



**Editor's Note:** Look out for the next issue where we will feature Dr. Patrick Sosnay, from the Johns Hopkins Cystic Fibrosis Center. Dr. Sosnay will review the importance of CFTR and what it tells us about lung disease.



### eCysticFibrosis Review VOLUME 4, ISSUE 9

## Behavioral treatment to improve dietary adherence and weight gain in children with cystic fibrosis

### In this Issue...

Despite the importance of nutrition to health and survival in patients with cystic fibrosis (CF), most children with CF are unable to achieve the 120% to 150% recommended daily intake of energy estimated as necessary to promote optimal nutritional status. Families of children with CF report dietary recommendations are one of the most difficult aspects of CF treatment, with most studies reporting that only 16% to 25% of children achieve the recommended energy intake. Parental barriers to dietary adherence for children with CF include lack of knowledge about dietary recommendations, caloric value of food, and effectively managing child behaviors during meals.

In this issue, we review recent studies that:

- Compare the results of behavior plus nutrition intervention to nutrition education alone on caloric intake and weight gain for children ages 4 to 12 years
- Compare behavior plus nutrition and nutrition alone interventions to standard nutritional care as delivered in the clinical setting for children ages 4 to 12 years
- Describe the effects of implementing a standardized nutrition classification system
- Explore the barriers to sustaining treatment improvement to dietary adherence as children with CF transition from toddlerhood to early school age
- Describe a web-based quality improvement approach to maintaining and measuring the effects of a nutrition education intervention

#### Program Information

- [CME/CE Info](#)
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#### Length of Activity

- 1 hour Physicians
- 1 contact hour Nurses

#### Release Date

December 19, 2013

#### Expiration Date

December 18, 2015

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**After participating in this activity, the participant will demonstrate the ability to:**

- Describe the components of a behavioral intervention to improve caloric intake and weight gain in children with cystic fibrosis
- Explain how to incorporate behavioral elements to make nutritional education alone more effective in improving caloric intake and weight gain over standard practice dietary counseling
- Describe how to use a standardized nutritional assessment and intervention algorithm to improve nutritional status in children with cystic fibrosis as part of ongoing clinical care

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Based on a review of the current literature, including national and regional measures, detailed conversations with expert educators at Johns Hopkins, and a survey of potential program participants, this program will address the following core patient care gaps:

**Disease-Modifying Therapies**

- Clinicians may be unfamiliar with recently introduced disease-modifying therapies and how

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they are altering the therapeutic landscape for patients with cystic fibrosis.

- Clinicians may be uncertain how to integrate genotyping into therapeutic decisions and how to communicate with patients and families about the relationship between genotype and therapy

#### **Nutrition**

- Many clinicians lack strategies to persuade patients to adhere to CF nutritional requirements, resulting in low body weight and nutritional failure in patients with cystic fibrosis.
- Many clinicians remain uncertain how to optimize pancreatic function in patients with cystic fibrosis.

#### **Treating CF Patients with Inhaled Antibiotics**

- Clinicians lack knowledge about the use of existing and emerging inhaled ABX to treat chronic pulmonary infections.
- Clinicians need more information to make informed decisions about the use of inhaled ABX in combination.
- Clinicians lack information about best practices for scheduling ABX therapy to suppress chronic airway infections.
- Common clinician assumptions about treating pulmonary exacerbations lack supporting evidence.
- CF clinicians are not aware of and/or are not actively advocating inhaled ABX patient-adherence strategies.

Johns Hopkins University School of Medicine  
Office of Continuing Medical Education  
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#### Planning Committee

#### **Michael P. Boyle, MD, FCCP**

Associate Professor of Medicine  
Director, Adult Cystic Fibrosis Program  
The Johns Hopkins University  
Baltimore, MD

#### **Peter J. Mogayzel, Jr., MD, PhD**

Professor of Pediatrics  
Director, Cystic Fibrosis Center  
The Johns Hopkins University  
Baltimore, MD

#### **Donna W. Peeler, RN, BSN**

Pediatric Clinical Coordinator  
Cystic Fibrosis Center  
The Johns Hopkins University  
Baltimore, MD

#### **Meghan Ramsay, MS, CRNP**

Adult Clinical Coordinator  
Cystic Fibrosis Center  
The Johns Hopkins University  
Baltimore, MD

## GUEST AUTHOR OF THE MONTH

#### Commentary & Reviews:

#### **Lori J. Stark, PhD, ABPP**

Professor of Pediatrics  
Director, Division of Behavioral  
Medicine and Clinical  
Psychology  
Cincinnati Children's Hospital  
Medical Center  
University of Cincinnati College  
of Medicine  
Cincinnati, Ohio



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Nutritional status is an important aspect of health in children with cystic fibrosis (CF). Achieving normal growth, defined as being at or above the 50<sup>th</sup> percentile for body mass index (BMI) weight for age and gender, is associated with better lung functioning as measured by forced expiratory volume in 1 second (FEV<sub>1</sub>).<sup>1</sup> Several factors compromise normal growth in children with CF, including fat malabsorption, chronic lung infections, and possibly increased resting energy expenditure. To offset these factors it is recommended that patients consume 120% to 150% of the recommended daily allowance (RDI) for energy, with 35% to 40% coming from fat. While great strides have been made overall in improving their nutritional status, 40% to 50% of children with CF ages 2 to 12 years remain below the 50<sup>th</sup> percentile BMI,<sup>2</sup> and few children (16% to 23%) can achieve the CF dietary recommendations.<sup>3-5</sup>

Studies have found that parents of children with CF report inadequate knowledge about nutrition in CF, including knowing which foods are higher in calories, how to boost calories in foods, and the importance of offering snacks.<sup>6</sup> Parent reports<sup>7</sup> as well as observational studies<sup>5,8,9</sup> have found that children with CF engage in challenging mealtime behaviors that are incompatible with adequate eating, including long meals (> 20 minutes) and dawdling, more than do children without CF. Parents of children with CF were also found to engage in less effective strategies to encourage eating than parents of children without CF, including giving more commands to eat, coaxing, feeding the child, and using physical prompts. A recent meta-analysis reported that across 10 studies of children with CF aged 18.6 months to 8.5 years, families of children with CF encountered more difficulties during mealtimes than families of children without CF, and these difficulties were associated with negative effects on overall family functioning.<sup>10</sup>

As reviewed in this issue, a randomized controlled clinical trial (RCT) by Stark et al demonstrated that over a nine-week intervention, teaching parents behavior management strategies to address these challenging child mealtime behaviors was more effective for immediate effect than teaching nutritional information alone to increase caloric intake and weight gain in children with CF. These strategies included teaching parents to attend to positive eating such as taking bites, chewing, and swallowing quickly during meals and ignoring child behaviors that were incompatible with eating such as dawdling, talking instead of eating, and complaints about food. Parents were also taught to provide privileges to their children for meeting specific calorie goals at meals and across the day. Children in the behavior intervention (BI) group achieved 149% of estimated energy requirement (EER) pre- to post-treatment and maintained 120% at the two-year followup, with no boosters over the post-treatment period. The nutrition-only arm of this trial also improved their caloric intake, achieving 129% EER, and weight pre- to posttreatment. At the two-year follow-up, both groups were at 120% EER and had attained similar nutritional status as measured by BMI z-scores, meaning, outcomes for children in both groups were better than at baseline.

The second study described in this review demonstrated that both behavioral plus nutrition education (BI) and nutrition education (NE) alone interventions led to better BMI z-scores than those attained by children receiving standard-of-care dietary counseling over the same 27-month period. Of particular note is the authors' hypothesis that the nutrition education alone (NE) arm of the initial RCT was more effective than standard care because it included behavioral elements. Parents were required to monitor their child's food and calorie intake daily throughout the treatment. They were given a calorie goal, which was then divided across snack and three meals into smaller weekly calorie goals. In addition to being given general nutrition information about high calorie foods, parents kept diet diaries were used to individualize the recommended boosters for increasing the caloric value of foods served and alternative foods. Parents were also given graphs of their child's caloric intake every week, compared to the weekly goal and the child's baseline caloric intake. In this way, parents (in the NE arm as opposed to standard care) could see the progress they were making toward the dietary goals and also had a "stopping point" in feeding their child.

The qualitative study by Filigno and colleagues showed that booster sessions may be needed for families of children with CF after behavioral intervention when children have developmental transitions (like starting school for the first time or receiving a second medical diagnosis that complicates their dietary recommendations). In this study, parents

reported retaining information about nutritional recommendations and use of behavioral strategies but could not always implement them because of new diagnoses, transition of responsibility for nutritional care of the child because of school attendance, and the ongoing stress of parenting a child with CF.

The two quality-improvement studies reviewed in this issue highlight the difference between passive nutritional education used by McDonald and colleagues and an active approach. Leonard and colleagues developed a classification system that identified and targeted children who were classified as less than "optimal" and provided evidence-based interventions including behavioral treatment, to these children. The investigators demonstrated that routine assessment of nutritional status can be accomplished in the context of a busy clinic and that behavioral treatment can be included in the treatment algorithm; they further showed that by adopting and following a standardized algorithm for all children below the 50<sup>th</sup> percentile BMI, they could raise the average BMI percentile across these patients by a full 19%. This study also demonstrated that intervening early and not waiting until children were in "failure" may be the best approach, as children in the "at risk" and "concerning" categories improved and could be moved into "acceptable" and "optimal" classifications.

**The studies reviewed in this issue suggest that the nutritional status of children with CF can be improved if weight status is systematically classified and targeted interventions are applied early.** Further, while behavioral treatment for child mealtime behaviors is effective in the short-term, taking a behavioral approach to nutritional intervention — where caloric goals are established and worked toward in a step-by-step manner — may be an alternative approach when a pediatric psychologist is not available to the CF Care Team. Many diet tracking applications are now available for smartphones that could make keeping a diet record easy and convenient for families of children with CF and allow the sharing of data with the CF Center dietitian, thereby making this a more feasible approach to helping families monitor and achieve the CF dietary recommendations.

#### Commentary References

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## TRIALING BEHAVIORAL AND NUTRITIONAL INTERVENTIONS

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Stark LJ, Quittner AL, Powers SW, et al. Randomized Clinical Trial of Behavioral Intervention and Nutrition Education to Improve Caloric Intake and Weight in Children With Cystic Fibrosis. *Arch Pediatr Adolesc Med.* 2009;163(10):915-921.

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This randomized control trial tested the efficacy of a behavioral plus nutrition education intervention (BI) compared to nutrition education alone (NE). Seventy-nine children with CF ages 4 to 12 years, who were below the 40th percentile weight for age, and their families were recruited from 5 CF Centers and randomized to treatment. Sixty-seven children completed the intervention. Children were excluded if they were on medication that would affect growth or appetite, receiving enteral or parenteral nutrition, had *Burkholderia cepacia* infection, had an FEV<sub>1</sub> < 40 percent of predicted, had diabetes, or had a developmental or mental health diagnosis of depression or psychosis. Outcome measures were change in calorie intake as measured by a weighted seven-day food diary and weight pre- to post-treatment. Children were then followed every six months for 24 months post-treatment.

Both intervention groups received seven treatment sessions over a nine-week period. In the BI group, parents received both nutritional information and child behavior management strategies to motivate children to meet their CF dietary recommendations and to manage food refusal and oppositional behavior at meals. These strategies included praising and attending to positive eating, ignoring dawdling and food complaints, using rewards for meeting calorie goals at meals, and setting time limits for meals (20 min). The nutritional education component set a calorie goal of an increase of 1,000 calories a day over baseline to be achieved by the end of treatment. This goal was then divided across snack, breakfast, lunch, and dinner. In this way, families were only working on increasing calories one meal at a time, had definitive goals, and learned a child behavior management strategy that helped them achieve the calorie goal. At each treatment session parents were provided a graph of their child's calorie intake showing progress against the weekly goal as well as a comparison to their child's baseline calorie intake. Children were also seen weekly and given practice meals where child behavior management strategies were used *in vivo* to encourage appropriate eating. Children were also given trophies at each session if they met their calorie goals at home across the week between sessions. In the NE group parents were given the same nutrition education as the BI group (described above) but were not provided training in child behavior management. Children were given a practice meal but were not encouraged to consume it and were given trophies just for showing up at the treatment session.

The study found that children in the BI group increased their caloric intake (+872 cal/day) pre- to posttreatment significantly more than children in the NE (+489 cal/day,  $P < .001$ ) and gained significantly more weight (1.47 kg compared to 0.92kg,  $P < .01$ ). The children in the BI group achieved the estimated energy requirement (EER) of 148% while the NE group achieved 127% ( $P < .001$ ). At the 24 month follow-up both groups were at 120% EER and 20% above their baseline calorie intake — they were no longer significantly different from each other on caloric intake or weight gain.

The study replicated the findings of previous uncontrolled pilot studies of the BI intervention in terms of the improvements in caloric intake and weight gain pre- to posttreatment, as well as maintenance of these gains at followup. The authors concluded that the BI was more effective than NE in achieving improvements over a short-term, while both were successful in maintaining gains over the 24 months following treatment. The surprising aspect of the study was the improvement in caloric intake and weight gain for the NE group. Even though the gains were not as great as the BI group pre- to posttreatment, the children in the NE group improved their caloric intake and weight gain over the nine weeks of treatment, whereas previous studies had not found a change in either as a result of education only. The authors hypothesize that the design of NE in the current study differed in important ways from nutrition education in other studies as well as to typical care. Specifically, the NE group was given

caloric goals that increased each week, had parents monitor their child's intake, and provided graphs showing the changes in caloric intake. The structure and components of the NE were very behavioral and they suggest that incorporating these strategies into standard nutritional care may improve efficacy even if a pediatric psychologist is not available to assist with child mealtime problems.

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## BEHAVIORAL AND NUTRITIONAL INTERVENTIONS VS STANDARD CARE

Stark LJ, Opiari-Arrigan L, Quittner AL, Bean J, Powers SW. The effects of an intensive behavior and nutrition intervention compared to standard of care on weight outcomes in CF. *Pediatr Pulmonol.* 2011 Jan;46(1):31-35.

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The authors of this study sought to understand how the children receiving either the behavioral intervention (BI) or the nutrition education (NE) alone compared on nutritional status as assessed by BMI z-score to children receiving "standard care" for nutrition during the same 27-month time period. The comparison sample of "standard care" was drawn from the CF Patient Registry. Children of the same age and gender, meeting the same inclusion/exclusion criteria, and from CF Centers of similar size, geographic region, and academic affiliation as the children enrolled in the RCT were targeted at a ratio of five patients for every one in the RCT. The comparison sample yielded 355 children with 1,701 clinical data collections of weight and height. The children in the BI and NE were combined to yield 67 participants from the RCT. This study also looked at pulmonary function as measured by FEV<sub>1</sub>.

The results indicated that the children in the RCT and comparison group were comparable at the initial assessment point; the RCT group had a BMI z-score of -0.63 and the comparison sample had a BMI z-score of -0.47. However, the RCT group showed less decline in BMI z-score over the 27 month period (-0.05) than children in the comparison sample (-0.21,  $P < .0001$ ). While the two groups did not statistically differ on FEV<sub>1</sub>, the children in the comparison sample had a decrease of 3.25% while the children in the RCT had an average decline of only 1.21%.

The authors concluded that intensive, weekly intervention that focuses on increasing caloric intake in a systematic manner that includes setting an overall caloric goal; breaking the overall caloric goal into smaller, achievable weekly goals; having parents track caloric intake; providing graphic feedback; and giving tailored, individualized nutritional recommendations based on the parent diet tracking (whether or not behavioral child management was offered) was more effective than the way nutritional counseling was being offered as part of standard care during the same time period. The authors further suggest that offering nutritional intervention in a more intensive and structured manner may improve growth outcomes.

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## BARRIERS TO MAINTAINING TREATMENT GAINS FIVE YEARS POSTTREATMENT

Filigno SS, Brannon EE, Chamberlin LA, Sullivan SM, Barnett KA, Powers SW. Qualitative analysis of parent experiences with achieving cystic fibrosis nutrition recommendations. *J Cyst Fibros.* 2012 Mar;11(2):125-130.

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This 2012 study provides a qualitative analysis of barriers to maintaining treatment gains five years post-treatment for eight of the 10 families of a child with CF who completed the behavior plus nutrition treatment. The children had received the intervention at an average age of



2.8 years. The children overall had demonstrated increases in weight-for-age z-scores and caloric intake that was maintained through a two-year follow-up, but declined between years 2 and 4.

Semistructured interviews were conducted to understand parents' experience of the behavioral intervention and the challenges they experienced between the transition from toddlerhood (age at end of study) to early school-age (age at four-year follow-up). All interviews with families were recorded and later coded for themes by three trained coders.

Four main themes emerged: 1) parent recall of strategies taught in the behavioral interventions (BI), 2) ongoing challenges, 3) new challenges, and 4) protective factors. Parents demonstrated solid recall of nutritional recommendations, including how to boost the caloric value of food using addables and spreadables, shopping for high-calorie foods, offering high-calorie beverages, and offering snacks to increase daily calories. Parents recalled how to use positive reinforcement and contingent privileges and to provide attention to positive eating behaviors. Half the families interviewed reported being able to adapt the behavior management strategies to new situations and incorporate new rewards for eating. Ongoing challenges reported by parents included parental stress specifically about parenting of a child with CF, the uncertain course of the disease, and continued feelings of pressure to ensure their child with CF ate. Picky eating by the child continued to be a challenge, as well as child noncompliance to eating and taking enzymes. New challenges included new diagnoses such as CFRD and ADHD; the transition to children taking greater responsibility for their own care; and the transition to school, where parents had less control over the types and portion sizes of food served. Families also reported several "protective factors" such as good communication with the CF care team, being able to ask the CF team for assistance, and eating family dinners together.

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## OUTCOMES OF A STANDARDIZED NUTRITION CLASSIFICATION PLAN

Leonard A, Davis E, Rosenstein BJ, et al. Description of a standardized nutrition classification plan and its relation to nutritional outcomes in children with cystic fibrosis. *J Pediatr Psychol*. 2010 Jan-Feb;35(1):6-13.

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This quality improvement study examined the systematic application of a standardized nutritional assessment and intervention protocol that included behavioral intervention on improving the nutritional status of patients below the 50<sup>th</sup> percentile of body mass index (BMI) for age and gender. Participants were 2 to 21 years of age and seen in the John Hopkins CF Center.

A standardized nutritional assessment and intervention algorithm was established that classified patients with CF into nutrition classification, designated as: (a) nutrition failure, (b) at risk, (c) concerning, (d) acceptable, or (e) optimal. Interventions aimed at maximizing caloric intake, optimizing nutrient absorption, and diagnosing and treating CFRD were implemented with patients falling within the "acceptable" classification or lower.

Interventions were tailored to individual patient needs and included increasing caloric intake by increased frequency of meals/snacks, use of high calorie foods/additives, use of supplements, and referral to a pediatric psychologist for behavioral intervention as needed to address child behaviors that posed barriers to implementing nutrition suggestions. Addressing absorption issues, including appropriate administration and timing of enzymes as well as assessing the child's ability to swallow pills, and referrals to gastroenterology if there was no weight gain after caloric intake and absorption had been optimized. Routine assessment was conducted for premonitory symptoms of CFRD, and a diagnostic evaluation was done if casual blood glucose values were abnormal and/or if caloric intake and absorption had been optimized without achieving any weight gain. Behavioral Intervention was initiated when concerns about child behavior, parent-child interactions at mealtime, family functioning or psychosocial stressors were identified. The behavioral strategies employed followed the child behavior management strategies described in the RTC trial reviewed above.





During the time of data collection 247 children received a nutritional assessment and 213 had at least 2 study visits. The average age of the patients seen was 12.4 years with equal distribution of males and females. The average BMI percentile for these 213 children increased from the 35.2 percentile to the 42 percentile during the study period ( $P < .005$ ), a 19% increase. In addition, the percentage of patients who were classified as "acceptable" or "optimal" increased from 61.5% to 70.4%.

The authors concluded that by taking a standardized approach to classifying the nutritional status of all patients and then systematically intervening to improve nutritional status, especially for children in the "concerning" and "at risk" categories, is an effective approach that can be implemented on a clinic-wide basis. In addition, they emphasized the importance of the behavioral intervention to identifying and overcoming barriers to increased caloric intake.

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## EMPOWERING PARENTS

McDonald CM, Haberman D, Brown N. Self-efficacy: Empowering parents of children with cystic fibrosis. *J Cyst Fibros*. 2012 Dec 24. pii: S1569-1993(12)00233-0.



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This quality-improvement study developed a website for parents of children with CF based on parent input of educational strategies they would find helpful in managing CF, with a particular focus on nutritional management. Using a Parent Advisory Council, the investigators developed the website to give parents reliable, positive, and current CF information and to promote parent self-efficacy in managing CF. The website posted a "CF Nutrition Tip of the Week" and emailed it out as a weekly newsletter. Over two years the site expanded to include other aspects of CF management and included a Facebook page that allowed parents to share recipes, personal stories, and management tips. Outcomes included parent nutrition knowledge and confidence in CF management as measured by the Mountain West CF Consortium Questionnaire (MWCFCQ) and the average body mass index (BMI) percentile of the Intermountain CF Center.

Although parent confidence in their daily management of CF nutrition increased, their knowledge of the nutritional content of foods did not increase, and the average BMI percentile achieved within their center only increased 2.5 percentile points (from the 41.6 percentile to the 44.1 percentile BMI) over 4 years.

The authors concluded that confidence in managing nutritional concerns may not translate to actions that achieve optimal growth or nutrition in children with CF. Changing nutritional outcomes appear to require more specifically targeted intervention.

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