

“YES TO LIFE” AND THE EXPANSION OF PERINATAL HOSPICE

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ABSTRACT Since the model of perinatal hospice was first proposed more than two decades ago, its growth has been exponential. Perinatal hospice, now also called perinatal palliative care, is a practical and compassionate model of care for those continuing a pregnancy following a prenatal diagnosis indicating that their baby has a life-limiting condition and might die before or shortly after birth. Well over 300 international perinatal hospice and palliative care programs have been created; many articles have been published in major medical journals; several textbooks and guides have now been published; protocols and training have been developed; and growing numbers of parents are choosing to continue their pregnancies when perinatal hospice care is offered. And now the idea has even reached Pope Francis.

For those of us gathered expectantly in the frescoed 16th-century Clementine Hall in Vatican City on a brilliant spring morning in May 2019, it was a profound moment when Pope Francis spoke the words “perinatal hospice” (in Italian, “*hospice perinatale*”). I wish all the medical professionals who have pioneered and developed this care over the last 25 years could have been in that majestic hall with us. Their cumulative work—along with the poignant stories of many families—is inspiring people around the globe and helping more people than they may ever know.

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The hour-long private papal audience for conference attendees was the culmination of a three-day conference titled “Yes to Life! Caring for the Precious Gift of Life in Its Frailness,” about caring for the most fragile of new human lives, especially through the accompaniment of perinatal hospice. It was co-sponsored by the Vatican Dicastery for Laity, Family and Life and Fondazione Il Cuore in Una Goccia Onlus, an Italian nonprofit led by Dr. Giuseppe Noia, who started a perinatal hospice program at Gemelli hospital in Rome. The multilingual event drew about 400 people from all around the world for presentations from obstetricians, neonatologists, bioethicists, and others about prenatal diagnosis, medical ethics, and more.

For anyone who might be encountering the concept of perinatal hospice for the first time, some explanation: perinatal hospice and palliative care is a practical and compassionate model of care for those continuing a pregnancy following a prenatal diagnosis indicating that their baby has a life-limiting condition and might die before or shortly after birth. (A note about terminology: *fetus* is of course the correct medical term, as is *gravida* for a pregnant woman. But many parents in this situation use the word *baby* and prefer that their health-care professionals do so as well.) As prenatal testing continues to advance, more families are finding themselves in this heartbreaking situation. In many places, abortion still is the default recommendation—or the only option presented—and parents who desire to continue their pregnancies often feel abandoned. Perinatal hospice accompanies these parents as they embrace the life of their baby for however long the baby is able to live.

Perinatal hospice 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. It involves siblings and extended family and friends, as well as memory-making such as photography. Palliative care can also include medical treatments intended to improve the baby’s life. Perinatal hospice is not a place. It is a model of care, an extra layer of support that can easily be incorporated into standard pregnancy and birth care just about anywhere. Perinatal hospice is a beautiful and practical response to one of the most heartbreaking challenges of prenatal testing.

The concept and the term “perinatal hospice” first appeared in the medical literature in 1997 in an article by Dr. Byron Calhoun, a US maternal-fetal medicine specialist who was one of the presenters in Rome (Calhoun et al. 1997). This model integrates the philosophy and expertise of hospice and palliative care with best practices in perinatal bereavement care for miscarriage, stillbirth, or infant death.

As the concept of perinatal hospice has spread, and as palliative care has become a medical subspecialty in its own right, this concept has also come to be called “perinatal palliative care.” Like palliative care for adults, perinatal palliative care is not limited to end-of-life care and can include medical treatments intended to improve the baby’s life. This is especially important for life-limiting conditions such as trisomy 13 or trisomy 18 that are often dismissed as “incompatible with life,” a “lethal diagnosis,” or a “fatal fetal abnormality,” but for which extended survival can be possible (Linebarger 2016). Perinatal palliative care allows these babies to lead the way. For many parents, even a life that lasts only a few minutes after birth is infinitely meaningful. In addition, for parents who are given a stark choice between termination or intensive medical intervention that would be unduly burdensome to the baby, perinatal palliative care offers a third way.

This innovative and compassionate model of care aligns well with core principles of palliative care, including these from the World Health Organization: Palliative care “affirms life and regards dying as a normal process” and “intends neither to hasten or postpone death” (WHO 2020). As one Australian neonatologist and bioethicist wrote, “We are now reaching palliative care’s final frontier—the needs of infants and foetuses who are dying before they have even been born” (Wilkinson 2013).

This concept not only draws upon the field of hospice and palliative care, it incorporates advances in perinatal bereavement care that also have developed over the last few decades. For many years, speaking about the death of a baby was considered taboo. Parents were forbidden from even seeing a newborn who was stillborn or dying and were told to “forget about it” and have another one. Babies’ bodies often were disposed of as medical waste. Although caregivers may have been motivated by compassion, in hopes of protecting parents (and perhaps themselves) from emotional pain, some parents eventually stepped forward to say that this pretend-it-never-happened approach was deeply damaging. Together with caregivers, they worked together to develop practices that would foster healthier grief.¹ Many hospitals have now adopted best practices for perinatal bereavement care, including encouraging parents to see and hold their baby if they wish; assisting parents in collecting keepsakes such as footprints and photographs; providing respectful care of the baby’s body after death; and acknowledging the baby as a unique and irreplaceable child.²

Growth in perinatal hospice has been exponential. PerinatalHospice.org (2020) now lists well over 300 international perinatal hospice and palliative care programs. (Most programs are based in hospitals or clinics, some are hos-

¹ For example, see Share Pregnancy & Infant Loss Support, founded in 1977, and Resolve Through Sharing Bereavement Services at Gundersen Health System, founded in 1981.

² See *Now I Lay Me Down to Sleep*, an international network of thousands of professional photographers who volunteer to provide grieving families with remembrance photography of their baby, founded in 2005. See also the pioneering work of photographer Todd Hochberg, toddhochberg.com.

pice-based, and a few are faith-based or independent.) Many articles have been published in major medical journals, and several textbooks and guides have now been published, including the new *Handbook for Perinatal and Neonatal Palliative Care* (Limbo, Wool, and Carter 2019). Protocols and training have been developed (PerinatalHospice.org 2020). Growing numbers of parents are choosing to continue their pregnancies when perinatal hospice care is offered—in one study, as high as 85% (Calhoun et al. 2003). According to a literature review published in the *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, “The science suggests that perinatal palliative care is welcomed by parents and is a medically safe and viable option” (Wool 2013, 372). And a 2019 committee opinion on perinatal palliative care from the American College of Obstetricians and Gynecologists, also endorsed by the Society for Maternal-Fetal Medicine and American Academy of Pediatrics, encourages health-care providers and institutions to develop perinatal palliative care programs (ACOG 2019).

And now the idea has even reached Pope Francis. The heart of his address in May 2019 was a passionate defense of fragile nascent life, a strong endorsement of perinatal hospice and palliative care when a baby is not expected to survive for long, and an urgent call for pastoral action to create “networks of love” for these families. (He spoke in Italian, and attendees were given printed translations of his prepared text in English, Spanish, and French.) Some passages that resonated deeply with me include the following:

perinatal comfort care is an approach to care that humanizes medicine, for it entails a responsible relationship with the sick child, who is accompanied by the staff and his or her family in an integrated care process. The child is never abandoned, but is surrounded by human warmth and love.

This is particularly necessary in the case of those children who, in our current state of scientific knowledge, are destined to die immediately after birth or shortly afterwards. In these cases, treatment may seem an unnecessary use of resources and a source of further suffering for the parents. However, if we look at the situation more closely, we can perceive the real meaning behind this effort, which seeks to bring the love of a family to fulfilment. Indeed, caring for these children helps parents to process their mourning and to understand it not only as loss, but also as a stage in a journey travelled together. They will have had the opportunity to love their child, and that child will remain in their memory forever. . . .

The practical, human and spiritual difficulties are undeniable, but it is precisely for this reason that more incisive pastoral action is urgently needed to support those families who accept sick children. There is a need to create spaces, places and “networks of love” to which couples can turn, and to spend time assisting these families. . . .

Thank you, then, to you who are working for all this. Thank you, in particular, families, mothers and fathers, who have welcomed life that is frail . . . all of you are supporting and helping other families. Your witness of love is a gift to the world.

A personal note: this model of care had not yet spread when I needed it for myself. In 1999, my husband and I were blindsided by a prenatal diagnosis of hypoplastic left heart syndrome for our third child, Gabriel. Although the topic of perinatal hospice had begun appearing in the medical literature, our perinatologist and other caregivers may not have heard of it yet. When my husband and I inquired about the possibility of hospice, we were told that hospice could be called in after our son was born. But when babies might have a life expectancy of hours or even minutes, enlisting hospice after delivery is of little help. Parents often feel lost and need expert support beginning at the time of diagnosis, as we discovered for ourselves.

The term “perinatal hospice” doesn’t appear at all in my 2003 memoir about our experience, *Waiting with Gabriel*, although our entire story is suffused with the spirit of it. As I often say, our hopes for our son were that his life would be free of pain and filled with love. And it was. It was only after that book’s publication that I stumbled across Dr. Calhoun’s first article proposing the idea of perinatal hospice. When I saw the term, I thought, “That’s it! That’s exactly what we were trying to do!” It gave me words for what we had attempted to create on our own. I had a strong sense that someone should be doing more to help spread the word about this, and my second book, *A Gift of Time* (Kuebelbeck and Davis 2011), and my website both grew out of the realization that I could do my part to help.

Although my family did not receive formal perinatal hospice support, we were fortunate to be referred to one nurse who affirmed for us soon after the diagnosis that we still had a profound opportunity to parent this baby, and she helped walk with us on this path. (We were surprised when we later learned that we were her first family like this, and she has since accompanied hundreds of others.) Sometimes all it takes is one person. Maybe that person is you.

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