Dysthanasia in Pediatric Patients: A Bioethical Discussion

Distanásia Em Pacientes Pediátricos: Uma Discussão Bioética

Distanasia en Pacientes Pediátricos: Una Discusión Bioetica

RESUMO

Objetivo: O presente estudo desenvolve uma análise bioética, sob a ótica do principialismo, sobre a distanásia na pediatria, com o objetivo de discutir tal prática no cenário médico, a tomada de decisão dos envolvidos e suas implicações bioéticas. **Método:** Foi realizada busca nas bases SciELO e PubMed para revisão de literatura. **Resultados:** A distanásia consiste em um tratamento que apenas prolonga a dor, tornando qualquer investimento na cura uma agressão à dignidade humana. Quando o paciente é uma criança em proximidade da morte, a dificuldade dos profissionais se torna ainda maior. **Conclusão:** Faz-se necessária maior atenção ao currículo, suscitando discussões e reflexões sobre o tema, a fim de capacitar profissionais a lidar com a finitude e desempenhar seu papel de oferecer apoio e conforto, assim como ajudar as famílias a identificar o que a qualidade de vida significa para elas e de que forma é possível alcançá-la.

DESCRITORES: Distanásia; Distanásia e crianças; Eutanásia, distanásia e ortotanásia; Suporte de vida pediátrico; Dilemas na pediatria.

ABSTRACT

Objective: This study develops a bioethical analysis, from the perspective of principlism, on dysthanasia in pediatrics, with the aim of discussing this practice in the medical setting, the decision-making of those involved and its bioethical implications. **Method:** A search was conducted in the SciELO and PubMed databases for a literature review. **Results:** Dysthanasia consists of a treatment that only prolongs pain, making any investment in a cure an attack on human dignity. When the patient is a child close to death, the professionals' difficulty becomes even greater. **Conclusion:** Therefore, greater attention is needed to the curriculum, raising discussions and reflections on the subject, in order to train professionals to deal with finitude and play their role of offering support and comfort, as well as helping families to identify what quality of life means to them and how it can be achieved.

DESCRIPTORS: Dysthanasia; Dysthanasia and children; Euthanasia, dysthanasia and orthothanasia; Pediatric life support; Dilemmas in pediatrics.

RESUMEN

Objetivo: Este estudio desarrolla un análisis bioético, desde la perspectiva del principialismo, sobre la distanasia en pediatría, con el objetivo de discutir esta práctica en el ámbito médico, la toma de decisiones de los involucrados y sus implicaciones bioéticas. **Método:** Se realizó una búsqueda en las bases de datos SciELO y PubMed para revisión de la literatura. **Resultados:** La distanasia consiste en un tratamiento que sólo prolonga el dolor, haciendo de cualquier inversión en su cura un atentado a la dignidad humana. Cuando el paciente es un niño próximo a morir, las dificultades de los profesionales se hacen aún mayores. **Conclusión:** Por tanto, es necesaria mayor atención al currículo, estimulando discusiones y reflexiones sobre el tema, con el fin de formar profesionales para lidiar con la finitud y desempeñar su papel de ofrecer apoyo y conforto, además de ayudar a las familias a identificar qué significa para ellas la calidad de vida y cómo se puede alcanzar.

DESCRIPTORES: Distanasia; Distanasia y niños; Eutanasia, distanasia y ortotanasia; Soporte vital pediátrico;

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INTRODUCTION

Dysthanasia, also called therapeutic obstinacy, refers to a treatment that only prolongs pain, making any attempt at a cure a violation of human dignity, with the aim of postponing death at all costs. The Greek prefix dys means "to distance" and thanatos means "death". Thus, dysthanasia refers to the excessive prolongation of a patient's death. This term can also be used as a synonym for useless or futile treatment. It is a medical practice in which, in an attempt to save the life of a terminally ill patient, the patient is subjected to great suffering. (1)

The decision to resuscitate a patient who has undergone consecutive interventions during his illness, together with the patient's desire for recovery at all costs, instead of assisting or allowing a natural death, ends up prolonging his pain and suffering. (1)

When the patient is a child, close to death, the professionals' difficulty becomes even greater, due to the idea, in the collective imagination, that "children cannot die", something that is considered natural when it comes to the elderly. Thus, dealing with the death of a child proves to be more challenging, as the loss is experienced as a triple failure: first, because the professionals feel that they would not have had the method, the talent, or the skills to save the child; second, because, as adults, they were unable to protect the child from complications; and third, because they betrayed the parents who trusted them with the most valuable thing in their lives. Inevitably, this failure increases the reactions of grief and intensifies the feelings of helplessness, guilt, anger, and sadness presented by the professionals. (2)

The principle of “best interests” is a key element of policy-making in all areas of medical practice. Often, when a patient lacks autonomy, as is the case with pediatric patients, these decisions become more complex. Therefore, the discussion of how medical practice should approach decision-making is of fundamental importance. (3)

Studies show that children with fatal illnesses create immense emotional stress for those who care for them, be they parents, relatives, hospital staff or doctors. Article 18 of the Statute of Children and Adolescents (ECA) states that “It is the duty of all to protect the dignity of children and adolescents, protecting them from any inhumane, violent, terrifying, humiliating or embarrassing treatment. (...)". Therefore, it is essential that the multidisciplinary health team carefully analyzes the case so that the patient does not suffer unnecessarily. (2)

This study aims to discuss dysthanasia in pediatrics, decision-making and its bioethical implications, based on the principlism of Beauchamp and Childress. However, concepts such as euthanasia, orthothanasia and dysthanasia, with an emphasis on the third, added to the bioethical principles of principlism will be analyzed in light of a discussion on the autonomy of pediatric patients and their families in therapeutic decisions.

METHOD

This is a literature review, in which a search for articles indexed in the Scientific Electronic Library Online (SciELO) and PubMed databases was carried out, using the following descriptors: “dysthanasia”; “dysthanasia and children”; “euthanasia, dysthanasia and orthothanasia”; “pediatric life support”; “dilemmas in pediatrics”. Although other research sources were also used, as listed in the bibliographic references, priority was given to articles that met the following criteria:

- Be published in Portuguese, English and Spanish;
- Be available in full in the database in the form of a scientific article, including systematic reviews and case reports;
- Have been published in the last 10 years.

For the analysis and discussion of the articles, the theoretical frame-

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work of Bioethics was used, favoring Principlism Bioethics, as developed by Beauchamp and Childress. Additionally, the book Palliative Care in Pediatric Practice by the Pediatric Society of the State of São Paulo (SOPESP, 2019) and the CREMESP website were used to support bioethical concepts.

DISCUSSION

1. Bioethical Approach

1.1 Euthanasia

Euthanasia consists of shortening an individual's life in order to alleviate their suffering and end their pain. The practice is illegal in Brazil, and the Brazilian Code of Medical Ethics of 1988 contains articles on the subject that are against the participation of doctors in euthanasia. Currently, euthanasia is permitted in five Western European countries: the Netherlands, Belgium, Luxembourg, Spain and Switzerland; in two North American countries: Canada and the United States, in the states of Oregon, Washington, Montana, Vermont and California; and in Colombia, the only country in South America. (4)

1.2 Orthothanasia

Orthothanasia is also known as "correct death" and "natural death without scientific interference", that is, disproportionate methods are not used to prolong life, such as artificial ventilation and other invasive procedures. (5) The main objective of orthothanasia is to promote a dignified death, without delay and without causing death. This practice emphasizes the importance of respecting the patient's limits and the finitude of life. (6)

1.3 Dysthanasia

Dysthanasia, also called therapeutic obstinacy, consists of prolonging the death process, through invasive treatments and procedures that aim only to extend the patient's biological life, without covering the patient's quality of life, dignity, mental and emotional health. (5)

Therefore, it is possible to conclude that, by prolonging the biological life of a patient with a non-reversible condition, one moves away from the proposed principles of humanized medicine and the very essence of life. (5)

1.4 Principlism Optics

Bioethical principles are essential to reduce the high number of ethical-professional lawsuits filed for iatrogenesis. Therefore, principlist bioethics must be analyzed in each specific situation and understood by health professionals, with the purpose of acting for the benefit of the patient, preventing harm, respecting their rights and seeking equity. (7)

The basic principles of bioethics are beneficence, autonomy, nonmaleficence and justice. Beneficence refers to the ethical duty to maximize benefit and minimize harm; autonomy requires that individuals capable of deliberating on their personal choices should be treated with respect for their decision-making capacity; nonmaleficence determines that the doctor's action should always cause the least harm or damage to the patient's health - an action that does not cause harm. It is universally enshrined through the Hippocratic aphorism primum non nocere - first do no harm, whose purpose is to reduce the adverse or undesirable effects of diagnostic and therapeutic actions on human beings; and, finally, justice, which establishes equity and impartiality. (8)

It can be said that dysthanasia violates the bioethical principles of beneficence and non-maleficence, since it harms the patient more than it maximizes the benefits. In a patient with a terminal illness, for example, with no real expectations of improvement, prolonging life only brings pain and suffering. The complexity increases even more when we talk about pediatric patients, in whom the principle of autonomy is exercised by the family. (9)

1.4.1 Autonomy

The term "autonomy" derives from the Greek - autos (own) and nomos (rule, government, domain, law). It represents the capacity for self-government, for making one's own choices, deciding what is best for one's quality of life, physical and mental health, as well as for one's social relationships. It is based on presenting, in a clear and transparent way, what is happening to the subject and the options that biomedical science makes available to them, respecting their decision about what they understand to be best for themselves. (8)

The principle of autonomy applies differently in pediatrics because, in this case, those responsible decide what actions will be taken, given that patients are dependent and vulnerable, with cognitive and discernment capacities still under development. If the young patient does not have the capacity to decide on matters concerning his or her own health, then this right falls to his or her parents or guardians by proxy, as "substitutes". Thus, autonomy, in the context of childhood, ends up being replaced by the concept of best interests, that is, decisions made by parents or legal guardians in the "best interests" of that child. (10,11)

1.4.2 Beneficence

This principle dictates that the physician must maintain absolute respect for human beings and will always act in their best interests, even after death. He or she will never use his or her knowledge to cause physical or moral suffering, to exterminate human beings or to allow or cover up

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attempts against their dignity and integrity, as stated in the Code of Medical Ethics (CEM) in its chapter 1, article VII. (12)

1.4.3 Non-maleficence

It is the obligation not to intentionally cause harm or damage to the individual. (8) The patient's permanent vegetative state, for example, ensures that no treatment can restore the vitality of his or her organism. With this in mind, the therapies performed may be seen as ineffective, prolonging the life process of an incurable patient.

The context in question implies physical, emotional, psychological and spiritual suffering for the patient, moving away from beneficence and non-maleficence. At the same time, it is up to the doctor to prevent dysthanasia, since the family tends to seek endless treatments to have their loved one back to life. (1)

1.4.4 Justice

It establishes equity as a fundamental condition; the ethical obligation to treat each individual in accordance with what is morally correct and appropriate, to give each person what is due to them. Resources must be distributed evenly, with the aim of reaching, with greater efficiency, the greatest number of people assisted. (8)

2. Importance of bonding and communication with family

Effective communication between the doctor and the patient is an essential part of a consultation. However, achieving this is not always an easy task and requires a lot of skill, knowledge and empathy on the part of the doctor. Good communication allows the patient to better understand their condition and comply with the proposed treatment. In the medium term, this adequate communication allows the creation of a bond between doctors and health services with patients, which further facilitates adherence to the suggested therapies and access to health services, feeling welcomed and trusting the professionals who are there. (13)

In pediatrics, communication has particular characteristics, given that the child is still in cognitive, psychological and social development. Although the child must be heard, if he or she has cognitive capacity, the decision-making process is up to the medical team and the person responsible for the child, who is responsible for the final consent. (14)

Furthermore, patients in the ICU or with a poor prognosis should have their families well informed about their condition, possible outcomes and actions to be taken with the expected course of the disease. Therefore, it is up to the doctor to explain the child's situation to caregivers and family members as many times as necessary, so as not to create unrealistic expectations or minimize denial, when making difficult decisions. (14)

CONCLUSION

Dysthanasia is a practice influenced by several factors - cultural, religious, ethical, moral, personal, and also by the professional training of health agents. In this sense, when discussing the possible approaches for a patient with no prospect of cure, consensus between the multidisciplinary team, the patient and the patient's family may be difficult to achieve.

The practice of dysthanasia violates the bioethical concepts of Principlist Theory, in the opposite direction to the Hippocratic aphorism primum non nocere - first do no harm, whose purpose is to reduce the adverse or undesirable effects of diagnostic and therapeutic actions. For this reason, prolonging the dying process should be strongly discouraged among health professionals.

The multidisciplinary team that accompanies the patient has the duty to welcome, explain and guide family members about the most appropriate choices for the individual's physical and mental well-being, discouraging decisions aligned with therapeutic obstinacy.

Furthermore, it is the role of health professionals to understand and deal with the process of death, death itself and mourning, actively supporting family members at all stages. The psychological, emotional and behavioral aspects must be addressed by a team of professionals from different areas, understanding and respecting the stages of mourning.

Therefore, it is essential to devote more attention to the curriculum during professional training, promoting discussions and reflections on dysthanasia and its negative impacts on the patient and their dignity, training health professionals to discourage this practice in front of family members. It is also important to address, in higher education, the complexity of the finitude of life and implement practical scenarios in palliative wards, so that students can experience a better relationship with death and thus play their role in helping families identify what quality of life means to them and how it can be achieved, becoming capable of offering the support and comfort they need.

Paraphrasing the writer Rubem Alves, “The idea that medicine is a fight against death is wrong. Medicine is a fight for the good life, of which death is a part.”

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