



Intensive Multidisciplinary Intervention for Young Children with Feeding Tube Dependence and Chronic Food Refusal: An Electronic Health Record Review

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Objective To assess characteristics and outcomes of young children receiving intensive multidisciplinary intervention for chronic food refusal and feeding tube dependence.

Study design We conducted a retrospective study of consecutive patients (birth to age 21 years) admitted to an intensive multidisciplinary intervention program over a 5-year period (June 2014-June 2019). Inclusion criteria required dependence on enteral feeding, inadequate oral intake, and medical stability to permit tube weaning. Treatment combined behavioral intervention and parent training with nutrition therapy, oral-motor therapy, and medical oversight. Data extraction followed a systematic protocol; outcomes included anthropometric measures, changes in oral intake, and percentage of patients fully weaned from tube feeding.

Results Of 229 patients admitted during the 5-year period, 83 met the entry criteria; 81 completed intervention (98%) and provided outcome data (46 males, 35 females; age range, 10-230 months). All patients had complex medical, behavioral, and/or developmental histories with longstanding feeding problems (median duration, 33 months). At discharge, oral intake improved by 70.5%, and 27 patients (33%) completely weaned from tube feeding. Weight gain (mean, 0.39 ± 1 kg) was observed. Treatment gains continued following discharge, with 58 patients (72%) weaned from tube feeding at follow-up.

Conclusions Our findings support the effectiveness of our intensive multidisciplinary intervention model in promoting oral intake and reducing dependence on tube feeding in young children with chronic food refusal. Further research on the generalizability of this intensive multidisciplinary intervention approach to other specialized treatment settings and/or feeding/eating disorder subtypes is warranted. (*J Pediatr* 2020;223:73-80).

Feeding disorders in children are often complicated by predisposing medical conditions, oral-motor delays or deficits, dietary deficiencies, and/or disruptive mealtime behavior that perpetuate restricted food intake.^{1,2} To manage these interrelated problems, expert consensus recommends a multidisciplinary approach to assessment and intervention.¹ The standard treatment of children with complex feeding problems frequently involves intensive multidisciplinary intervention in day hospital or inpatient settings to expand oral food intake and reduce dependence on oral or enteral nutrition supplementation.² To coordinate treatment and monitor potential complications (eg, aspiration, marked weight loss, allergic reactions), the professional team may include psychologists, physicians, dietitians, speech-language pathologists, and occupational therapists. Children needing this level of care meet the criteria for avoidant-restrictive food intake disorder (ARFID). Manifestations of ARFID include faltering growth, nutritional deficiencies, and the need for oral nutrition supplementation or tube feeding to support growth and meet energy and nutrient needs.³ ARFID is also associated with high levels of caregiver stress, child social difficulties, and impaired family functioning.

A meta-analysis of 11 studies reported intensive multidisciplinary intervention outcomes for 593 patients (314 boys and 279 girls; age range, 15.7-48 months) with tube feeding or oral nutritional supplementation.² Nine reports were nonrandomized studies presenting outcomes from retrospective chart reviews; 2 were randomized controlled trials (RCTs). The most common treatment approaches used behavioral intervention and/or rapid weaning from tube feedings. Overall, 71% (95% CI, 54%-83%) of 454 patients were successfully weaned from feeding tube dependence. Treatment gains endured following discharge, with 80%

Accept	Rapid acceptance
ARFID	Avoidant/restrictive food intake disorder
EHR	Electronic health record
IMB	Inappropriate mealtime behaviors
MC	Mouth clean
RCT	Randomized controlled trial

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(95% CI, 66%-89%) of 414 patients successfully weaned from tube feedings at follow-up (1-24 months posttreatment). Treatment also increased oral intake and reduced disruptive mealtime behaviors and parenting stress. These supportive findings for intensive multidisciplinary intervention from the meta-analysis are consistent with previous single-subject⁴ and qualitative⁵ reviews.

Although converging evidence supports intensive multidisciplinary intervention for chronic feeding problems, the low methodological rigor of previous studies limits conclusions regarding the efficacy of this model of care. Shortcomings of extant studies include the lack of uniformity in outcome measurement and inconsistent reporting of patient characteristics. In addition, previous nonrandomized studies had several potential biases, particularly the lack of standardized data abstraction protocols, failure to use independent reviewers to record data, limited reporting of interrater reliability, and failure to use existing guidelines to document outcomes.^{6,7} In the present study, we examined the clinical presentation, intervention characteristics, and treatment outcomes in a sample of children receiving intensive multidisciplinary intervention for feeding tube dependence in line with the Strengthening the Reporting of Observational Studies in Epidemiology statement.

Methods

This retrospective cohort study involved an electronic health record (EHR) review of consecutive patients admitted to an intensive multidisciplinary intervention day treatment program specializing in the assessment and treatment of severe pediatric feeding disorders (birth to age 21 years) over a 5-year period (June 2014-June 2019). To be included in the EHR review, patients had to (1) meet diagnostic criteria for ARFID (A3a) based on dependence on enteral feeding (eg, gastrostomy tube, nasogastric tube, or gastrostomy-jejunostomy tube) not attributable to a concurrent medical condition or not better explained by another mental disorder in terms of severity and/or presentation in line with *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* criteria³; (2) require intervention to improve the volume and variety of solid food intake to replace enteral feeding due to chronic food refusal; and (3) be medically stable to permit weaning from tube feeding. The review excluded patients who received parenteral nutrition or patients with acute medical problems (eg, aspiration) that prohibited the introduction of oral intake. Two investigators independently reviewed all consecutive admissions to determine eligibility during the study period and resolved disagreements on inclusion or exclusion by consensus.

Treatment Setting

Treatment occurred in a multidisciplinary, day treatment feeding program located in the southeastern US. Patients admitted to the program participated in 4 therapeutic meals per day, 5 days per week (Monday through Friday), totaling

20 therapeutic meals per week. A team of feeding therapists, working under the supervision of a multidisciplinary team, conducted the therapeutic meals. The multidisciplinary team included psychologists, physicians, nurse practitioners, registered dietitian nutritionists, speech-language pathologists, occupational therapists, and social workers. Before the admission, the multidisciplinary team conducted a detailed clinical evaluation (~2 hours) to determine program eligibility. During this evaluation, the multidisciplinary team used a discipline-specific EHR template to document the behavioral, medical, nutritional, and oral-motor history for each patient. The assessment included a physical examination and a detailed clinical interview regarding the symptom onset and course, past treatments, current mealtime practices, current oral feeding skill, developmental history, and behavioral screening. Anthropometric data and dietary analysis (eg, 3-day food record) were recorded for all patients. Swallow safety was assessed, and medical clearance of treatment was determined by the speech-language pathologist and physician, respectively.

During admission, therapeutic meals followed a regular schedule (eg, 9:30 a.m., 11:00 a.m., 12:30 p.m., 3:15 p.m.) for a preset duration (ie, 40 minutes per meal) in a private treatment room with an adjacent observation room. Patients sat in a developmentally appropriate seat (eg, highchair, booster seat). Treatment rooms contained a table, feeding utensils (eg, maroon spoons, Nuk brush, rubber-coated baby spoon), bib, serving tray, data collection forms, and a food scale with an intake log. The meal schedule was designed to provide adequate time for digestion. The longer break between meals 3 and 4 permitted a nap if needed. The standard length of admission was 40 treatment days; however, the length of stay varied based on clinical complexity.

Intervention

Our intensive multidisciplinary intervention model rests on 3 assumptions. First, feeding disorders are most often due to conditioned food aversion (ie, pairing unpleasant consequences such as pain, nausea, impaired swallow safety, and/or fatigue with eating). Second, this conditioned aversion begets disruptive mealtime behaviors (eg, intense tantrums, tearful protests) to avoid contact with food, which perpetuates food refusal. Third, limited oral intake of solid food reduces the child's opportunities to develop oral-motor skills of chewing and swallowing.^{2,8} Therefore, treatment aims to diminish aversive experiences associated with oral intake and establish a positive and developmentally appropriate relationship with food while also setting realistic expectations for progress based on a child's oral-motor skill status. To achieve these aims, intervention involved 2 primary mechanisms for change. Behavioral intervention was the central method to introduce foods, promote oral intake, and expand dietary diversity. Through our clinical practice, we developed a standard sequence of reinforcement techniques, bite persistence (ie, contingency contacting, escape extinction), and stimulus fading/antecedent manipulation protocols.⁹ Treatment also involved use of modified bolus placement with

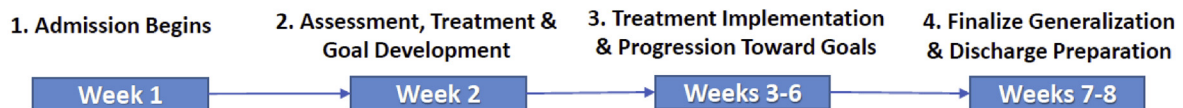
patients with moderate-to-severe oral-motor deficits as indicated.⁸ Parent training was the central method for structuring meals and transferring treatment gains from clinic to the home setting. The sequence and steps for parent training followed a sequential, proficiency-based process, with caregivers transitioning to serve as the primary feeder by discharge.

In addition to behavioral intervention and parent training, treatment included nutritional counseling, mechanical and nutritive oral-motor therapy, and medical oversight to monitor growth and promote a nutritionally complete diet, assess and advance skill deficits, and ensure adequate safeguards to address potential medical concerns that may emerge during the course of therapy (respectively). In a previous RCT, we described and evaluated this model of care using a treatment manual designed to standardize the sequence of treatment.⁹ Admission followed 4 distinct stages (Figure 1), with caregiver involvement throughout the admission to define goals, learn and adopt child-specific treatment protocols, and transfer treatment gains to the home setting. At discharge, treatment continued in less-intensive outpatient care. Caregivers were encouraged to maintain structured meals to improve oral intake and progress with weaning from tube feedings if not fully accomplished in day treatment. Additional mealtime goals often focused on promoting feeding independence (eg, self-feeding) and skill development (eg, chewing). Table I outlines the core components and interdisciplinary roles of this intensive multidisciplinary intervention model.

Systematic weaning from tube feeding was coordinated with transition to oral intake. Caregivers met with a registered dietician nutritionist to develop a plan to reduce enteral supplementation. Weaning from tube feedings commenced when the patient consumed approximately 1 ounce of food per meal. The reduction in enteral supplementation was designed to be calorically neutral—that is, the amount of formula decreased from tube feeding equaled calories consumed during therapeutic meals. The goal for oral intake in the therapeutic meals involved acceptance of food items from all food groups (eg, 4 fruits, 4 vegetables, 4 grains, and 4 proteins) plus a dairy (or equivalent) drink. In most cases, intervention started with pureed food to promote taste exposure and reduce the need for chewing, which may be impaired in children with longstanding food refusal.

To accomplish the balance between enteral supplementation and oral intake, the tube feeding regimen followed the schedule of therapeutic meals (eg, mid-day supplementation after morning therapeutic meals). The dietitian adjusted the volume of enteral supplementation according to calories consumed during meals to ensure a nutritionally complete diet through the combination of oral and enteral intake. We designed this approach to weaning to promote age-appropriate growth while using tube feeding as a bridge to support health while the patient and family establish developmentally appropriate eating patterns. Moreover, this approach sought to reduce the potential for overfeeding and the understandable caregiver sense of urgency to

Treatment Stage:



Major Objectives:

Orientatic n and assessment:

- Semi-structure home baseline meal observation
- Family program orientation
- Care team employs standardized intake assessments and checklists
- Multidisciplinary team develops treatment plan

Initiate feeding intervention:

- Begin therapeutic activities
- Co-constructed treatment goals defined
- Grams target established
- Caregiver education regarding treatment approach and child response
- Ongoing monitoring and data review by multidisciplinary team

Treatment refinement and initiation of generalization:

- Psychologist monitors response to intervention and modifies treatment as needed
- Multi-disciplinary team revisits goals with family, based upon patient response to intervention and progress with advancing oral intake
- Begin caregiver training; home visit(s) to begin generalization

Discharge and follow-up planning:

- Home-based meal plan finalized; caregiver conducting therapeutic meals at home during evenings and weekends
- Finalize discharge plan
- Step-down to outpatient clinic

Enablers:

Structured Meal Protocols + Bite-by-Bite Data Collection

Parent/Caregiver Training, Education & Engagement

Treatment Integrity Monitoring + Outcomes Data Collection + Analytics

Multi-Disciplinary Care Delivery and Rounding

Figure 1. Description of therapeutic activities by treatment stage during the intensive day treatment admission.

Table 1. Program pillars and role of multidisciplinary team members in the integrated intensive multidisciplinary intervention with behavioral intervention and parent training

Program pillars	Description
Detailed data collection	Operational definitions permit recording of mealtime performance (eg, bite acceptance, swallowing, inappropriate mealtime behavior). Data are aggregated into 5 bite sessions to evaluate trends track progress using percentages and guide the introduction of treatment elements during admission.
Standardized treatment protocols	Feeding protocols outline the structure and sequence of mealtime interactions. Standardization includes scripted instructions, uniform bite volume, prespecified persistence when presenting mealtime demands, and consequences for appropriate and inappropriate mealtime behaviors.
Formalized decision rules	The introduction of treatment elements is based on the patient's response, as reflected in the ongoing data collection process, and child-specific targets of feeding intervention (eg, accepting bites, retention of food, swallowing).
Patient-Specific Intervention	Behavioral techniques (eg, bite spacing, use of praise, extending meal duration) are flexibly applied in a child-specific manner but introduced sequentially to compare progress across patients and refine the behavioral protocols on a programmatic level.
Discipline	Contribution
Psychology	Oversees structured meals involving behavioral techniques to promote exposure and intake of new foods and caregiver training to support transfer of treatment gains to the home setting. Models protocols, provides in-meal training, and conducts structured meals as needed in support of feeding therapists.
Nutrition	Monitors nutritional intake to ensure balanced nutrition and optimal growth and adjusts tube feeding schedule based on tolerability and success of oral intake. Decreases formula volume via tube as oral intake increases during therapeutic meals. Provide ongoing nutrition education to caregivers as indicated.
Medicine	Screens for and manages preexisting medical conditions that may contribute to feeding disorder, and addresses new medical problems with appropriate laboratory testing, medication management, and referrals as needed throughout the admission. Rounds on all cases on a weekly basis at a minimum and provides onsite medical support as indicated.
Speech-language pathology and occupational therapy	Assesses swallow safety and establishes seating and positioning for safe feeding practice. Conducts weekly skill-based therapy to promote oral-motor coordination for mastication and swallowing through teaching a variety of lingual movement to control solid and liquid boluses. Rounds on all cases on a weekly basis at a minimum and provides direct consultation on case specific concerns (eg, texture advancement, liquid viscosity) as indicated.
Social work	Provides caregiver support and care coordination by connecting families with resources to ensure continued access to care (eg, transportation, lodging). Assists with discharge planning to maintain progress following discharge.

“push” oral intake to meet caloric needs. This approach was not intended as a form of “appetite manipulation”¹⁰ or “hunger provocation”¹¹ as described in some intensive multidisciplinary intervention programs. For patients who enter treatment underweight or overweight, tube feeding volumes were adjusted to promote movement toward healthy growth measures. Finally, most patients entered the program with minimal to no oral intake; however, for patients who had some level of oral intake at admission and/or after intake was established during therapy, the dietitian worked with caregivers to ensure that no food was offered at least 1 hour before therapeutic meals.

Measures

Treatment Completion. We calculated completion rate by dividing the number of patients who completed intervention by the total number of patients who entered the intensive multidisciplinary intervention program for feeding tube dependence times 100.

Clinical Characteristics. The assessment documented developmental (eg, autism spectrum disorder) and medical (eg, prematurity, food allergies, gastroesophageal reflux disease) histories, the onset and course of feeding problems, as well as previous therapeutic efforts to address feeding problems.

Weight Status. Weight was measured on a digital scale (Scale-Tronix stand-on scale model 5002; Welch Alyn, Skaneateles Falls, New York) with the patient wearing light clothing and shoes removed. Weight-for-age was referenced against sex- and age-specific Centers for Disease Control and Prevention childhood growth charts.¹²

Mealtime Performance. A feeding therapist recorded bite-by-bite data on mealtime performance and grams consumed during all treatment meals. The key mealtime variables for the current analysis were rapid acceptance (5 s Accept), mouth clean (MC), inappropriate mealtime behaviors (IMB), and grams consumed. These observations were operationally defined and scored as follows: 5 s Accept, entire bite deposited within 5 seconds of the initial presentation; MC, no residual food larger than the size of a pea remaining inside the mouth 30 seconds after the food was deposited by visual inspection by the feeding therapist using a 3-step prompting sequence (vocal, model, and physical); IMB, child turning away from the bite presentation, pushing away the spoon, cup, food, or the feeding therapist's hand. We converted 5 s Accept, MC, and IMB into percentages by dividing occurrence of a target behavior divided by the total number of bite presentations multiplied by 100. The clinic standard involved collection of interobserver agreement during a minimum of 20% of each patient's meal sessions, with a mean agreement of $\geq 80\%$ on

target variables. Data abstraction focused on the first clinic meal (fed by a caregiver) at admission and the average performance during the final 3 days following generalization of treatment gains to caregiver (ie, discharge).

Percent Oral Intake. A dietitian identified a daily calorie target for each patient based on assessment of stress, activity, and estimated resting energy expenditure (ie, Schofield equation).¹³ An average calorie/gram conversion of clinic food was calculated using nutrition analysis software.¹⁴ The percent oral intake was calculated by dividing calories consumed during therapeutic meals by the daily calorie target. Daily oral intake included grams of food consumed in clinic and home minus grams of emesis expelled during meals (collected in therapeutic bibs and weighed on a scale).

Percentage of Patients Weaned. To confirm completed weaning from tube feedings, a team member or referring provider (eg, dietitian, pediatrician, gastroenterologist, psychologist) documented the transition to full oral feeding in the EHR. We calculated the percentage of patients weaned by dividing the number of patients who achieved this milestone by the total number of patients during the study period multiplied by 100.

Treatment Goals. At admission, caregivers and the multidisciplinary team co-constructed treatment goals following a review of the patient's feeding status, and a review of the caregivers' primary aims for intervention. Treatment goals were documented and used to guide the admission.

Caregiver Satisfaction. We developed a 9-item posttreatment questionnaire to assess (1) satisfaction with the approach to intervention (eg, "Overall, how satisfied are you with the feeding intervention?"); (2) acceptability of the model of care (eg, "In general, the treatment approach is appropriate for children with chronic feeding concerns"); and (3) perceived effectiveness of the intervention (eg, "In general, how effective was treatment in improving your child's feeding at home?"). Items were rated on a 5-point scale from 1 (ineffective/dissatisfied/disagree) to 5 (effective/satisfied/agree), with higher scores reflecting greater levels of satisfaction, perceived effectiveness, and planned adoption. Scores of 4 or 5 were counted as "yes." All other scores were counted as "no." One item—"If a friend was in need of similar help, I would recommend this treatment to him/her"—provided data to calculate a net promotor score (ie, promotors/"yes" – detractors/"no"). **Table II** (available at www.jpeds.com) presents scale items and outcomes.

Data Extraction and Reliability

A systematic procedure with corresponding protocol (available on request) guided data extraction from the EHR for eligible subjects. Five members of the research team independently double-coded all data extracted. Three of the 5 coders served as blinded coders to the purpose of the study; the remaining 2 coders provided a reliability check for extracted

data. The double-entered data allowed for the calculation of percent agreement. Coder agreement was 89.5% (range, 60%-100%), exceeding the 80% acceptable standard of agreement recommended during quantitative synthesis of research.⁴ Discrepancies in the double coded data were resolved by consensus. The Institutional Review Board of the Emory University School of Medicine approved the study protocol.

Statistical Analyses

Descriptive statistics were calculated for all variables of interest and included counts and percentages for categorical variables and the median, IQR, and range for continuous variables. Longitudinal data were analyzed using repeated-measures ANOVA. Given the skewed distribution for many of the continuous outcome measures, data were ranked before analysis. Analysis was carried out on the ranked data; results are presented as raw medians and IQRs for each time point of interest. The Kenward-Roger approximation was used to estimate the degrees of freedom. Results from the repeated-measures ANOVA are presented as F-statistics with corresponding numerator and denominator degrees of freedom, with associated *P* value testing for an overall effect of time. Post hoc pairwise comparisons were performed to determine which time points were significantly different. For the outcome, percentage of patients weaned, the McNemar test was used to compare correlated proportions between the different time points. Analysis was conducted using SAS version 9.4 (Cary, North Carolina, USA),¹⁵ and statistical significance was assessed at the 0.05 level, unless noted otherwise.

Results

Patient and Intervention Characteristics

During the 5-year study period, 229 patients were admitted to the day treatment program. Of these, 83 children met the study entry requirements (**Figure 2**; available at www.jpeds.com). Eighty-one of the 83 patients (46 boys and 35 girls; mean age, 49 ± 37 months; range, 10-230 months) completed intervention (98% treatment completion rate) and were included in the current analysis. **Figure 3** (available at www.jpeds.com) presents the age distribution of the patient cohort. The average duration of admission was 38 ± 7 days (range, 11-52 days). In 75% of cases (n = 61), feeding problems emerged during the first year of life; 67% of cases since birth (**Table III**). Based on parent report at admission, the duration of restricted oral intake was 33 months (range, 6-154 months).

Parents of 69 cases (85%) reported previous feeding therapy of >9 months. The most frequently reported treatment modality involved outpatient therapy with a speech-language pathologist (66.7% of cases), followed by treatment with an occupational therapist (11%). A history of at least 1 medical complication or developmental problem was reported in all children. Common co-occurring conditions

Table III. Patient characteristics at admission to the intensive multidisciplinary intervention program (N = 81)

Characteristics	Value
Age, mo, median (IQR) (range)	40.0 (25-62) (10-230)
Sex, n (%)	
Female	35 (43)
Male	46 (57)
Ethnicity, n (%)	
Hispanic	3 (4)
Non-Hispanic	78 (96)
Age of onset, mo, median (IQR) (range)	0.0 (0-4) (0-211)
At birth, n (%)	54 (68.4)
Duration of problem, mo, median (IQR) (range)	33.0 (19-52) (6-154)
Previous intervention reported, n (%)	69 (85)
Previous intervention duration, mo, median (IQR) (range)	9.0 (4-15) (0.25-84)
Medical concerns, n (%)	
Gastroesophageal reflux disease	66 (81)
Prematurity	46 (57)
Cardiopulmonary	37 (46)
Developmental delay/autism	31 (38)
Failure to thrive	21 (26)
Food allergies	5 (6)
Other	
Behavior problems during meals, n (%)	
Turns head away from food	69 (85)
Pushes away food	66 (81)
Crying	49 (60)
Vomits during meals	29 (36)
Gagging	27 (33)
Spits food out of mouth	19 (23)
Throwing food	17 (21)
Negative statements	17 (21)
Leaves the table	15 (19)
Aggression	9 (11)
Holds food in mouth/refuses to swallow	8 (10)

alone or in combination documented in the EHR included gastroesophageal reflux disease (81%), prematurity (57%), cardiopulmonary disease (46%), and/or developmental disorder (eg, autism spectrum disorder; 38%). Seventy-four patients (91%) presented with 2 or more medical or developmental problems. All caregivers described 1 or more disruptive mealtime behaviors, such as turning the head away from food (85%), pushing the food away (81%), crying (60%), or vomiting during meals (36%), that directly interfered with efforts to promote oral intake.

At discharge, 13 children (16%) were self-feeding; 68 (84%) required a caregiver to present bites. Based on developmental and experienced-based skill considerations, most children (78%) required pureed texture. Treatment for a subset (14%) of mostly older patients (ie, age ≥ 6 years) involved table texture food; the remaining patients (8%) were beginning texture exposure (eg, wet ground, minced, or chopped food) by discharge. Seventy-eight of 81 patients (96%) returned for follow-up in the outpatient clinic (mean time between discharge and last follow-up, 12.7 ± 10 months).

Treatment Outcomes

The EHR documented a 70.5% increase in calories via oral intake at discharge across the entire sample; 33% of patients

(n = 27) were completely weaned from tube feeding by discharge (Table IV). Treatment gains corresponded with a 91.3% improvement in bites rapidly accepted and a 99.1% increase in MC; disruptive mealtime behaviors decreased by 68.37%. Transition to oral intake and improved mealtime behaviors occurred with stability in weight status. At follow-up, 72% of patients (n = 58) were weaned from tube feeding. Improvement in mealtime behaviors persisted at discharge levels, and weight status remained stable.

Treatment Goals and Parental Satisfaction

The mean number of co-constructed treatment goals was 14 per case (range, 7-9). On average, the sample achieved 89% of the target treatment goals (range, 69%-100%). Behavioral goals included rapid acceptance and swallowing of food for $\geq 80\%$ of bites with disruptive behaviors in $\leq 20\%$ of bites; nutrition involved agreement regarding a prespecified targeted percent oral calories at discharge, which averaged 65% (range, 20%-100%) for the sample; parent training focused on successful implementation of the meal plan in the home setting, which was achieved in all cases as tracked by parent-reported home data logs during evenings and weekends.

Sixty-seven of the 81 families (83%) completed the 9-item survey on satisfaction, social acceptability and perceived effectiveness (Table II). Parents reported a high degree of satisfaction with intervention, with an overall rating of 4.92 (of possible 5.0). All 67 caregiver respondents indicated improvement in their child's feeding and satisfaction with the approach. Sixty-six (99%) caregiver respondents indicated that they would recommend treatment to a friend, resulting in a net promotor score of 98%.

Discussion

Using established guidelines for observational studies,⁶ this EHR documented treatment outcomes for a cohort of patients with restricted oral intake (ie, accepting $\sim 2\%$ of nutritional needs) requiring enteral supplementation. Previous outpatient treatment was unsuccessful. In addition, patients had complex medical histories, developmental delays, or both. In all cases, food refusal corresponded to disruptive mealtime behavior (eg, tantrums, tearful protests). Overall, there was a 70% increase in oral calorie intake and more than two-thirds of children showed a notable decrease in disruptive mealtime behavior. One-third of the sample fully weaned from tube feedings at discharge. The percentage of patients fully weaned from tube feeding was 72% at follow-up, indicating that treatment gains endured and expanded. Weight status (weight-for-age) was maintained as patients weaned from artificial supports. Taken together, these findings support our intensive multidisciplinary intervention model, which uses behavioral intervention to establish a mealtime structure; includes parent training to establish structured meals in the home setting; and uses nutrition education to replace tube feeding with increased oral intake over time. Based on responses from 83% of caregivers at

Table IV. Admission, discharge, and follow-up outcomes for patients receiving intensive multidisciplinary intervention for tube dependence (N = 81)

Outcome Metrics*	Admission	Discharge	Follow-up	F-Statistic (P Value)
Age, y, median (IQR)	3.4 (2.2-5.4)	3.5 (2.4-5.5)	5.1 (3.2-7.0)	
Consumption indicators				
Patients weaned, n (%)	0 (0) ^a	27 (33.3) ^b	58 (71.6) ^c	—
% calories met by oral intake, median (IQR)	0 (0-0) ^a	70.5 (54.2-100.0) ^b	—	F _(1, 79) = 761.6 (<0.001)
Direct mealtime observation, median (IQR)				
% bites rapidly accepted	7.5 (0.0-59.5) ^a	98.8 (96.1-99.8) ^b	100.0 (100.0-100.0) ^c (n = 78)	F _(2, 153) = 136.9 (<0.001)
% bites MC	0.0 (0.0-22.9) ^a (n = 80)	99.1 (97.0-100.0) ^b (n = 80)	100.0 (93.7-100.0) ^b (n = 71)	F _(2, 149) = 184.6 (<0.001)
% IMB	70.5 (24.4-100.0) ^a (n = 80)	2.13 (0.82-4.87) ^b (n = 80)	2.1 (0.0-10.0) ^b (n = 78)	F _(2, 151) = 70.9 (<0.001)
Anthropometric data, median (IQR)				
Weight, kg	12.6 (10.7-17.1) ^a	12.7 (10.8-18.2) ^a	14.7 (12.7-19.3) ^b (n = 79)	F _(2, 156) = 50.5 (<0.001)
Weight, percentile for age	10.2 (2.9-39.5) ^a	13.1 (2.9-36.5) ^a	10.2 (2.8-34.5) ^a (n = 79)	F _(2, 156) = 0.86 (0.426)
Weight, z-score for age	-1.3 (-1.9 to -0.3) ^a	-1.1 (-2.0 to -0.4) ^a	-1.3 (-1.9 to -0.4) ^a (n = 78)	F _(2, 155) = 0.06 (0.938)
Treatment goal summary, median (IQR)				
Goals established, n		15 (13.0-16.0)		—
Goals achieved, %		92.3 (84.6-100.0)		—

*Groups with the same letter superscript are not statistically different at the 0.05 level of significance.

discharge and low attrition, the treatment approach was acceptable to parents. All but 1 patient (66 of 67; 99%) indicated that they would recommend this treatment to other parents of children with chronic food refusal.

The proportion of patients weaned at discharge (33%) is lower than the average of 71% reported in the previous meta-analysis.² However, a closer appraisal of nonrandomized studies included in the meta-analysis reveals important differences in intensive multidisciplinary intervention feeding programs. Programs that focus on weaning from tube feedings as the primary outcome report a higher success rate at discharge (range, 81.4%-100%). In contrast, programs that integrate behavioral techniques report overlapping, but generally lower successful tube weaning at discharge (range, 43%-90%). Of the 11 programs included in the meta-analysis, 6 adopted a rapid approach designed to discontinue tube feeding within a week.¹⁶ This approach assumes that rapid weaning from enteral supplementation stimulates hunger and promotes increased oral intake. However, the 6 studies that applied the rapid tube weaning approach reported weight loss at discharge, suggesting oral intake did not adequately offset the cessation of tube feeding. In some cases, the loss of weight required resumption of tube feeding. Four of 5 studies that used behavioral intervention without rapid discontinuation of enteral supplementation indicated stabilization or improvement in weight.² Furthermore, although intensive multidisciplinary intervention programs that rely heavily on behavioral intervention reported lower success rates of tube weaning at discharge, 4 of 5 studies achieved a higher percentage of successful weaning from tube feeding at follow-up, ranging from 7%¹⁷ to 23%¹⁸ increased intake posttreatment. This pattern is consistent with the increase in success rate from 33% to 72% in the present study.

In this EHR, we adopted the STROBE methodology to plan the study, guide data abstraction, and structure the study results. The aim of the STROBE statement is to

improve the quality of observational research by providing greater transparency in the design, conduct, and reporting of results.¹⁹⁻²¹ This report provided a clear case definition and clear inclusion and exclusion criteria. Our model of intensive multidisciplinary intervention includes a multimeasure assessment and emphasizes the role of disruptive mealtime behavior as a barrier to oral intake. The study also took advantage of our systematic collection of progress on prespecified child-specific goals, mealtime behaviors, consumption, and growth during day treatment, at discharge, and follow-up. A limitation of this study, shared with other observational studies, is that our results support association but not causation.²⁰ Previous testing of this model of care in an RCT⁹ provides some evidence for causation, however. This study also focused on patients in a specialty clinic, and the findings might not be generalizable to the wider population of children with chronic food refusal or ARFID. Finally, study outcomes were limited to patient-centered data available in the EHR. Our dataset did not include detailed pretreatment and posttreatment assessment of oral-motor coordination and daily living skills, precise measures of nutritional insufficiencies and disruptive mealtime behavior, or information about medical accommodations or testing (eg, food allergy) involved during the course of treatment. With these limitations in mind, further enhancing the evidence-base will require comparing and contrasting different intensive multidisciplinary intervention models of care (eg, inpatient hospitalization, hunger provocation) and evaluating response to intervention across different patient subgroups (eg, different medical conditions, developmental complexity, other ARFID subtypes). Results warrant continued research investigating on the application of this intensive multidisciplinary intervention approach in other specialized treatment settings and/or with other feeding/eating disorder subtypes. ■

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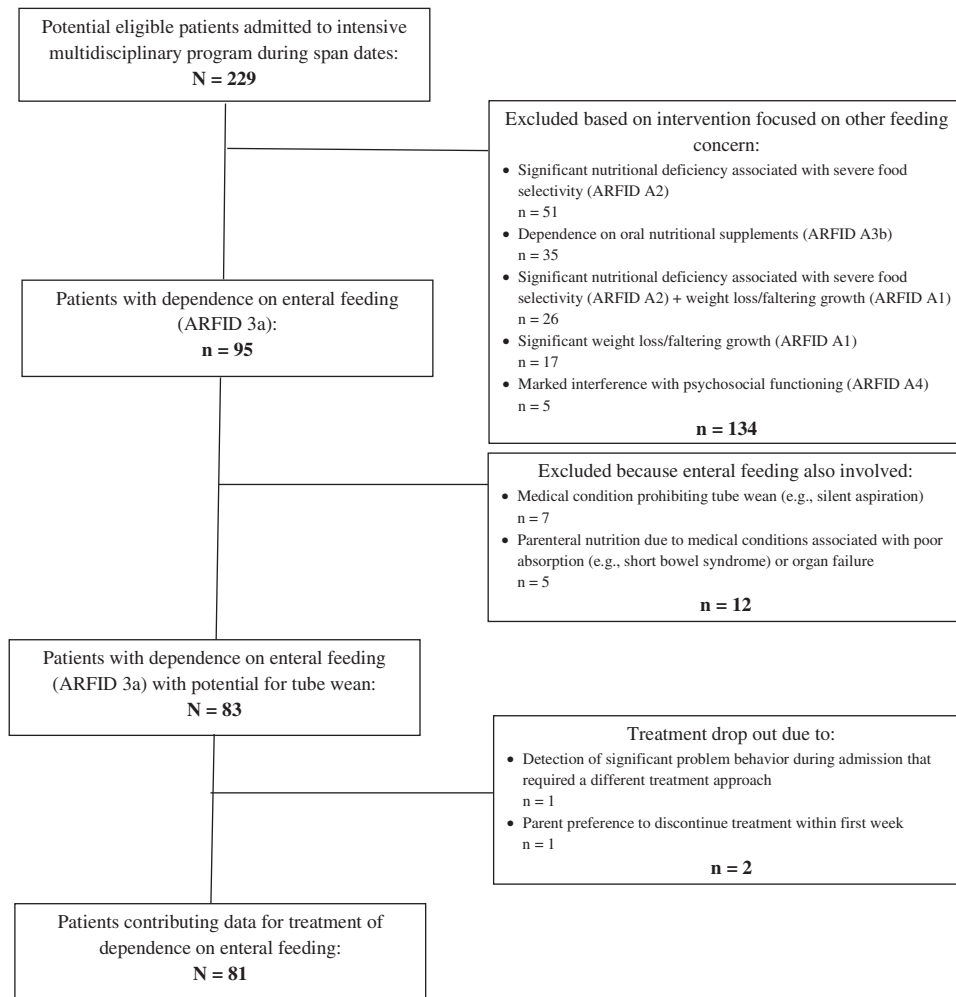


Figure 2. Flow diagram of included and excluded patients in the EHR review focusing on children receiving intensive intervention for feeding tube dependence.

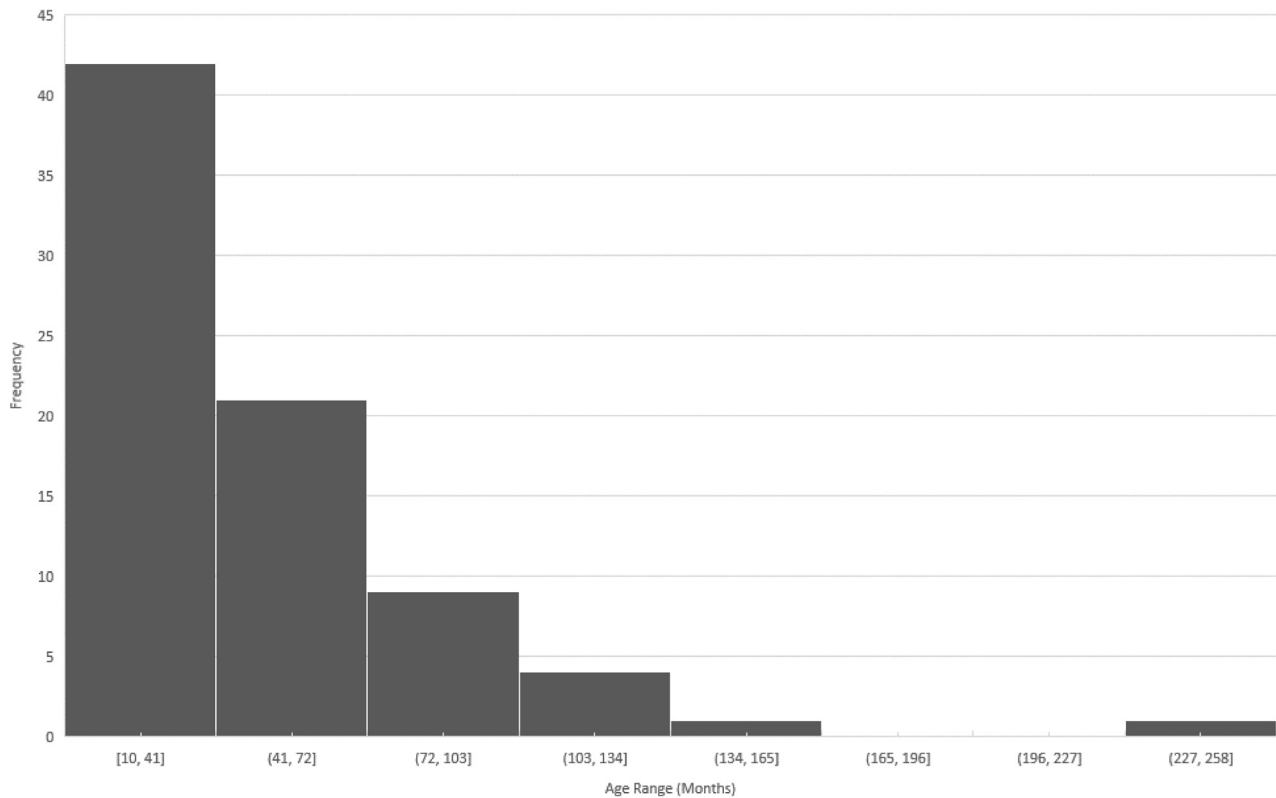


Figure 3. Histogram presenting age distribution at admission of patients receiving the intensive multidisciplinary intervention for feeding tube dependence.

Table II. Caregiver Satisfaction rating of the intensive multidisciplinary intervention model (N = 67)

Satisfaction scale item	Average rating (SD)	Number (%) rated 4/5
1. Overall, how satisfied are you with the feeding intervention?	4.91 (.29)	67 (100)
2. The staff was responsive to the needs of my child and family during treatment.	4.89 (.31)	67 (100)
3. If new feeding problems arise, I would return to this clinic for services.	4.93 (.32)	66 (99)
4. In general, how effective was treatment in improving your child's feeding in clinic?	4.93 (.26)	67 (100)
5. In general, how effective was treatment in improving your child's feeding at home?	4.92 (.27)	65 (97)
6. Compared to when we started the program, my child's feeding is (1, worse to 5, improved)	4.96 (.21)	67 (100)
7. This is an acceptable intervention for my child's feeding concerns.	4.88 (.54)	66 (99)
8. In general, the treatment approach is appropriate for children with chronic feeding concerns.	4.91 (.38)	65 (97)
9. If a friend was in need of similar help, I would recommend this treatment to him/her.	4.94 (.30)	66 (99)