Pediatric Palliative Care
Where Passion and Compassion Merge

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Advocate Health Care

Session Objectives

• Expand participants knowledge of similarities and differences in palliative care versus hospice in pediatric patients
• Improve participants knowledge of how to identify pediatric patients who would benefit from Palliative medicine
• Enhance participants appreciation for a team approach to patient care
• Improve participants knowledge of pain and symptom management in pediatric palliative care

Pediatric Palliative Care 101

• Similarities and differences in palliative care versus hospice in pediatric patients
• Identifying pediatric patients who would benefit from Palliative medicine
• Appreciation for a team approach to the care of the pediatric patient
Statistics

- 81 million children in the United States
- Children represent 25% US population
- United States 2.5 million deaths annually
- About 50,000 deaths are pediatric 0-19 (2.2%)
- Half of childhood deaths are in first year of life
- Half of infant deaths are in the first month of life

Symptoms in Dying Children

- 89% suffered from at least one symptom in their last month of life, most with 4-5 symptoms
- Most common reported symptoms:
  - Pain
  - Fatigue
  - Dyspnea
  - Constipation
  - Nausea/Vomiting
  - Poor appetite

  Wolfe, NEJM, 342:5; 2010

Causes of Deaths
Infants with Complex Chronic Conditions

1. Cardiovascular (32%)
2. Congenital / genetic (26%)
3. Respiratory (17%)
4. Neuromuscular (14%)

www.nhpco.org, Facts & Figures on Pediatric Palliative Care and Hospice
Causes of Death
Children 1-19 with Complex Chronic Condition

1. Malignancy (43%)
2. Neuromuscular (23%)
3. Cardiovascular (22%)

Kinds of Care Available to Infants and Children with Complex Chronic Conditions

- Curative Care:
  - Focused on a cure to an illness and the prolongation of life
- Palliative Care:
  - Focused on comfort and quality of life that may be provided with other curative or life prolonging treatment
- Hospice Care:
  - Focused on comfort and quality of life when a cure is not possible

Models of care

- Curative Care
  - Inpatient acute care by Primary Care Physician or Hospitalist +/- Subspecialist(s)
  - Outpatient Primary Care Clinic/Subspecialty Clinic
  - Home Care Physicians
- Palliative Care
  - Inpatient consultation palliative care teams
  - Pediatric, neonatal and perinatal
  - Inpatient palliative care unit
  - Outpatient Palliative Clinic
  - Home Palliative (Home, Rehab, Nursing home)
- Hospice Care
  - Home hospice (Home, Nursing home) routine care or crisis management
  - Inpatient Crisis Management- in hospital or hospice facility
  - Respite – in Nursing Home or Hospice Facility
Palliative Care

- Interdisciplinary care that aims to enhance comfort, relieve suffering and improve the quality of life for patients with advanced illness or with a terminal illness but may not want or qualify for hospice
- Provides expert control of pain and symptoms in addition to offering practical support for patient and family
- Can be integrated into every stage of illness along with all other appropriate medical treatments (coexists with curative measures)
- Neither hasten or postpone death

Palliative Care

- Patient and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering.
- Provided through the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.
- Honor families goals, hopes and priorities respecting the parents through shared decision making
- Encourage advance care planning through on-going dialogue with health care team and family

Goals of Palliative Medicine Team

- Optimize symptom control
- Optimize functional status when appropriate
- Promote highest quality of life for patient & family
- Educate patient and family to promote understanding of the underlying disease process and expected future course of illness
- Establish an environment that is comforting & healing
- Alleviate isolation through commitment to non-abandonment, communication and sustain relationship
Goals of Palliative Medicine Team

• Plan for discharge to appropriate level of care in a timely manner (facilitate transition to hospice when appropriate).
• Assist actively dying patients & their families in preparing for and managing life closure.
• Extend support beyond the lifespan of the child to assist families in their bereavement.
• Serve as educators and mentors to staff
• Promote a system of care that fosters early identification of palliative appropriateness, timely access to palliative care services, and complex case management with coordination of available services.

Palliative Care - vs - Hospice

• Focus: Comfort and quality of life
• Team: APN/MD, +/- CNA, SW, Chap
• Visit Frequency: 3-5 per week
• Expected Outcome: relief from distressing symptoms, ease pain and enhance quality of life
• Timing: no time restrictions, at any time and any stage of illness whether terminal or not
• Treatment: comfort at any stage, no expectation that life-prolonging or aggressive therapies will be avoided
• Location: Hospital, outpatient, home, rehab/SNF, ECF/NH
• Payment: Medicaid/Medicare/PI

• Focus: Comfort and quality of life
• Team: MD/APN, RN, CAN, SW, Chap, Vol
• Visit Frequency: 2-5 per week
• Expected Outcome: relief from distressing symptoms, ease pain and enhance quality of life at end-of-life
• Timing: end-of-life, considered terminal, with prognosis of 6 months or less
• Treatment: typically elect to forego extensive life-prolonging treatment for terminal diagnosis, may receive curative treatment for acute illnesses
• Location: Hospital, outpatient, home, ECF/NH, Hospice Facility
• Payment: Medicaid/Medicare/PI

The Intradisciplinary Teams

Inpatient Palliative Care - vs - Hospice

• Inpatient Palliative
  • MD/APN Case Manager
  • LCSW
  • Chaplain
  • Child Life, Music Therapy
  • PharmD, OT/PT/OTR Nutrition

• Inpatient Hospice
  • Hospice RN Case Manager
  • Hospital primary RN
  • Hospitalist
  • Hospice MD - indirectly
  • Hospice LCSW/Chaplain

Outpatient Palliative Care

• MD/APN/CSW

• Hospice Facility and Respite
  • Hospice RN, MD, LCSW and Chap

Home Palliative Care

• MD/APN Case Manager
  • +/- LCSW/Chaplain/OT/PT/Speech

• Hospice MD
  • +/- Primary Care Physician
  • Hospice CSW/Chaplain/Volunteer
Concurrent Care for Children Requirement (CCCR)

- March 23, 2010, President Obama signed The Patient Protection and Affordable Care Act (PPACA) into law enacting a new provision, Section 2302, requiring the state Medicaid program to pay for both curative/life prolonging treatment and hospice services for children who qualify.
- children under the age of 21
- diagnosed with a life-limiting illness
- eligible for Medicaid or the Children's Health Insurance Program (CHIP)
- The CCCR provision (Section 2302 of the ACA) states that a voluntary election of hospice care for a child cannot constitute a waiver of the child's right to be provided with, or to have payment made for, services that are related to the treatment of the child's condition, for which a diagnosis of terminal illness has been made.
- May receive all services that are related to the treatment of a child's life-limiting illness.
- This allows these young people to have palliative and hospice care services while they are receiving other disease-modifying treatments.

Concurrent Care for Children Implementation Toolkit

Section 2302 of the Patient Protection and Affordable Care Act

- District of Columbia Pediatric Palliative Care Collaboration with National Hospice and Palliative Care Organization (NHPCO)

PALLIATIVE CARE TEAM FOR CHILDREN AND FAMILIES

- Inpatient Services
- Inpatient Palliation Care Unit
- ICU
- Child Care
- Primary Care Physician
- Therapy programs
- Specialty clinics
- Consultation Services
- School
- Community
- Home Care
- Child and Family
Advanced Care Planning

• The child should participate to the fullest extent possible, given his or her illness experience, developmental capacities, and level of consciousness.
• Regardless of the prognosis, respect for the child requires that he or she be given a developmentally appropriate description of the condition along with the expected burdens and benefits of available management options, while soliciting and listening to the child’s preferences.

Consider Palliative Care In Patients With:

• Conditions for which curative treatment is possible but may fail
  • Cancer diagnosis requiring treatment with high symptom burden
  • Advanced or progressive cancer or cancer with a poor prognosis
  • Complex and severe congenital or acquired heart disease

Consider Palliative Care In Patients With

• Conditions requiring intensive long-term treatment aimed at maintaining the quality of life
  • Human immunodeficiency virus infection
  • Cystic fibrosis
  • Severe gastrointestinal disorders or malformations such as gastroschisis
  • Severe epidermolysis bullosa
  • Severe immunodeficiencies
  • Renal failure in cases in which dialysis, transplantation, or both are not available or indicated
  • Chronic or severe respiratory failure
Consider Palliative Care In Patients With:

- Progressive conditions in which treatment is exclusively palliative after diagnosis
  - Progressive metabolic disorders
  - Certain chromosomal abnormalities such as trisomy 23 or trisomy 18
  - Severe forms of osteogenesis imperfecta
  - Muscular dystrophy
  - Leukodystrophies

Consider Palliative Care In Patients With:

- Conditions involving severe, nonprogressive disability, causing extreme vulnerability to health complications
  - Severe cerebral palsy with recurrent infection or difficult-to-control symptoms
  - Extreme prematurity
  - Severe neurologic sequelae of infectious disease
  - Hypoxic or anoxic brain injury
  - Holoprosencephaly or other severe brain malformations
  - Severe traumatic brain injuries

Diagnoses in Pediatric Palliative Care

- Genetic/Congenital (40%)
- Neuromuscular (40%)
- Oncologic (20%)
- Respiratory (12%)
- Gastrointestinal (10%)
- Cardiovascular (8%)

Some children with multiple diagnoses
Illness Trajectories

Varying Role of Palliative Care

Pediatric Palliative Care 102

• Pain and symptom management in pediatric palliative care
  • Assessment
  • Management
Ability to Report Pain May Be Limited or Impairment

- Developmental
  - Young age (neonates, infants, young children, stressed child)
  - Cerebral palsy/Cognitive delay
- CNS insult
  - hypoxic ischemic encephalopathy (HIE)
  - anoxic encephalopathy
  - traumatic brain injury
- Specific diagnosis
  - genetic disorder (muscular dystrophy, spinal muscular atrophy)
  - congenital anomaly (holoprosencephaly)
  - structural brain malformation (lissencephaly)
  - metabolic disorder (mitochondrial disease, Tay-Sachs)
- Iatrogenic (intentional) Sedation/Unconsciousness

Identifying presence of pain

- Behaviors seen in validated pain assessment tools for nonverbal children with neurologic impairment
  - Vocalizations (crying, moaning)
  - Facial expression (grimacing, fussy)
  - Consolability
  - Interactivity (withdrawn, less active)
  - Movement (pulled legs up)
  - Tone and posture (arching, stiffening)
  - Physiological responses (sweating)

Assessment Tools

Assessment Tools

Pediatric pain assessment scale for children who have difficulty verbalizing pain

<table>
<thead>
<tr>
<th>Category</th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face</td>
<td>No particular expression</td>
<td>Occasional grimace or frown, withdrawn, disinterested</td>
<td>Frequent to constant quivering chin, clenched jaw</td>
</tr>
<tr>
<td>Legs</td>
<td>Normal position or relaxed</td>
<td>Unsteady, restless, tense</td>
<td>Kicking, or legs drawn up</td>
</tr>
<tr>
<td>Activity</td>
<td>Lying quietly, normal position or relaxed</td>
<td>Squirming, shifting back and forth, nurse leans or shifts</td>
<td>Crying steadily, seems or acts frightened or overstimulated</td>
</tr>
<tr>
<td>Cry</td>
<td>No cry (waning or adapts)</td>
<td>Mouths or whimpers, occasional complaint</td>
<td>Difficulty to console or comfort</td>
</tr>
<tr>
<td>Consolability</td>
<td>Contact, school</td>
<td>Resistant to occasional touching, hugging, or being talked to, distractible</td>
<td></td>
</tr>
</tbody>
</table>

Pediatr Nurse 1997;23(3):293-7

Assessment Tools

Nominal pain assessment scale

<table>
<thead>
<tr>
<th>CRIES</th>
<th>Indicators</th>
<th>Scoring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nominal postoperative pain</td>
<td>Crying</td>
<td>No</td>
</tr>
<tr>
<td>Score: 4 initiate nonpharmacologic measures</td>
<td>Requires oxygen for Sat &gt;95%</td>
<td>No</td>
</tr>
<tr>
<td>Score: &gt;4 initiate pharmacologic and nonpharmacologic measures</td>
<td>Increased vital signs</td>
<td>No</td>
</tr>
<tr>
<td>Expression</td>
<td>Sleeplessness</td>
<td>None</td>
</tr>
<tr>
<td>Nausea</td>
<td>Wakes frequently</td>
<td></td>
</tr>
<tr>
<td>Abdominal pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurologic pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vasovagal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autonomic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appetite</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body position</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Temperature</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


Identifying the Source of Pain

Suffering

- Hyperalgesia
- Spasticity
- Autonomic pain
- Dysphoria
- Neurogenic Pain: Somatic or Visceral
- DogEats
- Neuroinflammatory Pain: Somatic or Visceral
- Neurocognitive Pain
- Neuroemotional Pain
- Neurobehavioral Pain
Classification of Pain

• **Nociceptive**: represents the normal response to noxious insult or injury of tissues such as skin, muscles, visceral organs, joints, tendons, or bones.
  - Examples include:
    - Somatic: musculoskeletal (joint pain, myofascial pain), cutaneous; often well-localized
    - Visceral: hollow organs and smooth muscle; usually referred

• **Neuropathic**: pain initiated or caused by a primary lesion or disease in the somatosensory nervous system.
  - Sensory abnormalities range from deficits perceived as numbness to hyperesthesia (hyperalgesia or allodynia), and to paresthesia such as tingling.
  - Examples include:
    - diabetic neuropathy, postherpetic neuralgia, spinal cord injury pain, phantom limb (post-amputation) pain, and post-stroke central pain.

http://projects.hsl.wisc.edu/GME/PainManagement/sessions.4.html

Classification of Pain

• **Inflammatory**: a result of activation and sensitization of the nociceptive pain pathway by a variety of mediators released at a site of tissue inflammation.
  - The mediators that have been implicated as key players are proinflammatory cytokines such as IL-1-alpha, IL-1-beta, IL-6 and TNF-alpha, chemokines, reactive oxygen species, vasoactive amines, lipids, ATP, acid, and other factors released by infiltrating leukocytes, vascular endothelial cells, or tissue resident mast cells.
  - Examples include:
    - appendicitis, rheumatoid arthritis, inflammatory bowel disease, and herpes zoster.

http://projects.hsl.wisc.edu/GME/PainManagement/sessions.4.html

Classification of Pain

• **Pain Intensity**: Can be broadly categorized as: mild, moderate and severe. It is common to use a numeric scale to rate pain intensity where 0 = no pain and 10 is the worst pain imaginable:
  - Mild: ≤ 3/10
  - Moderate: 4/10 to 6/10
  - Severe: > 7/10

• **Time course**: Pain duration
  - Acute pain: pain of less than 3 to 6 months duration
  - Chronic pain: pain lasting for more than 3-6 months, or persisting beyond the course of an acute disease, or after tissue healing is complete.
  - Acute-on-chronic pain: acute pain flare superimposed on underlying chronic pain.

http://projects.hsl.wisc.edu/GME/PainManagement/sessions.4.html
Management

- Don’t delay for investigations or disease treatment
- Unmanaged pain ⇒ nervous system changes
  - amplify pain
- Treat underlying cause (e.g., radiation for a neoplasm, stabilization for fracture)

WHO 3-step Ladder

1 mild
- ASA
- Acetaminophen
- NSAID’s
- ± Adjuvants

2 moderate
- A/Codeine
- A/Hydrocodone
- Tramadol
- ± Adjuvants

3 severe
- Morphine
- Hydromorphone
- Methadone
- Fentanyl
- Oxycodone
- ± Adjuvants

Medication Alternative Routes of Administration

- Oral
- Enteral feeding tubes
- Transmucosal
- Rectal
- Transdermal
- Parenteral (SC, IV, IM)
- Intraspinal (Epidural & Intrathecal)
Macy Catheter
The catheter was developed to make rectal access more practical and provide a way to deliver and retain liquid formulations in the distal rectum.

Opioid Dosing Basics
- Dosage initially based on weight
- Same escalation principles as in adults (start low, increase in increments)
- Tolerance may develop over time with chronic use
- Uncontrolled pain can manifest as drug seeking behavior
- No upper dose limits except due to side effects
- Taste can be a limiting factor
- ALL patient on opioids should have a bowel regimen prescribed (instruct parents to hold if loose stools and resume if not stool in 24 hours)

Opioid Dosing Basics
- Begin opioid naive patient on short-acting
- If requires 4 or greater doses per day consistently, add long-acting opioid (extended release) for chronic pain in combination with short-acting opioid for breakthrough pain
- Do not use long-acting opioid for breakthrough dosing
Opioid Dosing Basics

- Dehydration, renal failure, severe hepatic failure
  - ↑ dosing interval, ↓ total dosage
- If dose escalation → adverse effects or no improvement in pain, then consider
  - alternative
    - route of administration
    - opioid (‘opioid rotation’)
  - adjuvants
  - use a non-pharmacological approach

Morphine

- Gold standard for moderate or severe pain
- Increased half-life and diminished clearance in neonates.
- Starting doses for infants about ½ of older children.
- Infants more sensitive to respiratory depression.
- If intravenous, give slow IVP
- In renal impairment has risk of active metabolite accumulation; lower dose, increase frequency or change to Hydromorphone or Fentanyl

Codeine

- Use in mild pain only, limited use in severe pain
- Maximum recommended dose (60mg) produces analgesia equal to 600mg aspirin
- Combination product with acetaminophen
- Highly variable metabolism makes it unreliable
- Not a preferred agent
Hydrocodone

• Mostly available in combination with acetaminophen, aspirin or ibuprophen
• DEA changed from Schedule III to Schedule II controlled substance on 8/22/2014 made it less convenient prescribe
• Preferred over codeine
• Vicodin, Norco, Lortab combination products
• Hydrocodone alone, liquid preparation

Fentanyl

• Used in anesthesia, procedural sedation
• Acute moderate to severe pain
• Patch has found use in some cancer and chronic non-malignant pain
• Patches are high enough dose that can't be used in opioid naive children based on weight
• Lowest dose 12 mcg/hr patch

Methadone

• Used in chronic pain
• Long half-life therefore longer time to steady state
• Should not be used for breakthrough pain
• Effective for neuropathic and nociceptive pain
• Only liquid long-acting formulation
• Monitor EKG, can cause or worsen prolong QTc
• Caution: death with misuse or improper use
Sustained-release Opioids

- Children often cannot swallow pills
- Even lowest dosages of sustained release products may be too high for children
- High rates of gastrostomy tubes in pediatric palliative care population necessitate liquid formulations
- Kadian, sustained released morphine capsule, when opened pellets can be given via gastrostomy tube
- Morphine extended release capsule can be given rectally

Co-Analgesics

- Antidepressants - amitriptyline, nortriptyline
- Anticonvulsants - valproic acid, phenytoin
- Anxiolytics - lorazepam, diazepam, midazolam
- Corticosteroids – dexamethasone
- Anesthetics - lidocaine, ketamine, propofol
- Barbiturates - phenobarbital, pentobarbital

Sample Dosing for Nonopioid Pain Medications

<table>
<thead>
<tr>
<th>Drug</th>
<th>Age</th>
<th>Route and Dose</th>
<th>Pregnancy</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminophen</td>
<td>Pediatric</td>
<td>po: 10-15 mg/kg</td>
<td>4-6 h</td>
<td>Max 50 mg/kg/day</td>
</tr>
<tr>
<td>codeine</td>
<td>2-17 y</td>
<td>po: 5-10 mg/kg</td>
<td>4-6 h</td>
<td>Max 60 mg/kg/day</td>
</tr>
<tr>
<td>ibuprofen</td>
<td>12 m-2 y</td>
<td>po: 1-2 mg/kg</td>
<td>4-6 h</td>
<td>Max 40 mg/kg/day</td>
</tr>
<tr>
<td>ketorolac</td>
<td>2-17 y</td>
<td>IV: 0.5 mg/kg</td>
<td>6-8 h</td>
<td>10 mg q6h or max 100 mg/day</td>
</tr>
<tr>
<td>ketorolac</td>
<td>&gt; 17 y, &gt; 50 kg</td>
<td>po: 10 mg/kg</td>
<td>6-8 h</td>
<td>Max 100 mg/day</td>
</tr>
</tbody>
</table>

Sample Initial Opioid Dosing in Pediatrics

Table 3. Initial Opioid Doses in Children

<table>
<thead>
<tr>
<th>Drug</th>
<th>Age (yr)</th>
<th>Route</th>
<th>Dose (mg/kg)</th>
<th>Total Dose (mg)</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>10mg</td>
<td>3-4</td>
<td>by mg/kg</td>
<td>0.5</td>
<td>15</td>
<td>q 4-6 h</td>
</tr>
<tr>
<td>5mg</td>
<td>5-8</td>
<td>by mg/kg</td>
<td>0.5</td>
<td>10</td>
<td>q 4-6 h</td>
</tr>
<tr>
<td>10mg</td>
<td>9-12</td>
<td>by mg/kg</td>
<td>0.5</td>
<td>15</td>
<td>q 4-6 h</td>
</tr>
<tr>
<td>15mg</td>
<td>1-2</td>
<td>by mg/kg</td>
<td>0.5</td>
<td>15</td>
<td>q 4-6 h</td>
</tr>
<tr>
<td>20mg</td>
<td>1-2</td>
<td>by mg/kg</td>
<td>0.5</td>
<td>15</td>
<td>q 4-6 h</td>
</tr>
<tr>
<td>30mg</td>
<td>1-2</td>
<td>by mg/kg</td>
<td>0.5</td>
<td>15</td>
<td>q 4-6 h</td>
</tr>
</tbody>
</table>

Note: Doses are based on the recommended starting dose for each opioid. Dosing may need to be adjusted based on the patient’s response and tolerance.

Sample Equianalgesic Dose Chart

<table>
<thead>
<tr>
<th>Drug</th>
<th>Parenteral Dose</th>
<th>PO Dose</th>
<th>Parenteral PO Dose</th>
<th>Oral Dose</th>
<th>Parenteral PO Dose</th>
<th>Oral Dose</th>
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</thead>
<tbody>
<tr>
<td>10mg</td>
<td>3-4</td>
<td>3.5</td>
<td>1.5</td>
<td>1.5</td>
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<td>5mg</td>
<td>5-8</td>
<td>3.5</td>
<td>1.5</td>
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<td>1.5</td>
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<tr>
<td>15mg</td>
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<td>3.5</td>
<td>1.5</td>
<td>1.5</td>
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<td>1.5</td>
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<td>30mg</td>
<td>1-2</td>
<td>3.5</td>
<td>1.5</td>
<td>1.5</td>
<td>1.5</td>
<td>1.5</td>
</tr>
</tbody>
</table>

Note: Doses are based on the recommended starting dose for each opioid. Dosing may need to be adjusted based on the patient’s response and tolerance.

Pediatric Palliative Care Summary

- Pediatric Patients are not small adults
- We care for the family unit
- ALL patients on opioids should have a bowel regimen prescribed
Pediatric Palliative Care Summary

- The heterogeneity of illnesses, many rare, requires the involvement of many disciplines and specialists.
- Many children have genetic diseases so that there may be more than one affected child in a family.
- Heterogeneity of illnesses results in varying life expectancy
- Medical care at home has lengthened historic prognosis

Pediatric Palliative Care Summary

- The time course of some illnesses is extremely variable; pediatric palliative care may extend over years, even decades. Prognosis is very difficult.
- A broad developmental spectrum is represented, including changes in the individual child through time.
- Pediatric hospice care tends to be more expensive, and palliative and/or curative oriented therapies may happen in concert with active end of life care.

Pediatric Palliative Care Summary

- Kids have specific developmental needs which are dependent upon age, but also impact of disease, developmental capacity, etc.
- Family centered care: family as the unit of care
- Emotional intensity: tends to be a concern for adult specific providers, and is realistic.
Not talked about, always a consideration:

- Artificial nutrition and hydration
- Other common symptoms:
  - Constipation: all patient on opioids should have a bowel regimen
  - Nausea, vomiting, bowel obstruction
  - Anxiety
  - Depression
  - Insomnia
- Legal and ethical issues of non-autonomous individuals
- Informed consent vs. assent

Thank You!

Questions ???

CASES (if time allows)

Additional References

AAP Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations
Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatrics 2013;132;966

Understanding Hospice and Palliative Care
National Hospice and Palliative Care Organization
www.nhpco.org

Pediatric Palliative Care
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Case Presentation Day 1

- 3 year old pontine glioma diagnosed 07/07
- Chemotherapy x3 and radiation therapy
- Worsening over 1 week
  - Unable to walk
  - Weaker on left
  - Slurred speech
- Enrolled with home palliative/hospice program
- 1 Day cough, fever sore throat
- Hours PTA progressively less responsive

Case Presentation Day 1

- ED
  - Respiratory failure → intubated
  - Discussion with Primary Oncologist (Children's)
    - Tumor progression in spite of chemotherapy
    - Terminal stage
    - No further treatment
  - Oncology consult/PICU consult
    - Discussed terminal cancer status
    - Parents agreed to discontinuue life support measure later today
  - Transferred to PICU

Case Presentation Day 1

- PICU
  - CT head
    - Large infiltrating mass centered in the pons, extending into the midbrain superiorly and inferiorly into medulla and upper spinal cord
  - Supportive care on mechanical ventilator
    - Dopamine, high dose decadron, epinephrine x1
  - Palliative, Social service and spiritual consults
Case Presentation

Day 2

11:00pm: Failed weaning of ventilator to CPAP

12:00pm: Palliative/PICU/Parent conference
- Reviewed terminal cancer diagnosis
- Goals of care outlined
- Code status changed to No Cardiac Resuscitation

3:00pm Parents request to withdraw life support at 1:00am (time child was born)
- Palliative/comfort orders written

7:00pm Patient more awake
- Parents request NO withdrawal, but maintain No CPR

Case Presentation

Day 3-6

- Parent request delay extubation until...
  - Celebrate child’s birthday (Make-A-Wish)
  - Obtain second opinions (Texas, Alabama)

- Support care continued on ventilator

- TPN converted to enteral nutrition

Birthday party Day#6- off unit, on ventilator

Case Presentation

Day 6

PICU/Parent Conference to clarify treatment option

1. Daily trial of weaning to CPAP/extubation
   - once extubated, discharge home with hospice

2. If fails CPAP trial
   - Extubate to oxygen mask
   - Extubate to T-piece/O2 (avoid upper airway obstruction)
   - Allow natural death, providing end of life/comfort care in hospital

- Discussed progression of terminal brain stem tumor
- Seizures
- Coma
- Death in spite of ventilator
Case Presentation
Day 7-9

* Parents request wean to extubate,
  * with plan to reintubate if necessary
* Day #7: Extubated successfully
* Day #9: Discharged home with hospice

Case Presentation
Readmitted 6 Days Later

* Seizure at home
* Day #1
  * Choked on banana, apneic at home, banana removed, labored breathing
  * Brought to ED, goal of care revisited with parents
  * DNR revoked to allow intubation
  * Do not perform chest compression
  * Provide cardiac stimulating medication
  * Provide NG nutrition, antibiotics, comfort care
  * Continue to see alternative medical provider (2nd opinions outstanding)

Case Presentation
Day 2-7

* Supportive care on mechanical ventilator
* Day #7
  * 11:00am Ventilator support withdrawn
  * 9:45pm Child expired in parents arm