

# Care planning for patients receiving palliative care in an oncology intensive care unit

Planejamento da assistência ao paciente em cuidados paliativos na terapia intensiva oncológica

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## Keywords

Palliative care; Intensive care units; Patient care; Oncology

## Descritores

Cuidados paliativos; Unidades de terapia intensiva; Assistência ao paciente; Oncologia

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## Abstract

**Objective:** To study the understanding of health professionals in relation to end-of-life patient care in an oncology intensive care unit, and discuss the objectives they seek to achieve when planning care from a palliative point of view.

**Methods:** Descriptive study, with a qualitative approach, conducted in the adult ICU of a cancer hospital. Twenty-five professionals participated in the study: 12 nurses, eight physicians, two nutritionists and three physiotherapists. The inclusion criterion was: working in the sector for one year or more. Professionals on vacation or medical leave during the data collection, which took place between December 2015 and May 2016, were excluded. The data collection technique used was the semi-structured interview. Thematic content analysis was employed to analyze the data, in the following stages: preanalysis; exploration of the material or codification; treatment of the results, inference and interpretation.

**Results:** The three categories encompass contextual particularities according to the severity of the cases, disease stages and treatments, end-of-life condition, medication and management difficulties. However, a need was noted to promote comfort, attend to families and invest in the integration of palliative and critical care.

**Conclusion:** Care planning from a palliative perspective in this context is in the initial stages; challenges for putting it into practice are listed, with a concern to humanize care. It is suggested to use an interconsultive model for integration of specialties, through institutional characteristics.

## Resumo

**Objetivo:** Analisar o entendimento dos profissionais de saúde acerca da assistência ao paciente em cuidados ao fim da vida na unidade de terapia intensiva (UTI) oncológica, e discutir os objetivos que buscam alcançar ao planejar a assistência na perspectiva dos cuidados paliativos.

**Métodos:** Estudo descritivo, com abordagem qualitativa, realizado na UTI adulto de um Hospital do Câncer. Participaram do estudo 25 profissionais: 12 enfermeiros, oito médicos, dois nutricionistas e três fisioterapeutas. Respeitou-se o critério de inclusão: estar atuando no setor por tempo maior ou igual a um ano. Foram excluídos profissionais de férias e de licença médica durante o período de coleta de dados, que transcorreu entre dezembro de 2015 a maio de 2016. A técnica de coleta de dados foi a entrevista semiestruturada. Para análise dos dados utilizou-se a análise de conteúdo temática, seguindo as etapas: pré-análise; exploração do material ou codificação; tratamento dos resultados, inferência e interpretação.

**Resultados:** As três categorias abrangem particularidades contextuais pela gravidade dos casos, fases da doença e tratamentos, terminalidade da vida, medicalização e dificuldades gerenciais. Entretanto, evidenciou-se a necessidade de promover conforto, atender a família, e investir na integração dos cuidados paliativos e críticos.

**Conclusão:** O planejamento assistencial na perspectiva dos cuidados paliativos no contexto é incipiente; elencam-se desafios para a prática e preocupa-se em humanizar a assistência. Sugere-se o modelo interconsultivo para integração das especialidades, mediante características institucionais.

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## Introduction

Technological and scientific advances, as well as public policies, have contributed to the early diagnosis and treatment of cancer, but they are unable to reduce its incidence and, consequently, its impact on the health conditions of the Brazilian and world population. Given this reality, cancer mortality rates are high and death largely takes place in hospitals, particularly intensive care units.<sup>(1,2)</sup>

Although health professionals undergo situations permeated with risk and uncertainty, tied to the dialogue of life and death, palliative measures in this regard are essential. This is especially the case in ICUs where death assumes its pathological nature, to the detriment of the natural inclination of the unit in favor of life, in that the evolution of science and the collective and political consciousness have been focused on fighting against death.<sup>(2)</sup>

The conflict between critical care and palliative care occurs against the backdrop of this paradigm, especially when dealing with death processes in end-of-life care that require decisions regarding therapeutic limits. Although the characteristics of cancer can facilitate its prognosis based on the progressive decline in the patient's clinical conditions during this final stage of life, insistence on therapeutic intervention is not uncommon in ICUs.

Therefore, planning end-of-life care for ICU patients can be complex, conflictive and challenging, presenting ethical dilemmas that initially raise questions regarding the definition of reversibility or not, followed by various decisions, such as whether to invest in treatment or not, feed or not, or even, indicate or not ICU admission.<sup>(2-7)</sup>

Consequently, this study sought to explore the understanding of health professionals in relation to end-of-life care for patients in an oncology ICU, as well as discuss the objectives to be achieved in planning care from a palliative point of view.

## Methods

This descriptive qualitative study was conducted in the adult ICU of Cancer Hospital 1 of the José

Alencar Gomes da Silva National Cancer Institute (INCA), located in the city of Rio de Janeiro, Brazil. This sector has 19 beds: ten for clinical oncology and nine for surgical oncology.

Twenty-five professionals participated in the study: 12 nurses, eight physicians, two nutritionists and three physiotherapists. The inclusion criterion was: having worked in the sector for one year or more. Professionals on vacation or medical leave during the data collection period, which took place between December 2015 and May 2016, were excluded.

The data collection technique employed was the semi-structured interview, based on the following script: What is your understanding of end-of-life care for patients in the oncology ICU? Have you ever provided this type of care in this unit? If so, what was it like? If not, what do you think it would be like? How did (would) you plan your actions? Did (would) you have difficulties? What objective did (would) you seek to achieve when planning the care for this type of patient? How did the care team participate in this situation? In your work, do you adopt palliative care concepts? How was your relationship with the family members? Do you feel you could provide better care for these patients? In what way? What would you need?

The interviews were conducted individually, at a prescheduled location, date and time, according to the participants' preferences. Each interview lasted an average of 30 minutes. All the testimonies were recorded in audio and fully transcribed, identified by alphanumeric codes. After this stage, the participants were revisited on the field in order to validate their testimonies.

Thematic content analysis was used to analyze the data, in the following stages: preanalysis; exploration of the material or codification; treatment of the results, inference and interpretation.<sup>(8)</sup> The last stage was based on national and international conceptual frameworks related to palliative care, ICUs and the best scientific evidence.

The study obtained approval from the Research Ethics Committee of the Anna Nery School of Nursing, as the applicant institution (Opinion No.1.275.38), and INCA, as a coparticipant institution (Opinion No. 1.324.491).

## Results

Three categories emerged, as presented in chart 1.

## Discussion

Discussing palliative care in ICUs can be paradoxical, in that the practices seem incompatible, since end-of-life patients may not benefit from the technologies available in this unit, due to the irreversibility of the disease, which is manifested in multiple spheres of the human being and presages death. Nevertheless, end-of-life patients are often in ICUs, receiving care intended to reverse the clinical situation and that seeks to harness technological advances to relieve suffering and provide comfort, which distinguishes therapeutic (dis)proportionality.

The process of caring for ICU patients from a palliative point of view is multifaceted, wrought with contradictions, negative feelings and little humanized care. Coping with death is also challenging, since there are ethical and paradigmatic dilemmas, in that health professionals are educated and trained based on a model that prioritizes disease and cure.<sup>(4)</sup>

Furthermore, death awakens in professionals an awareness of their own finiteness, creating internal conflicts and doubts about the effectiveness, objectives and relevance of the care provided. Decision-making processes, primarily focused on a single person, especially generate questions regarding the ability to reverse the situation, resulting in insistence on therapeutic measures.<sup>(9)</sup>

**Chart 1.** Inferences, empirical categories and the testimonies of the professionals

Category 1. Particularities of the adult oncology ICU and its relationship with palliative care and medication	
Witness	Inferences
"I've worked in other ICUs and there is a comparison of end-of-life expectancy in each one. In oncology, it is clear because the patient is admitted and palliative care starts immediately" (Nursing P24).	High complexity of the profile of patients, related to rapid evolution of the disease, aggressive treatment and high mortality.
"This is not an ICU whose mortality rate is due to inadequate care, but because patients arrive here already in a critical state, making us an ICU that provides end-of-life care [...]" (Physiotherapy P6).	
"It is difficult to define patients where there is no hope of recovery. I imagine due to lack of knowledge and difficulty in assuming risk [...]" (Physiotherapy P12).	Lack of knowledge on the subject. Delay in establishing the prognosis. Concerns about ethical and legal repercussions.
"I think we have more end-of-life than intensive care patients in our sector, two for every one, so either we need to rethink which patients come here or receive more information about palliative care" (Nursing P25).	Predominance of patients receiving end-of-life in the oncology ICU. Need to screen each case to facilitate appropriate indication of critical care, as well as for ongoing education.
"We are highly limited to few types of care; the truth is we do the basics, which is to alleviate pain. We could provide more comprehensive support or perhaps offer palliative care much earlier. After the person is intubated, then sedated, I think morphine and palliative care could be started [...]" (Medicine P18).	Medication as the main approach for relieving symptoms. Insistence on therapeutic intervention and undermining the patient's autonomy. Need for early integration of critical and palliative care.
Category 2. Promoting the patient's comfort in end-of-life care in the oncology ICU	
Witness	Inferences
"The dedication of professionals must remain the same; what changes is the care focus, which shifts more to treating symptoms [...]" (Medicine P8).	Promotion of comfort as a care planning goal. Focus on physical symptoms.
"[...] maintain physical integrity, respect for the body, for the life therein, for the family coming to see the patient, who wants, as much as possible, to see the patient, as being presentable and looking cared for [...]" (Nursing P10).	Respect for the body. Sensitivity in caring for the family's needs, ensuring the person's dignity, seeking to provide care based on a clean and comfortable appearance.
"Do not perform any procedure, any invasive testing, nothing that requires transportation, nor create any type of discomfort such as glycemic monitoring or finger insertion, try to leave the patient properly hooked up, which is what you have here, mechanical ventilation, do not treat hypotension, let things flow according to the natural course of the disease" (Medicine P22).	Minimize futile therapy to promote comfort, while at the same time employing technological resources to prolong life, which is contradictory.
Category 3. Limits and challenges in planning end-of-life care for patients in the oncology ICU	
Witness	Inferences
"Palliative care does not go with intensive care. Patients are cared for because they occupy a bed, but there is no direct relationship with the activities of this unit [...]" (Medicine P20).	Incompatibility between critical and palliative care. Inappropriate indication of intensive care. Patients with no reasonable expectation of recovery should not be admitted to the ICU, since they will not benefit from it.
"[...] A patient with no hope of recovery occupies a place that could be for a patient that has possibilities. I think that such palliative care patients could have better quality of life staying with their family rather than coming to the ICU, being subjected to invasive and unnecessary procedures [...]" (Nursing P1).	
"The objective is usually determined by the person who will provide the treatment, i.e., the physician. So, if the situation is defined by the physician as without hope, or if he or she is unable to establish this... we get mixed up in our objectives as well [...]" (Physiotherapy P12).	Decision-making limited to the physician. Difficulty working as a team and communicating.
"It's tiring to look after a patient where nothing has been established, since one day you have to do everything and then the next day you undo it all. This is not good from a technical perspective and even worse emotionally [...]" (Nursing P25).	Professionals are not prepared to deal with patients in the process of dying or with death. Shortcomings in professional training. Indicates the needs for emotional support.
"If a critical patient is always ill in the ICU, regardless of what led to the deterioration, it represents an undue occupation of beds. We act according to the need; this results in pressure, even if disguised; there is no specific place for patients without hope of recovery [...]" (Medicine P20).	Need to establish palliative care nursing. Complex ethical questions that may involve legal decisions and institutional policy.

This study examined end-of-life care in an ICU, from the perspective of the specialty of oncology. Despite the evolutive characteristics of cancer, they facilitate to a certain extent the survival prognosis and forecast compared to other chronic diseases that develop slowly. The difficulties expressed throughout the testimonies were similar to the context of a general ICU.

When dealing with cancer patients, it is understood that their clinical condition is affected by variables related to the disease itself and the treatments, which has a negative impact on quality of life, particularly if they are manifesting physical symptoms and undergoing anticancer treatments, even for palliative purposes.<sup>(9)</sup> Such manifestations, when acutely exacerbated, can require ICU admission. Care planning, from that point on, should focus on stabilizing and improving such causes that, on the other hand, may be resistant to treatment, in addition to treating new infections that often arise from being hospitalized. Ultimately, there may be no therapeutic possibilities of recovery.

The transition from curative to palliative care in oncology ICUs is a frequent occurrence and does not mean, in some cases, that the indication of intensive care was incorrect. When this happens, it is important to recognize therapeutic limits and manage the situation based on principles that govern human care, bioethics and palliation. However, since during the first hours of hospitalization, expectations of good results may run high among professionals and family members, it is difficult to accept the situation and make this transition.<sup>(10)</sup>

Ethical dilemmas and conflicts mainly stem from lack of alignment with palliative care principles, as per the recommendations of the World Health Organization, when dealing with life-threatening chronic diseases and the need to implement palliative measures from the time of diagnosis, although the usefulness of these is much clearer and more evident as the disease progresses and reaches high levels of suffering, where medicine can no longer work against the disease, but in favor of the person.<sup>(11-14)</sup>

The need for early integration of curative and palliative care in ICUs has been addressed in the

literature. Among the various strategies to promote this practice, there is unanimous agreement about ongoing investment in health professionals, since, regardless of the model to be followed, they will have the means to recognize patients in need of palliative care, make a better diagnosis and even screen those eligible or not for intensive care.<sup>(15-17)</sup>

In light of these difficulties, it should be emphasized that, according to the recommendations of the Federal Council of Medicine, contained in Resolution No. 2156/2016, which establishes ICU admission and discharge criteria, this service is intended for patients with critical clinical and risk conditions, but who are likely to survive and recover. This Resolution also stipulates that physicians, in cases of incurable and terminal diseases, provide palliative care rather than insist on useless diagnostic or therapeutic actions. Therefore, in Article 6, ICU admission must comply with specific criteria, ordered in priority from one to five. The last priority, i.e., the fifth, applies to patients with characteristics where there are no therapeutic possibilities of recovery.

Different care options must be considered for end-of-life patients in the hospital context. However, over the course of this process, the current view does not exclude this profile of patient from the ICU, where it is urgent to provide palliative care whenever necessary.

Based on the scientific evidence and the study of the reality investigated, the consultive model is suggested as the most appropriate for implementing palliative care in the ICU, in view of the fact the institution has a specialized unit in palliative care, as well as specialized human capital. With this model, a specialized team can be mobilized through an agreement among professionals from different categories, and when working jointly with emergency teams, it can play an essential role in the process for screening patients, as well as promptly assist with possible indications for ICU admission and end-of-life decision-making.<sup>(10,17)</sup> However, medium and long-term strategies can be considered and implemented concomitantly, in order to invest continually in the integration between curative and palliative care in the ICU. This integration is associated with



better flow in clinical management and hospital discharge processes, with a significant reduction in readmissions, fewer referrals to the ICU, lower costs and greater quality of care.

Among the contradictions and problems in implementing an integration model based on consulting with a palliative care specialist, many health professionals may consider this type of intervention unnecessary, since they consider comfort measures to be common in their area of work and, for this reason, palliative care ends up not being recognized as a specialty.

Another measure that could facilitate care planning in this context is shared decision making, based on open and honest discussions regarding reasonable treatment options. This implies clear and constant communication, aimed at establishing a relationship of trust, especially with family members. Faulty communication raises false hopes of recovery, resulting in the refusal to accept therapeutic limits and triggering processes of pathological grief.<sup>(18)</sup>

Prognostication is a challenge, accompanied by dilemmas in various domains, such as technical, ethical and legal. Insufficient knowledge and/or lack of interest in palliative care, reluctance to accept that it is no longer possible to keep seeking for a cure and the feeling of impotence in the face of inevitable death are issues that influence decision making, resulting in undue occupation of beds, overcrowding, futile or useless treatment and misuse of financial resources in the ICU.<sup>(6)</sup>

Concerns about ethical and legal repercussions related to decision making, especially medical, interfere with the implementation of palliative care. Care planning and decision making are complex stages in this process, given the difficulty of reaching a consensus and defining which types of care should be continued and which ones suspended, or even, not implemented, which leads to the need for specific protocols.<sup>(19-21)</sup>

A limitation of this study was the time restraints of professionals for the interviews, which in some cases were interrupted, interfering with the flow and development of ideas. Also, since this research was conducted in one single location, future studies in

regard to other specialties, other integration models between critical and palliative care, or that enable care protocols are essential for delving deeper into issues related to end-of-life in intensive care units.

## Conclusion

Although professionals recognized the importance of palliative care, their understanding of it was weak, associating such care only with patients clearly in the final stages of life. There was no apparent concern to provide palliative care in the continuation of care after discharge from the ICU, for example. The emphasis was on physical care. In addition, difficulties related to screening, prognosticating and recognizing patients in need of palliative care, sharing decision making among team members and planning comprehensive care, combined with fears of ethical and legal repercussions, especially for physicians, were negative intervening factors for providing palliative care in the oncology ICU. Also worth noting was the lack of training of professionals on the subject, insufficient communication between teams and with family members, and divergent opinions in relation to therapeutic approaches.

## Collaborations

Santos DCL, Silva MM, Moreira MC, Zepeda KGM and Gaspar RB contributed toward conception and design, data analysis and interpretation, writing of the article, relevant critical review of its intellectual content and final approval of the version for publication.

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