SPECIAL ARTICLE

Palliative care protocol in fetal medicine for care of the pregnant women and their fetuses

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Abstract

Perinatal palliative care is an emerging field in fetal medicine, which encompasses fetal abnormalities with conditions that limit fetal or neonatal life in a humanized manner. This protocol was developed based on a literature review and proposes a care model for pregnant women with a prenatal diagnosis of such conditions at the Instituto de Medicina Integral Prof. Fernando Figueira (IMIP). The objective is to standardize care and ensure clarity in communication with parents and family members. The topics covered include: perinatal palliative care, fetal diagnosis of life-limiting conditions, communication, eligibility criteria, conduct, prenatal care, birth, perinatal bereavement, and the puerperal period. It should be noted that this protocol was developed considering regions and/or health institutions with limited technological and/or financial conditions and can be adapted to different contexts.

key words *Palliative care, Perinatology, Prenatal care, Congenital abnormalities*

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Introduction

The implementation of new routines in healthcare institutions requires the creation of protocols that contribute to the continuous improvement of care, patient safety, and communication among teams.[1] In perinatal palliative care, systematization through continuing education and protocols ensures greater uniformity in the care provided for pregnant women and fetuses with life-limiting conditions.[2,3]

The concept of palliative care was extended to perinatology in 1997; however, in Brazil, until 2017, there was no protocol for the follow-up of palliative care during prenatal care. In 2025, *Lei 15,139* (the Brazilian Law) was enacted, establishing the *Política Nacional de Humanização do Luto Materno e Parental* (National Policy for the Humanization of Maternal and Parental Grief,) which aims to ensure humanized care for women and families during grief due to gestational loss, fetal death, or neonatal death, and to provide public services to reduce potential risks and vulnerabilities for those involved. The law also provides for the promotion of awareness campaigns, protocols, professional education, and specialized care for pregnant women and their families.[4]

In this context, the present protocol was developed to guide clinical practice at the maternity unit of the *Instituto de Medicina Integral Prof. Fernando Figueira* (IMIP), which provides care for pregnant women and their fetuses diagnosed with life-limiting conditions who are candidates for perinatal palliative care. This document guides healthcare teams through the necessary steps to offer compassionate care, ensuring clarity in decision-making, standardized referrals, and more effective interprofessional communication. It is noteworthy that this protocol may be adapted to other regions and institutions with similar technological and/or financial resources.

Methods

A scoping review of the literature was conducted in the MEDLINE/PubMed and *Biblioteca Virtual em Saúde* (BVS) (Virtual Health Library) (BIREME/SciELO/LILACS) databases, using the following descriptors: "prenatal care" and "palliative care".

All study designs published between February 2015 and May 2025 involving the selected descriptors were considered for inclusion. The following were excluded: studies that did not address perinatal palliative care during pregnancy; studies that did not present guidelines for models of care; studies written in languages other than English, Portuguese, or Spanish; and studies focusing exclusively on palliative care for a specific disease or group of diseases. For the definition of key concepts, other studies outside the eligibility criteria were also referenced.

The selected articles were analyzed, highlighting available resources and the experience in care in the fetal medicine unit at IMIP. Based on these sources, the concept of perinatal palliative care, the eligible fetal anomalies and their diagnostic criteria, communication guidelines, prenatal and delivery care, bereavement, and postpartum approaches were defined, and besides the development of a birth plan to be discussed with patients and families during prenatal care, was also included.

After the literature review and protocol drafting, the document was presented in two clinical meetings (internal and external) for discussion with specialists in perinatal medicine and subsequently in two additional meetings with three experts (internal and external members).

Perinatal palliative care

Perinatal palliative care is a compassionate, family-centered model of care for pregnant women who choose to continue their pregnancy after a prenatal diagnosis of a fetus with a life-limiting condition. It prioritizes the patient's expectations and choices, aiming to relieve suffering, preserve dignity, and promote quality of life, respecting the beliefs and wishes of families regardless of the newborn's survival time. It provides families with an opportunity to experience both birth and the dying process with minimal interference.[3,5]

With technological advances, the diagnosis of fetal malformations has become possible at increasingly earlier gestational ages, making palliative care essential from prenatal care through the postnatal period for eligible patients.

Diagnosis of Life-Limiting Fetal Conditions

Fetal malformations occur in approximately 3% of pregnancies and account for about 40% of perinatal deaths.[6] Lethal fetal conditions, such as anencephaly, alobar holoprosencephaly, bilateral renal agenesis, bilateral multicystic kidneys, and trisomies 13 or 18, occur in about 2% of the cases.[7]

Fetal malformations detected by ultrasonography may be associated with chromosomal abnormalities, and genetic diagnosis may be obtained through invasive tests (chorionic villus sampling, amniocentesis, or cordocentesis for fetal karyotyping or microarray), depending on availability, or through noninvasive prenatal screening tests (NIPT - non-invasive prenatal test). In cases of suspected anomalies, diagnosis must be confirmed after birth and, when indicated, the specific neonatal palliative care protocol it should be followed. (Neonatology).[8]

It is important to emphasize that a diagnosis of a lethal fetal malformation does not necessarily imply immediate death; it may occur in intrauterine, during the peripartum or neonatal period, or even months after birth.[9] There is no consensus on which malformations should be considered lethal, as prognosis can vary and, in rare cases, survival may extend beyond expectations.[10]

The fetal medicine specialist is generally responsible for diagnosing fetal malformations identified during pregnancy.[11,12] In the context of palliative care, for families who wish to continue the pregnancy, the use of terms such as "lethal" or "incompatible with life" to describe life-limiting conditions may cause hopelessness, and hasty communication may lead to lasting trauma.[13] The moment of diagnosis represents a period of extreme vulnerability for parents and families. Some pregnant women will research the fetal condition, others may feel guilty, and some will remain in shock.[10,14]

For the purpose of this protocol, at IMIP, all patients must have the fetal diagnosis confirmed by a fetal medicine specialist from the institution, as well as the follow-up ultrasonographic evaluations. It is recommended that, for patients who choose to continue the pregnancy, the terms "life-limiting condition" or "fetal and/or neonatal life-limiting condition" be used instead of "lethal malformation," in order to reduce the emotional impact on families.

Communication

The communication of a fetal condition must be conducted individually, using clear and accessible language, in a private setting, and with respect for the patient's and family's beliefs and questions, with proper documentation in the medical record. The conversation may begin by asking what the patient already knows about her baby, especially if the diagnosis has been previously suspected.[10,12,15] Communication can be structured in two stages: first, discussing the fetal life-limiting condition, and subsequently, within the same meeting, informing the patient about referral to palliative care. Referral can occur at any point in the pregnancy once the diagnosis is established, and should be made by the fetal medicine specialist.[12]

Communication is a key tool for quality healthcare delivery, representing a skill that can be learned and refined. Several studies propose techniques for more empathetic and effective communication. The following principles and techniques are suggested for difficult conversations in palliative care: choose a calm and private environment; introduce oneself; provide clear information about diagnosis and prognosis; gather relevant data (e.g., test results); speak clearly and avoid technical jargon; communicate progressively, assessing what the patient knows and wants to know; avoid false reassurance; allow time for the patient to speak; practice active listening; be aware of nonverbal communication (from both professional and patient); involve family or caregivers when possible; balance realism with hope; and begin a care plan as soon as feasible.[16,17] This communication should be carried out both by the fetal medicine professional during the ultrasound examination and by the healthcare professionals monitoring the patient.

During these discussions, information should be provided regarding the fetal anomaly, its current status, and its natural evolution, addressing all parental questions about the condition, follow-up, and the meaning of palliative care, including what procedures will be performed with the fetus. At this stage, referral to psychological support services is strongly recommended.[12,16]

Candidates

Eligibility for perinatal palliative care varies according to country, available resources, and cultural factors. In general, fetal or neonatal life-limiting diseases are the main indications for this type of care.[9,12,18]

In Brazil, within the field of fetal malformations, pregnancy termination is legally permitted only in cases of anencephaly. For other anomalies with limited survival prognosis, elective termination is not legally provided for, although judicial authorization may be sought if the patient so desires. In such scenarios, prenatal follow-up becomes essential, both for women who choose to continue the pregnancy in cases of anencephaly and for those with other life-limiting conditions whose pregnancy will continue (by patient choice or judicial decision). It is crucial that healthcare teams are trained to provide guidance, emotional support, and counseling.[9,18]

The indication for palliative care should consider fetal diagnosis and prognosis, as well as the personal meaning of the condition for the patient and her family.[9,19] Several anomalies identifiable during pregnancy may have a limited prognosis and should be reassessed after birth (Table 1).[3,12,14,15,18,20] Palliative care may coexist with intensive care approaches when appropriate, as any patient with a life-threatening condition can receive palliative care, even if death is not imminent.[17] However, in cases involving long-term life-limiting conditions, palliative care is often ethically more appropriate than intensive interventions, as it prevents suffering without altering the outcome.[9,21] In addition to the listed conditions, other anomalies may be considered on a case-by-case basis, depending on prognosis and therapeutic resources available (e.g., complex congenital heart disease, large fetal tumors, airway obstructions, rare syndromes).

Table 1

Fetal/neonatal life-limiting conditions eligible for perinatal palliative care and main criteria for indication. Recife (PE), 2025.

Fetal Condition	Diagnostic Investigation*	Preferred Type of Delivery
	Genetic Conditions	
Trisomy 13 or 18	• Ultrasound • Fetal karyotype (if not performed, palliative care may be indicated depending on strong clinical suspicion and severity of associated fetal malformations).	• Vaginal delivery
Triploidy	• Ultrasound • Quantitative β-hCG	• Vaginal delivery
	Musculoskeletal System Abnormalities	
"Lethal" skeletal dysplasias	• Ultrasound showing severe micromelia, narrow thorax, CT/CA ratio < 0.6, and polyhydramnios • Fetal karyotype	• Vaginal delivery
	Central Nervous System Abnormalities	
Anencephaly	• Ultrasound report (signed by two physicians), including two images—one sagittal and one transverse—of the fetal head showing absence of cranial vault and cerebral parenchyma. • If legal termination of pregnancy: may be performed in any maternity unit upon signing of the informed consent form, which must be attached to the medical record. • If pregnancy is continued: maintain prenatal follow-up and palliative care.	• Vaginal delivery
Alobar holoprosencephaly	• Ultrasound showing fusion of cerebral hemispheres into a single ventricle. • Fetal karyotype (may be associated with trisomy 13).	• Vaginal delivery
Extensive encephalocele	• Ultrasound showing skull defect with severe externalization of brain tissue (comparable to anencephaly).	• Consider vaginal delivery. • Cesarean section if exclusive palliative care not defined or in cases of macrocrania (HC >400 mm).
Hydranencephaly	• Ultrasound with findings of severe ventriculomegaly occupying almost the entire skull, with no remaining cortex.	• Vaginal delivery • If BPD >10.5 cm or macrocrania, cesarean delivery at term (consider <37 weeks). • If HC <400 mm at term, discuss elective induction to avoid cesarean.
Iniencephaly	• Ultrasound showing occipital cranial defect, fixed extension of the fetal head, shortened spine, absence of some vertebrae, and exposure of the spinal canal.	• Vaginal delivery
	Cardiac Abnormalities	
Hypoplastic left heart syndrome	• Ultrasound or fetal echocardiography showing small left ventricle, hypoplastic aorta, and mitral hypoplasia.	• Vaginal delivery
Cantrell's pentalogy	• Ultrasound showing complete pentalogy (omphalocele with ectopia cordis, heart defect, diaphragmatic hernia, and pulmonary hypoplasia).	• Vaginal delivery
	Urinary System Abnormalities	
Bilateral renal agenesis	• Ultrasound showing absence of kidneys or renal arteries.	• Vaginal delivery
Bilateral polycystic kidney disease	• Ultrasound showing enlarged hyperechogenic kidneys and oligo/anhydramnios after the 17th week.	• Vaginal delivery • Consider cesarean section if AC increased due to renal volume.
Bilateral multicystic dysplastic kidney disease.	• Ultrasound showing cysts replacing renal parenchyma, absence of renal pelvis, nonvisualized bladder, and anhydramnios in the second trimester.	• Vaginal delivery
Urethral obstruction	• Ultrasound showing megacystis, sometimes extending into the urethra. • In complete obstruction, anhydramnios from the second trimester is observed.	• Vaginal delivery • If severe megacystis, consider aspiration to enable vaginal delivery, or cesarean if necessary.
	Other Anomalies	
Cystic hygroma	• Ultrasound showing a large septated nuchal edema. • Fetal karyotype.	• Vaginal delivery • Cesarean if the hygroma is large enough to cause dystocia.
Conjoined twins (inoperable)	• Ultrasound showing fused twins sharing vital structures. • Severe prognosis, but each case must be evaluated individually by a multidisciplinary team.	• Vaginal delivery • Cesarean if advanced gestational age (prevents passage through the birth canal).

Body stalk syndrome	• Ultrasound showing extensive thoracoabdominal wall defect with externalized organs covered by amnion and placenta, severe kyphoscoliosis, and short umbilical cord.	• Vaginal delivery
Severe nonimmune hydrops fetalis	• Ultrasound showing subcutaneous tissue edema and fluid accumulation (effusion) in at least one compartment, possibly with hydropic placenta and polyhydramnios. • Fetal karyotype. • Risk definition: degree of effusion, affected sites, gestational age, and associated conditions (genetic diseases).	• Vaginal delivery • Cesarean if severe edema prevents passage through the birth canal.
Acardia	• Ultrasound in monochorionic twin pregnancy showing "pump" fetus and acardiac fetus. • Explain to the family that the acardiac fetus can not be preserved.	• Delivery route depends on the condition of the "pump" fetus (alive).
Sirenomelia	• Ultrasound showing fusion of lower limbs with associated genitourinary and gastrointestinal anomalies.	• Vaginal delivery
Congenital high airway obstruction syndrome (CHAOS)	• Ultrasound showing enlarged, hyperechogenic lungs with cardiac compression, possibly ascites or hydrops. • MRI if necessary to assess obstruction level.	• Assess delivery route depending on CA due to risk of dystocia.
	Malformations with combined intensive and palliative care approaches	
Congenital diaphragmatic hernia with severe pulmonary hypoplasia.	• Ultrasound showing abdominal contents in the thoracic cavity, cardiac compression with axis deviation, and reduced lung size (O/E LHR <25%). • Fetal karyotype	• Vaginal delivery. • Await spontaneous labor until 39 weeks (if no maternal comorbidities). • At birth, plan early neonatal intubation

*Obstetric or morphological ultrasound preferably performed by a specialist in fetal medicine. Fetal karyotype performed, if available.
CT/CA = chest circumference/abdominal circumference ratio; HC = head circumference; O/E LHR = observed-to-expected lung-to-head ratio; EXIT = Ex Utero Intrapartum Treatment.

When prognosis is uncertain, a multidisciplinary clinical meeting should be convened for discussion and consensual inclusion in palliative care. Neonatal follow-up may redirect the therapeutic plan according to the newborn's clinical evolution, family values, and available healthcare resources.

Conducts

Given the various life-limiting fetal conditions listed in this protocol, a schematic summary was developed, including the diagnosis and the preferred route of delivery for patients who will continue prenatal follow-up at the institution (Table 1). It is emphasized that the timing of pregnancy termination (labor induction or cesarean section) should be guided by the patient's comorbidities or medical indications. If the patient presents no comorbidities and maintaining the pregnancy does not pose additional maternal risk, spontaneous labor should be awaited.

Prenatal care

Prenatal care in fetal medicine consists of monitoring pregnant women through counseling, diagnosis, screening, and risk assessment of adverse maternal and fetal conditions [6] In the presence of a prenatal diagnosis of a fetus with a life-limiting condition, prenatal counseling must be conducted by a multidisciplinary team composed of an obstetrician, fetal medicine specialist, neonatologist, psychologist, social worker, anesthesiologist, surgeon, and other qualified professionals, depending on the diagnosed congenital abnormality.[11,12]

The pregnant woman and her family must receive compassionate support, appropriate referrals, management of comorbidities, and both routine and condition-specific prenatal examinations, aiming to identify the cause and provide general guidance about the pregnancy and fetal condition.

Palliative care should be introduced to the family, with the development of a care plan jointly created by the healthcare team and the patient. The plan must be respected regardless of which professionals are present at the time of birth.[13]

With the diagnosis in the gestational period, families often experience anticipatory grief. Being informed of a possible perinatal death allows family members to reflect on their wishes and beliefs and gives the team time to prepare for delivery.[8] It is essential to validate the feelings of the pregnant woman and her relatives, emphasizing their role as caregivers. Parenthood persists regardless of the pregnancy outcome; thus, it is important to help families create memories, value their choices, and give meaning to the pregnancy.[11]

During prenatal care, discussions may include how to respond to strangers who ask about the pregnancy, suggestions for books or reading materials, conversations about cultural or religious aspects, and the possibilities of home-based perinatal palliative care, depending on the fetal anomaly.[7,16]

Healthcare professionals should gather diagnostic information, practice effective communication, repeat information whenever requested, provide ongoing clinical follow-up, and plan the next steps collaboratively with the pregnant woman and her family or chosen companions.[3,5]

Guidelines for prenatal follow-up

Prenatal care in fetal medicine at IMIP is conducted at the women's outpatient clinic by specialists in fetal medicine, with possible participation of medical residents and students.

Patients' care begins in the fetal medicine sector, the women's outpatient clinic, or the obstetric screening/emergency unit. Patients with suspected fetal diagnoses should be referred to the fetal medicine unit for diagnostic confirmation through ultrasonography performed by specialists in fetal medicine or through invasive testing, as indicated and depending on institutional availability. If a life-limiting fetal condition is confirmed, the patient will be referred to fetal medicine prenatal care to initiate perinatal palliative care (Figure 1).

The prenatal follow-up of these pregnant women was organized in a structured care pathway at the women's outpatient clinic at IMIP (Figure 2). The initial assessment may be conducted by the fetal medicine team. However, if the first consultation occurs in the high-risk or routine prenatal care clinic and a fetal malformation is detected, the initial assessment can be carried out at that point, with a follow-up appointment scheduled with the fetal medicine unit.

1.1) First consultation

During the first consultation, an interview is conducted by the fetal medicine specialist. Patient identification data are recorded in the medical chart. The patient receives a prenatal card, which must be filled out, and her vaccination card should be reviewed and updated if necessary. Rapid tests and routine laboratory exams are requested, and any previously performed exams are evaluated (Figure 2).[22]

The interview includes an investigation of personal and reproductive history, lifestyle, occupation, medications in use, complications, maternal comorbidities, and family history. The obstetric history should record the number of pregnancies and deliveries, history of miscarriages or fetal deaths, fetal growth restriction, malformations, twin pregnancies, associated diseases, and type of delivery. Risk factors such as smoking, illicit drug use, alcohol consumption, medications, and radiation exposure must be investigated, along with any pregnancy related or unrelated symptoms. A complete physical examination (clinical, obstetric, and gynecological) must be performed.[6,22]

When a malformation is suspected, the professional should clarify the etiology, prognosis, and characteristics

Figure 1

Flowchart for the reception and referral of patients who are candidates for perinatal palliative care in the prenatal fetal medicine department of the *Instituto de Medicina Integral Prof. Fernando Figueira* (IMIP). Recife (PE), 2025.

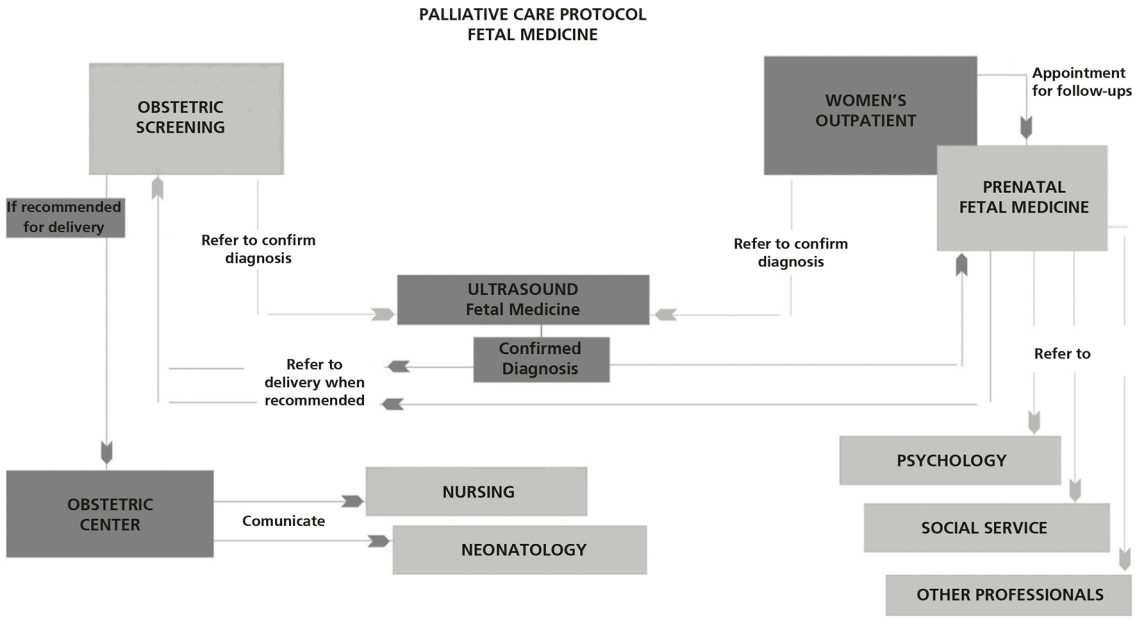
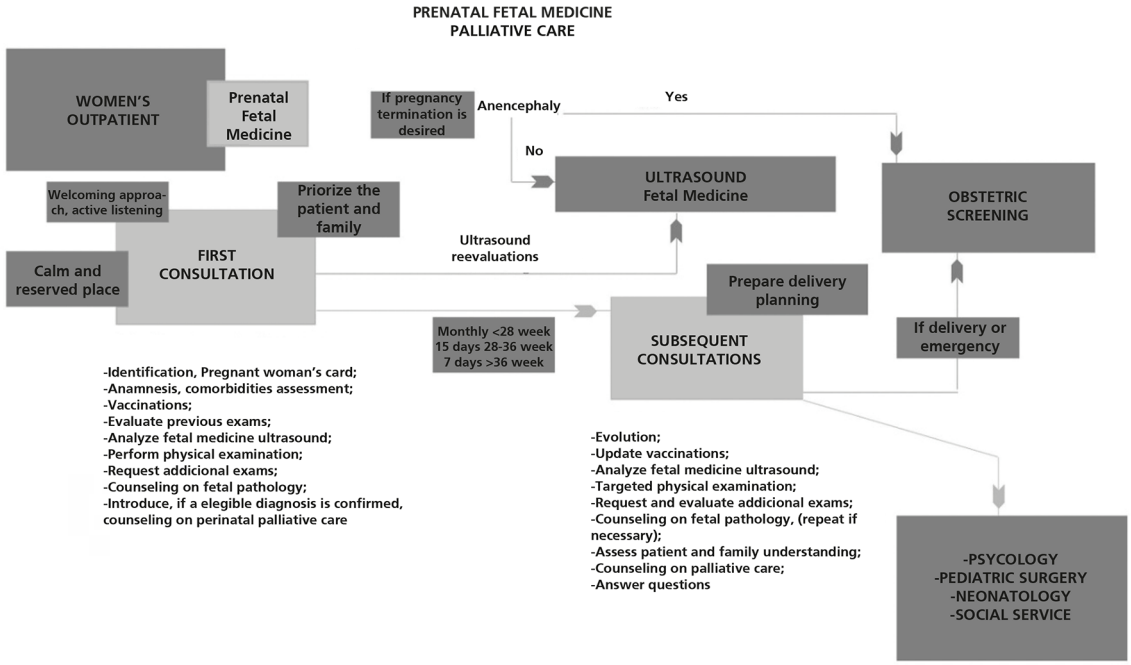


Figure 2

Flowchart of prenatal care for pregnant women who are candidates for perinatal palliative care at the Instituto de Medicina Integral Prof. *Fernando Figueira* (IMIP). Recife (PE), 2025.



of the condition; request any necessary confirmatory exams (referral for ultrasonography with fetal medicine); and discuss the possible follow-up and conduct options, such as palliative care or karyotyping by amniocentesis, depending on indication and the patient's and family's wishes.[6,22] The patient should be informed that diagnostic confirmation will occur after the ultrasonography performed by the fetal medicine team, at which point the indication for palliative care will be re-evaluated.

1.2) Cases of pregnancy termination

In cases of anencephaly, the pregnant woman may choose to terminate the pregnancy without judicial authorization, and should be referred to a maternity hospital (Figure 2). The patient must present an ultrasound report (signed by two physicians) confirming the diagnosis, including photographic documentation (two images: one sagittal and one transverse view of the cephalic pole) demonstrating absence of the cranial vault and brain parenchyma. The patient must also sign an Informed Consent Form (ICF), which must be attached to the medical record.[18]

In cases of other fetal malformations considered life-limiting conditions, if the patient wishes to terminate the pregnancy, a medical report with confirmatory ultrasonography must be prepared, preferably including a psychological assessment of the pregnant woman, a signed letter from the patient requesting judicial authorization for pregnancy termination, and a referral letter from the attending specialists to the court. The patient may be referred to the social services department for guidance on legal procedures. Once judicial authorization is granted, the patient may be referred for pregnancy termination. If authorization is denied, prenatal care should continue as usual, focusing on palliative care.[18]

For pregnancies of 22 weeks or more, feticide should be discussed with the patient prior to hospital admission, along with signing the ICF, as it increases the likelihood of successful termination/induction. The procedure should be performed by a fetal medicine specialist, under ultrasound guidance, using intracardiac potassium chloride (KCl).[18] The patient should then be referred to the obstetric unit (at the maternity hospital of her choice) for induction of labor.

1.3) Follow-up consultations

During follow-up visits (Figure 2), the diagnosis and management options should be reviewed, and perinatal palliative care should again be offered to the patient and her family.

Continuous and periodic follow-up throughout pregnancy ensures adequate prenatal monitoring and should follow the pre-established schedule for high-risk or routine prenatal care. (monthly until the 28th week, biweekly from the 28th to the 36th week, and weekly at term), or at shorter intervals depending on maternal

comorbidities. [22] It is important to note that for patients who have opted for perinatal palliative care, more frequent prenatal visits are not necessary solely due to fetal abnormality.

Each visit should include assessment of previously requested exam results (laboratory and ultrasound), verification of vaccination status, targeted physical examination, and identification of associated maternal diseases.[22] In subsequent consultations, a birth plan should be developed based on the patient's and family's wishes, guided by the healthcare professional, and documented both in writing for the patient and in the medical record.[5,12,19]

1.4) Referrals

Multidisciplinary assessment is essential for palliative care follow-up, and psychological referral should be offered whenever desired. Approximately 20% of women experiencing gestational loss develop mental health disorders within one year, making psychological evaluation crucial. Referral to psychiatry should also be considered when necessary, for conditions such as depression, anxiety, or other disorders requiring medication.[23]

Referral to social services should be made in cases of social vulnerability or when coordination with the patient's local healthcare network is needed.[16]

In some cases, evaluation by neonatology or pediatric surgery may be required to determine the feasibility of neonatal treatment. Patients with congenital diaphragmatic hernia with severe pulmonary hypoplasia, giant omphalocele, severe congenital heart disease, or severe ventriculomegaly may have a potential treatment plan but can still benefit from perinatal and postnatal palliative care.[24] Whenever possible, consultation with a pediatric palliative care specialist is recommended to align prenatal information with postnatal care planning.

1.5) Ultrasound follow-up

Ultrasound examination is necessary from the patient's first contact with the healthcare service for diagnostic confirmation and appropriate referrals. The frequency of ultrasounds should be determined individually, but at least once per trimester. In addition to providing diagnostic support, these exams also offer opportunities for the patient and family to connect with the baby and create memories[11,16] It should be noted that during the second-trimester morphological ultrasound, measurement of cervical length for preterm birth screening is not recommended in life-limiting conditions (major fetal malformations), since progesterone therapy or cervical cerclage is not indicated in such cases.[25,26]

1.6) Prenatal care plan

It is important to establish a checklist outlining the prenatal care plan to be followed at the outpatient clinic — that is, a structured care plan to guide healthcare professionals during consultations and facilitate patient reception at the institution (Figure 3).

Birth Plan

The birth plan provides parents with the opportunity to discuss their needs and expectations, helping them to anticipate and prepare for the grieving process. Studies show that having a birth plan increases parental satisfaction and reduces anxiety, fear, and stress.[11,19] The plan should be developed jointly with family members, obstetricians, neonatologists, and perinatal palliative care specialists, serving as an opportunity to explore and document the parents' wishes.[11,12,19]

Vaginal delivery should always be encouraged, as it is a physiological process and poses lower maternal risk. Intrapartum fetal monitoring should be discussed among the medical team and family, given the risk of fetal clinical deterioration and intrapartum death; monitoring may be omitted or spaced out if deemed appropriate by the team and in accordance with the parents' wishes.[3,25] It is important to note that vaginal delivery can still be performed even in cases of compromised fetal vitality. However, the clinical conditions of both the mother and fetus must be considered, as well as the family's wishes regarding a cesarean section when the parents desire to meet their baby alive. This decision should also take into account religious beliefs and weigh the potential risks of surgical delivery (Figure 4).[3,16,19]

The birth plan should include the baby's and mother's names, family preferences, guidance for healthcare professionals, as well as the mode of delivery and immediate newborn care. It is advisable to discuss religious aspects during the plan's development—such as rituals after birth—and to provide opportunities for parents to create memories (e.g., taking photos), ensuring the family's comfort during this moment.[11,19]

All topics should be listed in the birth plan, with flexibility for adjustments based on the needs of the mother and family, and space should be provided for individual notes related to each case or institution. The relevant items should be marked according to the agreement reached during consultations. It is important to emphasize that the birth plan serves as a guide to prepare for the moment and may be adapted or modified as needed.

Figure 3

Prenatal palliative care plan in fetal medicine at the *Instituto de Medicina Integral Prof. Fernando Figueira* (IMIP). Recife (PE), 2025.

- Patient's name, baby's name
- Fetal diagnosis
- Gestational date
- Comorbidities
- Vaccination
- Consultations
    - First consultation
        - Anamnesis, personal and family medical history, obstetric history
        - General focused physical examination, obstetric, and gynecological assessment
        - Additional exams (routine prenatal tests) and oncotic cytology (update if necessary)
        - Referral for diagnostic confirmation (fetal medicine ultrasound)
            - In cases where the patient wishes to terminate the pregnancy:
                - Anencephaly – refer the patient to a maternity service for pregnancy termination (as provided by Brazilian law); the patient must present an ultrasound report with two images (sagittal and transverse views) confirming the diagnosis, signed by two physicians;
                - Other life-limiting conditions – issue a letter so that the patient may initiate the judicial request for pregnancy termination;
                - Referral for termination may be performed at any gestational age.
            - If the patient chooses to continue the pregnancy, schedule subsequent consultations.
    - Subsequent consultations - Routine prenatal follow-up; provide counseling on perinatal palliative care; review diagnosis and address any questions as needed.
        - Consultation frequency:
            - Monthly until the 28th week;
            - Biweekly from the 28th to the 36th week;
            - Weekly after the 36th week;
            - Shorter intervals may be scheduled depending on maternal comorbidities.
- Ultrasound examinations
    - Initial assessment with fetal medicine – confirm diagnosis.
    - Reassessments as indicated by the specialist, at least once per trimester.
- Referrals
    - Psychology
    - Social Service
    - Neonatology
    - Pediatric Surgery
    - Other specialists as required, depending on the fetal abnormality
- Counter-referral to the family health unit
- Delivery planning preparation

Source: author's elaboration

Figure 4

Delivery planning - palliative care/fetal medicine from the *Instituto de Medicina Integral Prof. Fernando Figueira* (IMIP). Recife (PE), 2025.

Patient: _____

Partner/Spouse: _____

Baby's name: _____

Fetal diagnosis: _____

Relevant ultrasonographic findings: _____

_____

_____

Preferred type of delivery: Vaginal ☐ Cesarian ☐

Support person present during labor: Yes ☐ No ☐

Mother's preference regarding intrapartum fetal monitoring (to be discussed): Yes ☐ No ☐

Analgesia desired (if available): Yes ☐ No ☐

Respect privacy and ensure a reserved environment.

Minimize vaginal examinations.

After Birth:

Wishes to see the baby after delivery: Yes ☐ No ☐ (If no, offer again later)

Wishes to perform any religious ritual: Yes ☐ No ☐

Explanation provided regarding perinatal palliative care: Yes ☐ No ☐

- Promote initial care for the newborn (timely cord clamping, maintain temperature, and assess respiratory comfort);

- Do not perform resuscitation maneuvers or invasive procedures.

In case of perinatal death: ☐

Explanation provided regarding induction of vaginal delivery: Yes ☐ No ☐

Wishes to create memories: Yes ☐ No ☐

Take photos ☐ Keep a lock of hair ☐ Dress the baby ☐

Put on a diaper ☐ Add an accessory ☐ Placenta print ☐

Hand / footprint ☐ Provide identification bracelet ☐

Source: author's elaboration

Birth

At birth, the birth plan, if one exists, should be respected, and whenever possible, the delivery should take place in a private environment (If available).

Providing respectful care can help facilitate the grieving process. Healthcare professionals should act as they normally would with newborns who are not receiving palliative care, naturally and empathetically. Performing a physical examination, taking the patient's history, monitoring contractions, explaining delivery room procedures, and following standard care routines can help the patient and her family feel integrated into the maternity experience like any other.[23]

In case of intrauterine death, the professionals must be prepared to describe the stillborn baby, if requested by the mother, and to explain what will be examined.

Descriptions of features such as skin discoloration, peeling, marks, umbilical cord discoloration, edema, and known malformations may help minimize the family's initial shock.[23]

The neonatologist is generally responsible for the initial assessment, maintaining temperature, ensuring comfort, and preventing respiratory distress in the newborn. Parents should be offered quality time with their baby, and referrals should be made collaboratively at the appropriate moment. When neonatal intensive care is needed, interventions should prioritize comfort, pain relief, and symptom control.

If an intervention no longer contributes to improving the patient's quality of life, treatment should be reassessed. Withholding invasive support or discontinuing ongoing procedures are ethically appropriate measures in cases of lethal or poor prognosis. Conflicts may arise among professionals or between the healthcare team and the family; in such cases, further discussions, second opinions, or additional tests may support shared decision-making.

In cases of spontaneous preterm labor, tocolysis or antenatal corticosteroid therapy should not be performed.[27] Similarly, for preterm premature rupture of membranes (PPROM), antibiotic therapy should not be used to prolong latency. Each case should be discussed with the mother, weighing the risks and benefits of maintaining the pregnancy versus inducing labor.[28]

Perinatal grief

Perinatal grief refers to losses occurring at any point during pregnancy up to the newborn's first month of life. In the event of peripartum death, family preparation must be planned, including communication. The healthcare team's involvement in this experience is crucial for supporting the grieving process. Professionals should be sensitive to each patient's specific needs to ensure comprehensive care. Referral to psychological support should be considered and offered in all cases.[23]

Nursing and medical teams may offer opportunities to create memories throughout prenatal care, such as performing three-dimensional (3D) ultrasounds and recording videos or fetal heartbeat sounds; taking photos of the baby or body parts; saving a lock of hair (protected by national law)[4]; dressing the baby; making placenta prints or hand/footprints; writing letters to the family; keeping hospital bracelets; and preparing a memory box, according to the mother's wishes and staff availability at the time of birth (Figure 4). Cultural and religious beliefs must be respected. Attention should be given to the family structure, baby's name, chosen companion, and privacy.[4,16,23]

When perinatal death occurs, healthcare professionals should take special care. If the mother does not wish to see the baby, the family should be reassured that such feelings are normal. A family member or companion may be offered the opportunity to see or photograph the baby (to prevent possible regret later), and the mother may do so at another moment if desired. If the family wishes to see the baby, a private space should be provided. The baby should not be washed (to preserve olfactory memory). The mother should be informed about possible malformations and may choose to cover certain areas, and should also be told that spasms (in recent deaths) or skin peeling may occur.[23]

Families must receive clear information about bureaucratic procedures related to the baby's transport and burial. [29] The medical, nursing, and social service teams should guide them on obtaining a death certificate (D.C.) or referral to the death verification service, when needed, and explain the process for contacting a funeral home, registering at the notary office, and arranging transport. A certificate may be issued with the date and place of birth, the chosen baby name, and, if possible, footprints or fingerprints.[4] Families should also be informed that, if they wish, the stillborn or neonatal death can be registered under the chosen name, legally permitted (in the state of Pernambuco since 2014[30] and, starting in 2025, nationwide[4]). The social service team should also be involved in cases of social vulnerability or when coordination with the local health network is needed.[4,11]

Puerperal period

The patient who experiences perinatal loss faces the physical and emotional changes without her newborn by her side. Some mothers may initially breastfeed if death occurs in the neonatal period, while others may not have that opportunity when death occurs earlier or when life-limiting conditions prevent feeding.[4,31]

It is important that the healthcare team should discuss lactation management with the mother. Some may wish to donate breast milk as part of their grieving process. If the mother chooses not to donate, medication can be offered to suppress lactation (Figure 4). The *lei nacional* 15.139/2025 (Brazilian National Law) ensures the right of bereaved mothers to donate breast milk.[4]

Mothers are entitled to maternity benefits in cases of stillbirth or neonatal death (*art. 358 da Instrução Normativa – IN nº 128 de 2022 do* PRES/INSS) (Article number), upon presentation of a medical statement.[32] Waged employees under the *Consolidação das Leis do Trabalho* (CLT) (Consolidation of Labor Laws) are entitled to 120 days of maternity leave and job stability from pregnancy confirmation until five months after childbirth.

This does not apply to pregnancy losses before the 22nd week (miscarriage), for which the mother is entitled to 15 days of leave. For civil workers (statutory employees), the right for leave duration varies by jurisdiction.[23]

Psychological follow-up, a support network, and communication with the local primary healthcare team are essential for bereaved mothers. The social service team at the hospital must facilitate coordination with the local health system.[11] A puerperal consultation should be carried out, either at the hospital where the delivery occurred or at a local health center, to provide guidance on postpartum care (surgical wound, breasts, lochia, postpartum depression screening, and puerperal complications).[22,23]

Final Considerations

This protocol results from a critical synthesis of national and international literature, adapted to the context of a high-risk maternity hospital in the Northeast of Brazil. IMIP, a philanthropic institution within the *Sistema Único de Saúde* (SUS) (Brazilian Public Health System), despite limited diagnostic and care resources, serves as a regional reference center, caring for a large number of high-complexity patients. The development of this care model aims to standardize internal workflows, improve interprofessional communication, and guide shared decision-making from prenatal care through the puerperal period. Its pragmatic nature and low additional cost (mainly inherent to hospitalization) make it replicable in institutions with similar profiles, fostering multidisciplinary networks capable of providing family centered perinatal palliative care. Its implementation is recommended with continuous professional education, indicator monitoring (e.g., adherence to birth plans, proportionality of interventions, referrals to Psychology/ Social services), and periodic review to ensure ongoing updates and the quality of perinatal palliative care services.

Authors' contribution

Souza ASR, Figueredo DVA: project design and conception, interpretation and analysis of included studies, manuscript writing and revision.

Faquini SLL, Guerra GL: project design and conception, manuscript revision.

All authors approved the final version of the article and declare no conflicts of interest.

Data Availability

All data supporting the findings of this study are contained within the article itself.

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