Review Article

Analysis of the historical evolution of the concept of palliative care: a scoping review

Análise da evolução histórica do conceito de cuidados paliativos: revisão de escopo

Análisis de la evolución histórica del concepto de cuidados paliativos: revisión de alcance

Lorena Campos de Souza[1] https://orcid.org/0000-0002-3338-9425
Virna Ribeiro Feitosa Cestari[1] https://orcid.org/0000-0002-7955-0894
Vitória Pessoa Nogueira[1] https://orcid.org/0000-0002-6150-8938
Marilia Alves Furtado[1] https://orcid.org/0000-0003-2672-9679
Ingrid Mikaela Moreira de Oliveira[1] https://orcid.org/0000-0002-8901-362X
Thereza Maria Magalhães Moreira[1] https://orcid.org/0000-0003-1424-0649
Marina de Góes Salvetti[2] https://orcid.org/0000-0002-4274-8709
Vera Lúcia Mendes de Paula Pessoa[1] https://orcid.org/0000-0002-5441-5311

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Corresponding author
Lorena Campos de Souza
E-mail: lorena.2306@hotmail.com

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Edvane Birelo Lopes De Domenico
(https://orcid.org/0000-0001-7455-1727)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, SP, Brazil

Abstract

Objective: To analyze the historical evolution of the concept of palliative care and identify its essential elements.

Methods: This is a scope review based on the Joanna Briggs Institute Reviewer's manual, which included the definitions of palliative care from scientific articles selected from health databases and portals. Twenty-one studies were selected for analysis. The IRaMuTeQ® software was used to group the data.

Results: From 1993 to 2020, the most cited definition of palliative care was that of the World Health Organization. The palliative approach was implemented in the physical, biopsychosocial and spiritual spheres for patients with acute or chronic illnesses to promote comfort, dignity and quality of life. The essential elements identified in the definitions were life, care, quality, family, multidisciplinary team, comfort, and relief.

Conclusion: It was found that the definition of palliative care has matured, by adding elements to guarantee a dignified quality of life, regardless of type of disease, and integrating family and interprofessional team in this process.

Resumo

Objetivo: Analisar a evolução histórica do conceito de cuidados paliativos e identificar seus elementos essenciais.

Métodos: Revisão de escopo fundamentada no manual do *Joanna Briggs Institute Reviewer's* que incluiu as definições de cuidados paliativos oriundos de artigos científicos selecionados de bases e portais da saúde. Foram selecionados 21 estudos para análise. Utilizou-se o software IRaMuTeQ® para agrupamento dos dados.

Resultados: De 1993 a 2020 a definição de cuidados paliativos mais citada foi a da *World Health Organization*; a abordagem paliativa foi implementada nas esferas físicas, biopsicossociais e espirituais, a pacientes com enfermidades agudas ou crônicas para promover conforto, dignidade e qualidade de vida. Os elementos essenciais identificados nas definições foram: vida, cuidado, qualidade, família, equipe multidisciplinar, conforto e alívio.

Conclusão: Constatou-se amadurecimento na definição de cuidados paliativos, ao agregar elementos para garantia de qualidade de vida digna, independentemente do tipo de doença, e integrar família e equipe interprofissional nesse processo.

Resumen

Objetivo: Analizar la evolución histórica del concepto de cuidados paliativos e identificar sus elementos esenciales.

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[1] *Universidade Estadual do Ceará*, Fortaleza, Ceará, Brazil.
[2] School of Nursing, *Universidade de São Paulo*, São Paulo, SP, Brazil.

Conflicts of interest: nothing to declare.

Métodos: Revisión de alcance fundamentada en el manual del *Joanna Briggs Institute Reviewer's* que incluyó las definiciones de cuidados paliativos provenientes de artículos científicos seleccionados de bases y portales de salud. Se seleccionaron 21 estudios para el análisis. Se utilizó el software IRaMuTeQ® para la agrupación de datos.

Resultados: De 1993 a 2020 la definición de cuidados paliativos más citada fue la de la *World Health Organization*. El enfoque paliativo fue implementado en la esfera física, biopsicosocial y espiritual a pacientes con enfermedades agudas o crónicas para promover bienestar, dignidad y calidad de vida. Los elementos esenciales identificados en las definiciones fueron: vida, cuidado, calidad, familia, equipo multidisciplinario, bienestar y alivio.

Conclusión: Se constató la maduración de la definición de cuidados paliativos al agregar elementos para garantizar la calidad de vida digna, independientemente del tipo de enfermedad, e integrar la familia y el equipo interprofesional en ese proceso.

Introduction

Technological and scientific development has enabled the early diagnosis of many diseases, anticipating appropriate therapy, which provides greater opportunities for cure and thus extends life span. Despite these advances, some diseases, especially chronic ones, persist and cause limitations that require specific care and significant lifestyle adjustments.(1) Aging and chronicity require health systems to focus more on policies aimed at people with advanced diseases and palliative needs.(2)

The search for approaches that restore the balance of damage and limitations caused by diseases led to the conception of principles and actions that today are grouped under the umbrella of palliative care (PC).(3) The definition of PC was initially proposed by English social worker, nurse and physician Cicely Saunders who, from the 1950s onwards, developed knowledge and practices to better care for people who were dying.(4) However, limiting PC to patients with chronic or incurable diseases restricts its proper application and restricts its benefits in the face of conditions with uncertain prognoses.

There is a constant struggle for the full implementation of PC, in order to go beyond the merely technical aspects. In most countries, PC is aimed at patients with terminal neoplastic diseases with no possibility of cure.(5) However, the PC field is extensive and innovative in health care as it juxtaposes treatments and an integral approach. PC consists of perceiving the human being in its entirety and considering their physical, social, emotional, mental and spiritual needs. Thus, given these plural demands and polysemy, the objectives of this study are to analyze the historical evolution of PC definitions and identify its essential elements.

Methods

This is a scoping review study, prepared in accordance with the Joanna Briggs Institute guidelines, contained in its manual released in July 2020.(6) To prepare this review, we followed the Preferred Reporting Items checklist for Systematic Reviews and Meta-Analyses - extension for Scoping Review (PRISMA-ScR) recommendations.(7)

The research question construction followed the Population/Problem, Concept and Context (PCC) strategy, where "P" = definitions of PC, "C" = PC and "C" = pathologies independent of their acute or chronic nature. Thus, the following question is constituted: What are the essential elements present in the evolution of the concept of PC in its use in the most diverse situations of illness?

To achieve the study objectives, there was a refinement of articles found based on eligibility criteria. Therefore, studies that brought the definition of PC were included, electronically published in full, without restriction of language or year of publication. Research reports, editorials, letters to the editor, review studies and abstracts published in event proceedings were defined as exclusion criteria.

The paired search took place on March 26, 2021, in the electronic databases Latin American and Caribbean Literature on Health Sciences (LILACS) and the *Índice Bibliográfico Español en Ciencias de la Salud* (IBECS), Science Direct, Web of Science, Scopus, PubMed portal, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, Embase and Scientific Electronic Library Online (SciELO). The descriptors were used according to the terminology Descriptors in Health Science (DeCS) and Medical Subject Headings (MeSH), EMTREE and natural language, integrating them through the Boolean operators "AND" and "OR".

Thus, the search strategy for retrieving the studies was: (concept formation) OR (formation, concept) OR (definition) AND (palliative care) OR (palliative assistance) OR (supportive care, palliative) OR (palliative treatment) AND (disease), adapted to each database. It was decided to carry out the search with the descriptors in English, as the equation enabled the identification of a greater number of articles.

The results obtained in the databases were exported by Mendeley® for removal of duplicates, selection and screening of studies by three researchers independently. Disagreements were resolved through critical discussion among reviewers in order to reach a consensus during the data extraction process for each included study. Subsequently, they were organized in a Microsoft Excel® database, adapted from the JBI instrument to characterize the production: identification (title, authors, language, country, place, journal and year), methodological aspects (design, approach, theme and population target) and main results (definitions and theoretical frameworks of PC concepts).

To unveil the essential elements of PC, the definitions extracted from the selected articles were analyzed using the software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ), version 0.7, Alpha 2. Initially, classical textual statistics were explored, using basic lexicography and specific search for groups of words. As a multivariate analysis, we opted for similarity analysis (similarities).

Finally, the compilation and integration of results was carried out, with the intention of presenting a global view of all the material, through a thematic construction, organized according to the elements that influenced the evolution of the definitions of PC.

Results

The initial sample found was of 161 studies available in the data sources, using the crossing of descriptors. All articles found were read and using the eligibility criteria, 69 were excluded because they were reviews, editorials, guidelines and letters to the editor. Of the remaining 92, 71 did not contain the concept of PC. Therefore, the final sample consisted of 21 articles (Figure 1).

Chart 1 brings the characterization data of the selected articles and the definitions of PC in the analyzed articles, with their respective theoretical frameworks.

The studies were from four continents, with emphasis on the American, with publications from Brazil (04; 19.1%),(9,11,18,22) United States (02; 9.5%),(14.27) Canada(23,25) (02; 9.5%) and Mexico (01; 4.8%).(17) It is noteworthy that a study was carried out in health institutions in more than one continent.(19) Regarding the language, it was found that English (8,10,12-21,23-28) was the most frequent with 18 articles (85.7%).

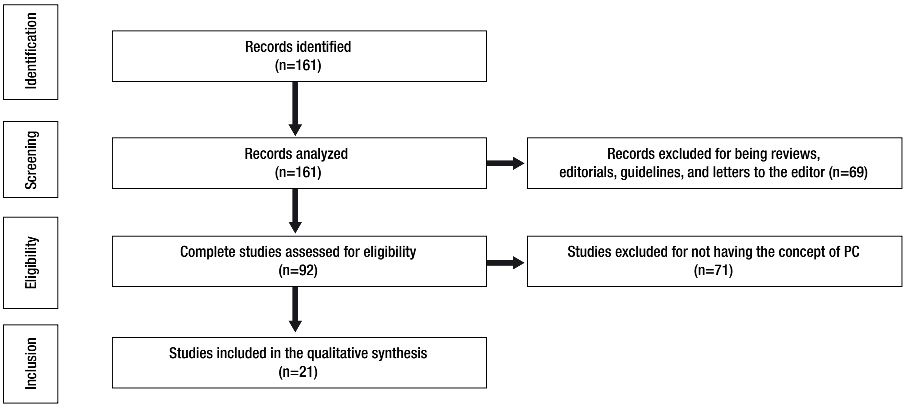

Figure 1. Flowchart of selection of publications for scoping review, adapted from the PRISMA model

Chart 1. Characterization of selected articles

Authors Year/Country	Design	Frameworks	Definitions
Porzsolt F/1993/ Germany(8)	Descriptive	Bruera et al. (1986)	Approach to alleviate symptoms, prevent impending problems, improve quality of life and extend survival, if possible.
Santos OM/2011/ Brazil(9)	Descriptive	WHO (2002)	Approach that aims to improve the quality of life of patients who face problems arising from an incurable disease with limited prognosis and/or serious disease (life-threatening) and their families, through the presence of a multidisciplinary team and relief of suffering, using early identification, proper assessment and rigorous treatment of symptoms not only physical, such as pain, but also psychosocial and spiritual.
Tosello B et al./2015/ France(10)	Exploratory	*République française* (2002)	Active and continuous care provided by a multidisciplinary team in an institution or at home, with the objective of alleviating pain, reducing mental suffering, preserving patients' dignity and supporting their family and friends.
Silva MM et al./2014/ Brazil(11)	Descriptive	WHO (2007)	PC is promoted by a multidisciplinary team, aiming to improve the quality of life of persons and their families in the face of a life-threatening disease, through the prevention and relief of suffering, early identification, impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms
Wright R et al./2020/ United Kingdom(12)	Action research	WHO (2011)	Multidisciplinary biopsychosocial-spiritual care of a person with serious illness and his/her family.
Damani A et al./2020/ India(13)	Descriptive	Roma et al. (2011)	Holistic care of physical, psychological, social and spiritual health, with a focus on alleviating widespread suffering through effective symptom control, promoting quality of life, and making complex decisions, all of which play an important role in care.
Padmanabhan DL et al./2020/ EUA(14)	Exploratory	WHO (2012)	An approach that improves the quality of life of patients and their families who face the problems associated with potentially fatal diseases through the prevention and relief of suffering through the identification, assessment and early treatment of pain and other physical, psychosocial and spiritual challenges.
Qu X et al./2018/ China(15)	Descriptive	Kang, Zhu and Liu (2012)	Approaches that improve the quality of life of patients and help their families overcome the problems associated with life-threatening illnesses, to help the terminal patient experience peace, comfort and dignity.
Pavlic DR et al./2019/ European countries(16)	Exploratory	WHO (2013)	Holistic approach that improves the quality of life of patients and their families facing problems associated with life-threatening illnesses. It offers prevention and relief from suffering through early identification, diligent assessment and treatment of pain and other physical, psychosocial or spiritual problems.
Zuniga- Villanueva G et al./2019/ Mexico(17)	Exploratory	WHO (2014)	Comprehensive approach that focuses on improving the quality of life of children, in its final stages and is usually provided for life-threatening illnesses with poor prognosis.
Zalaf LR et al./2017/ Brazil(18)	Cross-sectional	WPCA (2014)	A holistic approach that improves the quality of life of children with life-limiting illnesses through a family-centered approach to care and alleviation of physical, psychosocial and spiritual suffering
Xiang YR et al/2018/ China(19)	Descriptive	Hu and Feng (2016)	Comprehensive treatment of physical, psychological, social and spiritual care for terminal patients, aiming at improving the quality of life of patients and their families.
Çeliker MY et al./2017 /Cambodia(20)	Descritivo	WHO (2016)	An approach that improves the quality of life of patients and their families facing life-threatening disease-associated problems through the prevention and alleviation of suffering through early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.
Ofosu-Poku R et al./2020/ Ghana (21) Ribeiro JR et al./2019/ Brazil(22)	Exploratory Descriptive	WHO (2017)	An approach that promotes quality of life for users (adults and children) and their families who face problems associated with life-threatening diseases, preventing and alleviating suffering through early identification, correct assessment and treatment of pain and other physical, psychosocial or spiritual problems.
Fassbender K/2017/ Canada(23)	Descriptive	Fassbender (2017)	Care that helps patients and families to address physical, psychological, social, spiritual, and practical issues and their associated expectations, needs, hopes, and fears, as well as preparing and managing the end of life and death process, coping with loss and grief during illness.
Zapponi S et al./2018/ Italy(24)	Exploratory	Zapponi et al. (2018)	Different set of treatments that are basically provided to people near death and to people with incurable diseases, preference for cancer patients than to patients with serious infectious diseases
Brainbridge E et al./2010/ Canada(25)	Descriptive	CHPCA (NI)	Support to assist those at the end of their lives to spend their remaining time in comfort and dignity.
Borimnejad L et al./2014/ Iran(26) Kozlov E et al./2017/ USA(27)	Descriptive	Vanderbilt Health (NI)	Specialist care that focuses on patients facing life-threatening illnesses or injuries, with the aim of providing experience and treatment plans for symptom control, as well as practical and emotional support, considering the whole patient and their situation. It is not just for end-of-life patients
Radbruch L et al./2020/ Multicentric(28)	Descriptive	Radbruch et al. (2020)	Active holistic care of individuals of all ages with health-related suffering, with the intention of improving the quality of life of patients, their families and their caregivers.

NI - not informed; CHPCA - Canadian Hospice Palliative Care Association; WHO - World Health Organization; WPCA - World Palliative Care Alliance; USA - United States of America

The articles were published between 1993 and 2020, with predominance from 2011 to 2020 (19; 90.5%) and 2020, with five articles (23.8%).(12-14,21,28) The journals that most published on the subject were the Journal of Pain and Symptom Management(14,28) and the Chinese Medical Sciences Journal,(15,19) with two publications each (9.5%). Regarding the method, there was a predominance of descriptive studies(8,9,11,13,15,19,20,22,23,25-28)(13; 61.8%), with a qualitative approach(8-11,13,15,16,19-28) (17; 80.9%).

The themes were quite diversified, with completeness and knowledge being the most prevalent, with six (28.6%) publications each; followed with themes addressing chronic diseases (05; 23.7%), the experiences of patients, family members/caregivers and professionals with PC (03; 14.3%) and infectious diseases (01; 4.8%).

The references used by the authors of the selected articles were extracted from different sources, published from 1986 to 2017, mostly from the World Health Organization. Over the years, the definitions of PC have been adding elements that have made it possible to expand its use. What used to restrict PC to care to relieve pain and suffering, recent definitions highlight the implementation of multidisciplinary biopsychosocial and spiritual care for patients with acute and/or chronic illnesses, to promote comfort, dignity and improve quality of life.

Still, PC covered different populations, such as children,[20] lay adults,[27] cancer patients, patients and caregiver families,[12] Twitter users,[14] health students and professionals[9-11,13,18,19,21,22,24,26] and services and representatives specialized in PC.[15,16,17,23,25,28]

In this study, similarity analysis allowed us to understand the essential elements of PC (Figure 2). One can see the similarity of the generated figure with a river and its elementary constituents. The river of life, demanding care and quality, requires the attention of an interprofessional team focused on the needs and management of symptoms, in order to promote comfort and maintain dignity. It is observed that the disease emerges directly from life, influenced by other sub-affluents: suffering, physical, spiritual, and pain.

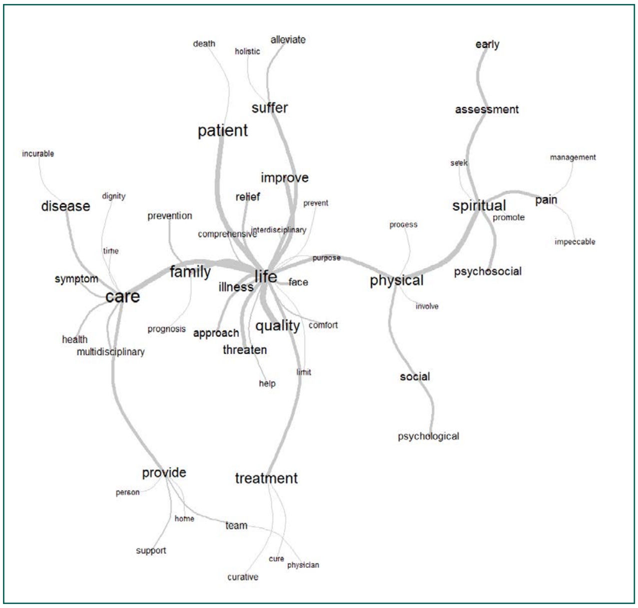

Figure 2. Similarity analysis of palliative care definitions

Discussion

Each year, the number of people who need PC increases. Currently, around 40 million people are indicated for PC, but only 14% receive them. Furthermore, 78% of those who need to receive care from PC professionals live in low- and middle-income countries.(29) In Brazil, the estimate of palliative indication for 765,855 people in 2020 and the understanding that each and every individual deserves to be supported and treated with quality in their suffering, as well as that of their families, led to publication of Resolution 41 by the Ministry of Health, which regulates PC provision as part of continuous care integrated into the Unified Health System (*Sistema Único de Saúde*).(30)

However, to make it possible, some changes must occur in the way of thinking and offering PC, such as the expansion of levels of health care and training of professionals so that they are able to disseminate the concept of PC in their workplaces and perform palliative actions.(30) Now, planning strategies for implementing PC requires, above all, an understanding of the term. Therefore, the need to know and interpret its definitions and learn how to integrate them into care practice is reiterated.

The analyzed articles brought definitions developed over 34 years (1986 to 2020). The oldest linked PC to symptom relief and problem prevention to improve quality of life and extend survival, when possible. Although this definition expands that of Cicely Saunders, published in 1967 and limited to patients in the terminal stage of life, there are still important gaps that must be addressed in the care process. Care must be conceived as a way of living, of being, of expressing oneself. It involves all behaviors and attitudes developed to favor the potential of individuals cared for and maintain or improve the human condition in the process of living.(19)

Due to the concern and interest in patients' totality and quality of life, the WHO published, in 1990, a definition that characterizes the palliative approach as active and total care for cancer patients, unresponsive to treatment and with limited life expectancy. However, the shortcomings of this definition led to its reformulation in 2002. PC started to contemplate any disease situation - physical, psychosocial and spiritual problems - of an acute or chronic nature, to integrate everyone involved in the care process (patients of any age group, family members/caregivers and professionals from the multidisciplinary team), in any environment (hospital or home).(16,20,21) Furthermore, in 1998, a definition of PC aimed at the pediatric population was formulated, defined as total care for children diagnosed with neoplastic diseases, including support for their family.(31)

It is noteworthy that the definition of PC adopted by most authors had as theoretical reference the WHO.(9,11,12,14,16,17,20,22) However, there was a discrepancy between the referenced years of the definition, which ranged from 2002 to 2017. From the most recent documents published by the WHO,(32) available on its website, it was found that the last definition of PC was published in 2002, since such publications are presented as a citation of this one.

Starting from the broader interpretation of PC, countless people were benefited, as patients with cardiovascular, neurological and infectious diseases were reached, including those with the new coronavirus.(13) However, the purpose of PC still seems to be linked to terms such as 'terminal patients' and 'cancer patients', as demonstrated in some definitions used by selected authors.(24) There is perceived resistance and limited perception of the reach of such care up to this moment.

Recent studies work with PC from a perspective that involves the entire process of human finitude and the stages of mourning experienced. In these studies, the authors' concern with adopting definitions that consider, in the palliative approach, expectations and feelings linked to illness and preparation for the end of life and the process of death is noticeable, how to deal with the loss and phases of grief.(17,23)

Grief presents itself as a normal and foreseen reaction with the breaking of a bond, of an affective bond with meaning put in an individual way, experienced in a contextual and subjective way.(18) For this reason, the importance of PC for the relief of physical, spiritual and supportive symptoms is undeniable. However, without stressing that the implementation of PC is associated with the end of life.

Over the years, it was observed that the definitions of PC underwent successive modifications as they incorporated elements that allowed for the expansion of its scope. Similarity analysis revealed some of these elements, such as care, patient, life, and quality. However, one ramification that had great prominence was the disease. Despite the updates, there is still a strong focus on the definitions of PC in the disease. By emphasizing the provision of such care to people with threatening diseases, rather than prioritizing suffering individuals, as proposed by the new definition of PC by the IAHPC (The International Association for Hospice and Palliative Care), which was based on the team's suggestion of the Lancet Commission,(28) can lead to a lack of understanding and consensus on when to start offering PC.

Emerging directly from the disease, but also from quality, the importance of family in the definitions is noted. Family can be defined as those closest to patients in terms of knowledge, importance and affection, and includes the biological, acquired, chosen and friends.(33) In the palliation process, patients must have a support network. Thus, the inclusion of family and important people for individuals is essential for physical and emotional support, which justifies the presence of the term in the definition of PC.

Other words stood out in similarity, such as multidisciplinary, interdisciplinary, comprehensive and holistic. Despite being represented inexpressively, they were interconnected to more robust words. In order to achieve patient-centered care, it is necessary to strengthen the multidisciplinary team, for the treatment not only of physical symptoms, such as pain, but also of social, moral, ethical, psychological and spiritual aspects.(34)

Barriers to an efficient implementation of PC are many, including unnecessarily restrictive regulations for morphine and other essential opiates,(35) scarcity of adequate policies, programs, resources and training,(29) factors that contribute to people in need of such care not having adequate access. The indication of PC is hampered by professionals' lack of knowledge, as well as the perception that palliation means abandonment and reduction of hope for patients and their families and the unavailability of PC services.

In care practice, PC is still highly concentrated on cancer patients, although this component is no longer present in the most recent definitions, with a vision of palliation still associated with abandonment and the absence of alternatives. It is noteworthy that such definitions need to be not only revisited and periodically updated, but also disseminated so that their concepts reach all levels of health care and benefit all patients in need of palliation.

The study also has limitations, due to its nature. As this is a review, some studies were not available for full reading, thus being excluded from the research.

Conclusion

The concept of PC has evolved and matured over the years, extending the promotion of comfort beyond the area of oncology. New elements were added to the definition, expanding the audience to be assisted and adding to its scope all physical, psychosocial and spiritual problems, in addition to integrating the family and multidisciplinary team in the process. Despite the evolution, it is noted that the concept of PC is still centered on the disease and not on health or quality of life, which should be the main purpose of this care, since the focus is no longer to enable a dignified death, but a life with more quality. This study enabled the vision of how the concept of PC evolved and how it has still been used in practice, demonstrating the need for a greater understanding of its constituents and essential elements, in order to strengthen the proper use of the term and an adequate implementation of such important practice in health. We suggest the development of new studies, in different contexts and with different populations, to streamline the definition and promote its dissemination, in addition to expanding the implementation of its premises in care practice.

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