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QUALITATIVE ANALYSIS OF PARENT EXPERIENCES WITH ACHIEVING CYSTIC FIBROSIS NUTRITION RECOMMENDATIONS

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To address the risk of undernutrition in patients with CF, patients are encouraged to achieve dietary intakes of 120–150% of the daily recommended intake (DRI) of calories for individuals without CF and 40% of those calories from fat (1). Despite these treatment recommendations, a significant number of patients with CF remain underweight and adherence rates to the calorie intake recommendations range from 12–16% (2). Therefore, optimizing nutritional management and developing effective strategies to improve dietary adherence are critical for promoting growth, quality of life, and long-term survival in patients with CF (1, 3).

While achieving adequate nutrition is a central element of optimal CF care (1), Modi and Quittner (4) found that both children and parents lacked knowledge about nutrition, including the importance of offering snacks, taking enzymes before a meal or snack, and boosting calories. Even when families have knowledge of the recommended care practices for a chronic illness there are often barriers to following recommendations that negatively impact illness management and family functioning (5, 6). A common barrier to nutrition adherence in CF, particularly in early childhood, is the occurrence of challenging mealtime behavior. Many of these mealtime behaviors are developmentally-appropriate, yet warrant targeted intervention because increased behavior problems at mealtime are associated with lower caloric intake (7) and decreased child weight status (8). These problematic behaviors have also been found to impact family functioning at mealtimes in families of children with CF (5, 6, 8).

To address these mealtime behaviors the CF Foundation recommends a behavioral approach be integrated into standard nutrition care, when possible, for children with CF as early as post-positive newborn screen (1, 9, 10). This recommendation is based on findings from a series of studies by Stark, Powers, and colleagues that documented increased adherence to calorie recommendations (11–13) and improved growth (12, 13) using the combined behavior-nutrition approach.

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The Powers et al. (11) study was the first to demonstrate that dietary adherence and growth could be improved in children as young as toddlers with CF using an eight-week behavior-nutrition (BN) intervention. The treatment emphasized nutrition counseling to increase energy intake (i.e., recommending types of foods and use of addables/spreadables) and child behavioral management training (i.e., including differential attention and contingency management skills). Longitudinal outcomes for the cohort reflected increases in weight-for-age z-scores and energy intake for the majority of children from posttreatment to the two-year time point. However, at the four-year time point, energy intake and weight for age z-scores declined for over half of the children (14). Notably, the decline in nutritional and growth outcomes between follow-up years two and four was simultaneous with the children entering school.

Previous literature has described the mealtime behavior challenges present in toddlerhood and school-age cohorts separately, however research has yet to specifically examine the challenges families face as they transition from toddlerhood to school-age. The Powers et al. (14) data suggest that this is a crucial time in child development to identify factors that affect optimal growth. The aims of the current study were to: 1) better understand how families used the strategies taught in a behavior-nutrition intervention and 2) identify the challenges with CF management families experienced during this developmental transition, particularly nutrition. Qualitative analysis is an optimal methodology to achieve these aims (15).

Method

Participants

Eight parents of children with CF participated in a semi-structured interview approximately five years following completion of the Powers et al. (11) clinical trial. One family in the original trial was lost to follow-up and did not participate in the interview. The mean age at posttreatment in the trial was 2.8 years (SD=0.5) and mean age of the children at the time of the interview was 8.2 years (SD=0.8). Five of the eight children were male. See Table 1 for disease-related data. The study was approved by the institutional review board of the medical center, and written informed consent was obtained from parents prior to participating in any study procedures.

Semi-structured interview

Stem questions (Table 2) were developed a priori by study authors and were driven by the study aims. The purpose of the semi-structured interview was to systematically collect information from parents by asking uniform stem questions, while offering the flexibility for parents to provide additional relevant information and allow the interviewer to ask clarifying questions. The interview was conducted by the first author who was familiar with all families from previous research interactions. Seven of the interviews were conducted over the phone, and one interview was conducted face-to-face while the child was admitted to the CF inpatient unit. The average length of the interviews was 24 minutes (SD =8.8). Parents received $20 in compensation for their participation.

Data analysis

Interviews were audiotaped using a USBBLAST™ recording device and were given an identification number to anonymize content. The interview and thematic analysis was informed by Grounded Theory (16) and interview content was coded using the approach specifically described by Braun and Clarke (15). Thematic analysis is a method for identifying, analyzing and reporting patterns within data that is rigorous, systematic and iterative. The process includes becoming familiar with the data set through repeated

reviewing of the transcript data, generating initial codes (i.e., data extracts of the interview determined to be meaningful), searching for themes, reviewing themes, defining and refining themes, and describing findings (15).

The thematic analysis started with the process of verbatim transcription of the collected interview data as well as field notes for two interviews that had audio quality concerns. Each transcript was reviewed independently by three trained coders (a postdoctoral research fellow, a registered dietitian, and a bachelors-level research assistant) and a line-by-line content analysis was used to identify major themes and memorable quotes. Regular analysis meetings were held to discuss the identification of extracted key codes from the interviews as well as identified themes. When discrepancies occurred, the coders clarified the meaning of emerging themes by reviewing transcripts for contextual supporting information to inform a consensus interpretation of the text. The consensus themes were then compared to themes identified by a fourth and independent reliability coder. When the reliability coder identified a theme beyond those identified by consensus, the group would review the theme and its contextual information to determine if the theme would be incorporated or excluded.

Themes were defined as specific content that was mentioned more than three times throughout each interview or specifically identified as a core issue in relation to the overall content of the interview. Memorable quotes from interviews were extracted to support theme identification. Identified themes served as the structure of the thematic framework for each interview. Next, a higher-order framework was created for the entire data set by pooling and systematically arranging all individual themes. A small number of themes were dropped from the final analysis due to insufficient content overlap and power to stand alone as a separate theme, and reflected sufficient data collection to achieve saturation. The iterative process produced a final thematic representation of parent responses.

Results

Themes identified from the parent interviews were categorized into four main domains: a) parent recall of strategies from the BN intervention, b) ongoing challenges impacting CF care, c) new challenges impacting CF care, and d) protective factors (17). See Table 3.

Domain 1: Parental recall of information from the behavior-nutrition intervention (See Table 4, Quotes 1.1–2.5)

Major themes: Nutrition recommendations: Nutrition recommendations consisted of four major themes, and represented parent-reported strategies specific to how to achieve CF nutrition recommendations. Parents reported learning how to boost calories of foods using addables and spreadables (n=6 families). Parents discussed learning to shop for high-calorie foods (n=5), offer high-calorie beverages (n=5), and to offer snacks to increase daily calories (n=3).

Major themes: Behavior recommendations: Behavior recommendations consisted of 3 major themes, and represented treatment recommendations specific to how to improve child behavior. Parents recalled learning how to deliver both positive consequences (i.e., praise and rewards) and negative consequences (i.e., removal of privileges) to manage mealtime behavior (n=4). Several parents reported that prior to the intervention, they spent a great deal of time pleading with and coaxing their children to encourage them to eat. Parents discussed the value of learning to intentionally provide attention to eating behavior like taking bites rather than non-eating behavior such as refusing food (n=3). Parents also reported learning to adapt behavior management strategies to new situations based on child's preferred rewards (n=4).

Domain 2: Ongoing challenges that impact CF management (See Table 4, Quotes 3.1–5.4)

Major theme: Parental stress: Parental stress (n=4) was one of the three themes identified as an ongoing challenge. Parental stress included fears related to the uncertainty of the course of CF and stress about parenting a child with a chronic illness. Parents also felt a sense of intense desperation to get their child to eat, including preparing separate meals for the child so that the child would eat.

Major theme: Picky eating: Ongoing challenges with picky eating and food refusal were commonly mentioned in spite of picky eating being a direct treatment target of the BN intervention (n=3). Some parents stated that the child may be compliant with all other areas of CF care, but that picky eating is still of concern.

Major theme: Behavioral noncompliance: The third ongoing challenge was general behavioral noncompliance (n=7). Behavioral noncompliance included refusal to eat, take enzymes, and complete a fecal fat test.

Domain 3: New challenges that affect CF care (see Table 4, Quotes 6.1–8.5)

Major theme: New diagnoses: In addition to the ongoing challenges, families encountered new challenges that impacted CF management. The first major theme in this domain involved families managing the care associated with new medical or psychiatric diagnoses (n=3). For this sample diagnoses included Cystic Fibrosis-Related Diabetes (CFRD) and Attention Deficit Hyperactivity Disorder (ADHD).

Major theme: Transfer of treatment responsibility: The second major theme represented difficulty with transfer of treatment responsibility from parent to child (n=3). At the time of the BN treatment, the children's care was managed exclusively by the parents. However at the time of the interview, parents reported challenges with their children taking consistent increased responsibility for certain aspects of CF management.

Major theme: Transition to school: Another major theme discussed by families was the difficulty managing the transition to school (n=5). First, parents voiced concerns about not being able to monitor calories consumed during the school day. Moreover, parents stated that their child was being offered smaller portions at school and consequently needed to compensate for decreased lunch intake at home, typically at dinner. Parents also mentioned the negative impact of missing school due to illness and hospitalization. Finally, parents discussed their struggles with partnering with schools to ensure that their children receive the appropriate accommodations. Some parents had success with educating the school administration and staff about CF, and one school was willing to implement a reward system to encourage eating. Unfortunately, parents also discussed challenges with garnering the school's cooperation to provide appropriate accommodations.

Domain 4: Protective factors (See Table 4, Quotes 9.1–10.2)

Major theme: Family—Several parents mentioned protective factors specific to the family that had a positive impact on CF management (n=5). Family factors included parents communicating effectively with the CF team, including asking for help when needed, and eating family dinners together. Parents talked about the family communicating more openly and honestly with the child about CF now that the child is older as an important way for the child to learn about CF and understand the importance of adhering to treatment recommendations. Finally, one parent started a family competition to encourage the child to gain weight.

Major theme: Child—Several parents mentioned factors unique to the child that have a positive impact on CF management (n=6). Child factors included: a) increased understanding of the importance of eating more calories with age, b) increased behavior compliance with age, and c) generally enjoying food and eating well. Parents also talked about the child being hungrier with age and eating more with age. In addition, when the child enjoyed snacks, nutrition recommendations were better able to be achieved.

Discussion

This is the first investigation conducted to understand family experiences with an empirically-supported behavior-nutrition (BN) treatment aimed to improve growth in children with CF. Data from this qualitative study draw attention to challenges that families face and highlight general areas for early and ongoing clinical assessment and intervention. Some of the challenges discussed by families are specific to the developmental transition between toddlerhood and school-age and have not received a great deal of attention in the CF literature.

Generalizability of the study findings is supported by the similarity of the study sample to previous research samples in two main areas. Prior to participating in the BN intervention, parents in the study had variable levels of knowledge about nutrition care in CF (4). Moreover, parent-reported responses to their children's mealtime behavior prior to the intervention were similar to previous findings by Powers, Patton, & Byars (18), including the use of coaxing and pleading with their children during mealtimes to encourage them to eat.

While similar to previous samples in some respects, this cohort was able to provide a unique and valuable perspective that can be used to guide CF clinical care improvement and science. The families in the current study received an evidence-based treatment and were able to discuss many of the salient nutrition and behavioral recommendations that they learned. Families continued to use the strategies in some way several years later because they found them helpful. Notably, in spite of being directly targeted in the BN treatment and likely addressed in routine CF care, several parents reported that picky eating and behavioral noncompliance persisted beyond toddlerhood. Some families had only variable success with the recommendations, an outcome commonly observed in clinical trials and routine clinical care.

This study brings attention to new barriers to adherence and challenges that families may encounter as children move into early school-age that notably co-occur with ongoing challenges, such as parent stress. The most frequent new challenges described by families included the transition to school and transfer of treatment responsibility from parent to child. Previous qualitative research in the area of CF physiotherapy education also documented that preparing families for challenging developmental transitions is necessary (16). The transition to school is multifaceted because many potential stressors are introduced at this time such as increased schedule demands, school absences due to illness, and decreased influence over nutrition intake. The complex challenge associated with transfer of treatment responsibility has been actively studied in other pediatric populations. Family-based interventions have been developed that provide education and problem-solving skills (19, 20) to address the parent-child conflict associated with this process (21). This work has yet to be done in CF.

The American Academy of Pediatrics (AAP) recognizes anticipatory guidance as a key aspect in the promotion of healthy physical, emotional, and social development for children and adolescents (22). The European Academy of Paediatrics (EAP) affirms the importance

of this preventative approach. However, healthcare providers sometimes miss opportunities to provide anticipatory guidance to parents, in spite of parents wanting this information (23). In line with the pediatric academies' focus on prevention, the Cystic Fibrosis Foundation has developed anticipatory guidance handouts detailing how to work with school settings to ensure appropriate accommodations, (24) and behavior-nutrition handouts to encourage positive eating behavior for children aged birth to 2 years (25).

The length of time between the end of the clinical trial and the interview was approximately five years and therefore the passing of time may have affected reported experiences with the BN intervention. In addition, given the increased focus on nutrition in CF care at our institution and many others during this time period, it is possible that parent recall of the intervention was influenced by recommendations or information received during standard CF care prior to the interview. In spite of the small sample of families interviewed, sufficient thematic saturation was supported by the limited number of themes that were excluded from the final analysis. However if more parents were available to be interviewed, novel ideographic content may have emerged.

Findings from the current study highlight the need for CF teams to provide families with anticipatory guidance regarding how to manage mealtime behavior, the transfer of treatment responsibility process, and preparing for the transition to school. These parent-reported needs align closely with those discussed by other parents of children in CF (26) who endorsed that they would like information about child behavior delivered through a parenting program, and that they preferred access to the program before the onset of child behavior problems. Moreover, while a behaviorally-based nutrition intervention is recommended as part of evidence-based care for children with CF with growth deficits, few children are able to receive this type of treatment due to the availability of trained providers and the feasibility of the treatment when conducted in a face-to-face format. Given these barriers, a promising avenue is developing, testing, and disseminating a web-based behavior-nutrition intervention.

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Table 1

Growth and Disease-Related Variables From CF Clinic Visit Closest to Time of Interview

ID	*Height z-score*	*Weight z-score*	*BMI%*	*PA*	*FEV*^{1}
1	0.58	1.65	97.5	--	120%
2	−0.58	−0.29	48.2	--	107%
3	0.44	0.31	52.8	+	104%
4	1.78	1.05	57.9	--	99%
5	−0.07	0.39	71.3	--	104%
6	−0.77	−0.86	27.9	--	105%
7	0.76	0.08	30.7	+	71%
8	−0.42	0.30	82.4	--	119%

Note. BMI= Body Mass Index; PA= Pseudomonas Aeruginosa positive culture; FEV^{1}= Forced Expiratory Volume in 1 Second

Table 2

Parent Interview Stem Questions

1	What suggestions about mealtime, snacks and increasing calories do you continue to find to be helpful for your child?
2	What suggestions about mealtimes, snacks, and increasing calories do you find are no longer helpful for your child? Please explain why.
3	As your child has grown older, what new challenges do you face related to his or her eating?
4	Do you feel like the strategies that you learned during the study apply to your child's eating and behavior now, since he or she has gotten older?
5	What have your experiences been like over time? For example, did it take you a certain amount of time to feel comfortable using a particular strategy that you learned during the study? What changes have you noticed in your child's eating and behavior (both desirable and undesirable) since your entry into the study?
6	What other feedback would you like to share about your experiences in the study?

Table 3

Summary of Consensus Major Themes for Four Core Domains

Domain 1: Parental recall of information from the behavior-nutrition intervention	
Nutrition recommendations	
1	Boosting calories through addables/spreadables
2	Identify high-calorie food alternatives
3	Use of high-calorie beverages
4	Use of snacks to increase daily calories
Behavioral recommendations	
1	Contingency management
2	Shift from positive to negative attention
3	Flexible use of strategies
Domain 2: Ongoing challenges that affect CF management	
1	Parental stress
2	Picky eating
3	Behavioral noncompliance
Domain 3: New challenges that affect CF management	
1	New diagnoses
2	Transfer of treatment responsibility
3	Transition to school
Domain 4: Protective factors	
1	Family factors
2	Child factors

Table 4

Memorable Quotes from Parent Interviews

Domain 1: Parental recall of information from the behavior-nutrition intervention	
Major themes: Nutrition recommendations	
1.1	All the little tips with trying to add butter or oil or anything as much as you can. I wouldn't think about doing [this] before.
1.2	So it is a matter of finding what your child will eat and what you can do to boost the calories.
1.3	…but I kind of keep an eye out for the things with extra calories.
Major themes: Behavior recommendations	
2.1	When we went to the store I would say 'okay this is your reward [picking snack] for eating so well this week'.
2.2	It would be like 'child eat, eat, eat, try this try that'. It was all about her, the time was.
2.3	…to praise her and not give her the negative attention, because that was all she was getting.
2.4	He kind of understands that he misses the beginning of the show if he doesn't eat fast enough.
2.5	I just kind of revamped them [behavioral strategies] a little bit as he goes through different stages.
Domain 2: Ongoing challenges that impact CF management	
Major theme: Parental stress	
3.1	I was desperate for her to eat.
3.2	He was so tiny and I just wanted him to get bigger because he lost so much weight in his first year of life, and I just wanted to hurry up and get him bigger.
3.3	You feel bad because then you're thinking, you know he could be sick tomorrow and end up in the hospital and all he can remember is mommy yelling at him...But I look at it this way, I can't stop being a parent because of that.
3.4	It's never-ending [stress]. I'll put it that way. Never-ending.
Major theme: Picky eating	
4.1	He will go hungry before he eats something he doesn't like.
4.2	It has always gone on [picky eating]. He's just picky and stubborn.
Major theme: Behavioral noncompliance	
5.1	He wouldn't take the enzymes and they said to open the capsules up and put them in applesauce or something…Once he saw the little bead things he threw the whole plate away.
5.2	It is impossible to get that child to poop in that cup. He just will not do it, in that little bowl thing [fecal fat test].
5.3	With him I've noticed, and his teachers know, that when he starts to get sick he starts to get cranky and he's defiant.
5.4	It wasn't tantrums as much as stubbornness because he didn't want to eat. He would sit there for an hour and a half if you let him and he still would not eat it.
Domain 3: New challenges that affect CF care	
Major theme: New diagnoses	
6.1	At first she didn't want to eat because she did not want to get the shot [insulin]. But then we got past that because that day she had the low blood sugar. I think she felt so bad, but she realized that she needed more [food].
6.2	When I go grocery shopping I will get things with less sugar in them because I have hyper kids.
Major theme: Transfer of treatment responsibility	
7.1	She doesn't get them [enzymes] for herself and she's almost nine.
7.2	[We have to] make sure she gets her enzymes when she gets in her snack thing [drawer]. And she does not make any change in her behaviors herself.
Major theme: Transition to school	

Domain 1: Parental recall of information from the behavior-nutrition intervention

8.1 When she goes to school there is more of a challenge sometimes because she throws her lunch away and you don't always know what the intake is.

8.2 I try to get the more calories usually in at dinner.

8.3 He wasn't having enough time to eat. So they let him go take his pills early and go on over and start eating before the rest of the kids got there. So that seemed to help out.

8.4 He is the only kid at his school who has CF so I had to go and talk to all the teachers and … have a meeting with them and explain to them…about mealtimes and he gets his pills at lunch and everything and explain to the nurse… about it.

8.5 And yet he came home one day and he had to poop so bad…And I'm like 'why didn't you go at school.' And he said… he went… and asked the teacher if he could go to the bathroom and she told him no. So I had a serious problem with that, and I told her she cannot tell my son no. If he has to go to the bathroom you have to let him go.

Domain 4: Protective factors

Major theme: Family

9.1 I received that book that has the pictures in it when he has pseudomonas and bacteria… I sat down with him and I did explain to him 'you know here is what mom's lungs look like'. And he said 'well how come mine aren't as pink as yours'. I did explain to him 'well child because of the mucus and because all that affects your lungs, they have trouble breathing'.

9.2 I'm very set on family dinners... If the child sees you eating all your food, they are more prone to eating it all.

9.3 But I constantly encourage him to eat so he does get that big belly. And he says. 'Oh one of these days I'm going to be fat like dad, I'm going to have a big belly like dad, and I'm going to be number one big belly in the family.' Things you have to say, I mean it's more encouragement.

Major theme: Child

10.1 [Child] likes BBQ wings and can eat a whole bag and be happy the rest of the day.

10.2 [Child] has always been a big snacker.