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Clinical-epidemiological profile of children in palliative care

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Abstract

This study analyzes the clinical-epidemiological profile of children assisted by the palliative care services of a reference hospital in Ceará, Brazil. A retrospective, quantitative, case series cohort study was conducted with 56 patients aged up to 2 years, 11 months and 29 days. Nervous system and circulatory system diseases, congenital malformations, deformities, and chromosomal anomalies were the most common illnesses. Severe and non-progressive disabling conditions were the main criteria for inclusion in palliative care. As for family conference, the mother was present in 94.6% of the cases. Death (58.9%) was the main outcome, being associated with circulatory system and nervous system diseases, use of respiratory device and mechanical ventilation, requesting sector and palliative care. In conclusion, pediatric palliative care aimed at non-cancer patients has generated new hospital demands, requiring a trained team sensitive to this new reality.

Keywords: Palliative care. Pediatrics. Health profile. Epidemiology. Nursing.

Resumo

Perfil clínico-epidemiológico de crianças em cuidados paliativos de um hospital

O objetivo deste artigo é analisar o perfil clínico-epidemiológico de crianças acompanhadas por um serviço de cuidados paliativos em um hospital pediátrico de referência no Ceará. Trata-se de estudo de coorte retrospectivo, quantitativo, do tipo série de casos, realizado com 56 pacientes de até 2 anos, 11 meses e 29 dias de idade. As doenças mais comuns foram as do sistema nervoso, circulatório, malformações congênitas, deformidades e anomalias cromossômicas. As condições incapacitantes graves e não progressivas foram o principal critério para inclusão na paliação. Na conferência familiar, a mãe esteve presente em 94,6% das ocasiões. O desfecho predominante foi óbito (58,9%), apresentando associação significativa com as doenças do aparelho circulatório, sistema nervoso, uso de dispositivo respiratório e ventilação mecânica, setor solicitante e cuidados paliativos. Conclui-se que os cuidados paliativos pediátricos não relacionados a crianças com câncer têm gerado uma nova demanda a nível hospitalar, exigindo uma equipe capacitada e sensível a essa nova realidade.

Palavras-chave: Cuidados paliativos. Pediatria. Perfil de saúde. Epidemiologia. Enfermagem.

Resumen

Perfil clínico-epidemiológico de los niños en cuidados paliativos en un hospital

Este artículo pretende analizar el perfil clínico-epidemiológico de los niños bajo cuidados paliativos en un hospital pediátrico de referencia en Ceará (Brasil). Este es un estudio de cohorte retrospectivo, cuantitativo, de tipo serie de casos, realizado con 56 pacientes de hasta 2 años, 11 meses y 29 días de edad. Las enfermedades más prevalentes fueron las del sistema nervioso y circulatorio, malformaciones congénitas, malformaciones y anomalías cromosómicas. Las condiciones incapacitantes severas y no progresivas fueron el criterio principal para incluir en paliación. En la conferencia familiar, la madre estuvo presente en el 94,6% de las ocasiones. El desenlace predominante fue la muerte (58,9%) asociada significativamente con enfermedades del sistema circulatorio, sistema nervioso, uso de aparato respiratorio y ventilación mecánica, sector demandante y cuidados paliativos. Los cuidados paliativos pediátricos no relacionados con niños con cáncer generan una nueva demanda a nivel hospitalario, requiriendo un equipo capacitado y sensible a esta nueva realidad.

Palabras clave: Cuidados paliativos. Pediatría. Perfil de salud. Epidemiología. Enfermería.

The authors declare no conflict of interest.

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Due to long-term survival of patients with complex chronic diseases (CHD) enabled by increased early diagnoses and therapeutic advances, palliative care, service aimed at relieving suffering and improving the individual's quality of life, has gained much relevance in health services[1].

In pediatrics, palliative care is understood as the active and comprehensive care provided to children and adolescents from diagnosis to end-of-life, covering the physical, emotional, social, and spiritual dimensions. It focuses mainly on maintaining the child's or adolescent's quality of life and providing family support[1].

World Health Organization (WHO)[1] data estimate that 40 million people need palliative care annually. As for children, most (98%) live in low- and middle-income countries. Thomas Lynch's[2] study on the availability of palliative care services to the population pointed to an expansion of such services globally; however, only 136 countries (58%) offered at least one palliative care service in 2011.

Mapping performed by the Brazilian National Association for Palliative Care (ANCP)[3] observed an increase in the number of establishments offering these services in the country, with 177 palliative care services recorded up to August 2018. Of these, only 21% served the pediatric public.

This study also showed that less than 10% of Brazilian hospitals are assisted by a palliative care team, a reality that negatively interferes with managing users who are potentially dealing with death and suffering[3].

On average, 830 hospitalizations are performed monthly[4] at Albert Sabin Children's Hospital (Hias). A reference in the diagnosis of rare diseases and CCD, the institution provides treatment in several pediatric, clinical, and surgical specialties. Since 2017, the hospital has been supported by a pediatric palliative care (PPC) service.

The PPC team at Hias is both advisory and non-static, providing back-up care and technical-pedagogical support in its various inpatient units, except for the oncology specialty, which has a specific palliative care team.

It is a core multidisciplinary team[5] consisting of a palliative doctor, a nurse, a psychologist, and a social worker, that is engaged at the discretion of the attending physician by requesting an opinion. This arrangement allows to establish shared care among the reference care teams, combining care with the complex needs of patients and their families.

Importantly, the PPC service advisory team does not assume care coordination, rather it acts as a support group that guides palliative measures. The therapeutic care plan is discussed and elaborated using family conference, a more sophisticated systemic approach tool for communication management and family involvement.

Experience as a resident pediatric nurse in this context allowed to recognize the PPC team as a powerful disseminator of palliative care as an approach in constant contact with other care teams from several hospital units. Nonetheless, difficulties in working with teams unaware of this perspective remain and more time is needed for this adaptation.

Considering the need to improve pediatric care through palliative care, academic literature in pediatrics began better exploring the subject from early 21st century, with most studies focusing on palliative care for children living with cancer.

Conversely, few studies on palliative care discuss non-oncological pediatric diseases. Hence, further expanding knowledge on the clinical and epidemiological profile of children receiving non-oncological palliative care can favor the development of strategies aimed at providing comprehensive care to this population.

Objective

This study sought to analyze the clinical-epidemiological profile of children assisted by a palliative care service at a public reference pediatric hospital in the state of Ceará.

Method

Study design, period, and place

A retrospective, quantitative, case series cohort study was performed following the Strengthening the Reporting of Observational studies in Epidemiology (Strobe)[6] initiative. The research was conducted at the Hias pediatric palliative care service, a reference institution in the state health network of Ceará, from August 2020 to February 2021.

Population, inclusion and exclusion criteria

Our study sample consisted of 56 children up to 2 years, 11 months, and 29 days old, admitted to the PPC between 2018 and 2019. A family conference was held with the child's relatives, the reference care team, and the PPC service staff as inclusion criteria. Children diagnosed with cancer were excluded from the survey, as they were outside the target audience.

Study protocol

Clinical (including obstetric, delivery and postpartum), epidemiological, and sociodemographic data were collected using an instrument developed by the author. First we evaluated the request forms for inclusion in the PPC, observing the inclusion and exclusion criteria, as well as other data. Subsequently, we analyzed the medical records of all eligible patients.

Results and statistical analysis

Collected data were entered and stored on the Microsoft Office Excel program, version 2010, and analyzed by the Statistical Package for Social Sciences (SPSS) software, considering ACT's classification for Children with life-threatening conditions and their families. PPC-eligible conditions were classified into four groups (Chart 1)[7].

Chart 1. Conditions eligible for pediatric palliative care (Fortaleza/CE, Brazil, 2021)

Group	Example
Conditions where cure is possible but may fail.	Complex congenital or acquired heart disease, organ failure with recommendation for transplant, etc.
Clinical conditions requiring complex and prolonged treatment.	Cystic fibrosis, sickle cell anemia, chronic renal failure, neuromuscular diseases, etc.
Situations in which treatment is palliative from diagnosis.	Severe forms of osteogenesis imperfecta, some chromosomal abnormalities such as trisomy 13 and trisomy 18, etc.
Severe and non-progressive disabling conditions.	Extreme prematurity, severe cerebral palsy, severe anoxia, etc.

Source: Sociedade Brasileira de Pediatria[7].

Dichotomous variables were analyzed by Pearson's chi-square, considering statistically significant *p*-values less than or equal to 0.05 and a 99% confidence interval.

Results

For a clear picture of the PPC patients' profile, we will present results regarding sociodemographic and clinical-epidemiological data in tables.

Results show a slight prevalence of female patients (51.8%) and infants (76.8%), most coming from municipalities outside the state capital and metropolitan region of Fortaleza (51.9%) (Table 1).

Nervous system diseases (53.6%), followed by congenital malformations, deformities and chromosomal anomalies (48.2%), and diseases of the circulatory system (32.1%) were most prevalent cumulative diseases—that is, that which could manifest together with another type of disease—in this age group. A noteworthy example is that 76.8% of children with diseases of the circulatory system presented some type of congenital heart disease.

Clinically, 58.9% of the patients required some form of respiratory support, such as an oxygen mask/catheter, non-invasive ventilation or invasive mechanical ventilation, whereas 48.2% required a gastric/enteral tube or gastrostomy for feeding.

Table 1. Sociodemographic and clinical-epidemiological characteristics of children assisted by pediatric palliative care service (Fortaleza/CE, Brazil, 2021)

Sociodemographic profile	N	%
Gender		
Male	27	48.2
Female	29	51.8
Age group		
Neonate (>28 days)	12	21.4
Infant/Preschooler (29 days-2 years, 11 months and 29 days)	44	78.6
Origin (n=54)		
Fortaleza and metropolitan region	26	48.1
Other municipalities in the state	28	51.9
Clinical-epidemiological profile		
ICD chapter (n=56)		
Respiratory tract diseases	3	5.4
Endocrine, nutritional, and metabolic diseases	3	5.4
Diseases of the circulatory system	18	32.1
Nervous system diseases	30	53.6
Diseases of the digestive system	3	5.4
Congenital malformations, deformities, and chromosomal anomalies	27	48.2
Genitourinary diseases	7	12.5
Need for respiratory support		
Yes	33	58.9
No	23	41.1
Need for invasive mechanical ventilation		
Yes	27	48.2
No	29	51.8
Need for feeding device		
Yes	33	58.9
No	23	41.1

continues...

Table 1. Continuation

Sociodemographic profile	N	%
Number of admissions		
1	27	48.2
2	11	19.6
>3	18	32.1
Number of intensive care unit (ICU) admissions		
None	13	23.2
1	39	69.6
>2	4	7.1

ICD: International Classification of Diseases

Regarding hospital admission, 48.2% were hospitalized only once, 19.6% were admitted twice, and 32.1% reported more than three hospitalizations. Note that 69.6% of the sample were admitted to the ICU at least once.

Regarding the obstetric and delivery data of the PPC-monitored children, mothers were aged 15 to 35 years (77.5%) and had attended between one and six prenatal consultations (56.8%) (Table 2). As for childbirth, most children were delivery by C-section (56.3%), at full term (61.7%), with normal weight (65.2%), and good vitality (67.5%).

Table 2. Obstetric, delivery, and postpartum characteristics of children assisted by pediatric palliative care service (Fortaleza/CE, Brazil, 2021)

Obstetric variables	N	%
Maternal age (n=40)		
15-35	31	77.5
>35	9	22.5
Number of prenatal consultations (n=37)		
None	1	2.7
1-6 consultations	21	56.8
>7 consultations	15	40.5

continues...

Table 2. Continuation

Obstetric variables	N	%
Childbirth variables		
Means of delivery (n=48)		
Natural	21	43.8
C-section	27	56.3
Classification according to gestational age (n=47)		
Premature	18	38.3
Full term	29	61.7
Classification according to birth weight (n=47)		
Extremely low (<1,000 g)	2	4.4
Very low (<1,500 g)	4	8.7
Low (<2,500 g)	8	17.4
Normal (2,500-4,000 g)	30	65.2
Macrosomic (>4,000 g)	2	4.4
Apgar rating at the fifth minute (n=40)		
Moderate asphyxia	9	22.5
Mild asphyxia	4	10
Good vitality	27	67.5

Pediatric palliative care profile analysis shows that most children had severe and non-progressive disabling conditions (58.9%) and were under continuous palliative care (71.4%) (Table 3). Pediatric and neonatal intensive care units placed the most requests for the PPC commission's opinion (60.7%). Most children (89.3%) had only one family conference, with the mother participating in 94.6% of the occasions, followed by the father (55.4%) and the attending physician (46.7%). We found little participation of other health professionals (1.7%). As for the outcome, most children died (58.9%) and 41.1% were discharged or transferred from the hospital.

Of the specific clinical and PPC variables analyzed, only diseases of the circulatory system, nervous system, use of respiratory device and mechanical ventilation, requesting sector, and types of palliative care showed significant association with the outcome (death) (Table 4).

Table 3. Pediatric palliative care profile (Fortaleza/CE, Brazil, 2021)

Pediatric palliative care profile	N	%
Classification according to the eligible conditions		
Conditions for which cure is possible but may fail	9	16.1
Conditions requiring complex and prolonged treatment	2	3.6
Conditions where treatment is palliative from diagnosis	12	21.4
Severe, non-progressive disabling conditions	33	58.9
Type of pediatric palliative care		
Exclusive care	16	28.6
Continuous care	40	71.4
Sector requesting the palliative care commission's opinion		
Special patient wards/blocks/units	22	39.3
Pediatric and neonatal intensive care units	34	60.7
Number of family conferences		
1	50	89.3
2	6	10.7
Participation in the family conference		
Attending physician	26	46.4
Other health professionals	1	1.7
Mother	53	94.6
Father	31	55.4
Sibling	4	7.1
Aunt/uncle	14	25
Grandparents	9	16.1
Others	6	10.7
Child's outcome		
Discharge/transfer	28	41.1
Death	33	58.9

Table 4. Association between clinical and palliative care variables related to the outcome death (Fortaleza/CE, Brazil, 2021)

Variables	Death		*p*
	No	Yes	
Type of disease			
Respiratory tract diseases			
Yes	1 (25)	3 (70)	0.498*
No	22 (42.3)	30 (57.7)	
Diseases of the circulatory system			
Yes	3 (16.7)	15 (93.3)	0.011*
No	20 (52.6)	18 (47.4)	
Nervous system diseases			
Yes	17 (53.1)	15 (46.9)	0.034*
No	6 (25)	18 (75)	
Diseases of the digestive system			
Yes	1 (25)	3 (75)	0.498*
No	22 (42.3)	30 (57.7)	
Congenital malformations, deformities, and chromosomal anomalies			
Yes	6 (27.3)	16 (72.7)	0.091*
No	17 (50)	17 (50)	
Use of health device			
Nutritional support device			
Yes	16 (48.5)	17 (51.5)	0.177*
No	7 (30.4)	16 (69.6)	
Breathing support device			
Yes	8 (24.2)	25 (75.8)	0.002*
No	15 (65.2)	8 (34.8)	
Mechanical ventilation			
Yes	7 (12.5)	23 (74.1)	0.026*
No	16 (55.2)	13 (44.8)	
Characteristics of pediatric palliative care			
Requesting sector			
Nursery	14 (63.6)	6 (36.4)	0.006*
Pediatric intensive care unit	9 (26.5)	25 (73.5)	
Type of pediatric palliative care			
Exclusive	3 (18.8)	13 (81.3)	0.032*
Continued	20 (50)	20 (50)	

**Pearson's chi-square test*

Discussion

Historically, palliative care has been associated with terminally ill patients, usually affected by neoplastic diseases. In pediatrics, although most publications focus on cancer patients, this concept also extends to other conditions [8].

Difficulties in understanding palliative care, or even therapeutic obstinacy, has negatively impacted children's and adolescents' quality of life worldwide. According to Irina S. Tirado-Perez [9], few children with life-threatening diseases have access to palliative care services, leading many to live without symptom relief, in inadequate conditions, away from family, and enclosed in a hospital environment until the time of death.

Our findings indicate that most PPC-monitored children attended at Hias suffer from severe and non-progressive disabling conditions and conform to the criteria for receiving palliative care concomitant to disease treatments. Diseases of the nervous system, congenital malformations, chromosomal anomalies, and diseases of the circulatory system (such as congenital heart diseases) are also eligible for palliative care. In this regard, we found a significant association (p=0.011) between presence of diseases of the circulatory system and death.

Despite no statistical association, congenital malformations are one of the main mortality causes in children up to 1 year of age. Congenital heart disease is the most frequent malformation found, being the second cause of death within 30 days of life [10]. As we listed congenital heart diseases as diseases of the circulatory system in this study, this may explain the significant association found.

Prenatal and childbirth profile showed that 75.6% of the mothers were outside the gestational risk range, had attended between one and six prenatal consultations, and gave birth to full term and normal weight children. Besides obstetric conditions, PPC-eligible diseases also reflect the therapeutic advances that have taken place since the second half of the 20th century. Technological improvements have enabled greater life expectancy and, consequently, increased the prevalence of pediatric chronic diseases [11,12].

Clinically, 58.9% of the patients required some form of respiratory support and/or nutritional device, such as a gastrostomy. In healthcare, technology has the main role of remedying the child's limits and dependencies, helping to balance bodily functions [13]. Thus, children with complex chronic conditions are more dependent on technology and require multiple medications and treatments. Our findings showed a significant association between the use of a respiratory device (p=0.002), such as invasive mechanical ventilation (p=0.026), and the outcome death. Due to their level of severity and dependence these patients are at greater risk of death.

Moreover, this group can undergo prolonged and frequent hospitalizations, and admissions to pediatric intensive care units (PICU) are common. In this regard, our research found that 32.1% of the evaluated children reported more than three hospital admissions.

Importantly, 60.7% of support requests for palliative care services came from the PICU. This finding may point to a late request for palliative care support, reflecting a misunderstanding of many health professionals about when to start this practice, as they believe that palliation should begin only during the active dying process. This fact was reinforced by the significant association between PICU's request for an opinion and the death outcome, reflecting the greater severity and imminent risk of death of these patients.

Importantly, the current literature advocates the inclusion in palliative care after diagnosis of a life-limiting or life-threatening disease [7]. This measure would help patients and their families to accept and adapt to the disease, impacting their quality of life.

One strategy for implementing this care is to hold a family conference. In the present study, 89.3% of the children attended at least one family conference. By employing this tool, the palliative care team can bond with the patient and their family and create a moment to discuss the disease, the response to treatment, plans and perspectives, allowing them to share anxieties, concerns, and questions [14].

The family conference allows for a more democratically elaborated therapeutic plan that favors care adherence and the prominent role of the family while considering the patient's wishes. It also improves the therapeutic relationship and trust between the care team, the family, and the patient.

The attending physician did not attend 53.6% of the family conferences, with only the palliative care physician present, which reveals relative adherence to palliative care and little understanding by health professionals of the importance and central role of PPC at these moments.

We identified a low participation of other healthcare professionals in the family conference. This finding may be associated with work overload, which disfavors these professionals' attendance or even their awareness of the topic. Decisions regarding palliative care must involve and recognize that all interlocutors are important, including the multidisciplinary team and the family, and not only the physician[15].

As for family participation, we observed an expressive presence of the mother, which highlights the key role women play in caring for children during the health-disease process. However, it also reveals the burden assumed by them, since besides being mothers, they play the concomitant roles of wives, workers, daughters, housewives, etc.

Moreover, the process of a child's hospitalization disrupts the family's daily life and the mothers' physical and emotional well-being, manifesting itself through feelings such as insecurity, fear, and sadness[16].

Thus, the whole family must be included in this process, since children do not always have the necessary cognitive development to understand their health condition. Moreover, a strong, interconnected, and aware family support network is of paramount importance for an effective PPC process.

Study limitations

The sample size and difficulty in obtaining medical record information, due to missing or superficially registered data, were the main limitations in our research. Future studies should prospectively follow up patients under palliative care to obtain data not covered in this study.

Contribution to the area

Our research deepens the knowledge on children under palliative care for non-oncological conditions, thus contributing to a palliative practice adapted to their specificities. Its findings may also support strategies aimed at promoting these patients' quality of life.

Final considerations

Our discussion shows that the PPC, previously associated exclusively with end-of-life care, has expanded both in meaning and scope. In this regard, this study found a predominance of severe and non-progressive disabling conditions, highlighting the impacts resulting from health-related advances. Such reality has enabled the survival of children and adolescents.

Concomitantly, the offer of PPC services has increased, although not expressively. Providing training in palliative care for health professionals is essential since they are responsible for the health care of the child/family binomial.

The outcome death showed statistically significant association with diseases of the circulatory system, nervous system diseases, use of respiratory device and mechanical ventilation, PICU's request for a PPC opinion, and exclusive palliative care.

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Participation of the authors

Igo Borges dos Santos, lead author, collected, tabulated, and analyzed the data. Joana Maria Rocha Sales systematized the results. Isabel Regiane Cardoso do Nascimento advised the research project and collaborated in writing the discussion. Vanilla Oliveira Alencar formatted the article and organized the references. Cesár Augusto Ferreira Gomes de Andrade, Cinara Carneiro Neves, and Luana Nunes Caldini collaborated by reviewing the manuscript.

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