



The perception of oncology ICU professionals regarding the practice of palliative extubation

A percepção dos profissionais da UTI oncológica frente à prática da extubação paliativa

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ABSTRACT

Introduction: Palliative extubation is an ethically and legally supported practice; however, there are still difficulties in understanding the concept, erroneously relating palliative extubation to euthanasia.

Objective: To analyze the perception of oncology ICU professionals of a private hospital in São Paulo regarding palliative extubation procedure and the interfaces in the care provided by the team.

Methods: This is a descriptive exploratory study with a qualitative approach, in which a semi-structured interview was used; and as a data processing technique, the Collective Subject Discourse (CSD), which analyses empirical data of a verbal nature, in order to configure a collective subject with a social discourse.

Results: The analysis of the interviews culminated in 13 categories of discourse, which described the practice of palliative extubation in the oncology ICU, the insertion of palliative care, the difficulties that permeate the multi-professional team, and the approach to the family.

Conclusion: The conceptual description of palliative extubation is well known by the team, as they know how to distinguish palliative extubation from euthanasia. However, there are difficulties in practical performance, which can have a direct impact on patient care, communication with the family and the safety and well-being of the professional involved.

Keywords: Airway Extubation; Palliative Care; Intensive Care Units; Medical Oncology; Bioethics.

RESUMO

Introdução: A extubação paliativa é uma prática respaldada ética e legalmente; entretanto, ainda existem dificuldades na compreensão do conceito, relacionando erroneamente a extubação paliativa com a eutanásia.

Objetivo: Analisar a percepção dos profissionais da UTI oncológica frente ao procedimento de extubação paliativa e as interfaces na assistência prestada pela equipe.

Métodos: Trata-se de uma pesquisa de caráter descritivo exploratório e abordagem qualitativa, na qual foi utilizada a entrevista semiestruturada; e como técnica de processamento de dados, o Discurso do Sujeito Coletivo (DSC) que trabalha a análise dos dados empíricos de natureza verbal, a fim de configurar um sujeito coletivo portador de discurso social.

Resultados: A análise das entrevistas culminou em 13 categorias de discurso, que descreveram a prática da extubação paliativa na UTI oncológica, a inserção dos cuidados paliativos, as dificuldades que permeiam a equipe multiprofissional e a abordagem à família.

Conclusão: Observa-se que a descrição conceitual da extubação paliativa é bem conhecida na equipe, assim como eles sabem distinguir a extubação paliativa da eutanásia. Entretanto, há dificuldades no desempenho prático, o que pode impactar diretamente na assistência ao paciente, na comunicação com a família e na própria segurança e bem-estar do profissional envolvido.

Palavras-chave: Extubação; Cuidados Paliativos; Unidade de Terapia Intensiva; Oncologia; Bioética.

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INTRODUCTION

Technological progress has been accompanied by life-prolonging resources that raise bioethical questions about living and dying, such as the discussion of withdrawing support when suffering outweighs the benefits of a treatment, designating procedures as futile. Among the alternatives for therapeutic limits, palliative extubation (PE) stands out, defined by the interruption of mechanical ventilation in patients with irreversible diseases when the aim of the treatment is to provide care, comfort and allow the disease to take its natural course until death¹⁻⁶.

This perspective corroborates the definition of palliative care advocated by the World Health Organization (WHO) published in 1990 and revised in 2002, as “an approach that promotes the quality of life of patients and their families facing life-threatening illnesses through the prevention and relief of suffering”⁷⁻⁹.

Although palliative extubation is a practice with legal ethical support, there are still difficulties in understanding the concept, erroneously relating palliative extubation to shortening the patient's life span (euthanasia); which hinders effective communication between the team members themselves and with the family^{2,4-5,10-14}.

Thus, this research aimed to analyze the perception of oncology ICU professionals regarding the palliative extubation procedure and the interfaces in the care provided by the team.

METHODS

This is a descriptive exploratory research with a qualitative approach, using a semi-structured interview ([Supplementary material](#)) designed for this purpose and ratified by a committee of experts¹⁵⁻¹⁸.

The Collective Subject Discourse (CSD) technique was adopted in the study for data processing, which consists of analyzing the verbal material by bringing together the individual discourses by semantic similarity, forming a discourse-synthesis written in the first-person singular. Based on the analysis of the interviews, key expressions were highlighted which presented the same central ideas and anchors¹⁶⁻¹⁸.

As this is a qualitative study, an intentional sample was adopted, selecting representative people from each professional category. The target audience was professionals from the multi-professional team of an oncology ICU, who were invited to take part in the study. After accepting and signing an informed consent form, they took part in a recorded interview lasting a maximum of 60 minutes, which was then transcribed.

CHARACTERIZATION OF THE STUDY PARTICIPANTS

Six professionals from the following categories took part in the study: Intensive Care Physician, Physiotherapist, Nutritionist, Pharmacist, Nurse, and Nursing Technician, who work in an oncology ICU and were identified in the study by the letter P followed by the order in which they took part in the interviews.

The participants were aged between 39 and 44. They had been working for between eight and twenty years and had worked in the oncology ICU for between three and eighteen years. Only two professionals (P5 and P6) reported specialization in palliative care and of the six interviewees, five had already accompanied a family member and/or friend in palliative care.

RESULTS AND DISCUSSION

Palliative extubation protocol

The discourse below shows that oncology ICU professionals are unaware of the existence of an institutional protocol for palliative extubation. The interviewees believe that the palliative care team follows a protocol, but that there is no document established for the ICU team.

I know there is a protocol for the palliative care team [...] but there is no specific ICU protocol for palliative extubation. (P2)

Characterization of palliative care

The discourses express that the professionals' understanding is in line with the WHO concept⁷. However, when the answers were analyzed in detail, it is clear that those who were trained in the subject (P5 and P6) presented a discourse with technical depth and refinement in the description of the concept, highlighting the complexity of palliative care, especially with regard to investigating the values and what is fundamental in the life of the patient and their family as a guiding point in the care provided¹⁰⁻¹¹.

Most people think that palliative care is when there is nothing left to do, but for me it is different, that is when there is a lot to do, to control the symptoms, to give comfort, I think to understand what the person needs, what they understand as quality of life in order to be able to support not only them, but also their family members. (P5)

Palliative care in the oncology ICU

The results analyzed point to the difficulties in integrating the palliative care team into the oncology ICU. In the referral hospital, there is a flow of authorization from the doctor in

charge of the case for other medical teams to take part in the patient's care. What the interviewees point out is that some medical teams have difficulties in discussing the objectives of care and accepting the therapeutic limit, preventing the possibility of greater palliative care action within the ICU.

You provide quality of life for the patient, regardless of how long they live here. This encompasses everything, physical, spiritual, moral and everything that guides every living being. (P6)

Despite this, the results show that ICU professionals consider the work of the palliative care team within the intensive care unit to be positive and important, including providing technical and emotional support to professionals, who often feel insecure when dealing with end-of-life care issues with the family.

As the literature itself points out, the integration of palliative care in the ICU can bring benefits in terms of reducing futile treatments, facilitating communication between the family and the team, favoring the alignment of care objectives and support at the end of life¹⁹.

Here in the ICU [...] the biggest difficulty we have is regarding the medical teams [...] many of the doctors do not even accept palliating the patient, because they think the patient is about to die [...] we see many patients who could be palliated but are not because of the (senior) medical team. (P4)

We get a lot of support from the palliative care group, especially in the ICU. So, this helps a lot, because they interact with us, with the professionals, and bring us experience and security when it comes to a decision and a procedure like this (palliative extubation). (P6)

Characterization of palliative extubation

The statements showed that oncology ICU professionals were familiar with the concept of palliative extubation, as described in the literature. It involves removing the invasive mechanical ventilator in the face of an irreversible clinical condition, with the aim of promoting comfort and relief for the patient, allowing the disease to take its natural course^{7-4,6-11}.

Palliative extubation is the withdrawal of invasive ventilatory support from the moment it is considered that the patient is no longer benefiting from this treatment, [...] it is being futile. (P2)

[...] It would be a measure of comfort not only for the patient, but also for the family [...] Taking away something that is very uncomfortable [...] It is a care measure. (P3)

Palliative extubation in the oncology ICU

Regarding the practice of palliative extubation in the oncology ICU, the highlighted discourse points to the low occurrence of the procedure, and the hypothesis is that early alignment between team-patient-family on the objectives of care, which reduces the occurrence of unnecessary intubations, in cases where this support would not be indicated.

Another point discussed is that patients intubated in the oncology ICU have critical clinical conditions, presenting multiple organ dysfunctions, and die before the possibility of palliative extubation is discussed.

These results show that when palliative care is included early in the care of cancer patients in the ICU, the occurrence of inappropriate invasive measures decreases. The lack of indication for palliative care is significantly associated with futile treatments in the ICU for patients with advanced cancer, reaffirming the importance of early palliative care in patient care¹⁹.

Most (oncology) palliative patients are either extubated to the end [...] or they are patients who are intubated and end up not being able to extubate (due to their clinical condition). So palliative extubation is not that common in our ICU. (P6)

Positive feelings about palliative extubation

The professionals' discourse showed that when the palliative extubation decision is aligned between the team and the family, taking into account the patient's wishes and principles, the team feels that they are providing care and relieving the patient's/family's suffering. However, when alignment generates noise, the team feels insecure, which can have an impact on the care offered.

It is important to highlight the words of P6, who said that she felt safer and more capable after her qualification in palliative care, which gave her the technical and emotional support to care for patients and their families more autonomously and safely. The literature shows that the lack of adequate education in end-of-life care increases the variability of decisions in the ICU. Educational training for the multi-professional team and technical knowledge of end-of-life care also help in the management of these patients⁵.

It was a feeling of care. Palliative extubation is part of a type of care [...] that offers comfort in many ways, it brings comfort to the patient, to the family [...]. (P2)

Before I was a postgraduate in palliative care, it caused a bit of anguish not knowing how everyone would react and how this patient would turn out. Am I going to extubate them, is they going to be too bad? [...] Is they going to be

short of breath? [...] Conflicts that are ours. And with the family member by my side. (P6)

Conflicting feelings about palliative extubation

From the statements, it is clear that the main discomfort for the team is in making the decision to carry out the palliative extubation procedure, which generates feelings of insecurity, fear, worry, and fear of causing the patient's death.

As the literature itself points out, professionals still associate the dyspneic patient's well-being with the provision of oxygen support or invasive ventilation; or they relate palliative extubation to shortening the patient's life span and inducing death, often making difficult an effective communication between team members themselves and with the family^{2,5,10,13,19}.

Another aspect that causes discomfort to the team is the management of symptoms after palliative extubation, such as dealing with respiratory and hemodynamic decompensation, pressure, and tachycardia. The team needs to be prepared to ensure the patient's comfort, maintaining analgesia, and controlling symptoms such as pain, agitation, and dyspnea²⁰.

Associated with this, insecurity was identified in the provision of care and support for the family, in the face of the active process of the patient's death. The results show that professionals are poorly prepared to handle end-of-life care, which can have an impact on patient and family care^{5,13}.

I felt that I had not done the right thing at that moment, because the patient became uncomfortable, tachycardic, sweaty, with high blood pressure. (P1)

Sometimes the greatest discomfort is defining whether or not this patient really benefits from the treatment, from the medication, but the moment you come to the conclusion that he does not benefit, it is because he has already been in the ICU for a while, and it is clear that this treatment is futile. (P2)

I have to confess, sometimes there is a feeling of defeat, especially when the last few minutes are so hard. These are still situations that make professionals very uncomfortable. Witnessing the end of someone's life is not easy, and many feel a lot of discomfort when it comes to doing this, watching the family member in anguish, and still performing a palliative extubation on a patient who does not know how long they will stay; 'what if they die'? [...] you extubate and the patient stops straight away, [...] 'I extubated, was it me?' Would they have stayed longer if they had been intubated? (P6)

Palliative extubation practice difficulties

The statements below reflect the difficulties listed by the interviewees in the practice of palliative extubation, describing a lack of technical knowledge and unfamiliarity with the institution's palliative extubation protocol. Another factor is the alignment of conduct with the family, because as the literature itself points out, technical and emotional preparation is needed to ensure an appropriate approach to family members, helping with the anticipatory grieving process^{5,13}.

If the professional, in addition to knowing the concept of palliative extubation, does not have a technical understanding of post-procedure symptom control and how to communicate with the family, care becomes deficient and there is also a chance of suffering for the professional carrying out the work.

Since palliative extubation is a complex procedure, it therefore requires the presence of professionals with experience in palliative care, involving communication skills, adequate planning, participation of the multi-professional team and advanced knowledge of symptom control^{1,3}.

Finally, the results of this category show that disagreements between teams and between family members make it difficult to take decisions to withdraw invasive measures, increasing the suffering of the family and the ICU care team, which is caught between the different teams involved in planning the patient's care.

The lack of standardization. When the palliative care team is together, the ICU team feels safer. [...] Not being specialized in palliative care is a hindrance when it comes to guiding the team through the palliative extubation procedure. Not having technical knowledge of the palliative extubation protocol, of the steps to follow. (P1)

The difficulty is sometimes for the family to accept that the case has become palliative. [...] it is not that the family has difficulty accepting the palliative extubation itself, but understanding that their care is now no longer curative, it is palliative. (P3)

I notice disagreements sometimes within the team and sometimes within the family. Sometimes between the children, one accepts and the other does not, so they have to talk. There are usually several team in charge, so some teams do not agree, some teams wish to try something else. [...] I think these disagreements are the most difficult parts. (P5)

Benefits of palliative extubation practice

The main benefits identified in the professionals' statements are providing comfort, relieving suffering, and caring for the patient and their family. In this context, palliative extubation

is considered as a form of care that relieves suffering and avoids the artificial prolongation of life^{3-4,9}, which corroborates what the literature shows, referring to a reduction in symptoms of depression in the families of patients who have been removed from mechanical ventilation^{3-4,10}.

I think the greatest benefit is that it brings comfort to both patients and their families, in the sense of not prolonging a treatment that is known to be bringing no benefit and prolonging life in an artificial way. (P2)

In general, there is a benefit for the patient, the family, and the team, which ends the prolongation of a suffering that keeps going on and on. (P5)

Legality of palliative extubation

This category reveals that the professionals are aware of the legality of the palliative extubation procedure, with the exception of P3, who is not sure.

In general, the interviewees felt safe carrying out the procedure, as long as the decision was agreed with the team and the family and documented in the medical records. The professionals' perception is in line with the studies that refer to palliative extubation as ethically accepted in Brazil; in addition to mentioning the need for documentation to support the procedure, including as a factor that ensures possible negative impacts on the healthcare team^{2,6}.

I am not afraid, I think that if everything is very well documented, explained and with the technical, scientific knowledge that we have today, we can do this safely. (P1)

I believe it is legal. I do not think it would be done here in the hospital otherwise. I do not really know. It must have some legal basis. (P3)

I do not think it is illegal. If it is something that has been discussed, aligned with the objective of care, to leave everything on record, talk to the family, if the patient does not answer for themselves; if everything is documented, then it is legal. (P5)

Palliative extubation and euthanasia

It is worth highlighting that the professionals identified a difference between the concepts of palliative extubation and euthanasia, referring to the former as a measure of comfort and relief of the patient's suffering, and not responsible for bringing forward death, while the latter is an intentional action to shorten a person's life, causing them to die¹¹.

It is recognized that the appropriate approach to end-of-life care does not aim to hasten death, but rather to bring comfort and dignity to the patient and their family in the

natural process of dying. Thus, palliative extubation refers to the practice of orthothanasia, i.e., not prolonging the life of a terminally ill patient by artificial means¹⁹.

However, when the interviewees' statements were analyzed, we noticed some misunderstandings when describing the differences between the two concepts. For example, the statements of P1 and P4, who believe that the difference between euthanasia and palliative extubation lies in the support given to the family in palliative extubation; while in euthanasia, there would be no support or the understanding that when the action is defined solely by the family, it would be euthanasia; and when it is a joint patient-family choice, it would be palliative extubation.

Another statement that also draws attention is that of P3, who believes that palliative extubation can be responsible for the patient's death, in cases where after the orotracheal tube is removed, the person dies. The discourse of this health professional also reveals an incoherence in the concepts of dysthanasia and orthothanasia.

The misunderstandings in the discourse become clear when analyzing what the literature says about the difference between these two concepts. Palliative extubation does not cause death, but there is a possibility of survival (hours, days, weeks) after the tube is removed. There is no way of specifying the time, what will determine this is the natural course of the life-threatening illness¹⁴. Euthanasia, on the other hand, is an action that causes the death of a person, which can be active (killing the other person through a course of action) or passive behavior (omitting a relevant action), leaving the person to die^{7,11}. In P2's statement, it is possible to see the clarity between these concepts.

Euthanasia is intentionally interrupting a person's life support. [...] there is not all that much care [...] you just turn things off and do not do anything else. I do not think there is any post-euthanasia support. (P1)

[...] palliative extubation, is the withdrawal of artificial life support that is not bringing benefit to the patient, so in this sense maintaining mechanical ventilation would be dysthanasia and palliative extubation would be orthothanasia, but we would not be acting artificially at the end of the patient's life, which would be euthanasia. What we would be doing is stopping artificially prolonging their life without any benefit. (P2)

It is confusing. I do not think it is euthanasia. I think it is comfort. But it raises doubts, because if you think about it, you are no longer offering respiratory support. If the person needs the tube, it is because they are unable to breathe on their own. So, this could speed up the patient's death.

Euthanasia is you causing it, dysthanasia is you failing to offer maintenance [...] I am ill, I am in a hospital, and I say to the doctor 'give me something to end it', and then they have access to it. That is euthanasia. Dysthanasia is failing to promote the maintenance of life. I think it is called dysthanasia. Like, I am giving the person antibiotics and I stop giving them. The person receives tube feeding and I stop giving it. I am not causing it, but I am taking away what is keeping them alive. (P3)

I think they are two different things [...] for me, palliative extubation is a comfort for everyone, euthanasia I think is more the other person' (family) choice to take that weight off [...] like "let us get it over with and let us kill them". (P4)

Palliative extubation and respiratory drive

Another category that appeared in the interviewees' statements refers to the questioning of performing palliative extubation on patients without respiratory drive. This collective discourse reveals differences of opinion within the teams and discomfort among the professionals involved in the procedure, as shown in the interviews below.

P1 believes that extubation of patients without respiratory drive constitutes euthanasia, while P2 believes that if the absence of drive is due to the clinical and irreversible condition of the disease, the withdrawal of ventilatory support is the possibility of returning the patient to the natural course of the disease, without prolonging the process of death.

P2's perception corroborates the literature, which points out that in the case of patients whose imminent death is expected and there is no benefit in continuing mechanical ventilation, palliative extubation (PE) is a comfort measure, since the presence of the orotracheal tube may prolong agonizing death. It is important that, after palliative extubation, assistance is provided to control signs and symptoms until the moment of death⁶.

Palliative extubation should therefore be considered when all attempts to wean the patient off ventilation have failed, i.e., even in cases where the patient has no respiratory drive; and when maintaining ventilatory support has become inappropriate and unresponsive. Therefore, it is an option when the patient's quality of life is completely impaired, with no hope of improvement and when it becomes clear that support is causing the patient unnecessary suffering²¹.

In palliative extubation, there is respiratory drive, even if it is irregular. And it takes care to advise the family about the possible outcomes after extubation, emphasizing that keeping the support is prolonging the patient's suffering. [...] the patient who has no respiratory drive and I am going

to remove the tube, I know that he will stop due to hypoxia because they will not breathe; that is euthanasia. (P1)

This is a question that generates much doubt, and it is really a very difficult issue, but I think it falls into the same consensus, if the patient does not have the drive due to the clinical situation of the disease, and has no possibility of recovery, in this sense ventilation is prolonging their life in an artificial way. (P2)

Family approach

Finally, the last category identified that technical knowledge about palliative care enables and prepares the professional for discussions within the ICU, reducing anguish, doubts, and emotional conflicts in the face of alignments with the family about decision-making, especially regarding the withdrawal of invasive supports, such as the palliative extubation procedure^{2,5,13}.

It is recognized that the lack of technical knowledge on the subject has repercussions on the feeling of insecurity and discomfort when addressing this issue with the family, especially topics such as finitude and therapeutic futility^{3,5}.

Communication with the family must be based on trust and a clear understanding that withdrawing life support does not mean suspending the patient's care. Healthcare professionals should make it clear to families that the team will continue to provide supportive treatment and comfort²⁰.

Palliative extubation is not simply a medical procedure, but a form of care that aims to relieve suffering and avoid prolonging death. Therefore, it must be ensured that the healthcare team approaches the family in an appropriate manner, allowing the grieving process to begin early, with end-of-life decisions being shared with the patient (when possible) and family members, in order to favor better assimilation of the inevitability of death²¹.

Therefore, it is necessary to explain to the family all the steps of the extubation process and to emphasize that the team's main objective is to provide comfort to the patient²¹.

I would not feel comfortable talking to the family about palliative extubation. I think about that to approach something complex, I would need more experienced and knowledgeable people to talk to the family. I could talk a bit, but not get straight to the point. [...] I would ask the family to talk to someone specific in palliative care who has more experience in this area. (P1)

Today (after specializing in palliative care) I feel more comfortable approaching or allowing family members to ask me questions. [...] A few years ago I was a little more uncomfortable because it was also very new to me. So, it was

uncomfortable to welcome someone into a topic that I did not even know a great deal about it. (P6)

CONCLUSION

In view of the results obtained, health professionals in the oncology ICU are familiar with the concept of palliative extubation and its benefits for patients and their families. Although they point out there are differences between this practice and euthanasia, including legal differences, they still have doubts, especially about the practical performance of the procedure.

What seems to be linked to these difficulties is the lack of technical knowledge about palliative extubation and what palliative care involves, which has a direct impact on the patient's care, communication with the family and the safety and well-being of the professionals involved.

It is recognized that the palliative extubation procedure is not restricted to the palliative care team, but that during the extubation process it is important to have professionals experienced in the removal of mechanical ventilation, as well as those with knowledge on symptom management, complex and/or refractory suffering and skills in communicating bad news to family members.

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SUPPLEMENTARY MATERIAL

INTERVIEW

Identification data and variables

1. Age
2. Gender
3. Profession
4. Religion
5. Time since graduation (years)
6. Length of ICU experience (years)
7. Do you have, or have you ever had a family member or a friend in palliative care? (Who?)
8. Do you have any professional qualifications in palliative care (courses, specialization, master's, doctorate etc.)?
9. In your work, have you ever accompanied someone in palliative care?
10. Does the ICU where you work has a protocol for palliative extubation?

Perception of the palliative extubation

1. What do you understand by palliative care?
2. What do you understand palliative extubation to be?
3. Have you ever participated in a palliative extubation procedure?
 - a) If yes, what was it like, how did you feel?
 - b) If not, what do you imagine it would be like to take part? (Were there any refusals to take part?)
4. What benefits and difficulties can you identify in the practice of palliative extubation?
5. Are you concerned of being sued or do you think the practice of palliative extubation may be illegal in Brazil?
6. Do you think there is a link between palliative extubation and euthanasia?
7. If the patient's family approached you about the possibility of palliative extubation, would you feel comfortable talking about it?