

# Enhancing Care and Support: The Role of Perinatal Palliative Care in Navigating Life-Threatening Fetal Diagnoses

Sarah Ziane\*

Department of Pain Management and Palliative Care, Queensland School of Medicine, Australia

## Abstract

Perinatal medicine is currently grappling with an increasing array of intricate fetal ailments that can now be detected prior to birth. The advancement of potential life-extending interventions for both pre and postnatal care adds to the unpredictability of prognoses. For medical professionals tasked with guiding families through these complex situations, identifying those who could benefit from early palliative care referrals poses a considerable challenge. We propose that every expectant mother carrying a fetus diagnosed with a life-threatening condition, where prioritizing comfort-oriented care during birth is a valid ethical choice, should be provided with prenatal palliative care support. This support, irrespective of the chosen care strategy, can facilitate well-informed decision-making, offer valuable psychological and grief assistance, and allow for comprehensive care planning that encompasses ways to honor and cherish the life of the fetus or newborn, regardless of its duration.

**Keywords:** Perinatal palliative care; Life-threatening fetal diagnosis; Family support; End-of-life care; Patient-centered approach; Maternal-fetal care; Prenatal and postnatal care; Pediatric palliative care

## Introduction

Recent advancements in perinatal medicine have ushered in opportunities for earlier identification and intervention in cases involving fetuses with intricate medical complexities. Some fetal diagnoses that were once life-threatening have witnessed such remarkable success in medical and surgical interventions that prospects for long-term survival and functional well-being are undeniably optimistic [1,2]. However, there exists another subset where modern medical knowledge has yet to uncover effective solutions, inevitably leading to the in utero or early infancy demise of the affected infants [3]. Between these two ends of the spectrum lies a burgeoning array of diagnoses where a substantial level of prognostic ambiguity persists. Might novel or experimental fetal interventions potentially alter the course of a previously fatal ailment? Could resuscitative endeavors, advanced neonatal intensive care, surgical interventions, and cutting-edge technology extend life significantly beyond conventional projections? In instances of successful survival, what quality of life can be anticipated, and over what duration? Navigating these intricate and often uncertain scenarios necessitates an adaptable and multidisciplinary approach to effectively provide support to families. Perinatal palliative care, as outlined by the American College of Obstetricians and Gynecologists (ACOG), encompasses a strategic framework aimed at enhancing the quality of life and comfort for newborns afflicted with various conditions that are deemed to be limiting in their early infancy [4]. This field has expanded significantly over recent decades, incorporating care routes for expectant mothers confronting life-threatening fetal diagnoses and also encompassing neonates diagnosed with life-threatening conditions after birth. During the prenatal period, perinatal palliative care maintains its emphasis on families who have expressed their intent to: (a) proceed with the pregnancy, and (b) pursue a care regimen that prioritizes comfort while avoiding aggressive measures to prolong life due to the severity of the prenatally detected fetal anomaly [5-8]. Nevertheless, this approach extends palliative care support solely to a minority of families grappling with intricate and life-threatening fetal diagnoses. Acknowledging the concurrent role of palliative care alongside life-prolonging treatments, we contend that this more comprehensive approach should evolve into the standard of

care within perinatal medical practice. Early engagement of palliative care is imperative subsequent to any diagnosis of a life-threatening fetal condition, with the intention of enriching informed decision-making and offering sustained assistance throughout the uncertain journey, regardless of the family's chosen path. Palliative care professionals are well-suited to extend supplementary psychosocial backing to families during the pregnancy period, as concerns frequently persist regardless of subsequent postnatal choices. Even families that are unequivocally committed to pursuing life-prolonging measures following delivery can derive advantages from continuous support during what frequently evolves into an arduous, protracted, and still indeterminate odyssey [9]. Depending on the specifics of each scenario, palliative care practitioners can play a role in planning and delivering exceptional end-of-life care after birth, or they can transition into an enduring role providing supportive care for infants grappling with ongoing medical complexities and mortality risks. Irrespective of the chosen course of care, these professionals can also assist families in engaging in activities that facilitate memory creation and bonding. While the significance of such endeavors is readily acknowledged as a baby approaches the end of life, our observations underline their comparable importance for families whose infants are undergoing intensive medical care.

Lastly, palliative care teams can establish avenues for early and sustained grief support in the event of a pregnancy loss or the passing of the infant. When confronted with a life-threatening fetal diagnosis, families are confronted with a intricate web of decisions that demand careful consideration. The balance between continuing the pregnancy or opting for termination may raise queries regarding their associated

**\*Corresponding author:** Sarah Ziane, Department of Pain Management and Palliative Care, Queensland School of Medicine, Australia, E-mail: sarah\_5243@yahoo.com

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risks and benefits, necessitating support in either scenario [10]. The potential interventions aimed at prolonging the life of the fetus or newborn can display considerable variation contingent upon the nature of the diagnosis. The notion of transferring care to alternate maternity providers or facilities might also emerge as a viable option to access specific interventions. To enable parents to grant fully informed consent, it holds paramount significance that they possess a comprehensive grasp of and appreciation for all feasible avenues of care, along with a thorough understanding of what each approach entails.

Just as a surgeon is summoned to counsel families about the potential advantages and drawbacks of a particular surgical procedure, it is equally essential for palliative care experts to be engaged in elucidating the potential contours of comfort-oriented end-of-life care for an infant afflicted with a specific diagnosis. These specialists are uniquely positioned to elucidate the array of choices encompassing symptom management and care settings, especially those situated outside of a hospital environment (such as home or residential hospice care) [11]. The equitable availability of palliative care support should be extended to every family contending with a life-threatening fetal diagnosis where a comfort-focused care trajectory could be a reasonable therapeutic route, regardless of whether it aligns with the family's ultimate choice. Such an approach ensures that the breadth of information and support furnished to a particular family is impartial and not unreasonably influenced by the specific care options they opt for. In earlier times, specific fetal diagnoses were categorized as "lethal." However, contemporary perinatal medicine acknowledges the problematic nature of this terminology, recognizing that a considerable degree of uncertainty often surrounds the prognosis associated with a so-called "lethal" fetal diagnosis. Advancements in imaging and genetic testing are leading to earlier identifications. Even when a diagnosis appears clear in the early stages, understanding a baby's unique phenotype can evolve over the course of the pregnancy as its physiological aspects, growth, and development are closely monitored. Technological progressions in both pregnancy and neonatal care, such as advanced imaging techniques and fetal surgery, as well as surgical and intensive care support for neonates, are also continuously evolving. Not only is the term "lethal" distressing for families, but its accuracy within this context becomes dubious as perinatal medicine continues to advance [12,13].

Given the often uncertain nature of prognosis, the incorporation of palliative care should coincide with considerations of other interventions. Palliative care is centered on exploring care goals that can shape care planning along the trajectory. Decision-making tends to be a dynamic process as families gradually accumulate additional insights from a range of multidisciplinary providers. Families' preferences and their comprehension of what aligns with their baby's best interests can evolve over time. Some may have a clear preference for focusing solely on comfort or pursuing life-extending interventions. For others, devising plans that encompass both options based on the evolving course of pregnancy and early neonatal progress better reflects their care objectives [14]. Understanding the full spectrum of care options for an infant after birth also facilitates discussions between maternity care providers and families regarding care during pregnancy, labor, and delivery. Indeed, the care goals that shape the baby's plan of care can also impact decisions during labor and delivery, including the choice of delivery location, the extent of fetal monitoring, and the threshold for interventions like cesarean section in cases of fetal distress. Palliative care teams can delve into matters that offer valuable insights as maternal and neonatal care providers offer recommendations for the

labor and delivery process. Detailed birth plans that encompass not only medical details but also aspects of honoring the baby and creating cherished memories can empower families to maintain a semblance of control in situations where they may feel their ability to exert control is compromised [15]. Ambiguity can also emerge throughout the end-of-life journey for an infant receiving comfort-focused care. For families who opt for this approach, establishing an early rapport with a palliative care team can offer insights into the most suitable care setting should the baby surpass the initial hours or days following birth. While certain families lean towards hospital care, others contemplate the possibility of home or residential hospice discharge. Palliative care teams are well-versed in the array of supportive resources available beyond the hospital setting and within a specific community. They can sustain their involvement over time, ensuring that if a child outlasts initial expectations, care goals can persistently be readdressed in the company of familiar care providers.

## Discussion

The emotional distress linked to carrying a baby with a life-threatening condition commences at the point of diagnosis, rather than being confined to the moment of the baby's passing. This holds true even when there is potential for a positive outcome due to successful medical interventions. Families frequently undergo a grieving process due to the transformation in their child's prospects or the loss of what was presumed to be a healthy and "normal" future. Palliative care resources can serve as a valuable aid in helping families recognize and access support for their grief at an early stage. These resources facilitate connections with the unborn child during pregnancy or in the initial stages of neonatal care through activities that establish a legacy, fostering a healthier grieving process in the long run. Certain circumstances elevate the risk of complex grief, particularly for parents who must terminate a pregnancy due to the fetal diagnosis, those who lack surviving children or grapple with fertility issues, or women who lack a supportive partner. Initiating early intervention can also enable prompt and suitable referrals for the subset of patients who may require broader mental health or psychiatric support. For parents who experience fetal or neonatal loss, the need for grief support often intensifies in the immediate aftermath of the loss. However, it remains equally relevant months or even years later. Specific life events, such as a subsequent pregnancy, may also necessitate heightened support. Palliative care providers can play a crucial role in guiding families on accessing grief resources when needed in the future. Initiating these connections early on also helps raise parents' awareness about the anticipated trajectory of their grief journey over time. The methods through which perinatal palliative care providers can offer assistance to primary maternal-fetal care teams can manifest differently based on the pregnant woman's care setting and the existing resources accessible to her and her family. Many patients diagnosed with a life-threatening fetal condition are directed to high-risk obstetrical centers where access to perinatal palliative care support is increasingly prevalent, either through independent programs or as a component of broader pediatric palliative care initiatives. Some community-based hospitals have also extended this care option, particularly when families opt for approaches that can be administered closer to their residence. For medical facilities lacking local proficiency in this domain, virtual consultation and ongoing support, encompassing both families and maternity care providers, present a viable solution, especially when local perinatal palliative care resources are not accessible. While face-to-face consultations may be the preferred choice for certain providers and families, our institutional experience demonstrates that exceptional perinatal palliative care can be effectively delivered through virtual

visits and digital resources.

## Conclusion

Incorporating perinatal palliative care can offer a vital supplementary layer of assistance alongside the multitude of other providers who aid patients and families grappling with a life-threatening fetal diagnosis. Regardless of whether the care objectives or course of the fetal condition are fully comprehensible, palliative care teams play a pivotal role in enhancing informed decision-making, navigating the realm of uncertainty, and extending grief support. Normalizing the early integration of palliative care subsequent to a fetal diagnosis can foster the development of a continuous therapeutic relationship between families and palliative care teams. Whether the palliative care team ultimately assumes a supportive role for infants undergoing intensive interventions or occupies a more central position in facilitating high-quality end-of-life care, their assistance throughout periods of uncertainty and grief should be viewed as complementary. Initiating perinatal palliative care involvement at an early stage for all families confronted with a life-threatening fetal diagnosis can contribute to optimizing care throughout the pregnancy and beyond.

## Acknowledgement

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## Conflict of Interest

Author declares no conflict of interest.

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