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Original Article

Neonatal palliative care: clinical and epidemiological profile of patients treated at a referral hospital

Cuidados paliativos neonatais: perfil clínico-epidemiológico de pacientes atendidos em um hospital de referência

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ABSTRACT

Introduction: Neonatal palliative care offers improvement in quality of life and relief from suffering for newborns and their families in the face of diagnoses that lead to increased morbidity and mortality.

Objective: To describe the profile of the population cared for by the Pediatric Palliative Care (PPC) service who were admitted to the Neonatal Intensive Care Unit (NICU) of a referral hospital in Curitiba, PR, Brazil.

Method: This is a retrospective, cross-sectional and descriptive study, based on the analysis of the medical records of patients seen by the service between September 2020 and June 2023. The data was analyzed using descriptive statistics.

Results: During the selected period, 303 patients were seen, the majority of whom were male (50.8%). The main clinical conditions involved prematurity (35.3%) and diseases of the nervous system (14.5%). Most of the diagnoses were “conditions for which a cure is possible but may fail.” In view of this, it was agreed with family members and staff to limit support for 11.6% of the neonates. Regarding outcomes, 17.6% of the patients died during their stay in the NICU, the remaining patients were medically discharged from the NICU and 9.8% were referred to the pediatric ward before discharge so that the mothers had the opportunity to be trained in the care of their babies.

Conclusion: The NICU houses newborns with complex conditions who benefit from the practice of PPC. Therefore, recognizing the profile of these patients allows the team to better direct their actions and, consequently, provide better support for the newborn and their family.

Keywords: Palliative Care; Intensive Care Units, Neonatal; Perinatal Death; Congenital Abnormalities; Brazil.

RESUMO

Introdução: Os cuidados paliativos neonatais propõem melhorias na qualidade de vida e alívio do sofrimento para recém-nascidos e familiares diante de diagnósticos que levam a um aumento da morbimortalidade.

Objetivo: Descrever o perfil da população atendida pelo serviço de Cuidados Paliativos Pediátricos (PCP) que estava internada na Unidade de Terapia Intensiva Neonatal (UTIN) de um hospital de referência em Curitiba-PR.

Método: Trata-se de um estudo retrospectivo, transversal e descritivo, a partir da análise do prontuário de pacientes atendidos pelo serviço entre setembro de 2020 a junho de 2023. Os dados foram analisados por estatística descritiva.

Resultados: No período selecionado, foram atendidos 303 pacientes, sendo em sua maioria do sexo masculino (50,8%). As principais condições clínicas envolviam prematuridade (35,3%) e doenças do sistema nervoso (14,5%). A maioria dos diagnósticos enquadra-se como “condições para as quais a cura é possível, mas pode falhar”. Diante disso, foi acordado com familiares e equipe pela limitação de suporte de 11,6% dos neonatos. Com relação aos desfechos, 17,6% dos pacientes foram a óbito durante o internamento na UTIN, os demais receberam alta médica da UTIN, sendo que 9,8% foram encaminhados à enfermaria pediátrica antes da alta para que as mães tivessem oportunidade de serem treinadas em relação aos cuidados de seu bebê.

Conclusão: A UTIN abriga recém-nascidos com condições complexas, os quais se beneficiam com a prática dos PCP. Por isso, o reconhecimento do perfil desses pacientes permite o melhor direcionamento das ações da equipe e, consequentemente, melhor suporte para o neonato e sua família.

Palavras-chave: Cuidados Paliativos; Unidades de Terapia Intensiva Neonatal; Morte Perinatal; Anormalidades Congênitas; Brasil.

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INTRODUCTION

Neonatal Intensive Care Units (NICU) are a specialized environment for the care of newborns with high-risk clinical dysfunctions that require continuous monitoring and/or specific therapies. Among the main conditions that lead to these admissions are congenital anomalies; prematurity; weight less than 1,000 grams; the need for invasive mechanical ventilation; the use of vasoactive drugs; treatment for serious infection; among others[1].

In this context, there are diseases that threaten the continuity of life, resulting in a current and growing need for the practice of Palliative Care (PC) within pediatric and neonatal health services. The term palliative comes from the Latin *palliare*, which means to alleviate, relieve, or attenuate[2]. Thus, this form of care aims to ensure an improvement in the quality of life of patients and their families, through measures such as relief of suffering, symptom control and psychological, social, and spiritual support[3].

In pediatrics, the indication for PC is mostly for patients with congenital and genetic diseases, followed by chronic neurological and onco-hematological conditions[4,5]. The implementation of this care should occur progressively, based on the evolution, complications and limitations imposed by the disease, but always individualizing the needs of the child and their family[2].

However, even though PC is on the rise, it is not available to the entire population. According to the latest Global Atlas published by the World Health Organization (WHO) in 2019, the worldwide availability of PC services for patients with non-communicable diseases was only 39%[6].

In the Brazilian scenario, where this study was held, the development of PC was considered by the WHO to be class 3B, being characterized by the following factors: progression of activism in PC in various locations with the growth of local support in these areas; multiple sources of funding; availability of morphine; various palliative care and hospice services from a variety of providers; provision of some training and education initiatives by palliative care and hospice organizations[7].

The literature on PC in the NICU is still incipient and there are few publications on the subject, the main ones coming from world literature. In this context, it is essential to know the population that has been cared for in neonatal units, in order to contribute to the organization of the service, as well as to help produce scientific literature on the subject. That said, this study aims to characterize the profile of the population who were admitted to the Neonatal Intensive Care Unit (NICU) being monitored by the Pediatric Palliative Care (PPC) service at a referral hospital in Curitiba-PR, Brazil.

METHOD

This is a retrospective, cross-sectional and descriptive study using data from the medical records of patients in the Pediatric Palliative Care (PPC) service of the NICU of a referral hospital in the city of Curitiba-PR, Brazil. The institution has 20 Neonatal Intensive Care Unit beds and eight Conventional Neonatal Intermediate Care Unit beds, serving the entire state of Paraná. The hospital provides more than 90% of its care for patients from the Unified Health System (SUS, in its Portuguese acronym).

The research was approved by the Research Ethics Committee under CAAE protocol n° 58232322.8.0000.0103.

Participants

The records included those of patients who were admitted to the NICU and were referred for follow-up by the PPC service. There were no exclusion criteria.

Procedure

The medical records of patients seen by the service between September 2020 and June 2023 were analyzed. The medical records are electronic and were identified using the International Classification of Diseases (ICD), attributed during hospitalization.

The fetal diagnosis classification was based on the model by Himelstein et al.[8], consisting of the following categories: (1) conditions for which a cure is possible, but may fail (e.g., complex congenital or acquired heart disease etc.); (2) conditions that require complex and prolonged treatment (e.g., cystic fibrosis, sickle cell anemia, chronic renal failure, neuromuscular diseases etc.); (3) conditions in which treatment is only palliative since diagnosis (e.g., chromosomal abnormalities, trisomy 13 and 18 etc.); (4) severe and non-progressive disabling conditions (e.g., extreme prematurity, severe cerebral palsy, severe anoxia etc.).

The information from the medical records was described in a Microsoft Excel spreadsheet. No other instrument was used to collect the data. The results were analyzed using descriptive statistics in Microsoft Excel software, version 2010.

RESULTS

During the period described, the PPC service monitored 303 patients. The average length of stay in the NICU was 48 days (St. dev. ± 44 days), with the longest period being 369 days. Sociodemographic data and birth variables are shown in Table 1.

Table 1. Sociodemographic data and obstetric variables of the newborns monitored by the service (n=303).

Sociodemographic profile	N	%
Gender (n=303)		
Female	147	48.5
Male	154	50.8
Indeterminate	2	0.7
Obstetric variables at birth	N	%
Gestational age (n=303)		
Premature (< 37 weeks)	181	59.7
Term (> 37 weeks)	122	40.3
Weight (n=303)		
Extreme low weight (< 1,000 g)	58	19.2
Very low weight (1,000 – 1,499 g)	44	14.5
Low weight (1,500 – 2,499 g)	87	28.7
Normal (2,500 – 3,999 g)	110	36.3
Macrosomic (> 4,000 g)	4	1.3
Apgar score in the first minute (n=291)		
Severe asphyxia (0-3 points)	85	29.2
Moderate asphyxia (4-6 points)	76	26.1
Good vitality (7-10 points)	130	44.7
Apgar score at the fifth minute (n=291)		
Severe asphyxia	16	5.5
Moderate asphyxia	39	13.4
Good vitality	236	81.1

There was a slightly higher proportion of males (50.8%) in the sample. With regard to delivery, most of the newborns were born prematurely (less than 37 weeks) (59.7%), with normal weight (36.3%) and good vitality in the first (44.7%) and fifth (81.1%) minutes of life.

Table 2 shows the diagnoses found among the neonates and their classification in the groups of conditions eligible for PPC.

It should be pointed out that the most prevalent clinical conditions were prematurity (35.3%), followed by diseases of the nervous system (14.5%), diseases of the circulatory system (12.5%) and chromosomal syndromes and anomalies (10.9%). Moreover, the majority of patients had conditions for which a cure was possible but may have failed (45,5%).

Figure 1 shows the gestational ages at birth of the patients included in this sample. Regarding diseases of the nervous system, it was noted that the majority of diagnoses referred to neonatal anoxia (5.3%), followed by ventriculomegaly (2.3%) and myelomeningocele (2.3%).

Among the patients with genetic syndromes, the main diagnosis was Down's Syndrome (5.9%), followed by patients with genetic stigmas to be identified (2.3%), due to their deaths occurring before diagnosis. Moreover, four patients with Edwards' Syndrome and four others with Patau's Syndrome were identified. Table 3 shows the devices used by the patients at the time of discharge.

At the time of de-hospitalization, 4.1% of the neonates were using a gastrostomy, 4.1% a tracheostomy, 2.4% a colostomy and 1% a nasogastric or nasoenteral tube. Moreover, in terms of ventilatory support at the time of discharge, most of the patients were on room air, and only 3% were using supplementary oxygen.

The PPC team agreed with family members and staff to limit support for 11.6% of the neonates. In terms of analyzing the outcomes, 17.6% of the patients seen died during their stay in the NICU. The remaining babies were medically discharged from the NICU, of which 9.8% were sent to the pediatric ward before discharge so that the mothers had the opportunity to be trained in how to care for their baby.

Table 2. Pediatric palliative care profile.

Pediatric palliative care profile (n=303)	N	%
Classification according to clinical condition / diagnosis		
Diseases of the circulatory system	38	12.5
Diseases of the respiratory system	13	4.3
Diseases of the digestive system	26	8.6
Diseases of the nervous system	43	14.2
Genitourinary diseases	5	1.6
Infectious diseases	5	1.6
Hematological diseases	1	0.4
Oncological diseases	5	1.6
Orthopedic diseases	2	0.7
Otorhinolaryngological diseases	1	0.4
Multiple congenital malformations	24	7.9
Prematurity	107	35.3
Chromosomal syndromes and anomalies	33	10.9
Classification by group of eligible conditions		
Conditions for which a cure is possible but may fail	138	45.5
Conditions that require complex and prolonged treatment	72	23.8
Conditions in which treatment is palliative from the time of diagnosis	15	5.0
Severe, non-progressive disabling conditions	78	25.7

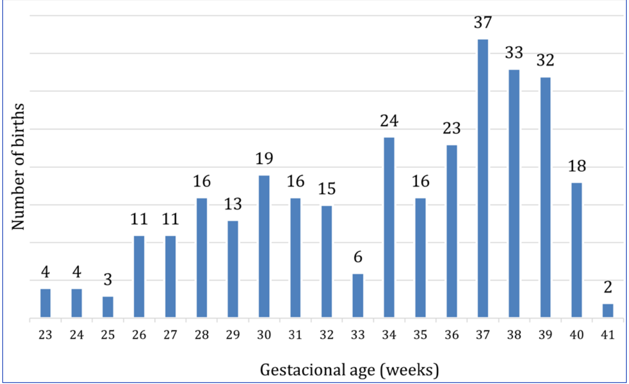

Figure 1. Number of births by gestational age of the patients in the sample (n=303).

Table 3. Neonates in the sample who need to use devices upon discharge (n=303).

Use of devices (n=296)	N	%
Need for colostomy device		
Yes	7	2.4
No	289	97.6
Need for gastrostomy device		
Yes	12	4.1
No	284	95.9
Need for nasogastric/nasoenteral tube device		
Yes	3	1.0
No	293	99.0
Need for a tracheostomy device		
Yes	12	4.1
No	284	95.9

DISCUSSION

PPCs are an essential approach to caring for newborns with life-threatening health conditions, offering comprehensive support for the baby, their family and the team. This care is not limited to the terminal phase, but encompasses pain management, comfort and well-being from the moment of diagnosis. Early implementation in NICUs can minimize suffering and improve quality of life, regardless of prognosis[9,10].

The main causes of NICU admissions include complications related to prematurity, low birth weight, congenital malformations, sepsis and other complications during childbirth[11]. These and other life-threatening conditions are the main indications for PC in the neonatal period[12]. Thus, the data presented in this study shows that most of the newborns monitored by the service had some of these conditions and therefore met the criteria for receiving PC, associated with conventional treatments.

When analyzing the death outcome aspect in the current Brazilian scenario, the country recorded approximately 22,000 deaths in the neonatal period in 2021, 74.5% of which were in the early neonatal period (0 to 6 days of life). This represents a mortality rate of 8.3 per 1,000 live births[13]. At the same time, in this study, 17.6% of the 303 patients treated by the PPC service died during hospitalization, due to the progression and/or complications of their illnesses.

The main clinical condition presented by the patients in this sample was preterm birth. Prematurity is classified into three groups by the WHO, according to gestational age at the time of delivery: extreme preterm infants (less than 28 weeks); early preterm infants (between 28 and 33 weeks); and late preterm infants (34 to 36 weeks)[14].

Short-term complications of prematurity include respiratory syndromes, necrotizing enterocolitis, sepsis, neurological symptoms, visual, eating and hearing difficulties. In the long term, the child may have poor neurodevelopment, high rates of hospitalization, socio-emotional difficulties and learning problems[15]. In this sense, prematurity is a matter of urgency for the world's health bodies, as it accounts for approximately 13.4 million newborns, or 9.9% of all live births[16].

The other clinical conditions found in these studies are mostly related to congenital malformations. It is estimated that 240,000 newborns die worldwide within 28 days of birth each year due to congenital disorders[16]. A congenital malformation is defined as any functional or structural alteration in the development of the fetus, which is capable of resulting in symptoms shortly after birth or even years later[17].

In Brazil, the most common congenital malformations are those related to the heart system, accounting for 1 case in every 100 births[18]. Malformations associated with the neurological system also have a high incidence in the current health system. Among the most common are spina bifida occulta, spina bifida cystica, bifid skull, microcephaly, hydrocephalus and Chiari malformation[19].

Previous studies have shown that the most frequent way of dying in neonatal patients is cardiorespiratory arrest which is irreversible after resuscitation maneuvers, with deaths due to abstention or suspension of treatment accounting for 44.4% of cases[20]. In this study, the limitation of support was agreed with family members and staff for 11.6% of neonates, which may show a difficulty with this reality.

PC is essential for the management of patients and their families, from birth to the end of life, as it is able to offer relief from pain, suffering and monitoring of complications. The understanding of the measures needed to guarantee comfort and quality of life in intensive care has grown in recent years. However, one of the greatest difficulties in the neonatal period is therapeutic obstinacy associated with reluctance to apply PC to patients with no prospect of a cure[21].

In this study, at the time of de-hospitalization, 4.1% of neonates were using a gastrostomy, 4.1% a tracheostomy and 2.4% a colostomy. These procedures are often necessary for de-hospitalization, allowing family members to live with the patient despite the care required.

However, it is necessary to discuss the ethical dilemmas related to the use of invasive procedures on neonates with serious conditions. There is a fine line between necessary treatments and therapeutic obstinacy, i.e., when professionals apply measures that do not help the patient improve and, on the contrary, end up causing more harm and suffering[22].

It is worth pointing out that neonatal PC is a treatment that involves not only newborns at the end of their lives, but also those with complex medical conditions and uncertain prognoses[23]. Therefore, this form of care can be implemented at any stage of the NICU stay and can continue after the patient has been discharged through outpatient follow-up, as occurred with 82.4% of the sample in this study.

When comparing this study with research carried out in a hospital in Ceará (a state in northeastern Brazil) it was observed that, although the results from Ceará included patients up to two years, 11 months and 29 days of age, both identified diseases of the nervous system and congenital malformations as some of the main causes for the need for PPC in the population analyzed. In addition, they both recorded a considerably high death rate, 17.6% in the study presented in Paraná and 58.9% in the Northeastern study[24].

Finally, both trials found that the majority of PPC patients had incurable or terminal clinical conditions. This analysis highlights the need to reformulate the objectives of PC in Brazil, expanding its availability to all conditions that require relief from suffering and improving the quality of life of patients and their families[24].

The main limitation of this study concerns its retrospective methodology, given the availability of information. Collecting and analyzing the data depended on it being properly registered in the medical records, which in some cases were incomplete. Moreover, another important limitation of this study is its single-center nature. Thus, some bias can be expected in the results obtained.

CONCLUSION

This study provided a better understanding of the profile of patients cared for by a neonatal PC team at a referral hospital. This information helps to structure the service, directly contributing to the practices carried out and impacting on the quality of life of neonates and their families.

The data found is in line with the literature on the subject. Prematurity and the high mortality rate in the neonatal period stand out as a challenge for health services and society in general.

In view of the scarcity of studies on the subject in the country, further research in the area is recommended, with the aim of broadening understanding and helping to guarantee and expand neonatal PC.

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