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Pediatric Palliative and Hospice Care

Providing Supportive Care for Children and Families

Suzanne Black, RN, MSN, CFNP
Sarah Koetting, RNII, BSN, CPN

3/2010

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Objectives

- Identify nursing roles and responsibilities at end of life
- Define pediatric palliative care and the role of the pediatric nurse.

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Defining Palliative Care

"The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care."

Taken form *Clinical Practice Guidelines for Quality Palliative Care* – The National Consensus Project..

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WHO Definition of Palliative Care for Children

"Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to family.
- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.

Taken form *Clinical Practice Guidelines for Quality Palliative Care* – The National Consensus Project.

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- 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 centres and even in children's homes (WHO 2008)"

Taken form *Clinical Practice Guidelines for Quality Palliative Care* – The National Consensus Project.

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Some Numbers

- ~ 74,000 deaths occur annually in the US comprised of children & young adults
- Age grouping according to CDS:
  - 47% 15-24 years old
  - 9% 5-14 years old
  - 6% 1-4 years old
  - 38% infants

Lindley et al. Providing Hospice Care to Children and Young Adults. A descriptive Study of End-of-Life Organizations. Journal of Hospice and Palliative Nursing. 2009;11(6):315-23

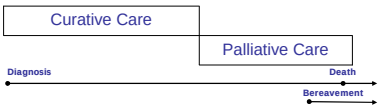
Groups of Life-Threatening Disease in Children

Group	Examples
Disease for which curative treatment may be feasible but may fail	Cancer Complex congenital or acquired heart disease
Diseases in which premature death is anticipated but intensive treatment may prolong good quality life	Cystic fibrosis Muscular dystrophy HIV infection and AIDS
Progressive disease for which treatment is exclusively palliative and may extend over many years.	Neurodegenerative disease Chromosomal abnormalities
Conditions with severe neurological disability that, although not progressive, lead to vulnerability and complications likely to cause premature death.	Cerebral palsy Hypoxic encephalopathy

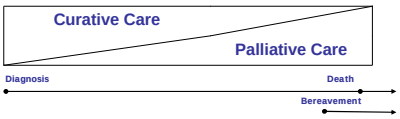
Adapted from Goldman A. ABC of palliative care: special problems of children. BMJ.1998;31:49; and Himelstein B, Hilden JM, Boldt AM, et. al. Medical progress: pediatric palliative care. N Engl J Med. 2004; 350:1752

Traditional View of Care Domains

Mutually exclusive domains of curative care versus palliative care



Concurrent Domains of Curative Care And Palliative Care



AAP & WHO support an integrated model of palliative care "in which the components of palliative care are offered at diagnosis & continued throughout the course of illness, whether the outcome ends in cure or death"

Nurse's Role

- Presence
- Anticipating
- Preventing
- Treating
- Promoting
- Advocacy

A pain assessment scale is used to:

A. Measure pain intensity

B. Evaluate character of pain

C. Graph compliance with medication regimen

D. Measure cultural differences in perceiving pain

The grief process can best be described as:

A. An abnormal condition requiring extensive counseling

B. A time-limiting process occurring through specific stages

C. An internal process unique to each person with variable time frames

D. A universal experience involving shock, confusion and reinvesting in life

For a hospice patient, palliative radiation therapy is most likely to be use to treat:

A. Hypercalcemia
B. Bowel obstruction
C. Spinal cord compression
D. Malignant cardiac tamponade

A patient whose pain is well controlled with sustained release oxycodone 20 mg by mouth every 12 hours presents with new onset confusion. The advanced practice nurse recognizes that:

A. An intraspinal infusion of opioids is warranted
B. Confusion attributed to opioids alone is uncommon
C. The opioid dosage should be lowered
D. Opioid rotation is recommended

Which approach is the best technique for communicating with a dying school-aged child?

A. Guide the conversation so that child can be led to asking appropriate questions
B. Use concrete explanations because dying children often regress in their development
C. Provide opportunities for the child to express feelings through play and art
D. Gently lead angry outbursts back to more adaptive forms of communication

What is an important consideration when promoting a family's acceptance of their child's chronic condition at the time of diagnosis?

A. Parent's frequently have no prior knowledge of the disorder
B. Reactions to a diagnosis of a chronic condition and death are similar
C. Denial is a common and maladaptive response
D. Holding the parent's hand during tearful outbursts indicates empathy

When using the FACES pain rating scale to assess a child's pain, the correct procedure involves which of the following:

A. Ask the parent to match the child's expression to one of the drawings.
B. Ask the child to point to the face that best shows how much pain she has now.
C. Hold the scale next to the child's face and determine which drawing looks most like the child's expression.
D. Ask the child which face "on average" reprents the way she feels.

A young child with congenital heart disease experiences significant intraoperative cerebral ischemia. He is receiving care in a pediatric intensive care unit. Which of the following must be present before integrating palliative care principles into this child's care?

A. An order not to escalate life-sustaining medical interventions
B. A prognosis of 6 months or less, if the disease runs its normal course
C. An understanding that palliative care can include both intensive care and life-prolonging therapies
D. Transfer of the child out of the ICU

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A 14-year-old boy is recently diagnosed with osteogenic sarcoma. There is no evidence of metastasis, and they primary tumor is small. There is a good chance he can be cured of his disease with surgery and chemotherapy; nevertheless, he exclaims, "Why is God doing this to me? I don't' want to die!" The best response to his question is to listen to his concerns, reassure him that he is very likely to be cured, and:

A. Explore his concerns and call from more spiritual support as needed

B. Share your views about religion and God's intentions

C. Suggest that his anxiety may interfere with his ability to get better

D. Suggest that his spiritual distress is inappropriate, given his prognosis

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A 3-year-old child underwent surgery for a Wilm's tumor 2 days ago. He continues to report severe pain, despite receiving regular dosages of acetaminophen. When addressing staff concerns about pain treatment, which of the following is a correct statement?

A. Children of all ages are at higher risk of respiratory depression from opioids compared with adults

B. Children are at higher risk of addiction because of neurologic plasticity

C. Children do not experience severe pain because they have not yet developed the nerves necessary to transmit pain

D. Children should receive pain medication, including opioids, consistent with their level of pain.

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An adolescent with end-stage cancer who previously had a stable opioid regimen now requires escalating dosages of opioids for pain relief. Which of the following is the most likely cause of the child's request for increased dosages?

A. Development of tolerance

B. Development of addiction

C. Progression of the cancer

D. Depression; the request may be a veiled suicide attempt

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Peter, a 6-year-old boy who received a bone marrow transplant, is expected to die in the next 72 hours. His 8-year-old sister was the marrow donor. She and her 4-year-old brother haven't seen Peter in several weeks and are asking to visit him in the ICU. His parents ask for advice about letting them visit. They are fearful that the children will be overwhelmed by the experience. The healthcare team can assist the parents in supporting their children by:

A. Reassuring the parents that the children can visit Peter, but help the parents first explain to the children what they will see, and then offer to accompany them

B. Explaining that there is no good reason to subject young children to such a terrible situation

C. Advising against this, as the sister may feel especially guilty, having been his donor

D. Telling the parents that the visit is advisable as long as the parents do not dry in front of their children

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A nonverbal child has a history of chronic pain from pancreatitis. Which of the following is usually the least helpful indicator for assessing chronic pain in nonverbal patients ?

A. Difficulty being consoled

B. Self-limited movement

C. Change in blood pressure

D. Decreased interactions with her environment

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A 10-year-old boy has generalized bone pain that he rates as 8/10 at the time of diagnosis of leukemia. Which of the following medications would be the most appropriate therapy for managing his pain?

A. Pentazocine

B. Codiene

C. Acetaminophen

D. Morphine

Angela is an 8-year-old child with a variant of spinal muscular atrophy and difficulty breathing. The best method of measuring her dyspnea is to:

A. Count her respiratory rate

B. Ask her to rate her breathlessness on a 0 to 10 scale

C. Observe the degree of accessory muscle effort

D. Measure her oxygen saturation by pulse oximetry

SAMPLE QUESTIONS

Taken from:

- NBCHPM Certification Exam Prep Questions
- Hutton N, Levetown M, Grager G. AAHPM's Unipac 8: A Self-Study Program, The Hospice and Palliative Medicine Approach to Caring for Pediatric Patients. 3rd ed, 2008.
- Hockenberry MJ Wilson D. Wong's Nursing Care of Infants and Children. 8th ed St Louis: Mosby, Inc.;2007:936-38

Pain & Symptom Management

- Overview
- Please email Jill.Guilfoile@cchmc.org for PDF of modules taken from ELNEC Pediatric Palliative Care July 2008

- Improving communication and strengthening relationships: "*Difficult Conversations*"
- Illness and dying through the eyes of a child
- Experience of the family during the child's illness
- Bereavement experiences of parents and siblings after a child's death

Improving Communication and Strengthening Relationships
"Difficult Conversations"

History of paternalism / protecting the patient

Conceal most things from the patient while you are attending to him. Give necessary orders with cheerfulness and serenity...revealing nothing of the patient's future or present condition. For many patients...have taken a turn for the worst...by forecast of what is to come.

Hippocrates

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Why is it so hard to communicate "bad news"?

- Fear of being blamed
- Fear of the unknown and untaught
- Fear of unleashing a reaction
- Fear of expressing emotion
- Fear of not knowing all the answers
- Fear of illness and death

Buckman, 1984

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Clinician anxiety and dread

- Clinicians report anxiety and dread when discussing serious diagnoses, impending death, and death
- Anxiety and dread can compromise communication and intervention

Hilden et al., 2001
Ahrens and Hart, 1997

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Buckman 6-step protocol

- Start off well
- Find out how much the patient knows
- Find out how much the patient wants to know
- Share the information (aligning and educating)
- Respond to the patient's feelings
- Planning and follow through

Buckman, 1992

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To communicate well:

- Ask what the family knows and understands
- Ask what is important now to the family
- Speak frankly
- Avoid jargon
- Slow your rate of speaking
- Allow silence and tears, and avoid the urge to talk to overcome your own discomfort

Rabow and McPhee, 1999; Fallowfield, 1993; Vandekieft, 2001; Buckman, 1992

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Experts in end-of-life care. . .

- Spend nearly twice as much time with patients
- Less verbally "dominant"
- Less treatment and biomedical issues discussed
- More psychosocial and lifestyle discussion

Roter et al., 2000

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Acknowledging parental anguish

Acknowledge with statements such as:
- "*This must be very difficult for you.*"
- "*This must be a parent's worst nightmare.*"
- "*I can see that your hearts are broken.*"

Avoid statements such as:
- *"I know how you feel."*

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"Is it okay to show my emotions?"

- Most families view a clinician's show of emotion in a positive light
- Clinician emotions are often interpreted as a sign of caring by families
- Monitor and pace yourself
- Seek opportunities to process and understand your own emotions

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Hoping for the best, while preparing for the worst

Although it may seem contradictory, hoping for the best while *at the same time* preparing for the worst is a useful strategy. . . .By acknowledging all possible outcomes, patients and their physicians can expand their medical focus to include disease-modifying and symptomatic treatments and attend to underlying psychological, spiritual, and existential issues.

Back et al., 2003

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Illness and Dying through the eyes of a child

About Watches

I like wearing
Lots of watches
For two reasons.
First,
If they are all set
A little different,
No one's ever
Too late, or
Too early, or
Right on time.
They just "are."

Second,
With all these
Watches on me,
It's like having
"All the time
In the world!"
And never having
To think about
The end of time,
Or about dying.

Mattie Stepanek,
Journey Through Heartsongs

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A four-year-old boy coveted the child life specialist's Mickey Mouse watch. He tried it on, inspected it from every angle on his wrist, and said: "I like time. I wish I could wear a whole armful of watches." Later that day, in describing the watch to the therapist, he sighed, "I just wish that I had armfuls of time."

Sourkes, Armfuls of Time, 1995

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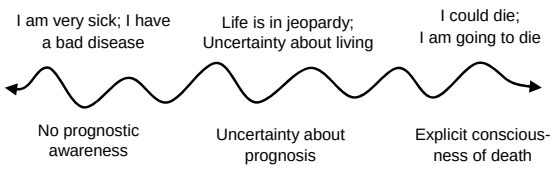
Awareness Continuum



Adapted from Sourkes, 1995
and Bluebond-Langner, 1995

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Awareness is fluid, not static, and gleaned from:

The "wisdom of the body"

- Knowledge of the illness
- The urgency and intensity of treatment
- Emotions of family and caregivers
- Encounters with other patients

Sourkes, 1995

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Variables Affecting Child's Understanding and Coping with Illness and Death

- Child's age and level of cognitive development
- Child's personality and life experience
- Child's loss history, including, for example: illness, death, trauma, parental divorce, geographical moves
- How parents convey their cognitive and spiritual understanding of death
- How parents and other family members convey their emotions and ways of coping
- Style and patterns of communication in the family
- Availability of social support to child and family

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A three-year-old boy played the same game with a stuffed duck and a toy ambulance each time he was hospitalized. The duck would be sick and need to go to the hospital by ambulance. The boy would move the ambulance, making siren noises.

Sourkes, The Deepening Shade,1982 and Armfuls of Time, 1995

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Therapist: How is the duck?
Child: Sick.
Therapist: Where is he going?
Child: To the hospital.
Therapist: What are they going to do?
Child: Make him better.
Therapist: Is he going to get better?
Child: Yes, better.

Sourkes, 1982 and 1995

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Same child, during his final admission:

Therapist: How is the duck?
Child: Sick.
Therapist: Is he going to get better?
Child: [shaking his head slowly]
Duckie not get better. Duckie die.

Sourkes, 1982 and 1995

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"The best treatment of the dying youngster can be based only on the knowledge of what his approaching death means to him and how this young patient can reasonably cope with this very personal reality."

Easson, 1970

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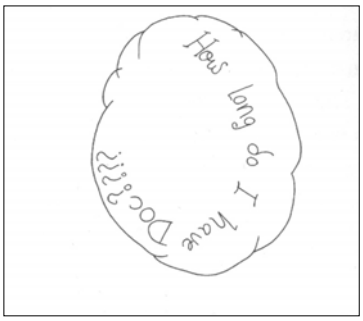

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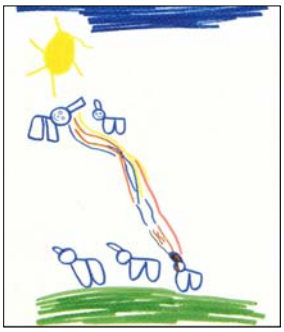

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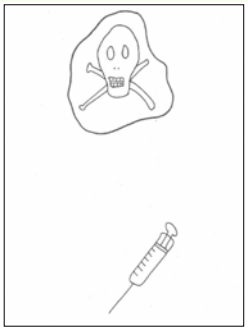

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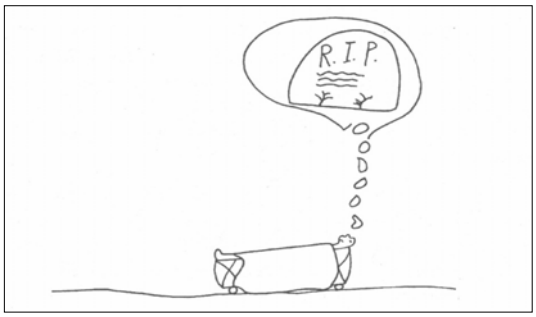

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Swinging

So high. . .
Wind tickles my tummy
Plays with my feet
Gives my hair a ride
So high. .
Grab a leaf from a tree
Reach a so-far-up branch
See over the edge of my earth.
So high. . .
Meditate on being
Touch all my thoughts
Think about friends
And families and
Brothers and sisters.
So high. . .
Leave this world for a bit
Jump into Heaven for a moment
Then, swing back into my life again,
So high. . .

Mattie Stepanek,
Journey Through Heartsongs

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Someday, as we are all quiet
the sun will stop
shining and the world
will stop. All that will
be heard is music.
-Amy, age ten.

Sourkes, 1995

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Spirituality and Meaning Making

When children are coping with seriously illness," psychological themes connect almost imperceptibly, but quite vividly at moments, with a spiritual inwardness." *(Robert Coles)*

Quoted in Sourkes, 1995

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The Child's Experience of Suffering and Lossa

A seven-year-old girl told her parents that she was too tired to fight any more and that she wanted to give up. She added: "If I have to continue suffering, I would rather be in heaven."

Sourkes, 1995
a

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The Child's Experience of Suffering and Loss

Therapist: Are you in any pain?
Does anything hurt?
Child: My heart.
Therapist: Your heart?
Child: My heart is broken. . .
I miss everybody.

Sourkes, 1995

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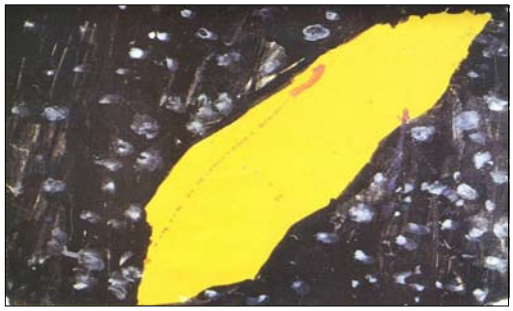

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Ways to Connect with Children

- Consider the range of creative approaches: e.g. play, art, storytelling, music, books, writing, conversation.
- When can practitioners without special training use these approaches?
- When is it appropriate to involve a specialist in the use of these approaches?
- What grade would we give our institution for responding to children's emotional and spiritual needs?

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Focal Questions

- What is this child experiencing?
- How is this child making sense or meaning from his/her experience?
- What does this child's approaching death mean to him/her?
- How is he/she coping with this reality?
- How are we as a team responding to this child's emotional and spiritual needs?

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Experience of the Family During the Child's Illness

Honoring Parent Values when Benefits are Marginal or Uncertain

Understand that:

Ethics and law grant parents discretion in treatment decisions when the prognosis for quality of life is poor and the benefits of proposed treatment(s) are marginal or uncertain.

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Honoring Parent Values when Benefits are Marginal or Uncertain

Assessment of burdens and benefits of various treatment options should include consideration of the child's current and future:

- physical pain and suffering
- cognitive functioning
- potential for human relationships.

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Honoring Parent Values when Benefits are Marginal or Uncertain

Recognize that:

Caring individuals may make very different decisions on behalf of gravely ill children. Therefore same or similar cases may be handled quite differently, depending on the family's values and goals of care.

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Honoring Parent Values when Benefits are Marginal or Uncertain

Acknowledge that:

Family views are highly individualized. Therefore assumptions should not be made about a family's values based on ethnic, cultural, or religious stereotyping.

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Honoring Parent Values when Benefits are Marginal or Uncertain

- Work with parents to anticipate the likely illness trajectory and set appropriate goals of care in ways that respect their values and preferences.
- Help parents evaluate their treatment preferences in terms of the likely consequences of each choice.

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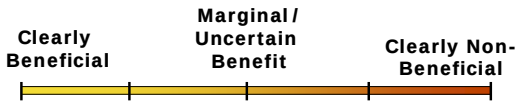
Conceptual Framework Assessment of Benefit



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Professional Obligations

- Work with parents to clarify goals of care.
- Anticipate and ensure that the parents fully understand the potential consequences of all treatment options.
- Provide your own recommendation and rationale.
- Work with parents to devise a treatment plan based on their current decision.
- Treat the parents with compassion and respect.

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Culture and Religion

- A family's culture and religion may have a significant impact on their values and their treatment decisions.
- May be useful to talk to the family about their beliefs.
- However, families' values and goals of care are highly individualized. Do not make assumptions based on ethnic, cultural or religious stereotypes.

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Bereavement Experience of the Parents and Siblings After a Child's Death

Bereavement

"The overall experience of family members and friends in anticipating the death of a loved one, and in living through and adjusting to life beyond that death."

Parkes, 2001

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Challenging mainstream assumptions

- Traditional grief theories argue that grief is a universal process that people go through in similar ways.
- These stage and task theories assume that grief involves the "working through" of grief and the relinquishment of attachment ties.
- Newer grief theories call into question these assumptions, based on new research with grieving people, including bereaved parents.

Neimeyer, 2001

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New focus on cognition and meaning-making

- Traditional grief theories have assumed the centrality of emotion and "catharsis" in the grieving process.
- Newer grief theories supplement the traditional focus on emotion with greater attention to the cognitive and meaning-making processes involved in mourning.

Neimeyer, 2001

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No necessary endpoint in grieving

- Traditional grief theories have posited a point of "closure" or endpoint in grieving.
- Newer grief theories challenge the assumption that there is any discernible end point in grieving, positing instead that the bereaved are engaged in an ongoing renegotiation of meaning over time.

Neimeyer, 2001

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Bereaved parents' experience of the continuing bond

- Sense of the child's presence
- Seeing, hearing, smelling, touching, or talking to the child
- Belief in the child's continuing active influence on thoughts or events
- Incorporation of the characteristics or virtues of the child into the self

Klass et al., 1996

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Bereaved parents' experience of the continuing bond *(continued)*

"These phenomena, like other spiritual experiences, have about them a sense of the uncanny, a sense of mystery, wonder, and awe. It feels to the parent as if the child is still active in the parent's world. Although they fully know the child is dead, parents also know that the child remains immortal."

Klass, 1999

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Bereaved parents and continuing bonds

"In the resolution of their grief, parents maintain the bond with their dead child, albeit in new forms. Maintaining a bond in the resolution of grief, as opposed to doing grief work to break the bond with the deceased, will strike some readers as pathological because for most of the twentieth century the purpose of grief has been seen as withdrawing emotional energy from the deceased, thereby freeing the survivor to make new attachments in the present. It is clear, however. . .that people do not do as the theory said they should, and that their continuing bonds with the dead are resources for creative, healthy living in the present."

Klass, 1999

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Angels, Saints, and Bodhisattvas

"For many parents, their children function like angels, saints, and bodhisattvas in the world's religious traditions, bridging the gap between transcendent and everyday reality because they participate in both realms."

Klass, 1999

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Bereaved parents' web of meaning

Mourning process for bereaved parents occurs within a web of mutually interdependent and constantly interacting bonds and meanings:

- How the universe works
- Place and power of the self
- Bond with the child
- Bond with transcendent reality
- Meaning of the parent's life
- Meaning of the child's death
- Community/family membership

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Klass, 1999

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As an Expected Death Approachesa

- Discuss the status of the patient
  - Gentle repetition and clarification of the goals of care
  - Futility of life-prolonging therapies
  - Irreversibility of the unfolding events
- Be aware of relevant traditions

After Expected Death…

- Care shifts from patient to family/caregivers
- Different loss for everyone
- Invite those not present to bedside

After Death Has Occurred

- Prepare the body
- Moving the body
  - A confrontation with reality
  - Family presence
  - Intolerance of closed body bags