Symptom Management

Project ECHO Core Competency

June 7, 2023

Drs. Kevin Weingarten & Natalie Jewitt
it’s nice to meet you...
Disclosures

• We will not be discussing pain
• Our talk today relies on you - our amazing audience
• Many medications used in pediatric palliative care are off-label
Objectives

At the end of this talk, the audience will be able to:

• Explain how goals of care impact symptom management strategies
• Describe symptom management strategies for:
  • Seizures
  • Feeding intolerance
  • Sialorrhea
  • Neuroirritability
  • Dyspnea
• Access resources specific to symptom management in pediatric palliative care
Where do you start when discussing symptom management?

...with a family’s goals of care
Prolong life  Comfort
Arevia is a 6-day-old, term baby girl with severe hypoxic ischemic encephalopathy.

Her breathing is stable on room air. She has intermittent seizures on maintenance phenobarbital. She has an uncoordinated suck and is deemed unsafe to orally feed.

You have been consulted for palliative care support.
How does this story unfold?
Seizure management

If focus is to prolong life...
   call neurology.

If focus is on comfort, consider...
   your route
   your location of care
   your maintenance
   your breakthrough
# Pediatric Palliative Care Approach to Pain & Symptom Management

Dana Farber Cancer Institute/Boston Children’s Hospital
Pediatric Advanced Care Team

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dosage Details</th>
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</table>
| **LORazepam** | 2mg/mL; 0.5mg, 1mg, 2mg tabs  
0.1 mg/kg (4–6 mg) PO/SL/PR/IV q15 min x 2 |
| **Midazolam** | 2mg/mL, 5mg/mL  
0.2 mg/kg SL, intranasal, or IV (10 mg) x 2; 5mg/mL with mucosal atomization device (MAD) for intranasal |
| **Diazepam** | 2.5mg, 5mg, 10mg rectal gel  
2–5 years: 0.5 mg/kg q15 minutes x 3  
6–11 years: 0.3 mg/kg q15 minutes x 3  
> 12 years: 0.2 mg/kg q15 minutes x 3 |
| Feeding |
|---------|------------------|
| If focus is to prolong life... | If focus is on comfort, consider... |
| insert a feeding tube. | oral care |
| | skin care |
| | counselling |
Arevia’s parents chose to pursue a G-Tube and a few years have passed.

Arevia has had ongoing difficulty with feeding intolerance and secretions. She has had multiple admissions to hospital with aspiration pneumonias.

You receive a page that Arevia is back in the ED with fever and respiratory distress.
How does this story unfold?
Secretion management

- Medications
  - Ophthalmic atropine 0.5-1%, 1-2 drops SL q4-6h
  - Glycopyrrolate 40-100mcg/kg/dose tid-qid
  - Scopolamine patch (1mg) behind ear q72h
- Salivary duct ligation
- Botox
- Decrease fluid intake
Feeding intolerance

‘start big and then titrate down’

consider softeners +/- stimulants

PEG 3350

...or constipation?
WHAT YOU NEED TO KNOW: CONSTIPATION

Slowing of the bowels causes stool to become hard, dry, and difficult to pass. This sometimes causes a large mass of impacted stool in the rectum (the part of the bowel that holds stool). Stool builds up behind the impaction and may leak liquid stool out of the anus, soiling a child’s underwear.

Contact your health-care provider if your child or youth:
- has severe pain or pain lasting longer than 30 minutes
- gets a fever
- has vomiting
- loses weight
- wakes up from sleep to pass stool
- keeps crying and you can’t soothe them
- develops cracks in the skin around the anus (anal fissure)
- has intestine drooping out the anus (rectal prolapse)
- is still having problems with constipation after following the above plan for two weeks
- has lots of blood in the stool

How is constipation treated?
Children and youth usually need medication for a few months, along with some other steps to resolve constipation. They can take medication by mouth or through the rectum (bum). We usually suggest medications by mouth. You won’t need a prescription, but you may have to ask the pharmacist for these medications.

Step 1: PEG3350 bowel clean out
The first step is to clean out the bowels using an oral laxative that has polyethylene glycol 3350 (PEG3350). Not all laxatives have this key ingredient, so read the label carefully. Some common brands that have PEG3350 are Lax-a-Day®, Restoralax®, Relaxa® and Clearlax®.

<table>
<thead>
<tr>
<th>Weight</th>
<th>Dose of PEG3350</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>7–10 kg</td>
<td>2 tsp in 100 mL fluid</td>
<td>Twice a day for 3 days</td>
</tr>
<tr>
<td>11–13 kg</td>
<td>3 tsp in 150 mL fluid</td>
<td>Twice a day for 3 days</td>
</tr>
<tr>
<td>14–19 kg</td>
<td>4 tsp in 200 mL fluid</td>
<td>Twice a day for 3 days</td>
</tr>
<tr>
<td>20–34 kg</td>
<td>5 tsp in 250 mL fluid</td>
<td>Twice a day for 3 days</td>
</tr>
<tr>
<td>35–50 kg</td>
<td>5 tsp in 250 mL fluid</td>
<td>3 times a day for 3 days</td>
</tr>
<tr>
<td>50+ kg</td>
<td>10 tsp in 500 mL fluid</td>
<td>3 times a day for 3 days</td>
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</tbody>
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Bowel clean out routine for children older than six months.
Feeding intolerance

• Consider formula alternatives or changes to feeding schedule
• Assess for and treat reflux
  • Test gastric pH
  • Start or optimize a proton pump inhibitor
  • Start or optimize a motility agent
• Assess candidacy for fundoplication or post-pyloric feeds
• Decrease total feed volume
Arevia is now 7 years old.

Family reports increasing episodes of irritability they cannot explain.

They worry about her quality of life.
How does this story unfold?
Neuroirritability (neuropain)

Unexplained irritability in neurologically impaired children

Only diagnosed after somatic pain sources have been ruled-out

Consider potential triggers
Neuroirritability (neuropain)

- Gabapentinoids
- Tricyclic antidepressants, Opioids, CloNIDine
- Methadone, Cannabanoids
Less than 1 year later, Arevia is back in the ED with increased work of breathing.

Family asks to see you.
How does this story unfold?
Dyspnea

- Subjective sensation of being unable to breathe adequately
- Usually accompanied by anxiety
- Does NOT correlate with RR, SPO2, blood gases
Dalhousie Dyspnea Scale
Dyspnea

Treat underlying cause based on goals of care

Resist the urge to crowd

Keep the room light

Position, position, position

Open a window or use a fan

Distraction and guided imagery
## Dyspnea

<table>
<thead>
<tr>
<th>Opioids</th>
<th>Benzodiazepines</th>
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<tbody>
<tr>
<td>25-50% of analgesic doses</td>
<td>Correlation between dyspnea and anxiety</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Oxygen</th>
<th>Other Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use controversial</td>
<td>Non-invasive ventilation</td>
</tr>
<tr>
<td>Oxygen vs room air</td>
<td>Radiation/steroids</td>
</tr>
<tr>
<td>Seems to be helpful when both dyspnea and hypoxia present</td>
<td></td>
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Resources

**Courageous Parents Network**

Pediatric Palliative Care Approach to Pain & Symptom Management

Dana Farber Cancer Institute/Boston Children’s Hospital Pediatric Advanced Care Team

**Basic Symptom Control in Paediatric Palliative Care – new edition May 2022**

**SickKids Paediatric Advanced Care Team (PACT)**
Reflections

1. What is your key takeaway from today’s session?

2. What is something new that you plan to apply to your clinical practice?

3. What challenges do you face in your practice when it comes to symptom management?

4. What have others found helpful?
References


• Heneghan et al. Dana Farber Cancer Institute / Boston Children’s Hospital Pediatric Advanced Care Team. Pediatric Palliative Care Approach to Pain and Symptom Management. 2020.


Thank you!