Perinatal Palliative Care

A Resolve Through Sharing Position Statement

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Introduction

Palliative care addresses quality-of-life concerns for patients with progressive, debilitating diseases. It ensures end-of-life treatments that enhance comfort and improve the quality of life (Resolve Through Sharing, 2021a). Palliative care neither hastens nor postpones death (World Health Organization, 2002). According to Limbo et al. (2019), since the early 2000s, perinatal palliative care has moved into its own distinct area, separate from other palliative care domains.

“Perinatal palliative care is clinically unique because the two patients embodied in the maternal-fetal dyad are assessed simultaneously, with plans of care tailored to the needs of each” (Wool & Black, 2020, p. 4).

Perinatal palliative care dignifies the experience of parents and their support system during this difficult time. The needs of the patients are assessed continuously, and all treatment options are explored and evaluated. No therapy or pathway is excluded from consideration. Individual choices and decisions guide plans of care.

While perinatal palliative care should be offered in every situation where a potential life-limiting or life-threatening condition is discovered, barriers to providing or offering the care (e.g., clinician’s lack of knowledge or understanding) and barriers to accessing the care (e.g., travel time, distance, expense) exist (Leuthner & Lamberg Jones, 2020a).

This statement defines and explains perinatal palliative care. Herein, Resolve Through Sharing posits that, regardless of the site of care or goals of care, excellent interprofessional perinatal palliative care can and should be provided in all situations where there is a possibility of perinatal death or death from the pregnant person’s condition.

Key Questions

- What is perinatal palliative care?

  A philosophy of care, independent of the goals of care or treatment decisions, that prioritizes pain and symptom management during the perinatal period

- Who should participate in and who would benefit from a perinatal palliative care pathway?

  Pregnant persons, fetuses, newborns, parents and other decision makers, and providers

- Why practice perinatal palliative care?

  To improve certain outcome measures, allow for goal identification and guided decision-making, and provide opportunities for meaning-making for both staff and family

- When should perinatal palliative care supports be initiated?

  When there is an indication of a life-limiting or life-threatening condition in a fetus, newborn, or pregnant person

- How can excellent perinatal palliative care be practiced in all situations?

  Through organizational commitment to practicing diversity, equity, inclusion, and anti-racism; supporting professional education; and supporting professional well-being

What is perinatal palliative care?

Perinatal palliative care is a philosophy of family-centered and person-centered care that addresses hopes and goals of those experiencing the diagnosis of a potential life-limiting condition in their fetus or newborn and addresses the physical and mental health of the pregnant person experiencing the same. Psychosocial, emotional, and spiritual support and guided decision-making are essential components of the perinatal palliative care paradigm.

This inclusive philosophy of care is not dependent upon the goals of care or treatment decisions. It can be integrated with life-prolonging, supportive care or be the primary focus of care. A definitive diagnosis or prognosis is not a requirement for initiation of perinatal palliative care.

Goals and benefits of perinatal palliative care as a philosophy and practice are “finding good choices when everything seems bad” and demedicalizing death (Beder, 2020).

Perinatal palliative care embodies the following:

- providing education on diagnosis and prognosis
- describing all ethically appropriate treatment options
- exploring hopes and goals, and aligning treatment plans accordingly
- assisting with advance care planning and providing decisional support
- managing pain and symptoms
- providing logistical support
- guiding through uncertainty

Perinatal palliative care should be offered as an option when, due to a life-threatening or life-limiting diagnosis, the outcome of a pregnancy may result in miscarriage, fetal death by pregnancy termination, stillbirth, or neonatal death. All patients and families experiencing perinatal loss benefit from this specific support. To better understand how this practice might be applied in cases of

Definitions

Perinatal hospice

- A subset of perinatal palliative care, perinatal hospice is exclusively comfort care. “A proportion of neonates with LLCs [life-limiting conditions] survive to discharge. Those whose life expectancy is less than 6 months are eligible for hospice” (Muñoz-Blanco et al., 2020, p. 41).

Life-limiting condition

- A life-limiting condition is usually diagnosed through testing during the perinatal period. Life-limiting conditions may be genetic or chromosomal syndromes that have neurologic, biologic (e.g., cardiac, kidney), and/or cognitive manifestations.

Adverse maternal diagnoses

- When there is an adverse maternal diagnosis, a pregnant person’s health may be severely compromised if a pregnancy is carried to term. Examples include autoimmune disease diagnosed during pregnancy, blood or bleeding conditions, and cardiac and/or pulmonary conditions worsened due to the stress of pregnancy.

Benefit versus burden

- If the predictable benefit of treatment outweighs the burden, treatment should continue. When the benefit of treatment is unclear or the burden of treatment is high, it can be ethically acceptable to forgo cure-directed treatment after engaging in a shared decision-making process.

Conscientious objection

- Conscientious objection is raised on moral or religious grounds (Merriam-Webster, n.d.)

miscarriage and pregnancy termination, consider principles of palliative care such as pain management and relationship-based care of the patient and fetus (e.g., offering options such as respectful disposition and seeing and holding the baby).

Who should participate in and who would benefit from a perinatal palliative care pathway?

The provider's perspective of the family should include the fetus or newborn and the patient and/or parent(s). Their support system generally includes trusted relationships (e.g., friends, relatives, spiritual advisors) and other decision makers as identified by the patient. In order to practice unbiased, inclusive care, providers should keep in mind that the "who" may be affected by the plan for the pregnancy (e.g., adoption, surrogacy). The "who" may also be affected by the identity of those within the family (e.g., LGBTQ+ patients and/or parents, single parents, pregnant teens, victims of sexual assault, individuals who do not see themselves as parents).

The perinatal palliative care philosophy should govern care wherever the family and support system are present—clinic, home, hospital, and more. Perinatal palliative care philosophy promotes that provision is conducted by those trained professionals who are part of a palliative care program. Interprofessional teams consist of physicians (e.g., maternal/fetal medicine specialists, neonatologists, pediatric subspecialists, geneticists), sonographers, nurses, genetic counselors, ethicists, social workers, chaplains, and a host of others, as determined by individual organizations. Some specialties may not be available in rural and inner-city areas, but the principles of perinatal palliative care can be practiced by any healthcare professional who is adequately trained (Ziegler & Kuebelbeck, 2020). To ensure palliative care support is available to all, areas not served by an established perinatal palliative care team can develop a consultative relationship with a tertiary referral center whenever possible.

Definitions

Perinatal

- Perinatal describes the periods leading up to, including, and directly following birth (i.e., prenatal, natal, early postnatal).

Ethical dilemma

- The ethics of decision-making prior to a baby being born are not equivalent to the ethics of decision-making after a baby is born. The following is an example of an ethical dilemma: A pregnant woman who is a Jehovah's Witness refuses blood product for herself prior to her baby being born, even though doing so might put the baby at-risk of death. (However, after the baby is born, if a blood transfusion is needed, even if prognosis is uncertain, the parents cannot refuse what would be considered "life-sustaining" treatment on the basis of their religious beliefs.[1])

Life-prolonging

- Life-prolonging treatments extend beyond comfort care. They might begin as a trial to test effectiveness. For example, cardiac surgery may extend life without the long-term success being known.

Racial concordance

- Having professionals and employees reflective of the population served is referred to as racial concordance (Greenwood et al., 2020).

Paradoxically involuntary

- Some parents describe assessing the pathways of continuing the pregnancy or ending the pregnancy as "paradoxically involuntary," meaning the word "choice" is not representative of their decision-making process.

Why practice perinatal palliative care?

In general, palliative care, when implemented early in a diagnosis or prognosis, improves the following outcome measures while still acknowledging death is imminent: quality of life, length of life, cost of care at the end of life, medical utilization, bereavement scores, pain management and medical scores, and adjustment scores (Beder, 2020).

"Parents who receive an adverse fetal or maternal diagnosis during pregnancy face difficult decisions as they consider options: life-sustaining therapies, perinatal palliative care, adoption, and pregnancy termination" (Lamberg Jones et al., 2016). Perinatal palliative care should be offered in all these situations with the understanding that families may travel several pathways throughout their journey.

Patients and/or parents have hopes and goals for their pregnancy before and after diagnosis (e.g., adoption could be planned before a life-limiting diagnosis or as a result of such). Guided participation, a theory of teaching and learning, offers a framework for identifying goals and providing decisional support (Pridham et al., 2018). “One can identify numerous issues in caring for a baby with a life-limiting fetal diagnosis, before, during, and after birth. One issue might be the parents sharing with the healthcare professional that they do not want their baby to suffer” (Limbo & Walter, 2020, p. 142). Through guided participation processes and competencies, issues such as these can be explored.

Hopes

Healthcare professionals can support parents in identifying potentially achievable hopes and expectations. Hopes may change as more information becomes available. As parents hope for the baby to survive, healthcare professionals can help them plan for the possibility of the baby dying. If one hope seems unlikely to be fulfilled, providers may ask, “What else might you be hoping for?” (Rosenberg & Feudtner, 2016). Worries, fears, and concerns should be explored and addressed. Providers may say, “I’m wondering if preventing your

Myths and Facts

Myth: Perinatal palliative care is only for those who choose to continue pregnancy and wish for a natural death for their child.

Fact: Perinatal palliative care is for all patients and families who might experience perinatal loss. Perinatal palliative care can be offered as an option when, due to a life-threatening or life-limiting diagnosis, the outcome of a pregnancy may result in miscarriage, fetal death by pregnancy termination, stillbirth, or neonatal death. It involves parallel planning for birth and death.

Myth: Perinatal palliative care is the same as doing nothing and/or giving up on the outcome.

Fact: Perinatal palliative care is an aggressive comfort intervention that always provides options for doing something.

Myth: Choosing perinatal palliative care means you can’t have any hopes or goals achieved.

Fact: During perinatal palliative care provision, providers can help parents find good choices when everything seems bad. Healthcare professionals can support parents in identifying hopes, expectations, and potentially achievable goals.

Myth: Perinatal palliative care is only available at large medical centers.

Fact: No matter the size of a healthcare organization, perinatal palliative care services can and should be available to all who need them. This includes having trained experts in bereavement support and established relationships with fetal care centers.

baby from suffering is most important to you. Can you tell me more about what suffering means to you?"

Exploring Meaning

- "What does a miracle mean to you? Can you share some examples of miracles that you are hoping for in this situation?"
- "I wonder what is on your mind about this" (Pridham et al., 2018).
- "When you think of being a 'good' parent, what does that look like?"
- "Considering the circumstances, what would be a 'best' choice? What would be a 'right' choice?"
- "What might it look like [or 'be like'] to consider surgery?"
- "Help me understand what 'suffering' means to you."

Members of the interprofessional team (e.g., chaplains, social workers, child-life specialists) can provide appropriate information and resources. Professionals should inform patients and parents of possible alternate outcomes regarding their decisions and hopes (e.g., parents choose pregnancy termination but experience a live birth; parents hope their baby lives after birth, even if briefly, but the baby dies in utero).

Goal identification and shared decision-making

The aim of the team is to support the identified goals of the pregnant person and/or parent(s). Goals may be influenced by the following: patient health complications, fetal condition, and fetal prognosis. Families' decision-making may be shaped by past experiences; by race, ethnicity, and culture; by what an influential other encourages; and by religious beliefs, spiritual constructs, and other values. Healthcare professionals should explore the meaning of the pregnancy and the diagnosis or prognosis (e.g., parenting roles, hopes to fulfill parenting goals, decision-making). In a nonprescriptive way, the expert guide can ensure parents are informed of what the future might hold, what decisions might need to be made, and what the treatment choices might be. The guide should engage the patient and/or parent(s) by inviting their thoughts and focusing on the positives when exploring treatment options.

Sometimes the ethics of treatment decisions are unclear. The healthcare team should always attempt to engage in a shared decision-making process with families, but the healthcare team's input is especially needed in cases when the burdens of treatment appear greater than the predicted benefits.

The treatment team should be transparent about the information and the process for decision-making. They should also explore and integrate, as possible, the family's beliefs and goals in treatment decisions.

Although consent must be obtained, parents are the final decision-makers concerning the treatment plan, regardless of the preferences of the healthcare team. Parents should be informed the team will always try to honor their beliefs and values regarding treatment plans; they should also be informed that overriding circumstances may require the team to continue with treatment.[1]

"A PPC [perinatal palliative care] philosophy should guide care as soon as a concern is detected in order to support families through the uncertainty of diagnosis and decision-making" (Lamberg Jones & Leuthner, 2020a, p. 19). As a pregnancy progresses, changes in information may lead to the need to adjust goals. As goals change, treatment plans must be adapted accordingly and communicated throughout the interprofessional team.

Depending on the parental preferences, there could be several types of perinatal palliative care discussions and treatment plans. Plans may change as situations develop, but parents may choose any of the following as a starting point:

- A teen couple who sees themselves as parents wish to minimize the suffering of their baby; therefore, they choose pregnancy termination.
- A couple who does not recognize the fetus as a baby cannot manage the future life-limiting condition and choose surgical termination.
- A couple is informed by their physician that continuing the pregnancy would risk future reproductive health; therefore, they choose medical termination.
- A pregnant transmasculine person who sees himself as “Papa” wants to minimize the suffering of his baby, and he wishes to continue his pregnancy to optimize time with the baby but has limited resources; therefore, he exclusively chooses comfort care at home.
- A woman who sees herself as a mother and has unlimited resources wishes to extend time with her baby; therefore, she chooses a trial period of supportive treatment, including resuscitation and care in a neonatal intensive care unit.
- A couple wishes their newborn to be treated like any baby without the diagnosis of a life-limiting condition; therefore, they and their surrogate choose all fetal and/or neonatal surgical treatment options available.

The decision to intervene with active care (that is, treatments that are intended to prolong life) is based on an ability to meet stated goals rather than affect the underlying condition.

When should perinatal palliative care supports be initiated?

Perinatal palliative care should be offered as part of prenatal and postnatal counseling and care. Care should minimally start at the detection of a potentially life-limiting condition and should continue through pregnancy, birth, hospital treatment, and home care, as applicable. Regardless of families’ goals and treatment decisions, all newborns and delivering patients can receive perinatal palliative care, including pain and symptom management. Bereavement care and grief support should be integrated into the continuum of care from diagnosis through follow-up.

Goals and treatment preferences as well as choices for pain and symptom management can be documented into an advance care plan as decisions are made.

Advance care planning

An advance care plan, also known as a birth plan, operationalizes families’ identified goals to ensure consistency, coordination, and continuity of care. In these often paradoxically involuntary situations, an advance care plan can facilitate the journey when the only available choices and options may feel senseless and heartbreaking.

Birth plans can and should be developed at any gestational age and for any mode of delivery. Options for birth planning, including memory-making, planning for disposition of the body, spiritual support, and access to child life support, may or may not be available—especially in cases of miscarriage or termination—depending on the organization and how or whether they have integrated these options into their care. The care plan is a co-creation of the family and their care team. Providers can outline available options and help families make the plan that is best for them. In this way, parents need not feel alone in determining what is in their baby's best interest.

It is essential that providers understand that while some patients consider the option of pregnancy termination unacceptable for personal reasons regardless of the presence of life-limiting fetal conditions, others may welcome an opportunity to discuss termination pathways as part of the advance care planning process (Henner et al., 2020). Since many insurance policies do not cover termination, even in the case of life-limiting fetal diagnosis, a medical induction in a hospital may not be possible, even if it would be the preferred mode of delivery. In such cases, providers may be able to make referrals for services elsewhere.

The advance care plan

- documents the desired care during pregnancy,
- documents the desired care during birth,
- documents the desired care following birth, and
- outlines referral to and coordination with appropriate resources when a higher level of care is required to meet the identified goals.

Thorough documentation and regular communication give parents a measure of control, enhancing transitions with sites and providers as needed. Such a transition may occur if the newborn survives beyond the perinatal period and is moved to pediatric palliative care. The advance care plan is a dynamic document that is updated as goals of care change. "Goals should be specific and incremental. Be prepared to rapidly execute elements of the directive, recognizing some may be out of order, modified, or even no longer possible" (Resolve Through Sharing, 2021b). As always, when discussing options, recognize that offerings included as an organization's standard of advance care planning (e.g., memory-making, photos) may not be what parents want. Staff must check internal biases and personal preferences when developing advance care plans with families. Professionals should never pressure parents to do what providers think needs to or should be done (Resolve Through Sharing, 2021b).

Exploring Meaning

In this statement, the word "baby" is used within a relational context. "Fetus" and "newborn" are used as descriptive terms. In some cases, persons view themselves as parents; in other cases, persons do not view themselves as parents at the time. In either case, patients and their support systems may use the following descriptors: fetus, pregnancy, and/or baby. How and when they use these descriptors can provide insight to healthcare professionals. Providers should always listen to and follow the lead of those under their care.

Bereavement support

Because a family's bereavement process can begin at diagnosis, bereavement support should be provided accordingly. When parents hear unexpected news, they may experience shock—feeling numb and overwhelmed. Soon after diagnosis, parents may begin to grieve the loss of the accepted or hoped-for pregnancy, birth, and newborn. Their grief may be compounded by how the loss is felt by others (e.g., children in the household, grandparents). Their grief may intensify with the realization that they will outlive their child. Parents often benefit from connecting with other families navigating similar circumstances.

How can excellent perinatal palliative care be practiced in all situations?

Access to care, sensitive communication, continuity, coordination, and consistency of care among providers and between sites are critical to the effective delivery of palliative care. Providers should recognize that patients' and/or families' spiritual practices, cultural beliefs, support system, financial situation, time away from work, and parenting concerns with the future newborn and current children may all be factors in limiting understanding of and access to perinatal palliative care.

Diversity, equity, inclusion, and anti-racism

Relationship-based and evidence-based care must be practiced through a diversity, equity, inclusion, and anti-racism lens. However, exclusionary othering exists in many healthcare organizations at the systemic level. Exclusionary othering is characterized by domination and subordination and is often fueled by unconscious bias. Attributes such as skin color, spoken language, physical abilities, age, and perceived gender serve to elevate one's otherness (Canales, 2000). Because these attributes are immediately apparent and often seem to highlight differences rather than similarities, they can be used to justify discriminatory ideas and behaviors (Resolve Through Sharing, 2021b). These can creep into perinatal palliative care programs. Potential consequences are marginalization, oppression, alienation, and limited opportunity. Race, ethnicity, language, sexual orientation, gender identification, culture, religion, and socioeconomic status should not alter care.

Goals and Benefits of Providing Perinatal Palliative Care

Finding good choices when everything seems bad

- "And if I start with the ability to find good choices when I'm dealing with children dying, which most people say is the worst bad that could be, and I can find good, then we all can find good" (Beder, 2020).

Demedicalizing death

- "Supporting the care team starts with not just formal acknowledgement of their contributions but also a deeper recognition of the powerful impact of relationship-based care on those who are suffering" (Lamberg Jones & Leuthner, 2020b, p. 351).

Supporting care teams

- "Feeling competent in their provision of end-of-life care creates positive feelings in the care provider…and can also prevent a suboptimal experience for both provider and patient" (Lamberg Jones & Leuthner, 2020b, pp. 352-353).

To ensure compassionate care for all patients, an organization's senior leadership must be committed to maintaining a culture that supports diversity, equity, and inclusion. Making persons feel as "others" may be caused by implicit and explicit racial or sexual orientation bias. Bias or sensitivity training alone is not sufficient as a method for creating an environment where all feel welcome. In perinatal palliative care, staff should be of diverse backgrounds so that those receiving care see someone "who looks like me"—racial concordance—or "who lives as I live." Advisory groups that include representation of, for, and by Black, Brown, Indigenous, and other systemically marginalized groups (e.g., LGBTQ+, housing insecure, impoverished, unwillingly unemployed) should be created with the goal of receiving input on delivering perinatal palliative care services. The key to inclusiveness at the individual level is "suspending judgment." "An effective conversation demands that all our own cultural, social, and ethical belief systems are put aside, and we are willing to learn and work within the belief systems of a specific family (Gold, 2007)" (Major-Kincade et al., 2020, p. 69).

Education

Palliative care education and bereavement education should be provided as part of all professional healthcare training. Supplemental perinatal palliative care education is widely available to multiple professions and is strongly recommended to those caring for pregnant persons and newborns. Organizations should provide training support (i.e., funding, paid time off, required continuing education) for professionals in these roles. Palliative, hospice, and bereavement organizations—many of which are interprofessional—offer education, formalized training, and certification.

All members of the perinatal palliative care team should be equipped to provide evidence-based bereavement support. Several team members may specialize in caring for grieving families. Resolve Through Sharing-trained healthcare professionals provide comprehensive bereavement support in the palliative care setting.

Professionals' self-awareness and well-being

Staff providing perinatal palliative care can experience stress, moral distress, ethical dilemmas, compassion fatigue, and conscientious objection. Reframing (i.e., embracing goals and benefits of providing perinatal palliative care over stressors and challenges) can help engage staff in finding positive outcomes from the work they do. Anticipatory guidance and debriefings can lessen staff-related distress. Sources of stress could include professional conflicts; heated family responses; decisional conflicts; and miscarriage, death by termination, stillbirth, or death of a newborn. Opportunities to connect with each other and seek wellness should be consistently provided.

Conclusion

Perinatal palliative care should be offered in every situation where a potential life-threatening condition is detected in a fetus, newborn, or pregnant person; a definitive diagnosis or prognosis is not required. Guided participation theory offers a framework for advance care planning through goal-identification and shared decision-making. Relationship-based and evidence-based care requires intentional practice through a diversity, equity, inclusion, and anti-racism lens; continuous assessment of potential barriers for families; ongoing staff education in palliative care and bereavement support; and regular opportunities for staff to connect with each other and seek wellness.

At the heart of perinatal palliative care are families—patients/parents and their unborn or newborn babies. Every goal of care and decision about treatment and other preferences revolve around this group. They do not go this path alone, but rather in partnership with knowledgeable and compassionate experts.

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