



## eCysticFibrosis Review Volume 3 Issue 9

### Interventions to Improve Nutrition in Patients With Cystic Fibrosis



#### In this Issue...

Nutritional status has long been identified as a strong predictor of outcomes in patients with cystic fibrosis (CF) and has been the focus of many quality improvement efforts in CF care. Many factors contribute to high caloric demands in patients with CF, including inefficiencies in digestion and absorption of nutrients, increased work of breathing, and a chronic inflammatory state. The high number of daily calories required to maintain nutritional goals adds to the burden of care for both patients and their families. Behavioral challenges pose additional obstacles to attaining nutritional goals, particularly in toddlers and young children, as such difficulties interfere with eating the required amount per meal and the number of meals per day, as well as with medication compliance. Later in adolescence, body image issues may affect teenagers' desire to accept and to strive for the higher body mass index goals recommended by their health care providers.

In this issue, we review new research highlighting the strong positive impact of early behavioral and nutritional education; explore predictors of long-term response to such interventions; discuss how body image may affect compliance with nutritional recommendations in adolescents; and present data describing positive outcomes with gastrostomy tube placement for supplemental enteral intake.

### LEARNING OBJECTIVES

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

- Explain the benefits of early intensive behavioral and nutritional counseling on long-term nutritional goals in patients with cystic fibrosis (CF)
- Identify risk factors for poor compliance with nutritional goals, and the value of early behavioral, psychological, and nutritional counseling interventions, among patients with CF
- Discuss the benefits of gastrostomy tube for enteral nutritional supplementation

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#### Release Date

April 26, 2012

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## COMMENTARY

Nutritional status is a key predictor of survival and outcomes among individuals with cystic fibrosis (CF).<sup>1-3</sup> High-calorie, high-fat diets are recommended for patients with CF, with the goal being to achieve a body mass index (BMI) > 50th percentile for age and sex, which has been associated with improved pulmonary function.<sup>4</sup> Achieving and maintaining this nutritional goal can be challenging, however. Poor appetite, early satiety, abdominal pain, and bloating all interfere with adequate calorie intake in individuals with CF. Digestion and absorption of ingested nutrients are dependent on timely dosing of supplementary pancreatic enzymes. In addition to these digestive difficulties, patients with CF face increased metabolic demands that require higher caloric intake compared with their healthy counterparts to achieve timely growth. Interventions that target and ameliorate these obstacles are needed to facilitate attaining and maintaining nutritional goals.



Problem behaviors that begin in toddlerhood can interfere with adequate calorie consumption to support growth. “Picky eating” habits can have a significant adverse effect on the nutritional status of children with CF because of their high metabolic demands. For this reason, behavioral interventions for improving caloric intake and nutritional status among children with CF have been investigated over the past two decades. Whether behavioral interventions were superior to nutritional education alone in achieving improvements in caloric intake and nutritional status was examined by Stark and coworkers in a 2009 study.<sup>5</sup> Children who participated in the behavioral intervention experienced higher caloric intake and weight gain at the conclusion of the study than did those in the nutritional education group. Two years after the intervention, however, children in both groups had similar anthropometric measures and averaged 120% of the daily estimated energy requirements. What was not apparent from this study was how children who received neither behavioral intervention nor nutritional education fared over time in terms of nutritional status and meeting caloric intake goals. The 2011 study by Stark and colleagues, presented in this issue, was conducted using data from the first clinical trial to evaluate the effect of behavioral and nutritional interventions in children with CF versus standard of care in a comparator group from the US Cystic Fibrosis Foundation (CFF) Patient Registry who had received no standardized nutritional or behavioral interventions during the study period. This follow-up analysis provides us with the evidence needed to support implementation of these time- and resource-intensive interventions in clinical care.

Recognizing the fact that behavioral and nutritional education interventions can be difficult to implement across the board in all CF centers, Opiari-Arrigan and collaborators (reviewed in this issue) conducted surveys of the parents of patients as part of the 2009 Stark clinical trial<sup>5</sup> to identify factors associated with improved outcomes from the behavior and nutritional interventions. Importantly, the surveys assessed not only factors specific to the child, but also parental attitudes and maternal depressive symptoms as possible contributors or detractors to successful outcomes. The main finding from this study was that mealtime behavioral problems in children were predictive of poor outcomes from the behavioral and nutritional interventions. Rather than not enrolling these patients in such interventions, however, early referral to behavioral intervention—that is, intervening before mealtime problems actually develop—is supported by the data. Indeed, early attention to parenting skills in CF families would likely improve long-term outcomes, not only in terms of nutritional status, but also in terms of compliance with medication regimens and respiratory therapies.

The challenges involved in meeting nutritional goals do not end in childhood. Adolescents and young adults are particularly at risk for declining nutritional status, as damage to their organs progresses. A rapid decline in BMI Z-score during adolescence is associated with a greater decline in forced expiratory volume in 1 second (FEV<sub>1</sub>) during early adulthood.<sup>6</sup> Both nutritional status and FEV<sub>1</sub> are strong, independent predictors of survival in persons with CF.<sup>2,3</sup> Simon and colleagues (reviewed in this issue) demonstrate that in their study nearly 45% of adolescent girls with CF were dissatisfied with their body size and desired a thinner figure, even when their current BMI was less than the guideline recommendations. Although eating disorders have not been identified at higher rates in adolescents with CF,<sup>7-9</sup> the societal ideal body image internalized by these patients is clearly less than what has been determined to be optimal for best outcomes in CF. As a result, without necessarily meeting formal criteria for eating disorders, many adolescents with CF, particularly females, are at increased risk for disordered eating behaviors in their attempts to maintain a weight that does not meet established nutritional recommendations.<sup>7-9</sup> Identifying these restrictive patterns by care providers is important for helping to guide effective interventions. Additional research is needed to develop adequate interventions to meet and maintain BMI goals in the adolescent age group.

Gastrostomy tube placement for supplemental feeding is occasionally used as a means of meeting BMI recommendations in individuals with CF. Patients and their families are generally not interested in establishing a stable enteral feeding route.<sup>10</sup> A greater awareness of the possible benefits of a gastrostomy tube for supplemental enteral feeds might change these attitudes, however. Evidence from two recent studies on the benefits of gastrostomy tube placement in patients with CF is reviewed in this issue. According to Best and associates, on average, gastrostomy tube placement results in improvements in BMI and stabilization of lung function, as measured by percent predicted FEV<sub>1</sub>. Bradley and colleagues found that children at their institution who received gastrostomy tubes for

supplemental nutrition were significantly more likely to have improvements in BMI Z-scores six months after tube placement than were matched CF controls from the CFF Patient Registry ( $P < .001$ ). However, this difference was no longer significant at one year post-placement. Previous small, nonrandomized trials have also shown improved BMIs after placement of gastrostomy tubes for supplemental enteral feeds.<sup>11,12</sup> No randomized clinical trials, however, have evaluated the efficacy of gastrostomy tube placement for supplemental enteral feeds. Further, there is no standardized regimen for supplementing enteral intake. Placement of a gastrostomy tube alone is not sufficient to attain desired nutritional goals, as it must be matched with consistent use of an appropriate formula in adequate amounts to make a difference. Further research in this area is warranted.

### Commentary References

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## EFFECTIVENESS OF BEHAVIORAL AND NUTRITIONAL INTERVENTIONS VS STANDARD CARE IN CHILDREN WITH CYSTIC FIBROSIS

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;1;46(1):31-35.

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This study examined two-year outcomes among children with CF who participated in a behavioral plus nutritional education intervention versus those from the CFF Registry who received standard of care. The subjects and comparators were 4 to 12 years of age, had a CF diagnosis confirmed by a sweat test, had pancreatic insufficiency, and were under the 40th percentile for weight for age and gender, or less than 40% weight for height. This is a



subsequent analysis of a clinical trial reported in 2009 by Stark and colleagues.<sup>1</sup> Findings from the original trial indicated that children who had undergone either a behavioral plus nutritional education intervention or a nutritional education intervention alone benefited from the interventions, with weight gain and increased daily energy intake that continued through the two years of follow-up. In the original trial, however, all patients received some form of intervention—either the behavioral plus nutritional intervention or the nutritional intervention alone. Thus, in the current study, data from the original trial were compared with data gathered from age-matched CF controls in the CFF Registry who were seen in their respective CF centers during the study period and who met the same inclusion criteria as did the clinical trial participants.

The children in the clinical trial group were demographically similar to those in the CFF Registry comparator group. Two years after the intervention, clinical trial participants, on average, had BMI Z-scores that declined less than those of the comparator group. No statistically significant difference was noted in decline in FEV<sub>1</sub> percent predicted between trial participants and the CFF Registry comparator group.

The authors concluded that a short-term, intensive intervention aimed at behavior and nutrition is more efficacious than standard of care and can result in long-term improvements over the standard decline in nutritional status. Stark and associates had previously demonstrated that this nutritional intervention improves energy intake from baseline to 27 months post-intervention. The current study demonstrates that the improvements observed in the original clinical trial can be more conclusively attributed to the intervention.

## Reference

1. 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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## PREDICTORS OF SUCCESS WITH BEHAVIOR AND NUTRITIONAL INTERVENTIONS IN CHILDREN WITH CYSTIC FIBROSIS

Opipari-Arrigan L, Powers SW, Quittner AL, Stark LJ. **Mealtime problems predict outcome in clinical trial to improve nutrition in children with CF**. *Pediatr Pulmonol*. 2010;45(1):78-82.

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In a companion study to the 2009 one by Stark and colleagues,<sup>1</sup> the investigators analyzed the characteristics of parents and children before entry into the trial to see whether they could find predictors of good outcomes. The authors compared baseline nutritional status, mealtime behavior problems, and maternal depressive symptoms as pretreatment characteristics. The treatment outcomes that were evaluated included caloric intake and weight. The investigators hypothesized that fewer mealtime behavior problems and lower maternal depressive symptoms would be associated with better outcomes. A parent report instrument, the Behavioral Pediatric Feeding Assessment Scale (BPFAS), was used to measure the severity and frequency of problem behavior at mealtimes. The Center for Epidemiological Studies – Depression Scale was used to assess maternal depressive symptoms. Three-day fecal fat studies were performed at baseline and post-treatment to assess fat absorption. Hierarchical multiple regression analyses for each of the primary outcome measures (dependent variables) was conducted.

A significant predictor of change in caloric intake from baseline to post-treatment was the group assignment (intensive behavioral intervention plus nutritional education versus nutritional education alone), accounting for 17% of the variance in outcome. After adjusting for this effect, the measure of frequency of mealtime behavior problems accounted for 11% and the maternal depressive symptoms score for 6% of the variance in outcome. When analyzing predictors of weight gain after treatment, baseline weight and fat absorption both affected weight change (10% and 2%, respectively), as did treatment group assignment (9%). After



controlling for these effects, the BPFAS frequency score accounted for 6% of the variance. Maternal depressive symptoms did not affect the change in weight.

The authors concluded that less frequent mealtime behavior problems were associated with improvements in caloric intake and weight gain over the course of the nine-week clinical trial. They further concluded that because children who weighed more and had fewer mealtime behavior problems at baseline benefited the most from the intervention, early referral for behavioral and nutritional counseling is important. Interestingly, children who weighed more at baseline gained the most weight after the treatment. According to the authors, although this further supports early referral for behavioral and nutritional counseling, other genetic and environmental factors that were not assessed in this study might be adversely contributing to baseline weight and poor weight gain following the intervention. Nonetheless, the earlier the mealtime behavior problems are addressed, the less likely they are to have a negative long-term effect on nutritional status.

## Reference

1. 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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## IS POOR BODY SATISFACTION ASSOCIATED WITH INADEQUATE CALORIC INTAKE IN YOUTH WITH CYSTIC FIBROSIS?

Simon SL, Duncan CL, Horky SC, Nick TG, Castro MM, Riekert KA. **Body satisfaction, nutritional adherence, and quality of life in youth with cystic fibrosis**. *Pediatr Pulmonol*. 2011;(11):1085-1092.

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Simon and colleagues evaluated the relationship among body satisfaction, nutritional intake, and quality of life in youth (9 to 17 years of age) with CF. The authors hypothesized that female youth with a negative body image would exhibit poorer dietary compliance and quality of life. This was an observational, cross-sectional study conducted at two sites—one in rural Florida and the other in metropolitan Maryland. A total of 54 families participated in the study. The subjects completed the self-report version of the Cystic Fibrosis Questionnaire-Revised (CFQ-R) to assess the impact of CF on health-related quality of life (HRQOL). Body satisfaction was determined by having the participants identify their body figure on a nine-point black and white figure scale, followed by identifying their ideal body figure on the same scale. Patients were then categorized as treatment-consistent if they wanted to gain weight or if their BMIs were = 50th percentile and they desired to maintain their weight; treatment-inconsistent patients were those who wanted to lose weight or whose BMIs were < 50th percentile and they wanted to maintain their weight.

The majority of participants (72%) were treatment-consistent with respect to their desire to gain or maintain weight based on current BMI. Notably, 45% of females were treatment-inconsistent, compared with only 8% of males. Additionally, females were more likely than males to have lower scores on the Physical component of the HRQOL. On average, the percent of the dietary reference intake consumed by treatment-inconsistent youth was 47% less than that consumed by treatment-consistent youth. Lung function, as measured by FEV<sub>1</sub> percent predicted, was positively correlated with BMI percentile. Lung function was also positively associated with the Physical, Body Image, and Respiratory subscales of the HRQOL. Females who were treatment-inconsistent had lower Emotional HRQOL scores than did treatment-inconsistent males.

The authors concluded that body satisfaction is a significant concern in many youth with CF. In particular, they point out that females were more likely to be dissatisfied with their body and to have lower Emotional HRQOL scores. Their poor body satisfaction could thus be conflicting with the nutritional goals set by their care providers to optimize their health. Previous studies comparing body image satisfaction and nutritional status in adults with CF have shown that



except for those receiving enteral tube feedings, females desire a lower BMI than their actual BMI.<sup>1,2</sup> In contrast, male adult patients with CF generally desire a higher BMI than their actual BMI. The current study similarly demonstrates that in youth with CF, females are more likely to have a negative body image and desire a body weight that is incongruent with established nutritional goals.

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2. Abbott J, Conway S, Etherington C, et al. [Perceived body image and eating behavior in young adults with cystic fibrosis and their healthy peers](#). *J Behav Med*. 2000;23(6):501-517.

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## GASTROSTOMY TUBE PLACEMENT IMPROVES BMI AND STABILIZES LUNG FUNCTION IN PATIENTS WITH CYSTIC FIBROSIS

Best C, Brearley A, Gaillard P, et al. **A pre-post retrospective study of patients with cystic fibrosis and gastrostomy tubes**. *J Pediatr Gastroenterol Nutr*. 2011;53(4):453-458.

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In this study, Best and colleagues assessed the efficacy of gastrostomy tube placement on improvements in nutritional status and pulmonary function in patients with CF. This was a retrospective study that spanned eight years, from 1989 to 2007. Subjects were included in the study if they had measures of BMI and percent-predicted FEV<sub>1</sub> for two years before gastrostomy tube placement. Additionally, at least five FEV<sub>1</sub> measurements had to be present before gastrostomy tube placement. Follow-up measurements of BMI and percent-predicted FEV<sub>1</sub> were taken at 12 months, two years, and four years post-gastrostomy tube placement. Since the study spanned a long time period during which changes in CF care could affect outcomes, each subject served as his or her own control. Median BMI percentile was compared 24 months pre-gastrostomy and 12 months, 12 to 24 months, and 36 to 48 months post-gastrostomy tube placement. A longitudinal mixed model analysis was used to compare the rate of decline in percent predicted FEV<sub>1</sub> before and after gastrostomy tube placement. The same model also allowed for an immediate change in FEV<sub>1</sub> that may result from the surgical procedure itself.

A total of 46 patients were included in the study, 33 (20 boys, 13 girls) less than 18 years of age (range 5-15 years, mean 11 years), and 13 (8 men, 5 women) older than 18 years of age (range 18-50 years, mean 26 years). Data on the 46 patients were analyzed at 1 year post-gastrostomy tube placement, on 39 patients at two years, and on 29 patients at four years. In this population, placement of a gastrostomy tube was associated with improvements in BMI percentile at one, two, and four years post-gastrostomy tube placement. These improvements were not uniform, however, as the women who were evaluated did not experience an improvement in their BMIs (n = 5). The rate of decline in percent predicted FEV<sub>1</sub> decreased significantly in men and girls post-gastrostomy tube placement. A trend toward improvement in the rate of change of percent-predicted FEV<sub>1</sub> after gastrostomy tube placement was observed in women. Because the rate of decline in percent predicted FEV<sub>1</sub> in boys was small before gastrostomy tube placement, the change post-gastrostomy tube placement was not significant. Gastrostomy tube placement had no impact on percent predicted FEV<sub>1</sub> immediately after gastrostomy tube placement. There were no predictors of poor outcome after gastrostomy tube placement. In this study, changes in percent predicted FEV<sub>1</sub> after gastrostomy tube placement were not significantly correlated with changes in BMI percentile.

Gastrostomy tube placement in patients with CF improves BMI percentile and is associated with stabilization in lung function, as measured by percent predicted FEV<sub>1</sub>. Previous studies have shown that gastrostomy tube placement is associated with improvements in BMI but have not shown improvements in pulmonary function. The current study is important, as it demonstrates both an improvement in BMI and stabilization in pulmonary function (as measured by the rate of change in percent predicted FEV<sub>1</sub>) following gastrostomy tube





placement. The limitation of this study involves the fact that it is retrospective, and thus changes in CF care could have affected improvements in BMI, as well as stabilization of pulmonary function. In addition, the number of women included in the study was low. Differences between the sexes should be explored further.

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## GASTROSTOMY TUBE PLACEMENT IS ASSOCIATED WITH MORE RAPID IMPROVEMENTS IN BODY MASS INDEX

Bradley GM, Carson KA, Leonard AR, Mogayzel PJ Jr, Oliva-Hemker M. **Nutritional outcomes following gastrostomy in children with cystic fibrosis.** *Pediatr Pulmonol.* 2012 Feb 1. doi: 10.1002/ppul.22507. [Epub ahead of print]

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The authors of this study concluded that children with CF who have a BMI <50th percentile for age may benefit from a gastrostomy tube, supporting their statement with their finding of a 10-fold higher likelihood of achieving a BMI >50th percentile at 6 months post-gastrostomy versus controls. The aim of this retrospective, case-controlled study was to determine if patients with CF and BMI < 50th percentile who received supplemental feeding through a gastrostomy tube were more likely to achieve a BMI > 50th percentile compared with matched controls who were treated with a standardized nutritional protocol. Secondary outcomes of the study involved a comparison of the differences in percent-predicted FEV<sub>1</sub>, number of pulmonary exacerbations, and number of hospitalizations between patients with gastrostomy tubes and matched controls. Twenty subjects 2 to 20 years of age who received a gastrostomy tube for nutritional supplementation between January 2005 and April 2010 were enrolled in the study. Each of the 20 gastrostomy-tube-fed patients was pair-matched with a non-gastrostomy-tube control by age, sex, pancreatic status, BMI percentile, and percent predicted FEV<sub>1</sub>. Data were collected at the time of gastrostomy tube placement, at six months, and at 12 months post-placement.

At the six-month evaluation, the mean BMI Z-score was significantly improved in gastrostomy vs controls ( $P < 0.001$ ). However, this difference was no longer statistically significant at the one-year mark. The change in weight Z-scores was positive and significantly better in patients with gastrostomy tubes than controls at both the six-month and 12-month evaluations ( $P < 0.001$  and  $< 0.01$ , respectively). Changes in lung function as measured by percent predicted FEV<sub>1</sub> did not differ between the tube-fed patients and the controls at either of the follow-up visits. In addition, no difference in the number of pulmonary exacerbations or hospitalizations was reported between the groups.

The authors of this study concluded that children with CF who have a BMI < 50th percentile for age may benefit from a gastrostomy tube, supporting their statement with their finding of a 10-fold higher likelihood of achieving a BMI > 50th percentile at six months post-gastrostomy vs controls. However, this difference was no longer significant at 12 months post-gastrostomy. The authors cite two previous studies that showed a positive association between rapid improvement in BMI and better lung function as measured by FEV<sub>1</sub> percent predicted to support the use of supplemental gastrostomy feeds<sup>(1,2)</sup>. The study did not find a difference in pulmonary function across the two groups over the one-year period of observation, however. Moreover, data on the consistency of use of the gastrostomy tube for enteral supplementation were not evaluated. It is possible that with time and improvement in weight and BMI status, patients stop using the gastrostomy tube for supplemental feeds. Randomized, prospective studies of the efficacy of gastrostomy tube placement that monitor for adherence to nutritional supplementation are needed.

### References

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