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**Critical Care Update: ASPEN/SCCM Guidelines**

Praveen Goday MBBS, CNSC, Medical College of Wisconsin  
Heather Skillman MS, RD, CSP, CNSC, Children’s Hospital Colorado  

**Arsenic and Soy, Oh Boy! What is the Science and What Do We Advise?**

Justine Turner MD, University of Alberta  
Wendy Elverson RD, Boston Children’s Hospital  

**Nutritional Evaluation and Management...Gastrostomy Tube Weaning**

Jessica Brown, RD Children's Hospital of Orange County  

**Breakout Sessions:**

- Motivational interviewing: Celiac disease  
  Ann Scheimann MD, MBA, Johns Hopkins University Medical School  

- Determining calorie, fluid and micronutrient needs for a child with severe special needs  
  Patricia Novak, MPH, RD, CLE, Nutrition Consultant  

**Pediatric Feeding Disorders: Guidelines**

Susanna Huh MD, Boston Children’s Hospital  
Colleen Lukens PhD, Children’s Hospital of Philadelphia  
Pamela Dodrill, PhD, CCC-SLP, Boston Children’s Hospital
I would like to welcome you all to the fifth annual NASPGHAN/CPNP Nutrition Symposium. We have an amazing program pulled together for our symposium this year. We’re so glad to have all of us together again for learning, networking and collaborating with our colleagues form other disciplines. We greatly appreciate everyone’s feedback from last year’s Symposium and hopefully this is the best year yet. We expanded the nutrition content available throughout the annual meeting to allow participants to take full advantage of their included registration to the NASPGHAN annual meeting. We’ve incorporated even more multi-disciplinary presentations. We’ve also increased the number of presentations focused on the daily application of our clinical knowledge for complex patients. Keep the great feedback coming so we can continue to provide a useful experience at the Symposium!

Our Council also continues to grow – we now have 175 members from throughout North America and Mexico, and we have made great strides towards our council goals. We’ve gotten much more involved in nutrition education and CME for our NASPGHAN colleagues, we’re just about to release our first Nutrition Pearls, and we continue to work on our web presence. We will have a brief council meeting again at this year’s Symposium. I encourage everyone to attend to learn about what we are currently doing and what we have planned next.

We hope you enjoy this year’s symposium. Please take advantage of the full meeting, including NASPGHAN and APGNN presentations. Next year, we’ll meet in Hollywood, FL – hope to see all of you there as well! Thank you so much for being here.

Sincerely,

Amber Smith, MBA, RD, CD
President, Council for Pediatric Nutrition Professionals
CPNP Founders
Thanks to the following companies for their support of this event and the establishment of the Council of Pediatric Nutrition Professionals

Abbott Nutrition

Dr. Schar

Mead Johnson Nutrition

Nestlé Nutrition

QOL Medical

Support for this year’s symposium has been generously provided by:

Abbott Nutrition

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Nestle
NASPGHAN/CPNP Nutrition Symposium
Friday, November 3, 2017

7:00am – 5:00pm Joint Sessions with APGNN/NASPGHAN See NASPGHAN Program
6:00pm Reception Neopolitan 2

NASPGHAN/CPNP Nutrition Symposium
Saturday, November 4, 2017

7:00am – 5:00pm Neopolitan 3 and 4

7:00am CONTINENTAL BREAKFAST AND BUSINESS MEETING

8:00am – 8:15am WELCOME
Justine Turner MD, MPH, NASPGHAN Nutrition Committee Chair

8:15am - 9:10am CRITICAL CARE UPDATE: ASPEN/SCCM GUIDELINES
Praveen Goday MBBS, CNSC, Medical College of Wisconsin
Heather Skillman MS, RD, CSP, CNSC, Children’s Hospital Colorado
Learning objectives:
1. Review the 2017 ASPEN Guidelines for nutrition in the critically ill child
2. Examine the evidence base for the recommendations in the guidelines

9:15am - 10:10am ARSENIC AND SOY, OH BOY: WHAT IS THE SCIENCE AND WHAT DO WE ADVISE?
Justine Turner MD, MPH, University of Alberta
Wendy Elverson RD, LDN, Boston Children’s Hospital
Learning objectives:
1. Review current evidence and gaps in knowledge regarding arsenic and soy recommendations for infants and children
2. Discuss how to address these concerns in practice

10:15am - 10:30am BREAK Exhibit Hall

10:30am - 12:00pm JOINT SESSIONS WITH NASPGHAN/APGNN

Obesity (NASPGHAN) Milano 5 - 6
Eosinophilic Esophagitis (NASPGHAN) Augustus 1 - 2
Liver (NASPGHAN) Augustus 3 - 4
IBD Nutrition (NASPGHAN) Augustus 5 - 6
Esophageal Motility (APGNN) Milano 1 - 2
Rumination (APGNN) Milano 1 - 2

12:00pm - 1:00pm LUNCH/POSTER SESSION/EXHIBITS
1:00pm - 1:50pm  NUTRITIONAL EVALUATION AND MANAGEMENT OF CHILDREN WITH FEEDING PROBLEMS DURING GASTROSTOMY TUBE WEANING
Jessica Brown RD, CSP, CNSC, CLEC, Children's Hospital of Orange County
Learning objectives:
1. Review the implementation and monitoring of gastrostomy tube weaning in the pediatric population
2. Discuss nutritional strategies used during the gastrostomy tube weaning process
3. Identify resources for parent education on age-appropriate eating.

2:00pm - 3:10 pm  Breakout Sessions:
(Each attendee will have option to pick (3) 20 minute sessions)
1. **Oral abstract presentations**  Octavius 19
   Session 1
   CHILDHOOD OBESITY PREVENTION IN WIC: OUTCOMES OF THE MA-CORD STUDY
   Jennifer Woo Baidal
   PRELIMINARY EXPERIENCE OF THE MODIFIED ATKINS DIET FOR CHILDREN WITH PRADER-WILLI SYNDROME
   Grace Felix
   Session 2
   HIGH N-6:N-3 FATTY ACID RATIOS IN PRETERM INFANTS FROM A COASTAL SAN DIEGO POPULATION DESPITE MATERNAL N-3 DIETARY ENRICHMENT
   Jae Kim
   SYSTEMATIC REVIEW OF HYPERSENSITIVITY TO PARENTERAL NUTRITION, by Vikram Jacob Christian
   Session 3
   PREVALENCE AND RISK FACTORS OF VITAMIN B12 DEFICIENCY AMONG CHILDREN WITH INTESTINAL FAILURE: A CASE CONTROL STUDY
   Lissette Jimenez
   RISK FACTORS FOR COPPER DEFICIENCY IN PEDIATRIC INTESTINAL FAILURE PATIENTS RECEIVING PARENTERAL NUTRITION: A LONGITUDINAL ANALYSIS
   Megan McGivney

2. **Motivational interviewing Pearl for Practice:**  Octavius 20
   Application in Celiac disease
   Ann Scheimann MD, MBA, Johns Hopkins University Medical School
   Learning objectives:
   1. Review principles of MI including counseling skills
   2. Discuss how to successfully implement MI with the Celiac patient

3. **Sharing patient education materials:** Apps, handouts, websites
   Topics: Obesity and inflammatory bowel disease  Octavius 21
   Abigail Lundin MS, RD, UCSF Benioff Children's Hospital of Oakland
   Learning objectives:
   1. Exchange ideas on treatment of obesity and IBD with social media, apps, website, and fitness trackers.
   2. Discuss improving outcomes for educating patients/families by interactive sharing of education materials.
4. **Determining calorie, fluid and micronutrient needs for a Octavius 22 child with severe special needs**
   Patricia Novak, MPH, RD, CLE, Nutrition Consultant
   Learning objectives:
   1. Review nutrient requirements for severely developmentally delayed child
   2. Identify potential nutrient deficiencies
   3. Discuss ways to implement nutrition recommendations

3:15pm - 5:00pm  **PEDIATRIC FEEDING DISORDERS: GUIDELINES**
Susanna Huh MD, Boston Children’s Hospital
Colleen Lukens PhD, Children’s Hospital of Philadelphia
Pamela Dodrill, PhD, CCC-SLP, Boston Children’s Hospital
Learning objectives:
1. Review why a new definition for Pediatric Feeding Disorders is needed and explain the definition of Pediatric Feeding Disorder
2. Describe how adoption of this new paradigm will improve growth and nutrition outcomes in children with Pediatric Feeding Disorder
3. Describe the four integral domains involved: (1) Medical (2) Nutrition (3) Feeding skill (4) Psychosocial
Critical Care Update:
A.S.P.E.N. / SCCM Guidelines

Heather E. Skillman, MS, RD, CSP, CNSC
Children’s Hospital Colorado

Praveen S. Goday, MBBS, CNSC
Medical College of Wisconsin

Disclosures

• Praveen Goday has the following disclosures:
  – Fresenius Kabi (past)
  – Shire Pharmaceuticals
  – Nutricia
• Heather Skillman has the following disclosures:
  – Honorarium received from ASPEN and Colorado Society for Parenteral and Enteral Nutrition for speaking at the respective conferences in 2017

Introduction

• Guidelines
  – American Society for Parenteral and Enteral Nutrition (ASPEN)
  – Society of Critical Care Medicine (SCCM)
• Guideline group
  – physicians, nurses, pharmacists, dietitians, and statisticians
Process

• 2032 citations scanned
  — PubMed/MEDLINE, EMBASE
• 16 randomized controlled trials and 37 cohort studies chosen
• GRADE criteria (Grading of Recommendations, Assessment, Development, and Evaluation)

GRADE methodology

<table>
<thead>
<tr>
<th>Quality of Evidence</th>
<th>Weighing risks vs benefits</th>
<th>GRADE recommendations</th>
<th>Clinical Guideline Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>High to very low</td>
<td>Net benefits outweighs harms</td>
<td>Strong</td>
<td>We recommend</td>
</tr>
<tr>
<td>High to very low</td>
<td>Trade-offs for patients are important</td>
<td>Weak</td>
<td>We suggest</td>
</tr>
<tr>
<td>High to very low</td>
<td>Uncertain trade-offs</td>
<td>Further research needed</td>
<td>We cannot make a recommendation at this time</td>
</tr>
</tbody>
</table>
Target of the guideline

- Critically ill child (>1 month and <18 years) expected to require a length of stay ≥2–3 days
- Not intended for neonates or adult patients

Nutrition assessment of the critically ill child

Evidence

<table>
<thead>
<tr>
<th>Design</th>
<th>Aim</th>
<th>Primary findings N = 1622</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prospective Observational Cohort</td>
<td>To determine the influence of BMI z score on: 1) 60-day mortality 2) Hospital-acquired infections 3) Length of hospital stay 4) Mechanical ventilation-free days</td>
<td>17.9% - underweight 14.5% - overweight 13.4% - obese</td>
</tr>
<tr>
<td></td>
<td></td>
<td>60 day mortality: Higher in underweight</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hospital acquired infection: Higher in underweight and obese</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ventilator free days (VFD): Underweight with 1.3 fewer VFD than normal weight</td>
</tr>
</tbody>
</table>

Bechard, 2016
Guideline

• Q1A: What is the impact of nutritional status on outcomes in critically ill children?
• R1A: Malnutrition and obesity are associated with adverse clinical outcomes
• Patients in the PICU should undergo detailed nutritional assessment within 48h of admission
• Nutrition status of patients should be re-evaluated at least weekly throughout hospitalization

Guideline

• Q1B: What are the best practices to screen and identify patients with malnutrition or those at risk of nutritional deterioration in the PICU?
• R1B: Validated screening methods for the PICU population to identify patients at risk of malnutrition must be developed
• Weight and length on admission, head circumference <36 months
• Z-scores for BMI-for-age (weight-for-length <2 years), or weight-for-age (if accurate height is not available)

Interpretation

• Both underweight and overweight status have been associated with worse morbidity and mortality
• Use of a uniform approach to defining pediatric malnutrition is imperative
• A validated method to screen critically ill children for malnutrition risk may help allocate resources to high-risk patients
• Periodic nutrition re-evaluation is essential
Energy Requirement and Delivery in the PICU

Evidence

• Energy target
  – Mechanically ventilated, critically ill children
  – N=500, multicenter, mean age: 4.5 ± 5.1 years
    • Enteral energy intake >67% prescribed goal associated with reduced mortality
  – N=107, ARDS, median age: 5.2 (IQR 1-10.4) years
    • Energy intake >80% Schofield equation by day 3 associated with reduced mortality

Mehta, 2012; Wong, 2016

Guideline

• **Q2A:** What is the recommended energy requirement for critically ill children?

• **R2A:** Measured energy expenditure by indirect calorimetry (IC) should be used to determine energy requirements and guide prescription of the daily energy goal
### Guideline

**Q2B: How should energy requirement be determined in the absence of IC?**

- **R2B:** Most published predictive equations are inaccurate and lead to unintended overfeeding or underfeeding.
- Schofield or FAO/WHO/UNU equations may be used without the addition of stress factors.
- Harris-Benedict, and RDA/DRI should not be used.

### Guideline

**Q2C: What is the target energy intake in critically ill children?**

- **R2C:** At least two-thirds of the prescribed daily energy requirement by the end of the first week in the PICU.
- Cumulative energy deficits in the first week of critical illness are associated with poor clinical and nutritional outcomes.
- Prevent cumulative caloric deficit or excess: individualize requirements, timely initiation and attainment of energy targets.

### Interpretation

- Use measured energy expenditure by IC, or Schofield or FAO/WHO/UNU *without* stress factors to determine energy requirements.
- Achieving delivery of 100% of energy requirements may not be needed.
- Avoid adverse outcomes with iatrogenic underfeeding and overfeeding.
**Protein Requirement in Critically Ill Children**

**Evidence**

<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Age</th>
<th>PRO Intake</th>
<th>Method</th>
<th>PRO Balance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Van Waardenburg, 2009</td>
<td>18</td>
<td>4 wk–12mo</td>
<td>2.8g/kg/d</td>
<td>IC, UUN</td>
<td>Positive</td>
</tr>
<tr>
<td>De Betue, 2011</td>
<td>18</td>
<td>4wk–12mo</td>
<td>3.1g/kg/d</td>
<td>Isotope</td>
<td>Positive</td>
</tr>
<tr>
<td><strong>Cohorts</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Botran, 2011</td>
<td>41</td>
<td>1mo–16 yrs</td>
<td>3.1g/kg/d</td>
<td>IC, UUN</td>
<td>Improved</td>
</tr>
<tr>
<td>*Chaparro, 2016</td>
<td>74</td>
<td>0–16 yrs</td>
<td>1.5g/kg/d</td>
<td>TUN</td>
<td>Positive</td>
</tr>
<tr>
<td>*Wong, 2016</td>
<td>107</td>
<td>1-10 yrs</td>
<td>1.5g/kg/d</td>
<td>EN PRO delivery</td>
<td>Improved PICU outcomes</td>
</tr>
</tbody>
</table>

IC – Indirect Calorimetry; UUN – Urine Urea Nitrogen; Total Urea Nitrogen; *Combined EN + PN

**Guideline**

- **Q3A:** What is the minimum recommended protein requirement for critically ill children?
- **R3A:** A minimum protein intake of 1.5 g/kg/d
- Protein intake >1.5 g/kg/d has been shown to prevent cumulative negative protein balance
- To attain a positive protein balance, infants and young children may require much higher doses
Guideline

• **Q3B**: What is the optimal protein delivery strategy in the PICU?

• **R3B**: Provide protein early in the course of critical illness to attain protein delivery goals and promote a positive protein balance

• Higher protein intake may be associated with lower 60-d mortality in mechanically ventilated children

Guideline

• **Q3C**: How should protein delivery goals be determined in critically ill children?

• **R3C**: The optimal protein dose associated with improved clinical outcomes is not known

• **RDA** protein is not recommended in critically ill children

Interpretation

• Association between protein intake and balance

• Negative protein balance may result in loss of lean muscle mass, which may lead to poor outcomes

• No significant increase in renal function markers with variations in protein dosing

• Adequacy of enteral protein intake is associated with improved survival
Provision of Enteral Nutrition in Critically Ill Children

Evidence

• Is EN feasible in critically ill children?
  – Initiation of EN within 48-72 hours of PICU admission

<table>
<thead>
<tr>
<th>Study</th>
<th>Children</th>
<th>N</th>
<th>EN by 48 hrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Petrillo-Albarano, T; 2006</td>
<td></td>
<td>91</td>
<td>100%</td>
</tr>
<tr>
<td>Lopez-Herce, J; 2006</td>
<td></td>
<td>526</td>
<td>62%</td>
</tr>
<tr>
<td>Mehta, NM; 2012</td>
<td></td>
<td>440</td>
<td>72%</td>
</tr>
<tr>
<td>Mikhailov, TA; 2014</td>
<td></td>
<td>5105</td>
<td>27%</td>
</tr>
<tr>
<td>Mehta, NM; 2015</td>
<td></td>
<td>985</td>
<td>60%</td>
</tr>
<tr>
<td>Canarie, MF; 2015</td>
<td></td>
<td>444</td>
<td>80%</td>
</tr>
</tbody>
</table>

Evidence

Challenges to Optimal Enteral Nutrition

- Availability of EN
- Feasibility of EN
- Feasibility of EN interruptions
### Evidence

- **Is EN feasible in critically ill children?**
  - The provision of EN and use of vasoactive drugs

<table>
<thead>
<tr>
<th>King, W; 2004</th>
<th>Patients N=91</th>
<th>Panchal, A; 2014</th>
<th>Fed N=188</th>
<th>Nonfed N=151</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dopamine: &lt; 6 µg/kg/min</td>
<td>5%</td>
<td>VIS score Day 1</td>
<td>10</td>
<td>15&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
<tr>
<td>Dopamine: ≥ 6 µg/kg/min</td>
<td>31%</td>
<td>VIS score Day 2</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Dopamine + NE</td>
<td>42%</td>
<td>VIS score Day 3</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Dopamine + NE + EPI</td>
<td>6%</td>
<td>VIS score Day 4</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

*VIS: Vasoactive-inotropic score; <sup>a</sup>p < 0.05

### EN in Critically Ill Children

- **Does EN benefit this group?**
  - Improved survival has been reported with optimal energy and protein intake by the enteral route.

<table>
<thead>
<tr>
<th>Mikhailov, TA; 2014</th>
<th>N = 5105</th>
<th>5.3%</th>
<th>EEN&lt;sup&gt;a&lt;/sup&gt; pts. less likely to die; OR 0.51</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wong, JJ; 2016</td>
<td>N = 107&lt;sup&gt;b&lt;/sup&gt;</td>
<td>54%</td>
<td>Mortality ↓ to 35% and 14%&lt;sup&gt;c&lt;/sup&gt;</td>
</tr>
<tr>
<td>Mehta, NM; 2012</td>
<td>N = 500</td>
<td>8.4%</td>
<td>Mortality ↓ if energy intake &gt; 33%&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Mehta, NM; 2015</td>
<td>N = 1245</td>
<td>6.5%</td>
<td>Mortality ↓ if protein intake &gt; 60%&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>a</sup>EEN: Early enteral nutrition on 25% of goal; <sup>b</sup>Cohort of ARDS pts.; <sup>c</sup>If caloric and protein intake of 80% REE and 1.5 g/kg<br> <sup>d</sup>Percentage of adequacy intake: intake/prescribed.

### EN in Critically Ill Children

- **What is the optimum method for advancing EN in the PICU population?**
  - Use of a stepwise algorithmic approach

<table>
<thead>
<tr>
<th>Study Design, population</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Petrolo-Albarano, T; 2006</td>
<td>Retrospective, Before-after protocol; 91 &amp; 93 pts.</td>
</tr>
<tr>
<td>Meyer, R; 2009</td>
<td>Prospective, After protocol of 355 pts. over 4 periods</td>
</tr>
<tr>
<td>Hamilton, S; 2014</td>
<td>Prospective, Before-after protocol; 80 &amp; 80 pts</td>
</tr>
<tr>
<td>Kaufman, J; 2015</td>
<td>Prospective, Before-after protocol; 108 &amp; 260 pts. S1&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>e</sup>S1: Stage 1 palliation for single ventricle physiology
EN in Critically Ill Children

• What route (gastric or small bowel) of EN feeding is best?

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Population</th>
<th>Time to start feeds</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Horn, D; 2003</td>
<td>RCT</td>
<td>45 pts.; continuous (N=22) vs. intermittent (N=23)</td>
<td>NS*: stool volume, diarrhea, vomiting, use of prokinetics</td>
<td></td>
</tr>
<tr>
<td>Horn, D; 2004</td>
<td>RCT</td>
<td>45 pts.; continuous (N=22) vs. intermittent (N=23)</td>
<td>NS: volume of formula (mL/kg/d) or GRV/kg in 72 h</td>
<td></td>
</tr>
<tr>
<td>Meert, K; 2004</td>
<td>RCT</td>
<td>74 pts MV*: gastric (N=32) vs. small bowel (N=42, then 35)</td>
<td>NS: Percentage of aspiration or feeding intolerance</td>
<td></td>
</tr>
<tr>
<td>Sanchez, C; 2007</td>
<td>Prospective</td>
<td>526 pts. on transpyloric feeds; early &lt; 24 h (N=202), late &gt; 24 h (N=324), 10 y study</td>
<td>Early group: Less days in SPN (0.2 vs. 0.9 days); and abdominal distention (3.5% vs. 7.8%)</td>
<td></td>
</tr>
</tbody>
</table>

*: RCT: Randomized controlled trial; *: Non-significant; GRV: Gastric residual volume; MV: Mechanical ventilation; SPN: Supplemental parenteral nutrition

• When should EN be initiated?

<table>
<thead>
<tr>
<th>Author</th>
<th>Design</th>
<th>Population</th>
<th>Time to start feeds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Briassoulis, G; 2005</td>
<td>RCT</td>
<td>PICU, N=50</td>
<td>12 hrs</td>
</tr>
<tr>
<td>van Waardenburg, D; 2009</td>
<td>RCT</td>
<td>PICU, N=20</td>
<td>24 hrs</td>
</tr>
<tr>
<td>Sánchez, C; 2007</td>
<td>Prospective</td>
<td>PICU, N=526</td>
<td>24 hrs</td>
</tr>
<tr>
<td>López-Herce, J; 2008</td>
<td>Prospective</td>
<td>PICU, N=65</td>
<td>24 hrs</td>
</tr>
<tr>
<td>Petrillo-Albarano, T; 2006</td>
<td>Retrospective</td>
<td>PICU, N=93</td>
<td>6 hrs</td>
</tr>
<tr>
<td>Michailov, T; 2014</td>
<td>Retrospective</td>
<td>PICU, N=1515</td>
<td>48 hrs</td>
</tr>
<tr>
<td>Canarie, M; 2015</td>
<td>Retrospective</td>
<td>PICU, N=444</td>
<td>48 hrs</td>
</tr>
</tbody>
</table>

Guideline

Q4A: Is EN feasible in critically ill children?

R4A: EN is preferred in the PICU
  – EN is feasible
  – Can be safely delivered to critically ill children including those receiving vasoactive medications

• Interruptions to EN should be minimized
Guideline
• **Q4B**: What is the benefit of EN in critically ill children?

• **R4B**: Improved clinical outcomes associated with
  – Early initiation of EN (within 24–48 hrs of PICU admission)
  – Achievement of up to two-thirds of the nutrient goal in the first week of critical illness

Guideline
• **Q5A**: What is the optimum method for advancing EN in the PICU?

• **R5A**: Use a stepwise algorithmic approach to advance EN

• The stepwise algorithm must include
  – bedside support to guide the detection and management of EN intolerance
  – the optimal rate of increase in EN

Guideline
• **Q5B**: What is the role of a nutrition support team or a dedicated dietitian in optimizing nutrition therapy?

• **R5B**: A nutrition support team, including dedicated RD, should be available
  – timely nutrition assessment
  – optimal nutrient delivery
  – optimal nutrient adjustments
Guideline

- **Q6A**: What is the best site for EN delivery: gastric or small bowel?
- **R6A**: Gastric route is the preferred site for EN
  - Insufficient data
- **Postpyloric route**
  - unable to tolerate gastric feeding
  - high risk for aspiration
- **No recommendation**
  - continuous vs intermittent gastric feeding

Guideline

- **Q6A**: When should EN be initiated?
  - **R6B**: EN should be initiated in all critically ill children within the first 24–48 h after PICU admission, unless contraindicated
  - Use of institutional EN guidelines
    - eligibility for EN
    - timing of initiation
    - rate of increase
    - detecting and managing EN intolerance

Interpretation

- EN is feasible in the PICU
  - Interruptions should be minimized
- Use of a stepwise algorithmic approach decreases time of initiation of EN and increases nutrition goal intake
- There is a benefit of survival of enteral adequacy for caloric and protein intake
Parenteral Nutrition in Critically Ill Children

Evidence

- Single large RCT
- Three-center RCT (PEPaNIC)
  - ~700 receiving early PN (within 24 hours)
  - ~700 receiving late PN (not given until day 8)
- Inclusion criteria
  - Expected ICU stay ≥ 24 hours
  - Moderate to high risk of malnutrition (≥ 2 on STRONGkids)

Fivez 2016
Evidence

- Results of PEPaNIC trial
  - No difference in mortality
  - In children receiving late PN
    - Lower rate of acquisition of a new infection
    - Shorter stay in the PICU
    - Shorter duration of mechanical ventilation
    - Lower need for renal-replacement therapy

Evidence

- Overall limitations
  - Only 24% of late PN cohort was still in the PICU by day 8
  - Proportion of severely malnourished children likely low

- Nutrition limitations
  - Majority of children had energy expenditure estimated using equations
  - Majority of children were receiving significant EN by day 4
  - Different glycemic control protocols in each centers

- Outcomes limitations
  - Non-standard definitions of acquired infections
  - Presence of indwelling devices not reported
  - New vs infection present at baseline?
Guideline

• **Q7A:** What is the indication for and optimal timing of PN in critically ill children?

• **R7A:** Do not initiate PN within 24 h of PICU admission

Guideline

• **Q7B:** What is the role of PN as a supplement to inadequate EN?

• **R7B:** In children tolerating EN, advance EN stepwise and delay commencement of PN

• Unknown
  – Supplemental PN to reach a specific energy goal
  – Timing of supplemental PN when EN is insufficient

Interpretation

• Supplemental PN should be delayed until 1 wk
  – normal baseline nutrition
  – low risk of nutrition deterioration

• PN supplementation for children who are unable to receive any EN during the first week

• Supplemental PN in the first week
  – severe malnutrition
  – risk of nutrition deterioration
  – unable to advance past low EN volumes
Practical application of these guidelines

Nutrition Status and Screening

- Use a uniform approach to defining pediatric malnutrition
- Complete nutritional assessment within 48h of admission
- Periodically re-evaluate nutritional status and requirements

Energy

- Recommend IC to assess energy requirement
- In the absence of IC, use Schofield or FAO/WHO/UNU equations without the addition of stress factors
- Achieve target of at least two-thirds of the prescribed energy requirement by the end of the first week in PICU
- Prevent cumulative caloric imbalance
  - individualization of requirements
  - timely initiation
  - attainment of targets
Protein

- Provide a minimum protein intake of 1.5 g/kg/d
- Provide up to 3 g/kg/d in infants and young children
- Provide protein early in the course of critical illness
- Do not ramp-up protein or wait to supplement

Enteral Nutrition

- Promote EN as the preferred mode of nutrient delivery in critically ill children
- Initiate EN within 24-48h and achieve up to two-thirds of the goal in the first week in the PICU
- Use a step-wise algorithmic approach to advancing EN
- Consider the gastric route as the preferred site for EN

Role of Nutrition Team/PICU RD

- Be available in PICU as part of the nutrition support team or as a dedicated PICU dietitian
- Perform timely nutrition assessments to optimize nutrient delivery
- Make adjustments according to response to nutrition delivery and the course of illness
**Parenteral Nutrition**

- Avoid initiation of PN within 24h of PICU admission in critically ill children, advance EN step-wise
- Provide PN to children unable to receive any EN in the first week after PICU admission
- Supplement inadequate EN with PN in the first week in malnourished children
- Delay PN initiation until 1 week for patients with normal baseline nutrition at low risk for deterioration

---

**Thank you!**

**Questions?**
ARSENIC & SOY: WHAT IS THE SCIENCE AND WHAT DO WE ADVISE?

Wendy Elverson RD LDN  
Boston Children's Hospital  
Justine Turner MD PhD  
University of Alberta

Disclosures

• Wendy Elverson – no financial relationships with a commercial entity to disclose

• Justine Turner – no financial relationships with a commercial entity to disclose

Objectives

• Talk about two controversial ingredients for infants and children
  – Why parents worry
  – What we need to know
    • So we know when to worry
    • So we can give sound nutritional advice
A PARENT ASKS...

- Is it ok that we are thickening baby Jane’s (4 months old, 2 month corrected) formula with rice cereal? Is this the best choice?
WHAT IS THE MEDICAL SCIENCE?

**Inorganic Arsenic (As):** highly toxic & bioavailable

**Organic As:** toxicity less understood, less bioavailable

**Young Children at Increased Risk**
- Vulnerable periods of growth and development
- Greater exposure to diet contaminants per kg weight
- Dietary patterns that increase exposure
- Longer post-exposure lifespan
Infant and Child Exposure

European Food Safety Authority determined 1% increased risk for lung, skin, bladders cancers and skin disorders if consuming 0.3-0.8 mcg/kg/d As.

Exposure and Risk

Organic and Brown Rice

Wu et al, Epidemiology, 2015

Karagas et al, JAMA Pediatrics, 2016

Signes-Pasor et al, Food Chemistry, 2016

Dask et al, Science of the Total Environment, 2017

Axagio et al, JAMA Pediatrics, 2016
Health Outcomes

No association with increased cancer risk or cardiovascular disease risk in US population?

– Based on Nurses Health Study Populations I & II (1984-2010)
– and male Health Professionals Population Study (1986-2008)

Murade et al, AUCN, 2015

Trends in Exposure

• Retail sales of rice in the United States (U.S.) were US$2.8 billion in 2011 compared to US$2.4 billion in 2006
• The average American eats plain rice 1.5 times a month
• Non-White Americans have the highest rates of rice consumption: 71% Asian, 59% Black, 47% Hispanics and 27% White Americans eat rice
• Consumers are increasingly choose foods that are whole grains, high fiber, organic, gluten-free
• High arsenic levels have been found in U.S. rice, due to farming on soil that was once treated with pesticides for cotton farming (South Central Gulf region)

Fig. 1. Global and Asian per capita rice consumption, data source: FAO; world database (2000) and U.S./U.S. population database (2005).

NPD Group - National Eating Trends® Database 2010

THE SCIENCE IN PRACTICE
Parent Question

• Is it ok that we are thickening baby Jane’s (4 months old, 2 month corrected) formula with rice cereal? Is this the best choice?

FDA Recommendations

• April 1st, 2016
• Proposed limit iAs in infant rice cereals
  – <100 ppb

• Are these recommendations strict enough?
Thickening with Rice Cereal and Infants

- Indications
  - Dysphagia
  - GERD
  - Aspiration risk
- Risks of not thickening
  - G-tube feeding dependence
  - Aspiration
  - Respiratory failure
  - Oral aversion

Oral Feedings has Better Outcomes than Gastrostomy Tubes.

- Retrospective, 114 patients (documented aspiration via VFSS)
- Median admissions: Oral (1) and Gtube fed (2)
- Days inpatient: Oral (2) and Gtube (24)
- No difference in pulmonary related admissions between the two groups
- Bias in study (increased co-morbidities in G tube group)

AAP Guidelines on Thickeners

“Until more data regarding arsenic are available, interim advice is needed regarding alternatives to rice cereal as a thickening agent for use in feedings for infants and older children. Following review of current evidence and deliberation, the group reached a consensus that oatmeal be used as the preferred thickener instead of rice cereal”
Are these recommendations practical???

### Thickeners

<table>
<thead>
<tr>
<th>Thickener</th>
<th>Ingredients</th>
<th>Challenge</th>
<th>Estimated cost/4 fl. Oz. bottle (Nectar thick)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant rice</td>
<td>Rice</td>
<td>Potential arsenic concern</td>
<td>7 cents</td>
</tr>
<tr>
<td>Infant oat</td>
<td>Oat</td>
<td>Clumps</td>
<td>7 cents</td>
</tr>
<tr>
<td>Simply Thick*</td>
<td>Xanthan gum, sodium benzoate</td>
<td>NEC association/cost. Use is controversial in infants.</td>
<td>35 cents</td>
</tr>
<tr>
<td>Gel Mix®</td>
<td>Carob bean gum</td>
<td>Needs to be heated. Can’t prepare in advance. Not recommended before 6 months or beyond nectar thick</td>
<td>48 cents</td>
</tr>
<tr>
<td>Think it Clear®</td>
<td>Xanthan gum</td>
<td>Controversial for infants</td>
<td>NA</td>
</tr>
<tr>
<td>Think it®</td>
<td>Corn (Maltodextrin, modified food starch)</td>
<td>Gritty texture. Controversial for infants.</td>
<td>NA</td>
</tr>
</tbody>
</table>

### Thickening and Exposure

- **FDA 2014**: 76 samples of Infant Rice Cereal
- **Range of results**: 20.8-176 ppb. Average 103 ppb
- **Ppb = ug/kg**
- **1 Tbsp. Rice cereal = 4 grams (2.5-4) = 0.4 ug**
- **6 month old boy, 50th%ile WT/age on nectar thick**
  - WT: 8kg
  - 24 fl. Oz. Formula per day = 12 tablespoons rice cereal
  - 4.8 ug inorganic arsenic = 0.6 ug/kg/d

[European Food Safety Authority determined 1% increased risk for lung, skin, bladder cancer and skin disorders if consuming 0.3-0.8 mcg/kg/d.](https://www.fda.gov/Food/FoodborneIllnessContaminants/Metals/ucm319870.htm)
Parent Question

• Is it ok if my 5 year old daughter with cow’s milk protein allergy and celiac disease drinks rice milk as a primary beverage and eats quite a bit of rice products?

Avoid Panic

Consumer Reports 2012
Inorganic Arsenic in rice and rice products

<table>
<thead>
<tr>
<th>Rice Product</th>
<th>Origin</th>
<th># of brands</th>
<th># of Samples</th>
<th>Inorganic Arsenic (ppb)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White, long grain enriched</td>
<td>Missouri</td>
<td>1</td>
<td>3</td>
<td>41</td>
</tr>
<tr>
<td>White, Basmati</td>
<td>India</td>
<td>3</td>
<td>9</td>
<td>55</td>
</tr>
<tr>
<td>White, Jasmine</td>
<td>Thailand</td>
<td>2</td>
<td>6</td>
<td>70</td>
</tr>
<tr>
<td>Long/extra long grain Enriched</td>
<td>Louisiana, Arkansas, Texas</td>
<td>4</td>
<td>13</td>
<td>97</td>
</tr>
<tr>
<td>White, Basmati</td>
<td>California</td>
<td>1</td>
<td>4</td>
<td>32</td>
</tr>
<tr>
<td>Short grain, Brown</td>
<td>California</td>
<td>1</td>
<td>3</td>
<td>300</td>
</tr>
</tbody>
</table>
Brown Rice (Consumer Reports 2012)

<table>
<thead>
<tr>
<th>Rice Product</th>
<th>Origin</th>
<th># Brands</th>
<th># samples</th>
<th>Inorganic Arsenic (ppb)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short grain</td>
<td>California</td>
<td>1</td>
<td>3</td>
<td>61</td>
</tr>
<tr>
<td>Long grain</td>
<td>Missouri</td>
<td>1</td>
<td>4</td>
<td>147</td>
</tr>
<tr>
<td>Long grain/Whole grain/Basmati</td>
<td>Arkansas/Louisiana/Texas</td>
<td>4</td>
<td>12</td>
<td>153</td>
</tr>
</tbody>
</table>

Rice Based Products (FDA testing 2012)

<table>
<thead>
<tr>
<th>Product</th>
<th>Samples tested</th>
<th>As (ug) per serving</th>
<th>ug/Kg/d (18 kg child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non dairy rice drinks</td>
<td>65</td>
<td>3.3</td>
<td>0.18</td>
</tr>
<tr>
<td>Grain based bars</td>
<td>86</td>
<td>1.7</td>
<td>.09</td>
</tr>
<tr>
<td>Rice cakes</td>
<td>59</td>
<td>4.3</td>
<td>.23</td>
</tr>
<tr>
<td>Baking mixes (muffin/cake)</td>
<td>24</td>
<td>3</td>
<td>.16</td>
</tr>
<tr>
<td>Pasta</td>
<td>23</td>
<td>6.6</td>
<td>0.37</td>
</tr>
<tr>
<td>Rice (Basmati)</td>
<td>53</td>
<td>3.5</td>
<td>0.19</td>
</tr>
</tbody>
</table>

5 year old GF, CMF (18 Kg)

- Sample rice products in one day recall
  - Breakfast: 1 glass of rice milk
  - Lunch: ½ cup rice (white basmati, California)
  - Snack: Cereal bar made with brown rice syrup
  - Dinner: ½ cup dry rice pasta prepared
  - Snack: 1 cup rice milk, 1 serving rice cakes

- Estimated Arsenic Consumption: 18.4 ug = ~1 ug/kg/d
General Recommendations for Limiting Inorganic As Intake: Fruits and Vegetables

- Variety
- Wash
- Limit or avoid juice (apple and pear may be higher than other juices). US limit for juice is 10 ppb.
- Consider peeling beets, turnips, carrots, radishes and potatoes
- Home gardens: test soil

http://www.dartmouth.edu/~arsenicandyou/Dartmouth-Toxic-Metals-Superfund-Research-Program

General Recommendations for Limiting Inorganic As Intake: Rice

- Consider choosing white Basmati rice from India, Pakistan or California
- Rinse, Rinse, Rinse *
- Vary grains
- Limit consumption of packaged foods containing: rice flour, brown rice syrup and rice
- Cook like pasta (using 6x water)

* Test well water

http://www.dartmouth.edu/~arsenicandyou/Dartmouth-Toxic-Metals-Superfund-Research-Program

Gluten Free Whole Grains

- Amaranth
- Buckwheat
- Corn
- Millet
- Montina
- Quinoa
- Oats
- Sorghum
- Teff

**Flax seed and chia seed are not whole grains but have nutrition profiles very similar to whole grains
Rice Free Gluten Free Flour Blend

- ½ cup potato starch
- ¼ c tapioca starch
- 2 tbsp. amaranth or millet flour
- 2 tbsp. sorghum flour

- Courtesy of Oonagh Williams - Chef/Instructor
  - Merrimack NH 603-424-6412

A PARENT ASKS...

- My infant is allergic to cow’s milk protein. We are paying for extensively hydrolyzed formula out of pocket. My baby tried soy yogurt and tolerated it well. Can we give her soy formula instead of her current formula?

WHAT IS THE POPULAR SCIENCE?
WHAT IS THE MEDICAL SCIENCE?

The Modern Soybean

Poor Protein quality
IMPROVED

High Phytates content
competes with mineral
REDUCED Phytates and
FORTIFIED

Rich in Phytoestrogens
Like isoflavones
Reproductive function?

High Aluminum &
Manganese Content
CAUTION
RENAI FUNCTION
Neurodevelopment?
Evidence of Nutritional Safety

• Modern Soy Formula for healthy term infants compared to Cow Milk Formula
  – Equivalent growth
  – Equivalent bone mineral accrual
  – Equivalent immune function
  – Equivalent cognitive and behavioral outcomes school age
  – Equivalent educational outcomes adulthood

Systematic Reviews
Vandenplas et al, British Journal of Nutrition, 2014
Mendez et al, AJCN, 2002

... and lack of evidence

• Very low birth weight infants limited and small trial data suggests poor weight gain Naude et al, South African Medical Journal, 1979
• and increased risk of osteopenia of prematurity

Evidence in Allergy

• Common antigen FPIA, FPIES, FPE (with CMP)
  Nowak-Wegrzyn et al, Journal of Allergy: Clinical Immunology, 2015
• Uncommon IgE mediated allergen in children Katz et al, Clinical Reviews in Allergy and Immunology, 2014
• No role in allergy prevention De Silva et al, Allergy, 2014
• If used for CMP allergy, no benefit for acquisition CMP tolerance Bern Coates et al, Journal of Pediatrics, 2013
Where the Evidence is Murky...

- Soy formula = high exposure to isoflavones
  
  - Isoflavones have adverse effects reproductive function rodents, sheep, marmosets...
  
  - Biological activity human infants uncertain
  
  - Early menarche/menstrual duration/discomfort

Cao et al, Journal of Exposure Science and Environmental Epidemiology, 2009
Badger et al, Journal of Nutrition, 2002
Adjent et al, Paediatric and Perinatal Epidemiology, 2012; Strom et al, JAMA 2001

THE SCIENCE IN PRACTICE

A PARENT ASKS...

- My infant is allergic to cow’s milk protein. We are paying for extensively hydrolyzed formula out of pocket. My baby tried soy yogurt and tolerated it well. Can we give her soy formula instead of her current formula?
Where We Stand: Soy Formulas

The American Academy of Pediatrics (AAP) finds that isolated soy protein-based formulas are as safe and nutritionally equivalent alternative to cow's milk formula for term infants whose nutritional needs are met from breast milk.

The AAP specifically recommends the use of soy formulas for the following:

- Term infants with galactosemia or hereditary lactase deficiency
- Term infants with documented transient lactase deficiency
- Infants with documented immunoglobulin E-mediated allergy to cow milk who are not also reactors to soy protein
- Infants seeking a vegetarian-based diet for a term infant

The use of soy protein-based formula is not recommended for the following:

- Preterm infants with birthweights less than 1500 g
- Prevention of colic or allergy
- Infants with cow milk protein induced enterocolitis or enteropathy

Around the Globe and Phytoestrogens

**United Kingdom**
- Soy formula not recommended speak to your doctor about other alternatives
- Soy may be recommended by your doctor if your baby won't take other formulas or if you choose a vegan diet for your baby

**Canada**
- Breast milk, first choice
- CMPA: protein hydrolysate formula (Cost may be prohibitive)
- Consider limit soy to; those with galactosemia, cultural or religious preference.

**ESPGHAN**
- Severe persistent lactose intolerance
- Galactosemia
- Vegan diet preference
- Can be an option after 6 months of age if eHF formula refused due to taste or if cost a limiting factor.


Cost of Formulas

<table>
<thead>
<tr>
<th>Type of formula</th>
<th>Volume</th>
<th>Cost (approximate)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cow's milk based</td>
<td>658 g can</td>
<td>$27/ ~160 fl. Oz.</td>
</tr>
<tr>
<td>Soy based</td>
<td>658 g can</td>
<td>$28/ ~158 fl. Oz.</td>
</tr>
<tr>
<td>Extensively hydrolyzed</td>
<td>658 g (1.9 x 343 g cans)</td>
<td>$53/ 150 fl. Oz.</td>
</tr>
<tr>
<td>Amino Acid based</td>
<td>658 g (1.6 x 400 g cans)</td>
<td>$64/155 fl. Oz.</td>
</tr>
</tbody>
</table>

Based on non generic US brand.
Let's Compare
(Unsweetened/fortified)

<table>
<thead>
<tr>
<th>Beverage</th>
<th>Calories</th>
<th>Prot</th>
<th>Fat</th>
<th>Calcium</th>
<th>Vitamin D</th>
<th>Cost per 32 fl. Oz.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almond milk</td>
<td>30</td>
<td>1.5</td>
<td>2.5</td>
<td>300</td>
<td>100</td>
<td>$1.50</td>
</tr>
<tr>
<td>Coconut milk</td>
<td>45</td>
<td>0</td>
<td>4.5</td>
<td>100-300</td>
<td>100</td>
<td>$1.39</td>
</tr>
<tr>
<td>Hemp milk</td>
<td>80</td>
<td>2</td>
<td>8</td>
<td>300</td>
<td>100</td>
<td>$3.99</td>
</tr>
<tr>
<td>Oat Milk</td>
<td>130</td>
<td>4</td>
<td>2.5</td>
<td>350</td>
<td>100</td>
<td>$2.19</td>
</tr>
<tr>
<td>Pea milk</td>
<td>100</td>
<td>8</td>
<td>4.5</td>
<td>450</td>
<td>125</td>
<td>$2.86</td>
</tr>
<tr>
<td>Rice milk</td>
<td>70</td>
<td>0</td>
<td>2.5</td>
<td>250</td>
<td>100</td>
<td>$1.89</td>
</tr>
<tr>
<td>Soy milk</td>
<td>80</td>
<td>7</td>
<td>4</td>
<td>300</td>
<td>100</td>
<td>$1.85</td>
</tr>
</tbody>
</table>

*Added sugar may be necessary if higher calorie beverage if necessary.

Bioavailability of Calcium

- Calcium source:
  - Soy beverages: Calcium carbonate
  - Pea, Almond, Coconut, Hemp, Flax: Tricalcium phosphate
- Minimal Studies:
  - Heaney et al. JADA 2005


Controversial Ingredients: Conclusion

- Are the risks biologically plausible?
- Does evidence of risk - beyond animal studies or retrospective diet studies in humans - exist?
- Is that data relevant to your patient?
- Can you address these concerns with sound nutrition advice?

NOT MILK?
LIMIT Factory and Processed foods

Variety’s the very spice of life, that gives it all it's flavour.”

— William Cowper
Disclosures

I have no financial relationships with a commercial entity to disclose.

Objectives

- Review the implementation and monitoring of gastrostomy tube weaning in the pediatric population
- Discuss nutritional strategies used during the gastrostomy tube weaning process
- Identify resources for parent education on age-appropriate eating
Survey Results

- Results of a 2016 national survey from the ASPEN Enteral Nutrition Weaning Consensus Statement Committee
- Illustrate current weaning practices amongst professionals across the United States.

Prerequisites for Tube Weaning

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making progress eating</td>
<td>77%</td>
</tr>
<tr>
<td>Appropriate weight for length/height</td>
<td>55%</td>
</tr>
<tr>
<td>Demonstrating appropriate growth</td>
<td>86%</td>
</tr>
<tr>
<td>Tolerates bolus or intermittent feeds</td>
<td>67%</td>
</tr>
<tr>
<td>Medically stable</td>
<td>86%</td>
</tr>
<tr>
<td>Safe swallow on clinical evaluation</td>
<td>92%</td>
</tr>
<tr>
<td>Other</td>
<td>8%</td>
</tr>
</tbody>
</table>


Early Intervention = Better Outcomes

**Growth Assessment Prior to Wean**

- Children should be appropriately nourished prior to tube weaning
- Pt's typically do not gain weight until 3 months post treatment
- Pt's may present with weight loss during g-tube weaning
- CHOC – our goal is generally >90% IBW

---


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**Quotes from parents**

- “I feel like I’ve failed as a parent”
- “I don’t know what to do”
- “He’s never going to eat that”
- “My dining room is a battle zone”
- “I feel like I’ve failed as a parent”
- “It’s just easier for me to feed him while he’s watching TV”
- “The people in the drive thru know me by name – I go every day because that’s all she will eat”
Importance of the Interdisciplinary Team

• Gastroenterologist
• Nurse
• Nurse Practitioner
• Speech Language Pathologist
• Occupational Therapist
• Registered Dietitian
• Psychologist
• Social Worker
• Parent/Caregiver

Members of the Weaning Process

N = 196

<table>
<thead>
<tr>
<th>Professional</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric Psychologist</td>
<td>42%</td>
</tr>
<tr>
<td>Pediatric Speech/OT</td>
<td>72%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>67%</td>
</tr>
<tr>
<td>Nurse Practitioner/PA</td>
<td>34%</td>
</tr>
<tr>
<td>Nurse</td>
<td>34%</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>67%</td>
</tr>
<tr>
<td>Dietitian/DTR</td>
<td>93%</td>
</tr>
<tr>
<td>Parent/Caregiver</td>
<td>73%</td>
</tr>
<tr>
<td>Other</td>
<td>7%</td>
</tr>
</tbody>
</table>


CHOC Multidisciplinary Feeding Program

Physician/Nurse Practitioner
Oversees medical and pharmaceutical interventions. Manages common conditions such as reflux, constipation, and hydration as well as instances of acute illness (e.g., fever, vomiting).

Psychologist
Provide psychotherapeutic interventions to assist the child and family with anxiety and behavior management. Provide consultation and support to improve parent-child relationship.

Clinical Social Worker
Assist families with adjustment to the inpatient program and provide psychosocial support to facilitate positive coping and response to feeding interventions.
CHOC Multidisciplinary Feeding Program

Occupational and Speech Therapy
Lead feeding therapy sessions and provide parents with strategies to facilitate improved mealtime interactions.

Registered Dietitian
Determine calorie and fluid needs, monitor growth and nutritional status, and provide guidance during the GT weaning process to optimize nutritional intake.

Child Life Specialist
Provide developmental play opportunities (e.g., food play, art therapy) to assist the child with his/her adjustment to the hospital stay.

The Art of Tube Weaning

“The magic of tube weaning is in the work of the therapists – Speech, Occupational Therapy and Psychology. The medical provider’s job is to diagnose and treat underlying disorders and work with the diettitian to monitor the progressive decrease in calories by tube, to facilitate a smooth transition off the tube.”

– Sarah Edwards, DO
Clinical Nutrition Week 2017

SO....HOW DO WE HELP?
Optimizing Hunger

1. Structured meal & snack schedule
2. Consolidate gtube feeding regimen
3. Systematic gtube reduction
4. Appetite stimulants
5. Manage constipation
6. Blenderized tube feedings

Structured Mealtimes

- 3 meals & 2-3 snacks
- No grazing
- Set schedule
- Limit mealtime duration
- Family-style meals at table

Tube Feeding Consolidation

- Tube feedings should be provided during or after oral opportunities are offered
- Tube feedings should be initiated while the patient is seated at the table
  - Child starts to associate eating at the table and satisfying hunger
- Consider a higher calorie formula (1.5 kcal/cc)
Systematic Gtube Reduction

- Intensive inpatient tube weaning programs\(^1\)
  - Tube feedings are decreased by \(\geq 50\%\) on admission, and further reduced throughout the admission

- Outpatient setting\(^2\)
  - Tube feeding reduction follows a more conservative step-wise approach to promote hunger while minimizing weight loss.
  - Initiating tube weaning may be started at a 10-25% reduction


Hunger Provocation

- Randomized cross-over study
- Group A
  - 2-wk inpt hunger provocation
  - TF Decr by 50% on admit
  - TF DC’d by HD #6
  - Structured mealtimes 4-5x/day
- Group B
  - 4-wk outpt feeding program
  - TF Decr by 20-25%
  - Seen by same multidisciplinary team 1x/wk for 4wks

Hunger Provocation

- Success defined as
  - ≥75% orally fed at end of treatment
  - 100% orally fed & gaining wt at 6mo
  - Allowed 15% wt loss
- Group A: 82% (9/11) were successful
  - Average wt loss of 8.8%
- Group B: 9% (1/11) were successful
  - 10/11 reassigned to Group A w/ 100% success
    - Average wt loss of 5.9%
- Overall:
  - Group A: 86% (18/21) were successful (p<0.001)
  - Group B: 9% (1/11) were successful


Rapid Tube Weaning Program

- Inpatient tube weaning program
  - Length of stay is 10-14 day
- Psychologists feed 3 meals/day, 7 days/wk
- RD monitors calorie intake, weight, hydration
- Daily wt
  - Acceptable wt loss of <5%
- Monitor USG, urine ketones, BG
- Risks for appetite manipulation
  - Dehydration (60% USG >1.020)
  - Acute malnutrition
  - Acute anorexia secondary to ketoacidosis (45% >trace ketones)
  - Acute hypoglycemia (15% BG <50mg/dL)

Alan Silverman, Ph.D. Children’s Hospital of Wisconsin Feeding Program: 2017 Pediatric Feeding Conference, Nationwide Children's

Appetite Stimulant

- Cyproheptadine
- Ensure pt has adequate oral motor skills prior to use
- To sustain effectiveness - cycle use
  - 5 days on, 2 days off
  - 2wks on, 1 wk off
- Potential side-effects
  - Drowsiness
  - Excitability
### Appetite Stimulant

Use of Cyproheptadine in Young Children with Feeding Difficulties and Poor Growth in a Pediatric Feeding Program

<table>
<thead>
<tr>
<th>Feeding Behaviors</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eats more</td>
<td>39 (48)</td>
</tr>
<tr>
<td>Accepts more food variety</td>
<td>11 (13)</td>
</tr>
<tr>
<td>Easier to feed</td>
<td>11 (13)</td>
</tr>
<tr>
<td>Asks more food</td>
<td>9 (11)</td>
</tr>
<tr>
<td>Self-feeds more</td>
<td>9 (11)</td>
</tr>
<tr>
<td>No change</td>
<td>3 (4)</td>
</tr>
</tbody>
</table>

Parental report of feeding behavior changes during cyproheptadine treatment (n=82)


### Constipation Management

- Constipation suppresses appetite
- Decreasing tube feeds also decreases fluid administration
- Add water as needed to TF regimen during weaning
- Monitor stool pattern
- Monitor hydration
  - Daily weights
  - Food Logs
  - Urine dips PRN

### Table 1

<table>
<thead>
<tr>
<th>Demographics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyproheptadine</td>
<td>24 (30)</td>
</tr>
<tr>
<td>Polystyrene glycol/MOM</td>
<td>9 (30)</td>
</tr>
</tbody>
</table>

**Legend:**
- GT = gastroschisis tube
- MOM = Milk of Magnesia
- PP = proton-pump inhibitor
- SD = standard deviation

As reported from medical records.

*Used for transient hyporesponsivity.


Copyright © 2017 by European Society for Pediatric Gastroenterology, Hepatology, and Nutrition and North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition.
Short Term Outcomes Using Blenderized Tube Feedings Among Gastrostomy Dependent Children

- Retrospective chart review was completed for 50 gtube dependent pt's, who initiated BTF at CHOC from 2013 to 2015.
- 7 pt's were excluded d/t pending f/u with GI.
- Pt's on full blends and pt's on combination feeds were included.
  - Combination feeds were defined as a mixture of commercial formula and blenderized food.

Table 1: Demographics

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>24</td>
<td>56</td>
</tr>
<tr>
<td>Female</td>
<td>19</td>
<td>44</td>
</tr>
<tr>
<td>Age at Initiation</td>
<td>5 yr</td>
<td></td>
</tr>
<tr>
<td>Reason for Blends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent request</td>
<td>28</td>
<td>65</td>
</tr>
<tr>
<td>Provider request</td>
<td>20</td>
<td>47</td>
</tr>
<tr>
<td>Formula intolerance</td>
<td>11</td>
<td>26</td>
</tr>
<tr>
<td>Abnormal stooling</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Natural alternative</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Full Blends</td>
<td>20</td>
<td>47</td>
</tr>
<tr>
<td>Combination Feeds</td>
<td>23</td>
<td>53</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding Problems/Dysphagia</td>
<td>39</td>
<td>91</td>
</tr>
<tr>
<td>Vomiting/Reflux/Fundoplication</td>
<td>31</td>
<td>72</td>
</tr>
<tr>
<td>Constipation</td>
<td>15</td>
<td>35</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>26</td>
<td>60</td>
</tr>
</tbody>
</table>

Poor tolerance of tube feedings
Improvement prevalence and 95% confidence intervals among patients with full blends and combination feeds

Bennett et al. JPEN. 2015;61(2):s203-s204.

## Blenderized Tube Feeding Outcomes

<table>
<thead>
<tr>
<th>Study/Year</th>
<th>Study Design</th>
<th>n</th>
<th>GI Symptoms</th>
<th>Change in BMI z -score</th>
<th>Kcals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bennett et al 2015</td>
<td>Retrospective</td>
<td>43</td>
<td>100% ↓ abn stool 82% ↓ gtube intolerance 88% ↓ vomiting</td>
<td>-0.13 (-0.5 wt/age)</td>
<td>Plan to ↑ 1.2x</td>
</tr>
<tr>
<td>Gallagher et al 2015</td>
<td>Prospective feasibility</td>
<td>16</td>
<td>71% had emesis at start, ↓ to 50%</td>
<td>-0.206</td>
<td>↑ 1.5x</td>
</tr>
<tr>
<td>Pentuik et al 2011</td>
<td>Retrospective</td>
<td>33</td>
<td>52% had &gt;75% ↓ retching 73% had ≥ 50% ↓ retching</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>CHOP/2015 NASPGHAN Presentation</td>
<td></td>
<td></td>
<td></td>
<td>↑ 1.15-1.2x</td>
<td></td>
</tr>
</tbody>
</table>

## Improved Oral Intake

Figure 2. Change in oral intake in children (n = 33) using the pureed by gastrostomy tube diet as reported by their parents. NPO = nil per os (ie, nothing by mouth).

Published in: Scott Pentuik, Therese O’Flaherty; Kathleen Santoro; Paul Willging; Ajay Kaul; JPEN J Parenter Enteral Nutr 35, 375-379.
DOI: 10.1177/0148607110377797
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Oral Blends

Chocolate Banana Smoothie (45 kcal/oz)
1 cup Milk, 2%
¼ cup Black beans
¼ cup Spinach, raw
½ item Banana
2 pieces Dates
2 TBS Cocoa powder
2 TBS Honey
1 TBS Almond butter
1 TBS Flax seed meal

Berry Oatmeal Smoothie (24 kcal/oz)
1 cup Kefir
½ cup Juice
½ cup Berries
½ cup Mango
¼ cup Oats, dry
½ item Avocado
1 TBS Wheat Germ
1 TBS Honey

Behavioral Modification

• Long-term enteral nutrition dependence may lead to eating behavior disorder\(^1\)
• Therefore, hunger provocation may not be as effective if provided as the sole modality to tube weaning
• Study reporting better outcomes when:\(^2\)
  − Tube feedings were decreased by 25% from baseline
  − Behavioral modification techniques were implemented

Parent Training

- Parental training is an important treatment modality for complicated feeding disorders

Continuum of Parent Participation in therapy

1. Indirect Observation: parent is watching the meal, but child is unaware
2. Direct Observation: child is aware that parent is present in the room during meal
3. Co-leading: therapist assigns parent a role during the meal
4. Parent leads meal with therapist present in the room
5. Parent leads meal with therapist observing indirectly and able to provide verbal prompts via earpiece

Nutrition Monitoring

- During wean (inpatient)
  - Daily calorie counts
  - Daily weights
- Follow-up after wean
  - 3-day food record analysis at 3 months
  - Weight checks
    - 2 weeks
    - 1 month
    - 3 month
Monitoring During Wean – Survey Data

- Frequency of Monitoring
  - 26% Weekly
  - 23% Couple times a month
  - 19% Monthly

- Who monitors wean?
  - 48% Entire team
  - 29% Dietitian
  - 20% Physician
  - 5% Nurse Practitioner
  - 3% SLP/OT

Acceptable Weight Loss During Weaning (1-3 months)

- N = 163

Tracking Progress of a Wean

- N = 184
Oral Supplements

- Use of oral supplements as a foundation to tube weaning
  - Bridge nutritional requirements while oral intake of solid foods increase
- Encourage a variety of flavors to prevent taste-fatigue or jagging
- Goal:
  - Meet caloric requirements
  - Wean supplement stepwise

Anchor Foods: Tools for the RD

- Targeting nutrients
  - Fortified dairy or dairy substitute
  - Cereal or enriched grain
  - Brightly colored fruit or vegetable
  - Protein Food

Berall G, Milano K. EC Nutrition. 2015

Sample Food Record – 1200 calories
Anchor Foods: Tools for the RD

- Targeting nutrients
  - Fortified dairy or dairy substitute
  - Cereal or enriched grain
  - Brightly colored fruit or vegetable
  - Protein Food

1 Waffle + spread
1 ½ slices Bread
1 ½ cup Crackers
1/4 oz Pretzels
1 ½ TBS Peanut butter
4 Chicken Nuggets
1/3 cup Broccoli + oil
1 ½ cup Strawberries

Meets ≥80% of DRI's for 4-8 year old for vitamins, minerals, EFA - Except Vitamin D

Food Group Patterns

Food Group Patterns

USDA Food Patterns

For maximum benefit to children, include a variety of foods. This means eating a variety of foods from each of the Food Groups. Eating foods that are high in fiber and lower in sugars and fats is important. Fortifying foods is helpful in making foods more nutritious.

Diet Analysis using Food Groups

<table>
<thead>
<tr>
<th>Food Group</th>
<th>Goal</th>
<th>Intake</th>
<th>% of Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grains</td>
<td>5 oz</td>
<td>2 1/4 oz</td>
<td>45</td>
</tr>
<tr>
<td>Vegetables</td>
<td>2 cups</td>
<td>1 cup</td>
<td>50</td>
</tr>
<tr>
<td>Fruit</td>
<td>1 1/2 cups</td>
<td>1 cup</td>
<td>66</td>
</tr>
<tr>
<td>Dairy</td>
<td>2 1/2 cups</td>
<td>1 2/3 cup</td>
<td>66</td>
</tr>
<tr>
<td>Protein</td>
<td>5 oz</td>
<td>7 1/2 oz</td>
<td>150</td>
</tr>
</tbody>
</table>
Figure 1. Example of food chain: French fries to chicken pot pie.

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Portion Size Education

Food Models
MyPlate Meal and Snack Patterns for 1000-1600 Calories

Criteria for Tube Removal

- No longer using the tube for ≥3-6 months
  - Including medications/fluids PO
- After cold/flu season
- Experience with acute illness w/o using tube
- Demonstrating wt gain
Criteria for Tube Removal

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not use tube during cold/flu season</td>
<td>56%</td>
</tr>
<tr>
<td>Balanced diet appropriate for ability</td>
<td>54%</td>
</tr>
<tr>
<td>Does not use tube for meds/vitamins</td>
<td>88%</td>
</tr>
<tr>
<td>Does not use tube during illness</td>
<td>80%</td>
</tr>
<tr>
<td>Maintains proportionality on growth curve</td>
<td>69%</td>
</tr>
<tr>
<td>Gains weight</td>
<td>91%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
</tbody>
</table>

Case Study

- TJ is an 8 year old boy with diagnosis of feeding problems.
- Born pre-term at 36 weeks gestation via C-section.
- Initiation of Feeding Difficulties: Birth
  - Complex medical history including hydrocephaly, Chiari II malformation, spina bifida, seizures, ADHD, GERD, and delayed gastric emptying.
  - Gtube placed at 14 mo of age

Initial Outpatient Evaluation

- Demonstrates functional oral motor skills for accepted foods but has a hypersensitive gag reflux resulting in vomiting at mealtimes.
- Enjoys trying a variety of foods, however motivation to eat appropriate portion sizes is low and has a poor appetite.
- Wt is down 2 # (4%) in the 2 wks since DC of night feedings.
- Frequent diarrhea
Nutritional Plan:
• Add an additional 4 ounces of a 1.5 kcal/cc formula by gtube after dinner
• RD outpatient referral to initiate a blenderized feeding regimen
• Provide structured meal/snack times at a table
• Offer oral feeding first followed by gtube feeds while seated at the table
• Already receiving cyproheptadine, 5 nights/wk

Pre-Admit to Inpatient Program
• Continues to vomit 4-5x/wk
• Resolution of diarrhea with initiation of blends
• Gtube: 400 ml blenderized formula given TID via bolus after breakfast, lunch and dinner
  ~1350 calories/day
• Oral Intake: 3 meal opportunities, 1-2 snack opportunities
  200-500 calories/day

Nutrition Plan
• Decrease GTT feeds by 67% on admit.
  - Give 400 ml blenderized tube feedings after he falls asleep.
  - Followed by 100 ml free water flush.
  - Give an additional water flush of up to 240mL (minus what he drinks at bedtime snack)
• Structured mealtime schedule, 3 meals, 3 snacks
At Discharge (19 Days)

- Meeting 110% of calorie goal & 105% of fluid goal PO
- Admit wt: 25.9kg, DC wt: 25.8kg

<table>
<thead>
<tr>
<th>Food Group</th>
<th>% of Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grains</td>
<td>50</td>
</tr>
<tr>
<td>Vegetables</td>
<td>40</td>
</tr>
<tr>
<td>Fruit</td>
<td>&gt;100</td>
</tr>
<tr>
<td>Dairy</td>
<td>&gt;100</td>
</tr>
<tr>
<td>Protein</td>
<td>60</td>
</tr>
</tbody>
</table>

Take-Home Messages

- Weaning should encompass a team approach
- Tube reduction with the addition of behavioral therapy has been effective for increasing oral intake
- Using “anchor foods” is a quick tool to assess a food record for adequate nutrition and provide feedback for food introduction.
- Weight trends should be monitored to prevent >5-9% weight loss
- Parents/Feeding therapist benefit from age-appropriate portion size education to provide the “just-right” challenge

Acknowledgments

- ASPEN Enteral Nutrition Weaning Consensus Statement Committee
  - Ann Davis, PhD
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  - Wednesday Sevilla, MD
  - Beth Lyman, RN
  - Jessica Brown, RD
  - Kelly Corkins, RD
  - Traci Nagy
  - Brandis Goodman
References

References

References
References


Questions?
Motivational Interviewing Pearls for Practice: Application in Celiac Disease

ANN SCHEIMANN MD MBA
JOHNS HOPKINS SCHOOL OF MEDICINE

Patient Outcomes in Celiac Disease

- Majority of emphasis in celiac disease has been molecular/cellular markers (only 9% of recent citations analyzed treatment)
- Diet access/control paradigm changes between children and adolescents
  - Teens are subject to peer influences
  - Kumar et al. 44% of celiac teens were noncompliant with diet

Motivational Interviewing

- "Patient-centered style of counseling, goal to elicit intrinsic motivation for change encouraging patients to resolve their resistance to change"
- Developed in the 1980s to treat addictions
**Stages of Change**

- Precontemplation
- Contemplation
- Preparation
- Action
- Maintenance
- Relapse

**Motivational Interviewing**

- **Goal:** Help families work through ambivalence
- Ambivalence to change normal
- Change affected by motivation not information
- Motivation affected by interaction
- Empathic technique
- Reflective listening
- Shared decision making
- Agenda setting

**Key Tenets of Motivational Interviewing**

- Partnership: avoid “expert trap”
- Acceptance, empathy, affirmation
- Validation of self worth
- Acceptance of autonomy/self determination
- Affirmation of strengths and prior efforts
- Compassionate discussion
- Elicit personal drivers toward making change
Motivational Interviewing Techniques

- Tone
  - Nonjudgmental
  - Empathic
  - Encouraging
- Do not try to
  - Fix denial
  - Confront irrational behavior
  - Convince or persuade
- Do not try to help families express
  - Reasons for changing behavior
  - Impact of behavior upon life goals
- Help families make well-informed, thoughtful choices

Processes of Motivational Interviewing

- Engage: Friendly greeting, introduction
- Focus: Invite family to select topic as well as rationale of choice
- Evoke: Assess readiness to change and transition to planning
- Plan: Ask permission prior to giving advice, have free dialogue, set goals as a partnership, assess barriers

Reflective Listening

- Follows an open-ended question
- Makes no assumptions about the participant's meaning
- Reflects back what you heard the participant say to elicit more input
- Encourages personal exploration
- Conveys empathy to client and builds rapport
Reflective Listening Phrases

- It sounds like you...
- It’s difficult/easy for you to...
- You realize that...
- You’re having trouble/success with...
- You understand that...
- You feel that...
- You do/don’t see the need to ...
- Let me see if I understand you...

Phrases for Open-Ended Questions

- Tell me why...
- Tell me about...
- Tell me how you have...
- I’m interesting in hearing why you...
- I’d like to hear your thoughts about...
- Explain what you might do...
- Give me some examples of...

Diet Change and Disease Management

- Dietary change rather than a “pill” can be overwhelming
- Food lists, culinary skills, home resources, finances can create stress
- Some patients/families are frightened and ready for change
- Some families are angry and resistant to change
Dietary Change and Disease Management

- Tools to use at intake:
  - What was it like for you to receive the diagnosis?
  - What concerns you the most about the diagnosis?
  - How might this diagnosis change the way you live and do things?

Handling Ambivalence: DARN CAT

- Preparatory
  - Desire to change: I really want to stop...
  - Abilities to change: I can do this....
  - Reasons to change: If I stop, this will help...
  - Needs for change: I need to stop because...

- Mobilizing change
  - Commitment to change: I am going to start......
  - Activation: I did .........
  - Taking steps: I already did........

Goal Setting and Contracting

- Short and long-term goal setting
  - Short-term: focus on specific behaviors
  - Long-term: reasonable

- Introduce one at a time
  - Guard against New Year’s Resolution
  - Allow goal modification if frustrated

- Contracting: maintain goal-directed focus
  - Small frequent goals and rewards
S.M.A.R.T. Goals

- Specific: who, what, when, where, why, which
- Measurable: concrete data for reaching goal
- Attainable: goal is reachable
- Realistic: clinician/family believe feasible
- Timely: set time frame

Goal setting and contracting in Celiac disease

- For clients ready to make changes in diet, diet modifications can provide new opportunity to increase their meal repertoire/adventure
- Switch from flour to corn tortillas-framed as new horizon for quesadillas
- Try one new gluten-free food/week
- Encourage families/teens to use reliable gluten-free/celiac websites
- Offer tips if families are open to help with transition with initial focus on small manageable changes that minimize preparation time

Supplemental Motivational Interviewing Exercises

On a scale of 0 to 10 (0 is not ready or confident and 10 is very ready or confident):

0       5      10

How ready are you to make changes in your (your families) diet?

How confident are you that you can make the change in your (your families) diet?
**Supplemental Motivational Interviewing Exercises**

<table>
<thead>
<tr>
<th>Short Term Costs</th>
<th>Short Term Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td>a)</td>
</tr>
<tr>
<td>b)</td>
<td>b)</td>
</tr>
<tr>
<td>c)</td>
<td>c)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Long Term Costs</th>
<th>Long Term Benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>a)</td>
<td>a)</td>
</tr>
<tr>
<td>b)</td>
<td>b)</td>
</tr>
<tr>
<td>c)</td>
<td>c)</td>
</tr>
</tbody>
</table>

Use to identify/troubleshoot re: barriers and assist with goal setting

---

**Using Motivational Interviewing with Time Constraints**

- Engage: start with open ended question, reflect and provide feedback re: time allotment
- Focus on a few options to explore re: possible change
- Evoke: discuss selection made, rationale, level of motivation
- Plan: discuss implementation, options, barriers, level of confidence
Nutritional Needs of Children with Significant/Severe Special Needs
Patricia Novak MPH RD CLE

I have the following financial relationships to disclose:

Nutricia: Speaker and Blog Posts

No Products or services produced by this (these) company (companies) are relevant to my presentation.

Personal Bias

• I am not an inpatient dietitian
• I am usually not a hospital clinic dietitian
• I am often at the home or community level
• I am often training dietitians, early interventionists, occupational therapists and physical therapists.

Who is the determination of needs for?
“severe special needs”

- Harsh, extreme
- Serious
- Grave, critical
- Causing discomfort or distress
- Difficult to endure, perform
- Rigidity, exact or methodical

“severe special needs”

- Distinct or particular kind or character
- Being a particular one
- Distinguished or different from what is usual or ordinary
- Having a specific function
- Extra-ordinary or exceptional

Determining needs…

- …in a situation that is extreme, extra-ordinary, distinct and particular?
- Why determine needs? What is the function of your recommendations?
- What are the critical considerations that lead to accurate recommendations that do not cause harm?
### Acute vs Chronic Needs

- **Acute**
  - Medical crisis
  - Procedures
  - Repair
- **Chronic**
  - Prevention
  - Developmental/health changes
  - Social

### Increased Energy Need

- Poor growth or weight gain
- Metabolic factors
  - Respiration: epithelial and muscle function
- Medical factors
  - Decubiti
  - Infection
  - Procedures
- Hx of insufficient intake
  - Dysphasia
  - Limited tolerance, GERD

### Results of Underfeeding

- Can further increase need - vicious cycle
  - Poor skin integrity or low fat pads increase risk of decubiti
  - Poor immune function
- Poor Growth
  - Poor nutrition (Stallings et al, Am J Clin Nutr 1996;64(4):627-34)
  - Stunting with low weight for age may be due to syndrome/genetics, lack of weight bearing, brain damage (Riley et al, Paediatr Child Health, 2012; 17(9): e98–e101 & Marchand et al 2006 J Ped Gastro Nutri 43:123-135)
Overestimation of Need

- Subjective:
  - Malnutrition is not always energy deprivation
  - Expectation of elevated need/habit
    - Particularly common as children age with shorter stature proportionally increasing over time
  - “We like them over the 50th percentile”
  - Culture of weight gain
  - “He eats 50-60 ml per day”, intake overestimated (Stallings et al, Am J Clin Nutr 1996;64(4):627-34)

- Objective:
  - Standard Calculations used
  - Absent or inaccurate measurement data
    - Measurements of children with special needs usually inaccurate due to contractures, asymmetry, scoliosis, athetosis, atrophy, immobility, cooperation, equipment (Riley 2012)
    - Alternative measurements such as skin folds not obtained or difficult to obtain (Reiken et al. Am J Clin Nutr 2011;94:759–66).

Harm with Over Feeding

- Metabolic
  - Hypertryglycemia
  - Hepatic and respiratory dysfunction
  - Predisposition to fat not muscle deposition

- Developmental
  - Interferes with mobility

- Social
  - More difficult to care for
  - Unrealistic goals set up for failure
  (Riley 2012)
Determining Energy Needs

- Indirect Calorimeter
- Estimations, are we getting it right? No.
- Up to 75% of estimations in error, usually overestimations
  - Normed with typically developing children
  - Dependent on height or fat free mass - both altered in special needs

- Individual History is an often neglected part of the equation
  - Intake
  - Growth
  - Health Status
  - Diagnosis
- Hard to obtain serial measurements and intake data to base an estimate

All have limitations

- Different equations suggested for different dx:
  - 80% of RDA (Riley et al. Paediatr Child Health 2012; 17(9): e98–e101)
Traditional Estimations

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Energy Requirement</th>
</tr>
</thead>
</table>
| Cerebral Palsy 5-11 years | 13.9 kcal/cm mild-moderate activity  
                      | 11.1 kcal/cm severe restriction                      |
| Athetoid               | Up to 2-3x expected for typical activity               |
| Trisomy 21 Boys:      | 16.1 kcal/cm                                           |
|                        | Girls: 14.3 kcal/cm                                    |
| Prader Willi           | 10-11 kcal/cm                                          |
|                        | 8.5 kcal/cm wt loss                                    |
| Myelomeningocele       | 9-11 kcal/cm                                           |
|                        | 7 kcal/cm wt loss                                      |

~ 50% of RDA after infancy


Moving from Calculations: Art of Assessment

- Energy Needs
- Respiration
- Muscle Tone
- Activity/Ambulation
- Growth
- Method of Eating
- Fat Free Mass/Activity
- Food Composition
- Equipment- electric vs manual; walker vs crutches (42%)

Fat Free Mass/Activity

**Reduces Needs**
- Lesion/damage altering neurologic and endocrine function
- Hypotonia
- Lack of weight bearing
- Lack of ambulation

**Increases Needs**
- Athetosis
- Spasticity
- Ambulation: greater energy expenditure than typical
- Equipment: electric vs manual; walker vs crutches (42%)

Dynamic Factors

- Oxygen use
- Catch-up, typical 1-4% need
- Respiratory
- Oral vs Enteral vs Parenteral
- Muscle Tone
- Fat Free Muscle Mass
- Fat Free Muscle Mass
- Muscle Tone
- Growth
- Method of Eating
- Food Composition
- Respiration
- Activity/Ambulation

A Starting Place

- Estimation of Need
  - Dx specific Calculation or REE
  - Complete consideration of factors, including accurate measurements, consider skinfolds (Oeffinger et al Dev Med Child Neurol 2014;56(5):475-81.
  - Actual intake assessed, over time
    - Keep an eye out for bibs and towels

Vitamin and Mineral Needs

- Most research on CP, “malnutrition” in 46-90%
- Malnutrition correlates with Gross Motor Function Classification Scale (GMFCS)
- Nutrients found at risk are common
  - Iron, Magnesium, Folic Acid, D, zinc, B12 (Penagini et al Nutrients 2015, 7, 9400–9415)
Vitamin & Mineral Needs

Risk of V/M Deficiency

- Commercial formula use
  - Lack trace elements (Selenium) and Carnitine
  - Volume tolerance may prevent intake of appropriate amount needed to meet need
  - Energy need may be so low that impossible to consume adequate vitamin and minerals
- Supplementation may not resolve
  - Supplements may also lack trace minerals
  - Utilization or bioavailability of supplements

Medications

- Seizure
  - D, folate, K, Carnitine, calcium
- Reflux
  - Magnesium, iron, calcium, B12
- Diuretics
- Fiber supplements for constipation
- Antibiotics
  - Influence microbiome
Fluid Needs: Getting Enough?

• Bowels
  – Diarrhea
  – Constipation 25-75% of kids with special needs
  – Slow motility, diet, medication
• Urine
  – Incontinence, difficult to assess
  – Color, odor
• Physical exam: Skin, Mucosal
• Holliday-Segar?

Fluid

Loss: sweat, diaphoresis
Bowels
Tolerance
Disease states
Fluid Needs
Medications

Addressing Fluid

• Food as fluid
  – Fruits and vegetables with high water content
• Delivery
  – In between meals
  – Viscosity with dysphagia
• Dysphagia
  – Minor involvement can have great impact (Rimpel, 2015)
• Thickeners can bind
• Free water in formula
• Grain fiber requires water to work!
So what to do?

- There is no recipe, no specific calculation that can be used in isolation.
- It is an art, calculation needs to be combined with the child’s individual characteristics plus common sense
- Collaborate with parent, child, community to obtain accurate past and present data to create realistic / individual goals

Future Directions

- Under-served population, under-investigated group that uses a large share of health care resources.
- Aligning realistic and accurate recommendations with institutional requirements
- “Future studies should address the role of the central nervous system in regulating energy metabolism in this population.” – Hogan 2016

Thank you

“When we try to pick out anything by itself, we find it hitched to everything else in the Universe.” – John Muir

PatriciaNovakRD@gmail.com
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Outline

- Introduction
  - Rationale for a new definition
  - Review of diagnostic criteria and ICF framework
- Describe the four integral domains involved
  - Medical
  - Nutrition
  - Skill
  - Psychosocial
- Case discussions

WHY A NEW DEFINITION?

Rationale for a new definition

- Conceptual framework beyond disease-oriented or unilateral diagnostic paradigms
- Consistent, comprehensive, interdisciplinary terminology
- Disease diagnoses may not predict function
Limitations of existing definitions

• Signs and symptoms cross traditional boundaries between disciplines

• Diagnostic paradigms from one clinical specialty
  • Do not capture the complexity of feeding disorders
  • Limit comparison of methods and outcomes across disciplines

Examples of existing definitions

<table>
<thead>
<tr>
<th>Association</th>
<th>Term</th>
<th>Comments about definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Speech-Language-Hearing Association</td>
<td>Pediatric Dysphagia</td>
<td>• impaired oral, pharyngeal, and/or esophageal phases of swallowing; definition medical &amp; skill-based</td>
</tr>
</tbody>
</table>
| Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) | Avoidant/Restrictive Food Intake Disorder (ARFID) | • If medical condition, severity of eating disturbance must exceed that typically associated with condition  
  • does not include children whose primary challenge is a skill deficit |
| International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) | F98.2: Other feeding disorders of infancy and childhood (feeding difficulties) | • requires the absence of organic disease  
  • non-specific, poorly defined diagnostic category |
Limitations of existing definitions: Williams syndrome

- Feeding difficulties are part of phenotype
- May not have dysphagia
- May have organic disease
  - Developmental delay, cardiac disease, low birthweight

ICF Framework: Disability and functioning

Implications of new definition
DEFINITION

Impaired oral intake that is not age appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction.

ICF Framework

Proposed Diagnostic Criteria for Pediatric Feeding Disorder

A. A disturbance in oral intake of nutrients, inappropriate for age, lasting ≥2 weeks, associated with ≥1 of:

1. Medical dysfunction
   a. Cardiorespiratory compromise during oral feeding
   b. Aspiration or recurrent aspiration pneumonitis

2. Nutritional dysfunction
   a. Malnutrition
   b. Specific nutrient deficiency or significantly restricted intake of ≥1 nutrient resulting from decreased dietary diversity
   c. Reliance on enteral feeds or oral supplements to sustain nutrition and/or hydration
Proposed Diagnostic Criteria for Pediatric Feeding Disorder (cont’d)

3. Feeding Skill dysfunction
   a. Need for texture modification of liquid or food
   b. Use of modified feeding position or equipment
   c. Use of modified feeding strategies

4. Psychosocial dysfunction
   a. Active or passive avoidance behaviors by child when feeding/fed
   b. Inappropriate caregiver management of child’s feeding and/or nutrition needs
   c. Disruption of social functioning within a feeding context
   d. Disruption of caregiver-child relationship associated with feeding

Other key considerations

B. Absence of the cognitive processes consistent with eating disorders
   • Acute (<3 months) versus chronic (> 3 months)
   • Cultural sensitivities
     • Feeding behaviors vary by culture
     • PFD does not exist when feeding behaviors in any culture are not associated with dysfunction
Proposed Diagnostic Criteria for Pediatric Feeding Disorder

A. A disturbance in oral intake of nutrients, inappropriate for age, lasting ≥2 weeks, associated with ≥1 of:

1. Medical dysfunction
   - Cardiorespiratory compromise during oral feeding
   - Aspiration or recurrent aspiration pneumonitis

Medical conditions causing and caused by Pediatric Feeding Disorder

<table>
<thead>
<tr>
<th>Impairment causing PFD</th>
<th>Dysfunction caused by PFD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disorders that affect oral, nasal, or pharyngeal function</td>
<td>Malnutrition and its sequelae</td>
</tr>
<tr>
<td>Aerodigestive disease</td>
<td>Aspiration, recurrent aspiration</td>
</tr>
<tr>
<td>Airway</td>
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<tr>
<td>Pulmonary</td>
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<td>Gastrointestinal</td>
<td></td>
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<tr>
<td>Congenital and other heart disease</td>
<td></td>
</tr>
<tr>
<td>Neurologic, developmental, and psychiatric disorders</td>
<td></td>
</tr>
<tr>
<td>Iatrogenic</td>
<td></td>
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</tbody>
</table>

Serious or chronic conditions can impair feeding skill acquisition

- Impaired mechanics of normal feeding or swallowing
  - Anatomic, dysmotility
- Upper GI tract dysfunction primarily from GI anomaly or disease, or secondarily from respiratory pathology
- Unrecognized health condition
- Prolonged illness or interventions interrupt typical feeding, cause aversive perioral experiences
Disorders that affect oral, nasal, or pharyngeal function

- Oropharyngeal and laryngeal anomalies and injuries
  - Ankyloglossia, macroglossia
  - Labial or palatal clefts
  - Velopharyngeal insufficiency
  - Choanal atresia
  - Tonsillar hypertrophy

Aerodigestive disease

- Airway
  - Laryngeal clefts
  - Vocal fold paralysis or injury
  - Airways malacia
  - Subglottic stenosis
  - Vascular ring/sling
- Pulmonary
  - Bronchopulmonary dysplasia
  - Recurring pneumonia
  - Any process resulting in tachypnea

MECHANISMS

- Poor coordination of suck-swallow-breathe
- Tachypnea, dyspnea
- Aspiration

Upper GI tract anomalies or disease

- Esophagitis
  - Peptic, eosinophilic, infectious
- Inflammation
  - Ulcers
  - Celiac disease
- Motility disorder

Liacouras et al. J Allergy Clin Immunol; 128:3-20
Congenital and other heart disease
- Hypoplastic left heart syndrome and other conditions that result in staged single ventricle repair
- Septation defects
- Tetralogy of Fallot
- Associated pulmonary hypertension
- Myocarditis and other causes of heart failure

Neurologic, developmental, and psychiatric disorders
- Autism
- Cerebral palsy and other disorders of motor dysfunction
- Anxiety
- Attention deficit / hyperactivity disorders

Proposed Diagnostic Criteria for Pediatric Feeding Disorder
A. A disturbance in oral intake of nutrients, inappropriate for age, lasting ≥2 weeks, associated with ≥1 of :

2. Nutritional dysfunction
   a. Malnutrition
   b. Specific nutrient deficiency or significantly restricted intake of ≥1 nutrient resulting from decreased dietary diversity
   c. Reliance on enteral feeds or oral supplements to sustain nutrition and/or hydration
Nutritional dysfunction

- Intake of nutrients insufficient to meet nutritional requirements, resulting in "cumulative deficits of energy, protein or micronutrients" that may adversely impact growth, development, and other health outcomes
- Excessive nutrient intake

Nutritional consequences of pediatric feeding disorder

- Macronutrient
  - Energy, protein, fat
- Micronutrient
  - Vitamins and minerals
- Critical non-nutritive elements
  - Water, fiber
- Dietary diversity

Macronutrient deficiency or excess

- Undernutrition (malnutrition)
  - 20-25% of patients with PFD
  - Impaired weight gain
    - Need for tube feeding
  - Stunting
  - May combine with other risk factors for malnutrition
    - Malabsorption, higher energy requirements, catabolism
- Overweight
Micronutrient Deficiency or Excess

- "Critical" micronutrients
  - Calcium
  - Vitamin D
  - Iron
  - Zinc
  - Vitamin C
  - Vitamin A
- Possible even if weight gain and linear growth are adequate

Deficient intake of non-nutritive elements

Fiber

Water

Inadequate dietary diversity

- Macronutrient or micronutrient deficiency
- Impaired social functioning
- Cultural appropriateness
Proposed Diagnostic Criteria for Pediatric Feeding Disorder

A. A disturbance in oral intake of nutrients, inappropriate for age, lasting ≥2 weeks, associated with ≥1 of:

3. Feeding Skill dysfunction
   a. Need for texture modification of liquid or food
   b. Use of modified feeding position or equipment
   c. Use of modified feeding strategies

Feeding skill disorders

Etiology
- Structural &/or functional
- Sensory &/or motor
- Pre-oral phase (self-feeding), oral phase, &/or pharyngeal phase
Feeding skill disorders

**Oral phase**
(sucking, drinking, chewing, biting)

- Under- or over-response to sensory aspects of liquids and food textures inhibiting acceptance and/or tolerance
- Reduced strength, coordination, range of motion-inhibiting oral movements required for acceptance, control, manipulation and/or oral transit of liquids and food textures

**Pharyngeal phase**
(swallowing, airway protection)

- Under- or over-response to bolus during pharyngeal transit or residue remaining post-swallow
- Reduced strength, coordination, range of motion, timing impacting pharyngeal transit of liquids and food textures
- Ineffective swallowing and/or airway protection

**Feeding skill - function**

- To be fully functional, a child’s feeding skills must be:
  - Safe
  - Age appropriate
  - Efficient
Feeding skill - dysfunction

• Unsafe PO feeding:
  • Aspiration
  • Adverse cardio-respiratory events (e.g. apnea, bradycardia, increased work of breathing)
  • Adverse mealtime events (e.g. coughing, choking, gagging, vomiting, discomfort, stress, fatigue, refusal)

Feeding skill - dysfunction

Delayed/ disordered PO skills:
  • Unable to consume age-appropriate liquid and food textures
  • Unable to use age-appropriate feeding utensils and devices
  • Unable to self-feed at age-appropriate expectations
  • Unable to use age-appropriate mealtime seating
  • Requires more feeding assistance or requires special feeding strategies relative to other children of same age

Inefficient &/or insufficient PO intake:
  • Prolonged mealtime duration
  • Insufficient PO intake

Infant feeding skills

Skills:
  • Suckling
  • Breastfeeding, bottle feeding
Infant feeding skills

Compensations

- Modify bolus
- Modify how bolus is delivered
- By-pass oral-pharyngeal region
- Modify utensils (e.g. bottle nipples)
- Modify position (e.g. side-lying)
- Modify strategy (e.g. external pacing)
- Thicken liquids
- Tube feeds

Child feeding skills

Skills:
- Mastication and drinking
- Biting, chewing, drinking from cup, self-feeding
4. Psychosocial Dysfunction
   a. Active or passive avoidance behaviors by child when feeding or being fed
   b. Inappropriate caregiver management of child’s feeding and/or nutrition needs
   c. Disruption of social functioning within a feeding context
   d. Disruption of caregiver-child relationship associated with feeding
Psychosocial Factors

Psychosocial Restriction
Pediatric feeding disorders develop as a result of and are maintained by factors within the child, caregiver, and environment.

Resultant Dysfunction
Observable child and caregiver behavior

- Child
- Caregiver
- Environment

Psychosocial Restrictions

- Developmental
  - Delay
  - Disorder
- Mental/Behavioral Health
  - Diagnosed disorder
  - Undiagnosed signs/symptoms of disorder
  - Dysregulated temperament/personality characteristics
Psychosocial Restrictions

- Social
  - Caregiver-child interaction problems
  - Cultural expectations

- Environmental
  - Disorganized/distracting feeding environment
  - Poorly timed schedule of feedings
  - Access to food/resources
  - Inadvertent reinforcement of food refusal behavior

Psychosocial Dysfunction

- Learned aversion
- Stress/distress
- Disruptive behavior
- Food over-selectivity
- Failure to advance to age-appropriate feeding
- Grazing behavior
- Caregiver use of compensatory strategies
Summary

- Existing definitions for pediatric feeding disorder are typically disease-oriented or unilateral.
- Proposed criteria define PFD as restricted oral intake that is not age appropriate and leading to dysfunction in at least one of four closely-related, complementary domains.
- Establishes common definition and terminology with implications for clinical practice, education, research, and advocacy.

CASES