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Inside...

COVID-19 in the Medically Complex Pediatric Population: Unforeseen Nutrition Care Side Effects

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Learning Objectives:

1. Describe ways nutrition can be impacted by the COVID-19 pandemic for children with medical complexity.
2. List interventions a RDN could make to help relieve caregiver stress as it relates to feeding and nutrition.
3. Discuss advantages and disadvantages of utilizing telehealth to provide medical nutrition therapy for children with medical complexity.
4. Identify what RDNs can advocate for in the future to keep children with medical complexity nourished and safe during this pandemic.

Keywords: medical complexity, COVID-19, telehealth, medical nutrition therapy, enteral nutrition

The Complex Care Center at Cincinnati Children's Hospital Medical Center acts as the primary care office for over 600 children, the majority of whom are classified as having medical complexity. Kuo, et al. defines medical complexity as a patient with chronic health problems involving multiple organ systems, usually requiring medical technology and a high health care utilization rate.[1] Across the country, the population of medically complex infants and children is small but growing, and it utilizes a large portion of health care resources, including medical nutrition therapy.[2-4] According to a recent study utilizing the National Health Interview Survey, prevalence of children aged 3-17 years having any developmental disability (including but not limited to cerebral palsy, attention-deficit/hyperactivity disorder, autism spectrum disorder), has

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increased from 12.8% in 1997-1999 to 17% in 2015-2017.[2] Such patients frequently present with complicated nutritional requirements. Nutritional concerns can include weight management diets and high-calorie diet plans, combined per os (PO) and pureed by gastrostomy tube feeds, and hypocaloric tube feeds. Close monitoring by a registered dietitian nutritionist (RDN) is imperative to design and manage the complex nutrition interventions needed to maintain the optimal health of each individual patient.[4,5] Under usual circumstances, our interdisciplinary team, including the RDNs, frequently assess the children in our practice to best monitor their growth and overall nutritional status as recommended by prior studies to improve nutritional outcomes.[5,6] However, when the country began to face the coronavirus disease 2019 (COVID-19) in the late winter/early spring of 2020, multiple facets of the daily lives of our clinic patients and families drastically changed, including alterations to the methods of chronic medical and nutrition management. In accordance with the stay-at-home orders given by the governors in the tristate area (Ohio, Kentucky, and Indiana) serviced by our clinic in the early part of the pandemic, primary care at our institution's clinic for medically complex children to put the safety of our patients and families first.[7-10] Telemedicine appointments with questionable video quality became a new norm, and in-person well-child-check appointments were rescheduled to later dates. This abrupt shift in the way medical nutrition therapy was monitored and delivered, as well as the overall change of day-to-day activities for families, generated changes in the nutritional, and thus overall, health status of these medically complex children. This review documents many of the observations and concerns noted as well as nutrition interventions applied by the RDNs in the Complex Care Center during these unprecedented times. We also offer suggestions for nutritional considerations in the event of future local, state, or national crises.

Impact of Changes in Day-to-Day Activities and Care

Children with medical complexity attend school; interact with peers, therapists, and teachers; and are able to explore the world outside their homes. However, with the stay-at-home orders issued by the states in the early part of the pandemic, families with medically complex children regularly complied, with some families choosing to follow the order even more strictly by declining their home care nursing for a period of time.[7-10] Most families with medically complex children rely on sending them to school or having someone in their homes to care for them so that the parents and other guardians can run errands, attend their own jobs and doctor's appointments, or spend time with other family members. Without school or additional caregivers, parents were providing the majority of care to their medically complex children. These alternative care options that were part of the families' regular routines prior to the pandemic are shown to decrease caregiver stress; therefore, when they are not available, caregiver stress likely increases.[11] In addition, in some instances, the authors observed that the patient received altered feeds from what was prescribed, resulting in unusual weight gain or weight loss.

It is important for the RDN to recognize the extra stress on families and consider ways the nutrition care plan can be adjusted to help the individual family. The following are some of the interventions the Complex Care Center RDNs implemented in attempts to reduce the overwhelming task of caregiving at this time:

- Adjusted feeding plans to best meet the family's hectic schedule
- Investigated alternative ways to mix the child's formula to reduce family stress
- If a child was on a homemade, blenderized diet and it was difficult for the family to shop in the store or have the correct foods delivered, offered a commercial, blenderized product that would be covered by insurance and delivered to the home
- Offered telehealth, when appropriate, to discuss nutrition needs
- Provided documentation of recent anthropometrics and labs required by Women, Infants, and Children Program (WIC) to reduce the need for the family to take the child to another appointment

We noted in our clinic that a few of the parents/full-time caregivers of our patients contracted COVID-19, leaving the children without caregivers. While the parents in the known cases managed to not pass the virus to their children, it still left the children without caregivers because their parents were either in the hospital or too sick to provide the level of care needed. Thus, the families had no other option than to have the children admitted to the hospital for expensive respite care stays. If a family had a backup caregiver, it was prudent of the RDN to communicate with the temporary caregiver as soon as he or she received notice of the new caregiver's role.[4] It has also been

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our observation that, given these children have not been maintaining their usual activity levels through therapies, school, and other activities, many have gained excess weight.[12] This includes individuals who receive their nutrition enterally. The detailed nutrition plan that was covering calorie expenditure prior to the COVID-19 pandemic now provides excessive calories due to decreased activity and can be classified as overfeeding. Excess weight gain caused by overfeeding can cause additional medical complications.[13] With this observation, the need for RDNs to be actively involved in the care of medically complex children is further supported.[4,14] Children who are fed enterally are usually prescribed either a specific enteral formula or a blenderized recipe using whole foods that provides them with life sustaining nutrition. At the beginning of the pandemic, Americans encountered empty shelves at the grocery stores, those for including shelf-stable foods, cleaning products, and paper goods.[15,16] This led to procurement concerns from parents/caregivers of those who use commercial tube feeding products and those using blenderized feeding recipes. For those using homemade, blenderized formulas, the ability to find typical ingredients was sometimes interrupted, and families required assistance with proper substitutions for certain foods. A handful of parents with enterally-fed children on commercial tube feeding products contacted the clinic office voicing concern over the supply of enteral formulas. Thankfully, to the date of this writing and knowledge of the authors, there has not been a national shortage on any of the commercial enteral formulas our patients are prescribed. Some patients who receive WIC and obtain their enteral formulas over the counter found empty shelves; however, clinic RDN's were able to strategize and successfully provide these children with similar available formulas or found alternate routes to support their usual product orders. The procurement of enteral formulas and supplies is a unique stressor to this population, especially during this ongoing pandemic. At the time of this writing, we are still experiencing personal protective equipment (PPE) shortages nationally. Families are reporting they are not receiving some of the usually provided PPE items with their enteral supply deliveries. While they are still able to care for the gastrostomy tube sites successfully, it is another added stressor.

Providing Telehealth to Medically Complex Patients

Many dietitians across the country had to learn quickly how to provide and gain access to telehealth services in order for nutrition management of outpatients to continue as families complied with stay-at-home orders. In order for remote visits to happen in our clinic, it was helpful to have Ohio Medicaid fully support telehealth visits, and as of November 15, 2020, continuation is now permanent.[17] Indiana and Kentucky also approved increased use of telehealth, but at the time of this writing, expansion of telehealth is approved only until the current public health emergency is declared over by the governors of each state.[18,19] An additional constraint to providing telehealth services from our center includes the fact that the states in which our patients live (Ohio, Kentucky, and Indiana) have different licensure requirements. At the time of this writing, RDNs from our institution are able to provide telehealth in Kentucky through a program that allows them to request temporary licensure during the current health emergency, but a similar program is not available in Indiana. There are great benefits to providing medical care via telehealth to families, including maintaining quality of care, improved access to healthcare, improved outcomes, and flexibility for both the family and providers.[17] Specific advantages to providing pediatric nutrition care via telehealth are numerous and include: the ability to have multiple caregivers and clinicians attend the appointment, clinicians observing the child in their home environment, providing in-depth education on a new diet regimen for the patient, and providing enteral and parenteral nutrition follow-ups.[20]

Benefits of In-Person Nutrition Assessments

Despite the numerous benefits of telehealth, the COVID-19 pandemic has shown us there are some concerns with providing nutrition care solely via telehealth in children with special needs and underscores the importance of having some in-person nutrition visits. The greatest challenge to providing nutrition care for children with complex medical needs via telehealth is the lack of ability to complete a nutrition focused physical exam (NFPE). It is difficult to use typical nutrition indicators in medically complex patients. Prior studies have shown that single anthropometrics such as body mass index, weight, and length/height may not be accurate in identifying malnutrition concerns in children with complex diagnoses like cerebral palsy and/or other neurologic

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conditions. Multiple indicators must to be utilized rather than a single data point.[21-23] The NFPE can provide valuable information regarding nutrition status, such as assessing muscle and fat stores and looking for signs of micronutrient deficiencies in nails, eyes, and hair.[22] This is difficult to accomplish when the child is not in your physical presence. When a telehealth visit is your only available option, obtaining a current weight for the patient is certainly helpful to complete a nutrition assessment. Families can utilize a home scale to weigh their child for the appointment, but depending on the child, that may be difficult. For children with limited mobility, standing on a simple bathroom scale is not an option. Most parents in our clinic are able to hold the child while they stand on the scale and then subtract their own weight to provide us with a current weight. Other children/young adults are too big for this method as the combined weight may exceed the scale's limit or the caregiver cannot lift the child without assistance from specialized lift equipment. Some lifts have scales that can be attached, but this may be cost-prohibitive for many families. Lastly, families having access to and the knowledge of appropriate technology to complete a telehealth visit is a challenge that can negatively affect the visit. In our clinic, there have been many telehealth visits cut short or simply not occurring due to poor connections, batteries dying, and/or the family being uncomfortable with managing the technology. Since telehealth limits the ability of the dietitian to complete a NFPE and technology can be unreliable, in-person visits will remain the RDN's preferred method to assess a patient accurately. Some challenges and potential adjustments or solutions are listed in **Table 1**.

Table 1: Addressing Challenges of Daily Clinical Operations

Challenge	Adjustment or Solution
Increased telehealth use	• Pre-visit planning to determine if families have the appropriate technology to complete the visit • Utilize TytoCare™ (TytoCare Ltd., New York City, NY) when able to improve the experience* • If state Medicaid has approved phone visits as a telehealth visit, may use as a backup
Home-based anthropometrics	• Educating families to obtain a home weight soon after the in-person visit and again on the day of their upcoming telehealth visit • Families were educated with information from the World Health Organization Job Aide[23]
Limited ability to perform an NFPE	• Review a prior NFPE from an in-person visit and ask the family questions regarding changes in hair, nails, and skin, or how clothes are fitting • Make an effort to be present during the provider's physical exam to practice social distancing

* TytoCare has the advanced technology to allow families to take high-quality pictures for a physical exam. At the time of this writing, our clinic is starting to introduce families to this technology, therefore; we are unable to discuss the pros and cons of using this device but anticipate it may be helpful in obtaining NFPE information through telehealth.[24]

Future Considerations

Despite the challenges the COVID-19 pandemic brought to light within the health care system, there have been beneficial learning opportunities for clinicians, families, and patients. For example, we believe telehealth is here to stay. It has been successfully utilized in the past in a few situations, but use will likely be much more commonplace going forward. Our clinic will continue to help provide patients and families with the best care possible, keeping in mind their safety, and will do this by continuing to:

- Address the current challenges of telehealth as well as determine what improvements may be made to allow us to provide the best medical nutrition therapy to children with medical complexity
- Limit in-person exposure as much as possible to help keep our patients and families safe[25,26]
- Assure patient and family safety when they come to an in-person visit by applying institutional guidelines for proper PPE use and sanitation procedures[25,26]
- Collaborate with the WIC RDN and communicate that their participant is actively followed by another RDN. In the absence of a waiver for physical presence, provide the child's anthropometrics, labs results, and documentation of their medical complexity to the WIC office so that they may be excused from their in-person visits

Lastly, the COVID-19 pandemic reminds us that preparation is important. In the future, dietitians working with children that have complex medical needs may consider including discussions on emergency preparedness during visits. This would provide the opportunity to

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discuss how to problem solve in the case of a supply shortage, caregiving emergency, and interruptions in normal services (no electricity, water, etc.).[4,27] Discussing these items now will allow families to be prepared to provide nutrition in a variety of unexpected situations including, but not limited to floods; hurricanes; tornadoes; and other local, state, or national emergencies.

Overall, the COVID-19 pandemic has been a thorough upheaval of what our clinic thought was an adequate system with plenty of ways to provide and monitor the nutrition status of patients in our clinic. Like many other medical teams around the globe, the Complex Care Center worked together to be creative, flexible, and stay up-to-date on ever-changing medical information in order to provide the best medical nutrition therapy possible to the children in our practice during this time. The lessons learned will undoubtedly continue to carry us through our current crisis as well as evolve with time for future, unforeseen calamities.

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Eosinophilic Esophagitis: An Overview of Disease and Nutrition

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Learning Objectives:

1. Understand the various symptoms and presentations that manifest with eosinophilic esophagitis
2. Identify the required diagnostic criteria for eosinophilic esophagitis
3. Identify nutrient related concerns for patients following an elimination diet
4. Identify common triggers for eosinophilic esophagitis and appropriate diet applications as a course of treatment

Keywords: eosinophilic esophagitis, diet interventions, gastroesophageal reflux disease, elimination diets, proton pump inhibitors, corticosteroids, elemental diet

Eosinophilic Esophagitis (EoE) is a chronic inflammatory, immune/antigen-mediated condition of the esophagus that is gaining recognition among clinicians due to its rising incidence and prevalence over the last several decades. EoE is a clinicopathological condition characterized by esophageal dysfunction and $\geq$ 15 eosinophils per high power microscopy field (defined as the field of view when histologically evaluating tissue biopsy under a microscope) on an esophageal biopsy in the absence of other inflammatory-related gastroesophageal disorders.[1] While EoE can affect people at any age, it is most common among pediatric patients, who account for over 65% of cases.[2] Once considered to be quite a rare disease, due to improvements in diagnostics EoE is actually the most common eosinophilic gut disorder, with prevalence currently estimated at 1 in 2,000 in the U.S.[3,4] Pediatric gastroenterologists are more likely to see a new patient with EoE than a new patient with Crohn's disease,[5] and over half of food impaction cases are a result of this condition.[6] Without proper treatment, EoE can lead to several complications in pediatric patients including esophageal remodeling and fibrosis, growth stunting, low bone mineral density, cognitive delays, and, in severe cases, esophageal rupture or Barrets esophagus.[7,8] Registered dietitians play an important role for patients with EoE because nutrition interventions are one of the primary treatment tools for EoE along with medications that target inflammation and other debilitating symptoms. Due to the varied pathology and presentation of EoE from person to person, treatment plans must be individualized by an interdisciplinary care team that may include dietitians, gastroenterologists, speech language pathologists, occupational therapists, psychologists, and social workers.

EoE is the result of an immune response to antigens from either food or airborne allergens (**Figure 1**).[2] It is complex to isolate the inciting allergens because EoE involves both IgE and non-IgE-mediated mechanisms,[9] and elimination diets that focus on results of IgE tests, such as the skin prick test, have not been very successful at relieving EoE symptoms.[7] However, it is important to evaluate a patient's IgE-mediated allergic reactions to determine patients who are at risk for anaphylaxis (14.8% of cases).[9] The immune response in EoE is mediated by Th2 interleukins,[2] but emerging research suggests there is also a connection between EoE and elevated levels of IgG4.[10]

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Unfortunately, there are currently no validated IgG allergy tests, and elevated IgG levels have been shown in both those with and without clinical allergic responses.[11] Furthermore, research of common skin and blood-based allergy tests including skin-prick and skin-patch tests, serum allergen-specific IgE, basophil activation tests and serum food-specific IgG shows that no allergy test is able to accurately predict food triggers that elicit clinical symptoms.[2] This adds a complicating layer to the diagnostic process and development of a treatment plan for patients with EoE. The most common food allergen that elicits an EoE response is milk (35%), and other common allergens include but are not limited to wheat, egg, soy, peanuts, and shellfish.[2,9,12]

There are both genetic and environmental components that contribute to the pathogenesis of EoE. The genetic etiology of EoE continues to be explored, as many shared and novel genetic variations have been associated with EoE risk. A genetic predisposition to EoE includes variants in genes such as CCL26 that play a role in altering the Th2-mediated immune response.[2,13] Additionally, environmental factors like increased environmental hygiene and reduced variability in gut microbiota, air quality or airborne pollen, or presence of gastroesophageal reflux disease (GERD) can contribute to epithelial damage to the esophagus, increasing vulnerability to external antigens.[2] When allergens are able to penetrate the esophageal epithelium, an immune response can be triggered and inflammatory cells are recruited, including eosinophils.[9]

Figure 1. Pathophysiology of Eosinophilic Esophagitis (EoE).

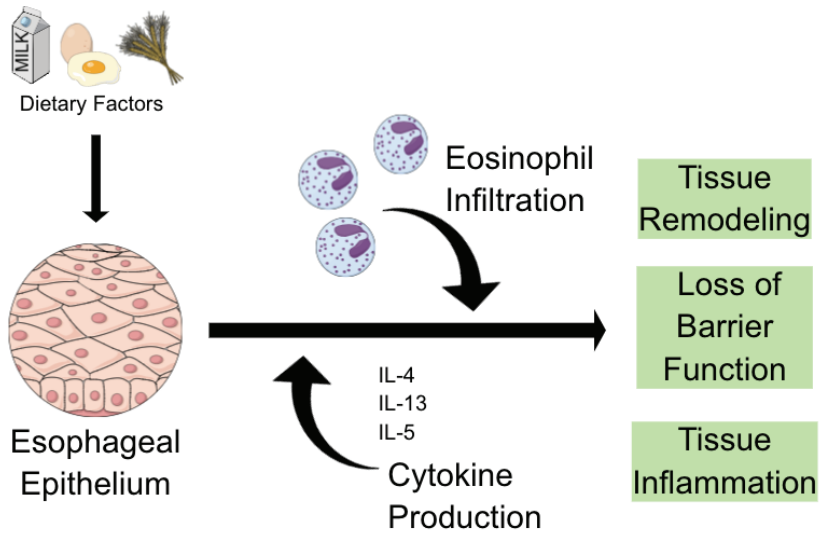

Figure legend: EoE is triggered by allergen exposure resulting upper gastrointestinal symptoms and inflammation characterized by immune cell infiltration, specifically eosinophils and local production of inflammatory compounds such as cytokines. Without treatment (pharmacological or diet interventions) worsening inflammation can lead to esophageal remodeling, rigidity, and dysfunction.[29]

Table 1: Symptoms & Diagnosis of Eosinophilic Esophagitis in Pediatric Patients

Clinical symptoms (primary)	Nausea, vomiting, food rejection, feeding problems and dysphagia, food impaction, reflux, heartburn, and chest pain
Clinical symptoms (secondary)	Malnutrition, unintended weight loss, developmental delays, growth stunting or low BMI-for-age, failure to thrive, ARFID, disordered eating, anxiety/depression
Endoscopic symptoms of esophagus	Circular rings, longitudinal furrows, exudates, mucosa edema, esophageal stenosis (10-25% have normal esophageal presentation)
Histological symptoms	> 15 eosinophils per high power field (x40 magnification). Basal zone hyperplasia with papilla hyperplasia, eosinophilic micro-abscesses, eosinophil degranulation and surface desquamation, and lamina propria fibrosis
Required Diagnostic Criteria for EoE: Esophageal dysfunction (confirmed by primary clinical symptoms or endoscopic symptoms on biopsy); ≥ 15 eosinophils per high power field (x40 magnification); exclusion of other gastroesophageal conditions	

Diagnosis

Clinical Symptoms

Symptoms of EoE can vary widely between patients and many symptoms overlap with other allergy or gastroesophageal-related conditions (**Table 1**). In infants and children (0-9 years of age), the most common symptoms include vomiting, food rejection, feeding problems, and dysphagia (kids may report that "food gets stuck"), and in adolescents (10-14 years of age) symptoms

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may also include food impaction, reflux, heartburn, and chest pain.[1,2,6] Left untreated, these symptoms of EoE can lead to esophageal stenosis, fibrosis, and remodeling,[2,9] which become harder to treat and reverse as the condition progresses. Secondary to these symptoms, EoE patients may also experience a combination of malnutrition, unintended weight loss, developmental delays, growth stunting or low BMI-for-age, and/or failure to thrive, especially in pediatric patients.[2,14] Patients dealing with symptoms of any allergy-related condition are also more likely to develop disordered eating and may show signs of Avoidant/Restrictive Food Intake Disorder[15] or experience psychological distress including anxiety or depression.[16] These psychosocial signs or a BMI or length-for-age below the 5th percentile may warrant further investigation. Since EoE symptoms are nonspecific, the condition is often misdiagnosed, and its frequency is underestimated.[9]

Patients with EoE may experience additional symptoms related to comorbid conditions that mask or modify symptoms of EoE. Since patients with EoE are more likely to have atopic diseases than the general population (two thirds of patients have a history of atopy), they may also experience symptoms of asthma, allergic rhinitis, or dermatitis.[9] There is a complex relationship between EoE and GERD. They are not necessarily mutually exclusive conditions, as once previously perceived, and symptoms of EoE may overlap or be exacerbated by the presence of GERD.[1] GERD is often the initial differential diagnosis for EoE, which can delay EoE diagnosis.[9] About 50% of patients will observe improved symptoms when treated for GERD with proton pump inhibitors (PPIs),[2] but some will not respond to this treatment. Even for those who do, it is important to recognize that only some symptoms will be relieved and other symptoms will need to be addressed with alternative methods.

Endoscopic & Histological Symptoms

In patients with EoE, an endoscopy may reveal esophageal abnormalities including circular rings, longitudinal furrows, exudates, or mucosa edema as well as esophageal stenosis, which can contribute to food impaction.[9,17] The EoE Endoscopic Reference Score is a classification system for endoscopic findings that has been validated among children in the U.S. aged 2-17 and can be used to support an EoE diagnosis. However, endoscopic findings are not the only way to diagnose EoE because 10-25% of patients present with normal endoscopic appearance of the esophagus.[2,18]

Multiple biopsies along the proximal, middle, and distal esophagus are required for EoE diagnosis, and at least five are required to reach 100% sensitivity.[9] EoE is histologically characterized by $\geq$ 15 eosinophils per high power field (x40 magnification).[1,2,6] Other histological signs of EoE include basal zone hyperplasia with papilla hyperplasia, eosinophilic micro-abscesses, eosinophil degranulation and surface desquamation, and lamina propria fibrosis, but these are not required for diagnosis.[9]

The current guidelines for confirming an EoE diagnosis were updated in 2017 at the AGREE (A working Group on ppi-REE) Conference in Chicago, IL, that included thought leaders in gastroenterology, allergy, and pathology.[1] Most notably, this change removed the need to observe the patient's response to a PPIs trial as a part of the diagnostic criteria, instead classifying PPIs as a potential treatment option.[1] With these updates, diagnostic criteria include the following: 1) clinical and/or endoscopic symptoms of esophageal dysfunction; 2) $\geq$ 15 eosinophils per high power field on esophageal biopsies; 3) comprehensive assessment that rules out other possible causes of esophageal eosinophilia.

Interventions

While there is no known cure for EoE, interventions can target relieving or eliminating clinical symptoms and healing of the esophageal mucosa.[19] Combination therapy may be needed, and each patient's treatment plan should be tailored to the individual. There are three components to treatment options for EoE including pharmaceutical interventions (PPIs or topical steroids), nutritional interventions (dietary alterations or elimination diets), and/or esophageal dilation.[2,6,19] Esophageal dilation is used to address severe esophageal stenosis and is more commonly used in adults with EoE than in pediatric patients,[9] so it will not be covered in this report.

Pharmaceutical Interventions

Medications may be used as one of the initial treatment options for EoE to ease the severity of symptoms. The two drug therapy options for EoE include PPIs and corticosteroids.[1,2]

Proton Pump Inhibitors (PPIs)

Based on the most updated recommendations from 2017, PPIs can be used as a first line treatment for EoE due to their low cost, good safety profile, and evidence that suggests PPIs can reduce symptoms and signs of inflammation for about 50% of pediatric and adult patients with

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EoE.[1] However, PPIs are not effective for all EoE patients, likely because they are more effective for patients with concurrent GERD.[1,9] Additionally, PPIs cannot improve or prevent all symptoms, so other therapies should also be considered. While PPIs have an encouraging safety profile, chronic use of PPIs is associated with increased risk for infection (particularly pneumonia and *Clostridium difficile* diarrhea), hypomagnesemia, vitamin B12 deficiency, chronic kidney disease, and dementia.[20,21]

Corticosteroids

Steroids are used as a means to quickly reduce symptoms of EoE and work in a majority of patients (85%).[4] Topical steroids are administered in a swallowable form as to best coat the affected area. These steroid treatments are either budesonide in viscous gel or fluticasone propionate nebulizer that can be swallowed rather than inhaled.[9] Evidence suggests that budesonide is more effective than fluticasone,[9] but there are limited studies comparing their efficacy. Topical steroids are effective at eliminating underlying inflammation and help prevent development of fibrosis,[4] but the impact of treatment varies depending on whether evaluating clinical or histological symptoms. Clinical symptoms appear to be better addressed by topical steroids (71%) than histological symptoms (51%), but both are improved with this drug therapy.[9]

Long-term corticosteroid therapy (3-6 months) can lead to adverse outcomes in pediatric patients including adrenal insufficiency or neuropsychiatric side effects such as cognitive disorders and behavioral changes.[9,22] Chronic corticosteroid use in pediatric patients can induce a myriad of potential adverse effects including osteoporosis, avascular necrosis of bones, Cushingoid body habitus, acne, hypertension, gastritis, amenorrhea, glaucoma, diabetes mellitus, and immunosuppression, and topical steroids pose a greater threat on behavioral issues than inhaled steroids.[22]

Table 2: Eosinophilic Esophagitis Dietary Therapies

Diet Therapy	Diet Application
Elemental diet, amino acid formula based	PurAmino, PurAmino Junior, Alfamino, Alfamino Junior, Elecare, Elecare Jr, Neocate, Neocate Jr. This may require energy feeding.
Four food elimination diet (FFED)	Avoidance of dairy, wheat, egg, and soy
Six food elimination diet (SFED)	Avoidance of dairy, wheat, egg, soy, nuts and seafood
Tailored/empirical elimination diet	Based on result of skin prick test and atopy patch testing. Foods commonly tested include cow's milk, egg, wheat, soy, peanut, beef chicken, corn, potato, and rice. Patch testing's accuracy requires further investigation.

Adapted from the Pediatric Nutrition Reference Guide 12th Edition, Texas Children's Hospital[30]

Nutrition Interventions

Dietary therapy is a necessity to management of EoE and treatment of its symptoms. Nutrition interventions include an elemental diet or various elimination diets (**Table 2**).[1,2,9,12]

Elemental Diet

An elemental diet provided as an amino acid-based formula is the most effective dietary intervention that can provide relief of clinical symptoms within 7-10 days and 95-98% histological remission within 4-5 weeks.[9] The elemental or hypoallergenic formula diet is the strictest and most effective form of dietary therapy. An elemental formula (such as Neocate, Elecare, or Puramino) is made from amino acids which are the basic building blocks for proteins. It is completely free of any milk or soy proteins. As such these formulas are very well tolerated and should not cause an allergic reaction.[23] After treatment with an elemental diet, symptoms are shown to recur when food proteins are reintroduced through an open food challenge, which highlights that allergens from food are responsible for clinical and histological esophageal inflammation.[2]

The elemental formulas, however, have poor palatability and often require a nasal gastric tube to promote the correct consumption for adequate nutrition.[2,4,9] It is also a higher-cost option that is not covered by all health insurance and can have detrimental implications on quality of life due to psychosocial disturbances.[2,9] While it may offer quick relief and can be a good option for infants who are not yet consuming solid foods, it is not realistic to consider an elemental formula diet as a long term solution for the treatment of EoE. Other dietary therapies should be evaluated on a patient-to-patient basis.

Elimination Diets

Elimination diets are a good long-term dietary therapy for EoE and can

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come in a variety of forms. Types of elimination diets include a four-food elimination diet (FFED), six-food elimination diet (SFED), or a tailored/empirical elimination diet. The FFED entails the elimination of milk, wheat, eggs, and soy, the four most common food allergens responsible for EoE. The SFED eliminates two additional common allergens for an overall diet that excludes milk, wheat, eggs, soy, nuts/peanuts, and fish/shellfish. As a first-line treatment, elimination diets can be just as effective as pharmacological interventions. More specifically, the SFED can provide similar efficacy (82%) as topical corticosteroid therapy (85%) and at a much lower cost.[2] However, especially for pediatric patients, eliminating six food types can be challenging to adhere to, so the FFED (60%) is often the first step for dietary treatment in younger populations along with the appropriate drug interventions. Since milk is the most common allergen for EoE, if a stepwise approach to dietary therapy is chosen, dairy products should be the first food eliminated. Dairy elimination alone provides 57% efficacy among patients age 20 years or younger.[12]

A tailored elimination diet relies on results from skin prick and atopy tests and clinical history to determine which foods to eliminate, and it usually includes five to seven foods.[9] There is high variability in efficacy of a tailored elimination diet ranging from 45%-77%, but remission of symptoms is greatest when the diet includes elimination of milk (75%).[9] The tailored elimination diet can lead to the largest list of eliminated foods, which can make adherence to recommendations even harder. Additionally, as previously mentioned, allergy tests may not be reliable and may isolate allergens that are unrelated to the patient's EoE symptoms. As such, the tailored elimination diet is not as highly recommended as the SFED or FFED.[9]

For any dietary eliminations prescribed for a patient, special awareness should be paid to the associated nutrients that may also be eliminated from the diet. See **table 3** for nutrients of concern for patients treated with elimination diets for EoE. As such, dietitians are a critical part of the care team when considering diet therapy for EoE to ensure the patient receives adequate nutrition.

Table 3: Nutrients of Concern for Eosinophilic Esophagitis Elimination Diets

Food Avoided	Monitor Intake of These Nutrients
Fish	Protein, niacin, vitamin B6, vitamin B12, vitamin E, phosphorus, and selenium
Shellfish	Zinc, magnesium, copper, and selenium
Eggs	Vitamin D, vitamin B12, vitamin B6, pantothenic acid, selenium, riboflavin, and biotin
Corn	Thiamin, riboflavin, niacin, iron, and chromium
Milk	Calcium, vitamin A, vitamin D, riboflavin, pantothenic acid, and phosphorus
Peanuts	Niacin, magnesium, vitamin E, manganese, and chromium
Tree nuts	Vitamin E, magnesium, copper, manganese, and phosphorus
Soybeans	Thiamin, riboflavin, vitamin B6, folacin, calcium, phosphorus, magnesium, iron, and zinc
Wheat	Thiamin, riboflavin, niacin, iron, selenium, fiber, and chromium

Source: Nutrition Care Manual[31]

The Care Team

The Role of Dietitians

Since dietary therapy is an intrinsic component of the treatment of EoE, a dietitian plays an integral role on the patient care team. A dietitian is trained in medical nutrition therapy and can collaborate with the patient care team to create a nutrition care plan and intervention based on the patient's nutrition status and diagnosis. Since specific food allergens can contribute to symptom exacerbation and poor outcomes, it is important to encourage and monitor adherence to the patient's diet prescription. Support from a dietitian improves adherence to a prescribed elimination diet without compromising quality of life.[24,25] The dietitian works with the patient, the caregivers, and other providers to determine the best dietary therapy, how to initiate the intervention, offer in-depth diet education, and ensure nutritional adequacy. One of the greatest sources of stress for parents of children with feeding problems is not having an understanding of if and when foods and nutrients are lacking in their child's diet and how to incorporate them within the parameters of the diet prescription.[26] The dietitian provides education and food preparation techniques that address these concerns.

Pediatric patients have a unique set of nutritional needs in order to support adequate physical, social, emotional, and psychological development. Thus, dietitians who work with pediatric patients with EoE should be proficient at providing appropriate nutrition recommendations for this population as well as understand how

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best to administer education to these patients and their caregivers.[27]

The American Academy of Allergy, Asthma, and Immunology has outlined the following steps that a dietitian can take when working with a patient with EoE.[25] See **table 4** for an outline of the following steps: 1) Conduct a nutritional assessment. This includes assessing the patient's anthropometry, diet history, lab values, and potential barriers to diet adherence. This can help assess for potential malnutrition; inadequate development; nutrient deficiencies; and potential social, psychological, or economic barriers; 2) Eliminate dietary allergens. This will require extensive diet and label reading education for patients with EoE and their caregivers. Label reading education should cover reading ingredients lists, identifying "hidden" ingredients or alternative ingredient names, and an understanding of cross contamination and precautionary allergen labels on food packages. Additionally, education that supports management of the prescribed diet including recommended kitchen staples, types of permissible foods, and managing dining away from the home should be included; 3) Individualize elimination diet to meet nutritional needs. The dietitian will ensure that the patient is able to meet nutrient and energy needs based on the patient's nutrition status. A dietitian can support this by providing sample recipes and nutrient-dense foods that fit within the elimination diet; 4) Provide practical substitutions for eliminated foods. The dietitian should assess how certain eliminated foods can lead to potential nutritional inadequacies and offer alternatives. For example, most wheat products are enriched with essential vitamins whereas most wheat-free items are not; dairy products are a good source of calcium and vitamin D and many dairy-free alternatives are not. It is important for the dietitian to recommend alternative food sources of the appropriate nutrients that are eliminated from the diet; 5) Monitoring and evaluation. The dietitian can assess how well the patient is able to maintain the elimination diet and how it impacts quality of life using motivational interviewing, food records, and food frequency questionnaires. They can also monitor for nutritional deficiencies and appropriate growth with labs and a nutrition focused physical exam. During this phase, the care team may also recommend that the patient receive periodic biopsies to monitor how histological symptoms respond to the diet. When monitoring and evaluating the elimination diet, the dietitian should assess whether the patient requires additional support from targeted nutrition supplements.

Table 4: Steps for Working with Pediatric Patient with Eosinophilic Esophagitis

Steps	Context
1. Conduct a nutritional assessment	• Anthropometry • Lab value assessment • Assess potential social, psychological, or economic barriers to diet adherence Goal: Assess for malnutrition, nutrient deficiencies/ inadequacies, development or growth delays, barriers to treatment adherence
2. Eliminate dietary allergens	• Diet education • Label reading education • Management of diet prescription: making food choices, stocking kitchen staples, tips for dining away from home, recipes Goal: Diet adherence, quality of life maintenance
3. Individualize elimination diet to meet nutritional needs	• Assess nutrient and energy needs • Provide food suggestions and recipes to help meet needs Goal: To maintain nutritional adequacy of elimination diet
4. Provide practical substitutions for eliminated foods	• Assess potential nutrient inadequacies that can arise from elimination diet • Suggest substitutions and alternatives Goal: To avoid nutrient deficiencies
5. Monitoring and evaluation	• Anthropometry • Lab value assessment • Nutrition focused physical exam • Motivational interviewing • Food records or food frequency questionnaires • Assess need for targeted nutrition supplements Goal: Maintenance of diet, adequate growth and development, improved symptoms, improved quality of life

The Importance of an Interdisciplinary Team

Allergic conditions and/or food allergies among pediatric patients are multifaceted, involving medical,

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sensory, oral motor, swallowing, and behavioral factors that need to be addressed by a team of providers from various disciplines.[26] Each factor requires unique specialized knowledge which guides the appropriate makeup of the interdisciplinary care team. The team for patients with EoE may include gastroenterologists (specializing in food allergy), nurse practitioners, speech pathologists, and registered dietitians who have experience working with pediatric patients and who specialize in treating patients with allergic conditions and/or food allergies. Additional team members may include an allergist, occupational therapist, behavioral psychologist, and social worker depending on the patient's needs. Adopting an elimination diet for EoE can increase the cost of groceries,[28] which should be considered when forming the interdisciplinary care team. A collaborative approach is key, and health care providers must work together in every stage of the patient's care from assessment to treatment and follow up. The care team should develop strategies and tools for effective communication, and each member of the team must recognize the importance of the others. This approach not only improves efficacy and outcomes but improves the healthcare experience of the patient and the caregivers.[26]

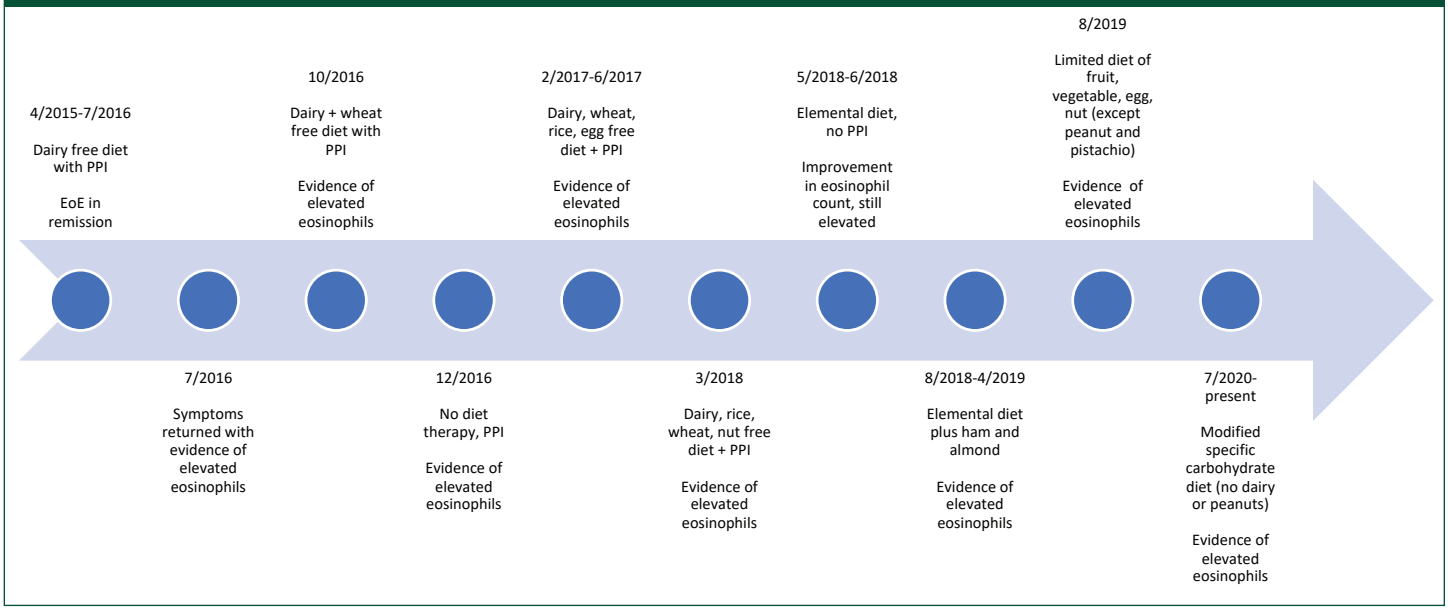
Case Studies

The following case studies exemplify the broad spectrum of presentation and treatment plans for EoE. While aspects of the condition are specific to the individual, many of the same nutrition-related concerns exist among patients.

Case study #1

TR is a 17-year-old female with a history of eosinophilic esophagitis and allergic rhinitis. In 2014 (age 11) she presented with persistent abdominal pain. An abdominal x-ray revealed a significant stool burden at the time and she was placed on MiraLAX. An increased frequency in stooling did not alleviate her pain. She had a normal complete blood count, comprehensive metabolic panel, celiac panel, and erythrocyte sedimentation rate. Her weight-for-age consistently tracked along the 50th percentile from age 8 to present, and her body mass index fell between the 50th percentile to the 70th percentile from age 8 to present; growth/weight gain was not a concern for her care team. After lab review, she was then treated with omeprazole daily and a probiotic without improvement. She then had an upper endoscopy which showed elevated eosinophils in both the esophagus and colon which led to diagnosis of EoE. Many interventions including diet therapy and medication have been put in place to date without full resolution of EoE. During the course of diet interventions and manipulation, she has supplemented with iodine (12.5 mg twice weekly), vitamin D (10,000 IU/day), vitamin B12 (2,500 mg/day), and calcium citrate powder (2,380 mg/day), which are monitored by repeat labs. She has had repeat endoscopies between dietary changes with no notable improvement on biopsy. A

Figure 2. Timeline of EoE management and treatment in 17-year-old female patient



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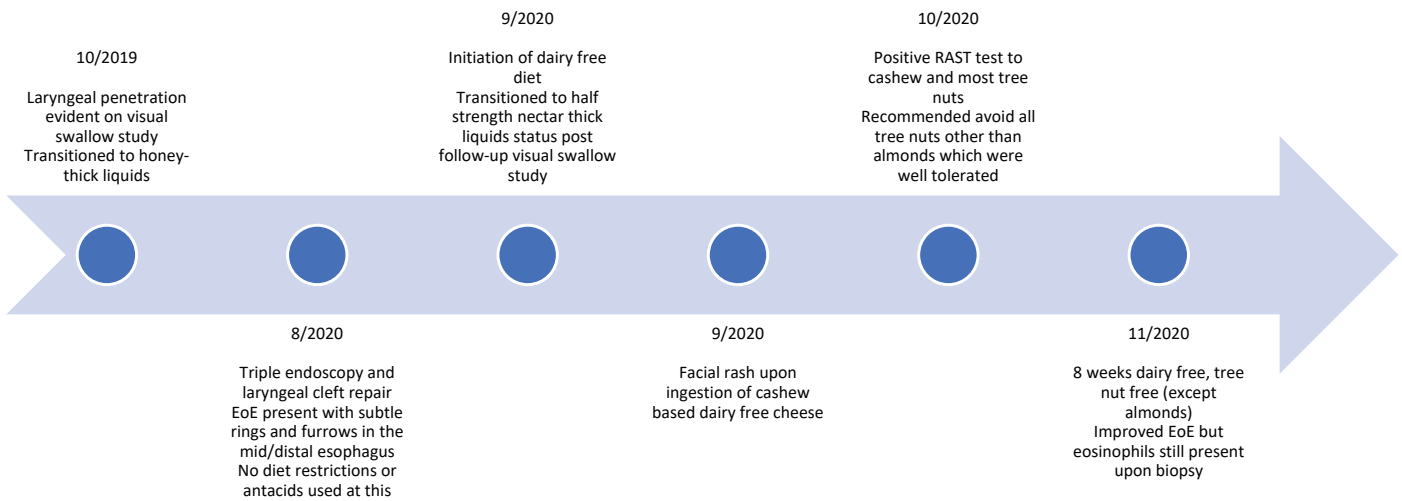
visualization of disease management and interventions is outlined in **figure 2** (on previous page). In the figure, the text stating "evidence of elevated eosinophils" was confirmed via endoscopy. In August 2018, she started an elemental diet; this was the patient's choice over a steroid trial. Discussions with the patient and immediate family ensure diet adherence. The patient has not been able to achieve EoE remission since 2016 and continues to implement various diet modifications to manage symptoms. Follow-up discussions will include pharmacological interventions to trial for symptom management.

Case study #2

KS is a 30-month-old female with a birth weight of 9 pounds, born full term yet requiring a NICU stay for persistent pulmonary hypertension of the newborn requiring supplemental oxygen and a nasogastric tube for nutrition and feeding related to dysphagia with deep penetration, which resulted in use of thickened formula. She was weaned off oxygen and nasogastric tube by 4 months of life. Since birth, she received and continued on Enfamil AR. Since birth, weight-for-length has fallen between the 55th percentile to the 93rd percentile currently. Both her weight-for-age and length-for-age have tracked along the 96th percentile and 90th percentile, respectively. No evidence of inadequate nutrition or growth has been found related to EoE. She has a history of gastroesophageal reflux, dysphagia with cough, and aspiration requiring honey-thick liquids for almost 2 years of life. During infancy she tolerated milk-based thickened formula and transitioned to 1% milk at 12 months of age. When she consumed "juicy" foods (i.e. watermelon, strawberries), she would experience symptoms of coughing and irritability. She is now status post triple endoscope for repair of laryngeal cleft, with subsequent finding of EoE on endoscopy. The pathology at the time of the triple scope revealed rings and furrows in the mid/distal esophagus, and 20 eosinophils per high powered field (HPF) in distal, 25 eosinophils in mid, and 25 eosinophils in proximal esophagus with evidence of subepithelial fibrosis. At this time, she had no dietary restrictions and had not used antacids. Since repair of laryngeal cleft, she has tolerated juicy foods and ½ strength nectar-thick-consistency liquids. Additionally, the patient started on a dairy-free diet and had an adverse reaction to dairy-free cashew-based cheese; subsequently she had a positive RAST testing to tree nuts. Follow-up upper endoscopy improved on an 8-week dairy-free, tree nut-free (except almonds) diet but there were persistent eosinophils in the proximal esophagus. The pathology revealed 1 eosinophil per HPF in distal, 0 eosinophils in med, and 21 in proximal esophagus, with evidence of basal cell hyperplasia. A visualization of disease trajectory and interventions can be found in **figure 3** below. She continues to be followed by her care team and works with the dietitian to monitor adverse food reactions, selective eating in toddlerhood, and nutrition deficiencies related to multiple dietary restrictions.

Figure 3. Timeline of EoE management and treatment in 30-month-old female patient.



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Conclusion

For each patient described in these case studies, nutrition was a major component of their treatment plan. Each experienced similar nutrition related concerns including the likelihood of nutrient deficiencies while following a diet that required elimination of at least one major food, assessment of quality of life on an elimination diet, and ability to maintain long-term diet adherence. The cases also highlight the challenges of managing EoE symptoms and treatment, further highlighting how these patients may also deal with psychosocial disturbances including disordered eating, anxiety, and trouble eating in school or other social settings. The importance of including a dietitian on the care team for patients with EoE cannot be underestimated, as diet therapy and adherence are the cornerstones for treatment of EoE.

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Food for Thought: Two Case Studies on Blenderized Tube Feeding Diets and Successful Tube Weaning

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Learning Objectives:

1. List the clinical applications of blenderized tube feeding
2. Discuss the benefits of food and nutritional variety for tube-fed children
3. Describe the interdisciplinary approach to tube weaning

Key Words: blenderized tube feeding (BTF), tube weaning, enteral nutrition, interdisciplinary

Background:

Tube feeding, often referred to as enteral nutrition (EN), refers to the delivery of nutrients through the gastrointestinal tract, which meets part or all of an individual's caloric requirements.[1] EN can include nutrient delivery through an oral diet via liquid supplements or via a feeding tube.[1] For the purpose of this article, we will refer to EN in the context of feeding via a feeding tube. Many adults and children alike are reliant on tube feedings at home to deliver adequate nutrition and hydration. Studies using Medicare and Medicaid data in the United States indicate that the use and incidence of home enteral nutrition (HEN) is on the rise in the U.S., while the incidence of home parenteral nutrition (HPN), or intravenous nutrition support, is decreasing.[2]

There are many conditions for which children have tubes placed for feeding and hydration, including complex medical diagnoses and physical, anatomical, or neurologic conditions.[3,4] HEN can also be used in situations of pediatric feeding disorders, not otherwise specified by the above conditions.[5] In many situations, when feeding tubes are placed in small children for medical, structural, or behavioral/psychosocial reasons, the goal is often to eventually have the child wean from EN and gain the skills for accepting oral feedings. Further, the goal is to meet their nutritional needs and growth goals through an oral diet. Studies indicate that the younger a child is, the easier it may be to wean them from EN to an oral diet.[6,7] Lively, et al. explains this may be due in part to less psychological dependence on the tube.[6] Tube-fed children who are trialed on oral feedings can develop and display oral feeding problems. Some of the behaviors that tube-fed children display when oral feedings are presented include gagging, oral-motor hypersensitivity, tongue chewing, and withdrawal from food offered.[8]

In the past decade, caregivers, patients, and clinicians alike have shown an increased interest in utilizing whole food blenderized tube feeds in an effort to mitigate feeding intolerance concerns. Several clinical studies have documented the effects of blenderized tube feeding (BTF) and the associated reduction in gastrointestinal complications, increased gut microbiota diversity, decreased healthcare costs, reduction in hospital admissions, and improvements in quality of life.[9,10,11] In a study by Pentiuk et al., gastrostomy-fed children with a history of severe gastroesophageal reflux disease, with symptoms of gagging and retching post-Nissen fundoplication surgery, were found to have significant decrease in gagging and retching after transitioning to a BTF diet.[9] Pentuik et al. indicate the mechanism of how BTF decreases gagging and retching is not completely clear, but it is possible that the viscosity of BTF may slow down the rate of gastric emptying and the blended food may stimulate a hormonal response that has a positive impact on gastric motility, which may contribute to a decrease in retching and vomiting.[9] The decrease in gagging and retching can decrease oral aversion and promote oral intake in children.[9,10]

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Additionally, Hron, et al. indicate that BTF may improve stooling patterns in tube-fed children, which is likely related to the incorporation of whole foods and several types and quantities of fiber.[11] The interest in BTF comes largely from enteral nutrition consumers and caregivers with up to 80% of these groups reporting interest.[12] Barriers to receiving dietitian support exist in relation to BTF, as only 24% of dietitians have reported confidence in managing patients receiving BTF.[13]

Case Studies:

The following two case studies demonstrate the success of interdisciplinary care in the tube weaning of two children and the clinical benefit of having a variety of foods and BTF in the process of tube weaning. Patient 1 was able to progress to completely 100% oral feeds despite a history of malnutrition, feeding difficulty, and G-tube placement. This patient was able to wean completely from his feeding tube within one year of starting weekly intensive feeding therapy with a speech-language pathologist (SLP) trained in feeding and a registered dietitian nutritionist (RDN). An occupational therapist, pediatric gastroenterologist, and pediatric endocrinologist also played vital roles as consultants to the SLP and RD as needed. Patient 2 was able to improve oral intake and reduce oral aversion once started on BTF despite a history of bloody stools and multiple formula trials, including elemental formula. The following case studies focus on BTF, intensive feeding therapy, and an aggressive tube weaning approach.

Case Study – Patient 1

The patient, TG, was followed by a pediatric RDN bi-weekly and a SLP/feeding therapist weekly. TG was breastfed and also supplemented with bottles of expressed breastmilk, with a significant deceleration in weight gain velocity and height gain velocity over a six-month period of time from 6-12 months. Past medical history included elevated liver function tests (LFTs), lower extremity edema, and tongue and lip tie. TG was admitted to a children's hospital with dehydration and vomiting at 13 months after presenting to the ER. He was initially started on nasogastric feedings, however, a decision was made to place a gastrostomy tube (G-tube) after one week of hospitalization for longer-term nutrition support due to a history of inadequate intake.

From 13-15 months old, TG was fed expressed breastmilk fortified to 30 cal/oz with a partially hydrolyzed infant formula via G-tube, administered intermittently via an enteral feeding pump, which provided 765 mL, 720 kcal (90 kcal/kg), 11 g protein (1.4 g/kg).

At 16 months, TG was transitioned to 30 cal/oz feeds exclusively with the partially hydrolyzed infant formula, which provided 775 mL, 750 calories (90 cal/kg), 17.5 g protein (2.1 g/kg). Several feeding options were presented to the family, and the decision was made by the family with the support of the RDN to transition TG to a commercial BTF product by bolus feeds at age 17 months, which provided 880 mL and 720 calories (74 cal/kg). He developed significant loose stools and diaper rash. As a result, at 18 months old, TG was transitioned to another commercial blenderized tube feeding product with nutritional variety, which he tolerated better. Commercial formulas, and even the majority of commercial BTF products, are monotonous in nature, meaning that the consumer is fed the same ingredients every day for every meal. The commercial BTF product with nutritional variety used in this case offers a variety of meals to give the consumer both a choice in what they consume as well as variety in their diet (i.e. each meal contains different ingredients). This regimen provided 870 mL and 874 cal (89 cal/kg). Between 17-18 months of old, TG also had a tongue and lip tie revision at the recommendation of the SLP, which helped increase his tongue mobility for oral feedings. Between 19 and 20 months old, TG started showing increased interest in table foods. He continued to get 100% of his estimated needs from his bolus tube feeds, but began to take some table foods by mouth at family meals. As a result, his tube feeds were able to be weaned by 25% at 20 months old. Based on calorie counts from his oral intake as well as improved growth indices, TG's tube feeds were weaned to 50% at 21 months old. At 22 months old, TG's tube feeds were stopped completely, as his table food intake was estimated to meet his nutritional needs and he was meeting appropriate growth parameters, with a length and weight above the 50th%ile and weight for length z-score of +0.99. **Table 1** provides an overview of TG's time on enteral nutrition.

Over 12 months, TG received a G-tube, initiated enteral feeds by pump, transitioned to commercial formula by bolus feeding, and gradually increased his table food intake to meet 100% of his estimated nutritional needs. His tube feeding regimen was successfully decreased by 25, 50, and then 100% while increasing oral intake, which resulted in a complete discontinuation of his

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enteral nutrition in the span of about three months.

Case Study – Patient 2

The second patient, SP, was born full term, with a history of LGA (large for gestational age), hypoglycemia, cardiac dysfunction (Atrial Septal Defect), ASXL2 gene mutation, a choroid plexus papilloma (benign brain tumor), a history of seizures, and G-tube dependence. As an infant, SP was started on standard infant formula by bottle but a swallow study shortly after birth found aspiration, and he was switched to tube feeds by G-tube. He was discharged from the neonatal intensive care unit (NICU) on a partially hydrolyzed infant formula fortified to 27 cal/oz. Due to persistent emesis, he was transitioned to an extensively hydrolyzed infant formula, also fortified to 27 cal/oz, which did not improve emesis. SP continued on this formula regimen until age 12 months. At 12 months, he was transitioned to peptide-based pediatric formula, however, he experienced gas and gastrointestinal (GI) upset. Next, he was switched to pediatric amino acid-based formula due to blood in stool; however, this persisted. He was seen by a pediatric gastroenterologist in June 2016 to rule out GI disease. After a rectal exam, blood in the stool ceased and did not return.

Our team initially assessed SP via a referral from the Early Intervention Program at 16 months old. His family reported poor formula tolerance including frequent retching, emesis, gagging with oral stim, difficulty tolerating position changes, severe oral hypersensitivity, severe oral aversion, and heme-positive stools. He had a history of trialing multiple partially hydrolyzed formulas and his family wanted to explore using whole food boluses by G-tube instead of continuing to seek other formula options. He was taking a ready-to-feed hypoallergenic formula with added cornstarch via G-tube by syringe bolus during the day and by pump feedings overnight at a continuous rate. The formula was providing 942 mL free water, 933 calories (73 cal/kg), and 17.3g protein (1.36 g/kg). At the time of his assessment, he was at the 98th percentile and 100th percentile respectively for height and

Table 1: TG Timeline

Date	Significant Event	Nutritional Information	Growth Parameters
Age 12 - 15 months	Fed breastmilk fortified to 30 kcal/oz via G-tube using feeding pump	765 mL 720 kcal (90 kcal/kg) 11 g protein (1.4 g/kg)	@12 mo Weight z-score -1.76 Length z-score -2.52 Weight/length z-score -0.63
Age 16 months	Transitioned to 30 kcal/oz partially hydrolyzed infant formula via G-tube	775 mL 750 kcal (90 kcal/kg) 17.5 g protein (2.1 g/kg)	Weight z-score -2.06 Length z-score -2.88 Weight/length z-score -0.94
Age 17 months	Transitioned to a commercial BTF product. Simultaneously transitioned from intermittent pump feedings to bolus feedings	880 mL 720 kcal (74 kcal/kg)	Weight z-score -1.56 Length z-score -2.38 Weight/length z-score -0.62
Age 18 months	Transitioned to a commercial blenderized tube feeding with nutritional variety due to loose stools and diaper rash	870 mL 874 kcal (89 kcal/kg)	Weight z-score -1.98 Length z-score -2.27 Weight/length z-score -0.05
Age 20 months	Started showing more interest in table foods		Weight z-score -1.18 Length z-score -2.05 Weight/length z-score -0.26
Age 21 months	Tube feeding weaned by 25% due to growing interest in table foods		Weight z-score -1.09 Length z-score -2.08 Weight/length z-score -0.09
Age 22 months	Tube feeding weaned to 50%		Weight z-score -0.74 Length z-score -2.33 Weight/length z-score +0.58
Age 24 months	Tube feeding completely discontinued		Weight z-score -1.5 Height z-score -1.67 BMI z-score -0.21

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weight, despite calorie intake below DRI for age. He was also receiving feeding therapy with an experienced SLP, but progress with table foods and purees had been slow. SP was taking tastes of pureed food one time per day, but his parents reported that it was a struggle. He underwent a video fluoroscopic swallow study (VFSS) and was cleared to take nectar-thick
liquids. Hypoglycemia was a persistent issue for SP. His family was advised to add cornstarch to his feeds by the endocrinologist, and began putting cornstarch in his tube feeding at 3 months of age to regulate his glycemic control.

The RDN recommended a trial of a BTF diet with a commercial product by bolus via G-tube, initially with small volumes (15-30 mLs) two times per day, with corresponding decreases in his carbohydrate supplement for BG control. Over the next nine months, SP transitioned to bolus feeds of commercial BTF five times per day. BTF were initiated by bolus feeding at 30 ml/feeding and gradually increased to a goal of 120 ml/feeding. His G-tube feeding regimen also included some hydrolyzed formula, oatmeal, chocolate milk, cornstarch, and a soluble fiber supplement to further help with BG control and regulation. He received a continuous nighttime feeding of skim milk, cornstarch, and a soluble fiber supplement. This regimen provided a total of 1434 cal (98 cal/kg), 35g protein (2.4 g/kg), 1076 mL free fluid. SP was also noted to make progress with oral feedings, as he was taking up to 2.5 oz of jarred baby food purees per mealtime.

By 33 months old, SP was taking three meals of pureed foods orally per day or was consuming a commercial BTF formula orally as meal replacement. He continued to receive his continuous overnight G-tube feeding to help with blood glucose regulation (skim milk, cornstarch and soluble fiber supplement). He also received a 160 mL G-tube feeding in the morning (chocolate milk, water, oatmeal, cornstarch and a soluble fiber supplement). His regimen of oral feeding, one bolus G-tube feeding and an overnight G-tube feeding provided 1100 mL fluid, 950-1000 calories (56-60 cal/kg), 32-35g protein (1.9-2.1 g/kg). He continued to progress with the variety and textures of table foods that he was willing to eat. At 4 ½ years old (53 months), SP started school. He was initially G-tube fed at school twice per day but was able to transition to oral meals and snacks without G-tube supplementation during the day.

Table 2 provides an overview of SP's time on enteral nutrition

Discussion:

Both patients successfully transitioned to oral diets, inclusive of a wide variety of foods and textures. TG was able to successfully wean to 100% oral feedings without use of his G-tube to meet his estimated energy, nutrient and hydration needs. SP was able to transition to three meals and two

Table 2: SP Timeline

Date	Significant Event	Nutritional Information	Growth Parameters
< age 12 months	27 kcal/oz partially hydrolyzed infant formula, persistent emesis, transitioned to extensively hydrolyzed infant formula		N/A
Age 12 months	Transitioned to pediatric peptide-based formula, symptoms of gas, GI upset, and bloody stools. Transitioned to a ready-to-feed amino acid-based formula; symptoms persist	942 mL 933 kcal (73 kcal/kg) 17.3 g protein (1.36 g/kg)	N/A
Age 16 months	Begun trialing commercial BTF with nutritional variety		Weight z-score +1.64 Length z-score + 3.18 Weight/length z-score +0.24
Age 26 months	Diet plan consists of commercial BTF with nutritional variety 5x/d, formula, oatmeal, chocolate milk, and soluble fiber supplement. Improvement in oral intake, decrease in oral aversion	1076 mL 1434 kcal (98 kcal/kg) 35 g protein (2.4 g/kg)	Weight z-score +1.85 Height z-score +2.34 BMI z-score +0.46
Age 33 months	Progressed to three oral meals/d with pureed foods or consuming commercial BTF with nutritional variety. One bolus feeding/d	1100 mL 950-1000 kcal (56-60 kcal/kg) 35 g protein (2.1 g/kg)	Weight z-score -0.06 Height z-score +2.74 BMI z-score -0.29
Age 53 months (4 years, 5 months)	Started school, transitioned to full oral feedings		Weight z-score +1.55 Height z-score +1.97 BMI z-score +0.72

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snacks per day orally which provided 75% of his daily estimated caloric needs, with supplemental nocturnal G-tube feedings and a bolus feeding in the morning before school providing the other 25% of calories and to maintain glycemic control.

In both cases, the overarching treatment goal was to decrease tube dependence, normalize the feeding experience, and allow for enjoyment of family meals and activities surrounding food. Goals were achieved due to parental motivation, a blenderized tube feeding diet which decreased vomiting and reflux, intensive feeding therapy, a significant and monitored decrease in caloric provision from tube feeding, and an interdisciplinary approach. Both patients were seen by the SLP weekly with a focus on increasing oral-motor skills and acceptance of a variety of tastes and textures. Frequent communication between sessions with the RDN occurred to discuss progress and update the RDN on skills. During co-treated sessions, the RDN, SLP, and family would discuss caloric goals, family food goals, and strategies to adjust foods to meet these goals to fit the child's current oral-motor skills. As the RDN began to reduce the number of sessions needed, the SLP continued to treat the child weekly, verifying the oral motor skills continued to develop and progress. Consultation and additional support was provided by occupational therapy and pediatric medical specialists including gastroenterology, otolaryngology (ENT), and endocrinology as appropriate. Both patients also transitioned from an elemental or semi-elemental formula to a blenderized tube feeding diet prior to starting any tube weaning and prior to progressing with their oral intake.

Diet is a contributor to the health of the gut microbiota.[10] Further, nutritional variety is positively correlated with gut bacteria diversity.[10] The health of the gastrointestinal system, and therefore gut microbiota, is an interesting concept when evaluating the impact of BTF. Gallagher et al. reported positive changes to the gut microbiota in pediatric patients who were changed from formula to blenderized diets.[10] Interestingly, one of the patients in this case series had reduced intolerance symptoms and eventual independence from his feeding tube once switched to a commercial BTF product with variety from a commercial BTF product without variety. This finding could point to the importance of nutritional variety and coalescence between overall health and the gut microbiota.

The concept of nutritional completeness is a significant concern of clinicians working with tube-fed patients, which may be a barrier to prescribing BTF. Interestingly, literature has demonstrated equal or greater micronutrient content amongst BTF, with the exception of vitamin D, from a variety of foods with no supplement added when compared to formula.[10,11] Additionally, formulas described as being nutritionally complete have led to micronutrient deficiencies, which reinforces the belief that micronutrient needs should be tailored to the individual patient and closely monitored by the RDN.[14]

Conclusion:

As progress occurs in a stepwise fashion, it proved an effective strategy to transition the tube-fed children presented in these case studies from a commercial formula to a commercial BTF prior to the initiation of a tube wean. It normalized the feeding experience and potentially reduced the impact of adverse GI side effects experienced from tube feeding to decrease oral aversion. These case studies have demonstrated that children can have adequate growth on a BTF, and have demonstrated improved progress with oral intake on such an approach. It is important to be mindful of the endpoint when a child is started on a tube feed.

For most children, tube feeding should be a temporary part of their medical care along the path to overall growth and development, including the development of age-appropriate self-feeding skills and eventual tube weaning. A team approach is essential to safely wean children from tube feed regimens in order to take all aspects of the child's health and wellness into account. These aspects include the acquisition of adequate oral-motor skills through a trained speech or occupational therapist, the ability to meet the nutritional demands of growth independent of the tube as assessed and managed by a skilled dietitian, and the stability of the child's medical status directed by a physician. Additionally, the social-emotional impact of tube feeding reliance and potential parental stress plays an essential role in the success of the wean, thus necessitating attention to mental health and well-being of the parent and the child. Overcoming tube dependence with an interdisciplinary approach is ultimately the key to success for children ready to wean from feeding tubes.

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From the Editor:

We are now coming up on almost a year of living in a pandemic. The coronavirus has changed the way we live and the way we practice as a profession. As I was putting together this issue, I realized how fortunate I am to be working with pediatric dietitians who are so dedicated to their practice, that they volunteered their time to contribute to the *Building Blocks for Life* during this global crisis. All of these articles were written during a global pandemic- amid added stress and uncertainty. We would like to thank all of the authors, and the *BBFL* associate editors for their time and dedication in writing and editing these very important pieces. We are humbled to be working with professionals so dedicated to their field.

We are proud to bring you this issue which covers relevant clinical topics- including eosinophilic esophagitis (EoE), caring for children with medical complexity during a global pandemic, and case studies utilizing blenderized tube feeds as a tool to assist in weaning tube fed dependent children to an oral diet. The EoE article reviews the disease, including diagnostics and management and then reviews two case studies. The article on caring for children with medical complexity during a global pandemic describes challenges in providing MNT to children during the coronavirus pandemic, and offers solutions to some of the challenges experienced by the authors. Our third article describes the use of blenderized tube feedings, and how they can be used to wean children who are dependent on tube feedings.

We would like to acknowledge that our CPEs were on hold, however it is our plan to resume CPEU offerings in the upcoming Winter or Spring Issue. We will continue to bring those valued CPEUs to our readers!

Additionally, we are always looking for new and interesting pieces written by PNPG members. We are especially interested in sharing your experience or research on pediatrics and COVID-19. This could be a piece showcasing case studies illustrating management of pediatrics with COVID-19, or how your practice has changed during the pandemic. We know this past year has required a lot of us to have to think outside of the box- we would love to feature your article. Please email the BBFL editorial team if you are interested in submitting content at pnpgbbfl@gmail.com. We are looking forward to hearing from you.

We hope you enjoy this issue of *Building Blocks for Life* – Happy Reading!

Amy Gelfand, MS, RDN, CNSC
Editor, Building Blocks for Life

Editor's Notes

LOOKING AHEAD TO THE NEXT ISSUE OF *BUILDING BLOCK FOR LIFE*

Volume 43, No. 4 We have exciting topics in line for the Winter edition of BBFL! Upcoming article topics include food insecurity, infant feeding choices, and a piece on cystic fibrosis.

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Dan Frazier is a Business Development Manager with Real Food Blends. The article was written as part of his normal employment. None of the patients received product that was paid for by the company.

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