

PERINATAL AND NEONATAL PALLIATIVE AND HOSPICE CARE

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Issue #70 | February 2023

Issue Topic: Perinatal and Neonatal Palliative and Hospice Care

Welcome to the 70th issue of our Pediatric e-Journal. In this issue, we focus on perinatal and neonatal palliative and hospice care. Our goal is to explore how and why perinatal and neonatal palliative and hospice care have spun off from the broader scope of pediatric palliative and hospice care. We want to show what is distinctive of perinatal and neonatal care in this field, as well as how they extend the more general principles of pediatric palliative and hospice care.

How can all obstetric and newborn services incorporate perinatal/neonatal palliative care principles? What are the advantages for palliative and hospice care programs of developing involvements in perinatal and neonatal care? What would be involved in a pediatric palliative and hospice care program doing so? Why is that extension of care desirable and even necessary?

The descriptions of perinatal and neonatal palliative and hospice care programs in this issue answer these questions. Those answers are also supported by the voices of parents who have been served by perinatal and neonatal palliative and hospice care programs, and by the history of the growth of such programs.

We do not expect that a single issue of our e-Journal will cover every possible aspect of this emerging field, but we hope to stimulate discussion on at least some of its major dimensions—and perhaps also to bring to readers' attention some of its lesser-known aspects.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Hospice and Palliative Care Organization. The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Suzanne Toce. Chuck Corr is our Senior Editor. Archived issues of this publication are available at <https://www.nhpc.org/palliativecare/pediatrics/>

Comments about the activities of NHPCO's Pediatric Advisory Council, its e-Journal Workgroup, or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. We are currently discussing topics for future issues in 2023 like pediatric palliative care education and training for PPC providers and programs, education and resources for adult hospice programs that are asked to care for a child, and multidisciplinary approaches to pediatric symptom management. If you have any thoughts about these or any other topics, contributors, or future issues, please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the NHPCO Pediatric Council, or the National Hospice and Palliative Care Organization.

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Heath Ditucci

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This poem is a lament on the death of a child for whom, "We never got to bring you home."

Helping through the Hurt

Jade Tarr, Aaron's mother

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This mother was awaiting the birth of her third child when she learned that this unborn boy had Trisomy 13 and might not live to be born or might not be expected to survive after birth. She and her entire family were understandably shocked and confused. A palliative care team, along with their natural support networks and other trisomy families, provided support and guidance. The author suggests lessons for other families facing similar challenges and for the medical professionals who serve such families.

The Story of the Comfort Cub

Marcella Johnson, Baby George's mother

p. 5

This author writes: "In 1999, when I was six months pregnant, I found out that my sweet baby boy had a life-limiting disease called Osteogenesis Imperfecta Type II. Needless to say my husband and I were devastated." Help came from the Early Intervention Program at San Diego Hospice, an innovative perinatal palliative hospice care program. When she later visited her son's grave with a persistent deep ache in her arms and chest, her Dad suggested she take hold of a terracotta pot that he gave her. Surprisingly, feeling the weight of the pot brought solace and comfort. Thinking about this and about the stuffed animals that friends had brought to baby George's funeral helped Marcella think to herself, "What about creating a weighted teddy bear about the size and weight of a newborn baby?" This led to the development of The Comfort Cub Program now implemented widely in hospitals and other situations to combat empty arm syndrome.

Insights Gained from Stories of Pregnancy Loss: Celebrity Moms in Their Own Words

Ann Fitzsimons, BS, MBA

p. 8

We often think that celebrities are privileged to live wonderful lives that do not share the many problems faced by other ordinary people. In this article, we learn that "the lived experience of losing a baby to miscarriage or stillbirth unites all these women in an unspoken bond that transcends titles, income, and notoriety (or the lack thereof), through heartbreak, and eventually healing." The article identifies many common themes in the experiences shared by celebrity mothers both with each other and with other mothers who have experienced the death of a child shortly before or immediately after birth. "What is different, however, about a celebrity mom losing a baby during pregnancy is that often it plays out on a very public stage which can further complicate how they deal with and process their grief." Even though formal programs of perinatal palliative/hospice care are not seen in comments from these celebrity mothers, "it's clear from these quotes that the principles of perinatal palliative and hospice care were absolutely being operationalized."

Identifying and Addressing Factors Contributing to Perinatal and Infant Losses to improve the PPC/Hospice Care We Deliver to Our Racial/Ethnic Families

p. 13

Ann Fitzsimons, BS, MBA, and Christy Torkildson, PhD, RN, PHN, FPCN, HEC-C

This article explores some of the many factors that affect the perinatal and infant loss experiences of mothers and families that are less privileged economically and socially than the celebrity moms examined in the preceding article. The authors note that, "while not perinatal specific, there also appear to be underlying differences and disparities in pediatric and palliative end-of-life care, with poverty, socioeconomic status, social class, and family structure as some of the broader contextual influences that may be contributing to these disparities." The authors review social determinants of health care, together with "awareness of/familiarity with/understanding of hospice," that may be significant variables in the experiences of these families, and they close with a series of suggestions about "what can, and should, we do in perinatal (and even more broadly, pediatric) palliative and hospice care to address these racial/ethnic disparities so that all of our families who experience a perinatal baby or pediatric child loss receive the equitable and compassionate care they so deserve during and after these losses."

The Impact of Pregnancy or Infant Loss and How to Help

p. 17

Rose Carlson, Share Pregnancy and Infant Loss Support, Inc.

"For many families, the moment they receive a positive pregnancy test is a defining moment that changes their life forever...Another defining moment occurs when excitement changes to shock with the news that the baby has died or has a life-limiting diagnosis." This article describes three typical needs parents generally have when they lose a baby: "They want others to realize what a tremendous impact the loss of their beloved baby has had on them"; "They need to be given permission to experience and express all their feelings of grief"; "They worry that others will forget their baby, especially if they have a subsequent child." Under each of these headings, this article offers a list of ideas as to how others can help.

Perinatal Palliative Care: Past, Present, and Future

p. 20

Amy Kuebelbeck, Gabriel's mother and Editor, www.perinatalhospice.org

Drawing on both her personal experiences of coping with the death of a child and on her professional involvements, this author describes the origins and history of the development of perinatal palliative care programs, how such programs stand today, and her vision for such programs in the future. She argues that, "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."

Perinatal Palliative Care = Good Care

p. 24

Suzanne S. Toce, MD, FAAP

In this article, Dr. Toce writes: "As a neonatologist, over the decades in practice I have integrated perinatal palliative care (PnPC) principles into the routine care of the fetuses with potentially life-limited conditions, newborns in the neonatal intensive care unit (NICU), and their families under my care." She identifies and explains who would benefit from perinatal palliative care, describes "What strategies might support inclusion of a PnPC mind set when caring for fetuses, babies, and families?", and concludes that, "The key is to normalize the universal concepts and practice of perinatal palliative care principles into the prenatal and postnatal conversations with the parents and the care of the newborn. Perinatal palliative care is simply good care!"

Perinatal Palliative Care: Prenatal Diagnosis of Lethal Condition

p. 26

Marilyn A. Fisher, MD, MS

"An especially challenging situation facing the palliative care provider occurs when the beginning of life may also be the end of life. This is the situation confronting a perinatal palliative care professional." In the particular case described in this article, there was a lack of amniotic fluid around the fetus. As a result, the "female fetus had a compressed chest and low lung volume, consistent with lethal pulmonary hypoplasia. We prepared Ms. Smyth, her partner, and their older child for the imminent death of the baby, who would be named Natalie, in the delivery room." Readers will be interested and surprised to learn the outcome of this case.

Perinatal Palliative Care: A Cohort Showing Equity, Family Experiences, and Outcomes

p. 29

Cara Buskmiller, MD MS, Maia Austin, MS II, and Pranuthi Gadde, MS II

"This article describes a retrospective cohort study of perinatal palliative care families in Houston, Texas, to lay out the current state of perinatal palliative care in a large medical center attached to a fetal therapy program." Reflecting on experiences with 187 families divided into two groups (no intervention vs. any intervention), the authors conclude that, "Prenatal life-limiting diagnoses involve at least two people—the fetus(es) and the pregnant woman—and often deeply impact the whole family. This study showed that perinatal palliative care can be offered equitably in a high-volume center, demonstrates that PPC can offer parents an experience that matches their choices about carrying and delivering their child, and advocates that interventions can be appropriate for some families, even interventions like C-section and parts of neonatal resuscitation. Perinatal palliative care is an important option that should be available to families with life-limiting fetal diagnoses because it addresses the unique family dynamics of a tragic situation while caring for social and psychological health."

Perinatal Palliative Care within a Multispecialty Fetal Care Center: Providing a Space for Active Parenting through Longitudinal Decision-Making Support

p. 33

Amy B. Schlegel, MD, MS

Here, the author draws on her experiences with an interdisciplinary perinatal palliative care team in a large children's hospital to argue that, "Including Perinatal Palliative Care specialists within multispecialty centers providing fetal evaluations and interventions allows expectant parents to benefit from inclusion of Palliative Care skills in their comprehensive care. Expertise in communication around exploring goals of care, engaging in shared decision-making, and navigating a parental role in the face of uncertainty or medical complexity strikes an important balance with diagnostic expertise and explanations of medical intervention regularly encountered by families facing complex fetal diagnoses." She describes the team, its referral processes, its interdisciplinary structure, and the way it provides longitudinal perinatal palliative care.

Perinatal Palliative Care as a Bridge Between Participants in Complex Medical Cases

p. 37

Cheri B. Salazar, RN, MS, CPNP-PC/AC, CHPPN, Elyse Hansen M.Ed., and Mariam Diskina, MD

This article describes the role of a perinatal palliative care team in a pregnancy in which the mother was "carrying diamniotic dichorionic identical twin boys. This pregnancy was complicated by premature rupture of membranes of twin B at 13 weeks' gestation, which resulted in anhydramnios and was expected to lead to lethal pulmonary hypoplasia." In addition, "This case was further complicated by the father's diagnosis of stage 4 hepatocellular carcinoma" (and his death at a later stage in the process), the presence of an older child at home, and because these events occurred during the COVID-19 pandemic. After describing the challenging events that occurred in this case, the authors conclude that, "It is the role of the palliative care team to integrate the wishes of the parents with the best interests of their child and family with the medical recommendations such that a cohesive, maximally values-aligned plan is made."

A Role for Community Hospitals in Providing Perinatal Palliative Care

p. 41

Tammy Ruiz Ziegler, MA, BSN, RN, CPLC

The author of this article argues that, "When extensive prenatal assessment indicates the infant will clearly not benefit from aggressive treatments and parents have chosen comfort care, community hospitals may provide care for these babies and their families in programs with comprehensive, individualized palliative care closer to their home." She provides evidence that, "Locally delivered PnPC [perinatal palliative care] can be developed with the assistance of already-existing training materials and resources, be customized to the needs of individual families, and be provided to families at minimal cost. The cohort of potential patients may be small, but PnPC in their community may be the best setting for these infants and their families." Advantages of community hospitals in this field are described, together with how community hospitals might work together with referral hospitals to provide excellent care, and what might be useful in planning for perinatal palliative care at a community hospital.

Heartbeat Recordings in the NICU

p. 46

Elisabeth Bombell, MT-BC

"Infants admitted to the NICU are medically fragile and sensitive to their unfamiliar environment, sometimes due to surgical and complex diagnoses in addition to prematurity. For families, any interventions such as heartbeat recordings that promote engagement and connection are welcome as they grasp for opportunities to know and to be known by their baby. Heartbeat recordings can be an integral component of perinatal palliative care and fetal/neonatal recordings can be part of memory making in case of neonatal death." This article explains what a heartbeat recording is, shows why it might be offered, describes the role of a music therapist in the process, and acknowledges potential limitations in this procedure.

Neonatal Pharmacokinetic Considerations in Symptom Management

p. 50

Melissa Hunt, PharmD, BCPPS

This author writes that, "The neonatal period (first 4 weeks of life) represents a time of rapid change, development, and risk. With advances in medical technology, infants are surviving that would not otherwise, increasing the need for palliative care in this population...Managing symptoms in the population can be especially challenging." She then goes on to discuss common symptoms, assessment, non-pharmacological therapies, pharmacology, pharmacokinetics, absorption, distribution, metabolism, and elimination, to conclude that, "Utilizing some of the above principles can help guide thought processes. As always, managing symptoms in neonates should be patient specific."

Readers' Corner Articles

p. 55

Suzanne S. Toce, MD, FAAP

In this issue, Dr. Toce provides three Readers' Corner articles, each providing a brief summary and discussion of the value of the publication under discussion. They are:

1. *Handbook of Perinatal and Neonatal Palliative Care: A Guide for Nurses, Physicians, and Other Health Professionals* (2020) by Limbo, Wool, and Carter ("you NEED this book now")
2. New Guiding Principles in Response to Dobbs vs. Janson and Related Issues, from the National Coalition for Hospice and Palliative Care and National Pediatric Palliative Care Task Force
3. *Perinatal Palliative Care: A Resolve Through Sharing Position Statement* (2022), an update of the previous 2009 and 2016 position statements of this well-established organization focused on perinatal bereavement

Items of Interest

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My Little Piece of Art

By Heath Ditucci

Is it wrong
My little song
Your resting tomb
Within the womb
Is it wrong
My little piece of art
That in her drink
You did depart
Is it ok
My flesh and bone
We never got to bring you home
Your mothers voice
Your mothers words
The last sweet lullaby
You felt and heard
Your final place of rest
Below her heart
Her heaving chest
That aches with sorrow
For tomorrow
When she rises from her sleep
For another we couldn't keep

Helping Through the Hurt

Jade Tarr

Aaron's Mother

jadie_lyn_8@hotmail.com

My name is Jade Tarr. I am a wife, teacher, and Mom to 4 beautiful children. I want to share my family's journey with our son, Aaron, who was diagnosed with a genetic disorder called Trisomy 13 (Patau Syndrome). My hope in sharing our journey with you is to spread awareness, to help newly diagnosed families feel supported, and to guide healthcare professionals to better understand how they can help families like mine through clear communication, fostering a genuine relationship, and truly hearing the family's goals of care for their child.

It was Monday morning. We had just spent the weekend celebrating our youngest's 3rd birthday and sharing the news that baby number 3 was another boy. What were we going to do in a house of 3 boys! As I was in class preparing for the day, I joked with the educational assistant asking if there were support groups and she reassured me that her 3 boys had made it to adulthood. My phone rang a few minutes later and I quickly went to the hallway to answer it. It was my family doctor telling me that my 20-week scan had come back with multiple concerns. He said, "Jade it doesn't look good. I don't think your baby is going to survive." I'm not even sure how the rest of the conversation went but I hung up the phone and collapsed to the floor crying. How could this be? We had just had such an amazing weekend. Our boys were so excited to be big brothers. I had to tell my husband. I had to leave. My mind was racing when our vice-principal came around the corner and ran to help me off the floor. Before I knew it, I was home walking into our house trying to figure out how I was supposed to shatter my husband's world and tell him what the doctor had just told me.

The next days and weeks were a whirlwind of emotions, questions and, confusion. How could this be happening? What did this mean for our family? Our doctor had called us back and went over the information again with the understanding that I had probably been in shock when he called the first time. It still did not feel real. How? Why? Are you sure? We had a geneticist call us in the days following and she confirmed what our family doctor had warned; with multiple concerns affecting different systems of the body, it was most likely caused by a genetic condition. She described the different tests available, and we decided to do amniocentesis. She suggested that if it was a genetic disorder, we should terminate the pregnancy and that we could always try again for a healthy baby. Using phrases like "incompatible with life" and "no quality of life," we were left with little hope.

Our heads were spinning, and we were nowhere near ready to make such an important decision. A few days later, we received confirmation of the news we were dreading; our baby had Trisomy 13. Trisomy 13 is characterized by three copies of the 13th chromosome in most or all of the body's cells. Many affected fetuses die before birth, and about half of babies born alive die during the first weeks. Some of the characteristics associated with this condition include severe intellectual disability, heart defects, brain and spinal cord abnormalities, cleft lip, cleft palate, extra finger or toes, and poorly developed eyes. Most sources state that only 5-10 percent of these children survive to their first birthdays.

Receiving a life-limiting diagnosis is heartbreaking. The whirlwind of appointments, decisions, grief, and stress puts an immense amount of strain on families. The first piece of advice I would give to newly diagnosed families is to find support systems. For us this was our family, friends, church community, palliative care team, and finding online support groups of other trisomy families.

Shortly after diagnosis, our palliative team provided us with information on this disorder and resources for how to talk to our boys about death and losing a sibling. This team became our contact and was the voice between us and

the many medical specialists who would eventually care for Aaron. They booked appointments, held conference calls, and helped communicate our desires to all those involved. They explained the medical challenges that Aaron was likely to face. When it came to the end of Aaron's life, this team helped ensure that our boys could meet their brother. They helped us navigate hospital restrictions during COVID and connected us with a grief counselor who made suggestions of ways we could remember Aaron.

Since the diagnosis, our connection with other trisomy families has been our biggest blessing. From Diagnosis to Delivery is one of these wonderful Facebook groups where I found so much support. It allowed me to connect with other parents who understood what we were going through, it gave me hope and an accurate picture of what the reality is for trisomy families. It provided support free of judgment no matter what level of care we chose for our son. It showed me what life could be like for a family with a child who survived, hearing of those who were thriving with this same diagnosis. It let me hear words of wisdom from families who had lost their babies in the womb and those like Aaron who were born and lived a short time. It is a place where families shared their knowledge of medical procedures, where you could get support, ask questions, and be warned about common difficulties you may face. They provide families with shared documents such as a variety of birth plans and even Trisomy specific growth charts that can be shared with your own care team. These groups connected me with other families in my area and other families whose babies or children had similar medical concerns to Aaron's. Having firsthand knowledge, suggestions, and support from families that were going through or had gone through similar situations was more valuable than any Google search.

My final suggestion for families is to remember is that it is okay to grieve and process this diagnosis differently. My husband chose to grieve privately while I processed our journey by sharing publicly through making our own Facebook page to document our journey. This helped me to keep everyone updated without having to have the same conversation multiple times. It made in-person conversations easier and helped people know how they could support us. This diagnosis often means being put in the position where you must make many life-altering decisions. At times, my husband and I had differing views and had to work through our decisions. It is important that each family member is given the opportunity to communicate what feels right to them. Every child and family are different, so take the time you need, ask as many questions as you need to, and ask those questions as many times as you have to. If you feel you need a second medical opinion or need a different doctor or specialist that is supportive of you and your child, do not be afraid to communicate this to your team. It is okay to take extra time to make decisions or to process the information that you were given. There is no right way to grieve. Allow yourself the grace to know that you are doing what you feel is best for you and your family given the information you have.

What would I want medical professionals to know about working with families with a life-limiting diagnosis? That each family comes to you with different values, belief systems, and preferences, and it is important that you take the time to listen and make sure the family feels heard. I was questioned several times about why I would want certain interventions for my child. After Aaron was born, there were a lot of difficult medical decisions to be made. Our palliative care team had changed from the original team who helped us develop our goals from when we were first diagnosed. As a result, we felt like we were standing alone. Once again, we had to recommunicate our goals of care and work on establishing a new relationship. All this during occurred a time when we were navigating new information and wanting to spend precious moments with our son. At the end of Aaron's life, when the most difficult choices had to be made, members of our team who did not take the time to get to know us began to tell us what we should do rather than listening to our wishes. Thankfully, we had a nurse in the NICU who made a world of difference. In her few shifts with our family, she listened to our hopes and goals for Aaron's care. Even with difficult news, she communicated clearly and was honest with us when explaining the different choices we had and the ramifications that were involved with each choice. She truly wanted the best for our son and we finally felt like we had someone who was on our team. Her connection to our family made all the difference.

Finally, what I would like medical teams to understand is that these families are coming into your care at a time when they have been devastated with the loss of the hopes and dreams they had for this child. They are coming to you with raw emotions, and they need your utmost compassion and care. We beg you not to make assumptions simply based on the diagnosis, but to communicate clearly with families to understand the care they want for their

child. In those difficult moments families shouldn't be fighting for care but rather should be given grace to make the decisions that they feel honor their child and their beliefs.

I am writing this in hopes of bringing change and lessening the burden on the next wave of families who find themselves navigating this journey. I dream of a relationship between medical care teams and families that will make facing these gut-wrenching decisions easier and that parents are connected early to resources such as other families who have walked this path. I hope that medical teams will better acknowledge the joy and love that these children can bring to families, and that they not only follow families through the birth and first few months but also follow up with children who do make milestones and thrive so that they can better inform the next family to come into their care. I hope that the research will expand to investigate the care that helps these babies thrive and that updated statistics and data would be easily accessible to our medical teams. Ultimately, receiving a life-limiting diagnosis such as Trisomy 13 is the most stressful and devastating moments of these families' lives and the support, knowledge, and relationship with their care team and medical professionals can make a world of difference.

The Story of the Comfort Cub



Marcella Johnson

Baby George's mother

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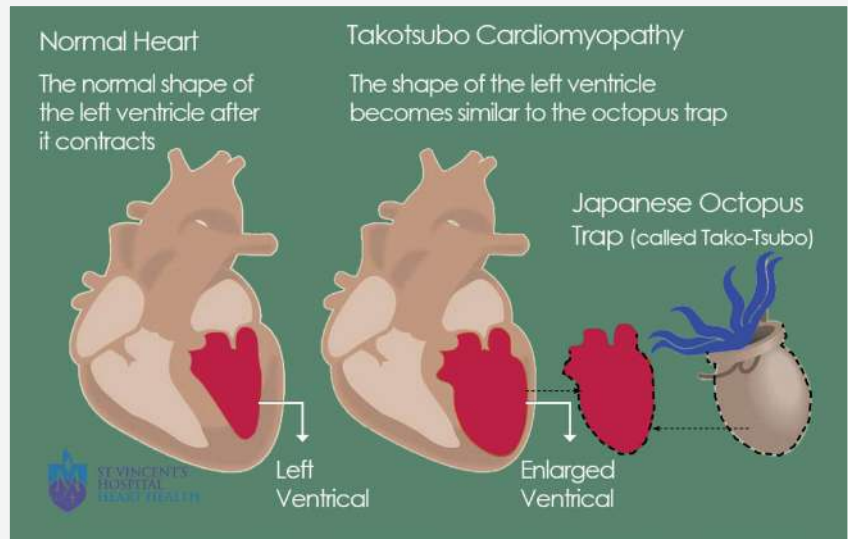
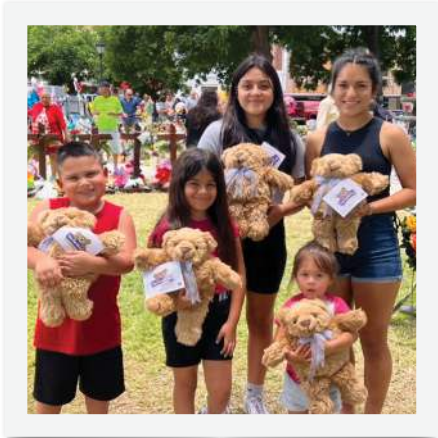
In 1999, when I was six months pregnant, I found out that my sweet baby boy had a life-limiting disease called Osteogenesis Imperfecta Type II. Needless to say my husband and I were devastated. After receiving the diagnosis, a genetics counselor suggested that we call San Diego Hospice as they had a new program that might be able to help us. My husband and I were among the first parents to enter a perinatal palliative hospice program in the United States. It was called "The Early Intervention Program."

Making that call was very difficult. To actually say the words out loud that my baby was going to die was almost more than I could bear. I remember breaking down in tears just trying to get the sentence out. The love and compassion that I received on the other end of the line by the Director, Liz Sumner, is something I will never forget. Her kindness, reassurance, and care were my first inklings that maybe there was some hope and that I wouldn't have to take this journey alone. The road was not easy, but with the guidance of my hospice team, my family and I were able to do the best we possibly could. Putting together a birthing plan was the single most helpful tool for me. It gave me some control in a very difficult situation where I felt I had no control at all. Our regular meetings helped us navigate our way through and taught us how to prepare our other three children ages 2-6 for the impending birth and death of their baby brother.

Even with all the excellent care, I was not prepared for the deep emotional sorrow I felt and the unusual physical symptoms I was experiencing. My arms were aching and the pain in my chest and heart wouldn't go away. My doctors had no explanation as to why this was happening. I was told the pain would eventually go away. That was not very comforting for me to hear and I figured I'd just have to live through it. But the pain persisted and the only thing that made me feel better was to put pressure over my heart as though to stop the bleeding of an open wound.

About a week or so after my son's funeral, I found myself wanting to go visit him at the cemetery. However, I was in a particularly dark place and I did not want to be alone. I called my Dad and asked him if he would meet me there. When I arrived, my Dad was already at the cemetery. He was holding a beautiful terracotta pot of flowers that someone had recently sent to the gravesite. I still had that persistent deep aching in my arms and chest. I was basically feeling awful. My Dad suggested I take this lovely flower pot home but I could have cared less. I had no interest in anything at that point. The trouble was that he would not stop talking about how nice it would be to have the flowers at home to lift my spirits. In order to get him to stop talking, I reluctantly took the flower pot from him. Much to my surprise, the moment I got the weight of that flower pot in my arms, I felt the aching in my heart and in my arms immediately go away! It made a significant difference in how I was feeling. I wanted to say something to my Dad about it, but it just seemed so odd. I found myself not wanting to put the flower pot down when I got home. So, I carried it around the house in my arms for the rest of the day. I thought I had lost my mind!

In an effort to expedite my grieving, I tried to read every book, article, and pamphlet available about the loss of a child. I learned that it was not uncommon for women who lost a child to seek out weighted objects to hold in order to relieve the pain and void in their arms. I thought that something weighted should be created to be given to mothers who have lost a child to help alleviate their extraordinary pain. I also felt it should be given to the mother before she left the hospital, because having to leave the hospital empty-handed was one of the most excruciating



moments of my life. I felt inspired to try to help other women who were experiencing this same great loss. I wasn't sure how I would do it, but I knew something needed to be done.

At the funeral, all of our friends brought stuffed animals to donate to our local Children's Hospital in honor of my son. At home, I still had a big pile of stuffed animals to deliver. I saw a Beanie Baby at the top of the pile. That's when I thought to myself, "What about creating a weighted teddy bear about the size and weight of a newborn baby?" The idea of creating

a stuffed animal appealed to me because it was something that a woman might already have in her home, yet its therapeutic value would only be known to her privately. In the privacy of her home, she could name it, pick it up, hug it, dress it up, cuddle or sing to it, whatever brought her comfort.

I set out to make my first weighted teddy bear prototype. I filled it with split peas to give it weight. Then I brought it to my social worker, Jennifer Smerican, at San Diego Hospice to see what she thought of the idea. She thought it was great and asked me if I could make several more. I then went to the hospital where I delivered my baby and asked my social worker, Karen Anderson, what she thought of the idea. She wholeheartedly liked the concept, too. The word about this therapeutic teddy bear started to spread. I could no longer keep up with the demand by making the bears by hand. The Comfort Cub is now professionally manufactured and no longer made with split peas, as we realized if they got wet, they would sprout!

The Comfort Cub Program became a non-profit organization in 2015. Interest in The Comfort Cub continued to grow to all of the hospitals in San Diego and, now in our 24th year, The Comfort Cub is used at top hospitals all across America. We now know that the pain I was experiencing in my heart was due to stress induced cardiomyopathy. This is also called Broken Heart Syndrome and can be brought on by extreme grief. The pain I was experiencing in my arms after the loss of my child is called Empty Arm Syndrome. This is when your arms are literally aching to hold your child. We also learned why the weight of The Comfort Cub helps to provide comfort and alleviate pain. It is called "Deep Touch Pressure Stimulation" (DTPS). DTPS is firm, gentle pressure that is applied to the body relaxing the nervous system. This therapy creates an overall sense of calm and well-being by releasing the neurotransmitters serotonin, dopamine, and oxytocin when pressure is applied. It works similar to the science of a weighted blanket. Once we understood that The Comfort Cub could help in any situation where the body needs to be calmed, we started to branch out into other areas.

Although it was originally created for mothers who lost a child, The Comfort Cub is now being used to provide relief for the loss of any loved one, trauma, mental wellness, autism therapy, and any situation where someone is experiencing a broken heart. We have also helped with healing after tragedies such as Sandy Hook and the Las Vegas Route 91 shooting. We most recently provided over 1,000 Comfort Cubs to the victim's families, elementary school children, teachers, staff, community members, and first responders in Uvalde, Texas. Our current focus is on helping with mental health issues brought on by the ripple effects of COVID-19 in school children K-12th grade.

We are always looking for new ways to put The Comfort Cub to good use. Let us know if you are aware of an area you feel could benefit from the use of The Comfort Cub. Please contact our Program Manager, Janice Dillard at Janice@thecomfortcub.org.

On a personal note:

My deepest thanks to all of you who work in the field of hospice care. You are a very special group of human beings. You're like first responders who run in when the rest of the world is running away from something they find too difficult to deal with. Not everyone is willing, nor has the talent to do this important and difficult work.

Thank you for helping to save my life, my family, and my marriage. Losing my son, Baby George, was the lowest point in my life. If it were not for my compassionate hospice team (Director, Liz Sumner, Chaplin, Josie Rodriguez, Nurse, Lisa Newby, and Social Worker, Jennifer Smerican) I'm not sure this story would ever be told.

Insights Gained from Stories of Pregnancy Loss: Celebrity Moms in their Own Words

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"Perhaps the path to healing begins with three simple words: 'Are you OK?'"

Megan Markle, Duchess of Sussex

Whether a Duchess, a Hollywood actress, a Royal, a British TV Personality, a Country or Pop Singer, a President's wife, or a loving, every-day, non-celebrity Mom, the lived experience of losing a baby to miscarriage or stillbirth unites all these women in an unspoken bond that transcends titles, income, and notoriety (or the lack thereof), through heartbreak, and eventually healing.

For a subject that has been silent, and in many ways, "taboo" to talk about for so long presumably due to the stigma and shame associated with it, celebrity moms have only recently begun to speak out and share their baby losses with the world in the hopes of helping other moms who suffer the same fate realize they are not alone, that they can get through this, and that there is life on the other side of this loss. However, this is not to say that the baby losses of celebrity moms are somehow more important than the many babies lost to moms not known on a national or international stage. In fact, when the celebrity is stripped away, these stories are simply moms who experienced what so many other women do each year, but who don't have a platform to share their lessons from these experiences. A review of some celebrity stories on losing babies to miscarriage or still birth highlights that at the core of these experiences, all of these moms—celebrity and non-celebrity—are more alike than different, and that the insights gained around what losing their baby was like are universal.

Common Themes Expressed in their Baby Loss Experiences

In reviewing several news and magazine articles in which celebrity moms speak about their miscarriages, stillbirths or other pregnancy losses, several themes emerge. While these are not new, to hear the raw pain, guilt, isolation, anger, regret, and myriad of other feelings expressed by these Moms in their own words, are a poignant reminder of how much work the field still has to do to support the moms, dads, and siblings who experience the loss of a baby during pregnancy.

These themes include:

- **The loss of a baby during pregnancy (or any child) is one of/maybe THE most heartbreaking loss a family can suffer, AND they often suffer in silence**
 - "Paul and I were heartbroken, but I knew it was common. I just thought, 'This wasn't meant to be.'" (when she miscarried at 10 weeks), Christina Perri (American singer/songwriter)
 - "You don't talk about it because it's too raw," Zara Tindall (Queen Elizabeth's granddaughter)
- **A mother's intuition or premonition that something "is not right" with the baby is often accurate and needs to be heard, listened to, and medically-addressed**
 - "I felt a sharp cramp...and my sense was that something was not right. I knew as I clutched my first child, that I was losing my second," Megan Markle (Duchess of Sussex)
 - "I remember waking up and thinking I hadn't felt my baby kick for most of the night which was unusual because he was so active...I tried all the things they tell you to do, but he wasn't moving, so I drove myself to the hospital at 7 months pregnant." Amanda Holden (British TV personality)
 - "I was home and I realized I hadn't felt the baby move. After that, everything happened in slow motion" as the couple rushed to the hospital where doctors couldn't find a heartbeat, Christina Perri
- **How the experience and loss is different for their husbands/partners than it is for them**
 - "It's hard for the guys, it's a different feeling of loss, isn't it?", Tara Zindall
 - Megan Markle, in an Opinion Piece for the New York Times, wrote after her miscarriage that she watched her husband's Harry's "heart break as he tried to hold the shattered pieces of mine" as they both grieved their baby, the same, but differently.
 - "Just as the baby was going to come out, my husband Chris had to leave the room, he couldn't bear it," Amanda Holden
 - "Chris was terribly British about it, went once [to therapy] and was like, 'Right, I'm cured', whereas I continued to go," Amanda Holden
- **Anger, sadness, guilt, loss of control to being alone/isolationism, and so many more are common feelings experienced by these moms during/after the loss of their baby during pregnancy**
 - "There was so much anger, pain and sadness," Christina Perri
 - "Losing a child means carrying an almost unbearable grief, experienced by many, but talked about by few. In the pain of our loss, my husband and I discovered that in a room of 100 women, 10 to 20 of them have suffered from miscarriage. Yet despite the staggering commonality of this pain, the conversation remains taboo, riddled with (unwarranted) shame, and perpetuating a cycle of solidarity mourning," Megan Markle
 - "It reminded me that I can't be in control of everything," Carrie Underwood (American country singer)
- **The words and actions of healthcare professionals during this experience matter so much in how the mom/parents will fare after the baby dies**
 - "I was made to feel like a 'game show contestant' when a doctor told me that I was 'going home empty-handed' after my stillbirth," Amanda Holden
- **Moms also often blame themselves, thinking they did something wrong.**
 - "I just felt like everything was my fault, and I felt so responsible—what did I do wrong? "I'd had a Filet-O-Fish from McDonald's the day before, and I panicked it was that or all kinds of things. I felt pretty neurotic. You really blame yourself," Amanda Holden
- **Some women feel they're somehow "less than" other women if they struggle with infertility, miscarriage, or stillbirth."**
 - "We sit in our own pain, thinking somehow we're broken," Michelle Obama (President Obama's wife)
- **Some keep thinking it can't/shouldn't be happening to them**
 - "It's not something you ever envision yourself having to deal with," Carrie Underwood

■ Shock and disbelief are common reactions when parents are first told their baby has died

- "The midwife said to an obstetrician going by, 'Can you please go in. I can't hear the baby's heartbeat.' And then I heard this guttural screaming...I thought it was another person making the noise," Amanda Holden
- "It was so shocking [when they learned at 30 weeks that their baby had a rare type of bowel obstruction and would require surgery at birth], Christina Perri

■ They go from "celebrating" to "crying devastating tears" in no time once they're told the baby has died.

- "I heard the heartbeat, which was the most beautiful music I ever heard in my life," Beyonce said in an HBO documentary, but then at her next appointment, the baby didn't have a heartbeat.
- "They told me, 'It's a girl, and she's born silent,' and we just started crying hysterically," Christina Perri

■ Pregnancy loss just screams unfairness to parents

- The weeks after the loss "were a blur"...my milk came in—I had this postpartum body with no baby. That just felt so unfair," Christina Perri

What is different, however, about a celebrity mom losing a baby during pregnancy is that often it plays out on a very public stage which can further complicate how they deal with and process their grief. Zara Tindall, Queen Elizabeth's granddaughter, spoke about her first miscarriage experience in a London paper in 2018, in which she stated that the hardest part of this miscarriage was having to let the world know because news of the pregnancy had been made public. Zara said, "This one's not right. I had to go through having the baby because it was so far along." Carrie Underwood, Country Singer, commented, "I was falling apart on the inside, despite putting on a brave face for my family and fans."

Interventions During the Baby Loss (Perinatal Hospice)

While it may seem like these celebrity moms were not supported well during their pregnancy losses, we don't really know, as only one or two of these moms actually spoke about what kind of support they received and what memory-making/legacy activities they were offered or given. And while none of these moms called the types of interventions and comfort care that was provided to them "perinatal palliative care or hospice," it's clear from these quotes that the principles of perinatal palliative and hospice care were absolutely being operationalized:

Amanda Holden (TV British Personality)

- "We lost our baby Theo at 28 weeks, and they very sensitively moved me into another room so I could deliver him without having to hear the lovely babies screaming on a normal ward."
- Amanda was told she could take home some keepsakes of Theo. "Theo was put into a little room so his body could be preserved and we could go and see him as much or as little as we wanted."
- "Jackie (one of their nurses) talked to me about the keepsakes we could have, to remind ourselves of Theo forever. We got his footprints and a little bit of his hair and the blanket he was born in."
- "I kept saying, I can't hold a dead baby. I was absolutely terrified...Jackie (the nurse) wrapped him up and I said, 'Jackie, I can't do it. I can't hold him.' Jackie said, 'He's absolutely gorgeous, you need to see him.' That's when I held him, even though he was fast asleep. The one thing I remember is his perfectly formed eyebrows, which all my children have."
- "I personally would like to thank the nurses...Jacki Nash got me through so much..."

Christina Perri, a singer, also commented that, "Then we had time to hold her, meet her, and say goodbye."

What Has Helped Them

Chrissy Teigen, a model and wife of singer John Legend, commented one year after the loss of her son Jack mid-pregnancy that, "They (the hospital staff) told me it would get easier, but yeah, that hasn't started yet." However, these moms did get through their pregnancy loss in a variety of different ways, including remembering their child, getting support from others, seeking understanding through spiritual exploration, attending therapy, among others, as outlined below:

■ Continuing to remember their babies

- "Jack worked so hard to be a part of our little family, and he will be, forever." And, "We will always love you," Chrissy Teigen
- "There is not a day that goes by when I don't think about Theo, especially when a new school year begins," Amanda Holden
- "I don't know if Paul or I will ever not feel that longing for Rosie...but she will always be in my heart," Christina Perri
- "I guess you wait for things to stop hurting at some point. I will always mourn those children, those lives that were a shooting star, a breath of smoke...," Carrie Underwood

■ Support from/Talking to Others

- "Thank you to everyone who has been sending us positive energy, thoughts, and prayers. We feel all your love and truly appreciate you," Chrissy Teigen
- "I had too many people to talk to, talking to somebody is absolutely paramount," Amanda Holden

■ Embarking on spiritual journeys to find meaning to the loss

- Beyonce once commented that she had had several miscarriages and that after them, she said, "I began to search for deeper meaning when life began to teach me lessons I didn't know I needed."

■ Hypnotherapy

- "It was to help me believe in my body again, to give me the confidence I could have another baby, and do it all again...The sessions were about trying to make me have positive images about seeing a baby, and that it was going to happen. It really helped," Amanda Holden

■ Therapy/Counseling

- Christina Perri credits couples therapy for helping to heal her marriage which was impacted by her pregnancy losses, as she commented, "There was just so much darkness between us. I had to work really hard in including him in my grief."

■ Sharing Their Stories/Speaking their Truth

- "Some (moms) have bravely shared their stories; they have opened the door, knowing that when one person speaks truth, it gives license for all of us to do the same. We have learned that when people ask how any of us are doing, and when they really listen to the answer, with an open heart and mind, the load of grief often becomes lighter--for all of us. In being invited to share our pain, together we take the first steps toward healing," Megan Markle
- Despite her own personal heartache, Carrie Underwood confessed that sharing her pain publicly helped her feel like "a weight lifted" off her shoulders and that she wasn't alone. "It's not a dirty secret," she added. "It's something many women go through."

Finding Resolution & Using Their Notoriety to Help Other Moms

Christina Perri, singer, is quoted as having said after her daughter's stillbirth, "I turn my tragedy into something beautiful," and this is true for so many moms and dads after the loss of a baby or child in utero or after birth. They need to do something with all those hard and big feelings, and oftentimes, it's putting that energy into something that will help others who may have to experience a similar situation of losing a baby during pregnancy. Some work to fundraise

to find a cure or treatment for what killed their baby, others advocate for change so these losses don't occur at all, or so often, while still others become volunteers with organizations supporting these families.

A few examples of what some of these celebrity moms have done using their celebrity platforms include:

- Amanda Holden set up Theo's Hope, which raises and provides funds for a bereavement counselor at the hospital where she birthed her son.
- Christina Perri has, and continues to, petition the American College of Obstetricians and Gynecologists to change their screening protocol and offer more women screening for blood disorders, which if identified, could potentially be corrected to stave off some pregnancy losses caused by them. "After what I have been through, I will dedicate my life to helping other women. I truly believe that this is Rosie's purpose."

Reflection

There is no right or wrong way for parents to experience the loss of a baby through miscarriage, stillbirth, or some other natural loss. In researching for this article, it became clear some celebrity, and other moms, choose to share their stories of pregnancy loss, while others grieve in private. However, all need support at some point in this journey whether it's during or after the baby has died. While the field of perinatal palliative and hospice care has grown immensely in recent years, it's clear not all moms receive this care. So we all need to continue to work to raise awareness and educate on what it is and how to offer it to these families during and after the pregnancy loss. And sometimes, it may be something as simple as asking the mom who is losing/has lost a baby during pregnancy, "Are you OK?", which may be just the question needed to open the door to her sharing her experience and asking for what she and her family needs to become "whole" again on the other side of this loss.

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Identifying and Addressing Factors Contributing to Perinatal and Infant Losses to Improve the Ppc/Hospice Care We Deliver to our Racial/Ethnic Families

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It is well documented that infant mortality rates are higher, and in some cases, significantly higher, among non-Hispanic black (10.6 IMR per 1,000 live births) and Hispanic (5.0) babies when compared to non-Hispanic white (4.5) babies. This also holds among pre-term births; whereby non-Hispanic black women have a 2x higher risk for preterm birth vs. non-Hispanic white women. Also of concern is that this problem appears to be worsening. While preterm birth rates fell in the US from 2007-2014, this gap between non-Hispanic white and non-Hispanic black women increased during this period. As a result, racial disparity in pre-term births and infants under one year of age remains a public health concern in the United States. And while there has been research conducted into why this occurs, the reasons seemingly are poorly understood, although sociodemographic factors appear to be a factor in these deaths.

Relatedly, while not perinatal specific, there also appear to be underlying differences and disparities in pediatric and palliative end-of-life care, with poverty, socioeconomic status, social class, and family structure as some of the broader contextual influences that may be contributing to these disparities. However, there is not enough specific pediatric palliative/hospice care research currently available to fully understand the potential causes of these racial disparities in depth. A broader review of the literature available on causes for some of these racial disparities in infant deaths suggests that social determinants of health (SDOH) are a major contributor to these infant deaths and, as such, can help shed light on potential inequities in perinatal and pediatric palliative care and hospice as well. This research categorizes SDOH into economic stability, education, healthcare access and quality, neighborhood and built environment, and social and community context. A closer look at some of these factors suggests that:

- Experiencing racial abuse and racism are correlated with adverse health outcomes among racial/ethnic groups, with black individuals being more likely to experience elevated stress because of racial discrimination. Black families have an increase in adverse birth outcomes, and specifically low/very low birth weight and preterm delivery at a three-fold rate of other races/ethnicities.
- Not all racial/ethnic groups have any/adequate access to affordable healthcare insurance. This is especially true for American Indians and lower socio-economic non-Hispanic Blacks, depending on their geographic location. There are recent indicators that those enrolled in non-Medicaid expansion states have comparable rates of low birth weight and prematurity.

- Racial/ethnic groups also do not receive access to as high a level of quality of care as their white counterparts, as illustrated by one study showing that black families received the lowest quality of neonatal care in the NICU of any racial/ethnic group.
- Infants of non-white families who are socioeconomically disadvantaged and/or on public welfare have a lower level of family engagement in the NICU vs. white families, in terms of things like Kangaroo care, visitation, traditional holding, and infant massaging, all of which have been shown to have positive outcomes for NICU babies.
- Where families live (e.g., a higher proportion of black families living in poor urban/suburban environments) has been associated with higher infant mortality among the minority populations who may reside there.
- A lack of physicians and clinics/hospitals in their neighborhoods/communities, i.e., no close geographic access to them and a shortage of PCP's in many black residential areas also known as neighborhood deprivation, is often associated with an elevated risk of preterm birth, with this effect largest in non-Hispanic blacks
- A lower material education has also been shown to contribute to higher maternal and infant mortality rates.
- Some genetic variations in racial/ethnic groups can be/are associated with a higher incidence of preterm births.

A recent study from the National Hospice and Palliative Care Organization entitled *Hospice Through the DEI Lens* conducted among Blacks, Hispanics/Latinos, Whites, and LGBTQ populations helps to shed light on these racial/ethnic groups' awareness of/familiarity with/understanding of hospice. (Note: This study was not pediatric-specific.) Key findings from the study among these populations suggests that:

- Awareness of palliative care is not very high.
- Many are not knowledgeable about hospice (i.e., when is the right time to transition to, that care can be provided at home, that it is a Medicare benefit, etc.)
- Cultural, language, and sexual orientation differences are seen as key potential barriers to receiving respectful and non-judgmental care by hospice workers.
- Blacks (vs. Whites) are significantly more likely to want a religious or spiritual component to be part of the hospice experience, and they would be more comfortable with a hospice worker of their ethnicity.
- Hispanics/Latinos see language as a significant barrier for non-native English speakers, and more than half would need hospice workers who spoke the language of their loved one to feel comfortable. Written materials in English are also a barrier for them.

While these findings aren't specific to perinatal palliative/hospice care, a case can be made that some of these factors are also at play in providing PPC care to families experiencing the loss of a baby during pregnancy/birth or shortly thereafter. Working under this assumption, it raises the question of what can, and should, we do in perinatal (and even more broadly, pediatric) palliative and hospice care to address these racial/ethnic disparities so that all of our families who experience a perinatal baby or pediatric child loss receive the equitable and compassionate care they so deserve during and after these losses.

Implications from this brief literature review would suggest the following awareness of/familiarity with/understanding of hospice: **Consider the impact of systemic racism and how to counter it when offering and/or delivering perinatal/pediatric palliative and hospice care to racial/ethnic groups.**

- Do an internal check-in and become more self-aware of your own implicit or explicit biases, which could impact how you approach, interact with, and treat racial/ethnic families prenatally or perinatally when they are experiencing the loss of their baby.
- Help lobby and advocate for equitable access to health insurance and healthcare for racial/ethnic groups, including for Concurrent Care.
- Commit to volunteering for DEI initiatives that are working on improving policies, cultures, and quality of care practices in your hospices, hospitals, and in the community-at-large.
- Be part of helping to prioritize resource allocation at hospitals that serve racial/ethnic populations at higher risk for preterm and infant mortality.
- Look to and learn from models of care or community organizations who have had success at outcomes that have helped to reduce infant morbidities (e.g., California Perinatal Quality Care Collaborative) and/or who are working to improve preconception health, pregnancy health, and infant health to reduce preterm birth and IMR (Cradle Cincinnati, March of Dimes).

- Recognize that if Mom stays healthy(ier), then the baby has a better chance of delivering full term and healthy. PPC should also be addressing the maternal health of racial/ethnic groups in its holistic approach to caring for the whole family.
- In recruitment and hiring PPC staff, work to recruit a workforce representative of the patients and families you serve. Racial/ethnic families are likely to be more comfortable when being cared for/by people they feel an affinity with (i.e., same race/ethnicity).
- Encourage practices that promote more family engagement/contact with the baby, whether born alive or not, to help improve the outcomes for all of them.
- Examine your presence and coverage in neighborhoods deprived of PPCs/clinics/hospitals where infant mortality is known to be higher, in part, because of no close access to this care.
- Look at developing materials that are customized to racial/ethnic groups—that is, that are designed to be cognizant of their awareness/understanding (or lack thereof) of perinatal palliative/hospice care and that take into account their cultural and religious/spiritual beliefs as well, while addressing other barriers to hospice like language.

While there is no “one-size-fits-all” solution to closing the gap in racial/ethnic disparities for these potentially marginalized populations we serve in perinatal and pediatric palliative care and hospice, if we all work together to implement policies and practices that help to achieve health equity, no matter what a family’s racial/ethnic background, we will begin to improve the care these families deserve at a most vulnerable time of losing their baby. While we may not be able to take on all of these suggestions, even beginning to address them one at a time is a start, and we owe it to these racially and ethnically-diverse families to try.

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The Impact of Pregnancy or Infant Loss and How to Help

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For many families, the moment they receive a positive pregnancy test is a defining moment that changes their life forever. Their initial reactions may be anything from excitement to disbelief to worry. They may have wondered about the impact a new baby would have on their future.

Another defining moment occurs when excitement changes to shock with the news that the baby has died or has a life-limiting diagnosis. The loss of hopes and dreams the parents and other family members may have had can be emotionally and physically overwhelming, crippling even. The intense feelings and other reactions of grieving parents, no matter how far into the pregnancy the loss occurs, can come as a surprise not only to them but to their loved ones as this type of loss is frequently ignored and misunderstood by those who have not experienced it before.

While the impact and grief from a pregnancy or infant loss differ for everyone, there are several things parents and their families have in common, and there are ways to help if you are a caregiver or simply know someone who has gone through this tragic loss.

The following is not an exhaustive list but are a few of the needs parents who lose a baby generally have:

They want others to realize what a tremendous impact the loss of their beloved baby has had on them.

While bereaved families do often receive a great deal of caring love and support in the early days and weeks after their baby dies, that support sometimes quickly dwindles away. Research has shown not only that parents typically need more support than their family members and friends are willing and/or able to give them but also that friends and family members usually expect parents to grieve only for a short period of time and then return to normal. Unfortunately, this expected period is usually significantly less than what the grieving parent requires (Umphrey & Cacciatore, 2011). This can leave parents feeling alone, scared, and misunderstood. They may wonder, "Is something wrong with me because I am still grieving so deeply?" They often tell us they have changed and will never go back to being the person they were before, though that is what their loved ones typically expect when they say things like, "I just want my happy friend/daughter/sister back!"

How others can help:

- Simply acknowledging the tremendous impact this loss has had is sometimes the most important thing bereaved parents need.
- For many bereaved parents, the moment they discover they are pregnant, they think about the baby they are going to have, so be sensitive when talking to them as medical terms such as "fetus," "products of conception," and "spontaneous abortion" can be offensive to a parent who identifies their loss as a baby.

- Do not assume that because you see a bereaved parent smiling and enjoying life that they are now “over it.” Finding moments of joy is part of the process of moving forward, but it does not mean they have forgotten about their baby and are no longer sad and grieving.
- Do not say things such as, “You are young, you can have another baby,” or, “At least you have other children,” or “At least you were early in the pregnancy.” These statements dismiss the grief they are experiencing and make them feel judged as if something is wrong with them because they are grieving as deeply as they are. Anything that starts with the words “at least” should never be spoken to a grieving parent.
- Instead, validate what is happening to them. Sentiments such as, “I am so sorry for what you are going through,” or “I care and will support you however I can,” make them feel loved, cared for, and supported.
- Understand that if you ask a grieving person how you can help them, they may not know. Remember, this is a time of shock and disbelief for them. Rather than saying, “Let me know if I can help you,” be more specific in your offer of help and say things such as, “I would like to bring you dinner next week. What day would be good?” or, “Would you like me to take your son for a play date on Friday?”

They need to be given permission to experience and express all their feelings of grief.

We often think of grief as a linear process, but it is not; one does not go through steps or phases in a certain timeline. Parents can feel numerous emotions and other reactions to their losses at different times, including shock, numbness, denial, frustration, anger, jealousy, guilt, depression/anxiety, and more. The grieving person does not experience these reactions in any certain order or in stages; they may feel more than one at the same time. Also, certain occasions and dates can unexpectedly trigger a resurgence of fresh grief reactions and waves of emotions they thought they were finished with. Grief is complicated, and everyone grieves in his or her own way.

How others can help:

- Allow the parents to feel whatever they are feeling and experience whatever reactions they are experiencing at any given time. You may think they should have moved beyond certain feelings, but it is normal to have setbacks and times when emotions resurface.
- Recognize that partners often grieve and express that grief in different ways. One may want to talk more about the loss, while the other does not. One may become immersed in projects and work. Always encourage couples to openly communicate their feelings and needs with each other while informing them that grief may look different for each of them. Assure them this is okay.
- The loss of a child is a catastrophic event, so expect that you may see the grieving person behaving in ways that seem unusual for them. Know this is normal, and do not express any expectations you have of how you think they should be dealing with their loss.
- Do not expect a parent grieving the death of their baby to “get over it” and move on, no matter how long it has been. Grieving the death of a child, no matter the age of the child, is generally life-long, and parents appreciate knowing others recognize this (Cholette & Gephart, 2012). They will eventually find ways to move forward, but it takes time, and the amount of time is different for everyone.
- Do not take it personally if the grieving parent needs to withdraw for a time. Some parents want to surround themselves with their family and loved ones, but others want to keep close only to their partner and/or children. The holidays can be especially difficult times for bereaved parents, and while others may think that being around family and traditions will be helpful, it may not be what the grieving family needs or wants.

They worry that others will forget their baby, especially if they have a subsequent child.

Most grieving parents want to know that others miss and love their baby as much as they do. They want their baby to be remembered on his or her due date, birthdays, holidays, and other meaningful times. They worry that once they have another baby, everyone will assume they are no longer grieving the baby who died, but oftentimes, they grieve even more deeply for a period as they relive the trauma of the loss and realize all they missed out on with their baby who died.

How others can help:

- Say their baby's name. Ask them about their memories and experiences. You will not make the parents sad or remind them of their loss by bringing up their baby. Most bereaved parents appreciate knowing others still care for and love their baby, too.
- Follow their lead. If the parents organize events, parties, or ways to honor their baby, participate in them. Some parents ask others to do random acts of kindness or make donations to organizations on their baby's special days, and they appreciate when their loved ones join them.
- Know that it is common for parents to continue to find ways over the years to honor their baby who died. This does not mean they are "stuck in grief." It means they still miss their child and his or her place in the family. It means they want to honor the unbreakable bond of love they feel.
- Encourage them to honor their baby in whatever way they feel is healing and helpful.

Each year in the United States, 1 in 4 pregnancies ends in loss, 1 in 160 babies are born still, and there are 24,000 infant deaths. Chances are, everyone knows someone who has experienced this type of tragic loss, yet those who go through it often grieve in silence. At Share, we offer hope and encourage families to continue to honor the love and the bond they will always feel to their baby who died. Parents who have their grieving needs met have better healing outcomes and can experience prolonged grief disorder if their needs are not met (Lundorff et al., 2017). Share provides the space and care they need; this reassures them that they do not have to go through this loss alone.

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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.

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Perinatal Palliative Care = Good Care

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As a neonatologist, over the decades in practice I have integrated perinatal palliative care (PnPC) principles into the routine care of the fetuses with potentially life-limited conditions, newborns in the neonatal intensive care unit (NICU), and their families under my care.

Specifically, which of the fetuses, neonates, and families in the perinatal intensive care setting should be supported by PnPC? In other words, which of the above benefit from:

- Attention and management of pain and symptoms
- Psychosocial, emotional, and spiritual support of the family and loved ones
- Logistical support
- Decisional support, anticipatory guidance, and advance care planning frequently including a birth plan

The answer? **All of them!**

Consider the following examples of cases appropriate for PnPC that may present in the perinatal period:

- You are asked to provide antenatal consultation with Antonia and Joachin. In response to poor fetal growth, a genetic evaluation was done and confirmed a female fetus with Trisomy 18, a severe genetic condition with high infant mortality, often with congenital heart disease and other birth defects including microcephaly (a small brain). You collaborate with the parents and develop a contingency advance care plan, knowing that the plan may need to be adjusted after birth when additional information is available.
- Parents Andrea and Stefan are devastated when their newborn Paul is delivered at 36 weeks via urgent cesarean section and admitted to the NICU. Paul has hypoglycemia and poor feeding necessitating IV fluids and tube feedings. This was definitely NOT in their very detailed birth plan. They are grieving the loss of their hoped (and planned) for delivery experience and "perfect" baby.
- Baby Angela is a former 25 week gestation premie now 4 months old and still needing oxygen and monitoring for her oxygen level, heart rate, and respiratory rate. Her 17-year-old single mother, Amy, is having difficulties with the logistical requirements for Angela's imminent discharge.
- Cai is a 39-week Hmong boy transferred emergently with a likely lethal form of osteogenesis imperfecta. The congenital bone condition was not diagnosed antenatally as the mother was cared for by a traditional Hmong healer. In the Hmong culture, Cai's paternal grandfather is the decision maker. How do you care for this baby, support the parents and extended family, and negotiate a culturally competent care plan that minimizes the suffering of the baby and optimizes support for the family?

What strategies might support inclusion of a PnPC mind set when caring for fetuses, babies, and families?

- Normalize the concept of palliative care regardless of the goals of care. Be attentive to the principles of PnPC from the time of diagnosis of a potentially life-limiting condition.
- Routinely identify and manage pain and symptoms
 - Neonatal pain scores are available and should be regularly documented for all patients
 - Educate yourself about safe, effective management of neonatal pain and symptoms
 - Provide analgesia for painful procedures
 - Document identification and treatment of pain and symptoms in the chart

- Ensure emotional, psychosocial, and spiritual support for the parents and their support system.
 - Screen the families to identify their needs
 - Ensure access to a social worker, chaplain, and others as needed
 - Communicate in a respectful way. Using words such as "potentially life-limiting" or "life-threatening" is often preferred over "lethal."
 - In the event of an impending or actual fetal or neonatal death
 - Ensure access by parents, siblings, and other support people
 - Obtain mementoes, support legacy making
 - Inquire about organ/tissue donation
 - Determine care of the body and support funeral planning
 - Integrate bereavement services. Ensure follow up when a fetus or newborn dies.
- Logistical support – "Discharge planning begins at admission"
 - The social worker can screen for such post-discharge needs as housing, transportation, medications, breast pumping equipment, formula, medical equipment, and home health nursing
 - During the hospital stay, there may be needs for transportation, lodging, and meals
- Decisional support
 - Inform the decision makers (usually the parents) how decisions are made in the NICU. Our goal is to support the best interest of the baby.
 - Manage expectations. Describe the current problems, likely trajectories, and potential treatment options.
 - Be nimble. Plans are fluid and may change as new information becomes available and/or the baby's condition changes.
 - Inquire about how parents/decision-makers guide their preferences. What are their goals? Are there religious or cultural practices that need to be considered?
 - Support parents/decision makers in choosing a treatment plan from the ethically acceptable plans.
 - Develop an initial birth plan and/or advance care plan and possible reasons for varying from the plan
 - Keep the parents updated about progress and whether the advance care plan is still appropriate to the baby's current condition
 - If the baby's condition changes or pertinent new information becomes available, review and update the advance care plan as appropriate
- Communicate
 - Document the contingency plans in the medical record and communicate with hospital and post discharge providers
 - Ensure that current and future providers are aware of changes in condition or plan.
- Be inclusive
 - Practice the principles of PnPC regardless of whether or not there is formal involvement of a PnPC team
 - Include support for all families including those where the pregnancy is terminated for a fetal life-limiting condition
 - Celebrate diversity. Be culturally/religiously sensitive and ensure that your organization has access to translators who might help with both language and cultural/religious traditions. Encourage a diversity in the staff
 - Support the staff caring for these babies and their families

Staff do not need to label this philosophy "palliative care." There may be misperceptions or preconceived notions about this nomenclature. The key is to normalize the universal concepts and practice of perinatal palliative care principles into the prenatal and postnatal conversations with the parents and the care of the newborn.

Perinatal palliative care is simply good care!

Perinatal Palliative Care: Prenatal Diagnosis of Lethal Condition

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The job of the palliative care professional is a difficult one, requiring acknowledgement of multiple aspects of a patient's life, requiring an understanding of how the illness may affect each aspect of the patient's life, and helping to ascertain a plan of management for the patient so that the disease has the most minimal possible impact on the patient's life. An especially challenging situation facing the palliative care provider occurs when the beginning of life may also be the end of life. This is the situation confronting a perinatal palliative care professional. One of the roles of the perinatal palliative care provider is to help obstetricians/maternal fetal medicine specialists to communicate fully to expecting families regarding what is happening with their fetus, whether any diagnostic or therapeutic interventions are available, potential risks and benefits of such procedures, and what to expect for the fetus/neonate in the future. Similarly, the perinatal palliative care provider can help to interpret the obstetrician's information into data that is easier to understand, help the family to process this information, and help the family to analyze their own value system, thus, assisting them, when possible, in determining what management choices are in the best interest of their fetus. Likewise, the perinatal palliative care provider can involve the neonatology team in these conversations regarding patient management, since, generally, the neonatology team would be present at the time of delivery of the neonate to follow through with the post-delivery management plan. The perinatal palliative care provider can, therefore, be an integral part of the patient management team, facilitating communication and critical decision-making among all interested parties.

An unfortunate, but fairly common, scenario facing perinatal palliative care providers is when there has been prolonged rupture of membranes for many weeks or months during gestation. Generally, such fetuses have normal chromosomes and are normal in every way other than the effect caused by the prolonged rupture of membranes. When the amniotic fluid constantly leaks out of the amniotic sac, the fetus no longer has the buffer of a bag of fluid around him. The uterus walls then press up against his body and against his chest. Consequently, his chest wall does not grow appropriately, and the lungs within his chest can't grow either. His hands, feet, and face appear flattened by the constant pressing against the wall of the uterus. Even if he stays in the uterus until full term and the remainder of his body grows, his chest and lungs can't grow. At birth, he will have lungs that are too small to support life. This is called pulmonary hypoplasia and is usually deadly at the time of birth, when babies are called upon to use their lungs to breathe for the very first time. When pulmonary hypoplasia is not suspected and the neonatology team tries valiantly to save a newborn baby who is having severe respiratory distress by placing a breathing tube into his windpipe and blowing large volumes of air into his lungs, the underdeveloped air sacs "pop," causing a pneumothorax, and air accumulates around the lung, compressing the lung, and further impeding its function. When there is a chance for life, in cases of respiratory distress due to pneumothorax without pulmonary hypoplasia, generally, neonatologists will place a chest tube in between the ribs to drain out the air, but when the lungs are known to be too small to support life, such a procedure would cause a dying baby to have additional pain without preventing his death.

I had the pleasure to be the perinatal palliative care provider to Ms. Smyth. Ms. Smyth was expecting her second baby. Her first child was a healthy 8 year old. Ever since 13 weeks gestation, the community obstetrician had noted that there was no amniotic fluid around the baby. Repeated studies were inconclusive as to whether the fluid was leaking out through a rent in the amniotic membrane or whether the fetus was not urinating to create amniotic fluid. However, the fetal kidneys looked normal on ultrasound, and fluid seen in the bladder attested to their likely normal function. Assuming that there was a rupture in the membranes, the community obstetrician let Ms. Smyth know that, likely, infection would enter the uterus and the previable fetus would be expelled during preterm labor. When the pregnancy reached 24 weeks and the fetus had not died nor been expelled, the community obstetrician transferred care of Ms. Smyth to our medical center.

At our medical center, our maternal fetal medicine specialist noted that there was essentially no amniotic fluid and Ms. Smyth's female fetus had a compressed chest and low lung volume, consistent with lethal pulmonary hypoplasia. We prepared Ms. Smyth, her partner, and their older child for the imminent death of the baby, who would be named Natalie, in the delivery room. We discussed with the family the likely outcome of rapid neonatal death due to pulmonary hypoplasia, and discussed the futility of placing a chest tube to treat pneumothorax, and the futility of attempting to ventilate, via an endotracheal tube. The obstetricians administered prenatal steroid doses to Ms. Smyth to try to induce fetal lung maturity, but we had a discussion as to whether this might give the family false hopes that the steroids would help the baby to survive, even though we knew that she had lethal pulmonary hypoplasia.

Our pediatric palliative care team spent time with Ms. Smyth's 8-year-old daughter and explained that her little sister would be born sick and would survive only a few minutes after birth, and that her parents would be sad, but that this sad event had nothing to do with the 8-year-old's behavior. After finding that the 8 year old desired to touch the baby, we made arrangements for her to be brought into the labor suite shortly after delivery to hold her little sister. We provided a lovely white gown with pink ribbons interwoven into the fabric for the baby to wear. We arranged for the clergy member of the Smyth's choice to be present in the labor suite to say a prayer, perform a baptism, and to give additional support at the time of Natalie's birth. We arranged for additional palliative care team members to be present in the delivery suite to perform various palliative care roles, including sitting with the family, devoting special attention to the 8-year-old sibling, doing hand and foot molds, ear prints, collecting a lock of hair, and creating a memory book for the family. We arranged for a professional photographer to be present to photograph, for the memory book, the baby with her family.

After intense discussions with the obstetricians/maternal fetal medicine specialists, Ms. Smyth expressed her desire that, due to Natalie's anticipated unavoidable death, she and her family would like to hold and comfort the baby at the time of birth, during Natalie's dying process. They decided to not pursue a c-section even if, as a fetus, Natalie were showing signs of distress. They appropriately decided to not have the neonatology team perform painful and futile aggressive interventions.

The neonatology team was kept up to date on the non-interventional plan of management. At the time of birth, the plan was for Natalie to be brought to the radiant warmer, dried, briefly assessed for presence of pulmonary hypoplasia, dressed in her gown, then brought to her family to hold.

At 34 weeks gestation (6 weeks before full term), Ms. Smyth started having fevers and an abnormal blood count, suggesting chorioamnionitis (infection in the uterus). There was no evidence of fetal distress at that time, but Ms. Smyth's life was in danger due to the infection. In order to save Ms. Smyth's life, the uterus needed to be rapidly emptied of its developing abscess, so Natalie needed to be delivered by c-section for maternal reasons.

I had the pleasure of also being the neonatologist at the delivery of the baby. Natalie was delivered via c-section with her mother awake and her father at Ms. Smyth's bedside, and her big sister and aunt immediately available in the anteroom, as well as the photographer, the clergy member, the palliative care team members with the baby's pink and white gown and the clay for molds of her hands and feet, scissors for the hair clipping, and the ink pad for her ear prints. The baby was brought to the radiant warmer, dried, and I assessed her.

It was a boy. The hands, feet, and nose did not look particularly flattened. Importantly, the chest did not look particularly small, and the baby was crying, but he was also grunting (a sign of respiratory distress). It seemed that several of the prenatal findings (sex, severity of the pulmonary hypoplasia) may have been inaccurate. I immediately went to talk with the family to let them know that the baby was actually a boy, that we health professionals may have been a bit wrong about a few things, and that there may actually be some hope for life. I asked their permission to place a breathing tube to give standard ventilatory assistance for babies with respiratory distress, and to give surfactant in case his lungs had some degree of prematurity. (I was also thankful that the prenatal steroids had been administered to Ms. Smyth.) I said that I would not do anything else heroic, painful, or of questionable efficacy without their consent. They gave me permission to do some basic resuscitation. The baby's oxygen levels were not adequate while breathing room air, but improved to normal when we gave 50% oxygen. He needed less oxygen after we placed an endotracheal tube and gave surfactant. The parents, and sister, had a chance to touch the baby before we brought him to the NICU and placed him on a ventilator. The chest x-ray showed minimal evidence of pulmonary hypoplasia. There was a tiny pneumothorax which did not progress and did not make him unstable. The baby's parents and sister came to the bedside and touched and held the baby. His lungs improved rapidly over the next 2 days, and, on day of life 3, he was able to have his breathing tube removed and start working on feeding by mouth. Over time, he put on weight and was able to keep his body temperature stable without relying on incubator heat. He went home in healthy condition 2 weeks before his due date. He was renamed Nathan.

This vignette describes the role of the perinatal palliative care provider in coordinating care amongst multiple health care providers (especially obstetricians/maternal fetal medicine specialists, neonatologists and NICU team members, pediatric care teams, and all their support personnel), providing compassionate and thoughtful analysis of patients' conditions regarding whether particular interventions would be in the best interest of the patients, communicating honestly and frequently with families, and being versatile when unexpected changes are encountered.

Perinatal Palliative Care: A Cohort Showing Equity, Family Experiences, and Outcomes

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Introduction

There are approximately 3.75 million births in the US each year,¹ and about 3%-5% of babies are diagnosed with one or more birth defects.² Unfortunately, some birth defects cannot be cured with surgery or other medical treatments, and result in the death of the fetus or newborn, either during pregnancy or shortly after birth. For these life-limiting cases, the goal of medical management shifts from trying to find a cure to providing as much comfort to the patient as possible,³ a model of care known as palliative care.

Perinatal palliative care is a subset of pediatric palliative care. The term "perinatal" refers to the time before, during, and right after birth, describing this model which applies to fetuses who have been diagnosed with life-limiting conditions.³ One goal of perinatal palliative care is to improve the comfort of the fetus or newborn as much as possible, largely after birth. Another goal of perinatal palliative care is to care for the pregnant woman's mental and physical health during and after pregnancy by facilitating collaboration between a multidisciplinary team of mental health and obstetrical providers.³ Additionally, perinatal palliative care also addresses the whole family's social and emotional wellbeing.⁴ This can involve grief counseling for the family before and after the birth, memory-making activities,³ and engaging child life specialists so that older siblings can process their emotions and develop age-appropriate coping strategies.⁵ Although palliative care has been gaining recognition in recent decades,⁶ very few studies have been conducted of families who receive it.⁴ Because there is a lack of research on perinatal palliative care, many of the guidelines related to perinatal palliative care have been adapted from what is known about palliative care for adults and children.⁴ This article describes a retrospective cohort study of perinatal palliative care families in Houston, Texas, to lay out the current state of perinatal palliative care in a large medical center attached to a fetal therapy program.

Methods

The design of this study on perinatal palliative care (PPC) was a retrospective cohort, in which two or more groups are compared by examining their records. The primary outcome was whether the birth plan created in advance by the family matched the actual events at delivery. The PPC team in this study is made up of a neonatologist, a pediatric palliative care physician, two pediatric palliative care nurses, and a maternal-fetal medicine physician. The study also looked at clinical outcomes and resource utilization, as secondary outcomes.

This study compared two groups of families who received PPC. One group of families chose "no intervention," meaning they chose not to have fetal monitoring, C-section as a mode of delivery, or neonatal intervention. These neonates received comfort care if born alive. The second group included families who asked for one or more of these interventions, and they were called the "any intervention" group. Their interventions ranged from intermittent or continuous fetal monitoring to cesarean delivery for the sake of meeting a living neonate, and even to parts of neonatal resuscitation (including medical code, chest compressions, and intubation).

All families receiving a PPC consultation at the Fetal Center of the University of Texas Health Science Center at Houston from 2016 to 2020 were screened to be potentially included in the study. Patients were included if they saw the PPC team for life-limiting anomalies and chose to continue the pregnancy. Patients receiving consults as a step toward surgery that would cure the fetus and patients who chose termination were excluded from the study.

Results

187 families received PPC consults and met the criteria for this study. When demographic data were compared, families in both groups had similar maternal age, race, ethnicity, marital status, insurance carrier, and median household income for their zip code (the study did not examine the individual family's income).

The delivery experience exactly matched the family's birth plan in 89% of cases. The "no intervention" group was significantly more likely to have a match between their birth plans and birth events than the "any intervention" group (98% vs 81%). When a mismatch was present, the main reason was that the newborn did not survive until the interventions planned by the family due to the expected progression of the baby's condition. There were 7 newborns who were given increased medical support due to a change in plans and subsequently survived long enough to be discharged to home hospice. All of these children later died at home. It was more likely for the families in the "any intervention" group to switch to "no intervention" than the opposite (24% vs 6%). A switch in intervention plans was most likely to occur during an outpatient consult, and the part of the family's plans that changed was most likely to be related to neonatal management. Investigators could not always tell from their review of records whether a difference in their birth plan and delivery events was a result of medical error, or whether the family requested a last-minute change.

The secondary outcomes included maternal delivery outcomes and patient resource utilization. Both study groups had preterm deliveries after 30 weeks, and the reasons for preterm delivery were similar between groups. Reasons included timing the delivery so family could attend, changes in the fetal malformation, and maternal indications. No maternal deaths or intensive care unit admissions occurred among the study subjects.

Unsurprisingly, families who asked for some interventions used more resources. The only resource that was used similarly by both groups was PPC consults, although most families still only needed 1 birth planning consultation to develop their final birth plan (79% of "no intervention" group and 76% of "any intervention" group). The "any intervention" group had more ultrasounds, longer delivery lengths of stay, and were more likely to have an NICU admission, also with longer lengths of stay. The "no intervention" group had higher rates of labor induction, whereas the "any intervention" group had higher rates of cesarean delivery. In the "no intervention" group, there were 18 NICU admissions, 16 of which were for comfort measures like feeding and morphine, and 2 of which were for families who updated their plan to include some interventions.

Discussion

Prenatal life-limiting diagnoses involve at least two people—the fetus(es) and the pregnant woman—and often deeply impact the whole family. This study showed that perinatal palliative care can be offered equitably in a high-volume center, demonstrates that PPC can offer parents an experience that matches their choices about carrying and delivering their child, and advocates that interventions can be appropriate for some families, even interventions like C-section and parts of neonatal resuscitation. Perinatal palliative care is an important option that should be available to families with life-limiting fetal diagnoses because it addresses the unique family dynamics of a tragic situation while caring for social and psychological health.

Women experienced perinatal palliative care safely in this study, even if they asked for a C-section for the sake of meeting a living neonate. In this study, families who chose some intervention had higher rates of intraamniotic infection (IAI) and postpartum hemorrhage (PPH). However, these complications were found to be related more to the mode of delivery and not to whether interventions were chosen. Specifically, women who had vaginal deliveries were more likely to have IAI and women who had cesarean deliveries were more likely to have PPH. Like all patients, PPC patients should be carefully counseled about risks associated with induction of labor and cesarean delivery.

As many as one in five families who asked for some intervention experienced a change in their plan, mostly to stop postnatal interventions. This should not be viewed as a negative result or a problem to be fixed, but rather as a sign that plan-changing should be openly discussed with families who ask for some interventions. If a family asks about fetal monitoring during labor or any components of neonatal resuscitation, it is a signal that providers should clearly describe how those interventions may play out, help families make value-consistent choices, and discuss with them that they may be more vulnerable to changes in their plan. Providers should not coach or coerce patients to settle on fewer interventions for the sake of an unchanging inpatient plan. Instead, providers should help families build insight and use methods like shared-decision making or the teach back method to help them articulate how they plan to use these interventions. The study highlights one example of a family that understood that ventilation could not prevent their child's death, but requested brief ventilation so that the infant could live long enough to be baptized. Providers caring for families such as this can help families choose or avoid interventions as need be, so that they achieve value-consistent goals.

In the authors' experience, one of the most important aspects of perinatal palliative care are providers that champion the delivery of the diagnosis and therapy options in a way that maintains the role of the fetus within the family. Delivering the diagnosis well is the first step of supportive care of the family as they adjust to and grieve with the reality of expecting a disabled child or a child with a very short life span. One way of delivering of a diagnosis within the family's existing vision of their fetus is to ask whether they have chosen a name; if they have, use that name throughout description of the diagnosis and plan. Another way of building a tone of palliative medicine is to openly describe the family as the first and most important part of care for the fetus. The family as a setting of care is always in place, whether the fetus receives problem-oriented (i.e., curative or therapeutic) management options, or goal-oriented (i.e., comfort or palliative) management options. This very realistic framing helps families remember that regardless of what they choose, the medical team realizes that the family will aim at what is best for their youngest child.

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Perinatal Palliative Care within a Multispecialty Fetal Care Center: Providing a Space for Active Parenting through Longitudinal Decision-Making Support

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I am continually humbled by the unique words parents share as they lean into conversations with our Interdisciplinary Perinatal Palliative Care team. For many families who face life-limiting or complex fetal conditions, frightening or frankly heartbreaking news has been conveyed through a series of diagnostic evaluations over several days or weeks. Some families sit down with us bracing themselves for further bad news and the pain of revisiting a list of anomalies or statements about an expected poor outcome. Other families, unfamiliar with Palliative Care, may be guarded with uncertainty of what lies ahead for our scheduled consultation. As the conversations progress, however, stories of love, pain, joy, hope, fear, and need unfold. Together, parents and Perinatal Palliative Care providers explore experiences, values, and hopes that establish a foundation for decision-making support that extends longitudinally through ongoing pregnancy and the early life of their child.¹⁻⁴

Including Perinatal Palliative Care specialists within multispecialty centers providing fetal evaluations and interventions allows expectant parents to benefit from inclusion of Palliative Care skills in their comprehensive care.⁵⁻⁷ Expertise in communication around exploring goals of care, engaging in shared decision-making, and navigating a parental role in the face of uncertainty or medical complexity strikes an important balance with diagnostic expertise and explanations of medical intervention regularly encountered by families facing complex fetal diagnoses.^{8,9} When expectant parents identify goals of care that focus on comfort and peaceful time parenting after delivery, families and care teams benefit from providers' skills in anticipating end-of-life care needs, preparing for symptom-management, and coordinating home-based palliative and hospice resources.¹⁰ For parents who are learning about neonatal intensive care diagnoses with high likelihood of interventions such as cardiac surgery, ECMO, renal replacement therapy, or long-term ventilation, Perinatal Palliative Care providers assess and address the unique parenting experience of preparing to welcome a child with medical complexity and inherent risk of neonatal death. These conversations become a foundation for rapport that carries longitudinal Perinatal Palliative Care expertise through the pregnancy, baby's delivery, and into the child's neonatal care course. Some families experience a shift from uncertainty to greater clarity or more specific prognostic insights as the fetal course progresses or after meeting their child, and rapport and familiarity with their Perinatal Palliative Care specialists can be central to supporting the active parenting role of clarifying, shifting, or reframing goals of care.

Program Description

Within The Fetal Center at Nationwide Children's Hospital, our interdisciplinary team of Perinatal Palliative Care providers delivers longitudinal, family-specific care to expectant parents facing fetal diagnoses that will lead to serious illness in the newborn. In addition to a classically viewed Palliative Care role with those parents facing conditions where families may identify goals of care that focus on comfort or limited medical intervention, Perinatal Palliative Care also becomes part of the multispecialty consultant team for families who are receiving diagnoses where fetal or early neonatal intervention is necessary, conveying increased risk of serious illness and complex medical course. While some families utilize our exploration of value-systems and parental hopes to consider whether medical intervention in the face of a poor prognosis matches their goals of care, other families acknowledge the benefit the space we create to find a balance between an expected or potential medical course and the value-system from which they as parents make decisions for their child.

Referral Process

While some families self-refer to The Fetal Center, the majority of families that receive consultative care through our program are referred by Obstetric and Maternal Fetal Medicine providers within Central Ohio. Providers who diagnose a serious or life-limiting fetal condition frequently refer patients to our Fetal Center specifically for Perinatal Palliative Care consultation. Patients who desire additional evaluation in the setting of a potentially life-limiting fetal diagnosis, who seek the opportunity to explore possible life-sustaining therapies or interventions, or who are referred for a Comprehensive Fetal Center visit will have Palliative Care included in their multispecialty visit if their referring diagnosis falls within our trigger list for Perinatal Palliative Care consultation. While the list is not exhaustive, it allows us to capture the majority of patients with the most serious conditions, ensures consistent practice and access to Palliative Care consultation for all patients with serious fetal diagnoses, and normalizes our team's role in care of families making decisions for their child regardless of specific goals of care or therapeutic plans:

- Anencephaly
- Alobar holoprocencephaly or complex CNS malformation
- Trisomy 13, Trisomy 18, or other complex aneuploidy
- Bilateral renal agenesis/MCDK with oligo/anhydramnios sequence
- Congenital diaphragmatic hernia with O:E ratio \leq 25% or LHR $<$ 1
- Skeletal dysplasia with high risk of pulmonary hypoplasia (Chest/AC $<$ 0.6, FL/AC $<$ 0.16, or Cardiac/Thorax $>$ 50%)
- Single-ventricle cardiac lesion
- Other high risk congenital heart lesions with significant risk for fetal/neonatal death
- Airway-compromising anomalies with high expectation of need for tracheostomy (i.e., neck mass, CHAOS, etc.)
- New or progressive complication of fetal condition (i.e., hydrops fetalis)
- Planned fetal therapy or intervention

Interdisciplinary Team Structure

Our core interdisciplinary Perinatal Palliative Care team is comprised of Palliative Care physicians and advanced practice nurses, a Palliative Care social worker, and our Fetal Center chaplain. As we identify experiences and needs unique to each family over the course of their longitudinal care, we regularly extend this core team to include Certified Child Life Specialists, Lactation Consultants, Genetic Counselors, Psychologists, or Home-Based Palliative Care and Hospice team members. For families receiving multispecialty consultation and ongoing evaluation within the Fetal Center, the Fetal RN Coordinators become instrumental in team communication and coordination of collaborative care. Partnership with providers from other medical and surgical specialties varies from patient to

patient and is tailored to the unique conditions identified in the fetus. While some families meet solely with the Perinatal Palliative Care team, others meet with a group of specialists that includes core members from our team. Of note, inclusion of our Perinatal Palliative Care physicians within regularly scheduled collaborative meetings (i.e., Fetal Board, Single-Ventricle Team) has allowed us to truly gain a "seat at the table" in terms of growth of our Center's multispecialty care of patients facing complex and serious illness in their newborns.

Longitudinal Perinatal Palliative Care

We aim to provide compassionate and expert longitudinal Perinatal Palliative Care starting from the identification of complex or life-limiting fetal diagnosis through ongoing pregnancy and the child's neonatal care course. Acknowledging that each pregnancy journey and each parental experience with a life-limiting fetal diagnosis is unique, the structure of our initial visit focuses on truly hearing the parenting experience of learning of and about their child, assessing their medical understanding and prognostic awareness of their child's diagnosis through conversation, and exploring the unique values and experiences that define them as parents. We utilize secure EMR communication, telephone, telehealth, and follow-up visits to continue family-centered and patient-specific longitudinal care. Most families who create goals of care that include stabilization, evaluation, and intervention for their child have follow-up visits in our Fetal Center, allowing for ongoing fetal evaluation coordinated with longitudinal Perinatal Palliative Care support of decision-making and parenting experience. For families who identify comfort-focused goals of care, our team participates in a delivery planning care conference with the parents, their maternal and neonatal healthcare providers, and the hospital's chaplain, allowing for a transition of collaborative family centered care toward the delivery hospital space.

We greatly respect that there is a fluidity of parental decision-making in the face of serious illness in one's child. While prenatal diagnostic assessments reveal tremendous information about fetal conditions and offer valid foundations for prognosis, making decisions for the medical care of a child that has not yet been born is a tremendously unique and often heart-wrenching experience. Creating a Perinatal Palliative Care program within a comprehensive, multispecialty Fetal Center has allowed us to establish both a literal and figurative space for active parenting through longitudinal decision-making support.

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Perinatal Palliative Care As a Bridge Between Participants in Complex Medical Cases

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Introduction

One in every 100 pregnancies will end with a fetal loss after 20 weeks' gestation.¹ Some of these losses are unexpected, while others are anticipated based on genetic anomalies, birth defects, or pregnancy complications. Some of these babies are born alive, but are not expected to survive after birth. In such cases, the families have difficult decisions to make regarding management during pregnancy, at delivery, and after birth. These decisions are further complicated by legal issues and policies that surround the unborn child.

Perinatal palliative care has been a beacon for families who are faced with these decisions and losses. The introduction of palliative care services reduces family stress and anxiety and provides the families with options.¹ Some choose to terminate the pregnancy, if the gestational age is within federal and state limits. Others choose to carry the baby to term with a clear care plan regarding interventions before, during, and after delivery. These care plans are created with the help of a multidisciplinary team that includes the perinatal palliative care team, the obstetrics and gynecology (OB/GYN) service, Maternal/Fetal Medicine (MFM), and many other services depending on the gestation and the issues facing the fetus. In some cases, the neonatal intensive care (RNICU) may be involved or subspecialties such as cardiology or neurology. The palliative care team is the driver in the process and solely responsible for making sure that the care plan is implemented, and the family's wishes are met.²

Case Study

I first met the Smith¹ family in the office of Dr. Thomas, the mothers' OBGYN. She had called me the week prior with the consultation. The expectant mother was 15 weeks' gestation carrying diamniotic dichorionic identical twin boys. This pregnancy was complicated by premature rupture of membranes of twin B at 13 weeks' gestation, which

resulted in anhydramnios and was expected to lead to lethal pulmonary hypoplasia. Additional consultations were sought at a quaternary care center with OB/GYN, MFM, and palliative care regarding next steps. The parents proceeded with expectant management in hopes that the amniotic sac would seal, but after two weeks mother was still leaking fluid daily. The parents began the discussion about selective reduction with their team of doctors and decided, given the extremely poor prognosis for twin B, to move forward with termination of twin B. The goal being to prolong the gestation time of twin A and decrease chances of preterm delivery. However, during an ultrasound at 18 weeks 6 days gestation, twin B was now the presenting twin. If the parents moved forward with selective reduction, there was a greater percent chance that the mother would go into preterm labor and lose both babies.

This case was further complicated by the father's diagnosis of stage 4 hepatocellular carcinoma. If the mother were to have the selective reduction and deliver at 21/22 weeks she would be faced with extremely premature babies or the death of both babies while her husband was in hospice care. Therefore, the parents elected comfort care for twin B to minimize the risk of a preterm delivery. Palliative care, and pregnancy management were moved closer to their home to minimize the mother's time away from her husband and son.

The parents were very clear on their views of what they wanted for their unborn sons. They wanted comfort care for twin B, as he would have poor lung development due to the anhydramnios and he would have little to no life expectancy. They wanted twin A to have as much chance as possible. I explained that there is a perinatal palliative care service at Sparrow Hospital and that Dr. Thomas could place a consult with the neonatal intensive care (RNICU) team so that we could set up a plan for twin A in the event that the mother delivered early. We would also set up a consult with our local MFM team to have them involved for their input and guidance. If at all possible, the mother wanted to deliver the boys vaginally, with twin B remaining in the Labor and Delivery room with her while RNICU assessed twin A. The mother's biggest concern was having to care for a severely disabled child alone after her husband died. In consultation with the RNICU team, we discussed having a step-by-step approach with twin A, and that the further along she was able to carry the babies the less chance twin A would have to suffer from prematurity related brain injury.

Three weeks after being placed on hospice, the father died from complications of cancer. I met with mom at her next visit with Dr. Thomas for an ultrasound and we talked about her grief and plans moving forward without her husband. It was very emotional for her to have the ultrasound. Worried about how her grief would affect her during delivery, the mother elected for a scheduled cesarean section. Dr. Thomas and I explained how delivery team would work with her to cope with the loss of twin B and also help her celebrate the birth of twin A. I set up a multidisciplinary team meeting to discuss her case so that everyone involved in the delivery would be aware of her birth plan. Dr. Thomas would attend and present her case as the OB representative.

Due to the COVID-19 pandemic, the meeting with RNICU, MFM, OB, Palliative Care, and the mother was virtual, so the mother and I logged in together from her home. The RNICU physicians explained the complications of preterm deliveries and the mother expressed that she would like extraordinary measures provided to twin A as long as his brain scans were free from significant bleeds. During the meeting we also discussed head ultrasounds and intraventricular hemorrhages and how they would be done and how we would discuss them each step of the way. We clarified the birth plan for each baby with the RNICU and MFM team. Twin B would receive comfort care if born alive, and stay in Labor and Delivery (alive or deceased) and twin A will go to RNICU assuming preterm birth. The mother expressed her wishes to have both twins together before twin B was taken away to be cremated, and it was explained that it could be arranged once twin A was stable.

As the mother had been leaking amniotic fluid since 13 weeks due to preterm premature rupture of membranes, the biggest concern for her doctors was the greatly increased chance for chorioamnionitis putting both the mother and babies both at risk of infection and death. At 27 weeks 2 days gestation the mother was admitted and held for observation for bleeding. The team called me to see her. She was worried about the possibility of going into labor that early and the risk to twin A. Additionally, she was worried about her son at home and grief stricken given by that her husband had only been deceased for a month. Because the bleeding and contractions had stopped after 48 hours of observation, the mother was discharged.

At 28 weeks 6 days gestation, only 48 hours after she was discharged, the mother started to have very painful, persistent contractions that continued to increase in length and intensity. She was readmitted to Labor and Delivery. Her support person was not able to be with her because of COVID-19 restrictions. She was accessed in triage and it was quickly determined that she would need to have an emergency C-section due to concerns for placental abruption. Because of the birth plan we created, I was able to be notified of her labor and quickly rushed to the hospital at 4:30 in the morning. She was alone in the operating room and grateful someone had called me to come in and be there with her. I missed the arrival of twin B, who most likely died during her traumatic labor. I was able to see twin A as they were wheeling him to the RNICU. I comforted the mother and told her how well twin A was doing and that twin B did not suffer at all. She was grateful for that. She was relieved that she was “no longer a ticking time bomb” not knowing when the babies would come and not knowing what would happen. I stayed with her until she went to recovery. The labor and delivery nurses held twin B in the bereavement room until the mother was recovered and ready to see him.

When I returned later that morning, I brought twin B to see mom. She held him and expressed that she was surprised how comforting it was to hold him. I checked on twin A while he was settling in the RNICU and stable on BiPAP. When her mother and father arrived, we all went up to the RNICU so both she and twin B could meet twin A together. She spent the rest of the day holding twin B, and that evening I accompanied twin B to the morgue with the nurse. The mother’s grief was complicated. She grieved her newborn son, her husband, his absence at the birth of their sons and the death of Twin B, she grieved for her son at home who was without her and worried about her and his new brother. I worked with OB to help the mother get through this.

Twin A spent 85 days in the RNICU. During that time, I rounded with the RNICU team periodically, and set up and attended team meetings to discuss twin A’s care. Most notably when the mother had questions or issues that she needed further help with I was able to facilitate conversations with the appropriate RNICU team members. I helped her work through her grief of losing twin B, and her husband. I also was there to assist with the challenges that came with becoming a solo parent of a NICU baby and an older son at home. When discharge day finally arrived, I accompanied her and the baby home to finally be reunited as a family of three and meet big brother for the first time. I have made a few follow-up visits with them. They are adjusting to life and settling in well at home. I meet up with them at twin A’s subspecialty appointments to assist in discussing his further medical needs and progression.

Discussion

Perinatal Palliative Care enhances the quality of life for infants with terminal and complicated medical conditions in multiple ways: birth plan creations, symptom management, and psychosocial support for families. Perinatal palliative care plays an essential role in decision-making and conflict management during the antenatal, intrapartum, and neonatal periods [3]. Bereavement support for families, as well as support for families with children who will survive for extended periods, is provided through pediatric palliative care and hospice programs.

This case was challenging because of the many complex and competing factors. Recognizing this, the mother’s obstetrician, Dr. Thomas, involved perinatal palliative care early on in her pregnancy. Typically, previsible prolonged premature rupture of membranes (PPROM) is managed either expectantly or with induction of labor. Continuation of pregnancy puts the mother (and fetus) at risk of infection, dysfunctional labor, preterm delivery, placental abruption, cord prolapse, fetal deformation, retained placenta, postpartum hemorrhage, sepsis, and need for classical cesarean. These risks may be undertaken by the mother in the hopes of prolonging pregnancy to and beyond viability to maximize the baby’s survival and decrease morbidity. However, the earlier the membranes rupture, the worse the prognosis—early second trimester rupture of membranes often impairs fetal lung development to the point that the extrauterine life is not possible, regardless of the gestational age at delivery. In such cases, families may choose termination to minimize maternal risks given exceedingly unlikely fetal benefit.

The opportunity to meet with the mother early in her pregnancy and establish a relationship was vital. This also allowed me to meet with the father and have a discussion with both of them and confirm their wishes to proceed

with comfort care of twin B. Including the father in these discussions and so many initial decisions about the birth plan was significant to the mother and to the team. Establishing a relationship with the mother to support her in this complex and risky pregnancy was especially important with the death of the father and her lack of support locally.

The careful coordination of care with the multidisciplinary team through discussion and documentation was to the mother's benefit when she went into labor early and alone, without her support person available due to COVID-19 restrictions. The OB resident knew to call perinatal palliative care and, therefore, the mother had support. Additionally, there was no confusion over the plan for either baby.

Throughout the RNICU stay, the palliative care team was able to help the mother handle situations in which she felt that members of the RNICU team were at odds with her wishes or didn't understand what she was asking. Her main concern was with breastfeeding and her devotion to being able to exclusively give her baby breastmilk without formula. This put the mother at odds with the nutritionist leading to a team meeting to discuss the flexibility of giving breastmilk over formula for the majority of his feedings. As medical providers, we have the knowledge to understand what is happening and as the physicians, dieticians, nurses, OTs, PTs, etc., are focused on the day to day care for the infant, we are focused on the whole family, the long term and the how every detail affects the family and the child.

Throughout all this, the mother had to leave her older son (age 6) under the care of friends while she went to the hospital every day to be with twin A. He feared she would not return, or that she was sick like daddy. I helped coordinate a new psychologist to work with big brother on his grief, and anxiety.

In complex cases with competing focuses, the palliative care team initially facilitates the elucidation of different perspectives and then helps to streamline and unify care. The OB/GYN team is focused on the pregnancy and optimizing maternal and fetal health, which can sometimes be at odds with each other. The RNICU team is focused on the infant's health and maximizing survival while incorporating the recommendations of pediatric consultants focused on their individual body systems. It is the role of the palliative care team to integrate the wishes of the parents with the best interests of their child and family with the medical recommendations such that a cohesive, maximally values-aligned plan is made. Establishing a relationship with the family early on in care helps to build trust and become a truly integrated team member and advocate as the pregnancy progresses and decisions are made, scans discussed, birth plans detailed. A multidisciplinary team approach is essential so that all members are aware of the case, the family's wishes, the birth plan, the plan for the child(ren), and the bereavement needed.

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A Role for Community Hospitals in Providing Perinatal Palliative Care

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What is Perinatal Palliative Care?

Resolve Through Sharing (RTS), an organization that has provided bereavement education since 1981 and introduced many standards in perinatal loss care, describes perinatal palliative care (PnPC to differentiate it from pediatric palliative care) in the following way:

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...goals and benefits of perinatal palliative care as a philosophy and a practice are "finding good choices when everything seems bad".¹

What is the status of Perinatal Palliative Care in the U.S.?

The concept of PnPC was mentioned in the medical literature as far back as 1997.² Even before that, neonatal palliative care was described as being delivered in a neonatal intensive care unit.³ In the last 25 years, PnPC programs have been growing and diversifying, as have publications about these services.^{4,5} About 350 programs are currently listed at www.perinatalhospice.org, a clearinghouse of information about perinatal palliative care. PnPC has been endorsed by a committee of the American College of Obstetricians and Gynecologists, together with the Society for Maternal-Fetal Medicine and the American Academy of Pediatrics, and applauded by parents who have experienced this form of care.^{6,7,8}

Who Needs Perinatal Palliative Care?

Parents who learn during pregnancy that their child may die before or shortly after birth face multiple, difficult challenges. Advances in prenatal testing and diagnosis can provide parents with a life-limiting diagnosis. At the time of diagnosis, a clear, unbiased explanation of all options from termination to palliative care and any possibility of treatment options needs to be given. A significant cohort will choose to continue their pregnancies and adopt a palliative approach to their infant's abbreviated life. PnPC is a model of care that seeks to respond to the needs of these parents, needs that might otherwise or previously have gone unmet.

What Is or Might Be the Role of Community Hospitals in Providing PPC?

Leuthner and Jones give an excellent description of different levels of PnPC with smaller community hospitals can be an ideal place to provide "Primary Perinatal Palliative Care", medium sized hospitals with maternal-fetal and neonatology services capable of caring for many cases requiring some degree of evaluation with "Secondary Perinatal Palliative Care" and large referral centers capable of providing the highest levels of evaluation and care as well as "Tertiary Perinatal Palliative Care."⁹

When extensive prenatal assessment indicates the infant will clearly not benefit from aggressive treatments and parents have chosen comfort care, community hospitals may provide care for these babies and their families in programs with comprehensive, individualized palliative care closer to their home.¹⁰

Locally delivered PnPC can be developed with the assistance of already-existing training materials and resources, be customized to the needs of individual families, and be provided to families at minimal cost. The cohort of potential patients may be small, but PnPC in their community may be the best setting for these infants and their families. One survey of 75 PnPC programs identified 42 that were hospital-based; of these latter, 17 were identified as regional or community hospitals.¹¹ PnPC does not need to be limited to large referral hospitals.

What are Some Advantages of Community Hospitals in Providing PnPC?

Familiarity

In a community hospital setting, mothers, other family members and friends are likely to be familiar with the institution and may have previously received services there. The hospital is likely to be close to their homes, thus eliminating the need for travel to a tertiary care center which might be a significant distance away.

Service Cohesion and Logistic Simplicity

In a large hospital, it becomes challenging to discuss a specific case prenatally with every potential physician/provider and nurse who might care for a particular patient and family. In a community hospital setting however, the mother may already know all of the physicians at her obstetric (OB) office and there may only be a small number of neonatologists/pediatric providers who might be at the delivery. Adequate time prior to delivery may make it possible to reach most of the nursing staff with specific information about the case and even plan which rooms would be the best location for delivery and post-partum care. Teams in the different care areas know each other's strengths and the more compact size of a maternity care area can assist quick adaptation to family needs. Rather than going to a different hospital or floor to get from Labor & Delivery to the NICU or Mother-Baby, they may only need go down a short hallway. From security helping park their car to a transport person being briefed on which chit-chat to avoid with this couple, relationships at all levels can facilitate optimal delivery of services.

Normalcy

Throughout the provision of PnPC, the goal of enabling families to maintain as much normalcy in their experiences can guide care in a community hospital. Parents who chose PnPC want support in their decision, respect for their infant, to not be feel abandoned, attention to individual wishes, guidance in how to bring their larger family through this crisis, and opportunities to participate in caring as much as possible. Being in a familiar setting with their normal support system can not only allow them some normalcy in the moment, they have those with whom they shared the experience to process and reminisce memories with later.

Support from Local Networks

When receiving PnPC in a community hospital, a family can receive support from friends/neighbors/ family who live in the area, as well as from members of their own faith community (in addition to pastoral care from the hospital

chaplain). Members of the family's normal support network can help in taking care of the family home/pets, running errands, and helping with the family's other children. For situations where long visits might be hard for the siblings, lessened travel distances can make shorter (and possibly more frequent) sibling visits possible. Births that are centered in a local community hospital can increase possibilities for participation from those who are important to the family but who might not be able to travel to another city to provide support.

Bereavement Care Both Before and After the Death

Family and friends can come to the local hospital thus creating important shared memories with the people in their daily lives. Some may participate in memory-making activities such as making molds of hands and feet or dressing the baby. Parents may be able to enlist a friend or local photographer to take memorial photographs. Siblings can take part in these and other aspects of the infant's brief life. A local funeral home that may have cared for family members in the past will have easy and familiar access to the community hospital. Funeral services personnel may be able to retrieve the infant's body from the mother's room in a community hospital, rather than from a hospital morgue. Parents could be spared the complexity and expense that would have been involved in transporting the infant's body from a distant tertiary care institution. With family and the funeral home both in the local community, it will be easier to plan funeral and burial or other memorial rituals. Finally, many community hospitals already have in place support groups for parents, sibling loss activities, and annual memorial events, and such institutions may find it easier than large medical centers to accommodate alternative requests for bereavement support at the time of death or later.

How Might Community Hospitals and Referral Hospitals Work Together to Provide Excellent Care?

Having community hospitals (which normally use them as their tertiary referral center) offer perinatal palliative care could increase options that referral centers have to offer families. When it has been determined that aggressive treatment therapies would not benefit babies who are being worked up prenatally, rather than continuing on the path of referral to highest levels of care, the teams at both the referral center and the outlying community hospital could engage in discussion to help the family discern the best location to deliver based on goals of care. Back up plans for what circumstances might trigger a change in the plan of care could be decided upon ahead of time

If not all outlying community hospitals offer perinatal palliative care, the referral hospital may refer a family to a community based hospital who does offer the service which might still be closer to home than the tertiary center. Additionally, some referral neonatal centers do not have birth services. If a case looked as if that palliative care might be needed in the delivery room rather than the NICU, the tertiary hospital might suggest local services for that baby/family.

There are many scenarios where small details might sway the benefit of community hospital vs referral center delivery. It is helpful to identify key contact perinatology and neonatology providers who are willing to provide consultation and support once care is transferred to the community center. The outlying hospitals and the referral centers having good working relationships is pivotal in coordinating optimum care for these cases.

If pediatric care providers in community hospitals are not yet comfortable with symptom control and other aspects of palliative care medicine, the referral hospital could be a resource for clinical education and information about available continuing education opportunities. It is especially helpful if a specific small group of providers at the referral hospital stay in close contact with the teams at the outlying hospitals.

What Might be Useful in Planning for PnPC at the Community Hospital?

Having a staff member who can function as a perinatal palliative care coordinator is important to a program's success. In addition to constant communication with the family, the coordinator must engage in antenatal discussions with OB, neonatal/pediatric, and Mother-Baby staffs to prepare to implement the advance care/parenting plan developed with the parents. Part of the postnatal plan addresses family preference of what care-area the baby is likely to stay in. Most families choose for the infant to stay with the mother in her care area but other options exist. The neonatologist/pediatric provider is the key person who will assist the family in deciding what changes might be considered to the baby's treatment plan based on last minute changes and/or differences between the baby's expected condition and baby's actual presentation at birth. These contingency possibilities should be discussed during the planning phase.

Conclusion

"Community delivery settings are ideally positioned to provide a family-centered experience for families expecting an infant with a short life. Despite the hospitals' smaller size, caregivers in these hospitals have distinct advantages in offering families customized birth/life/death experiences for infants with life-limiting conditions. For many practical reasons, including the smaller physical setting of care and core staff and convenience for families, a hospital in a smaller community creates an ideal setting for PPC for families who choose to deliver locally."⁹

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Heartbeat Recordings in the NICU

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The Neonatal Intensive Care Unit (NICU) can be characterized by a variety of experiences and emotions for infants, parents, and families. Within its walls can be found challenges of separation and reconnection, periods of loss and grief, and moments of laughter and joy. Infants admitted to the NICU are medically fragile and sensitive to their unfamiliar environment, sometimes due to surgical and complex diagnoses in addition to prematurity. For families, any interventions such as heartbeat recordings that promote engagement and connection are welcome as they grasp for opportunities to know and to be known by their baby. Heartbeat recordings can be an integral component of perinatal palliative care and fetal/neonatal recordings can be part of memory making in case of neonatal death.

Interdisciplinary approaches in the NICU are important for fostering infant development and integration of the whole family. As the music therapist on my team, I focus my work on facilitating and fostering positive auditory and musicking experiences that relax and comfort the infant and promote the infant's family as musical caregivers. Given that a NICU admission is defined as a moment of separation between baby and parents, often sudden and unexpected, the goal of any clinician in the NICU is reunification and promotion of the parent-infant relationship (Treherne et al., 2017). Heartbeat recordings are a simple and effective way to address the infant's auditory experience, facilitate an opportunity for parents to provide for their child, and, in conjunction with other music therapy interventions, lift up parents as musical caregiver through creative expression.

What is a heartbeat recording?

Heartbeat recordings are defined simply as a recording of heart tones, in this case of either the infant or the family members. Using a digital recording stethoscope device and/or a doppler, clinicians can capture brief recordings of heart tones that can be then looped or edited to varying degrees with a recording or music editing application. The recording of a heartbeat itself can be used by non-music therapists to support the family. However, when offered as a music therapy intervention, the music therapist will work with the family in a music process in which the heartbeat may be used as part of a song for expression and connection.

Why offer a heartbeat recording?

In its most fundamental form, heartbeat recordings can be used with premature infants to enhance and familiarize their environment. Auditorily, the womb is characterized by rhythm, repetition, and predictability (Ullal-Gupta et al., 2013). One familiar sound that is suddenly removed when an infant is born prematurely is that of their mother's heartbeat. By recording the mother's heartbeat clinicians can offer a sense of normalcy for infants in a relatively non-intrusive manner. There is evidence that recorded heartbeat sounds are soothing and decrease pain for infants in the NICU (Rossi et al., 2018). Additionally, researchers found that the act of providing their own recorded heartbeat for the child improved mothers' comfort, sense of cohesion, and personal growth as caregiver (Corrigan et al., 2022).

In my practice I have offered maternal heartbeat recordings to enhance the infant sound environment when the parents are limited in their ability to visit their child and participate in kangaroo care. After recording the heartbeat and editing the sound to extend around 2 minutes, I provide an iPod and pillow speakers at the bedside for the nurses to use. Nurses are instructed to use the recording only after hands on care and, for extremely premature infants, to provide physical containment during presentation of the recording in line with our standard developmental care practices in our unit that aim to reduce risk of overstimulation and state disorganization.

Recordings of the infant's heartbeat may also be offered to address parent/caregiver feelings of separation and closeness. For parents who are back at work during the day or even hospitalized themselves due to birth complications, heartbeat recordings can provide a sense of closeness when they need to be far away. In a study by Corrigan et al. (2022) examining the ways in which parents used recordings of their infant's heartbeat, some parents indicated using the recordings while they were at work, when they were in spaces of their home without their baby, and to share with extended family. In my years as a music therapist, we have occasionally had parents who were admitted themselves after birth either due to birth complication (i.e., high blood pressure or HELLP syndrome), or due to a preexisting condition that required hospitalization after giving birth (i.e., congenital heart defect). In those cases, I have offered an exchange of heartbeat recordings as a way to bring the mother's presence into the infant's new environment and to support the bonding process by providing a recording of the infant's heartbeat for the hospitalized mother.

Probably the mostly commonly utilized purpose of heartbeat recordings among music therapists and non-music therapy clinicians would be for legacy building and memory making in the case of end of life and bereavement. In addition to hand and/or foot molds, prints, and other arts-based memory-making tools, heartbeat recordings can provide an auditory memory for families experiencing the loss of their child. In a study surveying bereaved parents on their experience with heartbeat recordings in pediatric palliative care, participants indicated the recording to be comforting and a way to maintain connection with their child after loss (Andrews et al., 2020).

While the heartbeat recording alone is a cherished memory, the involvement of a music therapist can provide an opportunity for families to process anticipatory grief and potentially gain continued support after hospitalization during bereavement. In the same study, participants who chose to pair their child's heartbeat with a song referenced the memories the recording preserved as they chose to record songs that they sang with their child (Andrews et al., 2020). While not in a pediatric setting, Schreck et al. (2022) recorded similar responses from bereaved family members of adult oncology patients who shared that listening to their recordings offered comfort during major events like birthdays and triggered fond memories related to the songs they chose.

When should a music therapist be involved?

Though the simple act of recording a heartbeat or heart tones is itself not owned by music therapy, the process of developing and integrating family in that recording process, particularly in the NICU, is greatly enhanced by the involvement of a music therapist. Aside from addressing anticipatory grief and bereavement support for families leading up to and after their infant's death, music therapists can also implement heartbeat recordings to promote creative expression, to facilitate a musical caregiving process, and as a way to reframe a chronic illness. Walden et al. (2021) conducted a qualitative study on the use of heartbeat recordings with families of children diagnosed with progressive neurodegenerative diseases during both the pre-loss and loss phases. Parents regarded the heartbeat recording as a powerful connection to their child that honored both the medical and parental view of their experience. Parents also spoke about the importance of the song selection process, which took into account the message, the song characteristics, and the legacy of their family.

Music therapists engaging with NICU patients in this process will employ techniques such as the song of kin, in which parents identify a song of connection with their infant that honors their family, culture, and identity (Loewy, 2015). Music therapists may also engage parents in a songwriting process to allow parents to tell their child's and

their family's stories. This song may also serve as a way for them to provide for their infant by taking an active role in creating something for them, rather than being a spectator to their care.

Limitations

The NICU environment in particular has a number of limitations to completing heartbeat recordings. The biggest limitation is medical equipment: if the infant is on an oscillator or jet ventilator support, the digital stethoscope will not pick up heart tones simply because of the volume of these respiratory devices. Similarly, certain levels of ECMO support may limit or impact the sound of heartbeat tones as well. At times, using the doppler to record heart tones may be an option. This process would require the recording/music mixing application, a microphone, and a doppler device. In the case of ECMO, I recommend you work with your bedside staff and providers to assess the best method of recording, if appropriate.

Additionally, it is important to remember the importance of gaining family consent prior to completing heartbeat recordings as there may be religious or personal reasons that families choose not to participate in such a process. This may be a limitation in the case of families that cannot be present with their child often. I recommend involving your music therapist if you have one as well as your spiritual care staff to assess if offering memory making such as heartbeat recordings will be appropriate.

Conclusion

Heartbeat recording interventions offer support for family connection, comfort, and legacy building at varying levels of complexity and depth. Non-music therapy clinicians can offer simple recordings to enhance the infant's environment or reconnect parents and infants when separation is ongoing or during pre-loss phases. However, involvement of a music therapist can provide depth to this intervention that allows for parents to address anticipatory grief and process their experience in the NICU and with their child's chronic illness and/or long-term admission.

For resources on recording stethoscopes and music editing applications please reach out to the author at elisabeth.bombell@aah.org

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Neonatal Pharmacokinetic Considerations In Symptom Management

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The neonatal period (first 4 weeks of life) represents a time of rapid change, development, and risk.¹ With advances in medical technology, infants are surviving that would not otherwise, increasing the need for palliative care in this population.² Premature or extremely low birth weight (Table 1) neonates typically require intensive follow up due to their complicated medical histories. Managing symptoms in the population can be especially challenging.

Table 1. Classification of Neonatal Birth Weight^{3,4}

Classification	Criteria
Extremely low birth weight (ELBW)	< 1,000 g (2 lb 3 oz)
Very low birth weight (VLBW)	< 1,500 g (3 lb 5 oz)
Low birth weight	< 2,500 g (5 lb 8 oz)

Some of the more common symptoms seen in the neonatal population include:

- Seizures
- Myoclonus
- Dyspnea
- Pain
- Secretions
- Thrush
- Reflux
- Gas
- Complications of congestive heart failure, including fluid overload

Assessment

Since neonates are unable to express discomfort verbally, age-appropriate assessment strategies should be utilized. Often more objective measures can be utilized, such as heart rate (considering age specific normal values). For example, an increased heart rate may indicate pain in a neonate. Other indications of pain in a neonate include high pitched crying, brow furrowing, nasolabial bulge, and squeezing the eyes shut.

Non-Pharmacological Therapies

Non-pharmacological therapies should be first line in most situations, especially in infants and children. These strategies can include massage, music, and minimizing stimulation and painful procedures. Some therapies are

more specific to the neonatal period, including swaddling, kangaroo care, nesting, and non-nutritive sucking (e.g., pacifier, sucrose). Neonates may also have difficulty maintaining their temperatures and may require warmth.⁵

Pharmacotherapy

Neonatal pharmacotherapy is complicated by developmental limitations that affect the pharmacokinetics of most drugs. Infants should be monitored for clinical response throughout therapy and medications adjusted as needed. Medication doses will be determined based on gestational age, weight, and indication. Doses may need regular adjustment as patient weight increases. Neonates lose approximately 10% of their body weight during the first week of life. During this time, birth weight should be used for medication dosing.

Preservative free products should be used whenever possible. Preservatives, such as benzyl alcohol and propylene glycol, have been associated with serious side effects, including gasping syndrome, lactic acidosis, seizures, and death. Gasping syndrome includes symptoms of metabolic acidosis that progresses to respiratory distress, gasping respirations, and possibly death.

Immunizations may be given according to standardized schedules even in premature infants, although benefits and burdens must be weighed depending on patient's life expectancy. Hepatitis B vaccine is more effective if given once patients reach 2,000 gm but should not be delayed beyond 30 days of life.⁸

Pharmacokinetics

Many pharmacokinetic parameters are altered in neonates (Table 2), affecting how the body handles drugs compared to older children and adults. For example, drugs are typically absorbed more slowly in neonates, therefore prolonging time to onset of action and peak levels. Hepatic metabolism (e.g., glucuronidation) is slower and matures around six months of age. Clearance is typically slower due to immature kidney function. At birth, serum creatinine levels are reflective of the mother's renal function. Glomerular filtration rate increases rapidly in the first two weeks of life (maturation is slower in premature neonates). Once renal function begins to mature, serum creatinine levels are generally much lower than seen in adults since neonates have decreased muscle mass.

Absorption

At birth, the pH of gastric contents is neutral due to the presence of residual amniotic fluid. Acid output begins within minutes after birth, but infants have decreased capacity to secrete gastric acid compared to adults. In fact, gastric pH doesn't reach adult values until about 3 years of age. This is even more pronounced in premature neonates because gastric acid is rarely present in fetal stomachs prior to 32 weeks gestation. Therefore, oral drug absorption may be altered in children less than 3 years of age. They will have decreased absorption of acidic drugs, such as phenytoin, carbamazepine, and valproic acid. Decreased absorption may result in decreased serum levels, requiring higher doses to achieve therapeutic levels. On the other hand, neonates have increased absorption of basic drugs, such as erythromycin and penicillins.

For drugs formulated in lipid-based vehicles or lipophilic drugs that require solubilization by bile acids, maturation of biliary function can play a key role in absorption. Concentrations of bile salts within the intestinal lumen are decreased in infants less than 6 months of age. This results in decreased absorption of lipid-soluble drugs, such as benzodiazepines or fat-soluble vitamins.

Gastric emptying time is prolonged and often irregular in infants until about 6 months of age. This can cause delayed drug absorption for medications absorbed in the intestines since the medication stays in the stomach

longer and takes longer to reach the site of absorption. On the other hand, medications absorbed in the stomach may have increased absorption since the content stays in the stomach longer. Once again, this may affect dosing. Increased absorption of a medication may mean smaller doses are needed. Gastrointestinal motility can also be irregular, making it difficult to predict peak drug concentrations.

Normal colonization of bacterial flora doesn't occur until 4-6 days of life. Intestinal flora is required for vitamin K dependent clotting factors. Therefore, vitamin K must be administered to neonates at birth. Due to decreased oral absorption of fat-soluble vitamins in neonates, vitamin K is administered intramuscularly.

Typically, intramuscular administration is avoided in neonates due to the variable rate and amount of absorption. Reduced muscle mass, decreased blood flow to the muscle, and increased percentage of water within the muscle all lead to variable absorption via this route.

Neonates usually have increased absorption of topical products since the skin is thinner and more permeable to medications.

Rectal absorption can be erratic in neonates. Retention time is often the rate-limiting factor since younger children and infants have increased high-amplitude pulsatile contractions of the lower gastrointestinal tract. Suppositories that deliver their contents over hours will very likely be expelled prior to providing the entire drug dose. Also keep in mind the size of the patient when administering medications rectally. The catheter tip should be inserted less than 1 inch into the rectum in neonates.

Distribution

Infant body composition can affect drug distribution. Due to the increased water composition and decreased fat composition, water soluble drugs (e.g., aminoglycosides) have increased volume of distribution, while lipophilic medications (e.g., LORazepam) have a lower volume of distribution. Serum albumin and protein concentrations are decreased in neonates. Therefore, drug binding to plasma proteins will be decreased, resulting in increased free drug (e.g., phenytoin). Some medications (e.g., ceftriaxone, sulfamethoxazole) displace bilirubin from protein binding sites. Neonates are unable to adequately excrete bilirubin, resulting in elevated bilirubin levels. Due to the increased permeability of the blood-brain barrier, neonates are at risk for accumulation of bilirubin in the brain, known as kernicterus.

Metabolism

Maturation of enzyme activity occurs at different ages for different metabolic pathways, affecting the clearance of some drugs. Depending on the pathway that a drug undergoes to get metabolized in the body, some drugs are metabolized more rapidly than an adult and some are metabolized slower compared to an adult.

Levels of CYP enzymes increase steadily throughout infancy, maturing to adult levels by one year of age. For example, alcohol dehydrogenase enzymes that are less than 4% of adult values in infants. Therefore, infants can't metabolize alcohol and elixirs containing alcohol should be avoided.

Sulfation develops in utero and is well developed at birth. Glucuronidation is only about 10% of adult values at birth. Morphine is metabolized via glucuronidation. This partially explains why infants less than 3 months of age are at increased risk of respiratory depression and why doses are significantly lower in this population. Acetaminophen is primarily metabolized through glucuronidation, but it is also metabolized through sulfation, so neonates are able to metabolize acetaminophen via sulfation instead of glucuronidation. On the other hand, infants are unable to metabolize ibuprofen until about 6 months of age because of the CYP enzymes and glucuronidation involved in its metabolism.

Elimination

Although the body uses many organs to facilitate the removal of drugs and their metabolites, the kidneys are the major organ of elimination. Nephrogenesis is complete by 36 weeks gestation, yet maturation continues throughout childhood, especially the first year of life. Although the kidney is fully developed at birth, the different components of renal elimination are not, including glomerular filtration, tubular secretion, and tubular reabsorption. Renal function isn't completely mature until all three of these processes are developed at about one year of age. Decreased renal function in infants leads to significantly reduced clearance, so medications are removed more slowly, and their half-life is prolonged. Neonates often require longer dosing intervals. For example, fluconazole's half-life is considerably longer in premature infants (88 hours vs 18-25 hours). Consequently, fluconazole dosing in infants less than 29 weeks gestation and less than 14 days of age is q72 hours compared to q24h for term neonates.

Effective symptom management in neonates can be more challenging due to different pharmacokinetic properties. Utilizing some of the above principles can help guide thought processes. As always, managing symptoms in neonates should be patient specific.

Table 2. Neonatal Pharmacokinetic Alterations^{1,3,6}

Function	Alteration	Neonatal Function	Compared to Older Children
Enteral Absorption	Gastric pH	High at birth (6-8) Decreases after 24 hours	Decreased bioavailability & increased absorption of acid-labile drugs
	Gastric emptying	Feeding dependent; Variable	Unpredictable rate of drug delivery to intestinal mucosa
	Intestinal motility	Slower	Prolonged time to achieve maximum plasma concentration
	Lipase levels & bile salts	Decreased	Decreased bioavailability of lipid soluble drugs
	Efflux transporters	Reduced	Altered bioavailability
Rectal Absorption	Permeability and first pass to portal circulation	Higher if administered into distal rectum; If deep administration, first-pass effect may alter bioavailability	Increased bioavailability if drug absorbed into lower or distal segment of rectum Typically, increased absorption
Intramuscular Absorption	Perfusion, muscle mass, and activity	Usually decreased Increased capillary density in neonatal muscle	Decreased rate of absorption due to decreased cardiac output Potential local trauma
Transdermal Absorption	Surface area-to weight ratio	Increased	Increased absorption
	Stratum corneum	Incompletely formed	Increased absorption
	Vasomotor control	Immature	Increased absorption
Inhalation	Mucosal permeability	Increased	Systemic exposure
Distribution	Total body water	Increased volume of distribution	Reduced peak and threshold concentrations at weight dosing
	Extracellular water	Increased	Further expands volume of distribution
	Body fat composition	1% of adult level in preterm and 15% in term infants	Lower lipophilic drug disposition

Function	Alteration	Neonatal Function	Compared to Older Children
Blood-brain Barrier	Permeable barrier	Immature	Increased potential permeability
Protein Binding	Plasma proteins	Decreased	Increased free/unbound drug available to receptors
Metabolism	Biotransformation primarily involving hepatic enzymes	Decreased	Drug dependent; renders some drugs more active and some less active; often affects clearance
Hepatic Blood Flow	Extraction or removal of active drug by metabolism	Increased cardiac output to liver increases hepatic flow	Increased clearance of drugs with high intrinsic hepatic clearance
Renal Elimination	Glomerular filtration	Dependent on renal blood flow; reduced in premature infants; reaches adult levels by two years of age	Most drugs have delayed clearance with increased half-life elimination with individual variability
	Tubular secretion	Reduced active secretion	Delayed excretion and prolonged half-life
	Tubular reabsorption	Reduced	Dependent on renal blood flow, glomerular filtration rate, urine output, urine pH, and tubular secretion
Clearance	Multisystem function	Reduced	Accumulation

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Readers' Corner

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Limbo R, Wool C, Carter BS., *Handbook of Perinatal and Neonatal Palliative Care: A Guide for Nurses, Physicians, and Other Health Professionals*. New York, NY, Springer Publishing Company LLC, 2020.

Summary: This is a well-written, easy to read ~400-page textbook geared toward interdisciplinary professionals caring for fetuses, newborns, and parents in the perinatal setting. While not new as it was published in 2020, it seemed appropriate to bring this to our readers' attention. This book provides definitions and clarity, defines skills needed to provide perinatal palliative care, and describes strategies to operationalize palliative care in the perinatal setting.

Who: All professionals who deal with fetuses and newborns and their families will likely benefit from this well-written guide to providing palliative care in the perinatal setting.

What is special about this book?

- **Approach:** Not only is there evidenced-based information, but there are also real life case studies that help the reader imagine how to operationalize the principles. Having a "roadmap" to help chart one's path is helpful, especially in this situation where, especially in the prenatal situation, the information is incomplete, and the destination of the "road" may be unclear. Evidence-based decision making, advance care planning, and a compassionate approach towards the family, the fetus/newborn, and the staff are central to perinatal palliative care.
- **Target readers:** These include obstetric and neonatal nurses, physicians (OB, neonatologists, anesthesiologists, surgeons, geneticists, pediatric subspecialists, etc.), physical and occupational therapists, and others.
- **Impact:** The principles of perinatal palliative care can be applied as soon as a probable diagnosis of a potentially life limiting condition is made.
- **Exercises:** There are helpful and stimulating questions that professionals might be expected to answer. For instance: "What are the chances of success?" "What would my baby's development be like?" There are helpful issues reviewed that the team will likely need to address. Helpful pain scales are included. Processes such as withdrawing no longer beneficial life-sustaining support are reviewed. There is a lot of practical, helpful information that helps the staff operationalize the principles of palliative care in the perinatal setting.

Where and how can I apply this information? One does not need a specific perinatal palliative care program to provide the care! The pertinent fetus/newborn, the family, and the staff all benefit from the principles.

When should I get this book? If you care for pregnant women, fetuses, and/or newborns, you NEED this book now. (It is available on Amazon for <\$50 – and it gets 5 stars!)

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National Pediatric Palliative Care Task Force Releases New Guiding Principles in Response to Dobbs vs. Janson and Related Issues. National Coalition for Hospice and Palliative Care and National Pediatric Palliative Care Task Force. <https://www.capc.org/blog/the-national-pediatric-palliative-care-task-force-releases-new-guiding-principles/>

Summary: This statement was generated because of concern about the impact of Dobbs vs. Jackson on perinatal palliative care and its providers. As this would criminalize comfort-focused care for newborns with life-limiting conditions, the act is a threat to parents' decision making and would limit the ability of care givers to practice evidence-based, compassionate medicine.

Who might find this information useful? Perinatal providers of palliative care and families dealing with a fetus or newborn with a life-limiting condition.

What is special about this statement? Guiding principles help clarify the position of the National Pediatric Palliative Care Task force concerning perinatal decision making. The guiding principles include:

- The opportunity for everyone to receive comprehensive evidence-based, goal concordant care
- The opportunity for clinicians to practice evidence-based medicine without fear
- The ability for individuals (or their decision-makers) in consultation with their health care teams to decide medical issues privately and without government interference

Where and how can I apply this information? For perinatal palliative care providers, it is important to consider these principles when guiding the family in making difficult decisions where the fetus or newborn has a life-limiting condition. The consequences for the providers following these guidelines might be significant. The consequences of letting those other than the parents, in conjunction with trained perinatal clinicians, decide what is best for their child are monumental.

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Resolve Through Sharing. (2022). *Perinatal palliative care: A Resolve Through Sharing position statement*. La Crosse, WI: Gundersen Lutheran Medical Foundation, Inc. Available through Gundersen Medical Foundation, www.ResolveThroughSharing.org; 608.775.4747 | 800.362.9567 x54747

Summary: This is an update of the previous 2009 and 2016 position statements of this well-established organization focused on perinatal bereavement. (I should mention that I was a major contributor to all 3 versions.)

Who might find this information useful? Perinatal providers and families dealing with a fetus or newborn with a life-limiting condition.

What is special about this document? While the principles of perinatal palliative care remain unchanged, the application of these principles has evolved. This position statement addresses:

- The needs of families choosing medical termination not just those choosing to continue the pregnancy
- The importance of diversity, equity, and inclusion
- Initiating perinatal palliative care principles upon the diagnosis of a life-limiting or life-threatening diagnosis in the fetus, newborn, or pregnant mother and offering formal care by the perinatal palliative care team

There is a clear review of definitions, the target population, benefits of practicing palliative care in the perinatal setting, myths and facts, goal identification and hopes, ethical decision-making, advance care planning, bereavement support, staff education, and professional self-awareness and well-being.

Where and how can I apply this information? While this position statement talks about offering perinatal palliative care as an option soon after the life-threatening diagnosis, I strongly believe that once the diagnosis has been made, the principles should be followed regardless of whether or not the family accepts care by the palliative care team.

Items of Interest!

1. Subjects and Contributors for Future Issues of this E-Journal

Our future issues will be centered on the following main themes. If you have any thoughts about these or any other topics, contributors, or future issues, please get in touch with Christy at Christy.Torkildson@gcu.edu or Suzanne Toce at tocess@gmail.com.

Issue Topics: 2023 (Note: Subject to Change at Work Group's Discretion)

- Issue #71: Education & Training for Pediatric Palliative and Hospice Providers/Programs Care; contributions due 31 March 2023.
- Issue #72: Education & Resources for Adult Hospices Caring for Kids What are the barriers, what is difficult to overcome in PPC; contributions due 31 May 2023.
- Issue #73: To Be Announced – Send us your suggestions!!!

2. [Registration is open for the NHPCO Interdisciplinary Virtual Conference April 24-26 with a focus on Quality and Safety.](#)

- It's never too early to plan for the NHPCO Interdisciplinary Virtual Conference in 2024! The call for proposals will open in September 2023!

3. [The Annual NHPCO Leadership Conference will be in Little Rock, Arkansas October 2-4, 2023. Call for proposals opens March 17th.](#)

4. [Did you know that the State Coalitions from Pennsylvania, Illinois, and California, with support from the Shiley Haynes Institute for Palliative Care and the HAP Foundation, host monthly, affordable webinars with continuing education units available? You can register](#) for one or the entire series, with discounts for multiple registrations.

5. [On that same note, did you know there was a network of state coalitions and folks interested in helping with or starting a state coalition for Pediatric Palliative Care?](#) For more information, contact Betsy betsy@ppcc-pa.org

6. [The AAHPM/HPNA Annual Assembly is coming up, March 22-24, 2023, in Montreal, Canada!](#) More information can be found on [AAHPM's website](#).

7. [End-of-Life Nursing Education Consortium \(ELNEC\) project](#) has several upcoming courses.

8. [EPEC-Pediatrics will be held May 22-24;](#) please, email EPEC.Pediatrics@ucsf.edu for more information.

9. [Recently, the California Advocacy Network for Children with Special Health Care Needs announced their foundation had committed to increasing access to journal articles that may be difficult for family members and non-profit staff to access to improve "effective and equitable systems" as "access to scholarly work is essential to system improvement."](#) More information can be found on the [California Advocacy Network for Children website](#). It may be helpful to contact your state's chapter to determine what resources they may have!

10. [Courageous Parent's Network has a wealth of resources for parents, caregivers, and providers.](#) The list is too long to add here so please [check out their website](#).

11. **Join NHPCO on Thursday, March 2 at 3 p.m. ET for Cultural Humility in Pediatric Care, an interactive Project ECHO session that will explore the importance of providing culturally competent care for pediatric patients and families in hospice and palliative care.** [Register](#) for the 2023 series or visit the [Project ECHO page](#) for more information. Project ECHO is an innovative program designed to create virtual communities of learners by bringing together healthcare providers, subject matter experts, and the wider community using case-based learning and fostering an "all teach, all learn" approach. Recognizing that diversity expands across many dimensions of our identity, the 2023 Project ECHO curriculum will focus on inclusive topics addressing various aspects of diversity and cultural competence in healthcare.

Previous Items of Interest:

12. **The Pediatric Palliative Care Coalition of Pennsylvania, the Greater Illinois Pediatric Palliative Care Coalition, and the Funeral Service Foundation have created a community resource to guide families through the funeral/memorialization planning process:**

When a Child Dies: Planning Acts of Love & Legacy

This resource is available in both English and Spanish and is FREE, thanks to generous funding from the Funeral Service Foundation. You pay only a nominal shipping fee. More information can be found at [When A Child Dies](#).

13. **Pediatric Go Wish Together:** A conversation game for parents and pediatric caregivers; developed by Meghan Potthoff, Ph.D., APRN-NP, PPCNP-BC, CPNP-AC in collaboration with Coda Alliance. This game is "developed to help parents navigate the unimaginable journey of their child's illness." "It is a tool that provides parents and providers a way to think and talk about what's most important to the child". More information can be found at [Pediatric Go Wish Together](#)
14. **Have you heard of the new organization PallCHASE: Palliative Care in Humanitarian Aid Situations and Emergencies?** Their primary ambition is the relief of suffering, and their purpose "To work in partnership through a visible and effective network to advocate for palliative care integration in humanitarian situations or emergencies...". Please visit their website for more information, healthcare professional training and resources in a variety of languages! [Click HERE](#) to check out their website!
15. **Another great new group is the Child Life in Hospice and Palliative Care Network, which provides child life specialists working in hospice or palliative care access to resources, education, research, and networking opportunities to establish and provide best practice care for patients and families experiencing a serious illness.** They are requesting that interested members fill out a brief survey, sign up today at [CLHPN](#)
16. **A Toolkit of Autism, Grief, and Loss Resources by Hospice Foundation of America**
[The toolkit](#) will include a variety of materials and resources, such as:
 - suggestions for responding to the grief experiences of autistic adults;
 - ways to provide for choice and inclusion in rituals;
 - tips for communicating the news of death;
 - social stories on grief for adults;
 - videos about grief, including interview clips with autistic adults and their families;
 - two complimentary continuing education (CE) programs for professionals; and much more!
17. **A resource for pregnancy or infant loss is [Share: Pregnancy & Infant Loss Support](#).** Share was started in 1977 in response to the urging of one bereaved family by Sr. Jean Marie Lamb, OSF. Initially providing support groups, they now offer online support groups, education, and support for families and caregivers.

18. NHPCO Palliative Care Online Resources: NHPCO has a variety of pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics. Also, more palliative care resources are available at www.nhpc.org/palliativecare, including:

- Community-Based Palliative Care
- Legal and Regulatory Resources
- Webinars and Courses
- Plus, more for NHPCO members

Palliative Care Programs and Professionals

Founded in 1978, National Hospice and Palliative Care Organization (NHPCO) is the world's largest and most innovative national membership organization devoted exclusively to promoting access to hospice and palliative care and to maintaining quality care for persons facing the end of life and their families. Join NHPCO Today!

[Individual Palliative Care Membership](#)

[Palliative Care Group Application](#) - Save by registering your entire team

19. The Pediatric Palliative Care Coalition of Pennsylvania (PPCC) has made a new resource available – a Sibling Grief and Bereavement Toolkit. This Toolkit has been developed to address the needs and concerns of children and teens who have experienced the death of their sibling with medical complexities. Please see the associated article in this edition! Below is a link to the toolkit and one of the activities – **"Make a Feelings Chart"**.

[View the PPCC Sibling Grief and Bereavement Toolkit.](#)

Toolkit Activity

For children who are grieving the loss of their siblings, returning to school can be a difficult transition. Check out this month's highlighted activity from the toolkit that may help children and teens in the upcoming school year.



Make a Feelings Chart by [downloading the activity](#). PPCC invites you to share this information with parents, caregivers, medical professionals, providers, therapists, etc.

20. Pediatric Hospice and Palliative Care Resources:

- **CaringInfo**, a program of the National Hospice and Palliative Care Organization, provides free resources to help people make decisions about end-of-life care and services before a crisis. www.caringinfo.org

NHPCO's Palliative Care Resource Series includes pediatric palliative resources like:

- Communication Between Parents and Health Care Professionals Enhances
- Satisfaction Among Parents of the Children with Severe Spinal Muscular Atrophy
- Consideration for Complex Pediatric Palliative Care Discharges
- Songs of the Dying: The Case for Music Therapy in Pediatric Palliative and
- Hospice Care
- Nonpharmacological Pain Management for Children
- Sibling Grief
- Pediatric Pain Management Strategies

- Communicating with a Child Experiencing the Death of a Loved One: Developmental Considerations
- In an effort to standardize the medication coverage process for children receiving concurrent care, the NHPCO Pediatric Advisory Council developed a new resource for providers titled *Determination of Hospice Medication Coverage in CHILDREN*.

21. Trends in Pediatric Palliative Care Research

Every month, PedPalASCNET collects new pediatric palliative care research. For past lists visit their blog, browse in their library, or join the Zotero group. View the New Citation List in their library.

Please note the archived issues are available as a community-service by NHPCO and can be found at www.nhpc.org/pediatrics or by reaching out to Pediatrics@nhpc.org.



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