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Palliative care in intensive care units: an integrative review

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Abstract

Our integrative review sought to identify therapeutic decisions for palliative care in intensive care units. Bibliographic search conducted on the Virtual Health Library using the descriptors “palliative care,” “intensive care units” and “delivery of health care” returned 1,579 studies, of which seven were included in the final sample. Textual analysis was performed using the Iramuteq software. From the main results and words—“patient,” “end of life,” “family,” “intensive care unit,” “hospital”—we produced a co-occurrences tree, resulting in two categories and four subcategories. Currently, the spread of chronic noncommunicable diseases and increased life expectancy call for the large-scale use of this type of care, improving quality of life, care and academia.

Keywords: Palliative care. Intensive care units. Delivery of health care.

Resumo

Cuidados paliativos em terapia intensiva: revisão integrativa

Trata-se de revisão integrativa com o objetivo de identificar decisões terapêuticas de cuidados paliativos em unidade de terapia intensiva. A busca foi realizada na Biblioteca Virtual em Saúde com os descritores “cuidados paliativos”, “unidades de terapia intensiva” e “atenção à saúde”, e encontrou 1.579 pesquisas, das quais sete constituíram a amostra final. O material foi analisado por meio do *software* Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires. Uma árvore de similitude foi produzida a partir dos principais resultados e dos vocábulos “paciente”, “término”, “família”, “unidade de terapia intensiva”, “cuidados paliativos”, “hospital”, resultando em duas categorias e quatro subcategorias. Na atualidade, com avanços das doenças crônicas não transmissíveis e aumento da expectativa de vida, vislumbra-se a possibilidade de utilizar esses cuidados em grande escala, gerando melhorias na qualidade de vida, assistencial e acadêmica.

Palavras-chave: Cuidados paliativos. Unidades de terapia intensiva. Assistência à saúde.

Resumen

Cuidados paliativos en cuidados intensivos: revisión integradora

Esta revisión integradora pretende identificar las decisiones terapéuticas de cuidados paliativos en una unidad de cuidados intensivos. La búsqueda se realizó en la Biblioteca Virtual de Salud, con los descriptores “cuidados paliativos”, “unidades de cuidados intensivos” y “cuidado de la salud”, la cual resultó en 1.579 estudios, de los cuales siete compusieron la muestra final. Para el análisis del material se utilizó el *software* Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires. Se elaboró un árbol de similitud desde los resultados principales y las palabras “paciente”, “finitud”, “familia”, “unidad de cuidados intensivos”, “cuidados paliativos”, “hospital”, lo que dio como resultado dos categorías y cuatro subcategorías. Teniendo en cuenta los actuales avances en las enfermedades crónicas no transmisibles y el aumento de la esperanza de vida, este tipo de cuidados puede utilizarse a gran escala, pues genera mejoras en la calidad de vida, asistencial y académica.

Palabras clave: Cuidados paliativos. Unidades de cuidados intensivos. Atención a la salud.

The authors declare no conflict of interest.

In the case of chronic degenerative diseases with no prospect of cure, palliative care (PC) can and should be offered. PC has the potential to improve the quality of life of patients and their families by preventing and alleviating suffering through early detection and by treating pain and other physical, psychological, social and spiritual problems, including grieving¹.

Besides being aware of the need for PC, it is important to note that demographic data show the aging of the Brazilian population due to the significant reduction in the fertility rate and increased longevity. This process, which has occurred rapidly, has not been addressed by a reorganization of society as a whole—or even of the health area—to meet emerging demands².

Agostinho, Botelho and Moraes³ note that according to United Nations estimates, by 2060 the number of individuals aged 65 or over will exceed 60 million. The rapid growth of the percentage of older adults in the population is a global phenomenon that challenges health systems in many countries.

With the aging of the world population comes also an increase in both chronic diseases of a progressive nature, that cannot be cured, and non-communicable chronic degenerative diseases (NCDs). Treatment in such cases is PC. Every year, about 20.4 million people need end-of-life PC; approximately 94% of them are adults, of whom 69% are senior citizens⁴.

Regarding chronic degenerative diseases or non-curable progressive diseases, it is worth mentioning that finitude is a human life condition that should not be seen as a pathology to be cured. Therefore, it is necessary to relieve suffering when possible and, when not, to help people depart with dignity⁵. Even when the preservation of life, in the biological sense, is no longer the focus of patient care, living is still an essential issue in terms of the relationship between people⁶. This view helps understand the intimate relationship between PC and bioethics, especially concerning the care of people who are dependent at the end of their life.

Therefore, as a science related to human survival which defends the improvement of

living conditions, bioethics raises reflections on human action, seeking to ensure the well-being and survival of the species based on its fundamental principles: autonomy, beneficence, non-maleficence and justice⁷. It can also be viewed from the personalist approach, according to which people are protagonists of their own life; in other words, it is about guaranteeing the recognition of individuals, their identity and essence, because only then will we know how to respect them⁸.

The biggest ethical challenge of PC is to support people in their process of finitude, and relates to the goal of preserving their dignity and alleviating suffering and pain at the end of life⁹, in this context, the importance of PC is evident, as is the reorganization of health services in order to ensure its supply. It is necessary to break the taboo surrounding death and approach it in a more natural way in order to spare patients from senseless and prolonged agony, so that, at that moment, their personal values and beliefs are respected, allowing them to complete this cycle of life with dignity¹.

As the goal of such care is to minimize the physical and psychological suffering of patients, the procedures to be adopted must be the least invasive possible. The performance of any invasive palliative procedure should aim to alleviate symptoms, restore organ function, improve quality of life and body image, and optimize patient care. Pharmacological treatment involves the use of drugs to relieve pain, dyspnea, nausea, vomiting, constipation, diarrhea, fatigue, sweating, pruritus, depression and anxiety¹⁰.

Since most hospitals do not have yet an institutionalized PC committee and there is a large increase in patients in these conditions, it is highly important to observe how therapeutic decisions are being made and whether they are actually beneficial to patients. Healthcare providers often establish a way of administering PC that they deem best, when in fact they are using inappropriate procedures and medication. Based on these considerations, the goal of this study was to identify, in the scientific literature, therapeutic decisions regarding PC performed in intensive care units.

Method

This study was carried out through an integrative literature review, a method that enables the synthesis of knowledge from the outcomes of significant studies, combining data from the literature to incorporate feasibility and purpose¹¹. The integrative review followed defined criteria, according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), consisting of five steps: identification of the research question; identification of relevant studies, valid for the investigation; screening of studies; mapping of data extracted from included studies; and synthesis and narrative of outcomes¹².

The Pico strategy was used to establish and identify the object of study. Pico is an acronym for population (adult patients), intervention (PC protocols) and context (intensive care units). This strategy makes it easier to identify key topics, enabling a better study design. According to the Pico outcomes—identified concepts and themes—the following guiding question was established: what scientific evidence is there regarding PC protocols used in adult patients hospitalized in intensive care units?

Based on the research question, suitable keywords were selected in Health Sciences Descriptors (DeCS) for the database search. The controlled descriptors and correlates used were: “palliative care,” “intensive care units” and “health care.” The search for titles and articles in the databases and the identification of the study were carried out between January and April 2022.

The identification stage started from the selection in the databases indexed in the Virtual Health Library (VHL). The search was carried out through combinations of the descriptors, using the Boolean operators “and” and “or.” As an inclusion criterion in the screening stage, it was determined that the publications should be original articles,

published in full, with no time frame, and in Portuguese, English and Spanish. Studies that did not address the subject and gray literature, such as dissertations, theses, reviews and reflection articles and duplicate papers, were excluded.

Then began the eligibility and inclusion stage, carried out by the researcher. This was done by using an instrument designed to extract and analyze data from the studies selected for this stage. The following items were listed: authors and year of publication, study title and site, type of study and number of participants, objective and outcomes. Full reading of the papers resulted in the final stage of inclusion of the studies, with the data tabulated in the 2010 Microsoft Office Excel software and subsequently submitted to analysis.

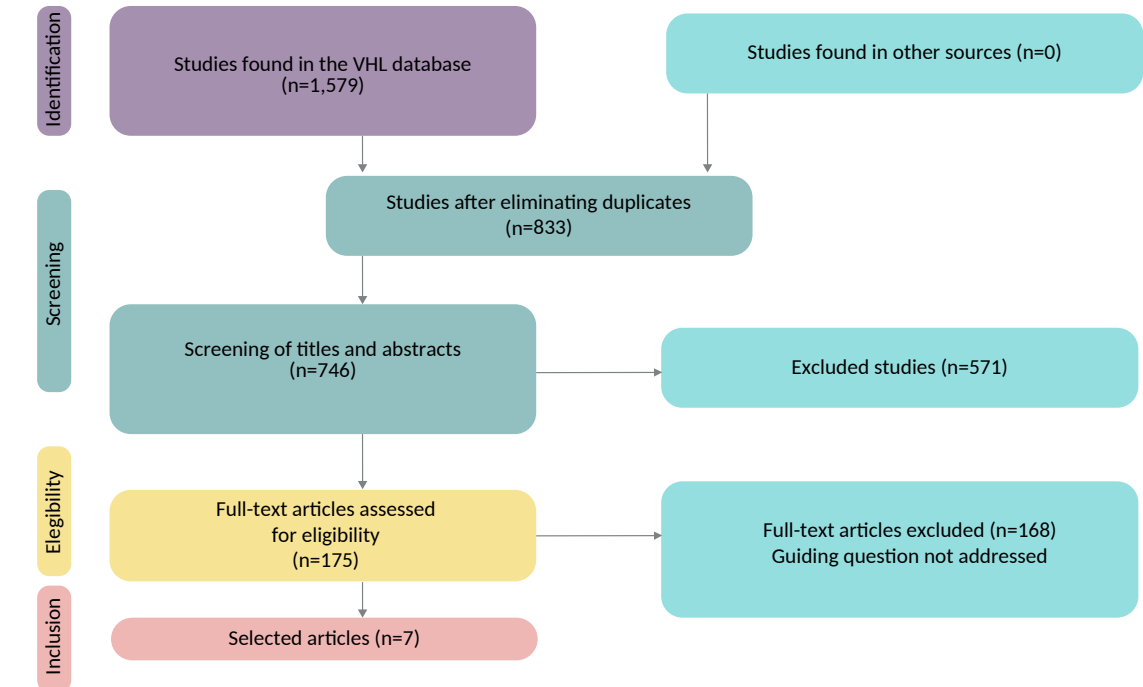
The data were operationalized using Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires (Iramuteq) software, version 0.7 alpha 2¹³. A text corpus was built up based on the initial categories that emerged from the content analysis, with excerpts of the interviews that addressed the goal proposed by this study.

Analysis of similarities was then used, which makes it possible to identify the occurrence of words in the text corpus and the connection between them, and then group them in core and periphery groups, generating a similarity tree that helps in the identification of structures¹³. Two final categories originated from the convergence between the initial categories obtained from the content analysis and the organization of the data by the software.

Result

The database search resulted in 1,579 publications that, screened for the eligibility criteria, resulted in a final sample of seven articles (Figure 1).

Figure 1. Flowchart of the screening process of studies in databases/data libraries to compose the sample of this integrative review (Maringá/PR, 2022)



Source: adapted from Page and collaborators¹²

Chart 1 features a summary of the primary studies, with author(s), year, title, study site, study type, number of participants, goals and outcomes. Studies published in 2020 and 2021 predominated, with three articles in each year. Regarding country

of origin, there was a predominance of Brazilian publications (42.8%; 3), followed by works from Canada (28.6%; 2) and from the United States and Turkey, both with one article each (14.3%). Most are observational cohort studies (71.4%).

Chart 1. Summary of selected studies according to year and country of publication, title, author(s), type of study, goal and outcome (Maringá/PR, 2022)

Author and year	Title and country	Study type and no. of participants	Objective	Outcome
Alliprandini and collaborators; 2019 ¹⁴ (A1)	"End-of-life management in intensive care units: a multicenter observational prospective cohort study"; Paraná, Brazil	Observational cohort n=201	To evaluate which patients hospitalized in five ICUs in the city of Cascavel/PR are eligible for the performance and administration of PC.	Among the patients who died during the period, proper PC criteria was performed in only 15%, with terminal extubation being one of the rarely performed procedures.
Irmak and collaborators; 2020 ¹⁵ (A2)	"The comparison of the survival rates of intensive and palliative care units"; Ankara, Turkey	Observational study n=112	To compare survival rates in the intensive care unit and the palliative care unit.	Long-term survival rates proved similar between the intensive care unit and the PC unit.

continues...

Chart 1. Continuation

Author and year	Title and country	Study type and no. of participants	Objective	Outcome
Hua and collaborators; 2020 ¹⁶ (A3)	"Association between the implementation of hospital-based palliative care and use of intensive care during terminal hospitalization"; New York, United States	Observational cohort n=73,370	To determine whether the implementation of hospital-based palliative care was associated with decreased ICU use during terminal hospitalizations.	A 10% reduction in the use of intensive care during terminal hospitalizations was identified in hospitals with PC programs in place.
Clara and collaborators; 2020 ¹⁷ (A4)	"The palliative care screening tool as an instrument for recommending palliative care for older adults"; Espírito Santo, Brazil	Cross-sectional study n=594	To evaluate the use of the Palliative Care Screening Tool and its agreement with the Palliative Performance Scale, as well as describe the causes of hospitalization in older adults receiving palliative care and in the ICU.	The Palliative Care Screening Tool proved to be of great importance in referring patients to PC due to its high sensitivity.
Reeve and collaborators; 2021 ¹⁸ (A5)	"Community implementation of the 3 Wishes Project: an observational study of a compassionate end-of-life care initiative for critically ill patients"; Ontario, Canada	Observational and descriptive n=101	To evaluate the adaptability of the 3 Wishes Project to an intensive care unit and describe the patients treated with this palliative approach, as well as local implementation strategies.	99.2% of terminal wishes were met at an average cost of US\$5.39 per patient, and for 89.8% there was no cost. The program comforted patients and relatives.
Takaoka and collaborators; 2021 ¹⁹ (A6)	"Scale-up and sustainability of a personalized end-of-life care intervention: a longitudinal mixed-methods study"; Ontario, Canada	Longitudinal n=369	To describe how the 3 Wishes Project, a personalized end-of-life intervention, was scaled up and maintained in an intensive care unit.	The 3 Wishes Project began as a study and was integrated into clinical practice as an accessible and sustainable care approach.
Lacerda and collaborators; 2021 ²⁰ (A7)	"Mechanical ventilation withdrawal as a palliative procedure in a Brazilian intensive care unit"; São Paulo, Brazil	Retrospective cohort n=282	To describe characteristics and outcomes of patients undergoing withdrawal from mechanical ventilation and compare them to patients with mechanical ventilation and limitations of life support therapy (limited or withdrawn), but without removal of mechanical ventilation.	The authors observed that there is no association between withdrawal of mechanical ventilation and increased hospital mortality.

Figure 2 features the similarity tree produced from the main outcomes of the studies that comprise this review, highlighting the following words: “patient” (n=50), “palliative care” (n=27), “wish” (n=19), “hospital”/“ICU” (n=18), “studies”

(n=17), “end” (n=12), “life” (n=12), “death” (n=12), “family” (n=10) and “protocols” (n=10). These words originated categories that helped identify the structure of the representational field of therapeutic PC decisions made in an intensive care unit.

Figure 2. Similarity tree generated by Iramuteq software (Maringá/PR, 2022)



The words “patient,” “end,” “family” and “life” generated category 1, called “Patient, family and end-of-life limitation,” from which two subcategories emerged: “wish to protect patient dignity” and “procedures to preserve life or not.” In turn, the terms “palliative

care,” “hospital”/“ICU” and “studies” resulted in category 2, entitled “intensive care unit as a place to provide palliative care.” Two subcategories emerged: “implementation of palliative care protocols” and “performance of invasive procedures.”

Discussion

The analysis of the scientific production showed that despite the important advances, PC directed to patients with no prospect of cure and their families is still provided in an incipient and limited manner, given the high complexity of the care and the difficulties of professionals. The identification in this study of reduced scientific production on the subject indicates a gap to be filled by healthcare providers.

Patient, family and end-of-life limitation

ICUs are still related to the pain and suffering of patients and their families. The use of complex technologies, poor communication between medical staff, patients and family members, the severity of clinical cases and, above all, the imminence of death are factors that emphasize that relationship. Many doubts, fears and insecurities permeate not only the mind of patients, but also of families, who commonly suffer, and of healthcare providers, whose proximity to patients in hospital is conducive to bonding.

Intensive care is characterized by the use of many technological resources and specialized treatments that sometimes go beyond the wish and decision of patients and their families. However, the finitude of life seems to be increasingly better understood, as are the limits of healing. Most studies on PC in ICU have aimed to invest in the quality of life and dignity of patients affected by a disease with no prospect of cure.

Wish to protect patient dignity

The common wish to protect the dignity of patients in the final stages of life can be expressed and represented by the medical team and family members. Two studies used for this purpose the 3 Wishes (3WP) project, a program aimed at terminally ill patients that upholds the dignity of these people, providing meaningful connections between patients, families and physicians in intensive care. Such connections are encouraged with a focus on patients' preferences and legacies—one of the program's strengths^{18,19}.

As shown in the study by Reeve and collaborators¹⁸, 3WP made it possible to meet more than 99% of terminal wishes, at low or no cost. Wishes range from enhancing the clinical environment with personal belongings to celebrations of life and musical performances. In the study, the wishes included celebrations, rituals, decoration of the patient's room and music, as well as various forms of connection with loved ones, including pets. The program contributed to the comfort of patients and relatives in the process of coping with and accepting death¹⁸.

In Ontario, Canada, 3WP began as a study and, given its effectiveness in supporting and providing comfort to all involved—not only patients and family, but also the multidisciplinary team—became part of clinical practice, consolidated as an approach that enables more humanized care which is also accessible and sustainable¹⁹.

For those studies, 3WP was a vehicle for greater recognition of patient dignity and a means of showing compassion for patients and families, insofar as it provided individualized care. Among its strengths is the possibility of meeting almost all end-of-life wishes by providing personalized, accessible and terminal intervention^{18,19}.

Thus, care for life, regardless of its duration, aims to revive the terminal patient's willpower¹⁴. That is why PC should be provided by a competent healthcare team, focused on providing comprehensive care, with adequate attention and support, enabling a more dignified and comfortable death¹⁶. It is important to take care of the symptoms and avoid invasive treatments that are not beneficial.

Procedures to preserve life or not

The limitation of life support involves recognizing the uselessness of the treatment and has been discussed as a way to allow patients to have a dignified death, with less suffering and according to their conditions. It includes making clinical decisions such as withdrawing or ceasing to offer advanced life support and maintaining current measures, without additional treatment for new clinical occurrences until death occurs²⁰.

There are four reasons for limiting ICU patient life support: the patient's or family's wish to interrupt treatment; the futility of the treatment to face the conditions; the prospect of low quality of life; and the difficulty of undergoing the treatment to revert the clinical conditions in question²¹.

The implementation of PC requires the acknowledgment of responsibility in the interaction between medical staff, family and patients in order to guarantee the patient's autonomy in a condition in which there is no prospect of cure. When this autonomy is not respected, the healthcare provider may be trying to protect the patient and relative from learning about the prognosis. In doing so, however, they deny the individualization of care, the condition of the patient as a subject, which is reflected in obstacles to the operationalization of PC.

A study carried out in ICUs in Brazil found that one third of the patients who died in those units had an indication of palliative care management at the end of life; however, PC was adequately performed in only 15% of patients. In addition, a prolonged delay to start the administration of the criteria was pointed out. Among the components that were rarely or never administered, terminal weaning/extubation was the most prominent¹⁴.

Withdrawal of mechanical ventilation (MVR), also known as palliative extubation, is appropriate when mechanical ventilation (MV) is no longer in line with the patient's values regarding the prognosis and likely outcomes. The results of the study by Lacerda and collaborators²⁰ showed that withdrawal of mechanical ventilation was not associated with increased hospital mortality, compared to ventilated patients with limitations of life support therapies who were extubated. However, the length of stay in the hospital was shorter.

Palliative extubation occurs when the absolute priority in care is to provide comfort and allow natural death to occur. It is indicated in cases where the patient's quality of life is unacceptable, when there is no hope of improvement and all attempts at weaning have failed, and maintenance of ventilatory support becomes inappropriate. In short, when it becomes clear that the support is causing unnecessary suffering²².

Intensive care unit

A place to provide palliate care

In recent years, efforts have been made to increasingly engage patients and families with the ICU care team and in decision-making, recognizing that the constant presence of the family with the critically ill patient enables better results and well-being for both. Engaging patients and family members in care is currently an integral part of humanized treatment²³.

Enabling care providers and family members to share space in healthcare services is a challenge to be met by health managers. Although the benefits of the presence of relatives for the patient's quality of life are recognized, outside the prospect of cure they are often disregarded when determining the care plan that guides the actions of the multidisciplinary team²⁴.

The risk of the patient dying in the intensive care unit causes stress in the family, whether emotional, cognitive or social, which results in feelings of uncertainty, denial, anger, despair, hope, guilt, anxiety and fear of the death of the relative. Thus, the family becomes the object of care of the multidisciplinary team, with a number of demands that need to be met²⁵.

Implementation of palliative care protocols

Long-term survival rates proved to be similar between the intensive care unit and the palliative care unit (PCU) in a study by Irmak and collaborators¹⁵. Although the PCU does not change patient survival, studies suggest that the use of aggressive therapies in the ICU may speed up the natural death of patients, so avoiding their use tends to have positive effects on survival.

PC services in hospital units aim to support the healthcare teams of the different sectors in order to help patients adapt to the life changes imposed by the disease. In addition, they can encourage reflection required to face this life-threatening condition for patients and families²⁶. In hospitals with PC programs in place, a 10% reduction in the use of intensive care during terminal hospitalizations was identified^{16,17}.

PC involves different types of professionals—physicians, nurses, social workers and, if necessary, speech therapists, physical therapists and occupational therapists—in order to provide psychological and social support to patients and relatives, thus offering prolonged survival with better quality of life²⁶. In the terminal phase of serious and incurable illnesses, physicians may limit or suspend procedures and treatments that prolong the patient's life, guaranteeing the necessary care to alleviate the symptoms that lead to suffering. In this sense, the perspective of comprehensive care is considered, respecting the will of the patient or their legal agent.

The study by Clara and collaborators¹⁷ showed the need for early diagnosis through the use of two scales—the Palliative Care Screening Tool (PCST) and the Palliative Performance Scale (PPS)—which proved to be decisive for referring patients to PC¹⁷. Both these instruments are used to indicate palliative care. The former has high sensitivity and is based on four criteria: underlying diseases, associated diseases, patient's functional condition and patient's personal conditions. The latter makes it possible to establish a prognosis and evaluate the patient's functionality through five parameters: mobility, activity and evidence of disease, self-care, intake and awareness. It assigns values from 0% to 100%, where 0% means death and 100% means no functional change. Palliative care is indicated when patients score below 40%¹⁷.

The study also revealed that early and correct diagnosis to initiate palliative care is a major challenge in health services, due to institutional barriers such as lack of sufficient beds for palliative patients, inadequate number of PC committees, poor training of professionals in PC and few PC programs in health institutions¹⁷. Another important issue relates to the increase in expenses with unnecessary procedures and technologies, which cause an increase in physical and psychological suffering in patients and families due to treatments that prolong life without modifying the outcome of clinical conditions¹⁷.

Performance of invasive procedures

PC programs forego most diagnostic tests and life-extending treatments in favor of symptom relief. They also instruct the dying person and

relatives about appropriate treatment and comfort. Although PC programs do not have this emphasis, good PC can prolong life to some extent, perhaps by avoiding the potentially serious side effects of surgery and aggressive drug treatments²⁶.

The study by Lacerda and collaborators²⁰ presented palliative extubation as an appropriate procedure when MV no longer meets the prognosis. Thus, during hospitalization, the patient may no longer have the prospect of clinical improvement, and the interests of the family and of the actual patient may clash with invasive measures.

Study limitations

One limitation presented by this study is the small amount of records analyzed, due to the inclusion criteria. Another limitation contributed to the small number of articles: the search in only one database, which indicates the emerging need for new investigation in different databases, considering the breadth of the subject and the increase in life expectancy and in degenerative chronic diseases.

Final considerations

The results of this study shed light on the state of the art in PC therapeutic decisions made in intensive care units. Currently, the advance of non-communicable diseases and increased life expectancy open the possibility of using such care on a large scale, which could have an impact on improving the quality of life, of health care and of academic studies.

Studies have shown beneficial effects of PC, but this specialty is still unknown to society in general and many healthcare providers. Based on the principles of bioethics, its importance is reinforced by guaranteeing fundamental rights related not only to life, but also to death.

It is important to expand discussions and studies on PC in the medical field, since it is a subject that raises ethical questions among healthcare providers. Currently, the focus is on longevity and the absence of pain and suffering:

we avoid thinking about death other than wishing it to be a swift and painless process.

PC seeks to provide comfort and pain relief to patients, avoiding turning death into a long

and painful process. PC principles and bioethical principlism corroborate the need to prevent healthcare providers from adopting irrelevant treatments that unnecessarily postpone death.

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