

# Classification of newborns hospitalized in a neonatal unit regarding the indication of palliative care

Classificação de recém-nascidos internados em uma unidade neonatal quanto à indicação de cuidados paliativos

Clasificación de los recién nacidos hospitalizados en una unidad neonatal respecto a la indicación de cuidados paliativos

Josihelle Gumboski<sup>1</sup> <https://orcid.org/0000-0003-0312-7659>

Lidiane Ferreira Schultz<sup>2</sup> <https://orcid.org/0000-0001-5146-7442>

Giséle Gomes Floriani<sup>1</sup> <https://orcid.org/0000-0002-8595-801X>

Carine de Freitas Milarch<sup>2</sup> <https://orcid.org/0000-0001-9978-0454>

Amanda de Oliveira<sup>2</sup> <https://orcid.org/0000-0003-4352-7745>

Ana Beatriz Cardoso<sup>2</sup> <https://orcid.org/0000-0002-9541-4374>

Carla Beatriz Pimentel Cesar Hoffmann<sup>1</sup> <https://orcid.org/0000-0003-4525-1455>

## Abstract

**Objective:** To classify newborns hospitalized in a neonatal unit into categories of palliative care, describe the outcomes, and associate clinical and sociodemographic data.

**Methods:** A descriptive study with a quantitative approach was conducted. The participants were newborns hospitalized in a neonatal unit of a public maternity ward. Statistical tests were used to assess the association between variables.

**Results:** A total of 26 participants, with 17 (65.4%) being preterm, 14 (53.8%) female, and 18 (69.2%) weighing less than 2,500 grams. Regarding outcomes, 18 (69.2%) deceased, 5 (19.2%) were discharged with follow-up, and 3 (11.5%) were transferred. Regarding palliative care classification, 9 (34.6%) were categorized with a diagnosis of conditions with a considerable risk of death, followed by 8 (30.8%) at the limit of viability.

**Conclusion:** The study provided information about the conditions of newborns requiring palliative care, allowing healthcare professionals to have a comprehensive understanding of various situations.

## Keywords

Neonatal intensive care unit; Newborn; Palliative care

## Resumo

**Objetivos:** Classificar recém-nascidos internados em uma unidade neonatal em categorias de cuidados paliativos, descrever os desfechos e associar dados clínicos e sociodemográficos.

**Métodos:** Estudo descritivo com abordagem quantitativa. Os participantes foram recém-nascidos internados em uma unidade neonatal, de uma maternidade pública. Utilizaram-se os testes estatísticos para verificar a associação entre as variáveis.

**Resultados:** Total de 26 participantes, sendo 17 (65,4%) pré-termo, 14 (53,8%) do sexo feminino e 18 (69,2%) com peso inferior a 2.500 gramas. Sobre o desfecho, 18 (69,2%) foram a óbito, 5 (19,2%) tiveram alta com acompanhamento e 3 (11,5%) foram transferidos. Referente à classificação para cuidados paliativos, 9 (34,6%) foram categorizados com diagnóstico de doença com risco considerável de morte, seguidos por 8 (30,8%) no limite de viabilidade.

**Conclusão:** O estudo forneceu informações sobre condições dos recém-nascidos que requerem cuidados paliativos, permitindo que profissionais da saúde tenham uma visão abrangente de diversas situações.

## Descritores

Unidade de terapia intensiva neonatal; Recém-nascido; Cuidados paliativos

## Resumen

**Objetivo:** Clasificar a los recién nacidos hospitalizados en una unidad neonatal en categorías de cuidados paliativos, describir los resultados y asociar datos clínicos y sociodemográficos.

**Métodos:** Se realizó un estudio descriptivo con enfoque cuantitativo. Los participantes fueron recién nacidos internados en una unidad neonatal de una maternidad pública. Se utilizaron pruebas estadísticas para verificar la asociación entre las variables.

**Resultados:** Un total de 26 participantes, siendo 17 (65,4%) prematuros, 14 (53,8%) mujeres y 18 (69,2%) con un peso inferior a 2.500 gramos. En cuanto a los resultados, 18 (69,2%) fallecieron, 5 (19,2%) fueron dados de alta con seguimiento y 3 (11,5%) fueron trasladados. En relación con la clasificación de cuidados paliativos, 9 (34,6%) fueron categorizados con un diagnóstico de enfermedad con riesgo considerable de muerte, seguidos por 8 (30,8%) en el límite de viabilidad.

**Conclusion:** El estudio proporcionó información sobre las condiciones de los recién nacidos que requieren cuidados paliativos, permitiendo que los profesionales de la salud tengan una comprensión completa de diversas situaciones.

## Descriptoros

Unidad de cuidados intensivos neonatales; Recién nacido; Cuidados paliativos

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<sup>1</sup> Maternidade Darcy Vargas, Joinville, SC, Brasil.

<sup>2</sup> Faculdade IELUSC, Joinville, SC, Brasil.

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**Corresponding author:** Josihelle Gumboski | E-mail: josihellegumboski268@gmail.com

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## Introduction

Advances in science and technology result in an increase in the survival of newborns (NBs) who have life-threatening factors, such as malformations, prematurity and low birth weight.<sup>(1-3)</sup> The neonatal intensive care unit (NICU) and the Conventional Neonatal Intermediate Care Unit (UCINCo) are fundamental sectors in the care of these NBs.<sup>(1,3,4)</sup>

It is evident that, with the increase in the survival of newborns, there is also an increase in children with severe disabilities, which affect the quality of life and which, often, are not capable of being cured.<sup>(1,2,5)</sup> This scenario makes clear the importance of perinatal and neonatal palliative care (PC), conceptualized as an active and comprehensive approach carried out by multiple professionals, from diagnosis, throughout the child's life, death and beyond. The objective of CPs is to alleviate the physical, emotional, psychosocial and spiritual suffering of children and their families, through early actions and impeccable assessments to improve quality of life.<sup>(6-8)</sup>

Neonatal PCs have several significant implications for families of critically ill newborns or those with life-threatening conditions, offering emotional support, clear information, opportunities to participate in care, and a compassionate approach to facing difficult challenges related to the newborn's health.<sup>(6,7)</sup> Effective communication is a vital bridge between healthcare professionals and families, ensuring that family members have clear information to understand the newborn's condition, available treatments, possible complications and care options, allowing them to make informed and aligned decisions. with their values and desires, in addition to emotional support, to express their concerns and feelings, while receiving guidance to deal with these emotions.<sup>(6,7)</sup>

The establishment of protocols with defined PC indication criteria, classification of diseases and PC conditions makes their indication an early and objective task.<sup>(5,6,8,9)</sup>

Protocols provide guidance for complex ethical decisions and facilitate communication between healthcare professionals, parents, and other family members, ensuring that everyone understands the plan of care, considering the best interests of the newborn, the parents' wishes, and clinical options avail-

able. These protocols can be reviewed and improved based on clinical experience and research, ensuring that neonatal PCs evolve to meet needs.<sup>(5,6,9)</sup>

There are limited studies that point to the number of newborns and children who require PC and the capacity to offer services to this population. In the United Kingdom, the number of RNs requiring access to PC services annually is estimated at 1,473, 1 per 10,000 inhabitants.<sup>(10)</sup> In Brazil, little is known about the number of newborns and children who require PCs, however a mapping of PCs showed an increase in pediatric PC services in the last 10 years, demonstrating a recent evolution in the area, despite the distribution of these services being inequality between Brazilian regions.<sup>(11)</sup>

This research is justified by the need to generate information about NBs recommended for neonatal PCs, to support managers in expanding, developing and planning strategies and actions aimed at improving the care provided to these NBs and their families.

Therefore, the objectives of this study were to classify newborns admitted to a neonatal unit into palliative care categories, describe the outcomes and associate clinical and sociodemographic data.

## Methods

This is a descriptive, cross-sectional, retrospective and documentary study with a quantitative approach, carried out in 2022, at the Darcy Vargas Maternity Hospital, located in the Municipality of Joinville, in the northeast of Santa Catarina.<sup>(12)</sup> 612 medical records of newborns who were admitted to the NICU and UCINCo, from January to December 2021, and their respective mothers were analyzed.

The inclusion criteria were the medical records of newborns hospitalized in the neonatal unit in 2021, who were eligible for at least one of the five categories of PCs in the NICU. The medical records of RNs who did not have sufficient information to collect data were excluded.

The data were collected by three researchers trained for the study through the electronic records of newborns and mothers, in the Hospital Services Management System (SGS HOSPITALAR), of the maternity ward.

The study variables relating to the newborn were: gestational age (in weeks), birth weight (in grams),

sex (female/male), length of stay in the unit (in days), clinical diagnosis during prenatal care (if there was), clinical diagnosis during hospitalization, diagnosis during hospitalization or condition that indicated PC, use of pain relief medications (yes/no), artificial life support measures, nutrition of newborns who died, in the last 24 hours of life (enteral, parenteral or fasting), resuscitation (yes/no), and outcome of hospitalization (death, transfer, discharge with follow-up). Regarding the mother, the performance of prenatal care with the fetal medicine team was investigated (yes/no).

RNs were classified according to five categories for indicating CPs for RNs admitted to the NICU.<sup>(8)</sup>

Category 1: prenatal or postnatal diagnosis of a disease that is not compatible with life (example: bilateral renal agenesis, anencephaly).

Category 2: prenatal or postnatal diagnosis of a disease that presents a considerable risk of death or high morbidity (example: serious malformations associated or not with hypoplastic left heart syndrome, extensive meningocele with hydrocephalus).

Category 3: NBs at the limit of viability, for whom neonatal intensive care is considered inappropriate (example: extremely premature babies).

Category 4: Newborns with postnatal conditions with a high risk of compromising quality of life and who are receiving artificial life support or may need it at some point (example: hypoxic-ischemic encephalopathy).

Category 5: postnatal conditions in which the newborn is experiencing unbearable suffering in the progression of their disease or its treatment (example: gastroschisis evolving into short intestine).

After collection, the data were tabulated and organized with the support of Microsoft® Excel 2007. We chose to analyze the association of 11 variables (gestational age, sex, length of stay, prenatal diagnosis, prenatal care with the fetal medicine, prematurity as a diagnosis for hospitalization, use of pain relief medications, artificial life support measures, resuscitation, death and place of hospitalization). To verify the association between the newborn's birth weight and the 11 variables, Fisher's exact test was used, and the chi-square test was performed to analyze the association between the five categories for indicating PCs for newborns, with the 11 variables, as well as to analyze the association of the diagnosis or condition that

indicated the CP with the variables birth weight and categories of CPs.

The data were statistically analyzed using the SigmaPlot 12.0 program (Systat Software Inc., San Jose, USA), in which the confidence interval was 95% and the significance level adopted was  $p \leq 0.050$ . The descriptive analysis was carried out by calculating absolute (n) and relative frequency (%), and the results were presented in the form of tables and graphs.

The study was guided by Resolution No. 466/12, of the National Health Council (CNS),<sup>(13)</sup> and approved by the Research Ethics Committee – 5.256.839 of the Hans Dieter Schmidt Regional Hospital, under CAAE opinion: 56046022.0.0000.5363, on February 22, 2022.

## Results

612 medical records of newborns admitted to the maternity's neonatal unit in 2021 were analyzed. Of these, 26 were included in this study, corresponding to 4.2%. According to the characterization of the 26 neonates admitted with indication of PCs, 17 (65.4%) were classified as preterm, followed by 9 (34.6%) classified as full-term, of the total. Among the 17 preterm babies, 8 (47%) were classified at the limit of viability, with a gestational age of less than 24 weeks. Regarding birth weight, 18 (69.2%) newborns were born weighing less than 2,500 grams (g), 7 (26.9%) had adequate weight and 1 (3.8%) was macrosomic. It is noteworthy that 3 (11.5%) weighed less than 500 g. Regarding gender, 14 (53.8%) were female and 12 (46.2%) were male. Regarding the place of hospitalization, 23 (88.5%) of the NBs were admitted to the NICU and 3 (11.5%) to the UCINCo. The length of stay of 16 (61.5%) was less than 7 days, followed by 4 (15.4%) who remained hospitalized for 8 to 14 days, 4 (15.4%) with a length of stay greater than 30 days and 2 (7.7%), from 15 to 30 days.

Regarding the classification for PCs (Table 1), 9 (34.6%) were categorized with a prenatal or postnatal diagnosis of a disease that presents a considerable risk of death or high morbidity, such as malformations of the central nervous system, complex heart diseases, malformative syndromes, among others, followed by 8 (30.8%) newborns at the limit of viability, consisting of newborns with a gestational age less than or equal to 24 weeks, for whom neonatal intensive care is con-

sidered inappropriate. The main cause of hospitalization of newborns was prematurity, corresponding to 15 (57.7%), followed by congenital malformation, 7 (26.9%), severe perinatal asphyxia, 2 (7.7%) and respiratory discomfort, 2 (7.7%). Regarding the outcome of hospitalization, 18 (69.2%) died, 5 (19.2%) were discharged with outpatient follow-up and 3 (11.5%) were transferred.

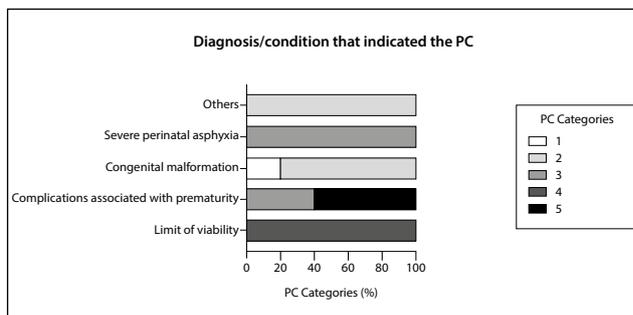
**Table 1.** Classification and hospitalization outcome of newborns with an indication for palliative care admitted to a neonatal unit

Variables	n(%)
Classification of newborns with indications for care palliatives	
Category 1	2(7,7)
Category 2	9(34,6)
Category 3	8(30,8)
Category 4	4(15,4)
Category 5	3(11,5)
Clinical diagnosis during prenatal care	
Yes	8(30,8)
No	18(69,2)
Prenatal care with the fetal medicine team	
Yes	7(26,9)
No	19(73,1)
Clinical diagnosis of admission to the neonatal unit	
Prematurity	15(57,7)
Congenital malformation	7(26,9)
Severe perinatal asphyxia	2(7,7)
Respiratory discomfort	2(7,7)
Outcome of hospitalization	
Death	18(69,2)
Discharge with outpatient follow-up	5(19,2)
Transfer	3(11,5)
Total	26(100,0)

Source: SGS HOSPITALAR, 2022.

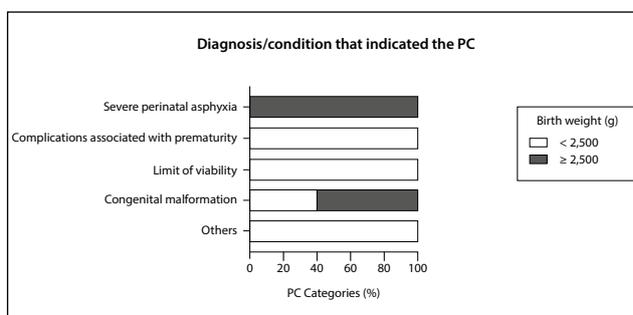
Of the clinical diagnoses that indicated PCs, 10 (38.5%) were related to complex congenital malformation or some malformative syndrome, 8 (30.8%), to limit of viability, 5 (19.2%), to associated complications to prematurity, 2 (7.7%), hypoxic-ischemic encephalopathy, and 1 (3.8%) had another diagnosis. Figure 1 shows the relationship between the categories and diagnoses that indicated PC; It is observed that malformations are present in categories 1 and 2, considering that some malformations, such as anencephaly, are classified as diseases not compatible with life, and are therefore included in category 1, while other malformations are suitable for category 2, with considerable risk of death or high morbidity. The same occurs in the condition “complications associated with prematurity”. Some fall into category 4, with a high risk

of compromising quality of life, and others, into category 5, postnatal conditions in which the newborn is experiencing unbearable suffering in the progression of their disease or its treatment.



**Figure 1.** Relationship of the diagnosis or condition that indicated palliative care with the palliative care categories

When relating the diagnosis or condition that indicated PCs to the newborn’s birth weight, it was found that newborns weighing less than 2,500 g had, in the majority, a viability limit of 8 (30.8%), followed by conditions associated with prematurity 5 (19.2%). Newborns weighing more than or equal to 2,500 g had a clinical diagnosis of malformations (6 – 23.1%) and severe perinatal asphyxia (2 – 7.7%) (Figure 2).



**Figure 2.** Relationship of the diagnosis or condition that indicated palliative care with birth weight, in grams (g)

Pain relief medications were used in 16 (61.5%) of the newborns during hospitalization. Regarding artificial life support measures or therapeutic investment, 19 (73.1%) received mechanical ventilation, 11 (42.3%) received surfactant, 10 (38.5%) received vasoactive drugs, 8 (30.8%) received transfusion of blood products, 2 (7.7%) received nitric oxide and 2 (7.7%) received other measures, such as chest and abdominal drain, pericardial puncture and chest puncture. It is worth noting

that some NBs received multiple artificial life support measures, but 6 (23.1%) did not receive any artificial life support measures. Regarding cardiopulmonary resuscitation, 21 (80.8%) newborns underwent some maneuver at some point. Of the 18 newborns who died during hospitalization, in the 24 hours prior to death, 11 (61.1%) were fasting, 5 (27.8%) were receiving enteral nutrition and 2 (11.1%), nutrition parenteral. Table 2 shows the association of clinical and sociodemographic data of newborns classified as having PCs indicated according to birth weight. Prenatal care with fetal medicine was significantly associated ( $p = 0.001$ ), and pregnant women who did not undergo prenatal care with the fetal medicine team had a higher proportion of newborns with low birth weight (17 – 89.5 %), and the newborns of women who underwent such monitoring had a higher proportion of births weighing more than or equal to 2,500 g (6 – 85.7%). Gestational age and prematurity as a diagnosis of the newborn upon admission were also significantly associated ( $p = 0.001$ ) with birth weight, and premature newborns had the highest proportion weighing less than 2,500 g (16 – 94.1%) and all who were hospitalized due to prematurity and weighed less than 2,500 g (15 – 100%).

When combining the clinical and sociodemographic data of newborns classified with indication for PC with the categories for indication of PC, the prevalence of preterm neonates in category 3 was identified, with 8 (44.4%), full-term in category 2, with 5 (62.5%), girls in category 2, with 5 (35.7%) and boys in categories 2 and 3, with the same proportion, 4 (33.3%). Prenatal monitoring of pregnant women in fetal medicine was significantly associated with the indication categories for PCs, with  $p = 0.001$ , with all newborns classified in category 2 of PC. For newborns who were not followed up in prenatal care by fetal medicine, there was a higher prevalence in category 3 – 8 (42.1%) –, followed by category 4 – 4 (21.0%). Of the 9 newborns classified as category 2, 7 (77.8%) had a clinical diagnosis during prenatal care, and of these 7, all were monitored by the outpatient fetal medicine team at the maternity hospital studied (Table 3).

## Discussion

Neonatal PCs need to be improved in three possible moments of care: before birth, in the delivery room

**Table 2.** Association of clinical and sociodemographic data of newborns classified as being indicated for palliative care, according to birth weight, in grams (g)

Variables	<2,500 n(%)	≥2,500 n(%)	Fischer p
Gestational Age			<0,001
Preterm	16(94,1)	1(5,9)	
Term	2(22,2)	7(77,8)	
Sex			0,401
Female	11(78,6)	3(21,4)	
Male	7(58,3)	5(41,7)	
Length of stay (days)			0,420
≤7	10(62,5)	6(37,5)	
>7	8(80,0)	2(20,0)	
Prenatal diagnosis			0,003
Yes	2(25,0)	6(75,0)	
No	16(88,9)	2(11,1)	
Prenatal care with the fetal medicine team			0,001
Yes	1(14,3)	6(85,7)	
No	17(89,5)	2(10,5)	
Prematurity as a diagnosis of Hospitalization			0,001
Yes	15(100,0)	0(0,0)	
No	3(27,3)	8(72,7)	
Use of medication for pain relief			0,189
Yes	13(81,2)	3(18,8)	
No	5(50,0)	5(50)	
Artificial life support measures			0,050
Yes	16(80,0)	4(20,0)	
No	2(33,3)	4(66,7)	
Resuscitation			0,281
Yes	16(76,2)	5(23,8)	
No	2(40,0)	3(60,0)	
Death			0,197
Yes	14(77,8)	4(22,2)	
No	4(50,0)	4(50,0)	
Place of hospitalization			1
NICO	16(69,6)	7(30,4)	
UCINCo	2(66,7)	1(33,3)	

and in the NICU.<sup>(14)</sup> Before birth, this is perinatal PC, in which it is possible to plan care for conditions diagnosed during pregnancy.<sup>(7,14)</sup> In the delivery room and, later, during hospitalization in the NICU, the best care must be offered, which must be centered on the newborn and the family.<sup>(14)</sup>

The PC model in the NICU must be interprofessional.<sup>(15)</sup> National and international studies demonstrate the need for training health teams in a series of skills for neonatal PCs, such as communication skills, including discussing a bad prognosis, giving bad news and talk about care at the end of life, in addition to the need for regular training of the interdisciplinary team to increase support for PCs.<sup>(16-19)</sup>

In this study, of the 612 medical records of newborns admitted to the neonatal unit, 26 (4.2%) present-

**Table 3.** Association of clinical and sociodemographic data of newborns classified with indication for palliative care, according to categories for indication of palliative care

Variables	Palliative care indication categories					Chi-square p
	1 n(%)	2 n(%)	3 n(%)	4 n(%)	5 n(%)	
Gestational Age						0,074
Preterm	1(5,5)	4(22,2)	8(44,4)	2(11,1)	3(16,6)	
Term	1(12,2)	5(62,5)	0(0,0)	2(25,0)	0(0,0)	
Sex						0,68
Female	2(14,2)	5(35,7)	4(28,5)	2(14,2)	1(7,14)	
Male	0(0,0)	4(33,3)	4(33,3)	2(16,6)	2(16,6)	
Length of stay (days)						0,361
≤7	1(6,2)	6(37,5)	5(31,2)	1(6,2)	3(18,7)	
≥7	1(10,0)	3(30,0)	3(30,0)	3(30,0)	0(0,0)	
Prenatal diagnosis						0,003
Yes	1(12,5)	7(87,5)	0(0,0)	0(0,0)	0(0,0)	
No	1(5,5)	2(11,1)	8(44,4)	4(22,2)	3(16,6)	
Prenatal care with the team fetal medicine						0,001
Yes	0(0,0)	7(100,0)	0(0,0)	0(0,0)	0(0,0)	
No	2(10,5)	2(10,5)	8(42,1)	4(21,0)	3(15,7)	
Prematurity as a hospitalization diagnosis						0,003
Yes	1(6,6)	1(6,6)	8(53,3)	2(13,3)	3(20,0)	
No	1(9,0)	8(72,7)	0(0,0)	2(18,1)	0(0,0)	
Use of medication for pain relief						0,146
Yes	2(12,5)	3(18,7)	5(31,2)	4(25,0)	2(12,5)	
No	0(0,0)	6(60,0)	3(30,0)	0(0,0)	1(10,0)	
Artificial life support measures						0,169
Yes	1(5,0)	5(25,0)	8(40,0)	3(15,0)	3(15,0)	
No	1(16,6)	4(66,6)	0(0,0)	1(16,6)	0(0,0)	
Resuscitation						0,371
yes	1(4,8)	6(28,6)	7(33,3)	4(19,0)	3(14,3)	
No	1(20,0)	3(60,0)	1(20,0)	0(0,0)	0(0,0)	
Death						0,094
Yes	2(11,1)	5(27,7)	7(38,8)	1(5,5)	3(16,6)	
No	0(0,0)	4(50,0)	1(12,5)	3(37,5)	0(0,0)	
Place of hospitalization						0,21
NICO	1(4,3)	7(30,4)	8(34,8)	4(17,3)	3(13)	
UCINCo	1(33,3)	2(66,6)	0(0,0)	0(0,0)	0(0,0)	

ed some diagnosis or condition that indicates neonatal CP. Two categories stand out: category 2, with prenatal or postnatal diagnosis of a disease that presents a considerable risk of death or high morbidity, composed mainly of newborns diagnosed with congenital malformations or malformative syndromes; and category 3, of newborns at the limit of viability, composed of newborns with a gestational age less than or equal to 24 weeks.

Congenital malformations involve a wide spectrum of changes in the structure or function of organs, present at birth and of prenatal origin, which normally result in a reduction in life expectancy and/or impairment of the normal function of the affected organs.<sup>(20,21)</sup> The clinical evolution of these patients and their survival are the

result of factors such as underlying disease, knowledge and resources available in the care unit. They are often rare diseases with little information regarding mortality after intervention and long-term sequelae.<sup>(20)</sup>

Congenital malformations were the second leading cause of admission to the neonatal unit, behind only prematurity. Other studies corroborate this finding.<sup>(22-24)</sup> In this research, of the clinical diagnoses that indicated PCs, 38.46% were related to complex congenital malformation or some malformative syndrome, 8 (80%) had an antepartum clinical diagnosis and 7 (70 %) had follow-up with the outpatient fetal medicine team. A study had similar data, with a 77% prevalence of major malformations, and 68% had a prenatal diagnosis.<sup>(1)</sup>

During prenatal care, diseases with well-established lethality or an undetermined prognosis can be diagnosed. The family approach must be carried out from the moment there is diagnostic confirmation of a life-threatening situation. This approach occurs through meetings between the family and the health-care team during prenatal care. In addition to allowing better planning of pregnancy and childbirth, this early diagnosis allows the initiation of perinatal PCs.<sup>(1,14,20)</sup>

A study that analyzed end-of-life care in the NICU showed that monitoring by the perinatal PC group allowed patients to spend less time in hospital. This information may be related to the smaller number of interventions that can prolong the death process in situations of recognized lethality.<sup>(20)</sup>

Pregnant women who underwent prenatal care with the fetal medicine outpatient team simultaneously with primary health care had a higher proportion of newborns with adequate birth weight. The need for quality prenatal care is highlighted, in order to provide early diagnosis of life-limiting conditions and offer qualified care from pregnancy onwards, in the case of congenital malformations, and to prevent risk factors that could lead to a extreme premature birth.<sup>(20,21,25)</sup>

Prematurity was the main cause of admission to the neonatal unit. Another study from the same maternity hospital, in 2020, shows similar findings.<sup>(23)</sup> Regarding clinical diagnoses or conditions that indicated CP, 30.8% of newborns were at the limit of viability, with a gestational age of less than 24 weeks, and 19, 2% were indicated due to complications associated with prematurity.

For preterm newborns, the probability of survival and the presence of short, medium and long-term morbidity vary widely according to gestational age, with a lower probability of normal development for more immature newborns.<sup>(26,27)</sup> Newborns with gestational age less than 23 weeks and birth weight less than 500 g are extremely immature and have little chance of survival without sequelae. For those with a gestational age between 23 and 24 weeks and 6 days, survival and outcomes remain uncertain.<sup>(26,27)</sup>

However, when considering care planning for extremely premature infants with gestational age below or at the limit of viability, one should not only think about the small probability of survival, but also the

future morbidity rate and, consequently, the quality of life. Of these patients, those who survive the neonatal period will still have an increased risk of death in childhood and approximately half of the survivors will have neurological development problems.<sup>(26,27)</sup> In the present study, all newborns with a gestational age less than or equal to 24 weeks died.

During hospitalization, 80.8% of newborns were resuscitated, 73.1% received mechanical ventilation, 38.5% received vasoactive drugs and 30.8% received a transfusion of blood products, among other procedures and artificial life support measures that cause pain. Pain relief medications were used in 61.5% of neonates at some point during hospitalization.

Controlling pain and stressful factors for the newborn is essential, as pain involves physiological causes and behavioral instability through an increase in cortisol, causing, in a compensatory process, changes such as increased heart rate, variations in respiratory rate, crying and irritability, leading to increased energy expenditure, among other complications.<sup>(14,28,29)</sup> The team must ensure pain relief through the use of non-pharmacological and pharmacological measures, application of scales, protocols for measuring and evaluating pain.<sup>(27-29)</sup>

Regarding the outcome of the newborns, 18 (69.2%) died, 3 (11.5%) were transferred to a reference hospital providing specialized care in the area of pediatrics in the city and 5 (19.2%) were discharged with outpatient follow-up. Of the 18 newborns who died during hospitalization, 11 (61.1%) were fasting, 5 (27.8%) continued to receive enteral nutrition and 2 (11.1%) received parenteral nutrition.

It is worth noting that, for patients who tolerate the diet, it should be offered, respecting the clinical conditions of the newborn, aiming for comfort, whenever possible prioritizing breastfeeding or suckling at the breast, and should only be suspended if it is causing suffering, which highlights the role of the multidisciplinary team in this care.<sup>(14)</sup>

Patients discharged from the neonatal unit must continue to be monitored on an outpatient basis, and it is necessary to monitor readmissions and the patient's evolution. For those who die, the family must receive support.<sup>(14,27,30)</sup>

Studies on neonatal and pediatric PCs are essential for the development of protocols and care practices in health institutions. The present study provides

information about the conditions of RNs who require CPs, allowing nurses and other health professionals to have a comprehensive view of the situations they may encounter, adjusting the care provided to each RN and family according to their specific needs, offering care individualized and compassionate.

It is recommended that more research be carried out on neonatal PC, as well as the promotion of this content in undergraduate and postgraduate courses in the health area, making it urgent to expand discussions on its concept and principles, in addition to the need training of the care team and the implementation of a bereavement clinic and strengthening of support groups to monitor newborns and family members.

## Conclusion

This study provided the identification of the clinical and sociodemographic profile and the classification of newborns admitted to a neonatal unit with indications for PCs. Preterm newborns, female and weighing less than 2,500 grams, were categorized for PC indication as newborns diagnosed with a disease with considerable risk of death or high morbidity, followed by viability limit. The outcome with the highest proportion was death. The research generated information to support managers in expanding strategies and developing actions, aiming to improve care for these newborns and their families.

## Contributions

Gumboski J, Schultz LF, Floriani GG, Milarch CF, Oliveira A, Cardoso AB e Hoffmann CBPC contributed to the design of the study, collection, analysis and interpretation of data, writing of the article and relevant critical review of the intellectual content and approved the final version to be published.

## References

1. Marçola L, Barbosa SM, Zoboli I, Polastrini RT, Ceccon ME. Análise dos óbitos e cuidados paliativos em uma unidade de terapia intensiva neonatal. *Rev Paul Pediatr.* 2017;35(2):125-9.
2. Secretaria de Estado da Saúde (São Paulo). Linha de Cuidado da Criança: Manual de Neonatologia. 2ª ed. São Paulo: SES/SP; 2018. 340 p. Disponível em: <https://docs.bvsalud.org/biblioref/ses-sp/2018/ses-37500/ses-37500-6986.pdf>

3. Silva LJ, Leite JL, Silva TP, Silva ÍR, Mourão PP, Gomes TM. Management challenges for best practices of the Kangaroo Method in the Neonatal ICU. *Rev Bras Enferm.* 2018;71(suppl 6):2948-56.
4. Segundo WG, Barros RM, Camelo NM, Martins AE, Ramos HD, Almeida CV. A importância das unidades de terapia intensiva neonatal (UTIN) e de cuidados intermediários neonatal (UCIN) para o recém-nascidos prematuros. *Rev Cienc Saúde Nova Esperança.* 2018;16(2):85-90.
5. Santana V, Gonçalves C, Santos E, Kawano P, Costa P, Lebrão C, et al. Indicação de cuidados paliativos neonatais: necessidade de uma diretriz? *Resid Pediatr.* 2019;9(3):275-83.
6. Barbosa SM, Zoboli I, Iglesias SB. *Cuidados Paliativos na Prática Pediátrica.* Rio de Janeiro: Atheneu; 2019.
7. Bolíbio R, Jesus RC, Oliveira FF, Gibelli MA, Benute GR, Gomes AL, et al. Cuidados paliativos em medicina fetal. *Rev Med.* 2018;97(2):208-15.
8. Mancini A, Uthaya S, Berdsley C, Wood D, Modi N. The ACT approach to children's palliative care. *A Neonatal Pathway for Babies with Palliative Care Needs.* ACT; 2009.
9. Rodrigues B, Boscolo A, Leão L, Reis M, Pimenta L, Lima J. Desafios na implementação de cuidados paliativos na neonatologia: Uma revisão integrativa. *Rev Pediatr.* 2022;12(4):1-4.
10. Cochrane H, Great Britain. Department of Health. *Palliative Care Statistics for Children and Young Adults: Health and Care Partnerships Analysis.* Department of Health; 2007. 68 p.
11. Ferreira E, Barbosa S, Costa G. *Mapeamento dos Cuidados Paliativos Pediátricos no Brasil: 2022. 1ª ed.* São Paulo: Rede Brasileira de Cuidados Paliativos Pediátricos (RBCPPed); 2022.
12. Histórico [Internet]. *Maternidade Darcy Vargas.* [citado 17 mar. 2023]. Disponível em: <https://mdv.saude.sc.gov.br/index.php/institucional/17-institucional/22-historico>
13. Brasil. Resolução no 466, de 12 de dezembro de 2012. Aprova diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. *Diário Oficial [da] República Federativa do Brasil.* 2012. Disponível em: <https://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf>
14. Ferreira EAL, Barbosa SMM, Iglesias SBO. *Cuidados Paliativos Pediátricos.* Rio de Janeiro: Medbook; 2023.
15. Marc-Aurele KL, English NK. Primary palliative care in neonatal intensive care. *Semin Perinatol.* 2017;41(2):133-9.
16. Mascarenhas D, Goyal M, Nanavati R. Neonatal palliative care practices: an Indian perspective. *Paediatr Int Child Health.* 2022;42(1):22-8.
17. Lee MC, Chen YC, Chen CH, Lu FL, Hsiao CC, Peng NH. Comparison of the Educational Needs of Neonatologists and Neonatal Nurses Regarding Palliative Care in Taiwan. *Am J Hosp Palliat Care.* 2016;33(3):264-71.
18. Gu L, Li ZZ, Peng NH, Zhou JF, Wei BR, Chang YC. Barriers to and Facilitators of Neonatal Palliative Care Among Neonatal Professionals in China. *Am J Hosp Palliat Care.* 2022;39(6):695-700.
19. Camilo BH, Serafim TC, Salim NR, Andreato AM, Roveri JR, Misko MD. Comunicação de más notícias no contexto dos cuidados paliativos neonatal: experiência de enfermeiros intensivistas. *Rev Gaúcha Enferm.* 2022;43:e20210040.
20. Gibelli MABC. *Cuidados de fim de vida em recém-nascidos portadores de malformações congênitas maiores em um centro de referência neonatal terciário no Brasil [Internet] [Doutorado em Pediatria].* São Paulo: Universidade de São Paulo; 2020 [citado 17 mar. 2023]. Disponível em: <https://www.teses.usp.br/teses/disponiveis/5/5141/tdc-08072021-105302/>
21. Ferreira KM, Vasconcelos NR, Carvalho VK, Pinheiro GN. A enfermagem neonatal e os cuidados paliativos em neonatos com graves problemas de saúde: uma revisão integrativa. *REASE.* 2021;7(12):1474-93.
22. Silva SC, Martins LM, Bernardino FB, Freitas BH, Pinto FA, Gaíva MA. Perfil clínico de neonatos admitidos em uma unidade de terapia intensiva neonatal. *Braz J Dev.* 2021;7(12):119510-21.
23. Gumboski J, Silva DI, Henrique LU, Schultz LF. Perfil clínico e demográfico dos recém-nascidos internados em uma unidade neonatal. *Rev Enf Contemp.* 2022;11:e4655.
24. Klumb MM, Milbrath VM, Gabatz RI, Aguiar JR, Silva LL, Vaz VG, et al. Perfil do recém-nascido internado na Unidade de Terapia Intensiva Neonatal: revisão integrativa. *Res Soc Dev.* 2022;11(13):e416111335799.
25. Veloso FC, Kassar LM, Oliveira MJ, Lima TH, Bueno NB, Gurgel RQ, et al. Análise dos fatores de risco na mortalidade neonatal no Brasil: uma revisão sistemática e metanálise de estudos observacionais. *J Pediatr (Rio J).* 2019;95(5):519-30.

26. Oliveira MA de. Cuidados paliativos para prematuros extremos com idade gestacional menor que o limite de viabilidade: reflexão bioética sobre a prática em uma unidade de terapia intensiva neonatal. 2020 [citado 17 mar. 2023]. Disponível em: <https://repositorio.unb.br/handle/10482/38341>
27. Gaiva MA, Rodrigues EC, Toso BR, Mandetta MA. Cuidado integral ao recém-nascido pré-termo e à família. SOBEP. 2021 [cited 2023 Jan 20]. Disponível em: <https://journal.sobep.org.br/wp-content/uploads/2021/10/Livro-cuidado-SOBEP-2.x19092.pdf>
28. Maciel HI, Costa MF, Costa AC, Marcatto JO, Manzo BF, Bueno M. Medidas farmacológicas e não farmacológicas de controle e tratamento da dor em recém-nascidos. Rev Bras Ter Intensiva. 2019;31(1):21-26.
29. Balda RC, Guinsburg R. Avaliação e tratamento da dor no período neonatal. Resid Pediatr. 2019;9(1):43-52.
30. Laguna TF, Lemos AP, Ferreira L, Gonçalves CS. O luto perinatal e neonatal e a atuação da psicologia nesse contexto. Res Soc Dev. 2021;10(6):e5210615347.