

## ORTHOTHANASIA AND DYSTHANASIA: PERCEPTION OF HEALTH PROFESSIONALS OF AN INTENSIVE CARE

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### ABSTRACT

Research involving the process of death regarding dysthanasia, which is defined as therapeutic obstinacy practiced with the aim to postpone death, and Orthothanasia, which is death in its natural process, without further treatment. The study aimed to recognize the perception that professionals of the health team working in an intensive care unit have about situations of Orthothanasia and Dysthanasia. The study was conducted in a university hospital. Data were collected through semi-structured interviews with 25 health professionals and submitted to thematic content analysis. Three related categories emerged: Seizing Orthothanasia and Dysthanasia; Realizing the decision-making context; Pondering Orthothanasia and Dysthanasia in the finitude of life. The perception of health professionals regarding Orthothanasia and Dysthanasia requires discussions that consider the ethical concepts involved in interventions adopted in the process of death in order to provide basis to the multidisciplinary team, family and patients in decision making at the end of life.

**Palavras-chave:** Health team. Intensive Care Unit. Orthothanasia. Dysthanasia.

### INTRODUCTION

Because the ICU is a place where specific and highly complex procedures and care are developed, this has a structure that is capable of providing support for critically ill patients, those with potential risk of death that require constant observation, working in ICU can be stressful for health professionals, as these place has a constant atmosphere of tension<sup>(1)</sup>.

It is known that the daily routine of an ICU is marked by antagonistic situations. Sometimes it is possible to save a patient but, in other cases, the treatment only extends the suffering because the patient has no chance of curability, and the process of dying is inevitable. In this context, professionals are subjected to pressure regarding decision-making in critical moments, with respect to extending or not the life in cases with poor prognosis<sup>(1,2)</sup>.

Among the concepts involving end-of-life, in this study, it is emphasized that dysthanasia aims to prevent death at any price, while orthothanasia proposes a dignified death which must occur at the right time, with the preservation of patient dignity, pain control and psychological support concerning issues relating to social and spiritual aspects<sup>(3)</sup>.

Orthothanasia has increasingly gained value as an ethical possibility to deal with suffering before irremediable death, and it is a legal practice in several countries. In Brazil, orthothanasia is implicitly backed by juridical principles and embodied in ethical and moral principles, but because there is no specific legislation for its practice, or causes legal uncertainty that leads to the continuing practice of dysthanasia<sup>(4,5,6)</sup>. The latter is considered by Bioethics as a difficult death caused by the objective of prolonging the biological life through intensive treatments but not valuing the

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quality of life and dignity in terminal situations<sup>(2,4,5)</sup>.

From this perspective, the practice of health professionals in the process of death should be based on the four bioethical principles (beneficence, non-maleficence, autonomy and justice) and comply with the regulation of professions involved in this care<sup>(7,8)</sup>.

The Federal Council of Medicine in the Article 1 of Resolution 1,805/06 and the Code of Medical Ethics of 2010 authorize doctors to restrict or suspend procedures and treatments that prolong the life of terminally ill patients<sup>(9,10)</sup>. The Code of Ethics of Nursing Professionals, Resolution nº 311/2007 of the Federal Council of Nursing, establishes the respect for life, dignity and rights of the individual, including the stage of death and postmortem, as a fundamental principle, and the Article 29 prohibits the participation in any act that anticipates the death of patient, giving to nursing care the duty to provide comfort, pain relief and dignity to the body that suffers. For physiotherapists, the respect for the integrity and dignity of human life from conception until death is the rule<sup>(11,12)</sup>.

Based on the issues discussed, and because this is a controversial issue, the present study aimed to investigate the perception that professionals of the health team working in an ICU have about situations of orthothanasia and dysthanasia. The study is justified by the important bioethical discussion required in the practice of health professionals acting on the decision-making process, which involve family members, patients and the ICU staff.

It is fundamentally important to discuss the ethical principles involved in terminal illnesses in order to guide the professional decision making, confirming, this way, the relevance of this issue, for both, the practical assistance and the research. Although numerous studies exist on the ethical aspects of the health care to people in the imminence of death, few address clearly and directly the knowledge and practice of orthothanasia and dysthanasia by health professionals.

## METHODOLOGY

Descriptive study with qualitative approach conducted with 25 health professionals working

in the ICU of a university hospital in Maceió/AL. The information was produced through semi-structured interviews, which were recorded and subsequently transcribed and deleted. The script of the interview consisted of questions related to the meaning of orthothanasia and dysthanasia that permeate the professional performance and consequently reflect in the perception of the theme.

Inclusion criteria did not apply to this study because all professionals were participants, excluding only the subjects who were on leave or on vacation during the period of data collection. In order to ensure anonymity of participants, the letter "P" (Professional) was used for identification, followed by Arabic numerals, considering the order in which interviews were conducted (P1 to P25).

Interviews were classified and analyzed according to content analysis technique, following the recommended steps: (1) pre-analysis; (2) exploration of the material and (3) organization of results, inference and interpretation<sup>(13)</sup>. The study was conducted in accordance with Resolution nº 466/2012 of the CNS/CONEP, and approved by the Ethics Committee of the Federal University of Alagoas, under protocol nº 663,589/2014. All participants signed an Informed Consent form.

## RESULTS AND DISCUSSION

The study included four doctors, three nurses, three physiotherapists and 15 nursing technicians. There was predominance of women, working in the ICU for up to 10 years, aged between 30 and 40 years, mostly married. The analysis allowed to recognize their perceptions about situations experienced in the professional practice related to orthothanasia and dysthanasia, as seen in the following three categories:

### Seizing Orthothanasia and Dysthanasia

This category reveals the understanding of participants on orthothanasia and dysthanasia. Their speeches showed that they felt uncomfortable and had an opinion concerning the subject, although they did not show to have domain of the ethical concepts discussed. It is expected that a professional who works in a

sector like the ICU, where they are subjected to and live with situations of intense suffering and death, acquire knowledge on this subject that is of utmost importance in their daily lives<sup>(5)</sup>. However, for the study participants, orthothanasia was not defined with clarity:

I know what is euthanasia, but the "ortho", no, I don't know [...]. (P1)

I don't remember [...]. (P6)

However, in the course of the analysis, it became clear in some speeches concerning ethical values outlined for orthothanasia that, although participants were not able to conceptualize it correctly, they give to this term the meaning of providing a dignified death to the patient:

You allow the patient to have a dignified death [...]. (P19)

Authors discuss dignified death, giving the individual the right to, at the end of life, receive care for the preservation of his dignity. This is guided by the principle of autonomy, which advocates free will, as well as the option for the treatment that the patient judges to be more favorable for him<sup>(7,14)</sup>. In this context, health professionals have a key role in providing a dignified and painless death by an assistance that may grant psychological, social and spiritual comfort<sup>(15)</sup>.

By not considering the invasive treatments in situations of end of life as viable, study participants attribute to such attitudes the meaning of futile or useless efforts. They believe that it is necessary to respect the human body limits and not persist with techniques of maintenance of life when the need is actually to respect the finitude.

The participants of this research agree with the premise that the option for the extension of the life through invasive procedures affronts the dignity in the finitude of life, confirming a previously conducted study<sup>(4)</sup>. Participants also agreed that the commitment in prolonging life promotes greater suffering for those involved in the process of death, and more than that, they think that this action incurs the designation of unnecessary resources. Another study added that these resources could be used in patients that have healing prognosis<sup>(16)</sup>.

Professionals perceive that the body's limits must be respected and care should coexist in the finitude of life without invasive measures that would contradict the principles of dysthanasia:

[...] you have to respect the limit of the body of the patient who do not indicate further invasive measures such as using vasoactive drugs, as some more invasive procedures, latest generation of antibiotics, which will not cause effect anymore on that case and can be removed [...]. (P3)

When asked about the definition of dysthanasia, they said that this mean the extension of life permeated by suffering:

Dysthanasia is prolonging the suffering [...] the extension of something that has no longer cure [...]. (P20)

Dysthanasia is when the health professional is prolonging the life [...] when the patient is not having an efficient prognosis [...]. (P12)

Professionals believe that death does not mean to save a life with investments in treatments which do not have the prospect of an efficient prognosis, inducing, thus, individuals in the end-of-life to dysthanasia. Thus, the latter concept can be understood as "a difficult and painful death, used for the postponement of death and prolongation of biological life without quality of life and without dignity, in order to increase the lifetime by all available resources"<sup>(4)</sup>.

Another interesting issue was that, in the perception of these professionals, ethical concepts, involving terminal illnesses are considered valid only for professional practice, but except personal experiences with the patients' families, often permeated with more intense emotional involvement and with a different perspective. For deponents, death must be faced naturally in the professional practice, but death is sensed differently when it happens to a family member:

These concepts that you may have are valid from the intellectual and professional point of view, but when you go to the emotional side, it loses meaning, because when you become the one whose family member is dying, everything is different, you want that everything be done to make that family member to live. (P9)

When the health professional learns that a loved one is in intensive care, in a situation

terminally illness, he feels helpless and undergoes a strong emotional impact. At this time, he becomes similar to the families of patients in the process of death who he attended in daily work. Study showed that in the situation experienced as a family member, the choice for dysthanasia was the choice that prevailed and the authors state that a discussion in society about dysthanasia and orthothanasia is necessary to the understanding that the extension of life is at the expense of the suffering of all involved<sup>(17)</sup>.

The understanding of orthothanasia and dysthanasia for these professionals has many faces, adding ethical concepts and experience to impart an understanding that may be consistent with the process of death, in the XXI century. They consider human dignity in terminally life very invaluable, despite the technological advances in this area. Their speeches show that dysthanasia is an option that they would choose or not in experiences where they are family members. So, it is not clear among them the understanding of orthothanasia and dysthanasia. A broad approach to the topic is indispensable in order to clarify doubts involving the process of dying.

### Realizing the decision-making context

This category covers an individualized look at orthothanasia and dysthanasia, revealing a humanist and godly character in orthothanasia considered a method to which we must turn when there is no more hope. In these cases, in view of the impossibility of cure, that at least the necessary care may be given to them:

[...] the patient is not curable, but he still can receive care, I think this summarises orthothanasia, it's when there is no cure, but you have to take care, to eliminate pain, suffering. (P20)

Alleviate suffering and provide care to patients in the final stage of life is necessary because, even without therapeutic possibilities, there is still much to do. Patients may receive considerable comfort and palliative care<sup>(15)</sup>.

However, it is noticed in the reports that orthothanasia should be a decision taken together. There should be a discussion within the team with the insertion of the family as well as its consent, based on criteria and protocols, and not only on professional experience:

[...] the assessment has to be done by various professionals, to say if new investments are indicated or not. (P4)

[...] I think we need to have a criterion for a decision based on protocol, because it is only based on the experience of some on duty, everyone is subject to error. (P3)

It is important to emphasize the need for discussion between the team and the patient's family for decision making, since by doing this, the decision would be based on bioethical and legal aspects, avoiding that the responsibility be over the professionals only<sup>(5,14)</sup>.

In speeches, professionals considered that doctors have a monopoly of choice in decision making regarding the process of death, when opting for dysthanasia or orthothanasia:

[...] these are medical decisions [...]. (P14)

The nurse follows the prescription, the medical prescription, the nurse will not criticize or deny a prescription before other professional, is not ethical, it goes to an ethical issue. (P8)

The final decision and the legal responsibility of conducting the treatment lie in the doctor's hands. However, the involvement of a multidisciplinary team and the family in taking decisions related to orthothanasia and dysthanasia is of utmost importance<sup>(2)</sup>.

The lack of communication between professionals has been reported, mainly from doctors. Their actions are reported as characterized by individualism and lack of continuity of the steps taken in patient care. Furthermore, the doctor's actions generate more suffering and distress to the family and the patient:

[...] we work with physicians, unfortunately they do not work following conduct, continuing conducts, they work each on giving their conducts, this makes the patient to suffer [...]. (P8)

Practices of doctors, when followed isolated, contribute to indecision in face of situations of end of life, causing discomfort to professionals from other areas who do not participate in the decision-making<sup>(14)</sup>.

It is considered important also that a dialogue with the family to clarify what is involved in orthothanasia and dysthanasia exist, once there is a lack of understanding of the issues that favor the practice of dysthanasia, because the family

member is emotionally involved and not prepared for the loss of the loved one. Such fact leads the professional to opt for life extension:

[...] a good relationship with the family is necessary, to avoid any problem, to decide this issue and explain that it will not bring much benefit, but the family sometimes is keen to invest and go to the last breath. (P3)

It is observed in the speech of P3 that the basis for the professional to opt for orthothanasia or dysthanasia is based on knowledge and experience on one hand and good relationship with the family on the other. This implies to present explanations that can be fully understood by the family, giving emotional support to both parties. This communication crosses all care actions, and the way it happens is the differential between beneficence and maleficence, noting that attempting to communicate in an environment dominated by the effective means to rescue the importance of the affective<sup>(5)</sup>.

Through communication, professionals consider necessary to provide psychological support for the family, involving the practice of hosting by both, the physician and the nurse, always exposing the truth about the patient's condition:

[...] a psychological work is needed, and the doctor must work together with the family [...]. When the doctor and the nurse approach the family, expounding upon the actual conditions of the patient, then it is easier [...]. (P8)

[...] when they are well guided by a group of well trained professionals [...] end up understanding that it is of no worth to prolong the suffering of someone, the patient ends up comforting himself [...]. (P16)

The offer of an active and affective assistance consists of actions that include all care spheres that may establish trust in the relationship<sup>(18)</sup>. A good communication between professionals, and between patients and families tend to reduce uncertainties and direct medical practices based on clear and relevant information, becoming a major factor in the discussion on decision-making at the end of life<sup>(19)</sup>.

Another important factor evidenced in speeches and concerning the decision-making

was religiosity. The subjects of the research consider religiosity capable of enabling the realization that life has absolute value and should be preserved in all circumstances, not being applicable to the professional the decision-making at the end of life, because this power belongs to God only:

[...] who are we to say that someone has a closed prognosis, we know, sometimes, for sure, whether it is appropriate or not that a patient leaves or not, through the experience of life that we have in an ICU, but I believe that, for God nothing is impossible [...]. (P11)

In this sense, a contradiction between the assurance acquired through knowledge and experience and the respect and observance of religious dogmas appears, as an ethical dilemma. Religiosity can enter in this process with the purpose of inducing the individual to motivations and impulses, in order to achieve greater personal strength that encourages the person to contemplate what he cannot control<sup>(20)</sup>. Thus, not deciding for dysthanasia can generate conflict, because it was considered impossible to dismiss the improvement of a terminal patient, defending the idea of the inexistence of irreversible situations:

[...] Patients who everyone thinks will not last a week and they last much longer and better, may even die later, but they evolve as if they had, like, great chances to leave the ICU and be able to have a life out there (P21)

Although health team professionals know that there is imminence of death in terminally ill patients, they hope that in some cases the clinical frame may be reversed and the patient may attain full recovery<sup>(14)</sup>. In such cases, it should perhaps be thought that the time that features the imminence of death has not come yet.

For health professionals, the prolongation of life has different interpretations. One is to extend the life, converging with the extension of the patient's suffering, and to prolong life, which can bring important consequences such as the possibility of saying goodbye to loved ones and solve unfinished problems.

[...] The first is that we see as a suffering that is being extended through a pathological condition and you interpret it as suffering [...] The other is interpreted as more time here on this plane, is not a relationship of religion, but it's lifetime [...] may

be a possibility of parting, to solve an unfinished problem, to apology, to forgive [...]. (P5)

Professionals participating in this study consider the practice of orthothanasia responsible for promoting comfort in the dying process, and the dysthanasia as promoting the hope for healing, and thus they understand that decision-making should be well worked out between the team, the family and the patient, because they recognize that they are facing a complex situation that involves many factors.

### **Pondering Orthothanasia and Dysthanasia in the finitude of life**

In the finitude of life, ethical aspects should be considered, and in the practice of professional involved in this study, orthothanasia and dysthanasia have been experienced constantly. Although they are not satisfied with the decision making in face of the process of death, they ponder the possibilities allowed, because the event of "death" is complex and involves an ambivalence focusing on ethical dilemmas. This requires serious discussion and aimed at pursuit dignity in the process of dying<sup>(17)</sup>.

In their reports, they pay attention to the lack of a protocol in order to regulate their practice and guide them in the choices:

É uma prática que se faz em qualquer UTI do mundo, né? Qualquer UTI do Brasil e acho que se faz adequadamente, só que eu acho que também a maioria não tem protocolo em relação a isso. (P3)

The presence of a protocol would allow greater legal support to the professional, when the diagnosis is out of therapeutic possibilities<sup>(21)</sup>. Thus, the practice of orthothanasia could provide numerous benefits to the patient and the family, as it seeks to avoid suffering and to promote comfort to the patient. However, they point out that it should be practiced consistently:

[...] I think that it prevents suffering [...] objectively prevents extra expenses, prevents sometimes a waste a material that would be used for another patient with more chances, with prognosis and I think that it brings benefits, yes. For the family too, but this must be very well discussed. (P3)

They emphasize that the patients are not the only recipients of the above benefits, the family

is also directly affected by the practice of orthothanasia:

I think so [there are benefits], the issue of pain [...] I think it has the benefit yes, both, for the family too, for the issue of pain. (P13)

The perception of the team, while working as professionals in the ICU, is that dysthanasia is predominantly negative, based on arguments that go from economic pragmatism to others linked to the dignity of the patient:

We realize [...] First, the loss, financial cost to the unit and to the patient and to the patient's family. (P1)

[...] you see the color of the patient, the patient's structure, that swelling, that odor that has passed many days, that they should have gone long

They consider that dysthanasia does not bring benefits in the process of death, but causes suffering and promotes the depreciation of the physical condition of the patient, causing too excessive and unjustified expenses.

No benefit, you will only prolong the suffering of the patient and family suffering. (P25)

Dysthanasia, as synonymous of unnecessary treatment, does not bring any benefit to the patient in a terminal phase, only negative consequences<sup>(5)</sup>. For subjects studied, dysthanasia can be an option when there are family reasons and they bring benefits only to the family, before circumstances which can come from selfish reasons or lack of knowledge and awareness of the family about the process of death:

[...] Sometimes, the family wants to keep the patient for financial reasons, as a matter of attachment to daily life, because they miss the person, the human being, financial attachment, emotional attachment and spiritual attachment [...] people are still unclear about the spiritual part [...] people are aware, but the mental ignorance is still very strong. (P8)

Understanding from family members and a good relationship with the professionals of the team are necessary, because often the impending death of a loved one can make each individual to act differently, in order to preserve life at all costs<sup>(14)</sup>. It was evident also the character that transcends the individual to the collective practices of orthothanasia and dysthanasia

analyzed in a broader context, not only of personal and discretionary convictions:

It is a very delicate thing, because it involves not only the scientific context, but also involves the religious context, involves the psychological context of the professional himself, the reference, the counter-reference, the transference, you have to respect that patient. (P19)

Although it is a prevailing understanding that the measures have metaindividual character, health professionals are able to understand the impact and possibilities arising from orthothanasia and dysthanasia, whether positive or negative. About orthothanasia, there is a demand for its regulation, in addition to providing benefits with the aim of promoting comfort to the patient and also benefit to the family. In turn, dysthanasia, it was seen by most of participants as something with no benefit at all, but there are some who cite benefits to family members only.

### FINAL CONSIDERATIONS

The study made it possible to know the perception that professionals of the health team working in the ICU have regarding ethical issues involved in the practice of orthothanasia and dysthanasia. It became evident the lack of ethical concepts about orthothanasia and dysthanasia, signaling the need for a more comprehensive

discussion with health professionals, with emphasis on the diverging stances as to such practices.

The offer of a dignified death is perceived as priority in patient care at end of life. This is because by doing this, there would be a reduction of the suffering of the patient and his family. This aspect is essential for the decision-making of the team. However, the multidisciplinary team should be open and involved unitedly in decision-making in face of death.

The study results were satisfactory, considering their contribution to understand this theme, and revealing the diverse views of all members of the multidisciplinary team. The study showed the need for further discussion on ethical issues, especially on orthothanasia and dysthanasia, as they are part of the daily routine of an ICU. Thus, changes in the decision-making when facing the process of death will be possible.

Finally, this work does not exhaust the subject, but it is expected that the proposal presented may encourage the deepening of discussions in these ethical issues. Furthermore, there is a great need for publications on this subject and on the ethical and legal aspects that back health professionals and the practice of nursing in the context of providing care in the process of death.

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## ORTHOTHANASIA AND DYSTHANASIA: PERCEPTION OF HEALTH PROFESSIONALS OF AN INTENSIVE CARE UNIT

### ABSTRACT

Pesquisa que envolve o processo de morte, abordando a distanásia, a qual se constitui na obstinação terapêutica a fim de adiar a morte, e a Ortotanásia, que se constitui na morte em seu processo natural, sem prolongar o tratamento. Teve como objetivo reconhecer a percepção dos profissionais da equipe de saúde que atuam em unidade de terapia intensiva, acerca das situações de Ortotanásia e Distanásia. Realizado em um hospital universitário. Os dados foram coletados por meio de entrevistas semiestruturadas com 25 profissionais de saúde e submetidos à análise de conteúdo temática. Emergiram três categorias relacionadas: Apreendendo a Ortotanásia e a Distanásia; Percebendo o contexto da tomada de decisão; Ponderando a Ortotanásia e a Distanásia na finitude da vida. A percepção dos profissionais de saúde referente à Ortotanásia e à Distanásia exige discussões referentes aos conceitos éticos que envolvem as intervenções no processo de morte, possibilitando um embasamento da equipe multiprofissional, familiares e pacientes na tomada de decisão no final da vida.

**Palavras-chave:** Equipe de saúde. Unidade de terapia intensiva. Ortotanásia. Distanásia.

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## ORTOTANASIA Y DISTANASIA: PERCEPCIÓN DE LOS PROFESIONALES DE SALUD DE UNA UNIDAD DE CUIDADOS INTENSIVOS

### RESUMEN

Investigación que implica el proceso de muerte, tratando la distanásia, que constituye en la obstinación terapéutica a fin de aplazar la muerte, y la Ortotanásia, que constituye en la muerte en su proceso natural, sin prolongar el tratamiento. Tuvo como objetivo reconocer la percepción de los profesionales del equipo de salud que actúan en la unidad de cuidados intensivos, acerca de las situaciones de Ortotanásia y Distanásia. Realizado en un hospital universitario. Los datos fueron recolectados a través de entrevistas semiestructuradas con 25 profesionales de salud y sometidos al análisis de contenido temático. Surgieron tres categorías relacionadas: Comprendiendo la Ortotanásia y la Distanásia; Percibiendo el contexto de la toma de decisión; Ponderando la Ortotanásia y la Distanásia en la finitud de la vida. La percepción de los profesionales de salud referente a la Ortotanásia y a la Distanásia exige discusiones sobre los conceptos éticos que comprenden las intervenciones en el proceso de muerte, posibilitando una base del equipo multiprofesional, familiares y pacientes en la toma de decisión en el final de la vida.

**Palabras clave:** Equipo de salud. Unidad de cuidados intensivos. Ortotanásia. Distanásia.

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