

Conceptual Insights on Palliative Care at the end of Life: A Systematic Review

Perspectivas conceptuales de los cuidados paliativos en el final de la vida: revisión sistemática

Perspectivas conceituais dos cuidados paliativos no fim de vida: revisão sistemática

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Abstract

Introduction: Qualified end-of-life care remains an international challenge. The frequent use of terms such as “Palliative Care” and “end of life” has certain implications on the prognosis of the patient and in determining effective decision-making related to appropriate care. However, is such terminology commonly used in the literature? However, whether such terminology is commonly used in literature remains unknown. The objective was to verify the terms used in the Brazilian and international scientific literature on palliative practice in the final stage of life and to describe the terminological understanding based on its usage characteristics. **Materials and methods:** Studies from the LILACS and Pubmed databases published from 2012 to 2017 using the descriptors “end of life,” “terminal stage,” “Palliative Care,” and “Hospice care” were included in this exploratory systematic review. **Results:** Ten articles were selected out of a total of 1909. A prevalence of American medical studies with heterogeneous methodological content that presented diverse conceptual proposals was identified. **Conclusion:** The analysis of these articles reinforced the need to work on the conceptual dissemination of palliative care with an emphasis on the implications of the use of this approach only at the end of life, which hinders the process of improving the quality of care at the time of death.

Keywords: Palliative care; end of life; terminal care; hospice care.

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Resumen

Introducción: la asistencia cualificada en el fin de la vida todavía es un desafío internacional. El uso frecuente de términos como *cuidados paliativos* y *fin de la vida* tienen implicaciones en el pronóstico del paciente y en la toma de decisiones efectiva para la oferta de cuidado adecuado. Pero, ¿su comprensión terminológica es de uso común en la literatura? El objetivo fue emplear los términos utilizados en la literatura científica nacional brasileña e internacional sobre la práctica paliativa en la fase final de la vida y describir la comprensión terminológica relacionada por sus características de uso. **Materiales y métodos:** revisión sistemática exploratoria en las bases de datos LILACS y Pubmed, en el periodo de 2012 a 2017, empleando los descriptores “final de vida”, “fase terminal”, “cuidados paliativos” y “cuidados en hospice”. **Resultados:** fueron encontrados 1909 artículos y seleccionados 10. Se identificó una prevalencia de estudios médicos norteamericanos, con un contenido metodológico heterogéneo, que presentaron propuestas conceptuales diversificadas. **Conclusión:** los artículos analizados reforzaron la necesidad de trabajar en la disseminación conceptual de los cuidados paliativos, detallando las implicaciones de la asociación a abordaje apenas, al final de la vida, factor que dificulta el proceso de mejoría en la calidad de la asistencia en la muerte.

Palabras clave: cuidado paliativo; fin de vida; cuidado terminal; cuidado interno.

Resumo

Introdução: a assistência qualificada ao fim da vida ainda é um desafio internacional. O uso frequente de termos como “cuidados paliativos”, “fim de vida” tem implicações no prognóstico do paciente e na efetiva tomada de decisão para a prestação de cuidados adequados. Mas o seu entendimento terminológico é de uso comum na literatura? O objetivo era verificar o emprego dos termos utilizados na literatura científica nacional brasileira e internacional sobre prática paliativa na fase final da vida e descrever a compreensão terminológica relacionada às suas características de uso. **Materiais e métodos:** revisão sistemática exploratória nas bases de dados LILACS e Pubmed, no período de 2012 a 2017, utilizando os descritores “fim de vida”, “fase terminal”, “cuidados paliativos” e “cuidados em hospice”. **Resultados:** foram encontrados 1909 artigos e 10 foram selecionados, identificou-se um predomínio de estudos médicos norte-americanos, com conteúdo metodológico heterogêneo e que apresentavam propostas conceituais diversificadas. **Conclusão:** os artigos analisados reforçam a necessidade de se trabalhar a disseminação conceitual dos cuidados paliativos, detalhando as implicações da associação para abordagem apenas no final da vida, fator que dificulta o processo de melhoria da qualidade do cuidado no fim da vida.

Palavras-chave: cuidados paliativos; fim de vida; assistência terminal; cuidado em hospice.

Introduction

During previous decades, palliative care has evolved from a philosophy of care to a recognized multidisciplinary approach with a growing number of clinical programs and cumulative experiences related with symptom control, psychosocial and spiritual care, communication, and decision-making in end-of-life care (1). This field is not limited to a single diagnosis, symptom, or characteristic; therefore, it has a marked heterogeneity in the scope of medical practice, includes various medical specialties and academic disciplines that contribute to its expertise, and evidences the need for an open discussion and of practical and scientific development (2).

The World Health Organization (WHO) has been structuring and updating the definition of palliative care (3) for decades with an aim to adapt to the new epidemiological, cultural, economic, and social demands, which require more rigorous evidence-based practices, the systematization of results, the evaluation of efficacy, and the subsequent reduction of healthcare costs. Therefore, the need to reliably define, evaluate, and implement palliative care has become all the more relevant in recent years (4).

However, the bibliography that supports this approach is complex and reflects diverse information and new nomenclatures attributed to modifications throughout the clinical course of life-threatening diseases (5). According to the Statements of the NIH Consensus Conferences regarding the improvement of end-of-life care (6), “There has been a lack of definitional clarity related to several concepts and terms [...] The lack of a definition of the key terms represents a barrier to research in improving end-of-life care.” Likewise, the International Association for Hospice and Palliative Care (IAHPC) (7), has identified a lack of consensus regarding the concepts surrounding palliative care, specifically in terms of the right time of application, target population, and participating competent professionals, which is one of the biggest challenges for its implementation. “[...] The terms “palliative care” and “hospice care” have been used for many years with different interpretations, and several palliative care organizations have in turn, adopted their own definitions.”

In 2017, the Lancet Commission on Global Access to Palliative Care and Pain Relief undertook an initiative to provide terminological uniformity for this specialty. Therefore, it published a report with an even broader concept of palliative care and recommended a review of the WHO definition that would reflect the advances of the health system and the settings with the highest demand (8).

Researchers in palliative care and in different disciplinary backgrounds with an interest in research in this field believe that this lack of clarity raises conceptual and methodological questions that affect how, when, and who should receive palliative care (9). This topic becomes even more relevant as the frequent use of terms such as “palliative care,” “end of life,” “hospice care,” and “terminal stage” affect the prognosis of patients.

When used properly, these terms favor the approach and type of care as well as the use of appropriate therapies, communication, and effective decision-making (10-12).

Whether such terminology is commonly used in literature remains unknown. This exploratory review sought to address this conceptual gap. The search was carried out by verifying the use of the terms used in Brazilian and international scientific literature published between 2012 and 2017 on palliative care at the end of life of patients. This made it possible to determine whether the terminological understanding in these studies was related to the practical and theoretical approach.

Materials and methods

A literature scoping review was performed (13). This methodology allows synthesizing a body of evidence (14,15), drafting a conceptual map of the existing literature, identifying research gaps (16), and evaluating the status of a research field for those outside the community of specialists (13,15). In contrast to a systematic review, the scoping review does not necessarily assess the quality of the evidence of the selected studies. The emphasis is on the state of current research. This enables us to identify what has been done so far, how it has been conceptualized, what the gaps in the theoretical framework are, and the empirical results, aimed at guiding and harmonizing future research (8). This study aimed to verify the terminologies used in the practice of palliative care in the final stage of life.

To ensure that the reviewers shared the same understanding of palliative care at the time of the analysis of the selected literature (year 2018), the updated conceptual proposal of the IAHPC (2018) was integrated. A holistic definition focused on the timely relief of suffering, applicable to patients of all ages, regardless of diagnosis, prognosis, geographic location, point of care, and income level (17).

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers. Palliative care comprises prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. It is applicable throughout the course of an illness, according to the patient's needs. (17)

After stating the problem, we limited the search to publications that provided a definition or conceptualization for the selected terms within palliative care, through exploratory mapping (18). Consequently, the review was carried out in five steps (19-21). The first step involved the identification and development of the research question by the reviewers: Is the terminology in palliative care commonly used in literature? The second step consisted of a search in two databases, Publisher Medical Literature Analysis and Retrieval System Online (PubMed) and scientific health information from Latin America and the Caribbean countries (LILACS), using keywords according to the MeSH (Medical Subject Headings) and DeCS (Descriptors in Health Sciences) terminology for each selected language: “palliative care,” “hospice care,” “end of life,” and “terminal care” in English; “Cuidados paliativos,” “fim de vida,” and “enfermedades terminais” in Portuguese; and “cuidado paliativo” and “final de la vida” in Spanish, using “or” and “and” Boolean operators respectively for each crossover.

The third step involved a screening process to select the articles. All documents were imported into the State of the Art Software (22) to organize and facilitate article selection. Initially, each of the authors performed this analysis. Any disagreement was later discussed

and solved by consensus. Therefore, all types of studies and methods that taxonomically described the search words, which were in Spanish, English, or Portuguese, were included. These studies comprised original articles, systematic and non-systematic reviews, conference summaries, guidelines, and editorials, published during a period of five years (2012–2017). The original search identified 1090 studies, but after the screening process and after detecting 14 duplicate articles, a total of 717 articles were discarded. Based on the title, we determined that these articles did not meet the inclusion concept nor context as these studies were pharmacological, surgical, and nutritional in nature. Other studies delved into family care, home care, and test validation or scale development. A total of 73 abstracts were selected and read, reaching a study sample of ten articles. PubMed was the database with the largest number of articles.

In the fourth step, the ten articles were organized into a data registration form, using a dynamic Excel® spreadsheet. The information entered included authors, country of institutional affiliation of the authors, year of publication, journal, objectives, method, and concepts of palliative care at the end of life.

The fifth step consisted of classifying the ten articles to identify the conceptual issues addressed by the authors in detail. Therefore, a thematic analysis was used to group the extracted results into specific characteristics (23). During the reading process, three groups of articles were identified: Group A included articles that addressed and described the concepts of palliative care and hospice care; Group B included articles that specifically addressed the terminal stage in palliative care; and Group C included articles on the end of life. Some articles were classified into more than one category.

Figure 1 shows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses elements to demonstrate the selection process (24).

Results

The findings are displayed in two parts. The first part included the evidence of the trends in palliative care at the end of life in literature as well as the use and frequency of different terms within this approach.

The second part included the classification of the articles into three thematic groups: those that refer to palliative care and hospice care, those that define the concept of terminal illness, and those that consider a time frame for the introduction of palliative care at the end of life.

Part 1. Description of the studies

The ten articles included one systematic review, one bibliographic review, an editorial article, two retrospective studies, three exploratory qualitative studies, an event summary, and one epidemiological study. American studies in the field of medicine were predominant, whereas multidisciplinary articles and articles from other disciplines were fewer in number. Six of the ten articles were published in 2014 with no publications found in 2017 (Table 1).

Table 1. Characterization of the articles included in the review

| n | Authors and year | Title | Journal | Profession | Country | Language | Type of study |
|----|---------------------------------|--|--------------------------------|-------------------|---------------|------------|-------------------------|
| 1 | Fraga et al. (25) (2012) | Significado, para os médicos, da terminalidade da vida e dos cuidados paliativo | Revista bioética | Multidisciplinary | Brazil | Portuguese | Qualitative exploratory |
| 2 | Azis et al. (26) (2012) | Palliative and End of Life Care Research: Embracing New Opportunities | Enfermagem Outlook | Nursing | United States | English | Academic event summary |
| 3 | Menezes and Barbosa (27) (2013) | A construção da “boa morte” em diferentes etapas da vida: reflexões em torno do ideário paliativista para adultos e crianças | Ciência & Saúde Coletiva | Medicine | Brazil | Portuguese | Qualitative exploratory |
| 4. | Burlá and Py (28) (2014) | Cuidados Paliativos: ciência e proteção ao fim da vida | Cad. Saúde Pública | Multidisciplinary | Brazil | Portuguese | Editorial |
| 5. | Garrido (29) (2014) | Cuidados Paliativos ao paciente em fase terminal | Revista Baiana de Enfermagem | Nursing | Brazil | Portuguese | Qualitative exploratory |
| 6. | Keim-Malpass et al. (30) (2014) | End-of-Life Care Characteristics for Young Adults with Cancer Who Die in the Hospital for Young Adults | Journal of Palliative Medicine | Multidisciplinary | United States | English | Retrospective |
| 7 | Hui et al. (31) (2014) | Impact of Timing and Setting of Palliative Care Referral on Quality of End-of-Life Care in Cancer Patients | Support Care Cancer | Multidisciplinary | United States | English | Retrospective |
| 8 | Hui et al. (32) (2014) | Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “Hospice care” in the published literature, dictionaries, and textbooks | Support Care Cancer | Medicine | United States | English | Bibliographic review |

| n | Authors and year | Title | Journal | Profession | Country | Language | Type of study |
|----|----------------------------|---|---------------------|------------|---------------|----------|-------------------|
| 9 | Hui et al. (33) (2014) | Concepts and Definitions for “Actively Dying,” “End of Life,” “Terminal-ly Ill,” “Terminal Care,” and “Transition of Care”: A Systematic Review | Support Care Cancer | Medicine | United States | English | Systematic review |
| 10 | Meffert et al. (34) (2016) | Identification of hospital patients in need of palliative care - a predictive score | BMC Palliative Care | Medicine | Germany | English | Prospective |

As shown in Table 2, the keywords described in the articles were mostly “Palliative Care” (n=5), followed by “life” and “death” (n=2). All articles, regardless of their methodological approach, showed a tendency toward the clarification and differentiation of concepts (n=6) and recommendations on their practical implementation (n=4).

Table 2. Articles organized by keyword, objectives, and conceptual focus

| n | Keywords: | Objectives | Conceptual Focus |
|----|--|---|---|
| 1 | Life of the terminally ill Palliative, Medical Care | To understand the meaning of an end-of-life condition for physicians who work in oncology. | Dissociation between terminal care associated with brain death and palliative care, where they relate to the quality of life and comfort. |
| 2 | None | To assess gaps in knowledge that reflect the key domains of end-of-life and palliative research. | Several requests on the need for future guidelines in the end of life and palliative care research. |
| 3 | Palliative Care, life, death, adult/child | To address palliative care approaches focusing on the similarities and differences of a good death in the different stages of life. | Distinction on the approach to palliative care in adults and children, highlighting temporary considerations to the care provided. |
| 4. | None | To analyze the relevance of palliative care as a public health need. | Clarification from a bioethical approach between palliative care and the end-of-life phase. |
| 5. | Palliative Care, Terminal illness. Humanization of care | To describe the understanding of the strategies adopted by nurses in the promotion of palliative care for patients in the terminal stage. | Performs a distinction between palliative care and the terminal stage of life as adopted by nurses. |
| 6. | None | To explore the characteristics of death among young adults with cancer to assess their end-of-life trajectory. | Palliative care begins at the end of the care trajectory. Early palliative care is required. |
| 7 | Chemotherapeutic agents, Hospitalized patients, Neoplasms, Outpatients, Palliative Care, Quality of care | To examine how the timing and setting of referrals to palliative care were associated with the quality of care provided at the end of life. | The need to increase the availability of palliative care and expedite the early referral process on an outpatient basis. |

| n | Keywords: | Objectives | Conceptual Focus |
|----|---|--|---|
| 8 | Supportive Care, Palliative Care, Hospice Care, Definitions, Concepts | To identify concepts and definitions. | Development of a preliminary conceptual framework that unifies these terms throughout the ongoing care. |
| 9 | Active dying, end of life, terminal care, terminal patient, terminology, transition of care | To examine the concepts and definitions. | Identification of unifying concepts commonly used in palliative care. |
| 10 | Palliative medicine, terminal patients, palliative care needs, palliative care | To identify and describe the characteristics of patients' needs in palliative care and the risk factors for their development. | The need for palliative care not only in the last months of life but throughout the course of illness. |

Concerning the conceptual contents used in the development of the articles, nine of the ten articles used the term “palliative care” and “end of life” and, to a lesser extent (2 articles), the term “chronic disease” (Table 3).

Table 3. Terminology used in the articles

| Term | Number of articles |
|----------------------------------|--------------------|
| Palliative care | 9 |
| End of life | 9 |
| Life-threatening serious illness | 6 |
| Terminal care | 6 |
| Hospice | 4 |
| Terminal patient | 4 |
| Incurable illness | 4 |
| Chronic illness | 2 |

Part 2. Grouping based on conceptual characteristics

Group A. Palliative care and hospice care

All of the articles selected discussed palliative care and addressed characteristics of cultural (25), historical (26-28), cultural (26), procedural (23,28-31), and conceptual (31,32) nature; these last two approaches were specifically used in the published literature on palliative oncology. A homogeneous definition of palliative care was not identified for all the articles analyzed; however, it was found that these articles extracted the terminology prescribed by the WHO, incorporating it verbatim (26-31). In other studies, essential characteristics of this approach were added: quality of life, comfort, symptom relief, interdisciplinary and comprehensive care, dignity, and family and caregiver bond (14,16,23).

In the international context, Hospice care appeared as a care modality in Palliative Care, in, aimed at care in the final stage of life. It is worth noting that hospice care is not widely used in developing countries (26-28).

Group B. Terminal stage as a condition and modality of care

The concept of terminal illnesses (24,26,28,32,33), on the other hand, was used with various more up-to-date definitions and was associated with a condition that threatens and limits life (29) and is incurable (26,27), chronic, progressive, and advanced (25), and results in death (28,31). This care was conceptually related to terminal care and considered as the care provided during the last stage of life, focused on guaranteeing a good death (26,27).

Group C. Life and prognosis in palliative care

Accordingly, the terms “end of life” and “terminal stage” were used as synonyms in the articles to refer to prognostic actions during the last stage of life. Yet, these terms were not used systematically in relation to temporality, indicating that such terms are used in a variable phase applied to days, weeks, and months (31-33). A survival prognosis does not imply that palliative care is provided only at the last stage of life. Its early, continuous, and culturally contextualized incorporation had conceptual and practical relevance in the reviewed literature (27,31-33).

Discussion

The purpose of this review was to verify the determining concepts of “terminal care,” “end of life,” “hospice care,” and “palliative care.” The review evidenced a shortage of references specifically directed to conceptualization, evidencing the need to adapt the standard definitions to improve clinical and research methodologies.

Overall, the search revealed a diverse range of definitions for these terms, with significant placements. Nonetheless, the lack of consensus brought to light some disparities that are explored below.

When examining “palliative care” and “hospice care,” significant similarities as well as differences between these terms can be found. Both denote multidisciplinary care to optimize quality of life, but they also carry a negative preconception associated with death and misfortune, specifically in the pediatric population, termed as “social drama” (25,27,34).

Different organizations have requested to update the concept of palliative care in children, which was created by the WHO in the 90s, to include the holistic approach within the concept (7), allowing for more professionals that can provide support to the “drama” that pediatric death represents. Although, other studies expose a theoretical and practical

expansion in the vision of pediatric palliative care (35-37), the fact that its terminology is not officially stipulated reduces the probability of being understood by a non-specialized audience.

On the other hand, hospice care shows variation regarding the scope of the service, with a shorter time limit than palliative care. Although, chronologically speaking, the word “hospice” is older at an international level (32), the type of care provided is less referenced in the literature and interpreted within the entire palliative care approach only when there is an estimated survival of <6 months (38,39).

As a term, “palliative care” was the most consistent in the literature. The outcomes showed that conceptual understanding is strongly associated with the WHO definition, capturing the essential characteristics, and mentioning its theoretical content more frequently. These findings are consistent with other studies (38,40), where total, active, and individualized patient care, family support, interdisciplinary teamwork, and effective communication were identified as four relevant conceptual attributes. However, another research identifies many challenges in the current WHO definition (developed in 2002) on palliative care for adults, as it is limited to the problems associated with life-threatening illnesses, instead of focusing on the needs of patients with serious, chronic, and complex illnesses (7).

It could be stated that thanks to the philosophy and defined principles that have supported the practice for decades, there is an agreement on how palliative care should be provided (41,42). All the articles reviewed unanimously stated that palliative care serves patients with Incurable illness and in the end-of-life phase. However, some questions remain unanswered when distinctions are made between the perspectives under which it is practiced (43) and the point of the disease course at which this care should be provided (44). There are still doubts related to difficulties in developing accurate prognostic criteria (9).

The aforementioned points were verified in the applicability of the concepts “end of life,” “care,” and “terminal illness,” which are used in various articles to classify and establish a prognosis, in a variable that includes days to months (27,31-33). These terms were used in more than 50% of the articles (24-26,28,31-33). However, conditions such as “terminal” and “final” cause difficulties in the real interpretation of palliative care, considering that they may imply the idea of abandonment, fainting, hopelessness, or end (45-47). As expressed by Medina, “These difficulties with language can also be interpreted as manifestations of a cultural rejection to accepting the process of death, placing it in a context of fragility” (41). Therefore, the tendency to anticipate sensitivity toward palliative practice beyond the classical conception of terminal illness remains a challenge.

This controversy was anticipated in reviews by other authors in the areas of research (9,4), health (41), and clinical practice (42), who suggest improving the referral process to early palliative care (34,44,48), presenting the need to incorporate this palliative care early,

by integrating it as part of the care path instead of introducing it in the last months or days of life of the patient.

The former concept of impossible cure, in the context of a serious and critical illness, at an advanced or irreversible stage, is now replaced by the concept of treatments that modify the illness (7,43,49). The concomitant work of different specialties with pharmacological, surgical, and rehabilitative approaches in palliative care can integrate the patient and family in the planning of care (48-50).

Palliative care has been traditionally subordinated, specifically to the value of preserving life (51). However, the current conceptual domain seeks to consider and identify the supreme importance of involving political, legislative, governmental, and educational work of health-care professionals, patients, and families, due to its impact on the clinical, organizational, resource, and ethical areas (48-53).

The IAHPC concept adopted for this review (17) echoes more than 129 organizations and 88 countries that participated in its creation. Thus, it configures a new time for palliative care, by enabling the understanding and magnitude of this care.

It includes aspects related to early identification in its conceptual expansion, its applicability throughout the illness, its implementation in conjunction with disease-modifying treatments, and the recognition and respect for the cultural values and beliefs of the patient and the family. In addition to its incorporation in all care settings and at all levels (primary to tertiary) with trained professionals in this field, and with a specialized multidisciplinary team for the referral of complex cases.

Despite the applicable measures taken, this review has some limitations. It should be noted that this study was limited to articles indexed in two databases; therefore, it does not represent the totality of the global academic work on the terminological understanding of palliative care at the end of life. Consequently, this study depicts a partial discussion at the conceptual level; however, it can be considered representative with regards to the analysis of the literature reviewed.

The articles analyzed expressed with actions the need to invest in the conceptual dissemination of palliative care, describing the implications of introducing this approach only at the final stage of life, a factor that hinders the process of improving the quality of care at the time of death.

The authors of the review are based in Brazil, and within the Brazilian context, it is important to articulate the studies that are based on epistemologies focused on conceptual approaches, recognizing the contextual specificities that may result in the appropriation of terms in palliative care as there are fewer published articles.

Developing new methodological or conceptual approaches specifically for each language is relevant and could be the subject for future research that would provide common ground for clinical and research communication by enabling the standardization both for palliative

care professionals, the general population, and patients' families, to introduce culture and training in palliative care.

Authors' contribution

All the authors contributed to the stages of the analytical process, preparation of the manuscript, and approval of the final text.

Conflict of interest

None declared.

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