Management of the Dying Child
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Objectives
- Review pediatric mortality data
  - Which children die
  - Where do children die
- Review the clinical assessment of the dying child
- Understand basic end of life symptom management
- Understand bereavement services and grief support

Pediatric Mortality Data

American Death
2010 census data analyzed by CDC

American Pediatric Death
2010 census data analyzed by CDC

Disclosures
Rachel Vandermeer, MD, has no relationships with commercial companies to disclose and she will not be discussing unapproved uses of FDA-licensed medications.
**Pediatric Death Rate**

Per 100,000 kids
- < 1 year of age: 623.4 (0.62%)
- 1-4 years: 26.5 (0.027%)
- 5-9 years: 11.5 (0.012%)
- 10-14 years: 14.3 (0.014%)
- 15-19 years: 49.4 (0.049%)

**Pediatric Death Rate**

Per 100,000 kids
- < 1 year of age: 623.4
- 1-4 years: 265
- 5-9 years: 11.5
- 10-14 years: 14.3
- 15-19 years: 49.4
- 80-84 years: 6,134.1 → 10x infant death rate!!

**How Children Die**

Centers for Disease Control and Prevention
Injury Prevention and Control: Data and Statistics
WISQARS (Web-based Injury Statistics Query And Reporting System)

**Rank** | Disease
---|---
1 | Congenital anomalies Unintentional injury Unintentional injury Unintentional injury
2 | Short Gestation Congenital anomalies Cancer Cancer Suicide
3 | Maternal complication Homicide Congenital anomalies Suicide Homicide
4 | SIDS Cancer Homicide Congenital anomalies Cancer
5 | Unintentional injury Heart Disease Resp Disease Homicide Heart Disease
6 | Placental cord membranes Influenza/pna Heart Disease Heart Disease Congenital anomalies
7 | Bacterial sepsis Resp Disease Influenza/pna Resp Disease Influenza/pna
8 | Resp disease Sepsis Cerebrovascular Influenza/pna DM
9 | CV disease Benign Sepsis Com complicated

**How Children Die**

<table>
<thead>
<tr>
<th>&lt;1 year</th>
<th>1-9</th>
<th>10-24</th>
<th>0-24 years</th>
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</thead>
<tbody>
<tr>
<td>CV</td>
<td>24%</td>
<td>18%</td>
<td>20%</td>
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<tr>
<td>Cancer</td>
<td>2%</td>
<td>36%</td>
<td>48%</td>
</tr>
<tr>
<td>Neuro</td>
<td>15%</td>
<td>9%</td>
<td>1%</td>
</tr>
<tr>
<td>Genetic</td>
<td>22%</td>
<td>5%</td>
<td>13%</td>
</tr>
<tr>
<td>Resp</td>
<td>15%</td>
<td>4%</td>
<td>10%</td>
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<tr>
<td>Renal</td>
<td>5%</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Heme/imm</td>
<td>1%</td>
<td>5%</td>
<td>3%</td>
</tr>
<tr>
<td>Metabolic</td>
<td>1%</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>GI</td>
<td>1%</td>
<td>2%</td>
<td>1%</td>
</tr>
</tbody>
</table>

**Where Children Die**


Clinical Assessment
- The Conversation
- Medical Management
- The Environment
- Grief support

General:
- Comfortable??
- Grimacing, frowning, tears
- Fever

Neuro:
- Responsiveness
- Agitation
- CV
  - BP-downtrending?
  - Pressor support?
  - Pulse-peripheral compared to central

Resp
- Dyspnea
- Tachypnea
- Work of breathing
- Hypoxemia (FiO2, iNO requirement)
**The Physical Exam**
- GI
  - Distention
  - Emesis
  - Constipation
- Skin
  - Mottling
  - Perfusion
  - Ulcers
  - Edema

**The Conversation**
- Goal: Warning Shot
- Pre-Conversation
  - Ask tell ask
  - I worry

**The Environment**
- Grief support

**Management of the dying child**
- Clinical Assessment
  - The Conversation
  - Medical Management
  - The Environment
  - Grief support

**Blood gas**
- Hypercarbia
- Oxygentation
- Acidosis
  - Lactic acid

**BMP**
- Acidosis
- Creatinine/BUN
- NH3
- Head imaging
  - Brainstem pathology

**Labs**
- Timetable
  - Pre-Conversation
    - Warning shot
  - Breaking Bad News
  - Education about end of life

**The Timetable**
- Blood gas
  - Hypercarbia
  - Oxygentation
  - Acidosis
  - Lactic acid
- BMP
  - Acidosis
  - Creatinine/BUN
  - NH3
  - Head imaging
    - Brainstem pathology

*Goal: Warning Shot*
• Ask-Tell-Ask
  Ask
  • What do you know
  Tell
  • Explain medical situation
  • I worry
  • Set time limited trials
  • Give 3-4 indicators of improvement/deterioration
  Ask
  • Assess understanding
  • Have you thought about what would happen if Johnny does not get better

• Education About End of Life
  • What is the plan?
    • Ventilator
    • Antibiotics
    • Pressors
    • TPN/Feeds
    • IV Fluids
    • Pain

• Education About End of Life
  • What will it look like?
    • Consciousness
    • Breathing
    • Agitation
    • Terminal secretions (death rattle)
    • Autoresuscitation

• Clinical Assessment
  The Conversation
  • Medical Management
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• Symptoms of Death
  Pain- opioid
  Dyspnea- opioid
  Agitation- lorazepam
  Secretions- glycopyrrolate
  • atropine drops
  Fever- rectal tylenol
  Nausea- IV/ODT ondansetron

• Comfort Care
  Morphine Drip
Opioid Rules
- Safe because predictable
- Start low
- Peak effect 10-15 min
- Can dose q15 min
- Increase dose by 1.5-2x if ineffective
- Somnolence precedes resp depression
- No max dose

Pain
- <30 kg
  - Morphine
  - 0.05mg/kg IV
  - Be prepared
    - Have multiple doses in Pyxis
    - Q15min order
    - Be at bedside

>30 kg
- Morphine
  - 1-2mg IV and increase as needed
- Hydromorphone (Dilaudid)
  - IV HM 6X > IV morphine
  - 0.1-0.2mg IV (NOT mg/kg)

Special Circumstances
- ICU
  - Fentanyl
- Kidney Failure
  - Active Morphine metabolites excreted via kidney
  - Use low doses, decrease frequency
- Morphine Allergies
  - Use other opioid medication

Dyspnea
- Subjective
- Responsive to Opioids
  - Need lower doses than used for pain
  - Blowing air (fan)
  - O2 (helps family not patient)
- Tachypnea and increased WOB also tx’d with opioids at end of life

Agitation
- Etiology?
  - Pain
  - Dyspnea
  - Terminal agitation
  - IV lorazepam
**Terminal Secretions**
- Family Education
  - Normal, not harmful or distressing to patient
- IV Glycopyrrolate
- Atropine drops
- Will cross BBB
- Scopolamine patch
- Will cross BBB
- Needs 4 hours to work

**Nausea and Fever**
- Nausea
  - IV ondansetron
  - >40 kg
  - Consider promethazine
    - IV and rectal forms
  - Farrell bag/NG
- Fever
  - Rectal tylenol

**Other Issues**
- Access
  - SQ options
    - morphine
    - hydromorphone
    - lorazepam
  - SL options
    - morphine (Roxanol)
    - atropine drops
    - GT/NG

**Clinical Assessment**
- The Conversation
- The Environment
- Grief support

**Environment**
- Location of death
  - Hospital versus home
  - What is needed to make child and FAMILY comfortable?
  - Can child survive trip home?
  - If home, OOH DNR

**Hospital Death**
- Avoid team transfers if possible
- Limit room activity
  - Turn off alarms/monitors
  - Private room if possible
  - Limit unnecessary staff entry
- Allow ALL family at bedside
Pediatric Death Timeline

- Pre-conversation
- Suspension of terminal diagnosis
- Palliative consult
- Family Meeting 1
- Hand molds
- Photos
- Funeral arrangements
- Silence alarms
- Minimize lines
- Family at bedside
- Photos
- Bathing and clothing of child
- Family Meeting 2
- Prepare siblings
- Obtain medications
- Hold child
- Bathing and clothing of child
- Family at bedside
- Photos
- Helpful Consults
- Palliative Care
- Chaplaincy
- Baptism
- Family support
- Child Life
- Memory making projects
- Social work
- Gather family
- Funeral arrangements
- Financial resources

Clinical Assessment
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Management of the dying child

Grief Support
- Staff Grief Support
- Debriefing
- Go say goodbye
- Attend funeral
- Speak to peers/mentors

Grief Support
- Family Grief Support
- NICU-Sarah’s Heart Bereavement box
- Perinatal loss
- Palliative service
- Chaplain follow up
- Attend funeral
- Child Bereavement Center
- Call from physician at 2 weeks
- Send Cards

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Thank You
Questions??

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