The Art and Science of Nursing in Pediatric Palliative Care
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July 2010

Objectives
Identify one pharmacologic and one non-pharmacologic treatment for a child experiencing pain at end of life.
List two examples of common communication myths.
Give one example of “being with” a child and family at the end of life.

Need for Palliative Care
- Increased availability and use of technology
- Technology as a constant presence

Differences Between Adult and Pediatric Palliative Care
- Developmental level of patient
- Variable time course
- Potential of multiple specialists
- Genetic diseases
- Consent/assent issues in minors
- Sibling issues

Pediatric Death
- Trauma ranks highest
- Pediatric illness could benefit from palliative care

Demographics/Social Trends
- 55,000 US children between 0-19 years die each year
- Infants < 1 year account for half
- 75-85% of children die in hospital – many in intensive care
- 900,000 birth tragedies/year
The Scope of Pediatric Palliative Care

Common Symptoms at End of Life
- Pain and Discomfort
  - Disease related
  - Musculoskeletal
  - Neuropathic
  - Procedure related
  - Treatment related
  - Dyspnea
- Anxiety
- Sleep deprivation
- Nausea
- Constipation/Diarrhea
- Deconditioning

Michael
- Michael is a 5yo who presents with a recurrent spinal cord tumor. He complains of back pain and is admitted for pain control and further evaluation.
Managing Pain

- What am I treating?
  - Other distress? Why?
- How should I treat it?
- How often?
- By what route?

“Step Ladder” Approach to Analgesia Management

- Mild pain
- Moderate pain
- Severe pain
- IV opioid
- APAP/NSAID
- Adjuvant

Analgesia Titration

- Quickest way to titrate to comfort may be with IV administration
- Use previous requirements as starting point
- After stable, use 24 hour requirements as guideline for conversion to oral/transdermal administration
- Consider adjunctive medications depending on pain type, concurrent issues, drug interactions

Opioid Dosing

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose (IV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>morphine</td>
<td>0.05 – 0.1 mg/kg q2h</td>
</tr>
<tr>
<td>fentanyl</td>
<td>.5 – 2 mcg/kg q1h</td>
</tr>
<tr>
<td>hydromorphone</td>
<td>.015 – 0.03 mg/kg q2h</td>
</tr>
<tr>
<td>meperidine</td>
<td>???</td>
</tr>
<tr>
<td>methadone</td>
<td>0.05 – 0.1 mg/kg q4-6h</td>
</tr>
</tbody>
</table>

Conversions

- 1 mg IV MSO₄ = 50-100 mcg fentanyl
- 1 mg IV MSO₄ = 0.2 mg hydromorphone
- 1 mg IV MSO₄ = 1 mg IV methadone
- 1 mg IV MSO₄ = 3 mg PO MSO₄
- 1 mg PO MSO₄ = 1 mg PO oxycodone
- 1 mg IV methadone = 1mg – 0.5 mg PO

Patient Controlled Analgesia

- Can be used as young as 6yo
- Allows patient to titrate opioid analgesia to his/her own effective concentration
- Allows patient to balance between analgesia and side effects
- Gives patient control over part of their own care
- PCA by proxy
Michael is stable on 24 mg of IV morphine per day and family would like to transition to PO and think about going home. His weight is 20kg.

**PO Opioid Analgesia**
- Transition from IV to PO
- Calculate average 24 hour requirement
- Utilize sustained release to provide major portion of opioid requirements (Oxycontin, MS Contin, methadone) for severe pain
- Short acting for breakthrough pain
- If patients requires regular use of short acting agent, consider increase in SR
- May have less side effects vs. IV administration

**Oral Opioid Options**
- Oxycodone (Oxycontin, Percocet, Tylox)
  - 0.1 – 0.2 mg/kg q3-4h
  - Remember APAP component
- Morphine (IR, SR)
- Hydromorphone
- Hydrocodone (Loratab)
- Methadone
- Codeine

**Transdermal fentanyl**
- Fixed release over 72 hours
- Sizes: 12.5, 25, 50, 75, 100 mcg/hr
- Can still use IR oral preparations for breakthrough pain
- Should never be first line
- Conversion can be tricky
- 45 mg/24 hour MS requirement min

**Conversions**
- 1 mg IV MSO4 = 50-100 mcg fentanyl
- 1 mg IV MSO4 = 0.2 mg hydromorphone
- 1 mg IV MSO4 = 1 mg IV methadone
- 1 mg IV MSO4 = 3 mg PO MSO4
- 1 mg PO MSO4 = 1 mg PO oxycodone
- 1 mg IV methadone = 1mg – 0.5 mg PO

**Michael**
- 24 mg IV MSO4 x3 = 72 mg PO MSO4
- 72 mg PO MSO4 = 72 mg PO oxycodone
- Start with 20 mg Oxycontin bid (40mg per day)
- 5 mg oxycodone q3h prn
- **Reassess** in 24 – 48 hours
Long Term Opioid Considerations
- Constipation – stool softeners
- Nausea – antiemetics, drug rotation
- Itching – naloxone, nalbuphine, antihistamines, medication rotation
- Neurotoxicity – benzodiazepines, medication rotation
- Tolerance – medication rotation

Analgesia with NSAIDs
- Musculoskeletal pain
- Bony pain
- As basal analgesia with opioid or opioid/APAP combo for breakthrough
- As part of “balanced analgesia” for severe pain
- Considerations: platelet inhibition, GI irritation

NSAIDs
- Ibuprofen:
  - PO
  - Tablet, liquid forms
- Ketorolac
  - Potent IV analgesic
  - PO form (10 mg tabs)
  - Loading dose no longer recommended
  - IV administration +/- PO ≤ 5 days
- Acetaminophen
  - No anti-inflammatory effect
  - PO/PR
  - IV? Maybe be coming
  - Often in combo with opioids

Michael
- With continued progression, he begins complaining of shooting, sharp pain down his right leg and a burning pain in the lateral aspect of the leg. He also has mild nausea and some urinary retention.
- He is becoming withdrawn and is less interactive.
- Family requests re-admission to hospital

Re-Admission Plan
- Family Conference
- Communication
- Medical and Nursing Care
Myths of Communication
- Communication is deliberate
- Words mean the same to BOTH the speaker and listener
- Verbal communication is primary
- Communication is one way
- Can’t give too much information

Fundamental Communication Skills
- Behaviors to Cultivate
  
  Tell me about “Elizabeth”
  “Tell me more”

Attentive Listening
- Encourage them to talk
- Be silent
- Acknowledge their feelings
- Avoid misunderstandings
- Don’t change the subject
- Take your time in giving advice
- Encourage reminiscing

What/How to Communicate
- Determine how much child/family want to know
- Set the right atmosphere
- Communication with child based on developmental age
- Respect culture
- Kleenex

Mind the Details
- Walk into the room
  - Don’t stand in the doorway
- Sit down and appear relaxed
- Do not keep looking at the time
- Allow time for questions
- Say how they can reach you if they have more questions

EXPECT DIFFICULT QUESTIONS/STATEMENTS
- Why me/my child?
- What could I have done to prevent this?
- Isn’t there some experimental treatment?
- Should I get another opinion?
- Will you keep me/my child from suffering?
- You can’t let me/my child die
- Why are you giving up?
Communication Guidelines LANGUAGE

<table>
<thead>
<tr>
<th>UNCLEAR/DISTRESSFUL</th>
<th>HELPFUL</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s time to pull back.</td>
<td>Let’s discontinue treatments which are not providing benefit.</td>
</tr>
<tr>
<td>There is nothing more we can do.</td>
<td>We should change the goals of care.</td>
</tr>
<tr>
<td>A miracle may turn things around.</td>
<td>In my experience, I have not seen a child in this situation survive.</td>
</tr>
</tbody>
</table>

HELPFUL PHRASES          | AVOID                                      |
--------------------------|--------------------------------------------|
May I just sit here with you? | It was a blessing...                        |
Is there anyone I can call for you? | You have other children to think about.    |
How can I be of help? | I know how you feel.                        |
Would you like me to talk with your other family members, or be there with you when you talk with them? | This will make you a better/stronger person. |

COMMUNICATING WITH PATIENT/FAMILY

- Avoid:
  - “There is nothing more we can do.”
    - Leads to loss of hope
    - Feelings of abandonment
  - Instead try
    - “We can’t cure your child, but we can care for him and your family until his death.”
      - Provide definitive treatment plan/goal
      - Give hope for quality of life/limited suffering

LISTEN WITH THE PARENT’S EARS

<table>
<thead>
<tr>
<th>YOU SAY</th>
<th>PARENT HEARS</th>
</tr>
</thead>
<tbody>
<tr>
<td>His creatinine is better.</td>
<td>He will get well.</td>
</tr>
<tr>
<td>She is stable today.</td>
<td>She is getting better.</td>
</tr>
<tr>
<td>We have an experimental treatment.</td>
<td>This new therapy will cure my child.</td>
</tr>
<tr>
<td>Do you want us to do CPR?</td>
<td>You think CPR will help.</td>
</tr>
<tr>
<td>Do you want us to “do everything” for your child?</td>
<td>Doing everything means you think my child will survive and get well.</td>
</tr>
</tbody>
</table>

“DOING EVERYTHING”

- Do not ask “do you want us to do everything for your child?”
  - All patients/families want us to “do everything”
  - Instead say what you mean

- It does NOT automatically mean “heroic” efforts and resuscitation attempts
- It does mean providing comprehensive care
  - Pain management
  - Symptom management
  - Addressing physical/spiritual needs

SEMANTICS

Use the “D” (death/die) word

- Parents need concrete terms
- Don’t use “catch” phrases such as “expire, lose or pass on”
- Eliminates vague/confusing messages
- Effects decisions
DNR CLARIFICATION

DNR does NOT mean: “DO NOT TREAT”

DNR means: “DO NOT RESUSCITATE”

It is appropriate to discuss/obtain DNR status while continuing treatment, especially with recurrent/progressive disease

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Care Plan

• Medical Plan
  • Pain Management
    • Back to IV-Still not effective
  • Symptom Management
    • Nausea, poor sleep, agitation, urine retention, fatigue

• Nursing Plan
  • Support MD plan
  • Supportive Care

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Adjunctive Medication

• Tricyclic antidepressants – sleep, neuropathic pain, headaches
• Anticonvulsants – neuropathic pain, headaches
• Alpha 2 agonists – neuropathic pain, somatic pain
• Muscle relaxants – muscle spasm
• Local anesthetics – neuropathic pain
• Ketamine – somatic pain, neuropathic pain

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Complementary Approach

• Nausea-ginger, sea bands, suppositories, probiotics, glutamine

• Urinary Retention-watermelon juice, celery juice, peppermint spirits, lavender

• Pain-Arnica, acupressure, acupuncture, heat and cold

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Complementary Approach

• Fatigue-increase hydration, increase protein, vitamin B(6), probiotics, aromatherapy/orange
• Cachexia-fish oil
• Sleep issues-melatonin, sound machines, NightWave sleep assistant
• Compounded “anything”-ativan, valium, compazine, morphine

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Sedation in Palliative Care
**Indications**
- Air hunger
- Agitation/delirium
- Patient/family choice
- Intractable pain

**Principle of Double Effect**
- The treatment is potentially beneficial but may also have harmful effects
- The clinician intends the beneficial effect, not the harmful effect, although the harmful effect may be foreseen
- The harmful effect is not necessary in order to achieve the beneficial effect
- The symptoms are severe enough to constitute a compelling reason to expose the patient to the risk of the harmful effect

**Sykes N, Thorns A. Lancet 2003**
“We conclude that patients are more likely to receive higher doses of both opioids and sedatives as they get closer to death. However, there is no evidence that initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death.”

**Care Plan**
- **Medical Plan**
  - Pain Management
  - Back to IV-Still not effective
  - Symptom Management
    - Nausea, poor sleep, agitation, urine retention, fatigue
- **Nursing Plan**
  - Support MD plan
  - Supportive Care
**Spiritual Assessment**

*In your worst moment, what gives you strength?*

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**The Art of Symptom Management**

- **Assessment**
  - “As I started looking, I found more and more.” Valerie Steele
  - “Attend to” not alleviate suffering and symptoms

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**Michael**

- Sleeping most of the time
- Pain and symptoms under excellent control
- Family "sitting vigil" at bedside
- *Now What??*

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**Role of the Nurse**

- The importance of presence
  - Being vs Doing
- Maintaining a realistic perspective
- Nurses as the safety net

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**Role of the Nurse**

- Anticipating
- Preventing
- Treating
- Promoting
- Advocating

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**A Good Death?**

- Free from Pain
- Therapies Exhausted
- Personalized Care
- Desired Setting
- Memory Making

*Not all deaths are “good”*
At The Time of Death

- Being With
- Staying After
- Walking Out

Opportunities for Growth

- Personal growth
- Caring for ourselves
- Achieving a peaceful death
- Child/family perspective
- Professional perspective

Final Thoughts

We need both the science and art of nursing to care for children and their families at the end of life

Don’t be afraid to “think outside the box” in providing pain and symptom management

Communication is the cornerstone in planning and providing care for children and their families

Your presence is a gift that only you can provide for families at the end of life

We can do no great things, only small things with great love

Mother Teresa