

## DYSTHANASIA, EUTHANASIA, ORTHOTANASIA: THE PERCEPTIONS OF NURSES WORKING IN INTENSIVE CARE UNITS AND CARE IMPLICATIONS

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*This study aimed to analyze the perceptions of nurses working in the Intensive Care Unit (ICU) of a University Hospital in Brazil concerning dysthanasia, orthotanasia and euthanasia and characterize potential implications of their perceptions for care. This quantitative study was carried out with the application of a questionnaire to 27 nurses after approval from the institution's Ethics Committee and authorization from participants were obtained. None of the nurses were able to explain euthanasia, half of them explained dysthanasia, and only a third explained orthotanasia, 65.39% recognized some of these processes in their daily practice, 25.9% believed nurses cannot provide any contribution even being familiar with these concepts and their applicability, 82.36% believed that knowledge of bioethical principles is relevant but only 14.81% were able to mention these principles. The bases of nurses' professional practice were not homogeneous and knowledge about the subject was limited. Orthotanasia, bioethical principles and the delivery of humanized care should be the foundation of nursing care.*

**DESCRIPTORS:** bioethical issues; humanization of assistance; intensive care units; euthanasia; communication

## DI STANASIA, EUTANASIA Y ORTOTANASIA: PERCEPCIONES DE LOS ENFERMEROS DE UNIDADES DE TERAPIAS INTENSIVA E IMPLICACIONES EN LA ASISTENCIA

*Los objetivos de este estudio fueron analizar las percepciones de los enfermeros que actúan en la UTI de un hospital universitario, en Brasil, sobre distanasia, ortotanasia y eutanasia y caracterizar las posibles implicaciones en la asistencia. Se trata de una investigación con abordaje cuantitativo, aplicándose un cuestionario en 27 enfermeros, después de la autorización del Comité de Ética de la Institución y de la aceptación formal de los sujetos. Ningún enfermero supo explicar la eutanasia, la mitad ofreció un concepto de distanasia y apenas un tercio la ortotanasia. Del total, 65,39% reconocen alguno de esos procesos en su práctica diaria, 25,9% afirman que no creen que el enfermero pueda contribuir sabiendo esos conceptos y su aplicabilidad, 82,36% relataron ser importante saber los principios bioéticos, sin embargo solamente 14,81% supieron citarlos. El fundamento para actuar profesionalmente, entre los enfermeros, no fue homogéneo y el conocimiento acerca del tema todavía es limitado. La búsqueda por la ortotanasia, los principios bioéticos y la humanización de la asistencia deberían ser fundamentos de su asistencia.*

**DESCRIPTORES:** discusiones bioéticas; humanización de la atención; unidades de terapia intensiva; eutanasia; comunicación

## DI STANÁSIA, EUTANÁSIA E ORTOTANÁSIA: PERCEPÇÕES DOS ENFERMEIROS DE UNIDADES DE TERAPIA INTENSIVA E IMPLICAÇÕES NA ASSISTÊNCIA

*Os objetivos deste estudo foram analisar as percepções dos enfermeiros que atuam em UTI de um hospital universitário, no Brasil, sobre distanásia, ortotanásia e eutanásia e caracterizar as possíveis implicações na assistência. Trata-se de pesquisa com abordagem quantitativa, aplicando-se questionário em 27 enfermeiros, após autorização do Comitê de Ética da Instituição e aceite formal dos sujeitos. Nenhum enfermeiro soube conceituar eutanásia, metade conceituou distanásia e apenas um terço a ortotanásia. Do total, 65,39% reconhecem algum desses processos em sua prática diária, 25,9% afirmam não acreditar que o enfermeiro pode contribuir sabendo desses conceitos e sua aplicabilidade, 82,36% relataram ser importante saber os princípios bioéticos, mas somente 14,81% souberam citá-los. O fundamento do agir profissional dos enfermeiros não foi homogêneo e o conhecimento acerca do tema ainda é limitado. A busca pela ortotanásia, os princípios bioéticos e a humanização da assistência deveriam ser fundamentos de sua assistência.*

**DESCRIPTORES:** temas bioéticos; humanização da assistência; unidades de terapia intensiva; eutanásia; comunicação

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## INTRODUCTION

**D**ysthanasia is the term for futile or useless treatment, which does not benefit a terminal patient. It is a process through which one merely extends the dying process and not life *per se*. Consequently, patients have a prolonged and slow death, frequently accompanied by suffering, pain and anguish. When one invests in healing a patient who has no chance of cure, s/he is actually undermining the person's dignity<sup>(1)</sup>. Advanced measures and their limits should be assessed to benefit the patient and not to hold science as an end in itself<sup>(2)</sup>.

Euthanasia is currently conceptualized as an action that aims to end the life of a human being taking into account humanistic considerations in relation to the person or society<sup>(3)</sup>; it is unethical and illegal in Brazil<sup>(2)</sup>. Nurses should be aware of their ethical code, which clearly prohibits (article 29): "Promoting euthanasia or participating in practice intended to facilitate a patient's death"<sup>(4)</sup>.

Orthotanasia refers to the art of promoting a humane and correct death, not subjecting patients to misthanasia or dysthanasia and not abbreviating death either, that is, subjecting them to euthanasia. Its great challenge is to enable terminal patients to keep their dignity, where there is a commitment to the well being of patients in the final phase of a disease<sup>(3)</sup>.

The fundamentals of professional practice are based on four bioethical principles of the principlist model and corroborate the promotion of well being for people in the dying process: autonomy, justice, beneficence and nonmaleficence, and should guide professionals' practices, reflections and attitudes<sup>(5)</sup>.

Health promotion and bioethics are joined for the defense of life and have the common goal of improving quality of life and respecting human dignity<sup>(6)</sup>. Dying with dignity is a consequence of living with dignity and not only surviving with suffering<sup>(3)</sup>. Life should be lived with dignity and the dying process, which is a constituent part of human life, should occur with dignity. Therefore, we should demand for the right of a respectful death, including reflecting on excessive therapeutic methods<sup>(2)</sup>. From this perspective, nurses are key to the preservation of patients' dignity.

Not discussing these issues results in more suffering for victims of dysthanasia and results in their dignity being injured in the dying process. There will be a contradiction in professionals' behaviors where

there is a great deal of investment in patients with no chance to recover, whereas these resources could be used to save lives with real chances of recovery, which consequently generate questions about the criteria used in ICUs<sup>(7)</sup>.

The participation of nurses in these processes is essential in identifying situations in which bioethical principles and rights of patients are not being considered so as to intervene when necessary, ensuring humanization and the patient's overall security<sup>(5)</sup>. To achieve this goal, it is unquestionable that nurses need to have appropriate knowledge of the concepts of dysthanasia, euthanasia and orthotanasia.

A considerable amount of research is found in Latin America addressing terminal patients. However, there is a scarcity of publications about practices, decision-making processes, involvement of family members and patients, or changes in treatments based on awareness and responsibility demanded by bioethics<sup>(8)</sup>.

All nursing professionals, including those in leadership positions and with postgraduate education are also responsible for searching and adopting respectful, ethical and responsible measures in addition to humanizing the care delivery process in order to provide the highest benefit possible to patients<sup>(5)</sup>.

## OBJECTIVES

To analyze the perceptions of dysthanasia, euthanasia and orthotanasia of nurses working in the ICU of a large university hospital.

To characterize, through the nurses' reports, potential implications for nursing care based on their knowledge about these subjects.

## METHOD

This exploratory, descriptive and quantitative study was carried out through a questionnaire with 27 (100%) nurses who work in nine ICUs of a large university hospital in São Paulo, SP, Brazil after approval of the Research Ethics Committee was obtained.

Nurses were contacted in their units and informed about the study's objectives. Those who

agreed to participate in the study signed a free and informed consent term. Then they received the questionnaire that contained eight semi-open questions regarding their professional background: information related to time since graduation, time working in ICUs and whether they attended graduate programs. Instruments were collected after being fully completed and then analyzed afterwards so that when answers started to repeat, data collection was suspended. Data collection lasted three months.

Answers were grouped by thematic unit and presented according to the frequency they appeared. Discussion was carried out based on the themes that emerged in the reports.

## RESULTS

Twenty-seven nurses were interviewed, 96.3% were female. The average age was 39.37 years, SD of 9.6 years, the youngest was 23 years old and the oldest was 59 years old. The average of time since graduation was 7.9 years and time working in ICUs was 5.2 years, SD of 6.5 and 4.4 years, respectively.

Nurses with specialization amounted to 48.15% of the total. Of these, 46.15% were specialists in intensive therapy and 53.85% in other fields such as hospital administration, nephrology, obstetrics, emergency services, organs and tissues procurement and pre-hospital care.

None of the interviewees explained the concept of euthanasia, confirming the current lack of understanding of this concept, however, 55.55% referred to it as an action that abbreviates life. They did not correlate this fact to humanistic considerations for people or to society, which is the current concept; 22.22% believed it was an action that abbreviates the life of a terminal patient and 22.22% either acknowledged they were unable to describe it or incorrectly described it.

Dysthanasia is understood as the act of artificially extending life with no benefits for the patient in the view of 54.5% nurses and as a slow death with suffering by 9.1% of them; 36.4% either did not answer, acknowledged they were unable to answer or incorrectly answered it.

Orthotanasia was described by 32.1% as death in its natural time, not postponing or abbreviating it; 14.3% death with no suffering or "good

death"; 53.6% did not answer, acknowledged they were unable to answer or incorrectly answered it.

The majority of nurses (65.39%) stated that these processes occur in their daily practice, among these, 82.35% mentioned dysthanasia, 52.94% orthotanasia and 11.76% euthanasia.

Among the subjects who reported the occurrence of dysthanasia, 79% correctly described it. Orthotanasia was correctly described by 67% and 50% described euthanasia as an action that abbreviates life.

We asked if knowledge about these concepts would enable nurses to contribute somehow and appropriately apply them in their daily routine and, if the answer was yes, how they could contribute. The majority (70.4%) answered yes and 25.9% answered no. Among those who believed that knowledge on the subject would enable nurses to contribute, 42.9% said their contribution would be to provide appropriate care, and 23.8% believed they could contribute to scientific knowledge but also understood that the final decision about treatment resides with the physician. Also, 9.5% believed they could contribute through dialog with the entire team, patients and family members, 9.5% reported they could contribute through the reflection of their actions under a legal perspective, 4.8% believed that one "should invest in therapies" whenever there was still life, 4.8% believed nurses can contribute but not in the institution they work for and 4.8% do not know how to contribute.

When asked about what guided them in the face of a situation when dysthanasia was already in effect, answers were diverse: 21.62% believed that the ideal of delivering care with dignity guided their practice; 10.81% that providing support to the family; 10.81% reported they were guided by their beliefs or opinion; 8.11% by communicating with the team; 8.11% through respect; 5.4% through knowledge; 5.4% based their actions on ethics; 2.7% their belief in God; 2.7% common sense; 2.7% rapid solution of situations and 18.92% do not know or did not answer.

Discussion about the bioethical principles and reflections involved are very long, however, the model is still one of the most common and accepted in Brazil, also appropriate in its application to healthcare because it supports maintaining the dignity of patients. In this way, this was the model used in this study.

When asked about the bioethical principlist model, 14.81% of the nurses were able to mention the four principles: autonomy, justice, beneficence

and nonmaleficence. The others (82.36%) incompletely answered it but reported they considered this knowledge important in their daily routine: 35.29% to guide and adapt care, 23.53% to avoid errors, 14.71% to respect patients and 8.83% to follow ethics.

The majority, 88.89% of nurses believed that nurses, family members and patients themselves should participate in decision-making processes. All reports included appropriate communication, especially how to inform patients and family members about their autonomy.

Nurses provided heterogeneous answers when asked what were the fundamentals of their professional practice. The most common themes were humanization in 21.74% of answers and respect in 13.04%. Other themes also emerged: ethics, helping others, science, beliefs and values, favoring autonomy, focusing on healing, law, family, providing quality of life and justice/nonmaleficence.

## DISCUSSION

We understand that it is not easy to fully conceptualize "euthanasia", "dysthanasia" and "orthotanasia", considering the complexity of the subjects. However, in a workplace in which professionals face some of these situations, knowledge about these themes is extremely important.

Euthanasia is currently conceptualized as taking the life of a human being due to humanistic considerations to the person or to the society<sup>(3)</sup>. Nurses' conceptualization of euthanasia does not include all these aspects. One possibility that explains such a finding is the dissemination of this concept in the media. The media is more accessible than scientific mediums of information and the concepts presented by nurses are similar to those presented by the media.

Nurses should be aware of their code of ethics, which clearly prohibits (article 29): "Promoting euthanasia or participating in practice aimed to facilitate a patient's death"<sup>(4)</sup>.

So that there are no negative implications for care delivered by intensive care professionals, whose practice many times straddles the divide between life and death, it is necessary that nurses master this concept so they do not violate this ethical code, and identify when the team is in danger of doing so, not cooperating with them but positively and

respectfully discussing the subject with a view to provide orthotanasia.

As a little more than half of participants conceptualized it, dysthanasia is the artificial extension of life beyond the limit determined by common biological processes, postponing death as long as possible<sup>(3)</sup>. One merely extends the dying process, not life *per se*. It is a term for futile or useless treatment, with no benefit to the terminal patient<sup>(1)</sup>. The concept is complemented by slow and prolonged death, frequently accompanied by suffering and anguish. However, this is only a complement of the concept and not the concept *per se* as 9.1% reported<sup>(1)</sup>.

Nurses should always have this concept in mind, reflect about it in relation to their practice in the face of the several stages through which patients' diseases develop, so that they do not assist any dysthanastic measure, adding suffering to people who are experiencing the dying process.

Health professionals are supported in extending life through advanced measures in some cases, such as in the case of patients in a vegetative state but with an authorization for organ donation or for some other benefit from the perspective of the family or patient. In such cases, the concept of futility does not apply<sup>(9)</sup>.

Only a third of the participants correctly described orthotanasia, that is, a death not characterized by dysthanasia, misthanasia or euthanasia; a death in its natural time. The great challenge is to maintain the dignity of patients in their final stage of life, where there is commitment to the promotion of well being because it allows patients and their families to face death with more tranquility, accepting death as part of life and not as a disease that needs to be healed<sup>(3)</sup>.

The majority of nurses acknowledge dysthanasia in their daily practice. The large number of professionals who acknowledged this practice in their routine corroborate the need of nurses to master these concepts so they are able to recognize these practices and act accordingly, that is, effectively promoting discussions with the team based on bioethics and on their own code of ethics, always aiming to provide appropriate care, taking into account that nursing is the professional category that is in constant contact with the patient and stays the longest with them.

We know that therapeutic possibilities to artificially maintain a life in an ICU are endless. Thus, there is a great chance of appealing to dysthanasia practices, causing suffering and, if there is no appropriate rationale taking into account ethics and humanization, distancing patients from the practice of orthotanasia.

Despite the fact that the majority believed in the importance of this knowledge and its implementation in care, 25.9% of the interviewed nurses reported it was not important to know the concepts of dysthanasia, euthanasia and orthotanasia. However, the knowledge and applicability of these concepts is essential because an aware professional knows that not all technically possible interventions are ethically correct and also knows the difference between helping someone to live and impeding someone's death<sup>(10)</sup>. Knowledge and reflection about these concepts in each moment of a patient's dying process enable nurses to contribute in discussions between the interdisciplinary team, patients and family members, promoting appropriate care.

The nurses' role as well as that of other professionals is to make a link between efficient solidarity and human and scientific competence at the service of fragile patients who are passing away<sup>(1)</sup>.

This study corroborates the need for providing scientific training and training in humane treatment to health professionals in order to accomplish the most beneficial care possible<sup>(5)</sup>, regardless of how the institution works or the degree of autonomy nurses have, since the autonomy of these professionals is proportional to their scientific capacity.

The answers regarding what guides the actions of these professionals when they face dysthanasia were heterogeneous. However, practice should be based on a set of measures aimed to achieve a dignified death, not extended suffering, pain and anguish. On the contrary, patients should be allowed to die with dignity and have care delivery based on ethics<sup>(1,4,11)</sup>, safeguarding individuals' rights, ensuring humanized care and security<sup>(5)</sup>. From this perspective, nurses should promote discussions related to each implemented action, taking into account the singular and particular moment of patients. The discussion should be dynamic and held jointly with other members of the health team, family members and patients so as to critically reflect whether these actions are aligned with bioethical and humanized principles of care and orthotanasia.

Nurses should carefully consider situations experienced in their practice so they do not endorse the implementation of useless therapies. Not critically thinking about these issues leads health professionals to maintain life "at any cost", without discussing or questioning, which contradictorily favors dysthanasia<sup>(7)</sup>.

The current nursing practice, whose precursor is Florence Nightingale, has been guided by ethics since its beginning, which is presented as a link between the knowledge of biology and the humanities<sup>(11)</sup>. Even today, ethical principles defend justice, competence, responsibility and honesty with a view to promote the human being as a whole<sup>(4)</sup>. Nurses should rethink these principles in relation to the practice of dysthanasia so as to guide their actions in every moment.

It is also the nurses' duty to respect and acknowledge the right of clients to make decisions about their own person, treatment and well being, and respect human beings in death and post-death<sup>(4)</sup>. Therefore, nurses need to ensure that patients and family members receive truthful information so they can make applicable, free and conscious decisions and exercise their autonomy<sup>(5)</sup>.

The nurses' role in the face of any situation, and particularly in a situation of dysthanasia, is to ensure care delivery by their teams and other professionals to patients and their family members, regardless of the institutional philosophy or organizational culture. For those who fight for life and are guided by bioethics, it is a certain and fundamental truth that care delivery cannot cease in the face of an incurable case<sup>(1)</sup>.

Bioethics is a sphere in which professionals can discuss and reflect acquired scientific knowledge in relation to the incorporation of new healthcare technology, especially in intensive therapy<sup>(12)</sup>.

Bioethics has been incorporated in the historical-social construction of nursing, which ensures new fundamentals to face daily challenges of linking care/ethics and care/technique, integrating principles and competencies in a context of care and responsibility for respecting human beings, health promotion and relieving suffering<sup>(11)</sup>.

Despite the fact that only 14.81% of the nurses fully mentioned the four bioethical principles, 82.36% believed knowledge of them is important in their daily practice, based on the information, even if incomplete, they have about the theme from an

academic perspective. We observed that even lacking exact knowledge of the principles, they acknowledged their importance because they affirm that these principles are instruments that help them to provide appropriate, ethical and respectful care, avoiding potential errors.

Few were able to mention the four bioethical principles, however, these principles should guide professional practice so as to ensure individuals' rights, avoiding biological, psychological, social or spiritual risks and harm. When nurses are guided by bioethical principles and reflect on them, they provide humanized care originating in actions based on respect for the right to dignified healthcare delivery<sup>(5)</sup>.

Communication permeates all care actions involved in the dying process as well as all dimensions of the human being. The way professionals communicate with patients and family members is remembered forever by those involved (i.e. how it was when a loved one passed away). Reflecting about communication in an environment where effectiveness predominates means to recover the importance of the affective<sup>(13)</sup>.

The majority believed they should participate in decision-making processes, including patients and family members, always referring to appropriate communication, especially using it to promote autonomy.

Nurses should also reflect on their inclusion and active participation in the decision-making process, helping to solve problems involving ethics in an ICU based on orthotanasia, bioethical principles, humanized care, and dignity to the human being in life's final process as well as to help patients and family members<sup>(14)</sup>. For that, scientific training and training in humane treatment is needed<sup>(5)</sup>. Nursing is the professional category that is the closest to and spends the longest time with patients, which enables them to obtain valuable information about patients so as to have a holistic view of these patients and pass information to the team so it can be used in the resolution of ethical dilemmas.

It is known that respecting patients' autonomy and their right to make decisions about their treatment in addition to justice, beneficence and nonmaleficence, which are the fundamental principles of ethical nursing care, are essential to achieve people's integral well being<sup>(3)</sup>, corroborating the concept of orthotanasia.

A very open question was asked to determine what the basis of their professional practice was, aiming to allow participants to freely express themselves and their answers were heterogeneous. Humanization appeared in the majority (21.74%) of answers and ethics in 8.7%, although, none of the nurses considered the search for orthotanasia. Heterogeneous answers show the need to standardize language in the professional practice in regard to euthanasia, dysthanasia and orthotanasia and bioethical principles. Through constant respect for the four bioethical principles permeated by humanization of care, one can achieve orthotanasia offering dignity, security and the best care delivery possible.

Nurses' actions should be based on the search for orthotanasia, which is the art of providing a good, humanized and dignified death to those under their responsibility, so as to integrate ethics with science and technical abilities<sup>(3)</sup>. The four bioethical principles of the principlist model should also guide their actions, which should be characterized by responsibility with a view to ensure patients' rights, offering humanized care and security, avoiding risks and harm to patients<sup>(5)</sup>.

It is a privilege to be in front of a terminal patient and learn his/her history, because each person is magically unique and, when nurses share this final moment, they can ease and facilitate it. Removing the band of the daily routine and having the view that daily and simple acts have important meaning, permits nurses to rejoice and have gratitude for participating in something so simple and humane as death<sup>(15)</sup>.

The simultaneity paradigm is an important reflective tool that can aid care delivery because it helps one to recover the perspective of humanity in intensive care. It considers the person as a whole, as something that is larger than the sum of its parts, and yet that each part is the representation of the whole<sup>(16)</sup>. Attention to each detail expressed by the patient and family members, whether verbal or non-verbal, is essential to have a perspective of the patient as a whole and, thus, individualize care, essential to humanization, bioethics and orthotanasia.

The emphasis of permanent education and undergraduate institutions' attention to support the implementation of bioethical principles in nurses' practice concomitantly with orthotanasia is needed. The nurse should direct the quality of discussions within the interdisciplinary team and also

concerning the patient's direct care, corroborating the findings of a study that evaluated the application of bioethical knowledge in clinical cases after intensive training in the subject, and evidenced that professionals justified their answers with more detail and depth and with better incorporation of theoretical language<sup>(17)</sup>.

## FINAL CONSIDERATIONS

This study showed that nurses have to acquire more knowledge to effectively implement

bioethical principles and the practice of orthotanasia as well as to emphasize that permanent education and undergraduate institutions should pay attention to this subject in order to promote quality in discussions in interdisciplinary teams and direct care.

The study was carried out in a hospital in São Paulo and therefore generalization and incorporation of its findings to all professionals in the category of nursing is not possible. Further research is needed to explore the difficulties related to the heterogeneity of actions and nurses' knowledge including euthanasia, dysthanasia and orthotanasia, bioethical principles and care to terminal patients.

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