

# Death During Childhood

Jovana Pavisic

Developmental and Behavioral Pediatrics

June 17, 2014

# Overview

- Background
- Cognitive development of the concept of death
- Issues in helping the dying child
- Communicating with the dying child
- Conclusions

# Overview

- **Background**
- Cognitive development of the concept of death
- Issues in helping the dying child
- Communicating with the dying child
- Conclusions

# Background

- In the U.S. ~50,000 children <19 years of age die each year
- > 50% of deaths occur within the first year after birth
- Major causes of death after 1 year of age are accidental
- Cancer is the most common cause of non-traumatic death in children
- How a child copes with his or her own “anticipated” death deserves special attention



**Ways to Live Forever (2010)**

# Background

- Psychosocial research in the 1970s shows:
  - Children pick up on visual and emotional cues that something serious is happening to them, and frequently know that they are dying
  - Children with a terminal illness have a more developmentally advanced understanding of death than their peers
  - Children of all ages express their knowledge and emotions about death in various ways, verbal and non-verbal, and seek support through the process
- Addressing issues around death with the child can help the parents after the child has died

# Overview

- Background
- **Cognitive development of the concept of death**
- Issues in helping the dying child
- Communicating with the dying child
- Conclusions

Irreversibility

Finality (non-  
functionality)

Adult Concepts  
of Death

Inevitability  
(universality)

Causality



# Developing the Concept of Death

- Based on psychologist Jean Piaget's levels of cognitive development based on chronological age
- Must also consider developmental level, prior experiences with death, family's cultural and religious beliefs

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

# Sensorimotor Stage (< 2 years)

0-2	Sensorimotor —Preverbal —Reflex activity → purposeful activity —Rudimentary thought	Expresses discomfort with separation	Infancy
-----	--	--------------------------------------	---------

- Learn through senses and developing motor skills
- Pre-verbal, express feelings through behavior
- Separation anxiety develops
- Death as a word or an event has no conceptual meaning
- Sense separation and emotions of others
- Response: behavioral changes, anorexia, irritability, insomnia, hypervigilance, loss of interest and withdrawal from the environment, regression



# Preoperational Stage (2-6 years)

2-6	Preoperational		
	— <i>Prelogical</i>	Uses word "dead" but only to distinguish "not alive"	3 yr
	—Development of representational or symbolic language	Limited notion; may express no personal emotion but may associate death with sorrow of others	4 yr
	—Initial reasoning	Avoids dead things; imagines death as a personified being; believes he will always live, only others (especially those older than he) die	5 yr
		Associates death with "old age"; may be violent and emotional about death including representations (eg, magazine pictures) or may display intense curiosity about dead things	6 yr

- Inanimate objects are alive in the same sense that people are alive
- Magical thinking can lead to guilt and fear
- Death is reversible and contingent on external factors (i.e. being old)
- Likely to show little emotion at first encounter with death
- Sense the sorrow of others and respond by mimicking crying or being consoling
- Around age 6, develop logical thinking, recognize death is final, response to death changes



**Stolen Summer (2002)**

# Concrete Operational Stage (6-10 years)

6-12	Concrete operational — <i>Logical</i>	Morbid interest in details (eg, graveyards, coffins, possible causes); seeks answers through observation of decomposition, etc; suspects he himself may die	7 yr
	—Problem solving restricted to physically present, real objects that can be manipulated	Less morbid, more expansive; interested in what happens after death; accepts, without emotion, that he, too, will die	8 yr
	—Development of logical functions (eg, classification of objects)	Understands logical and biologic (eg, absence of pulse) essentials of death; can accept full and rational explanation of death process	9-10 yr

- By age 9-10, child's use of the word "dead" approximates adult understanding of the term
- Understand that death is possible at any point in life and could happen to them



# Formal Operational Stage Adolescence

12+	Formal operational — <i>Abstract</i> —Comprehension of purely abstract or symbolic content —Development of advanced logical functions (eg, complex analogy, deduction)	Meaning of death appreciated but reality of personal death not accepted	Adolescence
-----	---	---	-------------

- Adult understanding of death and capable of self-evaluation and insight (think about his own death)
- Acceptance of personal death is difficult, copes through denial, may attempt to confront or deny death
- Question existential implications of death



# Overview

- Background
- Cognitive development of the concept of death
- **Issues in helping the dying child**
- Communicating with the dying child
- Conclusions

# Considerations for the Dying Child

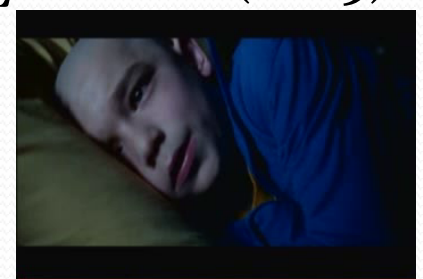
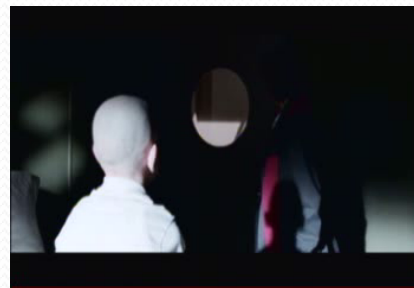
- Physical needs: minimizing discomfort and pain
- Emotional support: opportunity to express and share personal feelings, utilizing projective techniques, addressing personal guilt and shame
- Social support: maintaining normalcy, patient and family as part of treatment team
- Anticipatory grieving
- The dilemma of “open awareness”



A Lion  
in the  
House  
(2006)



Oscar and the Lady in Pink (2009)





# Overview

- Background
- Cognitive development of the concept of death
- Issues in helping the dying child
- **Communicating with the dying child**
- Conclusions

*Peter was diagnosed with cystic fibrosis before 1 year of age. At the age of 15 years, he was admitted to the hospital for his first unscheduled therapy. He had struggled to stay on task with his therapy regimen and now had pneumonia. He was sick and seemed depressed, but when asked if there was anything he wanted to talk about, the conversation turned toward getting his driver's license in several months. Peter went home after 2 weeks and did well for a time, but had to return to the hospital 1 month later. His thoughts during this admission focus on getting better so he can attend an upcoming rock concert. At his discharge follow-up visit, he asks if he is going to die.*

# Communication Needs of Dying Children

- Seriously ill children understand that “something” is going on and want information about their illness and treatment
- Environment of honest and open communication and concern
- Toddlers and pre-school age children: understand that they are sick and are getting medicine to make them better
- School-age children: understand that they have an illness, know it by name, and know when and why procedures and/or treatments will be uncomfortable
- Adolescents: comprehend the diagnosis and treatment more fully, require more detailed explanations, may want more discussions about prognosis

# Communicating with the Dying Child

**Table 94-2.** Principles involved in informing children about a terminal illness or impending death

Inform the child over time in a series of conversations. During the initial conversation, it is important to convey that the child has a serious illness.

If the child asks directly whether he or she is going to die, initially explore the reason for the question and the child's concerns (e.g., "Are you afraid that you might die?" "What are you worried about?"). Do not provide false reassurances ("No, don't worry, you're going to be okay.") but always try to maintain hope ("Some children with your sickness have died, but we are going to do everything we can to try and help you get better.").

Focus initial discussions on the immediate and near future. Young children have a limited future perspective. Dying "soon" to them may mean minutes, hours, or days and not months or years.

Answer questions directly, but do not overwhelm the child with unnecessary details.

Assess the child's understanding by asking him or her to explain back to you what you have discussed.

Reassure the child of the lack of personal responsibility or guilt. For this reason, avoid the use of the term bad in the description of the illness (e.g., "You have a bad sickness.").

# Communicating with the Dying Child

- “Tell me what you’re thinking”
- Fear of death often means fear of pain or discomfort, emphasize appropriate management of pain and side effects!
- Do not say to a child what you do not believe
- Create diverse and age-appropriate settings (can utilize therapeutic play activities, reading materials, art or music)
- Utilize multidisciplinary team (oncologist, PCP, therapist, child life specialist, palliative care specialist, familiar volunteer, parent)



**My Sister's Keeper (2009)**



# The “6 Es” Strategy

- **Establish** an agreement with parents, children, and caregivers early on in the relationship with them concerning open communication.
- **Engage** the child at the opportune time.
- **Explore** what the child already knows and wants to know about the illness.
- **Explain** medical information according to the child’s needs and age.
- **Empathize** with the child’s emotional reactions.
- **Encourage** the child by reassuring him/her that you will be there to listen and to be supportive.

## **TABLE 2. Symptoms of Problematic Adjustment To Death\***

- Irritability
- Separation anxiety and clinging
- Fear of the dark
- Noncompliance
- Regressive behaviors (eg, thumb-sucking, enuresis, baby-talk)
- Somatic complaints (at times mirroring the loved one's illness)
- Sleep or eating disturbances
- Anhedonia—decreased interest in play or other activities
- Poor concentration and subsequent poor grades
- Preoccupation with death

*\*Suggestive of problematic adjustment if symptoms are severe and/or prolonged.*

# Overview

- Background
- Cognitive development of the concept of death
- Issues in helping the dying child
- Communicating with the dying child
- **Conclusions**



# Conclusions

- Child's understanding of death is determined by chronological age, developmental level, prior experiences with death, and family's cultural and religious beliefs
- Seriously ill children have a developmentally advanced understanding of death and what death means to them
- Children of all ages express their emotions about death in a variety of verbal and non-verbal ways
- Communicating openly and honestly with children about death reduces anxiety and feelings of isolation, and can improve cooperation of the child and child-parent bonding and coping with the disease process

# References:

- Augustyn, M., et al. (2011). *The Zuckerman Parker Handbook of Developmental and Behavioral Pediatrics for Primary Care*. Philadelphia, PA, Wolters Kluwer, Lippincott Williams & Wilkins.
- Barakat, L. P., et al. (1995). "Management of Fatal Illness and Death in Children or Their Parents." *Pediatrics in Review* 16(11): 419-423.
- Beale, E. A., et al. (2005). "Silence Is Not Golden: Communicating With Children Dying From Cancer." *Journal of Clinical Oncology* 23(15): 3629-3631.
- Greenham, D. E. and R. A. Lohmann (1982). "Children Facing Death: Recurring Patterns of Adaptation." *Health & Social Work* 7(2): 89-94.
- Jankovic, M., et al. (2008). "Communicating with the dying child: An invitation to listening—a report of the SIOP working committee on psychosocial issues in pediatric oncology." *Pediatric Blood & Cancer* 50(5): 1087-1088.
- Linebarger, J. S., et al. (2009). "Coping With Death." *Pediatrics in Review* 30(9): 350-356.
- Sahler, O. J. Z. and S. B. Friedman (1981). "The Dying Child." *Pediatrics in Review* 3(5): 159-165.
- Schonfeld, D. J. (1993). "Talking with children about death." *Journal of Pediatric Health Care* 7(6): 269-274.
- Movie Clips From: *A Lion in the House* (2006), *Oscar and the Lady in Pink* (2009), *Ways to Live Forever* (2010), *Stolen Summer* (2002)



**Thank You!**

**Questions?**