# **Original Article**=

# End-of-life comfort in intensive care: the perception of the multidisciplinary team

Conforto no final de vida na terapia intensiva: percepção da equipe multiprofissional Bienestar al final de la vida en unidad de cuidados intensivos: percepción del equipo multiprofesional

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#### **Descritores**

Cuidados paliativos; Conforto do paciente; Unidades de terapia intensiva; Equipe de assistência ao paciente; Teoria de enfermagem

#### **Descriptores**

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# **Abstract**

Objective: To analyze the perception of the multidisciplinary team about end-of-life comfort in intensive care.

**Methods**: This is a qualitative, descriptive and exploratory study conducted with 50 professionals of the health team of an Intensive Care Unit of a private hospital in the state of Bahia. A sociodemographic questionnaire and semi-structured interviews were used to collect data, which were analyzed using thematic content analysis technique and discussed in the light of the Peaceful End-of-Life Theory.

Results: Professionals revealed that the health care of patients in palliative care in the Intensive Care Unit is directed to the need to promote comfort. Thus, three categories emerged: 1. Relieving pain to promote comfort; 2. Providing comfort to achieve peace, dignity and respect; 3. Approaching loved ones and faith as a comfort strategy.

Conclusion: Comfort was the concept of the Peaceful End-of-life Theory that stood out in the perception of the multidisciplinary team. It was promoted by all categories in its care practice to palliative patients, motivated by the identification of the basic needs of these patients. Comfort related to physical well-being was the most present in the speeches, signaling the need for multidisciplinary training for holistic comfort assistance. The theory used has been recognized as an important tool to support interventions that help in the search for a peaceful end-of-life.

#### Resumo

Objetivo: Analisar a percepção da equipe multiprofissional sobre o conforto no final de vida na terapia intensiva.

**Métodos:** Estudo qualitativo, de caráter descritivo e exploratório, realizado com 50 profissionais da equipe de saúde de uma Unidade de Terapia Intensiva de um hospital privado da Bahia. Utilizou-se um questionário sociodemográfico e a entrevista semiestruturada para coleta de dados, que foram analisados pela técnica de análise de conteúdo temática e discutidos à luz da Teoria do Fim de Vida Pacífico.

Resultados: Os profissionais revelaram que a assistência à saúde de pacientes em cuidados paliativos na Unidade de Terapia Intensiva é direcionada a necessidade da promoção do conforto. Assim, emergiram três categorias: 1. Aliviando a dor para promover conforto; 2 Proporcionando conforto para alcançar paz, dignidade e respeito; 3 A aproximação com entes queridos e fé como estratégia de conforto.

Conclusão: O conforto foi o conceito da Teoria do Final de Vida Pacífico que se destacou na percepção da equipe multiprofissional, sendo promovido por todas as categorias na sua prática assistencial a pacientes em paliação, motivado pela identificação das necessidades básicas desses pacientes. O conforto relacionado ao bem-estar físico foi o mais presente nos discursos, sinalizando a necessidade de capacitação multiprofissional

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para uma assistência do conforto de forma holística. A teoria utilizada foi reconhecida como uma importante ferramenta para subsidiar intervenções que auxiliem na busca por um final de vida pacífico.

#### Resumen

Objetivo: Analizar la percepción del equipo multiprofesional sobre el bienestar al final de la vida en unidad de cuidados intensivos

Métodos: Estudio cualitativo, de carácter descriptivo y exploratorio, realizado con 50 profesionales del equipo de salud de una Unidad de Cuidados Intensivos de un hospital privado del estado de Bahia. Se utilizó un cuestionario sociodemográfico y la entrevista semiestructurada para la recolección de datos, que se analizaron con la técnica de análisis de contenido temático y se discutieron de acuerdo con la Teoría Final de Vida Pacífico.

Resultados: Los profesionales revelaron que la asistencia a la salud de pacientes en cuidados paliativos en la Unidad de Cuidados Intensivos se orienta hacia la necesidad de promover el bienestar. De este modo, surgieron tres categorías: 1. Aliviar el dolor para promover el bienestar; 2. Proporcionar bienestar para tener paz, dignidad y respeto; 3. Acercarlos a los seres queridos y a la fe como estrategia de bienestar.

Conclusión: El bienestar fue el concepto de la Teoría Final de Vida Pacífico que se destacó en la percepción del equipo multiprofesional, de forma que todas las categorías lo promueven en la práctica asistencial a pacientes en cuidados paliativos y es motivado mediante la identificación de las necesidades básicas de estos pacientes. El bienestar físico fue el más presente en los discursos, lo que advierte la necesidad de capacitación multiprofesional para brindar asistencia de bienestar de forma holística. La teoría utilizada se reconoce como una importante herramienta para ayudar en las intervenciones que buscan un final de vida pacífico.

# Introduction

The influence of technological pragmatism and curative paradigm of the biological model in health care, especially that aimed at patients with end-stage disease, induces most of them to end their lives in the Intensive Care Unit (ICU). (1) In this sense, the multidisciplinary team experiences a change in the care paradigm, seeking to improve the Quality of Life (QoL) of those who face problems associated with life threatening diseases. The team involves caring for suffering beyond physical symptoms, including the support of a multidisciplinary team and meeting the basic needs of the patient and family. (2)

Comfort, associated with pain relief, closeness to loved ones, dignity and respect promotion, and the experience of peace are concepts of the Peaceful End-of-Life Theory (PELT), which come close to the principles of palliative care (PC). This theory, created by nurses Cornelia Ruland and Shirley Moore, aims to improve QoL and patient with end-stage disease, related to nursing interventions and specific outcomes for these patients.<sup>(3)</sup> Thus, it can be classified as a predictive and medium-range theory,<sup>(4)</sup> providing subsidies to PC care practices, in order to provide a peaceful end-of-life.

The theory has good reach in promoting comfort in palliative environments, enabling actions that contribute to the finding of stability of care based on the wishes and basic needs of patients. (5) However, as this is a recent theory, not testable in Brazil and incipient in the scientific scenario, more

publications are needed to guide patient with endstage disease care in the ICU. (6)

The ICU PC is directly linked to comfort promotion. PELT calls the experience of comfort as relief from discomfort, the state of ease and peaceful contentment, which makes life easier or more enjoyable. Given the growing number of patients with end-stage disease admitted to these units and the need to promote a peaceful end-of-life for these individuals, the following guiding question was used: what is the perception of the multidisciplinary team about end-of-life comfort in intensive care?

Care for patient with end-stage disease in the ICU is complex, conflicting and challenging. The current biomedical model, technological advances and frequent coping with death are common obstacles, requiring professionals to provide a foundation of clinical care in order to promote QoL to these patients. Thus, the objective of this study was to analyze the perception of the multidisciplinary team about end-of-life comfort in intensive care.

# Methods =

This is a qualitative, descriptive and exploratory study, guided by the COREQ tool, carried out in an Immunological ICU of a large private hospital in the city of Salvador, state of Bahia. The study site was defined due to the high number of patients under palliation.

Fifty professionals participated in the study: 13 doctors, 13 nurses, nine physiotherapists, nine

nursing technicians, three nutritionists, two social workers and one psychologist. Participants who have already cared for PC patients in the ICU; working time longer than one year with critically ill patients and belonging to the permanent staff of the unit were included in the study. Professionals who were on vacation or sick leave during the data collection period from November 2018 to May 2019 were excluded.

Data collection took place through a sociodemographic characterization questionnaire and semi-structured interview, conducted in private rooms of the unit, previously scheduled according to the availability of the professional. The statements were recorded in audio and fully transcribed.

Professionals were interviewed until they reached data saturation by category. The interview was conducted by the questions: What are the main basic needs of patients with PC in ICU? What do you consider to be comfort in PC patient care?

The statements were analyzed according to Bardin's content analysis technique, through the following steps: 1) pre-analysis; 2) exploration of the material; 3) treatment of results and interpretation, (8) discussed in light of PELT concepts.

The guidelines and regulatory standards for research with human beings, present in Resolution 466/12<sup>(9)</sup>, were respected. They were approved by the Locus Hospital's Research Ethics Committee, under Opinion 2,890,509 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 93808218.9.0000.0048. Participants signed the Informed Consent Form. To maintain anonymity of participants, they were identified by the initial letter of the category, followed by the order of the interviews (D01, D02; N01, N02).

# Results

There was a predominance of women (72%) and young adults (aged 30 to 45 years with 70%), with a mean age of 37.5 years. As for specialization, 56% have in ICU and none in PC. Although all participants stated that they have already provided care

to patients with end-stage disease, only 32% had an approach on the subject at graduation, especially nurses (53.8%).

From the identification of the basic needs of patients with PC in the ICU, the participants directed the care to the concepts of PELT, prioritizing comfort promotion.

Three categories emerged: 1. Relieving pain to promote comfort; 2. Providing comfort to achieve peace, dignity and respect; 3. Approaching loved ones and faith as a comfort strategy.

# Relieving pain to promote comfort

PELT brings out as an essential concept in patient care to provide experience of not feeling pain. To promote pain relief, it is necessary, in addition to the prescription of analgesia, to adopt non-pharmacological measures, addressing psychosocial and spiritual aspects. Pain relief was considered by all professional categories to be a fundamental aspect in palliative patient care, according to reports:

Absence of pain. He can have everything, but if he has no pain, in my view, I think we are achieving the goal. **PH08** 

Making the patient comfortable, taking pain and anguish away. **N10** 

Professionals also emphasized comfort promotion directed to physical needs to relieve symptoms common to the patient in PC, such as dyspnea and nausea, adequate nutritional therapy, respiratory aid and sedation for difficult to control ventilatory discomfort:

Need to relieve pain, he can't feel pain at all, not either discomfort, so sometimes put on continuous sedation for patient who has breathing problem. **D13** 

It ranges from an approach to facilitating his mainly respiratory part so that he has no difficulty, to the use, when necessary, of invasive ventilation to provide breathing comfort. **PH07** 

Some participants emphasized the suspension of procedures to improve patient comfort in PC and to avoid painful interventions. This conduct was highlighted by doctors, nurses and physiotherapists, according to the statements:

We only give basic life support, do not use vasoactive drugs, do not enter antibiotics, do not do dialysis, do not offer diet, do not take exams. **D05** 

We stop being more invasive. The medications are being more spaced; we try to prioritize what really brings comfort. **N11** 

The patient went into palliation, it's comfort! We do not touch on the issue of oxygen therapy, ventilatory parameters. Search as best as possible not to interfere, not to prolong that. **PH02** 

Participants believe that avoiding invasive procedures, tests and medications that will not change the course of the disease are ways to reduce discomfort. Decision-making related to the work process involving the PC are measures used to improve comfort.

# Providing comfort to achieve peace, dignity and respect

Professionals, in informing how they work to promote patient with end-stage disease comfort, recognize the need to ensure dignity and respect in the process of death and dying:

When the patient is under PC, it is his right to dignified death, his right to die among the equals, not to be a number, a bed, to be the father, the mother, the son. **N08** 

Participants emphasized comfort-promoting care measures to provide patients and families with a peaceful experience by controlling anxiety and restlessness, addressing fear and their concerns:

Sometimes people are expecting someone to listen to them, sometimes anxiety or fear is that. Trying to listening, talking, not lying on information, transmitting calm and tranquility. **NT03** 

The professional categories, especially the psychologist, physiotherapists, nurses and nutritionists, exposed the importance of psychological comfort. It was perceived through the dialogue related to fears in this phase, demonstration of affection, attention, words of courage and strength, as testimonials:

Directing care for patient comfort is sometimes a longer visiting time. He is a patient who has millions of days in the ICU and never went outside to see the sun, so we can put in the chair, assess with the team. All you can do to make him more relaxed, to suffer less, I think is valid. **N07** 

The main focus is to bring comfort, not to nurture, since the nutritional conduct will not change the prognosis of this patient. Our therapy will not increase the patient's life days but will bring the patient's days to life. **N03** 

They require a little more of your attention, a little more of affection, touch, words. **NT06** 

Psychological comfort is also offered through the provision of leisure and eating activities, according to the patient's desire. These were interventions perceived by professionals as tools to achieve experience of dignity and respect.

# Approaching loved ones and faith as a comfort strategy

Participants revealed that they value family closeness during the end-stage phase, represented by the extension of the full-time visit. Bonding as an instrument to provide patient/family safety and spiritual support for the relief of suffering were some suggested alternatives for promoting ICU comfort:

Actions are to do some case study with them, talk to them, make orientations, family meetings, to understand this patient and his family context. **SW01** 

Has the family shown anxiety or anguish? So I always approach the question of faith. That faith must be kept, its religion sought, whatever it may be. **PH06** 

We offer religious assistance. Here at the hospital there is a chaplain, but when this family is not Catholic, we offer them the possibility of bringing in an outsider who is of importance to this patient. **PS01** 

Family members approach during hospitalization was perceived as a mechanism to reduce hostile environmental factors, highlighting some precautions to make the environment more comfortable:

Sometimes bring something that resembles the house, some religious object. They like to bring rosaries, saints, crystals, so I relax. **N07** 

During the service, lighting the room with natural light might be an interesting action to make the environment a bit more humane. **PH08** 

Due to the features and invasiveness of ICUs, participants propose alternatives to improve the environment and bring the family closer to care.

### **Discussion**

Although the present study has limitations to perform in only one ICU of a private hospital, restricting it to a universe that may not represent the reality of other teams, it indicates the need to develop care planning that favors holistic comfort. All professionals reported comfort as an essential element of PC in the ICU. PELT proposes that the patient experience comfort.<sup>(3)</sup>

The results found go beyond the logic of a medium-range predictive theory, as professionals have shown to use care practices to promote a peaceful end-of-life that are not standardized in protocols. The perception of the multidisciplinary team on PC corroborates the concepts of PELT, suggesting the identification of the basic needs of each patient and multidisciplinary discussion to build a care plan, based on scientific evidence, aimed at promoting comfort. Creating intervention strategies for pain relief, closeness with loved ones, peace/dignity/respect promotion and appreciation of faith are di-

mensions of care that enable a peaceful end-of-life and that may be used as protocol of nursing team performance in future studies.

A qualitative study conducted in a Salvador ICU showed that promoting comfort means relief from physical discomfort, such as pain and respiratory distress; offering social and emotional support to the person and family; guarantee of hygiene measures and prevention of skin lesions. Ensuring this integrity helps to prevent physical, emotional and social discomfort.<sup>(10)</sup>

A study conducted with nurses in Rio de Janeiro, Brazil, identified that pain relief and comfort promotion were interpreted as synonyms in the PC setting. However, understanding that well-being promotion is not limited to pain control is fundamental to offer multidimensional care. These are different PELT concepts and tools for PC development, complementing or influencing each other.<sup>(11)</sup>

Participants report that avoiding invasive procedures, tests and medications that will not change the course of the disease are ways to reduce discomfort in end-stage. These measures contribute to the improvement of patients' QoL, being one of the objectives of PELT. (3) Recognizing the moment when treatment is considered futile directly influences the conduct of ICU care. This stage of planning and decision making is considered complex by those involved, pointing to the need for specific organizational protocols that provide security in this process. (12,13)

A study in London identified four different trajectories of PC approach: 1. Curative care since admission; 2. Oscillation between healing and comfort care; 3. Definitive change for comfort care; 4. Comfort care from admission. The conflict occurred most commonly in the pattern two trajectories. Families better accepted standard three. (12) Several ethical issues involve this moment of decision, in most cases, centered on the medical figure, which can provide communication, education and discussion between patient and family. (13)

Comfort is also achieved through gentle relationships that express tranquility and understanding between professionals and patient/family. The family feels secure in meeting their needs, clear and

truthful information and the conviction that their relatives are receiving qualified care from a pharmacological, technological and human standpoint. This means that comfort will depend on practices that value humanity associated with rationality. (14,15)

A study performed in a cardiac ICU showed the main skills in performing PC. Among 46 skills, private and safe environment promotion stands out; recognition and support of family needs and physical comfort. Only one quote was related to spiritual needs.<sup>(16)</sup>

In contrast to the above authors, some professional categories of this study emphasized measures to provide emotional comfort through spirituality. A study conducted in southern Brazil showed that, by using spirituality, it is possible to offer patients comfort by creating a bond and encouraging faith, obtaining a beneficial response in the resignification of finitude. (17,18)

The nursing team was the closest to holistic care, showing concern not only with physical comfort, but emotional, social and spiritual. The diagnosis of impaired comfort can be an aggravation to the ICU patient. Nurses are primarily responsible for assessing and implementing measures that value multidimensional well-being, being closer and taking care as an instrument of their work.<sup>(19)</sup>

The dignified and peaceful death, the one that brings together the the PELT elements should be a priority for ICU policy planning and management. Discussions of patient prognosis and early decision-making with the family, holistic care plan, preparation of the family and staff for the dying process, and a private and constructive environment set the stage for a decent end-of-life. (20) Research participants cite these measures as comfort promotion tools performed by them.

ICU is a complex and feared environment. Hospitalization is associated with negative factors, such as physical limitations, lack of privacy, disturbing lighting, constant noise, harsh technology with equipment and family distancing. Most stressors are unalterable as they represent necessary support for patient recovery. A possible alternative for building a more comfortable environment is investing in supportive, trusting and ethical relationships be-

tween team members and patients, based on simple attitudes such as sensitive listening, welcoming and ambience. Other alternatives reported by participants is to bring the family closer, through extended visit, bring patients' belongings, leisure and lighting.

Comfort promotion, from PC decision to family mourning, becomes a moral imperative in the face of this experience. (22) In the ICU, it is expected to be the primary focus of the PC. Comfort at PELT is supported by three pillars: relief from discomfort, relaxation and satisfaction. These premises are essential in the pursuit of QoL, enabling full well-being. (3) In this context, the multidisciplinary team must be able to provide assistance based on actions that prioritize comfort, ensuring dignity and respect in the process of finitude.

### **Conclusion**

Comfort was the concept of PELT that stood out in the perception of the multidisciplinary team. It was promoted by all categories in its care practice to patients with end-stage disease in the ICU and motivated by the identification of their basic needs, whether inserted in physical, psychological comfort, or promoted by the modification of environmental conditions. In light of the PELT, it is observed that comfort was associated with other concepts for peaceful end-of-life promotion, reinforcing the possibility of assistance based on theories. The nursing team was the closest to holistic comfort, highlighting other dimensions such as spiritual. However, the comfort provided through pain relief and physical symptoms was the most cited by professionals, signaling the need for training that awakens multidimensional promotion. Multidisciplinary interventions based on the concepts of theory can be used in other palliative services, helping in the search for a peaceful end-of-life. This study contributes knowledge in the field of PC and PELT. It directs the care offered to promote comfort to patients with end-stage disease in the ICU, implying future actions that seek PC systematization based on the identification of each patient's basic needs.

It also reinforces the importance of conducting new research in the area, to broaden discussions on the subject and PELT.

# **Collaborations**

Pires IB, Menezes TMO, Cerqueira BB, Albuquerque RS, Moura HCGB, Freitas RA, Santos ALS and Oliveira ES contributed to the study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and version approval final to be published.

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