2011 National Conference
The National Association of Catholic Chaplains

One Day at a time:
Companioning Caregivers in Perinatal Loss

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Workshop Framework: Pathways

Gain insight through
• Being Attentive
• Being Intelligent
• Being Reasonable
• Being Responsible

• Participate
• Take in new information
• Apply what you know
• Integrate information into practice
Being Attentive: Affirming

- Introductions
- Your Expectations
- Your Strengths and Need for knowledge in Perinatal Care

Pre workshop Objectives

- Describe two ways to empower parents around the time of perinatal death
- Identify the chaplain’s holistic effect on staff during a crisis
- List two actions to minimize effects of moral distress
Overview of Perinatal Loss

- Definitions of Loss
- Definitions of Perinatal Loss

Exploring and Inquiring: Framework for Crisis & Loss

- Lindemann-Coconut Grove Disaster
- Davidson-Perinatal Survivors & SHARE
PHASES OF BEREAVEMENT
Shock and Numbness

- Resistance to stimuli
- Judgment making
- Function impeded
- Emotional outbursts
- Stunned feelings

Intensity of the characteristics of shock and numbness during the 2 years following the death of a loved one

PHASES OF BEREAVEMENT
Searching and Yearning

- Very sensitive to stimuli
- Anger / guilt
- Restless / impatient
- Ambiguous
- Testing what is real

Intensity of the characteristics of searching and yearning during the 2 years following the death of a loved one
PHASES OF BEREAVEMENT

Disorientation

- Disorganized
- Depressed
- Guilt
- Anorexia
- Awareness of reality

Intensity of disorientation during the 2 years following the death of a loved one

Reorganization

- Sense of release
- Renewed energy
- Makes judgments better
- Stable eating and sleeping habits

Intensity of reorganization of searching and yearning during the 2 years following the death of a loved one
I. Empowering...

- To positively affect the experience of the dying patient and their family.

- To provide informed caring for the well-being of others (Carper, 1978).

The Challenge

- Helping the family to understand in their own time and space.
- Helping the staff to recognize the family’s need to have time.
- Minimizing the suffering of the child while the parents are learning.
### The Outcome

- To know the difference between curing and caring. (hope)
- To identify the stress felt when caring for a dying patient.
- To recognize understanding in a parent.
- To successfully and with dignity reach the end of life for a dying child and his parents.

### First Steps

- Empowerment
  - Competent before the crisis
- Best Practices
  - Immediate buy-in
  - Regular informational meetings
  - Early recognition of unique role
  - Road map-care path
  - Buddy system
  - Environment
The Margin of Viability Does Not Assume the Margin of Quality of Life.

photo

Regulations do not mandate treatment until death is certain

The Limit of Viability

- Each organ system has its own timeline for growth and maturation for existence outside of the uterus.
- The respiratory system is the main system that limits viability.
  - Branching of airways begins around 16 weeks.
  - Potential for sustained gas exchange is seen as early as 22 weeks.
Teamwork:
Go Ahead Stick Your Neck Out!

Expectations of Parents

• Pain Relief
• Pain Relief
• Pain Relief
• Recognition as a parent first, partner in care second
• Someone to really listen
• Consistency during a horrible time
• Help them to say good-bye
Their Journey

- Anticipatory Grief-the ‘If Only’s’
- Emotional Curves- unscheduled news; phone call; usual ups & downs; gender differences
- Communication differences-team agreements

Their Journey Continues

- Shock and numbness
- The confident person beneath the crisis
- Involve parents on team at admission
- Continuously educate
- Continuously offer opportunities to talk
- Elevate parent, to parent helper
- Utilize parent in planning, changing the unit
- Request feedback
The Storm

Loss
- Losing peer group
- May not feel competent
- No comparison

Crisis
- Denying the symptoms
- Reality of the inevitable

Palliative Care in the NICU

- Unlike hospice, palliative care can be integrated with curative treatment
- There is a need to assess future quality of life based on responsiveness of child
- The earlier you develop the relationship with the team the easier it is to introduce palliative care
- Palliative care can transition to hospice care
Build a Care System
that can make seven promises...

to a child/family who is “not expected to survive childhood...

photo

The seven promises a physician should make to a dying patient, according to the report, are:

• You will have the best of medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.
• You will never have to endure overwhelming pain, shortness of breath, or other symptoms.
• Your care will be continuous, comprehensive, and coordinated.
• You and your family will be prepared for everything that is likely to happen in the course of your illness.
• Your wishes will be sought and respected, and followed whenever possible.
• We will help you consider your personal and financial resources and we will respect your choices about their use.
• We will do all we can to see that you and your family will have the opportunity to make the best of every day.
Debrief To Improve

• Measure the intangible outcomes
• Did this baby die peacefully?
• Were family members given the chance to say goodbye?
• Did the child experience the family’s definition of a “good death”?
• What can we learn from this family?

Empowerment

• Have we empowered parents?
• Have we empowered staff?

• Have we used companioning to go beyond the medical model of treating?
II. Discussion of articles

     photo

III. Chaplain’s Effect on Staff

     • Who are you?
     • How are you described by staff?
     • What do they tell families you will do?
     • What do you do?
     • How is that communicated?
From a Nurse

The chaplain completes the disposition paperwork

The chaplain does the blessings

The chaplain stays when there are no answers

• photo
• For the family: spiritual counseling has always been an option. And the need has risen sharply.
• There is a shift in the way people are meeting their spiritual needs.
• For the staff: to discuss the ‘why’ of what they do and their patients.
• To slow down the pace and let them ‘feel’ the good they do.

Only Human

• Stifling personal emotions have been equated with “professionalism” for nurses and doctors.
• The more open and willing to discuss the event, the better job of coping
• The feeling they did all they could, they advocated for their patient, they worked as a team= success even if the patient dies.
Prolonging Life vs. Suffering

• In each situation guide the nurse to think: what is happening?
• Whenever there distress over a clinical decision, there is also a feeling of energy depletion
• Consider the amount of responsibility the nurse feels for what is happening and how much the nurse actually has.
• Gather resources and post them so they are easy to see, don’t assume they know.

Warning!

• Beware of
• Prolonged stress response
• No outlet
• Horizontal Hostility
Common Feeling-not shared

- Profound sense of frustration, failure, & sadness.
- Due to frequent interaction with family & patient, but many times limited involvement in the decision making process.
- Feeling of helplessness and/or...

Moral Distress

Self Care = Quality of Care

- Consequences of poor self care/burnout:
  disrupted sleep
  irritability,
  flash backs,
  emotional exhaustion,
  depersonalization,
  low sense of accomplishment
Compassion Fatigue

- photo

Change the Focus

Moral Distress

Moral Courage
• DVD Nurses Grieve Too

The Cost

• Recognize what caring for a dying patient and their family does to you

• Changing the “fight”
The Feeling: “failure”? 

- You are not the expert! 
  - But you do have expertise! 
  - Think about what you do as “emotional labor”. 
    - It's very hard work.

Companioning vs. Treating 

- Treat comes from the Latin root word: “Tractare” 
- Tractare means to drag! 
- Patient means “passive long term sufferer”

Not very empowering!
A Change in Thinking

• Companion-”someone with whom you share a meal, a friend, an equal”

• Companioning is about “being”
  » Alan Wolfelt.

Companioning Is:

• Companioning is about honoring the spirit; it is not about focusing on the intellect.
• Companioning is about curiosity; it is not about expertise.
• Companioning is about learning from others; it is not about teaching them.
• Companioning is about walking alongside; it is not about leading.
• Companioning is about being still; it is not about frantic movement forward.
• Companioning is about discovering the gifts of sacred silence; it is not about filling every painful moment with words.
• Companioning is about listening with the heart; it is not about analyzing with the head.
• Companioning is about bearing witness to the struggles of others; it is not about directing those struggles.
• Companioning is about being present to another person’s pain; it is not about taking away the pain.
• Companioning is about respecting disorder and confusion; it is not about imposing order and logic.
• Companioning is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.
GROWING
And through the tears
And the sadness
And the pain
Comes the one thought
That can make me internally
smile again:
I
Have
Loved

• photo

• "Blessed Are Those Who Mourn Quickly and Efficiently For They Meet Our Criteria For Managed Care."

• Buddhist teaching that says, "In the beginners mind there are many possibilities; in the experts mind there are few."
Role/reaction review

- Full term infant with Hypoplastic Left Heart
- 35 week infant with cleft lip, Spanish speaking parents
- Withdrawal of life support, child breathes spontaneously
- 5 month old infant with pulmonary hypertension, elevated CO₂, air hunger, slow decline.