End of Life Care for Children

Pediatric Project ECHO
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Disclosures

• Financial/Conflicts of Interest
  – None

• Medications
  – Some medications discussed are ‘off-label’

• Will not be discussing ACP or symptoms already covered in other CC sessions
Take a moment and write down a professional or personal experience of end-of-life care.

Identify what went well or did not go well.
Objectives

• To identify and communicate when end of life is approaching

• To anticipate and have a plan for care at end of life including location of care

• To develop an approach to pain and emergencies at end of life
KEY elements for excellent EOL Care

- Anticipation
- Preparation
- Communication, communication, communication
Identifying the End-of-Life Period

- Period of time when the child has no realistic hope for cure
- Timing very variable
- Dependent on the disease and circumstances
  - Eg. Weeks to months for cancer vs minutes to hours if withdrawal of life-sustaining therapy
# Assessing Clinical Status to Help with Prognosis Wording

**Fragility:** degree of risk of a significant deterioration

**Instability:** rate of change in child’s wellbeing

<table>
<thead>
<tr>
<th>Robust</th>
<th>Fragile</th>
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<table>
<thead>
<tr>
<th>Stable</th>
<th>Unstable</th>
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- **CNS:** seizures, increased ICP, hemorrhage
- **CVS:** heart function, arrhythmia, hemodynamics
- **Respiratory:** central +/- pulmonary
- **GI:** nutritional status, obstruction
- **Immune System:** sepsis

- **Symptom Burden:** pain, nausea, feeding intolerance, dyspnea etc.
- **Care Need Change:** feeding, respiratory, transfusion support
- **Functional Change:** eating, ambulation, interaction/engagement
- **Developmental Change:** loss of or failing to meet milestones
Communication about prognosis at EOL

- Clear, compassionate communication
- Involve key staff members and family
- Direct
- Cure no longer possible
  - Quality > quantity of life
Question - Poll

• Most parents who talked about death with their child who had a life-limiting illness regretted it.

  – True
  – False
Communication with the child

- Dependent on age, developmental stage, family communication style, culture

- Evidence suggests no parent who talked to their child regretted it but some (27%) who did not, wish they had (Kriebergs et al. 2004)

- Encourage open communication but do not force

- Be truthful and direct at appropriate developmental level

- Allows for legacy building, memory making
• Encourage parents to ask siblings what they understand

• Encourage involvement in EOL care

• Prepare parents for divergent reactions

• Use your allied health resources
Important considerations in EOL care

- Location
- Goals
Location of Care

- Majority of US children die in hospital (56%) and >85% of those die in an ICU (Field et al. 2003; Feudtner et al 2007)

- More children die in hospital than is desired by parents and families
  - Evidence shows children with underlying complex chronic conditions are increasingly dying at home (Feudtner et al 2007)
Location of Care
Special considerations for EOL care at home

• Written care plan with contingencies

• Must have 24 hr coverage for nursing and physician support

• Medications and Equipment
Further therapy?

- Transition from curative or goal directed therapy to palliative care can be very difficult for families

- Evidence suggest that children who receive cancer-directed therapy during EOL period suffered from a greater number of symptoms than those who did not receive treatment (Heath et al. 2010)

Early initiation of discussion

May change over time
Other important considerations when EOL is approaching

- Memory Making
- Autopsy
- Organ donation
- Funeral arrangements
- Bereavement supports
The Dying Process

• Characterized by
  – Decreased oral intake
  – Diminished awareness of thirst or hunger
  – Natural progression towards coma and death
Identifying when death is imminent

- Prognostication is imprecise
  - The shorter the time left, the more accurate estimates tend to be
  - Ask permission if it would be helpful to know what to expect
  - Cannot always know the exact moment
Signs of impending death

- Profound progressive weakness
- Sleeping much of the time
- Little interest in food and drink
- Difficulty swallowing
- Disorientation to time, with increasingly short attention span
- Urinary incontinence or retention
- Oliguria or anuria
- Dropping BP not related to hypovolemia with rising weak pulse
- Changes in respiratory rate and pattern, may include Cheyne-Stokes breathing
- Noisy breathing, airway secretions
- Mottling and cooling of the skin
- Mental status changes, such as delirium, restlessness, agitation and coma

*these signs may not be present in the case of brain death and child is on a ventilator (e.g. MVC)
Physiologic changes at death and afterward

- Secretions through mouth/nose
- Incontinent of urine/stool
- Livor mortis

- Rigor mortis
  - Chemical change causing stiffening of the body’s muscles due to changes in myofibrils of muscle tissues
Anticipatory Guidance for Time of Death

• No ‘right’ way to act or behave

• No pressure of time

• Different practices related to handling on the body depending on different religious or cultural background
Interventions when death is approaching

- Consider discontinuing things that are no longer helping the child

- When death imminent do not need to aggressively treat same symptoms as previously
  - Constipation
  - Bedsores
  - Anemia
If able and wish to eat and drink this should be offered

ANH are medical interventions not a comfort measure

Anorexia common at EOL

Can be withdrawn “when such measures only prolong and add morbidity to the process of dying.” (AAP)

Clear consensus that little if any discomfort when ANH withdrawn

AAP – Forgoing Medically provided nutrition and hydration in Children, 2009
Textbook of Interdisciplinary Pediatric Palliative Care
If you have ever been involved in a case where ANH has been discontinued please share in the chat how this made you feel as a HCP.
Anticipate symptoms at EOL

• “Optimum control of pain and other symptoms is the foundation of excellent palliative care, and is the cornerstone that facilitates attainment of all the other goals in care at end of life.” (Oxford textbook for PPC)

• Symptom control can have major impact on parental grief and psychological coping
Be prepared and anticipate

• May involve intensification of current care
  – Higher doses
  – More frequent doses
  – New symptoms
  – Worsening of previously controlled symptoms

• Discuss ahead of time and have a plan

• Ensure alternate route for PO medications is available
Poll

• In children, what are the 3 most common symptoms in the last week of life?

  – A) pain, fatigue, loss of appetite
  – B) fatigue, dyspnea, nausea/vomiting
  – C) pain, dyspnea, constipation
  – D) pain, fatigue, nausea/vomiting
Symptoms during the last week of life in pediatric patients

- Pain 84%
- Loss of Appetite 73%
- Fatigue 63%
- Nausea/Vomiting 58%
- Dyspnea 55%
- Constipation 47%

n = 473

T. Dangel (Poland)
R. Drake (Australia)
A. Goldman (UK)
T. Hongo (Japan)
J. Wolfe (USA)
Pain Assessment

- Numerical Rating Scale
  - Most developmentally normal children > 8 years old

- Faces Pain Scale – Revised
  - Age range 4-16 years
• Done by HCP
• Ages 2-7 years
• Used for those who are unable to communicate their pain
• Can be used in kids with developmental delay

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**FLACC Pain Assessment Tool**

<table>
<thead>
<tr>
<th>Categories</th>
<th>Score 0</th>
<th>Score 1</th>
<th>Score 2</th>
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<tbody>
<tr>
<td>Face</td>
<td>No particular expression or smile</td>
<td>Occasional grimace or frown, withdrawn, disinterested</td>
<td>Frequent to constant frown, clenched jaw, quivering chin</td>
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<tr>
<td>Legs</td>
<td>Normal position or relaxed</td>
<td>Uneasy, restless, tense</td>
<td>Kicking, or legs drawn up</td>
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<tr>
<td>Activity</td>
<td>Lying quietly, normal position, moves easily</td>
<td>Squirming, shifting back and forth, tense</td>
<td>Arched, rigid, or jerking</td>
</tr>
<tr>
<td>Cry</td>
<td>No cry (awake or asleep)</td>
<td>Moans or whimpers, occasional complaint</td>
<td>Crying steadily, screams or sobs, frequent complaints</td>
</tr>
<tr>
<td>Consolability</td>
<td>Content, relaxed</td>
<td>Reassured by occasional touching, hugging, or being talked to, distractable</td>
<td>Difficult to console or comfort</td>
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What tools do we have to manage pain?
Non-pharmacologic
Pharmacologic

• Non-opioids
  – Acetaminophen
  – Ibuprofen and other NSAIDs

• Opioids
  – Morphine
  – Hydromorphone
  – Oxycodone
  – Fentanyl
  – Methadone
Opioids

- Common concerns and barriers

- Consider:
  - Choice of drug
  - Route
  - Dosing needs
  - Scheduled + prn
  - Side effects

<table>
<thead>
<tr>
<th>Drug</th>
<th>Initial Dose PO*</th>
<th>Initial PO Dose &gt;50kg</th>
<th>Initial Dose IV*</th>
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</thead>
<tbody>
<tr>
<td>Morphine</td>
<td>0.2-0.3 mg/kg q3-4hr PO</td>
<td>15-20mg q3-4hr PO</td>
<td>0.05-0.1 mg/kg (2.5-5 mg) q2-4hr IV</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>0.04-0.08 mg/kg (1-2 mg) q3-4hr PO</td>
<td>2-4mg q3-4hr PO</td>
<td>0.015 mg/kg (0.2-0.6 mg) q2-4hr IV</td>
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Adjuvants

- Amitriptyline/nortriptyline
- Gabapentin/Pregabalin
- Steroids
- Ketamine
- Topical agents
- CBD
- Bisphosphonates
- Radiation
- Regional nerve blocks
Intractable Pain

- Considered an emergency
- Rapid titration of opioids may be required
- Need to be experienced
- Some published protocols
Delirium

- Disturbance of consciousness, change in cognition, and perceptual disturbance that develops over a short period, usually hours to days and fluctuates over time (DSM definition)
  - Under recognized
  - May miss it if you don’t assess it
• Up to 85% of adult palliative care patients experience delirium (Massie, Holland, 1983)

• Possible causes: often multifactorial

• Are some pediatric tools for delirium screening
  – Pediatric Confusion Assessment Method for the ICU (pCAM-ICU)
  – Preschool Confusion Assessment Method for the ICU (psCAM-ICU)
  – Cornell Assessment of Pediatric Delirium (CAPD)
Treatment of delirium

• Correct the correctable
  – Within treatment goals

• Familiar people or toys present

• Low lighting

• Soothing music

• Orient patient with clock, calendar

• Maintain correct sleep-wake cycle
Pharmacologic treatment of delirium

- **1st generation antipsychotics**
  - Haloperidol 0.01-0.02mg/kg PO tid
  - Methotrimeprazine 0.05-0.1mg/kg/dose PO/SC q4-8h prn

- **Second generation antipsychotics**
  - Eg. Risperidone, olanzepine
  - Lack of IV/SC formulations

- **Benzodiazepines**
  - Lorazepam, Midazolam
  - Some consensus that these should not be first line

- **May combine antipsychotics with benzodiazepines if needed**
Palliative Care Emergencies

• Pain crisis
• Bleeding
• SVC obstruction
• Spinal Cord Compression
• Hypercalcemia
• Intestinal obstruction
Compassionate palliative care involves

- Anticipation
- Preparation
- Communication, communication, communication
What is your key takeaway from today’s session?
References


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• Diagnostic and Statistical manual of Mental Disorders.

• Field MJ, Behrman RE, editors: Patterns of childhood death in America, Institute of Medicine of the National Academy of Sciences, 2003, the National Academy of Press, pp 41-71.


• McMaster Children’s Hospital Pediatric Palliative Care Medication Dosing & Common Phrase Guide. September 2015.


• Serious Illness Conversation Guide – Pediatrics. Canuck Place Children’s Hospice.


Questions?