Brief Report: Parent Perspectives of Nutritional Status and Mealtime Behaviors in Children with Sickle Cell Disease

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Objective To qualitatively evaluate parent perspectives of eating problems, nutritional status, and the potential for nutritional intervention in children with sickle cell disease (SCD).

Methods Twenty parents of children with SCD participated in one of three focus groups to discuss questions related to the study’s objectives. Three coders rated transcripts to identify common perceptions and experiences (themes) among participants.

Results Poor appetite and its impact on nutritional and general health were particular concerns for parents. Parents addressed eating challenges with dietary supplementation, limit setting, and compromising at meals, often without consultation from health professionals. An intervention program should include facilitators, such as flexible scheduling and incentives to counter barriers, such as scheduling and child care conflicts.

Conclusions Parents of children with SCD reported a range of eating behavior challenges. Parents presented ideas on how nutritional intervention could be culturally sensitive and on how to promote participation in such programs.

Key words nutrition; mealtime challenges; pediatric sickle cell disease; focus group; intervention.

Sickle cell disease (SCD) is a genetic disorder that causes severe hemolytic anemia and is most common in people of African ancestry. Although the gene does not affect growth, approximately one third of children with SCD are below the 5th percentile for height or weight (Henderson, Saavedra, & Dover, 1994; Heyman et al., 1985; Phebus, Gloninger, & Maciak, 1984), with 17% below the 5th percentile for both measures (Henderson et al., 1994). Growth deficits are apparent in children with SCD as early as 6 months of age (Hendricks-Ferguson & Nelson, 1999). By 9 years of age, height and weight deficits approach one standard deviation below reference patterns, and become more pronounced as children mature (Barden, Kawchak, Ohene-Frempong, Stallings, & Zemel, 2002; Henderson et al., 1994; Stevens et al., 1986). Furthermore, some children with SCD have nutrient deficiencies in zinc, folate, and vitamin B6 (Leonard, Zemel, Kawchak, Ohene-Frempong, & Stallings, 1998; Kennedy et al., 2001). Maintaining adequate nutritional status has been hypothesized to reduce long-term morbidity and mortality in patients with SCD (Vermeylen & Cornu, 1993).

Preliminary studies have suggested that vitamin, mineral, and behavioral nutrition interventions may improve growth in children with SCD (Zemel, Kawchak, Fung, Ohene-Frempong, & Stallings, 2002); however, there has been little mention of psychosocial considerations. Despite the fact that nutritional and growth deficits are well documented, few studies have assessed parent perspectives of eating behaviors, nutritional

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status, and growth in children with SCD. One study concluded that per parent report, dysfunctional eating patterns were prevalent in 25% of children and adolescents with SCD, with 57% having mild to moderate pica symptoms (Lemanek et al., 2002). Despite literature documenting the severity of nutritional and growth deficits in children with SCD, routine nutritional counseling is not a standard of care as it is in other pediatric chronic illnesses, such as cystic fibrosis and diabetes mellitus. It is unclear what impact early nutritional and behavioral education might have on shaping parent perspectives about their child’s eating behaviors and physical development. However, before nutrition strategies can be developed, we need to understand what challenges patients and parents face in managing nutritional issues. Understanding parental viewpoints is especially critical for health care providers so that nutritional intervention programs can be developed that are culturally relevant and anticipate potential barriers to participation and adherence. Appropriate cultural adaptation and implementation is important given that eating behaviors, mealtime routines, body image, and parenting practices are commonly influenced by cultural and family factors (Airhihenbuwa et al., 1996; Ricciardelli & McCabe, 2001).

The goal of this study was to use focus groups to qualitatively assess how parents perceive eating patterns, growth, and nutritional status in their children with SCD and to assess interest in and barriers to participation in a nutrition intervention program. Focus group assessment is ideal for gathering detailed data to design effective and culturally focused intervention programs (Heary & Hennessy, 2002; Jones & Broome, 2001).

Methods

Participants
Eligible were parents of children ages 3 to 5 and 13 to 15 years with SCD-SS disease, as were parents of children ages 3 to 15 years with SCD genotypes other than SS. Caregivers of children ages 6 to 12 years with SCD-SS were excluded because they were eligible for another study that may have biased parent discussion in focus groups. Participants were recruited using a variety of methods, including face-to-face contact at an SCD health fair or SCD clinic, as well as letters and phone calls. Of the 31 eligible parents who were reached via in-person or telephone contact, 8 declined due to scheduling conflicts, transportation challenges, or lack of interest, and 3 failed to attend. Thus, 20 parents/guardians of children with SCD participated in one of three focus groups held at a major children’s hospital. The mean age of the parent or guardian participant was 39 years (SD = 8.7, range = 28–58), and all participants but 1 were primary caregivers of a child with SCD. Seventeen (85%) participants were biological mothers or female guardians, 2 (10%) were biological fathers or male guardians, and 1 was a babysitter who came with a mother of a child with SCD. All participants were African American and 3 had two children with SCD. Given that many children ages 6 to 12 years were ineligible for this study, data on child age were reported categorically. The child sample comprised children ages 3 to 5 (26.1%), 6 to 8 (21.7%), 9 to 11 (26.1%), and 12 to 14 (26.1%). The mean age of children was 8.6 years (SD = 3.7, median = 8.5, range = 3–14). Income was rated using a 7-point ordinal scale. The median family income level was $35,000 to $44,999 per year, with ranges in income from $15,000 to $24,999 (12%) and $65,000 and above (33%). For participating, parents received $30 and a parking voucher. The protocol was approved by the hospital’s institutional review board.

Procedures
Focus group questions were developed and refined during a series of meetings with the SCD health care team (physicians, nurses, social workers) and experts in nutrition, psychology, focus groups, and qualitative analysis. To better understand parental perspectives of disease-management challenges and the potential barriers to intervention efforts, focus group questions were organized around the following:

1. Disease management issues: What are the challenges for parents of children with SCD related to disease management, including nutrition management?
2. Parenting strategies/behavioral challenges: What are general behavioral and mealtime challenges for parents of children with SCD and how are they addressed?
3. Facilitators and barriers to intervention: What are facilitators and barriers to participation in intervention programs and adherence to treatment recommendations?

Each set of questions was discussed in two of the three focus groups. Each focus group session was held on a weekday evening and lasted 60 to 90 minutes. A trained moderator and an assistant, both of whom were African American women, conducted the sessions,
which were audiotaped and videotaped with participant permission. Tapes were transcribed verbatim and coded by three trained coders for themes.

**Data Analysis**

Focus group data were analyzed using consensus ratings (Krueger, 1998) among three trained coders (two were involved in the development of the questions and one was an independent expert). Each coder independently read the transcripts before coding to facilitate understanding of the depth and breadth of information discussed in the focus groups. Coders then independently reviewed the three transcripts by coding all transcribed discussions using one of four categories:

- **Question/Prompt.** Included mostly facilitator discussion as she presented questions to the group, used prompts to gain clarification, or elicited further discussion.
- **Major Themes.** Topics that represented “shared experiences” as discussed in-depth by members of the group with little or no dissension; or topics that had breadth as they recurred through interactive discussion among group members.
- **Minor Themes.** Topics brought up by a member of the group that were relevant to the goal of the study but did not appear to reflect the shared experience of the group due to the lack of breadth or depth of the discussion.
- **Other Topics/Other Discussion.** Topics that were off-topic from the questions posed or the direction of the group discussion or were otherwise not related to the goals of the study.

The final list of major themes consisted of topics that were rated as such by all three coders. All other themes that emerged were considered to be minor themes. The summary of themes was compiled in a meeting with all three coders to resolve discrepancies in ratings.

**Results**

Themes were collapsed across the three focus groups. Below they are summarized by the three topic areas and questions explored in the study as described in the Procedures section.

**Disease Management Issues and Strategies**

Parents identified three major themes regarding disease and nutritional management issues: (1) low weight status, (2) emphasis on hydration, and (3) importance of child responsibility for disease management.

**Low Weight Status**

Parents acknowledged that their child with SCD was often smaller and thinner than his/her siblings and peers; however, they generally accepted thinness as a feature of SCD. Parents perceived low weight to be a consequence of pain episodes, hospitalizations, and/or generally reduced appetite, even in the absence of pain. Parents were more likely to be concerned about delayed puberty, poor eating, and general health issues than they were about their child’s thinness. One parent described the concerns expressed by many parents: “My daughters are a year apart. The older one that has SCD is very tall and slender. And they are one pound apart. One is 39 pounds, the other is 40 pounds.”

**Emphasis on Hydration**

Parents discussed efforts to keep their children well hydrated, particularly during periods of pain or poor appetite. The importance of hydration in the management of SCD is highly reinforced by health providers. Parents encouraged their children with SCD to drink plenty of fluids, often as a compromise for not eating meals, particularly when they were ill. Parents viewed getting children to drink as important to shortening pain episodes (minimizing splenic complications) and as a strategy for encouraging appetite. Children were more likely to drink water or caffeinated beverages than milk or juice. Many parents made comments to the effect: “I think water is good for them because if you’re thirsty you might have dehydration. And the water and fluids will help them pass through the pain episode quicker. We all know how to take care of them when they go through pain. Get the fluids in, even if they don’t want to eat right now.”

**Importance of Child Responsibility for Disease Management**

Although parents acknowledged the importance of proper disease management and the potential risks associated with nonadherence, they also stressed that children had to be responsible for taking care of themselves, particularly when they were well. This belief also held with respect to eating and meal preparation. Parents rationalized that children needed to develop the self-care skills they would need as adults. For other parents, self-management was a practical issue that was related to large family size or parents’ inability to supervise the child at all times. As one parent mentioned, “It’s her responsibility now because she is the sick
person. And if something happens in life, nobody is going to take care of you better than yourself.”

**Mealtime Challenges and Parenting Strategies**

Common challenges included reduced and variable appetite, picky eating, and aversion to meat. Parents attempted to manage eating problems using a range of strategies, including adding dietary supplements, setting limits, rationalizing the problem, and compromising or negotiating with children. Examples of parent comments with respect to mealtime challenges and strategies include:

“Sometimes I give her one of those Ensure™ [nutritional beverages]. I give her a granola bar or something with nutritional value.”

“I think I realize one of our biggest mistakes as your child is growing is to say, ‘Oh when she's hungry, she's gonna eat.’ And I'm waiting for this child to be hungry and to feed her, instead of just encouraging her to eat. And now it's like I'm ready to encourage her.”

**Barriers and Facilitators to Intervention**

Barriers to participation in an intervention program included time constraints, transportation, availability of child care, and meeting the needs of children without SCD. As one parent noted, “I have two [children with] SS [SCD-SS] and two asthmatics. School is starting now and you have to do homework afterwards, and you never know when a crisis is coming.” Parents also made several suggestions for how to improve motivation and participation in a nutritional intervention program, such as ensuring convenient scheduling, providing child care, and having an appropriate explanation of how the program would benefit children with SCD. Parents also mentioned the importance of communication with parents and providing incentives to participants in the program. As one parent commented, “There are a couple of options—give people a game plan [for how to get their children to eat]. Sometimes this works one week and won’t work the next week. Give us a couple of different options.” Another parent suggested, “State the purpose of the group, the goals, the scope of time. What is the hope? What are you going to give? People have to know what the advantages for them are.” Parents offered suggestions for how to increase participation, such as, “Have a day where you cook recipes. Have someone come in and cook a whole meal and provide so many calories, so much protein, so many carbs [carbohydrates], so much fat.”

**Discussion**

Although research supporting the importance of nutritional status for physical and mental health in children with SCD is increasing, we understand little about barriers to providing optimal nutrition interventions and how to design effective interventions. The current study provides qualitative information on how parents of children with SCD perceive their child’s nutritional status, dietary intake, and mealtime behaviors. Although many parents reported concerns about their child’s low weight status and delayed pubertal onset, there was greater consensus that eating and mealtime challenges were prevalent in children with SCD. In particular, children with SCD are often picky eaters and have variable appetites. Some of this variability was perceived to be related to SCD (pain, hospitalization) and some was attributable to developmental or seasonal factors. Parents mentioned that what may be a problem when children are sick may not be of concern when they are well, and vice versa. Parents generally accepted that children would “rebound” following illness; however, the literature supports a view that even a return to normal eating patterns may not be sufficient to maintain adequate nutrition and wellness (Malinauskas et al., 2000).

Of note, most parents viewed drinking water instead of eating as acceptable behavior, particularly when children were not hungry or when they were sick. The acceptance of drinking water, which provides no calories or nutrients, as a compromise to eating is likely due to disease-management education that emphasizes that hydration is essential to the prevention and treatment of pain events. In addition, parents rarely set limits on what their children drank, allowing them to drink coffee and soft drinks without encouraging a preference for more nutritional beverages, such as milk.

Poor appetite and other mealtime behavior problems reported by parents often led them to try a range of strategies to get their children to eat, including offering nutritional beverage supplements and high-calorie, high-fat foods and cooking a second meal. In all of the focus groups, frustration related to the child’s poor appetite was expressed more often than frustration related to the parent’s feeding strategies. Focus group analyses also revealed that parent frustration was most often related to concerns about health as opposed to growth.

Comments made by the parents also highlighted the fact that eating and parenting practices are frequently
grounded in families’ cultural and ethnic identities. One salient example was parents’ expectations that their child needed to be independent in self-care, including preparing and eating meals. This concept is consistent with literature suggesting that African American parents are more likely to encourage independence in their children than are parents from other ethnic groups (Bulcroft & Carmody, 1996). Hence, intervention needs to promote child empowerment first and foremost, but it also needs to promote understanding of the importance of parental oversight of food-related issues in children with chronic diseases. Parents also mentioned that during the school year, their child ate one to two meals outside of the home, which must also be considered.

While parents in this study were not well informed on the nutritional risks associated with SCD, they were interested in learning more about nutritional aspects of the disease and how they could improve their child’s eating behaviors and nutritional health. Data suggest that an intervention should be “health focused,” rather than “weight focused.” Furthermore, an intervention plan would need to balance health education with parental support so as to educate, but not alarm, parents. Parents also suggested strategies for publicizing the groups, making the groups creative, and allowing for make-up sessions. Providing incentives for children with SCD and siblings and ensuring that programs balance the needs of the child with SCD with the nutritional and dietary needs of other members of the family is also important. Achieving balance may be accomplished, in part, by providing information for other family members on relevant health topics (e.g., obesity, high blood pressure and diabetes). Participation would be enhanced by providing child care and transportation or parking assistance and ensuring convenient and flexible scheduling.

Findings from this preliminary study should be interpreted in light of the study’s limitations, including the fact that participants were a small and variable sample of parents of children with SCD and that there was no control group with whom to compare findings. Conducting a comprehensive study of nutrition and eating behaviors in a larger sample of children with SCD and comparing findings with a healthy control group or another pediatric sample (e.g., children with cystic fibrosis) would advance research in this area and allow for broader interpretations of data. Continued research is needed and will help to identify what nutritional issues/themes are unique to children with SCD, which ones are generalizable across pediatric conditions, and which ones are inherent in a child’s developmental progression.

In summary, parents were generally aware of their child’s poor appetite and appreciated that growth deficits may have implications for their child’s general health. While they expressed concern about eating and weight, they reported little success in the strategies they had been implementing to deal with food refusal. Parents confront these challenges with minimal or no input from health providers. These data provide information that may aid in the design of a nutrition intervention program for children with SCD and their parents. Behavioral nutrition programs have been successfully implemented with children across a number of pediatric chronic conditions, such as cystic fibrosis, insulin-dependent diabetes mellitus, hypercholesterolemia, phenylketonuria, and encopresis (Mackner, McGrath, & Stark, 2001), and hold promise for children with SCD. Interventions for children with SCD will need to be sensitive to the concerns of parents and will need to consider ways in which parenting and eating practices are culturally influenced, as highlighted in the current study.

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