



RESEARCH

The dilemmas of the professionals of the intensive care unit in face of the terminality

Gisly Macêdo de Sousa¹, Marinalva de Araújo Lustosa¹, Valéria Sena Carvalho¹

1. Programa de Residência Multiprofissional Integrada em Terapia Intensiva do Adulto, Departamento de Psicologia, Universidade Estadual do Piauí (Uespi), Teresina/PI, Brasil.

Abstract**The dilemmas of the professionals of the intensive care unit in face of the terminality**

The intensivists are in a context that involves terminality and its bioethical impasses. This article presents the results of a field study, with a quantitative and qualitative approach, carried out with 12 intensivists of a state public hospital. A sociodemographic questionnaire and a semi structured interview, recorded in audio and later transcribed, were used for the research. Content analysis was performed using the Iramuteq software to treat the collected data. The study shows that the professionals understand the end of life and the resulting ethical dilemmas in a superficial way, lacking the basis for the decisions about the best therapy for the patient. It was possible to perceive that the experiences of professionals are permeated by different difficulties and feelings. It is necessary that there be investment in continuing education to work on the themes of bioethics and terminality.

Keywords: Bioethics. Intensive care units. Hospice care.

Resumo**Dilemas de profissionais de unidade de terapia intensiva diante da terminalidade**

O objetivo geral deste artigo é compreender como profissionais intensivistas vivenciam a terminalidade e seus impasses bioéticos. O estudo apresenta resultados de pesquisa de campo quali-quantitativa com 12 intensivistas de um hospital público estadual. Foram utilizados na coleta de dados questionário sociodemográfico e entrevista semiestruturada, gravada em áudio e transcrita posteriormente. Os dados foram processados com auxílio do *software* Iramuteq, que analisa textos estatisticamente. O estudo evidencia como os profissionais compreendem de forma superficial o fim da vida e os dilemas bioéticos decorrentes, faltando base para decisões terapêuticas. Pode-se perceber que a vivência dos profissionais é permeada por dificuldades e sentimentos diversos. Por fim, conclui-se que é necessário investir em educação continuada para trabalhar temas da bioética como a terminalidade.

Palavras-chave: Bioética. Unidades de terapia intensiva. Cuidados paliativos na terminalidade da vida.

Resumen**Dilemas de los profesionales de una unidad de terapia intensiva frente a la terminalidad**

El objetivo general de este artículo es comprender cómo los profesionales intensivistas vivencian la terminalidad y sus impases bioéticos. El estudio presenta resultados de un estudio de campo cuali-cuantitativo con 12 intensivistas de un hospital público estadual. Para la recolección de datos se utilizaron un cuestionario sociodemográfico y una entrevista semiestruturada, grabada en audio y transcripta posteriormente. Los datos fueron procesados con ayuda del *software* Iramuteq, que analiza textos estadísticamente. El estudio evidencia cómo los profesionales comprenden de forma superficial el fin de la vida y los dilemas bioéticos resultantes, careciendo de una base para las decisiones terapéuticas. Se puede percibir que la vivencia de los profesionales está permeada por dificultades y sentimientos diversos. Finalmente, se concluye que es necesario invertir en formación continua para trabajar temas de bioética como la terminalidad.

Palabras clave: Bioética. Unidades de cuidados intensivos. Cuidados paliativos al final de la vida.

Aprovação CEP-Uespi 2.153.848

Declararam não haver conflito de interesse.

Because they deal with situations where there is no possibility of cure, often witnessing the death of patients, intensivists have direct contact with the dying process^{1,2}. It is in the intensive care unit (ICU) that issues related to death and their implications on the relationship between health professionals, patients and family members are most clearly evident^{2,3}. Therapeutic decisions must be constantly made in this environment, requiring professional agility and assertiveness for the ICU to fulfill its purpose: to take care of lives^{2,3}.

Daily, intensivists face situations that require reflection and the return to ethical principles that support their conduct⁴. These are dilemmas that lead to bioethical issues such as dysthanasia, euthanasia, orthothanasia and palliative care, especially in the case of patients for whom there is no longer a possibility of cure^{4,5}. In this context, understanding the terminality and accepting the finitude of life is fundamental for professionals to direct their actions^{1,6}.

Numerous discussions have been raised about the end of life and the terminology used for the subject. This article adopts the terms “patient with a terminal disease” or “terminally ill patient”, used by Siqueira, Pessini and Siqueira³ to refer to people whose underlying disease has no cure, with the end-of-life outcome. Irreversibility is defined by consensus of the health team, which uses objective data (medical records, clinical condition, examinations)^{3,4,6}. After establishing this condition, the main objective of care becomes palliative care³⁻⁶.

This study has the general purpose of understanding how intensivists experience bioethical dilemmas related to the death of patients. Therefore, the following specific objectives were established: to identify the dilemmas faced in terminal patient care, to investigate the values underlying the conduct of these professionals and to define the main difficulties and feelings experienced in face of the problems posed by the situation. The following guiding questions have been established: How do intensivists understand bioethical dilemmas and the end of life? What is the ethical basis for decision making? And how do they deal with these situations in treating terminally ill patients?

Seeking to contribute to the bioethical reflection, the study focuses on one of the issues that most affect health care today, highlighting how professionals, in the technoscientific era, face deadlocks related to terminality through a holistic approach.

Methods

This study presents results of a qualitative and quantitative exploratory field study conducted in the ICU of a medium-sized state public hospital, considered a reference center for tropical medicine in the country. Serving states in the North and Northeast, the hospital has 134 beds, seven for the adult ICU and multidisciplinary team: nurses, physiotherapists, speech therapists, physicians, nutritionists and nursing technicians, with the support of the staff of the *Residência Integrada Multiprofissional em Terapia Intensiva do Adulto – Rimtia* (Adult Intensive Care Multiprofessional Integrated Residence), composed by a nurse, a psychologist and a physiotherapist.

The research was carried out with a total of 12 intensivists: physicians, nurses and physiotherapists (the other categories, complementary or technical, were excluded because they were not present in full shift in the ICU or because they were not directly involved in decision making). Selection for sampling was random and included four professionals from each category. Inclusion criteria were: to be part of the hospital staff; to have at least two years of experience in ICU; to be present at least two shifts per week during the research period; and to agree to answer the questions by signing a free and informed consent form.

The study complied with the Resolution 466/2012 of the Conselho Nacional de Saúde (National Health Council), having been approved by the Ethics and Research Committee of the State University of Piauí and by the direction of the hospital where it was held. For data collection, a sociodemographic questionnaire and a semi-structured interview were used. With an average duration of 20 minutes, the interviewees' answers were audio-recorded and transcribed to facilitate content analysis. The talks took place between July and December 2017, in a private room, to ensure privacy and confidentiality.

The corpus resulting from the transcriptions was interpreted through content analysis, according to the method proposed by Bardin⁷. In the quantitative analysis, the frequency with which characteristics (words) appear in the text was identified; in the qualitative one, the set of these characteristics is considered in a certain fragment of the corpus, allowing its semantic analysis.

Therefore, in the first phase of pre-analysis, the material was organized and the recordings were transcribed; in the second phase, the analytical description was performed, with an in-depth study of

the content through coding and categorization, based on the statistical analysis of the Iramuteq software, version 0.7 alpha 2, developed by Pierre Ratinaud⁸. Finally, the third step included the inferential interpretation of the material, with reflection and significance of what was analyzed.

Results and discussion

The analysis of sociodemographic data allows us to understand the profile of ICU intensivists analyzed. The sample consisted of 12 professionals (n=12) randomly chosen: four physicians, four nurses and four physiotherapists. Among them, 67% are female and 33% are male; 67% are Catholic, 25% are protestant and 8% do not profess belief; 50% are between 25 and 35 years old, and 50% over 36 years old; 17% have less than five years of training, 25% between five and ten years, and 58% over eleven years. The average ICU experience is 11 years (25% between 2 and 5 years; 25% between 6 and 10 years, and 50% more than 11 years); 58% work in one ICU and 42% work in two.

A total of 12,868 occurrences (words, forms, vocabulary in general) were observed in the interviews. The corpus was divided into 351 elementary context

units (ECU), among which 307 (87.46%) were matched by descending hierarchical classifications of text segments (TS) of different sizes, indicating the degree of similarity in the vocabulary of the six resulting classes and the significance of content use. For better statistical understanding, the classes resulting from the analysis are distributed in the dendrogram of Figure 1 and the correspondence factor analysis (CFA) of Figure 2, uniting statistical analysis and description of the categories that will be the basis of the discussions.

The classes were generated from the chi-square test (χ^2); in them, similar evocations (words, forms, expressions) emerge, and the most representative for each class are expressed. An χ^2 greater than 3.80 was taken as the base because it corresponds to $p < 0.05$. The most significant speeches are discriminated according to significance analysis and will be presented in the discussion of each category.

The FCA (Figure 2) allows associating text with words and classes, considering the frequency, represented in a Cartesian plane. Note that words of all classes are presented in a centralized segment that expands to peripheral points, showing a significant distance between 5 (terminality) and 4 (difficulties), and 1 (bioethical dilemmas) and 2 (decisions).

Figure 1. Descending hierarchical classification dendrogram with partitions and corpus content

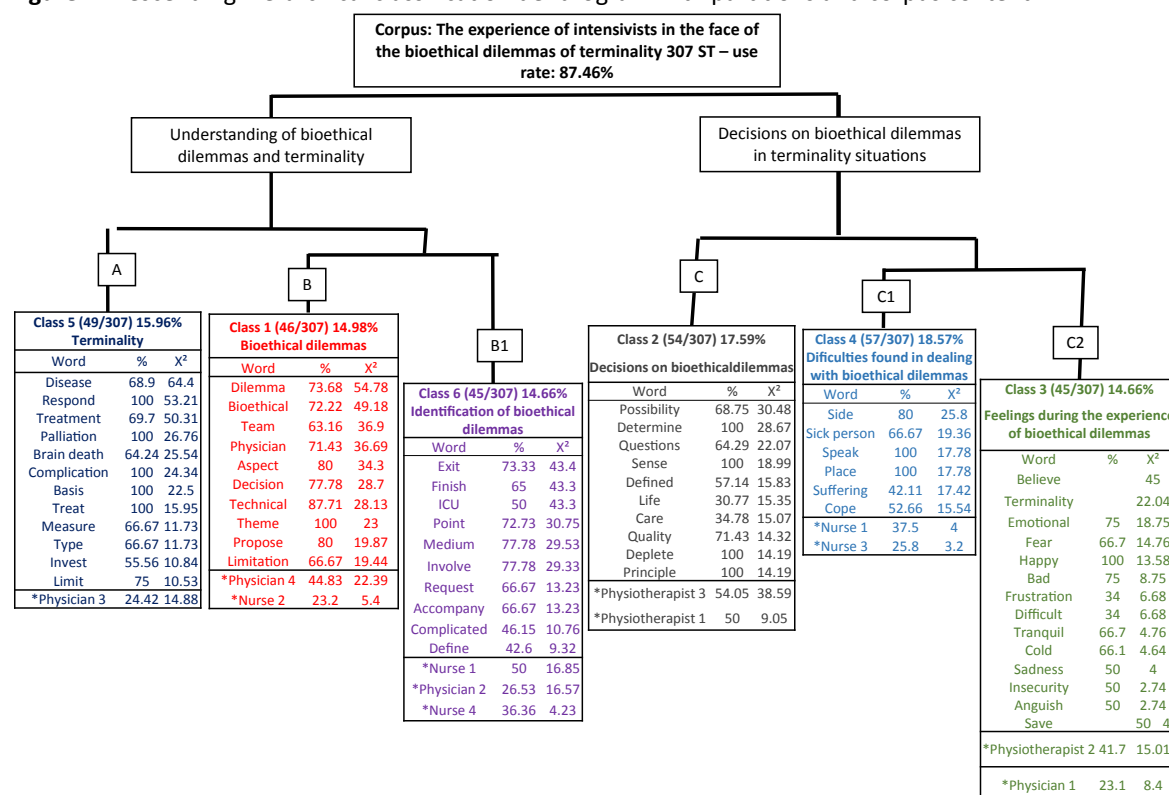
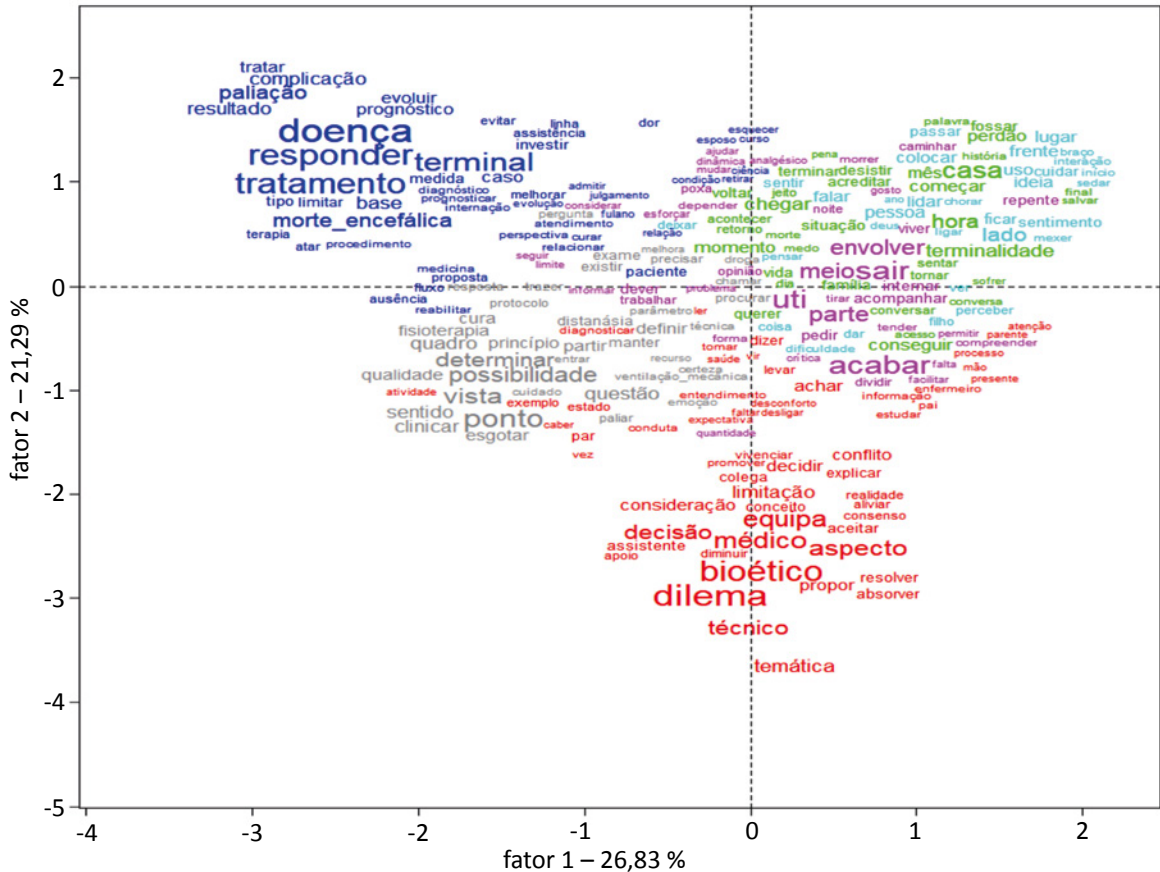


Figure 2. Correspondence analysis



Dark blue: Class 5 (terminality); red: Class 1 (bioethical dilemmas); lilac: Class 6 (identification of bioethical dilemmas); gray: Class 4 (decisions in bioethical dilemmas); light blue: Class 4 (difficulties found in dealing with bioethical dilemmas); green: Class 3 (feelings during the experience of bioethical dilemmas).

The understanding of bioethical dilemmas and terminality

Category B, “bioethical dilemmas” (Class 1), comprises 14.98% of the corpus (f = 46), consisting of words and radicals in the range of $x^2 = 3.9$ (“understanding”) to $x^2 = 54, 78$ (“conflict”). In addition to the two terms that establish the range, the category includes words such as “bioethics” ($x^2 = 49.18$), “team” ($x^2 = 36.9$), “physician” ($x^2 = 36.69$) and “decision” ($x^2 = 28.7$).

The analysis demonstrates that the theme “bioethics” was identified by the participants as difficult, complicated and complex. In general, the interviewees mentioned ethical impasses related to patient care, defining them as questions for which there is no immediate answer, requiring personal principles and values to answer them. Among the principles cited are the respect for human dignity, autonomy, and beneficence and non-maleficence; among the values, religion and personal beliefs.

Issues related to the definition of life and death were also addressed, such as euthanasia, dysthanasia, and palliative care:

“Bioethical dilemmas’ I think are all that takes into account the ethical and personal concepts of situations in the patient’s life” (Physician 4);

“It’s hard to say, but they are dilemmas related to decisions about the patient’s life. It is very difficult to deal with them” (Nurse 2);

“It’s quite difficult, it will pose questions to which you won’t know the answer. It will be hard to answer. You have to use certain principles to direct the way you will act” (Physiotherapist 2).

From the testimonials, it is possible to realize that the physicians interviewed have a more definite understanding of these impasses. The qualitative analysis shows that it is mainly the physiotherapists

and nurses who find the most problems to understand the theme, defining it as complicated and difficult to conceptualize. Also, the results indicate that about 30% of the physiotherapy and nursing professionals interviewed said they did not remember the topic and recognized the need to study it.

These two professional categories also stated that decision making regarding bioethical dilemmas is the responsibility of the physicians. The professionals, therefore, demonstrated a distance from deliberation on life and death-related issues, as pointed out in the following statement: *“decisions in bioethical dilemmas are very complicated. Usually, it is the medical staff who decide this part. They decide. I just do what they say”* (Nurse 3). Thus, the findings of this study corroborate what Machado⁴ points out: although bioethics is interdisciplinary, in practice, there is still little involvement of categories other than physicians in ethical decisions related to terminality, which eventually perpetuates the biomedical model.

Bioethics can be understood as the interdisciplinary study of problems generated by biomedical progress (at the individual, institutional or social level), their repercussions and their value systems^{3,5,9,10}. The field of knowledge aims to prevent technology from becoming an instrument that prolongs suffering and delays the inevitable process of death at any cost, subjecting the patient to agony by artificial methods^{3,6,10}.

When reflecting on life and death, bioethics presents issues present in the daily life of health professionals, discussing topics such as prolonging life, dying with dignity, euthanasia, assisted suicide and palliative care^{3,5,11}. It is also reflected in the maintenance or withdrawal of life support and the judgment of who should prevail to make this decision: staff, patient or family¹¹.

Category A, “terminality” (Class 5), corresponds to 15.96% of the corpus (f=49 ST), comprising the interval between $\chi^2=3.86$ (relate) and $\chi^2=64.4$ (disease). In addition to the latter, the most represented words are: “answer” ($\chi^2=53.21$), “treatment” ($\chi^2=50.31$), “terminal” ($\chi^2=43.21$) and “palliation” ($\chi^2=26.76$).

From these data and the analysis of the reports, it is possible to realize that professionals understand the terminality from the description found in the scientific literature, which relates it to the ill person without prospects for a cure and palliative care, adopted in this context. In this sense, the end of life is inevitable, especially when the

underlying disease does not respond to treatments, the individual is compromised and there is no possibility of recovery/rehabilitation.

Participants report that, in the situation in which the patient’s death is imminent, palliative treatment should be adopted, seeking comfort and relieving pain and suffering, in order to offer quality of life and favor dignified death. The intensivists talk about the possibility of rehabilitating the sick so that he at least lives longer in his home; However, the importance of allowing family members to be in the ICU at the end of life was not mentioned:

“Terminally ill patients are patients who have terminal cancer, [for which] they can no longer do any kind of therapy or a disease that is no longer responding to treatment.” (Physician 3);

“A terminal patient is a patient to whom any form of treatment will not improve the prognosis or cause it to evolve, having a discharge or something like delaying the inevitable outcome, which in this case, is death” (Nurse 4).

This understanding is in accordance with the vision of the Sociedad Española de Cuidados Paliativos (Secpal)¹², which developed a guide with essential elements for terminal patient care based on the following criteria: presence of an advanced, progressive and incurable disease; lack of reasonable possibilities to respond to specific treatment; various intense, multiple and multifactorial problems or symptoms; major emotional impact on the patient, family and therapeutic team, related to the explicit or non-explicit imminence of death, and life prognosis of less than six months. In this context, it is a fundamental premise not to label the potentially curable patient as terminal. The World Health Organization (WHO)¹⁰ also points out that for terminally ill patients, treatment may be limited, but should not be interrupted, as curative and palliative care must go hand in hand and there are a variety of resources and actions to be taken to ensure a dignified death.

Corroborating the principles of palliative care, participants consider that the exhaustion of resources for healing and the acceptance that the person is heading towards the end does not mean that there is nothing else to be done^{5,6,11}. According to Machado⁴, and Monteiro and collaborators⁵, once the terminal condition has been declared, there is a wide range of palliative actions to be offered to both the caregiver and family members, aiming not only at pain relief and

at reducing discomfort. but above all the possibility of facing the end of life in the company of people who offer listening and support.

In the subcategory "identification of bioethical dilemmas about terminality" (Class 6), 45 ST were evaluated, corresponding to 14.66% of the corpus. The class comprises the interval between $x^2=3.01$ (to die) and $x^2=43.4$ (to exit). The most significant words were: "finish" ($x^2=43.34$), "ICU" ($x^2=43.34$), "involve" ($x^2=29.33$), "accompany" ($x^2=13.23$), "complicated" ($x^2=10.76$) and "define" ($x^2=9.32$).

Despite the team's difficulty in naming and defining bioethical dilemmas intrinsic to end-of-life situations, and the non-involvement of some categories in decision making, during the interview participants described some problems faced in their area of work.

Nurses highlighted the following difficulties: revealing the diagnosis of AIDS in patients with coma to family members; trying to heal or offer comfort; investing or not in ostomy and special dressings; provide food-related care and bathe terminally ill patients; and even when to invest in treating these patients. In turn, physiotherapists cited decisions regarding the use of oxygen therapy (noninvasive ventilation or mechanical ventilation), measures related to ventilator weaning and analysis of motor mobilization. These critical issues were analyzed based on the charity principle.

The medical team reported dilemmas arising from the acceptance of palliative therapies by relatives of the patient. Among them, the decision about sedoanalgesia; the choice, in the last minutes of life, between making the patient comfortable but sedated or completely aware, and reflections on whether the care provided is causing great suffering or not. These questions lead to the problem of the absence of protocols for palliative care and ICU terminality.

The context of the ICU brings complex bioethical dilemmas to intensivists, which permeate the areas of medicine, nursing, physiotherapy, and psychology. These points, reported in several studies, include: establishing the most appropriate intervention according to the patient's general health^{13,14}, nutrition/hydration^{13,14}, communication of bad news^{11,15}, family participation in decisions^{16,17}, interaction of professionals with relatives of the patient¹⁸ and court decisions to admit patients¹⁶, cardiopulmonary resuscitation¹⁶, vasoactive drugs¹⁶, mechanical ventilation^{16,17}, dialysis methods^{16,17}, antibiotics^{16,17}, blood transfusion and

blood products^{16,17}, end-of-life dignity¹⁵⁻¹⁷, respect for patient autonomy¹³⁻¹⁷, and disclosure of the diagnosis of AIDS to family members^{16,17}.

Decisions in bioethical dilemmas about terminality

Category C, "decisions on bioethical dilemmas" (Class 2), comprises the analysis of 54 ST, corresponding to 17.59% of the textual segments analyzed. Its range ranges from $x^2=4.12$ ("good") to $x^2=43.1$ ("point"). The words that stand out are: "possibility" ($x^2=30.48$), "determine" ($x^2=28.67$), "questions" ($x^2=22.07$), "defined" ($x^2=15.83$), "Life" ($x^2=15.35$), "care" ($x^2=15.07$), "quality" ($x^2=14.32$), "burnout" ($x^2=14.19$) and "principles" ($x^2=14.19$).

By analyzing the reports in this category, it is possible to identify which decisions are usually taken personally, with the most prominent expression being "my point of view", which indicates that each professional acts according to his conceptions. However, in the face of impasses, there is the influence of humanistic, religious and technoscientific values in the search to exhaust all therapeutic possibilities, respecting bioethical principles and providing quality care. Also, professionals reflect whether the technical decision is beneficial or not, and the subjective bias, the story that each carries, is important in this judgment.

The humanistic foundation of the decisions made by the participants involves values related to life and respect for the decisions of the patient when he gives up on life, as well as the "feeling" and personal perception of each case: *"I use a lot of feeling and also the feelings I perceive in conversation with family members. I try to understand the interaction of the family with the patient, and I also use the technical background, but I try to keep trying to recover the patient when there is something that tells me in particular that it will work"* (Physician 2).

Technoscientific knowledge supports definitions of finitude and whether a patient's disease is treatable or not. For this, all the treatment possibilities and the recovery process are analyzed. However, when the team does not perceive significant clinical evolution, they tend to accept terminality, and palliative care becomes the main conduct. To reach consensus on palliative treatment, knowledge of bioethics is used:

"From a technical point of view, to be as rational as possible, I try to analyze whether I have exhausted all the scientific possibilities that existed for that patient, only to accept that I can no longer rehabilitate him,

and the only thing I can do is make death possible. without respiratory distress, within those conditions” (Physiotherapist 1).

Many practitioners mention personal and religious beliefs as the basis for their decisions. Some actions are justified based on faith, God, religion, and personal values:

“I think that if I minimize mechanical ventilation parameters to facilitate patient terminality, I will go against my moral principles and values. I refuse to decrease breathing rates” (Physiotherapist 3).

Some professionals use defense mechanisms in the face of life or death decisions, such as distancing and attributing responsibility to the medical category. On the other hand, physicians report overload in decision making and say they feel the need to talk about it with other staff members and the patient’s family in order to share responsibilities:

“The therapeutic part is the medical team. Regarding whether or not you still have the possibility to rehabilitate [the patient], this is a medical thing. So it turns out I don’t get involved much. (...) [There are] teams that even talk to each other, but it’s always very complicated” (Nurse 1);

“Defining a patient’s terminality is a big responsibility, so we call the coordination to help, the team and the family.” (Physician 2).

Moreover, according to the FCA, Class 2 (“decisions”) is present in the speeches related to the understanding of bioethical dilemmas. It can be inferred that professionals rely on bioethical principles to define behaviors:

“Bioethical dilemmas are identified if it is the case to define whether that patient is on dysthanasia or not, whether I am doing more harm to that patient, or whether I decide to palliate. Will this situation bring less discomfort or allow them to stay awake with their family?” (Physician 1).

The behavior and attitude of intensivists seem to be based on personal values, and there is no certainty about the limit of their action, when to take palliative actions and with what focus. These doubts were also identified in the studies by Motta and collaborators¹⁸ and Moritz collaborators¹⁶. It is observed that the fear of legal reprimand interferes with the removal of futile measures, even with the

certainty that avoiding dysthanasia is a necessary ethical action¹⁶.

Despite the tendency to make decisions based on personal values and the lack of theoretical basis for defining conduct in bioethical dilemmas, the resolutions taken by practitioners are in line with the Belmont Report’s range of principles and rules, which, according to Durand¹⁹, is the guide that establishes principles (respect for people, beneficence and justice) to address bioethical dilemmas, according to the American tradition already proposed by William Frankena. We highlight the values: life, health, integrity, autonomy, intimacy, private life, body (non-objectification of the body), uniqueness, equality, sociability, solidarity, relationship, and coexistence.

Category D, “difficulties encountered in dealing with dilemmas” (Class 4), represents 57 ST, i.e. 18.57% of the corpus. It is the broadest category and most widespread in others, according to the FCA, relating to feelings and the report of dilemmas. Its frequency ranges from $x^2=4$ (“understand”) to $x^2=25.8$ (“side”). The most significant words are: “side” ($x^2=25.8$), “sick” ($x^2=19.36$), “speak” ($x^2=17.78$), “place” ($x^2=17.78$), “Suffering” ($x^2=17.42$), and “cope” ($x^2=15.54$).

The most frequently cited difficulty by intensivists was dealing with the suffering of the patient and family, as well as talking about death with them, as evidenced by Staniscia and collaborators²⁰. This problem was also noted by Kübler-Ross²¹, who demonstrated as professionals Health professionals suffer when accompanying terminally ill patients, demonstrating the difficulty of talking about the subject and seeking help to deal with their feelings.

There was a consensus among the categories regarding the age of the patients: the younger the harder it is to decide, accept and deal with the lack of cure: *“The younger, the harder to deal with. There was so much life ahead... They will leave a wife, young children. We keep putting ourselves in their place and asking ourselves: who will take care of the children? And we end up suffering with them” (Nurse 3).*

This finding corroborates the study by Vicensi²², who points out that, for each professional, there are more or less painful situations, depending on variables such as age or some patient trait that reminds of someone very close. In the present study, participants revealed that the times when they suffer the most are when they see and feel the suffering of family members in the medical bulletin, in visits and in receiving the news of death:

“The hardest thing for me is to deal with the family; it’s sad to see them crying. The relative is dying... Reporting the death and receiving the family here is very difficult for me” (Nurse 1);

“But the hardest thing is to see the family suffering. When the patient is there, is sedated, without pain, there is not so much concern about their suffering, I know they can die. I do my duty and try to give comfort for them to die with dignity” (Physiotherapist 3).

The medical category reported difficulties in dealing with teams that criticize palliative treatment and demonstrate little theoretical knowledge to understand decisions related to therapeutic limitation²³. Physicians say they are faced with few technological resources for more precise definitions of dysthanasia and brain death, as well as the absence of protocols that help solve bioethical deadlocks in terminally ill patients:

“My biggest difficulty is dealing with the team, who don’t understand the decisions and make unnecessary criticism. It is because some colleagues do not have well-defined concepts of euthanasia, dysthanasia, orthothanasia, and palliative care, to what extent care should be limited. Many do not even know what palliative care is, so they do not use and do not understand that at some point you have to promote more analgesia, you have to give that comfort” (Physician 4).

This study agrees with Machado⁴ when discussing the general knowledge deficiency of intensivists on issues related to terminality. The impact of this deficiency overloads mainly those who work in intensive care units and witness the suffering and death in their daily lives with patients without curative therapeutic possibilities⁵.

Class 3, subcategory “feelings experienced in the face of bioethical dilemmas”, addresses the team’s emotional aspects in dealing with end-of-life dilemmas. Corresponding to 14.66% of the ECU (f = 45 ST), the class covers the range of $\chi^2=2.74$ (“anguish”) to $\chi^2=18.75$ (“emotional”). The most significant words are: “believe” ($\chi^2=45$), “terminality” ($\chi^2=22.04$), “emotional” ($\chi^2=18.75$), “fear” ($\chi^2=14.76$), “happy” ($\chi^2=13.58$), “bad” ($\chi^2=8.75$), “frustration” ($\chi^2=6.68$) and “sadness” ($\chi^2=4$).

When experiencing situations related to terminality, the health team feels fear, anguish, frustration, sadness, and insecurity, or even happiness and tranquility. There are times when professionals

“believe” (a verb that refers to faith and hope), based on their personal beliefs and conceptions of life, death, and suffering, which interfere with emotional aspects linked to the end of human existence. As also evidenced in reports collected by Vicensi²², some show hopes in the ability of humans to recover and cope with their finitude; others experience fear, frustration, and failure:

“When the situation of a patient no longer responds to treatments, and they become terminally ill, we face the frustration of not being able to do everything, of having limits. There is fear, and the question: am I doing everything possible, is it correct, what I am doing?” (Physician 2);

“It’s the feeling of failure, that’s what happens too: ‘Wow, damn it, it didn’t work out’. There are a lot of feelings, the fear of making mistakes, the fear of not meeting expectations because everyone who hospitalizes a family member wants to take them home well” (Physician 1).

The data reinforce the findings of Monteiro and collaborators⁵, Staniscia *et al*²⁰ and Kovács²³, showing that the greatest difficulty for health professionals is in the relationship with the patient’s family, considering that, in most cases, the terminally ill patient in ICU remains sedated.

“Greater anguish when you say, especially to the family, that there is nothing to be done with that patient, that there is no mind-blowing treatment, there is nothing. So it’s painful too. For me, it generates extreme discomfort and drains the energies in a way that no physical activity can” (Physician 2).

Feelings of anguish, frustration, and fear may be due to the academic education in health, which emphasizes the figure of the professional as a hero who must save lives and defeat death at any cost²⁴. However, when death “wins”, it awakens in these professionals the worst feelings, resulting in wear and tear and defense mechanisms, denial, and distancing. Consequently, the suffering of patients and family members also increases²⁴.

On the other hand, when the patient’s wish is respected and dignified death is favored, feelings of happiness can be experienced: *“In patients who are already in this terminal situation, there is already some disinvestment of their own. They are tired of fighting already, after comings and goings to the ICU. They are already giving up on life, and for them, the*

greatest joy is giving up, being happy and giving up, and that's it. Then we feel happy because a natural death was favored" (Physiotherapist 2).

The FCA (Figure 2) points out that classes 4 ("difficulty"), 6 ("identification of dilemmas") and 3 ("feelings") are mixed, revealing that dealing with bioethical dilemmas in terminality brings several difficulties and feelings, as shown by the testimony of one of the interviewees:

"I asked to leave the afternoon [shift], I do not like to see the family suffering, I suffer too... I particularly try not to get too involved and end up not getting involved. As I work in the morning, I don't need to see family members, only when I have to report a death, which is very difficult for me" (Nurse 3).

An experience permeated with difficulties

Continuous contact with terminal patients provides the healthcare team with the opportunity to confront their own process of finitude. This confrontation, due to the lack of preparation to deal with life and death, can cause pain and suffering, as pointed out by Klüber-Ross²¹. Professionals then develop defense mechanisms that distance them from the patient and their families²⁰.

The obstacles to dealing with bioethical issues are mainly related to the lack of updating of intensivists. Among respondents, 58% graduated over 11 years ago. These professionals find it difficult to grasp the concepts of bioethics and terminality, which has repercussions on practical action, such as in situations where updated theoretical background is required to make ethical decisions based on humanitarian values^{5,6}.

The lack of preparedness to deal with these problems that require decision-making is related to gaps in the training of these professionals who, in general, whether in undergraduate or continuing education, are focused on generating technicians who are lifesaving heroes^{4,5,11}. However, intensivists lack knowledge in these situations, as the following statement shows:

"I feel uncomfortable dealing with terminality because I didn't study to deal with death, I studied to try to save lives whenever possible. But we only see one possibility, that of saving" (Physician 4).

The lack of certainty in decisions at these critical moments leads intensivists to use defense mechanisms to move away from direct contact with patients and

family members, in order to avoid reflection on their own finitude^{21,23}. The result is dehumanized care, which treats bodies rather than people²³.

This study indicates the need for continuing education for ICU professionals to have a better understanding of bioethics and terminality. According to Pessini and Drane¹³, faced with impasses, the person must be the foundation of all reflection, considering the otherness, that is, the interpersonal relationship. For this understanding to be inseparable from the daily practice of professionals, it is essential to reflect if what matters is life or quality of life. Faced with issues of postponing inevitable death and maintaining life at all costs, it is clear that it is essential to seek not only the extension of life but the inherent dignity of the human condition.

Final considerations

The present study sought to understand how intensivists experience bioethical dilemmas about terminality. The categories detected in the interviewees' statements were analyzed under two thematic axes and, finally, the problems faced by the professionals were discussed. Understanding bioethical issues is distinct from understanding terminality, decisions, and identifying such dilemmas. However, it was possible to notice that the professional categories have difficulty talking about bioethics-related subjects, revealing a little deep understanding.

Nursing and physiotherapy professionals have even more problems describing and discerning bioethical dilemmas, evidencing their distancing from the responsibility for deliberations in these cases. Although bioethics is interdisciplinary, there is little involvement of these categories, which may be due to deficiencies in vocational training.

Despite the difficulty in discussing and classifying the themes, all categories were able to describe the impasses experienced in the terminality of patients, as previously identified in the literature. It was found that intensivists understand terminality when associating the term to patients with no possibility of a cure, presenting the report of various behaviors that refer to palliative care. However, the impasse is in defining whether there is no prospect of a cure.

In addition to the difficulty in accurately discerning the patient's clinical condition, the team experiences other issues, such as the need to deal with the suffering of the patient and their families. Obstacles related to the technology needed to define how long it is worth investing in curative therapies and the lack of

preparation of the team to deal with different opinions and beliefs about the treatment were also highlighted.

To address these critical points, intensivists rely on humanistic and religious values, based more on personal beliefs than on theoretical principles, which generates emotional instability and insecurity regarding their conduct. Such beliefs and ideas lead professionals to experience different feelings, such as hope, fear, frustration, anguish, insecurity, happiness and sadness. To avoid these feelings, which reflect on withdrawal reactions and little involvement in terminal situations, intensivists mainly avoid contact with the patient's family, which needs humanized reception and treatment.

The problems presented by all categories point to the need for continuing education, related both to the knowledge and use of ethical principles in everyday situations and to the ability of professionals working in the ICU to reflect on these issues and face their own finitude. Therefore, the focus should be on bioethical reflection on death, as this is the best way to act with more efficiency and dignity in the health area. It is important to understand death as a natural, normal phenomenon, part of life and to know the bioethical principles that guide more assertive actions and minimize suffering. This brings the team closer to family members and patients, contributing to what we long for: the humanization of health care.

Referências

1. Pessini L. Vida e morte na UTI: a ética no fio da navalha. *Rev. bioét. (Impr.)* [Internet]. 2016 [acesso 11 maio 2016];24(1):54-63. DOI: 10.1590/1983-80422016241106
2. Araújo LZS, Neves WA Jr. A bioética e a fisioterapia nas unidades de terapia intensiva. *Rev Fisioter Univ São Paulo* [Internet]. 2003 [acesso 3 maio 2016];10(2):52-60. Disponível: <https://bit.ly/2XWMMHf>
3. Siqueira JE, Pessini L, Siqueira CEM. Conflictos morales al final de la vida: aspectos médicos, filosóficos y jurídicos. *Rev Colomb Bioét* [Internet]. 2013 [acesso 10 maio 2016];8(2):116-28. Disponível: <https://bit.ly/2FhD2QA>
4. Machado KDG. O profissional de saúde na unidade de terapia intensiva frente ao paciente fora de possibilidades terapêuticas: um olhar da bioética [dissertação] [Internet]. São Paulo: Centro Universitário São Camilo; 2007 [acesso 10 maio 2016]. Disponível: <https://bit.ly/2XronfC>
5. Monteiro MC, Magalhães AS, Féres-Carneiro T, Machado RN. Terminalidade em UTI: dimensões emocionais e éticas do cuidado do médico intensivista. *Psicol Estud* [Internet]. 2016 [acesso 11 maio 2016];21(1):65-75. Disponível: <https://bit.ly/2Krijiho>
6. Godinho AM, Leite SG, Dadalto L, coordenadores. *Tratado brasileiro sobre o direito fundamental à morte digna*. São Paulo: Almedina; 2017.
7. Bardin L. *Análise de conteúdo*. São Paulo: Edições 70; 2011.
8. Ratinaud, P. Iramuteq: Interface de R pour les analyses multidimensionnelles de textes et de questionnaires [software]. Version 0,7 alpha 2. França: Laboratório Lerass; 2009.
9. Schwartzman UP, Martins VCS, Ferreira LS, Garrafa V. Interdisciplinaridade: referencial indispensável ao processo de ensino-aprendizagem da bioética. *Rev. bioét. (Impr.)* [Internet]. 2017 [acesso 11 maio 2016];25(3):536-43. DOI: 10.1590/1983-80422017253210
10. Connor SR, Bermedo MCS, editores. *Global atlas of palliative care at the end of life*. Londres: WPCA; 2014.
11. Kovács MJ. Bioética nas questões da vida e da morte. *Psicol USP* [Internet]. 2003 [acesso 11 maio 2016];14(2):115-67. Disponível: <https://bit.ly/2ISpFaf>
12. Sociedad Española de Cuidados Paliativos. *Guía de cuidados paliativos* [Internet]. Madrid: Secpal; 2014 [acesso 11 maio 2016]. Disponível: <https://bit.ly/2MYhJd7>
13. Pessini L, Drane J. *Bioética, medicina e tecnologia: desafios éticos na fronteira do conhecimento humano*. São Paulo: Loyola; 2005.
14. Magalhães CBA, Vasconcelos TB, Ferreira SS, Alcântara Neto JM, Sales RP, Vasconcelos RS *et al*. Temas atuais sobre bioética em terapia intensiva: uma revisão narrativa integrativa. *Conexão Ci* [Internet]. 2013 [acesso 11 maio 2016];8(2):73-86. Disponível: <https://bit.ly/2WULgUN>
15. Torres WC. A bioética e a psicologia da saúde: reflexões sobre questões de vida e morte. *Psicol Reflex Crit* [Internet]. 2003 [acesso 11 maio 2016];16(3):475-82. Disponível: <https://bit.ly/2x3yad9>
16. Moritz RD, Machado FO, Heerdt M, Rosso B, Beduschi G. Avaliação das decisões médicas durante o processo do morrer. *Rev Bras Ter Intensiva* [Internet]. 2009 [acesso 11 maio 2016];21(2):141-7. Disponível: <https://bit.ly/2x5CJDK>
17. Gregório Neto J. *Conflitos éticos vivenciados por enfermeiros relativos a pacientes terminais* [dissertação] [Internet]. São Paulo: Universidade de São Paulo; 2010 [acesso 11 maio 2016]. Disponível: <https://bit.ly/2MZySmx>
18. Motta LCS, Oliveira LN, Silva E, Siqueira-Batista R. Tomada de decisão em (bio)ética clínica: abordagens contemporâneas. *Rev. bioét. (Impr.)* [Internet]. 2016 [acesso 11 maio 2016];24(2):304-14. DOI: 10.1590/1983-80422016242131

19. Durand G. Introdução geral à bioética: história, conceitos e instrumentos. 4ª ed. São Paulo: Loyola; 2012.
20. Staniscia ACM, Pereira L, Guimarães CPA, Mekler PL, Rezende F. Dificuldades emocionais vivenciadas pelos médicos intensivistas da unidade de terapia adulto de um hospital geral privado. Rev SBPH [Internet]. 2011 [acesso 11 maio 2016];14(1):41-73. Disponível: <http://bit.ly/21OgBWz>
21. Kübler-Ross E. Sobre a morte e o morrer. 9ª ed. São Paulo: Martins Fontes; 2008.
22. Vicensi CM. Reflexão sobre a morte e o morrer na UTI: a perspectiva do profissional. Rev. bioét. (Impr.) [Internet]. 2016 [acesso 8 jan 2017];24(1):64-72. DOI: 10.1590/1983-80422016241107
23. Kovács MJ. Sofrimento da equipe de saúde no contexto hospitalar: cuidando do cuidador profissional. O Mundo da Saúde [Internet]. 2010 [acesso 11 maio 2016];34(4):420-9. Disponível: <https://bit.ly/2ZtSAIk>
24. Silva, LCSP, Valença CN, Germano RM. Estudo fenomenológico sobre a vivência da morte em uma unidade de terapia intensiva neonatal. Rev Bras Enferm [Internet]. 2010 [acesso 11 maio 2016];63(5):770-4. Disponível: <https://bit.ly/2Y08fyL>


Participation of the authors

Gisly Macêdo de Sousa performed the research and wrote the manuscript. Marinalva de Araújo Lustosa was responsible for the critical review, with Valéria Sena Carvalho, who also supervised the study and approved the final version.


Correspondência

Gisly Macêdo de Sousa – Rua Santa Filomena, 3.020, quadra 30, casa 20, Conjunto Renascença I, Renascença CEP 64082-290. Teresina/PI, Brasil.


Gisly Macêdo de Sousa – Especialista – gislymacedo@gmail.com

 0000-0003-2324-6807

Marinalva de Araújo Lustosa – Especialista – marylustosa@yahoo.com.br

 0000-0002-9112-0678

Valéria Sena Carvalho – Mestre – valeriasena.vip@hotmail.com

 0000-0002-7487-2886



Annex

1. Socio-demographic questionnaire

Age: () Below 25 years old () between 25 and 35 years old () above 35 years old

Gender: M () F () Other () _____

Religion: () Catholic; () Protestant; () Spiritist; () None; () Other _____

Marital Status: () Married; () Widow(er); () Separated; () Single; () Other _____

Professional Training: () Nurse () Physiotherapist () Physician

How many shifts per week are you present in the unit where the survey is applied? _____

How long have you been working in the ICU? _____

How many ICUs do you work in: () Only one () two () more than two ICUs

How long since your graduation () less than 5 years () between 5 and 10 years () more than 10 years

2. Semi structured interview

A) How do you understand the concept of patients beyond curative therapeutic possibilities?

B) What are the bioethical conflicts experienced when you have to decide on the best therapy for the terminally ill?

C) How do you feel when dealing with life-threatening critically ill patients?

D) How do you resolve the bioethical conflicts experienced in the ICU?

E) What are the main difficulties faced in caring for patients with poor prognosis?