

# Difficulties Faced by Nurses in Feeding People with Advanced Dementia in Palliative Care: Scoping Review

Dificuldades dos Enfermeiros na Alimentação da Pessoa com Demência Avançada em Cuidados Paliativos: Revisão de Escopo  
Dificultades de los Enfermeros en la Alimentación de Personas con Demencia Avanzada en Cuidados Paliativos: Revisión del Alcance

## RESUMO

**Objetivo:** Mapear o conhecimento sobre as dificuldades dos enfermeiros na alimentação da pessoa com demência avançada em cuidados paliativos. **Metodologia:** Scoping Review baseada na metodologia do Joanna Briggs Institute. Utilizaram-se as bases de dados Web of Science, PubMed e B-On. Com a seguinte equação booleana a norrear a pesquisa: "(palliative care OR end-of-life OR terminal care) AND (dementia) AND (nutrition OR feeding) AND (nursing)". Foram selecionados para revisão 8 estudos. **Resultados:** As dificuldades dos enfermeiros e dos profissionais de saúde em geral na alimentação da pessoa com demência avançada em cuidados paliativos prendem-se com: formação insuficiente, comunicação ineficaz, falta de disponibilidade, recursos humanos insuficientes, trabalho em equipa ineficaz, fatores religiosos, fatores socioeconómicos e dilemas éticos. **Conclusão:** Investir na formação contínua, no desenvolvimento de estratégias de comunicação eficazes e na promoção de investigação que suporte a prática clínica quotidiana é fundamental para superar as dificuldades identificadas pelos enfermeiros.

**DESCRITORES:** Cuidados Paliativos; Demência; Alimentação; Enfermagem

## ABSTRACT

**Objective:** To map knowledge about the difficulties nurses face when feeding people with advanced dementia in palliative care. **Methodology:** Scoping Review based on the Joanna Briggs Institute methodology. The Web of Science, PubMed, and B-On databases were used. The following Boolean equation guided the search: "(palliative care OR end-of-life OR terminal care) AND (dementia) AND (nutrition OR feeding) AND (nursing)." Eight studies were selected for review. **Results:** The difficulties faced by nurses and healthcare professionals in general in feeding people with advanced dementia in palliative care are related to: insufficient training, ineffective communication, lack of availability, insufficient human resources, ineffective teamwork, religious factors, socioeconomic factors, and ethical dilemmas. **Conclusion:** Investing in continuing education, developing effective communication strategies, and promoting research that supports daily clinical practice is essential to overcome the difficulties identified by nurses.

**DESCRIPTORS:** Palliative Care; Dementia; Nutrition; Nursing

## RESUMEN

**Objetivo:** Mapear el conocimiento sobre las dificultades de los enfermeros en la alimentación de personas con demencia avanzada en cuidados paliativos. **Metodología:** Revisión exploratoria basada en la metodología del Joanna Briggs Institute. Se utilizaron las bases de datos Web of Science, PubMed y B-On. La siguiente ecuación booleana sirvió de guía para la búsqueda: «(cuidados paliativos O final de la vida O cuidados terminales) Y (demencia) Y (nutrición O alimentación) Y (enfermería)». Se seleccionaron 8 estudios para su revisión. **Resultados:** Las dificultades de los enfermeros y los profesionales de la salud en general para alimentar a las personas con demencia avanzada en cuidados paliativos están relacionadas con: formación insuficiente, comunicación ineficaz, falta de disponibilidad, recursos humanos insuficientes, trabajo en equipo ineficaz, factores religiosos, factores socioeconómicos y dilemas éticos. **Conclusión:** Invertir en formación continua, en el desarrollo de estrategias de comunicación eficaces y en la promoción de la investigación que respalde la práctica clínica diaria es fundamental para superar las dificultades identificadas por los enfermeros.

**DESCRIPTORES:** Cuidados paliativos; Demencia; Alimentación; Enfermería

### Rita Adriana Correia da Costa Pereira

Master's degree in Nursing Care for People in Palliative Situations. Nurse at the Basic Emergency Service of Hospital Conde de Bertiandos – ULSAM, Portugal.  
ORCID: <https://orcid.org/0009-0006-7566-230X>

### Bruno Miguel Gomes Pereira Feiteira

PhD in Nursing Sciences. Visiting Professor at the Polytechnic Institute of Viana do Castelo,

Portugal – School of Health Sciences. Nursing Specialist. Master's degree and Specialist in Palliative Care. Nurse Manager at Hospital da Luz – Póvoa de Varzim, Portugal.  
ORCID: <https://orcid.org/0000-0003-3530-981X>

### Maria Manuela Amorim Cerqueira

PhD in Nursing Sciences. Coordinating Professor at the Polytechnic Institute of Viana do Castelo, Portugal – School of Health Sciences. Master's degree and Specialist in Palliative

Care. Specialist in Community Nursing. Nursing UICISA  
ORCID: <https://orcid.org/0000-0001-8118-5366>

**Received:** 01/18/2026

**Approved:** 02/04/2026



## INTRODUCTION

Increased longevity and the growing incidence and prevalence of degenerative diseases such as dementia represent one of the most significant challenges for contemporary health systems and, in particular, for nursing practice. In this context, understanding the difficulties associated with feeding people with advanced dementia becomes a strategic priority to ensure dignified care.

Dementia syndromes are characterized by progressive deficits in cognitive and functional abilities, gradually making the person dependent on others for activities of daily living<sup>(12)</sup>. Dementia increases with aging and can have different possible etiologies, with Alzheimer's dementia being the most common. However, regardless of the etiology of dementia, in advanced stages the existing problems and intervention strategies are similar<sup>(3-7)</sup>.

People with dementia often lose weight due to low food intake, which can occur even in the early stages of the disease. However, it should be noted that the decrease in basal metabolic rate reduces the caloric needs of the sick person. In addition, as in other terminal conditions, people with advanced dementia are expected to eat less as part of the natural progression of the disease at the end of life, and may maintain a minimum oral intake sufficient to provide comfort<sup>(1,8)</sup>.

Tube feeding, in addition to being ethically questionable, has several disadvantages: it does not improve nutritional, functional, or cognitive status; it does not reduce the risk of aspiration; it does not prolong survival or prevent pressure ulcers; and it can cause discomfort, agitation, or complications such as leaks, infections, blockages, or displacements, which may require additional interventions that compromise the patient's dignity, such as immobilization of the limbs.

In addition, it prevents the patient from enjoying food, and in the final stages, fluid overload can aggravate respiratory secretions, dyspnea, and edema. Its only advantage is to provide standardized calories and nutrients and reduce the caregiver's time and effort<sup>(6-7, 9-14)</sup>.

Current literature does not recommend the use of tube feeding in people with advanced dementia. As an alternative, oral feeding is recommended according to the tolerance and willingness of the sick person, that is, comfort feeding<sup>(6)</sup>. Comfort feeding consists of the caregiver offering food orally, chosen according to the patient's preferences, consistency, and quantity tolerated, without causing discomfort, with the main objective of providing comfort rather than nutritional intake<sup>(6-7)</sup>. Oral feeding should be offered slowly, in small amounts, sufficient for the patient's reduced needs. Care such as oral hygiene, adequate food consistency, correct positioning during meals, an appropriate environment, the use of thickeners, and the reduction of sedative drugs that impair swallowing are essential<sup>(10,15-17)</sup>.

Addressing feeding problems in people with advanced dementia, namely the initiation or maintenance of tube feeding, is one of the main clinical decisions to be made in palliative care (PC). From an ethical and legal point of view, it is legitimate not to proceed with artificial feeding in the terminal phase of dementia if this procedure is contrary to the person's values and no benefits are expected<sup>(6,10)</sup>.

PC is fundamental in the provision of specialized care for advanced, incurable, and progressive diseases. However, people with non-oncological diseases (such as dementia) are referred to PC less frequently and later in the disease process<sup>(18)</sup>. In view of the above, we decided to conduct

a *scoping review* to map knowledge about the difficulties nurses face in feeding people with advanced dementia in CP.

## METHOD

This is a *scoping review* (ScR) study, as proposed by the *Joanna Briggs Institute* – JBI<sup>(19)</sup>.

Based on the PCC (Population, Concept, and Context) strategy, we constructed the following research question: What difficulties do nurses face when feeding people with advanced dementia in palliative care? The objective was to map the difficulties nurses face when feeding people with advanced dementia in palliative care.

The following inclusion criteria were used: articles in Portuguese, English, or Spanish, available in full text free of charge, published within the last 5 years (2019-2024), and primary studies (qualitative, quantitative, and mixed). The exclusion criteria were: literature reviews, conference articles, opinion articles, books and book chapters, conference reviews, brief comments, editorials or book reviews, theses/dissertations, or reports. Studies that did not include nurses or did not specify their participation were also excluded, as were studies that did not include the difficulties nurses face in feeding people with advanced dementia and studies that did not include PC.

In the first phase, we conducted a random and exploratory search using terms related to nurses, feeding in advanced dementia, and palliative care in order to understand which applicable descriptors were most commonly used. This search was conducted in the Virtual Health Library.

Subsequently, we defined the following Boolean equation: (palliative care OR end-of-life, OR terminal care) AND (dementia) AND (nutri-

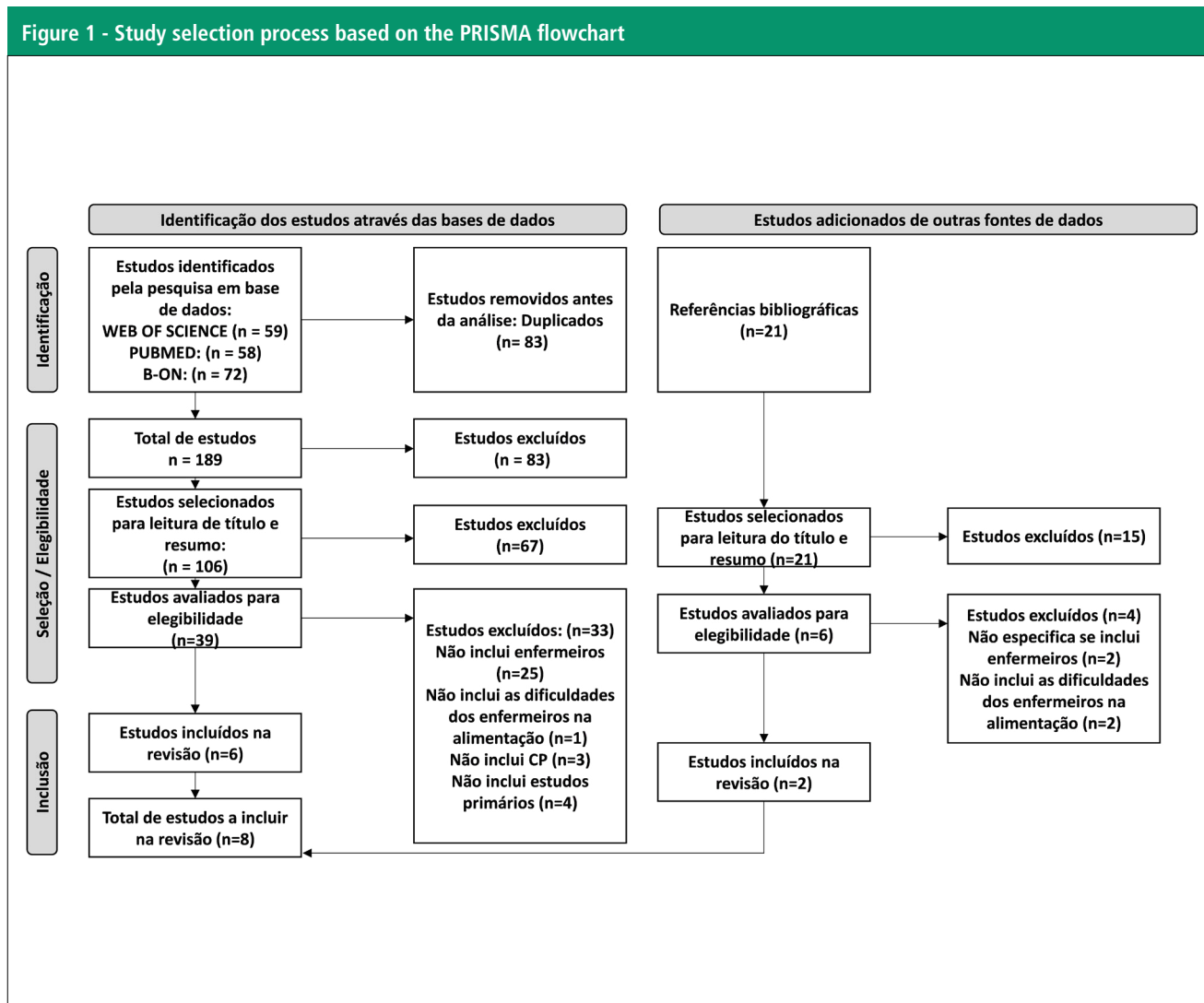
tion OR feeding) AND (nursing). This equation was used in the same way when searching the PubMed, Web of Science, and B-ON databases. The database search was conducted on October 26, 2024, at 5 p.m. Lisbon time.

## RESULTS

In the search, the results were presented using illustrations in order to systematize and make their analysis

more perceptible. A total of 189 studies were identified in the three databases (Web of Science, PUBMED, and B-ON). Duplicate studies in the different databases were excluded (a total of 83 duplicate studies), leaving 106 studies for reading the titles and abstracts, of which 39 were selected for full reading and eligibility assessment, with 33 studies excluded and 6 included in the study. All bibliographic references from the 6 included studies

were analyzed based on the inclusion and exclusion criteria, resulting in 2 additional studies, for a total of 8 studies eligible for this *scoping review*. It should be noted that studies with disagreement regarding their eligibility were discussed between the researcher and two reviewers until consensus was reached. Figure 1 shows the study selection process, using the PRISMA flowchart, adapted from the JBI.



Source: Prepared by the authors, 2025

The data extracted from the research (8 studies) are presented in a summarized form to show the final

sample of studies included in the scoping review (Table 1).

**Table 1 - Presentation of the Scoping Review studies**

No	Title	Author; Year; Country	Study design	Sample/Participants
E1	Implementation of evidence-based guidance for dementia palliative care using participatory action research: examining implementation through the Consolidated Framework for Implementation Research (CFIR)	Coffey et al. 2021 Ireland	Mixed study (pre- and post-implementation) Staff questionnaire (pre- and post-implementation) Practice audit: records of residents with dementia (pre- and post-implementation) Telephone interviews with directors (post-implementation)	Pre-implementation: Questionnaires: 69 healthcare professionals, of whom 59 are nurses or HCAs (healthcare assistants) Post-implementation: Questionnaires: 45 healthcare professionals, of whom 42 are nurses or HCAs (healthcare assistants) Interviews: 4 directors of the study sites, 3 of whom are nurses
E2	Ethical challenges in end-stage dementia: Perspectives of professionals and family care-givers	Hochwald et al. 2021 Israel	Qualitative study, semi-structured interviews	24 healthcare professionals (nurses, doctors, and social workers, 13 of whom worked in PC) and 40 family caregivers
E3	The Impact of Nursing Homes Staff Education on End-of-Life Care in Residents With Advanced Dementia: A Quality Improvement Study	Di Giulio et al. 2019 Italy	Quantitative study: multicenter, comparative, and observational	13 hours of lectures and case discussions on PC were held for professionals (346 nurses—including 46 head nurses, 140 nursing assistants, 128 physicians, 70 physical therapists, 36 occupational therapists, 24 psychologists, seven social workers, and one bioethics consultant) Analysis of medical and nursing records of 10 residents with advanced dementia who died before the training sessions and 10 who died after them
E4	The Complexity of Nutritional Problems in Persons with Dementia: Expanding a Theoretical Model	Van Buuren et al. 2023 Netherlands	Qualitative study: interviews in 3 focus groups	20 healthcare professionals (including 2 nurses) with experience in dementia and nutritional problems in dementia
E5	Eating and drinking-related care for persons with advanced dementia in long-term care	Lockett et al. 2023 Australia	Qualitative study: observation of 36 family conferences, recorded on audio, of which 32 included the person with advanced dementia and care related to eating/hydration	Healthcare professionals, including at least 32 nurses and at least 32 family members
E6	A bridge to cross: Tube feeding and the barriers to implementation of palliative care for the advanced dementia patient	Greenfeld et al. 2022 Israel	Qualitative study: semi-structured, face-to-face interviews.	27 healthcare professionals (13 nurses, 6 physicians, 5 nutritionists, and 3 social workers)
E7	Barriers to Staff Involvement in End-of-Life Decision-Making for Long-Term Care Residents with Dementia	Sutherland, et al. 2019 Canada	Qualitative study: semi-structured interviews	12 nurses and 9 healthcare assistants
E8	Dementia palliative care: A multi-site survey of long-term care STAFF'S education needs and readiness to change	Timmons et al. 2021 Ireland	Quantitative study: cross-sectional, descriptive, and correlational	69 healthcare professionals (32 nurses, 27 healthcare assistants, and 10 other healthcare professionals, including 6 geriatricians, 2 pharmacists, 1

Source: Prepared by the authors, 2025

The 8 selected studies were published between 2019 and 2023. We found that 2 studies were published in 2019, 3 studies were published in 2021, 1 study was published in 2022, and 2 studies were published in 2023. As of the date of the search, no eligible studies published in 2024 had

been identified.

In terms of study type, most were qualitative (5 studies), 2 were quantitative, and 1 was mixed.

In terms of nationality, we found that this topic has been studied in several countries, namely Ireland, Israel, Italy, the Netherlands, Australia, and Canada, which shows a cross-cutting

and international concern.

We also present the objectives and results of the studies comprising the final sample, with reference to the objective of the *scoping review* (Table 2).

**Table 2 - Summary of the objectives and results of the Scoping Review studies**

No.	Objectives	Results
E	Identify and explore factors that affect the implementation of CP guidelines in people with dementia.	Demotivation and resistance to change among staff; lack of time and human resources to implement training; unwillingness to attend training; low awareness of learning needs; limited support from healthcare staff; need to involve all professionals; insufficient continuity of care.
E2	Explore and describe differences and similarities in the perceptions of healthcare professionals and family members regarding care for people with advanced dementia.	Difficulty in recognizing dementia as a terminal illness; ethical dilemmas in CP; communication and resource failures; lack of knowledge of the patient's wishes; difficulty in deciding on artificial feeding; difficulty in addressing the end of life; differences between professionals and family members about CP in advanced dementia.
E3	Compare end-of-life care for people with advanced dementia before and after training in CP.	Before training: communication gap between professionals and families; lack of recognition of dementia as a terminal illness; lack of training. After training: improvement in the quality of care, especially in the palliative approach to feeding and hydration.
E4	Explore the scope and applicability of a theoretical model of nutritional problems in people with dementia.	Difficulties in decision-making due to ethical and moral dilemmas; late detection of eating problems; poor multidisciplinary collaboration; lack of knowledge about eating problems and which professional to consult; lack of continuity of care; shortage of professionals and time; inability of people with advanced dementia to make decisions; ineffective communication and religious differences between professionals and family members.
E5	Explore decision-making and care planning regarding feeding and hydration in family meetings for people with advanced dementia.	Difficulty for clinicians to involve families in decision-making; predominance of clinician-led decisions; ineffective communication; need for greater empathy; need to teach family members about manual oral feeding care for people with dementia.
E6	Clarify the attitudes and knowledge of healthcare professionals in decision-making about feeding difficulties and tube feeding in people with advanced dementia in PC.	Lack of understanding of the concept of "comfort feeding"; lack of training in nutrition in advanced dementia; difficulty in managing religious, cultural, social, and economic differences in decisions about artificial feeding; residential facilities with greater use of feeding tubes associated with lower costs for families and patients.
E7	Analyze barriers and facilitators to the involvement of the healthcare team in decision-making about end-of-life care in people with advanced dementia.	Lack of training; failure to apply a holistic model of care; discomfort of the team in discussing death; lack of time; lack of knowledge of patients' preferences; ineffective communication with family members; fear of providing incorrect information about the predictable course of the disease.
E8	Analyze the situational status of three long-term residential care facilities prior to implementing training for staff on PC in dementia.	Lack of training in PC in dementia, especially in therapeutic management, pain control, and nutrition/hydration; staff demotivation and powerlessness to change.

Source: Prepared by the authors, 2025

In order to summarize the results, we present the following table, which shows the difficulties nurses face in feeding people with advanced dementia in palliative care (Table 3).

**Table 3 - Difficulties experienced by nurses in feeding people with advanced dementia in CP**

Difficulties experienced	Studies referenced	Number of references (n)	FR (%)
Insufficient training	E1, E2, E3, E4 E5, E6, E7, E8	8	100
Ineffective communication	E2, E3, E4, E5, E7, E8	6	75
Lack of availability	E1, E4, E7	3	37,5
Insufficient human resources	E1, E2, E4	3	37,5
Ineffective teamwork	E1, E4, E8	3	37,5
Religious factors	E2, E4, E6	3	37,5
Socioeconomic factors	E4, E6	2	25
Ethical dilemmas	E2, E4	2	25

Source: Prepared by the authors, 2025

After analyzing the results, eight categories emerged regarding the difficulties nurses face in caring for people with advanced dementia in PC. These categories include: insufficient training, ineffective communication, lack of availability, insufficient human resources, ineffective teamwork, religious factors, socioeconomic factors, and ethical dilemmas. Of the categories defined, insufficient training is the most frequently mentioned category, having been identified in 100% of the studies, followed by ineffective communication, present in 75% of the studies. The remaining categories range from 25% to 37.5% of the studies.

## DISCUSSION

Dementia is a disease whose incidence increases with aging. It is degenerative in nature, causing a progressive decline in a person's cognitive and functional abilities, leading in its advanced stages to dependence on self-care<sup>(1-2)</sup>. Dysphagia is common in people with dementia and can cause dehydration, weight loss, malnutrition, and aspiration pneumonia. It is estimated to affect about 45% of institutionalized people with dementia<sup>(9)</sup>. People with advanced dementia have complex healthcare needs and benefit from PC, which promotes symptom relief and comfort<sup>(20)</sup>.

The analysis of scientific literature identifies several difficulties encountered by nurses in feeding people with advanced dementia in palliative care, notably: insufficient training<sup>21-28</sup>, ineffective communication<sup>22-25, 27-28</sup>, lack of availability<sup>(21,24,27)</sup>, insufficient human resources<sup>(21-22,24)</sup>, ineffective teamwork<sup>(21,24,28)</sup>, religious factors<sup>(22,24,26)</sup>, socioeconomic factors<sup>(24,26)</sup> and ethical dilemmas<sup>(22,24)</sup>.

Insufficient training is the main difficulty faced by nurses when feeding people with advanced dementia

in PC. All studies identify insufficient training as a limitation<sup>(21-28)</sup>. In fact, the study by Branco & Capelas<sup>(29)</sup> also states that healthcare professionals have a training deficit in the area of dementia and CP. Similarly, Bolt et al.<sup>(30)</sup> in a study of 416 nurses who had been working with people with dementia for an average of 15.6 years, reveal that the majority have no additional training in CP (56%).

Nurses emphasize the need for training in strategies that facilitate oral feeding<sup>(24-25)</sup> and identify the late recognition of difficulties in feeding sick people as a barrier<sup>(24)</sup>, as well as a lack of understanding of the term "comfort feeding"<sup>(26)</sup>. The lack of knowledge and training on feeding in advanced dementia is further evidenced in the study by Greenfeld et al.<sup>(26)</sup> where most of the health professionals interviewed expressed the belief that tube feeding prolongs life or prevents clinical complications. In fact, current literature recommends oral feeding according to the tolerance and willingness of the person with advanced dementia, i.e., comfort feeding, and does not recommend the use of feeding tubes<sup>(6)</sup>, except as a temporary measure where the causes of appetite and weight loss are reversible<sup>(10,31)</sup>.

Insufficient human resources and precarious employment contribute to the late recognition of the difficulties inherent in feeding sick people and cause a lack of continuity of care, disrupting in-depth knowledge of the needs of people with advanced dementia and their families. This result is consistent with the findings of Gomes<sup>(32)</sup>, who, in a qualitative study, reports that CP nurses do not have enough time to perform all interventions with quality and that most professionals feel demoralized.

In addition to insufficient human resources, there is a lack of availability of health professionals for

the multidisciplinary care of people with advanced dementia and eating problems<sup>(21-22,24)</sup>. Nurses report that the lack of time to feed people with dementia results in rushed feeding/hydration, which can lead to an increased risk of aspiration. This lack of availability also applies to the difficulty in attending training aimed at CP in dementia, especially when it takes place during working hours<sup>(21)</sup>. In fact, Midtbust et al.<sup>(33)</sup> in a qualitative study of 20 nurses found that time pressure and increased care demands cause professionals more pressure and difficulty in providing care.

Analysis of the studies revealed that nurses identify ineffective teamwork as a perceived difficulty<sup>(21,24,28)</sup>. The lack of collaboration among nurses may result from a lack of knowledge, limited availability, and a shortage of professionals permanently assigned to care units, disrupting continuity of care<sup>(24)</sup>. This set of factors leads to demotivation and the team's inability to change. In fact, Midtbust et al.<sup>(33)</sup> show in their study that the extensive use of temporary staff among nurses and doctors threatens the continuity and planning of palliative care.

Ineffective communication is another difficulty experienced by nurses. These communication deficits can occur both between healthcare professionals and between healthcare professionals and family members<sup>(22-25, 27-28)</sup>. Based on Lockett's findings<sup>(25)</sup> we can see that decisions are very much centered on healthcare professionals and that there is no real openness for the person and family to be an active part of this decision-making process. In fact, Cunha et al.<sup>(34)</sup> & Lopes et al.<sup>(35)</sup> emphasize the importance of Family Conferences to optimize communication between healthcare professionals, the family, and the person, facilitating the decision-making process.

Difficulties in communication be-

tween healthcare professionals and family members interfere with the family's understanding and consensus on the overall goals of care. Any discussion of artificial nutrition/hydration should be supported by evidence, and alternatives that support quality of life should be presented<sup>(24-25)</sup>. On the other hand, the empathetic attitude of healthcare professionals is said to be constructive in shared decision-making with family members<sup>(25)</sup>. In fact, Rainsford et al.<sup>(36)</sup> state that transparent communication and a collaborative approach are crucial for shared decision-making.

Decision-making by healthcare professionals and family members is complex when it comes to people with advanced dementia, as they are no longer able to exercise their autonomy and due to all the ethical issues involved<sup>(22,24)</sup>. These decisions are not always consensual when nutritional intake becomes (almost) impossible or unsafe, especially when norms and values regarding the end of life differ<sup>(25)</sup>. The ethical dilemmas in PC mainly concern the choice of "comfort" over "life prolongation," clarifying the prior wishes of people with advanced dementia, and the decision whether or not to use artificial feeding<sup>(22,23)</sup>. Indeed, Bolt et al.<sup>(30)</sup> report that in end-of-life communication, the greatest difficulties encountered by nurses are dealing with family disagreements (58%) and involving people with dementia in end-of-life decision-making (41%).

The guidelines dictated by the religious beliefs of family members related to the "sanctity of life" or "starving to death" are another difficulty encountered. In this context, finding a balance between being professional and showing respect for religion was considered important<sup>(24)</sup>. Gil et al.<sup>(37)</sup>, in a study conducted in Israel with 17 family members of people with advanced dementia from different re-

ligions (mostly Judaism, Christianity, and Islam), found that despite being provided with detailed information about the ineffectiveness of feeding tubes, the vast majority of family members opted for their placement. All interpreted "God's will" or religion as supporting the use of the procedure rather than comfort feeding. In fact, Clarfield et al.<sup>(38)</sup> in a comparative study found that the use of feeding tubes in dementia in hospitals in Israel (52.9%) was much more prevalent than in Canada (11%). It was found that people with dementia who are Jewish have higher rates of feeding tube use.

Economic conditions also influence the decisions made by both family members and healthcare professionals<sup>(24,26)</sup>. In fact, Mitchell et al.<sup>(39)</sup> in a study comparing the costs associated with caring for nursing home residents with dementia, with and without feeding tubes, suggest that there are financial incentives to place feeding tubes in residents with advanced dementia. Indeed, Finucane et al.<sup>(46)</sup> also note that financial incentives favor tube feeding for gastroenterologists, hospitals, and residential facilities for the elderly.

This *scoping review* has some limitations, namely the inclusion of studies published only in Portuguese, Spanish, and English, and the use of articles with free full access can be pointed out as another limitation.

## CONCLUSION

The provision of CP to people with dementia and their families is essential to ensure quality of life and minimize suffering. Due to the complexity of the disease, which affects multiple dimensions of the individual, nurses must be prepared to respond to physical, emotional, social, and spiritual needs, ensuring humane care at all stages of dementia.

The main difficulty in feeding people with advanced dementia is the lack of training of health professionals, which directly influences the quality of care. Other barriers include ineffective communication between professionals and family members, insufficient and high turnover of human resources, lack of permanent teams, and poor continuity of care, hindering the early detection of feeding problems, the implementation of comfort feeding, and the education of family members.

Ineffective teamwork and limited collaboration between multidisciplinary professionals increase demotivation, which is exacerbated by knowledge gaps, poor communication, and lack of availability. Socio-economic and religious factors and ethical dilemmas make care decisions complex, especially when people with advanced dementia are unable to make decisions, requiring dialogue and consensus between professionals and families.

It is therefore increasingly urgent to invest in research and training in PC, particularly on caring for people with dementia involving complex areas such as eating disorders .

## References

1. Ciccarelli P, Mattos E. Nutrição enteral em idosos com demência em cuidados paliativos. *Rev Bioét.* 2021;29(2). Disponível em: <http://dx.doi.org/10.1590/1983-80422021292480>
2. Dias D, Rezende N, Freitas F, Lobo R. Os impactos da alimentação na pessoa idosa com Alzheimer. *Contribuciones a las Ciencias Sociales.* 2024;17(12):1-23. Disponível em: <file:///C:/Users/AEPL%20-%20PF%C2%BA%20JO%-C3%83O/Downloads/314+N12+Contribuciones.pdf>
3. Santana I, Cunha L. Demências: manual para médicos. Coimbra: Faculdade de Medicina da Universidade de Coimbra; 2005.
4. Santana I, Farinha F, Freitas S, Rodrigues V, Carvalho A. Epidemiologia da demência e da doença de Alzheimer em Portugal: estimativas da prevalência e dos encargos financeiros com a medicação. *Acta Med Port.* 2015;28(2):182-188.
5. Parnera J, Nitri R. Demências: da investigação ao diagnóstico. *Rev Med (São Paulo).* 2015;94(3):179-184. Disponível em: <http://dx.doi.org/10.11606/issn.1679-9836.v94i3p179-184>
6. Pessoa A, Almeida P, Marinho R, Duque F, Amaral T, Pinho J, et al. Alimentação na demência avançada: Documento de Consenso da Sociedade Portuguesa de Medicina Interna e da Associação Portuguesa de Nutrição Entérica e Parentérica. *Rev Soc Port Med Interna.* 2020;27(1):81-88.
7. Coelho V, Vidal E. Alimentação em pacientes com demência avançada: o que precisa saber? Botucatu: Faculdade de Medicina de Botucatu – UNESP; 2021. 23 p.
8. Hoffer J. Tube feeding in advanced dementia: the metabolic perspective. *BMJ.* 2006;333:1214-1215. Disponível em: <http://www.bmj.com/content/333/7580/1214.full>
9. Easterling C, Robbins E. Dementia and dysphagia. *Geriatr Nurs.* 2008;29:275-285. Disponível em: <https://doi.org/10.1016/j.gerinurse.2007.10.015>
10. Neto I, editor. Manual de cuidados paliativos. 2ª ed. Lisboa: Núcleo de Cuidados Paliativos, Faculdade de Medicina da Universidade de Lisboa; 2010. p. 247-263.
11. Burlá C, Azevedo D. Cuidados paliativos nas demências. In: Carvalho R, Parsons H, editores. Manual de cuidados paliativos. 2ª ed. Rio de Janeiro: Academia Nacional de Cuidados Paliativos; 2012.
12. Esquível S, Sampaio J, Silva C. Alimentar a vida ou sustentar a morte? Uma reflexão em equipa partindo de um caso clínico. *Rev Port Med Geral Fam.* 2014;30(1):44-49. Disponível em: <http://www.rpmgf.pt/ojs/index.php/rpmgf/article/view/11243/10968>
13. Sapeta P, Alves D. Alimentação entérica na pessoa com demência: efeitos, indicações e benefícios. *Rev Ibero-Am Saúde Envelhec.* 2016;2(1):422-437.
14. Barcellos A, Santos A, Sales M. Hidratação e nutrição na demência. São Paulo: Academia Nacional de Cuidados Paliativos; 2020. 32 p.
15. Busto F, et al. Abordaje de la disfagia en la demencia avanzada. *Rev Esp Geriatr Gerontol.* 2009;44(Supl 2):29-36.
16. Gallagher R. Swallowing difficulties: a prognostic report. *Can Fam Physician.* 2011;57:1407-1409. Disponível em: <http://www.cfp.ca/content/57/12/1407.short>
17. Santos B, Andrade M, Silva R, Menezes E. Disfagia no idoso em instituições de longa permanência: revisão sistemática da literatura. *Rev CEFAC.* 2018;20(1):123-130. Disponível em: [http://www.scielo.br/pdf/rcefac/v20n1/pt\\_1982-0216-rcefac-20-01-00123.pdf](http://www.scielo.br/pdf/rcefac/v20n1/pt_1982-0216-rcefac-20-01-00123.pdf)
18. Baptista M. Cuidados paliativos em doentes não-oncológicos: as mesmas necessidades e as mesmas respostas? [dissertação]. Univ. da Beira Interior; 2022. Disponível em: <http://hdl.handle.net/10400.6/12871>
19. Aromataris E, Lockwood C, Porritt K, Pilla B, Jordan Z, editores. JBI manual for evidence synthesis. 2024. Disponível em: <https://synthesismanual.jbi.global>
20. Eisenmann Y, Golla H, Schmidt H, Voltz R, Perrar K. Palliative care in advanced dementia. *Front Psychiatry.* 2020;11:699. Disponível em: <https://pmc.ncbi.nlm.nih.gov/articles/PMC7394698/>
21. Coffey A, Hartigan I, Timmons S, Buckley C, Lehane E, O'Loughlin C, et al. Implementation of evidence-based guidance for dementia palliative care. *Implement Sci Commun.* 2021;2(1):137. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/34895359/>
22. Hochwald IH, Yakov G, Radomyslsky Z, Danon Y, Nissanholtz-Gannot R. Ethical challenges in end-stage dementia. *Nurs Ethics.* 2021;28(7-8):1228-1243. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/34112013/>

23. Di Giulio P, Finetti S, Giunco F, Basso I, Rosa D, Pettenati F, et al. The impact of nursing homes staff education on end-of-life care in residents with advanced dementia. *J Pain Symptom Manage*. 2019;57(1):93-99. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/30315916/>
24. Van Buuren C, Van der Steen J, Olthof-Nefkens M, Bakker C, Koopmans R, Perry M, et al. The complexity of nutritional problems in persons with dementia. *J Alzheimers Dis*. 2023;96(1):183-192. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/37742638/>
25. Luckett T, Pond D, Mitchell G, Chenoweth L, Amgarth-Duff I, Disalvo D, et al. Eating and drinking-related care for persons with advanced dementia in long-term care. *Collegian*. 2023;30(4):548-556. Disponível em: <https://www.sciencedirect.com/science/article/pii/S1322769623000306>
26. Greenfeld MS, Gil E, Agmon M. A bridge to cross: tube feeding and barriers to implementation of palliative care for the advanced dementia patient. *J Clin Nurs*. 2022;31(13-14):1826-1834. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/32734659/>
27. Sutherland N, Wiersma E, Vangel P. Barriers to staff involvement in end-of-life decision-making for long-term care residents with dementia. *Can J Aging*. 2019;38(3):255-267. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/30739636/>
28. Timmons S, O'Loughlin C, Buckley C, Cornally N, Hartigan I, Lehane E, et al. Dementia palliative care: a multi-site survey of staff education needs and readiness to change. *Nurse Educ Pract*. 2021;52:103006. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/33690020/>
29. Branco N, Capelas M. Fatores que condicionam a acessibilidade aos cuidados paliativos dos doentes com demência. *Cad Saúde*. 2020;12(1):41-46. Disponível em: <https://doi.org/10.34632/cadernosdesaude.2020.5833>
30. Bolt S, Meijers J, Van der Steen J, Schols J, Zwakhalen S. Nursing Staff Needs in Providing Palliative Care for Persons With Dementia at Home or in Nursing Homes: A Survey. *J Nurs Scholarsh*. 2020;52(2):164-173. Disponível em: <https://pmc.ncbi.nlm.nih.gov/articles/PMC7078976/>
31. Davies N, Barrado-Martín Y, Vickerstaff V, Rait G, Fukui A, Candy B, et al. Enteral tube feeding for people with severe dementia. *Cochrane Database Syst Rev*. 2021 Aug 13;8(8):CD013503. Disponível em: <https://pmc.ncbi.nlm.nih.gov/articles/PMC8407048/>
32. Gomes M. A escassez de tempo como limitação à prática de enfermagem numa Unidade de Cuidados Paliativos [dissertação]. Lisboa: Univ. de Lisboa; 2024. Disponível em: [https://repositorio.ulisboa.pt/bitstream/10400.5/95727/1/13385\\_Tese.pdf](https://repositorio.ulisboa.pt/bitstream/10400.5/95727/1/13385_Tese.pdf)
33. Midtbust M, Alnes R, Gjengedal E, Lykkeslet E. Perceived barriers and facilitators in providing palliative care for people with severe dementia. *BMC Health Serv Res*. 2018;18:709. Disponível em: <https://link.springer.com/article/10.1186/s12913-018-3515-x>
34. Cunha D, Carvalho P, Anastácio Z. Diretrizes práticas na conferência familiar em cuidados paliativos: uma visão integrativa. *Int J Dev Educ Psychol*. 2024;2(1):39-48.
35. Lopes F, Paiva G, Arrais R, Giaxa R. Online family meetings: a significant care resource during the pandemic. *Cad ESP CE*. 2022;16(1):116-121.
36. Rainsford S, Dykgraaf SH, Kasim R, Phillips C, Glasgow N. Strengthening advance care planning in rural residential aged care through multidisciplinary educational case conferences: A hybrid implementation effectiveness study. *Prog Palliat Care*. 2021;29(4):199-208. Disponível em: <https://doi.org/10.1080/09699260.2021.1872136>
37. Gil E, Agmon M, Hirsch A, Ziv M, Zisberg A. Dilemmas for guardians of patients with advanced dementia regarding tube feeding. *Age Ageing*. 2018;47(1):138-143. Disponível em: <https://doi.org/10.1093/ageing/afx161>
38. Clarfield A, Monette J, Bergman H, Monette M, Ben-Israel Y, Caine Y, et al. Enteral feeding in end-stage dementia: a comparison of religious, ethnic, and national differences in Canada and Israel. *J Gerontol A Biol Sci Med Sci*. 2006;61(6):621-627. Disponível em: <https://pubmed.ncbi.nlm.nih.gov/16799146/>
39. Mitchell S, Buchanan J, Littlehale S, Hamel M. Tube-feeding versus hand-feeding nursing home residents with advanced dementia: a cost comparison. *J Am Med Dir Assoc*. 2003;4(1):27-33. Disponível em: <https://www.sciencedirect.com/science/article/pii/S1525861004702613>
40. Finucane T, Christmas C, Leff B. Tube feeding in dementia: how incentives undermine health care quality and patient safety. *J Am Med Dir Assoc*. 2007;8(4):205-208. Disponível em: <https://doi.org/10.1016/j.jamda.2007.01.007>