

Bioethics applied to palliative care: a public health issue

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Abstract

Palliative care is a set of actions aimed at improving patients' and family members' quality of life when no curative treatment is available. It encompasses physical, psychological, spiritual and social care, understanding death as a natural process whose outcome should be accelerated or delayed. Of the 131 articles on bioethics and palliative care published in the last five years selected, this integrative review analyzes 10. These studies highlight the importance of bioethics for palliative care, addressing themes such as definitions, death, end of life and the need for a multi-professional interdisciplinary team. Spirituality also plays a relevant role, putting the patient and family members as central to decisions made based on effective communication. Palliative care aims to provide comfort, dignity and comprehensive support for patients with advanced illnesses, allowing them the maximum quality of life possible.

Keywords: Palliative care. Hospice care. Bioethics. Public health.

Resumo

Bioética aplicada aos cuidados paliativos: questão de saúde pública

Cuidados paliativos são um conjunto de ações que visam melhorar a qualidade de vida do paciente e de sua família quando a doença já não responde a tratamentos curativos. Abrangem cuidados físicos, psicológicos, espirituais e sociais, entendendo a morte como um processo natural, não acelerando nem retardando seu desfecho. Esta revisão integrativa qualitativa selecionou 131 artigos sobre bioética e cuidados paliativos publicados nos últimos cinco anos, analisando 10 deles. Esses estudos destacam a importância da bioética no contexto dos cuidados paliativos, abordando temas como definição, morte, final de vida e a necessidade de equipe multiprofissional interdisciplinar. A espiritualidade também desempenha papel relevante, com o paciente e a família no centro das decisões, baseadas em uma comunicação eficaz. Cuidados paliativos buscam proporcionar conforto, dignidade e suporte integral para pacientes em fase avançada de doenças, permitindo que tenham o máximo de qualidade de vida possível em seus últimos momentos.

Palavras-chave: Cuidados paliativos. Cuidados paliativos na terminalidade da vida. Bioética. Saúde pública.

Resumen

Bioética aplicada a los cuidados paliativos: una cuestión de salud pública

Los cuidados paliativos constituyen acciones para mejorar la calidad de vida de los pacientes y sus familias cuando la enfermedad ya no responde a los tratamientos curativos. Abarcan la atención física, psicológica, espiritual y social, considerando la muerte como un proceso natural y sin acelerar ni retrasar su desenlace. Esta revisión integradora cualitativa seleccionó 131 artículos sobre bioética y cuidados paliativos publicados en los últimos cinco años, y analizó diez. Los estudios destacan la importancia de la bioética en los cuidados paliativos, abordando cuestiones como la definición, la muerte, el final de la vida y la necesidad de un equipo interdisciplinar multiprofesional. La espiritualidad también desempeña un papel importante, con el paciente y la familia en el centro de las decisiones basadas en una comunicación eficaz. Estos cuidados proporcionan confort, dignidad y apoyo integral a los pacientes terminales permitiéndoles una mayor calidad de vida posible en sus últimos momentos.

Palabras clave: Cuidados paliativos. Cuidados paliativos al final de la vida. Bioética. Salud pública.

The authors declare no conflict of interest.

When a multidisciplinary and interdisciplinary medical team is faced with a terminal patient, it must mobilize actions that seek not to preserve and maintain life but to slow it down and protect it. Aware that it will no longer be possible to opt for the preservation and maintenance of life, the team needs, in unison, to strive to ensure that suffering is alleviated and the quality of life is maintained until the end¹.

Envisioning reflections on human action to ensure the well-being and survival of humanity, bioethics, a human survival-related science, seeks to defend the improvement of living conditions based on the fundamental principles of autonomy, beneficence, non-maleficence, and justice. In the wake of bioethics, it is accepted that all advances in the biomedical sciences must be at the service of humanity, with a conscious and constantly evolving ethical position that seeks balanced responses to current conflicts².

Bioethics as a field was born in the United States between the late 1960s and early 1970s when a series of historical and cultural factors drew attention to applied ethics. Oncology researcher Van Rensselaer Potter 1971 created and proclaimed the new term “bioethics” in his book *Bioethics: Bridge to the Future*, as Mori points out³. In this scenario, palliative care emerges as an ethical modality in the care of patients who will be in hospice care due to a chronic illness.

Discussing this modality requires first recalling the understanding of some supporting concepts: hospice care and irreversibility. Hospice care, or terminal state, must be understood as the moment in which, inevitably, the evolution of a particular disease will result in death, even with the adoption of therapeutic intervention measures⁴.

Irreversibility, what cannot be reversed, must be understood in an evolutionary process referring to the patient's state in the face of the action and consequences of the disease that affects them. The condition of the irreversibility of a property of a system implies that it can undergo changes that take it from an initial state A to a final state B in such a way that it becomes impossible to return to the initial state, even if the causes of the initial transition are changed⁴.

These concepts are defined based on objective and subjective data collected and/or identified by a multidisciplinary team composed of the areas of medicine, nursing, physiotherapy, nutrition, speech therapy, occupational therapy, psychology, and neuro-psycho-pedagogy, with the support of an effective social service, associated with the humanization team, for example. The objective is to establish a diagnosis or prognosis and, thus, define the therapeutic and patient care strategy⁵.

According to the World Health Organization (WHO)⁶, palliative care represents a set of physical, psychological, spiritual, and social care actions provided to individuals whose illness no longer responds to curative care. The objective is to improve the patient's and their family's quality of life by identifying and relieving pain and understanding death as a natural process without accelerating or delaying it. In this case, death becomes an expected outcome and should not be fought, which, however, does not mean that measures cannot be applied, as the patient and their family must receive specific therapeutic measures.

Gutierrez and Barros⁷ warn that palliative care must be given to patients whose diseases have little chance of reversing with the use of curative therapy from the moment of diagnosis and not just in the last hours of life. Palliative care provided in the initial phase has the prerogative of differentiated, individualized attention, considering the individual's particularities and needs as a person in a condition of dependence. Thus, the patient can receive pain control and relief from suffering in the physical, psychological, social, and spiritual dimensions⁵.

According to Wittmann-Vieira and Goldim⁸, even in the biological sense, preserving or saving life is no longer the focus of patient care, as, when it comes to relationships between people, living remains the fundamental theme. Offering palliative care does not mean that there is nothing more to do for the patient or family, but that the diagnosis is of a serious illness, which will evolve into a threat to life, and that a team together with professionals who specialize in the illness will take care of those who are sick and those around them.

In other words, “there is much to do” for the patient and their family.

According to WHO data, each year, approximately 56 million people around the world require palliative care⁹ and, according to Santos and collaborators¹⁰, in Brazil alone, the projection is of more than 1,166,279 patients in 2040. Therefore, the topic is clearly a significant public health issue¹¹, and its discussion is necessary in the light of bioethics so that there is dialogue, awareness, and understanding of the topic on the part of everyone involved.

Method

The method applied in constructing this article was an integrative literature review, synthesizing countless articles to condense results from studies on the same topic¹². The approach is qualitative as it deals with a level of reality that cannot be quantified, that is, it is a universe of meanings, motivations, aspirations, beliefs, values, and attitudes, which corresponds to a deeper space within relationships¹³.

We opted for an integrative review in the search for manuscripts that provided information on the topic, based on studies already published, pre-established as follows: 1) elaboration of the research question; 2) definition of inclusion and exclusion criteria; 3) definition of sampling;

4) evaluation of included studies; 5) interpretation of results; and 6) presentation of synthesis¹³.

The search was carried out in the SciELO and LILACS databases using the health sciences descriptors (DeCS) “bioethics” and “palliative care,” and the time frame covered the last five years (2018-2022). One hundred thirty-one articles were identified, whose abstracts were read in full.

Articles with a complete abstract in Portuguese, English, or Spanish, which addressed the topic of bioethics and palliative care and were open access, were included, and those with incomplete abstracts, with more than five years of publication and without defined descriptors, were excluded. Of the total that met the inclusion criteria, 27 were excluded because they were duplicated on the platforms, and, in the end, ten articles remained.

Furthermore, other essential articles on the topic were used as theoretical support to enrich and support the discussions. The informed consent form (ICF) was waived as it was an integrative review without the involvement of human beings.

Results

Table 1 condenses the main impressions contained in the articles researched.

Table 1. Summary of articles included in the integrative review

Authors; year	Journal	Title	Objective	Method	Conclusion
A Chaves and collaborators; 2021 ¹⁴	Revista Bioética	“Cuidados paliativos: conhecimento de pacientes oncológicos e seus cuidadores”	Verify the perception of palliative care, advance directives, and do-not-resuscitate orders of cancer patients and their caregivers and their relationship with healthcare professionals.	Quantitative descriptive research between 2018 and 2019 in the high-complexity oncology center of a Brazilian university hospital. The sample had 200 participants (100 cancer patients and 100 informal caregivers).	Lack of knowledge on the part of participants related to issues related to the end of life, as well as a conflict between dysthanasia and obstinate resuscitation. The results also report the importance of training healthcare professionals to perform their role.
B Lima MA, Manchola-Castillo; 2021 ¹⁵	Revista Bioética	“Bioética, cuidados paliativos e libertação: contribuição ao ‘bem morrer’”	Reflect on dying and bioethics’ contributions to the topic, whether through the traditional principles of autonomy and dignity or the defense of a new category, liberation, proposed by intervention bioethics based on Paulo Freire.	Qualitative research, with a hermeneutic, reflective, socio-critical, and analytical approach to demonstrate that liberation can contribute to training more critical, committed, and free professionals and patients capable of facing a moment of such vulnerability as death.	The article argues that adopting the concept of liberation in bioethical reflection on palliative care can contribute to the process of “dying well.”
C Floriani; 2021 ¹⁶	Cadernos de Saúde Pública	“Considerações bioéticas sobre os modelos de assistência no fim da vida”	Discuss the three care fields institutionalized in contemporary societies for end-of-life care and their respective models of death: euthanasia/assisted suicide, medical futility, and kalothanasia, the foundation of the modern hospice movement.	Essay analyzing how the proposed models impact patients’ lives and the conceptual fragility of some of the traditionally used flags, such as human dignity.	A bioethical debate is proposed regarding the need to rethink some postulates, especially those referring to euthanasia. It presents and analyzes the ethical and philosophical foundations of kalothanasia and its implications for the organization of good care practices at the end of life.
D Esperandio, Leget; 2021 ¹⁷	Revista Bioética	“Espiritualidade nos cuidados paliativos: questão de saúde pública?”	Present the state of the art on the topic, provide brief guidance on identifying spiritual needs, and describe four valuable tools for this care.	Integrative review, with studies from the Capes Journal Portal, the Virtual Health Library, SciELO, and PubMed, using the terms “spiritual care and palliative care,” “spirituality and palliative care,” and “bioethics.” Eighteen empirical studies published between 2003 and 2018 were found: four theses, two dissertations, and 12 articles.	It reflects on bioethics and public theology and their correlation with public health. The text presents recommendations to support public policies implementing spiritual care in Brazil’s palliative care.

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Table 1. Continuation

Authors; year	Journal	Title	Objective	Method	Conclusion
E Maingué and collaborators; 2020. ¹⁸	<i>Revista Bioética</i>	“Discussão bioética sobre o paciente em cuidados de fim de vida”	Identify factors that influence the decision-making of health professionals when dealing with end-of-life care patients admitted to intensive care units.	Quantitative research in two hospitals in Paraná between March and May 2018, with a sample of 45 multidisciplinary team members.	The article highlights the interviewees’ concerns regarding autonomy, protection of dignity, and preservation of patients’ and families’ quality of life through shared decision-making. However, the tendency of therapeutic obstinacy to fulfill professional duty showed the need for more discussions and training in palliative care to minimize ethical conflicts.
F Fusculim and collaborators; 2022. ¹⁹	<i>Revista Bioética</i>	“Diretivas antecipadas de vontade: amparo bioético às questões éticas em saúde”	Analyze the current context of the implementation of advance directives in Brazil based on the knowledge of professionals in the field of medicine and nursing, as well as identify potential contributions of bioethics to their implementation.	Exploratory, cross-sectional study with a quantitative approach, with the participation of 143 physicians and nurses. An electronic questionnaire was applied on an online platform, aiming to analyze the current context of the implementation of advance directives in Brazil based on the participants’ perceptions.	According to the article, knowing what the directives are facilitates the process of deliberation with the patient, with knowledge of bioethics being fundamental to support the decision of professionals when choosing the best conduct to be adopted.
G Cecconello, Erbs, Geisler; 2022. ⁵	<i>Revista Bioética</i>	“Conduitas éticas e o cuidado ao paciente terminal”	Analyze the approach aimed at terminally ill patients since ethics and care need to be present in a cautious relationship, which raises discussions and different interpretations in the medical environment.	Integrative bibliographic review based on the analysis and integration of works found in multiple online databases, such as SciELO, PubMed, the Federal Council of Medicine (CFM) portal, and the Code of Medical Ethics (CEM), in addition to journals, platforms and printed works. The search included publications from 2001 to 2020, and 23 articles were selected.	The approach to conducting and caring for terminally ill patients is critical, given the possibilities and disagreements that these can cause. The article concludes that a multidisciplinary team must provide palliative care to promote comprehensive care for patients and their families while respecting biopsychosocial and spiritual aspects.

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Authors; year	Journal	Title	Objective	Method	Conclusion
H Espindola and collaborators; 2018 ²⁰	<i>Revista Bioética</i>	“Relações familiares no contexto dos cuidados paliativos”	Narrative literature review, i.e., a non-systematic survey that does not specify keywords, descriptors, sources, and publication period.	The article aims to explore possible implications for family relationships at the end of life through a narrative literature review.	The article concludes that changes and losses in the illness process affect the patient and their family members. This justifies the need for assistance that offers care to these individuals and supports the physical, psychosocial, and spiritual suffering to which they are subject.
I Souza and collaborators; 2022 ²¹	<i>Revista Bioética</i>	“Dilemas éticos no direito de acesso aos cuidados paliativos na pandemia da covid-19”	List some ethical dilemmas related to the right to access palliative care in the context of the COVID-19 pandemic and encourage discussion, aiming to allocate resources equitably, according to doctrinal assumptions of the Unified Health System legislation.	This theoretical reflection references Norman Daniels’ approach to accountability for reasonableness.	The article makes it clear that it is essential to discuss the dilemmas highlighted so that the deliberation process in the allocation of health resources is done fairly, as directed by the principle of equity, and bioethical references can be used to provide greater transparency to decisions, so that the population can understand them as fair and justified.
J Campos, Silva, Silva; 2019 ²²	<i>Revista Bioética</i>	“Comunicação em cuidados paliativos: equipe, paciente e família”	Evaluate communication in palliative care and its influence on the team, patient, and family relationship.	Qualitative, descriptive, and exploratory research involving six participants at a public health hospital institution in Suzano, in the state of São Paulo. Data were collected in semi-structured interviews and evaluated using the content analysis technique.	The article establishes that a good relationship between the three parties through dialogue is fundamental. However, it is necessary to identify other phenomena beyond professionals’ communicative skills. From a bioethics perspective, communication stands out in assistance and creates a bond that enables shared decisions.

Discussion

The idea of death as a natural and inevitable process

According to article A¹⁴, technological and scientific advances in the post-Industrial Revolution era were responsible for a change in the pattern of population diseases, an increase in life expectancy, and the consequent growth of the elderly portion of the population. This scenario of demographic and epidemiological transition is associated with a decrease in infectious diseases and an increase in the incidence of chronic degenerative diseases, which today account for 70% of all deaths, totaling 41 million deaths per year worldwide. These deaths are related to a group of cardiovascular, endocrinological, osteoarticular, and neoplastic diseases.

In theory, the technological devices that consecrated progress and mitigated mortality rates continue to play an essential role in early diagnoses and treatments, in addition to being in fierce competition for intervention in the terminal stages of human life. Thus, in the face of technology, death has been understood as an undesirable accident caused by a disease that was not detected in time or, even due to the inability of physicians to act, and not as part of the natural cycle of life²².

As it is an experience that few are willing to talk about, the topic of death always presents itself as a challenge. However, when approached and named, death arouses curiosity, discomfort, doubts, emotions, and reflections. Kovács²⁴ states that the emotions generated in the context of death are responsible for silencing the curiosity generated. Consequently, most people cannot experience such feelings, running away from them and avoiding the topic.

The historian Philippe Ariès²⁵ collaborates with the theme by stating that death brings censorship, an idea of the forbidden, making people avoid talking about it, as it is considered failure and ruin. In the health field, there is a feeling of power related to the topic of death on the part of professionals, who, in their training, are forged to overcome, combat, and defeat it. However, according to Kovács²⁴, this sensation dissolves in the human fragility of these

professionals, who find themselves powerless in the face of death's pale and cold presence.

Looking naturally—defended by Cicely Saunder, as will be discussed in the following topic—devoid of prejudices and fears, could redirect how we think and talk about death, understanding that, despite being inevitable, it can be a good death. In this sense, article C¹⁶ addresses end-of-life care through a painless death, in which the patient's wishes are respected, with the possibility of dying at home, in the presence of family and friends, and without suffering for the patient, family, and caregivers.

In this context, the patient's pending issues would be resolved, and there would be a good relationship between the patient and their family and healthcare professionals. Such actions, however, require sensitive observation of the conditions in which the patient deals with their death to avoid frustrated expectations and of the cultural aspects in which the patient is inserted, especially when it comes to pluralistic societies, in which there are different conceptions of what a good death is²⁶.

Palliative care: Concepts and definitions

Article A¹⁴ shows that the concept of palliative care emerged in the 1960s through the work of physician, social worker, and nurse Cicely Saunders. Saunders dedicated herself to building work focused on assistance, teaching, and research, resulting in the creation of St. Christopher's Hospice in 1967 in London, which inaugurated an essential phase of expansion of the palliative movement²⁵.

Given the search for preserving the dignity of patients and providing support for patients and their families in the terminal stage of life, article B¹⁵ presents two pillars considered fundamental in palliative care: efficiency in controlling pain and other symptoms that arise in the final stage of disease and the extension of care to psychological, social and spiritual aspects of the patient and their families²⁷.

At first, while such care was specifically aimed at cancer patients, in the 2000s, the concept was expanded, adding neurological, cardiac, renal, and other illnesses in which life could be threatened.

As stated in article G⁵, through professional interrelationships, with the participation of a multidisciplinary team and the therapeutic process, palliative care provides a comprehensive care approach to the patient and their families. Therefore, several principles must be observed for palliative care to be effective, as established by the WHO in 2002:

*Palliative care is the assistance promoted by a multidisciplinary team, which aims to improve the quality of life of patients and their families in the face of a life-threatening disease through prevention and relief of suffering, early identification, impeccable evaluation and treatment of pain and other physical, social, psychological and spiritual symptoms*²⁸

On the other hand, article D¹⁷ shows that, unfortunately, most patients continue to receive inadequate assistance, focused only on the purpose of healing. The assistance provided in palliative care aims to eliminate the gap between scientific and humanistic knowledge, to rescue the dignity of life and the possibility of dying as desired²⁷. However, data from the WHO show that only 14% of those who have an indication of palliative treatment effectively receive it^{6,29}.

Recalling article G⁵, one should not forget the understanding that palliative care does not seek to rush death with euthanasia, much less prolong suffering at death's door, but rather to enable orthothanasia, which means a good death without unnecessary suffering. at that time and/or the patient's condition³⁰.

Dysthanasia, known as a "bad death," slow and with intense suffering, is little discussed in medical circles and refers to subjecting the patient to a situation of suffering or torture, aiming to save their life through ineffective treatment. Euthanasia, which would be the induction of death so that there is no suffering, is the subject of heated discussion in many countries, such as Brazil, where it is not permitted, being condemned in medical practice for violating the principles of ethics and morals. In this sense, euthanasia is considered to promote death and goes against the idea of prolonging life by reducing suffering, that is, it does not fall under beneficence or non-maleficence.

In summary, based on the right to autonomy, the preservation of social identity, and the dignity of life and death, palliative care provides comprehensive assistance to the patient without a therapeutic proposal for a cure. Thus, they effectively control pain and provide physical, emotional, psychological, and family quality of life, respecting the patient's autonomy and self-determination in an intimate relationship with bioethics, especially in caring for older people and people in conditions of dependence at the end of life³¹.

Bioethical dilemmas in palliative care

Bioethics emerged after the second half of the 20th century in the face of extraordinary technological advances in biomedicine, genetics, molecular biology, transplants, and palliative care. With the evolution of technology and information technology, the possibilities for intervention in human health conditions have expanded, and little by little, ethical issues have arisen from the applicability of these sciences, which have increased the power of intervention over life and nature^{32,33}.

Bioethics is concerned with the ethical use of new technologies in the medical sciences and with the adequate solution of the moral dilemmas they present³⁴, enabling the application of ethical principles to problems related to medical care practice³⁵. Thus, it seeks to understand and resolve existing moral conflicts with implications for practices in living and health, always respecting the values of a democratic and secular society².

Appropriating the moral conflicts and dilemmas in human relationships and understanding the human being as an individual possessing cognitive and moral competence, capable of acting freely and taking responsibility for their actions, is the core of bioethics. Therefore, a biomedical investigation requires reflection guided by ethics, as bioethics is a new knowledge that combines characteristics such as humility, responsibility, and interdisciplinary and intercultural competence and enhances the sense of humanity⁸. The dignity of the human being is built as ethical principles are observed in decision-making and interventions and

the interpersonal relationships of all segments and people involved³⁶.

Among the various trends in bioethics, principlist bioethics stands out, whose focus is the concern of human beings participating in research in the clinical-care area. Proposed by Beauchamp and Childress³⁷, this model applies the system of principles, such as beneficence, non-maleficence, autonomy, and justice, providing a new way of dialoguing with healthcare professionals.

The principle of beneficence refers to meeting individuals' vital and legitimate interests through knowledge and technical skills that minimize risks and maximize patient benefits³¹. Non-maleficence establishes that any professional intervention must avoid or minimize risks and damage, which implies not harming under any circumstances. This is considered a fundamental principle of the Hippocratic tradition of medical ethics, which advocates *creating the habit of two things: helping (assisting) or, at least, not causing harm*³⁶.

Autonomy refers to the freedom of action, considering that people possessing reasonable maturity and conscience are capable of choosing and acting according to their own desires. Respect for this autonomy is essential as long as it does not harm others³³. The principle of justice concerns the coherent and adequate distribution of social duties and benefits, based on equity and highlighting that identical situations must be treated equally and those that are not equal differently³⁴.

Multidisciplinary and interdisciplinary team

In article E¹⁸, interdisciplinarity is understood as absolutely necessary in the practice of palliative care, that is, there must be a multidisciplinary team that works in an interconnected manner in discussing and managing cases. The scope of care and therapeutic planning must involve the entire team in search of the best quality of life for the patient and their family members^{37,38}. The professionals involved must be technically qualified in scientific competence and constantly updated in the concepts of bioethics and humanization to promote adequate reception and care.

Palliative care does not refer exclusively to medical acts at the end of life, and discussing this topic goes beyond advocating a good death with

a humane and capable multidisciplinary team. This theme relates to life, how one lives, and how one can live when preserving or saving life in the biological sense is no longer possible⁸.

Finally, article E¹⁸ argues that the multidisciplinary team must continually reevaluate the patient's clinical condition, redefine treatment objectives, and consider palliative care, especially when there are limitations in disease-modifying therapy. When the disease is in an advanced stage, with signs that death is near, this phase is defined as hospice care.

Relationship between family and caregivers

Article H²⁰ shows that investigating family relationships at the end of life involves much reflection on concepts, principles, and conceptions about the family institution. Families are the nucleus of a society, the first support networks for individuals, and those responsible for individuals' formation, development, and socialization. At their core, they are governed by a set of rules that guide the relationships established between members, organizing interaction patterns, as well as the roles and responsibilities of each individual.

In the face of illness or imminent death, changes occur in the family organization and, consequently, in the roles played by family members. This justifies the inclusion of these people in the assistance provided by palliative care teams. The team's palliative care intervention helps the patient and family members face hospice care. This contributes to alleviating physical, psychosocial, and spiritual suffering since the family has already gone through a long journey of symbolic losses, such as social roles, autonomy, and identity, in addition to actual loss, that is, the death of the sick.

In this context, care must include honest and transparent communication, avoiding omissions and parallel conversations between professionals in front of family members. Maintaining the autonomy and dignity of patients and their families is always necessary.

Article G⁵ states that the patient and their family are a fundamental unit of care and that family members must receive assistance throughout the patient's illness process, thus avoiding the promotion of suffering that could negatively impact the course of the disease. The participation

of family, friends, and partners is of great value to the palliative care team, as they can help with the patient's needs, specificities, anxieties, and desires by getting to know them better than the professionals. It is expected that the family suffers and becomes ill along with the patient. Therefore, this suffering must be considered, welcomed, and included in the treatment³⁹.

Family members and/or guardians must also be informed about the non-possibility of a cure, with the patient's consent, so that family support, which is so essential, is effective. This type of news brings complications, and from the first conversation until the family mourning phase, psychosocial support becomes essential.

Spirituality in the face of palliative care

Article E¹⁸ states that, in the context of palliative care, spirituality is a source of meaning for the experience of illness, producing a feeling of well-being and quality of life, being a coping resource, support for the patient and their families and means of development and resignification of life. However, it is noteworthy that health professionals have difficulty identifying and meeting spiritual needs. A study identified that less than 15% of hospitalized patients had such demands met or received psychological support^{40,41}.

It is essential to highlight that, in the context of palliative care, the patient faces multifactorial suffering that goes beyond the limits of the physical body, manifesting itself in crises and spiritual conflicts that cannot be treated with medication and that can worsen the perception of pain. Cicely Saunders named this experience "total pain," arguing that it encompasses, in addition to the physical component, psychological, social, and spiritual suffering⁴². The search for meaning in suffering is situated in the person's life story context.

Likewise, ethical decisions are not isolated from the relational and social context of the treatment unit (patient and family), as Muldoon and King pointed out⁴³. In the patient's narratives, their values and beliefs are present, which help them find meaning and support their decisions.

Still, according to article E¹⁸, spirituality is considered by the WHO to be one of the intrinsic

components of good practices in palliative care. According to Resolution 41/2018, of the Brazilian Ministry of Health⁴⁴, which addresses the implementation of palliative care in primary care, this reflection is essential. Based on it, it is possible to effectively integrate the spiritual dimension into this type of assistance, improving the effectiveness of care for patients and those who accompany them. Different areas are invited to develop studies on the topic, producing evidence that transforms public policies and the praxis of bioethics in care to make it integral and person-centered⁴³.

Legal aspects of hospice care in Brazil

According to article G⁵, while palliative care emerged in Brazil around 1980, it was only at the end of the 1990s that it experienced considerable growth. Gradually, palliative practice gained space in Brazilian healthcare settings, but this type of care is still quite mystifying and unknown to many of the population, including healthcare professionals.

It is also worth highlighting that Brazil has no specific legal regulations focused on palliative care. Despite this, the Code of Medical Ethics (CEM), prepared by the Federal Council of Medicine (CFM)⁴⁵, ensures some points, such as the legitimacy of orthothanasia, advance directives of will (ADW), and the recognition of palliative medicine as a field of activity⁴⁶.

Another essential issue is ADW, discussed in article F¹⁹, in which therapeutic limits are established that must be respected if the patient can no longer express themselves at some point. ADW does not only refer to end-of-life wishes; it is also understood as manifestations of advance will that shall take effect when the patient cannot express themselves. They are divided into six types: living will, durable mandate, do-not-resuscitate orders, psychiatric advance directives, dementia directives, and birth plans.

However, as already mentioned in this article, the expression ADW refers to what is understood as a living will, according to Dadalto's perspective⁴⁷. In this aspect, ADW provides the patient with respect for the possibility of being welcomed and respected for their wishes in their final moments.

By honoring the self-determination of the sick person, the right to be the protagonist of their end with dignity is ensured when, in the use of their freedom to manage their well-being, they choose to suspend treatments that only prolong their suffering.

In the Brazilian context, the understanding that the application of ADW occurs mainly at the end of life justifies the association of knowledge on palliative care with that on ADW, statistically significant in study I²¹. Respect for the patient's wishes, determinations, and desires includes recognizing and responding to their and their family's needs with a broad, transdisciplinary vision.

The achievements of medical technology are recognized here, but with the exception that there must be a gradual and balanced transition between legitimate attempts to maintain life, when there are real chances of recovery, and the palliative approach, symptom control, without never disregarding the dimension of human finitude⁴⁸.

Furthermore, article I²¹ considers that health law, in addition to aiming to promote, prevent, and recover the health of individuals through a set of legal norms, also encompasses ethical concerns with topics that concern health. Ensuring ethics in health requires constant discussions about resource allocation criteria in all public spheres and the establishment of policies that can impact individual or collective health. Ethical considerations must align with universal ethics and society's values, aiming to reconcile interests and primarily seeking to maintain the dignity of the human being.

Communication with the patient and family

Finally, article J²² mentions a qualitative study on the importance of clear and direct communication between the team and, above all, with the patient and their family, avoiding technical terms unfamiliar to the patient as much as possible. In bioethics, dialogue with empathy and compassion is an essential strategy and skill for good teamwork, as it is necessary to understand the patient's anguish and suffering. Furthermore, the work shows that acceptance of the diagnosis and prognosis and adherence

to treatment are visibly influenced by the relationship between team and patient and how professionals guide communication.

There may be many guidelines, but the first step is always listening to the patient, as it enables evaluating the best way to pass on information in each case, given what is known about the patient and/or family. This attitude can reduce conflicts, anxieties, and fantasies from what the patient and their family members imagine about their health condition and the professional themselves, who reads the other from their private world⁴⁹.

Knowing how to listen more than talk directs communication to the patient's credible needs, allowing them to express their desires. This demonstrates respect for others, confirming their perception of their own health and the prerogative of establishing the limits of what they want to be aware of. Every patient indeed has the right to know, but not everyone has this need, and the person who will make it clear how far the professional should go in communication is the patient themselves⁴⁷⁻⁴⁹.

Furthermore, it is essential to respect the patient and family's time during dialogue so that they can understand the diagnosis, prognosis, and proposed care.

Final considerations

Palliative care is indicated for all patients whose disease threatens the continuity of life due to any diagnosis (not just oncological), with a prognosis of hospice care, whatever their age, and at any time these patients have expectations or needs.

The final phase of life is known as one in which the death process occurs irreversibly, and the prognosis of death can be defined in days, weeks, months, or even years. In this path, palliative care becomes indispensable and complex due to meeting the demand for specific and continuous attention to the patient and their family, preventing and/or reducing suffering, increasing the quality of life, and ensuring a dignified death. The management of each case must always be discussed and agreed upon between the patient—when able to respond for themselves—family

members, and the multidisciplinary healthcare team in an interdisciplinary manner.

This article briefly shows bioethics applied to palliative care, a modality increasingly in vogue and understood as a real and growing need. Thus, understanding the theoretical concepts of

this type of care and especially its praxis means that it is applied in the best possible way without violating the ethical principles that correspond to care, leaving the patient (and their family members) highlighted in terms of empowerment and protagonism of your own story.

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Received: 7.23.2023

Revised: 10.18.2023

Approved: 10.19.2023