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 with 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

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

Outpatient Program Outcomes

<table>
<thead>
<tr>
<th>Study Title</th>
<th>Study Design</th>
<th>Study Duration</th>
<th>Intervention Description</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sorensen et al., 2013</td>
<td>14 weeks</td>
<td></td>
<td>Intervention, including feeding tube management, oral-motor intervention, and caregiver education</td>
<td>A decrease in tube feeding time, improved swallowing, and reduced tube feeding complications</td>
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</table>
Day Treatment Outcomes

<table>
<thead>
<tr>
<th>Study (year)</th>
<th>Outcome Measure</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>typical case</td>
<td>Improved social interaction</td>
<td>Increased verbal fluency</td>
</tr>
<tr>
<td>typical case</td>
<td>Improved concentration</td>
<td>Reduced distractibility</td>
</tr>
</tbody>
</table>

Inpatient Treatment Outcomes

<table>
<thead>
<tr>
<th>Study (year)</th>
<th>Treatment Type</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>typical case</td>
<td>Medication therapy</td>
<td>Improved mood stabilization</td>
</tr>
<tr>
<td>typical case</td>
<td>Psychotherapy</td>
<td>Improved coping skills</td>
</tr>
</tbody>
</table>

A “Typical Case”
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
Successful Gastrostomy Tube Weaning Program Using an Intensive Multidisciplinary Team Approach

Jessica Brown, Cindy Lim, Andrew Lim, Danielle Brown, Helene Desai, 
Leigh Bellone, and Mitchell Kass

ABSTRACT

Objective: The present study evaluated the effectiveness of a multidisciplinary intensive feeding intervention in improving feeding outcomes in children with gastrostomy tube use. Method: A retrospective chart review was conducted on 20 children at CHOC Children’s Hospital, Orange County, CA, who were prescribed gastrostomy tube feeding for medical reasons. Feeding intervention consisted of daily structured feeding sessions, 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, and weekly collaborative conferences with the team. Results: Children with feeding difficulties had a median age of 12 months and a median weight of 10 kg. Children with feeding difficulties had a median age of 12 months and a median weight of 10 kg. Children with feeding difficulties had a median age of 12 months and a median weight of 10 kg. Children with feeding difficulties had a median age of 12 months and a median weight of 10 kg.

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.
Nutrition Management

- Create hunger
  - Increase 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

- Sensory Approaches
  - Sensory Warm Up
  - Intra/Extra-oral Stimuli
  - Grading taste and texture
  - Grading bolus size

- Food Chaining/Desensitization
- Oral Exercises/Stimulation

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**TABLE 5. Typical inpatient schedule**

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

*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).
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.

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

Note. IBW is the percentage of the ideal body weight for a patient. Oral kCal is the percentage of the total daily nutritional 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 intake to over 80% at goal at discharge. Treatment effects were maintained at one year post observation.

**Tube Wean Longitudinal Data**

**Psychological Outcomes Measures**

**Table 2**: Risk factors in psychological effects

<table>
<thead>
<tr>
<th>Source</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Rejection Rating</td>
<td>50</td>
<td>50.9</td>
<td>29.3</td>
<td>91.4</td>
<td>0.34</td>
</tr>
<tr>
<td>Parent Rejection Rating</td>
<td>50</td>
<td>50.9</td>
<td>29.3</td>
<td>91.4</td>
<td>0.34</td>
</tr>
<tr>
<td>Parent Anxiety in Mothers</td>
<td>50</td>
<td>50.9</td>
<td>29.3</td>
<td>91.4</td>
<td>0.34</td>
</tr>
<tr>
<td>Psychometric Behavior Rating</td>
<td>50</td>
<td>50.9</td>
<td>29.3</td>
<td>91.4</td>
<td>0.34</td>
</tr>
<tr>
<td>Peer</td>
<td>50</td>
<td>50.9</td>
<td>29.3</td>
<td>91.4</td>
<td>0.34</td>
</tr>
<tr>
<td>Parenting Stress</td>
<td>50</td>
<td>50.9</td>
<td>29.3</td>
<td>91.4</td>
<td>0.34</td>
</tr>
</tbody>
</table>

Higher scores on Child Rejection Rating, Parent Rejection Rating, Parent Anxiety in Mothers, and Psychometric Behavior Rating reflect problems in child functioning. Higher scores on Parenting Stress reflect greater parent-reported distress. T1 = Time 1 (intake); T2 = Time 2 (treatment); T3 = Time 3 (discharge).
Demographics and Tube Feeding History

Participants
- n=127
- 52% Male
- 71.4% White
- 19% Hispanic
- 4.5% African American
- 6.2% Asian
- 3.8% 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 +/- 2.3 years

Age at hospital admission
- 4.5 +/- 2.2 years

Oral percentage of caloric goal at clinic intake
- 10.5 +/- 10.8 percent

Percentage of Children with Adverse Nutrition Effects

<table>
<thead>
<tr>
<th>Condition</th>
<th>%</th>
<th>Mean (days)</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rehydration Solution</td>
<td>85</td>
<td>6.3</td>
<td>4.7</td>
</tr>
<tr>
<td>Tube feeding formula</td>
<td>17</td>
<td>0.31</td>
<td>1.3</td>
</tr>
<tr>
<td>Parenteral IV fluids</td>
<td>5</td>
<td>0.1</td>
<td>0.6</td>
</tr>
<tr>
<td>Urine Ketones</td>
<td>55</td>
<td>1.3</td>
<td>1.7</td>
</tr>
<tr>
<td>Concentrated Urine</td>
<td>58</td>
<td>1.3</td>
<td>1.7</td>
</tr>
<tr>
<td>Low Blood Sugars</td>
<td>12</td>
<td>2</td>
<td>0.3</td>
</tr>
</tbody>
</table>

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*

<table>
<thead>
<tr>
<th>Variable</th>
<th>% Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>60</td>
</tr>
<tr>
<td>Female</td>
<td>40</td>
</tr>
<tr>
<td>Gestational Age</td>
<td></td>
</tr>
<tr>
<td>33-37 weeks</td>
<td>20</td>
</tr>
<tr>
<td>28-32 weeks</td>
<td>10</td>
</tr>
<tr>
<td>&lt;28 weeks</td>
<td>27</td>
</tr>
<tr>
<td>Gastroesophageal Reflux</td>
<td>77</td>
</tr>
<tr>
<td>Gastrointestinal abnormality</td>
<td>30</td>
</tr>
<tr>
<td>Chronic lung disease</td>
<td>17</td>
</tr>
<tr>
<td>Congenital Heart Disease</td>
<td>13</td>
</tr>
<tr>
<td>Genetic Disorder</td>
<td>23</td>
</tr>
</tbody>
</table>

### CHOC Supplemental Slides

![CHOC building and people image]

### 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 graham a day. [http://www.fischoinonline.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 tube 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

**Stimulus**
UNDERLYING PROBLEM: Reflux, Oral Motor Dysfunction: Oral Aversion

**Response**
NEGATIVE BEHAVIORS: Fight, cry, gag, vomit, spit, throw food etc.

ATTENTION SEEKING BEHAVIOR
NEGATIVE PARENT-CHILD INTERACTION

**Consequence**
PARENT RESPONSE: Force feeding, allow grazing, ‘giving in’, inappropriate food selectivity, attention

How this Dynamic is Changed

**UNDERLYING PROBLEM:** Address and Resolve

**CHILD RESPONSE:** Establish Positive Associations and Responses to Food

**PARENT RESPONSE:** Re-introduce Parent Involvement and Use of Effective Strategies

PARENT-CHILD MOTIVATION: Improved interaction; improved participation

POSITIVE PARENT-CHILD INTERACTION
Results (continued)

- Average percent IBW at admit was 96% (±8), at discharge was 96% (±9) and at follow up was 94.3% (±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.

References

Resources

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