Resilience in the Face of Grief and Loss:
A Curriculum for Pediatric Learners

Part A: Section A.2
Understanding Grief and Loss in Children
Objectives

1.1 Describe the overarching process of grief and loss, including:
   
a. ranges of grief reactions: denial, anger, bargaining, depression, acceptance

b. difference between “normal” and “complicated” grief

1.2. Explain how the child’s concept of death develops from toddlerhood through adolescence
Objectives (continued)

1.3. Demonstrate knowledge of the stages of acquisition of information that occur in children with life threatening illnesses, including:

   a. What children understand and know as their disease progresses.

   b. How to assist children’s understanding in discussions of medical information.
Term Definitions

- **Grief**: a normal process in response to loss
- **Bereavement**: the state of having suffered a loss
- **Mourning**: the public expression of grief
- **Complicated grief**: persistent separation distress lasting more than 6 months and interfering with daily functioning
Components of Grief

- **Denial**: “This isn’t happening.”
- **Anger**: “It’s not fair!”
- **Bargaining**: “If I just behave better, things will be different.”
- **Depression**: “Everything sucks, what’s the point?”
- **Acceptance**: “I miss Shaggy, but things will be okay.”
Activity: Loss Exercise

Each participant takes 5 pieces of paper and writes down something of personal value on each piece. (Can be a person, pet, object, skill, opportunity, etc.) Then each participant finds a partner. They then each take three pieces of paper away from their partner.
Expressions of Childhood Grief

- Sadness
- Guilt
- Fear
- Numbness
- Withdrawal
- Disbelief
- Explosive emotions
- Regression
- Acting out behavior
- "Big Man" or "Big Woman" Syndrome
- Physical symptom
Grief in Children

- How a child experiences grief will depend on their developmental stage and personality
- Context of the relationship is also a key element
- Other important elements are
  - Nature of the death
  - Prior experiences with death or loss
  - Availability of family/social support
  - Behavior, attitudes and responsiveness of parents and other support individuals in their environment
Children have several “tasks” to accomplish during bereavement:

- Accepting the loss
- Experiencing the pain and other emotions associated with loss
- Adjusting to a new situation/environment
- Finding ways to memorialize/remember the individual who is gone
Complicated Grief

- Invasive and debilitating grief symptoms lasting more than 6-12 months

- Can include:
  - Yearning for deceased
  - Difficulty accepting death
  - Inability to trust
  - Excessive anger
  - Intense loneliness
  - Frequent pre-occupying thoughts about deceased
Complicated Grief Risk Factors

- Deep attachment to deceased person
  - Child, spouse, parent, sibling
- Unexpected death
- Traumatic death
- Prior experience with traumatic loss
Reflection

PBS “It’s my life” on “Dealing with Death” (6:39)

http://www.youtube.com/watch?v=WHUewQtLgNs&feature=related
Reflection

- What grief responses do the children identify in the video?
- What additional losses to the children identify?
- What coping mechanisms do the children identify?
Changing Face of Death

Before 1900s
- Intergenerational family units
- Limited effective medical interventions
- Common to experience births and deaths in the home

20th Century
- Hospitals and medical technology advance
- Resuscitation (CPR) developed in 1960

2000s
- Emphasis on youth and health
- Death as a medical failure
- Death occurring in medical facilities > home
Adult Understanding of Death

- Irreversibility
  - Death is permanent.

- Nonfunctionality
  - All life-defining functions cease at the time of death.

- Universality
  - All living things die, including self.

- Causality
  - There are physical reasons someone dies.
## Understanding of Death

<table>
<thead>
<tr>
<th>Age</th>
<th>Developmental Stage (Piaget)</th>
<th>Perception or Concern</th>
<th>Anticipated Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2 years</td>
<td>Sensorimotor</td>
<td>Sense separation and the emotions of others</td>
<td>Withdrawal Irritability</td>
</tr>
<tr>
<td>2 – 6 years</td>
<td>Preoperational</td>
<td>Dead = “Not Alive” Death as Temporary</td>
<td>Wonder about what the dead “do” Magical thinking (I am the cause)</td>
</tr>
<tr>
<td>6 – 10 years</td>
<td>Concrete operational</td>
<td>Morbid interest in death Others die ➔ I die</td>
<td>Exaggerated behavioral reactions to the idea of death and dead things</td>
</tr>
<tr>
<td>Adolescence</td>
<td>Formal operational</td>
<td>Adult concepts Existential implications</td>
<td>“But not me” Death as an adversary</td>
</tr>
</tbody>
</table>
Reflection

PBS “Sesame Street” Big Bird learns about death (Mr. Hooper dies) (4:33)

http://www.youtube.com/watch?v=9NjFbz6vGU8&feature=related
Reflection

- Where is Big Bird in his developmental understanding of death?
- How do the adults help support his understanding?
- How could you use this with parents or patients?
Reflection

Reflection

- What are your personal experiences with talking about death?
- What are your personal experiences being told about a death?
- What are your fears around talking about death with children?
Activity

Role play explaining the death of a grandparent to a child aged 3, 8, and 14 years old.
Understanding of Death – Impact of Experience
Stages in a Sick Child’s Acquisition of Information about His/Her Illness

Stage 1

- Child’s Information
  - “It” is a serious illness
  - Not all children will know the name of the disease

- Experience Required for Passage to This Stage
  - Parents informed of the diagnosis

- Child’s Self-Concept at This Stage
  - I was previously well but now I am seriously ill
Stages in a Sick Child’s Acquisition of Information about His/Her Illness

Stage 2

- Child’s Information
  - The names of the drugs used in treatment, how they are given and their side effects

- Experience Required for Passage to This Stage
  - Parents informed the child is in remission
  - Child is speaking to other children at clinic

- Child’s Self-Concept at This Stage
  - I am seriously ill but I will get better
Stages in a Sick Child’s Acquisition of Information about His/Her Illness

Stage 3

- Child’s Information
  - Purposes of procedures and treatments; relationship between procedures and specific symptoms

- Experience Required for Passage to This Stage
  - First relapse

- Child’s Self-Concept at This Stage
  - I am always ill and I might not get better
Stages in a Sick Child’s Acquisition of Information about His/Her Illness

Stage 4

- Child’s Information
  - Larger perspective of the disease as an endless series of remissions and relapses
- Experience Required for Passage to This Stage
  - Several remissions and relapses
- Child’s Self-Concept at This Stage
  - I am always ill and will never get better
Stages in a Sick Child’s Acquisition of Information about His/Her Illness

Stage 5

- Child’s Information
  - The disease is a series of remissions and relapses ending in death
- Experience Required for Passage to This Stage
  - Child learns of the death of an ill peer
- Child’s Self-Concept at This Stage
  - I am dying
Reflection

Watch one of the videos of a child describing their life with a life-limiting disease

- “My So-Called Lungs" from Hearing Voices: Radio Diaries (21:13) http://www.radiodiaries.org/my-so-called-lungs
- "Living with Muscular Dystrophy" by Bryan Arnold (5:36) https://www.youtube.com/watch?v=ZrPnmgs4rHM
- "My philosophy for a happy life" by Sam Burns (12:45) https://www.youtube.com/watch?v=36m1o-tM05g
Reflection

Write a reflective essay or discuss with your group how you perceive quality of life for a patient you have cared for with a chronic or terminal illness.
Strategies to Assist the Child’s Understanding of His/Her Illness

- Discover what the child understands about the illness before beginning the conversation.
- Look beyond age and verbal presentations for an indication of the child’s conception of illness and death.
- Answer what the child wants to know.
  - Children want to know different things at different stages in their illness.

Strategies to Help the Child Understand His/Her Illness

- Use terminology the child understands.
  - Draw pictures
  - Use diagrams
  - Check the child’s understanding by asking the child to explain what you have said with statements like “Now if you were the doctor how would you explain this?”

- Once is not enough
  - Don’t assume the child understands after one conversation.

- Be honest
  - Do not tell a child anything you do not believe.

Strategies to Assist the Child’s Understanding of His/Her Illness

- Don’t necessarily try to correct a child’s distorted ideas and magical feeling about his/her illness.
  - These thoughts may serve a purpose in coping.
  - It is unwise to break down such defenses unless you are sure more desirable concepts will take their place.

- Try to understand the family’s emotional coping style.
  - Family interaction and coping strategies have a large effect on a child’s adjustment to illness.

Talking to Ill Children About Goals of Care

- What are you looking forward to most of all?
- Is there anything that is worrying you or making you feel afraid?
- Is there anything about how you are feeling that is making you feel worried or afraid?