# WHEN CARING IS ESSENTIAL: CURRENT OVERVIEW OF CHALLENGES IN PEDIATRIC PALLIATIVE CARE

# QUANDO CUIDAR É O ESSENCIAL: PANORAMA ATUAL DOS DESAFIOS NOS CUIDADOS PALIATIVOS PEDIÁTRICOS

# CUANDO CUIDAR ES ESENCIAL: PANORAMA ACTUAL DE LOS DESAFÍOS EN LOS CUIDADOS PALIATIVOS PEDIÁTRICOS

https://doi.org/10.56238/sevened2025.029-017

**Anna Clara Lugato Daemon[1], Braian Bill Dias Cunha Oliveira[2], Iris Elizabethe de Almeida Pereira[3], Laura Silva Lopes[4], Cecília Mendes de Carvalho[5], Isabelli Lissa Rodrigues Freitas[6], Kaylane Schuvartz Beraldini Campos[7] and Renata Borba de Amorim Oliveira[8]**

## ABSTRACT

The health of children with life-threatening illnesses encompasses the physical, social, emotional, and spiritual dimensions, and, together with the support network, is the core of pediatric palliative care (PCC). The philosophy of family-centered care is a cornerstone of successful PCC practices. Understanding the barriers that limit this practice is important to consolidate strategies that reaffirm this comprehensive care. The still-mistaken understanding of palliative care often leads to it being confused with end-of-life care. This can create difficulties for both professionals and families, due to cultural issues and the emotional challenges involved with these complex clinical conditions. The current landscape of challenges surrounding PCC primarily involves sociocultural barriers, gaps in the professional training of the multidisciplinary team involved in care, and ethical, organizational, structural, and staffing issues. In an attempt to overcome the main difficulties associated with CPP care, it is possible to point out alternatives that involve technology, instrumentalization of services, incorporation of themes such as death into our culture, ethical debates as part of daily care, and other potentialities, in light of Brazilian legislation that supports this type of care.

---

[1] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: daemonannaclaradaemon@gmail.com

[2] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: oliveirabraianbill7@gmail.com

[3] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: iris.elizabethe927@gmail.com

[4] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: lopeslopeslaura0610@gmail.com

[5] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: cecilia.mc0314@gmail.com

[6] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: isabelli.freitas@yahoo.com

[7] Undergraduate student in Pharmacy. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center). E-mail: camposkaylaneschuvartz.kk@gmail.com

[8] Professor of the Undergraduate Course in Nutrition. Dr. in Sciences from the State University of Rio de Janeiro. Federal University of Rio de Janeiro (UFRJ-Macaé Multidisciplinary Center).
E-mail: oliveiraamorimrb@yahoo.com.br

**Keywords:** Palliative Care. Pediatrics. Barriers to Access to Health Care.

## RESUMO

A saúde de crianças que apresentam doenças ameaçadoras da vida engloba a dimensão física, as questões sociais, emocionais e espirituais, sendo, juntamente com a rede de apoio, o núcleo dos cuidados paliativos pediátricos (CPP). A filosofia do cuidado centrado na família revela-se como um alicerce das práticas bem-sucedidas em CPP. Compreender as barreiras que limitam esta prática faz-se importante para consolidar estratégias que reafirmem este cuidado integral. O entendimento ainda equivocado sobre o que são os cuidados paliativos faz com que eles sejam frequentemente confundidos com cuidados de fim de vida. Isso pode gerar dificuldades tanto por parte dos profissionais quanto das famílias, por questões culturais e pelos desafios emocionais envolvidos com essas condições clínicas complexas. O panorama atual dos desafios que cercam os CPP envolvem principalmente barreiras socioculturais, lacunas na formação profissional da equipe multiprofissional que precisa estar envolvida no cuidado, questões éticas, organizacionais, de estrutura e de quantitativo de recursos humanos. Na tentativa de suplantar as principais dificuldades ligadas à assistência em CPP, é possível apontar alternativas que envolvem a tecnologia, instrumentalização dos serviços, incorporação de temas como a morte na nossa cultura, debates éticos como parte do dia-a-dia assistencial e outras potencialidades, à luz da legislação brasileira que dá apoio à esta modalidade de assistência.

**Palavras-chave:** Cuidados Paliativos. Pediatria. Barreiras ao Acesso aos Cuidados de Saúde.

## RESUMEN

La salud de los niños con enfermedades potencialmente mortales abarca la dimensión física, social, emocional y espiritual y, junto con la red de apoyo, es el núcleo de los cuidados paliativos pediátricos (CPP). La filosofía de la atención centrada en la familia demuestra ser la base del éxito de las prácticas de SPC. Entender las barreras que limitan esta práctica es importante para consolidar estrategias que reafirmen esta atención integral. La comprensión aún errónea de qué son los cuidados paliativos significa que a menudo se los confunde con los cuidados al final de la vida. Esto puede crear dificultades tanto para los profesionales como para las familias, debido a cuestiones culturales y los desafíos emocionales que conllevan estas complejas condiciones clínicas. El panorama actual de desafíos en torno a la CPP involucra principalmente barreras socioculturales, brechas en la formación profesional del equipo multidisciplinario que necesita involucrarse en la atención, cuestiones éticas, organizacionales, estructurales y cuantitativas de recursos humanos. En el intento de superar las principales dificultades asociadas a la atención del CPP, es posible señalar alternativas que involucran tecnología, instrumentalización de los servicios, incorporación de temas como la muerte a nuestra cultura, debates éticos como parte del cotidiano del cuidado y otras potencialidades, a la luz de la legislación brasileña que ampara este tipo de atención.

**Palabras clave:** Cuidados Paliativos. Pediatría. Barreras de Acceso a la Atención Sanitaria.

## 1 INTRODUCTION

The World Health Organization states that palliative care plays an essential role in promoting quality of life by preventing and alleviating the suffering of people facing serious, progressive, and life-threatening illnesses, addressing not only pain and other physical symptoms, but also psychosocial and spiritual aspects—care that extends to ongoing support for families (WHO, 2019). This perspective is further expanded when it comes to the pediatric public, requiring specific approaches centered on the child as well as on his or her family nucleus (SBP, 2017).

In Brazil, although there are guidelines that guide practice, pediatric palliative care (PPC) still faces important obstacles to its full implementation, especially with regard to ethical, structural, sociocultural and formative barriers. In addition to the conceptual aspect, ethical challenges, such as the maintenance of futile treatments and the difficulty of establishing shared decisions, highlight the fragility of professional training and the lack of institutional support to deal with situations of great complexity (SANTOS et al., 2023; ROCHA et al., 2023).

Often, the restricted and mistaken understanding of palliative care, often confused only with end-of-life interventions, ends up postponing its indication, limiting the offer of reception and relief of suffering from the earliest stages of illness (LIMA et al., 2020).

Structural and organizational issues, in turn, include the lack of trained multidisciplinary teams, the absence of adequate environments, and the lack of institutional policies that consolidate the palliative approach as an integral part of care (SILVA and ROCHA, 2021).

Sensitive communication and the strengthening of the bond between professionals, patients, and families are, therefore, central aspects for care to be ethical, continuous, and truly humanized, recognizing the emotional, spiritual, and social dimensions involved (MOREIRA-DIAS et al., 2023). Thus, understanding the barriers that still limit the practice of PCP becomes essential to consolidate strategies that reaffirm the ethical commitment to comprehensive care because, even when a cure is no longer possible, care remains essential.

The Palliative Care Manual of the National Academy of Palliative Care defines that this modality of care should be offered from the time of diagnosis, regardless of the curative possibility, integrating with other therapies when necessary (ANCP, 2012).

Health, especially that of children with serious illnesses, transcends the physical dimension, reaching social, emotional and spiritual aspects, which makes the care process a profoundly humanized experience. Living with a life-threatening condition demands not only technical interventions, but also a sensitive understanding of socio-family suffering, recognizing the patient and the family as an indivisible care unit. The importance of promoting a humanized approach is based on the need to ensure that care is delivered with respect, compassion and respect for the rights of children and adolescents, as well as their families, in the face of the intense emotions and challenges that arise in the trajectory of life-threatening diseases. Thus, it is important to rethink the role of all those involved, with the aim of offering care that values life and ensures a dignified death, in addition to strengthening the sense of care as a practice of exchange, affection and respect for human dignity (SAINTS; MOREIRA; SEVILLE, 2023).

Reflecting on when a child should be eligible for palliative care is an important step in ensuring that they receive what they really need at a delicate time in their life. Often, the misunderstanding of what palliative care is causes it to be confused with the end of life, or to feel like giving up trying to cure. This generates resistance on the part of both professionals and families, due to cultural issues, fear, and emotional challenges imposed by the condition. When it comes to children, this feeling is even more intense because it is loaded with affection and hope. It is necessary to invest in the continuous training of those who provide care to deeply understand what this care means, its possibilities and its benefits. It is also essential to develop communication that is clear, loving and truthful, so that families can understand what is happening, what can be done, and, above all, that they can feel welcomed and respected in this difficult time. Another point is to understand that eligibility for palliative care is not a definitive decision, nor a boundary that excludes the child from possibilities of improvement or other treatments. Each child needs to be evaluated with technique and humanity, considering their clinical conditions, their feelings and also their beliefs, so it is possible to offer the best to ensure comfort, dignity and respect for their life routine, even in the midst of adversity. Thus, care begins to accompany the child in his disease process and always with the understanding that each life, no matter how small the hope of cure, deserves to be considered with affection, attention and sensitivity (LIMA et al., 2020).

## 2 DEVELOPMENT

The current panorama of the challenges surrounding the CPP mainly involve sociocultural, professional training, ethical, organizational, structural and human resources barriers.

The philosophy of family-centered care reveals itself as a silent foundation of successful practices in CPP. Elements such as collaboration, active listening, respect for dignity and shared decision-making are fundamental, showing that the recognition of the family as the protagonist of care is one of the most powerful ways to ensure quality of life for the child. However, it cannot be ignored that this partnership relationship is also crossed by imbalances of power, information and access. Sensitive and continuous communication, emotional support, and recognition of the family's suffering become indispensable strategies to mitigate the effects of these inequalities. The emotional and social impacts of a child's serious illness reverberate throughout the family system, generating stress, anticipatory grief, overload and, in many cases, financial insecurity. Professionals face the ethical challenge of welcoming suffering in a multidimensional way, without reducing it to the biological element. Attentive listening to losses — of functionality, of projects, of family identity — is an essential part of palliative care. The movement to seek human connection reveals the transformative power of relationships in the context of health. It is a continuous interactional process, in which the professional redefines his *Self* as he commits himself to the care of the other. It is necessary to legitimize the needs of the child, by respecting him as a subject of rights and by actively including the family in decisions, so that care becomes more than technical — it becomes ethical, affective and socially implicated. And it is in this space of presence that care, even in the midst of loss, can generate significant life experiences — for the child, for the family and also for those who care (MOREIRA-DIAS et al., 2023).

The effective implementation of SSC faces multiple challenges, one of the most important being the training and capacity building of the health professionals involved. Palliative care education should be seen as an overarching responsibility, including all members of the multidisciplinary team. For this approach to be effective, professionals need to have a holistic understanding that integrates physical, emotional, social, and spiritual aspects. Adequate training enables professionals to attend to these dimensions in their practices. Palliative care training prepares professionals to face ethical dilemmas that often arise in the care of children at the end of life, for example. Decisions about whether to continue or stop treatments are difficult and emotional. Education should include discussions about health ethics, patients' rights, and the importance of informed consent, allowing professionals to feel safe while respecting the dignity and preferences of patients and their families. Well-trained professionals address sensitive topics, such as prognosis and treatment options, with patients and families in a respectful dialogue. Training and training in CPP is not only an individual responsibility, but a collective commitment that must be adopted by all disciplines involved, in order to make it possible to face the various challenges inherent to the theme and provide truly humanized and respectful care (PAIXÃO et al., 2020).

The introduction of Palliative Care in pediatrics in Brazil is marked by a series of ethical barriers that manifest themselves at different levels. The lack of understanding about the nature and objectives of palliative care, both on the part of health professionals and families, often results in resistance to its early initiation. This is particularly evident in situations of high family vulnerability, where parents, often guided by cultural and religious beliefs, may opt for invasive treatments that prolong the child's suffering, rather than accepting a palliative approach that offers comfort in a condition of finitude. Therapeutic obstinacy - which refers to insisting on treatments that offer no real benefits - is a recurring phenomenon. The Code of Medical Ethics emphasizes the need to avoid unnecessary procedures in irreversible situations, but in practice, this guideline is not always followed, evidencing the need for more robust ethical support for health professionals. The implementation of CPP faces ethical barriers that require a multidisciplinary approach and continuous reflection on the practices and values involved. By respecting the dignity of life and offering adequate support, it is possible to not only alleviate suffering but also provide a space where death is seen as a natural condition of life, allowing families to find comfort and peace in difficult times. The practice of palliative care should be a collective commitment, where ethics and compassion intertwine to ensure that each child receives the care they deserve (SAINTS; MOREIRA; SEVILLE, 2023).

An important ethical dilemma present in pediatric palliative care in ICUs concerns the difficulty of professionals in dealing with end-of-life decisions, such as the suspension of life support treatments. A study conducted with Brazilian pediatric ICU teams showed that many professionals feel unprepared to make these decisions, even acknowledging, for example, the relevance of withdrawing invasive support. Most report fear of misinterpretations or legal implications. In addition, a paternalistic bias is observed in the relationships with the families, with the perception that the parents would not be able to participate in the decisions, which compromises the respect for autonomy. Ethical barriers also emerge within the teams themselves, with divergences among professionals regarding the adoption of palliative conducts. The fear of litigation and the lack of institutional support further aggravate this insecurity. These aspects show that, despite the technical recommendations, ethical and cultural challenges persist that hinder the full implementation of palliative care in the intensive care context (SOUSA et al, 2023).

Organizational barriers related to structure and human resources are also challenges in the implementation of CPP. Inadequate infrastructure and a lack of trained professionals limit access to quality care for children facing serious illnesses. Many health care facilities lack adequate palliative care units that are designed to meet the specific needs of pediatric patients and their families. This structural deficiency prevents the creation of environments that promote comfort and welcoming, which are essential for palliative treatment. Inadequate training and lack of specialization in the area result in teams that are often not prepared to deal with the complexity of care. This lack of expertise can lead to inadequate management of pain and other symptoms, compromising children's quality of life and support for their families. In many institutions, the curative approach still predominates, and the philosophy of palliative care is not fully integrated into the care protocols. Communication between the different health teams is also a critical factor. The fragmentation of services and the lack of coordination between teams make it difficult to continue care and share essential information about the patient's condition. The excessive workload and the pressure for immediate results can divert the attention of professionals to the palliative approach. When providers are overwhelmed, it is difficult to prioritize the quality of care and the time needed to interact with patients and families in a meaningful way. The allocation of inadequate financial resources to the area of palliative care also represents an obstacle. Many institutions face difficulties in obtaining sufficient funding to develop CPP programs. This financial limitation affects the ability to hire specialized professionals, implement adequate training, and maintain the necessary infrastructure to provide quality care. Overcoming these organizational barriers requires a real institutional commitment to the education and continuous training of all health professionals involved in palliative care (SILVA and ROCHA, 2021).

## 3 FINAL THOUGHTS

In an attempt to overcome the main difficulties linked to the to CPP care, we can point out alternatives that involve technology, initially incorporate ethical debates and other potentialities into the day-to-day.

The incorporation of telehealth in the CPP has been pointed out as a promising strategy to expand access and continuity of care, especially in contexts in which travel to specialized services is a challenge for families. We can point out benefits such as convenience, reduction of logistical stress, and the possibility of more frequent follow-up, but it is important to deal with the limitations of this approach format, such as the difficulty of establishing affective bonds with the team through screens, the feeling of emotional distance in critical moments, and the absence of face-to-face support in crisis situations. Even so, telehealth can represent a viable means of maintaining humanized and integrated care, as long as it is associated with sensitive approaches, active listening, and prior preparation for the use of this tool. In other words, the effectiveness of telehealth in CPP depends not only on the technology itself, but on the way it is conducted and integrated into the emotional and cultural context of the families (BLANCO-BLANCO et al., 2025).

The current reality of PCP in our country requires the instrumentalization of health professionals and institutional managers to enable the implementation of important tools for this modality of care in the day-to-day life of the units, consideration of communication techniques, awareness to improve the structure of services and discussion of dilemmas involving pediatric patients and families, in the light of the National Policy on Palliative Care, recently launched in Brazil.

## REFERENCES

Academia Nacional de Cuidados Paliativos. (2012). Manual de cuidados paliativos (2nd ed.). Rio de Janeiro, Brazil: ANCP. https://biblioteca.cofen.gov.br/wp-content/uploads/2017/05/Manual-de-cuidados-paliativos-ANCP.pdf

Blanco-Blanco, J., & et al. (2025). Perspectives and family experiences in the implementation of telehealth in pediatric palliative care: A qualitative approach. European Journal of Pediatrics, 184, 287.

Brasil. Ministério da Saúde. (2024). Portaria GM/MS nº 3.681, de 7 de maio de 2024. Institui a Política Nacional de Cuidados Paliativos - PNCP no âmbito do Sistema Único de Saúde - SUS, por meio da alteração da Portaria de Consolidação GM/MS nº 2, de 28 de setembro de 2017.

Lima, S. F., & et al. (2020). Dinâmica da oferta de cuidados paliativos pediátricos: Estudo de casos múltiplos. Cadernos de Saúde Pública, 36(9), e00164319.

Moreira-Dias, P. L., & et al. (2023). Buscando por conexão humana para transcender simbolismos dos cuidados paliativos em pediatria. Revista Brasileira de Enfermagem, 76(3), e20220476.

Paixão, S., & et al. (2019). Cuidados paliativos pediátricos: Necessidades formativas e estratégias de coping dos profissionais de saúde. Revista Portuguesa de Enfermagem de Saúde Mental, (Especial 7), 50–56.

Rocha, A. A., & et al. (2023). Pediatric palliative medicine in Brazil: An ethical reflection of medical practice. Acta Bioethica, 29(1), 39–48.

Santos, T. V. D., Moreira, M. C. N., & Sevilha, M. (2023). The ethics of care and pediatric palliative care: A potential dialogue. Ciência & Saúde Coletiva, 28(4), 1011–1019.

Silva, W. C., & Rocha, E. M. S. (2021). Atuação da equipe de saúde nos cuidados paliativos pediátricos. Revista Bioética, 29(4), 697–705.

Sociedade Brasileira de Pediatria. (2017). Cuidados paliativos pediátricos: O que são e qual sua importância? São Paulo, Brazil: SBP. https://bit.ly/2HrUo0U

Sousa, I. T., & et al. (2023). End-of-life care in Brazilian Pediatric Intensive Care Units. Jornal de Pediatria, 99(4), 341–347. https://doi.org/10.1016/j.jped.2023.02.003

World Health Organization. (2019). Palliative care. https://bit.ly/2HruiLU