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Perinatal Palliative Care: Past, Present, and Future

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When I first came across the words "perinatal hospice" about two decades ago, it was a lightbulb moment. It gave me words for exactly what my husband and I had tried to do.

Our son, Gabriel, was diagnosed at 25 weeks' gestation with hypoplastic left heart syndrome, a severe and incurable heart defect. After much research into surgical options and outcomes, and after many tears, we opted to protect him for the rest of his natural life and embrace that time, with the overriding goal of doing all we could to make his life after birth peaceful and filled with love. And it was. As we later inscribed on his gray granite gravestone: "He knew only love."

Origins of perinatal hospice and palliative care

It wasn't until several years later that I stumbled across a medical journal article that contained the words "perinatal hospice." It turned out that Drs. Byron Calhoun and Nathan Hoeldtke first proposed the concept in the medical literature in 1997,¹ two years before I needed it, and the idea made its debut in the American Journal of Obstetrics and Gynecology in 2001.²

"When the prenatal diagnosis of a lethal fetal anomaly has been established, some patients choose to continue their pregnancy. Currently, there is a paucity of medical literature addressing the specific management of families in this unique circumstance," they wrote. "We propose a model of care that incorporates the strengths of prenatal diagnosis, perinatal grief management, and hospice care to address the needs of these families."

The core idea is one of accompaniment, an idea that is both simple and profound. When parents choose to continue their pregnancies following a prenatal diagnosis indicating that their baby has a life-limiting condition and might die before or shortly after birth, perinatal hospice and palliative care helps parents embrace whatever life their baby might be able to have, before as well as after birth.

This support begins at the time of diagnosis, not just after the baby is born. It can be thought of as "hospice in the womb" (including birth planning, emotional support for the family, and preliminary medical decision-making before the baby is born), as well as more traditional hospice and palliative care at home after birth (if the baby lives longer than a few minutes or hours). It includes essential newborn care such as warmth, comfort, and nutrition. Palliative care can also include medical treatments intended to improve the baby's life. This approach supports families through the rest of the pregnancy, through decision-making before and after birth, and through their grief. This model of care enables families to make meaningful plans for the baby's life, birth, and death, honoring the baby as well as the baby's family.

Bringing palliative care into the perinatal period was a logical extension of the original vision of hospice and palliative care for older people nearing the end of life. As the benefits of hospice became apparent over the years, the concept was extended to children approaching death,³ then to gravely ill newborns,⁴ and then to babies with a

prenatal diagnosis indicating that they would likely die before or after birth.⁵ An Australian bioethicist and neonatologist called it “palliative care’s final frontier – the needs of infants and fetuses who are dying before they have even been born.”⁶

At first the concept was called perinatal hospice, because many of the life-limiting conditions diagnosed prenatally do result in a lifespan that is brief and appropriate for hospice care. But as this model of care has developed, its application broadened to also include care for babies who may have a longer lifespan, and the concept has become more frequently referred to as perinatal palliative care.

Perinatal hospice and palliative care today

Perinatal palliative care has grown exponentially, with at least 350 programs worldwide and countless more health care professionals providing this care on an informal or as-needed basis.⁷

Many articles and research studies have been published in major medical journals, demonstrating the benefits to babies and their families.⁸ Word has spread through books both for laypeople and medical professionals, as well as presentations at medical conferences, with even full conferences dedicated to the topic. Word also has spread through coverage in mainstream media including *The New York Times*, *The Wall Street Journal*, and *The Washington Post*.⁹

The concept has been endorsed widely, with many professional organizations and medical societies publishing statements in support of perinatal palliative care and encouraging health care professionals and institutions to develop programs. For example, the American College of Obstetricians and Gynecologists has issued a committee opinion, co-endorsed by the Society for Maternal-Fetal Medicine and the American Academy of Pediatrics, in support of this model of care,¹⁰ and the American Academy of Nursing issued a position statement calling it an “essential element of childbearing choices.”¹¹ The World Health Organization states that palliative care should be initiated immediately for family support when a life-limiting condition is discovered during pregnancy or at birth.¹² The concept has earned attention from influential nonmedical figures as well. Pope Francis has endorsed the idea, calling these programs “networks of love.”¹³

When I first began speaking and writing to help spread the word about perinatal hospice and palliative care, many health care professionals were unfamiliar with it yet curious and often instantly supportive because it addressed a need they had already witnessed in their practice. Today, the reaction generally skips ahead to: Yes, we already know we need to provide this care; how can we do it?

Fortunately, professional training and resources are now available. Several textbooks have been published in recent years,¹⁴ and training has been offered by organizations including the National Hospice and Palliative Care Organization, the Hospice and Palliative Nurses Association, the End-of-Life Nursing Education Consortium, Resolve Through Sharing Bereavement Services/Gundersen Health System, the Center to Advance Palliative Care, Columbia University Children’s Health/NewYork-Presbyterian Morgan Stanley Children’s Hospital, and more.¹⁵ A number of countries and organizations also have developed formal perinatal palliative care protocols and frameworks.¹⁶

Many hospitals and health care professionals have found that this extra layer of support can be incorporated relatively easily into standard pregnancy and birth care. And parents’ responses have been overwhelmingly positive.¹⁷

Visions for the future

One of my goals is to take my website down. By that, I mean that I hope maintaining a list of perinatal hospice and palliative care programs will soon be as superfluous as maintaining a list of all the hospitals that have emergency departments. Perinatal palliative care should be incorporated as seamlessly into maternity care as other

specialized maternity care that is sometimes needed, such as for preterm labor, gestational diabetes, or other situations that may arise. And perinatal palliative care should routinely be offered as a standard option for all expectant parents who receive a devastating prenatal diagnosis of a life-limiting condition.

I hope that perinatal palliative care will soon become incorporated into training for health care professionals including physicians, nurses, genetic counselors, and others, in medical school and nursing school curricula as well as additional continuing education for practicing professionals. Future obstetricians in particular should have baseline knowledge about providing this care.

In the meantime, although a formal program with an interdisciplinary team is ideal, in the absence of a formal program parents and caregivers can still create a perinatal palliative care experience when needed. In fact, that's what happened for my family. One nurse helped us to normalize our experience, helped us coordinate our birth plan with our medical team, and affirmed for us that we still had a profound opportunity to parent our baby.¹⁸ I learned much later that we were her first family traveling this as-yet-unnamed journey of perinatal hospice. We had no idea that we were her first; she was that good. She has since accompanied hundreds of other families like ours. Sometimes all it takes is one person. Maybe that person is you.

Amy Kuebelbeck is a journalist and is lead author of *"A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief"* (Johns Hopkins University Press, 2011; second edition forthcoming in 2023), author of the memoir *"Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life"* (Loyola Press, 2003), and editor of the website perinatalhospice.org, a clearinghouse of information about perinatal hospice and palliative care.

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7. See "Perinatal Hospice and Palliative Care Programs and Support," *Perinatal Hospice and Palliative Care*, <https://www.perinatalhospice.org/list-of-programs>
8. For a curated bibliography of relevant articles in medical journals, see "Resources for Caregivers," *Perinatal Hospice and Palliative Care*, <https://www.perinatalhospice.org/resources-for-caregivers>

9. See the Media Coverage page at perinatalhospice.org, <https://www.perinatalhospice.org/media-coverage>
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18. I would like to take this opportunity to express my deepest thanks to Annette Klein, R.N., of Allina Health Mother Baby Center at United Hospital in St. Paul, Minnesota. We are forever grateful.