# RECURRENT RESUSCITATION PROCEDURES IN PEDIATRIC PATIENTS: A BIOETHICAL DISCUSSION ON DYSTHANASIA

Akemi Svaiter Tominaga[1]
Ana Júlia Rodrigues Bezamat[2]
Bernardo Teixeira Amarante[3]
Júlia da Mata Dias Corrêa[4]
Ronaldo Melo Dias Neto[5]
Elizabeth Alt Parente[6]
Lays Costa Silva[7]

**Abstract:** The present study refers to a real case report, in which a bioethical analysis is developed, from the perspective of principlism, in the environment of a pediatric intensive care unit, with the objective of discussing the dysthanasia practiced in the medical setting and the decision-making of those involved in this case. A search was performed in the Scientific Electronic Library Online (SciELO) and PubMed databases for literature review. Dysthanasia consists of a treatment that only prolongs the pain, making any investment in healing an aggression against the dignity of the human person. When the patient is a child close to death, the difficulty for professionals becomes even greater. Therefore, it is necessary to pay greater attention 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

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[1] Student of the 10th period of medicine at the Estácio de Sá University (UNESA-IDOMED)
[2] Student of the 10th period of medicine at the Estácio de Sá University (UNESA-IDOMED)
[3] Student of the 10th period of medicine at the Estácio de Sá University (UNESA-IDOMED)
[4] Student of the 10th period of medicine at the Estácio de Sá University (UNESA-IDOMED)
[5] Student of the 10th period of medicine at the Estácio de Sá University (UNESA-IDOMED)
[6] Pediatrician, Master in Collective Health and Professor at Estácio de Sá University (UNESA-IDOMED)
[7] Family and community doctor, master in family health and professor at Estácio de Sá University (UNESA-IDOMED)

how it is possible to achieve it.

**Keywords:** “dysthanasia”; “dysthanasia and children”; “euthanasia, dysthanasia and orthothanasia”; “pediatric life support”; “Dilemmas na pediatrics”.

## INTRODUCTION

Dysthanasia, also known as therapeutic obstinacy, consists of a treatment that only prolongs pain, making any investment in healing an aggression against the dignity of the human person with the purpose of, at any cost, postponing death. The Greek prefix dis means “estrangement” and thanatos, “death”. Therefore, dysthanasia means an exaggerated prolongation of a patient’s death. The term can also be used as a synonym for useless or futile treatment. It is the medical attitude that, aiming to save the life of the terminal patient, subjects him to great suffering (Silva et al., 2021).

The decision to resuscitate a patient who has undergone consecutive interventions in his illness process and the patient’s desire for recovery at all costs, instead of helping or allowing a natural death, ends up prolonging his agony (Silva et al., 2021).

When the patient is a child, close to death, the difficulty for professionals becomes even greater, since there is in the collective imagination the idea that “children cannot die”, a fact that, in turn, is considered natural when it comes to the elderly. Therefore, the approach to death in a child proves to be more challenging, because the loss is experienced as a triple failure: first, because they would not have had the method, the talent, or the skills to save them; second, because, in their social role as an adult, they were unable to protect her from complications, and third, because they betrayed the parents who entrusted them with the most valuable asset of their lives. Inevitably, this failure increases the reactions of grief and intensifies the feelings of helplessness, guilt, anger and sadness presented by the professionals (Barbieri, 2014).

The principle of “best interests” is a key component of policies related to decision-making in all areas of medical practice. Often, when a patient lacks autonomy, as is the case with the pediatric patient, these decisions become more delicate. Therefore, the discussion about medical practice on how to deal with decision-making is of fundamental importance (Birchley, 2021).

Studies show that children with fatal diseases create immense emotional stress on those who care for them, whether parents, relatives, hospital staff or doctors. Article 18 of the Statute of the Child and Adolescent (ECA) says that “It is everyone’s duty to ensure the dignity of children and adolescents, keeping them safe from any inhuman, violent, terrifying, vexatious or embarrassing treatment. (...)”. Thus, it is essential that the multidisciplinary health team analyzes the case well so that the patient does not suffer unnecessarily (Barbieri, 2014).

This study aims to present and discuss a real case of dysthanasia in a pediatric patient and its interface with Bioethics, based on the principlism of Beauchamp and Childress. However, concepts such as euthanasia, orthothanasia and dysthanasia, with emphasis on the third, added to the bioethical principles of principlism will be analyzed in the face of a discussion about the autonomy of pediatric patients and their families in therapeutic decisions.

## CASE REPORT

F.G., 3 years old, male, only child with a desired pregnancy, married parents, mother teacher and father construction assistant, is referred from the hospital in the interior of the state to the pediatric ICU of the capital, due to dehydration and sepsis, after acute gastroenteritis. He had cardiorespiratory arrest during transport, and was rescued after 40 minutes in the ICU, in poor general condition, and requiring cardiocirculatory support, mechanical ventilation and, later, hemodialysis. The infectious condition evolved with meningitis. After 3 months of evolution, the patient was hemodynamically stable, but dependent on mechanical ventilation.

The neurological evaluation showed a permanent vegetative state, i.e., dependence on mechanical ventilation by apnea, without interaction with the environment or the people around it, without responses to external stimuli, without spontaneous or reproducible reactions to visual, auditory or tactile stimuli, without sphincter control, variable preservation of cranial and spinal nerve reflexes, autonomic functions of the hypothalamus and brainstem sufficiently preserved to survive with intensive medical and nursing care.

After extensive explanation of the clinical picture and its meaning to the parents, they opposed any proposal from the medical team, such as a non-resuscitation order in spontaneous cardiorespiratory arrest, other than full support of organic functions and cardiopulmonary recovery.

Four years have passed since the patient was hospitalized with a tracheostomized patient, fed by a tube, on mechanical ventilation and with an unchanged neurological condition. He had two fractures due to osteoporosis and sometimes received chronotropics because he had three severe episodes of cardiogenic shock.

The historical average length of stay of patients in this ICU is 5.4 days, with this patient occupying the space of 271 patients. The medical and hospital expenses paid by the health plan are, on average, R$15,500.00/month (total of R$744,000.00).

## METHODOLOGY

This is a qualitative descriptive study, in the format of a real case report, which included the search for articles indexed in the Scientific Electronic Library Online (SciELO) and PubMed databases, using the following descriptors: “dysthanasia”; “dysthanasia and children”; “euthanasia, dysthanasia and orthothanasia”; “pediatric life support”; and “dilemmas in pediatrics”.

In addition to these sources, as listed in the bibliographic references, others were consulted. However, the selection prioritized articles that met the following criteria:

- Be published in Portuguese, English or Spanish;
- Available in full as scientific articles, including systematic reviews and case reports;

- Published from 2010 to 2024.

For the construction of the case report, the article by Kipper and Hossne available on the website of the Bioethics Journal (available at the link: https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/viewFile/314/452) was used. The analysis and discussion of the clinical case were based on the theoretical framework of Bioethics, with emphasis on Principlist Bioethics, as proposed by Beauchamp and Childress. Additionally, the book Palliative Care in Pediatric Practice (SOPESP, 2019) and the website of the Regional Council of Medicine of the State of São Paulo (CREMESP) were used as sources to support bioethical concepts.

## DISCUSSION

### Clinical Approach

### Gastroenteritis

Gastroenteritis is inflammation of the lining of the stomach and the large and small intestines. Its symptoms include anorexia, nausea, vomiting, diarrhea, and abdominal discomfort. The loss of fluids and electrolytes resulting from these symptoms, and their non-replacement, can cause hemodynamic repercussions in the patient, leading to hypovolemic shock (a state of organ hypoperfusion that results in dysfunction) or hydroelectrolyte disturbances (the adequate level of electrolytes in the blood helps the body regulate volume, nerve impulses, muscle contractions, and acid-base balance). Most cases occur due to infection, but can also be caused by ingestion of drugs or toxins (Jameson et al., 2020).

## Sepsis

Sepsis is a response of the body to an infection, most often bacterial, that is life-threatening and causes dysfunction of vital organs. For the diagnosis of sepsis, in addition to the presence of infection, it is necessary that at least two of the four signs of systemic inflammatory response syndrome (SIRS) are present (Jameson et al., 2020). These signs are:

- Fever (T>38°C) or hypothermia (T<36°C);
- Tachycardia (HR>90 BPM);
- Tachypnea (RF>20 IRPM),
- Hypocapnia (partial pressure of $CO_2$ <32mmHg) or need for ventilatory assistance;
- Leukocytosis (>12000 cells/mm$^3$), leukopenia (<4000 cells/mm$^3$), or left shift (>10% rods).

## Vegetative state

The vegetative state is defined by the prolonged absence of reaction and alertness, caused by a dysfunction of the cerebral hemispheres, but with sufficient preservation to maintain autonomic reflexes, motor reflexes, and sleep-wake cycles. Patients may have complex reflexes, including eye movements, yawning, and involuntary movements caused by painful stimuli, but are unable to demonstrate consciousness (Jameson et al., 2020).

## When is intubation and hemodialysis indicated?

Orotracheal intubation is an essential procedure in medical practice, recommended when the patient has acute respiratory failure, ventilation or inadequate oxygenation, when airway protection is necessary in patients with reduced level of consciousness, according to the Glasgow Coma Scale, with parameter $\leq 8$ (Jameson et al., 2020).

Hemodialysis is indicated in cases where the patient has severe refractory hypervolemia (systemic arterial hypertension), severe metabolic acidosis ($pH < 7.2$), uremic syndrome (potassium $> 6.5$ or changes in the electrocardiogram), and when clinical treatment is refractory. It can be used in cases of intoxication by drugs and other toxins, azotemia and dysnatremia (Jameson et al., 2020).

## Importance of bonding and communication with the family

Effective communication between the doctor and the patient is an indispensable part of a consultation. However, achieving it is not always a simple 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 follow the therapeutic proposal. This adequate communication, in the medium term, facilitates the creation of bonds between doctors, health services and patients, which further promotes adherence to the suggested therapies and improves access to health services, making the patient feel welcomed and confident in the professionals who work there (Pinto et al., 2010).

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, decision-making goes through the medical team and his/her guardian, and the final consent is given (Gabarra et al., 2010).

In addition, patients in the ICU or with a poor prognosis should have their families well informed about the condition in which they are, possible outcomes, and conducts to be followed with the expected course of the disease. Thus, it is up to the physician to clarify the child’s situation as many times as necessary in front of caregivers and family members, so as not to generate unrealistic expectations or minimize denial at the time of making difficult decisions (Ferreira et al., 2018).

In the case under discussion, the patient was pediatric and was in the ICU with a poor prognosis, so the importance of maintaining good communication with the family is essential, evaluating the situation from different perspectives and in a permanent dialogical process.

## Bioethical Approach

### Euthanasia

Euthanasia consists of the shortening of an individual's life with the aim of relieving and bringing finitude to their suffering. This practice is illegal in Brazil, and the Brazilian Code of Medical Ethics of 1988 contains articles alluding to the subject, contrary to the participation of physicians in euthanasia (Felix et al., 2013). Currently, euthanasia is allowed 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 representative in South America (De Castro et al., 2016).

### Orthothanasia

Orthothanasia is also known as "correct death" and "natural death without interference from science", that is, in this practice, disproportionate methods are not used to prolong life, such as artificial ventilation and other invasive procedures (Cano et al., 2020). The main objective of orthothanasia is to promote a dignified death, without postponement and also without causing death. This practice emphasizes the importance of respecting the patient's limits and the finiteness of life (Felix et al., 2013).

## Dysthanasia

Dysthanasia, also called therapeutic obstinacy, consists of prolonging the death process, based on invasive treatments and procedures that aim only to extend the biological life of the patient, without covering the quality of life, dignity, mental and emotional health of the patient (Felix et al., 2013).

By correlating the concept of dysthanasia with the case report, it is possible to clearly notice the prolongation of the child's death process, promoted by bereaved parents who cannot accept the reality of their child, who has been in a permanent vegetative state for four years, completely dependent on artificial ventilation, without interaction with the environment and without response to external stimuli. The maintenance of ineffective treatments that painfully prolong biological life, such as full support of organic functions and cardiopulmonary recovery, a fact reported in the case under study, culminate in a death without dignity and without quality of life.

It is observed in the case that, after four years in the hospital, even with the numerous interventions (tracheostomy, nasogastric tube, mechanical ventilation), he remained with an unchanged condition and still developed fractures due to osteoporosis and needed to receive chronotropics in order to restore the heart rhythm.

Thus, it is possible to conclude that, by prolonging the biological life of a patient with a non-reversible condition, it distances itself from the proposal of the principles of humanized medicine and the very essence of life.

## Perspective of Principialism in the case

The clinical case presented here involves several complex bioethical issues, related to the treatment and medical decisions of a patient who is in a permanent vegetative state. In this sense, bioethical principles are of paramount importance in an attempt to reduce the exorbitant numbers of ethical-professional lawsuits filed for iatrogenesis. Therefore, principtive bioethics must be analyzed in each particular context and understood by health professionals, with the objective of acting for the benefit of the patient, avoiding harm, respecting their rights, and seeking equity (Salomão et al., 2021).

The basic principles of bioethics are beneficence, autonomy, non-maleficence and justice. Beneficence refers to the ethical obligation to maximize the benefit and minimize the harm; autonomy requires that individuals capable of deliberating on their personal choices should be treated with respect for their decision-making capacity; Non-maleficence establishes that the doctor's action must always cause the least harm or harm to the patient's health - an action that does not cause harm. It is universally consecrated 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 (CREMESP, 2020).

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

## Autonomy

The term "autonomy" derives from the Greek - autos (one's own) and nomos (rule, government, dominion, law). It represents the ability to self-govern, to make 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 (Iglesias, 2019). 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 him, respecting his decision about what he understands to be best for him (CREMESP, 2020).

The principle of autonomy applies differently in pediatrics because, in this case, the caregivers decide the actions that will be taken, given that the patients are dependent and vulnerable, with cognitive and discernment capacities still developing. If the little patient does not have the capacity to decide on the issues of his own health, then it is up to his parents or guardians to have this right by proxy , as "substitutes". Thus, autonomy, in the context of childhood, is replaced by the concept of best interests, that is, decisions made by parents or legal guardians in the "best interests" of that child (Pastura, 2018).

In the case cited, the patient's parents opposed any proposal from the health team, even after a detailed explanation of their son's clinical condition. As much as legal guardians have the right to make decisions for the individual, it is worth noting that this right has limits, especially when they are considered futile in the treatment, that is, they will not generate any improvement in the clinical condition.

## Beneficence

This principle dictates that the doctor will maintain absolute respect for the human being and will always act for his benefit, even after death. He will never use his knowledge to cause physical or moral suffering, for the extermination of human beings or to allow and cover up attempts against his dignity and integrity, as stated in the Code of Medical Ethics (CEM) in its chapter 1, article VII.

In this context, a comparison can be made with the patient in question, who is in a permanent vegetative state, with low quality of life, dependent on mechanical ventilation and full support of organic functions. It is questionable whether prolonging the patient's life is really beneficial, since the treatments do not have a positive effect on his clinic.

## Non-maleficence

It is the obligation not to intentionally cause harm or harm to the individual (Beauchamp;

Childress, 2002). The patient’s permanent vegetative state ensures that no treatment restores the vitality of his body. With this in mind, the therapies performed can be seen as ineffective, prolonging the life process of an incurable patient.

The context in question implies physical, emotional, psychic and spiritual suffering to the patient, moving away from beneficence and non-maleficence (Silva et al., 2021). In parallel, it is up to the doctor to prevent dysthanasia, since the family tends to seek endless treatments to get their loved one back to life.

### Justice

It establishes equity as a fundamental condition; ethical obligation to treat each individual according to what is morally correct and adequate, to give each what is due to him. Resources should be evenly distributed, with the aim of reaching the largest number of people assisted with greater efficiency (Beauchamp; Childress, 2002).

The patient in the case has access to resources, however the number of beds that were occupied only with his hospitalization harmed hundreds of individuals, which makes it impossible to fully distribute medical care. Thus, the principle of justice, in the bioethical conception, was not applied equally to all, harming the layer of the population that did not obtain health resources due to the prolonged hospitalization in question. The average length of stay in the ICU where the patient in question was admitted is 5.4 days, with the same occupying the space of 271 patients.

## FINAL CONSIDERATIONS

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 debating possible approaches for a patient with no prospect of cure, consensus between the multidisciplinary team, the patient, and the patient's family can be difficult to achieve.

The practice of dysthanasia infringes the bioethical concepts of the 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, the prolongation of the death process should be strongly discouraged among health professionals.

The multidisciplinary team that accompanies the patient has the role of welcoming, explaining and guiding the family members about the most appropriate choices for the individual's physical and mental well-being, discouraging decisions aligned with therapeutic obstinacy.

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

Therefore, greater attention to the curriculum is needed during professional training, raising discussions and reflections on dysthanasia and its harm to patients and their dignity, enabling health professionals to discourage this practice before 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 is possible to achieve it. becoming able to offer the support and comfort they need.

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