Bioethical principles applied in the light of palliative care

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ABSTRACT

Bioethics is a theme intrinsic to the reality of palliative care. In the Brazilian scenario, palliative care has been gaining space, revealing the need for the practice of humanized and ethical terminal care. Investing in quality of life, in the possibility of death with dignity and without suffering are some of the challenges of this practice. Our study aims at listing the main challenges, reflections and bioethical perspectives observed in palliative care. The analysis is based on a systematic review of articles conducted between January 2021 and April 2021. The results showed that the theme is a breeding ground and requires a multi and transdisciplinary focus. We concluded that it is extremely pertinent to include the teaching of bioethics directed to health professionals to continuously prepare them for the bioethical challenges inherent to the unfolding of human finitude

Keywords: Bioethics; Palliative Care.

RESUMO

Princípios bioéticos aplicados à luz dos cuidados paliativos

A bioética é um tema intrínseco à realidade do paliativismo. No panorama brasileiro, os cuidados paliativos têm conquistado espaço, revelando a necessidade da prática de uma assistência terminal humanizada e ética. Investir na qualidade de vida, na possibilidade da morte com dignidade e sem sofrimento são alguns dos desafios dessa prática Este estudo visa elencar os principais desafios, reflexões e perspectivas bioéticas observados à luz dos cuidados paliativos. A análise é feita com base em uma revisão sistemática de artigos realizada entre janeiro de 2021 e abril de 2021. Os resultados evidenciaram que o tema é terreno fértil e demanda acento multi e transdisciplinar. Conclui-se que é de extrema pertinência a inclusão do ensino da bioética direcionado aos profissionais de saúde, a fim de continuamente prepará-los para os desafios bioéticos inerentes aos desdobramentos da finitude humana.

Palavras-chave: Bioética; Cuidados Paliativos.

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Introduction

In the Greek mythological context, the goddess Eos, representative of the dawn and daybreak, asked Zeus to present her beloved, Tithonus – the prince of Troy – with the greatest gift a human could hope for: eternal life. Eos had her wish granted, but she had to see her lover's appearance and health deteriorate forever, after all, she had forgotten to ask for a fundamental ingredient: youth.

The mythological stories bring reflections on human relationships and the understanding of the world and our analytical mind. In this context, the myth of Eos and Tithonus awakens a special look at aging, a continuous process inherent to human life: to live is also to grow old.

Living beings are governed by a biological determinism: all are born, they grow, mature, age, decline and die. The timing and way in which these phases are processed depend on each individual, the genetic programming of their species and environmental and behavioral factors.

Analogously to what happens in many developed countries, the demographic changes experienced in Brazil have converged towards a fast and accentuated aging process and an increase in population longevity. This progressive increase is encouraging: life expectancy at birth in Brazil for both sexes, which was less than 50 years in the 1940s, rose to 74.8 years in 2013.¹ Since 1940, it has been 30.8 years more that the population is expected to live. These numbers represent gains and significant improvement in the population's health conditions.

In line with the dynamics of aging, the manifestation of organic dysfunctions and the consequent increase in the number of cases of chronic and progressive diseases is undeniable. In this sense, it is necessary to turn the medical gaze to the geriatric population and their needs, carefully evaluating the consequences of the aging process: considering the link between aging, mortality and functional disability, such changes can mean a persistent risk in the face of the increase in the disabled.²

This new reality requires from health professionals not only the construction of new perspectives, methods and techniques, but also a new look at the processes of illness in chronic-degenerative conditions in the elderly and other patients who, regardless of age, have incurable and progressive serious illnesses, especially when in advanced and terminal stages. In this context, health care is built in the light of palliative care.

Palliative care represents a great ally of the art of care and provides a better quality of life for the individual with a disease that threatens the continuity of life. This modality of care aims to prevent and alleviate suffering through symptom control and involves multidisciplinary, multidimensional and human care.³

Thus, it is essential to think about the limits of curative investment and respect the boundaries arising from the dignity of the person. The three perspectives – ethics, bioethics and palliative care – configure shared territories.⁴ Bioethics is an intrinsic theme in the reality of palliative care and engaging in this theme requires clarity of concepts and identification of potential difficulties that interfere directly and indirectly in the success of the service provided.

Methodology

This is a literature review of scientific journals about the relationship between bioethics and palliative care. The following procedures were adopted for surveying and analyzing the bibliographic documentation: identification of the theme; search and selection of data, analysis with establishment of inclusion and exclusion criteria; interpretation and presentation of results.

Based on the identification of the theme "Bioethical principles applied in the light of palliative care", a selection of data was carried out by means of a search for articles, predominantly from 2000 onwards, in the following databases: PubMed (National Library of Medicine and National Institutes of Health) and Lilacs (Latin American and Caribbean Health Sciences). The Health Sciences Descriptors (DeCS) used were: "bioethics" and "palliative care". In order to select the sample, we used inclusion and exclusion criteria for the studies. The study's eligibility criteria were based on the following points: 1) availability of free access, including a complete document and publication in Portuguese

and/or English; 2) thematic approach relevant to bioethical issues in the context of palliative care. Articles with limited relationship to the proposed theme, unavailable in full, or that were inconclusive were excluded. After analyzing the citations obtained, seventeen articles were found and, based on the aforementioned inclusion criteria, eight were selected for the preparation of this study.

Discussion

The term "palliative" derives from the Latin *pallium*, which means cloak, cape, and is similar to the English term hospice, which designates shelters and inns to shelter and care for pilgrims and travelers. In addition, *palliare* alludes to the act of protecting, supporting, sheltering. Thus, hospice and palliative care are synonymous, as they converge to minimize the possible pain and other symptoms of patients and, simultaneously, allow them greater autonomy and independence.

Palliative care officially emerged as a distinct practice in the area of health care in the 1960s, in the United Kingdom. However, the concept was only defined by the World Health Organization (WHO) in 1990 and updated in 2002. According to the WHO, palliative care represents a

set of measures capable of providing a better quality of life to patients with a disease that threatens the continuity of life and their families through the relief of pain and stressful symptoms, using an approach that includes emotional, social and spiritual support for patients and their families from the diagnosis of the disease to the end of life and extending into the mourning period.⁵

In summary, the terminal patient is a patient who has a progressive and incurable disease, with evidence of clinical deterioration. This condition and its consequences encompass individual aspects and affect the patient's family, thus requiring a humanized approach and assistance to the binomial patient and family. The estimable objective of the practice is to ensure a better quality of life for both the patient and their families.

The exercise of this comprehensive care is still little discussed, but it has been implemented and has gained visibility. Gradually, palliation techniques are being known and incorporated into the context of health care, generating autonomy, dignity, privacy and respect for the rights of human beings/patients. These four pillars build bioethics and constitute important tools for a humanistic conduct that is sensitive to human needs. Thus, in its performance, the health team seeks to recognize the individual to whom it will provide assistance – their needs and limitations – and develops unique strategies for that patient and their sphere.

The practice of palliative care establishes bioethics as a guiding principle and respects the terminal patient as a rightful citizen. Palliation aims to deal with physical, psychological, social, spiritual and practical issues, with their fears, expectations, needs and hopes; prepare for self-determination in managing the process of dying and the end of life; to deal with losses during illness and the period of mourning and reach their maximum potential, even in the face of adversity. The motto is: alleviate, prevent and promote opportunities for meaningful and valuable experiences, personal and spiritual growth and self-fulfillment.

Thus, the value of bioethical reflection is invaluable for this situation. Based on the principles of beneficence, non-maleficence, autonomy and justice, the application of the "ethics of life" to the dilemmas that permeate human finitude helps health professionals in palliative care with the possibility of relieving pain and suffering, even in certain situations, some procedures may influence the temporal duration of life, its abbreviation or extension.⁶

From this bioethical perspective, focused on palliative care and patients with no possibility of cure, it is worth remembering that terms such as euthanasia, dysthanasia and orthothanasia are also discussed. Briefly, euthanasia, a word of Greek origin, is understood as the idea of good death (*eu* = good + *thanatos* = death).⁷ As well as "euthanasia", the word "dythanasia" is also derived from words of Greek origin (*dis* = difficulty, deprivation + *thanatos* = death) and designates the exaggerated prolongation of life when there is no possibility of cure or improvement for the patient, a condition that generates agony, pain and suffering, by prolonging the process of dying.⁸ The term "orthothanasia" also it is formed by Greek radicals (*orthos*, right, correct + *thanatos*, death), and it

means the artificial non-prolongation of the natural process of death, being, therefore, considered as good death or desirable death.⁶

In the axis of the commitment to fight for life without maximizing interventions and humanizing care, palliative practice focuses care on the person and not on the disease, thus it is possible to clearly apply the bioethical pillars. The principle of beneficence is related to the duty to do good whereas the principle of non-maleficence implies not doing evil. The principle of justice emphasizes that identical situations must be treated equally and those that are not the same, treated differently, according to their differences. Respect for autonomy refers to the freedom of action with which each person chooses, and the concept of vulnerability is linked to the possibility of being hurt, of finding oneself diminished.

From the perspective of palliative care, building medical care provided on the pillars of justice, non-maleficence and beneficence, significantly contributes to emotional, social and spiritual support for patients and their families. The patient and their vulnerabilities must be welcomed, respected and well guided, leading to the relief and promotion of the best possible quality of life for the terminally ill and their family until the moment of death, in a truly human way, with respect to limits arising from the dignity of the person. At this point, the excellence of the doctor-patient relationship guarantees the construction of a bond that is undoubtedly necessary for the success of the experience in palliative care.

For patients in capable and competent palliative care, respect for their decision-making power is highlighted and the conviction that there are limits to care is firm, because they have to make sense for those who provide them and for those to whom they are provided. The art of caring for these patients involves acts of responsibility, solidarity and dedication, in addition to skills and abilities related to interpersonal relationships.

Thus, the theory of ethics of care in the context of palliative practices constitutes an important instrument for reflection on health actions, as it significantly contributes to the constant search for technical and moral excellence in the care provided.

"Suffering is only intolerable when nobody cares". Dame Cicely Saunders

Final considerations

The aging process represents the victory of some individuals in the fight against various challenges during the preceding stages. Old age is therefore a great trophy. This number of winners has increased each year, turning a privilege into a common fact.

The existence of this panorama opens the eyes to the need for procedural monitoring of geriatric patients from the moment their independence is preserved, followed by situations of dependence and vulnerability, expanding until their death. In association, care for all patients with chronic-degenerative and terminal illnesses should also be incorporated into the prism of palliative care. The medical care provided to the individual considers the way of acting, thinking, feeling and expressing themselves and builds an ethical and reflective practice in the doctor-patient relationship.

In this context, considering the relevance of bioethics, palliative care and terminality for the academic environment, as well as for practice, it is necessary to incorporate the study of bioethics associated with palliative care. It is of great value that professionals are continually prepared to recognize the ethical challenges intrinsic to the reality of palliative care. Building an ethical and reflective practice in the relationship with the patient depends on constant preparation, based on permanent and continuing education of health professionals. Therefore, it is essential to include the study, presentation and discussion of bioethical principles during the training of health professionals, in order to generate positive ammunition that is consistent with the real health needs of the population.

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