Palliative care for elderly people with Alzheimr's Disease

Cuidados paliativos à pessoa idosa com Doença de Alzheimer

Cuidados paliativos para ancianos con Enfermedad de Alzheimer

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How to cite: Jesus LS, Batista ACS, Silva RS, Pereira ARP, Almeida ARLP, Alves MB. Palliative care for elderly people with Alzheimr's Disease. 2024; 13(2): 392-405. Doi: https://doi.org/10.36239/revisa.v13.n2.p392a405

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Received: 22/01/2023
Accepted: 14/03/2023

RESUMO

Objetivo: Compreender as barreiras enfrentadas pela família com relação ao acesso aos cuidados paliativos por idosos com Doença de Alzheimer. **Método:** Revisão integrativa realizada nas bases de dados Medline, Lilacs, Binacis e Ibecs, utilizando os descritores "doença de Alzheimer", "cuidados paliativos" e "idoso", com recorte temporário de 10 anos (2012-2022). **Resultados:** Foram encontrados 158 artigos, dos quais 148 foram excluídos por não atenderem aos critérios da pesquisa, sendo 10 artigos selecionados para compor o corpus da pesquisa. Identificou-se dois pontos centrais envolvendo as barreiras enfrentadas pela família no acesso aos cuidados paliativos pelas pessoas idosas com Doença de Alzheimer, sendo respectivamente: 1) Desconhecimento da Doença de Alzheimer como uma doença progressiva e irreversível que leva a morte, portanto com necessidade de implementação dos cuidados paliativos e, 2) falta de serviços formais de cuidados paliativos para pessoas idosas com Doença de Alzheimer, especialmente para aquelas que estão em Instituições de Longa Permanência para Idosos. **Conclusão:** A partir dos resultados pode-se compreender os desafios e limitações do acesso das pessoas idosas com Doença de Alzheimer aos Cuidados Paliativos, que vão desde o desconhecimento sobre a Doença de Alzheimer, a carência de serviços de cuidados paliativos a limitação no conhecimento e discussões acerca da temática.
Descritores: Cuidados paliativos; Doença de Alzheimer; Idoso.

ABSTRACT

Objective: To understand the barriers faced by families in relation to access to palliative care for elderly people with Alzheimer's Disease. **Method:** Integrative review carried out in the Medline, Lilacs, Binacis and Ibecs databases, using the descriptors "Alzheimer's disease", "palliative care" and "elderly", with a temporary cut of 10 years (2012-2022). **Results:** 158 articles were found, of which 148 were excluded for not meeting the research criteria, with 10 articles selected to compose the research corpus. Two central points were identified involving the barriers faced by the family in accessing palliative care for elderly people with Alzheimer's Disease, respectively: 1) The lack of knowledge of Alzheimer's Disease as a progressive and irreversible disease that leads to death, therefore with implementation of palliative care and, 2) The lack of formal palliative care services for elderly people with Alzheimer's Disease, especially for those in Long-stay Institutions for the Elderly. **Conclusion:** From the results it is possible to understand the challenges and limitations of access for elderly people with Alzheimer's Disease to Palliative Care, ranging from lack of knowledge about Alzheimer's Disease, the lack of palliative care services to limited knowledge and discussions about of the theme.
Descriptors: Palliative care; Alzheimer's disease; Elderly.

RESUMEN

Objetivo: Comprender las barreras que enfrentan las familias en relación al acceso a cuidados paliativos para personas mayores con Enfermedad de Alzheimer. **Método**: Revisión integradora realizada en las bases de datos Medline, Lilacs, Binacis e Ibecs, utilizando los descriptores "enfermedad de Alzheimer", "cuidados paliativos" y "ancianos, con un corte temporal de 10 años (2012-2022). **Resultados:** Se encontraron 158 artículos, de los cuales 148 fueron excluidos por no cumplir con los criterios de investigación, siendo 10 artículos seleccionados para componer el corpus de investigación. Se identificaron dos puntos centrales relacionados con las barreras que enfrenta la familia para acceder a los cuidados paliativos de las personas mayores con Enfermedad de Alzheimer, respectivamente: 1) El desconocimiento de la Enfermedad de Alzheimer como una enfermedad progresiva e irreversible que conduce a la muerte, por lo que necesita la implementación de cuidados paliativos y, 2) la falta de servicios formales de cuidados paliativos para personas mayores con Enfermedad de Alzheimer, especialmente para aquellos en Instituciones de Larga Estancia para Personas Mayores. **Conclusión:** A partir de los resultados es posible comprender los desafíos y limitaciones de acceso de las personas mayores con Enfermedad de Alzheimer a los Cuidados Paliativos, que van desde la falta de conocimiento sobre la Enfermedad de Alzheimer, la falta de servicios de cuidados paliativos hasta los conocimientos y discusiones limitados sobre el tema..
Descriptores: Cuidados paliativos; Enfermedad de Alzhéimer; Anciano.

Introduction

Palliative care (PC) is an approach that aims to improve the quality of life of patients, as well as their family members who are facing problems associated with chronic diseases that threaten the continuity of life. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems. Promotes dignity, comfort, quality of life and adaptation to progressive diseases, using the best available evidence.[1]

They are presented as a model of care with an approach focused on the human being in its integrality and the need for intervention in symptoms of a physical, social, emotional and spiritual nature. It is a multiprofessional and interdisciplinary practice.[2]

The emergence of palliative care dates back to the 1960s in the United Kingdom, from the work of nurse, social worker and physician Dame Cicely Saunders, a pioneer in such an approach to care in the area of care, teaching and research. The creation of St. Christophers Hospice in London in 1967 represents a milestone in the historical trajectory of palliative care.[3] In the 1970s, the palliative movement arrived in the Americas, highlighting the work of psychiatrist Elisabeth Kübler-Ross, who was a member of Cicely Saunders. And, with the founding of a hospice in the city of Connecticut (United States) between 1974 and 1975, the movement spread, starting to integrate the care of patients without possibility of cure, in several countries of the Americas.[4]

In Brazil, the emergence of PC occurred initially in the 1980s, the end of the dictatorship, when the health system was focused only on curative practices, expanding in 1997, with the creation of the Brazilian Association of Palliative Care (ABCP). In 1998, the National Cancer Institute (INCA) inaugurated in the structures of this hospital, the unit HC IV (Hospital do Câncer IV), exclusively for the supply of PC. In 2005, the National Academy of Palliative Care (ANCP) was created, and a great advance was registered in 2011 when the Federal Council of Medicine (CFM) recognized PC as an area of medical practice, based on Resolution CFM 1973/2011.[5]

The movement for palliative care has grown substantially, since the late nineteenth century, worldwide. However, in Brazil, activities related to Palliative Care still need advances, especially a public policy that promotes access and funding for palliative care to all people, especially the elderly with chronic-degenerative diseases.[2] The subject is still the target of ignorance and much prejudice, since for some, palliative care is mistakenly confused with euthanasia, which in a more contemporary definition, can be understood as the use or abstention of procedures that allow to hasten or provoke the death of a person with an incurable disease, in order to free him from the extreme suffering that affects him.[6]

The increase in life expectancy and the achievement of longevity bring with them an increase in the number of elderly people with chronic and disabling diseases, with no possibility of cure, such as cardiovascular diseases, respiratory diseases and neurodegenerative diseases, such as dementias, all disease conditions in need of palliative care.[7]

Dementia is an irreversible neurodegenerative syndrome, of a chronic and progressive nature, in which there is an impairment of cortical functions, including memory, reasoning, orientation, understanding, calculation, learning

capacity, language and judgment, causing transformations in the quality of life and functional capacity of people affected by this disease. They are configured as one of the most important cognitive disabilities in elderly people, with the highest incidence being Alzheimer's Dementia (AD).[8]

There are many different forms of dementia, with AD accounting for 60-70% of cases. Knowing that these people may forget recent events and people's names; difficulty in communication and recognition of people; changes in behavior, including wandering and repeated questioning; unconsciousness; Among other changes with a growing need for assistance for self-care, palliative care becomes necessary and extremely relevant since it can provide comfort, minimizing the pain and anguish of the patient, their families and caregivers.[9]

Elderly people diagnosed with AD, throughout the course of the disease, have a series of comorbidities and frailties, which require long-term care.[10] It is also noteworthy that AD, because it is a syndrome with a wide range of symptoms, which become chronic over time and thus requires the implementation of palliative care, which is configured as a beneficial support capable of controlling the exacerbation of symptoms and promoting quality of life.[10]

In this perspective, PC emerges as a care practice provided by a multidisciplinary team, providing quality, holistic and humanized care.[11] This care is based on the valorization of life and the understanding of death as a natural condition, centered on the individual, the family and the caregivers, seeking to provide comfort and control and/or relieve symptoms, not only physical, but also psychosocial and spiritual, in order to achieve comprehensive care, guided by the ethical principles of human rights.[12]

Several factors still influence the palliative practice, among them the absence of specific discipline in the training of health professionals, as well as the scarcity of services and programs specialized in PC. In addition, the aging of the national population and the increasing incidence of chronic diseases make the growing need for PC a problem of enormous social impact.[13]

Given the above and all the complexity that caring for the elderly with Alzheimer's disease requires, as well as considering the importance of palliative care for these individuals, the following research question arises: what are the barriers faced by the family regarding access to palliative care by the elderly person with Alzheimer's disease?

In this sense, this study aims to understand the barriers faced by the family regarding access to palliative care by elderly people with Alzheimer's disease.

Method

This is an integrative literature review study that aims to summarize the results obtained on certain researches, themes or issues in a systematic, orderly and comprehensive manner.[14]

Data collection took place between March and May 2022, in the following electronic databases: Índice Bibliográfico Español en Ciencias de la Salud (Ibecs), Literatura Latino-Americana e do Caribe em Ciências da Saúde (Lilacs), Medical Literature Analysis and Retrieval System Online (Medline) and Bibliografía Nacional en Ciencias de la Salud Argentina (Binacis).

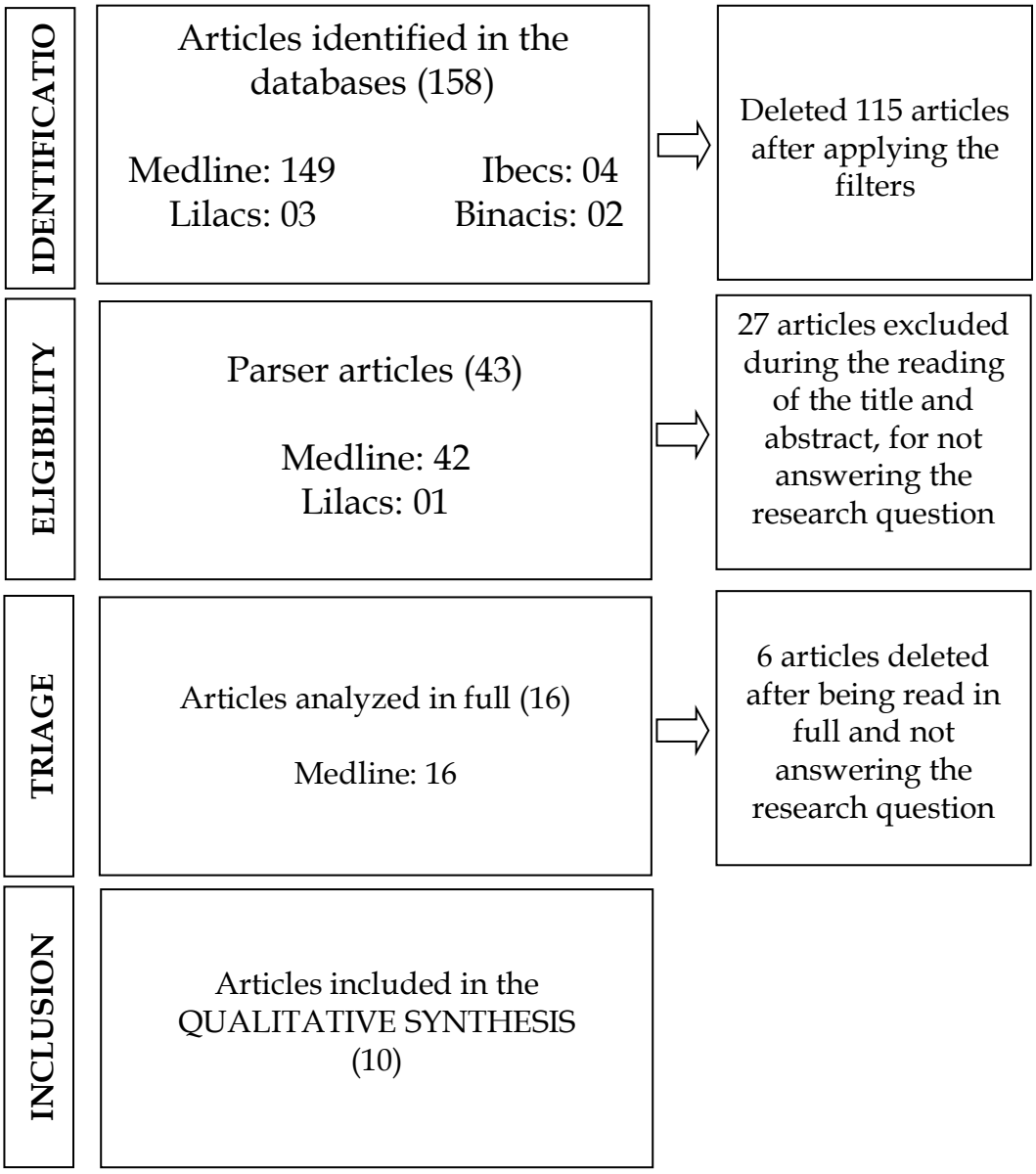
All articles that met the following criteria were included in this review: articles that were available electronically, in full, and that answered the research question of the study. The filters used during the searches were: full text, available in full, in Portuguese, English or Spanish, published in the last 10 years (2012 to 2022). And as exclusion criteria: theses, dissertations, course completion papers and revision studies.

The descriptors "Alzheimer's disease", "palliative care" and "elderly" were used and the combination in pairs from the Boolean logic AND was used as operator. The search strategies also included the synonyms of the descriptors: "Alzheimer's dementia" and "palliative treatment". The search results were not very expressive, resulting in a small number of articles in the Binacis, Ibecs and Lilacs databases, presenting a better outcome in the Medline database.

The survey in the databases resulted in 158 publications, of this total, two available in Binacis, four in Ibecs, 149 in Medline and three in Lilacs. After applying the filters defined as search strategies, it resulted in 43 articles, of which, after reading the titles and abstracts, 27 more articles were excluded, because they were not related to the theme, leaving 16 publications for detailed evaluation, of which six articles were excluded after reading in full, because they did not answer the guiding question. At the end, 10 articles composed the corpus of this review, as shown in Figure 01.

This is a research whose information was obtained from materials already published and available in the literature, so there is no intervention or direct approach to human beings, which eliminates the need to submit for approval to the Research Ethics Committee. However, the ethical aspects were assured, guaranteeing the authorship of the articles that composed the analyzed sample.

For the methodologic of the selection path of the articles, a table was elaborated with the phases of their selection, which was subdivided into: identification, eligibility, screening and inclusion, which followed the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[15]



IBECS: Spanish Bibliographic Index in Health Sciences; **LILACS: Latin American and Caribbean Literature in Health Sciences; MEDLINE:** Medical Literature Analysis and Retrieval System OnlinE; **BINACIS:** Bibliografía Nacional en Ciencias de la Salud Argentina.

Figure 1 - Flowchart of the selection phases of the articles of the integrative review. Senhor do Bonfim (BA), Brazil, 2023.

Results

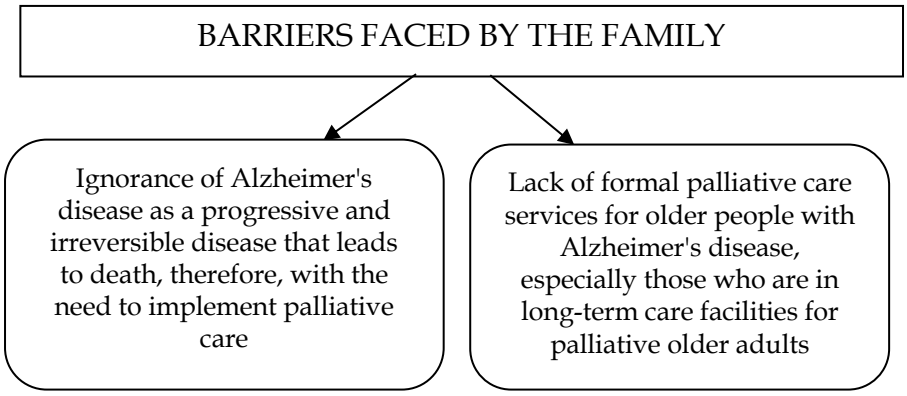
The 10 articles selected to compose the qualitative synthesis were all published in English, with two articles published in 2012, one in 2014, two in 2015, two in 2016, one in each year 2018, 2019 and 2020. All articles addressed the theme related to access to palliative care by elderly people with Alzheimer's disease, as shown in Chart 1.

Chart 1 - Distribution of selected articles, title/author(s), journal/year/database and implications. Senhor do Bonfim (BA), Brazil, 2022.

Studies	Periodical / Year / Database	Barriers faced
E1[27]	N Engl J Med/2015/MEDLINE	Formal palliative care services are lacking in most nursing homes. Barriers to access to palliative care, particularly the requirement of a life expectancy of less than six months.
E2[33]	Int Psychogeriatr /2015/MEDLINE	The principles of palliative care are not applied. Patients with dementia are often exposed to costly interventions that have little or no benefit and receive no psychosocial treatments.
E3[18]	J Pain Symptom Manage /2014/MEDLINE	High burden of symptoms and inadequate treatment at the end of life have been reported .
E4[21]	Health Econ Policy Law /2012/MEDLINE	Formal palliative care services are lacking and most older people with dementia die in long-term care facilities. End-of-life care for older people with dementia presents special ethical challenges that make it particularly difficult to withdraw from life-sustaining treatment or shift the focus from preserving life to providing palliative care.
E5[26]	Am J Alzheimers Dis Other Demen /2012/MEDLINE	Older people are subjected to aggressive medical care with limited or no benefits. Dementia is treated conventionally using a curative model of medicine that focuses on diagnosing the disease and aggressively treating all symptoms. Lack of specialized palliative care programs for older people with advanced dementia.
E6[20]	Perspect Psychiatr Care /2020/MEDLINE	Older people with dementia are not referred to palliative care programs. Lack of recognition that dementia is a terminal illness and the difficulty of accurately estimating life expectancy.
E7[28]	J Am Geriatr Soc /2019/MEDLINE	People with dementia receive unwanted care in the final stage of life. Patients with dementia receive palliative care in community settings.
E8[19]	J Am Geriatr Soc */2018/MEDLINE*	Difficulties in recognizing Alzheimer's disease in the final stage. Low supply of home palliative care for individuals dying from Alzheimer's disease. Difficulty recognizing Alzheimer's disease as a disease from which one can die.
E9[35]	J Soc Work End Life Palliat	Challenges to the provision of end-of-life care

	Care/*2016/MEDLINE*	for older people with dementia. Lack of understanding about Alzheimer's disease.
E10[34]	J Soc Work End Life Palliat Care/*2016/MEDLINE*	Difficulty in accessing palliative care services.

After the analysis of the qualitative synthesis it was possible to identify two central points involving the barriers faced by the family in relation to access to palliative care by elderly people with Alzheimer's disease, namely:



Discussion

The increase in life expectancy, which provides many older people with the achievement of longevity, is not always accompanied by healthy aging. Many people will experience longevity accompanied by chronic and disabling diseases, with no prognosis of cure, such as Alzheimer's disease.[16]

Although in recent decades there has been a great expansion of the offer of palliative care for people with incurable diseases, this modality of care is still configured as a minimally applied assistance in relation to the need of those who need palliation,[17] which denotes the need for further discussions on the subject, so that this theme should be part of the vocabulary of society, in order to demystify the ingrained misconceptions, such as the understanding that it is a condition of terminality.

In this literature review, studies indicate that the non-recognition of AD as a progressive and irreversible disease that leads to death, implies the non-provision of palliative care for elderly people with dementia. It is noteworthy that this lack of knowledge is a reality in the daily lives of both health professionals and family members who care for people with AD.[18-20]

Studies[21] related to the US population mention a considerable expansion of palliative care in recent decades, but also point out the underutilization of this modality of care, as well as highlight the difficulty for a person with AD to have access to PC. The author points out that the limitation in the referral of elderly people diagnosed with AD to PC services is due to the

difficulty/inaccessibility of the referral process of these patients due to the lack of professional training, both related to dementia syndromes, as a disease with a limited prognosis that has phases with stagnation and exacerbation of symptoms, as well as the benefits of palliative care in promoting comfort and quality of life for these patients and their Family.[22-23]

A study[24] that aimed to identify limitations and barriers that prevent or hinder the introduction of PC showed that patients with dementia have less access to PC. This is due to the lack of knowledge about this approach, in relation to its meaning, to its correct indication, not only by family members and caregivers, but also by health professionals. Another factor pointed out in the study is that the lack of knowledge about the determination of a prognosis for AD and its progression makes the need for the introduction of palliative measures less clear to the detriment of curative measures.

In addition to the lack of knowledge, the lack of communication between professionals and the family and/or caregivers is also configured as a barrier to access so that people with AD do not receive palliative care.[24] Without adequate information, the family and caregivers, who usually go through a process of suffering, overload and guilt, may have a misinterpretation of what PC means and have the erroneous belief of being abandoning or giving up on his sick relative.

In this sense, it is important that health professionals are well trained and oriented to an adequate communication with family members and caregivers, clarifying how the progression of AD occurs and how PC can benefit both the patient and those around him, promoting comfort and relief of symptoms and providing quality of life.

Alzheimer's disease is among the six most debilitating and functionally disabling diseases that affect older people, leading these people to cognitive loss and total dependence for activities of daily living. This factor is one of the causes of transfer of elderly people to Long-Term Care Institutions for the Elderly (LTCF).[25]

A study[23] conducted in the United States, in two LTCFs, found that 90% of elderly people with advanced AD live in these institutions. The authors also highlight that 67% of dementia-related deaths occur in LTCF and that less than 17% of these people have access to PC.

Results of studies[21,26-28] showed that the lack of formal PC services for elderly people with AD who live in LTCFs is characterized as a barrier to the implementation of this care. Although LTCFs have become the place of choice for the care of an increasing number of elderly people with progressive chronic diseases, such as dementia, evidence points to limiting factors for the provision of PC. Among these factors, the following stand out: the lack of knowledge of the caregivers of the institutions about the philosophical principles and the approach to palliative care; their attitudes and beliefs about death and dying; the lack of

medical support; the lack of privacy; the expectations of families in relation to care, in addition to hospitalization in cases of exacerbations.[29]

Although the evidence points to the real benefits of the implementation of PC for elderly people with dementia, including quality of death and improvement of family satisfaction, research[30] reveals that it is difficult for health professionals to implement Palliative Care programs in LTCFs.

The lack of formal PC services in these institutions, with a multidisciplinary team trained to identify the individual needs of each resident and draw up a care plan capable of attending to the patient in the biopsychosocial and spiritual aspects, as the philosophy of the PC[31] brings, translates as a reality for most LTCFs. In addition to not having a PC team, these institutions also do not have a referral service capable of supporting those who would be eligible for this care.

Given this, it is evident the need for LTCFs to expand their knowledge, especially at the level of palliative care they provide to residents and their families, because research identifies that although there may be an understanding of what constitutes a "good death" and even an interest of the care team, few really understand what the term "palliative care" means. this includes even the managers of the LTCFs, who demonstrate a level of misunderstanding about the PCs.[29]

The understanding that Alzheimer's disease is an irreversible and progressive dementia, from which one can die, brings with it necessary reflections on the orientation of families/caregivers and health professionals for the importance of implementing palliative care for elderly people with AD. Many people have a mistaken understanding that the palliative approach is intended to hasten death, rather than affirming life, considering dying as a natural process. The practice of PC at all levels of health care should be the premise of the care provided to patients with incurable and progressive pathologies, based on the (re)humanization of the dying process, strengthening the dignity of the human person in its fullness, promoting comfort and quality of life.[32] In addition, PC discourages therapeutic obstinacy, based on technical medicine that prioritizes the disease and not the patient.

Therefore, the nursing team, for being close to the patient most of the time, must remain attentive to the real needs presented by the patient, identifying them quickly and supplying them in the best possible way, always with the help of a multidisciplinary team to discuss the measures and adjust the conducts. For this, it is necessary that the professional performs the care according to the philosophical principles of the palliative approach, which differs from an interventionist and curative care.

As limitations found during this study was found a scarcity of publications related to the theme, access to palliative care for elderly people with Alzheimer's disease. The searches were not very expressive and demonstrate that although the theme is

expanding and the evidence about its achievements growing, the theme in question needs to be better explored.

Conclusion

Given the above, this research was able to understand the challenges and limitations of access of elderly people with Alzheimer's disease in Palliative Care. It is evident that this limitation is due to several factors, from the central points identified in the works obtained in the result, such as the lack of knowledge of Alzheimer's Disease as a progressive and irreversible disease that leads to death and the lack of formal palliative care services for elderly people with AD who are in Long-Term Care Institutions, to others involving the limitation in knowledge and discussions about the theme.

Palliative care for elderly people with dementia is an important health issue, because the heavy and aggressive interventions implemented in the care of AD patients in PC increase the costs of health care without necessarily reducing the mortality rate or promoting improved quality of life. The expansion of access to quality palliative approach to AD patients, besides being relevant, is urgent, given the prevalence with which the disease is rapidly increasing.

In addition, it is important to guide the families and caregivers of elderly people with AD, as well as to train professionals about the importance of palliative care, clarifying that the approach is beneficial, centered on quality of life, without the intention of accelerating death. Thus, it is necessary to develop actions that disseminate the valuable achievements of the implementation of PC in the lives of people who have AD. This review study may compose the framework of research on the subject in order to foster discussions for the elaboration of public health policies focused on this very important theme.

Acknowledgment

This study was funded by the authors themselves.

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