

PEDIATRIC PALLIATIVE CARE: BUILDING A SERVICE

CUIDADOS PALIATIVOS PEDIÁTRICOS: CONSTRUÇÃO DE UM SERVIÇO

CUIDADOS PALIATIVOS PEDIÁTRICOS: CONSTRUYENDO UN SERVICIO

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ABSTRACT

To present the experience of building and maintaining a pediatric palliative care service (PPC) in a hospital under the administration of the Health Department of the State of Ceará, Brazil. This is an experience report. The service began at the institution in 2017, with a minimal advisory team, including medical professionals, a nurse, a psychologist and a social worker. The growing recognition of the importance of palliation has required a reassessment of paradigms. These setbacks were faced not only with the patients' families, but also with the care teams. Despite progress, early referral remains a challenge in everyday life. Setting up a service dedicated to pediatric palliative care is a process that requires consideration of different elements. Discussing the structuring of such a specific service aims to share learnings and encourage the continuous evolution of the area, promoting a multidimensional approach to care.

Keywords: *Palliative Care; Pediatrics; Patient Care Team.*

RESUMO

Apresentar a experiência da construção e manutenção de um serviço de cuidados paliativos pediátricos (CPP) em um estabelecimento hospitalar sob a administração da Secretaria de Saúde do Estado do Ceará, Brasil. Trata-se de um relato de experiência. O serviço iniciou na instituição em 2017, com uma equipe mínima consultiva, incluindo profissionais médicos, enfermeira, psicóloga e assistente social. O reconhecimento crescente da importância da palição exigiu a reavaliação de paradigmas. Tais reverses foram enfrentados não somente junto às famílias dos pacientes, mas também junto às equipes assistenciais. Apesar dos avanços, o encaminhamento antecipado permanece como desafio no cotidiano. A instauração de um serviço dedicado aos cuidados paliativos pediátricos é um processo que demanda a consideração de elementos variantes. A discussão sobre a estruturação de um serviço tão específico visa compartilhar os aprendizados e incentivar a evolução contínua da área, promovendo uma abordagem multidimensional no cuidado.

Descritores: *Cuidados Paliativos; Pediatria; Equipe de Assistência ao Paciente.*

RESUMEN

Presentar la experiencia de la construcción y mantenimiento de un servicio de cuidados paliativos pediátricos (CPP) en un hospital bajo la administración del Departamento de Salud del Estado de Ceará, Brasil. Se trata de un relato de experiencia. El servicio comenzó en la institución en 2017, con un equipo consultivo mínimo, incluyendo profesionales médicos, una enfermera, una psicóloga y una trabajadora social. El creciente reconocimiento de la importancia de la paliación ha exigido una reevaluación de los paradigmas. Estos contratiempos se enfrentaron no sólo a las familias de los pacientes, sino también a los equipos asistenciales. A pesar de los avances, la derivación precoz sigue siendo un reto en el día a día. La creación de un servicio dedicado a los cuidados paliativos pediátricos es un proceso que requiere la consideración de diferentes elementos. Discutir la estructuración de un servicio específico de este tipo tiene como objetivo compartir las lecciones aprendidas y fomentar la evolución continua del área, promoviendo un enfoque multidimensional de la atención.

Descritores: *Cuidados Paliativos; Pediatría; Grupo de Atención al Paciente.*

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INTRODUCTION

In this manuscript, we aim to present the experience of the construction and maintenance of a pediatric palliative care service (PPC) in a hospital under the administration of the Health Department of the State of Ceará, Brazil. The pediatric hospital, founded in 1952, provides services to the entire state of Ceará, in a wide range of specialties. Its infrastructure includes an urgency and emergency center, wards, intensive care units (ICU) for neonates, children and adolescents, a surgical center, outpatient clinics and home care. Recognized in the Northeast as a reference in rare diseases, the hospital has advanced technology to treat children and adolescents with Complex Chronic Conditions (CCC). Most of the patients treated have health conditions that compromise and limit their lives¹.

In this context, Palliative Care emerges, which seeks to improve the quality of life of people with serious illnesses and their families, through a multidisciplinary team focused on the early relief of pain and biopsychosocial and spiritual symptoms². In pediatrics, this care is indicated for children and adolescents with congenital diseases, genetic diseases, chronic neurological conditions, onco-hematological conditions, and other complex chronic conditions³.

Palliative care was started by Cicely Saunders in England in 1967. In Brazil, the first service appeared in 1983 at the Hospital das Clínicas in Porto Alegre. The origin of the first pediatric palliative care service is not clearly defined in the literature. However, in 2022, the Mapping of Pediatric Palliative Care in Brazil recorded seven CPP services in Ceará, the highest number in the Northeast Region. Nationally, there are 90 services, with 52 located in the Eastern Region⁴.

Thus, as the complex needs of pediatric patients in Ceará grew, due to the increase in care and technological advances that extended life, it became urgent to form a specialized team. This need was evident in decision-making, symptom management, and addressing bioethical and social dilemmas. In response, in 2017, a hospital in Ceará implemented a CPP service.

Based on the need to disseminate knowledge and experiences with scientific and social bases, we chose to discuss the experiences of the service based on an experience report, which conveys the singularities of the experience and the challenges inherent to the trajectory on stage⁵.

METHOD

This is a report on the implementation of a PPC service in a public children's hospital in Fortaleza, Ceará, Brazil. Using the experience report as a methodological resource, it is emphasized that experiences precede reflection and analysis. Thus, its objective is to expand knowledge through critical and reflexive analysis of the contexts experienced⁵.

The time frame of this report refers to the period between the years 2017 and 2023, in which the process of implementation and remodeling of the service took place actively in the aforementioned pediatric hospital. The axis of the experience deals with the daily challenges for the implementation of a palliative care service that have become mechanisms for the improvement of the care provided. To capture the nuances of this

experience, the professionals who make up the CPP service used logbooks described by the professionals working in the service, participant observation, as well as systematic conversation circles within the CPP team.

RESULTS

In 2017, there was an exponential increase in the number of visits to the pediatric hospital in Fortaleza. As it is a reference in highly complex care, care for patients with advanced diseases or without a curative perspective has been intensified, bringing new challenges such as the control of complex physical symptoms and care for social and emotional vulnerabilities¹. Faced with the complexity of the cases, the hospital's medical teams resorted to the guidelines of the bioethics committee to make difficult decisions. Thus, a gap was identified in the training of professionals to manage decisions in the face of disease progress and imminent death.

Thus, the imperative need to found a specialized CPP service was highlighted. To this end, the hospital management organized meetings with the care team, the bioethics committee, and experts in the field. In addition, there was a need to organize educational sessions to train health professionals who would be directly involved in this type of care.

The project involved the formation of a multidisciplinary team to integrate care with the care team of the various sectors of the hospital, facing initial resistance due to outdated perceptions about its concept and relevance. The adaptation of care considered not only clinical aspects, but also the social and economic realities of patients and families.

The service was then implemented in 2017, aiming to address the challenges and promote necessary changes. Formalized by means of an ordinance of the hospital administration, it began with a basic multidisciplinary team, with the objective of providing support in the various hospitalization units, except for pediatric oncology, which already had a specialized team¹.

The referral process began to act from the completion of a service request form, signed by the medical team of the wards or ICU's, containing personal information, such as: name of the patient and legal guardian; Date of birth; medical record number and city of origin; clinical data, including the diagnosis and use of equipment such as tubes, tracheostomy, or mechanical ventilators; and a detailed explanation of the need for intervention by the specialized CPP team.

The service aimed to respond to requests within 48 to 72 hours. However, in the face of the progressive increase in demands, it has become impractical. Based on the accumulated experiences and the needs identified by the teams over the subsequent years, there was a continuous process of improvement and adjustment of the procedures for issuing opinions. Currently, we use the following eligibility criteria for admission: 1) bioethical conflicts, 2) treatments of refractory symptoms, 3) social vulnerabilities, 4) end-of-life care, 5) intense family and patient suffering related to diagnosis and prognosis, 6) intra-family conflicts that interfere with decision-making, and 7) therapeutic limitation.

If the patient is eligible, the unit and palliative care teams discuss the case. Admission leads to getting closer to the family to establish a bond that will facilitate the care process. Initially, Family Conferences (FC) were held in all cases, but with increased

demand and difficulties in attendance. The focus shifted to dialogue with the primary caregiver, maintaining FC when possible. The purpose of the meetings is to align expectations and develop a collaborative care plan.

Currently, the criteria for performing FC are: proximity to the end of life with patients already linked; worsening of the clinical condition, according to the eligibility criterion; patients already bound evolving with therapy limitation; unbound patients evolving with therapy limitation; end-of-life proximity to unrelated patients; conflicts with the care team that interfered in decision-making and in the care process; intra-family conflict that interferes with decision-making and the care process; reception of intense suffering related to diagnosis and prognosis; and difficulty in the dehospitalization process. Without exception, priority is given to the ICU over the ward.

Over the years, it has been observed that the predominant profile of patients treated by the PPC service is characterized by life-threatening CCC. These patients are grouped into six main categories and receive continuous follow-up from the moment of diagnosis, through the transition to adulthood. Categories include cystic fibrosis, severe pulmonary pathologies, epidermolysis bullosa, congenital heart diseases, metabolic disorders, neurodegenerative diseases, and chromosomal abnormalities. During the period analyzed, about 55% of the patients died, 16% were discharged with subsequent outpatient support, and 8% were assisted by home care services¹.

The CPP team works in all areas of the hospital, including emergency departments, wards, and ICUs. In addition, a unit dedicated to long-term care assists children with an indication of limited interventions (adequacy of therapeutic efforts), supporting them both in the final stage of life, with symptom management, and in the transition to safe dehospitalization, whether or not the child is dependent on mechanical ventilation.

Thus, we could see significant progress in the recognition of CPPs in recent years. This required deconstructions, not only among the families, but also among the care teams. Challenges persist for early diagnosis and referral. In addition, it is crucial to recognize that many of the resistances encountered have emotional roots, reflecting the difficulty of professionals in establishing and dealing with the imminent death of children.

DISCUSSION

To implement an effective palliative care service, it is essential to know the profile of patients and select a care model that aligns with the needs of the institution. A clear definition of the roles of the multidisciplinary team is also critical.

A study by the Abrinq Foundation⁶ points to a 39% increase in extreme poverty among children in Ceará, impacting approximately 753,000 young people. This scenario intensifies the challenges of hospital discharge in palliative care, due to the combination of socioeconomic and medical difficulties.

In this context, the hospital in focus conducted a detailed analysis of the profile of its patients, following SBP³ criteria, in order to adjust and specialize care. Priority was given to the care of children with multisystem pathologies, both congenital and acquired, which require a more complex and technologically advanced approach to care.

To meet the biopsychosocial needs of patients and their families, a basic multidisciplinary team was formed, following the minimum recommended structure, which includes a doctor, nurse, psychologist and social worker, with support from other specialties, when necessary. The importance of being an itinerant team to assist different areas of the hospital was also recognized, collaborating with the existing team in the creation of personalized care plans⁷.

Itinerant multidisciplinary teams are essential to improve early detection of patients, manage symptoms effectively, direct demands for appropriate referrals, and develop therapeutic plans that identify the stage of the disease early. They also suggest alternative treatments when necessary and promote continuing education for the teams, integrating the philosophy of palliative care in the institution.

However, the interaction with non-specialized teams presents challenges, requiring a process of adaptation and exchange of knowledge that can be time-consuming for the urgencies of the cases. This approach is in line with primary palliative care, allowing professionals with basic knowledge in the field to carry out palliative interventions. As the needs of patients and families intensify, the specialized team becomes more active, dealing with complex symptoms, support in progressive losses, management of anticipatory grief, end-of-life planning, bureaucratic issues, and adaptation to functional losses⁷.

It is understood that the efforts of the teams must be integrated to create an individualized care plan, addressing the physical, psychological, social and spiritual needs of the patient and family members. In this scenario, the Family Conference stands out as an essential intervention, aimed at improving communication between patient, family and medical team, and coordinating the care plan⁸.

The challenge of accepting palliative care persists as a challenge, since it has historically been linked to incurable and irreversible diseases. This leads health teams and family members to hesitate about their early adoption, associating them with the end of life. Consequently, palliative care is often requested late, limiting its potential to provide comprehensive relief to the patient⁹.

The accumulated experience underlines the importance of forming specialized PPC teams, with the aim of improving the quality of life of patients and their families. This practice challenges the demystification of taboos related to life and death, to conceptions of healing and care, requiring the formation of new paradigms. In this context, the World Health Organization emphasizes health education as a fundamental pillar for the development of public health policies aimed at Palliative Care. This includes the training and qualification of professionals and caregivers, aiming to increase recognition, knowledge and skills on the subject, which, in turn, favors behavioral changes¹⁰.

CONCLUSION

The implementation of the Pediatric Palliative Care service at the pediatric hospital in Fortaleza, which began in 2017, represents a significant advance in the care of children with life-threatening health conditions. The reported experience highlights the need for a multidisciplinary and specialized approach to face the complex challenges

imposed. The formation of a multidisciplinary team was essential to integrate palliative care with existing care, promoting holistic care that considers the biopsychosocial needs of patients and their families.

The importance of continuous education and training of health professionals in palliative care is emphasized, as well as the need to demystify taboos related to death and dying. The implementation of Family Conferences (FC), as a strategy to improve communication between the health team, the patient and his/her family and to coordinate the care plan, stands out as an innovative practice that aligns expectations and strengthens bonds.

Finally, this report illustrates the progress and challenges in the implementation of CPP services in a context of high complexity and vulnerability. The need for continuous adaptation of services to respond to the specific demands of patients and their families is highlighted, as well as the importance of public policies that support the development and expansion of palliative care as an integral part of the health system. The commitment to continuous improvement and professional training, together with the promotion of the demystification of palliative care, are fundamental to ensure the quality of life of pediatric patients and their families.

REFERENCES

1. Machado T, Neves C, organizadores. Cuidados Paliativos Pediátricos. Campestre de Goiás: Gráfica e Editora Aliança; 2023. 122 p.
2. World Health Organization. Integrating palliative care and symptom relief into primary health care: a WHO guide for planners, implementers and managers. [Internet]. 2018. Disponível em: <https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf>.
3. Sociedade Brasileira de Pediatria. Departamento Científico de Medicina da Dor e Cuidados Paliativos. Cuidados paliativos pediátricos: o que são e qual sua importância? Cuidando da criança em todos os momentos [Internet]. 2017. Disponível em: <https://bit.ly/3jzgiis>.
4. Ferreira E, et al. Mapeamento dos Cuidados Paliativos Pediátricos no Brasil. São Carlos: Ed. dos Autores; 2022.
5. Mussi RF de F, Flores FF, Almeida CB de. Pressupostos para a elaboração de relato de experiência como conhecimento científico. RPE [Internet]. 2021 Set 1 [citado 2024 Mar 1];17(48):60-77. Disponível em: <https://periodicos2.uesb.br/index.php/praxis/article/view/9010>.
6. Fundação Abrinq. Cenário da Infância e da adolescência no Brasil 2023. 1ª ed. São Paulo: Fundação Abrinq; [Internet]. 2023. Disponível em: https://observatoriocrianca.org.br/system/library_items/files/000/000/035/original/cenario-da-infancia-e-adolescencia-no-brasil-2023.pdf.pdf?1678125969.
7. Crispim D, Bernardes DCR. Organização e gerenciamento de serviços de cuidados paliativos. In: Carvalho RT, Rocha JA, Frank EM, Crispim DH, Jales SMCP, Souza MRB, editores. Manual da residência de cuidados paliativos: abordagem multidisciplinar. 2ª ed. São Paulo: Manole; 2022. p. 63-74.
8. Neto IG. A conferência familiar como instrumento de apoio à família em cuidados paliativos. Rev Port Med Geral Fam [Internet]. 2003 Jan 1 [citado 2024 Jan 22];19(1):68-74. Disponível em: <https://rpmgf.pt/ojs/index.php/rpmgf/article/view/9906>.
9. Batista GA, Alencar MS, Gondim AS. A experiência de paliar e de cuidar no maior hospital terciário do Ceará. Cadernos ESP [Internet]. 2021 Jul 27 [citado 2024 Jan 22];15(1):63-7. Disponível em: <https://cadernos.esp.ce.gov.br/index.php/cadernos/article/view/541>.
10. Michelson KN, Ryan AD, Jovanovic B, Frader J. Pediatric Residents' and Fellows' Perspectives on Palliative Care Education. Journal of Palliative Medicine. 2009;12(5):451-7. Doi: 10.1089/jpm.2008.0263.