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Issue Topic: Perinatal and Neonatal Palliative/Hospice Care

Welcome to the 49th issue of the ChiPPS E-Journal. This edition of our E-Journal offers a collection of articles that explore selected issues related to perinatal and neonatal palliative/hospice care of children and their families. We recognize that offering care at these early points in life is an important aspect of pediatric palliative/hospice services. As well, we appreciate that such care is offered in many different ways. A single issue on this subject will not do full justice to this subject area. Still, we were a bit surprised to receive a larger-than-ordinary collection of contributions for this issue. Consequently, we hope that the articles in this issue will spur increased awareness and discussion of these subjects. We welcome communications from anyone who has more to offer on these subjects.

This E-Journal is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's E-Journal Work Group, co-chaired by Christy Torkildson and Ann Fitzsimons. Archived issues of this publication are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-Journal Work Group, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Please contact Christy Torkildson at christytork@gmail.com or Ann Fitzsimons at ann@here4U.net

Produced by the ChiPPS E-Journal Work Group

PERINATAL PALLIATIVE CARE: TWO DECADES OF EXPONENTIAL GROWTH

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Twenty years ago, in 1997, the idea of perinatal hospice made its appearance in the medical literature for the first time. Inspired by a patient who chose to continue her pregnancy with a baby diagnosed prenatally with Trisomy 18, her medical team reflected on the care they had provided and proposed a model of support to improve the care for other patients to come.

"Because of early diagnosis of lethal fetal anomalies, the process of providing care for a grieving family no longer begins at birth, but at the time of diagnosis," they wrote. "The concept of *perinatal* hospice allows for continued support for the family from the time of diagnosis until the death of the infant."[1]
Ten years ago, in 2007, the concept had begun to spread enough that this ChiPPS e-Journal devoted three full issues to perinatal loss, including articles about prenatal diagnosis, prenatal advance care planning, birth planning, and discussion of perinatal hospice and palliative care.[2] An entire issue was devoted to perinatal palliative care in 2013.[3]

Now, in 2017, the growth of this practical and compassionate model of care has been exponential. Nearly 300 perinatal hospice and palliative care programs are on the international list at perinatalhospice.org[4]; training and protocols are available; and word has spread through numerous journal articles for medical professionals[5] as well as many stories in mainstream media such as *The New York Times*, MSNBC, and *The Washington Post*.[6]

Some background and definitions: Perinatal hospice and palliative care is a model of support for parents who choose to continue their pregnancies despite a prenatal diagnosis that indicates that their baby has a life-limiting condition. It integrates the philosophy and expertise of hospice and palliative care with best practices in perinatal bereavement care for miscarriage, stillbirth, and infant death.[7] This comprehensive support is provided from the time of diagnosis through the baby's birth, life, and death.

This support 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 can also include medical treatments intended to improve the baby's life. If and when the baby dies, many parents choose to take photographs[8] and collect footprints and other keepsakes, with the assistance of hospital staff. (In hospitals across the U.S. and elsewhere, helping families create memories during this fleeting time is considered best-practices standard of care.) This extra layer of multidisciplinary support can easily be incorporated into standard pregnancy and birth care. Rather than "doing nothing," perinatal hospice is an extraordinary form of physical and emotional care that honors the baby throughout his or her entire natural life as well as honoring the family.

When this model of care was first proposed, it was named perinatal hospice. For many of these babies, their lives after birth will be quite brief, so hospice is an apt description of the care they will need. As the idea spread, and as palliative care became a medical subspecialty in its own right, this concept has also come to be called perinatal palliative care. Of course, "palliative care" is a broader term that includes end-of-life hospice care—all hospice is palliative care, but not all palliative care is hospice. 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 is sometimes possible. Because palliative care is a broader term, and also because the word "hospice" unfortunately carries negative connotations for some people, some feel that calling it perinatal palliative care (or something else entirely) can be more comforting. One could argue that either term can be appropriate.

Among the indications that this model of care is reaching a critical mass:

- Professional training is available from multiple sources, including the Certification in Perinatal Loss Care from the Hospice and Palliative Nurses Association[9] as well as online training from the International Children's Palliative Care Network[10] and the National Hospice and Palliative Care Organization.[11]
- Detailed examples of program development and care pathways have been published by organizations including Resolve Through Sharing Bereavement Services, [12] Together for Short Lives (U.K), [13] and others.
- The American Academy of Nursing published a policy brief in 2016 endorsing the concept and calling for program development, allocation of resources for professional training, a credentialing process, and increased public awareness.[14]
- Updated prenatal testing practice guidelines from the American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine recommend that post-diagnosis counseling for parents should include the option of perinatal palliative care.[15]
- The international list of programs at perinatalhospice.org, which began with 27 programs in 2006, has now grown to nearly 300 programs in 47 U.S. states and 22 other countries. Program structures vary. Some freestanding hospices provide this support, while in many hospitals it is a natural extension of existing high-risk pregnancy care, existing perinatal bereavement protocols, or existing palliative care programs for pediatric patients.

When offered the option of perinatal palliative care, growing numbers of parents—in one study as many as 85 percent[16]—choose to continue their pregnancies and receive this care. A recent study in France found that the number of parents who continued pregnancies despite a severe prenatal diagnosis has risen 135 percent.[17] As one researcher concluded in a state of the science overview 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."[18]

Even so, much work remains. Barriers include lack of awareness among caregivers and parents; lack of referrals from obstetricians; lack of integration into maternity care in general; precarious funding; lack of professional training; assumptions that continuing a pregnancy with a life-limiting fetal anomaly could harm a mother's physical or emotional health; and assumptions that this approach would cause a baby to suffer. All of these barriers and concerns can and should be addressed as this model of care continues to develop in the future.

In closing, on a personal note: Back in 1999 I needed this kind of comprehensive support for myself, and nothing like it was available for us. My husband and I had learned through prenatal testing that our son, Gabriel, had an incurable heart defect. I searched for websites, books—anything—for reassurance from someone else who had gone through this experience of continuing a pregnancy and simultaneously preparing for birth and death. There was virtually nothing. Although the idea of perinatal hospice had been proposed in the medical literature two years before our baby's diagnosis, the concept had not yet spread. Fortunately, we had an empathetic nurse who affirmed for us that we still had a profound opportunity to parent our baby. She helped us with our birth plan and helped coordinate communication with the rest of our care team. We created a sort of perinatal hospice experience for ourselves, even though we didn't have those words for it at the time. I always say that Gabriel lived for nine months before he was born and for two-and-a-half peaceful hours afterward. He knew only love.

I eventually wrote a memoir, *Waiting with Gabriel* http://www.perinatalhospice.org/waiting-with-gabriel.html, which was the kind of story I had been searching for while I was pregnant. A few years later, I put my journalistic hat back on and collected stories from more than 100 parents for *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief* http://perinatalhospice.org/A_Gift_of_Time.html. It's like the book *What to Expect When You're Expecting* when this isn't what you were expecting at all. I invited developmental psychologist Deborah L. Davis, Ph.D., to co-author the second book with me because I had been helped greatly by her books *Empty*

Cradle, Broken Heart: Surviving the Death of Your Baby and *Loving and Letting Go*. In 2006 I also founded the website perinatalhospice.org http://perinatalhospice.org, hoping that it would become a place for parents and caregivers to find resources as well as a list of programs to help parents find the support they need as close to home as possible.

My goal is that my website will soon become unnecessary because every hospital and clinic that cares for pregnant women will skillfully and compassionately provide perinatal palliative care when needed. Until then, my hope is that these books and my website will help at least one other parent feel more empowered and less alone.

Amy Kuebelbeck is editor and founder of the website perinatalhospice.org, a clearinghouse of information for parents and caregivers. She 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) and author of the memoir Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life (Loyola Press, 2003). She has been invited to speak at numerous medical conferences across the U.S. and elsewhere. She also moderates a perinatal hospice email group for caregivers, which currently has more than 400 members. She lives in St. Paul, Minnesota, and can be reached at info@perinatalhospice.org.

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6. See Media Coverage at http://www.perinatalhospice.org/media-coverage.html.
7. See the work of Share Pregnancy & Infant Loss Support http://nationalshare.org, founded in 1977, and Resolve Through Sharing Bereavement Services at Gundersen Health System http://www.gundersenhealth.org/resolve-through-sharing/, which has been providing bereavement education to medical professionals since 1981.
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