Dimensions of Pediatric Palliative Care
– What Pediatricians Need to Know

Pediatric Palliative Care
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Pediatric Palliative Care
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

- ~53,000 children die each year
  - <1yr: birth defects, prematurity, SIDS
  - >1-19yrs: trauma (MVA, drowning, homicide, suicide); cancer, cardiac disease and congenital anomalies

- ~450,000 children live with chronic, life-threatening, activity-limiting complex conditions
- ~16,000 could benefit from palliative care

Pediatric Palliative Care 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

Disclosure statement:

I have nothing to disclose

Himelstein BP, et al. NEJM 2004


Feudtner, et al. Pediatric deaths attributable to CCs. Pediatrics 2000;106(1)205-9

Wolfe J, Kinds P, Sourkes B; Textbook of Interdisciplinary Pediatric Palliative Care, 2011
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Pediatric Palliative Care TENets
- 5) Integrates psychological & spiritual aspects of patient care
- 6) Offers a support system to help patients live as actively as possible until death

Pediatric Palliative Care 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

Pediatric Palliative Care 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

Pediatric Palliative Care TENets
- ‘Best practices’ standards:
  - AAP
  - World Health Organization
  - Institute of Medicine

Pediatric Palliative Care
- 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

1.4

**Pediatric Palliative Care**

- A) potentially curable conditions (i.e. malignancies)
- B) progressive conditions: intensive therapy prolongs and enhances life (i.e. cystic fibrosis)

**Pediatric Palliative Care**

- A) potentially curable conditions (i.e. malignancies)
- B) progressive conditions: intensive therapy prolongs and enhances life (i.e. cystic fibrosis)
- 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)

**Pediatric Palliative Care**

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

**Pediatric Palliative Care**

- 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)

1.4
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- 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.

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- 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

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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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- Case 1

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- Case 2