

Part A: Understanding Grief and Loss in Children and Their Families

Discussion Guide: Understanding Grief and Loss in Children

Learning Objectives for this Section

- 1.1 Describe the overarching process of grief and loss, including:
 - a. Components of grief: 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
- 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 diseases progresses.
 - b. How to assist children’s understanding in discussions of medical information

Relevant Milestones: PBL2, ISC2, PROF1

Note on coordination with the slide set. *Please feel free to add or remove slides and choose activities as appropriate to your group of learners. Within the slide set are several video clips to highlight key points. These clips can be used as part of the presentation or as separate discussion triggers.*

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

Introduction

Elizabeth Kubler-Ross described grief as having specific stages, moving from denial to anger to bargaining, then to depression and finally acceptance. In fact, while this is a useful framework for describing the components of grief, people do not move through the stages in a linear fashion. Recent research supports a more dynamic experience with movement in and out of these states over time.

Children experience grief in many ways—some large, some small. Small losses may include a favorite toy that goes missing, changing teachers with a new school year, or a friend who moves away. Larger losses may include moving to a new home or school or the death of a pet, a friend or family member. How children both interpret and express loss will be a function of their developmental stage and abilities, prior experiences and factors specific to the nature of the loss itself.

We, as medical practitioners, experience grief when we lose a patient, regardless of whether the death was expected or unexpected. Learning to recognize and effectively cope with this experience is an important component of professional development. It can help us to maintain empathy and prevent burnout.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Group Activity: How do we as medical care providers and individuals experience loss.

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.

Prompts:

- How does it feel to lose the items?
- Did anyone feel stages of grief?
- How does it feel to take the items?
- How does this relate to professional practice?

How Children Respond to Loss

Children's responses have both an internal and external context. The internal context is their age, stage of development, personality and prior experiences. The external context is the nature of the relationship, how the loss occurred (expected vs. unexpected, was the child present or not, etc.), the types of support they have available, and the response and responsiveness of their family system.

Demonstrations of grief are highly varied. Children may express:

- Loss/emptiness/sadness
- Relief
- Guilt and self-blame
- Fear
- Acting out behavior
- Explosive emotions
- Disorganization and panic
- "Big Man" or "Big Woman" syndrome (attempting to take on the family role of an older sibling or adult who has died)
- Regression
- Physiological changes
- Lack of feelings

All of these responses are within the normal range of grief reactions.

Complicated Grief: Complicated grief is defined as debilitating symptoms of grief lasting more than 6-12 months. Adults and children can experience complicated grief. Risk factors for complicated grief include high levels of attachment, sudden or unexpected death, traumatic death and prior experiences with traumatic loss.

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Discussion:

Trigger Tape: PBS "It's my life" on Dealing with Death (6:39) <http://www.youtube.com/watch?v=WHUewQtLgNs&feature=related>

Several children of different ages talk about the death of a loved one and how they are coping with the grief and loss, as well as how it has changed their understanding of life and death.

Discussion Prompts:

- What developmental stages are present in the videos?
- What coping mechanisms do the children identify?
- What additional losses do the children identify?

Development of the Child's Concept of Death

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

Under age 2 years. Children of this age often do not recognize death, but they do sense the emotions around them, and will miss a primary caretaker who is ill or who has died. Maintaining a routine and continuity of care is the best way to help them feel secure.

Ages 2-3 years. Even at this early age, it is important to use "real words" like death and died. Using euphemisms like "gone to sleep" or "passed away" can be confusing because children understand that they wake up from sleep and that people who go away come back. Even when they are told that someone has died, they may repeatedly ask where the loved one is, and even about when they are coming back. Answering questions in a calm and consistent manner is the most helpful. Children at this age often need to hear the information over and over again as they are processing it.

Ages 4-6 years. Many of the characteristics of the 2-3 year old development remain, particularly a belief that death is temporary, and the loved one will be returning (or even that they should go visit them). What is additionally challenging at this age is the tendency to think that they did something to cause the death, so called "magical thinking."

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Age 6-10 years. Children at this age tend to be very curious about death and dying. They may also be pre-occupied with skeletons, ghosts, and cemeteries.

Ages 10 and up. Children tend to be protective of the adults around them, and refrain from asking questions so as not to further upset them. Being as open as possible, and even setting aside opportunities to talk, may be really helpful for them. While there is importance in being heard or supported, teens may also want to fit in with their peers, so they may act as if they aren't grieving ('grief complicated by ambivalence').

An adult understanding of death means recognizing four major concepts:

- 1. Irreversibility:** Death is permanent.
- 2. Non-functionality:** All life-defining body functions cease.
- 3. Universality:** All living things die, including self.
- 4. Causality:** Dying is the result of physiologic malfunction.

It may be helpful to think about this 'adult understanding of death' the same way as 'abstract/formal operational thinking'. Both are the ultimate stage of development, but (1) not everyone reaches that level and (2) when stressed, it is human to revert to a more basic level.

These age ranges are approximate. As in every aspect of child development, chronologic age is but one determinant of how a child changes over time. Personal and family experience with loss, grief and death, exposure to books and other media and community events may all serve to move a child to a different stage of understanding.

Discussion

Video/Trigger Tape

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

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

Prompts:

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

Narrative for Reflection

GENERATIONS; *The Final Farewell, in a Child's Eyes*, in New York Times October 29, 2006

Prompts:

- Personal experiences with talking about death
- Personal experiences with being told about a death
- Fears around talking about death with children

Resilience in the Face of Grief and Loss:

A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

Role-play

Ask the learners to practice explaining the death of a grandparent to a child age 3, 8, and 14 years old.

Facilitator Notes

Consider first having the learners review either:

The Ira Kaufman Chapel Video Series on explaining death to kids:

<http://www.irakaufman.com/explaining-death-to-kids.cfm>

BC Children's Hospital's pamphlets on Grief and Loss:

<http://www.bcchildrens.ca/KidsTeensFam/A-ZPamphlets/G-HPamphlets.htm#Griefandloss>

Providers should support families in discussing the following topics openly and honestly with the child:

- Death is a part of the life cycle.
- The family's spiritual belief regarding what happens after death.
- It is all right to cry and to feel sad.
- It is all right to feel angry and resentful.
- It is all right not to want to talk to anyone for a while.

For the 3 year old: "I am sad because grandpa died."

- The body stopped working.
- The body does not breathe, see, smell, pee/poop, or move any more.
- The spirit of the person, and our memory of them will live on in different ways (according to the family's belief system).

For the 8 year old:

- Offer additional information on what led to death --- heart stopped working, cancer, etc.
- Be prepared to answer questions about what happens to the body.

For the 14 year old:

- Be prepared for more "What now?" types of questions, as the impact of the death on others may be recognized more at this age.

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A Curriculum for Pediatric Learners

Part A: Understanding Grief and Loss in Children and Their Families

How Children Acquire Information When They Face Life Threatening Illnesses

Stages by Which Children Acquire an Understanding of Illness			
Stage	Child's Information	Experience Required for Passage to This Stage	Child's Self-Concept at This Stage
1	"It" is a serious illness (Not all children will know the name of the disease)	Parents/child informed of the diagnosis	I was previously well but now I am seriously ill
2	The names of the drugs used in treatment, how they are given and their side effects	Parents/child informed the child is in remission Child is speaking to other children at clinic	I am seriously ill and I will get better
3	Purposes of procedures and treatments; relationship between procedures and specific symptoms	First Relapse	I am always ill and I might not get better
4	Larger perspective on the disease as an endless series of remissions and relapses	Several remissions and relapses	I am always ill and will never get better
5	The disease is a series of remissions and relapses ending in death	Child learns of the death of an ill peer	I am dying

Discussion

Choose one to listen to/view and discuss:

Trigger Tape: "Hearing Voices: Radio Diaries" My So-Called Lungs (21:13)

<http://www.radiodiaries.org/my-so-called-lungs>

Trigger Tape: "Living with Muscular Dystrophy" by Bryan Arnold (5:36)

<https://www.youtube.com/watch?v=ZrPnmgs4rHM>

Trigger Tape: "My philosophy for a happy life" by Sam Burns (12:45)

<https://www.youtube.com/watch?v=36m1o-tM05g>

Prompts:

- How do these children/teens describe their experience of a serious illness?
- What coping mechanisms do they identify?
- What desires do they express?
- How did your perceptions of quality of life change as you watched the video or listened to the recording?

Individual Exercise

Write a reflective essay about how you perceive quality of life for a patient you have cared for with a chronic or terminal illness.

- What did you find challenging or difficult about this particular situation?
- Why did you choose to write about it? What about it gives meaning? Is there something from your past that gives it special meaning?
- What are the different perspectives involved: i.e., patient, family, health care providers, the literature?
- What did you learn from this interaction? How might it change the way you practice medicine or interact with patients or families?

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.
- 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 for 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?