

Caring for Tube-Fed Children: A Review of Management, Tube Weaning, and Emotional Considerations

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Abstract

Enteral nutrition is the practice of delivering nutrition to the gut either orally or through a tube or other device. Many children are reliant on enteral feedings to either supplement their nutrition or as a complete source of their nutrition. Managing children on tube feedings requires a team of providers to work through such dilemmas as feeding schedules, weaning from tube feeding, sensory implications of tube feeding, treatment of pain or nausea associated with eating, oral-motor issues, and behavioral issues in the child and family. The purpose of the current review is to summarize the multidisciplinary aspects of enteral feeding. The multidisciplinary team consists of a variable combination of an occupational therapist, speech-language pathologist, gastroenterologist, psychologist, nurse, pharmacist, and dietitian. Children who have minimal oral feeding experience and are fed via a nasogastric or gastrostomy tube often develop oral aversions. Limited data support that children with feeding disorders are more likely to have sensory impairment and that early life pain experiences contribute to feeding refusal. There are inpatient and outpatient programs for weaning patients from tube feeding to eating. The parent-child interaction is an important part of the assessment and treatment of the tube-fed child. This review also points out many information gaps, including data on feeding schedules, blenderized tube feedings, the best methods for weaning children off enteral feedings, the efficacy of chronic pain medications with tube-fed children, and, finally, the necessity of the assessment of parental stress among all parents of children who are tube fed. (*JPEN J Parenter Enteral Nutr.* 2016;40:616-622)

Keywords

eating behaviors; pain; enteral nutrition; tube feeding; multidisciplinary

Enteral feeding, delivering nutrition through a tube or other device, is necessary when children are unable or unwilling to ingest sufficient nutrition to maintain adequate body composition and growth, but there is no problem with digestion. Approximately 4 in 100,000 children require enteral feeding,¹ with higher rates among children with chronic illness. The European Society for Pediatric Gastroenterology, Hepatology, and Nutrition's Committee on Nutrition published guidelines regarding indications and contraindications for tube feeding, as well as formulas, sites (gastric vs postpyloric), routes (nasogastric, gastric, etc), and complications.² However, these guidelines do not address specifically the multidisciplinary approach, blenderized tube feedings, feeding schedules, weaning from tube feeding, parent-child interactions, sensory implications, chronic pain treatment, oral-motor issues, and caregiver effects, which can be important components of caring for the tube-fed child. These topics will be specifically addressed in this qualitative review, as no guidelines currently exist regarding these topics.

Objective

The purpose of the current review is to summarize evidence regarding aspects of tube feeding that are not covered by the

recent European Society for Pediatric Gastroenterology, Hepatology, and Nutrition's Committee on Nutrition guidelines. While this is not a meta-analysis, it is modeled after other qualitative reviews,³ and it identifies areas where more research is needed, beginning with multidisciplinary treatment approaches.

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Methods

A qualitative analysis (ie, not systematic review) was performed to identify pertinent literature. Search strategies included a query of PubMed using the following key phrases: feeding schedules enteral, enteral nutrition children, oromotor dysfunction gastrostomy, bolus feeding, swallowing feeding tube, feeding schedules children, enteral nutrition children, feeding tube weaning children, and sensitivity oral-motor tube. Peer-reviewed publications were selected based on their high level of evidence and pertinence with regard to the multidisciplinary approach to caring for the tube-fed child. Regarding topics where there is a paucity of information, expert opinion and retrospective reviews were used.

Multidisciplinary Treatment

The multidisciplinary approach to tube feeding has evolved as clinicians have recognized that the etiology of feeding disorders is complex and multifactorial, requiring the expertise of providers across several disciplines. Feeding problems can include difficulties with child-caregiver interactions, social learning, developmental characteristics, nutrition status, and chronic illness. Team members often include an occupational therapist, speech-language pathologist, gastroenterologist, psychologist, and dietitian.⁴ The multidisciplinary team can also include pediatricians, laboratory personnel, surgeons, radiologists, nurses, pharmacists, and experts from psychiatry.⁵ Most experts also place a strong emphasis on the importance of the parent or primary caregiver's collaboration in treatment.^{6,7} While many of the disciplines listed above have overlapping roles in the care of a child with a feeding problem, distinct functions do need to be performed to successfully care for this population.

The roles of the dietitian, nurse, and pharmacist address issues related to both the development and implementation of the nutrition plan of care. The dietitian works with other providers to balance calories consumed orally with those delivered enterally. Caregivers are taught how to prepare and administer enteral formula by the dietitian and nurse. The nurse also provides education and support for the caregivers. It is often the nurse who identifies caregiver stress and anxiety related to enteral feedings.⁸ The nurse provides technical education and supervision while teaching about the enteral access device placement, management, and troubleshooting. Using the teach-back method of education, the nurse can assess the health literacy of the caregiver and the comprehension of information presented.⁹ The nursing staff also work with the caregiver on formula delivery methods, which may include using an enteral pump or bolus feeding apparatus. The pharmacist works with the caregiver on safe medication delivery via the enteral access device to prevent clogging. The pharmacist also educates the caregiver about liquid medications and possible osmotic diarrhea. Assessment of the competence of caregivers

in skills related to enteral formula delivery and enteral access device management is essential prior to discharge. This is often a collaborative effort on the part of the professionals working with the family.

The home health nurse and school nurse also provide important roles in caring for the tube-fed child. The role of the home health nurse is to support the parent in implementation of the plan at home. For school-age children, the school nurse may need to receive a copy of the plan of care, but the extent of his or her involvement will be affected by the policies set forth by the school system. Good communication between the core team of providers and the patient's home and school caretakers is essential for the care of the tube-fed child who is transitioning off enteral feedings. This is all part of multidisciplinary treatment.

However, we found no feeding disorder research comparing a multidisciplinary approach with a nonmultidisciplinary approach. The research that has been done focuses on the outcomes for children who attend these multidisciplinary programs. A multidisciplinary feeding team at the University of Glasgow conducted a retrospective chart review of their program over 5 years and found that of 41 referrals to their outpatient program, 78% were not requiring any tube feedings at a median 1.7-year follow-up from the program intervention.¹⁰ Finally, we found no research showing that parent collaboration changes outcome.

Conclusion and Comments on Multidisciplinary Treatment

- The multidisciplinary team for treating tube-fed children includes a variable combination of occupational therapist, speech-language pathologist, gastroenterologist, psychologist, pharmacist, nurse, and dietitian.
- Although there is an emerging consensus that multidisciplinary teams should be standard of care for treating tube-fed children, more research is needed regarding the effectiveness of a multidisciplinary approach and regarding the necessity of including parents in the collaborative care of feeding patients.

Blenderized Tube Feedings

There are several options when it comes to the composition of enteral feeding. Some providers or parents choose blenderized food instead of commercialized formula, based on anecdotal or published reports that some children have fewer side effects with a blenderized diet compared with a commercial formula.¹¹ In 1 uncontrolled trial of a blenderized diet with 33 patients aged 9 months to 9 years with postfundoplication retching and gagging, 17 of the 33 (52%) reported a 76%–100% reduction in gagging and retching with the blenderized food.¹¹ Furthermore, 57% of these children had increased oral intake

at the end of the trial. There are recommendations that blenderized food should be fed within 2 hours of preparation and avoided in immunocompromised patients to avoid the risk of bacterial contamination.¹²⁻¹⁴ Blenderized foods vary in their nutrition composition even when prepared by professionals,¹⁵ and bits of food may obstruct the feeding tube.¹¹ Patients on blenderized diets should be under the supervision of a health-care professional who can ensure that the patient's diet is providing the proper nutrients profile.

Conclusion and Comments on Blenderized Tube Feedings

- Limited evidence suggests blenderized tube feedings may reduce side effects in children with a fundoplication.
- Randomized controlled trials are needed to evaluate the effectiveness of blenderized tube feedings in children with and without fundoplication.

Feeding Schedule

Continuous drip feedings are frequently infused overnight to foster increased daytime mobility for the child and convenience for the family.¹⁶ Some clinicians theorize that children who are fed continuously overnight may recognize hunger during the day, which may increase oral intake. A controlled, crossover study in healthy adults revealed no difference in oral intake when participants received tube feedings on different schedules (12-hour diurnal, 12-hour nocturnal, and 24-hour continuous),¹⁷ but no such studies have been conducted in children. Also, nocturnal tube feedings have been theorized to disrupt circadian rhythms, which may lead to physiologic complications.¹⁸ Tube-fed children typically sleep during nocturnal feeds, which may make them susceptible to other adverse effects such as lower oxygen consumption, shifts in nitrogen and cortisol balance, and increased aspiration risk.¹⁸

Proponents of a bolus feeding schedule argue that it is more physiologic and mimics more of a mealtime pattern.¹⁰ A small, single-blind, placebo-controlled study in healthy adults was performed looking at the effect of bolus tube feedings on appetite, food intake, and appetite mediators. There was no change in hunger scores, but there was a decrease in oral intake when bolus tube feedings were administered, compared with placebo days when subjects were administered water boluses. In contrast, another controlled study¹⁷ in adult men showed no effect of continuous feedings on oral intake compared with placebo (continuous water administered by tube). Both of these studies had a small sample size of adult men, making it difficult to discern what this means for the pediatric population, but they do provide initial evidence that continuous feeds could be more effective in moving patients toward increased oral intake.

Conclusion and Comments on Feeding Schedule

- Effects of timing of tube feeding on appetite, oral food intake, and general well-being in children are not well understood.
- Experts disagree as to which type of feeding schedule is preferred: continuous feedings or bolus feedings, and no randomized trials have compared these outpatient feeding schedules.
- Results from adult studies support that continuous tube feedings may increase overall caloric intake in patients who eat orally.

Weaning From Tube Feeding

There is a consensus that combining nutrition modification and behavioral techniques is essential for successful weaning from tube feedings, regardless of the patient being weaned in an inpatient or outpatient setting.^{6,7,10,19-24} The most cited protocols for weaning include the Kennedy Krieger Institute and Graz models.^{5,25} Both recommend changing the patient's perceptions and interactions with food, through play and handling,^{23,26} and decreasing tube feedings to induce hunger.²⁴ Behavioral components such as structured meals, social modeling, and positive reinforcement can be crucial to success.²⁷ Diagnosis and treatment of any underlying chronic illness is also an important part of successful tube weaning.²⁸

A study by Ishizaki et al²⁴ characterizing 35 tube-fed children revealed that weaning before the age of 3 years (compared with weaning after 3 years of age) was a positive prognostic indicator for weaning more quickly from tube feedings. Another study with 41 tube-fed children older than 5 years found that those referred to a multidisciplinary program for weaning after age 5 years were more likely than those referred before age 5 years to still require tube feedings at their 5-year follow-up or to have taken longer than 1 year to wean.¹⁰ This supports the importance of instituting weaning as soon as the child meets basic criteria for readiness to wean.

Conclusion and Comments on Weaning From Tube Feeding

- Multiple nonrandomized studies suggest that successful weaning can be achieved with a combination of caloric reduction of tube feedings and behavioral modifications.
- Preliminary data support that earlier age at the initiation of feeding tube weaning promotes tube weaning.
- More research is needed regarding the necessary components for a successful wean.

Parent-Child Interaction

Parental involvement is essential for the success of the child, and there must be a strong commitment and readiness from the family in order for weaning to be successful.⁷ Chatoor²⁹ emphasizes the importance of not only addressing the child's feeding problems but also the importance of delving into the parents' feeding history, since this may have a large effect on the child-caregiver interaction. Satter³⁰ states that "feeding problems reflect a distortion between the parent-child interaction that interferes with the child's positive psychosocial development." The parent must subsequently be trained to become responsive and sensitive to the child's cues. These experts suggest that parent-child interaction and its effect on feeding are a significant component of the treatment process.^{6,21,22,31} Furthermore, experts have developed empirically supported measures³² and have even conducted treatment studies suggesting improved parent child interaction leads to significant improvement in the feeding process.³³

Conclusion and Comments on Parent-Child Interactions

- Experts agree that assessment of the parent-child interaction is an important part of the assessment and treatment of the tube-fed child.
- No empirical research exists regarding the impact of the parent-child relationship on the feeding process, and no research on improving the parent-child relationship has been conducted in the pediatric feeding literature.

Sensory Implications

Combined sensory input from touch, pressure, taste, smell, vision, hearing, proprioception, respiratory state, body position, hunger, thirst, and gastrointestinal condition all play roles in feeding and swallowing behaviors.³⁴⁻³⁷ Adverse sensory experiences during swallowing may have a negative effect on the development of feeding and swallowing skills.³⁸ Children with minimal oral feeding experience who are fed via a nasogastric or gastrostomy tube (G-tube) often develop oral aversions.^{28,38-40} Once aversions arise, children refuse to allow anything near their faces or mouths, and they are deprived of sensory information that guides development of swallowing skills. Also, children who are tube fed can lose previously learned oral-motor skills.^{38,41}

Arvedson and Brodsky³⁵ described sensory and motor issues that are important to consider when deciding whether a child is ready for tube weaning. These include the child's sensory response to food as well as posture, muscle tone, oral-motor coordination, and central alignment. These components translate into their ability to sit at a table and accept a bite. Davis et al⁴² provide one of the few studies assessing the relationship between sensory processing problems and feeding disorders. Retrospective review of patients presenting to their multidisciplinary feeding clinic

revealed that 81.4% of patients (53 of 65 patients evaluated) had some level of sensory impairment, as evidenced by an abnormal score on the Short Sensory Profile (SSP). The SSP is a brief questionnaire given to the caregiver that quantifies the child's global sensory impairment and has questions targeted for all of the senses.⁴² However, to date, no studies have been conducted on how treating sensory issues may improve feeding.

Conclusion and Comments on Sensory Implications

- Children with feeding disorders are more likely to have sensory impairment.
- More prospective studies are needed on the impact of treatment of sensory impairment in children who are tube fed.

Pain

Early life pain experiences may sensitize peripheral nociceptors and activate central nervous system arousal centers, which in turn amplify pain signals before they reach the sensory cortex. Descending inhibitory pain pathways are immature and unmyelinated in the neonate and therefore fail to modulate pain signals. Research has indicated that early life pain experiences could include nasogastric suctioning at birth, which increases the risk of hospitalization for chronic abdominal pain at the end of the first decade.⁴³ Also, data indicate that fundoplication is associated with a reduced threshold for gastric discomfort from pressure or distension.⁴⁴

Treatment of visceral pain can facilitate the transition from tube to oral feedings for medically fragile infants and toddlers.^{45,46} Pain treatments can consist of avoiding esophageal or gastric distension by providing nutrition via a gastrojejunal feeding tube and/or administering chronic pain medication, such as amitriptyline and gabapentin, for several months. Davis and colleagues⁴⁵ used an outpatient pain rehabilitation perspective to wean patients from tube to oral feedings. This method combined using amitriptyline and gabapentin, as well as gastrojejunal feedings, bypassing the stomach to desensitize it for 8 weeks before attempting oral feedings. They hypothesized that these medications, typically used for neuropathic pain, would help children with chronic feeding refusal reset abnormal pain perception. Nine of 10 participants were weaned from tube feedings.

Conclusion and Comments on Pain

- Early life pain experiences can contribute to pain perception later in life.
- Recent data show that treating visceral pain can improve oral intake in toddlers with feeding disorders.
- More studies are needed examining the effectiveness of pain treatments on oral intake in tube-fed children.

Oral-Motor Implications

Developmental feeding and swallowing skills are typically fully acquired by age 3 years.^{34,35,47,48} Illingworth and Lister⁴⁹ proposed a sensitive (or critical) period for acquisition of chewing skills. They cited several case studies of children who had not been given solid foods at a time when they first reached developmental capacity for this skill and then were later unsuccessful in learning or required extensive practice to learn to chew solids. Feeding and swallowing behaviors in the newborn are reflexive and gradually transition to learned, cortically mediated behaviors starting around 4–6 months of age, with complete disappearance of reflexive feeding by 8 months of age.^{50,51} Mason and colleagues³⁹ noted that an infant's willingness to try unfamiliar foods decreases over the last half of the first year, and the child's growing autonomy may contribute to food refusals in the second year. Mizuno and Ueda⁵² reported that it is very difficult to establish bottle feeding for the first time in children older than 6 months. Children who have limited oral intake have difficulty developing the oral sensorimotor skills needed for eating due to the motor learning principle of specificity, which dictates that motor learning is context specific.^{34,53} If sufficient practice time, task repetitions, and appropriate environmental supports are not provided for oral feeding, the child may have delayed development or acquire dysfunctional movement patterns for feeding.³⁴ The child who practices oral-motor movement patterns accommodates the characteristics of a variable presentation of food or liquid with varied eating experiences over time.^{34,36,54,55}

Conclusion and Comments for Oral-Motor Implications

- Critical periods for feeding skills occur during the first 3 years of life, and more research is needed examining skill acquisition after such critical periods.
- Oral feeding skills are learned over time with repetition and practice, and those children who are not exposed to such opportunities may not develop the necessary skills to eat, but more study in this area is needed.
- Treatment outcome studies are needed regarding oral-motor therapy as a treatment for children with feeding disorders.

Caregiver Effects

Tube feeding a chronically ill child constitutes a significant burden on a caregiver's time (approximately 7 h/d vs approximately 4 h/d for feeding a healthy child).⁵⁶ Research examining parental stress and burden is mixed. Some studies report that parents benefit from the assurance that tube feeding provides, while others show that parents believe tube feeding to be

an additional burden.⁵⁶⁻⁵⁹ Researchers have assessed caregiver concerns, expectations, and satisfaction regarding G-tube placement through a standardized questionnaire. Results indicate that caregivers' expectations were met, and the majority expressed satisfaction with the feeding tube and decreased time devoted to feeding.⁵⁷ Although there were economic costs, caregivers of gastrostomy-fed children did not report increased depression or decreased quality of life compared with caregivers of other chronically ill children.⁵⁶ In 2012, researchers employed a longitudinal design, following families from before feeding tube placement through 18 months after tube placement.⁵⁸ Scores on the parenting stress index (PSI) were unchanged across the 3 time points (baseline and 6 and 18 months after tube placement). Mothers self-reported overall psychological distress did not change from baseline to the 6-month time point but decreased 18 months after tube placement. In contrast, Pedersen and colleagues⁶⁰ found that parents of tube-fed children reported higher scores on the PSI than did parents of healthy children and parents of children with growth deficiencies or type 1 diabetes. Because caregiver burden and stress findings are mixed among parents of medically complicated children, it can be difficult for clinicians to determine which parents will be at high risk for developing stress related to G-tube placement.

Conclusion and Comments on Caregiver Effects

- Studies show conflicting findings regarding caregiver stress in parents of tube-fed children.
- More study is needed to determine whether feeding tube placement decreases or increases caregiver stress in children with feeding disorders.

Conclusions, Recommendations, and Future Research Directions

Conclusions

On the basis of the limited evidence presented in this review, we conclude the following:

1. The multidisciplinary approach to treating the tube-fed child is advisable and should ideally involve the collaboration of a pediatric gastroenterologist, psychologist, dietitian, occupational therapist, and speech-language pathologist.
2. Feeding treatment programs have used both bolus and continuous feeding schedules successfully.
3. Many behavioral and physical characteristics must be present prior to attempting feeding tube weaning, including ability of the child to sit at a table, accept a bite, and adhere to the concept of structured mealtimes.

4. Diagnosis and treatment of underlying chronic illness are an important part of assessing a child for readiness to wean off of tube feedings.
5. There may be a sensitive period of oral-motor feeding skill acquisition, during which it is very important that children are exposed to tasks requiring these skills.
6. Age and degree of exposure to oral feeding experiences may affect prognosis for success with weaning of tube feeding.

Recommendations

1. Tube-fed children should be treated with a multidisciplinary approach.
2. Blenderized diets, ideally under supervision of a healthcare professional, should be considered for tube-fed children who have difficulty with formula.
3. An overnight continuous tube-feeding schedule should be considered for children who eat orally and need to increase overall calorie consumption.
4. A combination of caloric reduction of tube feedings and behavioral modification should be used to facilitate tube weaning.
5. Assessment of the parent-child interaction should be a significant part of treating the tube-fed child.
6. Treatment of pain should be considered as part of a comprehensive feeding program.
7. Skills that teach chewing and promote oral intake should be initiated early to promote a shorter duration of tube feeding.

Research Directions

1. More treatment outcome studies need to be conducted regarding the effectiveness of the multidisciplinary approach to feeding problems.
2. Further randomized study is needed regarding blenderized vs formula feedings and regarding continuous vs bolus feedings to provide an understanding of whether one of these feeding methods promotes better feeding tolerance and whether they aid in facilitation of feeding tube weaning.
3. Regarding weaning from tube feeding, larger randomized trials are needed to determine the best methods for moving children from tube to oral feeding.
4. More research is needed regarding the importance of the parent-child relationship in the tube-fed child, specifically on oral intake and mealtime behavior problems.
5. Future research should focus on sensory issues in children who are tube fed and their effect on oral intake.
6. More study is needed on visceral pain in tube-fed children, with emphasis on effects of pain treatments on the promotion of oral intake.

7. Caregiver stress in children with feeding disorders needs further study.
8. More research is needed to explore the effect of tube placement in children on caregiver stress.
9. Further research about support systems and potential interventions for caregivers of tube-fed children is needed.

Statement of Authorship

S. Edwards, A. M. Davis, and P. Hyman contributed to the conception and design of the research; A. Bruce, B. Lyman, J. Cocjin, K. Dean, L. Ernst, H. Mousa, and O. Almadhoun contributed to the design of the research; S. Edwards, A. M. Davis, and P. Hyman contributed to the acquisition, analysis, and interpretation of the data; A. Bruce, B. Lyman, J. Cocjin, K. Dean, L. Ernst, H. Mousa, and O. Almadhoun contributed to the analysis and interpretation of the data; and all authors drafted and critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

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