(2):293. <http://dx.doi.org/10.17765/1983-1870.2018v11n2p293-298>.
31. Dornelles VJ. Atividade de lazer e novas tecnologias em pessoas com doença de Alzheimer. *Rev Motri Saude.* [Internet]. 2020; [cited 2022 Mar 4];2(1):1-13. Available from: [http://revista.fundacaojau.edu.br:8078/journal/index.php/revista\\_motrisaude/article/view/213](http://revista.fundacaojau.edu.br:8078/journal/index.php/revista_motrisaude/article/view/213)