

Perinatal Palliative Care

Committee Opinion 

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Committee on Obstetric Practice

Committee on Ethics

The American Academy of Pediatrics and the Society for Maternal-Fetal Medicine endorse this document. This Committee Opinion was developed by the Committee on Obstetric Practice with the assistance of committee member Russell S. Miller, MD and the American Academy of Pediatrics' liaison member James J. Cummings, MD; and the Committee on Ethics with the assistance of the American Academy of Pediatrics' liaison member Robert Macauley, MD and the Society for Maternal-Fetal Medicine's liaison member Steven J. Ralston, MD, MPH.

ABSTRACT: Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment. The focus of this document, however, involves the provision of exclusively palliative care without intent to prolong life in the context of a life-limiting condition, otherwise known as perinatal palliative comfort care. Once a life-limiting diagnosis is suspected antenatally, the tenets of informed consent require that the pregnant patient be given information of sufficient depth and breadth to make an informed, voluntary choice for her care. Health care providers are encouraged to model effective, compassionate communication that respects patient cultural beliefs and values and to promote shared decision making with patients. Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions. If a patient opts to pursue perinatal palliative comfort care, a multidisciplinary team should be identified with the infrastructure and support to administer this care. The perinatal palliative care team should prepare families for the possibility that there may be differences of opinion between family members before and after the delivery of the infant, and that there may be differences between parents and the neonatal care providers about appropriate postnatal therapies, especially if the postnatal diagnosis and prognosis differ substantially from antenatal predictions. Procedures for resolving such differences should be discussed with families ahead of time.

Recommendations and Conclusions

The American College of Obstetricians and Gynecologists makes the following recommendations and conclusions:

- Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. For the purposes of this document, the term “life-limiting” includes lethal fetal conditions as well as others for which there is little or no prospect of long-term ex utero survival without severe morbidity or extremely poor quality of life, and for which there is no cure.

- With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment. The focus of this document, however, involves the provision of exclusively palliative care without intent to prolong life in the context of a life-limiting condition, otherwise known as perinatal palliative comfort care.
 - Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions.
 - Although specific offerings may vary between institutions, some care components are generally advisable across perinatal palliative comfort care programs: a formal prenatal consultation; development of a birth plan; access to other neonatal and pediatric specialties, as needed; and support and care during the prenatal, birth, and postnatal periods, including bereavement counseling.
 - The birth plan is an individualized proposal for delivery and neonatal care and a critical prenatal component of perinatal palliative comfort care.
 - The perinatal palliative care team should prepare families for the possibility that there may be differences of opinion between family members before and after the delivery of the infant, and that there may be differences between parents and the neonatal care providers about appropriate postnatal therapies, especially if the postnatal diagnosis and prognosis differ substantially from antenatal predictions.
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Introduction

The prenatal diagnosis of a fetal abnormality that may be life-limiting necessitates challenging and complex discussions between patients and health care providers to establish individualized care plans. Historically, choices for patients faced with such a diagnosis were distilled down to a basic dichotomy: termination of pregnancy or pregnancy continuation with a plan for postnatal resuscitation and life-prolonging treatment **1**. Although each may be a valid option for some patients and families, for others perinatal palliative comfort care may be the preferred approach.

Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. With a dual focus on ameliorating suffering and honoring patient values, perinatal palliative care can be provided concurrently with life-prolonging treatment. The focus of this document, however, involves the provision of exclusively palliative care without intent to prolong life in the context of a life-limiting condition, otherwise known as perinatal palliative comfort care.

This publication is intended to clarify which patients would be appropriate candidates for perinatal palliative comfort care, to discuss essential components of this care, and to explore some of the challenges this kind of care poses for patients, health care providers, and health care entities.

Background

Although healthy newborn survival is expected for the majority of infants born in developed nations, this is not the outcome of some pregnancies. In the United States, 23,455 infant deaths were reported in 2015, of which two thirds occurred in the neonatal period **2**. Among these deaths, congenital malformations and chromosomal abnormalities were the most common cause, accounting for 20.6% of cases, followed by deaths related to prematurity and low birth weight, which comprised an additional 17.4% of cases.

Numerous conditions for which life is anticipated to be short or associated with extremely poor quality can be identified by modern prenatal diagnostic techniques. Lethal fetal anomalies are likely to be fatal in utero or shortly after birth. For the purposes of this document, the term “life-limiting” includes lethal fetal conditions as well as others for which there is little or no prospect of long-term ex utero survival without severe morbidity or extremely poor quality of life, and for which there is no cure. These severely morbid conditions may include those for which intervention is of questionable efficacy or deemed to be unacceptably burdensome to the neonate. In some cases (such as hypoplastic left heart syndrome), there may be ameliorative treatments available, but parents may choose not to pursue these treatments because of their invasiveness, complexity, or uncertain outcomes.

Patient Selection for Perinatal Palliative Comfort Care

Consideration for perinatal palliative comfort care requires that there first be a diagnosis of a life-limiting fetal condition. A life-limiting diagnosis may be obvious from fetal imaging or genetic testing, but this diagnosis also may require interdisciplinary input from maternal–fetal medicine specialists, geneticists, or pediatric subspecialists. However, it is important to note that although the medical ability to prenatally identify a life-limiting prognosis is high, it is not infallible. In a small, retrospective, single-center study that involved 49 women with pregnancies referred for perinatal palliative care, a specific life-limiting prenatal diagnosis was *not* confirmed postnatally in four cases, although in each of these the infant had a substantial comorbid condition **3**. There also have been case reports of prenatal genetic diagnoses that were not as phenotypically severe as anticipated **4**, which highlights the need to acknowledge any prognostic uncertainty that may exist and, when appropriate, seek postnatal confirmation of the diagnosis.

Once a life-limiting diagnosis is suspected antenatally, the tenets of informed consent require that the pregnant patient be given information of sufficient depth and breadth to make an informed, voluntary choice for her care **5**. Health care providers are encouraged to model effective, compassionate communication that respects patient cultural beliefs and values and to promote shared decision making with patients **6**. Information shared with the patient should detail the diagnosis, its anticipated prognosis, and interventions, if any, that may alter the natural disease course. The degree of confidence regarding a life-limiting determination should be discussed, and diagnostic and prognostic limitations disclosed. All care options should be discussed, including pregnancy termination (abortion, within legal limitations), prenatal and postnatal intervention intended to promote survival, and palliative comfort care, which may include interventions to promote comfort and improve quality of life without intending to promote survival.

Pregnant patients may want to include a spouse or partner, family members, other loved ones, trusted clinicians (such as a primary obstetrician–gynecologist), and religious and spiritual guides (if any) in these discussions. The emotional impact of these decisions will likely affect other family members, and the palliative care team should be prepared to offer emotional, spiritual, and mental health support where needed. A model of shared decision making between the pregnant patient, her family (if she desires), and the palliative care team will help to foster the partnership and communication that are essential to an effective palliative care program and the overall patient experience **6**.

If a patient opts to pursue perinatal palliative comfort care, a multidisciplinary team should be identified with the infrastructure and support to administer this care. There is no evidence to support an optimal model for providing perinatal palliative care **7**. Therefore, perinatal palliative care programs may differ between institutions based upon personnel, resources, and practice style. An effective perinatal palliative care team may include obstetric care providers, neonatologists, health care providers with expertise in pediatric palliative care, nurses, social workers, mental health professionals, religious counselors, lactation specialists, and child life specialists. The goal of this team is to provide support and continuity of care throughout pregnancy, delivery, and the postpartum and neonatal periods.

Components of Perinatal Palliative Comfort Care

A goal of this document is to provide a framework to support provision of perinatal palliative comfort care but not to be overly prescriptive or to mandate certain practices. Although specific offerings may vary between institutions, some care components are generally advisable across perinatal palliative comfort care programs: a formal prenatal consultation; development of a birth plan; access to other neonatal and pediatric specialties, as needed; and support and care during the prenatal, birth, and postnatal periods, including bereavement counseling **8**.

An initial consultation for perinatal palliative comfort care should include a review of the fetal diagnosis, an introduction to the goals of palliative medicine, and a review of the variety of decisions that the woman and her family may face both antenatally and in the newborn period. It can be helpful to identify the patient's preferred terminology (such as "baby," "pregnancy," or "fetus") and also to inquire if the fetus has been given a name, by which the fetus may then be referred if that is favored by the patient.

Other objectives of the initial consultation are to establish a therapeutic alliance for ongoing care, to validate a patient's decision to pursue palliative comfort care, and to ensure that the patient's goals align with reasonable expectations for the pregnancy. In a study that explored the hopes of parents of children who lived with trisomy 13 and 18, commonly cited parental goals after diagnosis included having a live birth, spending time as a family, bringing their child home, and giving their child "a good life" **9**.

The birth plan is an individualized proposal for delivery and neonatal care and a critical prenatal component of perinatal palliative comfort care. Intrapartum fetal monitoring and mode of delivery considerations should be clarified within the birth plan. For example, antenatal testing may be reasonably deferred for a fetus with a presumed life-limiting diagnosis provided the parents understand that the result may be an unmonitored fetal demise. Intrapartum fetal monitoring similarly may be deferred during labor because a cesarean delivery for fetal indications would entail maternal operative risks without prospect for lasting neonatal benefit.

Conversely, there may be scenarios for which intrapartum fetal monitoring, timed delivery, or cesarean delivery for fetal indications may be valid parts of a perinatal palliative comfort care birth plan. For example, intrapartum fetal monitoring and cesarean delivery may reasonably be requested by a well-informed patient who wishes to have a live birth or desires a religious ceremony involving a liveborn neonate. There may additionally be situations for which intrapartum monitoring of a fetus with a life-limiting condition can assist with maternal delivery management. One such circumstance involves a woman with a fetus with a life-limiting condition undergoing trial of labor after prior cesarean delivery. In this case, fetal heart rate monitoring may provide supplemental information regarding cesarean scar integrity that could contribute to safe maternal intrapartum care. Decisions regarding the appropriateness of intrapartum fetal monitoring in cases like this should be individualized.

The birth plan also must include plans for assessment and care of the newborn and should include considerations such as newborn bonding and skin-to-skin contact, warmth, hydration, feeding and lactation, management of respiratory distress, and pain control. The plan may be further tailored to address specific patient wishes such as who will attend the birth and what their roles will be in the delivery room. The birth plan ideally should be discussed with health care providers before delivery, placed in the medical record, and available for review by delivery care providers. It should be stressed that the plan for neonatal care is a provisional understanding and may be subject to reassessment if postnatal assessment reveals a different diagnosis or prognosis **3**.

When timing and logistics permit, patients who pursue perinatal palliative comfort care should have regular follow-up with the palliative care team. These ongoing interactions provide opportunities to address patient grief and other emotions, to review the birth plan and related concerns that may arise, to receive anticipatory guidance, and to identify additional opportunities for patient advocacy. Some patients may benefit from an emphasis on the routine aspects of pregnancy to normalize their experience, although this should be tailored to patient needs **8**. Repeated interactions with the perinatal palliative care team also may serve to reduce patient anxiety regarding the upcoming delivery.

When physically available, a member of the palliative care team should be present for the delivery of a patient pursuing a perinatal palliative comfort care plan. However, if a clear plan is in place and documented in the chart, it can be executed even if a member of the perinatal palliative care team is not present. In such a case, someone from the team should be available for consultation, if needed. The delivery should be a family-centered experience, with comfort and support offered to the newborn, parent, and family. In addition to supporting the plan established before birth, and if consistent with patient wishes, there may be opportunities for constructive memory making such as patient and family photography, collecting delivery keepsakes, recording the baby's heartbeat, and making molds of handprints or footprints.

After delivery, emotional and spiritual support should be provided for parents and their families. For neonates receiving palliative comfort care who survive the immediate newborn period, some parents may desire to have their newborn room with them during the postpartum period. When a patient opts for newborn rooming-in, the neonatal and palliative care teams should visit the family to ensure the baby's comfort and to provide practical and emotional support to the parents, while also respecting the family's privacy during this important time. These visits are intended to provide newborn palliative care at the bedside, to educate, to offer emotional support, and to minimize stress. Throughout this process, the newborn's parents and caregivers should be encouraged and allowed to participate in the care of the newborn, including feeding, bathing, and diapering. However, rooming-in may not be appropriate in all situations, and some patients may not desire it.

Some infants who receive palliative comfort care may survive long enough to be discharged from the hospital. In these cases, the perinatal palliative care team should work with parents and families to determine appropriate dispositions, which may include hospice care at home or in a health care setting.

After a child's death, bereavement counseling is strongly encouraged. Additionally, it is important to acknowledge that complex end-of-life decisions also can be stressful for physicians, nurses, and other members of the obstetric, neonatal, and palliative care teams, and institutions are encouraged to provide support for team members dealing with emotional distress **10**.

Often, there will be consonance and agreement between all family members, the obstetric team, and the neonatal team in devising care plans. Nevertheless, the perinatal palliative care team should prepare families for the possibility that there may be differences of opinion between family members before and after the delivery of the infant, and that there may be differences between parents and the neonatal care providers about appropriate postnatal therapies, especially if the postnatal diagnosis and prognosis differ substantially from antenatal predictions. Procedures for resolving such differences should be discussed with families ahead of time.

Challenges and Benefits

Although perinatal palliative care is a growing field, nationwide use remains low **11**. In a retrospective cohort study that involved more than 40 children's hospitals from across the country, neonates represented 41% of all hospital deaths but only 2% of them received palliative care services **12**. Factors contributing to low perinatal palliative care use include availability of programs, patient access issues, and physician education and training barriers. Despite these obstacles, the benefits of these programs justify their continued development.

The implementation of perinatal palliative care programs appears to influence the specific care provided to newborns with suspected life-limiting conditions. In one retrospective study that involved a single regional level IV neonatal intensive care unit, introduction of a perinatal palliative care program was associated with a significant increase in redirection of care and palliative medication use and a decrease in variability of use of end-of-life interventions **13**. Qualitative data similarly support the benefit of these programs. In a single-center study of parental perceptions regarding the care that their newborns with life-limiting conditions received from participation in a standardized program, most parents believed that their children were treated respectfully in a "caring, peaceful, and noninvasive environment," and that an overall state of comfort was achieved **14**.

The prenatal diagnosis of a life-limiting condition can be very stressful for patients and their families, eliciting feelings including grief, loss, and anxiety **15**. There is literature to suggest that parents can derive satisfaction from participation in a perinatal palliative care program, and this may facilitate adjustment to the news of a life-limiting fetal diagnosis. One study of parents who chose to continue pregnancies after life-limiting fetal diagnoses reported that, although perinatal palliative care was not available to all, the majority were happy “to meet their baby” after delivery even if the newborn lived only briefly after birth or was stillborn **15**.

Ethical Considerations

Women should have control over decisions that affect their bodies, and it should be their decision as to how to manage a pregnancy complicated by a life-limiting fetal condition **16**. Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions. Indeed, the tenets of informed consent require that patients be presented with this full array of reasonable and ethically acceptable options **5**.

Offering perinatal palliative care to pregnant patients should be seen as an opportunity to further their autonomy and promote beneficent care. Physicians should support patients and their families in a shared decision-making process that respects individual autonomy as well as the complex web of relations and emotional influences in their lives, while also guarding against coercion and undue influence from family members, spouses, partners, or even health care providers themselves **17**. Nonetheless, after birth, the ethics of complex decision making for newborns requires the input of both parents, when practical.

Conclusion

Perinatal palliative care refers to a coordinated care strategy that comprises options for obstetric and newborn care that include a focus on maximizing quality of life and comfort for newborns with a variety of conditions considered to be life-limiting in early infancy. Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions. Health care providers and institutions are encouraged to develop perinatal palliative care programs, which generally may include the following: a formal prenatal consultation; development of a birth plan; access to other neonatal and pediatric specialties, as needed; and support and care during the prenatal, birth, and postnatal periods, including bereavement counseling. Once a life-limiting condition is suspected antenatally, the tenets of informed consent require that pregnant patients be given information of sufficient depth and breadth to make an informed, voluntary choice for their care.

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