



PERINATAL PALLIATIVE CARE

Carolanne B. Hauck, M.A., B.C.C.

Staff Chaplain

Lancaster General Women and Babies Hospital

INTRODUCTION

Life-limiting conditions diagnosed prenatally pose special challenges to pregnant patients and their families, as well as to providers of obstetrical care. These challenges can be addressed by building relationships with patients and their families before birth. At Lancaster General Health's Women and Babies Hospital, a Perinatal Palliative Care Team (PPCT) has been created to foster relationships that facilitate a meaningful birth experience even when the projected medical outcome is poor.

PERINATAL LOSS

It is never easy to hear that a baby has died, and the grief of some families begins well before their baby's actual death. Some families live with the news that their baby is going to die for several months in advance. Confirmation of the news that their baby's condition is incompatible with life has an impact that some couples describe as "the worst day of our lives, even harder than the day our baby died."

When a baby dies at Women and Babies Hospital, either through miscarriage or still birth, it has been a longstanding practice to extend compassionate care to the mother and her family in a way that fosters the beginning of the long process of healing. By recognizing the impact of a loss on the family, the medical team is able to create a safe space in which families can navigate a suddenly foreign world; one from which a baby that was much anticipated and loved is now gone.

Prior to starting the PPCT, Women and Babies Hospital relied on a Bereavement Team which includes staff from all units and service lines. This team has implemented the Resolve Through Sharing (RTS) JACHO-recognized standard of care when a family is faced with loss. RTS is an evidence-based program that seeks to equip staff working with bereaved parents to utilize a holistic and interdisciplinary approach to comprehensive care for grieving patients and their families.

Since the family may experience a feeling of being robbed of the opportunity to make memories with their baby, they are encouraged to take the opportunity to make those meaningful memories while in the hospital. Staff honors couples' requests to spend as much or as little time as they wish to hold and parent their baby while they can. Given the opportunity, many patients find comfort in bathing and dressing their babies as well as accepting help from staff in order to create keepsakes such as footprints, photographs, and locks of hair, all of which are stored in a beautiful memory box that parents take home. Patients often leave the hospital wanting to express their appreciation for the care received at such a difficult time.

As I contemplated bereavement care and the couples who unexpectedly learn that their baby may die, I wondered if we as a team at Women and Babies could somehow extend that same compassionate care prenatally.

PERINATAL PALLIATIVE CARE TEAM BEGINNINGS

With the help of Kevin Lorah, MD, Medical Director of the NICU, and with support from the administration, we began to explore how we might better address the needs of families; not only those who know even before birth that their infant may die, but also those with infants in the NICU whose care has turned from initially curative to merely palliative. Perinatal palliative care quickly became part of our vocabulary as we reviewed the literature about how to address the challenges faced by patients and their families who were threatened with the death of their baby.

We found the book *Implementing a palliative care program in a newborn intensive care unit*,¹ by Gale and Brooks, to be very helpful, as it served as a blueprint for building a team. Also helpful were articles written by Gold,² which summarized women's experiences with healthcare providers after neonatal death; as well as articles written by Summner, Kavanaugh, and Moore,³ about the extension of palliative care into the

prenatal period. Catlin and Carter,⁴ provided information about the development of end of life protocols in the NICU and also helped us to better understand perinatal palliative care.

We learned from Catlin and Carter, that “Palliative care for newborns is holistic and extensive care for an infant who is not going to ‘get better.’ Palliative care focuses on both the infant and his/her family. Palliative care may initially be cure-oriented, disease modifying care and then intensify when that form of care is no longer helpful or appropriate. Palliative care is an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the infant’s living and dying. It is a team approach to relieving the physical, social, emotional, and spiritual suffering of the dying infant and the family.”

Within the Lancaster General Health community, we were grateful for support and advice from members of the adult palliative care team. Their team approach proved a model that we soon followed. The initial team included the addition of Cindy Castaldi, RN from the NICU, Sharon Kauffman, RN, Labor and Delivery, and WBH Social Worker Maria Delgado. Together we defined roles and services, outlined coordination of care, and wrote a mission statement to reflect the care we hoped to provide. As the team began to receive referrals from Obstetrics providers and physicians from Maternal-Fetal Medicine, a need arose to expand the team to include a Neonatal Nurse Practitioner, registered nurses from OR and PACU (post-anesthesia care unit), and other staff on an as-needed basis, depending upon the unique needs of each family.

COST

It is also important to mention that families referred for perinatal palliative care do not incur additional charges. Rather, each unit and service line of the hospital involved with the care of the patient supports the program by contributing its staff time. This team effort truly exemplifies the values of Lancaster General Health.

PPCT—WOMEN AND BABIES HOSPITAL; STRUCTURE AND FUNCTION

The team meets with the family shortly after a diagnosis is made to begin building trust, as well as a plan for delivery. Each member brings his or her unique expertise in order to help the patient and family find what will be most helpful for them

during the prenatal period, as well as through delivery and beyond.

- Neonatologist: confirms diagnosis, prognosis, and preference for care after birth. Communicates with the woman’s care provider. Provides consultation on pain/symptom management, ethical dilemmas, and decision making. Attends delivery and is primary physician for neonate.

- Chaplain: assesses spiritual concerns, coping strengths, and available support from family and community. Acts as a liaison between clergy, family, and staff as needed and offers ritual when appropriate to the family’s cultural and religious beliefs.

- Labor and Delivery (L&D) RN: helps family formulate a birth plan and initiates contact with the team when labor begins. Responsible for coordinating communication between the team, staff, and the family. Attends the delivery and follows patient through hospital stay and discharge.

- NICU RN: attends delivery and assists in stabilization of the baby, conducts pain assessment, and administers medications as ordered. If baby survives, the NICU nurse is responsible for the on-going nursing care plan for the infant.

- NICU Neonatal Nurse Practitioner (NNP): attends delivery and is responsible for the clinical management of the baby with the neonatologist. Supports the plan of care and facilitates communication of the family’s wishes to the team.

- Social Worker: helps families with practical matters such as the completion of insurance and Family Medical Leave Act forms. Coordinates team efforts with appropriate hospital departments and community resources to ensure a smooth discharge experience as well as follow-up of needs after discharge

PPCT PROCESSES

The initial contact with the PPCT usually takes place when an OB provider (Obstetrician, Certified Nurse Midwife, Family Physician, or Perinatologist) diagnoses a life-threatening or life-limiting condition, and contacts the L&D RN, Chaplain, or Neonatologist. Occasionally the patient or family may make the initial contact with the PPCT to request their involvement. The Neonatologist reviews the available medical information and, as necessary, discusses the plan of medical care with the OB provider, including any confirmatory testing or pending results. The PPCT plans an initial meeting, and the family is contacted to arrange a convenient time and place.

INITIAL MEETING

The main focus of the initial meeting is to develop rapport between the team and the family. Usually the family shares their baby's story with the two or three team members who are present. Families are generally eager to share their joys as well as their disappointments and concerns. The team listens particularly to obtain an understanding of how the family comprehends their baby's condition, as well as the family's support systems, coping skills, and needs. By asking open-ended questions and through active listening, the team learns how to best support the family. The family is assured that all plans are flexible and the team will be present to advocate for their wishes. The team shares contact information, and offers access to its various members for solutions to needs or questions that may arise. The family leaves the initial meeting feeling that they have been heard and supported, paving the way for a meaningful birth experience built upon trust and open communication.

COMMUNICATION

After the initial meeting, a summary of the session is discussed with the OB provider, including the patient's understanding of the condition, the patient's/family's desired plan (if known at that time), and any pending issues. The necessity and frequency of follow-up sessions are discussed and plans are made accordingly.

The team meets monthly, or as needed, to discuss current patients and their needs. The team utilizes creative thinking to devise plans that follow the expressed wishes of the family. Well ahead of the expected delivery, these plans are shared with the hospital staff members who will help carry them out.

Follow-up meetings are scheduled according to the family's needs. The family usually meets with the L&D RN to complete the birth plan and then with other team members as needed. Tours of the NICU and Labor and Delivery suites are offered. "Thinking of you" phone calls and cards are sent by the team periodically in order to maintain continuity of care.

DELIVERY

At least one team member is present to greet the patient when she and her partner arrive for delivery. Every effort is made to have the same staff members provide consistent care throughout the patient's stay. Team members who have a relationship with

the family but were not present for the delivery, visit periodically with the patient and her family to offer support and comfort.

Hospitality is offered through a relaxation of normal visitation rules. The kitchen provides drinks and snacks in a "Butterfly Cart" (named for the butterfly chosen by the bereavement team to signify perinatal loss), and couples are encouraged to invite their family and friends to meet their baby. A professional photographer from Now I Lay Me Down to Sleep Photography takes black and white photos of the baby with family. These photos are set to music, and given to the parents free of charge as a memento.

When the baby dies after delivery, post mortem care begins and includes the normal standard of bereavement care that is offered to all patients who have experienced a loss. When the baby lives longer than expected, and the family desires to take their baby home, practical as well as emotional preparations are made through the Social Worker, and include referrals for Hospice care.

The team makes every effort to attend memorial services, and bereavement follow-up care is provided which includes phone calls and cards, and a follow up meeting with team members.

CONCLUSIONS

Since September 2007, the Perinatal Palliative Care Team has supported more than 30 babies and their families. By providing many opportunities for communication with the PPCT, families who experience the challenges of delivering a baby with a poor prognosis feel supported and cared for during a time usually fraught with fear and anxiety. Patients often comment that it was very meaningful for them to come to the hospital for a delivery, with the assurance that a team of caring professionals whom they have come to know and trust were waiting to care for them and their baby. Typical comments include:

"We would like to thank all the nurses, doctors, and staff of Women and Babies for helping us through this tough time. Everyone has been so kind to us, I don't think we could have made it without the wonderful staff here. We have never met a more caring and good-hearted group of people. We will never forget all the people who stopped in to sit with us, laugh with us, cry with us, and offer their prayers. You will always be in our heart."

"When I saw you in Triage I knew it would be alright".

“It has not been easy but knowing how well our son has been looked over and cared for has brought some comfort. It’s hard to find the words to express how we feel about the wonderful people here, so we will simply say ‘Thank You’.”

“Before I met with the team, I was afraid my baby would be treated differently. He wasn’t going to live regardless. But everyone treated him like a real baby and I was so relieved.”

REFERENCES

1. Gayle, G, & Brooks, A. Implementing a palliative care program in a newborn intensive care unit. *Advances in Neonatal Care.* 2007; 6(1): 35-53.
2. Gold, KJ. Navigating care after a baby dies: A systematic review of parent experiences with health providers. *J Perinatol.* 2007;27(4): 230-237.
3. Summner, LH, Kavanaugh, K, & Moore, T. Extending palliative care into pregnancy and the immediate newborn period: state of practice of perinatal care. *J Perinatal and Neonatal Nursing.* 2006;20(1): 113-116.
4. Catlin, A, & Carter, B. Creation of a neonatal end-of-life care protocol. *J Perinatol* 2002; 22(3): 184-195.

Carolanne B. Hauck, M.A. BCC
Staff Chaplain
Lancaster General Women and Babies Hospital
690 Good Drive
Lancaster, PA 17604
717-544-3418
CBHauck@lghealth.org