UNDERSTANDING PERINATAL LOSS

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Loss, Grief and Bereavement

- Affects family and nurse
- Each person grieves in their own way
- Nurses facilitate grieving
- Interdisciplinary care is critical
Loss, Mourning, Grief, Bereavement

- Loss is absence of a possession/person
- Mourning is the outward, social expression of loss
- Grief is the emotional response to loss
- Bereavement includes grief and mourning
- Strongly influenced by culture
The Grief Process

- Begins before the death
- Not orderly or predictable
- Includes a series of tasks – “work”
- No one “gets over it”
- Grief work leads to living with the loss
Anticipatory Grief

• Grief before loss-
• prenatal diagnosis?
• Actual or fear of potential losses
• Uncertainty
Uncomplicated Grief

- Typical feelings, behaviors and reactions to loss
- Physical, emotional, cognitive and behavioral reactions
Complicated Grief

- Chronic grief
- Delayed grief
- Exaggerated grief
- Masked grief
Risk Factors for Complicated Grief

- Sudden or traumatic death
- Suicide, homicide
- Multiple losses
- Unresolved grief from prior losses
- Psychiatric Instability
Disenfranchised Grief

deprived of

When loss cannot be openly acknowledged or socially sanctioned
Risk Factors for Disenfranchised Grief

- Neonatal death
- Terminated pregnancy
- Child abuse death
- Unwanted/unplanned pregnancy
Effects of Grief on Family

- Related to their awareness
- Range of feelings
  - Anger
  - Anxiety
  - Sadness
  - Loneliness
  - Fear
Effects of Grief on Family

- The parents
  - Relationship is like no other
  - Responsible for protecting child
  - Mother and father have unique experiences
Effects of Grief on Family

- Grandparents
  - Source of strength
  - “Double sorrow”
  - Grief is two-fold for parents and grandchild
Effects of Grief on Family

- The siblings
  - Loss of sibling
  - Loss of family unit
  - Loss of parents to grief process
  - May feel they caused death
Children’s Grief

• Can be typical or complicated
• Reactions based on child’s age and developmental stage
• Symptoms unique to children
Grief Assessment

- Begins at time of admission or diagnosis
- Ongoing to detect complicated grief
Grief Assessment Includes:

- Type of grief
- Reactions
- Processes and tasks
- Influencing factors
- All family members (parents, siblings, extended)
- Siblings at risk
- Assess psycho/physiologic responses
Bereavement Interventions

- Plan of care
- Attitude
- Cultural practices
- What to say
- Anticipatory grief
Grief Interventions for Families

- Provide presence
- Active listening, touch, silence, reassurance
- Identify support systems
- Use bereavement specialists & resources
- Normalize & individualize the grief process
- Actualize the loss & facilitate living without the deceased
Grief Interventions (Parents)

▪ Before death
  ▪ Communication
  ▪ Memories
  ▪ Funeral planning

▪ After death
  ▪ Bereavement
  ▪ Follow-up
  ▪ Support groups
Online Support
LOSS IN THE PERINATAL SETTING
What do We Mean by Loss?

- Stillbirth
- Fetal Demise
- Ectopic Pregnancy
- Spontaneous Abortion/Miscarriage
- Neonatal Death
Expanded Definition of Loss

- Relinquishment for Adoption
- Surrogacy
- Genetic Termination
- Therapeutic Abortion
- Infertility
- Reduction of Multiples
- Delivery of a Sick Newborn
- Death of a Family Member prior to Baby’s
Expanded Definition of Loss

- Undesired Pregnancy
- Alone/Un-partnered
- Inadequate Resources
- Transport and Separation of Family and Baby
Antenatal Diagnosis

http://www.youtube.com/watch?v=ToNWquoXqJl
Myths About Grief

- Infant death is easier to get over because you hardly knew the child
- All losses are the same
- Grief declines steadily over time
- You will eventually “get over it”
- Bereaved parents do not have a relationship with the baby after the death
Grieving Far from Home
“Trauma of Transport”

- Away from family and friends
- Mother/baby separation
- Phone contact when the news is bad
- Diagnostic process is torturous
Grief and the Couple

- Almost always grieve differently
- Stable couples are more balanced than similar in their coping styles
- Acute grief leaves little reserve for parents to comfort one another
- Different coping styles can lead to resentments
At Risk for Stereotyping: Mothers

- Physical symptoms
- Need to talk about the loss
- Open expression of emotion
- Frequent and persistent thoughts about the baby
Attachment to the Pregnancy

“The physical, or somatic aspect of this loss is so tangible-obviously you have carried a human life, for however long, and may have already begun to parent this child. For many women, the child enters into daily awareness in the form of planning for him or her, or simply paying more attention to nutrition or other aspects of health that may have an impact on the development of the child. The mind/body experience of so many women translates as “I can't wait to hold this baby.” The wanting to hold is a very tangible, physical experience...that does not get fulfilled when the unborn child doesn’t survive.”

Noblitt-Keating (2012). There Was Supposed to be a Baby
At Risk for Stereotyping: Fathers

- Stoic
- Immersion in work/tasks
- Angry
- Need to protect
Duration of the Grieving Process

- No one can predict completion
- Grief work is never completely finished
- Healing occurs when the pain diminishes
4 Tasks of Mourning

- To accept the reality of the loss
- To work through the pain of grief
- To adjust to an environment in which the deceased is missing
- To emotionally relocate the deceased and move on with life

- Worden, J.W. 2002 Grief Counseling and Grief Therapy
The Phases of Grief and Bereavement

“(The stages) were never meant to tuck messy emotions into neat packages. They are responses to loss that many people have but there is not a typical response to loss. Our grief is as individual as our lives.”

Elisabeth Kubler-Ross
Phases of Bereavement

- Shock and numbness
- Searching and yearning
- Disorientation
- Reorganization and resolution
Shock and Numbness

“\textit{This isn’t really happening}”

- Most intense during first 2 weeks
- Characteristics:
  - Stunned, disbelief
  - Impaired decision making/functioning
  - Memory loss
  - Denial
  - Resistant to stimuli
Searching and Yearning

“How did this happen?”

- Can occur from 2nd week to 4th month
- Emotional characteristics include:
  - Testing what is real
  - Irritability
  - Preoccupation with the deceased
  - Obsession to get pregnant again
  - Resentment/bitterness
Searching and Yearning

- Physical characteristics
  - Weight gain/loss
  - Sleeping difficulties
  - Aching arms
  - Palpitations
  - Lack of strength
  - Headaches
Disorientation

“I will never get over this”

- Characteristics dominant 5th-9th month and may include:
  - Feeling of “going crazy”
  - Social withdrawal
  - Guilt
  - Sense of failure
  - Exhaustion
Guilt

“I know in my heart that her little body wasn't strong enough despite all the medical interventions, but that still does not make grieving for her any easier. We wanted so very badly to share so much more with her. I just feel like if my body hadn't failed us she would still be kicking around in my womb. Aside from saying goodbye to her, the guilt is one of the hardest things to let go of.”
Reorganization
“Maybe I will make it after all”

- 18-24 months after the loss
  - Sense of release
  - Renewed energy
  - Eating and sleeping habits improve
  - Increased attention to self care needs
  - Acceptance
Factors Influencing the Nurse’s Adaptation to Grief and Loss

- Professional training
- Personal death history
- Life changes
- Support systems
Caregiver Self Analysis

- Death anxiety
- Cumulative loss
- Grief
- Defenses
- Personal death awareness
Cumulative Loss in Health Care

- Succession of losses common to nurses
- May not have time to resolve losses before another loss occurs
Conclusions

- Care does not end with the death
- Families and other caregivers seek to find their own meaning and purpose
- Loss, grief and bereavement need to be assessed with ongoing intervention
- Caregivers must recognize and respond to their own grief
- Provide interdisciplinary care
Cultural Considerations
Culture

- A system of shared symbols
- Provides security, integrity, belonging
- Constantly evolving
Cultural Competence

- Cultural sensitivity
- Knowledge and beliefs
- Use of interdisciplinary approach
Components of Cultural Assessment

- Patient/Family/Community
- Birthplace
- Ethnic identity, Community
- Decision making
Components of Cultural Assessment

▪ Language and communication
▪ Religion
▪ Food preferences/prohibitions
▪ Economic situation
▪ Health beliefs re: death, grief, pain
Cultural Considerations and Communication

- Use of interpreters
- Conversation style
- Personal space
- Eye contact
- Touch
- Time orientation
- View of healthcare professionals
- Learning styles
Role of Family

- Who makes decisions?
- Who is included in discussions?
- Is full disclosure acceptable?
"SO WHAT DO I SAY?"
Avoid Saying Things Like…

● You are still young and can have more children
● It is worse to lose an older child
● At least you still have ____ (older child)
● The baby would have a difficult life
● Maybe this is for the best
● “When I lost my baby…”
● When did you last feel the baby move?
Avoid Religious Clichés

• “God gives you what you can handle”
• “This is God’s will”
• “The baby is in heaven with God”
• “God needed another angel”
Supportive Communication

▪ Acknowledge their terrible loss and express genuine sympathy
▪ Always use the baby’s name
▪ Assess the need for time alone with the baby
▪ Assure parents that pain will be managed effectively
Guidelines from Grieving Parents: What They Want to Say

● “Even if you don’t understand, these feelings are real for me.”

● “The best thing you can say to me is, I’m sorry for your loss.”

● Yes, I need help. Please sit with me while I cry. Don’t talk, just sit.”
Supportive Communication

- Model tenderness and caring for the baby during and after death
- Encourage parent involvement in rituals
- Acknowledge the loss of hopes and dreams
Supportive Communication

- Remind parents that couples may grieve differently and have different coping styles.
- Warn parents that people sometimes say insensitive things even though they mean well.
- There will likely be constant reminders of their loss (in the media, mailers, pregnant women, and babies, etc).
Nonverbal Communication

- Eye contact
- Power of touch
- Modeling with Gestures
What Can I Say?

“I am here to take care of you today. I will be close by even when I am not in the room.”

Many OB patients report that they felt like their pain was difficult for the nurse to observe and they were left alone.

“I was left alone because I didn’t have a baby in the room...”
What Can I Say?

“There are no words that I can say that will bring you great comfort. I am so sorry for your loss.”
What Can I Say?

Acknowledge the loss of future with that child for the entire family

“You had a lot of hopes and dreams for him”

Respect the place in the family structure of each child.

“She will always be your first baby.”

“He will always be your second baby son.”
What Can I Say?

“i cannot imagine the depth of your sadness and disappointment.”
What Can I Say?

“I will be with you through this difficult day and will listen to your cues about how to best care for you.”

• Give permission for a variety of emotional responses
What Can I Say?

“There is nothing that you did or did not do to make this happen. Let’s get the doctor to come in and answer some of your questions and concerns.”
What Can I Do?

“This is what will happen next…” (patients are disoriented in their grief and need to gain back some control)

“May I make some phone calls for you?”

“I am here to monitor your visitors as needed” (Parents are sometimes reluctant to express their need for privacy to family/friends)

Nonverbal communication: assess a patient/parent’s need for physical contact
Subsequent Pregnancy
Helpful Interventions

▪ Be aware of gravity/parity and acknowledge their previous loss
▪ Allow parents to talk about their fears
▪ Provide consistent caregivers and work on building trust
▪ Monitor often for reassurance
▪ Let them know that conflicting emotions are normal
Subsequent Pregnancies
(Special Considerations)

▪ There may be a distrust of medical systems
▪ Fear of repeating a tragic loss
▪ Women do not have confidence in their own bodies to deliver a healthy child
▪ They may still be grieving acutely as they remember the trauma of their loss
▪ The challenge of feeling sad and happy at the same time
Cardinal Rules of Grief Support
Taken from RTS Bereavement Services Manual

- Respect the silence and listen
- Admit our helplessness
- Be genuine
- Be with the person in grief
- Do not judge another’s grief
- Be clear about your own issues on death
- Know your limitations
The Art of Condolence

- Acknowledge the loss
- Express your sympathy
- Note special qualities of deceased
- Offer assistance
- Close with a thoughtful phrase
Developing a Program for End of Life Care
Where Do We Start?

- Communication with the family
- Gathering resources
- Creating the setting
- Saying goodbye
- Seeing and holding
- Mementos
- Services/Arrangements
- Emotional support after discharge
Bereavement Programs

- Formal or Informal
- Support groups at hospital site
- Mail correspondence
- Phone correspondence
- Annual memorial services
- Coordination with community agencies
Family-centered approach

Provides comprehensive and integrated care that addresses physical, emotional, psychosocial, and spiritual needs

Utilizes an interdisciplinary team

Encourages shared decision-making and goal setting
Maximizes life and neither hastens nor postpones death
CARE

Emphasizes physical, emotional, social and spiritual care with a focus on quality of life and relief of suffering.
HOPE

- Recognize that maintaining hope is a powerful tool for coping with a medical crisis and an uncertain outcome.

- Palliative care can occur side-by-side with treatments aimed at cure or at prolonging life.
RESOURCES

● Interdisciplinary approach
● Includes resources within the hospital as well as referrals in the family’s community
CHOICE

• Provide honest information about treatment options
• Honor personal, cultural, and religious beliefs and practices
Mementos
Mementos

Clothes to dress baby in
Resources
Keep in one place
Reconnecting
Guidelines for Pregnancy Loss

- Flag chart/room
- Refer to pastoral care/social work
- Offer option to see and hold baby/products of conception
- Arrangements
- Mementos
- Pathology/Genetics
- Referral to support
Pain and Comfort for Baby
Pain Management for Baby

- **Morphine**
  - PO: 0.2-0.5 mg/kg/dose q 4-6 hrs
  - IM/IV: 0.05-0.2 mg/kg/dose q 2-8 hrs

- **Fentanyl**
  - 1-2 mcg/kg/dose

- **Acetaminophen**
  - 10-15 mg/kg/dose
Care of the Family After Perinatal Loss

- Offer parents a room away from maternity if requested
- Flag room
- Referral to pastoral care
- Allow family as much time as needed with the baby
Stillbirth and Newborn Death

- Flag room
- Identify support person
- Allow parents opportunity to see and hold infant
- Bathe, dress baby
- Create mementos
- Autopsy?
- Discuss arrangements
Seeing and Holding

- Prepare parents for baby’s appearance
- Measures to prevent oozing
- Wrap baby in warm blankets
- Allow family as much time as needed and arrange for multiple visits if requested
Post Mortem Care

- Body Positioning
Body Positioning

- Supine position
- Rolls around head to prevent pooling
- Arms crossed and supported with blanket rolls
- Vaseline or Aquaphor can be applied to nares and mouth to prevent fluid leakage
- Wrap the baby mummy style and avoid pressure to the face
Home with Hospice

- Palliative care referral may be initiated while infant still in hospital by anyone (the earlier the better)
- Hospice referral made by Pediatrician