Palliative Care for the Pediatric Hospitalist: Caring for Children Hospitalized at the End of Life

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Disclosures

We have no financial relationships to disclose.
Outline

2:45-2:50  Introductions
2:50-3:05  Pediatric Palliative Care Overview
3:05-3:45  Case #1 and Discussion
3:45-3:55  Stretch !!
3:55-4:30  Case #2 and Discussion
4:30-5:10  Case #3 and Discussion
5:10-5:30  Wrap Up and Q&A Panel  Discussion

What is Palliative Care

- Comfort
- Quality of Life
- “Anti-Suffering”
- Relationships
- Emotional support
- Social support
- Spiritual support
- Bereavement care
The Role of the Palliative Care Team

- Physical, emotional, spiritual and social support
- Symptom Management
- Communication with the child and family
- Guidance in decisions
- Bereavement Support

Multi-Disciplinary Care Coordination
WHO Pediatric Palliative Care

An approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- The active total care of the child's body, mind and spirit
- Involves giving support to the family
- Begins when illness is diagnosed, and continues regardless of whether or not a child receives disease-directed treatment
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress
- Requires a broad interdisciplinary approach that includes the family and makes use of available community resources
- Can be successfully implemented even if resources are limited
- May be provided in tertiary care facilities, community health centers and in the home
Symptom Burden and Disease Progression

Complex Chronic Illness

Health Status

Time

Death

Decline

Crisis

Increasing Symptom Burden

Symptom Control at the End of Life

Prevalence

Suffering

Percent of Children

Fatigue, Pain, Dyspnea, Poor Appetite, Nausea/vomiting, Constipation, Diarrhea
### Points of Integration of Palliative Care Throughout the Illness Trajectory

**Roller Coaster**
- Symptom Management
- Adjusting to new baseline
- Advanced care planning
- Child understanding
- Support in decision making
- Sibling support

**Slow Decline**
- Symptom Management
- Advanced care planning
- Child understanding
- Support in decision making
- Sibling support

**End of Life**
- Maximizing symptom management
- Supporting decision making
- Navigating ethical situations
- Ensuring end of life plans are carried out
- Emphasize hopes, goals, and consistent plans

**Recovery and Adjustment**
- Symptom management
- Complex care coordination
- Bereavement loss of "well" child
- Siblings

**Klick and Hauer 2010**

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### Clinical Case #1

Sarah is an 11 year-old female with advanced stage cystic fibrosis requiring home BiPap admitted with dyspnea and increased work of breathing found to have a right lower lobe pneumonia. Despite broad spectrum antibiotic therapy and maximal supportive care her clinical condition has continued to deteriorate over the past 48 hours. She is rapidly approaching the maximum support available on the floor and there are discussions about ICU transfer.
Clinical Case #1

You are paged to her bedside because she is dyspneic and appears quite anxious. She is crying and refuses to go to the ICU. Parents are split around escalation of care to the ICU.

• What is your next step in medical management?
• How do you assess this family from a psychosocial standpoint?
• How do you communicate with Sarah and her parents around the escalation of care?

Breakout – Case 1

Medical Management
• Pharmacological, Non-Pharmacological/Integrative

Psychosocial Considerations
• Stakeholders?
• Consults or Supportive Care Involvement?

Next Steps? Anticipatory Planning
Dyspnea: Non-pharmacologic interventions

- Reassure
- Manage anxiety
  - Minimize loneliness
- Behavioral approaches
  - Relaxation
  - Distraction
  - Hypnosis
- Limit the number of people in the room
- Open window
- Educate

Dyspnea: Pharmacologic Interventions

Pharmacologic interventions

- Increase morphine
- Consider continuous infusion
- Consider anxiety component
  - If present add benzodiazepine
- Provide oxygen (if hypoxic)
In assessing for anxiety components, Sarah states she is hopeless, helpless and cannot sleep.

- What are you concerned about?
- How do you assess these symptoms?
- What can you do to help?

Hopeless, helpless and can’t sleep...

Depression, anxiety, insomnia

- Highly prevalent, under-diagnosed
- May prevent quality dying
- Effective management is possible

Risk Factors:
- Pain, other symptoms
- Progressive physical impairment
- Advanced disease
- Medications
  - Steroids
  - Benzodiazepines
- Spiritual pain
- Preexisting risk factors
  - Prior history, history of suicide attempt(s), family history
  - Social stress
  - Substance use
Components of Anxiety:

- Fear
- Uncertainty about future
- Physical issues
- Psychological issues
- Social issues
- Spiritual issues
- Practical issues

Presentation:

- Agitation
- Insomnia
- Restlessness,
- Sweating
- Tachycardia
- Hyperventilation
- Panic disorder
- Worry
- Tension

Non-Pharmacologic

- Compassionate exploration of issues
- Alternative medical approaches

Pharmacologic

- Benzodiazepines - Choose by half-life
- Diazepam (Valium): 0.1 mg/kg IV or PO;
  rectal gel - 0.2-0.5 mg/kg
- Lorazepam (Ativan): 0.05 mg/kg, PO, IV, or SL
- Midazolam (Versed): 0.05 mg/kg IV; 0.5 mg/kg PO
Depression - Assessment

• Somatic symptoms not always present

• Look for psychological, cognitive symptoms
  • Pain not responding as expected
  • Sad mood/flat affect, anxious, irritable
  • Worthlessness, hopelessness, helplessness, guilt, despair
  • Anhedonia, lost self-esteem

Depression – Clinical Management

Assessment is CRITICAL

Psychotherapeutic interventions
  - Cognitive approaches
  - Behavioral interventions

Medications

Combination of therapy
  - Psychotherapy
  - Medication

Referral
  - Psychology
  - Psychiatry
Depression - Pharmacologic Management

- Psychostimulants, SSRIs, Tricyclic and atypical antidepressants
- Choose by time to effect
  - Days – psychostimulants
  - Weeks / months – SSRIs, tricyclic antidepressants
- Start dosing low, titrate slowly
- Cross reactivity with other meds
- Consider consultation

Insomnia - Management

**Non-Pharmacologic**
- Regular sleep schedule, avoid staying in bed
- Avoid caffeine
- Cognitive stimulation
- Physical stimulation
- Avoid overstimulation
- Control pain during the night
- Relaxation, imagery

**Pharmacologic Management**
- Melatonin
- Antihistamines
- Benzodiazepines
- Neuroleptics
- Sedating antidepressant
- Careful titration
- Attention to adverse effects
Planning & Anticipatory Guidance

Helping Sarah & her parents make a decision around escalation in treatment in the ICU

Goals of care

<table>
<thead>
<tr>
<th>Cure</th>
<th>Prolong life</th>
<th>Comfort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hope</td>
<td>Hope</td>
<td>Hope</td>
</tr>
</tbody>
</table>

- **Morbidity**: High, Moderate, Mild, Minimal
- **Psychological attitude**: Win, Fight, Live with it, Embrace
- **Tumor effect**: Eradicate, Response, Arrest growth, None

Hope Hope Hope Hope Hope
Advance care planning

• Address concerns, honor personal values, support hope

• Care planning topics
  - Discuss disease-directed therapy – risk/benefit
  - Use of artificial life sustaining therapies
  - Communication with children about death
  - Preferences for the location of death
  - Opportunities for expression of love, gratitude, forgiveness and farewell

• Integrating PPC Principles, the little things...
  - Facilitating Family Visits
  - Bringing on the Sunshine
  - Comforting
  - Listening
  - Advocating
  - Communicating

Understand Hope

Hope
  - Quality that sustains the person in the presence of uncertainty
  - A response to severe distress that facilitates adaptation to a situation that can not be controlled
  - A desire of some good, accompanied with an expectation of obtaining it, or a belief that it is obtainable
  - Presupposes an accurate assessment and acknowledgment of the reality of the situation
  - May dictate care preferences

Prompt
  - “What are your hopes for your child and family?”
  - “What else are you hoping for?”
“She stood in the storm and when the wind did not blow her way, she adjusted her sails. HOPE anchors the soul.”

Role of MD - titrating guidance

[Diagram showing the relationship between outcome, probability of outcome, quality of life, and the chance of returning to an acceptable quality of life.]
Your Words Can Be Powerful

So you’re saying there’s a chance...

Goal-Directed Care

- Offering a Choice vs. Making a Recommendation

- Clinician’s thinking should be “transparent” to the decision maker(s)

- Prognosis
- Uncertainty
- Goals
- Decisions
- Hope
ACP Checklist

• Advanced Care Planning
• Symptom Control
• Emotional, Social, and Spiritual Care
• Care Continuity
• Bereavement Care

Checklist of Individualized Care Planning and Coordination processes

<table>
<thead>
<tr>
<th>Individualized Care Planning and Coordination</th>
<th>Comprehensive encounter completed and placed in medical record</th>
</tr>
</thead>
</table>

Advanced Care Planning

- Participation of child and family in decision making
- Negotiation with family regarding plan of care
  - Prognosis and goal-directed treatment options
  - Use of artificial hydration and nutrition
  - Use of artificial life-prolonging measures
  - Use of transfusion therapies (platelets, RBCs, etc.)
  - Use of antibiotics
  - Use of cancer-directed therapies (chemotherapy, radiation, surgery)
- Admission to the critical care unit or transfer to the floor
- POST/POLST/DNR signed and available in the medical record
- Advanced Care Plan/5 wishes/My wishes in chart, if applicable
- Unique patient/family requests identified and distributed to staff
- Appointment of health care agent in chart, if applicable
- Family conference offered to share the gravity of the patient's status with family members designated by primary care giver.
- Family notified that patient is imminently dying and medical decisions regarding care noted.
- Medication Review
- Need for vital signs
- Discussed need for further diagnostic tests, invasive/painful procedures, and labs
- Non-essential equipment reviewed (e.g., monitors)
- Discussion complete on preferences of where death will occur
- Hospice Care at Home
- Inpatient Hospice
- Hospital
- Home Hospice
- ICU
- Other
- Ethical issues identified, Ethics Committee consulted (as needed)
- Autopsy discussion
- Organ Donation
- Consent Completed (Autopsy or Organ Donation, when applicable)
- By whom? _________________________________________________

Starting the Conversation ...

Creating a Therapeutic Alliance

1. What is your understanding of your child’s illness/condition?
2. Tell us about your child as a person. What brings your child joy?
3. Knowing this about their illness, what is the most important thing to you? What are you hoping for? What else are you hoping for?
4. What are you worried about? What keeps you up at night?
5. Where do you find your strength? Is that helping you now?
Four days later Sarah appears to be rapidly approaching the end of life. She is intermittently awake and interactive, remains on high settings of BiPap 24/7, and has refractory dyspnea on 0.5 mg IV Morphine q 4 hours. She remains on MIVF and her last bowel movement was 4 days prior. She appears uncomfortable with labored respirations, pruritus, and a distended abdomen. Her grandparents have arrived and are concerned that she has not had any oral intake since prior to admission.
Breakout Case #2

Next Steps?

- **Medical Management**
  - Review Medication List
- **Psychosocial considerations**
- **Communication with Patient & Caregivers**
  - Patient, Parents and Extended Family
  - Nursing and Support Staff

Assess & Address Symptoms of Concern

**Common Symptoms**

- Nausea and vomiting
- Depression
- Fatigue
- Pain
  - Neuropathic
  - Somatic
- Dyspnea
- Anorexia
- Sleep disturbances
- Anxiety

(...Many others...)
Nausea and vomiting - Assessment

- Timing
- Other or associated symptoms
- What has worked before?
- Specific medications with bad side effects

Pathophysiology of Nausea

CTZ
- All transmitters

Other CNS
- Vestibular
  - ACH
  - Histamine
- ICP

Cortical Anticipation

Vagal
- Acetylcholine

GI Tract
- Serotonin - vagal
- ACH - peristalsis
  - Dopamine

Neurotransmitters

- Serotonin
- Dopamine
- Acetylcholine
- Histamine

Vomiting Center (Brainstem)
Nausea & Vomiting - Treatment

- Ondansetron/granisetron
  - Serotonin antagonist
  - Mostly for chemotherapy induced N/V @ CTZ
- Metoclopramide
  - Prokinetic (cholinergic) promotes gastric and small bowel activity
  - CTZ
- Dexamethasone
  - Other CNS i.e., ICP
- Benzodiazepines
  - Cortical
- Diphenhydramine Promethazine
  - Antihistamines
  - Vomiting center
- Haloperidol
  - Antidopaminergic
  - Neuroleptic
  - CTZ
- Aprepitant – Emend
  - NK-1 @ CTZ

Medical Management at the End of Life

Fluids and nutrition at end of life

- Medically administered hydration and nutrition can be burdensome for the dying child
  - Families may have strong feelings and beliefs tied to food and nutrition
- Offer small sips and tastes of favored liquids and food
- If medically administered fluids and nutrition are discontinued prepare families
  - The child may live for days to weeks
  - The child may appear increasingly dehydrated
Considerations as death nears closer:

- Role of life-sustaining interventions
- Locations of care and death
- Discussing with other family friends
- Faith transitions and cultural preferences
- Autopsy and post-mortem

Communication with Families

Questions/Scenarios to be prepared for . . .

- If my child is given opioids, can’t this hasten his/her death?
- Isn’t it cruel to stop providing at least a little nutrition or fluid?
- How will I know if he/she is suffering?
- Can he/she hear me?
- Can’t you just give her something to stop her suffering (hasten his/her death)?
- My husband and I (or family members) can’t agree about the code status. What should I do?
- If my child starts to get better (miracles happen) can we change the code status?
The provider’s response

- Anticipate your own anxiety as the condition progresses and death approaches
- Monitor your avoidance
- Child’s anxiety and the parent’s grief (particularly when expressed through outbursts of grief/anger) can be difficult
- Help bring parents back to the present moment – there will be time to rehash the past but one can’t bring back the present
- “Don’t just do something, stand there” (Be present)

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### Responding to Patient/Family Emotions and Articulating Empathy (NURSE)

<table>
<thead>
<tr>
<th><strong>Naming</strong></th>
<th>Name the emotion</th>
</tr>
</thead>
</table>
| **Understanding** | Acknowledge and appreciate the patient/family’s situation  
Avoid giving premature assurance or suggesting that you understand everything |
| **Respecting** | Acknowledge and respect the family’s emotions  
Offer praise whenever appropriate |
| **Supporting** | Express concern and a willingness to help  
Acknowledge the family’s efforts to cope. Do not promise or offer anything that you will not be able to deliver. |
| **Exploring** | Let the family member talk about what they are going through  
Explore sources of conflict (e.g. guilt, grief, culture, family, trust, etc.)  
Explore values behind decisions  
Ask more focused questions to confirm beliefs |
## Special Circumstances – Traumatic or Unexpected Deaths

Communicating with families after the serious traumatic injury or unexpected death of a child

<table>
<thead>
<tr>
<th>Interpersonal Actions</th>
<th>Interdisciplinary Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prepare</strong></td>
<td></td>
</tr>
<tr>
<td>• Clarify facts prior to family meeting</td>
<td>• Facilitate timely discussion b/tw family &amp; clinical staff after an event.</td>
</tr>
<tr>
<td>• Locate parents &amp; assist with notification of other vulnerable family members</td>
<td>• Alert staff to emerging conflicts/problems within the family.</td>
</tr>
<tr>
<td>• Identify potential strengths, vulnerabilities, coping styles of the family</td>
<td>• Misunderstanding of prognosis</td>
</tr>
<tr>
<td>• Prepare for fluctuations in emotion (guilt, anger, sadness, blame, self-blame)</td>
<td>• Conflicts about treatment options</td>
</tr>
<tr>
<td></td>
<td>• Identify psychosocial Red Flags</td>
</tr>
<tr>
<td></td>
<td>• Intentional/NAT, perception of preventable event, concurrent family stress (i.e. divorce)</td>
</tr>
</tbody>
</table>

### Support

- Convey Compassion & Empathy.
  - Avoid blunt or overly technical language/jargon.
  - Clear, simple language – AVOID euphemisms.
  - Remember to convey emotion.
- Establish Trust
  - Allow yourself extra time; avoid appearing rushed.
  - Answer parent’s questions in detail & prepare them for the events to unfold in days ahead.
- Reassure the parents of the child’s treatment and care.
- Provide a quiet, private, or semiprivate area for the family.
- Access SW, Chaplains, CLS, & any other referrals requested by the family.
- Help family maximize final visits with child whose death is imminent or who recently died receiving acute medical care.
- Engage in legacy-building tasks.
- Provide guidance on the final decisions (i.e. withdrawal of LSMT, organ donation, autopsy, funeral preparation).

### Follow-Up

- Plan formal & informal staff debriefings.
- Acknowledge the need for & make time to self-engage in self-care
- Make a follow-up telephone call to assess grief.
- Provide information on resources for community support & reinforce the availability of resources.
Parent Perspective

Justin is a 15 y/o male who recently returned home for end-of-life care for recurrent, progressive osteosarcoma (bone tumor). He was admitted 24 hours prior for control of pain related to bony metastasis. His home regimen of a long-acting opioid plus breakthrough agents was no longer sufficient. He presented to the ED after his mother called 911 because he was difficult to arouse after taking extra doses of his long acting morphine in an attempt to control his discomfort.

Clinical Case #3
Clinical Case #3

On your arrival to the floor his nurse asks you to immediately assess him because she says he is suffering. He is writhing in bed, grimacing, and his mother is sobbing at the bedside begging you to “do something.” Between sobs he gasps that his pain is a 12 (out of 10!) and he hurts everywhere.

Key pharmacologic Concepts

- **By the clock**
  - Should be given on scheduled basis
  - Provide adequate PRN doses for breakthrough
- **By the mouth**
  - Use least traumatic route of administration
  - Oral is not always the least traumatic means
  - Avoid rectal, No ‘SHOTS’
  - Most analgesics can be given in a variety of routes
- **By the child**
  - Individualized therapy
# Key drug classes

## NSAIDS
- Ibuprofen, Naproxen, Aspirin, Ketorolac
- **Advantages**
  - Effective anti-inflammatory and decrease bone pain
  - Accessible
  - Avoid side effects of opioids
- **Disadvantages**
  - Inhibit platelet function
  - Renal and GI toxicity
  - Mask fever
  - Require oral route
  - exception: ketoralac (Toradol)

## Acetaminophen
- **Advantages**
  - Does not interfere with platelet function
  - No gastrointestinal toxicity
  - No renal toxicity
  - Readily available
  - Inexpensive
  - Can potentiate opioids
- **Disadvantages**
  - Weak anti-inflammatory
  - Masks fever as sign of infection
  - Liver toxicity

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<table>
<thead>
<tr>
<th>Drug</th>
<th>Initial dose (mg/kg/dose)</th>
<th>Route</th>
<th>Interval</th>
<th>Maximum Dose</th>
<th>Formulation</th>
<th>Comments/Special Considerations for Use at the End of Life</th>
</tr>
</thead>
</table>
| Acetaminophen                     | 10–15                     | PO, PR| Q4h      | 1 g/dose; 4 g/day | T, CT, L, D, S | May mask fever  
Avoid use in patients with liver injury or disease |
| Ibuprofen                         | 5–10                      | PO    | Q6h      | 2.4 g/day; 3.2 g/day (adults) | T, CT, L, D | Useful for treatment of bone pain and pain associated with inflammation  
Discuss risks and benefits, given the risk of bleeding and gastritis |
| Choline magnesium trisalicylate   | 7.5–20                    | PO    | BID-TID  | 1.5 g/dose   | T, L        | May be useful in treatment of fevers at end of life; less effect on platelet function |
| Naproxen                          | 5–7                       | PO    | Q8-Q12h  | 1 g/dose; 4 g/day | T, L        | Can be dosed twice daily  |
| Ketorolac                         | 0.5                       | PO, IV| Q6h      | 30 mg/dose IV; 10 mg/dose PO | I, T        | Give as IV formulation  
Consider in bone pain  
Discuss risks and benefits, given the risk of bleeding, gastritis; avoid in renal dysfunction |
### Key drug classes - Opioids

- **Morphine** \(\rightarrow\) gold standard
  - Variety of routes, formulations
  - Large body of research
  - Used for moderate to severe/intractable pain

- **Fentanyl**
  - Used in anesthesia, procedural sedation
  - Acute moderate to severe pain
  - Patch has found use in some cancer and chronic non-malignant pain

- **Hydromorphone**
  - More potent than morphine
  - Available in high-potency formulations

- **Methadone**
  - Gaining favor as analgesic in chronic pain
  - Long half-life therefore longer time to steady state
  - Not useful in breakthrough pain

### Drug Classifications

<table>
<thead>
<tr>
<th>Drug</th>
<th>Initial dose (mg/kg/dose)</th>
<th>Route</th>
<th>Interval</th>
<th>Maximum Dose</th>
<th>Formulation</th>
<th>Comments/Special Considerations for Use at the End of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tramadol</td>
<td>1–2</td>
<td>PO</td>
<td>Q6h</td>
<td>100 mg/dose, 400 mg/day</td>
<td>T</td>
<td>Little experience with use in children Consider in adolescent/young adult patients.</td>
</tr>
<tr>
<td>Morphine</td>
<td>0.2–0.5</td>
<td>PO, SL, PR</td>
<td>Q3-Q4h</td>
<td>Titrate</td>
<td>T, L, D, S</td>
<td>Most commonly used; no ceiling dose Metabolites can accumulate in hepatic or renal dysfunction</td>
</tr>
<tr>
<td></td>
<td>0.1</td>
<td>IV, SQ</td>
<td>Q2-Q4h</td>
<td></td>
<td>I, T</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.3–0.6 (long acting)</td>
<td>PO</td>
<td>Q8-Q12h</td>
<td></td>
<td>SRT</td>
<td></td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>0.03–0.08</td>
<td>PO, PR</td>
<td>Q3-Q4h</td>
<td>Titrate</td>
<td>T, L, S</td>
<td>Metabolites can accumulate in hepatic or renal dysfunction</td>
</tr>
<tr>
<td></td>
<td>0.015</td>
<td>IV, SQ</td>
<td>Q2-Q4h</td>
<td></td>
<td>I, T</td>
<td></td>
</tr>
<tr>
<td>Methadone</td>
<td>0.2</td>
<td>PO</td>
<td>Q8-Q12h</td>
<td>Titrate</td>
<td>T, L</td>
<td>No active metabolites Use in addition to other opioids; may decrease rate of adjustment or decrease opioid requirement QTc prolongation in high doses</td>
</tr>
<tr>
<td></td>
<td>0.1</td>
<td>IV, SQ</td>
<td>Q8-Q12h</td>
<td></td>
<td>I, T</td>
<td></td>
</tr>
<tr>
<td>Fentanyl</td>
<td>0.5 - 1 μg/kg/h</td>
<td>TD</td>
<td>Q48-Q72h</td>
<td>Titrate</td>
<td>P</td>
<td>No active metabolites Associated with tachyphylaxis; might need to adjust doses more often</td>
</tr>
<tr>
<td></td>
<td>1 - 2 μg/kg</td>
<td>IV, SQ</td>
<td>Q1-Q2h</td>
<td></td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Oxycodone</td>
<td>0.05–0.15</td>
<td>PO</td>
<td>Q6h</td>
<td>Titrate</td>
<td>T, L</td>
<td>Only oral formulation; might limit use at the end of life Extended release oxycodone approved for patients age 11-16 years old; patients must be tolerating a minimum opioid dose equal to at least 20 mg of oxycodone per day before conversion to SRT</td>
</tr>
<tr>
<td></td>
<td>0.1–0.3 (extended release)</td>
<td>PO</td>
<td>Q12h</td>
<td>Titrate</td>
<td>SRT</td>
<td></td>
</tr>
</tbody>
</table>
# Key Drug Classes

## Adjuvant Analgesics

- **Tricyclic Antidepressants**
  - amitriptyline, desipramine, imipramine
- **Anticonvulsants**
  - carbamazepine, phenytoin, valproic acid, gabapentin
- **Neuroleptics**
  - chlorpromazine, haloperidol
- **Anesthetics**
  - mexiletine, lidocaine, midazolam, ketamine, propofol
- **Sedatives, Anxiolytics**
  - diazepam, lorazepam, midazolam, triazolam
- **Steroids**
  - dexamethasone

<table>
<thead>
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<th>Formulation</th>
<th>Comments/Special Considerations for Use at the End of Life</th>
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</thead>
<tbody>
<tr>
<td>Amitriptyline</td>
<td>0.1 mg/kg/dose</td>
<td>PO</td>
<td>QHS</td>
<td>0.5–2 mg/kg/dose; usually &lt;50 mg QHS</td>
<td>T</td>
<td>Higher doses associated with anticholinergic effects; usually do not titrate dose more than every 3–7 days Oral formation only Drug–drug interactions; QTc prolongation</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>5–10 mg/kg/day</td>
<td>PO</td>
<td>TID</td>
<td>50–70 mg/kg/day</td>
<td>T, L</td>
<td>Common side effects is sedation; worse when titrating more often than every 3–5 days Only oral preparation</td>
</tr>
<tr>
<td>Pregabalin</td>
<td>25 mg/dose if &gt;50 kg</td>
<td>PO</td>
<td>BID</td>
<td>150 mg BID</td>
<td>T</td>
<td>Limited experience in children Often trialed if dose limiting side effects of gabapentin</td>
</tr>
<tr>
<td>Bisphosphonates (zoledronic acid)</td>
<td>0.08–0.16 mg/kg OR 2.3 mg/m² IV Q4 weeks; infuse over 30–60 min</td>
<td>IV</td>
<td>Q4weeks</td>
<td>N/A</td>
<td>I</td>
<td>Requires close monitoring of electrolytes for several days after infusion Usually give in 3–5 day “burst” for acute bone pain Useful if other symptoms (N/V, fatigue) also present</td>
</tr>
<tr>
<td>Steroids (dexamethasone)</td>
<td>6–10 mg/m²/day</td>
<td>IV/PO</td>
<td>BID</td>
<td>12–16 mg/day</td>
<td>T, L, I</td>
<td>Usually give in 3–5 day “burst” for acute bone pain Useful if other symptoms (N/V, fatigue) also present</td>
</tr>
<tr>
<td>Ketamine infusion</td>
<td>0.025–0.1 mg/kg over 15 min, followed by a continuous infusion of 0.025–0.1 mg/kg/h</td>
<td>PO, IV</td>
<td>Continuous</td>
<td>0.5 mg/kg/hr</td>
<td>I</td>
<td>Consider premedication with glycopyrrolate and a benzodiazepine Can titrate dose every 10–15 min at bedside Dose can be transitioned to oral dosing for long-term use</td>
</tr>
<tr>
<td>Lidocaine infusion</td>
<td>Loading dose of 1.5–2 mg/kg over 30 min, followed by a continuous infusion of 1.5–2 mg/kg/h for 2–4 h</td>
<td>IV</td>
<td>Continuous</td>
<td>300 mg/hr</td>
<td>I</td>
<td>Loading dose given in presence of ordering physician Use with caution in patients with liver dysfunction, increased risk for toxicity</td>
</tr>
</tbody>
</table>
## Management of common opioid side effects

<table>
<thead>
<tr>
<th>Side Effect</th>
<th>Recommended Management</th>
<th>Clinical Pearls/Special Considerations at the End of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Constipation</strong></td>
<td><strong>Medication Type</strong>&lt;br&gt;Stimulant laxative&lt;br&gt;Peripherally constrained μ-receptor antagonists&lt;br&gt;Low-dose μ-receptor antagonists</td>
<td><strong>Example and Dosing</strong>&lt;br&gt;Senna&lt;br&gt;Methylnaltrexone, SQ Q 48h&lt;br&gt;Low-dose naltrexone infusion; dose 0.25–1 μg/kg/h&lt;br&gt;Nalbuphine ≥1–18 years: 0.1–0.2 mg/kg IV/SQ Q3 to 4h Maximum single dose: 20 mg</td>
</tr>
<tr>
<td><strong>Pruritus</strong></td>
<td><strong>Medication Type</strong>&lt;br&gt;Peripherally acting μ-receptor antagonists&lt;br&gt;Semi-synthetic opioid</td>
<td><strong>Example and Dosing</strong>&lt;br&gt;Nalbuphine&lt;br&gt;Typical (haloperidol), atypical (olanzapine)</td>
</tr>
<tr>
<td><strong>Nausea/Vomiting</strong></td>
<td><strong>Medication Type</strong>&lt;br&gt;5HT-3 receptor antagonists&lt;br&gt;Dopamine receptor antagonists&lt;br&gt;Pro-motility agent (also has dopaminergic activity)&lt;br&gt;Peripherally acting μ-receptor antagonists</td>
<td><strong>Example and Dosing</strong>&lt;br&gt;Ondansetron, 0.15mg/kg PO/IV Q8h; Granisetron, up to 1 mg PO/IV BID&lt;br&gt;Typical (haloperidol), atypical (olanzapine)&lt;br&gt;Metoclopramide, 1–2 mg/kg/dose IV&lt;br&gt;Low-dose naltrexone infusion; dose 0.25–1 μg/kg/h</td>
</tr>
</tbody>
</table>
### Management of common opioid side effects

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<tr>
<th>Side Effect</th>
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</thead>
<tbody>
<tr>
<td><strong>Fatigue</strong></td>
<td>Common and distressing symptom, especially in adolescent and young adult patients</td>
<td>Methylphenidate 5–10 mg Q AM; consider additional 5 mg in early afternoon</td>
</tr>
<tr>
<td><strong>Stimulants</strong></td>
<td></td>
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</tr>
</tbody>
</table>

**Clinical Pearls/Special Considerations at the End of Life**
- **PREVENTION** is key
- Patient on opioids and no preventive meds
- Abdominal pain was treated frequently with morphine
- **Intervention**
  - Miralax (polyethylene glycol) for “clean out”
  - Senna S (senna +/- colace) scheduled for prevention
  - Methylnaltrexone SQ injection Q 72 hours
Rapid Titration of pain medications

PAIN AS A CODE

• Patients with new onset or escalating pain
• Conduct thorough pain assessment
• Provide PRN dose of medication - STAT
• Reassess in 15 min if IV/SC, 30 if PO
• If no relief - give another PRN dose
• Repeat until pain relieved
• Notify physician if requiring frequent bolus doses, change in quality of pain

Maintenance pain therapy

• Used 5 bolus doses during past 4 hours
• Still with 4/10 pain
  - NOW WHAT?
• Provide breakthrough dose
• Increase basal rate by 25-50%
• Alternative = Increase basal rate by 50-75% of total used over 4 hrs
Oral to IV

Changing from oral to continuous IV infusion
- Calculate total amount of meds in past 24 hrs
- Make appropriate equianalgesic conversions
- If comfortable at current dose continue at same equianalgesic dose
- If pain is not controlled on current dose, increase equianalgesic dose by 25% to 50%

Other key issues
- Are breakthrough doses effective?
- What about side effects?

- Pt having terrible pruritus – “intolerable”
  - Naloxone
    - Low-dose naloxone infusion; dose 0.25–1 µg /kg/h to prevent or treat opioid induced pruritus
  - Diphenhydramine
    - Works for 1 hour then “intolerable” again
  - Change to hydromorphone
    - Equianalgesia calculation
    - 50-75% dosing → Incomplete Cross Tolerance

Maintenance pain therapy
Opioid Rotation

Based on 10mg parenteral morphine:

<table>
<thead>
<tr>
<th>Opioid</th>
<th>IV</th>
<th>PO</th>
<th>Conversion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine</td>
<td>10mg</td>
<td>30mg</td>
<td>3</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>1.5mg</td>
<td>7.5mg</td>
<td>5</td>
</tr>
<tr>
<td>Methadone</td>
<td>10mg</td>
<td>20mg</td>
<td>2</td>
</tr>
<tr>
<td>Fentanyl</td>
<td>0.1-0.2mg</td>
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</tbody>
</table>

Incomplete Cross-tolerance

- Switch from opioids
- Remember organ function and metabolism
- Equianalgesic guidelines
- Incomplete cross-tolerance
  - Start with 50-75% of equianalgesic dose of the new opioid if pain is controlled

*It was your medication’s side effects that caused those special effects.*
**Case continues...**

- Morphine increased and benzo drip added
- Patient has events of “outbursts” and ? pain events
  - Appears to be suffering
  - “Outbursts” very distressing to staff and family
  - Partially responds to both morphine bolus and benzodiazepine bolus
  - Other considerations?
  - Outbursts = periods of disorientation and agitation

**Delirium**

- Very common symptom at end of life
- Underdiagnosed
- Occasionally difficult to diagnose
- Usually responds well to treatment
  - Haloperidol scheduled
  - Benzodiazepine for agitated outbursts
  - Consider atypical neuroleptic if poor response
Justin -- Intractable Suffering

- Despite aggressive intervention, the patient continues to suffer from both pain and dyspnea
- Currently using VERY high levels of both morphine and benzodiazepines
- Having “Outbursts” very distressing to staff and family

What do you do?

Parent Perspectives

“Nothing is worse that seeing your own child dying and suffering in pain. I regret not doing more about it, not saying the right thing. I never told him that...(weeping)...I loved him.”

- St. Jude bereaved parent
Pain and hastening death

Questionnaire of 141 bereaved parents

- 13% considered hastening death, 9% discussed hastening death
- 34% would consider hastening death had their child been uncontrollable pain
- Consideration of hastening death increase if child is suffering from pain!

2001 survey of 449 (80% response rate) parents of children who died of cancer in Sweden:

<table>
<thead>
<tr>
<th>Parents reporting…</th>
<th>Pain not relieved</th>
<th>Difficult moment of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%), 196 (44%)</td>
<td>138 (31%)</td>
<td></td>
</tr>
<tr>
<td>Still affected 4-9 yrs after death</td>
<td>111 (57%)</td>
<td>78 (57%)</td>
</tr>
</tbody>
</table>

Kreicbergs UC, et al., JCO 2005

An Algorithm to Guide Clinicians Considering Palliative Sedation Therapy in Pediatric Patients

Original Articles

Pediatric Palliative Sedation Therapy with Propofol: Recommendations Based on Experience in Children with Terminal Cancer

Doratina L. Angelescu, M.D., Hunter Hamilton, B.B.A., Lane G. Faughnan, B.S., Lisa-Marie Johnson, M.D., and Justin N. Baker, M.D.

Pediatric Sedation With Propofol for an Adolescent With a DNR Order

Liza-Marie Johnson, Joel Frader, Joanne Wolfe, Justin N. Baker, Doratina L. Angelescu, John D. Lantos
Palliative Sedation Therapy (PST)

• Use of pharmacologic agents to reduce consciousness
• Intent of limiting patient awareness of suffering
• Reserved for patients with refractory AND intolerable symptoms
• Reserved for terminally ill patients approaching the end of life
  • Discuss risks and benefits with patient and family

Palliative Sedation Therapy (PST)

• Use of this phrase is discouraged and should be avoided!

• Terminology is very important

• Confuses purpose of medical intervention.
  - Purpose is PALLIATION of symptoms, NOT to hasten or facilitate death
  - Death may occur as double effect but is not the intention of PST
  - Appropriate PST not associated with worse survival

Developed in middle ages for situations in which it is impossible for a person to avoid all harmful actions

Classical formulations emphasize 4 conditions:

1) The act must be good or morally neutral
2) The good effect, and not the evil effect, must be intended
3) The bad effect must not be a means to the good effect
4) The good effect must outweigh the bad effect

Quill TE, Dresser R, Brock DW. *NEJM*, 337 (24) 1997: 1768-1771
Responding to Requests that “Everything” Be Done

Explore the meaning of the “do everything” request – this is a starting point...

“I respect how deeply committed you are, and we are also absolutely committed to figuring out what the best thing to do is. Let’s talk for a few minutes about what the different options might look like.”

“We always ask ourselves what we can do to help the patient. To answer this question, we have to be clear about what we are hoping for—recovery, comfort, dignity—and do all that we can that has a reasonable chance of getting us there.”

Responding to Requests that “Everything” Be Done

Reassure family that the team is fully committed to providing excellent care

- “There is nothing more we can do...” – full stop
- Commit to doing “the-best-something-that-we-can-do”

“I wish there was more that we could do that would halt the progress of this disease, but none of the treatments we have are able to do this. We are still devoted to taking care of your child and will do everything in our power to keep pain and discomfort away.”

**Doing everything includes recognizing when the limits of medicine have been reached.**
**Helpful Hints**

**COMMUNICATION, COMMUNICATION, COMMUNICATION**

- Breathe and “take a moment”
- Try to avoid drawing a line in the sand
- Time trials are your friends
- Bring in multidisciplinary team and consultants
- Consult Ethics Committee +/- Palliative Care Team Early

**Language matters**

- “Withdrawal of care” – NOOOOOOO
- “Do you want us to put a tube in your child to help them breath (even though I know this won’t be helpful)” – NOOOOOO

Relationship-based care → be willing to make recommendations

- “What would you do if this was your child?” – feel free to answer

---

**Moral Distress**

**Overly aggressive treatment**

- Prolonging the dying process
- Unnecessary tests and treatments (burdensome care)

**Inappropriate use of healthcare resources**

Perception that patient/family is receiving incomplete or inaccurate information

- Inadequate informed consent, or lying to patients

**Patient (family) preferences are disregarded by a physician**

**Intra-professional conflict**

**Disparate goals**

- Among family members, or between physician & family
Moral Distress – Identifying & Ameliorating Stress

Remember to support yourself, your nurses, your trainees.

<table>
<thead>
<tr>
<th>Stressors</th>
<th>Support Mechanisms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systems-Based Stressors</td>
<td>Systems-Based Interventions</td>
</tr>
<tr>
<td>Not understanding the difference between palliative and EOL care</td>
<td>Shadow senior staff member experienced in palliative care to facilitate clinical experience in caring for dying children and their families</td>
</tr>
<tr>
<td>Lack of a plan relating to medical care or uncertainty surrounding goals of therapy</td>
<td>Standard operating procedures to support children and families approaching EOL</td>
</tr>
<tr>
<td>Not knowing what to do with an imminently dying child and their family</td>
<td></td>
</tr>
<tr>
<td>Discontinuing basic nursing interventions (laboratory test results, vital signs, and so forth)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom-Based Stressors</th>
<th>Symptom-Based Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of education and hands-on training in palliative care</td>
<td>Educational courses and modules in palliative care</td>
</tr>
<tr>
<td>Not knowing what to expect as new symptoms develop at EOL</td>
<td>Expected trajectories of various diseases</td>
</tr>
<tr>
<td>Not being able to control pain or other distressing symptoms</td>
<td>Managing complex pain and other symptoms</td>
</tr>
<tr>
<td>Feeling helpless in helping to achieve patient and family comfort</td>
<td>Access to specialist in palliative care or pain management who can assist with symptom management</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interpersonal Stressors</th>
<th>Interpersonal Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not knowing what to say to family or having trouble identifying family needs and wants</td>
<td>Courses to facilitate communication skills of pediatric nurses providing inpatient palliative care</td>
</tr>
</tbody>
</table>

| Managing attachments to child and family | Clinical scenarios and education on professional boundaries and managing emotional attachments |

| Dealing with personal emotions and lack of time to debrief with others | Access to supervisor or support staff to whom they may speak freely about feelings and emotions |

“You have not known grief until you have stood at the grave of your child”

A. Lincoln (Willie died of likely typhoid fever)
Background: Parental Grief

- Parental grief is more profound, prolonged
- Increased risk for long-term psychosocial and psychical morbidities
- Bereavement impacts relationships, societal functions leading to isolation
- Isolation worsens physical and psychosocial issues

*Parents recognize the need for support (including institutional support) throughout their grief journey*

Immediately following death

- Allow the family time with the child’s body
- After death care of the body
- Spend time talking to family members
- Prepare for the transfer of the body
- Complete the death certificate
- Provide comfort to staff
About the death of a child

...impacts not only upon the individual parent but the parent dyad, family system, and society itself (Riches, 2000)

...even healthcare providers see it as being against the natural order of things, and may overlook, underestimate, or misinterpret the needs of the bereaved parents (Papadatou, 1997)

Decisional Regret

“...having regret is the worse part. She suffered so much during those last days. I did not know what to expect. I wish someone had prepared me for what was coming, she was...(crying).”

St. Jude bereaved parent
Talking about death with their children

(N=429 Bereaved Parents)

- 1/3 talked, 2/3 did not talk
- No parents regretted talking
- Decisional regret more likely in parents who sensed (47%) vs. did not sensed (13%) that their child was aware of his or her imminent death

Kreicbergs et al, NEJM 2004

Parent Perspective
WRAP-UP & TAKE AWAYS

“\textit{In the middle of every difficulty lies opportunity}”  
- Albert Einstein

Pearls . . .

- Communicate prognosis in sensitive manner
- Allow child and family to share preferences/needs
- Provide support to siblings and help them find ways to interact with dying brother or sister
- Prepare family for physical changes
Encourage family members to say goodbye; acknowledge the many ways in which people do this
Provide proactive treatment for pain and distressing symptoms
Send condolences to family after their child’s death

Failure to share prognosis in effort not to distress family
Not taking time to communicate carefully about preferences for resuscitation, continued therapy, medical nutrition and hydration, treatment priorities of family
Failure to anticipate and provide relief for pain and distressing symptoms
... Pitfalls

• Making assumptions that parents know everything their children are thinking and feeling
• Refusing to escalate opioids out of fears of fostering addiction, over sedation or other unintended effects

One Final Pearl ...

Beware of **SEAGULLS**

And Remember .....
Questions?

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- Deena.Levine@stjude.org
- Jennifer.Snaman@stjude.org *