

Interdisciplinary Inpatient Approaches To Weaning Tube Dependent Children From Enteral Feeding

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Disclosures

Drs. Silverman & Kim have no financial relationships related to the content of this lecture to disclose

Overview of Feeding Problems

- Lack sufficient volume or variety for adequate nutrition and/or lack of developmentally appropriate feeding
- 25-40% of toddlers and preschoolers have transient feeding problems
- Chronic feeding problems 5-10% of general population
 - 30% of children with chronic illness
 - 80% of children w/ disabling conditions
- Severe feeding problems that require medical attention and threaten long-term growth and development affect 3-20% of children
- Feeding problems account for 1-5% of hospital admissions
- Limited evidence that feeding disorders may evolve into eating disorders in adulthood

What does a feeding disorder look like?



Undernutrition-Short Term Effects

Moderate malnutrition

- Lower activity level
- Less enthusiasm for play and exploration
- Increased fussing
- Less positive affect
- Fewer vocalizations
- Tendency to stay close to mother
- Greater apathy



Severe malnutrition

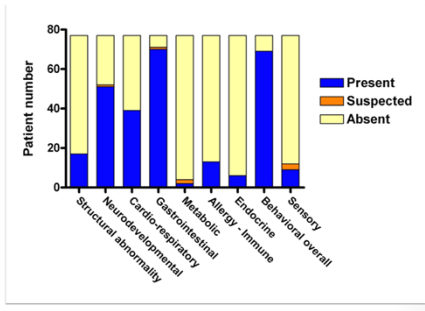
- Less active and exploratory; More apathetic; Less distress
- Reduced orienting to auditory stimulation
- Low amplitude cry
- Development generally remains poor

Undernutrition-Long term effects



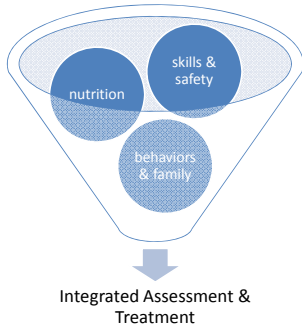
- Lower IQ than matched peers
- Poorer school achievement than peers
- Reasoning, perceptual-spatial function, fine motor function
- Children stunted in the first 3-years show deficits in later broad range measures of cognition
- Long term attention deficits, social deficits, more aggressive, more distractible, less independent
- Impairment of bonding; disordered parenting
- Increased parental & family stress

Who's At Risk

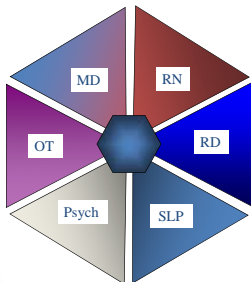


Children's Hospital of Wisconsin Feeding Clinic

How To Provide Care



Interdisciplinary Care



- Required to manage problems that are larger than any one discipline
- We learn from each other and over time, work primarily within a common region

Types of Interdisciplinary Interventions

- **Behavioral**
 - Stimulus control procedures
 - Extinction
 - Systematic desensitization
 - Differential attention
- **Nutritional**
 - Nutrition education
 - Manipulation of tube feedings
 - Other appetite manipulation
 - Structured mealtime scheduling
- **Oral-motor**
 - Oral-motor exercises
- **Other psychological**
 - Play therapy
 - Family therapy
 - Psychoeducation
- **Caregiver Training**
 - Teaching specific components of intervention to caregivers

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Systematic Review of Psychological Interventions for Pediatric Feeding Problems

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Objective: To conduct a systematic review of the research evaluating the effect of psychological interventions for pediatric feeding problems. **Methods:** A search was conducted for relevant studies using psychological interventions for pediatric feeding problems published between 1980 and 2013. Randomized controlled trials (RCTs) and nonrandomized studies that reported significant outcomes data were included. Primary outcomes were: (1) feeding behavior, nutritional status, and caregiver stress. A set of bias assessment was conducted and the quality of the evidence rated using Grading of Recommendations Assessment, Development, and Evaluation methodology. **Results:** 13 studies were identified and a summary confidence framework was used to report findings. **Conclusions:** The preponderance of evidence supports the efficacy of psychological interventions for the treatment of feeding problems. However, limited data and the paucity of studies using RCT methodology limit conclusions that can be drawn regarding the efficacy of these interventions. Future studies using more rigorous research methods are needed to enhance understanding of these interventions.

Key words: evidence-based practice; gastroenterology; nutrition; systematic review

Background: Feeding problems are identified if a child's eating behavior has an adverse effect on health or psychosocial functioning (Hansen-Frank, Warkentin, Kratoch, & Walsh, 2010; Iwata, Smith, & Smith, 1999). The behavioral manifestations of feeding problems, and thereby the target of psychological interventions, include food refusal, food aversion, or other disruptive behaviors incompatible with eating. Feeding problems are observed most commonly in early childhood but can persist into middle childhood. If unaddressed (Iwata et al., 1999; Walsh & Iwata, 2007), feeding problems are reported in approximately 25% of the general population (Charney, 1975), occur in up to 80% of children with developmental disabilities (Waldman & Brown, 2003), and are estimated to occur in 40–50% of children with chronic medical conditions (Iwata, Smith, Cohen, Moore, & Brown, 2010; Iwata & Smith, 1999; Thompson, Feibach, Kaye, Lerner, & May, 1993). Feeding disorders, characterized by chronic feeding problems, which impede long-term growth and nutrition, are estimated to affect 5–15% of children, making feeding disorders one of the most common conditions presenting for concern to pediatricians (Waldman, 2003). Behavioral contributors to feeding problems include medical, nutritional, developmental, environmental, social, and psychological factors. Identification and treatment of these contributors is an early sign of feeding development, resulting in good nutrition, subsequently good nutrition can impact weight gain, brain growth, and other functional health outcomes as well as cognitive development and emotional stability (Edrington & Taylor, 2005). Caregiver stress is also commonly associated with childhood feeding problems (Starns, Thomson, Kavan, & Charney, 2007; Walsh, Feibach,



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Outpatient Program Outcomes

Table 1. Characteristics of Included Studies

Study (study design)	Study duration	n	Intervention	Outcome
★ Bennett et al., 2000 (RCT)	7 intervention sessions with follow-up	64	Intervention: nutrition counseling (tube weaning) plus behavioral intervention Comparison: nutrition counseling (tube weaning)	No change in mealtime behavior Less time to tube weaning for intervention group At discharge, 13% of patients weaned from tube feeding At follow-up, 47% of patients weaned from tube feeding Greater proportion of caloric needs met through oral feeding for intervention group
★ Davis et al., 2009 (NRS)	14 weeks	9	Appetite manipulation through medication management and tube weaning plus pain rehabilitation	At discharge, 100% of patients weaned from tube feeding At follow-up, 89% of patients weaned from tube feeding
Sharp et al., 2013 (RCT)	8 intervention sessions	39	Intervention: behavioral intervention Comparison: no treatment (waiting list)	No changes in mealtime behavior No changes in dietary variety Significant reduction in parental stress for intervention group High rates of satisfaction reported by caregivers in intervention group

CHW Feeding & Swallowing Center

- NICU
- Herma Heart
- Physical Medicine and Rehabilitation
- Neurology
- Genetics
- ENT / Aerodigestive
- Craniofacial / Cleft palate
- Others

Feeding clinic

- 200 New visits yearly
- 2000 F/U visits yearly
- Interdisciplinary care

- Pediatricians
- Family physicians
- Schools
- Individual therapy providers
- Local, regional, national

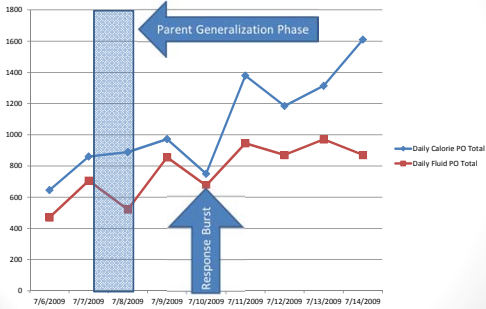
Nutrition Management

- Daily weights
- Oral calorie intake
- Oral fluid intake
- Days requiring supplementation (either by rehydration solution or GT formula)
- Treatment of nutrition instability
 - **Low blood glucose** (less than 60 mg/dL) - patient given 4 oz. juice orally or by GT. BG measurement taken 15 minutes later. This process is repeated until BG is greater than 60mg/dL
 - **Elevated urine ketones** (>trace) - Patients who demonstrated elevated urine specific gravities on greater than two consecutive measures received additional fluid
 - **Urine specific gravities** (>1.020) - Additional fluids were given via GT to prevent dehydration PRN

Behavioral Management

- 1st phase of treatment
 - All meals were fed by psychologists
 - Caregiver(s) observing remotely
 - Meals debriefed with caregivers upon completion of meal
- 2nd phase of treatment
 - Caregiver(s) transitioned into the feeding environment
 - Caregiver(s) gradually transition to the role of feeder
 - Psychologist gradually faded from the feeding environment
- 3rd phase of treatment
 - Caregiver(s) assume the role of feeder
 - Psychologist completely removed from the feeding environment
 - Psychologist coaches caregiver(s) remotely via an earpiece speaker

Daily Calories and Fluids



Discharge/Follow-up

- Routine follow up in our outpatient clinic
- Continued with community speech & language pathologist
- Remained free of tube fed calories post discharge but did have some supplemental hydration
- G-tube removed in follow-up clinic after it was not used >3 months

CHOC Children's Multidisciplinary Feeding Program

Overview & Outcomes



Successful Gastrostomy Tube Weaning Program Using an Intensive Multidisciplinary Team Approach

¹Jessica Brown, ²Cindy Kim, ³Audrey Lim, ⁴Shonda Brown, ⁵Hema Desai, ⁶Leigh Volker, and ⁷Mitchell Katz

ABSTRACT

Objectives: The present study evaluated the effectiveness of a multidisciplinary intensive inpatient model for gastrostomy tube (GT) weaning. **Methods:** A retrospective chart review was completed on 30 GT-dependent children, ages 1.9 to 14.4 years, admitted to the inpatient feeding program (length of stay 19 days) from May 2009 to December 2011. Admitted GT calories were decreased on admission by an average of 73% from home regimen. Patients were offered 3 meals and 2 to 3 snacks/day, including 3 intensive feeding therapy sessions (Monday to Friday), along with psychosocial support, nutrition guidance, and behavioral therapy. Daily calorie counts and weights were recorded. Patients returned for a postdischarge feeding evaluation at an average of 4 months and a clinic

(4). Children with feeding difficulties fail to consume an adequate volume and/or variety of food to maintain a healthy nutritional status. The use of gastrostomy tube (GT) feeds may be necessary to promote adequate nutrition and growth (5); however, these children often have difficulties resuming oral feeds long after their underlying medical issues have resolved, resulting in GT dependency. Many families who attempt oral feedings at home are often unsuccessful owing to lack of professional guidance, worries of weight loss, and difficulty coping with the child's negative behaviors during oral feedings (6). Feeding disorders are a multidimensional and complex problem that can stem from deficits in oral motor skills, orofacial/oral

Brown et al

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Treatment

- 19 day inpatient hospitalization
- Structured mealtimes
- Intensive daily sessions with feeding therapists (OT and SLP) and psychologist
- Supportive sessions with social worker and child life specialist
- Ongoing medical and nutrition monitoring
- Weekly collaborative family conference with the team

CHOC Children's Multidisciplinary Feeding Program

- Gastroenterologist
- Nurse Practitioner
- Psychologist
- Social Worker
- Speech Pathologist
- Occupational Therapist
- Registered Dietician
- Child Life Specialist



CHOC Inpatient Feeding Program's Philosophy

- Both parents and the child are considered an important part of the team and their input is valued as much as that of any other team member
- Throughout their entire inpatient process, parents are involved in daily consultation with team members and participate in weekly team conferences
- Treatment goals not only address feeding skills but also focus on enhancing the overall family dynamic and functioning
- Treatment incorporates other caregivers and family members

Readiness Factors for Inpatient Admission

- Age (2-6 years old)
- Developmentally >18 months
- Medically stable/Safe swallow
- Limited progress with outpatient feeding therapy
- Willingness to accept at least two textures by mouth
- Primary feeder able to commit to 3-week inpatient stay and adequate transition home
- Supportive social environment
- Insurance authorization/approval

Inpatient Process

Week 1: Improve the Child's Feeding Experience

- Goal: Increase child's ability and willingness to eat foods by mouth

Week 2: Maximizing The Child's Potential

- Goal: Increase the types and amounts of foods the child eats in a positive environment.

Week 3: Preparing for Transition Home

- Goal: Teach the child and parent ways to continue improving and having positive meal times at home.

Week 4: Home Implementation after discharge

- Goal: Families and the patient put into action at home everything they learned while in the Program

TABLE 5. Typical inpatient schedule

Time	Activity
0730	Daily weight and vitals
0800	Breakfast with OT/SLP*
0900	RD consultation; free time
1000	Snack with primary feeder
1030-1200	Playroom
1200	Lunch with OT/SLP*
1300	Psychology and SW consultation; free time
1500	Snack with OT/SLP*
1600-1800	Free time
1800	Dinner with primary feeder
1900-2000	Playroom
2000	Bedtime snack (if needed)

OT = occupational therapist; RD = registered dietitian; SLP = speech-language pathologist; SW = social worker.
 *Feeding sessions are with OT/SLP Monday to Friday (weekend meals with primary feeder; OT/SLP attends 1 weekend feeding session).

Nutrition Management

- Create hunger
 - Decrease TF 50-70% on admit
 - Consolidated meal schedule
 - Appetite stimulant
- Establish caloric needs
 - Goal of ≥80% prior to discharge
 - Daily calorie counts
- Use high calorie supplements/foods
- Monitor stooling pattern & hydration
- Monitor weight changes
 - Daily AM weights
 - Avoid >10% weight loss



Treatment Strategies

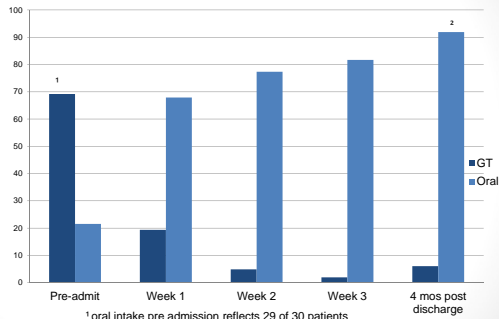
- Behavioral Approaches
 - Positive Reinforcement
 - Redirection/Extinction
 - Empower through Choice
 - Encourage Self Initiation
 - Social Modeling
 - Food Chaining/Desensitization
 - Oral Exercises/Stimulation
- Sensory Approaches
 - Sensory Warm Up
 - Intra/Extra-oral Stimuli
 - Grading taste and texture
 - Grading bolus size



Results

- **Prior to admission**, patients received 69% (± 25) of goal calories from GT feedings.
- **During admission**, average caloric intake by mouth as a percentage of goal increased over the course of weeks 1, 2, and 3 (68%, 77%, and 82% respectively), with a statistically significant increase between week 1 and 2 ($p=.001$) and week 1 and 3 ($p=.011$).
- **At discharge**, 90% had discontinued GT feedings with 49% (± 22) of oral intake coming from nutritional supplements. Ten percent were discharged on nighttime GT feeds, providing 25.7% (± 11.2) of goal calories.
- **At 1-year follow up**, 83% remained successfully off GT.

Percentage of Goal Calories



Intensive Inpatient Multidisciplinary Feeding Intervention is Successful for GT Weaning



Conclusions

- Best available evidence shows clinical effectiveness for selected patients
- Gains are maintained “long term”
- Cost effectiveness for tube wean
- Improved quality of life and parent-child relationships
- Currently greater clinical need than available resources

Additional Slides

CHW Supplemental Slides



Nutritional and Psychosocial Outcomes of Gastrostomy Tube-Dependent Children Completing an Intensive Inpatient Behavioral Treatment Program

Alan H. Silverman, Midge Kirby, Lisa M. Clifford, Elizabeth Fischer, Krausger S. Berlin, Colin D. Rudolph, and Richard J. Noel

ABSTRACT

OBJECTIVE: Limited published data describe the long-term effects of behavioral strategies to wean children from gastrostomy tube (GT) feeding dependence. This study presents descriptive nutritional and psychosocial outcomes observed during a 1-year period in medically complex GT feeding dependent patients who completed an intensive behavioral-based tube weaning program.

DESIGN: This was a retrospective study of prospectively and retrospectively collected data associated with a clinical cohort of 77 children diagnosed as having feeding disorder, GT feeding dependence (<1 year), and/or inability to maintain adequate growth via oral feeding, completing an intensive tube weaning program. Nutritional data (percentage of ideal body weight, and oral and enteral intake) as a primary outcome goal and psychosocial data (measures of behavior problem, quality of caregiver and child interaction, and parenting stress) were secondary goals and post-treatment nutritional data were also measured longitudinally at 1, 3, 6, and 12 months post-treatment. Data were grouped by treatment modality.

RESULTS: Median (interquartile range) feeding behavior, medication, and all of the patient, environmental, and caregiver risk factors in the distribution table from 1 treatment failure. Fifty-one percent of patients were fully weaned from tube feeding after 2 weeks and an additional 12% completed weaning in the subsequent follow-up time within 1 year. Patients maintained nutritional stability at the 1-year post-treatment follow-up appointment.

CONCLUSIONS: Intensive behavioral interventions are highly effective and safe for increasing long-term oral feeding abilities in oral feeding dependent children. Children and their families were recruited from the feeding and swallowing clinic at Children's Hospital of Pittsburgh between January 2007 and December 2009. The children recruited had demonstrated a sustained stability in nutrition intake

important immediate benefits (1,2), the ultimate goal in treatment is to introduce or reintroduce oral feeding.

In several studies (1,3-6) behavioral-based treatments have been shown to be effective in weaning GT-dependent children; however, these studies have been small in size and have not provided information about the long-term outcomes of these treatments. As an example, Ryan et al (1) reported outcomes for 9 children 18 to 23 years of age who completed intensive care to wean them from GT dependence. Results showed that at the time of discharge, 49% (n = 7) patients had completely discontinued GT feedings, and between the 2- and 4-month follow-up, an additional 2 patients were consuming all of their calories orally. Although promising, this study was limited by the small sample size, individual outcomes were not reported, and no longitudinal data were presented.

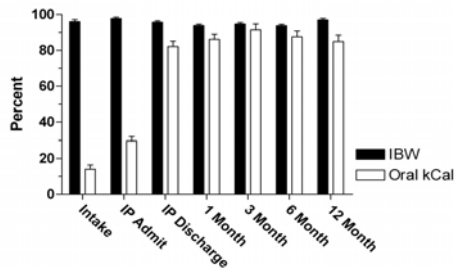
The primary purpose of this study was to describe an intensive program of behavior therapy designed to wean children who have failed traditional outpatient treatment from dependence on GT feedings.

METHODS

This was a retrospective study of prospectively and retrospectively collected data associated with a clinical cohort of 77 children diagnosed as having a feeding disorder, GT feeding dependence (<1 year), and an inability to maintain adequate growth via oral feeding, completing an intensive tube weaning program. Children and their families were recruited from the feeding and swallowing clinic at Children's Hospital of Pittsburgh between January 2007 and December 2009. The children recruited had demonstrated a sustained stability in nutrition intake

Key Words: behavior therapy, clinical outcomes, nutrition, tube weaning
LIPCX 2013;37: 468-472

Tube Wean Longitudinal Data



Note. IBW is the percentage of the ideal body weight for a patient's height. Oral kCal is the percentage of the total daily nutrition goal taken orally. The error bars represent one standard error. Patients remained at or above 90% Ideal Body Weight up to one year post-treatment. Oral kCal percentage of goal increased from approximately 25% of goal at admit to over 80% of goal at discharge. Treatment effects were maintained at the one year post-observation.

Psychological Outcomes Measures

TABLE 2. Paired samples tests for psychological effects

Source	Clinical range	N	Pre-treatment		Post-treatment		t	P
			Mean	SD	Mean	SD		
AVCE								
Child Resistance to Feeding	>33	61	38.82	8.69	28.56	9.18	8.04	<0.000
Positive Mealtime Environment	<12	61	15.67	4.75	17.64	3.87	-4.39	<0.000
Parent Aversion to Mealtime	>12	61	15.90	5.20	10.90	4.91	4.67	<0.000
MBQ								
Mealtime Behavior Problems	>78	64	80.59	15.54	59.27	14.56	6.23	<.000
PSI								
Parenting Stress	>90	58	75.36	17.51	71.82	18.64	1.08	0.283

Higher scores on Child Resistance to Feeding, Parent Aversion to Mealtime, Mealtime Behavior Problems, and Parenting Stress represent greater difficulties in these domains. Higher scores on Positive Mealtime Environment represent greater degree of positive interactions. AVCE = About Your Child's Health; MBQ = Mealtime Behavior Questionnaire; PSI = Parenting Stress Index; SD = standard deviation.

Demographics and Tube Feeding History	
Participants	n=127
	52% Male
	71.4% White
	13% Hispanic
	6.5% African American
	5.2% Asian
	3.9% Other
Gestation	34.3 +/- 5.9 weeks
Age at GT placement	0.9 +/- 1.1 years
Duration of GT feedings at hospital admission	3.7 +/- 2.1 years
Age at hospital admission	4.5 +/- 2.2 years
Oral percentage of caloric goal at clinic intake	13.5 +/- 19.8 percent

Percentage of Children with Adverse Nutrition Effects			
	%	Mean (days)	SD
Rehydration Solution	85	6.3	4.7
Tube feeding formula	17	0.31	1.3
Parenteral IV fluids	5	0.1	0.6
Urine Ketones	55	1.3	1.7
Concentrated Urine	58	1.3	1.7
Low Blood Sugars	12	2	6.3

Methods

- 30 GT dependent children (Mean age = 4 years) admitted from May 2009 to December 2011.
- On admit GT feeds were decreased from home regimen by an average of 70% and weaned during admission.
- Calorie counts and weights were recorded daily. Caloric goals were estimated based upon the previous home regimen and/or recommended dietary allowance for actual or ideal body weight (IBW).
- Patients received a total of 5-6 feeding sessions per day, of which 3 were intensive therapy sessions (Mon-Fri).
- In follow up, body weight and food logs were obtained on an average of 4 months post discharge.

Patient Demographics

n = 30

Variable	% Sample
Male	60
Female	40
Gestational Age	
33-37 weeks	20
28-32 weeks	10
<28 weeks	27
Gastroesophageal Reflux	77
Gastrointestinal abnormality	30
Chronic lung disease	17
Congenital Heart Disease	13
Genetic Disorder	23

CHOC Supplemental Slides



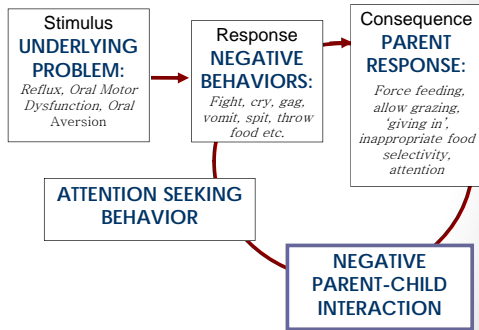
Goals of Treatment

- Phase I – Improve Feeding Experience
- Phase II – Just-Right Challenge: Maximizing the Child's Potential
- Phase III - Re-establish Positive Parent-Child Social Reciprocity
- Phase IV – Prepare for Transition to Home

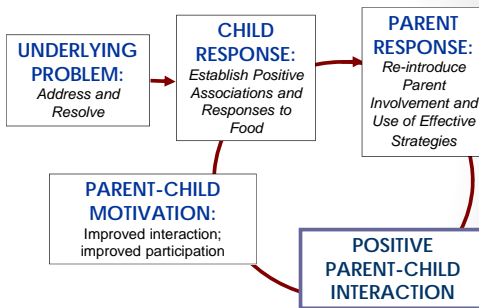
Patient Care – Blog Feedback

- A very big THANK YOU goes out to the feeding team, if it wasn't for them, Ryan would still be eating 3 teddy grahams a day.
(<http://www.fischersonline.com/feedingprogram.htm>)
- Now at home, Micah is enjoying and participating in family meals, makes his own selections at restaurants and surprising us by announcing new favorites like mustard and pickles. We had always considered his gtube a blessing which allowed Micah to become strong and healthy. Finding a program which helped Micah eat on his own was another gift which brings our family closer.
(<http://www.feedingtubeawareness.com/former-tubies.html>)
- It is weird being at home and seeing all the remnants of tube feeding and knowing that is a thing of the past. There are syringes on the kitchen counter, an extension that was hung to dry above the kitchen sink, button buddies on the dryer, closets full of supplies, an IV pole in her bedroom, and a mountain of formula in the laundry room... Coming home makes it all real. I have a little girl who EATS and eats enough to grow and thrive. I don't think I can say that enough. NAOMI EATS!!!!
(<http://byebyetubie.blogspot.com/2012/09/day-7-details.html>)

Parent-Child Feeding Dynamic

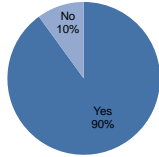


How this Dynamic is Changed

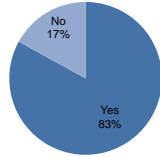


Success of the Multidisciplinary Inpatient Feeding Program

GT Support Discontinued by Discharge



Remain off GT Support at 12 months Post Discharge



Results (continued)

- Average percent IBW **at admit** was 96% (± 8), at discharge was 96% (± 9) and at follow up was 94.1% (± 7.4).
- **At follow up** (average of 4 months) 24 of 30 (80%) remained successfully off of GT feedings.
- **At follow up** calorie counts based on an average of 3 day food records were obtained for 26 out of 30 patients and demonstrated an average caloric intake by mouth of 91.9% (± 20.2) of goal calories.
- **At follow up** the 6 patients who remained on supplemental feeds received an average 30.5% (± 15.3) of goal calories by GT. This represented an average decline of 36.3% (± 43) from admit GT intake.

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Resources

- NASPHGAN - North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
 - www.nasphgan.org
- Society of Pediatric Psychology
 - www.spp.org/about/division/div54.aspx
- Academy of Nutrition and Dietetics
 - www.eatright.org
- American Society for Parenteral and Enteral Nutrition
 - www.nutritioncare.org
- AAP - American Academy of Pediatrics
 - www.aap.org
- ASHA - American Speech-Language-Hearing Association
 - www.asha.org
- Advancing Healthier Wisconsin (AHW)
 - www.mcw.edu/ndtn.htm
- Feeding Matters
 - www.feedingmatters.org
