Losing a baby, whether term or preterm, means losing a potential relationship full of hope and expectations. Parents lose an entire future.

The care given to a family before and following an infant’s death can set the stage for the family’s entire grieving process.

Grief is now considered a normal, healthy, dynamic, universal, and individual response to loss. It enables the bereaved to heal and integrate the loss into their life.

Grief is a multifaceted response to loss that includes psychological, behavioral, and physical reactions combined with cognitive, emotional, behavioral, social, spiritual, and somatic elements.
### Grief
- “Grief is a tidal wave that overtakes you, smashes down upon you with unimaginable force, sweeps you up into its darkness, where you tumble and crash against unidentifiable surfaces, only to be thrown out on an unknown beach, bruised, reshaped…”
  - Stephanie Ericsson, writer and grief survivor

### Complicated Grief
- Complicated grief is characterized by extended length of time of symptoms, the interference in normal function caused by the symptoms or by the intensity of the symptoms.
- It may also be the absence of grief and mourning, an ongoing inability to experience normal grief reactions.

### Palliative Care
- Curative treatments seek to reverse the disease process. Palliative treatments focus on relieving symptoms, regardless of their impact on the underlying disease process.
- The goal is to achieve the best quality of life for patients and their families.

### Palliative Care
- Palliative care maintains respect for the cultural and spiritual beliefs and practices of the family by using an integrated multidisciplinary approach.
- A partnership between the family and healthcare professionals, including nurses, physicians, social workers, and bereavement counselors.
“The goal is to add life to the child’s years, not simply years to the child’s life.”

- American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care

History

- John Bowlby (1960s):
  - Proponent of attachment theory: people strive to keep close the people and objects they care for.
  - Phases following loss include the urge to recover the lost object, disorganization and despair, and reorganization.

Grief Process

- Elizabeth Kubler Ross:
  - Five overlapping stages:
    - Denial
    - Anger
    - Bargaining
    - Depression
    - Acceptance

History

- Klaus and Kennell (1970s):
  Implications of parent-infant bonding in perinatal loss.
  - Observed a higher degree of mourning in mothers who had not touched their babies before their death and talked with their husbands about the death.
### Grief Process

- Bowlby (1960s) and Parkes (1990s) describe grief in phases:
  - Shock and Numbness
  - Yearning and Searching
  - Disorientation and Disorganization
  - Reorganization and Resolution

- Factors that may affect how families cope with grief:
  - Gender
  - Religion
  - Culture
  - Previous losses
  - Healthcare provider support

### Caregivers’ Role with Families

- Honesty
- Empowered Decision-making
- Parental Care
- Environment
- Faith/Trust in Nursing Care
- Physicians Bearing Witness
- Support from other Hospital Care Providers
  - Brosig et al., 2007

### Caregivers’ Role with Families

- Prior to and at the time of death:
  - Attaching (Bonding): Allow parents to spend as much time as they need with their baby.
  - Encourage the parents to hold their baby.
  - Refer to the baby by name.
  - Prepare family for what may happen as the baby dies (gasp, color changes).
  - Include other important support figures

Brosig et al., 2007
<table>
<thead>
<tr>
<th>Caregivers’ Role with Family</th>
<th>Making memories</th>
</tr>
</thead>
</table>
| Prior to and at the time of death:  
  - Provide privacy, but do not abandon  
  - It is okay to cry or show emotion  
  - Discuss baptism or any other ritual the family would like  
  - Do not minimize what the parents are feeling with catch phrases | “Holding on” rather than “Letting go”  
  - Bereaved mothers have expressed that their greatest fear is that their children will be forgotten.  
    - Promoting the creation of memories/mementos helps to keep the child’s memory alive. |

<table>
<thead>
<tr>
<th>Making Memories</th>
<th>Autopsy</th>
</tr>
</thead>
</table>
| ■ Photographs  
■ Plaster moldings of hands and feet  
■ Locks of hair  
■ Name cards  
■ Clothing  
■ Blankets | ■ Permission for autopsy should be requested for all deaths.  
  - Provide answers to unanswered questions  
  - Erase feelings of guilt  
  - May impact future pregnancies |
<table>
<thead>
<tr>
<th>After Death</th>
<th>Memorials</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Disposition of body:</td>
<td>■ Healthcare providers may continue to</td>
</tr>
<tr>
<td>- Whether choosing burial, cremation, or</td>
<td>support families and themselves by</td>
</tr>
<tr>
<td>donation of body, it is of utmost</td>
<td>attending funerals or memorials.</td>
</tr>
<tr>
<td>importance that families know that their</td>
<td></td>
</tr>
<tr>
<td>baby is treated with dignity and respect</td>
<td></td>
</tr>
<tr>
<td>even after death.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Follow-up</th>
<th>Grandparents</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Phone calls</td>
<td>■ Grandparents not only grieve for their</td>
</tr>
<tr>
<td>■ Meetings</td>
<td>grandchild, but they also hurt for their</td>
</tr>
<tr>
<td>■ Autopsy results</td>
<td>children.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Siblings

- Children of all ages grieve. The siblings should be included in the process as much as possible.
- Age appropriate discussions should take place with the sibling(s).
- Young children may not be able to verbalize their feelings.

Empty Arms

- Prepare the family for what comes next:
  - Physical symptoms
  - Differences in grieving
  - Holidays
  - Trigger events

What About YOU?

The Health Care Professional

Supporting the HCP

- Critical to recognize and support the HCP’s own grief experience
- HCP can't help others if their own basic needs are not met
- Supporting families is the goal
- Supporting HCP is part of the process to get to the goal
Nursing Staff Plays a Key Role in Providing Compassionate Care

- Facilitate the grieving process
- Many times nurses feel inadequately prepared
- Engler et al., survey (2004) 190 respondents
  - One of the “major stressors” identified by staff was dealing with grief, loss, and bereavement
  - Comfort and roles scores correlated significantly with number of years as a neonatal intensive care nurse
- Education on bereavement/end-of-life care could affect nurses comfort with caring for families of critically ill and/or dying infants.

Personal Loss

- Arises from a personal attachment
  - When the caregiver develops an awareness of the infant or family on a personal level
- As a personal attachment strengthens, the potential for experiencing a patient’s death intensifies
- Because it is still routine work, it may not be fully acknowledged, and may remain unresolved and & can have deleterious affects (Albert, 2001).

Cumulative Loss

- Succession of losses common for nurses
- May not have time to resolve losses before another loss occurs
- The repetitive emotional strain, in addition to reminders of one’s own mortality, puts HCPs at risk for experiencing compassion fatigue and burnout
- It’s important for the HCP to adapt or cope, otherwise may go into burnout

Factors Influencing the HCP’s Adaptation

- Professional training
- Personal death history
- Life changes
- Support systems
### Neonatal and Pediatric HCP Expressing Their Grief

- Do their own thing
  - Some express
  - Others suppress
- This is part of the job...“suck it up”
  - Not dealing with it....going to burn out

### The Impact

- Half of all children who die, die during infancy which means...many will die in either the NICU or PICU.
- NICU and PICU HCP need to be prepared to support bereaved families and themselves!
- One of the most stressful & important events for health care providers lies in the support of families experiencing the death of an infant.

### Real Experience

One nurse relates her story following a "routine" loss going home after work and noting that she “felt very little, just tired”.

She recalls:

“When the alarm rang for me to get ready for my next shift, I felt as though I had been beaten with a stick from head to toe. My body was stiff, my muscles were sore, and I was physically exhausted. I called in ‘sick,’ went in to make dinner, and sat down on the floor and sobbed. I couldn't stop. I cried for several minutes, seemingly without any control over it, and then marveled at what had just happened. I realized that it wasn’t about this one sweet baby girl. It was all of those children I'd lost...”

### Disenfranchised Grief

- Hidden grief often downplayed in the clinical setting.
- Many NICU nurses experience disenfranchise grief because it is considered “part of their job” or it takes away a certain level of professionalism if they are to grieve
- Unacknowledged, personal, work-place loss….a “grief that is experienced when a loss is not openly acknowledged, socially sanctioned, or publicly shared.” (Doka, 1989)
### Unresolved Disenfranchised Grief

- Interferes with normal grief resolution
- Many times these negative affects occur after the HCP has had time to go home and “let down”
- Chronic fatigue, decreased interest in exercise
- Irritability, overly critical
- Sadness, and/or intense sorrow, and helplessness.
- Headaches, weariness, emotionally labile, inability to concentrate, and feeling low, sickness, physically exhausted
- HCP need to identify their limitations and deal with personal challenges and need to be supported, without feeling guilty, during bereavement in the NICU.

### Compassion Fatigue

- Patient care continually draws upon the physical and emotional energies of HCP
- Triggered by the indirect trauma resulting from dealing with the tragedy of patient demise, viewing painful procedures, and experiencing the residual effects of exposure to human suffering
- Cardinal signs of compassion fatigue are fatigue and lack of energy
- If unrecognized and unaddressed, may progress to burnout, a state with more severe, long-term symptoms that are

### What HCP Can Do

- Quiet time
- Memorial
- Time off...rest/recreation
- Formal/informal debriefing
  - Support conference (focused on staff needs & caregiver concerns about work)
  - Closure conference (focused on staff feelings about a particular patient who had died & they had developed a relationship)
  - Informal may include gathering for lunch or coffee

### What HCP Can Do

- Promote an environment of care where colleagues respect the need to express grief and understand it is critical to the well-being of the HCP
- NICU is unusual because it is celebrating the joy of a beginning of life coupled with the pain of end of life care
- Need to develop a self-awareness of the impact of stress and energy available for work--need to identify one's own energy limits
What HCP Can Do

- Learn to request assistance without guilt
- Develop awareness of personal attitudes & beliefs about dying and death
- Work as a team...don’t do it on your own
- Attend to one’s own physical, psychological & social needs

Partners in Caring (Vanderbilt)

- A collaborative staff support program as a means to mitigate potentially negative outcomes of workplace stress to staff, patients and families.
- Staff support and motivational activities.
  - Motivational activities included events often used to enhance self-esteem and team (unit) cohesion. The goal: to allow for celebration in the midst of a potentially distressing environment.
  - Support to staff members by providing education and resources to help them examine some of the emotionally demanding experiences encountered in an ICU. A series of facilitated discussion groups, led by professionals with expertise on the chosen topic, was constructed.