Integration of Palliative Care for Pain and Symptom Management for Children with Serious Illness

Deborah Fisher, PhD, PPCNP-BC, CHPPN
Children's National Hospital, Washington, DC

Deborah Lafond, DNP, PPCNP-BC, CHPPN, FPCN, FAAN
PANDA Education Consultants, PLLC, Lakeland, FL

Disclosure Information

• The speakers have no conflicts of interest and no disclosures.

Acknowledgements

• Images used as open source from https://freerangestock.com
Objectives

• Identify barriers to adequate pain and symptom relief in palliative surgical care for pediatric patients with serious illness.
• List components of a thorough pain and symptom assessment.
• Describe pharmacological and non-pharmacological palliative therapies used to relieve pain and other distressing symptoms for pediatric patients with serious illness.

So what is the issue here?

• Surgical interventions commonly cause pain and discomfort
  • Incidence of moderate to severe pain post major surgical procedures in children for at least 24 hours post surgery. (Chou et al., 2016; Kelley-Quon, 2021)
  • Children tend to receive less medication to treat pain as compared to adults for same or similar procedures (Cimpello et al., 2004)
  • Children with serious illness often have multiple comorbidities

What do we mean by serious illness?

• Acute life-threatening illnesses
  • Trauma

• Acute life-limiting illnesses
  • Cancer

• Children with complex chronic conditions -- those who suffer functional or healthcare consequences from chronic illness
  • Metabolic/genetic conditions
  • Novel, Kleiner, & Strange, 2018; Yu et al, 2019; Savarese et al, 2020
PPC Patients:  
A prospective observational cohort study

- Results:  
  - N= 515 new or established patients  
  - Principle Dx:  
    - Genetic / congenital (40.8%)  
    - Neuromuscular (39.2%)  
    - Cancer (19.8%)  
    - Respiratory (12.8%)  
    - GI (10.7%)  
  - Medical technology:  
    - G-tubes (48.5%)  
    - CVC (22.3%)  
    - Trach (10.1%)  

- Reason for consult:  
  - Symptom mgmt (58.1%)  
  - Facilitating communication (48.6%)  
  - Decision making (42.1%)  
  - Coordination of care (35.3%)  
  - Transition to home (14.4%)  
  - DNR orders (11.8%)  

Feustner et al., 2011

Quality of Life

Primary Goals  
- Be Home  
- Qualify for a research/new treatment  
- Keep child stable to await “cure”  
- Comfortable  
- Able to participate in family’s enjoyments  

Technology  
- is viewed as quality of life enhancement  
- Allows child to be home  
- Able to be safe awaiting new treatment  
- Life prolongation in the setting of uncertain prognosis or trajectory

Barriers to Pain Management in the Seriously Ill Child
**Myths**

1. No pain in babies
2. Children will get used to pain
3. Children don’t feel as much pain as adults
4. Can’t reliably describe their pain
5. Opiates are dangerous for children
6. If distractable, then no pain
7. If doesn’t look to be in pain...
8. Pain medication will delay diagnosis
9. Opioids hasten death

Ferrell et al, 2021

**What are the barriers to pain management?**

- Opioid phobia
- Over sedation
- Goals of care for cure
- They are not “dying”
- They are too “fragile”
- Cost

Yu et al, 2019; Sisk et al, 2020

**Why should we worry about pain management?**

- Quality of life/ comfort
- Functional status
- Poor wound healing
- Energy expenditure
- Family suffering

Koga C., et al., 2001
Assessment of Pain in the Seriously Ill Child

- Listen to the child, they can accurately report pain
- However, many may be nonverbal
- Pain scales – KNOW THEM and USE THEM
- Anticipate pain
- Reassess!

ASPMN recommendations for nonverbal children

- FLACC
- DSVNI
- NPASS
- COMFORT
- CRIES
- CHEOPS
- CHIPPs
- DEGR
- PIPP
- Riley

Brock, Wolfe, & Ulrich, 2018

Herr et al., 2011
Pharmacologic and Non-pharmacological Approaches

Guidelines on the Management of Postoperative Pain

Management of Postoperative Pain: A Clinical Practice Guideline

From the American Pain Society, the American Society of Regional Anesthesia and Pain Medicine, and the American Society of Anesthesiologists' Committee on Regional Anesthesia, Executive Committee, and Administrative Council

Chou et al., 2016

Major Recommendations:
1. Educate
2. Assess surgical history & analgesia history
3. Reassess

Multimodal analgesia
- Local anesthesia
- Oral opioids
- PCA is preferred for IV
- Cognitive modalities
- Physical modalities

Multi Modal Pharmacotherapeutics

- Perception
  - Cognitive
  - Imagery
  - Relaxation
  - Education

- CNS

- Peripheral Sensitization

- Transmission modulation
  - Central α agonists (clonidine)
  - TCAs
  - SNRIs/SSRIs
  - Opioids/tramadol
  - Anticonvulsants (Gabapentin)

- Local anesthetics

- TENS

- Multimodal analgesia
  - Local anesthesia
  - Oral opioids
  - PCA is preferred for IV
  - Cognitive modalities
  - Physical modalities

Argoff, 2002
Bovill, 1997
Simpson, 2008
Mao, Gold & Backonja, 2011
NSAIDs + Opioids

- Meta-analysis
- N = 789 patients (17 studies)
  - posterior lumbar discectomy, laminectomy, or spinal fusion.
  - 400 patients - NSAIDs + opioids
  - 389 patients - opioids alone
- Results: Patients receiving NSAIDs + opioids had lower pain scores and consumed fewer opioids than the group receiving opioids alone.

Analgesic Adjuvants

- Baclofen, methocarbamol or other muscle relaxant
- Steroids
  - Good for neurepathic, bone and visceral pain
  - Decadron is preferred (less Na and K effects)
- Anticonvulsants
  - Good for neurepathic pain
- Sub anesthetic dose Ketamine?
- NSAIDs
  - EMLA, LMX4, lidocaine patch
  - Inhibits movement of sodium ions across nerve
- Steroids
- Mucoadilla
- Tricyclic antidepressants
  - Good for neurepathic pain
  - Amitriptyline, Nortriptyline - sedation, give at night
- Local anesthetics
  - 0.5% bupivacaine
- Clonidine

Physical Modalities

- TENS
- Acupuncture
- Massage
- Cold therapy
### Table 4. Surgical Procedures With Evidence for Opioid-Free Recovery

<table>
<thead>
<tr>
<th>General surgery</th>
<th>Otolaryngology</th>
<th>Urology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Umbilical/epigastric hernia repair</td>
<td>Myringotomy</td>
<td>Circumcision</td>
</tr>
<tr>
<td>Pyloromyotomy</td>
<td>Urethral dilation</td>
<td>Hypospadias repair</td>
</tr>
<tr>
<td>Soft tissue excision</td>
<td>Circumcision</td>
<td>MEATOTOMY</td>
</tr>
<tr>
<td>Pectus bar removal</td>
<td>Central line placement</td>
<td></td>
</tr>
</tbody>
</table>

Chou et al., 2016

### Pharmacological: Analgesics

- **Mild pain**: (1-4)
  - Acetaminophen
  - Adjuvants
- **Moderate pain**: (5-6)
  - Acetaminophen/ibuprofen
  - Consider opioids
  - Adjuvants
- **Severe pain**: (7-10)
  - Acetaminophen/ibuprofen
  - Opioids
  - Adjuvants

### Opioid sparing protocols

**Thoracic surgery**

- Opioids
- NSAIDs and/or acetaminophen
- Gabapentin or pregabalin
- Lidocaine
- Perivertebral block
- Epidural with opioid +/- caine
- Cognitive modalities
- Physical modalities

Chou et al., 2016

### Benefits of IV PCA

- Consistent control of pain
- Decreased opioid
- Self-administered as needed boluses
- Improvement in patient satisfaction
- Reduced risk of opioid complications
- Increased patient satisfaction
- Increased patient satisfaction

Polomano RC et al., 2008
SAFETY OF PCA IN CHILDREN

- A meta-analysis showed that the addition of continuous (or background) infusion to the demand (or PCA bolus) dose for IV-PCA is not associated with a higher incidence of respiratory events than PCA bolus alone in pediatric patients (in contrast to adults).
  George et al, 2016

Non-pharmacological interventions

- Healing Touch/ Reiki
- Aromatherapy
- Massage
- Acupressure/ Acupuncture
- Swaddling/ kangaroo
- Music/ Art Therapy

Palliative Care
How can palliative care help?

- Primary palliative care
- Specialist palliative care
- Multimodal symptom management
- Integrative medicine supports
- Psychosocial supports
- Debriefings

Taylor et al, 2020

Summary

- Children with serious illness have pain!
- It is imperative to attend to that pain for quality of life, functional status, comfort, and to mitigate all forms of suffering.
- Use your palliative care resources

Questions

- Deborah Fisher, PhD, PPCNP-BC, CHPPN
  - dfisher@childrensnational.org
- Deborah Lafond, DNP, PPCNP-BC, CHPPN, FPCN, FAAN
  - dlafond@pandaedcon.org