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IMPLEMENTATION OF PEDIATRIC PALLIATIVE CARE: RETROSPECTIVE ANALYSIS OF CHRONIC LONG-STAY PATIENTS AT HC-UFTM

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ABSTRACT

Introduction: Pediatric Palliative Care (PPC) represents a multidisciplinary approach that aims to alleviate the suffering and improve the quality of life of children with serious illnesses and their families. Although standardized in Brazil, the implementation of CPP still faces challenges, mainly due to the lack of specialized professionals and cultural resistance. This study aims to evaluate the effectiveness and scope of SSC in a referral hospital in Brazil, identifying barriers and potentialities to optimize this care. Goal: OBJECTIVE: To analyze long-term pediatric hospitalizations at the Hospital de Clínicas of the Federal University of Triângulo Mineiro (HC-UFTM) and to verify the flow of chronic patients who could benefit from SSC, seeking to understand the profile of hospitalizations and factors that influence late inclusion in this care. Methodology: A retrospective study was carried out based on the review of medical records of children hospitalized for more than 30 days between 2018 and 2022 in the Pediatrics sectors of HC-UFTM, including children's emergency room, nursery, pediatric ICU, and wards. Criteria such as length of hospital stay, pathologies, frequency of hospitalizations, and difficulties in discharge were analyzed. The data were organized into tables and frequency graphs for easy visualization. The study was approved by the Research Ethics Committee (CAAE: 57388722.7.0000.5154) and formalized in Plataforma Brasil. Findings:
A total of 180 medical records were analyzed, of which 106 hospitalizations lasted 100 days or more. Among the patients, 23.9% died and, of the 180, only ten were formally included in SSC. The main causes of hospitalization were prematurity (30.6%) and respiratory distress (22.8%). The analysis revealed that 87.5% of the patients included in PPC died on the same day or one day after the start of palliative care, suggesting the late introduction of this care. The lack of documentation and the abrupt disconnection of families from the team's follow-up reflect the need for improvements in the implementation of CPP. Conclusion:
The low incidence of SSC and the late introduction of care reflect structural and cultural challenges in the implementation of these services. There is an urgent need for investments in job training, infrastructure and ongoing support for families during the grieving process. Partnerships with institutions experienced in CPP can strengthen the quality of care, ensuring a more dignified and compassionate approach to children with serious illnesses and their families.

Keywords: Pediatric Palliative Care. Prolonged hospitalization. Quality of Life. Multidisciplinary Support. Implementation of Care. HC-UFTM.

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INTRODUCTION

Palliative care (PC) has historical roots dating back to the fifth century, when it was associated with the concept of "Hospice", a place intended to welcome pilgrims, generally linked to religious practices. However, the Hospice model, which gave rise to modern PC, only acquired hospital and structured characteristics at the end of the nineteenth century (MARCUS et al., 2020). In the 1960s, physician Cicely Saunders consolidated the concept of PC by establishing a model of care aimed at relieving suffering and promoting quality of life, especially in contexts of terminal illness (WOLFF et al., 2010). The World Health Organization (WHO), in 2018, defined PC as a set of practices aimed at preventing and relieving suffering, covering physical, psychological, social, and spiritual aspects of both patients and their families (BENINI et al., 2022).

In Brazil, pediatric palliative care (PPC) has expanded, albeit unevenly between regions and public and private health systems (KUMAR, 2011). Although standardized since 1998 by Ordinance No. 3,535 of the Ministry of Health, and incorporated into the Unified Health System (SUS) in 2002 through Ordinance No. 19, there are still significant gaps in access to SSC in reference hospitals, such as the Hospital de Clínicas of the Federal University of Triângulo Mineiro (HC-UFTM) (AMARRI et al., 2021). This context reflects challenges for the implementation of CPP, ranging from the population's lack of knowledge to the absence of specialized professionals and adequate structural and financial resources (ANGHELESCU; OAKES; HINDS, 2006).

PPC have specificities that distinguish them from PC in adults, such as the need to adapt to different stages of child development and the profound emotional impact on families (MOODY et al., 2011). These characteristics require an individualized care model, with a sensitive approach focused on the various dimensions of child suffering, including emotional, spiritual, and social aspects (THRANE et al., 2017). In this sense, the multidisciplinary team has a crucial role, as it needs to deal with the particularities and complexities associated with the care of children with potentially terminal illnesses (FEUDTNER et al., 2021).

When performed by trained teams with adequate infrastructure, CPP are able to significantly improve the quality of life of children and their families, providing symptom relief and psychological support, as well as preventive care in relation to grief (HIMELSTEIN, 2006). WHO recommends that PPC be planned and integrated on an ongoing basis, so that children with long-term needs can transition to PC as adults, when necessary, while maintaining the assistance of a specialized team familiar with their clinical history (MARCUS et al., 2020).

At HC-UFTM, the creation of the Pediatric Intensive Care Unit (Pediatric ICU) in 1995 marked a significant advance in child care, with about 330 annual hospitalizations, of which 70% are premature infants (MARTINS; DA HORA, 2017). However, the increase in the life expectancy of these children, especially those with complex chronic conditions, imposes new challenges to modern medicine, including iatrogenic diseases and the need for continuous PC for children with permanent sequelae (SALAMONDE et al., 2006). In view of this scenario, the present study was designed with the objective of analyzing long-term pediatric hospitalizations at HC-UFTM and evaluating the flow of chronic patients who could benefit from a structured CPP service (LAVÔR; PEREIRA, 2023).

METHODOLOGY

This retrospective study was based on two main methodological approaches: i) a literature review of the scientific literature on pediatric palliative care (PPC), and ii) the use of quantitative methods for the analysis of clinical records.

Data collection was carried out through the digital medical records of all pediatric hospitalization services of the Hospital de Clínicas of the Federal University of Triângulo Mineiro (HC-UFTM), including the children's emergency room, the nursery, the pediatric intensive care unit (pediatric ICU) and the pediatric wards. The medical records of patients hospitalized for a period of more than 30 days between 2018 and 2022 were included in the study. Each medical record was analyzed based on three main criteria: 1. Length of hospital stay, 2. Pathologies presented, and 3. Difficulties for hospital discharge.

After data collection, a quantitative analysis was carried out, based on the theoretical framework developed from the literature review. Frequency graphs and tables were prepared to visually present relevant aspects of the research and facilitate the understanding of the results.

Considering that this study involved exclusively the analysis of medical records, without direct contact with the patients, and that many lost follow-up in the service, the waiver of the Informed Consent Form was requested and obtained from the Ethics Committee of the Hospital de Clínicas of UFTM. The project was previously evaluated and approved by the Research Ethics Committee of the Federal University of Triângulo Mineiro, under the Certificate of Presentation for Ethical Appreciation (CAAE):

57388722.7.0000.5154, and opinion number: 5.434.194. In addition, the study was also registered and approved by the Teaching and Research Management (GEP) of HC-UFTM, and formalized in the Brazil Platform, in accordance with ethical and regulatory requirements.

RESULTS

180 medical records of children hospitalized for more than 30 days in the UFTM Pediatrics service between 2018 and 2022 were analyzed. Of this sample, 106 hospitalizations lasted 100 days or more. Among the 180 patients, 75 were female and 105 were male. Of the total, 110 were premature, and 114 patients were hospitalized only once, with the number of hospitalizations ranging from one to 23, resulting in an average of approximately 1.97 hospitalizations per patient.

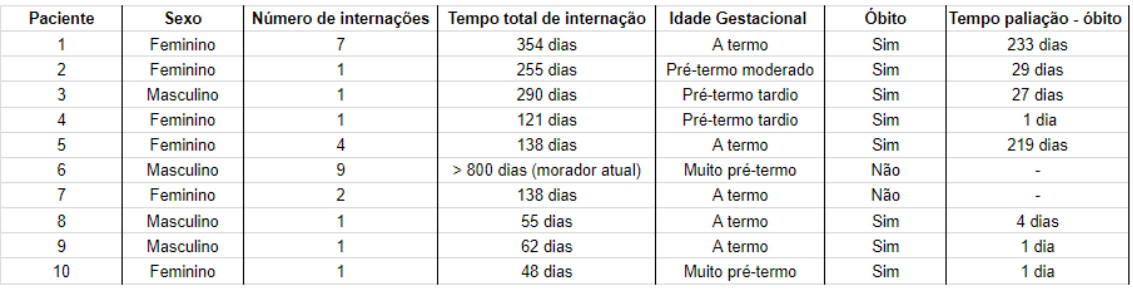
The mortality rate was 23.9%, and the main causes of hospitalization were directly related to prematurity in 30.6%, followed by neonatal respiratory distress in 22.8%, congenital diseases in 8.9%, and asphyxia in 3.9%. Less frequent reasons included neonatal hypoglycemia, submersion accidents, severe burns, infectious diseases, and central nervous system disorders. Common problems for hospital discharge included feeding difficulties, respiratory distress requiring mechanical ventilation, care-related infections, and fluid and electrolyte disturbances.

Among the 180 medical records analyzed, only ten children were formally placed in Pediatric Palliative Care (CPP). Children with records of "reserved prognosis and comfort clinical care", "management in terminal care" and other similar mentions were also included in the analysis. Of these ten children, eight died, one remains hospitalized, and one was transferred to her city of origin. Of the patients who died, 37.5% were placed in SCP one day before death.

Table 1 presents the profile of the patients placed in SSC. Of these, five were full-term infants, two were late preterm, two were very preterm and one was moderately preterm. Most of the children had only one hospitalization, with an average of 2.8 hospitalizations. Regarding gender, 60% were female and 40% male.

Regarding interventions, 70% of the children underwent surgeries during the hospitalization period, but only one was operated on after inclusion in the PPC. Regarding therapeutic procedures, blood transfusions were widely used, ranging from one to 28 transfusions per child; however, only 40% of transfusions occurred after the formal initiation of PPC. Among the underlying conditions, 40% of the patients had congenital heart diseases, 30% had central nervous system disorders, and 40% had physical alterations suggestive of genetic syndromes.

Table 1. Profile of patients placed in palliative care.



Paciente	Sexo	Número de internações	Tempo total de internação	Idade Gestacional	Óbito	Tempo paliação - óbito
1	Feminino	7	354 dias	A termo	Sim	233 dias
2	Feminino	1	255 dias	Pré-termo moderado	Sim	29 dias
3	Masculino	1	290 dias	Pré-termo tardio	Sim	27 dias
4	Feminino	1	121 dias	Pré-termo tardio	Sim	1 dia
5	Feminino	4	138 dias	A termo	Sim	219 dias
6	Masculino	9	> 800 dias (morador atual)	Muito pré-termo	Não	-
7	Feminino	2	138 dias	A termo	Não	-
8	Masculino	1	55 dias	A termo	Sim	4 dias
9	Masculino	1	62 dias	A termo	Sim	1 dia
10	Feminino	1	48 dias	Muito pré-termo	Sim	1 dia

Source: prepared by the author (https://docs.google.com/spreadsheets/d/18nMzSOpmBmYV1Ob1JmGMco_fSWATEBgV_cld7z2YIUA/edit#gid=127842268).

DISCUSSION

The analysis of the medical records revealed a low inclusion rate in Pediatric Palliative Care (CPP), indicating challenges and limitations in the effective implementation of this type of care in pediatrics. Previous studies have shown that the early introduction of PPCs can significantly improve the quality of life of children with serious illnesses, in addition to providing comprehensive support for their families, contributing to the relief of suffering and the management of complex symptoms (MARCUS et al., 2020). However, the reality observed at HC-UFTM, where most patients were included in PPC only at an advanced stage of the disease, reflects the obstacles pointed out in the literature for the consistent implementation of pediatric palliative care, especially in overloaded health systems (KUMAR, 2011).

The late implementation of SSC appears to be associated with a combination of factors, including a lack of specialized professionals and a high workload that limits careful follow-up and early management of these patients. As highlighted by Wolff et al. (2010), PPC programs require a multidisciplinary team that can integrate physicians, nurses, psychologists, and social workers to provide comprehensive and effective support. This approach, when properly implemented, not only meets the child's medical needs but also deals with the emotional and psychosocial aspects of the disease, which are essential for complete care (BENINI et al., 2022).

The complexity of pediatric care, especially in cases of severe conditions and poor prognosis, requires that the health team not only have specialized training, but also adopt a humanized approach that includes welcoming the bereavement and emotional suffering of families (ANGHELESCU; OAKES; HINDS, 2006). Moody et al. (2011) argue that this approach helps to establish a bond with the family, allowing them to feel supported and supported during the treatment process and especially during grief after the loss. However, at the HC-UFTM, the lack of detailed death records in 87.5% of the cases analyzed and the abrupt interruption of family follow-up after death reflect the need for improvements both in documentation and in continuous support to the family (HIMELSTEIN, 2006).

Resistance to the implementation of PPC in pediatrics, as observed in this study, may be related to cultural and emotional barriers that make the topic of infant death even more sensitive. Feudtner et al. (2021) state that, in societies where the death of a child is viewed with great resistance, there is a tendency to postpone discussions about prognosis and palliative care, avoiding directly facing the fatal outcome. This behavior can limit the introduction of SSC and lead to the inclusion of patients only at times very close to death, reducing the potential benefits of this care (THRANE et al., 2017).

In addition, the lack of qualified professionals for CPP and the high turnover of staff in hospitals affect the continuity and quality of care provided. Studies suggest that, for this care to become effective, it is necessary to invest in specialized training and an educational approach that helps professionals develop communication skills about prognosis and management of serious conditions in pediatrics (AMARRI et al., 2021). This type of training promotes not only technical preparation, but also greater sensitivity and ethics to deal with complex pediatric cases (DE LAVÔR; PEREIRA, 2023).

The integration of partnerships with institutions that have consolidated experience in CPP is also a recommended strategy to strengthen care. As highlighted by Martins and Da Hora (2017), partnerships can facilitate the exchange of knowledge, which contributes to the formation of a team that is better prepared to handle severe cases, ensuring that children receive the necessary support in a more appropriate and dignified way.

CONCLUSIONS

This study demonstrates the low incidence of Pediatric Palliative Care among children hospitalized for prolonged periods at UFTM, indicating the need for improvements in the implementation of this care. The results suggest that the late introduction of PPC may be associated with structural difficulties, lack of specialized training, and cultural resistance to the topic. The incomplete documentation of deaths and the early disconnection of families from follow-up by the health team show weaknesses in the approach to end-of-life in pediatrics.

The expansion of pediatric palliative care requires investments in professional training and in an infrastructure that promotes the continuity of support during and after the mourning period. In addition, collaboration with institutions experienced in SSC can facilitate the introduction of advanced and humanized practices, promoting an approach to care that respects the dignity and quality of life of patients and their families. These advances could substantially improve the care provided to children with serious and chronic illnesses, and their families, ensuring a more compassionate and caring transition in times of vulnerability.

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