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Ethical conduct and terminal care

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Abstract

Given its peculiarities, terminality highlights the need for an individualization of the therapeutic plan and integrality of assistance in health care. This article analyzed 23 scientific publications with thematics related to terminality and palliative care and discussed the therapeutic approach to the terminally ill patient and the incorporation of different integral practices in health. We sought to evidence that recognizing the characteristics of terminality makes it possible to establish the adequate prognostic study and implement a plan of care that supplies the necessities of the terminally ill patient, with care based of bioethical principles, respecting the will and particularities of the individual. We conclude that the palliative care constitutes an important instrument in managing biopsychosocial and spiritual angst of terminally ill people, by making ample assistance in care possible, promoting dignity, minimizing suffering, and bettering the quality of life of these patients and their families.

Keywords: Terminal illness. Bioethics. Terminally ill patients. Palliative care.

Resumo

Condutas éticas e o cuidado ao paciente terminal

Dadas suas peculiaridades, a terminalidade destaca a necessidade de individualização do plano terapêutico e integralidade da assistência no cuidado em saúde. Este artigo analisou 23 publicações científicas com temática relativa a terminalidade e cuidados paliativos e discorreu sobre a abordagem terapêutica do paciente em terminalidade e a incorporação de diferentes práticas integrais em saúde. Buscou-se evidenciar que o reconhecimento das características da terminalidade possibilita estabelecer adequado estudo de prognóstico e implementar plano de cuidados que supra as necessidades do paciente terminal, com assistência pautada em princípios bioéticos, respeitando a vontade e particularidades do indivíduo. Conclui-se que os cuidados paliativos constituem importante instrumento no manejo de angústias biopsicossociais e espirituais de pessoas em terminalidade, por possibilitarem assistência ampliada do cuidado, promovendo dignidade, minimização do sofrimento e melhora na qualidade de vida desses pacientes e de seus familiares.

Palavras-chave: Estado terminal. Bioética. Doente terminal. Cuidados paliativos.

Resumen

Conductas éticas y el cuidado al paciente terminal

Dadas sus peculiaridades, el final de la vida señala una necesidad de individualización del plan terapéutico y asistencia integral en el cuidado sanitario. Este artículo analizó 23 publicaciones científicas respecto al final de la vida y los cuidados paliativos y discutió el enfoque terapéutico del paciente terminal y la incorporación de diferentes prácticas integrales de salud. Se buscó demostrar que el reconocimiento de las características del final de la vida establece un adecuado pronóstico y puesta en marcha de un plan de cuidados que abarque las necesidades del paciente terminal, con asistencia basada en principios bioéticos, respetando la voluntad y particularidades del individuo. Los cuidados paliativos resultan ser un instrumento importante al manejo de las angustias biopsicosociales y espirituales de las personas en situación terminal, pues permiten un mayor cuidado, promoviendo la dignidad, mitigación del sufrimiento y una mejora de la calidad de vida de estos pacientes y sus familias.

Palabras clave: Enfermedad crítica. Bioética. Enfermo terminal. Cuidados paliativos.

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Stating that a patient is terminally ill is admitting that healing resources have come to end, and that death is imminent. However, this does not mean that conduct and care should be neglected. On the contrary, patients and their families should be offered all possible appropriate measures. At that moment, death is seen as a relief from suffering, no longer to be feared and opposed, and patients seek comfort and pain mitigation, making this limited lifetime as satisfying as possible for the patient.

Thus, it is essential to analyze the approach used with terminal patients since ethics and care must be present in a cautious relation, which raises discussions and different interpretations in the medical field.

Method and objective

This is an integrative bibliographic review which analyzed and integrated studies found in multiple online databases, such as SciELO, PubMed, the Brazilian Federal Council of Medicine (CFM), and the Code of Medical Ethics (CEM), in addition to journals, platforms, and printed works. Publications from 2001 to 2020 were included in the search, which used the following descriptors: "*paciente terminal*" (terminal patient), "*terminalidade*" (end of life), "*doença terminal*" (terminal illness), "*bioética*" (bioethics), "*condutas éticas*" (ethical conduct), and "*cuidados paliativos*" (palliative care).

In total, 23 publications were selected, comprising 17 scientific papers, four CFM resolutions, and two book chapters relevant to the subject matter for further detailed analysis, information integration, and discussion. We aimed to clarify the concepts of end of life and discuss possibilities for therapeutically approaching terminally ill patients, addressing ethical conduct toward end of life and the incorporation of comprehensive health care practices, especially palliative care (PC).

End of life

End of life can be understood as the time when the evolution of a certain pathological condition will inevitably result in death, despite any therapeutic intervention measures. The irreversibility of the disease, in turn, is defined based on objective and subjective data, collected and/or identified by the medical team to establish a diagnosis or prognosis and thus define the therapeutic and care strategy for patients [1].

Moral and ethical principles of end of life

Alleviating suffering and protecting life are principles which drive medical practice, complementing each other most of the time. Nevertheless, it is impossible to opt to preserve terminal patients' life above all. In this case, death becomes an expected outcome and should remain unopposed, which, however, does not mean that nothing should be done, as patients and their families need specific therapeutic measures. From a moral point of view, physicians and health teams act to alleviate suffering [2,3].

Based on this information, healthcare providers must apply the bioethical principles of beneficence, non-maleficence, autonomy, and justice [2], analyzing how, when, and what will determine which should prevail. Therefore, it is essential to identify whether patients are in a salvageable or inevitable death phase. In the former case, when the disease is treatable and healthcare providers can save patients, their first goal should be to preserve life. Thus, beneficence must prevail over non-maleficence, and health teams should use life-saving measures—dialysis, amputations, mechanical ventilation, transplants, etc., even though they might result in initial suffering [2,3].

In the latter case, in turn, when the disease is no longer treatable and death becomes inevitable, health teams' objective is no longer to search for a cure but rather to alleviate suffering. In this context, non-maleficence prevails. This principle overrides autonomy since a terminal patient is, in most cases, incapable of making lucid and well-thought-out decisions about tests, procedures, and treatments.

In this context, the support network—family or legal guardians—must exercise the principle of autonomy since this decision must not be unilateral but consensual, together with the medical team in charge. Finally, the principle of justice should not prevail over beneficence, non-maleficence, and autonomy though the support network must consider it in making the final decision. The rights of all must be undoubtedly respected, with justice.

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After all, any decision which would lead one of those involved, either professionals or patients, to harm themselves in any way would be unethical[2,4].

Signs and symptoms of terminal patients

Once the short life expectancy of this population is understood, non-specific parameters are observed, namely: progressive loss of body weight, reduction of plasma proteins, and functional loss, this last condition is a means of evaluating prognoses, especially regarding daily activities—impaired locomotion, the need for feeding aid (as in parenteral nutrition), and bowel and bladder incontinence[5].

In a retrospective study conducted in Portugal, Pulido and collaborators[6] observed that the prevalent signs and symptoms of terminally ill patients are pain, dyspnea, fatigue, delirium, mental confusion, fever, anorexia, nausea, and vomiting, in addition to emotional states such as anxiety and depression, classified according to the etiology of the studied diseases.

According to Susaki, Silva, and Possari[7], the process of dying most often involves the stages of denial, depression, and acceptance. In this context, denial occurs due to a belief in diagnostic errors or distrust of the competence of the healthcare team; depression can be understood as a lack of interest, apathy, and the patient's own silence; and acceptance is usually shown by a desire to bid farewell to family, friends, and acquaintances. In turn, bargaining, seen as a strong attachment to religion and spirituality, and anger, with insulting attitudes toward health professionals and patients' social circle, are less witnessed.

At this point, the active process of death comprises a period of agony over the last days or hours of life and, in general, brings a series of signs and symptoms with it, perceived through both physiological and psychosocial changes and spiritual suffering. Pain, an exceptionally relative experience which, in many cases, is underdiagnosed, must be carefully evaluated to offer terminal patients the greatest possible comfort[8].

Needs of terminal patients

Patients in the end-of-life process require special care, which, if provided, offers better quality of life and comfort, minimizing their suffering[7]. Above all, hospitals need to recognize the needs and desires of palliative patients and promptly provide them. According to Machado and collaborators[9], it is important to offer comfort measures with care practices and focus on symptomatic management, interrupting therapies which no longer have a purpose or bring considerable benefit to patients. Rather than recognizing patients in these conditions, the greatest difficulty might be identifying the moment they appear.

Initially, it is necessary to identify that the patient is in a terminal state using criteria which, according to Gutierrez[3], may be subjective: professionals' intuition, based on similar experiences, and patients' personal aspects, such as response to pain. It is also necessary to evaluate clinical aspects—functional, imaging, laboratory, and anatomopathological tests.

Once the patient's terminal condition has been recognized and diagnosed, it is essential to establish honest, frank, and measured communication—made possible by the cultivation of an interpersonal relationship with them—added to a humanistic approach. This should not only be via words conveying the message but also through attentive listening and use of non-verbal language. Although resources have in effect been exhausted, there is still much to do, given the symptoms and wishes of the patient.

Family members and/or legal guardians should also be informed of the impossibility of healing, if desired. Family support is essential at such difficult times, and it is important not to create a barrier of emotional isolation between patient and family. This kind of news brings complications and psychosocial support is essential from the first conversation to the family grieving phase[10].

The care adopted should provide well-being and analgesia, offering support during feeding, personal hygiene, and dressing. More humanized care forms positively contribute to patients' psyche, granting them greater freedom to express everything they are feeling[8]. According to Machado and collaborators[9], despite the abundance of drug therapies, drugs aimed at the symptomatic control of these patients are still scarce, suggesting a kind of medicine aimed basically at healing rather than palliative care.

As for active pain control, considering its multiple physical, psychosocial, and spiritual aspects, treatment should be provided by an interdisciplinary team, with strategies aimed at symptomatic relief, via comprehensive care, privileging care over cure. Thus, it is possible to adopt pharmacological measures, such as the administration of opioids, or non-pharmacological measures, such as relaxation techniques, acupuncture, and even transcutaneous electrical nerve stimulation [5].

Analysis of possible attitudes toward terminal patients

As mentioned above, medical conduct must be based on ethical principles which should be previously discussed with the team and the patient's family members or guardians. Thus, when considering the terminal phase, non-maleficence must prevail, and care must aim at providing comfort and relieving suffering.

The terminologies related to this phase are diverse and raise discussions about their application, for example: non-adoption and/or withdrawal of life support measures; do-not-resuscitate order (DNR); discontinuation of futile treatment; suspension of ordinary and/or extraordinary care; dysthanasia; and euthanasia.

Non-adoption and/or withdrawal of life support include interrupting any and all treatment or medical attitude used to preserve the patient's life when it is believed that this will fail to bring any benefits or even increase their suffering. Such interruption depends on the acceptance or consent of the actual patients or their family. In the case of DNR, the decision must be consensual between patients and physicians and, if the former is unable to decide, the discussion must take place between family members and physicians. However, if part of the family refuses, this attitude should not be taken, as it would go against the principle of autonomy [2,4].

DNR follows some ethical values: not extending the dying process when unnecessary; avoiding futile treatment; and offering resources which would benefit other patients. Interruption of futile treatment includes cancelling medical procedures which, despite the possibility of positive results, are temporary, so that patients end up returning to their initial state prior to treatment or to another which cancels out the administered procedure.

Furthermore, suspension of ordinary and/or extraordinary care raises discussions about terminology. Some physicians consider "ordinary measures" to be treatments which are acceptable or even standardized and "extraordinary measures" to be new and experimental approaches. Using an ethical connotation, in turn, the suffering caused by the decision to prolong life is what classifies them as ordinary or extraordinary. Thus, in the case of terminal patients, decisions which will keep them in a comfortable condition will be considered ordinary.

Another sphere also reports dysthanasia—that is, "bad death," a slow and intensely painful process—which is barely discussed in the medical milieu. It concerns leaving patients in a situation of suffering or torture, aiming to save their life through futile treatment. Lastly, euthanasia—induced or provoked death to avoid suffering—is a widely discussed issue in many countries (including in Brazil, which rejects it), condemned in medical practice for violating principles of ethics and morality. In this sense, euthanasia is viewed as promoting death and going against the idea of prolonging life by reducing suffering, that is, it fits neither in beneficence nor non-maleficence [2,4].

The introduction of therapeutic approaches based on PC is a powerful and effective strategy to provide well-being and improve the quality of life of terminally ill patients. Via adequate symptomatic management, interrelations multidisciplinary knowledge, and comprehensive care which respects the individual as a whole, PC can contribute so that the process of dying is unable of causing unnecessary suffering and having an even more dramatic effect on the lives of those involved with patients during their illness and after their death [5].

Palliative care

According to the World Health Organization (WHO), *palliative care is an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and* *treatment of pain and other problems, whether physical, psychosocial and spiritual* [11].

History of palliative care

PC emerged around 1960 in the United Kingdom, thanks to pioneer physician Cicely Saunders. A symbol of palliative practice in the world, Saunders, who, besides being a physician, was a nurse and social worker, represents the beginning of PC and its development as a science, aimed not only at care but also teaching and research, culminating, in 1967, in the creation of St. Christopher's Hospice, in London, a very important fact for the expansion of the palliative movement [12].

In 1969, with the publication of the book *On Death and Dying*, the Swiss-American psychiatrist Elisabeth Kübler-Ross also gained prominence in palliative care. A pioneer in PC in the United States, Kübler-Ross believed in an expanded care process and encouraged the creation of hospices—health facilities dedicated to the care of people beyond the possibility of cure—in that country [13,14].

In Brazil, PC emerged around 1980 but only grew considerably until the late 1990s. Gradually, palliative practice made progress in Brazilian healthcare but PC is still fairly mystified and unknown by a large part of the population, including healthcare professionals. It should also be noted that Brazil lacks specific constitutional regulations for PC but CFM and CEM ensure some points, such as the legitimacy of orthothanasia, advance decisions, and the recognition of palliative medicine as a field of activity [13-18].

The concept of palliative care

The first concept of PC, formulated by the WHO in 1990 and updated in 2002, was especially focused on patients undergoing cancer treatment, recommending care which was comprehensive, especially end-of-life care [11]. From then on, cancer care had a new key element, PC, alongside the previous main aspects: prevention, diagnosis, and treatment [19].

PC has long been associated exclusively with end of life but the specifics of this kind of care made it necessary to broaden the concept. In this sense, the WHO expanded the definition of PC in 2002, recommending its inclusion in the therapeutic approach of other pathological conditions [11]. In 2004, according to Gomes [13], the WHO reiterated such recommendations in a new document, defining PC as a key aspect of comprehensive care for degenerative diseases.

The current PC context has changed given the need for contemporary health practices in which care is unrestricted to the use of protocols. Its applicability has been expanded, and end of life—previously an almost exclusive goal of PC practice—has given way to the concept of life-threatening diseases.

The concept of areas covered by PC has grown, contributing to comprehensive care, considering individuals in all their physical, biological, psychological, and spiritual dimensions. moreover, the need to include the family in the care plan gained prominence to minimize suffering during the course of the disease and after the patient's death, with follow-up and care for grieving family members [14].

Principles of palliative care

PC provides a comprehensive approach to care to patients and their families. This is only possible via professional interrelations, with the participation of a multidisciplinary team in the therapeutic process. In this sense, several principles must be respected for palliative care to be effective, as established by the WHO in 2002 [11].

Relief of pain and unpleasant symptoms is a fundamental principle of dignified care and requires great knowledge so that positive results are achieved in the management of biological, psychosocial or spiritual symptoms [14].

Considering and treating death as a natural process is essential. PC views death as an expected event in life-threatening illness. This does not mean that PC seeks to hasten death by euthanasia; on the contrary, palliative practice neither speeds up death nor prolongs the dying process. PC enables orthothanasia—"good death," i.e., natural death, without conditions which provoke unnecessary suffering, caused by the course of the disease or by unnecessary therapeutic measures at that time [20].

Chronic or acute diseases which threaten a patient's life usually cause psychological damage due to a series of losses. Common among them are loss of autonomy, impaired self-confidence and self-esteem, physical limitations, and difficulty to do previously normal activities. These factors can generate intense psychic disorders, such as distress, depression, and hopelessness, contributing to worsening disease prognoses. Thus, integrating psychological and spiritual aspects is essential for effective patient care [14,21].

Patients and their families must be seen as a unit of care. Thus, the help of family members throughout the illness process is essential to prevent the patient's care network from becoming a factor which causes suffering and contributes negatively to the course of the disease. The biological, adoptive or acquired—friends and partners— family can cooperate with the PC team since they know the patient better than the professionals and understand their needs, specificities, anxieties, and desires. It is natural for the family to suffer and become ill together with the patient and thus their suffering must be validated, welcomed, and included in treatment [14,22].

PC especially aims to improve quality of life, minimize suffering, and positively influence the course of the disease. Thus, monitoring and palliative treatment should be started as soon as possible to enable adequate management of symptoms, prognostic studies, and planning for the occurrence of possible future conditions which may cause suffering, as well as combining life-prolonging measures which effectively produce satisfactory results [14].

The fundamental value of life, the transcendent value of human beings in their physical, psychic, and spiritual aspects, in addition to the relationship of priority and complementarity between individual and society, are essential points for bioethics. This is precisely one of the propositions of bioethics of protection, which can be seen as a primordial act and which, if properly considered, can serve as a theoretical-practical benchmark. The ethics of protection underpinning bioethics of protection is aligned with ethics of care, investigating the forms of action based on concrete problems, whether physical, psychic, social, economic or cultural [23].

Hence the importance of reflecting on the benefits to the care relationship derived from the use of communicative skills and attentive listening, aiming to expand the possibilities of assertiveness in PC approaches. It is argued that valuing listening and dialogue from the initial stages until the patient's death makes it possible to expand the field of multidisciplinary intervention based on the communication skills surrounding the empathic bond, especially with family members.

Final considerations

Given the above, the conduct and care approach adopted toward terminally ill patients is extremely important given the many possible attitudes and disagreements they may cause. Nonetheless, they both aim to provide comfort and relief of patients' suffering.

A terminally ill person shows signs and symptoms which cause physiological (anorexia, weight loss, pain, functional loss, etc.), psychosocial, and spiritual changes, thus requiring special care aimed at reducing suffering and improving quality of life. By means of simple, frank, and honest communication, followed by active listening, physicians should offer comfort measures and care practices, interrupting therapies which offer no benefits. An interdisciplinary team must be willing to manage symptoms, aiming at well-being and total analgesia.

PC can be offered in life-threatening conditions and must provide diagnostic assistance, prevent, and control symptoms, intervene by respecting all dimensions of individuals, their autonomy, and their particularities, and respect and establish adequate communication, culminating in the design of a unique therapeutic plan which addresses all patients' issues [13]. In summary, multidisciplinary teams should provide PC to offer comprehensive care for patients and their families, respecting their biopsychosocial and spiritual aspects.

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Emelly Gabriele Erbs, Leonardo Cecconello, and Letícia Geisler planned the study, analyzed and selected the bibliography, and jointly wrote the article. Leonardo Cecconello and Emelly Gabriele Erbs critically reviewed the manuscript.

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