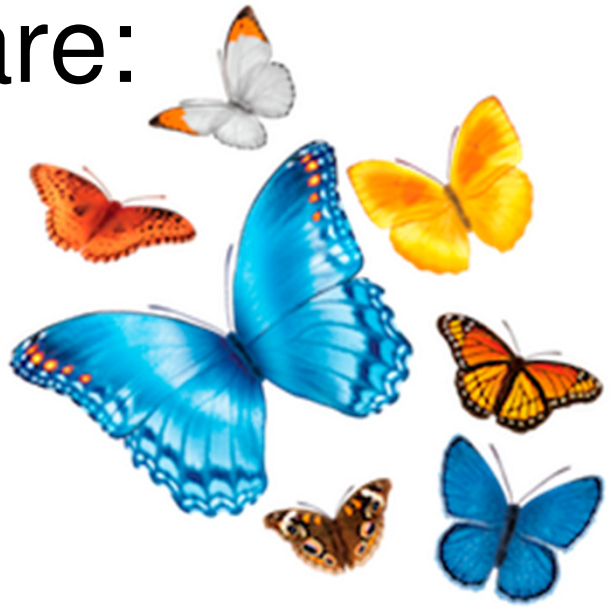
Perinatal Palliative Care: A Transdisciplinary Community Collaboration Model



Kamil Čák, DMin, BCC

Spiritual and Family Care Coordinator

Ohio Fetal Medicine Collaborative

@ Nationwide Children's Hospital

NATIONWIDE CHILDREN'S

When your child needs a hospital, everything matters.℠

Intro: Perinatal Hospice Video

The Problem

2009 Main Campus ALOS for NICU Patients with T18

30.6 days

The Solution

An integrated, community-wide perinatal palliative care strategy that would:

1. Identify appropriate patients prenatally
2. Develop a relationship with parents/family
3. Prepare parents for delivery and immediate post-natal period
4. Help create meaningful memories and support family prior to, during and after delivery

Key Palliative Care Concepts

1. Building a trusting relationship
   a. Setting the parameters of the relationship
   b. Heartfelt honesty
   c. Meaningful presence

2. Goal setting and periodic re-evaluation

3. Goal orientation (evaluate every action and intervention based on the answer to one question: Will this help us reach the family's goals?)

Why do we need PPC?

- Keeping the babies at the birth hospitals
  - Preventing unnecessary transfers to NCH
  - Keeping mom and baby together at a critical time
- Improved communication between hospitals and providers
  - Communication between MFMs, Neonatology at birth hospital, L&D, and Fetal Diagnostics at NCH

Why do we need PPC?

- Improved family-centered care
  - Honoring parental wishes
  - Providing parents with an opportunity to make informed decisions and communicate their wishes prior to delivery
  - Reducing psychosocial, emotional and spiritual suffering for the family through sensitive care attentive to cultural, religious and personal beliefs and values (Kauffman, Hauck & Mandel, 2010)

Why do we need the PPCP?

- Connecting families with appropriate resources
  - Delivery hospital Pastoral Care departments
  - Social Work and Case Management
  - Outpatient Hospice or PC when appropriate
- Care standardization
- Process standardization
- Better bedside staff support
  - Pre-planning reduces anxiety

Other Benefits

- Addressing of ethical dilemmas prior to delivery
- Virtually eliminating unnecessary NICU admissions
- Enhancing interdisciplinary communication

Inclusion Criteria

- Congenital anomalies incompatible with life
  - Trisomy 13
  - Trisomy 18
  - Trisomy 22 and other rare Trisomies
  - Neurological devastation
  - Renal agenesis
  - Certain cardiac anomalies
  - Other MCAs

Process

- Prenatal diagnosis is made by OB or MFM
- Referral to the Perinatal Palliative Care Team
- Coordinator is introduced by MFM to expectant mother (and family/support person if available) and discusses process

Process

- Coordinator facilitates care conference to discuss options of care for mother and infant (neo, OB, chaplain, NNP, Hospice)
  a. Neonatologist answers questions about the diagnosis and explains neonate's anticipated presentation after delivery
  b. Neonatologist or program coordinator explains potential interventions available for a neonate in distress

Process

c. Obstetrician explains delivery options
d. Psychosocial, spiritual, and bereavement issues are addressed
e. Family's wishes are recorded on a standardized form

Process

- Mother/family and PPCT develop birth plan
  - Delivery hospital neonatologist and OB/MFM involvement is key at this point
- Form signed by parents, physicians and program coordinator is distributed to L&D, Mother/Baby, NICU
- Referrals are made (funeral planning, pictures, hospice, lactation, etc.)

Process

- Letter to EMS is given to parents
- Tour of L&D, post-partum unit, and the NICU (if appropriate)

Process

- Program coordinator remains in contact with family, answers questions, and confirms that family remains comfortable with the plan as the due date approaches

- Mother delivers

Process

- If neonate is transferred to the children's hospital, program coordinator continues to provide support with decision-making

- If neonate is discharged to home with hospice, hospice team assumes medical and supportive care

Ohio Fetal Medicine Collaborative
Perinatal Palliative Care Plan

Mother's Name: _____ **MRN:** _____
Father's Name: _____
Infant's Name: _____ **MRN:** _____

This family was seen in prenatal consultation on ____/____/_____ by the Ohio Fetal Medicine Collaborative.

Please page the Ohio Fetal Medicine Collaborative's Spiritual and Family Care Coordinator (614-690-6031) when mother presents for delivery or for any postnatal comfort concerns.

Prenatal Diagnostics
EDC: ____/____/_____ **Induction/C section scheduled for:** _____
Delivery place: _____ Mode: _____ Gestation: _____
Fetal Diagnosis: _____

NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.℠

Gravida _____ Para _____ Chromosomes: _____

Echo results: _____

MRI results: _____

Risk factors for premature delivery: _____

Support persons present at the consultation and relationship to mother:

_____

Care Team:

MFM: _____

OBGYN: _____

Neonatologist: _____

Family Support Coordinator: Kamil Čák (pager 614-690-6031)

NNP: _____

Birth hospital nurse coordinator: _____

_____

_____

_____

Resuscitation Status for Baby (check all that apply):

Full code

Do not intubate

No bag/mask, assisted or mechanical ventilation

No chest compressions

No cardiac medications

May give Narcan 0.1 mg/kg IV/IM/ET in delivery room if suppression from maternal opiate exposure is suspected (if parents desire)

Selected Medical Interventions (check all that apply):

Blowby oxygen, humidified (____%)

Positive pressure ventilation at birth

Nasal cannula oxygen, humidified (____ LPM)

Suction

Morphine 0.15 mg/kg SL OR 0.05 mg/kg IV every 15 minutes as needed for pain behaviors or respiratory distress identified by caregivers or parents

Aerosolized Fentanyl 10 mcg as needed for respiratory distress identified by caregivers or parents

Ativan 0.05 mg/kg SL OR 0.05 mg/kg IV every 15 minutes as needed for agitation or seizure activity

Artificial hydration (required while baby is in the hospital)

Artificial nutrition

Natural hydration and/or nutrition (PO, breastfeed) as tolerated

No labs

Labs to be done	From	
chromosomes	cord blood	baby
microarray	cord blood	baby
_____	cord blood	baby

Medications must be available in appropriate concentrations and doses to avoid distressing delays in treating symptoms. We would suggest keeping at least 1 dose of each medication at the bedside if consistent with local policies.

Erythromycin eye ointment	___ Yes	___ No
Vitamin K	___ Yes	___ No
Neonatal Screen	___ Yes	___ No
Phototherapy for hyperbilirubinemia	___ Yes	___ No
Hepatitis B vaccine	___ Yes	___ No

Immediate Post-delivery Plan (check all that apply):

Mother holding baby immediately after birth

Mother breastfeeding in the delivery room if baby is stable

Baby to room in

Baby to be taken to well-baby nursery

Baby to be taken to birth hospital NICU/SCN

Baby to be transported to NCH

Comfort Measures for ALL Babies:

- Dry, suction, and warm baby
- Hat
- Minimal disruptions within medically safe practice for mother
- Lower lights (if desired by parents)
- Permit presence of parents and extended family as much as possible without disruption to work flow in the unit
- Siblings should be made comfortable; they may wish to write letters or draw for the baby
- Encourage parent/child bonding and interaction (if desired by parents):
- Bathe and dress the baby
- Feed the baby (if possible)
- Diaper the baby

Bereavement Preparation and Memory Making:

- Prints of hands/feet
- 3D molds of hands feet
- Pictures
- Lock of hair
- _____
- _____

Spiritual Care:

Religious preference: _____

Identified religious leader: _____

Baptism desired at time of birth: ↑Yes ↑No

Other religious/spiritual interventions: _____

_____

Consultations:

Pastoral Care
Social Work

_____

_____

_____

_____

In the event of child's death in hospital:

Autopsy	Yes	No
Tissue/Organ procurement	Yes	No

Funeral Home preference: _____

Rituals required for care of body: _____

Please notify: _____

In the event of child's survival to homegoing:

Hospice services should be arranged with _____

Hospice admission **must** occur on the day of discharge to coordinate for continuity of care from hospital to home. Please notify Spiritual and Family Care Coordinator who will coordinate these services.

Special Family Requests: _____

_____

Mother's Signature: _____ Date: _____

Father's Signature: _____ Date: _____

MD Signature: _____ Date: _____

S&FCC Signature: _____ Date: _____

Statistics

- Referrals in the past 22 months: 33+2

  (27 prenatal, 2 post-delivery referrals to assist with decision-making)

- Average patient care time per referral: 10 hrs

Statistics

Diagnoses:

- 10x T13
- 7x Anencephaly
- 3x Holoprosencephaly
- 3x MCA
- 3x Skeletal dysplasia
- 2x Renal agenesis/multicystic dysplastic kidneys
- 2x HLHS
- Urinary tract outlet obstruction
- T18
- anhydramnios
- Meckel Syndrome
- Triploidy

Statistics

ALOS for Main Campus NICU patients with T18:

2009	30.6
2010	17.2
2011	5.0

Program Creation Process

Literature review

Protocol design

Securing program manager support

Education

Program Creation Process

Incorporation and utilization of available resources

Utilization of existing staff through process standardization and collaboration in order to minimize additional staffing

Trandscisiplinary Design

Builds trust

Provides flexibility

Keeps costs low

Case Review: L.D.

L.D. is a G1 P0 30 y/o female (EDD 3/20/12)

Referred to PPC on 11/15/12 at 22 weeks

Pregnant with twins

One twin prenatally dx w/ skeletal dysplasia

Met with NCH Genetics on 12/5

PPC Conference scheduled for 1/10

Pt admitted to GMC in preterm labor on 1/5

Case Review: L.D.

Visited with pt at GMC, completed birth plan

Labor stopped, pt remained at GMC

Weekly visits/phone calls

Pt delivered on 1/23

Twin with SD died shortly after birth

Other twin admitted to NICU

Case Review: L.D.

Visited with pt at GMC, completed birth plan

Labor stopped, pt remained at GMC

Weekly visits/phone calls

Collaboration with GMC Pastoral Care

Pt delivered on 1/23

Twin with SD died shortly after birth

Case Review: L.D.

Other twin admitted to NICU

Labwork, autopsy @ NCH

MFM support with autopsy decision

Follow-up continues

Case Review: C.S.

C.S. is a G3 P1 21 y/o female (EDD 3/26/12)

Referred to PPC on 12/17/11 (@ 26 w)

Pregnant with twins

One twin prenatally dx w/ anencephaly

Father in US Navy, deployed

Spoke w/ mother # of times prior to PPCC

PPC Conference took place on 1/17/12

Case Review: C.S.

C.S. admitted to MCSA on 1/30/12

C.S. d/c a few days later

Worked on getting father here on leave

C.S. readmitted and twins born on 2/8/12

Twin with anencephaly lived minutes

Healthy twin admitted to NICU, now home

Case Review: A.B.

A.B. is a 23 y/o G3 P1 female, EDD 2/15/11

Referred to PPC on 9/22/11 (@ 19 w)

Fetus with confirmed T13, omphalocele, open NT defect, CHD, abnormal intracranial structures

PPCC on 10/20/11

Parents agreed to comfort care only

Case Review: A.B.

Mother connected with families online

Parents reconsidered, wanted “everything done”

Arranged for Genetics consult at NCH

2nd PPCC on 12/21/12

Ammended PPCP to allow for NCPAP

Case Review: A.B.

Spoke with mother a few days prior to induction, talked through plan again

Induced on 1/27/12, baby died early 1/28/12

Feedback

We feel so blessed to have had around eight hours with Mckinley. She's a beautiful little girl. We heard her make little baby sounds, got to touch her fingers and toes, gave her kisses, and enjoyed being her mommy and daddy. Of course, we wish she would have lived but so glad we got to meet her and hold her in our arms breathing and doing well.

Feedback

It brought closure to our journey and brought us many smiles (and tears). Thank You so much for your kind words. They do mean a lot to us as they are very encouraging and even though we know we made the right decision, it's still nice to hear others say it. We do have many supporters around us and we are very blessed.

Feedback

We have had homemade food made by others ever night since we have been home :-). Such a blessing. The best part is that we were able to donate her heart valves. This made all the difference to us. It's a great feeling to know that her death may bring life to another. We were also very blessed to have had the greatest nurses ever. They honestly changed my life.

Feedback

Through those first few days they were there for not only me but Jordan as well. They listened, they shared their hearts, they made sure we were both comfortable, showed us love, took care of not only me but Jordan as well, made us both laugh and smile during the hardest time of our lives,

Feedback

and we know God put us there in that time to have those nurses. We feel so blessed to have delivered Mckinley at Riverside. Everything went great and better than I ever thought it could. Again, Thank You so much. You have a very important job and do it well.

References

- Engelder, S., & Zeilinger, T. (2012). A model program for perinatal palliative services. *Advances in Neonatal Care, 12*(1), 28-36.

- Gale, G., & Brooks, A. (2006). Impementing a palliative care program in the newborn intensive care unit. *Advances in Neonatal Care, 6*(1), 37-53.

- Kauffman, S.G., Hauck, C.B., & Mandel, D.A. (2010). Perinatal palliative care: the nursing perspective. *Nursing for Women's Health, 14*(3), 188-197.

- King, G., et al. (2009). The application of a transdisciplinary model for early intervention services. *Infants & Young Children, 22*(3), 211-223.

- Leuthner, S. R., & Jones, E. L. (2007). Fetal Concerns Program: a model for perinatal palliative care. *MCN, 32*(5), 272-278.