Pass Through Wisdom and Legacy Building in Perinatal Loss

WVU Medicine Children’s Hospital
Morgantown, WV

Joshua M. Dower, MD Director Pediatric Supportive Care
Christy Orndorff, BSN, CHPPN, CPLC Nurse Coordinator
Objectives

- Understand common scenarios of perinatal loss
- Define clinical approach to patient and family
- Discuss the integration of narrative and tangible legacy
“Our present Western society is not willing to experience death, in the sense that it is hidden by a conspiracy of silence... As a consequence, parents are often not given permission by family or friends to mourn the death of their baby, and they are very often left alone in an apparently unsympathetic world, not knowing how to feel and not knowing how to cope.”
National Statistics

• Fewer parents today must endure the death of a baby
• The infant mortality rate has dropped considerably in the United States since the early 1900s
• The rate is now less than 1 percent
• 53-55,000 children die annually in the US
  • 2.5 million adults die/year
World Wide

- More than a half-million women die as a result of pregnancy and childbirth difficulties
- 2 million babies die within their first 24 hours
- 2 million more die within their first month
- 3 million are stillborn

(The Annual State of the World's Mothers Report)

That is over **Seven Million Families** that are devastated by tragic loss worldwide annually.
Infant death was greatly minimized.

Even into the 1980’s, many hospitals still prohibited parents from seeing or holding their stillborn babies.

Too often, the babies were never spoken of again.

Feelings of isolation, loneliness, guilt
“In 1972 When I Had My...”
In 1972, when I had my miscarriage they never let me see the baby. I didn’t even know if I was having a boy or a girl. They left me on a maternity floor. I had eaten spaghetti so they wouldn’t do the D&E until the next day. I was put in a room with a woman with a live baby. That was cruel. There was no burial - I was 5.5 months pregnant – Dr. G was rough, not compassionate. They just started an IV pitocin drip, I had it and they did a D&E. Nobody talked to me and nobody helped me. They never helped me grieve. I didn’t have any service for the baby that I lost. Tina, my daughter, was 19 months old.
The nurse said, “one good thing, you have a child at home.” When I got pregnant with Eric I was petrified. Nobody ever told me whether this would or wouldn’t happen again. I wish somebody would have written a letter for me, somebody would have talked to me, somebody would have told me I would be OK. Nobody talked to me about it – not even my family – they didn’t know what to say so they didn’t say anything – it was terrible. They need to know that baby was loved and a precious child.

What really helped? - knowing that our baby was in the hands of God.

– Barbara Dower
The reactions are so variable that it is essential to have a learning conversation first and help understand parental experience and expectations

- “I’m totally devastated”
- “I just have to live through it”
- You may mourn for the loss of a child – deeply, a little, or somewhere in between
- You may be relieved because you did not want to be pregnant – which can bring a different kind of guilt and grief
- You may bounce back and forth between emotions
- The grief can be delayed for months or years
  - It can be disenfranchised by those who don’t believe you should be so sad
A 28 yo G2P1001 at 24 weeks 0 days


Plan for inpatient management (NST tid and weekly US) until delivery at or before 32 weeks.
Clinical Course

- 2/10/16 – U/S revealed Twin A had no left kidney and continued with the curved cervical/thoracic spine. Twin B with anencephaly and no right kidney visualized.

- Received BMZ x 2

- 3/1/16 started on Magnesium Therapy x 24 hours for neuroprotection.

- Delivered via C/S at 32 weeks gestation on 3/7/16
Meet The Family

Parents: Tyler and Leigha Trippett

Twin daughters: Martina Grace & Julianna Faith
Born: March 7, 2016

Brother: 2 year old AJ

Hometown: Bridgeport, WV
Hope and Grief
Recognizes the quest for finding:

- the meaning of the situation as a whole
- the meaning of one’s life
- how one fits into the world existentially
- what legacy one leaves
- what lies ahead after illness and/or after death
- the many unanswerable why questions
They wanted hope for their daughter Martina who would have a NICU journey.

They wanted continued legacy for their daughter Julianna. For her life to make a difference to others.

“Even though her life was short, her legacy will live on for many years to come.”
Family and team meetings. What are the options?
Discuss end of life wishes with the family. What are their goals?
Prepare the family for the experience...what to expect
Ask the family how they want to spend time with their baby. Who do they want present? Music? Special blankets/outfits? Suggest what other families have done.
Family Centered Care (cont.)

- Invite family to participate in the care. Support family to help to include siblings.
- Encourage siblings to draw pictures, write letters, read books, sing songs.
- Be an active listener and use empathetic communication.
- Spiritual support.
- Have information for parents regarding decisions about services, burial, etc. Offer to make the phone calls.
- Ensure that quality care is continued with postpartum visits. Communicate with providers.
Heirloom Photography...capturing moments for family – “Now I Lay Me Down To Sleep”
www.nowilaymedowntosleep.org
Plaster of Paris molds of feet and hands
Clay prints, ink prints, paint on canvas
Legacy Building and Memory Making

- Charms – www.regalijewelery.com
- Transition Objects – Blankets and bears
- Angel Gowns – Littlest Angels in Pittsburgh, PA
Resources

- Provide families with grief books/pamphlets, including sibling resources. Partner with hospices in the area – bereavement camps.
- Follow-up throughout the first year (phone calls, cards)
- Provide a remembrance service

“My family and I were given the opportunity to honor and remember our infant daughter we lost at term at the Butterfly Release event at WVU Children's Hospital. We found a safe haven and comfort in being surrounded by other families who are walking a similar path of grief. As a grieving mom, one of my biggest fears is my child being forgotten. This ceremony gave us an opportunity to remember her as well as an overwhelming peace with the beautiful illustration of the butterflies' transformation into a new life. We can't express how grateful we are for being able to participate in such a wonderful event.”
Letter from a bereaved family

“It’s been really difficult being home and trying to put what’s left of our lives back together......kind of like putting together a 1000 piece puzzle without the picture.”
Thank you!!!

Questions???

Josh’s email: jdower@hsc.wvu.edu
Christy’s email: orndorffc@wvumedicine.org

Our Office Number: 304-598-4000 ext. 71102

*Photos by Lisa Brennen, LB Photography, Waynesburg, PA a volunteer with “Now I Lay Me Down To Sleep”