

doi: <http://dx.doi.org/10.11606/issn.1679-9836.v97i2p208-215>

Palliative care in fetal medicine

Cuidados paliativos em medicina fetal

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ABSTRACT: Fetal malformations affect approximately 3% of pregnancies, and the possibility of this diagnosis is one of the main concerns of parents and family members. When a malformation that implies potential mortality for the child is diagnosed, the pregnancy's follow-up needs to be planned, including diverse aspects such as thorough evaluation of the prognosis, organization of post-partum care, and follow-up with the family in a broad and integrated manner. Recently, palliative care concepts have been introduced into perinatology for this purpose. This article discusses the application of the palliative care model to the care of pregnant women and family members of fetuses with malformations.

Keywords: Palliative care; Fetus/abnormalities; Perinatology.

RESUMO: Malformações fetais acometem cerca de 3% das gestações, e a possibilidade desse diagnóstico é uma das principais preocupações vivenciadas pelos pais e familiares. Quando é diagnosticado uma malformação que implique em possível mortalidade da criança, é necessário o planejamento do seguimento da gestação, o que abrange diversos aspectos que incluem avaliação minuciosa do prognóstico, organização do cuidado após o parto, e seguimento da família de forma abrangente e integrada. Recentemente os conceitos de cuidados paliativos foram introduzidos na perinatologia com essa finalidade, e o presente artigo tem como objetivo discutir o modelo de cuidado paliativo aplicado no atendimento a gestantes e familiares de fetos com malformação.

Descritores: Cuidados paliativos; Feto/anormalidades; Perinatologia.

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INTRODUCTION AND HISTORY

Pregnancy is a time of a woman's reproductive cycle that involves intense physical, emotional, and social changes. During pregnancy, the couple and family members develop expectations for the expected child, including the expectation of a healthy child¹. However, this expectation may not be met in some situations, particularly when there is a diagnosis that places the pregnancy or child at risk. Fetal malformations affect approximately 3% of pregnancies, and extensive fetal malformations are diagnosed in approximately 1.2% of these cases², some with a fatal prognosis,^{3,4} which directly affects the couple's expectations.

Regardless of the severity of the disease, diagnosis of a fetal malformation has an impact on pregnant woman and their family members, and emotional changes, such as anxiety and worry, are recurrent^{5,6,7,8}. Among the potential impacts and feelings arising from the presence of a fetal malformation, Andrade⁹ describes a feeling of sadness, suffering due to the possibility of losing the child, guilt about the malformation, and concerns about the possibility of the child suffering and the reactions of the other children when they learn of the high-mortality fetal malformation.

In Brazil, a large number of fetal malformations are diagnosed prenatally, and many pregnant women carry these pregnancies to term due to individual choice, a late diagnosis, or legal restrictions. Full assistance must be offered to pregnant women to provide adequate support and, in the most serious cases, coordination of the pregnancy's follow-up and decision-making¹⁰.

When a fetal malformation is diagnosed, a detailed evaluation of the features of the fetal disease is indicated, including evaluation of the fetal prognosis and planning of care and follow-up of the pregnancy. Some fetal malformations have low severity, and some malformations are associated with high mortality; additionally, malformations for which there is no curative treatment may result in death before or after delivery⁹. In this case, the use of concepts from palliative care during the prenatal period may enable care integration, the possibility of preparing for delivery, and lower the subsequent emotional impact when there is the need for follow-up at a tertiary care unit and a risk of death is present during the perinatal period.

Palliative care was initially described in the adult population. This care approach recognizes and manages the pain and suffering of patients and family members as part of its recommendations¹¹. The definition used by the World Health Organization as described in 2002¹² is as follows:

“Approach that improves the quality of life of patients and their families facing the problems

associated with life-threatening illness through the prevention and relief of suffering. It requires early identification, evaluation, and treatment of pain and other problems, whether physical, psychosocial, or spiritual” (p. 26).

Therefore, palliative care must be indicated, since the diagnosis is based on the following principles: 1) promotion of the relief of pain and other unpleasant symptoms; 2) affirmation of life and consideration of death as a natural process of life; 3) does not accelerate or delay death; 4) integration of psychological and spiritual aspects into patient care; 5) offers a support system that enables the patient to live as actively as possible until the time of death; 6) offers a support system to help family members during the patient's disease and to manage grief; 7) multidisciplinary approach that focuses on the needs of the patients and their family members, including assistance in grief; 8) improvement of the quality of life and positive influence on the disease course; and 9) must be initiated as soon as possible together with other measures to prolong life, such as chemotherapy and radiotherapy, and must include all investigations needed to better understand and control stressful clinical situations¹².

After initiating and establishing follow-up of the adults and subsequently of the children as recommended by palliative care, a need for expansion to perinatology care was identified. The first records of an assistance model using the concept of palliative care in fetal medicine are from the 1990s. In the United States, the first medical discussion about the possibility of follow-up and planning of care for a fetus diagnosed with a lethal disease during the prenatal period using the family's values as a reference was held in 1997¹³.

In 2001, the same team proposed for the first time a model of follow-up for families deciding to carry the pregnancy to term after diagnosis of a lethal or high-mortality fetal malformation. The possibility of an accurate prenatal diagnosis and prognostic assessment were associated with knowledge of perinatal grief management and the concept of hospice deriving from adult palliative care to create the possibility of an integrated follow-up centered on the family. In the following years, the idea of this type of follow-up after a diagnosis of fetal malformation expanded, and other countries began to propose different types of assistance¹⁴.

History of palliative care and prenatal palliative care in Brazil

Palliative care in Brazil started in the 1980s and reached significant growth starting in 2000¹². In 2006, the Federal Medicine Council (Conselho Federal de

Medicina)¹⁵ published resolution no. 1,805/2006, which determined that “Doctors are allowed to limit or suspend procedures and treatments that prolong the life of a terminal patient with a serious and incurable disease provided the wishes of the person or legal representative are respected”.

Additionally, according to the Code of Medical Ethics¹⁶:

“In irreversible and terminal clinical situations, doctors will avoid performing unnecessary diagnostic and therapeutic procedures and will provide to the patients under their care all appropriate palliative care (...) In cases of incurable and terminal disease, doctors shall offer all palliative care available without performing useless or obstinate diagnostic or therapeutic actions, always taking into consideration the expressed wishes of the patient or, if he/she is incapable, those of the legal representative” (Code of Ethics, 2009 – Fundamental Principle XXII and single paragraph of article 41).

In 2006, discussions about palliative care during the neonatal period were initiated in Brazil. Bueno¹⁷ emphasized the importance of neonatal palliative care and the inclusion of the family in the process of assistance to the newborn at the final stage of life and discussions of the objectives of care.

Over the subsequent year, some authors¹⁸ reported that neonatal palliative care was indicated in cases where there was “no available treatment to provide substantial changes in the progression of the clinical presentation towards death”. These authors claimed that when the diagnosis was made early, the gestational period represented an opportunity for planning for the postnatal period¹⁸.

However, until 2017, there was no description in Brazil of a follow-up model in palliative care initiating during the prenatal period. The use of concepts from prenatal palliative care for the assistance of fetuses with high-mortality malformations was described that year in the country (“*Group for full support to pregnant women and family members of fetuses with malformations: use of concepts from palliative care in fetal medicine care [Grupo de atendimento integral às gestantes e familiares de fetos com malformação: utilização de conceitos de cuidados paliativos no atendimento em medicina fetal]*”). In the model described by the Group for Full Support (known as GAI in its Portuguese acronym), which was successfully implemented at the Obstetrics Clinic of the Clinical Hospital of the São Paulo University Medical School (Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo — HCFMUSP), integrated assistance to families was made available after diagnosis of a fetal malformation to prepare them for delivery and the

postpartum period, to allow conscious choices to be made regarding the child’s care, and to include the individual values of the families in preparation of the follow-up⁹.

Fetuses eligible for follow-up care in a palliative care model

The fetuses eligible for follow-up palliative care are those with a diagnosis of life-limiting diseases, which include the majority of major fetal malformations (i.e., malformations that require surgery or that restrict time or quality of life). Cultural differences among countries result in individualized selection of families eligible for prenatal follow-up in palliative care based on the values inherent to each country and society.

Historically, Hoeldtke and Calhoun¹⁴ suggested that in countries where therapeutic abortion was allowed, the option of continuing the pregnancy and conducting prenatal palliative care follow-up should be proposed to all candidate families together with a discussion of the possibility of having an abortion. They noted that during this discussion, the pregnancy’s follow-up should not be presented to the family as a passive attitude. Prenatal palliative care follow-up provides types of care for the fetus and the newborn that are actively discussed together with the team and the family to enable closeness and bonding with the unborn child, even though the child may not survive for long.

Leuthner¹⁹ discusses the application of palliative care during the prenatal period and in the delivery room, including care for diseases that may threaten the continuity of life but for which initial treatment and evaluation of the neonatal response must be provided. According to this author, the decision-making process for the offering of this type of care requires knowledge of three basic factors: the diagnosis, the prognosis, and the meaning of the prognosis to the parents.

In England, the British Association of Perinatal Medicine²⁰ presents indications for follow-up care of fetuses with a diagnosis of a disease incompatible with long-term survival or conditions that imply a risk of death or significant mortality.

In Brazil, in the model described by Andrade⁹, all fetuses with malformations are candidates for follow-up at a tertiary care unit and are eligible for follow-up care. Since the number of families assisted annually is large, the families of fetuses with an estimated mortality inferior to 50% are followed up in discussion groups, whereas those of fetuses with diseases with a higher mortality risk (estimated mortality above 50%) receive individual assistance.

In conclusion, in Brazilian society, the family is eligible for perinatal palliative care follow-up from the

moment a malformation that places the child’s life at risk is diagnosed, which enables full support from the time of diagnosis until the post-partum period.

Evaluation of the prognoses of fetuses receiving palliative follow-up care during the prenatal period

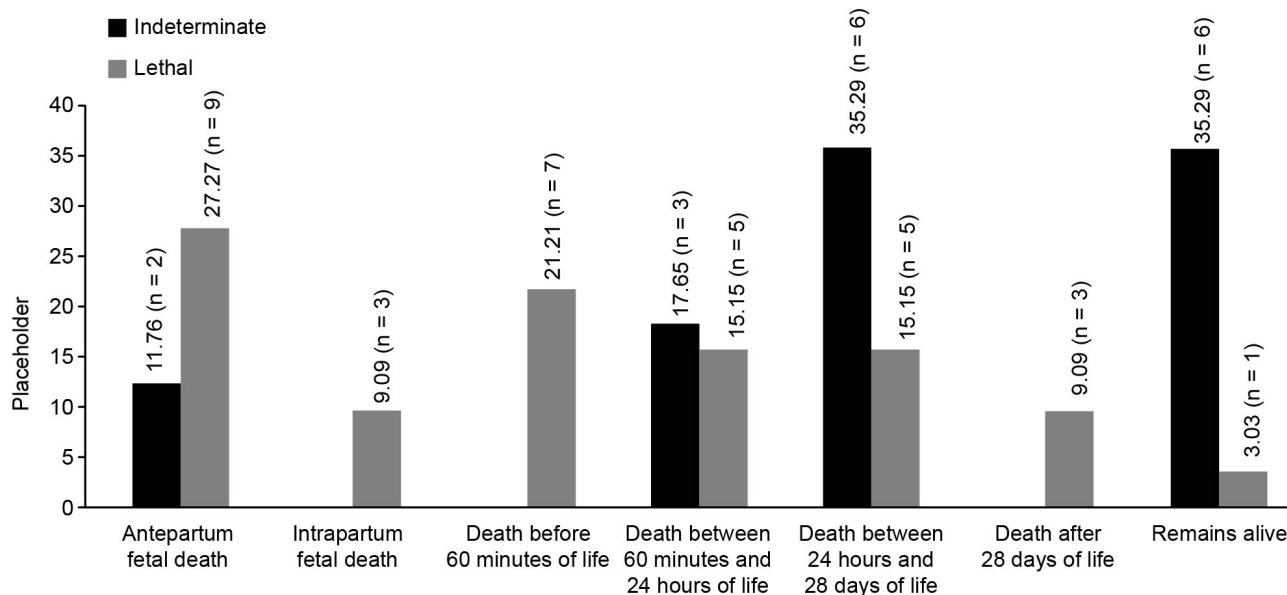
Assessment of the fetal prognosis is essential for the team and for counseling families and constitutes one of the first steps in follow-up care. Discussions about the possible outcomes and actions to be undertaken are initiated based on this evaluation. Additionally, the initiation of plans to communicate with the pregnant woman and family members follows the prognostic evaluation.

As suggested by Leuthner¹⁹, this evaluation may

consider lethal diseases for which the outcome is death after a short life, such as anencephaly²¹, and diseases with uncertain prognoses and high mortality for which there is the possibility of treatment to modify the disease course, such as severe congenital diaphragmatic hernia²².

Importantly, the classification of a fetal disease as lethal does not imply death immediately after delivery. For most diseases, there is a possibility of death occurring at different times during pregnancy and after delivery (intrauterine death, intrapartum death, in the first 24 hours, or even a few days or months after delivery)⁹.

Andrade⁹ presents the outcomes for fetuses with indeterminate and lethal prognoses and describes the broad time of death, which should be extensively discussed with the parents based on their wishes.



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Figure 1. Outcomes for fetuses of pregnant women followed up at the Group for Full Support (GAI) from May 2015 to September 2016 – HCFMUSP 2017

In addition to time of death, the family should discuss the possibility that follow-up according to a palliative care model may not change the outcome for the child.

In a retrospective study evaluating the postnatal outcomes of a population of 49 newborns with a prenatal diagnosis of life-limiting conditions whose parents were referred to prenatal counseling with the team, Parravicini and Lorenz²³ observed that all newborns died with a similar mean age of 2 days (both the 28 who received care with

comfort measures and the 17 who received intensive care). Therefore, the authors concluded that intensive care did not prevent the deaths of infants affected by life-limiting conditions.

Kukora et al.²⁴ compared pregnant women who attended a prenatal palliative care consultation with pregnant women who did not participate to describe the follow-up of fetuses with a prognosis of lethal or high-mortality disease and to determine whether the consultation changed long-term fetal survival. The authors observed that

although the prognoses for the fetuses of pregnant women who attended the consultation were more severe, there was no difference in long-term mortality, with observations of 21% fetal deaths, 67% in-hospital deaths, and 12% survival to discharge. At the same time, they observed that the frequency of families opting not to use artificial life support was significantly higher when the pregnant women attended a palliative care consultation, and those families were more likely to choose comfort measures and more contact with the child without using devices.

Perinatal palliative care follow-up during the prenatal period

During the family meetings conducted during the prenatal period, the healthcare team has the opportunity to evaluate the needs of each family and to identify their values. For this purpose, skills should be gathered from professionals from different areas, and the team members should recognize their own abilities and limits to action¹¹.

Hoeldtke and Calhoun¹⁴ suggested that the following professionals were essential when forming the team: an obstetrician, a nurse, and a social worker. In addition, the inclusion of other members, such as professionals from neonatology and psychology and chaplains, is recommended according to the specific needs of the families and the resources of each institution.

The follow-up must meet the requests of the families, which requires flexibility from the team. Team members must assure family members that they will be present and will provide the necessary support during follow-up and identify potential causes of suffering, including during delivery and the death of the newborn, if it occurs. Parents may be guided in their interactions with their other children, family members, and friends as needed, and the fetus should be accepted as an individual by the entire team to enable the formation of memories for the pregnancy¹¹.

Hoeldtke and Calhoun¹⁴ propose that the care that will be offered to the newborn if born alive should be discussed with the parents during the prenatal period.

Leuthner²⁵ expands the planning of the pregnancy's follow-up proposed by Hoeldtke and Calhoun¹⁴ to include coordination of the care plan for the newborn during the planning for the delivery and suggests practical assistance in the organization of procedures and rituals after death when requested by the parents.

Howard²⁶ proposes that in cases of a diagnosis of a major fetal malformation, the care must be centered on the family. Since pregnancy is a period of biological and

psychological transition in the life of a woman, the diagnosis of a fetal malformation makes this period emotionally devastating and is a time with little social support. For the author, follow-up has a principle to determine the individual preferences and needs of each family member with the aim of providing anticipatory guidance on potential outcomes based on the family's wishes.

Bhatia²⁷ states that the estimated mortality of each disease must be discussed during prenatal care in addition to the likelihood of complications and the type of treatment for each case to allow joint decision-making with the family in the interest of the fetus.

In the Brazilian model, outpatient assistance at GAI is provided by two members of the team who are preferentially from distinct professional backgrounds in the format of family meetings. Pregnant women are encouraged to attend the scheduled meetings with the family members who wish to join, and the importance of the presence of the parent or partner is emphasized. In this model, which is one of the first steps after referral, the team discusses the prognosis in weekly meetings with the aim of discussing medical action for the pregnant woman, the fetus, and the newborn based on the existing literature and consolidating information from all members of the team⁹.

Next, the family meetings start with the aim of getting to know the family and identifying their values and perceptions on the pregnancy, delivery, and care to be offered. During these meetings, *“the consequences of the several delivery paths and the possible types of fetal monitoring and neonatal support are discussed, as well as the consequences of the care objectives discussed with the family”*⁹.

Based on a deep knowledge of the family and the implementation of the medical actions proposed by the team, the process of making a joint decision about the care to be provided throughout the entire follow-up period is initiated, including building the delivery plan⁹.

Building the delivery plan

Planning for the delivery constitutes one of the fundamental steps in the follow-up of the families. According to English and Hessler²⁸, the care plan is included in the delivery plan and is built to allow the parents' participation in choices regarding the child by taking into consideration what they deem comfort, the period of time the family members will remain together, and the dignity of the brief moment the parents will have with the child in cases of lethal disease. The plan includes guidance on what to expect at the time of delivery, what the

environment will be like, the location where care will take place, and planning of records, such as photos and other mementos, which may be important for memories and the grief process if the child dies.

Moreover, when the fetus is diagnosed with a disease with short survival, one goal is to establish how the parents will experience the last minutes, hours, or days of the newborn's life based on an investigation of what the parents consider important. If the newborn is alive, it may be allowed and indicated in the delivery plan for him/her to be placed on the parents' laps if they wish, and the parents will be allowed to remain with the child for as long as they wish, including ensuring that care is provided while the newborn is being held by the parents whenever possible¹⁴.

In certain cases based on possibility and family interest, the procedures to be performed after death may be discussed, and a guiding booklet may be provided after the death⁹.

Time of delivery

The time of delivery is one of the most stressful and agonizing moments for the pregnant woman and family members when there is a diagnosis of major fetal malformation¹⁰.

Suassuna²⁹ states that the idealized child is perfect. Unlike the idealized child, a child with a malformation is a real child. This child no longer fills the role intended for him/her in the family's setting. This great frustration may create a serious breakdown in the relationship between parents and infants and significantly impact the bonding process for both parents in addition to generating feelings of guilt, aggressiveness, and sadness.

The actual cutting of the umbilical cord will interrupt placental oxygenation to the fetus, leading to the manifestation of symptoms of cardiac, pulmonary, and chromosomal diseases that often do not manifest to a large extent inside the uterus. Moreover, when the disease has short survival, the time of delivery is the time when the end of life may be initiated. Therefore, preparing the family for this moment is extremely important⁹.

The team on call when the delivery occurs should

know what was discussed and agreed upon with the family during the prenatal follow-up. This knowledge can be ensured through the medical records, the prenatal card, and the delivery plan itself. Moreover, the medical team on call must talk with the pregnant woman at the time of admission to verify whether she has any questions or changes regarding the actions previously defined during the meetings⁹.

Postnatal follow-up

Follow-up with the families after delivery is extremely important both for those who lose a child and will undergo the grief process and those who need support to accompany the child through the surgeries and intensive care unit stays inherent to most treatable major malformations. In validating the principle of offering support to assist family members during the patient's disease and dealing with grief, the "*Manual for Palliative Care*"¹² states that assistance to the patient's family requires the team to have the ability to manage conflict situations, stimulate the patient and family to think and speak freely about their experiences and legitimate suffering, and contribute to the development of experiences during the disease progression, death, and grief processes. Grief support needs to be provided for up to 12 months after the death to prevent and identify signs of complicated grief.

Moreover, observing how the prenatal follow-up influenced the delivery and how the family felt during that process are important steps⁹.

CONCLUSION

With the objective of conducting full follow-ups of fetuses diagnosed with malformations, their pregnant mothers, and family members, use of the palliative care model in the organization of care enables joint planning of the pregnancy, delivery, and post-partum period, and the follow-up can be adjusted to the values and requests of each family to allow shared decision-making.

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Submitted for publication: February 07, 2018

Accepted in: March 30, 2018