An Empty Cradle

Management of Perinatal Loss

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What is Perinatal Loss?

Perinatal Loss or Death- is defined as the unintended ending of a pregnancy at anytime before or during the birth. It also includes the death of a newborn in the 1st month after the birth.
# Types of Losses

<table>
<thead>
<tr>
<th>Types of Loss</th>
<th>Description</th>
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<tbody>
<tr>
<td>Miscarriage</td>
<td>Loss occurring less than 20 weeks gestation (early pregnancy loss) and weighing less than 500 grams</td>
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<tr>
<td>Stillbirth</td>
<td>Loss occurring greater than 20 weeks gestation (late pregnancy loss) and greater than 500 grams</td>
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<tr>
<td>Neonatal Death</td>
<td>Loss occurring from birth through 28 days of life</td>
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Perinatal Loss Statistics

- Miscarriage about 20-25% of all pregnancies; vast majority occur before 12 weeks gestation. These losses are not reported into US vital statistic data, therefore percentages reported here are estimates based on survey data.

- Stillbirth: about 6.05/1000 pregnancies

- Neonatal Death: about 3.0-7.5 per 1000 live births, with an average of 4.0/1000 for all mothers (CDC, 2013)
HISTORY OF PERINATAL SUPPORT IN UNITED STATES

• Perinatal Comfort Care, Hospice and Palliative Care reflect newer understandings about the caring for parents experiencing a perinatal loss

• Outdated practices included not allowing parents to see their who baby who was dying or stillborn

• A baby’s death was treated as a clinical and fleeting medical incident, something that the mother “should be protected from”
Into the 1980’s, caregivers were often advised parents to forget about what happened.

Babies’ bodies were often disposed of as medical waste.

Slowly caregivers recognized that this is a real baby and a real loss and that they were failing to honor the parents and the baby.
PERINATAL FAMILY SUPPORT

• Culturally sensitive, coordinated comprehensive continuum of care
  – before
  – during
  – after birth
Benefits of Perinatal Support Programs

Family Centered Care Facilitates Feelings Of:

- Competence
- Empowerment
- Hope
- Meaning
- Normalcy
- Emotional and spiritual support
- Compassion

The newborn is incorporated as a valued member of the family, the priority is comfort for the baby.
Utilization of Relational Learning Theory Application as it Applies to the Multidisciplinary Team Approach

Together, mentors, teachers learn from each other through the exchange of ideas, creating learning. Both are teachers and both are learners. (Pridham et al. 2006)

Gunderson Lutheran Medical Center pioneered in system wide bereavement care with the introduction Resolve Through Sharing (RTS.) RTS is the gold standard of care for perinatal loss in the US and in several other countries.

Telling and listening to stories promotes self-awareness, reflections, and transformation, necessary components of sensitive, compassionate bereavement care (Browning & Solomon, 2006)

Relational learning involves diverse perspectives (e.g., different disciplines, varied practice settings.)

Relational learning emphasizes considering possibilities over knowing what to say, willingness to explore being right or wrong, process of outcome, wondering over being sure.
In Summary

Relational Learning Theory supports growth and transformation on both professional and personal levels.

It makes being with others who are suffering central to caring, connecting, learning to experience.
Good Shepherd Hospices Gabriel’s Courage Interdisciplinary Team Members

- Team Leader
- Physicians
- Social Workers
- Nurses
- Bereavement Specialists
- Child Life Services
- Pastoral Care
- Volunteers

*All team members have specific training in perinatal loss*
The Interdisciplinary Team

Caregiving for grieving parents at times can be overwhelming, draining, and very time sensitive. It is unrealistic to think that one person or discipline can meet the needs of an individual or family.

The value of the IDT is twofold: Provides thorough and complete support to parents, family, friends. It reduces the likelihood of staff feeling burn out, and overwhelmed by the complexity of a situation.

IDT care requires teamwork, collaboration, and consultation.
The Multidisciplinary Team Approach

- Bi-monthly IDT meetings and as needed
- Consistent communication throughout care to all team members
- Review and adjustment of care plan as needed
- Medical record keeping
- On Call services
- Regular visits to family and as needed by all team members
- Individual, family, sibling counseling
- Support phone calls
- Supportive presence at birth as per birth plan, families desire
- Memory preservation
- Funeral and burial arrangements
- Bereavement follow up care
Bereavement Based Model of Care

Bereavement Care is integrated throughout the perinatal care continuum.

Bereavement support begins at the time of suspected or actual diagnosis and continues through follow-up care after the baby dies.

This continuum of care is an essential feature to our program.

A bereavement risk assessment is done at the time that Mom comes on to program and is done on an ongoing basis throughout the care and grief process.
Bereavement Based Model of Care

- Curing
- Palliation
- Death
- Bereavement

Parallel:
- Curing
- Palliation
- Death
- Bereavement

Integrative:
- Curing
- Continual
- Healing (including palliation)
- Death
- Bereavement

*Mindset of "Being With" and "Doing To"

Diagnosis

Time
The Birth Plan

The birth plan is the key to communication for the IDT team as well as the labor and delivery staff, honoring parent’s needs and wishes and can be adapted based on diagnosis and life expectancy.

This is the primary tool, enabling bereaved parents to make decisions on managing their pregnancy, needed support services, baby’s birth, death, delivery room care, discharge care and bereavement needs.
Birth Plan Promotes:

- Open communication between parent(s) and service providers
- Discussion about parental expectations
- Parental Empowerment
- Preparation for what might occur before, during and after baby is born
The birth plan helps to guide families in ritual and memory making throughout the pregnancy and at birth. We ensure the birth plan is completed, sent to doctors, labor and delivery staff. This ensures parents' wishes are known and supported.
Attachment Theory, Bonding and Grief

Grief is impacted by many things including cognitive, social and emotional development, spiritual values, cultural and ethnic heritage.

The more we attach, the more potential we have to experience grief.
Attachment During Pregnancy and Childbirth:

- Planning the pregnancy
- Confirming the pregnancy
- Accepting the pregnancy
- Feeling fetal movement
- Identifying the fetus as an individual
- Giving birth
- Hearing and seeing the baby
- Touching and holding the baby
- Caring for the baby
Memory Preservation

Encourage family’s to choose clothing, blankets, jewelry, keep sakes ahead of time

- 3-D sonograms
- Making memories during pregnancy, honoring, shower of love (baby Shane)
- Photography (Now I Lay Me Down to Sleep)
- Naming the baby
- Bathe/Dress the baby
- Baptism, Blessings, prayers
- Hospital Card with weight, height, time of birth etc
- Hand and foot prints and molds
- Lock of hair
- ID bracelet, blankets, jewelry, stuffed animals and clothing
- Gabriel’s Courage staff ensure items are kept before baby goes to morgue
Perinatal Bereavement

Bereavement support aides in healthy processing, and recovery.

Gabriel’s Courage encourages relationship building with the unborn baby as per the desires and willingness of the family.

Grief begins when mother, parents are told their baby has a life threatening illness not combatable with life. The baby may not survive the pregnancy, or die after birth.

Parents benefit from sensitive bereavement support as they process devastating information, throughout the pregnancy, delivery, after birth, and going home with an EMPTY CRADLE.
Bereavement Follow Up Care

- Assistance with funeral, burial services
- Supportive phone calls and visits from team members
- Supportive counseling to individuals, parents, family, siblings
- Education on grief, normal reactions
- Assess for complicated grief and make appropriate referrals
- Provide resources for perinatal support group programs and counseling
Bereavement and Relationship Centered Care

• Relationship is the center concept to the delivery of quality perinatal bereavement care

• Focusing on the relationship provides a framework to assist in guiding interventions that will be perceived as meaningful and helpful.

• First, you must recognize that becoming a parent affects every component of one’s life
  - Biological
  - Emotional
  - Psychological
  - Spiritual
Theory of Care Giving

Perinatal bereavement support and education are approached from both the theoretical and clinical perspectives. Gabriel’s Courage uses evidence based practice.

Supporting bereaved parents by guiding them in caregiving competencies makes sense if we place the idea within the context of principles of care that we follow.
Encouraging Care Giving

- Engaging with family around care giving issues when baby dies.
- Provide family centered care
- Parents are experts in their baby’s care as well as their own.
- Parents need time to decide what’s best for them.
- Parents should not be coerced to do anything that they are uncomfortable with.
Emergence of Relationship Care

- Concept began to emerge in the early 1950’s
- It wasn’t until the 1980’s that health care providers adopted family centered practices
- During this time, many hospitals began to develop Bereavement Teams and care standards with interventions based on relationships
Relationships Between Parents and Clinicians

Clear communication between parents and clinician is essential to developing trust

(Harvey, Snowdon, and Elbourne, 2008)
As clinicians, offer choices for all family members regarding interactions with the dying baby, they nurture trust. Parent’s report being influenced by clinician’s attitudes when presenting choices.

(Radestan et al., 2009)
Sitting quietly, observing, and remaining open and non-judgmental is important as each family has a unique perspective on this life event and their subsequent needs.

Know what is important to the family.

Allow for parents to change their minds.

Avoid coercion as it fractures trust.
Facilitating Parental Relationships With Baby

Our goal is to welcome the baby and honor the family.

Allowing parents to “parent” establishes a relationship of love and remembering.

- Holding
- Bathing
- Dressing
- Taking Pictures
- Meeting Family
The Sibling Relationship

Parents often ask for guidance with siblings. Many parents prepare their children for a new brother or sister.

- Ask the children directly if there is something special that they would like to do

- For parents who choose not to have their children involved at the time of death, mementoes can offer tangible touchstones
Some families feel abandoned by the healthcare teams.
Many parents benefit from repeated and extended opportunities to have close contact with their deceased baby’s body, including touching, examining, cuddling, and kissing.

For parents who want to have close and extended contact with this nurturing experience affirms their baby’s existence and importance, validates their role as parents to this child, offers meaningful opportunities to express their love and devotion, and cultivates treasured keepsakes and memories.

This experience can also help parent’s process traumatic events surrounding their baby’s death and have a more gradual goodbye, both of which are productive components of health grieving.
Families may need assistance with making arrangements both emotionally and financially. Gabriel’s Courage bereavement staff work closely with the funeral home to honor the family’s wishes.

Staff may be participants of the service if family desires. Staff presence is very supportive to the family in honoring their baby.

The journey with the family is significant to both family and caregivers. Attending services shows support in the bereavement process, helping to ensure that family knows the care will continue.
Lessons Learned...

Grief is not related to the length of the pregnancy or the length of life.

Grief is related to the relationship the parents have with their child.

Bonding is fundamental. The process of helping parents bond allows them to begin to grieve.
Lessons Learned...

Good care can not remove the pain of parent’s loss, bad care (lack of understanding and/or sensitivity) can make things worse.

Bereaved parents never forget the understanding, respect and genuine care.

What do families appreciate?
- guidance and support but not being directed or controlled
- use of baby’s name
- sensitivity, support and respect
- well informed staff and excellent communication
References


