

# Perinatal palliative care: reflections on an outpatient clinic

Julianna Rodrigues Beltrão<sup>1</sup>, Andreia Christine Bonotto Farias Franco<sup>2</sup>, Larissa Madruga Monteiro<sup>2</sup>, Janaína Ferreira Percegon<sup>2</sup>

1. Pontifícia Universidade Católica do Paraná. Curitiba/PR, Brasil. 2. Departamento de Cuidados Paliativos Pediátricos, Hospital Universitário Evangélico Mackenzie. Curitiba/PR, Brasil.

## Abstract

This study describes the profile of the population assisted by a pediatric and perinatal palliative care service at an outpatient clinic for pregnant women, at a reference hospital in Curitiba/PR. This is a retrospective, cross-sectional and descriptive study based on the records of patients treated between September 2020 and March 2022. Data were analyzed using descriptive statistics. The service received 130 referrals, with 115 pregnant women having at least one consultation with the pediatric and perinatal palliative care team. The mean age of patients was 30 years ( $\pm 7.2$ ). Regarding disease classification, most concern uncertain prognosis due to neurological alterations (22%), followed by chromosomal syndromes (18%). In light of this, 15% of pregnant women and their families agreed to limit support and 31% of the babies died. Knowledge of this information allows better targeting actions and, consequently, better support for the family of fetuses with malformations.

**Keywords:** Palliative care. Perinatology. Ambulatory care. Congenital abnormalities.

## Resumo

### Cuidados paliativos perinatais: reflexões sobre uma clínica ambulatorial

Este estudo descreve o perfil da população atendida por um serviço de cuidados paliativos pediátricos e perinatais em uma clínica ambulatorial para gestantes, em um hospital de referência em Curitiba/PR. Trata-se de um estudo retrospectivo, transversal e descritivo, baseado nos prontuários das pacientes atendidas entre setembro de 2020 e março de 2022. Os dados foram analisados por estatística descritiva. O serviço recebeu 130 encaminhamentos, sendo que 115 gestantes realizaram pelo menos uma consulta com a equipe de cuidados paliativos pediátricos e perinatais. A média de idade das pacientes foi de 30 anos ( $\pm 7,2$ ). Em relação à classificação da doença, a maioria diz respeito ao prognóstico incerto devido a alterações neurológicas (22%), seguido por síndromes cromossômicas (18%). Diante disso, 15% das gestantes e suas famílias concordaram em limitar o suporte de vida e 31% dos bebês morreram. O conhecimento dessas informações permite melhor direcionamento de ações e, consequentemente, melhor suporte para as famílias de fetos com malformações.

**Palavras-chave:** Cuidados paliativos. Perinatologia. Atenção ambulatorial. Anormalidades congênitas.

## Resumen

### Cuidados paliativos perinatales: reflexiones en torno a una clínica ambulatoria

Este estudio describe el perfil de la población atendida por un servicio de cuidados paliativos pediátricos y perinatales en una clínica ambulatoria para mujeres embarazadas, en un hospital de referencia en Curitiba/PR. Se trata de un estudio retrospectivo, transversal y descriptivo, basado en las historias clínicas de pacientes atendidas entre septiembre del 2020 y marzo del 2022. Los datos se analizaron utilizando estadística descriptiva. El servicio recibió 130 derivaciones, y 115 mujeres embarazadas tuvieron al menos una consulta con el equipo de cuidados paliativos pediátricos y perinatales. La edad media de las Pacientes fue de 30 años ( $\pm 7,2$ ). En cuanto a la clasificación de la enfermedad, la mayoría se refiere al pronóstico incierto debido a alteraciones neurológicas (22%), seguido de síndromes cromosómicos (18%). Ante ello, el 15% de las mujeres embarazadas y sus familias aceptaron limitar el soporte vital y el 31% de los bebés fallecieron. Conocer esta información permite orientar mejor las acciones y, en consecuencia, ofrecer un mejor apoyo a las familias de fetos con malformaciones.

**Palabras clave:** Cuidados paliativos. Perinatología. Atención ambulatoria. Anomalías congénitas.

The authors declare no conflict of interest.

Approval CAAE 58021922.9.0000.0103

The growing use of technology in prenatal examinations has allowed for early diagnosis of severe and life-limiting fetal diseases during pregnancy<sup>1</sup>. Fetal malformation is estimated to occur in 3% of live births in Brazil, with 1.2% being major malformations that can have serious consequences for the infant's health and, in some cases, be incompatible with extrauterine life<sup>2</sup>.

In this context, perinatal palliative care aims to provide comprehensive care to fetuses diagnosed with life-limiting conditions, as well as to pregnant women and their family, facilitating shared decision-making regarding the birth and postpartum plan<sup>2</sup>.

The concepts of palliative care were first applied in fetal medicine in the 1990s in the United States. In 2001, a follow-up model was discussed for families who choose to continue the pregnancy, providing means to care for the fetus and newborn with joint discussions between the care team and the family, enabling bonding and connection with the gestated infant, considering them as a patient. In Brazil, discussions on the application of this model in prenatal care began around 2006<sup>3</sup>, thus few medical centers offer specialized care in this area.

In 2013, a model of perinatal palliative care (PPC) was published, consisting of nine steps to promote comprehensive care: 1) identification of candidate fetuses/neonates; 2) agreement among the team that the fetus/neonate is a candidate; 3) informing the family about the prognosis; 4) assessing the family's initial wishes; 5) jointly developing an initial plan for the fetus/neonate; 6) multidisciplinary evaluation of the family's possibilities and wishes; 7) developing a care plan for the fetus/neonate; 8) planning for end-of-life moments; and 9) follow-up after death<sup>4</sup>. A specific follow-up model for PPC was described in Brazil only in 2017, which was successfully implemented at the obstetrics clinic of the Hospital das Clínicas of the University of São Paulo<sup>5</sup>.

This study aims to describe the profile of patients attended at the outpatient clinic for pregnant women of the PPC service of a referral hospital.

## Method

This is a retrospective, cross-sectional, and descriptive study conducted at the outpatient

clinic for pregnant women of the PPC service in a reference hospital in Curitiba, Brazil. The research was approved by the research ethics committee of Faculdade Evangélica Mackenzie do Paraná.

The clinic provides care to pregnant women referred from the public health care system following the detection of fetal malformations. Consultations are conducted by two specialized palliative care physicians and a psychologist, involving discussions on fetal diagnosis, prognosis, the development of a birth plan, among other topics. Grief counseling and support sessions are also offered.

## Participants

Patients who attended at least one consultation at the selected clinic and had their delivery at the same hospital were included. There were no exclusion criteria.

## Procedures

The medical records of patients attended between September 2020 and March 2022 were reviewed to collect the following information: age of the pregnant woman, gestational age at the first consultation, city of origin, gestational age at fetal diagnosis, religion, presence of a partner, pre-existing or gestational maternal diseases, infant's diagnosis, indication of support limitation, number of consultations conducted, and outcome.

Classification of fetal diagnosis was based on the models proposed by Andrade<sup>5</sup> and Leuthner<sup>6</sup>, which include the following categories: certain diagnosis and prognosis; uncertain diagnosis but certain prognosis; uncertain diagnosis and prognosis.

Data were analyzed using descriptive statistics using the IBM SPSS Statistics software.

## Results

The clinic received 130 referrals, and 115 pregnant women had at least one consultation with the PPC team during the study period. Table 1 presents the sociodemographic characteristics of the participants and other data related to the first appointment.

The mean gestational age of the participants at the time of the first appointment with the PPC

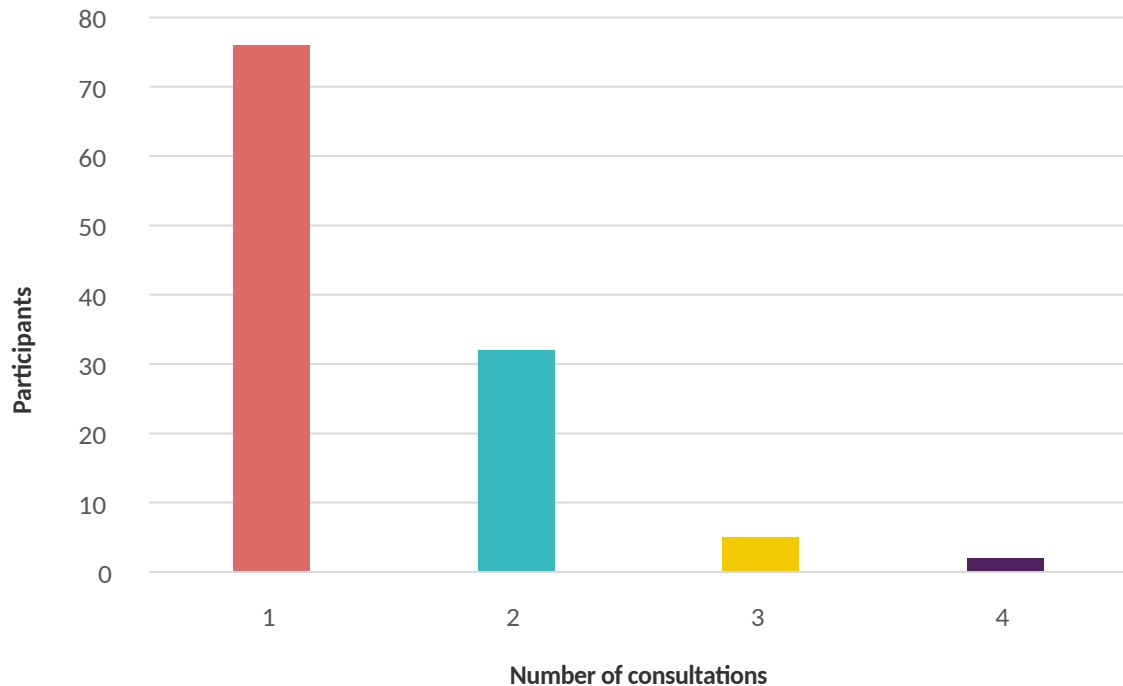
was 31 weeks, corresponding to the third trimester of pregnancy. Most (55%) were accompanied by their partner, followed by no companion (32%).

The majority identified themselves as Catholic (31%). Figure 1 demonstrates the relationship between the number of consultations conducted per patient.

**Table 1.** Sociodemographic characteristics (n=115)

Variable	Mean	Standard deviation
Age	30 years	±7.2
Gestational age	31 weeks	±5.6
Quantity		Percentage
Escort		
Companion	65	55%
None	38	32%
Uninformed	5	4%
Other family members	10	9%
Religiosity		
Catholic	36	31%
Evangelic	31	27%
Not informed	18	16%
Christian	11	9%
Has faith, no specific religion	9	8%
Other	10	9%

**Figure 1.** Number of consultations by patient



During the studied period, 163 appointments were conducted with 115 pregnant women. The distribution was as follows: 76 had one appointment; 32 participated in two appointments; 5 in three appointments; and 2 in four appointments.

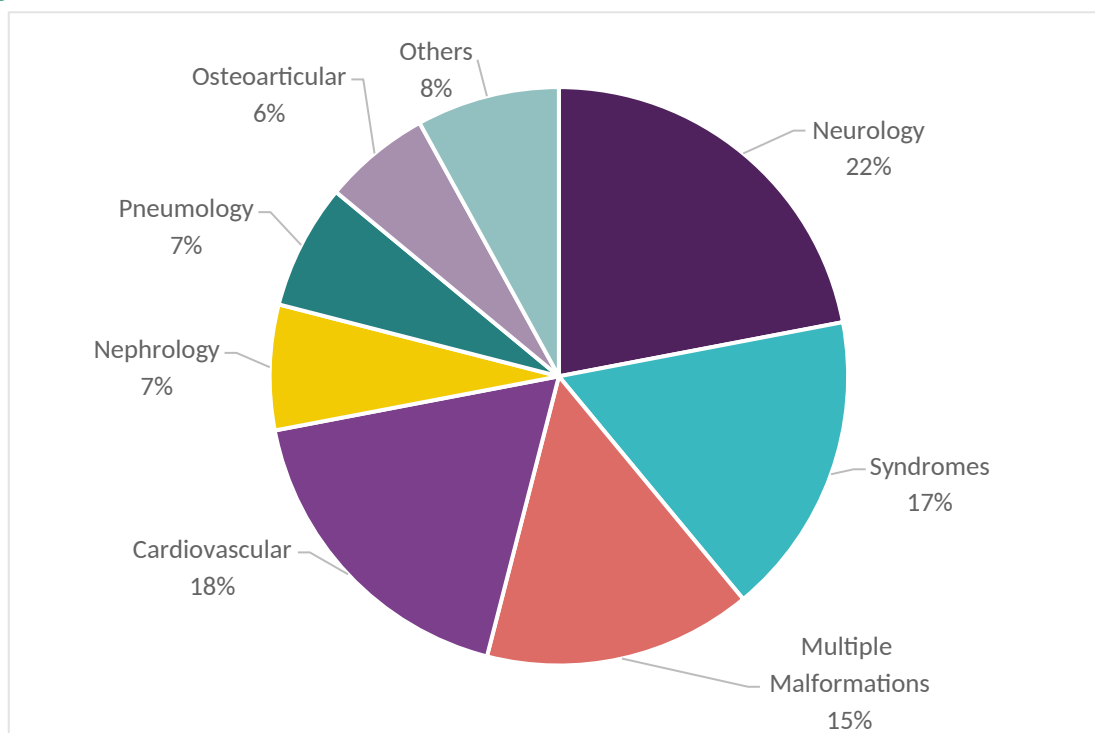
Regarding pre-existing conditions, most participants did not have any (57%), followed by hypothyroidism and obesity (each 10%). Similarly, the majority did not develop any diseases during pregnancy (63%), followed by gestational diabetes mellitus (20%).

The mean time of fetal diagnosis was the 20th gestational week ( $\pm 6.1$ ). According to the Leuthner<sup>6</sup> disease classification, most cases were associated with uncertain prognosis.

The corresponding medical areas for the diagnosis are shown in Figure 2, which include oncology (2%), gastroenterology (2%), obstetrics (1%), metabolic disorders (1%), and upper airway malformations (1%), among others.

Support limitation after birth was agreed upon with 15% of the pregnant women and their families. In the analysis of outcomes, 31% of the babies died.

**Figure 2.** Fetal diagnoses (n=115)



Most deaths occurred in the neonatal intensive care unit (NICU) (n=13), followed by intrauterine deaths (n=11), deaths in the obstetric center (n=10), in another hospital (n=1) and in the pediatric intensive care unit (PICU) (n=1).

## Discussion

Many conditions can lead to referrals to the PPC team, including cardiac, pulmonary, neurological, renal, skeletal malformations, or chromosomal

syndromes. Other studies have also identified a prevalence of chromosomal abnormalities or nervous system anomalies in their samples<sup>7-13</sup>.

Previous studies have shown that life-threatening diseases or conditions are commonly diagnosed in the second trimester of pregnancy, specifically between the 18<sup>th</sup> and 20<sup>th</sup> week. This is because most anatomical structures are then sufficiently formed, allowing adequate visualization by ultrasound examination<sup>7,10</sup>, which corresponds to the mean gestational age of 20 weeks at the time of diagnosis found in the present study.

Follow-up with the PPC service is indicated from the moment of diagnosis, regardless of gestational age<sup>14</sup>. However, this is not always observed in practice, as there is often a gap between these moments. In the present study, 11 weeks was the mean period, whereas data from the literature<sup>1,7,9,14</sup> mention 7 weeks.

Optimizing the interval between diagnosis and the start of specialized care is essential to ensure the quality of care for the family and the infant, considering the distress caused by the uncertainty of the situation and the need to make decisions regarding the care plan<sup>7,15</sup>.

Discussions about diagnosis, prognosis, estimated disease mortality, chances of sequelae should be held during prenatal visits, allowing families to discuss possible outcomes and the actions to be taken or limited for a live birth<sup>1,2,16</sup>. Care goals for infants diagnosed with lethal fetal anomalies are recommended to focus only on comfort and quality of life, limiting life-sustaining measures that could cause pain and suffering<sup>7</sup>. Delivery room support limitation, as reported in the literature, ranges from 9.9%<sup>17</sup> to 12%<sup>18</sup> of the samples, consistent with the 15% found in this study.

Regarding the outcomes of the monitored babies, previous findings from other PPC programs have shown fetal mortality rates ranging from 24%

to 45%<sup>7,10,11</sup>, corroborating the data found in the present study (30% of fetal deaths).

The main limitation of this study is its retrospective and single-site nature. For instance, sociodemographic information about spirituality and the presence of a companion during appointments were sometimes missing, impairing data analysis. Some results cannot be generalized to other centers.

## Final considerations

The present study provides a deeper understanding of the profile of pregnant women who used a reference PPC service. Knowledge of the information presented allows for better targeting of actions and, consequently, improved support for families of fetuses with malformations.

Although most findings corroborate the existing literature on the topic, a longer interval was observed between the time of diagnosis and the first consultation with the PPC team in this study. This emphasizes the importance of optimizing referrals to the service to ensure comprehensive attention to the fetus and their family throughout pregnancy, delivery, and postpartum. In conclusion, further studies are needed to capture the complexity of providing and receiving perinatal palliative care.

## References

1. Hoeldtke NJ, Calhoun BC. Perinatal hospice. *Am J Obstet Gynecol* [Internet]. 2001 [acesso 10 jun 2023];185(3):525-9. DOI: 10.1067/mob.2001.116093
2. Bolibio R, Jesus RCA, Oliveira FF, Gibelli MABC, Benute GRG, Gomes AL, et al. Cuidados paliativos em medicina fetal. *Rev Med* [Internet]. 2018 [acesso 3 jul 2023];97(2):208. DOI: 10.11606/issn.1679-9836.v97i2p208-215
3. Bueno M, Bussotti EA, Sakita NK, Barbosa SMM. Reflexões sobre cuidados paliativos no período neonatal. *Rev Prática Hosp* [Internet]. 2007 [acesso 22 maio 2023];IX(50):87-90. Disponível: <https://bit.ly/4d1LdxD>
4. Baldwin L, Bevan A. Palliative care for newborns. In: Lantos JL, editor. *Palliative care for infants, children, and adolescents: a practical handbook*. Baltimore: Johns Hopkins University Press, 2013. p. 277-88.
5. Andrade LSBC. Grupo de apoio integral às gestantes de fetos com malformação: utilização de conceitos de cuidados paliativos no atendimento em medicina fetal [tese de doutorado]. São Paulo: Universidade de São Paulo; 2017.
6. Leuthner SR. Fetal palliative care. *Clin Perinatol* [Internet]. 2004 [acesso 7 jan 2023];31(3):649-65. DOI: 10.1016/j.clp.2004.04.018
7. Marc-Aurele KL, Nelesen R. A five-year review of referrals for perinatal palliative care. *J Palliat Med* [Internet]. 2013 [acesso 7 jan 2023];16(10):1232-6. DOI: 10.1089/jpm.2013.0098

8. Hein K, Flaig F, Schramm A, Borasio GD, Führer M. The path is made by walking-mapping the healthcare pathways of parents continuing pregnancy after a severe life-limiting fetal diagnosis: a qualitative interview study. *Children (Basel)* [Internet]. 2022 [acesso 7 jan 2023];9(10):1555. DOI: 10.3390/children9101555
9. Marc-Aurele KL, Hull AD, Jones MC, Pretorius DH. A fetal diagnostic center's referral rate for perinatal palliative care. *Ann Palliat Med* [Internet]. 2018 [acesso 3 jul 2023];7(2):177-85. DOI: 10.21037/apm.2017.03.12
10. Doherty ME, Power L, Williams R, Stoppels N, Dumond LG. Experiences from the first 10 years of a perinatal palliative care program: a retrospective chart review. *Paediatr Child Health* [Internet]. 2021 [acesso 3 jul 2023];26(1):e11-6. DOI: <https://doi.org/10.1093/pch/pxz089>
11. D'Almeida M, Hume RF, Lathrop A, Njoku, A, Calhun BC. Perinatal hospice: family-centered care of the fetus with a lethal condition. *J Am Physicians Surg* [Internet]. 2006 [acesso 3 jul 2023];11(2):52-5. Disponível: <https://bit.ly/3y92Wo1>
12. Jalowska A, Krzeszowiak J, Stembalska A, Szmyd K, Zimmer M, Jagielska G, et al. Perinatal palliative care performed in obstetrics and neonatology wards and hospices for children: own experience. *Dev Period Med*. 2019;23(4):253-62.
13. Buchholtz S, Fangmann L, Siedentopf N, Bühler C, Garten L. Perinatal palliative care: additional costs of an interprofessional service and outcome of pregnancies in a cohort of 115 referrals. *J Palliat Med* [Internet]. 2022 [acesso 10 jun 2023];26(3):393-401. DOI: 10.1089/jpm.2022.0172
14. Limbo R, Wool C. Perinatal palliative care. *JOGNN* [Internet]. 2016 [acesso 10 jun 2023];45(5):611-3. DOI: 10.1016/j.jogn.2016.07.002
15. Flenady V, Boyle F, Koopmans L, Wilson T, Stones W, Cacciatore J. Meeting the needs of parents after a stillbirth or neonatal death. *BJOG* [Internet]. 2014 [acesso 10 jun 2023];121(s4):137-40. DOI: 10.1111/1471-0528.13009
16. Bhatia J. Palliative care in the fetus and newborn. *J Perinatol* [Internet]. 2006 [acesso 10 jun 2023];26(suppl 1):S24-6. DOI: 10.1038/sj.jp.7211468
17. Barbeyrac C, Roth P, Noël C, Anselem O, Gaudin A, Roumegoux C, et al. The role of perinatal palliative care following prenatal diagnosis of major, incurable fetal anomalies: a multicentre prospective cohort study. *BJOG* [Internet]. 2022 [acesso 10 jun 2023];129(5):752-9. DOI: 10.1111/1471-0528.16976
18. Tucker MH, Ellis K, Linebarger J. Outcomes following perinatal palliative care consultation: a retrospective review. *J Perinatol* [Internet]. 2021 [acesso 10 jun 2023];41(9):2196-200. DOI: 10.1038/s41372-021-00966-2

Julianna Rodrigues Beltrão – Master – [julianna.beltrao@hotmail.com](mailto:julianna.beltrao@hotmail.com)

 0000-0001-6417-2125

Andreia Christine Bonotto Farias Franco – Graduate (specialist) – [andreiabff@gmail.com](mailto:andreiabff@gmail.com)

 0000-0002-5302-292X

Larissa Madruga Monteiro – Graduate (specialist) – [larimonteiro78@gmail.com](mailto:larimonteiro78@gmail.com)

 0009-0002-0662-8096

Janaína Ferreira Percegoni – Graduate – [jana\\_percegoni@yahoo.com](mailto:jana_percegoni@yahoo.com)

 0000-0002-9471-3778

#### Correspondence

Julianna Rodrigues Beltrão – Rua Amazonas, 677 CEP 80610-30. Curitiba/PR, Brasil.

#### Participation of the authors

Julianna Rodrigues Beltrão study design; data collection; data analysis; manuscript writing. Andreia Franco study design; manuscript revision; study supervision. Larissa Monteiro study design; manuscript writing; manuscript revision; study supervision. Janaína Percegoni data collection; data analysis; manuscript revision.

Received: 10.11.2023

Revised: 6.7.2024

Approved: 6.12.2024