

# Perinatal Palliative Care: Approach To Congenital Abnormalities That Threaten The Continuity Of Life

**RESUMO** | Objetivo: identificar quais condutas são tomadas frente a fetos e neonatos com anomalias congênicas e fatores facilitadores e dificultadores para a atuação da medicina fetal e neonatologia neste escopo. Método: revisão sistemática da literatura realizada entre os anos de 2018 e 2022. Resultado: nas estratégias utilizadas para encaminhamento aos cuidados paliativos no pré-natal estão o apoio psicoespiritual priorizado à família e as opções de cuidado para avaliar até qual ponto intervir de forma invasiva no atendimento ao nascituro. Identificou-se que a falta de preparo profissional para abordar a família de um nascituro com mau prognóstico faz com que não tenham o tato necessário para tal ação. Conclusão: em um momento que a família passa por um processo de luto, exaustão emocional e necessidade de tomada de decisões, é imprescindível a capacitação dos profissionais para atuarem com qualidade, de forma a melhorar a organização do serviço e a assistência adequada.

**Descritores:** Cuidados paliativos; Anormalidades congênicas; Perinatologia; Neonatologia.

**ABSTRACT** | Objective: to identify what actions are taken against fetuses and neonates with congenital anomalies and facilitating and complicating factors for the performance of fetal medicine and neonatology in this scope. Method: systematic review of the literature conducted between the years 2018 and 2022. Results: in the strategies used for referral to palliative care in prenatal care are the prioritized psychospiritual support to the family and care options to assess to what extent to intervene invasively in the care of the unborn child. It was identified that the lack of professional preparation to approach the family of an unborn child with a poor prognosis makes them lack the necessary tact for such an action. Conclusion: at a time when the family goes through a process of mourning, emotional exhaustion and the need to make decisions, it is essential to train professionals to act with quality, in order to improve the organization of the service and adequate assistance.

**Keywords:** Palliative Care; Congenital Abnormalities; Perinatology; Neonatology.

**RESUMEN** | Objetivo: identificar qué actuaciones se realizan ante fetos y neonatos con anomalías congénitas y factores facilitadores y complicadores para la realización de medicina fetal y neonatología en este ámbito. Método: revisión sistemática de la literatura realizada entre los años 2018 y 2022. Resultados: en las estrategias utilizadas para la derivación a cuidados paliativos en la atención prenatal se prioriza el apoyo psicoespiritual a la familia y las opciones asistenciales para valorar hasta qué punto intervenir de forma invasiva en el cuidado del feto. Identificou-se que a falta de preparação profissional para abordar a família de um nascituro com mau pronóstico faz que não tenham o tato necessário para tal ação. Conclusión: en un momento en que la familia pasa por un proceso de luto, agotamiento emocional y necesidad de tomar decisiones, es imprescindible la capacitación de los profesionales para actuar con calidad, de forma que se mejore la organización del servicio y la asistencia adecuada.

**Palabras claves:** Cuidados Paliativos; Anomalías Congénitas; Perinatología; Neonatología.

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## INTRODUCTION

In the extended analysis of the course of life we have the cycle in which the human being is born, grows up, ages and only after that goes through the process of death. When it comes to fetal medicine, in some situations this life cycle can be altered, and death becomes a fact for the

newborn. Dealing with the process of perinatal and neonatal death is extremely delicate, since it demands from the professional team knowledge to handle this delicate situation in a technical and human way<sup>1,2</sup>.

According to the World Health Organization (WHO), palliative care can be characterized as the application of actions developed by a multiprofessional team with the objective of promoting quality of life for the patient and his family when facing a condition that threatens the continuity of life. Therefore, its premises are: relief of physical, psychological, spiritual, and social suffering. Palliative care in neopediatrics follows the same principles and uses interdisciplinarity in the search for improving the quality of life of children at risk of death, as well as welcoming and accompanying

their families<sup>3</sup>.

In the last decade, considering the advances in fetal medicine, it has become possible to identify congenital anomalies early and with great precision and accuracy. Syndromes with a known karyotype facilitate the decision making process about the conduct to be performed with the fetus and later with the neonate. One of the greatest difficulties for the palliative approach is the communication with the family about situations in which the anomaly is known to be lethal or in cases of fetuses with trisomy 13 and 18 are the most frequent cases that require exclusive palliative care.

During the prenatal period, if any fetal abnormalities are suspected, the professional must investigate genetic causes through karyotyping and detailed morphological exams so that a comprehensive care plan can be drawn up for the family. Once the condition of the fetus has been determined, health professionals must advise the family on what decisions can be made in the situation. Syndromes such as Edward's and Patau's are known for their lethality, and parental counseling must take into account the prognoses of the diseases, clarifying that the death process does not have a pre-defined time and that it can happen in utero or within months of the newborn's life<sup>4,5</sup>.

On the other hand, when talking about the implementation of perinatal palliative care we are facing a series of ethical dilemmas that permeate fetal medicine and neonatology. Identifying fetal viability, existing syndromes, and establishing conduct are delicate issues for the professionals who care for the pregnant woman. Currently, when analyzing the international context of perinatal palliative care there are three fronts that can be followed: terminating pregnancy by identifying anomalies known to be lethal; diagnosing possible syndromes still intrauterine and starting the palliative approach in the prenatal period; and finally waiting for birth to define if the support will be with invasive and curative

measures or if palliative care should be approached<sup>4,5</sup>.

Permeated with ethical and moral dilemmas, fetal medicine is still underdeveloped when it comes to palliative care. The feeling of helplessness, fear, and helplessness are frequent in the medical profession, which still does not have all the answers for the clinical cases that arise during their work. The health-disease cycle is focused on the curative model, and coming across cases in which a cure is not the option brings insecurity to the team; the situation is amplified when we deal with this reality in the neonatal period. It is necessary to understand the existence of medicine and care as something beyond curing, human beings go beyond a defective machine and therefore the biopsychosocial aspects must be prioritized for health care. The perinatal palliative approach is not due to an incompetence of professionals in treating the fetus, it is an advance that guarantees human dignity from the moment of prenatal care. Thus, the mourning process and the experience of that family that is born takes place in a more humanized way<sup>4,5</sup>.

Considering the problem exposed, the palliative care approach is an important tool capable of promoting human dignity in the different stages of life.

However, the perinatal and neonatal palliative approach to congenital anomalies that threaten the continuity of the newborn's life is still not very clear. Thus, this study aims to identify how the professional team conducts itself in the approach to families with infants diagnosed with congenital anomalies incompatible with life and the management performed, so that it is possible to elucidate the complicating factors for the perinatal palliative approach.

## METHODOLOGY

This is a systematic review conducted between the years 2018 and 2022. The databases Virtual Health Library (VHL)

were used for the search, which include: Nursing Database (Bdenf), Latin American and Caribbean Literature on Health Sciences (Lilacs) and Scientific Electronic Library online (SciELO) collection; and Medline database, through PubMed - National Library Of Medicine National Institutes Of Health. The search was refined using the following descriptors: Palliative Care, Perinatology, Neonatology, Fetal Medicine and Congenital Abnormalities. Articles that did not have a scientific character or did not fit the theme of the study were excluded. To ensure ethical consideration, all authors will have their studies rigorously referenced.

During the literature review process to analyze the articles the following aspects were considered: area of knowledge, variables studied, method, and relevance of the research. After delineating the inclusion and exclusion criteria of the articles, 23 productions were initially selected, and after a careful reading, 12 studies were chosen that fit the proposed theme. After reading the selected studies, a careful analysis was developed in an attempt to identify the most relevant themes of the articles so that they could then be organized, aiming to collect the necessary information to answer the research question.

## RESULTS

When analyzing the selected articles it was observed that most used a qualitative or qualitative/quantitative method for data description and analysis (83.33% of the sample). Regarding the databases, the number of articles in MEDLINE (PUBMED) was significantly higher (75%) when compared to the others. The publications that address the theme are mostly international and in English. The data regarding the criteria and characteristics of the articles are described in table 1.

The results of the search are shown in table 2 and were categorized according to the variables found in the selected articles.

**Table 1. Characteristics of the selected articles**

Study title	Authors	Journal	Type of study	Study title	Authors	Journal	Type of study	Study title	Authors	Journal	Type of study
Palliative care in fetal medicine <sup>4</sup>				Figueredo DVA, Souza ASR		Rev Bras Saúde Mater Infant.		Qualitative			
Interdisciplinary care of children with trisomy 13 and 18 <sup>6</sup>				Weaver MS, Anderson V, Beck J, Delaney JW, Ellis C, Fletcher S, et al		Am J Med Genet A.		Qualitative			
Malformação fetal incompatível com a vida: conduta de neonatologistas <sup>5</sup>				Rossini MM, Stamm AMNF		Rev Bioét.		Qualitative			
Developing a perinatal palliative care service package for women with fetal anomaly diagnosis: protocol for mixed methods study <sup>7</sup>				Raisi Dehkordi Z, Kohan S, Rassouli M, Zarean E, Malekian A		Reprod Health.		Qualitative-quantitative			
Comunicando más notícias sobre malformações congênicas: reflexões bioéticas e jurídicas <sup>8</sup>				Gazzola LPL, Leite HV, Gonçalves GM		Rev Bioét.		Qualitative			
Nurses' perceptions of the palliative care needs of neonates with multiple congenital anomalies <sup>9</sup>				Şener Taplak A, Gürol A, Polat S		J Hosp Palliat Nurs.		Qualitative-quantitative			
Obstetric complications in pregnancies with life-limiting malformations <sup>10</sup>				Quaresima P, Homfray T, Greco E		Curr Opin Obstet Gynecol.		Qualitative			
Early palliative care reduces stress in parents of neonates with congenital heart disease: validation of the "Baby, Attachment, Comfort Interventions" <sup>11</sup>				Callahan K, Steinhurtzel R, Brumarie L, Schechter S, Parravicini E		J Perinatol.		Qualitative-quantitative			
Perinatal palliative care performed in obstetrics and neonatology wards and hospices for children - own experience <sup>12</sup>				Jalowska A, Krzeszowiak J, Stembalska A, Szymd K, Zimmer M, Jagielska G, et al.		Dev Period Med.		Qualitative-quantitative			
Psycho-social approach of perinatal palliative care <sup>13</sup>				Tosello B, Dany L		Matern Fetal Neonatal Med.		Qualitative			
A randomised trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease <sup>14</sup>				Hancock HS, Pituch K, Uzark K, Bhat P, Fifer C, Silveira M, et al		Cardiol Young		Qualitative			
Congenital malformations, palliative care and postnatal redirection to more intensive treatment - a review at a Swiss tertiary center <sup>15</sup>				Pfeifer U, Gubler D, Bergstraesser E, Bassler D		J Matern Fetal Neonatal Med.		Qualitative			

## DISCUSSION

### Strategies used for prenatal referral to palliative care

When identifying a suspected or final diagnosis of a fetus with congenital anomaly, professionals are faced with an ethical and moral dilemma when approaching the family, especially the pregnant woman, regarding the baby's prognosis and continuation of pregnancy. In some countries (mostly developed countries) abortion is a legalized practice and becomes an option for the woman, but those who decide to continue with pregnancy often do not get the prenatal care in an adequate way. With the advances in fetal medicine it has become possible to perform intrauterine interventions to improve the baby's prognosis, but it is up to the doctor to assess whether the risk

the pregnant woman is putting herself at will actually have a significant impact on the survival of the fetus. Even with all the technological apparatuses that fetal and neonatal medicine has today, it is important that humanization and respect for integral care become the basis of prenatal care in an atypical pregnancy in which fetal death is a reality. It is important to understand that mourning will begin even before birth, once the family has broken the idealization of the imaginary baby and begins to face the newborn that they cannot foresee. Prenatal care should be used to provide parents with knowledge and inform them about care options, so that together the team can evaluate up to what point to intervene invasively in the care of the unborn child<sup>4,5</sup>.

**Table 2: Study categorization**

Variables	Sample N	%
Selected Articles	12	100
<b>Type of study</b>		
Quantitative	2	16,66
Qualitative	5	41,66
Qualitative-quantitative	5	41,66
<b>Year of publication</b>		
2018	2	16,66
2019	4	33,33
2020	4	33,33
2021	2	16,66
<b>Language</b>		
Portuguese	3	25
English	9	75
<b>Databases</b>		
LILACS	3	25
MEDLINE	9	75

## Management of the newborn in the delivery and postpartum process

During the birth of a baby with congenital anomalies, medical management must already be aligned with the parents. When the prognosis is certain, neonatologists have confidence to provide support that seeks the comfort of the newborn without curative interventions. Birth becomes a moment of bonding between parents and the baby and everything must be organized so that the triad can have a positive experience, even in a situation with a poor prognosis. Once the newborn is stabilized, skin-to-skin contact, breastfeeding, and the first care with the participation of the mother and father must be allowed and stimulated. In cases where the unborn child dies immediately, baby care must also be shared with the family, if they so wish; bath time, body preparation, and even skin-to-skin contact can be performed. Respecting the experience of that moment so long awaited by parents must be the focus of the team providing assistance, when the palliative approach starts in the prenatal period, the delivery and puerperium plan is worked out during pregnancy and ensures that

the baby's birth will be less traumatic for the family and more comfortable for the newborn, who will go through an adequate management of symptoms, ensuring his/her comfort<sup>7,11,13,15</sup>.

## Professional preparation to approach the family of an unborn child with poor prognosis

Fetal and neonatal medicine has undergone significant technological advances in the last decade, but even with all the scientific apparatus professionals still report a lack of preparation to address the psychosocial issues of a family with a fetus carrying an anomaly incompatible with life. Communicating difficult news is a complicated and delicate process for professionals, especially those who work in perinatal care, so they often leave to approach the family late and do not really clarify the baby's prognosis or pregnancy. The lack of training in specializations and graduations makes professionals resistant to face such bioethical dilemmas, or even makes them lack the necessary tact for such action. Therefore, implementing permanent education in health and inserting these topics in professional training becomes essential<sup>8,9</sup>.

## CONCLUSION

Palliative care in perinatal care still needs to be strengthened and developed; however, it is a very important tool in clinical medicine. At a time when the family goes through a grieving process, emotional exhaustion, and the need for decision making, health professionals are indispensable and face barriers that hinder the implementation of this approach. The following factors were identified as hindering the palliative care process: professional training, bioethical and moral dilemmas, obstacles in privacy with patients and family members, professional unpreparedness, among others. It was also possible to verify in the study the insufficiency of research that demonstrates the experience of the multidisciplinary team that works with palliative care in perinatology and fetal medicine. Thus, it is possible to perceive the need for studies that indicate the practice of professionals involved in palliative care and their training to act with quality, in order to improve the organization of the service and adequate assistance. 🐦

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