



CPNP ***NASPGHAN***
COUNCIL FOR PEDIATRIC
NUTRITION PROFESSIONALS

45TH
ANNUAL MEETING



Program

November 3 - 4, 2017
Neopolitan 3 - 4
Caesars Palace
Las Vegas, NV

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President's Welcome

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 from 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,

A handwritten signature in black ink, appearing to read 'A Smith', with a stylized, cursive script.

Amber Smith, MBA, RD, CD
President, Council for Pediatric Nutrition Professionals

2017 CPNP/NASPGHAN Nutrition Symposium

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

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

Abbott Nutrition

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**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	

4. **Determining calorie, fluid and micronutrient needs** for a child with severe special needs Octavius 22

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



Clinical Guidelines

Guidelines for the Provision and Assessment of Nutrition Support Therapy in the Pediatric Critically Ill Patient: Society of Critical Care Medicine and American Society for Parenteral and Enteral Nutrition

Nilesh M. Mehta, MD¹; Heather E. Skillman, MS, RD, CSP, CNSC²; Sharon Y. Irving, PhD, CRNP, FCCM, FAAN³; Jorge A. Cova-Bu, MD⁴; Sarah Vermilyea, MS, RD, CSP, LD, CNSC⁵; Elizabeth Anne Farrington, PharmD, FCCP, FCCM, FPPAG, BCPS⁶; Liam McKeever, MS, RDN⁷; Amber M. Hall, MS⁸; Praveen S. Goday, MBBS, CNSC⁹; and Carol Braunschweig, PhD, RD¹⁰



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aspen AMERICAN SOCIETY FOR PARENTERAL AND ENTERAL NUTRITION

SAGE



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

Quality of Evidence	Weighing risks vs benefits	GRADE recommendations	Clinical Guideline Statement
High to very low	Net benefits outweighs harms	Strong	We recommend
High to very low	Trade-offs for patients are important	Weak	We suggest
High to very low	Uncertain trade-offs	Further research needed	We cannot make a recommendation at this time

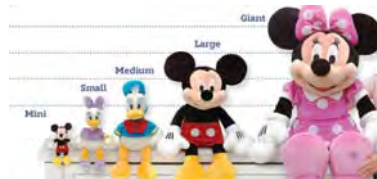
 

Target of the guideline

- 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

Design	Aim	Primary findings N = 1622
Prospective Observational	To determine the influence of BMI z score on:	17.9% - underweight 14.5% - overweight 13.4% - obese.
Cohort	1) 60-day mortality 2) Hospital-acquired infections	60 day mortality: Higher in underweight Hospital acquired infection: Higher in underweight and obese
Combined results from 2 multi-center studies	3) Length of hospital stay 4) Mechanical ventilation-free days	Ventilator free days (VFD): Underweight with 1.3 fewer VFD than normal weight



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 $\geq 80\%$ 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

Study	N	Age	PRO Intake	Method	PRO Balance
Enteral Nutrition RCTs					
Van Waardenburg, 2009	N = 18	4 wk-12mo	2.8g/kg/d	IC, UUN	Positive
De Betue, 2011	N = 18	4wk-12mo	3.1g/kg/d	Isotope	Positive
Cohorts					
Botran, 2011	N = 41	1mo-16 yrs	3.1g/kg/d	IC, UUN	Improved
*Chaparro, 2016	N = 74	0-16 yrs	1.5g/kg/d	TUN	Positive
*Wong, 2016	N = 107	1-10 yrs	1.5g/kg/d	EN PRO delivery	Improved PICU outcomes



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

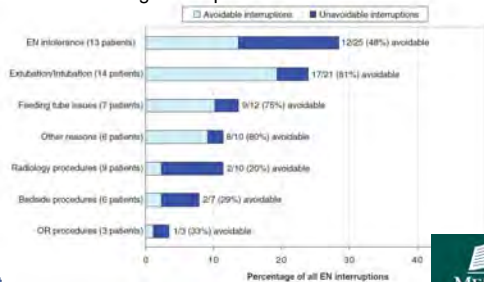
- Is EN feasible in critically ill children?
 - Initiation of EN within 48-72 hours of PICU admission

	Children	Enteral Nutrition by 48 hrs
Petrillo-Albarano, T; 2006	N = 91	100%
Lopez-Herce, J; 2006	N = 526	62%
Mehta, NM; 2012	N = 440	72%
Mikhailov, TA; 2014	N = 5105	27%
Mehta, NM; 2015	N = 985	60%
Canarie, MF; 2015	N = 444	80%



Evidence

Challenges to Optimal Enteral Nutrition



Mehta, NM; JPEN 2010



Evidence

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

King, W; 2004	Patients N=91	Panchal, A; 2014	Fed N=188	Nonfed N=151
Dopamine: < 6 µg/kg/min	5%	VIS score Day 1	10	15 ^a
Dopamine: ≥ 6 µg/kg/min	31%	VIS score Day 2	10	10
Dopamine + NE	42%	VIS score Day 3	5	5
Dopamine + NE + EPI	6%	VIS score Day 4	5	5

NE: norepinephrine; EPI: epinephrine

VIS: Vasoactive-inotropic score; *p < 0.05
Dopamine at 5 µg/kg/min; VIS = 5
Dopamine at 5 µg/kg/min + EPI at 0.05
µg/kg/min; VIS = 10
Dopamine at 5 µg/kg/min + EPI at 0.1
µg/kg/min; VIS = 15

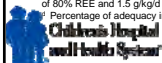


EN in Critically Ill Children

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

		Mortality	
Mikhailov, TA; 2014	N = 5105	5.3%	EEN ^a pts. less likely to die; OR 0.51
Wong, JJ; 2016	N = 107 ^b	54%	Mortality ↓ to 35% and 14% ^c
Mehta, NM; 2012	N = 500	8.4%	Mortality ↓ if energy intake > 33% ^d
Mehta, NM; 2015	N = 1245	6.5%	Mortality ↓ if protein intake > 60% ^d

^a EEN: Early enteral nutrition as 25% of goal; ^b Cohort of ARDS pts.; ^c If caloric and protein intake of 80% REE and 1.5 g/kg/d
^d 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

	Study Design; population	Outcomes
Petrillo-Albarano, T; 2006	Retrospective, Before-after protocol; 91 & 93 pts.	Goal feeding reduced from 32 hrs to 14 hrs
Meyer, R; 2009	Prospective, After protocol of 355 pts. over 4 periods	Time to initiate EN: I=15; II=8; III=5.5; IV:4.5 hrs
Hamilton, S; 2014	Retrospective, Before-after protocol; 80 & 80 pts.	Median time to reach goal from 4 days to 1 day
Kaufman, J; 2015	Prospective, Before-after protocol; 106 & 260 pts. S1P ^a	Patient-days with caloric goals met from 50 to 60%

^aS1P: Stage 1 palliation for single ventricle physiology



EN in Critically Ill Children

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

	Study Design; population	Outcomes
Horn, D; 2003 RCT ^a	45 pts.; continuous (N=22) vs. intermittent (N=23)	NS ^b : stool volume, diarrhea, vomiting, use of prokinetics
Horn, D; 2004 RCT	45 pts.; continuous (N=22) vs. intermittent (N=23)	NS: volume of formula (ml/kg/d) or GRV/kg ^c in 72 h
Meert, K; 2004 RCT	74 pts MV ^d ; gastric (N=32) vs. small bowel (N=42, then 30)	NS: Percentage of aspiration or feeding intolerance
Sanchez, C; 2007 Prospective	526 pts. on transpyloric feeds; early < 24 h (N=202), late > 24 h (N=324), 10 y study	Early group: Less days in SPN ^e (0.2 vs. 0.9 days); and abdominal distention (3.5% vs. 7.8%)

^a RCT: Randomized controlled trial; ^b Non-significant; ^c GRV: Gastric residual volume;
^d MV: Mechanical ventilation; ^e SPN: Supplemental parenteral nutrition



EN in Critically Ill Children

- When should EN be initiated?

Author	Design	Population	Time to start feeds
Brassoulis, G; 2005	RCT	PICU, N=50	12 hrs
van Waardenburg, D; 2009	RCT	PICU, N=20	24 hrs
Sánchez, C; 2007 ^a	Prospective	PICU, N=526	24 hrs
López-Herce, J; 2008 ^a	Prospective	PICU, N=65	24 hrs
Petrillo-Albarano, T; 2006	Retrospective	PICU, N=93	6 hrs
Mikhailov, T; 2014	Retrospective	PICU, N=515	48 hrs
Canarie, M; 2015	Retrospective	PICU, N=444	48 hrs

RCT: Randomized Controlled Trial; ^a same group of patients



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

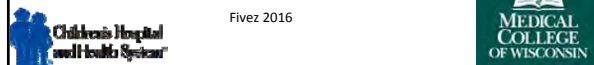


Parenteral Nutrition in Critically Ill Children

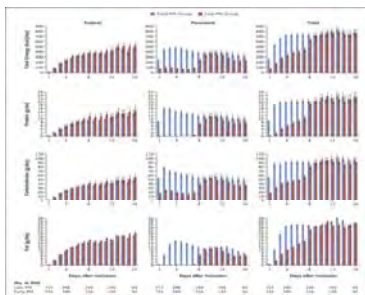


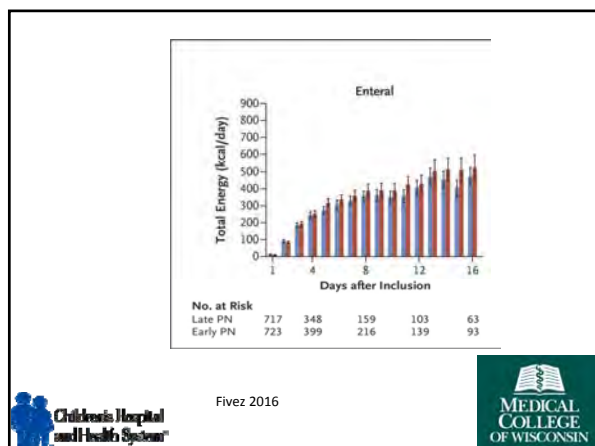
Evidence

- 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)



Evidence





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

Fivez 2016

Children's Hospital and Health System

MEDICAL COLLEGE OF WISCONSIN

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?

Fivez 2016

Children's Hospital and Health System

MEDICAL COLLEGE OF WISCONSIN

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?

CPNP

NASPGHAN

COUNCIL FOR PEDIATRIC NUTRITION PROFESSIONALS

NASPGHAN 2017

Annual Meeting & Postgraduate Course

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

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NASPGHAN

Disclosures

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

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

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NASPGHAN

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

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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?

NASPGHAN

WHAT IS THE POPULAR SCIENCE?

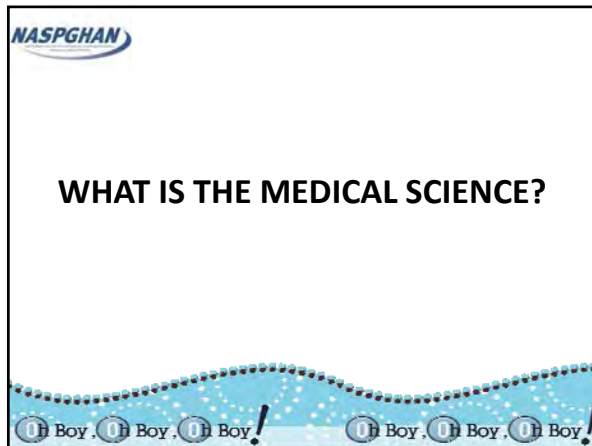
01 Boy 01 Boy 01 Boy! 01 Boy 01 Boy 01 Boy!

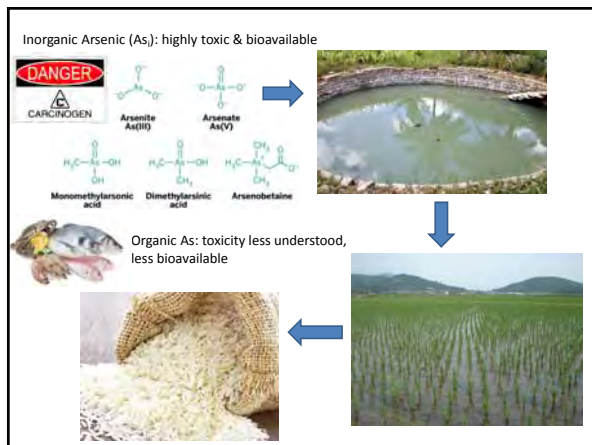
The More Rice Infants Eat, the Higher Their Arsenic Levels, Study Finds

Illegal arsenic levels in baby rice food products

Is Rice Cereal Really Safe for Babies?

White Rice Is Like Poison for Baby

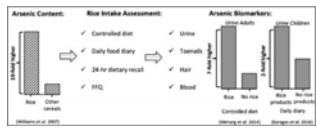




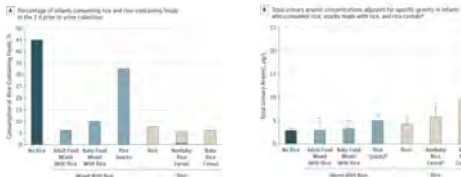
Young Children at Increased Risk

- 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

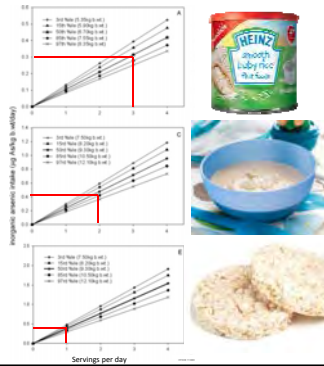


Davis et al, Science of the Total Environment, 2017



Karagas et al, JAMA Pediatrics, 2016

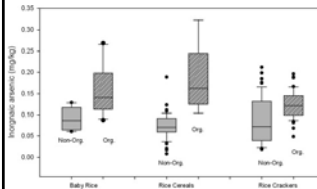
Exposure and Risk



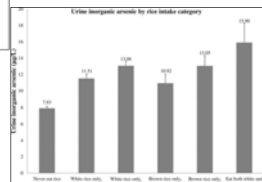
European Food Safety Authority determined 1% increased risk for lung, skin, bladders cancers and skin disorders if consuming 0.3-0.8 mcg/kg/d As_i

Signes-Pasor et al, Food Chemistry, 2016

Organic and Brown Rice



Signes-Pasor et al, Food Chemistry, 2016



Wu et al, Epidemiology, 2015

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)

Zhang et al, International Journal of Cancer, 2016
Muraki et al, AJCN, 2015

Trends in Exposure

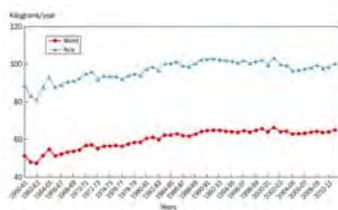


Fig. 1. Global and Asian per capita rice consumption.
Data source: PSD online database (USDA) and FAOSTAT population database (FAO)

- 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% Blacks, 47% Hispanics and 27% White Americans eat rice
- Consumers are increasingly choose foods that are whole grain, 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)

NPD Group - National Eating Trends® Database 2010



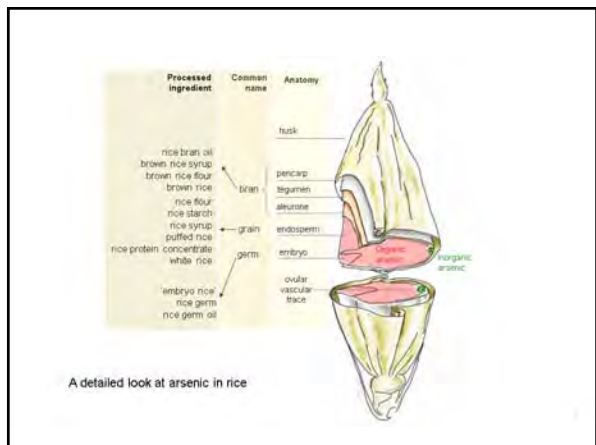
THE SCIENCE IN PRACTICE



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)

•Mcsweeney et. Al. J Peds 2016

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

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

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, 50thile 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

<https://www.fda.gov/Food/FoodborneIllnessContaminants/News/ucm319870.htm>

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,

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

Rice Product	Origin	# of brands	# of Samples	Inorganic Arsenic (ppb)
White, long grain enriched	Missouri	1	3	41
White, Basmati	India	3	9	55
White, Jasmine	Thailand	2	6	70
Long/extra long grain Enriched	Louisiana, Arkansas, Texas	4	13	97
White, Basmati	California	1	4	32
Short grain, Brown	California	1	3	100

Brown Rice (Consumer Reports 2012)

Rice Product	Origin	# Brands	# samples	Inorganic Arsenic (ppb)
Short grain	California	1	3	61
Long grain	Missouri	1	4	147
Long grain/Whole grain/Basmati	Arkansas/Louisiana/Texas	4	12	153

Rice Based Products (FDA testing 2012)

Product	Samples tested	IAs (ug) per serving	Ug/kg/d (18 kg child)
Non dairy rice drinks	65	3.3	0.18
Grain based bars	86	1.7	.09
Rice cakes	59	4.3	.23
Baking mixes (muffin/cake)	24	3	.16
Pasta	23	6.6	0.37
Rice (Basmati)	53	3.5	0.19

<https://www.fda.gov/downloads/Food/FoodborneIllnessContaminants/Meetings/UCM352467.pdf>

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)

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

* Test well water

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?



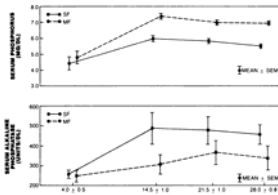
Evidence of Nutritional Safety

- 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



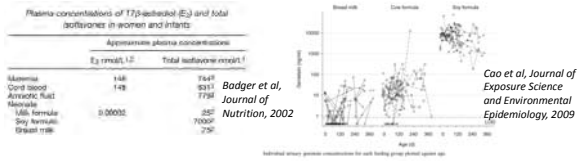
Shenai et al, Pediatrics, 1981

Evidence in Allergy

- Common antigen FPIAP, FPIES, FPE (with CMP) *Nowak-Węgrzyn 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 *Berni Canani 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

Adgent 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 a safe and nutritionally equivalent alternative to cow milk-based formula for term infants whose nutritional needs are not 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 lactose deficiency.
- Infants with documented immunoglobulin E-associated **allergy to cow milk** who are not also allergic to soy protein.
- Patients 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 birth weights less than 1800 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.

2015 <http://www.nhs.uk/cha/pages/can-i-give-my-baby-soya-based-infant-formula.aspx?CategoryID=62&>

<http://www.cps.ca/documents/position/use-soy-based-formulas>

*Koletko et al. Diagnostic Approach and Management of Cow's Milk Protein Allergy in Infants and Children: ESPGHAN GI Committee Practical Guidelines. JPGN Vol. 55(2): Aug. 2012:222-229

Cost of Formulas

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

Based on non generic US brand.

Let's Compare (Unsweetened/fortified)

Beverage	Calories	Pro	Fat	Calcium	Vitamin D	Cost per 32 fl. Oz.
Almond milk	30	1	2.5	300	100	\$ 1.50
Coconut milk	45	0	4-4.5	100-300	100	\$ 1.39
Hemp milk	80	2	8	300	100	\$3.99
Oat Milk	130	4	2.5	350	100	\$2.19
Pea milk	100	8	4.5	450	125	\$ 2.86
Rice milk	70	0	2.5	250	100	\$ 1.89
Soy milk	80	7	4	300	100	\$1.85

*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:
 - Zhao Y et. Al. Journal of Nutrition 2005.
 - Heaney et. Al. JADA 2005

Reference for comparison of other micronutrients: Singhal S. et. Al. A comparison of the Nutritional Value of Cow's Milk and Non-Dairy Beverages. JPGN 2017

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?



**LIMIT Factory and
Processed foods**



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



— [William Cowper](#)



Nutritional Evaluation and Management of Children with Feeding Problems During Gastrostomy Tube Weaning

Jessica Brown, RD, CSP, CNSC, CLEC

November 4th, 2017



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



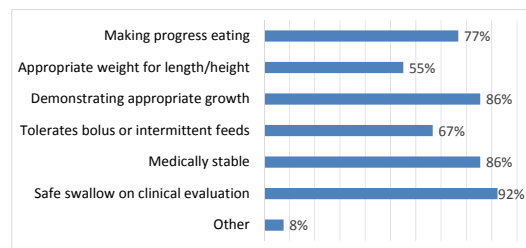
Survey Results

- 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

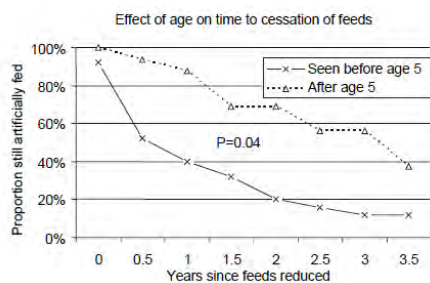
N= 207



ASPEN 2016 National Survey. ASPEN Enteral Nutrition Weaning Consensus Statement Committee.



Early Intervention = Better Outcomes



Wright C, et al. *Arch Dis Child*. 2011;96:433-439.

Early Intervention = Better Outcomes

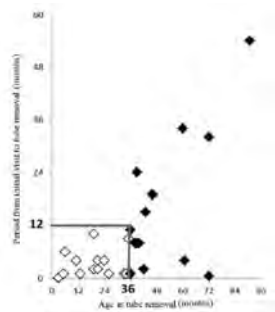


Fig. 1. Period from the initial visit to tube removal vs age at initial visit. ○, Tube removal at <3 years of age; ●, tube removal at ≥3 years of age.

Ishizaki A, et al. *Pediatrics International*. 2013;55:208-213.

Growth Assessment Prior to Wean

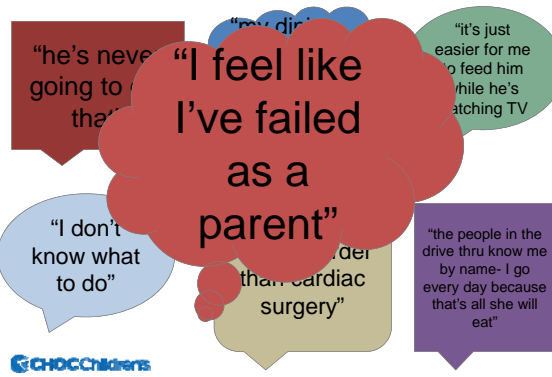
- Children should be appropriately nourished prior to tube weaning
- Pt's typically do not gain weight until 3 months post treatment¹
- Pt's may present with weight loss during g-tube weaning²
- CHOC – our goal is generally >90% IBW

¹Silverman A, et al. *JPGN*. 2013;57:668-672.

²Trabi T, et al. *Infant Mental Health Journal*. 2010;31:664-681.



Quotes from parents



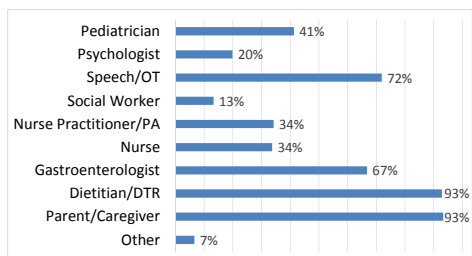
Importance of the Interdisciplinary Team

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



Members of the Weaning Process

N = 196



ASPEN 2016 National Survey. ASPEN Enteral Nutrition Weaning Consensus Statement Committee.



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 dietitian 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



CHOCChildren

Structured Mealtimes

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

CHOCChildren

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)

CHOCChildren



CHOCChildren

Systematic Tube Reduction

- Intensive inpatient tube weaning programs¹
 - Tube feedings are decreased by **≥50%** on admission, and further reduced throughout the admission
- Outpatient setting²
 - 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

¹Hartdorff. 2015; Byars. 2003; Brown. 2014; Kindermann. 2008.

²Benoit. 2000; Hartdorff. 2015; Wilken. 2015; Wright. 2011.

CHOCChildren

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

Hartdorff C, et al. *JPGN*. 2015;60:538-543.

CHOCChildren

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



Hartdorff C, et al. *JPGN*. 2015;60:538-543.

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

Feeding Behaviors	n (%)
Eats more	39 (48)
Accepts more food variety	11 (13)
Easier to feed	11 (13)
Asks more food	9 (11)
Self-feeds more	9 (11)
No change	3 (4)

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

Sant'Anna A, et al. *JPGN*. 2014;59(5):674-678.

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



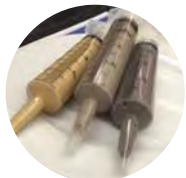
Table 1 Successful Gastrostomy Tube Weaning Program Using an Intensive Multidisciplinary Team Approach

Variable	n	%
No. patients included	30	100
Male	18	60
Female	12	40
Mean	30	
Age at admission	4.5	3.5
Duration of feeding problem	9 mo	4.4
Interventions		
Cyproheptadine	24 (80)	27 (90)
Polyethylene glycol/MOM	9 (30)	21 (70)
GT = gastrostomy tube; MOM = Milk of Magnesia; PPI = proton-pump inhibitor; SD = standard deviation.		
¹ As reported from medical records.		
² Used for visceral hypersensitivity.		
³ Outpatient.		
⁴ Inpatient.		

TABLE 1 Demographics

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.



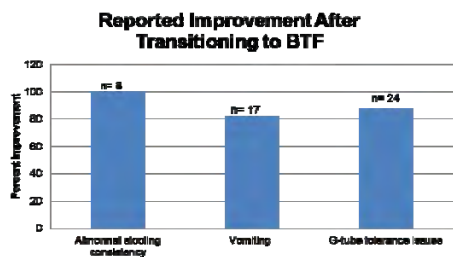
CHOCChildren

Table 1. Demographics

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

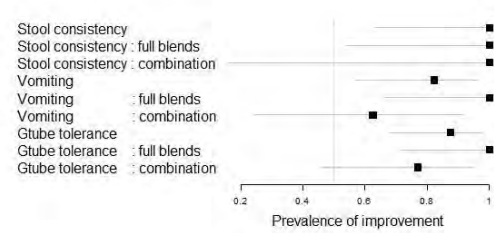
CHOCChildren

Poor tolerance of tube feedings



CHOCChildren

Improvement prevalence and 95% confidence intervals among patients with full blends and combination feeds



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



Blenderized Tube Feeding Outcomes

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



Improved Oral Intake

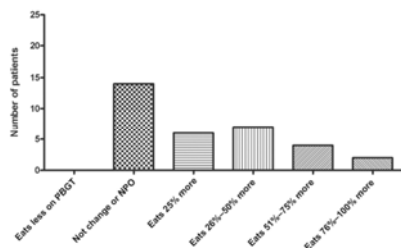


Figure 2. Change in oral intake in children (n = 33) using the pureed by gastrostomy tube diet as reported by their parents. NPO, nil per os (ie, nothing by mouth).

Published in: Scott Pentuk, Theresa O'Faherty, Kathleen Santoro, Paul Willging, Ajay Kulk. *JPEN J Parenter Enteral Nutr* 35, 375-379. DOI: 10.1177/0148607110377797
Copyright © 2011 American Society for Parenteral and Enteral Nutrition



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 (24kcal/oz)

- 1 cup Kefir
- ½ cup Juice
- ½ cup Berries
- ½ cup Mango
- ¼ cup Oats, dry
- ¼ item Avocado
- 1 TBS Wheat Germ
- 1 TBS Honey

Behavioral Modification

- Long-term enteral nutrition dependence may lead to eating behavior disorder¹
- 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

¹Dunitz-Scheer M, et al. *Infant Child Adolesc Nutr.* 2011;3:209-15.

²Benoit D, et al. *Journal of Pediatrics.* 2000;137:498-503.



Behavioral Treatment in Tube Weaning

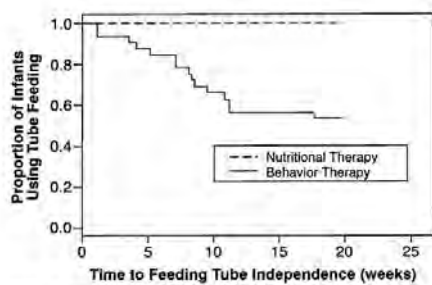


Figure 3. Proportion of infants using enteral tube feeding over time by treatment group



Benoit D, et al. *Journal of Pediatrics.* 2000;137:498-503.

Parent Training

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



Brown. 2014; Byars. 2003; Cornwell. 2010; Benoit. 2000; Silverman. 2013; Williams 2007; Wright. 2011.

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

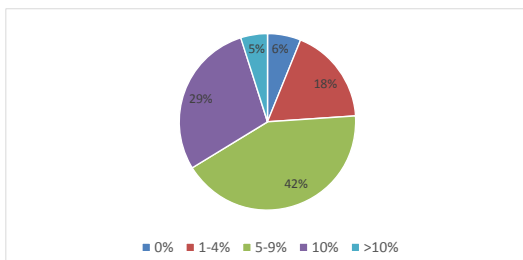
- Frequency of Monitoring
 - 26% Weekly
 - 23% Couple times a month
 - 19% Monthly
- Who monitors wean?
 - 48% Entire team
 - 29% Dietitian
 - 20% Physician
 - 5% Nurse Practitioner
 - 3% SLP/OT

ASPEN 2016 National Survey. ASPEN Enteral Nutrition Weaning Consensus Statement Committee.



Acceptable Weight Loss During Weaning (1-3 months)

N = 163

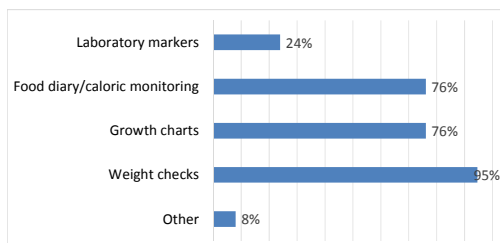


ASPEN 2016 National Survey. ASPEN Enteral Nutrition Weaning Consensus Statement Committee.



Tracking Progress of a Wean

N = 184



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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 gagging
- 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

CHOC Children's						
Child Name (Print Name)	Age at Visit (Print Date of Birth)	Visit Date (Print Date)	Visit Time (Print Time)	Visit Location (Print Location)	Visit Type (Print Type)	Visit Notes (Print Notes)
Day 1						
8 am	8:00 am	8:00 am	8:00 am	8:00 am	8:00 am	8:00 am
8:30 am	8:30 am	8:30 am	8:30 am	8:30 am	8:30 am	8:30 am
9 am	9:00 am	9:00 am	9:00 am	9:00 am	9:00 am	9:00 am
10 am	10:00 am	10:00 am	10:00 am	10:00 am	10:00 am	10:00 am
11 am	11:00 am	11:00 am	11:00 am	11:00 am	11:00 am	11:00 am
12 pm	12:00 pm	12:00 pm	12:00 pm	12:00 pm	12:00 pm	12:00 pm
1 pm	1:00 pm	1:00 pm	1:00 pm	1:00 pm	1:00 pm	1:00 pm
2 pm	2:00 pm	2:00 pm	2:00 pm	2:00 pm	2:00 pm	2:00 pm
3 pm	3:00 pm	3:00 pm	3:00 pm	3:00 pm	3:00 pm	3:00 pm
4 pm	4:00 pm	4:00 pm	4:00 pm	4:00 pm	4:00 pm	4:00 pm
5 pm	5:00 pm	5:00 pm	5:00 pm	5:00 pm	5:00 pm	5:00 pm
6 pm	6:00 pm	6:00 pm	6:00 pm	6:00 pm	6:00 pm	6:00 pm
7 pm	7:00 pm	7:00 pm	7:00 pm	7:00 pm	7:00 pm	7:00 pm
8 pm	8:00 pm	8:00 pm	8:00 pm	8:00 pm	8:00 pm	8:00 pm
9 pm	9:00 pm	9:00 pm	9:00 pm	9:00 pm	9:00 pm	9:00 pm
10 pm	10:00 pm	10:00 pm	10:00 pm	10:00 pm	10:00 pm	10:00 pm
11 pm	11:00 pm	11:00 pm	11:00 pm	11:00 pm	11:00 pm	11:00 pm
12 am	12:00 am	12:00 am	12:00 am	12:00 am	12:00 am	12:00 am



Anchor Foods: Tools for the RD

- Targeting

- Fortified
- Cereal
- Brightly
- Protein

1 Waffle + spread
1 ½ slices Bread
½ cup Crackers
½ oz Pretzels

1 ½ cup whole Milk
4 oz Yogurt

1 ½ TBS Peanut butter
4 Chicken Nuggets

1/3 cup Broccoli + oil
¼ cup Strawberries

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

Except
Vitamin D



Food Group Patterns

USDA Food Patterns

The Food Patterns suggest amounts of food to consume from the basic food groups, subgroups, and oils to meet recommended nutrient intakes at 12 different calorie levels. Nutrient and energy contributions from each group are calculated according to the nutrient-dense forms of foods in each group (e.g., lean meats and fat-free milk). The table also shows the number of calories from solid fats and added sugars (SFAAS) that can be accommodated within each calorie level. In addition to the suggested amounts of nutrient-dense forms of foods in each group.

Daily Amount of Food From Each Group

Calorie level ¹	1,000	1,200	1,400	1,600	1,800	2,000	2,200	2,400	2,600	2,800	3,000	3,200
Fruits ²	1 cup	1 1/2 cup	1 1/2 cup	1 1/2 cup	1 1/2 cup	2 cups	2 cups	2 cups	2 cups	2 1/2 cups	2 1/2 cups	2 1/2 cups
Vegetables ²	1 cup	1 1/2 cups	1 1/2 cups	2 cups	2 1/2 cups	2 1/2 cups	3 cups	3 cups	3 1/2 cups	3 1/2 cups	4 cups	4 cups
Grains ²	3 oz eq	4 oz eq	4 oz eq	5 oz eq	5 oz eq	6 oz eq	6 oz eq	7 oz eq	7 oz eq	8 oz eq	10 oz eq	10 oz eq
Protein Foods ²	2 oz eq	2 oz eq	2 oz eq	3 oz eq	3 oz eq	3 1/2 oz eq	3 1/2 oz eq	4 oz eq	4 oz eq	4 1/2 oz eq	5 oz eq	5 oz eq
Dairy ²	2 cups	2 1/2 cups	2 1/2 cups	3 cups	3 cups	3 cups	3 cups	3 cups	3 cups	3 cups	3 cups	3 cups
Oils ²	15 g	17 g	17 g	22 g	24 g	27 g	29 g	31 g	34 g	36 g	44 g	51 g
SFAAS ³	137	121	121	121	165	218	260	310	362	395	435	516



Diet Analysis using Food Groups

Food Group	Goal	Intake	% of Goal
Grains	5 oz	2 1/4 oz	45
Vegetables	2 cups	1 cup	50
Fruit	1 ½ cups	1 cup	66
Dairy	2 ½ cups	1 2/3 cup	66
Protein	5 oz	7 ½ oz	150



Daily Food Plan

Use this Plan as a general guide.

- These food plans are based on average needs. Do not be concerned if your child does not eat the exact amounts suggested. Your child may need more or less than average. For example, food needs increase during growth spurts.
- Children's appetites vary from day to day. Some days they may eat less than these amounts, other days they may want more. Offer these amounts and let your child decide how much to eat.

Food group	2 year olds	3 year olds	4 and 5 year olds	What counts as:
Fruits 	1 cup	1 - 1½ cups	1 - 1½ cups	½ cup of fruit? ½ cup mashed, sliced, or chopped fruit ½ cup 100% fruit juice ¼ cantaloupe ¼ kiwi ¼ kiwi
Vegetables 	1 cup	1½ cups	1½ - 2 cups	½ cup of veggies? ½ cup mashed, sliced, or chopped vegetables ½ cup raw leafy greens ½ cup cauliflower 1 small ear of corn
Grains Make half grain, grain whole	3 ounces	4 - 5 ounces	4 - 5 ounces	1 ounce of grains? 1 slice bread 1 cup ready-to-eat cereal ½ cup cooked rice or pasta 1 tortilla (7" or larger)
Protein Foods 	2 ounces	2 - 3 ounces	3 - 5 ounces	1 ounce of protein foods? 1 ounce cooked meat, poultry, or seafood 1 egg 1 tablespoon peanut butter ½ cup cooked beans or peas (chickpeas, lentils, etc.)
Dairy Choose low fat or fat free	2 cups	2 cups	2½ cups	½ cup of dairy? ½ cup milk 4 medium yogurt ½ ounce cheese 2 string cheese

Some foods are easy for your child to choose on their own. Like hard, small, whole fruits, hard or soft cheese, milk, and hard candy. Cut up foods such as fruit, dairy, eggs, and raw carrots into sizes smaller than the size of your child's thumb - about the size of a nickel.

There are many ways to divide the Daily Food Plan into meals and snacks. When the Meal and Snack Patterns and Ideas" is one how these amounts might look on your preschooler's plate at www.thecompassionatepreschooler.com

MyPlate Meal and Snack Patterns for 1000-1600 Calories

Meal and Snack Pattern A

2000 calories daily Food Plan

Meals: Breakfast, Lunch, Dinner

Snacks: Morning, Afternoon, Evening

CHOCChildren

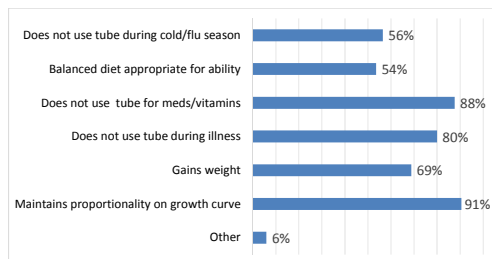
Criteria for Tube Removal

- 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

CHOCChildren

Criteria for Tube Removal

N= 170



ASPEN 2016 National Survey. ASPEN Enteral Nutrition Weaning Consensus Statement Committee.



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 reflex 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



Food Group	% of Goal
Grains	50
Vegetables	40
Fruit	>100
Dairy	>100
Protein	60



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



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 - Brandis Goodman



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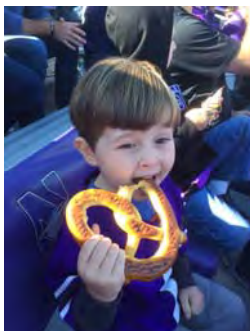


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Questions?



Motivational Interviewing Pearls for Practice: Application in Celiac Disease

ANN SCHEIMANN MD MBA
JOHNS HOPKINS SCHOOL OF MEDICINE

Patient Outcomes in Celiac Disease

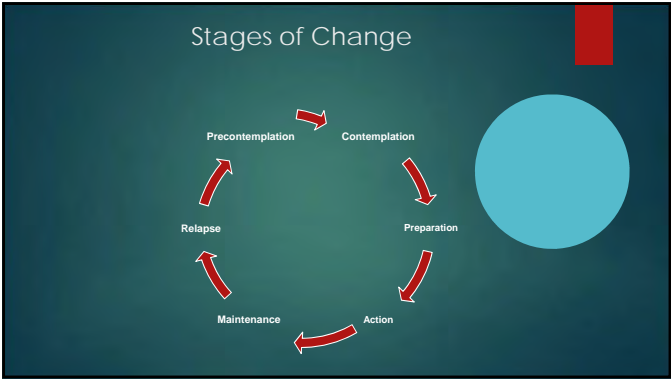
- ▶ Majority of emphasis in celiac disease has been molecular/cellular markers (only 9% of recent citations analyzed treatment)
- ▶ Diet access/control paradigm changes between children and adolescents
 - ▶ Teens are subject to peer influences
 - ▶ Kumar et al-44% of celiac teens were noncompliant with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

Simona, Esposito, Di Mase et al., JPCN 2010, 50:54-60. Kumar, Arch Dis Child 1988;63:916-20

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

Miller, Rolnick 2002



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/against 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 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

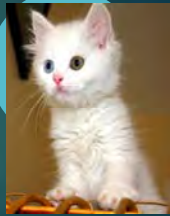
- ▶ Dietary change rather than a "pill" can be overwhelming
- ▶ Food lists, culinary skills, home resources, finances can create stress
 - ▶ Some patients/families are frightened and ready for change
 - ▶ Some families are angry and resistant to change

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 Years 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 the 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

Short Term Costs	Short Term Benefits
a)	a)
b)	b)
c)	c)

Long Term Costs	Long Term Benefits
a)	a)
b)	b)
c)	c)

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 Pedi 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
 - Minimally responsive children with CP; trach, vent dependent, tube fed. Needs determined to be **46%** lower than typical children. (Gale, et al. *J Parenter Enteral Nutr.* 2016 Aug 15)

- 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)
 - Harris-Benedict for BPD (Bott, L. et al. *European Journal of Clinical Nutrition* 2006: 60, 1323–1329.
 - Schofield for children with Muscular Dystrophy or CP *Am J Clin Nutr* 1996;64(4):627-34.
 - ✓ Krick for CP (Krick J., *Dev Med Child Neurol.* 1992;34(6):481-7.)
 - ✓ Reiken for CP using BIA or skinfold (Reiken et al. *Am J Clin Nutr* 2011;94:759–66).

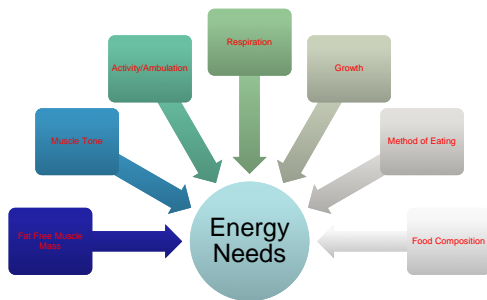
Traditional Estimations

Disorder (5-12 years)	Energy Requirement
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
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 for wt loss ~ 50% of RDA after infancy

Base on
centimeters or
kilograms?

S.W. Ekvall and V. Ekvall, eds. *Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment, and Treatment* 2nd Edition, 2005

Moving from Calculations: Art of Assessment



Fat Free Mass/Activity

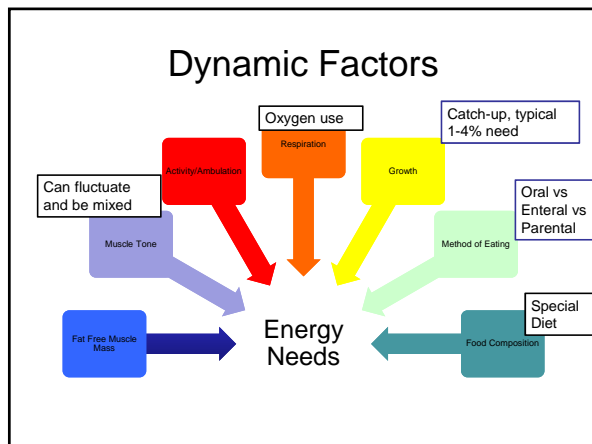
Reduces Needs

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

Increases Needs

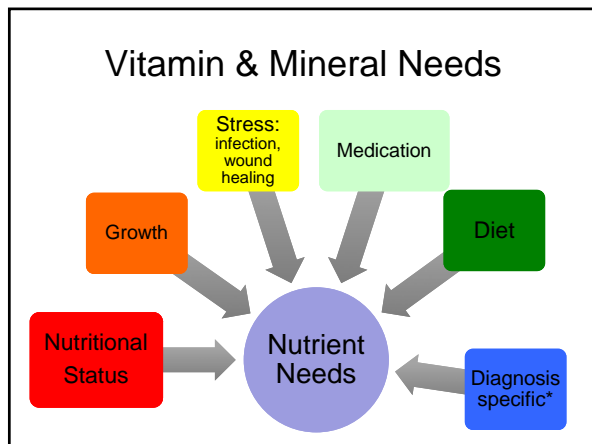
- Athetosis
- Spasticity
- Ambulation- greater energy expenditure then typical
- Equipment- electric vs manual; walker vs crutches (42%)

Bell, et al. *Am J Clin Nutr* 2010;92(2):313-319



- ### A Starting Place
- Estimation of Need
 - Indirect Calorimeter (Hogan et al Can J Diet Pract Res 2004; 65(3):124-30)
 - 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
 - feeding loss or GERD (Rimpel, *Phys Med Rehabil Clin N Am* 26 (2015) 39–56)
 - 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)

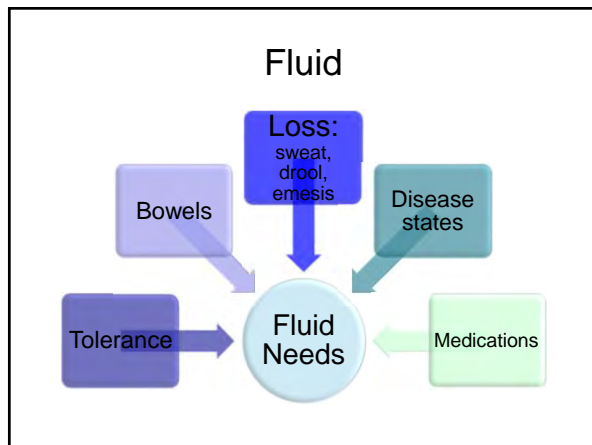


- ### Risk of V/M Deficiency
- Commercial formula use
 - Lack trace elements (Selenium) and Carnitine
 - Volume tolerance may prevent intake of appropriate amount needed to meet need
 - Energy need may be so low that impossible to consume adequate vitamin and minerals
 - Supplementation may not resolve
 - 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 ?



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

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PEDIATRIC FEEDING DISORDER: PROPOSED CONSENSUS DEFINITION AND FRAMEWORK

Susanna Y. Huh, MD MPH
Colleen T. Lukens, PhD
Pamela Dodrill, PhD, CCC-SLP

Faculty Disclosure

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Outline

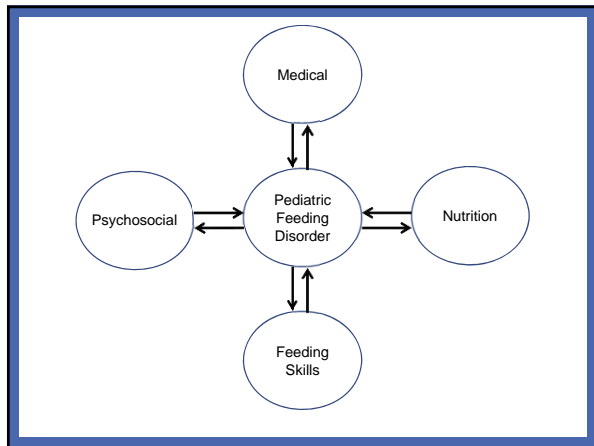
- Introduction
 - Rationale for a new definition
 - Review of diagnostic criteria and ICF framework
- Describe the four integral domains involved
 - Medical
 - Nutrition
 - Skill
 - Psychosocial
- Case discussions

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

Association	Term	Comments about definition
American Speech-Language-Hearing Association	Pediatric Dysphagia	<ul style="list-style-type: none"> • impaired oral, pharyngeal, and/or esophageal phases of swallowing; definition medical & skill-based
Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)	Avoidant/Restrictive Food Intake Disorder (ARFID)	<ul style="list-style-type: none"> • 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) R63.3: Feeding difficulties	<ul style="list-style-type: none"> • requires the absence of organic disease • non-specific, poorly defined diagnostic category

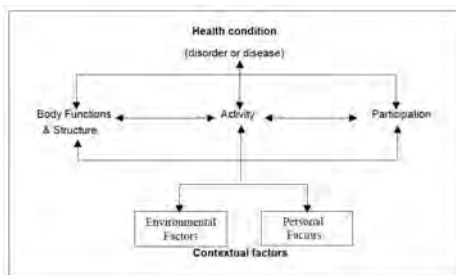
Limitations of existing definitions: Williams syndrome



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

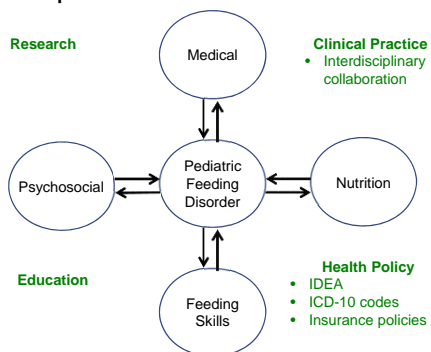
Pober et al. J Clin Invest. 2008;118(5):1606-1615

ICF Framework: Disability and functioning



WHO. Towards a Common Language for Functioning, Disability and Health. Geneva: 2012
WHO/EIP/GPE/CAS/01.3

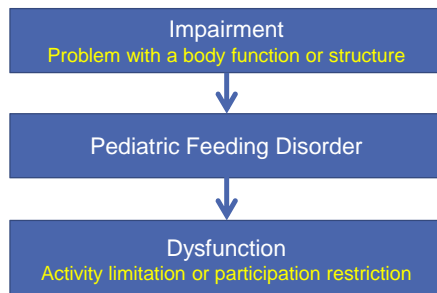
Implications of new definition



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

MEDICAL

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

Medical conditions causing and caused by Pediatric Feeding Disorder

Impairment causing PFD	Dysfunction caused by PFD
Disorders that affect oral, nasal, or pharyngeal function Aerodigestive disease Airway Pulmonary Gastrointestinal Congenital and other heart disease Neurologic, developmental, and psychiatric disorders Iatrogenic	Malnutrition and its sequelae Aspiration, recurrent aspiration

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



Before frenotomy



Image from <http://brochures.mater.org.au/brochures/mater-mothers-hospital/tongue-tie>

Aerodigestive disease

- Airway

- Laryngeal clefts
- Vocal fold paralysis or injury
- Airway 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

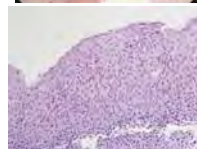
- Esophagitis

- peptic, eosinophilic, infectious

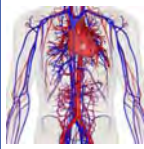
- Inflammation

- 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



Slide courtesy of Praveen Goday

NUTRITION

Proposed Diagnostic Criteria for Pediatric Feeding Disorder

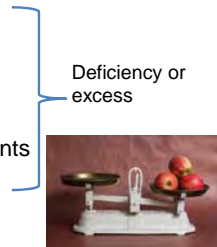
- A. A disturbance in oral intake of nutrients, inappropriate for age, lasting ≥ 2 weeks, associated with ≥ 1 of :
 2. Nutritional dysfunction
 - a. Malnutrition
 - b. Specific nutrient deficiency or significantly restricted intake of ≥ 1 nutrient resulting from decreased dietary diversity
 - c. Reliance 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

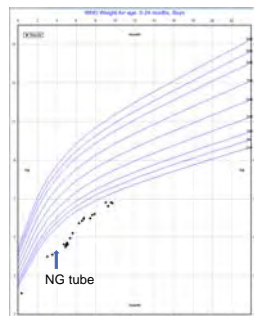
Nutritional consequences of pediatric feeding disorder

- 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



http://www.quickanddirtytips.com/sites/default/files/images/6275/constipation_kid_cartoon.jpg

Water



Inadequate dietary diversity

- Macronutrient or micronutrient deficiency
- Impaired social functioning
- Cultural appropriateness



SKILL

Pamela Dodrill, PhD, CCC-SLP

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

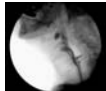
(sucking, drinking, chewing, biting)

- 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

Feeding skill disorders

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:

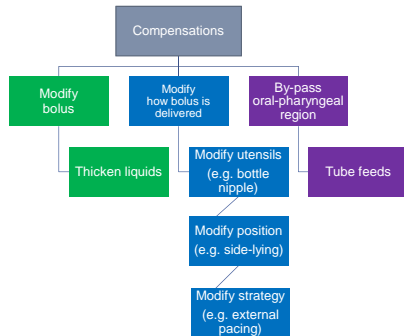
- Prolonged mealtime duration
- Insufficient PO intake

Infant feeding skills

Skills:

- Suckling
- Breastfeeding, bottle feeding

Infant feeding skills

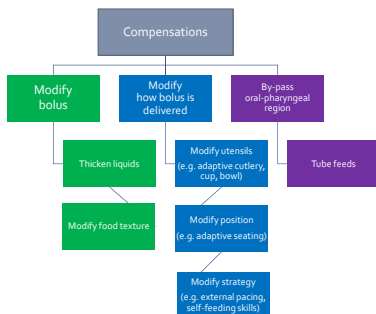


Child feeding skills

Skills:

- Mastication and drinking
- Biting, chewing, drinking from cup, self-feeding

Child feeding skills



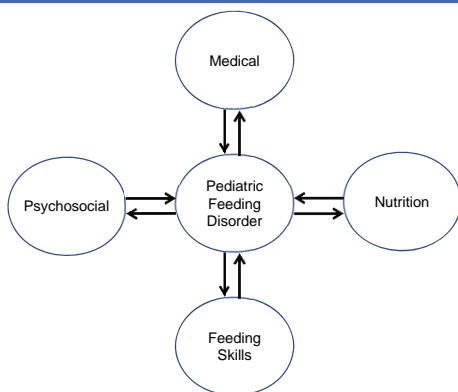
PSYCHOSOCIAL

Colleen T. Lukens, PhD




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

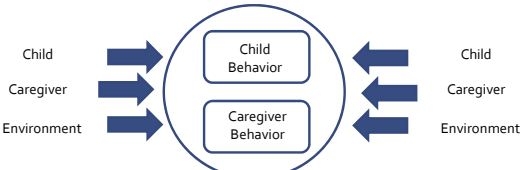


Psychosocial Factors


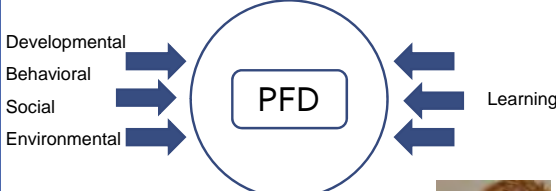


Psychosocial Restriction
 Pediatric feeding disorders develop as a result of and are maintained by factors within the child, caregiver, and environment

Resultant Dysfunction
 Observable child and caregiver behavior



Psychosocial Restrictions

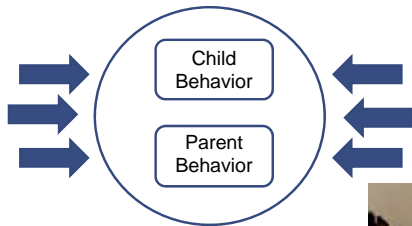
Psychosocial Restrictions

- 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



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
