Meeting Families Where They Are: Benefits of an interdisciplinary, community-based model of perinatal palliative care

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Objectives

- Describe biopsychosocial needs that families experience when faced with or anticipating pregnancy and/or infant loss, importance of supporting these families as early as possible, and the impact community based perinatal palliative care has on quality of life at all phases of the family’s experience.

- Identify interventions used along with specific ways in which interdisciplinary team members collaborate to address the ongoing needs of individual family members in order to optimize coping opportunities when faced with or anticipating pregnancy and/or infant loss.

- Define and discuss specific ways in which rituals and memory making help promote opportunities to heal and cope with grief and loss through validation of the meaning of the baby’s life, parental and sibling identity, and help in maintaining continued connection and bond, especially due to having potentially limited time with baby.
We have no actual or potential conflict of interest to disclose in relation to this program/presentation.
CompassionNet Perinatal Care Continuum

- **PREGNANCY**
  - Social Worker
  - Nurse Practitioner

- **GRIEF & BEREAVEMENT**
  - Chaplain
  - Child Life Specialist

- **FAMILY**

- **TIME OF BIRTH**
  - Physician

- **ONGOING PALLIATIVE CARE**
Why we created our Perinatal Program

- Recognized that stressors and suffering began at the time of diagnosis, even when made prenatally
- To support families that are anticipating the birth of a child with a potentially life-threatening condition

The impact of anticipating possible perinatal loss, the grief that comes with this, starts from the very moment a parent learns of their baby’s medical condition.

- Meet the family where they’re at, offering support and guidance along the continuum of care
Current Data 2010 through April, 2018

- 125 pregnancies
- 137 babies
  - 9 families are still pregnant (with 11 living babies)
  - 63 babies have died
  - 63 babies have survived
    - 33 are still enrolled in CompassionNet
    - 30 have been discharged from CompassionNet
Perinatal Deaths 2010-April, 2018

N=63

- died prior to birth (11)
- died within first day (19)
- died in first month (19)
- died within first year (12)
- died after first year (2)
Perinatal Loss

- Miscarriage (less than 20 weeks gestation)
- Ectopic Pregnancy
- Stillbirth (20 weeks and greater gestation)
- Neonatal Death (1st 28 days of life)
- Life-limiting Condition
Perinatal Attachment

Attachment begins during pregnancy
Reinforced by hearing fetal heartbeat, feeling baby’s movements, and seeing baby’s image via ultrasound

Learning of pregnancy ➔ beginning of expectations, dreams, plans for the future = Attachment
Unique Issues and Needs During Pregnancy

- Grief begins at time of diagnosis within pregnancy
- Juxtaposition of timing – what is & what “should be”
- Time during pregnancy becomes more precious- may be the only time parents have with their baby alive
- Self blame – body failed
- Wide range of social pressures
- For many – introduction into parenthood
Grief is multi-faceted, many layers of loss

- Loss of a normal pregnancy
- Loss of future hopes & dreams
- Loss of identity or role as a parent (more so if first child)
- Loss of peer group, isolation
- Loss of trust in one’s body
- History of loss often complicates further

High risk for disenfranchised or complicated grief

- Society often does not recognize perinatal loss with the same intensity or validation that parents may feel
- Others have not “seen” them “parenting”

Need for validation, ritual, meaning...
Need for Validation

Validation of identity as parent
- During pregnancy, after birth, after death

Opportunities for attachment, bonding and validation at the time of birth (and death)
- holding, naming, bathing, dressing baby
- planning for burial, cremation, funeral, memorial
- religious and spiritual rituals – blessing, baptism
- inclusion of other family members – socialize baby

Language
- Use baby’s name whenever possible
- Use of possessive pronouns – “your son,” “your baby girl,” etc.
- “Born Still” vs “Stillborn” – emphasizes baby’s personhood, birth
Fostering Continued Bonds

Continuing Bonds Theory
Memory Making
Photography
Hand & Foot Prints
Rituals
Pregnancy After Loss (PAL)

85% of women experience PAL within 18 months

Grieving loss while welcoming new baby
Managing ongoing anxiety
Attachment during pregnancy
Communication – sharing the news
In order to effectively communicate and help children understand grief and loss, we need to provide honest information about the facts and events. We also need to give them information about feelings, and about what to expect and about what not to expect.

In my experience as a child life specialist, I have learned that children work through their grief in bits and pieces. Play, school, and continuing with normal activities can be powerful tools that help children cope by modulating their grief, allowing them to “take breaks” from both their own and their parent’s intense grief. Children learn and work through play- it is natural for them and it also helps us, as caregivers, to navigate these hard conversations with them at all ages.
Considerations for Communicating with Siblings

• Honest- brief, simple explanations
  When children do not know the truth...
  ○ They are left to cope with the situation alone and tend to resort to their own notions and fantasies, which are often worse than the reality.
  ○ It is isolating and can be detrimental to their grieving process and trust.
  ○ Children hear and see more than parents realize.

• Developmental age
  ○ Refer to guidelines and references on developmental stages in grief, but recognize that these do not correlate precisely with every child, thus it is essential to assess each child’s individual developmental understanding and needs.
  ○ It is often underestimated what children are capable of processing.

• Relevant experiences
  ○ Do they have any other siblings?
  ○ Have they ever been to the hospital?
  ○ Do they have any other experiences with death?
Sibling Support – Child Life

- Preparation

- Memory Making
  - Importance of memory making with siblings
  - How siblings bond and build memories

- Bereavement
  - Ongoing memory making
Preparation

- Medical play
- Diagnosis education
- Connecting with NICU child life specialist
- Use pictures of NICU and medical equipment they will see when they visit
- Encourage sibling involvement as much as possible
Importance of Memory Making with Siblings

Providing support to siblings allows the sibling to feel included as a part of the family, helps with their own grieving, and makes the loss real for them. We almost always encourage families to bring the siblings up to meet their sibling. This is so important for bonding and memory making.

Memory Making...

- Gives siblings a “job” to do when they are at the hospital
- Provides an element of play with clay or painting that can be therapeutic for children and adults during a stressful time
- Provides a sense of family when you capture the prints of all of the kids and parents for possibly the only time
- These mementos help to keep the baby “real” to siblings who do not have the same attachment as their parents have
If appropriate, sibling support can include:

- Talking, singing and/or reading to their sibling
- Holding, touching, smelling, kissing their sibling
- Taking pictures of them together
- Helping to bathe/dress the baby (Amelia’s siblings helped choose an outfit for her and we made a blanket)
- If the parents have a picture of their living children on their phone, put the phone with the picture displayed next to the baby and take a photo.
- Record ultrasounds, with sound if possible, so they will have a permanent record of their baby’s heartbeat. Places like Build A Bear can place a recording of a heartbeat inside of a bear.
**Bereavement**

**Key Notes:**

- Kids will often play out the death in several ways – this helps them to integrate the reality of the death.
- Structure and routine are comforting.
- Short-term regressive behaviors are normal.

**Normal thoughts of siblings:**

- Did I cause the death?
- Will the rest of my family die too?
- Will I die too?
- I feel guilty for feeling happy or laughing
- I don’t want to make my mom or dad sad
- Relief, and are happy to think they have their mom and dad back
Encourage parents to find ways for the children to participate in ongoing memory making.

Ongoing Memory Making

Create their own scrapbook, photo album or journal

Design and make a garden stepping stone using marbles, mosaic tiles, stones, and other items

Make or buy a special piece of jewelry

Help parents design and plant a memorial garden

Make a memory box to keep important memories

Participate in yearly memorial rituals
Perinatal Eligibility Criteria and Examples

- **Two tiered – Insurance & Medical**
- **Insurance – Excellus/Univera**
- **Medical - The unborn child has been diagnosed in utero with a potentially life-threatening condition.**
  - **Examples (list not exhaustive):**
    - Trisomy 18
    - Potter Syndrome
    - Complex Congenital Heart Disease
    - Congenital Diaphragmatic Hernia
Community Partnering – The “Net”

- **Hospitals**
  - High Risk Maternal/Fetal Medicine, NICU, Inpatient Palliative Care

- **Home Care & Hospices**

- **Contracted Providers**
  - Creative Arts Therapy, Massage Therapy, Counseling, etc.

- **Schools**

- **Local Not-for-Profits**
  - Support Groups (Face2Face, A Caring Place)
  - Now I Lay Me Down To Sleep (NILMDTS)
  - Medicaid Service Coordinators
  - Funeral Homes
  - Ronald McDonald House
Ava

Perinatal diagnosis of Trisomy 18 and Congenital Anomalies

Referred at 19 weeks gestation

Ava with her family
CompassionNet Supports

During Pregnancy

- Frequent visits with Social Worker and Nurse Practitioner for emotional support, guidance, education, goals of care discussions, Birth Plan review
- Palliative Care Consult with CompassionNet MD to complete perinatal MOLST
- Emotional support and anticipatory guidance for siblings (ages 2&5) with Child Life Specialist

Following Birth & Death

- Child Life came to hospital to assist with siblings meeting their sister
- Social Worker & Nurse Practitioner visited hospital, held baby, offered guidance and advocacy with funeral plans and options
- Ongoing bereavement support for siblings with Child Life Specialist to help them cope with loss
- Ongoing bereavement support for parents through continued home visits with Social Worker and Nurse Practitioner
Gianna (5) holding Ava

Gianna’s art work
“I love Ava.”
Ahki

Perinatal diagnosis of Hypoplastic Left Heart

Referred at 26 weeks gestation

“His heart was sick. He died because I could not help him when he cried.” (Ahki’s brother, David - age 5)
**CompassionNet Supports**

### During Pregnancy
- Discussion and support of family’s goals of care and concerns
- Perinatal MOLST discussion
- Child Life to build rapport & help prepare siblings - David (5) & Anthony (13)
- Music therapy for siblings
- Anticipatory grief support
- Financial Assistance

### Pediatric Palliative Care
- Coordination of care and discharge planning
- Transition to home
- Integration with Peds Pal RN
- Interdisciplinary end-of-life care at home
- Memory making – including sibling participation
- SW provided assistance with home funeral planning

### Bereavement
- Support for Ahki to remain at home until home funeral & green burial
- Ongoing interdisciplinary grief support for 3 years (including through subsequent pregnancy)
Amelia

Perinatal diagnosis of Fetal Skeletal Dysplasia

Referred at 37 weeks gestation
## Sibling Support...Child Life

### Before Birth
- Met family at enrollment, able to hear their story
- Met siblings prior to birth in home setting, fostering development of trust and rapport
- Created a blanket for Amelia to wrap her in after she was born
- Prepared siblings using medical doll and supplies
- Facilitated hard discussions on siblings’ worries and their wishes if she died (to see her, hold her)

### After Birth
- Able to meet with siblings at hospital before they went back to NICU to meet Amelia for the first time
- Prepared them for how she would look & how the machines would look/sound
- Gave them ideas/suggestions on what they could do (touch her hand, sing, talk quietly to her...)
- Accompanied them to meet Amelia and encouraged them to touch & talk to her
- Answered questions they had
- Introduced them to NICU CCLS
- Assisted photographer
A year and a half later, Amelia’s mom, Megan shared that “I am so glad that you encouraged us to be upfront and honest with them. It was important to us that they knew what was happening. They were as prepared as they could have been without being too scared.”
Self-care

- Self-awareness
- Identifying & acknowledging triggers
- Self-acceptance
- Boundaries
  - Being present, holding another’s pain
  - Creating one’s own rituals
  - Individual & team
    - Formal & informal

“Be there for others, but never leave yourself behind.”
by Dostoevsky
References


Goldstein, Jody (1982). Where’s Jess: For Children who have a brother or sister die. Omaha, NE, Centering Corporation.


Schwiebert, Pat (2003). We Were Gonna Have a Baby, But We Had an Angel Instead. Portland OR, Grief Watch.

“Recognizing where there is attachment and love, and then a loss, grief will be experienced – regardless of when this loss occurs…”
– Resolve Through Sharing (RTS) Gunderson Lutheran Medical Center