

DEALING WITH DEATH IN THE NICU

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THE TOPIC OF NEONATAL DEATH

- Why I am here
 - On behalf of the bereaved parents
 - Because I am a *Parent Left Behind*
- As a *Parent Left Behind* my mission is to support parents on their life long journey of grief following the death of a child.

YOUR RESPONSE TO BEREAVED PARENTS

- You are already doing things right
 - Crying with them
 - Giving time/space to grieve
 - Helping them feel loved and supported
- What we say and do during the time surrounding the death is of critical importance in the short and long term grieving process for these parents.

ON BEING A NICU NURSE

- “NICU nurses deal with difficult emotional situations. The fragility and suffering of an extremely premature baby in life-threatening conditions and the feelings of anxiety and insecurity of family members are constant in their daily work.”
 - *Journal of School of Nursing* 11/14/2015, Taking care of the newborn dying and their families: Nurses' experiences of neonatal intensive care

DEATH IN THE NICU

- “For Humans, it is difficult to cope with and face death, even though it is a part of life, especially in the case of a newborn.”
- *Journal of School of Nursing* 11/14/2015, Taking care of the newborn dying and their families: Nurses' experiences of neonatal intensive care.

POSITIVE ATTRIBUTES OF HEALTH PROFESSIONALS

- Being sensitive
- Appearing experienced as a team
- Having compassion
- Encouraging parental involvement

NEGATIVE ATTRIBUTES OF HEALTH PROFESSIONALS

- Failure to communicate
- Failure to act as a team
- Lack of compassion
- Failure to address the individual needs of the suffering family

NEONATAL DEATH TRENDS

- Steady decrease in neonatal deaths over the last several decades
- Premature infants born as early as 22 weeks gestation may survive
- Nationally, babies born at 27+ weeks have a greater than 90% chance of survival
- Extreme prematurity and its complications are the leading cause of death in the NICU
 - *JAMA* September 8, 2015 Volume 314, Number 10, Trends in Care Practices, Morbidity, and Mortality of Extremely Preterm Neonates, 1993-2012
- In today's environment, NICU nurses may be more likely to face parents experiencing late pregnancy loss, especially in the case of multiples.

KATIE AND DUSTIN BRYANT

- NICU parents in 2013
- Elliot 28 week premie
- Experienced late pregnancy loss of twin
- Story illustrates complex nature of grief from losing a baby coupled with stress of having a living infant born with complex medical needs

THE BRYANT'S HEART-ACHE

- John Carter's death was sudden and unexpected
- Situation involved loss and continued pregnancy at the same time
- This scenario is unique to multiples
- Incidence of multiples in gestation is increasing over the past decades

MULTIPLES

- Twin pregnancies increased by 65% from 1980-2002
- Larger multiples increased by 400%
- Twins are 5 times more likely to die than singles
- Larger multiples are 12 times more likely to die than singles
- Fetal loss occurs in 5% of twin gestations and 18% of triplets
- Pregnancy risks with multiples— late pregnancy loss, possibility of need for planned pregnancy reduction, delayed interval delivery, premature delivery, and death of one or more than one multiple after birth

ON LOSING A MULTIPLE IN NICU

- Mother's quote: "I didn't want to bond with any more babies that could die."
- Half of mothers of lost multiples reported difficulty bonding with survivors
- Others report accentuated bonding
- Intense fear of losing the other baby or babies
- Anguish when witnessing other families with intact multiples
- *Journal of Perinatology* 2004; 24:714–722, How Bereaved Multiple-Birth Parents Cope with Hospitalization, Homecoming, Disposition for Deceased, and Attachment to Survivors

DECISIONS: HOW THE DEATH IS HANDLED

- When/ where or whether to see the baby
- Family member involvement
- Touching/dressing the baby
- Photography
- Funeral
- Autopsy

AFTER A BABY DIES

- Nurses are generally perceived as the health care provider most likely to provide emotional support
- Nurses also receive the highest ratings from families
- Doctors are typically rated as much less helpful and supportive
- Increased programming in grief sensitivity for doctors has not shown increased perceptions of doctor empathy
 - *Journal of Perinatology* (2007) 27, 230–237 Navigating care after a baby dies: a systematic review of parent experiences with health providers

KEY AREAS OF SATISFACTION/ POSITIVE INTERACTIONS

- Emotional Support
- Providing Tangibles
- Education and direct communication
- Sensitivity

KEY AREAS OF DISSATISFACTION/ NEGATIVE INTERACTIONS

- Lack of Communication among staff
- Avoidance or failure to interact with families following the death
- Lack of providing emotional support
- Frank insensitivity
 - “One thoughtless comment after a death may become engraved in a parent’s memory.”

LONG TERM OUTCOMES FOR PARENTS

- Parents have increased risk of depression, prolonged grief, delayed grief or PTSD
- In the first year after a NICU death parents are twice as likely to be seen for chronic medical conditions
- Increased likelihood to be medicated or to have complex regimens regarding medications
- Parents need reassurance about ambivalent feelings and lack of attachment, invasive thoughts of guilt or failure, anxiety for survivors, and delayed grief
 - *Pediatrics* V.132,#5, Parent Health and Functionality 13 Months after Infant or Child NICU/PICU Deaths. November 2013

THOUGHTS ON DISCHARGE

- Discharge planning and homecoming– difficult for parents
- Parents may not pay close attention to details and instructions
- Parents may need extra guidance or repetition
- Discussion should include grief support and resources
- Consider follow up phone call or letter from NICU staff weeks or even months after the death
- Remind OB/Gyn and other care givers of the death– don't ask “how is your baby” at follow up appointments
- Pediatrician can be a great source of comfort to family/ helps to let us know about the loss before we see the family

PROVIDING RESOURCES

Grieving Parents Support Group of NWA

Rev. Steve Sheely

Rolling Hills Baptist church

1400 E Rolling Hills Dr

Fayetteville, AR 72703

rhbaptist@sbcglobal.net

479-521-2660

Second Monday 6:00-7:15

Support Group for Child and Infant Loss/Miscarraige

Circle of Life 901

Jones Rd Springdale, AR

PO Box 8512

Fayetteville, AR 72703

Angela Kathman

(479) 750-6632

Second Monday 5:30-7:00

MEND Ministries

Kristin Piston

Fellowship Bible Church

1051 Pleasant Grove Rd

Rogers, AR 72758

MendMinistries@gmail.com

Second Tuesday 6:30-8:30

IN CONCLUSION

- I hope I have...
- Helped you understand more about the complex nature of bereavement after the loss of a child
- Increased your awareness regarding the emotional devastation and challenges these parents face
- Enhanced your ability to care for parents in the acute and ongoing settings of losing a baby
- Encouraged you to view grief as a lifelong journey

THANK YOU

- Kristin Evans and the Audrey Harris Vision
- Katie and Dustin Bryant
- Donna Fallin– videographer
- Parents Left Behind Committee
- Cameron Averitt Bobbitt– my precious child who left too soon, and encourages me every day to make a difference in honor of the life she didn't get the chance to finish

