Perinatal Hospice and Palliative Care: Connecting the Heart, Life & Spirit with the Perinatal Diagnosis

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Objectives

• Define the role of perinatal palliative care
• Outline specific interventions to be utilized throughout care
• Describe common reactions of families beginning at the time of diagnosis and extending through grief

WHO Definition of Palliative Care for Children

• Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.

• It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

• Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.

• Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources, it can be successfully implemented even if resources are limited.

• It can be provided in tertiary care facilities, in community health centers and even in children’s homes.

WHO; 1998a

What is Perinatal Hospice?

• A model of care for unborn children and their families beginning at the time of diagnosis.

• Hospice services provide a multidisciplinary team working to meet the medical, spiritual and emotional needs of a family.
  - A beautiful and practical response to rapidly advancing diagnostic technology
  - A continuum of care exists from the time of prenatal diagnosis through the death and beyond.
  - The family is placed in the central arena of care as the focus is on them rather than the baby’s diagnosis.

Our History...

The mission of Angel Babies of Hinds Hospice is to comfort, support, and uphold the dignity of families whose babies have a life limiting condition or whose babies have died.

Definition and Incidence Rate

• A fatal anomaly in the unborn is defined as any condition which is not compatible with life outside the womb

• In the U.S. between 0.2% - 0.5% of pregnancies will qualify for services

• The U.S. averages 2 - 4 million live births annually (Department of Health & Human Services, Nat’l Center for Health Statistics)

• The incidence of fatal birth anomalies is between 6,000 - 10,000 annually (CDC, 1998)
“When we received our baby’s diagnosis we were shocked and numb. How could this be happening to us? We didn’t know how to feel or where to turn.”

Connecting with the family
- Where is it most comfortable for the first meeting to take place?
- Connection and developing rapport
- Beginning the process of setting goals of care for the baby and the family
- Assess understanding of baby’s diagnosis and provide support and resources

Planning for the baby’s life starting in the present
- Getting to know the baby beyond the diagnosis and prognosis

Getting to know the baby and the family:
- Tell me about your family. Siblings? What do they know?
- How are loved ones responding to their baby’s diagnosis?
- Tell me about the experience of learning that you were pregnant.
- Have they had other pregnancies?
- Have they chosen a name for their baby and what was behind that choice.
- Tell me about your baby.

We work to companion families on their journey, allowing them to guide the course.

“When I received the diagnosis I was so scared and felt so out of control”
- Fears and concerns are identified
- Families are assisted and encouraged to take time to love and enjoy their baby in the present.
- Anticipatory planning begins
  - The remainder of the pregnancy
  - For birth
  - For life
  - For death
  - For the journey of grief
Continual assessment of coping, identifying how much can be tolerated.

The Pregnancy
- Provide emotional support
- Encourage memory making in pregnancy
- Provide resources on diagnosis
- Connect with peer support
- Identify fears and concerns

Assisting families to both welcome and enjoy their baby and, when necessary, to say good-bye

“Support of Angel Babies allowed us to make the most of the limited time that we had with our baby.”

The Birth...
- Provide emotional support
- Meet with labor and delivery nurse
- Assist family in making a birth plan
- Plan for memory making opportunities
- Assist in providing knowledge regarding choices for medical interventions
- Identify fears and concerns

The Life...
- Hospital
- Hospice Home
- Out-patient hospice care
“If our baby makes it home and only lives an hour will we have wasted your time?”

The Hospice Team

- The Family (The Core)
  - Physicians
  - Social Worker
- Nurse Case Manager
- Chaplain
  Other possible members: labor nurse, genetic counselor, volunteers, photographer, peer support

The Hospital

- What will you do with your time?
- Memory making ideas
- Visitors
- Providing emotional support for parents and family
- Chaplain or spiritual support
- Identify fears and concerns

Memory Making

- Photos
- Music
- Foot and hand prints
- Lock of hair
- Lullaby
- Touch
- Bathing
- Meeting family and friends

Big Brothers & Sisters

- Talking to children
- Allowing them to be part of the process
- Common fears and concerns
Brother Love

Hospice out-patient

“Our short stay at the hospice home allowed us the confidence we needed to take our baby home to live out the remainder of his life.”

- Families are able to have their baby in their own home
- 24 hour on-call staff is available
- Home visits are done by the hospice team

The Hospice Home

The hospice home staff took care of our baby’s medical needs, easing our minds and allowing us to bond and cherish our time together

- 6 Bed in-patient Facility
- Full staff
- Family Involvement

Time to be Mom or Dad...

Hospice Staff Challenges

- At times causes us to redefine our life view
- Pediatric specialty
- Staff becomes attached to the baby
- Possible boundary issues
- Emotional difficulty in caring for babies
- Sometimes it is harder to accept hospice philosophy
The death...
• Companion families as they say good-bye to their baby.

The death
• Assist in funeral/memorial planning
• Transportation to funeral home
• Time with baby at funeral home
• Caskets
• Identify fears and concerns

The death
• Assist in funeral/memorial planning
• Assist family in preparing their baby before transport to funeral home
• Transportation to funeral home
• Time with baby at funeral home
• Caskets

The Journey of Grief...
It is said that when an adult loved one dies, we lose what we have known. When a baby dies, we lose what is yet to be known – our future, our dreams, our hopes.

Bereavement Support
• We are not taught how to deal with the death of a baby. Friends and family don’t know what to say. It is anticipated that parents, especially fathers, will return to work in a few days. Nearly everyone expects the parents to be over their little one’s death and “back to normal” within a few months. Yet, parents are changed by the death of their baby. Families need information and support during their journey through grief and mourning.

Bereavement Services
• 13 month bereavement follow-up
  - Letters and Articles
  - Supportive phone calls
• Individual, couple and family counseling
  - In office
  - Home visit
• Support Groups
  - Couple’s group
  - Dad’s group
  - Early pregnancy loss group
  - Subsequent pregnancy group
  - Children’s and Teen’s group
  - Infertility support group
Bereavement Services
• Memory making events
• Memorial services
• Community Events

Benefits of Perinatal Hospice
• Allows families choices and full autonomy in coming to the best decision for their family.
• Families are supported throughout the pregnancy, rather than isolated.
• Focus at birth from shock, pain, and anguish to a time of bonding and enjoying the baby.
• Grief support received decreases the likelihood that complicated grieving will occur.

A mother’s wish…
Please:
• Acknowledge the sanctity of my child’s life not defined by age.
• Speak my child’s name even after they have died.
• Allow me to say good-bye in my own unique way.
• Validate and honor me as a mother even if I have no living children.

Grief begins at this time of diagnosis
• Grief response to the current losses.
• Grief response to what is anticipated.
Symptoms may include withdrawal and isolation, increased symptoms of anxiety and depression, guilt and regret, hyper vigilance to body functioning and pregnancy, acute awareness to others pregnancy and babies.

Common concerns and fears
• Will my child suffer/Is my child suffering?
• How will I cope with watching suffering or death?
• How will we cope as parents/family?
• Financial concerns
• Will I be okay?

Grief response after the death
• Physical symptoms related to pregnancy.
• Disbelief.
• Empty arms.
• Trauma reactions.
• Searching and yearning.
• Delayed grief at times, for father’s.
Unique triggers

- How many children do you have?
- Questioning of medical interventions/decisions made?
- Subsequent pregnancy
- Intimacy

Risk Factors

- Increase in longstanding depressive symptoms combined with a diminished sense of well being, lasting several decades beyond the death of a child.
  (Rogers, Floyd, Seltzer, Greenber, and Hong, 2008)
- Increased risk of suicide, which is higher the first month after loss of a child, yet remains elevated > post loss.
  (Li, Lauresen, Precht, Olsen & Mortensen 2005)
- Negative health impact
- Impact on family functioning
- Increase in drug and alcohol use

Interventions

- Connecting and creating a safe place for mourners to BE
- Educating/Normalizing
- Allowing the expression and sharing of feelings as tolerable
- Facilitate sharing of dreams and honoring needs of grief as defined by the griever

The Power of Empathy

The gift of the care provider

- The ability to sit and be present with families, often in silence.
- The professional expertise you bring
- Non judgmental support
- Self care
- The ability to see both the gifts that you give and that you receive

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