

# Multiprofessional knowledge about palliative care and palliative extubation in infectious diseases

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## Abstract

This exploratory, descriptive, and quantitative study investigated the perception and knowledge of healthcare professionals about palliative care and palliative extubation in infectious diseases. Data were collected at a reference hospital in Ceará between May and December 2023 using an electronic form to capture sociodemographic profiles, perception, and knowledge of the institution's care and management team in a convenience sampling. Most participants were black and brown people, aged between 20 and 67, single, Catholic, with higher education completed in private institutions and work experience between one and five years. They highlighted the existence of a palliative care team but stated that they had not received specific training and/or subjects in their academic training. They acknowledge being emotionally prepared to act at first but do not feel they have the practical skills necessary for palliative extubation. The need for formative changes in health care is highlighted.

**Keywords:** Palliative care. Health personnel. Health manager. Hospitals, general.

## Resumo

### Conhecimentos multiprofissionais sobre cuidados paliativos e extubação paliativa na infectologia

Este estudo, de caráter exploratório, descritivo e quantitativo, investigou a percepção e o conhecimento de profissionais de saúde sobre cuidados paliativos e extubação paliativa em infectologia. A coleta de dados foi realizada em um hospital de referência do Ceará, entre maio e dezembro de 2023, por meio de formulário eletrônico para captação de perfis sociodemográficos, percepção e conhecimentos de equipe assistencial e gerencial da instituição, em amostragem por conveniência. A maioria dos participantes eram pessoas pretas e pardas, com idade entre 20 e 67 anos, solteiras, católicas, com ensino superior concluído em instituições privadas e experiência de trabalho entre um e cinco anos. Destacaram haver equipe de cuidados paliativos, porém afirmaram não terem recebido em sua formação acadêmica capacitação e/ou disciplinas específicas. Reconhecem estar emocionalmente preparados para atuar num primeiro momento, porém não sentem ter habilidades práticas necessárias para a extubação paliativa. Destaca-se a necessidade de mudanças formativas em saúde perante o cuidado.

**Palavras-chaves:** Cuidados paliativos. Pessoal de saúde. Gestor de saúde. Hospitais gerais.

## Resumen

### Conocimientos multiprofesionales sobre cuidados y extubación paliativos en infectología

Este estudio, de carácter exploratorio, descriptivo y cuantitativo, investigó la percepción y el conocimiento de profesionales de la salud sobre cuidados y extubación paliativos en infectología. La recopilación de datos se realizó en un hospital de referencia de Ceará entre mayo y diciembre de 2023 mediante un formulario electrónico para captar perfiles sociodemográficos, percepción y conocimientos del equipo asistencial y directivo de la institución, en muestreo por conveniencia. La mayoría de los participantes eran personas negras y de piel morena, que tenían entre 20 y 67 años de edad, solteras, católicas, con educación superior concluida en instituciones privadas y experiencia laboral entre uno y cinco años. Destacó existir un equipo de cuidados paliativos, pero afirmaron no haber recibido capacitación y/o asignaturas específicas durante su formación académica. Reconocen que están emocionalmente listos para actuar en un primer momento, pero sienten que no tienen habilidades prácticas necesarias para realizar la extubación paliativa. Se destaca la necesidad de cambios en la formación en salud con relación al cuidado.

**Palabras clave:** Cuidados paliativos. Personal de salud. Gestor de salud. Hospitales generales.

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Palliative care (PC) goes beyond care provided at the end of life or in terminal situations: the most recent definition from the World Health Organization (WHO)<sup>1</sup> highlights that it is an approach aimed at improving the quality of life of patients of all ages who face serious and life-threatening illnesses. Thus, the approach is not limited to the patient alone but extends to their family members and caregivers.

Palliative care has as its primary objective the prevention and relief of suffering, covering physical pain and problems of a psychosocial and spiritual nature that may arise with the illness, which includes early identification and evaluation and treatment of these problems, ensuring a holistic and integrated approach to patient care. Therefore, it is essential to understand that PC is relevant at all stages of the disease, from diagnosis to the end of life, and not only in terminal situations. This person-centered approach seeks to provide comfort, dignity, and emotional support to the patient and their family amid the challenges faced during the disease<sup>2</sup>.

Considering this broad concept of life-threatening diseases and according to the stage in which they are found, several PC approaches exist. One of the most significant challenges for the health team that assists the patient is to perform an accurate and direct assessment to verify the need to indicate PC and identify what type of action would be most appropriate and beneficial according to each person's subjectivity and the stage in which the progression of their disease is found<sup>3</sup>.

In this context, evidence-based practice presupposes three principles: clinical experience, the use of the best available scientific evidence, and the preferences and values of patients. This last pillar is the critical point of PC, intending to contain the skill to integrate scientific evidence and clinical experience within what is relevant to the patient<sup>2</sup>.

Since the beginning of the development of PC, it has been understood that patients with acquired immunodeficiency syndrome (HIV/AIDS) are eligible for specialized care<sup>4</sup>. The most recent data indicate that in 2022, between 33.1 million and 45.7 million people were living with HIV around the world, with approximately 1.3 million newly infected and 630 deaths in the same period. These data highlight the continued need for integrated

and comprehensive care for this population, including the importance of PC in managing the condition and improving patients' quality of life<sup>5</sup>.

Despite the significant advances achieved with new antiretroviral therapies (ART), which positively impact patients' quality of life and survival, there are still considerable challenges. Many patients do not have access to optimal treatment, a large number do not adhere to the prescribed treatment, and there are cases in which, even among those who follow the therapy, viral resistance occurs. PC plays a fundamental role in the care of patients with HIV/AIDS despite the benefits of ART. Although they have revolutionized HIV treatment, providing prolonged life and improved quality of life, ART can also be associated with side effects and management challenges<sup>4,6</sup>.

In recent decades, technological advances have been made in life support in various healthcare sectors, enabling the recovery of many critically ill patients. However, patients with advanced diseases in the final stages of life, such as those with HIV/AIDS, when admitted to specific sectors, are constantly subjected to treatments related to prolonging life that are considered futile, which postpone the process of death<sup>7,8</sup>.

In this context, futile treatment in the healthcare field is defined as an ineffective therapeutic procedure that does not benefit the patient. Given that patients may experience irreversible worsening of their acute or chronic clinical condition, which will lead to death, the multidisciplinary team must assess clinical progress daily to redefine treatment goals and prioritize end-of-life PC when treatments no longer provide benefits<sup>9,10</sup>.

In the case of patients with an imminent expectation of death, for whom there is no benefit in continuing invasive mechanical ventilation (IMV), palliative extubation (PE) is seen as a measure capable of generating comfort. This is because the presence of the orotracheal tube and IMV can prolong physical and social suffering and even assistance suffering from those who provide care at the end of life<sup>11</sup>.

Thus, PC is an integrated global response to the needs of patients and families suffering from life-limiting illness, intending to improve quality of life and well-being. In this sense, healthcare

professionals' knowledge of PC and PE is crucial to accessing dignified, person-centered care based on a holistic and biopsychosocial model<sup>12</sup>.

However, when seeking to offer PC and PE in the context of infectious diseases, scientific gaps arise for the launch, development, and decision-making centered on a safe, scientifically supported, and humane practice. Thus, filling these gaps is required to support strategies so managers and other healthcare actors can develop good practices. In this context, this study investigated the perception and knowledge of healthcare professionals about PC and PE with a focus on infectious diseases in a referral hospital in the state of Ceará.

## Method

This article is an excerpt from the research entitled "Cuidados paliativos e extubação/desconexão paliativa: percepção de profissionais e gestores de um hospital de referência em infectologia no nordeste brasileiro." This exploratory, descriptive study with a quantitative approach is reported per the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE). It is worth noting that exploratory research aims to provide greater familiarity with the problem, intending to make it more explicit or constructing hypotheses. Its planning tends to be quite flexible, as it is vital to consider the most varied aspects related to the fact or phenomenon studied<sup>13</sup>.

While descriptive studies aim to describe the characteristics of a given population or phenomenon, they can also be designed to identify possible relationships between variables. Numerous studies can be classified as descriptive. Most of those conducted for professional purposes probably fall into this category<sup>13</sup>. Thus, the consolidation of the quantitative approach presupposes a context constituted and governed by invariable laws, which can be verified and predicted<sup>14</sup>.

The study was conducted on the premises of an infectious diseases hospital in the state of Ceará, linked to the State Health Department (SESA), a reference in the care of infections and communicable diseases throughout the state. The staff of this unit is composed of approximately

900 professionals, comprising the union of specialized outpatient services, clinical emergency, and other units necessary for life support<sup>15</sup>. This unit was chosen due to its structural size, its responsibility in the context of the regionalization of health in the state, and the fact that it is a reference for the entire state of Ceará.

One hundred one service professionals participated in the study as a non-probabilistic convenience sample. Thus, the eligibility criterion for participation was to qualify as a professional, regardless of employment relationship, with at least three months of experience in the service. Professionals who were away from work due to health demands were excluded, and the data collection period covered the months of May to December 2023.

The procedures for starting data collection initially focused on the application of a questionnaire on the Google Forms platform, based on questions about the sociodemographic profile (gender, age, ethnicity, family income, place of birth, housing situation, marital status, religion, professional training, level of specialty, time since training, and area of activity), with ten closed questions about the perception and knowledge of PC and PE in infectious diseases and one open question for suggestions about desires and needs of the studied topic.

The material was prepared based on the researchers' expertise. They developed a pilot test with three multidisciplinary residents (a physiotherapist, a psychologist, and a nurse), who demonstrated acceptability and understanding of the questions presented, supporting the consolidation of the questionnaire. It is worth noting that the professionals participating in the pilot test were excluded from the study's final sample.

Subsequently, data collection began with the provision of Google Forms via the WhatsApp digital platform. The research objectives were presented and clarified by reading the informed consent form (ICF) in total, and after acceptance and agreement expressed by signing the ICF, data collection began. Next, the recruitment of new participants was completed, and the data collected were organized in a Microsoft Office Excel 2013 spreadsheet, with subsequent descriptive analysis of absolute frequencies presented in tables.

## Results

The study included the participation of 101 healthcare professionals, most of whom were over 47 years old, representing 29 (29%) participants. Among these, the majority were female, 76 (75.2%), and self-identified as brown, 40 (42.6%). Regarding marital status, the majority were single, with 53 (52.5%) individuals in this condition, and concerning religion, Catholicism predominated, with 55 (58.1%).

Nurses represented the most numerous professional category, with 20 (20%) individuals. Regarding academic training, half of the professionals evaluated had completed undergraduate studies at private universities, and 40 (40.8%) had between 1 and 5 years of training. Regarding professional experience, 32 (32%) participants had been working in infectious disease services for more than six years, and regarding income range, the majority had income ranging from R\$ 2,501.00 to R\$ 5,000.00, totaling 45 (45%) individuals. These data provide a demographic and socioeconomic profile of the healthcare professionals participating in the study (Table 1).

**Table 1.** Socioprofessional profile of participants. Fortaleza/CE, 2023

Variables	N	%
<b>Age range (years)</b>		
19 to 25	18	17.8%
26 to 30	27	26.7%
31 to 36	16	15.8%
37 to 41	7	7%
42 to 46	4	4%
>47	29	29%
<b>Sex</b>		
Male	25	24.8%
Female	76	75.2%
<b>Self-reported skin color</b>		
Brown	40	39.6%
Black	10	9.9%
White	39	38.6%
Yellow	3	3%
Not declared	9	8.9%

continues...

**Table 1.** Continuation

Variables	N	%
<b>Marital status</b>		
Single	53	52.5%
Married	41	40.6%
Divorced	5	4.9%
Widowed	1	1%
Not declared	1	1%
<b>Religion*</b>		
Catholic	55	58.1%
Evangelical	26	14.8%
Spiritist	6	4.3%
Agnostic	7	6.5%
Atheist	2	2.1%
No religion	10	10.7%
<b>Profession*</b>		
Nurse	20	20%
Physical therapist	16	16%
Physician	18	18%
Nursing technician	16	16%
Nutritionist	7	7%
Speech therapist	2	2%
Social worker	3	3%
Administrative technician	3	3%
Pharmacist	4	4%
Psychologist	5	5%
Occupational therapist	2	2%
<b>Training institution</b>		
Private university	52	51.5%
Public university	47	46.5%
Private university as a scholarship holder	2	2%
<b>Time since graduation*</b>		
Less than 1 year	13	13.3%
Between 1 and 5 years	40	40.8%
Between 5 and 10 years	16	16.3%
Between 10 and 15 years	3	3%
More than 15 years	26	26.4%

continues...

**Table 1.** Continuation

Variables	N	%
<b>Income*</b>		
Up to R\$ 1,500.00	7	7%
Between R\$ 1,501.00 and R\$ 2,500.00	9	9%
Between R\$ 2,501.00 and R\$ 5,000.00	45	45%
Between R\$ 5,001.00 and R\$ 7,500.00	9	9%
Between R\$ 7,501.00 and R\$ 10,000.00	12	12%
Higher than R\$ 10,000.00	18	18%
<b>Area of activity</b>		
Intensive care	34	33.7%
Medical Clinic	31	30.7%
Outpatient	4	4%
Administrative/Management	8	7.8%
Other	24	23.8%
<b>Time experience in infectious diseases*</b>		
Less than 1 year	24	24%
From 1 to 2 years	22	22%
From 2 to 4 years	19	19%
From 4 to 6 years	3	3%
More than 6 years	32	32%

\* Percentages with variations - some participants did not complete the entire form.

The analysis of academic background reveals that, in general, most professionals (66.3%) did not have classes on PC during their undergraduate studies and that 85.1% did not have a specific course on the topic. After graduation, 70 (69.3%) participants did not have additional training in the context of PC, and 61 (60.4%) had never worked in the PC area. Surprisingly, despite this lack of experience and specific training, 51 (50.5%) participants stated they felt qualified to work in PC, and 96 (95%) expressed interest in attending training courses in this area.

In addition, most participants (61.4%) stated that they felt emotionally prepared to deal with PC, and 68.3% said that working in this context had no negative impact on their mental health. Another important fact is that 93 (92.1%) confirmed that the institution where they work has a multidisciplinary team in charge of PC (Table 2).

**Table 2.** Professional training for palliative care. Fortaleza/CE, 2023

Variables	N	%
<b>Participated in classes on palliative care during undergraduate studies</b>		
No	67	66.3%
Yes	34	33.7%
<b>Specific course on palliative care during undergraduate studies</b>		
No	86	85.1%
Yes	15	14.9%
<b>Training on palliative care after graduation</b>		
No	70	69.3%
Yes	31	30.7%
<b>Feel qualified to work in palliative care</b>		
No	50	49.5%
Yes	51	50.5%
<b>Feel emotionally prepared to work in palliative care</b>		
No	39	38.6%
Yes	62	61.4%
<b>Working in palliative care has negatively impacted your mental health at some point</b>		
No	69	68.3%
Yes	32	31.7%
<b>There is a multidisciplinary palliative care team at your institution</b>		
No	8	7.9%
Yes	93	92.1%
<b>Interested in participating in training on palliative care</b>		
Yes	96	95%
No	5	5%
<b>Years of experience in palliative care</b>		
Never worked	61	60.4%
From 1 to 2 years	21	20.8%
From 3 to 5 years	12	11.9%
From 6 to 10 years	5	4.9%
More than 10 years	2	2%

When asked about professional training in palliative extubation/disconnection within infectious diseases, 75 (74.3%) participants stated that they had already heard of this approach. However, surprisingly, 91% responded that the institutions where they studied did not yet offer

courses or training that addressed this specific topic, and 80.2% said there was no opportunity for practical experience related to PE.

As a result of this lack of training and practical experience, the majority of participants—83 professionals—stated that they did not feel confident performing palliative extubation or disconnection. These results indicate a significant gap in the preparation of healthcare professionals to deal with PE, highlighting the urgent need to develop training and education programs in this area (Table 3)

**Table 3.** Professional training for offering palliative extubation. Fortaleza/CE, 2023

Variables	N	%
<b>Heard about palliative extubation or disconnection in infectious diseases</b>		
Yes	75	74.3%
No	26	25.7%
<b>The institution has offered a course on palliative extubation or disconnection</b>		
Yes	9	9%
No	91	91%
<b>There were practical moments with palliative extubation or disconnection</b>		
Yes	20	19.8%
No	81	80.2%
<b>Feel confident in offering palliative extubation or disconnection</b>		
Yes	18	17.8%
No	83	82.2%

## Discussion

In the search to understand the perception and knowledge of healthcare professionals regarding PC and PE, especially concerning infectious diseases, a significant group stands out: people living with HIV/AIDS. Studies such as that of Souza and collaborators<sup>16</sup> identify this group as a strong candidate for needing PC due to the demand for symptom control and family support as part of the care.

In addition, the seriousness and high mortality rate associated with HIV/AIDS make this care

even more essential. This research highlights the importance of recognizing the specific needs of these patients and ensuring that they receive the necessary support to face the physical, emotional, and social challenges associated with their health condition<sup>16</sup>.

Given the results presented, it is clear that approximately half of the professionals interviewed are not trained to deal with PC, which can be attributed to a deficiency in their training. However, it is vital that they are well-qualified to provide care efficiently and promptly.

A study published in Brazil stated that it is crucial for institutions that train healthcare professionals to invest in student training to develop technical care skills and interpersonal skills, such as empathy, congruence, acceptance, and dialogue. These skills are essential for human care, especially concerning death and PC<sup>17</sup>. The results indicate a gap in PC training for healthcare professionals but also suggest a high level of interest and willingness to learn and train in this area, as well as a positive perception regarding the emotional preparation to deal with such care.

According to Gibbins and collaborators<sup>18</sup>, in the United Kingdom, there is recognition that the inclusion of PC teaching in undergraduate courses provides students with the development of skills that improve their professional performance in the general care of patients. This same study reveals the government's action in issuing clear recommendations that all medical students should receive primary teaching on the relief of pain and suffering and the care of terminally ill patients.

According to studies by Spalding and Yardley<sup>19</sup>, in the United Kingdom, institutions where PC training has been implemented have shown improvements in communication skills, teamwork, family support, and symptom management. This is essential to ensure quality, humanized care for patients and their families, contributing to improving the experience at such delicate moments as the dying process<sup>16</sup>.

In 2021, an evaluation of the training context for infectious diseases in Europe revealed that training in this area is offered in only 30% of nations, while specific PC training is provided in only 11% of countries. These figures highlight a significant gap in the training of health professionals, especially

concerning PC in infectious disease contexts. Given this scenario, it is imperative to improve educational curricula, aiming at higher training quality. It involves a joint effort by educational institutions, governments, and regulatory bodies to strengthen training in infectious diseases and reinforce training in specific PC for this area<sup>20</sup>.

Achieving this improvement in Europe requires reviewing and updating curricula, ensuring they include relevant PC content in infectious diseases. In addition, it is essential to implement effective assessment methods to ensure that students acquire the necessary knowledge and skills in this crucial health area. Investing in PC training for infectious diseases not only improves the quality of patient care but also helps to offer a more holistic and compassionate approach to the treatment of these conditions. This improvement in training contributes to more complete and humanized care, better meeting the needs of patients and their families<sup>20</sup>.

According to Lin *et al.*<sup>21</sup>, in a study conducted in India, training using clinical protocols can strengthen PC throughout the health system in India and worldwide. This approach can help standardize care and ensure consistent, high-quality care for patients requiring PC, emphasizing that providing PC training is an urgent need worldwide.

As Freitas<sup>22</sup> mentions, in Brazil, incorporating PC teaching into undergraduate courses is essential to ensure good practices in health care. This integration is seen as an essential prerequisite for adequately preparing future healthcare professionals, as there is a global concern about ensuring that they receive PC training during their training courses in a way that is integrated into the health system.

Regarding PE, in recent years, there has been a growing acceptance that withdrawing mechanical ventilation can be part of palliative actions in intensive care units (ICU)<sup>23</sup>. In a study that covered Argentina, Brazil, and Uruguay, there was variation in the results regarding the suspension of mechanical ventilation, identifying that this practice is almost always carried out by 48.2% of Argentine professionals, 25.8% of Uruguayans, and 18.9% of Brazilians. These numbers reflect differences in the acceptance and application of the withdrawal of mechanical

ventilation as part of palliative actions in the different countries studied<sup>24</sup>.

Based on the results of this study, PE requires specialized care and adequate training of the multidisciplinary team. Brazilian researchers point out that the withdrawal of ventilatory support from a patient represents a highly specialized form of care that requires the presence and availability of a multidisciplinary team with adequate training in symptom control and PC<sup>25</sup>. This fact highlights the importance of a well-trained interdisciplinary team to perform PE and the need for further studies and discussions on the subject, as it is still a method that is little applied in ICUs.

Therefore, it is crucial to invest in the ongoing training of the healthcare team, ensuring that all members are up-to-date and qualified to provide high-quality care to patients in PE situations. This will contribute to ensuring a safe, dignified, and respectful process for patients and their families.

## Final considerations

This study highlights the need to invest in training healthcare professionals from the undergraduate level onwards. To improve the health system concerning PC, educational institutions and training programs must review and strengthen their curricula to include more comprehensive and specialized education in PC. This may involve incorporating specific courses, clinical placements, and practical activities related to PC. These are key strategies to ensure that all patients requiring PC receive the support and assistance they need to live their health journey comfortably and with dignity.

In addition, it is essential to provide continuing education and training opportunities to healthcare professionals to update them on best PC practices and approaches so that they acquire and enhance the skills, knowledge, and competencies necessary to deal with the complex challenges associated with PC and PE. Continuing education can also promote a culture of learning and improvement within health teams, encouraging the exchange of experiences, collaborative teamwork, and the search for evidence-based best practices. Thus, there is the assurance that patients can receive high-quality and humane care, promoting their dignity, comfort, and well-being until the end of their lives.

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