

Death and Dying

Helping Children and Teens Cope and Grieve

Dan H. Kim, MD

Behavior and Development Rotation

UCI-CHOC

Outline

1. Developmental approach to understanding death
2. Recognizing the spectrum of grieving responses
3. Understanding the importance of communication skills and resources when dealing with a family that must cope with death

Vignette

Roger is a 4 year old healthy boy who is brought to your office by mom because she is concerned about his lack of appetite over the last 3 days. No other concerning systemic or GI symptoms. No relevant PMHx or FHx of medical or GI problems.

Upon asking Roger about his appetite, he asks, “Can Spot eat?”

Mom explains to you that Spot is a family dog that died 1 week ago.

Cognitive and Behavioral Aspects of Developing an Understanding of Death

Age	Developmental Stage (Piaget)	Perception or Concept	Anticipated Response
<2 years	Sensorimotor	Sense separation and the emotions of others	Withdrawal Irritability
2 to 6 years	Preoperational	Dead="Not alive" Death as temporary	Wonder about what the dead "do" Magical thinking
6 to 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 understanding Existential implications	"Why not me?" Death as an adversary

Understanding of Death

Four major concepts that comprise an adult understanding of death:

- (1) Irreversibility - death is permanent
- (2) Non-Functionality - life-defining bodily functions cease upon death
- (3) Causality - dying is a result of physiologic malfunctions
- (4) Universality - all living things die

Children who do not comprehend these concepts may rely on magical thinking, view death as punishment, or develop excessive guilt.

Communication is Key.

Involvement of children/teens in the death/grieving process is a personal choice. There is no “right way”.

- E.g. siblings at the bedside of dying child
- Important to prepare child for sights, sounds, smells at bedside, utilize nursing and child life staff
- Important to talk to the family about what to say, who does the telling, and when is the appropriate time.
- Offering explanations can trigger conversation, encourage questions

Recognizing Grieving Responses

Grief reactions occur in the emotional, cognitive, physical, and social domains.

Influenced by (1) developmental stage, (2) family coping style, (3) culture, (4) religion, (5) circumstances surrounding death

Common expressions of grief include repeated questioning, regressive behaviors, extreme emotions such as anger or fear.

Kubler-Ross introduced the 5 stages of grief - (1) denial, (2) anger, (3) bargaining, (4) depression, (5) acceptance -- can occur in ANY order and recur as the individual moves towards acceptance

Important to realize that grief is an ONGOING process, continues across development, and may come in “WAVES”.

Complicated Bereavement

Preschool- age: persistent separation anxiety >6 months after predictable home life has been established, continuing or worsening regressive behavior beyond 6 months from death

School-age: persistent or worsening school phobia or academic performance 3 months after death, detachment from peers or development of new social phobias, increasing behavioral concerns such as depression, moodiness, anger 3-6 months after death, physical complaints without organic complaints >3 months after death

Teenagers: increasing “high-risk” (e.g. drug, alcohol, sex, delinquency) behaviors, withdrawal from peers or group activities, persistent somatic complaints >3 months after death

What can we do as pediatricians?

- Active listening, show empathy, be ready to discuss death and dying with patient at the appropriate developmental level.
- Recognize that different families will have different coping mechanisms and grieving reactions. Recognize complicated bereavement and provide appropriate support or referrals.
- Consider close follow-up within a month following death to check-in on the child and family
- Provide counseling on normal versus complicated grieving responses.
- Early referral to psychology or grief counselor.

Express concern - it is OK to show emotion, tell them you're sorry that someone they cared about has died.

Be genuine - children's can tell when adults are authentic. Let the child appreciate that the loved one was important to them and that you are sorry they have experienced this loss.

Listen more, talk less. Simply, be present.

Open-ended questions - "How are you doing since your mother died?"

Limit the sharing of your personal experiences, keep the focus on the child's loss and grief.

Offer practical advice - suggestions on how to answer questions that might be posed by peers or how to talk with teachers about learning challenges.

Offer reassurance, but do not minimize their concerns. Let them know that over time, you expect them to be better able to cope with their distress.

Communicate your availability to provide support over time. Make the effort to schedule follow-up appointments, reach out by phone or email periodically.

Discuss topics openly and honestly

Death is a natural part of the life cycle.

The family's spiritual belief regarding life after death.

It's OK to cry and feel sad.

It's OK to be angry and resentful.

It's OK to not want to talk to anyone for a while.

Examples:

3 year old child: “I am sad because grandpa died”

Explanation: (1) the body stopped working. (2) the body does not breath, see, smell, pee/poop, or move anymore.

8 year old child:

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

14 year old teen:

Be prepared for “What now?” questions, the impact of death on others may be recognized more at this age.

Counseling adults on talking to their child after death.

- Although well-intentioned, **this is not the time to “cheer up” grieving individuals.** Anything that begins with “*at least*” is not helpful (e.g. “*at least* he isn’t in pain anymore”, “*at least* you have another brother”)
- Do not instruct the child on hiding their emotions - “You need to be strong; you are the man of the house now that your father is gone.”
- **Avoid communicating that you know how they feel.** - “I know exactly what you’re going through.”
- **Do not tell them how they ought to feel.** - “You must be angry.”
- **Avoid comparisons with personal experiences.** It shifts the focus away from the child’s experience. Insulting if the comparison seems less important (“I know what you’re going through with your father’s death. My cat died this past week.”) or confusing if the comparison appears worse (“I understand your grandpa died. When I was your age, my whole family died in a car accident.”) - child may feel compelled to comfort YOU or reluctant to ask for help.

References/Resources

[AAP - Discussion Guide on Understanding Grief and Loss in Children](#)

[Pediatrics in Review: Coping with Death](#)

[Pediatrics in Review: Supporting the Grieving Child and Family](#)