

Palliative care and limitation of life support in intensive care

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Abstract

The Limitation of Life Support has been applied in intensive care in cases of irreversible disease and futile treatment. In these situations, palliative care aims at preventing and alleviating suffering. It becomes essential to provide specific and ongoing care to patients and their families, enabling death with dignity. This study involved qualitative research carried out with 37 health professionals working within the multidisciplinary team in a Clinical Surgical Intensive Care Unit of a public hospital located in Curitiba, Paraná, Brazil. Through the thematic analysis of the data, four themes were formed, which made it possible to investigate the knowledge of the team regarding the subject and develop palliative care actions for patients with limitation of life support in intensive care. The professionals recognized the importance of Palliative Care for these patients in the Intensive Care Unit.

Keywords: Palliative care. Intensive care units. Patient care team. Life support care.

Resumo

Cuidados paliativos e limitação de suporte de vida em terapia intensiva

A limitação de suporte de vida tem sido aplicada na terapia intensiva em quadros de doença irreversível e tratamento improdutivo. Nessas situações, cuidados paliativos visam prevenir e aliviar o sofrimento e tornam-se essenciais para propiciar atenção específica e contínua para o paciente e sua família, possibilitando morte digna. Este estudo envolveu pesquisa qualitativa realizada com 37 profissionais da equipe multidisciplinar em unidade de terapia intensiva clínico-cirúrgica de hospital público em Curitiba, Paraná, Brasil. A análise temática dos dados estabeleceu quatro temas, que permitiram investigar o conhecimento da equipe sobre eles e elaborar ações de cuidados paliativos a pacientes com limitação de suporte de vida em terapia intensiva. Os profissionais reconheceram a importância dos cuidados paliativos à população em apreço naquela unidade.

Palavras-chave: Cuidados paliativos. Unidades de terapia intensiva. Equipe de assistência ao paciente. Cuidados para prolongar a vida.

Resumen

Cuidados paliativos y limitación del soporte de vida en cuidados intensivos

La limitación del soporte de vida se ha aplicado en terapia intensiva en cuadros de enfermedad irreversible y ante tratamientos improduticos. En estas situaciones, los cuidados paliativos surgen con el objetivo de prevenir y aliviar el sufrimiento y se tornan esenciales para propiciar una atención específica y continua para el paciente y su familia, posibilitando una muerte digna. Este estudio implicó una investigación cualitativa realizada con 37 profesionales del equipo multidisciplinario de una unidad de cuidados intensivos clínico-quirúrgica de un hospital público situado en Curitiba, Paraná, Brasil. El análisis temático de los datos estableció cuatro temas, que permitieron investigar el conocimiento del equipo sobre estos y elaborar acciones de cuidados paliativos para pacientes con limitación del soporte de vida en cuidados intensivos. Los profesionales reconocieron la importancia de los cuidados paliativos para la población en cuestión en dicha unidad.

Palabras clave: Cuidados paliativos. Unidades de cuidados intensivos. Grupo de atención al paciente. Cuidados para prolongación de la vida.

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Declararam não haver conflito de interesse.

Death is the only certainty in the realm of life. Its representation changes throughout history, and until the middle of the twentieth century it was accepted as a simple and familiar event. In the 1930s, death became related to the technological advancement of health, and, if before it used to happen at home, since then it began to occur in hospitals¹. The causes of death became preventable and the end of life was no longer seen as a natural event, becoming a possible failure of health professionals in choosing treatment and care².

In the hospital context, the implications of death on the relationship between health professionals, patients and family members are even more evident in the intensive care unit (ICU)³. Bioethics matters, such as the application of techniques and procedures for the maintenance of ICU patients' lives – especially those techniques and procedures that bring pain and suffering without promoting healing or quality of life (dysthanasia) – stand out.

Intensive care is characterized by the use of many technological resources and specialized treatments that sometimes surpass the desire and decision of patients and their families. Moreover, due to the complexity and severity of the disease, results can be discouraging, and the death process might be inevitable⁴. In this context, according to Trotta⁵, the provision of care to critically ill patients can have two outcomes: in one of them the patient's clinical status improves, with successful treatment and recovery of health, and in the other, it does not, with the patient being considered out of therapeutic possibilities.

Until very recently, even when the condition evolved with a poor prognosis, treatment was continued until death, including additional therapies for new diagnoses and resuscitation procedures in case of cardiac arrest. Currently, one can proceed with the limitation of life support, respecting the wishes of the patient and family, as presented in the Brazilian Code of Medical Ethics⁶ of 2009 and the Brazilian Code of Ethics of Nursing Professionals⁷.

The limitation of life support involves recognizing the futility of treatment and has been discussed as a way to enable dignified death for patients, with less suffering and according to their conditions. It comprises clinical decisions such as withdrawing or not providing advanced life support and maintaining current measures, without adding treatment for new clinical events until death occurs⁸. There are four reasons for limiting ICU patients' life support: the desire of patients or their relatives to stop treatment; therapy is considered futile for the patient's condition;

the expected quality of life is unacceptable or filled with suffering; and the burden of treatment to reverse clinical status is difficult to bear⁵.

Faced with the process of dying, ICUs are still associated with the pain and suffering of patients and their families. The use of complex technologies, poor communication between professionals, patients and families, the severity of clinical cases and, especially, the proximity to death are factors that accentuate this relationship. Thus, it is necessary to review the way decisions are presented to patients and family members, in order to minimize the fear and doubt regarding the recovery of quality of life and the restoration of health. This requires structural changes that prioritize communication between stakeholders, creating practices to make the dying process less distressing for everyone. In this sense, the strategy of integrating palliative care with intensive care has been renewing this field⁹.

Palliative care is defined by the World Health Organization (WHO) as *an approach that improves the quality of life of patients (...) and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*¹⁰. This is a multidisciplinary therapeutic strategy implemented by various specialties: medical, nursing, psychology, nutrition, physical therapy, speech therapy, social work, occupational therapy, pharmaceutical, as well as spiritual and religious advice¹¹.

Palliative care relates to life care, regardless of its remaining duration. It aims to regain the dignity and will of the terminally ill patient. For this reason, palliative care should be established by a team of competent, skilled, attuned and harmonious health professionals, with the objective of taking holistic care of the person, being attentive and accommodating, allowing a more dignified and comfortable death. It is important to take care of the symptoms and, if a cure is not possible, to avoid invasive treatments and surgeries that do not provide benefit¹.

From this perspective, the complex decisions related to end-of-life care in ICUs lead to the need to define priorities around this critical moment, when it is necessary to analyze the relationship of palliative care when deciding on the limitation of life support. Thus, it is evident that palliative care should be incorporated as a philosophy that underlies all ICU hospitalization¹².

The need to foster a more humane care practice for patients with limitation of life support hospitalized in the ICU of the hospital in question motivated this study. This research aimed to investigate the knowledge of the multidisciplinary team about the relation of palliative care in the limitation of life support and to build multidisciplinary actions regarding the topic of patient care.

Method

This is a qualitative research that aimed to understand the human experience as lived by health professionals¹³. The study was conducted in a clinical-surgical ICU of a public hospital, which provides care exclusively through the Sistema Único de Saúde (SUS) (Brazilian Public Health System), located in the city of Curitiba, Paraná, Brazil, during August and September 2017. This institution serves the following medical fields: maternal and child medicine, infectious disease, surgery for correction of congenital facial defects, and especially accidents in general. The hospital has 222 beds, 30 of them for the adult ICU, of which 20 are for the general ICU and 10 for the clinical-surgical ICU, where the research was conducted. The clinical-surgical ICU team is made up of multidisciplinary specialists.

According to the inclusion criteria, professionals from the multidisciplinary team who participated directly in patient care in the ICU routine for at least two months and who, after being informed, signed the consent form were selected. The study questioned 37 professionals, including nursing technicians, nurses, social workers, psychologists, physiotherapists and doctors.

Considering the ethical requirements of Resolution 466/2012 from the Conselho Nacional de Saúde (CNS) (Brazilian National Health Council)¹⁴, the objectives, methodology and voluntary nature of the research were explained to the participants and the signing of the informed consent form was requested, ensuring anonymity and confidentiality of the data. The project was submitted to and approved by the Research Ethics Committee of the Worker's Hospital.

To establish the sample, the researcher presented the project to all employees of the clinical-surgical ICU during the three shifts, inviting them to participate in the study. Data were collected through a self-applied research

instrument (see Appendix) containing four open questions about the proposed topic, applied individually during the participants' working hours. As a precaution and in order to ensure anonymity and maintain the confidentiality of their information, respondents were identified by the letter "P", used to symbolize the word "participant", associated with randomly assigned numbers – for example, (P1), (P2), (P3) and so on.

All material generated by the research instrument was subjected to thematic analysis, aiming to maintain coherence in the data evaluation process. According to Pope, Ziebland and Mays¹⁵, thematic analysis is a simple methodology commonly used in health research. For Braun and Clarke¹⁶, it is a method to identify, analyze and report themes in data, which organizes and describes in detail the information obtained and offers an accessible and flexible approach to research.

In this study, the six steps described by Braun and Clarke¹⁶ were performed: become familiarized with the data; generate individual codes; search for themes; review themes; define and name themes; and generate reports. Following these steps, the speeches obtained were read and reread, grouped, and their relationships were identified for coding and to generate interconnected themes. After this, all data were evaluated to verify that they had been included correctly, which is characteristic of this type of analysis¹⁵. The themes – which make up a set of expressions with similar characteristics extracted from the participants' experience and expressed in their data – were defined, then later compared and contextualized with the literature data.

Four themes were formed: 1) identifying the limitation of life support; 2) identifying palliative care; 3) applying palliative care to ICU patients with life support limitations; and 4) describing multidisciplinary palliative care actions for ICU patients with life support limitations. To facilitate the analysis process of the last theme, the answers were separated according to each professional category.

Results and discussion

Properly organized in the research analysis parameters, the results are presented below. Details of the participants' professional category, age, gender and duration of ICU experience are presented in Table 1.

Table 1. Characterization of participants according to professional category, duration of work, age and gender (Curitiba, 2018)

Professional category	Number of participants	Duration of ICU experience	Age (range)	Gender
Nursing technicians	18	From 2 months to 17 years	21-53 years	2 men 16 women
Nurses	6	From 2 months to 14 years	29-49 years	6 women
Physicians	5	From 1 to 8 years	30-38 years	2 men 3 women
Physiotherapists	3	From 2 to 7 years	24-31 years	3 women
Psychologists	2	4 years	30-38 years	2 women
Social workers	2	Approximately 10 years	43-51 years	2 women
Nutritionist	1	1 year	25 years	1 woman

Table 1 shows that the research instrument included several professional categories that make up the multidisciplinary team of the clinical-surgical ICU. Professions, ages and duration of experience varied, which enriches the data analysis, allowing diversity of answers for each theme, according to the purpose of this research.

The duration of experience in ICU ranged from two months (one nursing technician and one nurse) to 17 years (one nursing technician). Most respondents were women, with only four male participants (two nursing technicians and two physicians). Participants' ages range from 21 to 53 years, both extremes were from nursing technicians.

Identifying the Limitation of Life Support

Following the concept of limitation of life support – which involves the order to not resuscitate, to withdraw and not offer life support, avoiding futile treatments and prolonging suffering¹⁷ – and analyzing the team's statements, it was found that professionals involved in the study understood the theme, as this practice is part of the ICU routine. Many correlated issues involved with the limitation of life support, such as patients with a poor prognosis and the non-provision or withdrawal of futile treatments:

“Withdrawing or limiting support such as vasoactive drugs, routine examinations (...) in incurable patients, who do not have favorable prognosis” (P17);

“Do not institute measures (medication, procedures, invasive monitoring) that characterize therapeutic futility in a scenario of a known incurable disease that is evolving to terminality, thus avoiding dysthanasia” (P30);

“When the patient has an irreversible clinical status, in which advanced life support becomes futile. In this case, the removal of this support is indicated, or at least not adding further support to the current condition” (P32).

The limitation of life support has been applied as a strategy to minimize pain and suffering when the prognosis of the clinical status becomes irreversible, avoiding futile treatments and enabling death with dignity^{18,19}. These concepts, such as offering a dignified death, avoiding dysthanasia or not prolonging the patient's suffering, are verified in various ways in the participants' statements:

“To limit is to stop offering something that will not bring further change in the patient's prognosis, only prolonging the suffering” (P10);

“Restricting the provision of pharmacological resources, diagnostics, and advanced care support according to the patient's prognosis, that is, when it will not be feasible, maintaining the standard for a death with dignity” (P12);

“Where it favors the patient, a death with dignity and not prolonging the suffering of the patient and family” (P15).

Bioethical conflicts related to death, such as the difference between dysthanasia and orthothanasia, may arise during the decision-making to limit ICU life support. The involvement of the multidisciplinary team, with their specific skills and abilities, and the wishes of patients and their families are essential elements for this decision²⁰. Looking at the participants' statements, it was observed that some highlighted the involvement of the multidisciplinary team and patients' families in this process:

“It is when it is decided among the team involved in patient care and the patient’s family that they will no longer invest in treating the patient” (P21);

“A set of measures for the patient in an intractable or unrecoverable clinical status, it is limited to invasive procedures, broad-spectrum ATBs, non-resuscitation, and the bias is toward quality of life. The family remains participative and informed about the situation” (P23);

“Not offering certain care/parameters/drugs, doses by joint decision: assistant professionals, patient and family, in order not to cause dysthanasia” (P29).

The possibility of new diagnostics and treatments due to technology has allowed previously incurable diseases to be treated and critically ill patients to be maintained for long periods with vital support in the ICU. This technological advancement makes health professionals feel pressured to offer patients every possible resource, regardless of prognosis²¹. However, in some cases death is inevitable, and this approach that only prolongs the process of dying often causes more suffering and pain to patients and their families²².

The limitation of life support has the purpose of avoiding measures that do not result in the recovery of the person’s health, in a way meaning to lead the patient to “a dignified death”. The adoption of this perspective of death causes health professionals to discuss and confront the refusal or suspension of treatments considered futile, valuing the patients’ decision and maintaining their dignity in the final phase of life²³.

The multidisciplinary team sampled demonstrated understanding and being able to identify issues related to the theme. Respondents believe that it should be a joint decision between the professionals involved in care, the patient and his or her family, and should be a measure that does not prolong suffering but enables dignified death for patients with no possibility of improvement.

Identifying palliative care

Palliative care is defined as active and total care for patients whose disease does not respond to curative therapies, prioritizing pain control and psychological, social and spiritual symptoms with the objective of improving the quality of end-of-life²⁴. By analyzing the data obtained, there were repeated considerations related to the definition of palliative care, such as relief from suffering, offering

a dignified death, offering quality of life, pain relief and promoting patient comfort, concluding that the team understood the theme:

“[They are] a set of care in patients without therapeutic probabilities, enabling a dignified death and reduction of suffering patients that are incurable and in advanced stages of certain diseases, preventing relief from suffering and pain for both patient and family” (P17);

“Palliative care, for me, is keeping the patient comfortable, without pain, after everything has been done to provide quality of life” (P27);

“Set of measures aimed at patient comfort in a terminal or incurable phase of a disease” (P33).

Because it is a complex approach that aims to meet the varied demands of patients and their families, palliative care involves planning and execution by a multidisciplinary team. They involve the interpersonal relationship between those involved, being technical interventions secondary to the contact and interaction established between patient, family and team²⁵. It was found that professionals understood that palliative care is an approach that involves a multidisciplinary team, which should attend not only to patients, but also to their families:

“It is the care provided to patients, whose disease is irreversible and will lead to death, and also to their families aiming to promote well-being and dignity in the death process” (P1);

“It is a set of care that promotes the quality of life of patients and their families, providing relief from suffering, pain and other problems of a physical, psychosocial and spiritual nature” (P25);

“Care and comfort measures provided to patients, involving their families and the multidisciplinary team to assist patients when curative therapy is not possible” (P31).

Palliative care appeared in Brazil in the 1980s and was intended for terminally ill cancer patients²⁶. Some answers obtained in this study show that they are still understood as reserved primarily for terminally ill patients:

“These are the care or comfort measures we provide to alleviate the suffering of terminal patients” (P13);

“Care and assistance by a multidisciplinary team aiming at quality of life for patients with terminal illness” (P11).

However, in 2002 and again in 2017, broadening this understanding, palliative care was redefined as *an approach that improves the quality of life of patients (...) facing life-threatening disease-related problems*¹⁰. It was verified that some participants understand them as such, considering that this approach should occur from the beginning of the diagnosis:

“Measures to be taken to ensure comfort and relief from suffering. They should be initiated from the beginning of the diagnosis of an incurable chronic disease, in parallel with specific therapeutic care” (P30);

“These are care aimed at the clinical well-being of patients and should be initiated at any stage of their disease, regardless of whether it is terminal or not” (P32).

Some participants, nursing technicians, considered palliative care as the care itself provided by them in the ICU's daily life, as they are the professionals most involved in the care process. However, this understanding can be questioned, since palliative care is embedded in a humanized care model and should be treated not only as an obligation but be based on respect and compassion²⁷. The following statements demonstrate the participants' position:

“It is by maintaining normal care along with sedation and comfort measures” (P7);

“It is the same care as would be provided to a person who has a 100% chance of leaving the ICU: change of position, bath, dressing change, oral hygiene...” (P19);

“Palliative care is dispensing the prescribed medications, providing comfort, giving the same care as other patients” (P21).

According to Paranhos²¹, in order to die in a dignified manner, patients need quality of life, care centered on themselves and their families, shared decision making, relief from suffering, clear communication, a welcoming environment, a supportive relationship amongst all, and specific knowledge regarding the patients' care. The

discussion and the notion about palliative care improve the care provided by health professionals, revealing care services that are more humane and concerned with patients' and their families' well-being, pain relief and comfort, not being seen as simply following procedures²⁶.

In ICU, death is predictable, as their patients always have life-threatening health conditions. Thus, currently palliative care should be understood as a philosophy to be applied to everyone, concomitantly with pharmacological and technological resources, always considering the well-being of patients and their families²⁶.

It is concluded, through the statements of the interviewed team, that palliative care is understood as a multidisciplinary approach and consists of various interventions to relieve physical, psychosocial and spiritual suffering, ensuring better quality of life for patients and their families, and should be initiated on admission of the patient to the ICU in a humanized care model.

Palliative care to patients with life support limitations

The analysis of the results showed that all participants agreed that providing palliative and intensive care to patients with limitation of life support is beneficial, based mainly on the right of every human being to die without suffering.

Despite the particularities of each patient, they are most often admitted to the ICU when there is still the possibility of reversing the disease. However, the condition may evolve unfavorably, and staff should be prepared to identify when the benefit of intensive care ceases. In these situations, palliative care becomes indispensable and is complex enough to provide specific and continuous care for patients and their families²⁰.

It is important to highlight that, given the irreversibility of the disease and the nearness of death, the statement that “nothing else can be done” should be avoided, as there will always be treatment to control and relieve the patient's symptoms and suffering. For this to happen, the multidisciplinary team must be prepared to adapt intensive care to palliative care²⁰.

The participants' statements confirm the recognition of the benefits of planning and providing palliative care to patients with limitation of life support, aiming at their comfort and well-being, as well as that of their families:

“Yes, because it aims to alleviate suffering and humanize the process of death” (P1);

“Yes, I believe they contribute to a better quality of life, enable an ethical discussion about dysthanasia vs. orthothanasia, bring family members closer to care, and involve the team” (P2);

“Always! Although the patient has an indication of limitation of life support, it does not mean that he or she will not be cared for. This particular patient needs to have their comfort guaranteed and this occurs through palliative care” (P32).

Finally, as confirmed by the participants' statements, the ICU assists patients who need very complex care in a markedly technological environment, but, given the impossibility of improvement, palliative care should serve as an alternative to improve their quality of life, enabling a dignified death without suffering²⁰.

Multidisciplinary palliative care actions in ICU

Palliative care suggests the action of a multidisciplinary team, as it should take care of the individual in the physical, mental, spiritual and social dimensions. This requires the sharing of knowledge and responsibilities, aiming at the well-being and quality of life of patients and their families²⁸. This team must be able to meet these needs in an integral and humane way, articulating and promoting actions that guarantee dignified survival. and control of symptoms, producing adequate and harmonious care²⁵.

The following are the actions of the participants' professional practice combined with their perspective on the provision of palliative care to ICU patients with limitation of life support. The analysis of the statements shows that each professional category recognizes its role to establish more humanized care to patients with limitation of life support, making palliative care viable.

Comprehensive care, suggested by the practice of palliative care, is a way to view the patient from all angles, aiming to develop a proposal for an appropriate approach focused on their needs. Ignoring any of these dimensions leads to approaching the symptoms in a less effective and efficient way, since the assessment of the patient's condition and demands remain incomplete. The multidisciplinary team, with its multiple perspectives, can do this work in a comprehensive way²⁴. Nevertheless, the subject of the action is

always the patient, and their autonomy should be respected.

Responses to the research instrument were analyzed and synthesized according to the participants' professions, pointing out the care made most evident by the interviewees. However, it is noteworthy that these actions must be performed concurrently.

• **Nursing**

The nursing professional is fundamental to implementing palliative care, because their training is based primarily on “taking care”. Nurses and nursing technicians are responsible for meeting the basic needs of patients. In the case of palliative care, they collaborate in the search for a more dignified survival, performing actions that bring comfort to the patient, in addition to basic care²⁸.

In particular, it is the nurse's responsibility to manage patient care and, given their proximity to patients, to mediate the relationship between the multidisciplinary team and patients and their families²⁹. The following are the main approaches indicated by the analysis of the nursing team's responses:

- offer affection, dedication, love and respect so that the patient has a decent rest;
- promote comfort and well-being for patients;
- perform nursing care, such as body hygiene and hydration, oral hygiene, dressing change, alternation of position, cushion placement, bed positioning and massage, maintaining patients' dignity and quality of life;
- medicate as prescribed, avoiding pain;
- ensure proper diet, assisting when necessary, and report complications such as discomfort;
- respect the privacy and wishes of the conscious patient;
- discuss and help with their beliefs so that patients can find peace.
- say words of comfort, make patients feel good;
- maintain good ventilation, provide oxygen therapy, aspirate when necessary;
- welcoming the family, integrating them in the care giving, presenting the interventions performed on the patient, promoting tranquility;
- avoid unpleasant comments, providing a welcoming environment for patients and their families;

- communicate patients' difficulties and requests to other team members (physicians, nutritionists, physiotherapists, priests) whenever necessary.

Nursing professionals play an extremely important role in palliative care, controlling symptoms and pain relief and communicating with family members and patients. They also stand out in their integration and communication with the multidisciplinary team, encompassing biopsychosocial aspects and seeking to improve the quality of life and well-being of patients and their families³⁰.

• **Physiotherapy**

In situations involving palliative care, it is up to the ICU physiotherapist to use methods and resources of their profession to improve patient care, facilitating their adaptation to the progressive loss of functionality or even the onset of death, minimizing symptoms³¹. The main physiotherapeutic approaches found in the analysis in the answers were:

- relieve pain through mobilization, stretching and manual therapy;
- relieve respiratory distress through aspiration and bronchial hygiene;
- assist in maintaining good patient ventilation by adjusting oxygen use or noninvasive ventilation if necessary, and mechanical ventilation parameters when in use.

It is concluded that physiotherapists, using appropriate resources, techniques and exercises, together with the multidisciplinary team, provide patients with relief from suffering, pain and other stressful symptoms. They also provide support so that patients can stay as active as possible, with dignity and comfort, and assist family members in patient care³².

• **Medicine**

Medical professionals should work with the multidisciplinary team and ensure that the care reaches all biopsychosocial and spiritual aspects of patients and their families. Proper communication is extremely important, and physicians should ensure that the entire team works in the same direction. It is also up to these professionals to inform patients and their families about the clinical status²⁸. The following are the main approaches found in the analysis of the medical team's statements:

- actively participate in the process of deciding on the limitation of life support;
- coordinate and discuss with the multidisciplinary team regarding the patient's terminal condition and the clinical measures for comfort;
- welcome and guide the patient (when possible) and family members throughout the hospitalization process, allowing extended visits and religious support;
- provide relief of symptoms (dyspnea, pain, nausea, emesis, constipation, mental confusion, etc.) due to the pathological condition;
- offer comfort;
- adequate analgesics to avoid pain;
- meet the basic and hygiene needs of patients, involving their families in the care process and the multidisciplinary team to minimize the suffering of the infirm;
- reassess and readjust treatment according to patient responses.

It is up to medical professionals to act as a facilitating element for the entire team to work and help patients to exercise their autonomy; so that the choices and decisions are shared between patient, family and the multidisciplinary team²⁸.

• **Nutrição**

Proper nutritional intervention promotes well-being, symptom control, and improved quality of life for patients and their families³³. Biological, emotional, social, and cultural aspects of patients should be associated with diet, and nutritionists are the main agents in this process. Following are the nutrition practices identified in the responses to the survey instrument:

- assist the patient in the management of nutritional support, improving quality of life, adapting the diet to individual specific needs;
- comfort the family, when necessary, regarding nutrition concerns;
- assist in reducing gastrointestinal symptoms by adapting the diet, changing nutrients, adjusting the oral portions or modifying the volume and infusion rate of enteral nutrition.

Nutrition in palliative care should offer pleasure and emotional comfort, helping to reduce anxiety and to increase patient self-esteem and independence. It should allow greater integrity and better communication with family members, always

aiming at patients' quality of life and well-being while respecting their autonomy³⁴.

• **Psychology**

The psychologist seeks to alleviate the suffering, anxiety and depression of patients and their relatives in the face of death, helping them to talk about the problem and to cope with it²⁸. Their involvement is important both in the prevention and during the various stages of treatment. The following are some of the psychology service activities found in the results:

- provide emotional support to patients and their families, strengthening resources to cope with the situation in which they find themselves;
- help patients and their families cope with the process of anticipatory grief;
- assist the communication process between the multidisciplinary team and the family, promoting meetings between the parties and ensuring the understanding of the clinical status;
- help prepare the family to care for patients that are debilitated or will have after-effects.

The psychologists' job in palliative care consists of softening the various feelings such as stress, depression, suffering, by providing emotional support to patients and their families so that they can understand the disease process in its different phases²⁸.

• **Social work**

Social work has two important roles in palliative care. The first is to inform the team about the patient's life history so that the best treatment choice can be planned. The second is the link that they must establish between patient, family and staff, strengthening relationships and providing the necessary resources for patients to have a dignified death with the support of their families²⁸. Following are some of the social service activities raised in the analysis:

- contact the family whenever necessary;
- offer support to family members in coping with the approaching death of their loved one;
- guide the family regarding legal procedures after death.

The role of the social worker in palliative care boils down to knowing the life history of patients and their families, providing information and guidance to them and the team³².

Final considerations

It can be concluded that the study represents a small sample of the great complexity existing between two conceptions still under construction in the Brazilian scenario, which can take advantage of bioethics, as a field of knowledge, to improve decision-making. On the one hand there is the concept of intensive care, clothed in technology and the constant search for life recovery, on the other hand there is palliative care, aimed at maintaining the quality of life. However, this study, considering patients in intensive care with limitation of life support and from the perspective of palliative care, required participants to analyze their professional activities carefully, intensifying their critical sense regarding tasks and routines normally performed.

Thus, this study made it possible to bring together researchers and members of the ICU multidisciplinary team. Health professionals recognized the need to establish criteria for the care of ICU patients with limitation of life support and the importance of palliative care, making it possible to apply them through systematic actions of the multidisciplinary team.

The objectives of this study were achieved by identifying that the multidisciplinary team knew the themes "limitation of life support" and "palliative care", allowing actions to be developed in a systematic way. As a limitation of this study, it can be pointed out that there is difficulty in discussing and theoretically improving the relationship between the themes in question. It is necessary to correlate other topics, such as death and the dying process, bioethical concepts and dilemmas related to dying and end-of-life situations in intensive care units, in order to support the discussion.

The results also characterize the timid position of professionals regarding providing a dignified and painless death to patients who die in ICU from terminal diseases. This finding requires academics to plan new studies and institutions to provide opportunities for analysis and reflection regarding the work process of professionals, with a closer look at the palliative care of patients with limitation of life support.

It is suggested that future studies using different methods be performed to relate the themes, with the purpose of proposing assistance aimed at care focused on the quality of life of ICU patients in its various dimensions.

Referências

1. Kovács MJ. A caminho da morte com dignidade no século XXI. *Rev. bioét. (Impr.)* [Internet]. 2014 [acesso 15 set 2017];22(1):94-104. DOI: 10.1590/S1983-80422014000100011
2. Silva RS, Pereira Á, Mussi FC. Conforto para uma boa morte: perspectiva de uma equipe de enfermagem intensivista. *Esc Anna Nery* [Internet]. 2015 [acesso 15 set 2017];19(1):40-6. Disponível: <https://bit.ly/2Inamrg>
3. Vicensi MC. Reflexão sobre a morte e o morrer na UTI: a perspectiva do profissional. *Rev. bioét. (Impr.)* [Internet]. 2016 [acesso 15 set 2017];24(1):64-72. Disponível: <https://bit.ly/2FiMdjH>
4. Chaves AAB, Massarollo MCKB. Percepção de enfermeiros sobre dilemas éticos relacionados a pacientes terminais em unidades de terapia intensiva. *Rev Esc Enferm USP* [Internet]. 2009 [acesso 15 set 2017];43(1):30-6. Disponível: <https://bit.ly/31Q4Kxs>
5. Trotta EA. Expressão de coerção em enfermeiros, médicos e técnicos de enfermagem que assistem pacientes pediátricos em situação de limitação de suporte de vida [tese] [Internet]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2012 [acesso 15 set 2017]. Disponível: <https://bit.ly/2IPnUL2>
6. Conselho Federal de Medicina. Código de ética médica: Resolução CFM nº 1.931/09 [Internet]. Brasília: CFM; 2010 [acesso 15 set 2017]. Disponível: <https://bit.ly/2gyRqtD>
7. Conselho Federal de Enfermagem. Resolução Cofen nº 564, de 6 de novembro de 2017. Aprova o novo Código de Ética dos Profissionais de Enfermagem. *Diário Oficial da União* [Internet]. Brasília, nº 233, p. 157, 6 dez 2017 [acesso 15 set 2017]. Seção 1. Disponível: <https://bit.ly/2GBXolq>
8. Lago PM, Piva J, Garcia PC, Troster E, Bousso A, Sarno MO *et al.* End-of-life practices in seven Brazilian pediatric intensive care units. *Pediatr Crit Care Med* [Internet]. 2008 [acesso 15 set 2017];9(1):26-31. Disponível: <https://bit.ly/2L0vrt1>
9. Costa TF, Morais JMD, Oliveira AMM, Rodrigues FA, Montenegro SMSL, Holanda AR. Terminalidade e cuidados paliativos em UTI: discurso dos técnicos de enfermagem. *Rev Enferm UFPE* [Internet]. 2014 [acesso 15 set 2017];8(5):1157-63. Disponível: <https://bit.ly/2KnpNBV>
10. Cuidados paliativos. *Organización Mundial de la Salud* [Internet]. Notas descriptivas; 2018 [acesso 23 jan 2018]. Disponível: <https://bit.ly/2LJnLND>
11. Costa Filho RC, Costa JLF, Gutierrez FLBR, Mesquita AF. Como implementar cuidados paliativos de qualidade na unidade de terapia intensiva. *Rev Bras Ter Intensiva* [Internet]. 2008 [acesso 23 jan 2018];20(1):88-92. Disponível: <https://bit.ly/2lnbBq9>
12. Guliní JEHMB, Nascimento ERP, Moritz RD, Rosa LM, Silveira NR, Vargas MAO. A equipe da unidade de terapia intensiva frente ao cuidado paliativo: discurso do sujeito coletivo. *Rev Esc Enferm USP* [Internet]. 2017 [acesso 15 maio 2018];51:e03221. DOI: 10.1590/s1980-220x2016041703221
13. Dyniewicz AM. Metodologia da pesquisa em saúde para iniciantes. 2ª ed. São Caetano do Sul: Difusão; 2009.
14. Conselho Nacional de Saúde. Resolução CNS nº 466, de 12 de dezembro de 2012. Aprova diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial da União* [Internet]. Brasília, 13 jun 2013 [acesso 15 jul 2018]. Disponível: <https://bit.ly/20ZpTyq>
15. Pope C, Ziebland S, Mays N. Analisando dados qualitativos. In: Pope C, Mays N. *Pesquisa qualitativa na atenção à saúde*. 3ª ed. Porto Alegre: Artmed; 2009. p. 77-96.
16. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* [Internet]. 2006 [acesso 15 jul 2018];3(2):77-101. DOI: 10.1191/1478088706qp063oa
17. Piva JP, Carvalho PRA. Considerações éticas nos cuidados médicos do paciente terminal. *Bioética* [Internet]. 1993 [acesso 15 set 2017];1(2):139-44. Disponível: <https://bit.ly/2MUIGye>
18. Paiva FCL, Almeida JJ Jr, Damásio AC. Ética em cuidados paliativos: concepções sobre o fim da vida. *Rev. bioét. (Impr.)* [Internet]. 2014 [acesso 15 jul 2018];22(3):550-60. Disponível: <https://bit.ly/2WNU7vR>
19. Mazutti SRG, Nascimento AF, Fumis RRL. Limitação de suporte avançado de vida em pacientes admitidos em unidade de terapia intensiva com cuidados paliativos integrados. *Rev Bras Ter Intensiva* [Internet]. 2016 [acesso 15 jul 2018];28(3):294-300. DOI: 10.5935/0103-507X.20160042
20. Moritz RD. *Cuidados paliativos nas unidades de terapia intensiva*. São Paulo: Atheneu; 2012.
21. Paranhos GK. Argumentação dos intensivistas pediátricos da cidade do Rio de Janeiro sobre limitação de suporte de vida: uma análise bioética [dissertação] [Internet]. Rio de Janeiro: Fundação Oswaldo Cruz; 2011 [acesso 15 jul 2018]. Disponível: <https://bit.ly/2x13adZ>
22. Bitencourt AGV, Dantas MP, Neves FBRC, Almeida AM, Melo RMV, Albuquerque LC *et al.* Condutas de limitação terapêutica em pacientes internados em unidade de terapia intensiva. *Rev Bras Ter Intensiva* [Internet]. 2007 [acesso 15 jul 2018];19(2):137-43. Disponível: <https://bit.ly/2InkmRk>
23. Lago PM, Piva J, Kipper D, Garcia PC, Pretto C, Giongo M *et al.* Limitação de suporte de vida em três unidades de terapia intensiva pediátrica do sul do Brasil. *J Pediatr* [Internet]. 2005 [acesso 15 jul 2018];81(2):111-7. DOI: 10.1590/S0021-75572005000300005
24. Academia Nacional de Cuidados Paliativos. *Manual de cuidados paliativos*. Rio de Janeiro: Diagraphic; 2009.

25. Cardoso DH, Muniz RM, Schwartz E, Arrieira ICO. Cuidados paliativos na assistência hospitalar: a vivência de uma equipe multiprofissional. *Texto Contexto Enferm* [Internet]. 2013 [acesso 15 jul 2018];22(4):1134-41. DOI: 10.1590/S0104-07072013000400032
26. Falco HT, Nascimento D, Rodrigues TG, Soares MR, Rosa MLS, Dias J *et al.* Cuidados paliativos na unidade de terapia intensiva: uma discussão. *Enferm Rev* [Internet]. 2012 [acesso 15 jul 2018];15(2):191-201. Disponível: <https://bit.ly/2WOijhO>
27. Santana JCB, Caldeira CLG, Martins FPL, Andrade JD, Silva CCD. Vivências do cuidar de pacientes na terminalidade da vida: percepção de um grupo de acadêmicos de enfermagem. *Enferm Rev* [Internet] 2015 [acesso 15 jul 2018];18(2):29-41. Disponível: <https://bit.ly/2WTUgJO>
28. Hermes HR, Lamarca ICA. Cuidados paliativos: uma abordagem a partir das categorias profissionais de saúde. *Ciênc Saúde Coletiva* [Internet]. 2013 [acesso 15 jul 2018];18(9):2577-88. Disponível: <https://bit.ly/1SXbJat>
29. Nilson C. Cuidado paliativo na UTI: o papel da enfermagem na equipe multidisciplinar. In: Moritz RD. Op. cit. p. 103-6.
30. Luiz MM, Mourão Netto JJ, Vasconcelos AKB, Brito MCC. Cuidados paliativos em enfermagem ao idoso em UTI: uma revisão integrativa. *Rev Pesqui Cuid Fundam* [Internet]. 2018 [acesso 20 maio 2018];10(2):585-92. Disponível: <https://bit.ly/2WTFXZ6>
31. Gulini JEHMB. Cuidado paliativo na UTI: abordagem da fisioterapia. In: Moritz RD. Op. cit. p. 95-101.
32. Andrade BA, Sera CTN, Yasukawa SA. Papel do fisioterapeuta na equipe de cuidados paliativos. In: Academia Nacional de Cuidados Paliativos. Op. cit. p. 230-3.
33. Morais SR, Bezerra AN, Carvalho NS, Viana ACC. Nutrição, qualidade de vida e cuidados paliativos: uma revisão integrativa. *Rev Dor* [Internet]. 2016 [acesso 20 maio 2018];17(2):136-40. Disponível: <https://bit.ly/2lqQdD>
34. Nascimento AG. Papel da nutricionista na equipe de cuidados paliativos. In: Academia Nacional de Cuidados Paliativos. Op. cit. p. 227-9.

Participation of the authors

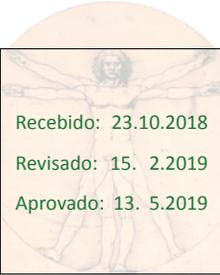
Martha Maria de Oliveira Pegoraro collected data and wrote the text. Maria Cristina Paganini supervised the work and revised the manuscript. Both authors conceived the study.

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Appendix

Research questionnaire “ICU palliative care: possibilities of care for patients with limitations of life support”

Name: _____ Age: _____

Profession: _____ Duration of experience in the ICU: _____

1. What do you understand as limitation of life support?

2. What do you understand as palliative care?

3. Do you think that palliative care in ICU can assist in the care for patients with limitation of life support? Why?

4. Regarding your professional practice, how can your work assist in the care of patients with limitation of life support?
Give examples.
