

# Orthothanasia in intensive care units: perception of nurses

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## Abstract

This article aims to understand the meaning of the process of dying with dignity in an intensive care unit from the perception of nurses. A qualitative study was performed with 12 nurses of the *lato sensu* nursing specialization course in adult, pediatric and neonatal ICUs of the Pontifical Catholic University of Minas Gerais, Brazil, through the discourse analysis approach proposed by Laurence Bardin. An interview was used as the research instrument. Following discourse analysis, five categories emerged as discussed throughout the article. It was concluded that, in the perception of the nurses, orthothanasia is a practice that respects human dignity through a dignified death. Additionally, it is surrounded by bioethical principles that allow the suspension of curative measures, providing space for palliative care as a mechanism for reducing the suffering and pain of patients in the terminal phase.

**Keywords:** Palliative care. Death. Terminally ill. Nursing. Intensive care units.

## Resumo

### Ortotanásia nas unidades de terapia intensiva: percepção dos enfermeiros

Este artigo tem como objetivo compreender o significado do processo de morrer com dignidade em unidade de terapia intensiva na percepção dos enfermeiros. Trata-se de pesquisa com abordagem qualitativa envolvendo entrevista com 12 enfermeiros do curso de especialização *lato sensu* de enfermagem em UTI adulto, pediátrica e neonatal da Pontifícia Universidade Católica de Minas Gerais, por meio do método de análise do discurso proposto por Laurence Bardin. Após a análise do discurso surgiram cinco categorias, discutidas ao longo do artigo. Conclui-se que, na percepção dos enfermeiros, a ortotanásia é prática que visa respeito à dignidade humana por meio de morte digna, além de estar envolta em princípios bioéticos que permitem suspender medidas curativas, dando espaço para o paliativismo como mecanismo de diminuição do sofrimento e da dor dos pacientes em fase terminal.

**Palavras-chave:** Cuidados paliativos. Morte. Doente terminal. Enfermagem. Unidades de terapia intensiva.

## Resumen

### Ortotanasia en las unidades de cuidados intensivos: percepciones de los enfermos

Este artículo tiene como objetivo comprender el significado del proceso de morir con dignidad en una unidad de cuidados intensivos en la percepción de los enfermeros. Se trata de investigación cualitativa con 12 enfermeros, de la especialización *lato sensu* del curso de enfermería en la UCI de adultos, pediátricos y neonatales, de la Pontifícia Universidad Católica de Minas Gerais, Brasil, a través del análisis del discurso de entrevistas tal como propuesto por Laurence Bardin. Después del análisis del discurso, surgieron cinco categorías discutidas a lo largo del artículo. Llegamos a la conclusión de que, en la percepción de los enfermeros, la ortotanasia es una práctica que busca el respeto de la dignidad humana a través de una muerte digna, además de estar rodeado de los principios bioéticos que proporcionan la suspensión de las medidas curativas, dando espacio para los cuidados paliativos, como mecanismo de reducción del sufrimiento y el dolor de los pacientes con enfermedades terminales.

**Palabras clave:** Cuidados paliativos. Muerte. Enfermo terminal. Enfermería. Unidades de cuidados intensivos.

Aprovação CEP-PUC Minas CAAE 07663912.9.0000.5137

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Declararam não haver conflito de interesse.

Throughout the twentieth century, technical and scientific advances have broadened our understanding of human physiology, and have therefore become determinants for the extension of life. However, such prolongation of life does not always occur with quality, as evidenced by the difficulties in the treatment of terminal patients in domestic environments, which instead favor institutionalized death in intensive care units (ICU)<sup>1,2</sup>. In hospitals, ICUs are spaces that provide technological and human resources aimed at the care of patients in a critical state and those at risk of death, who depend on nursing and medical assistance<sup>3</sup>.

These units of uninterrupted care are based on a shift system, which function through the rotation of a team. This interferes with the creation of a bond between professional and patient, as well as generating significant mechanization of care<sup>2</sup>. Therefore, due to its extensive “technological capacity”, a mistaken perception of the ICU is formed, which stigmatizes the professionals who work there as cold and indifferent to the professional-patient-family relationship, as if care in this area was directed at the machines, not the patients<sup>4</sup>.

Undoubtedly, the machines comprise the care provided in intensive care units, as they guarantee the advanced life support that critically ill patients need, and it is impossible to imagine this structure without the necessary technological resources<sup>5</sup>. However, what defines whether technology dehumanizes care is not the technology itself, but its influence on individuals and the meaning of what is human in each culture<sup>6</sup>. It is necessary to understand that technological resources represent, at various moments, the communication between critical patient and multidisciplinary team, as they identify situations of risk and the evolution of the patient by continuous monitoring of their vital signs<sup>6</sup>.

*Technology itself can be a factor that humanizes, even in the most technologically intense arenas of health care*<sup>7</sup>. A clear example of this is the care offered to critical or terminal patients. In such cases, technologies (venous infusion pump, monitoring of vital functions, etc.), together with the care provided by healthcare professionals, provide comfort and well-being, collaborating to achieve the recovery of health or a dignified and quiet death.<sup>8</sup>

Allowing the patient to die peacefully and with dignity is one of the main concerns of intensive therapy, which raises controversial issues from a bioethical point of view. Among these is the limitation of therapeutic effort (LTE), which is very common in ICUs due to the profile of patients in this area<sup>1</sup>.

This limitation can be understood as a conduct that restricts medical actions due to illness or trauma. In other words, it is the suspension of therapeutic investment in the face of the impossibility of the recovery of the patient and the imminence of death. There are several factors considered to define a patient in an LTE situation, with three points most of interest: the prognosis of the disease, its comorbidities and therapeutic futility.

After LTE is defined as a course of action, cardiorespiratory resuscitation, the administration of vasoactive drugs, dialysis methods and parenteral nutrition, highly invasive procedures which are not justifiable in situations such as these, are among the most commonly suspended or refused therapies<sup>1</sup>. In the current scenario, the multidisciplinary team should organize itself to offer to this type of patient palliative care that will provide relief from suffering and dignity during the process<sup>1,9,10</sup>. It is important to note that, when the patient is considered to be undergoing LTE, the therapeutic limitations are related to the curative function, and not to actions that generate comfort and pain relief, preserving their integrity.

In order for a multidisciplinary team to accept this limitation, its members must understand human finitude as a natural and chronological process of life, as well as understanding the legal issues of this action. However, understanding this concept is not simple, as *death brings the nursing professional face to face with their own finitude, generating internal conflict, and doubts about the effectiveness, goals and relevance of the care provided*<sup>11</sup>. In addition, many physicians insist on continuing curative treatment due to a fear of legal consequences, even though there are clear guidelines on the matter, both from the American Medical Association<sup>12</sup> and the Federal Council of Medicine (Conselho Federal de Medicina)<sup>13</sup>.

As a result of these difficulties in accepting the limitation of curative efforts, *dysthanasia* is practiced<sup>14,15</sup>. Considered therapeutic obstination or therapeutic futility, it is a controversial subject in the field of bioethics, being described in the dictionary of bioethics as a difficult or distressing death,<sup>16</sup> as its practice prolongs the suffering of the terminal patient without entailing any therapeutic benefit<sup>14,17</sup>. Such conduct harms human rights, leads to degrading and disrespectful treatment, negatively impacts biological life, and impairs quality in life and dying<sup>10,15</sup>. Faced with the impossibility of recovery, the persistent adoption of life-prolonging invasive treatments results from the denial of mortality,<sup>18</sup>

which disregards the fact that death is part of life and that treatment must always be dignified and humane<sup>18,19</sup>.

In this context, treatment is often considered disproportionate, especially when it merely prolongs the patient's physical and psychological suffering<sup>20</sup>. Siqueira-Batista<sup>20</sup> questions when to move from curative to palliative care, since the terminal patient always deserves kindness and respect. Palliative care contrasts with the suffering caused by dysthanasia. It consists of care provided by a multidisciplinary team, aimed at improving the quality of life of the patient and his family in the face of life-threatening illnesses, through the prevention and relief of suffering and early identification and treatment of pain and other physical, social, psychological and spiritual symptoms<sup>10,21</sup>.

Palliative care in ICUs is classified into three phases. The first of these concerns care for the relief of the discomfort caused by the disease and intensive care and aims at the patient's full recovery. In this case, death is unlikely. The second emphasizes care to promote physical and psycho-emotional comfort, employing, when necessary, resources that modify the disease, in anticipation of death in days, weeks or months. Finally, in the third phase there is the recognition that all therapeutic and curative proposals have not worked. Death is accepted as a fact and thus palliative care emphasizes the quality of life and comfort of the patient and family<sup>1</sup>.

From the knowledge of these phases, it is fundamental that palliative care based on the notions of respect and human dignity is provided in the intensive care setting. This aims to humanize care, contribute to the true sense of caring and provoke empathy in health professionals<sup>22</sup>. Humanization in intensive care proposes to rescue human characteristics as a constituent part of the hospital process and seeks to value the patient and their family<sup>23</sup>. Humane care emphasizes the patient's holistic view of the multidisciplinary team, as it contemplates all their needs and contributes as much as possible to improve their quality of life.

Humanization in intensive care units should condition the performance of the team. In this context, orthothanasia emerges as a complement to this "humanizing" assistance. By its etymological meaning, orthothanasia derives from the Greek *orthos*, which means "correct," and *thanatos*, meaning "death." In other words, death at the appropriate time with due respect to the limits of life<sup>24-26</sup>. Orthothanasia can also be considered a natural death, favoring the acceptance of the

human circumstance when faced with death, without abbreviating or prolonging suffering, but only providing, as far as possible, quality of life and relief of suffering in general.

This conduct allows the patient to understand human finitude and to die in peace, as it guarantees dignity in the process of death<sup>27</sup>. It also helps all those involved in this process – patient, team, family, friends – to accept death more calmly. This is because, from this perspective, death does not present disease as something to be healed, but the end of the cycle of life. From this point of view, it is emphasized that when caring for an individual in an irreversible or terminal clinical condition, the medical team should avoid unnecessary procedures and futile therapeutic measures.

The team should also put into practice all the palliative care required and respect the will of patients or, in situations where they cannot express their preference, the decisions of family members. Thus, they fulfill the most important ethical principle of medicine - non-maleficence<sup>13</sup>. Therefore, we ask: what is the perception of nurses about the practice of orthothanasia in intensive care units? What do these professionals, who experience this reality on a daily basis, understand about this practice? How do they face this reality?

Faced with such questions, this article aims to understand the meaning of the process of dying with dignity in an intensive care unit from the perception of nurses, considering the profile of the patients in this area and the incidence of situations in which orthothanasia is applied. As orthothanasia is a subject that has only recently been considered by bioethics, it is believed that this study will contribute to a better understanding of the perception of nurses in ICUs and, consequently, to improve the quality of life of patients in the process of death and dying.

## Method

This is an exploratory, descriptive research with a qualitative approach, based on the analysis of discourse proposed by Laurence Bardin<sup>28</sup>. An unstructured interview with a duration of approximately 30 minutes was conducted, contemplating the following guiding questions: What is the meaning of the process of dying with dignity (orthothanasia) in relation to patients hospitalized in the Intensive Care Unit? How do you perceive the prolongation of suffering in the Intensive Care Unit?

Data collection was carried out between August and September 2012 at the Continuing Education Institute of the Pontifical Catholic University of Minas Gerais (Pontifícia Universidade Católica de Minas Gerais - PUC Minas), Praça da Liberdade campus, in Belo Horizonte. Twelve nurses from the *latu sensu* nursing specialization course in Adult, Pediatric and Neonatal Intensive Care participated in the study. The directives established in CNS Resolution 466/2012 on research involving human beings were respected<sup>29</sup>.

Discourse analysis uses methods of describing the content of messages to obtain indicators that allow knowledge about the conditions of the production and reception of these messages to be inferred. That is, it intends to go beyond the meanings of a simple reading of the real. Pre-analysis is performed to organize the research systematically, and then the material is explored and the results selected. Finally, the inference and interpretation of the data concludes the analysis<sup>28</sup>.

An unstructured interview was used as a research instrument. To ensure anonymity, respondents were identified as Nurse 1, Nurse 2, Nurse 3, and so forth. After the transcription of their speech, the tapes on which the interviews were recorded were kept in a secure, confidential location. To meet the inclusion criteria, the research participants were required to have three years of experience in intensive care and be a student or teacher of the PUC Minas specialization course. The nurses who agreed to participate in the study received detailed information on its objectives and subsequently signed an informed consent form.

## Results and discussion

### *The prolonging of suffering in the ICU*

Death is something that fascinates and terrifies humanity. Its most critical aspect is its inaccessibility to the living, and philosophers and religious figures have constantly reflected on the subject in an attempt to understand and explain its purpose. Each culture interprets death differently, perpetuating such interpretations from generation to generation. In western culture, in recent decades the negative connotation of death has been accentuated by a perception of the efficiency of innumerable resources that prolong life. From this perspective, death is increasingly seen as loss, separation, a motive for despair, emptiness, or the abrupt interruption of life – in short, something unnatural.

The advancement of medicine has led to the discovery of cures or treatment for various diseases. Considering only the maximization of efforts to prolong life, these breakthroughs are seen as victories against diseases that were until recently unknown. However, such developments *can lead to an impasse when it comes to seeking healing and saving a life, with the maximum possible commitment, in the context of an impossible mission: to maintain a life in which death is already present*<sup>30</sup>. In this context, it was noted in the discourse that nurses insisted on curative measures and resisted limiting invasive procedures, acknowledging incomprehension and dehumanization at the process of dying of the patient:

*“I see very fragmented care in the ICU, with many invasive procedures. There comes a time when the patient deteriorates in the ICU, and we keep insisting to keep them alive connected to the machines.”* (Nurse 5);

*“I see the prolongation of suffering in the Intensive Care Unit, when the multidisciplinary team works exclusively to keep the patient alive”* (Nurse 6).

The attempt to prolong life at any cost causes increased suffering in patients, as they remain in the ICU with a reasonable prognosis. This practice in the units is evidenced in the discourse of the subjects:

*“I see many interventions that go beyond the limits of each individual. I think it is an abuse of power, I think a lot of dysthanasia is performed in the ICU”* (Nurse 2);

*“Yes, I still see a lot of suffering, a lot of prolongation of pain, the suffering of the patient”* (Nurse 5).

As dysthanasia is an extremely controversial issue, it is important to expand reflection and discussion among health professionals, especially those who work in the ICU. This reflexive process, which can be stimulated in specialization courses for professionals in various areas of health, should contemplate all aspects of bioethics, with the intention of fostering respect for the limits of intervention and prudent and humane conduct, as these practices influence the well-being of the patient, the family and the multidisciplinary team that provides care for them.

In addition to professional training, the existence of a living will must be discussed. Also known as a biological will<sup>31</sup>, the living will is a

document in which a patient expresses their wishes in relation to the treatments that will be administered if they become terminal or unable to express their will<sup>32,33</sup>. It is a little known device among professionals, institutions and family members - in this study, none of the 12 interviewees mentioned it. The purpose of this document is to guarantee a dignified death and patient autonomy, with the exception of euthanasia, which is not legally permitted in Brazil.

In other words: *it is, therefore, a written document (a form which gives more assurance both to the declarant and to those for whom it is intended) which contains the determinations of the patient, made while still lucid and capable, projected into the future – for when they lose their capacity to express their will – and guidance on what treatments and therapies they wish or wish not to undergo*<sup>34</sup>. In Brazil there is no specific legislation for the establishment of the living will, but the practice has been consolidated through people's desire that their wills are also respected in cases of incapacity. In addition, this practice does not violate existing legislation.

According to Ferreira<sup>35</sup>, the right to dignity (art. 1º, III, of the Federal Constitution (FC)), to life (art. 5º, caput, of the FC), to freedom of action (art. 5º, III, of the FC), to physical activity (art. 5º, III, of the FC) and the freedom of belief or religion (art. 5º, VI, of the FC) can be considered legal foundations for the establishing of the living will. In addition, regardless of whether or not it is established by law, the institution of the living will must be recognized in a notary's office and recorded in the patient's medical record. It aims to protect the patient's will in the eyes of physicians, health institutions, family and friends, ensuring that their wishes are fulfilled, provided that they are in accordance with ethical principles and do not violate the current legislation<sup>36</sup>.

### **Orthothanasia: perception in the treatment of patients**

A dignified death is not only a bioethical discussion, but also forms part of the concerns of the health professionals interviewed:

*"I believe that dying with dignity involves several aspects: to prevent iatrogenesis and harm that can affect the image of the person. Nursing professionals should be concerned with the appearance of the individual and the impact it has on the patient and family. Respect the patient's religious beliefs - a prayer, an orison, an energizing thought can bring peace in a difficult time ... provide psychotherapeutic*

*care for the patient and family members; be sensitive enough to understand what the patient and their family are going through, listen in a different way, aim to ensure the comfort of everyone"* (Nurse 1);

*"Providing the best possible care for the patient at that moment implies tranquility, respect and dignity not only for the patient but also for their family and the ICU professionals"* (Nurse 3).

Terminal patients require care as much as any other patient, but with a palliative, non-curative focus. These efforts aim to provide the best quality of life possible for such individuals and their families<sup>37</sup>. As a result, practices that limit therapeutic effort have been necessary in the day-to-day care of the ICU nurses, who describe the importance of prioritizing a wider discussion about the procedures to be taken:

*"I think it's something that is really lacking in hospitals, psychological work with these families, both in terms of receiving the news of, what do they call it ... it's not LTE ... it's DNR, a do not resuscitate patient, and I think for the family to receive this news they need to have very close psychological accompaniment, for them to see that prolonging the patient's suffering is worse for them. Often the patient is edematous, full of invasive drugs, and is suffering a lot, but the family wants this because they want to keep them alive, even if it's for one second, or two, but they want to keep investing, you know, and don't want to let the person rest in peace"* (Nurse 12).

Thus, it can be seen that the nurses defend the existence of the limitation of therapeutic conducts and believe that the mechanical prolongation of life causes enormous suffering for the patient. However, it is important to prepare the family, as the news of a curative impossibility is incredibly difficult to accept, as the proximity of the death of a loved one is a time for psychosocial and affective changes in the family group. The acceptance of the family is essential, because only after understanding orthothanasia, dysthanasia, and palliative care and its effects on their relative will they consent to the cessation of curative measures and the establishment of adequate palliative care.

### **Impacts of the difficulties of a team when facing death and dying process**

Care is perceived as the main objective of nursing in all stages of life, from birth to the process of death and dying. However, the moment of death is

still not easily accepted by most health professionals because of the sense of failure and great resistance to accept the finitude and terminality of life as the last stage of the natural process of being. These limitations and difficulties of health professionals in the face of death and dying are emphasized in the discourse:

*"I have seen patients suffering a great deal in the ICU, and the doctors prolonging their suffering, increasing "the nora," [noradrenaline] not allowing the patient to evolve in the process of death. We are not prepared to face death as a part of life" (Nurse 2);*

*"The medical professionals don't accept death, they do everything they can, everything" (Nurse 5);*

*"[The doctors] think they have to demonstrate that they're doing the maximum possible, worried that the nurses and the multi-professional team are going to think that they are, in quotes, 'killing the patient before their time'" (Nurse 11).*

These reports confirm the perceptions shared by Kübler-Ross<sup>38</sup> throughout his seminars, in which he described how difficult professionals find it to accept death. He describes how of 12 nurses, only one thought that "moribund" (as he describes them) patients needed their care<sup>38</sup>. Technology and the mechanization of health aggravate this conception, as they often emphasize the unpreparedness of professionals when faced with death by increasing their control over the length of life and the circumstances of dying. This power makes the professionals dependent on resources, further distancing them from the terminal patient<sup>39</sup>:

*"Our state-of-the-art technology has increased a lot, but we have forgotten human care (...) We must avoid this highly mechanistic, very technological care, and respect the process of caring for the patient, respect their process of dying too" (Nurse 2);*

*"Everyone should understand that sometimes it's better not to prolong the life of the patient with a multitude of technological apparatuses, but instead let the process take place with comfort and dignity" (Nurse 3);*

*"The limits of invasive interventions, it is all a part of common sense, of humanization, to not let the ICU become totally mechanical and cold" (Nurse 5).*

The interviewee statements reveal the mechanization of ICU care and the need to train the team to deal with the loss of patients, especially in the context of illness without therapeutic possibilities. Only by facing and accepting this situation is it possible to deal with these feelings and offer holistic and humanized care<sup>25,39</sup>. The fragmentation of care, the mechanization of care, and the non-acceptance of the finitude of life make it difficult to learn to cope with death. The stigma of death as a result of an accident or failure in treatment should be the first aspect to be addressed.

Often the natural condition of the pathophysiology of an individual prevails over all healing efforts, and the body no longer responds to treatment. Without trivializing death, the multidisciplinary team needs to be aware that the patient does not die from incompetence, and that even in this borderline situation, requires care that guarantees their dignity as a human being. Therefore, the feeling of impotence should give way to the understanding of death as another phase of life. As it is the last phase it is the last opportunity to grant the patient humanized care.

### **Legal aspects and bioethical principles in borderline situations**

Acceptance of death, the preparation of professionals, family participation and autonomy, and palliative care are indispensable for the success of the application of orthothanasia. However, in addition to concerns with ethics, compliance with legislation is required of every health professional. However, there are still many doubts regarding the subject, a fact evidenced by the declarations of the interviewees:

*"I think the first thing is to respect ethics, both of medicine and from the Ministry of Health and all the categories that function in the ICU, right? I think there is legislation for us to be able to work in intensive care today. So the first thing is: are we complying with legislation? This is a principle of respect for the patient, right? If we are providing proper care, we have no reason to err in any other process" (Nurse 10);*

*"If you come to intensive care unit today and ask about it, a lot of people will say, 'I do not know what ethics says about this, and I'm afraid.' So, I think there will be doubts about what our role is and our position on this. That's why the necessary suggestion would be larger, multidisciplinary discussion groups involving a nurse, a doctor, a physiotherapist, and a*

psychologist to discuss this situation because there are different thoughts about it and they need to be aligned to achieve assertive conduct” (Nurse 10).

Referring to these ethical aspects, the Federal Medical Council, on April 13, 2010, published a new version of the Code of Medical Ethics (Código de Ética Médica), in which article 41 states that *it is forbidden for the doctor to shorten the patient's life, or request this of the patient or their legal representative*<sup>40</sup>. The sole paragraph of the same article states that *in cases of incurable and terminal illness, the physician should offer all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into consideration the will expressed by the patient or, in the event of the impossibility of the same, that of their legal representative*<sup>40</sup>.

The Nursing Code of Ethics (Código de Ética de Enfermagem), meanwhile, makes clear in its fundamental principles that the exercise of the profession must consider respect for life, dignity and human rights in all its dimensions<sup>41</sup>. Associated with the resolutions of the federal councils of medicine and nursing are the fundamental notions of the bioethics of principlism. These are: *Autonomy (the ability to govern oneself)*, *beneficence (obligation for the welfare of others, it being necessary to take into account the wishes, needs and rights of others)*, *justice (fair treatment for any individual) and non-maleficence (no harm should come to the individual)*. *These principles should govern any action that is related to life, that is, from birth to terminality*<sup>42</sup>.

In this way, it can be seen that legislation prohibits euthanasia and encourages orthothanasia. However, the implementation of palliative care in ICUs is challenging, considering all the existing technology, which, in the perception of health professionals, can prolong human life. Allied to this erroneous interpretation is the absence of specific legislation, which causes insecurities in professionals, resulting in resistance and an attachment to dysthanasia<sup>43</sup>. In short, the subject discussed here raises a complex ethical-professional dilemma, filled with emotions that need to be shaped, rethought and discussed in the light of bioethical and legal principles, so that the individuals involved in this process have security and knowledge when carrying out orthothanasia.

### **The family in the process of death and dying and the acceptance of orthothanasia**

The family group is an organized whole. When a component becomes ill, there is disruption to

the unit, so the roles of each individual have to be reorganized. This brings a sense of emptiness to everyone, and soon, attentions turn to the component “removed” from the situation of coexistence. Feelings of insecurity, fear, sadness, anguish, anxiety and stress arise in relation to the condition of the individual and the environment in which they find themselves. This situation demands support from the health team. In the quality of illness and/or death, health professionals are pillars for a family, and are considered as fundamental in this process, as the patient's family members are never truly prepared for such a loss.

Although the family requires such support, it is not always professionals who can provide it, either due to a lack of preparation or by the characteristics of their environment and work dynamics. This situation is reflected in the discourses of the interviewees: *“I think there should be better interaction between the family members and the multidisciplinary team in relation to this (...). They do not participate in this process of dying and there's little interaction between the hospital and the family”* (Nurse 11). Hospital admission, especially in the ICU, usually occurs unexpectedly, resulting in a time of crisis for both the patient and their family. They all need help coping with this moment in the least traumatic way possible.

The family is engulfed by various feelings, mainly due to the fear of surrendering their relative to the care of an unknown health care team, without emotional ties, yet involving a unit that is stigmatized as being a place for critical and terminal patients. Furthermore, the emotional condition of the relatives is, in general, a determinant to accepting the evolution of the clinical picture of the patient, especially when the prognosis is negative. In his pioneering work, Kübler-Ross<sup>38</sup> identified three phases through which family members pass: denial, anger, and finally acceptance. He also affirms the need for support for this family and of listening in all phases, so that the feelings are expressed and mourning facilitated.

In order for the family to accept death as part of life, professionals must act effectively in the terminality phase, seeking to minimize the suffering of the family and the patient. It is up to the health team to clarify doubts, encourage positive attitudes and, above all, be sincere and accessible<sup>39</sup>. One can observe this perception in the discourse of the interviewees: *“It's really lacking in hospitals, psychological work with these families, both in terms of receiving the news of, what do they call it ... it's not LTE ... it's DNR, a do not resuscitate patient, and*

*I think for the family to receive this news they need to have very close psychological accompaniment, for them to see that prolonging the patient's suffering is worse for them" (Nurse 12).*

Dysthanasia invariably occurs due to the non-acceptance of finitude by the family nucleus, which does not understand or accept orthothanasia. Just as the family is critical to the patient's recovery process, it is essential to accept orthothanasia, which can provide comfort during the death process and allow a death with dignity. In many cases, it is the family that has the final say on the treatment to be prescribed for the patient. Therefore, the family group must be prepared and ready to decide in the best interests of the patient. In cases in which the evolution of the disease is irreversible and signs of the imminent end of life can be perceived, it is important that family members understand finitude, create a bond of trust with the team, trust that the best will be done for their loved one and receive psychotherapeutic support and humanized care.

### Final considerations

Elaborating the idea of having loved ones and/or patients in a terminally ill state is a complex and delicate process due to the diverse consensuses and perceptions about death and dying in our society. Family members and professionals have difficulty accepting the finitude of life, extending the lives of patients beyond curative therapeutic possibilities and increasing suffering and sadness due to persistent attempts at healing, which are ultimately in vain. The need to provide dignity to the terminally ill patient, and orthothanasia, arose as processes aimed at death and dying with dignity, in which the cessation of curative measures does not mean the end of care.

On the contrary, it reveals the beginning of a series of care aimed at easing suffering and acting for comfort. Palliative care avoids greater pain and suffering, providing quality of life to the patient as long they desire it, expressed by a living will or the interpretation of the patient's wishes, signed by their legal representative. The discourses selected in the study highlight the importance of nurses in the care process of terminally ill patients and the influence of their attitudes on family members. In addition, there is concern about the extensive use of technological equipment, since this feature may alienate the professional from the patient and make them seem more mechanistic and less human.

Thus, the understanding of death by the team favors the integration of the family into this process, the acceptance of orthothanasia, holistic care and, consequently, dignified death. The statements of the nurses indicate that many feel unprepared to act in such situations because they are not backed by a code of ethics that specifies their professional responsibilities, as well as those of other members of the multidisciplinary team. Some claim that they are unaware of the laws on terminality and others feel insecure about decision-making in relation to the adoption of the practice of orthothanasia.

They also affirm that the team has doubts about the right time to stop curative measures, which reveal the need for professional training in the light of legislation and reflection on the ethical and bioethical principles related to palliative care. Enveloped in all the ethical and legal questions that guide the practice of orthothanasia is the autonomy of the family, their understanding of the process of death and dying, and all the implications of the practical application of this concept. In general, the nurses stressed strongly the importance of family members in the decision to initiate palliative care.

They also emphasized that a disoriented family hinders the process, while a family that is aware of the benefits to the individual becomes a support for the patient and the team. The discourses show that for this to happen, special attention must be paid by the whole multidisciplinary team to the relatives of patients, in order to establish a bond that makes the experience less traumatic for all. Based on the perceptions of the nurses, it can be concluded that factors that influence decision making in complicated moments, such as the exercising of orthothanasia, are: making sure the family and the patient are informed; the coherent posture of the health professionals involved; and the observation of principles, concepts and attitudes guided by bioethics, aiming to safeguard the rights and dignity of the patient.

Caring for terminal patients requires much more than academic knowledge. It is necessary to deepen the bioethical discussion during specialization training and education, as was the case with the professionals involved in the present study. The analysis of the discourses, which reproduce aspects of their daily professional experience, show that it is necessary to understand that each patient is unique and has individual needs and characteristics. In this way, an interpersonal relationship that values the human person can contribute to humanizing the process of death and dying.



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#### Participation of the authors

Júlio César Batista Santana was responsible for planning the research project, submitting it to the Ethics Research Committee and interview analysis. Janaína Maria Machado Carlos and Jenniffer Kelly Assis de Barros collaborated in the planning of the project and data collection. All the authors contributed to the structuring of the article.

Recebido: 26.8.2016

Revisado: 12.11.2016

Aprovado: 23.12.2016