Let the Little Children Come to Me: A Perinatal Palliative Care Experience

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Following the perinatologist’s in utero diagnosis that the son she was carrying had anomalies incompatible with life, Ashley Cook became the first patient to be served by Hand in Hand, the perinatal palliative care program at The Women’s Hospital (TWH), Newburgh, IN. This article details the experience of Ashley, her husband Justin and son Skyler as they prepared for Chance’s birth and death. In addition, it describes the program’s creation and ongoing evolution as the palliative care team addresses the needs of hospital staff who attend these unique births as well as the families who experience them. The Cooks continue to share Chance’s story via local ethics retreats and articles such as this. The Hand in Hand program also has received recognition beyond the families it serves, including Evansville’s 2010 Celebration of Leadership in Health/Social Service award and the Spirit of Excellence CARES award presented by Modern Healthcare. TWH is an Innovation Exchange participant of the Agency for Healthcare Research and Quality (AHRQ).

AS I OPENED THE DOOR OF HIS MOTHER’S labor/delivery room, I was greeted by five-year-old Skyler, who was wearing purple surgical gloves. I squatted to meet him eye to eye. “Today is the day my baby brother will be born,” he told me. “He won’t be able to live very long because he has a big hole in his face, but at least I finally get to see him and hold him. I am going to help too.” With that, he trotted back to his mother’s bedside.

I was chaplain and contact person for parents Ashley and Justin Cook and their son Skyler, the first family to be served through a program initiated by The Women’s Hospital, Newburgh, IN. "Hand in Hand: Perinatal Palliative Care” had been on the drawing board since the hospital opened in 2001. We were well on our way with ideas, passion and the development of a team when the addition of an onsite perinatologist in 2008 pushed this initiative forward.

Fortuitously, Resolve through Sharing, which is a highly reputable training program for those who serve families grieving pregnancy loss or newborn death, held its first workshop focusing on perinatal palliative care in August 2009.¹ I attended along with an obstetrician, a bereavement team coordinator, a social worker, and the local SMILE on Down Syndrome representative. We returned energized with a renewed awareness that we were on the cutting edge of alternative care for special families and armed with models on which to design our own program.

Launching the perinatal palliative care program

In anticipation of a 2010 launch, we worked with our perinatologist, genetics counselor and head of neonatology to create an algorithm of care, brochures for parents and for professionals, contact sheets and mother’s care plan. The following charts detail the process from diagnosis through delivery:

- Patient referred with possible fetal abnormality – Attachment A.
- Subsequent visits – Attachment B.
- Admission – Attachment C.
We were presented with our first case in October 2009. I first met the Cooks during their meeting with the neonatologist as he explained the in utero diagnosis of fetal anomalies incompatible with life and how this would impact their baby. I introduced myself as the chaplain and explained that I would be the palliative care contact for them during the pregnancy, delivery and hospitalization as well as afterward, should they want my support. I assured them that I would only be present at their request. I added that I would be available to supervise visiting family members and friends as well as to shield them from any uninvited guests.

Along with members of the perinatal palliative care team, I worked to help this family create a birth plan, to educate them regarding choices and to define my role as the team’s point person. (See Attachment D for initial interview form.) As such, I was prepared to provide not only spiritual care but also to orchestrate any special needs. Their initial request was to keep their experience personal, private and as quiet as possible, even limiting interaction with other members of the team to necessary contacts, such as the genetics counselor and the perinatologist.

The focus of our program is to help the family begin to create memories and to reframe their experiences so that each and every moment of the baby’s life is counted and celebrated. By learning about their options, by empowering them to make choices and by supporting their choices, a powerless, painful situation begins to evolve into an experience filled with love and faith renewed. As they waited for Chance’s arrival, the Cook family connected in ways that were unimaginable to them when they first heard the painful words from the perinatologist, the genetics counselor and the neonatologist that he would not survive.

Gradually, they had come to trust us and, in turn, to teach us—lessons of courage, of endurance, of faith. Ashley and Justin mustered the strength and courage to continue a pregnancy with the only true assurance being that their baby would not live very long. They had no definite knowledge of what he would look like or how disabled he would be. Still they were determined to love and to be in a relationship with him through labor and delivery and whatever would come next.

Celebrating Chance’s birth

Now that longed-for day had arrived, and I discovered that the couple who initially requested to be “left alone” and had asked me to “kind of” keep visiting to a minimum was surrounded by family. Over the months of waiting, they all had acclimated so well that Ashley wanted them with her as they prepared to welcome Chance. She even made room in the birthing room for me, the chaplain.

With the assistance of the self-proclaimed “big brother,” the labor/delivery/recovery/postpartum registered nurse (LDRP RN) who had been attending to Ashley since her arrival at the hospital prepared for the birth. The couple had grown into this journey, and I witnessed an evolution of mood, of spirit, as they now looked forward to meeting their second son.

The rest of the birthing team joined the group. They were aware of the case background and anticipated this birth with some skepticism. In answer to their questioning looks and comments, I reiterated that this was a new experience for all of us. I assured them that I would be there for them also. Each of us worked to convert this into a walk of faith—being willing to learn from this unique birth that enriched our lives even as it challenged every bit of what we may have believed in before Chance came into our lives.

The birth plan was clear. The family wanted as much uninterrupted time as they could have with their baby—no heroic measures and no trips to the neonatal intensive care unit (NICU). Chance arrived after an uneventful labor, with his brother sharing space with the obstetrician and the LDRP RN. As soon as he was delivered, Chance took a deep breath, let out a hardy cry and continued to breathe without assistance. I could feel the relief of the respiratory therapist, the NICU nurse and the neonatologist as they realized that they would not need to venture further out on the limb of this uncomfortable, but at the same time blessed, adventure.
What a sight it was to see Skyler pull a stool up to the table as the NICU team examined Chance. Once he was swaddled in a warm blanket, Skyler carried him to his mother’s bed where his father and other family members waited.

Chance’s cleft did not include the palate; thus, he was able to nurse, and after twenty-four hours, he was discharged with his mother to in-home hospice care. The Woman’s Hospital has designated a hospice RN to serve families, such as the Cooks, in whatever ways they need. Establishing this relationship also eases the family’s burden when death occurs as it eliminates the need for a coroner autopsy and also facilitates the funeral process. In addition, hospice provides chaplaincy services to the parents and family, which continue at home until the child’s death, and a follow-up pastoral care support system for as long as the family desires.

Chance enriched the lives of his family for twenty-four days. On the morning he died, big brother Skyler again held him as extended family members came to say their good-byes. The day passed through celebrated rites of passage as all prepared to let go of Chance. In an echo of the birthing room, they now birthed him gently into death.

**Serving staff as well as families**

In the aftermath of our experience with Chance and his family, the team debriefed. The respiratory therapist spoke of anticipating internal conflict if Chance had not taken a breath, and she was not to resuscitate. The neonatologist acknowledged his desire to take the baby to NICU for continued assessment if there had been any differentiation between prenatal and birth diagnoses. The obstetrician had not been certain that she could let Chance be born naturally if the stress of vaginal birth caused too much strain on his system and threatened stillbirth. Ultimately, the initial turmoil of participating in this first experience of perinatal palliative care was a hurdle that the professionals approached and sailed over.

As a result of continued conversations with the professionals who participate in these unique births, and through consultation with local psychologists in attendance at our annual ethics retreat, we focused on the need for heightened care for our team and other staff members who assist. The impact of the birth and death of infants with grave anomalies, known as tertiary posttraumatic stress, may be as distressing emotionally for hospital staff as it is for those actually going through the trauma. Ramifications may be emotional, physical and/or spiritual. Recognizing this, we now provide regular debriefing sessions for discussion of any perinatal palliative care case or any other loss/near loss in our hospital. We hope that these help to normalize the need to verbalize experiences. One-on-one debriefing is available, also. By discussing it during orientation of new employees we present it as a common result of working in stressful hospital situations.

Several months later, Chance’s mother, aunt and grandmother came to share their story at our ethics retreat. As the adults talked about his baby brother, Skyler entertained himself with his toy cars. Ever the big brother, he played in the absence of the sibling he knew for a time counted not just by days and hours, but also by months of anticipation. He, and indeed all of us, had known Chance in so many ways and had shared his journey honestly and openly both before and after the birth. Through the generosity of Skyler and his family, who shared each step of their painful—yet joyful—journey, we were each witnesses to the magnitude by which one tiny baby could affect the faith of his extended family and all of us who were touched by him.

“For it is to such as these that the kingdom of heaven belongs.” (Matt. 19:14b NRSV)

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1 Bereavement Services/Resolve through Sharing, “Blueprint for a Perinatal Palliative Care Program,” Gunderson Lutheran Medical Foundation, Inc., Schaumburg, IL 2009.
Attachment A: Algorithm of care – 1

TSP = Tri-State Perinatology
TWH = The Women’s Hospital
MFM = Maternal Fetal Medicine

Patient Referred with Possible Fetal Abnormality

Patient comes to TSP from:
- TWH OB provider sites (Suites 2000, 2300, 2400 and 3500)
- Evansville area OB/GYN providers
- Family medicine providers
- Other community providers (Henderson, Owensboro, Tell City, Washington, Vincennes, and southern IL)

Phone call/contact made to TSP from referring providers office

Abnormal maternal serum screen

Appointment for ultrasound, genetic counseling and MFM consult is made within 1 business week or later if patient chooses.
If next available appointment is greater than 1 week out, office coordinator will be contacted to work patient in as soon as possible.

Fetal abnormality on ultrasound

Appointment for ultrasound and MFM consult is made within 1 business week or later if patient chooses.
If next available appointment is more than 1 week out, office coordinator will be contacted to work patient in as soon as possible.

Patient is mailed TSP new patient packet if time allows

Patient arrives for appointment

Office staff gets patient from waiting room, introduces self and walks patient to appropriate ultrasound or consult room

Ultrasonographer completes ultrasound and physician reviews images

MFM talks to patient and reviews options for further evaluation and treatment

Genetic counselor meets with patient, as indicated, to review fetal diagnosis and discuss options for further evaluation and treatment

Availability of additional resources are discussed and offered.
Appointments made for specialty services as indicated.

Perinatal Hospice program discussed with patient.
Program brochure given to patient as well as name and phone number of Perinatal Hospice team member

Physician and/or genetic counselor completes note with copies sent to: referring physician, Perinatal hospice team, TWH Message Center and other providers as needed or desired by patient.

Follow-up call is made to patient within one week of appointment to address any questions or concerns.

Arrangements made for patient to meet with Perinatal Hospice team member in conjunction with next schedule appointment or sooner if desired by patient.

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Attachment B: Algorithm of care – 2

**Subsequent Visits**

Patient/family makes decision to continue pregnancy

Referring provider discusses option of co-management with TSP vs. referral to TSP for OB care and delivery

Perinatal Hospice team member helps to facilitate follow-up appointments coordinating times with sensitivity to situation

Arrange additional ultrasounds with pictures to patient, as desired by family, if possible.

At next visit, arrange for patient to meet with Perinatal Hospice team member to review program and assess needs/desires of patient and family.

Patient is added to perinatal group meeting for team discussion

Arrangements are made for patient to meet with neonatology and Perinatal Hospice team member in conjunction with next scheduled visit, or sooner if desired, to develop birth plan.

Begin birth plan at subsequent visit. Preregister patient around 28 week visit. Notify home health agency.

Perinatal Hospice team member completes birth plan and disseminates to participating providers, hospice team and triage.

TSP = Tri-State Perinatology
Attachment C: Algorithm of care – 3

LDRP = Labor/delivery/recovery/postpartum

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Attachment D: Perinatal palliative care initial interview form

The Women’s Hospital

Hand In Hand
Initial Contact Information – Date_____ / _____ / _____

Pertinent Personal Information:

Baby Name ____________________________
Mother’s Name ____________________________
Father’s Name ____________________________
Address ____________________________

Alternate Address ____________________________
Phone Number ____________________________
How many weeks pregnant are you at this time? __________
Have you both spoken with a genetic counselor/perinatologist?
Yes ______ No ______ Date you spoke __________________

Social History:

Length of time married/together ____________________________
Children ____________________________

Have either of you experienced the death of a parent or close friend or family member? Other significant losses in life

________________________________________________________
________________________________________________________
________________________________________________________

How do you cope with such loss?

________________________________________________________
________________________________________________________
________________________________________________________
How do you make important decisions?

What has the physician told you about your baby’s condition?

Do you both feel as though you thoroughly understand what the physician has told you?

Do either of you have remaining questions about your baby’s condition?

How do you feel you are coping with all this new information?

What ways do you use to care for yourselves?

    Physically

    Spiritually

    Social Network

    Church affiliation/involvement

Information gathered by:
Signature: