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Enteral nutrition in older adults with dementia in palliative care

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Abstract

The number of older adults and, consequently, the incidence of chronic non-communicable diseases, including dementia, have increased exponentially. Dementia leads to progressive loss of functionality, including food-related complications. This article presents results of an integrative review on the current scientific evidence of enteral nutritional therapy in patients with dementia in palliative care. Articles published between 2009 and 2019 were included. Data were collected in November 2019 in five databases, based on the following search words: "enteral nutrition", "palliative care" and "dementia". After applying the inclusion criteria, 11 articles remained in the sample. The main findings of these publications were divided into three categories: "palliative care and care plan", "palliative care and enteral nutrition" and "enteral nutrition in older adults with dementia". The results call attention to the need for decision making to be based on scientific evidence.

Keywords: Dementia; Enteral Nutrition; Palliative Care.

Resumo

Nutrição enteral em idosos com demência em cuidados paliativos

O número de idosos e, consequentemente, a incidência de doenças crônicas não transmissíveis, entre elas a demência, têm aumentado exponencialmente. A demência leva a perda progressiva de funcionalidade, incluindo complicações relacionadas com alimentação. Este artigo traz resultados de revisão integrativa sobre as evidências científicas atuais da terapia nutricional enteral em pacientes com demência em cuidados paliativos. Foram incluídos artigos publicados entre 2009 e 2019. Os dados foram coletados em novembro de 2019, em cinco indexadores, a partir de busca pelos descritores "nutrição enteral", "cuidados paliativos" e "demência". Depois de aplicados os critérios de inclusão, 11 artigos compuseram a amostra. Os principais achados dessas publicações foram divididos em três categorias: "cuidados paliativos e plano de cuidados", "cuidados paliativos e nutrição enteral" e "nutrição enteral em idosos com demência". Os resultados chamam atenção para a necessidade de que a tomada de decisão se baseie em evidências científicas.

Palavras-chave: Demência. Cuidados paliativos. Nutrição enteral.

Resumen

Nutrición enteral en ancianos con demencia en cuidados paliativos

El número de ancianos y, en consecuencia, la incidencia de enfermedades crónicas no transmisibles, entre ellas la demencia, han aumentado exponencialmente. La demencia lleva a una pérdida progresiva de funcionalidad, incluidas complicaciones relacionadas con la alimentación. Este artículo presenta resultados de una revisión integrativa de las evidencias científicas actuales de la terapia nutricional enteral en pacientes con demencia en cuidados paliativos. Para ello, se incluyeron artículos publicados entre el 2009 y el 2019. Los datos se recopilaron en noviembre del 2019, en cinco indexadores, con base en los descriptores "nutrición enteral", "cuidados paliativos" y "demencia". Después de aplicados los criterios de inclusión, la muestra final consistió en 11 artículos. Los principales hallazgos de estas publicaciones se dividieron en tres categorías: "cuidados paliativos y plan de cuidados", "cuidados paliativos y nutrición enteral" y "nutrición enteral en ancianos con demencia". Los resultados llaman la atención sobre la necesidad de tomar decisiones basadas en evidencias científicas.

Palabras clave: Demencia. Cuidados paliativos. Nutrición enteral.

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Research

An intense demographic transition is currently under way in Brazil, with a rapid and exponential increase in the number of older adults in our population. We can attribute this phenomenon to several factors, such as decreased birth rates and infant mortality, increased life expectancy resulting from medical and scientific advances, increased access to health services and a lower incidence of infectious diseases. On the other hand, the increase in chronic non-communicable diseases, including dementias, marks the change in Brazilian public health [1,2].

Dementia syndromes are characterized by the presence of a progressive deficit in cognitive function compromising several brain functions, including memory, reasoning, orientation, understanding and learning ability, language, and judgment. Due to the marked loss of memory, dementia is a highly disabling chronic disease. With its progression, the individual gradually becomes dependent on daily living activities [1,3].

Dementia has several causes, some reversible and others irreversible. The most common is Alzheimer's disease, responsible for between 60% and 70% of cases [1]. According to the WHO [4], dementia affects 47 million people worldwide, being estimated that its incidence will increase to 75 million people in 2030 and 132 million in 2050. Projections for the Brazilian population point to an increase in the prevalence rate, in the 65-and-older population, from 7.6% to 7.9% between 2010 and 2020, that is, 55,000 new cases per year [1].

Scales to assess functionality are often used to define the best care plan for each patient. The most used and validated in Portuguese is the Functional Assessment Staging (Fast), which varies between stages designated with numbers from one (no objective or subjective difficulty) to seven (patient in serious condition, already presenting problems such as dysphagia, pressure injuries and sepsis) [5].

Approximately 90% of patients with dementia will develop problems related to eating, such as dysphagia, inability to eat alone and refusal to eat. Dysphagia is any difficulty in moving food from the mouth to the stomach caused by changes in the dynamics of swallowing. It is the most common reason for instituting enteral nutritional therapy, especially in a hospital environment, due to the risk of complications [5,6]. Thus, there is an indication for this therapy for older adults with severe dysphagia of neurological origin, to ensure nutritional supply, and maintain and improve nutritional status [7].

Artifices with oral nutritional supplementation or enteral nutrition are used, a procedure by which a nutrient solution is administered by tubes or orally. Enteral nutrition is used exclusively or partially to replace or complement oral feeding in patients malnourished or not, according to their nutritional needs, in hospital, outpatient or home care. The procedure aims at the synthesis or maintenance of tissues, organs or systems and is recommended when oral intake is insufficient (<60% of ideal nutritional needs), when there are diseases of the gastrointestinal tract that prevent oral feeding, and when there are alterations in the level of consciousness or impaired swallowing of muscular or neurological cause. The goal is to ensure an adequate supply of calories and the macro and micronutrients that maintain metabolism, avoiding the deleterious effects of malnutrition and sarcopenia, such as greater fragility, loss of physical performance, worsening cognitive decline, and increased rates of infections and mortality [7-11].

However, in each disease and in each of its stages, it is important to analyze the risks and benefits of nutritional therapy, considering ethical principles in decision making, such as patient autonomy and beneficence. When the nutritional picture becomes irreversible, the palliative approach should be an alternative [12]. In cases of patients who develop serious, progressive and incurable diseases, such as dementia, palliative care should be initiated from diagnosis [13].

Palliative care aims to improve the quality of life of patients and their families, relieving pain and other symptoms that cause suffering. Such care, focused on the person and not on the disease, is the only appropriate therapy during the active process of death. In dementia, besides focusing on quality of life, maintaining functionality and maximizing comfort are objectives of the care throughout the course of the disease [5].

The act of eating represents much more than the intake of calories and nutrients. It is directly related to emotional, socio-cultural, religious, and

life-long experiences. It is difficult to understand what leads the patient to lose weight – something common among patients in palliative care – without talking to family members or caregivers, who suffer and feel anguish in the face of this situation. For this reason, it is necessary to know the wishes of the patient and their family, considering the objectives of care and the stage of the disease [5,12].

Advance directives of will, guided by the bioethical principle of autonomy, allow individuals to register their will if a disease gets worse and they can no longer answer for themselves. This instrument, besides serving as an ethical and legal support for health professionals, aims to respect the will of patients, keeping them as the protagonist of their own life [13]. The awareness of dementia by the patient and their family – that is, understanding that it is a terminal illness and it is necessary to prioritize quality of life – gives them the opportunity to prepare for the proposal of end of life and decision-making [5].

This article presents the objectives of the use of enteral nutritional therapy in patients with dementia in palliative care according to the different stages of the disease, addressing its benefits and harms, as well as the ethical aspects and current scientific evidence on the topic. For this, the text brings results of an integrative review of the literature of the last ten years on enteral nutrition in patients with dementia in palliative care.

Method

We used the integrative review method to carry out this study, which allows incorporating evidence into clinical practice and synthesizing the scientific knowledge already produced on the investigated topic. The following steps were accomplished: 1) formulation of the research question; 2) establishment of inclusion and exclusion criteria; 3) definition of keywords, literature search and data collection; 4) critical analysis of the included studies and discussion of their results; and 5) synthesis of the knowledge produced [14-16].

The research question defined was: "What is the scientific knowledge produced in the literature on the use of enteral nutritional therapy in patients with dementia in palliative care?". Inclusion criteria comprised: studies published in the last 10 years (between 2009 and 2019), written in Portuguese, English or Spanish, available in full, and which addressed enteral nutrition, palliative care and dementia. Studies that addressed parenteral nutrition and that only dealt with specific diseases, such as cancer, were excluded.

Data collection was carried out in November 2019, in the databases Scientific Electronic Library Online (SciELO), Latin American and Caribbean Literature in Health Sciences (Lilacs), Capes, Cochrane and PubMed. The following keywords were used in the research, indexed in the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH), in English and Portuguese: "enteral nutrition", "palliative care" and "dementia" (*nutrição enteral*, *cuidados paliativos*, *demência*). As a search strategy, the descriptors were combined using the Boolean operators *and* and *or*.

Article analysis was performed first by reading the titles, followed by reading the abstracts and, later, reading the text in full, in addition to critical interpretation of selected articles by discussions between the researchers.

Results

The search resulted in 30 articles found in the following databases: PubMed (n = 21), Cochrane (n = 4), SciELO (n = 3), Capes Journals (n = 1) and Lilacs (n = 1). After reading the titles and abstracts and applying the inclusion criteria, 15 articles remained, which were read in full. Thus, 11 articles remained in the final selection (Figure 1).

The included studies were published between 2009 and 2019: 3 articles in 2010, 2 in 2014, 2 in 2017, and the rest (4 articles) each in a different year (2009, 2012, 2015 and 2016). In the other years considered, no productions were found that met the inclusion criteria. As for the place of origin, most studies were carried out in the United States (36.4%), followed by the United Kingdom (27.3%), Brazil (18.2%), Singapore and Chile (both with 9.1%).

As for the language, 72.7% of the articles were published in English, 18.2% in Portuguese, and 9.1% in Spanish. Table 1 presents data from the selected studies: title, authors, year of publication, country of origin, language, method used and main objectives.

Figure 1. Flowchart for article selection

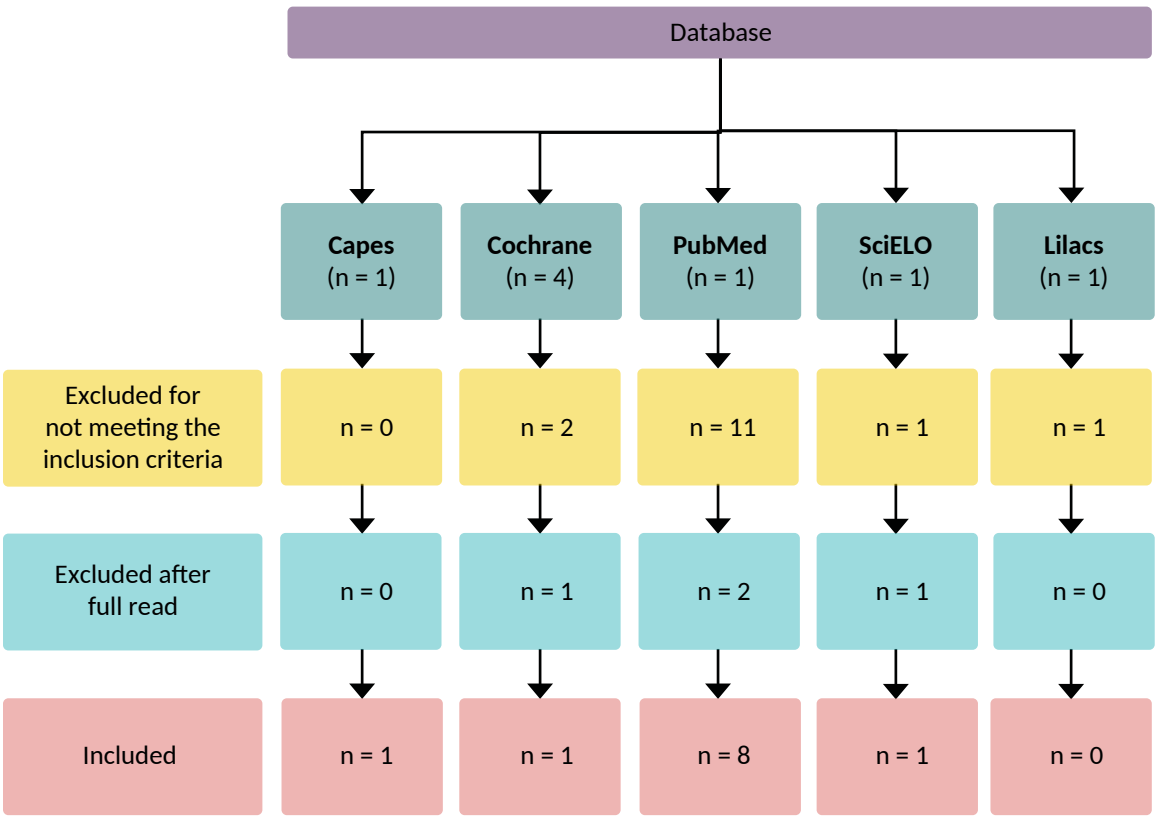

Table 1. Data summary

Title	Author(s); year of publication	Country of publication, language	Methodology	Objective
"Palliative care for people with dementia"	Sampson EL; 2010 [17]	United Kingdom, English	Integrative review	To review the literature on palliative care for patients with dementia.
"Cuidados paliativos en personas con demencia severa: reflexiones y desafíos"	Slachevsky A, Abusleme MT, Massa AA; 2016 [18]	Chile, Spanish	Narrative review	To discuss the problems generated by therapies used in patients with severe dementia, analyzing whether they are futile or excessive in the context.
"The role of gastrostomy tube placement in advanced dementia with dysphagia: a critical review"	Goldberg LS, Altman KW; 2014 [19]	USA, English	Systematic review	To evaluate the literature on gastrostomy in patients with advanced dementia and dysphagia.

continues...

Table 1. Continuation

Title	Author(s); year of publication	Country of publication, language	Methodology	Objective
"Consensos e dissensos na indicação e continuidade da terapia nutricional enteral nos cuidados paliativos de pacientes com doenças crônicas não transmissíveis"	Castro JMF, Frangella VS, Hamada MT; 2017 [20]	Brazil, Portuguese	Narrative review	To present consensus and dissent on the indication and continuation of enteral nutritional therapy in palliative care of patients with chronic diseases.
"Artificial nutrition and hydration in people with late-stage dementia"	Smith L, Ferguson R; 2017 [21]	USA, English	Narrative review	To examine evidence related to the use of nutrition and enteral hydration for patients with advanced dementia.
"Feeding decisions in advanced dementia"	Harwood RH; 2014 [22]	United Kingdom, English	Narrative review	To present the influence of nutrition and artificial hydration on advanced dementia, and the ethical and legal aspects to be considered for better decision-making.
"Enteral tube feeding for older people with advanced dementia"	Sampson EL, Candy B, Jones L; 2009 [23]	United Kingdom, English	Systematic review	To evaluate the results of enteral nutritional therapy in older people with advanced dementia who develop swallowing problems or have low food and nutritional intake.
"Ethical issues in artificial nutrition and hydration: a review"	Geppert CMA, Andrews MR, Druyan ME; 2010 [24]	USA, English	Narrative review	To assess nutrition and artificial hydration in life-threatening diseases, such as advanced dementia, and offer guidance to policy-making institutions and nutrition professionals.
"Nasogastric feeding at the end of life: a virtue ethics approach"	Krishna L; 2015 [25]	Singapore, English	Narrative review	To review the ethical and clinical impact of enteral nutritional therapy and provide information for decision-making in palliative care.
"Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia"	Palecek EJ *et al.*; 2010 [26]	USA, English	Manuscript	Encourage other feeding methods that do not use a nasogastric tube or gastrostomy, such as comfort oral feeding, as an alternative that brings a better quality of life.
"Sobrevida e complicações em idosos com doenças neurológicas em nutrição enteral"	Martins AS, Rezende NA, Torres G; 2012 [27]	Brazil, Portuguese	Observational prospective study	To evaluate the complications and survival of older adults with neurological diseases using enteral nutrition.

Research

Discussion

The review aimed to verify in the recent literature the use of enteral nutritional therapy in patients with dementia in palliative care, since it is a life-threatening chronic disease and nutrition is a marker of prognosis in these patients. To facilitate interpretation and discussion, the results were divided into three central themes: "palliative care and care plan", "palliative care and enteral nutrition" and "enteral nutrition in older adults with dementia".

Palliative care and care plan

As mentioned earlier, dementia is characterized by a progressive cognitive decline, which leads to loss of functionality and makes it an incurable chronic disease, increasing the need for non-curative treatment with a palliative approach. The goal of palliative care is to improve quality of life, maintain functionality and maximize patient comfort. Such care must be considered throughout the course of the disease, which develops in phases with different levels of functionality [5,12,17-20].

In advanced dementia, for example, patients present dependence on basic daily living activites, limited or absent verbal communication, inability to recognize family members and problems with appetite or swallowing that make feeding difficult or impossible [17,21,22]. However, Sampson, Candy, and Jones [23] emphasize that there is no consensus in the literature on what defines advanced or end-stage dementia, although many of the clinical practices are established according to the stage of the disease.

According to Harwood [22], the care plan must be very clear and previously established with the patient and their family, so that all interventions have an ethical basis, especially because decision-making is much more difficult in the advanced stage of the disease, when the patient's ability to consent is lost. The acceptance of the diagnosis of dementia and the knowledge about its natural evolution are important for the patient to prepare, by developing a care plan or advance directives of will [5]. It is up to the multidisciplinary team or the medical professional who monitors the case to clarify doubts, explain the prognosis of the disease and show alternatives to improve the quality of life of patients with dementia, preserving their autonomy and the right to be the protagonist of their own choices.

Palliative care and enteral nutrition

For the human being, eating is much more than ingesting nutrients as a means of subsistence, to regenerate organs and tissues and maintain life. Eating involves affective memories, social interactions, religion, culture and habits, which makes it a complex and quite controversial topic when approached in relation to palliative care [5,12,20].

In palliative care, nutrition is defined according to the objectives of care and the evolution of the underlying disease. It is considered an important factor, which helps treatment by delaying functional impairments and adverse events. When the disease can no longer be controlled, comfort, quality of life, and symptom relief are given priority. As the disease progresses, some individuals lose their autonomy for eating, and enteral nutrition can be established [5,20,24].

Many factors are linked to the option for enteral nutrition in palliative care, most of them related to the fear of food abstinence and the suffering it can cause in patients and their families, since food is considered a symbol of care and comfort. Its removal, along with the progression of the disease, causes weight loss, with an impact on physical, clinical, and psychosocial conditions, compromising the individual's quality of life [20,23-26].

The purpose of inserting a tube or ostomy – procedures for enteral feeding – is to prevent pneumonia, aspiration and the consequences of malnutrition, such as pressure injuries and infections, prolonging life by correcting malnutrition [23,25]. However, as the disease progresses and the patient reaches the final stage of life, the objective should no longer be nutritional adequacy, but the comfort and relief of symptoms, even if it means letting the patient remain fasting [5,12,20,24].

From the articles analyzed, the main findings are related to the inefficiency of enteral

nutrition, which does not increased survival or generated benefits such as avoiding pressure injuries, decreasing the risk of aspiration, and optimizing quality of life and comfort [18-26]. The withdrawal or suspension of nutritional support becomes an ethical dilemma, since family members, without participating in the discussion with the medical team, watch the implementation of artificial feeding in patients with advanced dementia, believing that this is the appropriate therapy. Decisions made thusly go against the principles of autonomy, beneficence and non-maleficence and the ideals of palliative care, which prioritize quality of life and consider the patient's wishes and values when defining clinical decisions [5,20,21,24,25].

Enteral nutrition in older adults with dementia

The most common complications for patients with dementia, especially at a more advanced stage, include eating-related problems: dysphagia, aspiration of food, inability to eat alone, resistance to eating, difficulty in chewing or using utensils, and changes in appetite [5,17,22-24,26]. Weight loss due to low food intake is frequent, and may occur in the early stages of the disease, even before diagnosis. However, it should be noted that the decrease in the basal metabolic rate reduces the caloric needs of these patients. As in other terminal conditions, the patient is expected to eat less as part of the natural progression at the end of life, and can maintain a minimum oral intake, sufficient to provide comfort [22,23,26].

As already mentioned, there are two alternative feeding methods when the oral route is no longer possible: the use of an enteral tube or ostomies (gastrostomy/jejunostomy). The decision on whether or not to use these methods is difficult, as it involves emotional and ethical aspects of the caregivers' practices. The adoption of procedures is often based more on individual beliefs of health professionals and family members than on scientific evidence [17,21].

The introduction or continuation of enteral nutrition in patients with dementia, although appropriate in some cases, causes greater agitation, discomfort and the need for sedation or bed restraints. There are side effects such as fluid overload, increased diuresis (leading to the need for catheterization), and respiratory and gastric secretions, which can cause nausea and vomiting. In ostomies, the surgical procedure has a high postoperative risk, including events such as aspiration pneumonia, esophageal perforation, tube migration, hemorrhage and wound infection [20,23,25].

According to the articles analyzed, there is a lack of data to corroborate long-term benefits of enteral nutrition in patients with advanced dementia. Research shows that its use does not prevent aspiration pneumonia, does not improve nutritional status and the healing of pressure injuries, does not decrease mortality or improve quality of life. There is also a lack of data on adverse effects of this intervention [17-26].

A prospective study conducted in Brazil in 2012 evaluated the complications and survival of older adults with neurological diseases using enteral nutrition, with a high degree of dependence. Most (91.2%) presented some type of complication, such as pneumonia, obstruction or loss of the tube, diarrhea, constipation, vomiting, periostomy leakage, reflux and myiasis, with a high death rate at the end of the study [27]. In a systematic review by Goldberg and Altman [19], people with gastrostomy had 54% mortality in one month and 90% mortality in one year. Other findings show that inserting gastrostomy during hospitalization increased the risk of mortality [24].

However, total suspension of enteral nutrition can cause discomfort to family members and professionals, since there is no evidence or guidelines for the continuity or suspension of the measure. Decisions are based on the patient's will or, when unable to decide for themselves, on the decision of the multiprofessional team with the consent of family members [20]. Suspending food simply restores the normal process of dying, which itself has natural analgesic and comforting properties [25].

From the legal and ethical point of view, an adult with the ability to decide can opt for the withdrawal or cessation of enteral nutrition. Furthermore, it is an act of humanity to allow death to proceed without providing nutrition/hydration

to terminally ill patients. The cause of death for patients with advanced dementia or in their final stages of life is not the suspension of nutrition or hydration, but rather the underlying disease [24].

The oral route is the preferred, physiologically adequate route for food. Depriving the patient of the taste, the sensation of different textures and flavors – and even of the interaction at the meal time –, decreases their self-esteem and dignity [5,18,20]. An alternative between enteral nutrition and suspension of food is the so-called "comfort food": administered orally, with a diet of the right consistency, to avoid the risk of aspiration but to ensure that the patient can taste the food and enjoy eating, even in advanced dementia [18,19].

Maximum patient comfort should be prioritized, with less invasive ways of providing nutrition and hydration. Respecting food preferences, non-standard routines and times, including more snacks and tidbits, can help in this strategy, since, in the advanced stages of dementia, notions of healthy eating are not as important as individual preferences for quantity and pleasure [21,22, 26].

In this way, patient-centered care reduces suffering and is an opportunity for activity, inclusion, engagement, social experience, and pleasure. Discussing the care plan with family members, writing advance directives of will, preferences and desires is the key to building open communication and a reliable relationship between patients, professionals, and family members [22].

Final considerations

The present review analyzed the recent scientific production on enteral nutrition in patients with dementia in palliative care. In case of absence of advance directives of will, given the difficulty in defining strategies for the care plan, the study hopes to provide information for decision-making based on scientific evidence, and not only on beliefs or on the routine performance of the team.

Enteral nutrition is part of a set of life-sustaining measures, essential for the recovery and maintenance of the patient's nutritional support. However, as the therapeutic objective changes, nutrition ends up becoming a futile measure, especially in end-of-life care. It is necessary to assess the real objectives of nutritional management in relation to the advanced stage of dementia, to improve the quality of life of the patients and respect their wishes and the wishes of their families. Comfort food is a viable alternative, which seeks to maintain the pleasure of food and social interaction during meals.

With the increase in life expectancy of the older population, the number of patients with dementia tends to increase. Therefore, it is necessary to educate caregivers and family members about clinical aspects and comfort measures, so that palliative care is applied from the onset of the disease. Open communication and building a trusting relationship with family members are essential in this process. Family members must be present at all stages of care, contributing to patient-centered decision-making.

Review studies have discussed the limitations of this type of intervention, as older adults in advanced stages of dementia would be unable to express their wishes. However, more recently, articles with a qualitative approach and case studies, have proposed practical communication tools that can be used by professionals with those responsible for older people [28].

The very characteristics of the topic, which refers to older adults with advanced dementia and marked cognitive impairment, who are greatly stigmatized, are factors that have limited the amount of qualitative studies worldwide – which, on the other hand, justifies the large number of reviews. In the Brazilian context, more review studies are needed to strengthen evidence-based practice and provide information for creating guidelines to guide clinical practice, as the topic is still surrounded by many taboos and ethical, emotional, religious, and cultural issues.

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Research

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