

Case Study: Providing Evidence-Based Behavioral and Nutrition Treatment to a Toddler With Cystic Fibrosis and Multiple Food Allergies via Telehealth[†]

Carrie Piazza-Waggoner, PhD,¹ Kathleen S. Ferguson, PhD,¹ Cori Daines, MD,^{2,3}
James D. Acton, MD,^{2,3} and Scott W. Powers, PhD, ABPP^{1,3,*}

Summary. Barriers to successful outcome for cystic fibrosis (CF) therapies can include distance from a CF care center, co-morbid conditions that require individualized alterations to the prescribed treatment, and patient-provider interactions, among others. We present the case of a 21-month-old female with CF for whom modifications of an efficacious behavioral and nutrition treatment were made due to food allergies and distance from the CF care center. She was classified as at-risk nutritionally. Following treatment a significant increase in energy intake (calories) was observed in addition to her meeting weight and height growth rates for a child of this age and gender who is growing normally at the 50th percentile. **Pediatr Pulmonol.** © 2006 Wiley-Liss, Inc.

Key words: behavioral intervention; food allergy; distance from care; cystic fibrosis; telehealth.

INTRODUCTION

Application of evidence-based care in clinical practice is imperative for optimal outcomes; yet, barriers exist to the delivery of such care. In treating individuals with cystic fibrosis (CF), these barriers can include distance from a CF care center, concurrent medical conditions that require individualized alterations to the prescribed treatment, adherence to treatment recommendations, patient-provider interactions, among others.^{1–4} Nutrition treatment is a fundamental aspect of CF care.^{5–9} Addressing barriers to evidence-based nutrition treatment is a priority for current clinical practice. We present the case of a 21-month-old female with CF for whom modifications of an efficacious behavioral and nutrition treatment program^{10–12} were made due to food allergies and distance from the CF care center.

CASE DESCRIPTION

The family of a 21-month-old female being followed by our CF center who had been classified as nutritionally at-risk⁶ was approached regarding participation in a clinical trial assessing a behavioral and nutrition intervention (BEH). The family consented and was randomly assigned to the waitlist/standard care condition. During this 8-week period her energy intake (as assessed via weighed diet diaries) declined 152 kcal/day (Time 1: 1,364 kcal/day;

105% recommended dietary allowance (RDA) to Time 2: 1,212 kcal/day; 93% RDA). Following the waitlist/standard care period, the family chose to participate in the BEH. The standard BEH included 7 weekly, face-to-face

¹Cincinnati Children's Hospital Medical Center, Division of Behavioral Medicine and Clinical Psychology, Ohio.

²Cincinnati Children's Hospital Medical Center, Cystic Fibrosis Center, Ohio.

³Department of Pediatrics, University of Cincinnati College of Medicine, Ohio.

[†]Data presented in poster format at the 18th annual North American Cystic Fibrosis Conference, St. Louis, MO (2004).

*Professor of Pediatrics Director.

Grant sponsor: NIH/NIDDK (to SWP); Grant numbers: R01 DK54915, K24 DK59973; Grant sponsor: General Clinical Research Center at Cincinnati Children's (NCRR); Grant number: M01 RR08084.

*Correspondence to: Scott W. Powers, Ph.D., A.B.P.P., Center for Child Behavior and Nutrition Research Division of Behavioral Medicine and Clinical Psychology MLC: D-3015 3333 Burnet Avenue Cincinnati, OH 45229-3039.

Received 19 October 2005; Revised 1 March 2006; Accepted 4 March 2006.

DOI 10.1002/ppul.20470

Published online in Wiley InterScience
(www.interscience.wiley.com).

nutrition counseling sessions. The goals of these sessions were to increase energy intake (via types of foods and addables/spreadables) and provide child behavioral management training to teach parents differential attention and contingency management skills. An individual therapy approach was used. The clinical trial demonstrated efficacy of BEH over the standard care condition.^{10–13} For this family a number of barriers were present. First, the family lived over 3 hours from the center which precluded weekly visits for face-to-face counseling. Second, nutrition recommendations would need to account for a number of specific food allergies; she was allergic to eggs and all nuts. As such, the intervention was modified for delivery via telehealth.

The initial visit remained the same; the family attended an hour-long session with a PhD level therapist (Psychology/Behavioral Medicine Fellow). This session was coordinated with a regular CF center appointment but took place in the Division of Behavioral Medicine and Clinical Psychology. During this session rapport was established between the family and therapist, how to weigh and measure for the diet diaries was reviewed, and the child's height and weight were obtained. Rather than face to face sessions, 6 weekly phone calls were then conducted with the child's mother. Prior to each scheduled phone call, the child's mother faxed 3-day diet records (compared to 7-day used in the larger clinical trial) to the therapist. These records were reviewed during the call and utilized to set weekly goals regarding energy intake. A general guideline involved increases of approximately 200 calories for snacks and 175 for meals, with a total goal of 600–800 calories per day change pre- to post-treatment.^{11,12} Similarly, prior to the phone session the therapist developed handouts from the materials to be covered from the treatment manual including suggestions for food choices and emailed them to the mother. Each session focused on one-meal/snack and parenting skills (e.g., limit setting). Parents were asked to use the behavioral parenting skills regularly at home at all meals and snacks. Table 1 contains weekly session content.

Between sessions the child's mother was able to email or call the therapist with any questions pertaining to the

implementation of the intervention. The therapist, rather than reply to email, would call the mother to provide answers to questions and discuss issues identified via email. Regarding changes to content of the behavioral treatment, the only substantive (rather than modal) modifications made for this family was that no meal was observed by the therapist during session 4. The therapist also worked with the CF nutritionist regarding any necessary modifications to nutrition recommendations due to the child's food allergies to eggs and all nuts.

Findings

Energy Intake and RDA

During the 8-week waitlist/standard care condition her energy intake (as assessed via weighed diet diaries) declined 152 kcal/day (Time 1: 1,364 kcal/day; 105% RDA to Time 2: 1,212 kcal/day; 93% RDA). From pre- to post-treatment, energy intake increased 503 kcal/day (pre-treatment: 1,212 kcal/day, 93% RDA to post-treatment: 1,715 kcal/day; 132% RDA). Following treatment, she was exceeding the recommendation of 120% RDA for children with CF. Across the follow-up assessments (3, 12, and 18 months), her energy intake continued to increase. At her most recent assessment in July 2005, she was consuming an average of 2,131 kcal/day (164% RDA). Figure 1 depicts energy intake and percent RDA across waitlist, treatment, and follow-up conditions for this child.

Percent Fat

As seen in Figure 2, her percent fat has also increased significantly following the modified BEH intervention. She met or exceeded the CF recommendation of 35% of calories from fat at the post 3- and 18-month assessments.

Weight and Height

Growth rates for a child of this age and gender who is growing normally at the 50th percentile are 1.0 kg and 3.5 cm over 6 months.¹⁴ Figure 3 illustrates her height and

TABLE 1—Content of the Behavioral Intervention Session by Session

Week	Session	Topic	Behavioral child management technique
1	1	How to keep a food record	None
2	Skip		
3	2	How to use snack to meet your child's energy needs	Differential attention (compliments, praise, and ignoring)
4	3	Breakfast: the most important meal of the day	Contingency management and meal duration
5	4	Practice meal: bring your child to treatment	Refining use of differential attention and limit setting
6	5	Lunch: consistency across situations	Limit setting: how to do it and do it well
7	6	Dinner: making it a family effort	Bringing all the skills together
8	7	Review: putting it all together and sick days	Review and problem solve: making behavioral techniques work for you

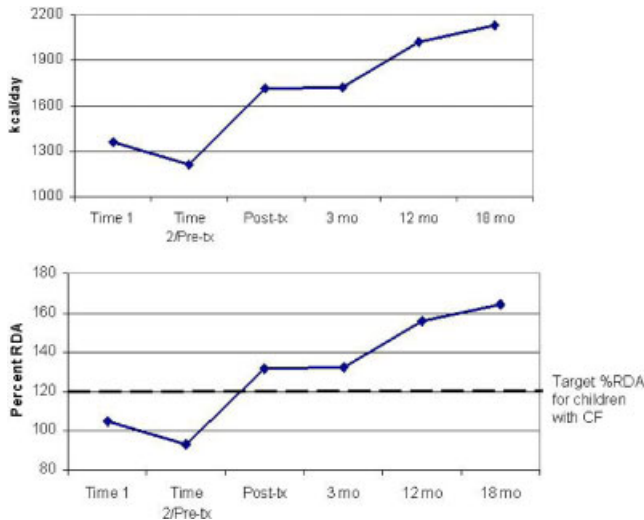


Fig. 1. Energy intake (kcal/day) and percent RDA across waitlist, treatment, and follow-up assessments.

weight velocities at the 3-, 12-, and 18-month assessments. She exceeded the growth velocity for height at all three-time points. While she exceeded the weight velocity at the 3- and 12-month assessments, at the most recent 18-month assessment her weight velocity was 0.825 (vs. goal of 1.0 kg).

DISCUSSION AND CONCLUSIONS

Young children with CF are not meeting the nutritional recommendations^{7,16,17} of energy intake of 120% or greater of the RDA and percentage of fat intake of 35% per day.^{6,9} These nutritional recommendations are considered the level of energy intake necessary for patients with CF to meet the goal of normal growth.⁶ Nutrition interventions that incorporate behavioral therapies have shown promise in increasing energy intake in children with CF.^{10–12,18,19}

This case study provides support that evidence-based behavioral treatment for toddlers and preschoolers with CF can be modified to address individual barriers to the delivery of optimal nutrition care. Both the therapist and mother independently reported high satisfaction with the

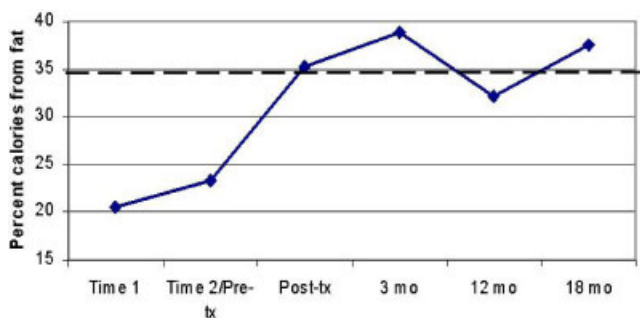


Fig. 2. Percent of calories from fat across waitlist, treatment, and follow-up assessments.

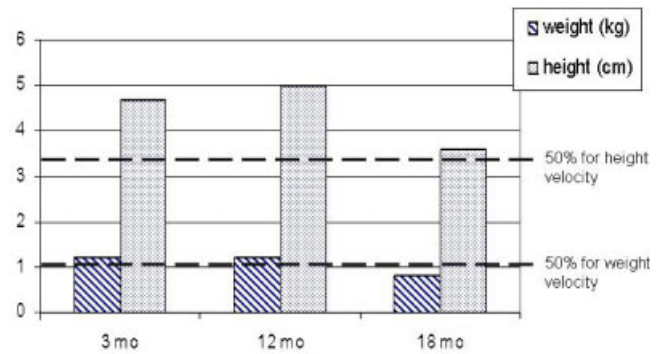


Fig. 3. Height and weight velocities at 3-, 12-, and 18-month assessments compared to normative growth expectation.

telehealth treatment modality and its effectiveness. This intervention, delivered via telehealth, resulted in clinically significant improvements in energy intake. Her dietary intake exceeded the clinical benchmarks of 120–150% RDA per day for energy suggested by the consensus conferences on pediatric nutrition in CF.^{6,9} It is clinically meaningful that her weight and height velocity was consistent with growth for same age and gender children at the 50th percentile. We also found the impact of treatment to be durable. Upon returning to usual care, she continued to maintain the clinically significant treatment gains through 18 months post-treatment; suggesting that the family was able to continue to implement the skills and knowledge provided without ongoing contact with the therapist. Providing treatment in this manner could make behavioral and nutrition intervention available to a number of families for which weekly travel to a clinic would have been prohibitive (e.g., extreme distance from center, transportation concerns, other time constraints).

Previous research has indicated that more traditional mental health services can be provided effectively via telehealth in rural and underserved populations.^{20,21} As many families now own home computers and have access to internet connections, the options for telehealth modality are also increasing (e.g., email/instant messaging, internet based audio and visual connections) as well as video conferencing and use of video phones. Utilizing a video connection to allow the therapist to observe a meal during session 4 as well as provide immediate feedback to the mother could possibly have strengthened the current treatment. There are also a number of ethical considerations when providing treatment via telehealth (i.e., providing services in a state in which the therapist is not licensed, state telecommunication regulations).^{20,22}

There are a number of parent and child factors which may have made this family a good match for behavioral treatment delivered via telehealth. First, the child's mother is an intelligent, high functioning woman who was able to easily understand suggestions and parenting strategies provided by the therapist. Related, the mother was able to

actively engage in the discussion with the therapist by asking questions and applying strategies discussed to the family's day to day activities. Additionally, she was motivated to increase her daughter's energy intake and, therefore, was invested in the treatment. She was also organized related to completing treatment monitoring and providing diet diary information to the therapist. Finally, she had good communication with the patient's grandmother who was the daycare provider, which greatly enhanced consistency in treatment implementation. Related to child factors, the child exhibited developmentally appropriate levels of behavioral challenges at meals and her general behavior outside of increasing intake was not a significant problem for this family.

This case is clinically significant as it provides evidence for the treatment effectiveness (i.e., an efficacious intervention successfully implemented into real word circumstances) for this behavioral and nutrition intervention. Future research assessing the generalizability of these findings is needed. For example, it will be important to assess the effectiveness of this intervention with a family whose child is exhibiting more significant behavior problems to further delineate which families benefit from telehealth intervention. Also, large-scale clinical effectiveness trials of this intervention are warranted to provide controlled evidence of the application of this therapy within the context of everyday care for families of young children with CF.

REFERENCES

1. Bender BG, Bender SE. Patient-identified barriers to asthma treatment adherence: Responses to interviews, focus groups, and questionnaires. *Immunol Allergy Clin North Am* 2005;25:107–130.
2. Brotanek JM, Halterman J, Auinger P, Weitzman M. Inadequate access to care among children with asthma from Spanish-speaking families. *J Health Care Poor Underserved* 2005;16:63–73.
3. Dimatteo MR. The role of effective communication with children and their families in fostering adherence to pediatric regimens. *Patient Educ Couns* 2004;55:339–344.
4. Winnick S, Lucas D, Hartman AL, Toll D. How do you improve compliance? *Pediatrics* 2005;115:e718–e24.
5. Konstan M, Butler S, Wohl M, Stoddard M, Matousek R, Wagener J, Johnson C, Morgan W. Growth and nutritional indexes in early life predict pulmonary function in cystic fibrosis. *J Pediatr* 2003;142:624–630.
6. Borowitz D, Baker R, Stallings V. Consensus report on nutrition for pediatric patients with cystic fibrosis. *J Pediatr Gastroenterol Nutr* 2002;35:246–259.
7. Powers SW, Patton SR, Byars KC, Mitchell MJ, Jelalian E, Mulvihill MM, Hovell MF, Stark LJ. Caloric intake and eating behavior in infants and toddlers with cystic fibrosis. *Pediatrics* 2002;109:75–80.
8. Stark LJ, Mackner LM, Patton SR, Acton JD. Cystic Fibrosis. In: Roberts MC, editor. *Handbook of Pediatric Psychology*, 3rd edition. New York: Guilford Press; 2003. p 286–303.
9. Ramsey B, Farrell P, Pencharz P. Nutritional assessment and management in cystic fibrosis: A consensus report. The Consensus Committee. *Am J Clin Nutr* 1992;55:108–116.
10. Powers SW, Byars KC, Mitchell MJ, Patton SR, Schindler T, Zeller MH. A randomized pilot study of behavioral treatment to increase calorie intake in toddlers with cystic fibrosis. *Child Health Care* 2003;32:297–311.
11. Powers SW, Jones J, Ferguson K, Piazza-Waggoner C, Daines C, Acton J. Randomized clinical trial of behavioral and nutrition treatment to improve energy intake and growth in toddlers and preschoolers with cystic fibrosis. *Pediatrics* 2005;116:1442–1450.
12. Powers SW, Piazza-Waggoner C, Jones J, Ferguson F, Daines C, Acton J. Examining clinical trial results with single subject analysis: An example involving behavioral and nutrition treatment for young children with cystic fibrosis. *J Pediatr Psychol* (in press).
13. Powers SW, Jones JS, Ferguson KS, Heidemann ML, Henry R, Piazza-Waggoner C, Daines C, Acton J. Behavioral treatment for toddlers and preschoolers with cystic fibrosis produces recommended energy intake and normal rates of growth. *Pediatric Pulmonology* 2004;S27:361.
14. Kuczmarski RJ, Ogden CL, Guo SS, Grummer-Strawn LM, Flegal KM, Mei Z, Curtin LR, Wei R, Curtin LR, Roche AF, Johnson CL. 2000 CDC growth charts for the United States: Methods and development. *Vital Health Stat* 2002;11:1–190.
15. Powers S, Patton S. A comparison of nutrient intake between infants and toddlers with and without cystic fibrosis. *J Am Diet Assoc* 2003;103:1620–1625.
16. Stark L, Jelalian E, Mulvihill M, Powers S, Bowen A, Spieth L, Keating K, Evans S, Creveling S, Harwood I. Eating in preschool children with cystic fibrosis and healthy peers: Behavioral analysis. *Pediatrics* 1995;95:210–215.
17. Stark L, Knapp L, Bowen A, Powers S, Jelalian E, Evans S, Passero MA, Mulvihill MM, Hovell MF. Increasing calorie consumption in children with cystic fibrosis: Replication with 2-year follow-up. *J Appl Behav Anal* 1993;26:435–450.
18. Stark L, Mulvihill M, Powers S, Jelalian E, Keating K, Creveling S, Byrnes-Collins B, Harwood I, Passero MA, Light M, Millar DA, Hovell MF. Behavioral intervention to improve calorie intake of children with cystic fibrosis: Treatment versus wait list control. *J Pediatr Gastroenterol Nutr* 1996;22:240–253.
19. Nickelson D. Behavioral telehealth: Emerging practice, research, and policy opportunities. *Behav Sci Law* 1996;14:443–457.
20. Bischoff R, Hollist C, Smith C, Flack P. Addressing the mental health needs of the rural underserved: Findings from a multiple case study of a behavioral telehealth project. *Contemp Fam Ther* 2004;26:179–198.
21. Frueh B, Deitsch S, Santos A, Gold P, Johnson M, Meisler N, Magruder KM, Ballanger JC. Procedural and methodological issues in telepsychiatry research and program development. *Psychiatr Serv* 2000;51:1522–1527.