

HCEA 2008 CONFERENCE HANDOUTS

PRESENTATION: The Elephant in the Room - Talking With Seriously Ill Children About Death

PRESENTER: Philene Cromwell RN, MS, PNP

CONTACT INFO: Office # 585 214 1522
Email Philene.cromwell@lifetimecare.org
Address CompassionNet
3111 South Winton Road
Rochester, N.Y. 14632

DATE: Thursday, September 18, 2008

LECTURE CONTENT:

Learning Objectives:

- To understand children's concepts of death within a developmental framework.
- To review relevant clinical research that will help guide you in your care of the terminally ill child.
- Increase your "comfort zone" when communicating bad news to children.

When a child asks.....Am I dying? Are you prepared to answer?

The Impact of a life threatening illness is profound and lasts a lifetime.

Children's understanding of death is influenced by their age, culture and life experiences and impacts the way we care for them and talk to them.

Children's Concepts of Death

Magical Thinking

- Ages 3-6 years
- Death as temporary and reversible
- Death is mixed up with trips/sleep
- May wonder what the deceased person is doing

- **Magical thinking- “bad thoughts” or unrelated events caused the illness or death**

Concrete Thinking

- **6-12 years**
- **Children begin to realize that a dead person can not function**
- **Age 7 – death is not reversible**
- **May become concerned with the physical suffering of the dead**
- **May develop misconceptions**
- **Concrete level of reasoning limits or compromises understanding**
- **Children often think of illness as punishment and separation as abandonment.**

(* Barbara Sourkes)

Abstract Thinking

- **Age 12 years and greater**
- **Thoughts more consistent with mature adult**
- **Teens- often do not recognize their own death as a possibility, yet when they do they may have an exaggerated sense of responsibility**
- **Thoughts and feelings may be inconsistent**
- **Vacillate between child like – adult like**
- **Need to be in control of their feelings**

Kids tend to over generalize

Children who are dying

- **Have a precocious understanding of the concepts of death**
- **Are often aware of their impending death even if not told**
- **Are further isolated when information is withheld**

Clinical research guides the clinical team in regards to facilitating difficult conversations

- 1. Children’s Awareness of Fatal Illness
(AJN)**

- 2. Talking About Death with Children Who Have Severe Malignant Disease
(N.ENGL J MED)**

3. Understanding of Prognosis Among Parents of Children Who died of Cancer (JAMA)

Follow the Lead of the Child

“Offering less information with the explicit invitation to ask for more affords a safety gauge of control for the child”

(*Barbara Sourkes)

Seek Permission

- **From the parents and from the child**
- **Does the child want to talk**
- **Does the child want to talk with you**
- **Ask the child to tell their story**

(*ELNEC)

IF YOU HAD THREE WISHES WHAT WOULD THEY BE?

DO NOT FORGET TO REVISIT THEIR WISHES!

Children may not be able to formulate their questions

- **Help them by sharing with them, other questions that kids often ask in similar circumstances.**
- **Encourage them to write their questions down.**
- **Offer your email address.**

Children who are dying

- **Seize the clues dying children give us**
- **Let children voice their concerns through stories, play and art**
- **Respect their wishes to talk...or not to**
- **Acknowledge the completeness of a child’s death...you will always be remembered.**
- **Empower the child – respect the need to be alone, yet share you will be there for them**
- **Never lie to a child**

(*Barbara Sourkes)

What to ask the Child

- **What do you want to know? (let me share with you what other kids like you want to know)**
- **What do you worry about?**

- Where do you want to die?
- Who do you want with you when you are very ill?
- Do you want me to talk with your friends or school mates?
- Is there anything I can do for you? Do you need me to help you accomplish anything?
- Do you want to know how you are likely to die?

What do Kids want to Know?

- Will my parents be OK without me?
- Who will be with me when I die/?
- Will I be in pain?
- What will happen to me when I am dying?

Siblings...The Forgotten Patient

Dying Children often Hope

Spirituality

- Do you ever talk to God in all that is happening?
- What do you talk with Him about?
- Is there anything that helps you when you're scared? When I am scared I think about God.
- Is spirituality important to you?

References:

1. Grollman E. Talking About Death a Dialogue between Parent and Child. Boston, Massachusetts: Beacon Press; 1990
2. Doka K. Talking to Children about Illness. In: Children Mourning, Mourning Children. Washington DC: Hospice Foundation of America, 1995: 31-39.
3. ELNEC Pediatric Palliative Care: Module 3: Communication. AACN & COH, 2003 Revised: August 2006.
4. Levetown M, Committee on Bioethics. Communicating With Children and Families: From Everyday Interactions to skill in Conveying Distressing Information. Pediatrics. 2008;121(5):1441-1460
5. Kriebel U, Vladimarsdottir U, Onelov E, Henter JI, Steinbeck G. Talking about death with children who have severe malignant disease. N Engl J Med. 2004; 351(12):1175-1186
6. Sourkes B. Armfuls of Time: the psychological Experience of the Child with a Life – threatening Illness. Pittsburgh, Pa: University of Pittsburgh; 1995.
7. Waechter EH. Children's awareness of fatal illness. Am J Nurs. 1971;71(6):
8. Wolfe L. Should Parents Speak with a Dying Child about Impending Death? N Engl J Med. 2004;351(12):1251-1253
9. Wolfe J, Klar N, Holcombe E, et al. Understanding of Prognosis Among Parents of Children Who Died of Cancer. JAMA. 2000;284 (19): 2469-2475