

BARRIERS ASSOCIATED WITH PALLIATIVE CARE IN DEMENTIA: A REVIEW OF THE LITERATURE

Barreiras associadas aos cuidados na demência: uma revisão da literatura

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ABSTRACT

INTRODUCTION: Dementia syndromes are a major cause of mortality and disability in the population. Although these patients bear a high burden of symptoms and comorbidities, the provision of palliative care is delayed until there are excessive symptoms or death is near. **OBJECTIVE:** To undertake an integrative review of the literature that addresses palliative care in the dementia syndromes, identifying limitations and barriers that preclude or hinder the introduction of palliative care for patients with dementia. **METHOD:** The MEDLINE (via PubMed), WEB OF KNOWLEDGE, and SCOPUS databases and the SCIELO Digital Library were searched to identify articles published in the last 10 years that addressed barriers to the introduction of palliative care in dementia. **RESULTS:** Six articles were identified, which discussed the following as main barriers: lack of knowledge, unpredictability of the disease, lack of criteria for indications, lack of communication, limited access and resources, beliefs and preconceptions in relation to death, and refusal by the patient and family. **CONCLUSION:** Additional investment is needed in education of professionals and the population on the indications and importance of palliative care, as well as in communication strategies as a way to facilitate the effective introduction of such care for people with dementia syndromes.

KEYWORDS: palliative care; hospice care; dementia; prognosis.

RESUMO

INTRODUÇÃO: A síndrome demencial destaca-se como importante causa de mortalidade e incapacidade na população. Apesar dos pacientes sofrerem elevada sobrecarga de sintomas e comorbidades, a introdução dos cuidados paliativos acontece de forma tardia em casos em que há excesso de sintomas ou proximidade da morte. **OBJETIVO:** Buscou-se realizar uma revisão integrativa da literatura que aborda os cuidados paliativos na síndrome demencial, identificando limitações e barreiras que impedem ou dificultam a introdução dos cuidados paliativos para pacientes com demência. **MÉTODOS:** Os termos e palavras-chave utilizados foram combinados nas bases de dados PubMed, Web of Knowledge e Scopus, e na Biblioteca Digital SciELO, para identificar os artigos dos últimos dez anos que abordassem as barreiras para introdução dos cuidados paliativos na demência. **RESULTADOS:** Foram identificados seis artigos que discutiam como principais barreiras: falta de conhecimento, imprevisibilidade da doença, ausência de critérios para indicação, falha na comunicação, acesso e recursos limitados, crenças e preconceitos em relação à morte e recusa por parte dos pacientes e familiares. **CONCLUSÃO:** É necessário investir na educação dos profissionais e da população sobre as indicações e a importância dos cuidados paliativos, e em estratégias de comunicação como forma de facilitar a introdução desses cuidados de forma eficaz para portadores de síndrome demencial.

PALAVRAS-CHAVE: cuidados paliativos; cuidados a doentes terminais; demência; prognóstico.

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Received on: 02/21/2018. Accepted on: 04/05/2018

DOI: 10.5327/Z2447-211520181800014

INTRODUCTION

The proportion of older adults in the world population is increasing progressively and significantly. This demographic transition, which is attributable primarily to medical advances in disease treatment and prevention, brings about changes in the morbidity and mortality patterns of the population, increasing vulnerability to the development and chronic progression of diseases.¹ The reductions in death rates and increases in prevalence of chronic diseases seem to be proportional to the socioeconomic development of the region of analysis,² which is consistent with health care in poor regions being more limited.

Despite broad etiological variation, chronic diseases generally have a slow, uncertain, progressive course with a low likelihood of cure; thus, they are associated with a great need for health services utilization, as well as declines in quality of life and functioning.³ In this context, there is evidence that more and more people are dying from dementia-related causes, which, in recent years, have become a leading cause of death and disability worldwide.⁴⁻⁶

In recent decades, investigators have searched for ways to respond to these emerging population needs. Cicely Saunders is widely recognized as the pioneer who improved the practice and philosophy of palliative care (PC) by initiating the modern hospice movement in the 1960s and founding, in her native UK, an institution that sought to care for patients at the end of life regardless of illness, religion, or social class.^{7,8}

The World Health Organization (WHO) defines PC as

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.⁹

Many professionals disregard the importance or necessity of this type of care for patients outside the context of terminal cancer, although it has been extensively demonstrated that patients with chronic diseases other than cancer experience a high symptom burden, great psychological distress, and a lack of communication and information about their condition.¹⁰ This situation is particularly important for patients with dementia syndromes (DS), diseases with a complex clinical picture and extended course that cause high rates of cognitive, functional, and physical impairment.¹¹

A person with DS may require PC at any stage of the disease process, as DS has a protracted course and most people die with dementia, not of dementia.¹² In addition, at the more advanced stages of illness, these patients require ongoing caregiver assistance for physiological needs, transportation, and personal care, such as eating, bathing, and dressing, which places a heavy burden on caregivers.¹³ These challenges, compounded by a lack of support and guidance on health, can contribute to an increased need for hospital admissions. This is corroborated by a previous Brazilian study that observed a significant increase in the number of in-hospital versus in-home deaths over the years, representing an economic and social challenge.²

Despite these needs, there is still a high prevalence of late PC initiation, when patients are experiencing excessive symptoms or are already in their last days of life.¹⁴⁻¹⁶ In addition, despite the benefits of PC to patients with DS, the true role of this approach is still poorly understood, raises many questions and faces several barriers, especially when it comes to initiation, as most of the scientific evidence supporting PC is from cancer patients and the majority of PC interventions were developed for this population.¹⁶⁻¹⁸

OBJECTIVE

The objective of this study was to carry out an integrative review of the literature that addresses PC in DS, identifying limitations and barriers that prevent or hinder the initiation of PC for patients with dementia.

METHODS

The MEDLINE (via PubMed), Web of Knowledge, and Scopus databases, as well as the SciELO Digital Library, were searched for this review. The terms and keywords used were combined through the use of search operators; however, as there are differences between the indexing processes of the aforementioned databases, the decision was made not to use standardized descriptors. The search strategy focused on articles that addressed: the timing of initiation or referral for PC; and the barriers, obstacles, adversities, or difficulties involved in initiating PC for patients with a diagnosis of dementia.

PC teams or services were defined as those composed of a multidisciplinary team, with professionals trained and qualified for this role, who worked in dedicated PC units, in-hospital support teams, home care teams, or hospice services.

The search was limited to scientific articles published between 2007 and 2017, in Portuguese or English, in adult populations (age 18 years or older), with no limitations on study setting, design, or quality. Articles with the following characteristics were excluded: literature reviews or editorials, articles that did not focus on patients with DS, or studies that somehow did not meet the objectives of this study, even if they addressed the topic of interest.

The articles selected were analyzed for their results and considerations on the topic of interest. The findings of this analysis were then described. The article selection process is summarized in Figure 1.

RESULTS

Six studies analyzed the timing of PC initiation from the point of view of health professionals, patients, and families, collecting information through questionnaires, medical records, or charts, and were selected for analysis. The selected studies highlight the main barriers that prevent initiation or transition of patients with dementia to palliative care. A summary of the characteristics of these studies, and the main barriers and limitations they report, is provided in Chart 1.

Seven barriers which hinder initiation of PC or lead to delayed reception of such care throughout the course of DS

were reported in the selected studies. Furthermore, Beernaert et al.,¹⁹ Ouchi et al.,²¹ and Beernaert et al.¹⁵ reported that patients who benefit from this approach do not receive it in the same quantity and intensity as compared with cancer patients.

These differences were described in several of the selected studies; notably, Beernaert et al.¹⁹ showed that patients with dementia are less likely to be referred to PC than cancer patients. In their sample, only 37% of patients with severe dementia received PC for physical and psychosocial symptoms, 23% less than in the cancer group; accordingly, they belonged to the group of patients with higher rates of symptoms such as pain, breathing difficulties, and psychological symptoms. This study also demonstrated that the timing of referral to specialized PC teams was also affected, with a lower median days between referral and death for patients with dementia (14 days) than for those with cancer (20 days).

Another study by Beernaert et al.¹⁵ found that only 48% of end-of-life patients with DS used a PC service, with an average referral time of 8 days before death, while almost all patients with cancer used such services, with an average referral time of 16 days before death.

Ouchi et al.²¹ found that only 49% of patients with severe DS received some form of PC consult during hospitalization,

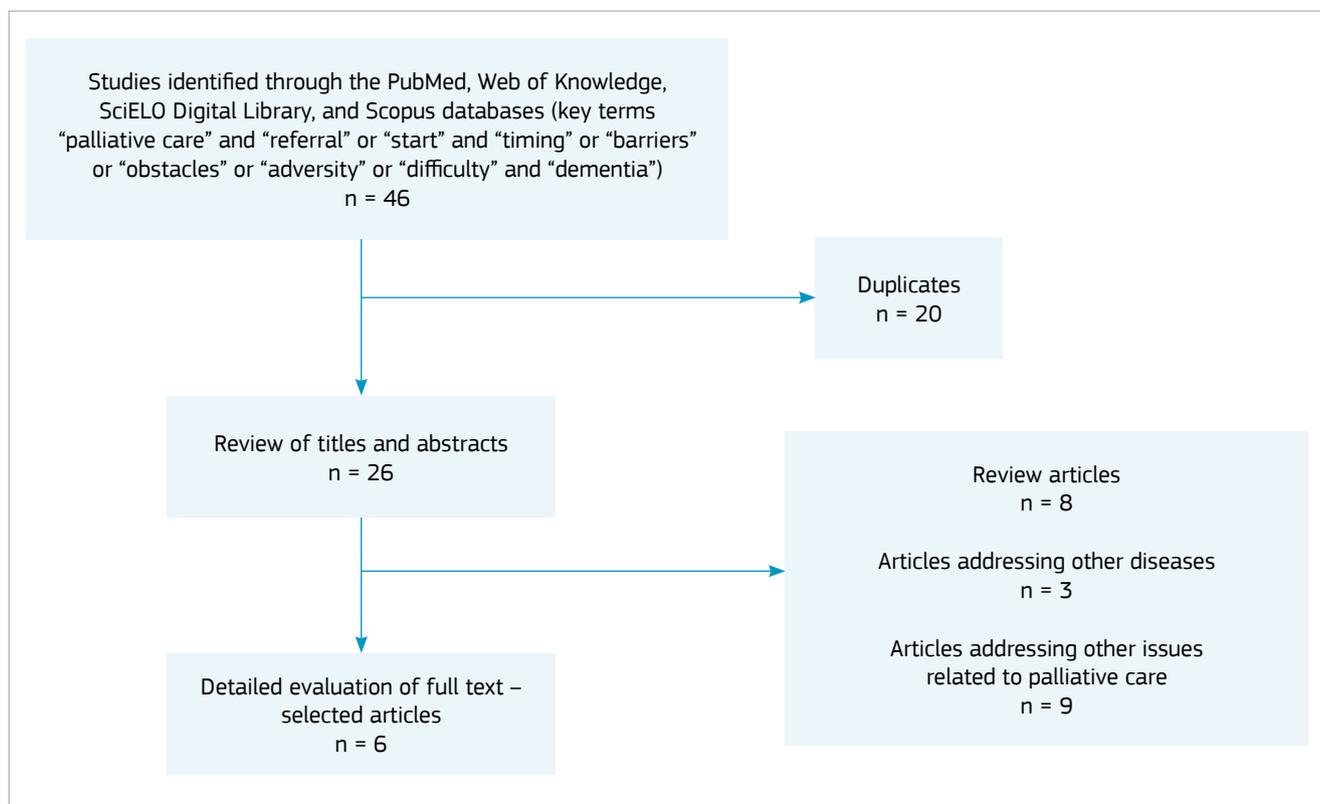


Figure 1 Flow diagram of article selection.

Chart 1 Summary of the selected studies.

Study, setting	Study design	Description	Barriers to introduction of PC
Upchurch & Thornton, 2012, ¹³ Georgia, USA	Cross-sectional study; questionnaires applied to physicians responsible for caring for patients with DS	12 physicians answered questionnaires designed to collect data on knowledge about hospice care, familiarity with the indications for this type of care, and barriers encountered when referring patients with Alzheimer's dementia	Lack of knowledge about PC; unpredictability of disease progression and difficulty in establishing a prognosis; absence of criteria for PC indication and eligibility; limited access to PC or limited PC resources; refusal by patients and family members
Beernaert et al., 2015, ¹⁵ Belgium	Cross-sectional study; end-of-life care questionnaires administered to physicians who cared for patients with potential PC needs	A sample of 6,871 patients with potential need for PC, who had died within a 6-month period, was stratified through data from the national health service. Questionnaires were sent to the physicians responsible for care in the period of interest, to collect information on the use of PC services and reasons for not using these services	Lack of knowledge about PC; absence of criteria for PC indication and eligibility; limited access to PC or limited PC resources; refusal by patients and family members
Beernaert et al., 2013, ¹⁹ Belgium	Retrospective cohort study that assessed characteristics in medical records of patients with potential PC needs	Medical records for the last 3 months of life of patients who died of COPD, CHF, dementia, and cancer over a 1-year period were evaluated; data were collected on the referral and timing of referral to PC services, the objectives of the treatment provided, sociodemographic characteristics and cause of death, in each disease group	Unpredictable disease course; difficulty in establishing a prognosis; absence of criteria for PC indication and eligibility
McCarty & Volicer, 2009, ²⁰ United States	Cross-sectional study; data collected via questionnaires and interviews with representatives of hospice-type facilities	14 agencies that provide hospice services answered questions about their characteristics and the barriers encountered by individuals with dementia when seeking hospice services	Lack of knowledge about PC; unpredictability of disease progression and difficulty in establishing a prognosis; absence of criteria for PC indication and eligibility; failures in communication among providers, patients, and family members; limited access to PC or limited PC resources
Ouchi et al., 2014, ²¹ United States	Cross-sectional study; questionnaires about barriers to initiation of PC were administered to health care providers	Rate of PC initiation for 51 patients diagnosed with advanced dementia who were admitted to an emergency department, after an educational intervention on the topic. Then, questionnaires administered to the providers who had cared for 23 of these patients were used to identify reasons and barriers to PC initiation by professionals who did not pursue PC	Lack of knowledge about PC; unpredictability of disease progression and difficulty in establishing a prognosis; absence of criteria for PC indication and eligibility; beliefs and preconceptions regarding death
Torke et al., 2010, ²² United States	Cross-sectional study; questionnaires and interviews were answered by representatives of PC services	Representatives of 426 programs offering hospice- and non-hospice PC were interviewed to assess the characteristics of their programs and the provision of PC to patients with dementia, seeking to identify the main barriers and needs associated with this type of care	Lack of knowledge about PC; unpredictability of disease progression and difficulty in establishing a prognosis; limited access to PC or limited PC resources

CHF: congestive heart failure; COPD: chronic obstructive pulmonary disease; DS: dementia syndrome; PC: palliative care.

despite being admitted to a tertiary teaching hospital and having high levels of dependence, as identified by the Functional Assessment Staging (FAST) scale. The main reasons reported to justify the low rate of PC referrals by the care team were:

- “clinician thinks PC would be inappropriate for this patient”;
- “clinician does not have the time”;
- “clinician is too busy”;
- “clinician does not want to go against the family’s wishes”.

DISCUSSION

This literature review clearly showed that patients dementia have less access to PC. These findings are consistent with other studies, which demonstrated that these patients receive significantly fewer referrals for specialized PC and less drug therapy with palliative intent than do patients with cancer, despite evidence that the symptom burden in people with advanced dementia and end-stage cancer is comparable.^{23,24}

One barrier that stands out for the initiation of PC in patients with dementia is limited knowledge about the palliative approach, what it entails, and its proper indications, as well as confusion regarding terminology — not only by the general population, but by health professionals as well, including physicians.^{13,15,20,21} This lack of education and awareness about PC has also been demonstrated in other recent studies,^{25,26} and highlighted by WHO as an important barrier to access to PC.²⁷

Said lack of knowledge can be compounded by poor communication between professionals, patients, and their families²⁰ regarding prognosis, therapeutic possibilities, and the potential benefits of PC in the treatment context. Inadequate communication results in a lack of information, which impairs patient and caregiver autonomy with respect to decisions about diagnosis, treatment, or even preparing for the end of life. This goes against the wishes of the general population; studies have shown that patients want to be informed about issues related to their life expectancy, prognosis, and available treatment options so they can make their own decisions.²⁸

Without adequate information, the family, which is usually suffering, overwhelmed and experiencing guilt, may misinterpret the meaning of palliative care; it is not unusual for families to believe that clinicians are “giving up” or “abandoning” the patient.²¹ Thus, it is very important that health professionals receive proper training and guidance on communication

skills,²⁵ which should be deployed clearly and early in the course of dementia.

Most of the studies assessed in this review highlighted two major barriers: the unpredictable course of dementia^{13,19-22} and the lack of predefined indications for palliative care.^{13,15,19-21} Several factors contribute to this, such as the wide range of signs and symptoms of DS and heavy burden of comorbidities, present in approximately 91% of cases, which include urinary incontinence, fecal incontinence, pressure ulcers, and a predisposition to infections.^{29,30}

Degenerative neurological diseases usually have a long, fluctuating, unpredictable course, which makes it difficult to ascertain if and when patients are at the end of life.²⁰ In addition, these conditions also have an emotional impact on the family, as they lead to changes in social roles, financial difficulties, and caregiver overload. These factors, compounded by the difficulties family members encounter when seeking to obtain correct information regarding the prognosis, often due to the lack of training of health providers, mean that families are unprepared for loss.³¹ This is often reflected in the lack of perception of dementia as a terminal illness.³²

Another factor that hinders prognostication is the fact that the course of SD alternates between moments of stability and exacerbations, which makes it unclear when clinicians should prioritize palliative measures rather than insist on curative intent.³³ Moreover, the combination of complex, specialized treatments, the high prevalence of cognitive impairment and communication difficulties, and difficult-to-manage symptoms make the recognition and management of signs and symptoms in dementia very challenging,^{22,34} which highlights the fact that specialized support is often needed by patient and caregivers.

End-of-life care for individuals with dementia is less systematized, less structured, less evidence-based than end-of-life care for patients with cancer.³⁵ In this regard, collaboration between the professionals involved in patient care—whether specialists or primary health care providers—is needed to better support their needs.³⁶ In a study conducted in the United Kingdom in 2013, Hussain et al.³⁷ demonstrated that addition of PC interventions to the treatment plan of patients with advanced neurological diseases led to lower rates of hospital admission, higher rates of in-home death, improved decision-making regarding living wills and advanced directives, and decreased caregiver stress.

This inconsistency as to when the palliative stage of DS begins, compounded by limited knowledge of the objectives of PC, makes the optimal timing of PC confusing, which, in turn, delays or altogether prevents its initiation.³⁸⁻⁴⁰ In an

attempt to mitigate these challenges, studies have sought to identify and validate tools or criteria for early indication of PC, generally on the basis of prognostic markers.^{41,42}

In a systematic review of the literature, Brown et al.⁴³ found that various methods have been used to define prognosis in dementia, including the Functional Assessment Staging Test (FAST) scale,⁴⁴ the Mini-Mental State Examination (MMSE),⁴⁵ the Advanced Dementia Prognostic Tool (ADEPT),⁴⁶ and the Karnofsky Performance Scale (KPS)⁴⁷. These instruments assess aspects such as functioning, cognition, nutritional status, and comorbidities. According to these authors, the identification and development of validated, reliable, sensitive, and accurate prognostic tools helps identify late-stage dementia and allow early care planning.

It should be borne in mind, however, that the wide range of scales available, which may be inaccurate or unable to standardize detection of advanced dementia, may hinder comparison among studies. Thus, it is always necessary to consider individual clinical judgment on a case-by-case basis and avoid generalizations.⁴³

In addition, one must not forget that PC is not necessarily prognosis-dependent, and can be initiated concomitantly with active treatment of the disease at any point in its course.³⁹ Thus, before any methods to support early indication of PC can be established definitively, a number of obstacles related to disease progression, health service structuring, and providers themselves need to be overcome. Additional studies are needed to guide this process.³⁸

Burnout among PC providers or lack of resources to meet the demands of end-of-life patients with dementia were barriers reported in some studies.^{13,15,20,22} However, the most common reality in many settings is a complete absence of PC support teams, a lack of knowledge, and even the impossibility of requesting support, especially in smaller hospitals far from major urban centers.⁴⁸

It is well known that differences in the provision of PC exist at a global level and even within the same country, and that much action must still be taken to ensure that this type of approach is widely recognized. According to Traue and Ross,⁴⁹ this lack of linearity and resources can be minimized if organizations define which types of care they can realistically deliver and focus on patients with the most complex needs, as the care needed by a patient with chronic illness does not always need to be provided by a PC specialist. This further highlights the need to disseminate palliative practices among multidisciplinary teams at all services. Also according to these authors, health professionals who specialize in other areas can be trained to provide symptom

control in situations relevant to their usual scope of practice area, thus allowing them to detect and treat specific symptoms in patients.

Preconceptions about the meaning of PC are another barrier observed,²¹ probably resulting from the association of this term with end of life or approaching death, making it difficult for health professionals, patients, and their families to accept this practice.^{13,15,39} This is considered as one of the most important barriers to access to PC, named by Lewis et al.⁵⁰ as “lack of acceptability of palliative care services”, and is more evident in disadvantaged population groups, due to stigma, mistrust, communication problems, and poor health education, as well as the lack of options for informal care in these groups. Once again, the need for health professionals to develop communication skills and facilitate a better understanding of aspects related to disease, death, and better acceptance of this process comes to the fore. This is one of the reasons why communication, when properly applied, is actually considered a therapeutic measure within palliative care.⁵¹

Some of the fears that many health professionals face regarding transition from active treatment to PC are also related to legal issues associated with this practice.³⁹ Fear of judicial retaliation scares clinicians away from comfort care measures and discontinuation of futile treatment; however, this type of situation is more common when professionals fail to deploy adequate communication skills and honesty with patients and their families since the beginning of treatment. In this sense, communication strategies focused on informed consent, shared decision-making, and advanced care planning have been proposed as tools to guarantee patient autonomy in decision-making and ensure greater patient and family involvement in the management of end-of-life care.^{52,53}

Countless other limitations are known to hinder transition from active treatment to PC in chronic non-cancer conditions, from paternalism and cultural issues involving health professionals through socioeconomic disadvantages to difficulties imposed by health facilities and managers.⁵⁴ These were not addressed in depth by the articles included in this review, and still need to be better evaluated in future research.

This review has some limitations which may compromise its findings. The selected articles were methodologically heterogeneous, including qualitative and quantitative approaches, which limits the possibility of carrying out a statistical comparison and reaching concrete conclusions. In addition, most of the studies had small samples or were retrospective. It is well known that retrospective designs

may be influenced by sampling, recall, and reporting bias, among other issues.

CONCLUSION

Several barriers are still associated with the transition to and initiation of PC in patients with dementia syndrome, who must often endure protracted insistence on therapeutically futile measures and only receive palliative interventions at the very end of life. These barriers are associated with variables related to patients, family members, and health care providers, mainly the lack of knowledge about palliative approaches, but are also due to the unpredictable, heterogeneous courses of dementia syndrome and the lack of clear criteria for when palliative care is indicated.

Future studies that are able to elucidate which criteria can be used to support initiation of palliative care for patients with dementia may mitigate these problems. However, even before such research is conducted, there is a need to improve awareness of the importance of palliative care among health professionals and the general population, as well as to improve communication skills, with a view to improving quality of life and reducing the symptom burden experienced by these patients.

CONFLICT OF INTERESTS

The authors report no conflict of interests.

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