Nutritional Management of Children with Medical Complexity

Jordan Beaulieu, RD
September 7, 2023
I (we) would like to begin by acknowledging the land on which SickKids operates. For thousands of years it has been the traditional land of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, Toronto is home to Indigenous Peoples from across Turtle Island. SickKids is committed to working toward new relationships that include First Nations, Inuit, and Métis peoples, and is grateful for the opportunity to share this land in caring for children and their families.

Art by Emily Kewageshig
Presenter Disclosure

- Relationships with commercial interests:
  - None
Learning Objectives

• Describe Children with Medical Complexity (CMC)
• Briefly review nutritional assessment of CMC
• Discuss common interventions for the nutritional management of CMC
  • Growth and Anthropometrics
  • Gastrointestinal Issues
  • Enteral feeding
  • Blenderized Tube Feeding (BTF)
  • Micronutrient deficiencies
• Review guidelines for monitoring and follow up
Children with Medical Complexity (CMC)

Individuals with:
- Presence of ≥1 complex chronic conditions; often multisystem & severe
- Significant functional limitation requiring technology (e.g. feeding tube)
- High health care utilization from different providers
- Caregiver identified high health care service needs

Account for <1% of all children but significant health-spending

Dewan & Cohen, 2013
Nutritional Assessment of CMC

- **Anthropometrics**
  - Head circumference
  - Weight
  - Length (<2 years) & height (>2 years if ambulatory)
  - Segmental length
  - Body Mass Index (BMI)
  - Mid-arm circumference, triceps skinfold, mid-arm muscle mass

- ESPGHAN recommends using WHO growth curves
- Disease-specific curves are growth references with limitations
  - Small sample size
  - May be based on children already suffering from malnutrition
Estimating Energy Needs

- Recommended use of WHO equation and an activity factor of $1.1 \times$ Resting Energy Expenditure (REE)
- Use the following equations to determine REE*

<table>
<thead>
<tr>
<th>Age Range (years)</th>
<th>Males (kcal/d)</th>
<th>Females (kcal/d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – 3</td>
<td>$60.9W - 54$</td>
<td>$61.0W - 51$</td>
</tr>
<tr>
<td>3 – 10</td>
<td>$22.7W + 495$</td>
<td>$22.5W + 499$</td>
</tr>
<tr>
<td>10 – 18</td>
<td>$17.5W + 651$</td>
<td>$12.2W + 746$</td>
</tr>
</tbody>
</table>

*Use as a starting point and titrate feeds based on weight response

World Health Organization, 1985; Marchand, 2009

Healthier Children. A Better World™
Adjusting Energy

- Most children with NI have **decreased energy needs** compared to healthy children, even with spasticity.

- Guide recommendations based on response from therapy:
  - Excessive weight gain: decrease calories by ~10%.
  - Suboptimal weight gain: increase calories by ~10%.

- No standardized recommendations for frequency of follow-up:
  - More frequently for infants or unstable children (e.g. 1-3 months).
  - Less frequently for older, nutritionally stable children.
Adjusting Protein

Protein
- No guidelines have been developed for protein requirements in children with disabilities
- Patients are at risk for protein insufficiency
  - Are often already protein-wasted, due to inactivity and poor dietary intake
  - Low energy requirements/intake = low protein intake
  - Are at high risk for pressure ulcers, already have them

- Start with an estimation using the RDA/DRI
  - US National Pressure Ulcer Advisory Panel recommends (adults):
    1.25 – 1.5 g/kg

- Consider using high-protein formula for children with ulcers or low caloric requirement
  - Higher-protein and adult formulas
  - Combination of adult & pediatric formulas
  - Addition of protein modules ($)
Adjusting Fluid

Fluids

• Usual maintenance requirements may not be appropriate

• ↑要求ments due to excessive losses
  • Drooling
  • ++ Sweating

• ↓ requirements for patients with inactivity and muscle wasting

• Typically, 75-100% of maintenance may be adequate and can be adjusted based on clinical status
Children with Medical Complexity: GI/Nutrition Sequale

Chronic problems in 80-90% of children with CP or other NI include:

- Malnutrition
- Feeding disorders
- Gastroesophageal Reflux Disease (GORD/GERD)
- Constipation
- Delayed gastric emptying
- Diarrhea

Chong, 2001; Marchand et al., 2006; Sullivan, 2008; Penagini et al., 2015
Oral-Motor Issues

• Poor oral motor control
  • ↓ intake
  • ↑ aspiration risk

• Liquids are difficult to manage
  • Loss of liquid from front of mouth
  • Premature escape of bolus into oro-pharynx > aspiration risk
  • Often better with bottle feeding

• Purees easier to manage

• Immature chewing skills
  • Oral motor skills correlate with developmental level & not chronological age

Marcus & Breton, 2013
Multidisciplinary nutritional assessment of the neurologically impaired child:
- weight, length, triceps skinfold
- dietary history (e.g., meal duration)
- evaluation of oral motor function

Adequate nutrition
  - Safe
  - Unsafe
    - Systematic reevaluation (yearly or on indication)
  - Ensure consistency, positioning
  - Unsafe

Inadequate nutrition
  - Safe
    - Optimize intake
    - Inadequate nutrition
      - Tube feeding (supplementary vs. exclusive)
      - GORE (Gastroesophageal Reflux Disease)
        - No
          - Gastrostomy
        - Yes
          - Controlled (PPI, diet)
            - Gastrostomy
          - Not controlled (PPI, diet)
            - Gastrostomy with fundoplication
            - Jejunostomy
Clinical Signs of Swallowing Issues

- Coughing/choking with oral feeds
- Change in voice quality during oral feeds
- Poor secretion management
- Sudden, significant drop in oxygen saturation with oral feeds
- Sudden, significant drop in heart rate with oral feeds
- Resistance to oral feeding
- Recurrent chest infections
- Recurrent unexplained fevers

Is aspiration from above or below?

Marcus & Breton, 2013; Miller, 2011; Tutor & Gosa, 2012
Feeding & Swallowing Interventions

Thickening Liquids:
- Thickened liquids improve swallow function when:
  - Oral motor control is decreased
  - Pharyngeal response is slow or delayed
  - Airway protection is compromised during swallowing
  - Reduced sensory or cognitive awareness

Thickening purees:
- If pharyngeal clearance is an issue thicker purees may be worse

Khooshoo et al., 2001; Kuhlemeier et al., 2001; Logemann, 1998; Marcus & Breton, 2013
Feeding & Swallowing Interventions

- **Positioning:**
  - To maximize oral motor function, airway protection
  - To improve suck, swallow, breathe coordination

- **Bolus size/Method of presentation:**
  - Slow flow versus fast flow nipple
  - Spoon versus cup
  - Open cup versus spout or straw

- **Speed of presentation of bolus:**
  - Sequential swallows versus single swallows with cup
  - Pacing sucking bursts & pauses with bottle

- **Increase sensory input:**
  - Modify temperature, taste, bolus size, texture

Marcus & Breton, 2013
## Gastrointestinal Issues: Symptoms

<table>
<thead>
<tr>
<th>GI Issue</th>
<th>Symptoms affecting oral feeding</th>
</tr>
</thead>
</table>
| GERD                     | Pain or discomfort part way through feeds  
Feeds well at beginning of feed but limits intake  
Vomiting may or may not be seen                  |
| Delayed Gastric Emptying | Decreased hunger  
Nausea, Gagging  
Vomiting- sometimes hours after a feed            |
| Constipation             | Decreased hunger  
Nausea, Gagging  
Vomiting  
Abdominal pain |
| Diarrhea                 | Malabsorption  
Dehydration |

Marcus & Breton, 2013
<table>
<thead>
<tr>
<th>Gastrointestinal Issues: Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GI Issue</strong></td>
</tr>
<tr>
<td>--------------------------------------</td>
</tr>
</tbody>
</table>
| GERD                                  | Medication- Acid blocker, prokinetics  
Extensively hydrolyzed or amino acid-based formula  
Positioning  
Blenderized tube feeds  
Continuous feeds, Consider post-pyloric feeds |
| Delayed Gastric Emptying              | Prokinetics  
Extensively hydrolyzed or amino acid-based formula  
Blenderized tube feeds |
| Constipation                          | Ensure adequate hydration  
PEG 3350  
2-3 oz prune juice  
Increase fibre |
| Diarrhea                              | Use of probiotics  
W/U for bacterial overgrowth  
Extensively hydrolyzed or amino acid-based formula  
Blenderized tube feeds |

Arvedson, 2008; Chong, 2001; Marchand, 2006; Penagini et al., 2015; Sullivan, 2008; Vandenplas et al., 2009
Oral Feeding in Context

- Consider the overall goals of feeding:
  - Optimize nutrition & growth
  - Quality of life (child & family)
  - Improve safety of oral feeding
  - Increase oral motor skills +/- wean enteral nutrition

- Oral feeding goals may change over time
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To Tube Feed or Not to Tube Feed

• Energy boost
• Adjust feeding schedule to stimulate hunger & thirst
  • Set time limits; structure feeding times
• Trial different formula (change taste; improve tolerance)
• Guide appropriate food/fluid choices > work with feeding therapist/parent
• Ensure adequate fluid volume (maintenance fluid) & nutrient distribution
To Tube Feed or Not to Tube Feed

• Decision to initiate is multi-faceted:
  • Medical
  • Financial
  • Cultural
  • Emotional

• Interdisciplinary team required

• Supplemental vs total enteral nutrition (EN)

Adams et al., 2014
<table>
<thead>
<tr>
<th>Variable</th>
<th>Benefit</th>
<th>Challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Outcomes</td>
<td>Weight gain</td>
<td>Excessive weight gain</td>
</tr>
<tr>
<td></td>
<td>Improved respiratory status</td>
<td>GI complications</td>
</tr>
<tr>
<td></td>
<td>Assured route for provision of fluids &amp; meds</td>
<td>Respiratory complications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Difficulties with the tube</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Ability to focus on other activities than feeding</td>
<td>Discontinuation of PO feeding</td>
</tr>
<tr>
<td>Socialization</td>
<td>Improved alertness, more interaction</td>
<td>Loss of PO feeding as source of interaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feeding equipment - mobility</td>
</tr>
<tr>
<td>Caregiving &amp; stress</td>
<td>Ease caregiver burden</td>
<td>Intensity of care needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parental sleep</td>
</tr>
<tr>
<td>Parent-Child Relationship</td>
<td>Reduced frustration with PO feeding</td>
<td>Loss of emotional component to PO feeding</td>
</tr>
<tr>
<td></td>
<td>Improve relationship</td>
<td>Loss of normality of feeding</td>
</tr>
<tr>
<td>Parent-Medical System</td>
<td>Support of health care professionals</td>
<td>Systems utilization</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Difficulties with respite care</td>
</tr>
<tr>
<td>Other</td>
<td>Potential for family cohesion &amp; sibling involvement</td>
<td>Inadequate access to services &amp; support</td>
</tr>
</tbody>
</table>
Formula Selection

• Infants should receive expressed breast milk or infant formula

• Older children may use standard (1.0 kcal/ml) polymeric feeds

• Blenderized feeds/real-food containing formulas

ESPGHAN, 2017; Johnson et al, 2015; Soscia, 2021; Gallagher et al, 2018
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Treatment Options - GERD

- Change in formula e.g., casein -> whey based
- Consider use of hydrolyzed or amino-acid based feed for improved tolerance
- Change in kcal/rate/volume
- PPI – often higher doses are needed (gastric pH)
- Prokinetics
- Post pyloric feeds

**TABLE 4. Infusion rates based on Pedrón Giner et al (102) and NASPGHAN (106)**

<table>
<thead>
<tr>
<th>Age</th>
<th>Initial phase rate</th>
<th>Advance rate</th>
<th>Suggested tolerated rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preterm</td>
<td>0.5–2 mL·kg⁻¹·h⁻¹</td>
<td>0.2–1 mL/kg every 8 h</td>
<td>4–8 mL·kg⁻¹·h⁻¹</td>
</tr>
<tr>
<td>Infant</td>
<td>1–2 mL·kg⁻¹·h⁻¹</td>
<td>1–2 mL/kg every 2–8 h</td>
<td>5–6 mL·kg⁻¹·h⁻¹</td>
</tr>
<tr>
<td>1–6 y</td>
<td>1 mL·kg⁻¹·h⁻¹</td>
<td>1 mL/kg every 2–8 h</td>
<td>1–5 mL·kg⁻¹·h⁻¹</td>
</tr>
<tr>
<td>≥7 y</td>
<td>25 mL/h</td>
<td>25 mL every 2–8 h</td>
<td>100–150 mL/h</td>
</tr>
</tbody>
</table>

NASPGHAN. Pediatric Enteral Nutrition: A Comprehensive Review.
NASPGHAN. Pediatric gastroesophageal reflux clinical practice guidelines. 2018
What are Blenderized Tube Feeds (BTF)?

- Pureed whole food and liquids administered directly into the gastrostomy tube (G-tube)
- Can be sole source of nutrition, supplemental nutrition, or as a combination of BTFs & formula feeds
- Blenderized feeds have been shown to have benefits (social and physiological), but food safety must be considered, as well as additional cost
## Treatment Options – GERD + Blenderized Tube Feeds

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Profile</strong></td>
<td></td>
</tr>
<tr>
<td>Medically Stable</td>
<td>Medically unstable or acutely ill</td>
</tr>
<tr>
<td>• ≥1 year of age</td>
<td>x ≤85% IBW</td>
</tr>
<tr>
<td>• Uncontrolled reflux</td>
<td>x ≥5% weight loss in last month</td>
</tr>
<tr>
<td><strong>Feed Type</strong></td>
<td></td>
</tr>
<tr>
<td>• Gastrostomy tube ≥ 12 French</td>
<td>x Nasogastric tube (NGT)</td>
</tr>
<tr>
<td>• Continuous OR bolus feeds</td>
<td>x Naso-jejunal tube (NJT)</td>
</tr>
<tr>
<td>• Polymeric, semi-elemental, elemental</td>
<td>x Gastro-jejunal tube (GJ tube)</td>
</tr>
</tbody>
</table>
Implementing Blenderized Tube Feeds

Planning the Schedule:

• Current G-tube feeds may be:
  • Bolus
  • Continuous
  • Combination

• Options for incorporating BTFs:
  • BTFs as 1 meal/day
  • 50:50 (BTF:Commercial Formula)
  • 100% BTFs

• BTFs:
  • Must be given as bolus feeds
  • May be given in conjunction with continuous formula feeds
  • Some equipment is required
Implementing Blenderized Tube Feeds

Some Considerations:

• Ensure variety of foods to meet micronutrient needs
• Salt should usually be added (~1/4 teaspoon/day)
• Introduce whole grains gradually to avoid constipation
• Ensure adequate hydration
• Avoid seedy fruits and vegetables such as berries
• Thoroughly cook/store all foods appropriately
Monitoring Blenderized Tube Feeds

• Routine anthropometrics while establishing blend
  • Every 2-4 weeks while establishing feeds
  • Monthly-annually once established

• Bloodwork
  • Generally not routinely required if diet is diverse
  • Standard suggested bloodwork for clinical presentations (e.g. bone health labs in children with medical complexity)
Treatment Options – Delayed Gastric Emptying/Abdominal Distention

- Using G-tube to vent/decompress (syringe vs Farrell bag)
- Slowed feeds
  - Boluses <15ml/kg
  - Continuous <8ml/kg
- Extensively hydrolyzed/amino acid based formula
- Blenderized tube feeds
- Management of constipation
- Use of prokinetics

Mazzeo & Mascarenhas Curr Probl Ped Adol Health Care 2021; Phippen et al. BMJ Support Palliative Care 2017
Treatment Options - Constipation

• Formula/diet changes – blenderized tube feeds
• Addition of fluid if safe
• Initial clean out > maintenance treatment (PEG3350, lactulose)
• Additional fibre (can also cause intolerance, distention, flatulence)
• 2-3oz prune juice
• Medications
  • Used for slow transit constipation
  • Can also help improve feeding intolerance/nausea
Monitoring Micronutrients

- Prevalence of micronutrient deficiencies between 10-55% in CMC
- High risk for deficiencies of:
  - Iron
  - Zinc
  - Calcium
  - Vitamin D
  - Vitamin C
  - Vitamin E
  - Selenium
  - Vitamin B12
  - Folic Acid
- Recommendation to provide DRI for micronutrients – monitor yearly unless change in clinical status, growth
- *C-Reactive Protein
Monitoring Micronutrients – Bone Health

• Decreased bone mineral density noted in ~60% of children with NI
• Fragility fracture prevalence: 20% in non-ambulatory children with CP
• Dietary Ca, PO4, Vitamin D are below DRI in 50-80% of children with NI

• Yearly labs
  • Ionized Ca, PO4, 25-OHD, PTH, ALP, urinary calcium/creatinine ratio

• Supplement Ca intake to DRI
  • Monitor for complications (nephrocalcinosis/stones)

• Supplement 800-1000 IU of Vitamin D per day

Coppola et al., 2009; Fehlings et al., 2011; Marchand et al., 2009
Monitoring Micronutrients – Jejunal feeds

Children on long-term jejunal feeds:

- Asses 1-2 times/year:
  - Serum Cu + ceruloplasmin
  - Selenium
  - CBC+MCV/ferritin/STR/iron
  - Zinc
  - Albumin
  - CRP

- Supplement via G-tube or orally if possible
- Recheck levels after supplementation in 1-3 month intervals

Broekaert et al., 2019
Monitoring Micronutrients - Recommendations

- No evidence-based guidelines for nutrient allowances specific for CMC
- Standard recommendations of vitamins, minerals and trace elements can be followed with exception of vitamin D, given the increased risk of deficiency
- Other considerations:
  - If there are multiple micronutrient deficiencies, are you able to use a multivitamin vs individual supplements
  - When recommending a supplement, suggest checking what types/formulations are available online (amazon, well.ca) or at your local pharmacy to help guide families
  - Route of administration
  - Cost
European Society for Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment

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THANK YOU!!


References


References


