GASTROINTESTINAL SYMPTOMS IN CHILDREN WITH SEVERE PSYCHOMOTOR DISABILITY: VOMITING, RETCHING, PAIN, AND FEEDING INTOLERANCE
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Maruzza Congress
24 October 2018

Objectives
- Appreciate sources of these symptoms that go beyond gastroesophageal disease and constipation (Attitude)
- Discuss alterations in fluid and nutrition requirements due to decreased metabolic expenditure in such children (Knowledge)
- Practice a step-wise approach to feeding intolerance, including in the last months of life (Skill)

Neurological Impairment (NI)
- Indicated by developmental label cerebral palsy
- A result of a CNS insult hypoxic ischemic encephalopathy (HIE), anoxic encephalopathy, traumatic brain injury (TBI)
- Associated with a specific diagnosis genetic disorder, congenital anomaly, structural brain malformation, or metabolic disorder
Retching, Vomiting, GI Tract Pain

Sources of symptoms?

Risk for Feeding Intolerance

- Nociceptive GI tract pain sources
- Alterations in the areas of the CNS that regulate intestinal motility, the vomiting center, and sensory input
- Metabolic expenditure less than estimated: risk of over-feeding and excessive fluids
Central pain
Abrupt onset of pain “out of the blue,” *Gastrointestinal (GI) tract pain* with distention

**Visceral hyperalgesia**
Sensitization of visceral afferent pathways, *gut pain* with distention

**Dysautonomia**
Facial flushing, sweating, hyperthermia, vomiting, *gut pain*

**Nociceptive pain sources**
GERD, pancreatitis, gallstones, UTI, renal stones

**Vomiting reflex**
Receptors in the emetic pathway (Ach, D2, H1, 5HT2, 5HT3)

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**Retching, Vomiting, GI Tract Pain**

- Thalamus: viscerosensory transmission *(Central Pain)*
- Hypothalamus: regulation of heart rate, temp, GI tract, blood pressure *(Dysautonomia)*
  - Medulla: vasomotor and vomiting centers

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**Nausea/vomiting mechanisms**

[Diagram showing various mechanisms and receptors involved in nausea and vomiting]

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Medication Trials

<table>
<thead>
<tr>
<th>Antiemetics:</th>
<th>Block receptors involved in the emetic pathway Ach, D2, H1, 5HT2, 5HT3</th>
</tr>
</thead>
<tbody>
<tr>
<td>-- Cyproheptadine</td>
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<tr>
<td>-- Levomepromazine</td>
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<tr>
<td>-- Ondansetron</td>
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<tr>
<td>Gabapentinoid</td>
<td>Visceral hyperalgesia, Central neuropathic pain, Dysautonomia</td>
</tr>
<tr>
<td>Tricyclic antidepressant</td>
<td>Visceral hyperalgesia, Central neuropathic pain</td>
</tr>
</tbody>
</table>

Interventions for emesis and feeding intolerance

- PPI, H-2 blocker, bowel meds
- Pro-motility drugs
- Jejunostomy-tube
- Fundoplication
- Anti-emetics
- Neuropathic pain medications
- Decrease in calories and fluids
- Trials before J-tube or fundoplication

Growth in children with SNI: Unique Issues

- Growth charts: typically developing children with average muscle mass
- Children with SNI often have decreased muscle mass
- Greater proportion of fat deposit compared to muscle mass
“Required” Calories

<table>
<thead>
<tr>
<th>Resting energy expenditure (REE) X stress/activity factor</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>REE X 1.6</td>
<td>Ambulatory</td>
</tr>
<tr>
<td>REE X 1.1</td>
<td>Nonambulatory (CP)</td>
</tr>
<tr>
<td>REE X 0.8</td>
<td>Many with SNI</td>
</tr>
<tr>
<td>REE X 0.6</td>
<td>Hypothermia, hypotonia, limited movement</td>
</tr>
</tbody>
</table>

58 individuals with SNI

<table>
<thead>
<tr>
<th>58 post-pubertal individuals</th>
<th></th>
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<tbody>
<tr>
<td>Average BMI</td>
<td>19</td>
</tr>
<tr>
<td>Average Kcal/day</td>
<td>912 Kcal</td>
</tr>
<tr>
<td>Average BEE*</td>
<td>1202 Kcal</td>
</tr>
<tr>
<td>Average factor</td>
<td>0.77 (0.5 – 1.3)</td>
</tr>
<tr>
<td>Average Kcal/cm</td>
<td>6.2</td>
</tr>
<tr>
<td>Average creatinine</td>
<td>0.4 (0.2 – 0.6)</td>
</tr>
</tbody>
</table>

*Calculated using Harris-Benedict equations

“Required” Fluid

- Holliday-Segar method: based on average caloric estimates
- Metabolic expenditure: approximately 100 mls needed for each 100 Kcals
- Using weight in children with SNI: can over-estimate fluid requirement
Feeding reduction trial

- Improved comfort that results in decreased toning
- Following ITB pump placement
- Persistent vomiting or GI tract discomfort
- Edema without a cause
- Decline in health

Feeding reduction trial

- Fear of inadequate nutrition
- Fear of dehydration
- Cultural views of weight and health

Ileus or Edema at End of Life

- Ileus and/or edema without cause: 13 (38%)
  - Acute or recurrent ileus: N=10 (30%)
  - Edema: N=6 (18%)
- Assessment: metabolic panel, urine analysis and culture
  - 11: pre-existing decline in health, function, QOL
  - 2 with severe anoxic brain injury
- Management: review options, provide suggestions
**Intractable**: not easily relieved or cured

- Test and “Fix”
  - Urinary tract infection
  - Cholecystitis
  - Pancreatitis
  - Mechanical obstruction
- Modify with risk for intractable
  - Dysautonomia
  - Central pain
  - Visceral hyperalgesia
  - Medulla (emetic center)

**Neurophysiology is complex**

- Hypothalamus, Thalamus, Midbrain, Pons, Medulla regulation
  - Heart rate, blood pressure, temperature
  - Arousal
  - Central neuropathic pain
  - Vasomotor (hypothalamus, medulla)
  - Intestinal motility, vomiting
  - Respiratory center

**Recurrent Ileus**

- 18 year old with severe NI
  - Seizure disorder, G-tube feeds
- Chronic bowel dysmotility
- Recurrent ileus, new episode:
  - 1200 ml vented out of G-tube
- Prior goals of care
  - Comfort, do not hospitalize
Recurrent Ileus Care Plan

- Interventions for persistent abdominal distention with discomfort or vomiting:
  - Vent G-tube, hold use x4 hours
  - If no stool that day, give fleet enema
  - Give pedialyte at 40 ml/hour x4 hours then 70 ml/hour x 24-36 hours
  - Give acetaminophen every 4 hours x 3
  - Use prn morphine as needed
  - Update team

Feeding Intolerance

- 4 year old with hydranencephaly
- Persistent vomiting, retching, pain
- Interventions: management of constipation, PPI, metoclopramide, erythromycin, J-tube, ondanestron
- Negative evaluation
- Continued symptoms

Medication Trials

- Testable/treatable vs non-testable
- Unable to “fix” CNS problems
- Preparing and hoping
- Lessen mixed message
- Intractable problems require goals
Feeding Intolerance

- Symptom treatment plan:
  - gabapentin, cyproheptadine, morphine
  - 30% decrease medical fluids/nutrition
  - "Best she has looked in 6 months"

Feeding reduction trial

- Trial of reduced feeds
- Determine what is "needed"
- Low risk, information gained
- Time to lessen emesis, discomfort, or edema, while determining if transient or irreversible
- Modify versus “fix”

Recurrent Ileus Care Plan

- Interventions for persistent abdominal distention with discomfort or vomiting:
  - Vent G-tube, hold use x2 hours
  - If no stool that day, give bisacodyl supp
  - Give pedialyte at 20 ml/hour x4 hours then 30 ml/hour x24 hours
  - Give acetaminophen every 4 hours x 3
  - Use prn morphine as needed
  - Update team
Care Plan Details
- Presenting problem: distention, pain
- Routine interventions: vent G-tube
- Non-pharmacologic strategies:
  - GI tract distention as a trigger: as-needed suppository or enema, vent gastrostomy tube, hold feeds and give electrolyte replacement overnight, reduce total feeds/fluids
- As-needed medications: anti-emetic, ibuprofen, morphine, clonidine

Feeding Intolerance
- Symptom treatment plan:
  - gabapentin, cyproheptadine, morphine
  - 30% decrease medical fluids/nutrition
- “Best she has looked in 6 months”
- 4 months later: return of pain, vomiting, development of edema
- TPN trial being considered

Language Suggestions
- “These features worry me…”
- “The tests were normal. It is unlikely that there is a fixable reason for these symptoms. This can be due to the body shutting down or changes in the area of the brain that regulate the blood vessels and the gut. In some, this won’t improve.”

**Language Suggestions**

- "We will give an amount by G-tube that her body is more likely to tolerate. We will discuss what that means if she doesn’t…"
- "I’m glad we are protecting her from feeds/fluids that her body can’t process now
- Decision to hold feeds/fluids: no regret, "lesser of 2 evils", "the only thing that made any sense"


**Feeding Intolerance**

- She is "suffering" more than half of her days: "struggling", "fighting to stay alive", "uncomfortable", and needing to be held and repositioned often to be comfortable
- This is in contrast to 6 months ago when the majority of her days were "comfortable" and "happy"

**Language Suggestions**

- **Acknowledge emotion:** I see your distress, I am sorry for how hard this is for you.
- **Address the concern:** Holding feeds and fluids has lessened the swelling and fluid that was causing her so much discomfort.
- **Redirect to an achievable goal:** Her face looks so relaxed, do you have the same observation?
Conclusions

- Overfeeding can be a source of symptoms
- Edema is a feature at the end of life
- Feeding intolerance can become intractable
- Empirical feeding reduction by 30% or greater can improve comfort

Thank you!

Keep in touch!

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References and Further Reading

- Artificial feeding for a child with a degenerative disorder: a family’s view. The mother and grandmother of Frawnos, Arch Dis Child. 2005;90(9):979.
References


Hope is some extraordinary spiritual grace that God gives us to control our fears, not to oust them. Vincent McNabb