Serious Illness in Perinatal and Neonatal Settings

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Serious Illness in Perinatal and Neonatal Settings

- Prenatal diagnosis of a fetal congenital anomaly or life-limiting condition
- Extreme premature baby born at the limit of viability
- Neonate with overwhelming illness not responding to aggressive medical treatment, or treatment which may be prolonging suffering

(Boss, et al., 2011; Leuthner, 2004b)

Leading Causes of Infant Death in 2014

(Heron, 2016)

Infant death (under 1 year of age)

1. Congenital malformations, chromosomal abnormalities (20.4%)
2. Disorders related to short gestation and low birth weight (18%)
3. Maternal complications of pregnancy (6.8%)

Neonatal death (under 28 days)

1. Disorders related to short gestation and low birthweight (25.9%)
2. Congenital abnormalities, chromosomal abnormalities (21.2%)
3. Maternal complications of pregnancy (10%)

Postnatal death (28 days through 11 months)

1. Congenital malformations, chromosomal abnormalities (18.8%)
2. Sudden Infant Death Syndrome (18.7%)
3. Unintentional injuries/accidents (13.8%)

Prenatal Decision-making

Discussions and decision-making guided by:

- The certainty of the diagnosis
- The certainty of the prognosis
- The meaning of that prognosis to the parents

(Leuthner, 2004 a &b)

Provision of Services in Perinatal PC: Multicenter Survey in the US (Wool et al., 2016)

Survey of existing perinatal palliative care programs in 30 states (n=75)

- Settings: Academic Medical Centers, Regional or Community Hospitals, Local Hospice/Palliative Care Organizations & Community-Based Support Systems
- Significant differences across programs re. types of fetal diagnoses seen, formal training in communicating difficult news to parents, processes to ensure continuity of care, and reimbursement avenues
- 100% of programs reported attention to spiritual needs and bereavement care

Provision of Services in Perinatal PC: Multicenter Survey in the US (Wool et al., 2016)

- Perinatal palliative care delivered by interdisciplinary teams
- 83% of programs reported a coordinator of care
- 82% of programs had team member available around the clock to meet parents' needs
- 70% of programs < 10 years old
- 38% of programs had formal measures for quality assessment

“Have no regrets.”

(Côté-Arsenault & Denney-Koelsch, 2016)

- n = 16 mothers & 14 fathers/partners receiving prenatal diagnosis of lethal fetal condition
- Developmental tasks of pregnancy:
  - Navigating relationships
  - Comprehending implication of the condition
  - Revising goals of pregnancy
  - Making the most of time with baby
  - Preparing for birth and inevitable death
  - Advocating for the baby with integrity
  - Adjusting to life in absence of baby

Establishing Relationship with Parents

- Open, supportive dialogue with parents to assess:
  - Meaning of the pregnancy
  - Understanding of the baby's diagnosis
  - Meaning of the diagnosis and prognosis
  - Expectations for their baby's care
  - Cultural or spiritual beliefs impacting family's decision-making
  - Family's support system
  - Parents' hopes and fears for their baby

(Boss, et al., 2011; Kobler & Limbo, 2011; Munson & Leuthner, 2007)

Co-Creating Goals of Care

- Collaboration between interdisciplinary team and parents to create plan reflecting the parents' preferences for their baby's care
- Determination of best interest for the baby, weighing treatment benefits and burdens
- Addressing needs of entire family
- Recognize shifting goals and needs as the baby's living unfolds

(Kobler & Limbo, 2011)

“I really do get the part that she will die. I keep waiting to talk about her living, but we only hear about the dying…

Are you the person will talk to us about living?”

~ Father two weeks after prenatal diagnosis of his unborn baby’s serious illness

Translating Discussions into a Plan of Care

- Meeting with neonatologist provides holistic view of baby's care needs (Miguel-Verges et al., 2009)
- Meeting with pediatric specialists to discuss options for interventions specific to the baby's condition
- Crafting plan of care may occur over days to weeks
- Individualized plan for childbirth education, lactation, sibling support
- Dissemination of plan of care to team and designation of key point person for the parents

(Boss et al, 2011; Kobler & Limbo, 2011; Loyet et al., 2016)

Caregiving in Mother's Narratives of Perinatal Hospice (Limbo & Lathrop, 2014)

For mothers, caregiving includes goals of:

- Protecting
- Nurturing
- Socializing
- Final acts of caregiving

Recommendation:
"Provide mothers every opportunity to care for their babies in ways that are normal and natural to them."

Birth Plan

- Overall goal of care for labor & delivery
- Preferred site & mode of delivery
- Fetal monitoring
- Maternal & fetal medications
- Parents' preference re. presence of family members
- Desired memory-making activities or ritual
- Communication plan with family/friends

(Boss, et al., 2011; Leuthner, 2004a; Kobler & Limbo, 2011; Munson & Leuthner, 2007; perinatalhospice.org)

“This is a special kind of nesting I can do to prepare for my son.”

~ A mother during a prenatal planning conversation

Neonatal Advance Plan of Care

- Opening statement summarizing parents' goals
- Initial delivery room management
- Extent of desired resuscitation measures
- Anticipated medical interventions, such as:
  - Ventilation/airway management
  - Pain & symptom management (pharm & non-pharm)
  - Hydration & nutrition

(Boss, et al., 2011; Leuthner, 2004a; Kobler & Limbo, 2011; Munson &Leuthner, 2007; perinatalhospice.org)

Neonatal Advance Plan of Care (cont.)

- Additional anticipated medical interventions:
  - Plan for extent of diagnostic testing
  - Comfort care measures
  - Family's presence & participation in baby's care and memory- making activities
- Preferred location for the baby's care
- Tentative plan should baby survive to when mother is discharged from postpartum care

(Boss, et al. 2011; Leuthner, 2004a; Kobler & Limbo, 2011; Munson &Leuthner, 2007; perinatalhospice.org)

Neonatal Advance Plan of Care (cont.)

- End-of-life care
  - Preferred location for baby's dying and death
  - Funeral director chosen by family
  - Autopsy or post-mortem biopsy/genetic testing
  - Organ or tissue donation plans
- Contact information for key team members

(Boss, et al., 2011; Leuthner, 2004a; Kobler & Limbo, 2011; Munson &Leuthner, 2007; perinatalhospice.org)

“Your birth and life
was such an incredible gift…
You were worth every contraction, pain
and anxiety just to see you.”

~Mother to her baby

Managing Care after Birth

- Baby's needs leading the way to planning and supportive care
- Anticipate symptoms baby may experience and prepare for potential interventions accordingly
- Continues reassessment and intervention as baby passes critical transition points
- Organize care to promote family-centered care, honoring parents' values, wishes and preferences

(Boss et al., 2011; Carter et al., 2012; Kobler & Limbo, 2011)

Neonatal Palliative Care

- Provision of astute symptom management (e.g., pain, dyspnea, seizures, secretions, agitation)
- Facilitation of goals and plan of care discussions with team and parents
- Collaboration with & support of interdisciplinary team
- End-of-life care & bereavement support
- Honoring relationship and hope

“We want to make decisions
[for our baby]
that would be what he would decide,
if he could choose for himself.”

~ Mother’s reflection

When Shifts Occur

- Reframing goals
- Preparation for next steps in care
- Important questions:
  - Site of care?
  - What should be added or changed for baby's care?
  - Who else should be involved?
  - What is most important?

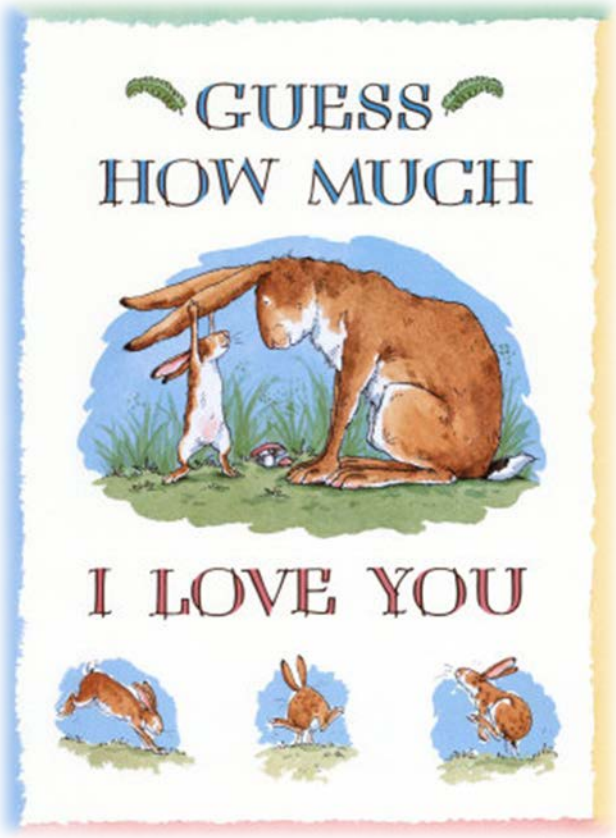
Safe Haven

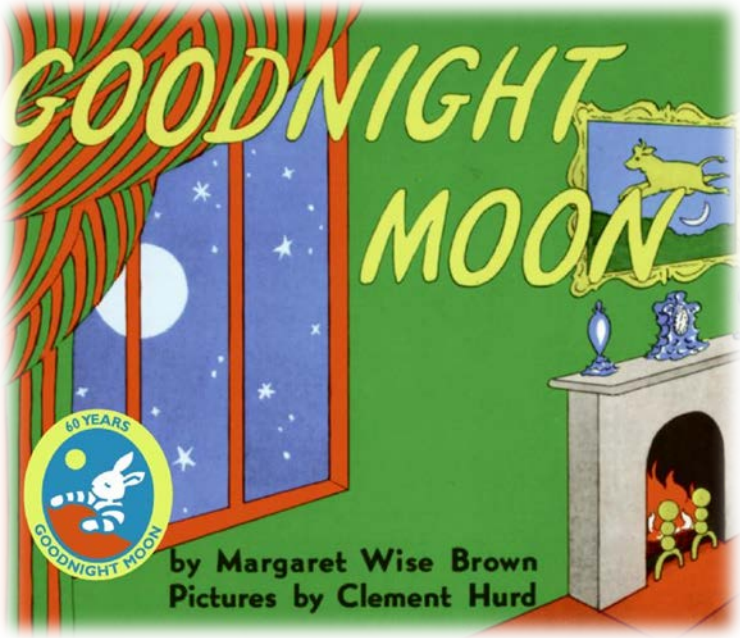
Honoring Relationship

Ritual provides the opportunity to combine traditional and in-the-moment experience.

(Limbo & Kobler, 2013)

Ritual


GUESS
HOW MUCH
I LOVE YOU


GOODNIGHT
MOON
60 YEARS
GOODNIGHT MOON
by Margaret Wise Brown
Pictures by Clement Hurd

“You were the calm center, a safe place, in the middle of our terrible storm.”

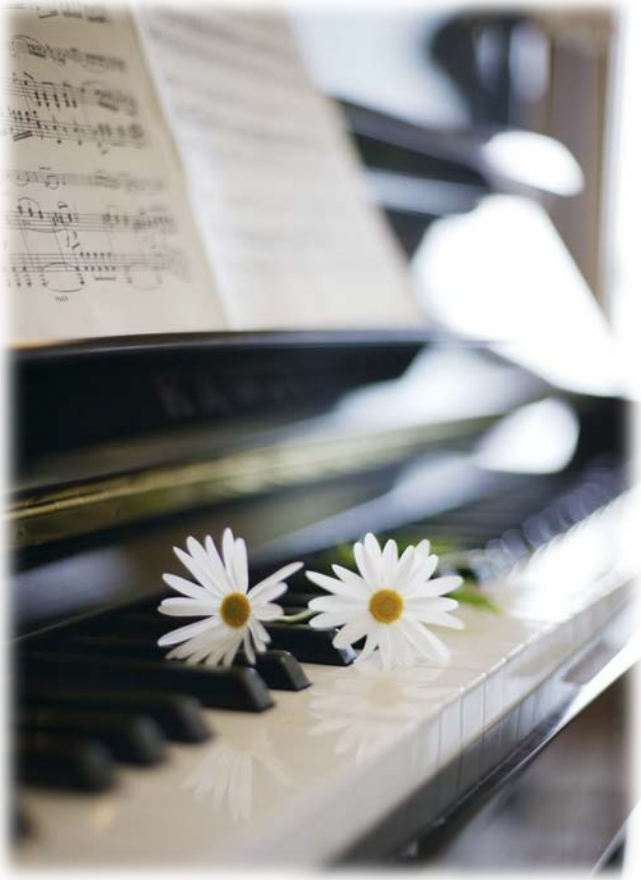
~ Mother to her child’s nurse

Team Support

- Mobilizing team resources following complex patient situations
- Effective team communication
- Administrative acknowledgement of caregiver experiences of grief and loss
- Team processing
- Reflective practice and self-awareness
- Role of ritual

(Kobler, 2014)

*“Please put this in the plan: ‘*Father will sing to his daughter.’”



Resources

- Perinatalhospice.org
  Comprehensive website includes listing of perinatal PC programs, information for families and health care professionals, sample birth plans, links to guidelines and standards of care, and online listserve

- American College of Obstetricians and Gynecologists, & Society for Maternal-Fetal Medicine. (2016). Practice bulletin: Prenatal diagnostic testing for genetic disorders. Retrieved from https://s3.amazonaws.com/cdn.smfm.org/publications/223/download-f5260f3bc6686c15e4780f8100c74448.pdfLeach

- American Academy of Nursing Policy Brief: Limbo, R., Brandon, D., Côté-Arsenault, D., Kavanaugh, K., Kuebelbeck, A., & Wool, C. Perinatal palliative care as an essential element of childbearing choices. In press.

Resources

- Hospice & Palliative Nurses Association
  - www.advancingexpertcare.org
  - *Conversations in Perinatal, Neonatal & Pediatric Palliative Care* (in press).
- Hospice & Palliative Credentialing Center
  - www.advancingexpertcare.org
  - Certification in Perinatal Loss Care (CPLC)
  - Certification in Hospice & Palliative Pediatric Nursing (CHPPN)
- RTS Bereavement Services www.bereavementservices.org
  - Limbo, R., Toce, S., & Peck, T. (2008-2016). *Resolve Through Sharing (RTS) position paper on perinatal palliative care.* (Rev. Ed.). La Crosse, WI: Gundersen Lutheran Medical Foundation, Inc.

Resources

- National Association of Neonatal Nurses: Position Statement on Palliative Care
  - Catlin, A., Brandon, D., Wool, C., Mendes, J., & NANN Board of Directors. (2015). *Palliative and End-of-Life Care for Newborn and Infants.* Chicago, IL: National Association of Neonatal Nurses. Retrieved from: http://nann.org/uploads/About/PositionPDFS/1.4.5_Palliative%20and%20End%20of%20Life%20Care%20for%20Newborns%20and%20Infants.pdf
- Perinatal palliative care quality measure
  - Wool C. (2015). Instrument development: Parental satisfaction and quality indicators of perinatal palliative care. *Journal of Hospice & Palliative Nurs*ing, *17*(4), 301-308.
- Pregnancy Loss & Infant Death Alliance plida.org
  - Position Statements, Guidelines, and Resources for clinicians providing perinatal bereavement care

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