Pediatric Palliative Care

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TPS Annual Meeting
September 19, 2013
Pediatric Palliative Care

- Disclosure statement:
  
  I have nothing to disclose
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- Objectives:
  - Recall the basic tenets of pediatric palliative care
  - Review current best practices related to pediatric palliative care
  - Identify multiple dimensions of pediatric palliative care
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- ~53,000 children die each year
- <1yr: birth defects, prematurity, SIDS
- >1-19yrs: trauma (MVA, drowning, homicide, suicide); cancer, cardiac disease and congenital anomalies

Himelstein BP, et al. NEJM 2004
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- ~ 450,000 children live with chronic, life-threatening, activity-limiting complex conditions

- ~ 16,000 could benefit from palliative care

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TENets

1) Patient & family center of the unit of care
2) Provide relief from pain/distressing symptoms
3) Affirms life and regards dying as a normal process
4) Intends neither to hasten nor to postpone death

Wolfe J, Kinds P, Sourkes B; Textbook of Interdisciplinary Pediatric Palliative Care, 2011
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TENets

5) Integrates psychological & spiritual aspects of patient care

6) Offers a support system to help patients live as actively as possible until death
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TENets

7) Offers a support system to help the family cope during child’s illness and in their own bereavement

8) Uses a team approach to address the needs of patients and their families
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TENets

9) Aims to enhance the **quality of life** and may positively influence the course of the illness

10) Is applicable early in the course of the illness- *in conjunction with* life prolonging therapies
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- ‘Best practices’- **standards:**
- AAP
- World Health Organization
- **Institute of Medicine**
Decisions Making

- Alternatives
- Uncertainty
- High-risk Consequences
- Interpersonal Issues
- Complexity
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- Decision making challenges:
  - 1) diverse/often rare illnesses
  - 2) variety of illness trajectories
  - 3) transition to palliative care less clear
  - 4) variable duration of care period (days-years)

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- 5) greater involvement of parents/legal guardians as direct caregivers & decision makers
- 6) increased reliance on proxy reporters
- 7) role of child involvement; ethical issues; assent/consent

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- A) potentially curable conditions (i.e. malignancies)

- B) progressive conditions: intensive therapy prolongs and enhances life (i.e. cystic fibrosis)
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- C) progressive conditions: curative or disease-altering therapy not available (i.e. neurodegenerative conditions)
- D) non-progressive conditions: death before adulthood likely from complications such as seizures/resp failure (i.e. severe CP)

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- Ethical *guidelines for making decisions* in pediatric palliative care:

- 3 DOMAINS---
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1) Where treatment is ethically obligatory because it is clearly beneficial for the child
2) Where treatment is clearly **futile** and should never be provided—(an ever shrinking but never entirely disappearing domain)
3) Where treatment outcomes are ambiguous/uncertain and in which doctors, parents, and children, must together make decisions about whether or not life-sustaining treatment should be provided.
Barriers to palliative care:

1) uncertain prognosis
2) family not ‘ready’
3) language/cultural barriers
4) time constraints
5) lack of properly trained health care professionals!
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- Communication needs:
  - Cognitive and affective!!!
  - ...must be responsive/flexible to the needs of child/family

FreyerDR. Care of the dying adolescent: special considerations. Pediatrics 2004;113(2):381-8
<table>
<thead>
<tr>
<th>Age Range</th>
<th>Characteristics</th>
<th>Predominant Concepts of Death</th>
<th>Spiritual Development</th>
<th>Interventions</th>
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<tbody>
<tr>
<td>0–2 yr</td>
<td>Has sensory and motor relationship with environment  Has limited language skills Achieves object permanence May sense that something is wrong</td>
<td>None</td>
<td>Faith reflects trust and hope in others Need for sense of self-worth and love</td>
<td>Provide maximal physical comfort, familiar persons and transitional objects (favorite toys), and consistency Use simple physical communication</td>
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<td>&gt;2–6 yr</td>
<td>Uses magical and animistic thinking Is egocentric Thinking is irreversible Engages in symbolic play Developing language skills</td>
<td>Believes death is temporary and reversible, like sleep Does not personalize death Believes death can be caused by thoughts</td>
<td>Faith is magical and imaginative Participation in ritual becomes important Need for courage</td>
<td>Minimize separation from parents Correct perceptions of illness as punishment Evaluate for sense of guilt and assuage if present Use precise language (dying, dead)</td>
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<tr>
<td>&gt;6–12 yr</td>
<td>Has concrete thoughts</td>
<td>Development of adult concepts of death Understands that death can be personal Interested in physiology and details of death</td>
<td>Faith concerns right and wrong May accept external interpretations as the truth Connects ritual with personal identity</td>
<td>Evaluate child’s fears of abandonment Be truthful Provide concrete details if requested Support child’s efforts to achieve control and mastery Maintain access to peers Allow child to participate in decision making</td>
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<tr>
<td>&gt;12–18 yr</td>
<td>Generality of thinking Reality becomes objective Capable of self-reflection Body image and self-esteem paramount</td>
<td>Explores nonphysical explanations of death</td>
<td>Begins to accept internal interpretations as the truth Evolution of relationship with God or higher power Searches for meaning, purpose, hope, and value of life</td>
<td>Reinforce child’s self-esteem Allow child to express strong feelings Allow child privacy Promote child’s independence Promote access to peers Be truthful Allow child to participate in decision making</td>
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- Palliative Care is to alleviate distressing symptoms:
  - pain; nausea; constipation; dyspnea; anorexia/cachexia
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- ... also to address-
- family needs/coping;
- spiritual needs;
- psychosocial needs;
- bereavement & grief
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- **Ultimate goal:**

- *Provide palliative and EOL care to children, so as to minimize their suffering and maximize their quality of life*
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- 1 slide of difficult decision making
- Goes here too
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- Case 1
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- Case 2