Disclosures

Rana Limbo has no real or perceived conflicts of interest that relate to this presentation.

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Objectives

1. Describe caregiving as a theoretical framework for understanding parental response to the death of a baby
2. List three examples of effective communication with bereaved parents
3. Discuss two types of keepsakes for parents and other family members
4. Describe two self-care activities for professionals
Statistics in the US

- 26,000 stillbirths
- 19,000 newborn deaths
- 1,000,000 miscarriages
- 40-100,000 ectopic pregnancies
- 5,600 babies die during infancy from life-threatening conditions

(American Pregnancy Association; MacDorman & Kimrey, 2009; Matthews & MacDorman, 2011; March of Dimes)

Theory of Caregiving

- Complementary to attachment; hard-wired
- Consists of nurturing, protecting, and socializing
- Examples of each of these:
  - Nurturing: Parent bathing the baby before or after death
  - Protecting: A mother wanting a hat for her baby, who has anencephaly
  - Socializing: Noticing that others call the baby by name, wanting to show baby's photos to others

(Bowlby, 1988)

Relationship

- Care providers strive for integrity in relationships with patients, families, and others
- Maintaining relationship in care provision and decision making may conflict with care provider's basic values and beliefs
- Staying connected is key to initiating, maintaining, and transitioning relationship

(Limbo & Kobler, 2010; Wilke & Limbo, 2012)
Miscarriage

• Most common type of perinatal loss and least understood
• Longitudinal study from the 80s showed 75% of women felt they lost a baby; 25% referred to miscarriage as "life event" (Limbo & Wheeler, 1986)
• Findings replicated

Importance of assessment

• “How are you doing with all of this?”
• “Tell me what things are like for you.”
• Listen for “baby” or “my baby”
• Response does not depend on length of pregnancy or presence or absence of other children

(Wilke & Limbo, 2012)
Early confirmation of pregnancy may also affect perception of the loss

Determine point of care

- At Gundersen Health System, 70% of women with miscarriage seen in emergency room
- Implement SOP that includes all points of care
- Ambulatory/outpatient clinics (family medicine, Ob/Gyn)
- Day surgery
- Operating room

(Bauckman, et al., 2009)

Care in the ER

- Educate staff
- Involve interprofessional team
- Carefully assess emotional response
- Include support person in discussion
- Provide miscarriage comfort supplies for diagnosis of “inevitable” or “threatened” miscarriage
- Make follow-up call
- Provide written material
Providing support after miscarriage

Respectful disposition

• In most states, no requirement for burial or cremation after miscarriage

• In some states, patients with miscarriage must be notified that they have a choice for disposition

• In most states, miscarriage is <20 weeks gestation

[Linde, Kobler, and Levang, 2010]
Stillbirth

Death Before Birth: Remembering Sarah

Key reminders

• Be “in the moment” with the parents and family: laughter and tears are complementary
• Handle the baby lovingly: Tami said she would never forget “…the nurse who patted her butt” (socializing)
• Explain what parents might see in language that makes sense: “You might see that the skin on her face has slipped and that her face is bright red in spots.”
• Work closely with genetic counselors or geneticists
Key reminders (continued)

• Caregiving theory: “My job is to keep her memory alive”; “I’m her mother and she’s my daughter”

Caring for Families Experiencing Stillbirth: A unified position statement on contact with the baby

Preamble

Stillbirth is recognized as one of the most traumatic experiences a parent can go through and may be associated with long-lasting psychosocial effects. Additionally, parents may have had limited or no previous experience with death. They are typically fearful and confused about what to expect and what options are available to them.

Seeing and holding a live baby after birth is a normal parental response. Seeing and holding a stillborn baby is also a normal sequence, and there is much evidence that doing so can be a valuable and cherished experience. Parents benefit from support and individualized guidance as they make their own decisions about how much time to spend with their baby, and as they determine when and how to lose this time.

Warland, J., & Davis, D. L. et al. (2011) Caring for families experiencing stillbirth: A unified position statement on contact with the baby. An international collaboration. (Downloadable from numerous websites including bereavementservices.org)
Perinatal Bereavement
Hospice and Palliative Nurses Association (HPNA) online education

Newborn Death

Setting | Potential Causes
---|---
• L&D | • Immaturity or prematurity
• NICU | • Sepsis
• ER | • SIDS
• PICU | • Shaken baby
• Congenital abnormalities

Being with dying newborns

• Nurses and babies are “in relationship”
  ◦ Call-to-presence
  ◦ Pattern of engagement with newborn and with parents
• Caring may involve moral distress: tension between and among those engaged with baby
• Reflection is key element of caring
• Significance of inter-professional team
• End-of-life caring is transformative

(Lindsay, Cross, & Ives-Baine, 2012)

Keepsakes to honor a baby
Zoe’s mom

Offering choices

• Standard of care to offer choice no more than three times over course of care
• Inter-professional team approach Non-judgmental tone
• Honoring when “no” means “no”

(Limbo & Kobler, 2010)

• Have you thought about taking photos of your baby?
• We take photos routinely. How does that sound to you?
• Families have shared with me that photos have been important to them.
Life-threatening diagnoses

- Examples:
  - anencephaly, trisomy 13 & 18
- Two dimensions
  - Grieving multiple losses
  - Arrested parenting

(Côté-Arnesault & Demay-Karlich, 2011)
Goal of PPC

- Primary goal: advance care planning and birth planning that reflect parents’ goals, values, beliefs, and feelings
- Goal is the baby’s comfort, care may include life-sustaining modalities (e.g., a trial of treatment)
- Support changing hopes
- Help parents prepare for leave-taking

[Huber & Limbo, 2011; Wool & Northam, 2011]

Hope in decision making

- “Given what you are now up against, what are you hoping for?”
- “Do you mind telling me what else you might be hoping for?”
- Hope for comfort and hope for a miracle often exist simultaneously

[Feudtner, 2009; Rosigno, et al., 2012]

PPC resource:
RTS Position Paper

www.bereavementservices.org/position


Children

The Mullens children

What to say to children

• “The baby’s body didn’t work anymore.”
• “Our baby died.”
• “It’s OK to feel sad—or not.”

[Leider & Kobler, 2008]
What can we do? Take-home points from Bridge to Hope

- Planning for a wished-for child
- Compassionate attitude of health care inter-professional team
- Importance of family support
- Remembrance of blessing ritual
- Ritual that grows from relationship: nurse holding baby
- Delivering bad news with “I wish…”

[Quit, Arvold, & Pratt, 2001]

Take-home points (cont.)

- Role of reflection in caregiver suffering
  [Papadatou, 2009]
- “Being with” is part of caring
  [Swanson, 1993]
- Parents need support from professionals
  - Acknowledge their feelings
  - Allow time for decision making
  - Encourage and welcome supportive family and friends

Take-home points (cont.)

- Look for meaningful moments from which ritual can arise
- Grounding oneself and reflection are part of self care

[Limbo & Kobler, 2013; Perry, 2008]
Awareness and self-care

PRAM
Pause
Reflect
Acknowledgement
be Mindful

(Limbo & Kobler, 2013)

PRAM

• Pause: Stop. Be still. Focus on something in your environment.
• Reflect on your own breathing. Think about what a relationship might look like between you and the person you are about to meet or see. Reflect on your feelings.
• Acknowledge your feelings. Name what you feel. Tell yourself it’s OK to feel as you do.
• be Mindful: Be in the moment by bringing your full attention and energy to the meaning of the relationship that has brought you here.

Self-care
Creating a culture of compassionate bereavement care

• Develop, support standard of care
• Create consistent care at any point of entry
• Look for increased patient and staff satisfaction

(Wilke & Limbo, 2012)

“Being connected...A key to my survival”*

• Create a transition ritual between work and home
• Touch a colleague’s shoulder to indicate your presence with them
• Offer to help
• Pause and reflect in the moment
• Allow time for debriefing
• Provide education to new staff

(*Kearney, et al., 2009)

Opportunities and Resources

• Hospital programs: Resolve Through Sharing® began in 1981
• Bereavement training in perinatal death, neonatal & pediatric, pediatric & adult; coordinator training
  ◦ www.resolvethroughsharing.org
• International Perinatal Bereavement Conference
  ◦ biennial: www.perinatalbereavementconference.org
• Pregnancy Loss and Infant Death Alliance (PLIDA)
• Certification in Perinatal Loss Care from the Hospice and Palliative Credentialing Center®
  ◦ hpcc.advancingexpertcare.org
References

- American Pregnancy Association: www.americanpregnancy.org

References (cont.)


References (cont.)

- March of Dimes: www.marchofdimes.com
References (cont.)

• Warland, J., & Davis, D. L. et al. (2011) Caring for families experiencing stillbirth: A unified position statement on contact with the baby. An international collaboration. (Downloadable from numerous websites including bereavementservices.org)

References (cont.)


Websites:
• Resolve Through sharing: www.resolvethroughsharing.org
• Hospice and Palliative Nurses Association: www.hpna.org
• www.perinatalhospice.org
• Pregnancy Loss and Infant Death Alliance: www.plida.org