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“I don't want them to feel different”: A mixed methods study of parents' beliefs and dietary management strategies for their young child with type 1 diabetes mellitus

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Abstract

Background—Many young children with type 1 diabetes (T1DM) do not consume a healthful diet; exactly why this occurs despite T1DM education remains poorly understood.

Objective—This study describes parents' perceptions of healthful eating for T1DM in young children and identifies factors related to parents' dietary management.

Design—A cross-sectional, mixed-methods study was performed. Parents completed a questionnaire, three-day weighed diet record, and a semi-structured interview regarding their perceptions of healthful eating for T1DM and their dietary management practices.

Participants/setting—Twenty-three families, recruited from a Pediatric Diabetes Clinic in the Mid-Western United States between February 2012 and April 2013, participated. Eligible families had a child with T1DM who was 1-6 years old, at least six months from diagnosis, and was following an intensive insulin regimen.

Statistical analyses performed—Mean scores and percentages were calculated from the diet diaries and parent questionnaires, while parents' interviews were coded to identify common themes.

Results—Results showed that while parents may believe they know what constitutes a healthful diet for T1DM, they do not always feed their child a healthful diet. Parent-identified barriers to healthful eating included: limited time to prepare homemade meals, perceived higher costs of

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healthier foods, the influence of peers on children's food preferences, and picky eating. Parents also discussed a desire not to limit their child's diet or make their child “feel different”, which many parents said often led them to give into child's requests for less healthful food options.

Conclusions—Parents of young children with T1DM identified several barriers to healthful eating that are common for all parents, such as time constraints, expense, and child food preferences. However, unique themes emerged including parents’ desire not to limit their child's diet or make their child “feel different.” Nutrition components of T1DM education should include psychological and behavioral strategies to help parents manage these unique concerns.

Keywords

diabetes; type 1; pediatrics; diet; education; medical nutrition therapy

Introduction

Despite advances in insulin pharmacotherapy and delivery options, diet is an important component of type 1 diabetes (T1DM) management.^{1,2} Diet relates to both glycemic control and risk of comorbid conditions.² For youths with T1DM, dietary recommendations focus on consuming a nutrient-dense diet consistent with the Dietary Guidelines for Americans and maintaining an adequate balance between carbohydrate intake and insulin levels to maintain blood glucose levels that are as close to normal as possible and achieve a glycated hemoglobin target of less than 7.5%.^{1,3}

In young children with T1DM (mean (M) age in years, standard deviation (SD)= 5.1 (1.1)), previous research has also shown a tendency towards diets that are low in fruits, vegetables, and whole grains.^{4,5} However, unlike adolescents, young children do not do their own meal planning and preparation; therefore, their diets are completely guided at home.¹ Thus, it is possible that some young children with T1DM consume an unhealthy diet because their parents do not know what constitutes a healthy diet. Alternatively, it is possible parents lack the behavioral skills to support their child in consuming a healthful diet. Developmentally, young children can be unpredictable in their food preferences and food intake. Within the context is T1DM, these child behaviors make it harder to accurately dose young children for insulin.^{1,6} Likewise, young children can show fear of novel food items (neophobia), a behavior that can lead to a limited food repertoire.^{7,8} Taken together, these challenges may lead some parents to construct primarily meals and snacks based on what they believe their child will accept regardless of the nutritional value. Finally, it is possible that parents of young children with T1DM perceive other barriers to healthy eating that are unique to their family or to optimal T1DM management (e.g., presence of other children in the home or the glycemic effects of specific foods). Importantly, lack of knowledge of healthy eating practices and lack of knowledge of behavioral strategies that encourage healthy eating in children can be directly modified via tailored behavioral nutrition interventions.⁹⁻¹¹ Also, it is possible that other unique barriers (e.g., co-morbid food sensitivities, fear of the glycemic effects of foods) may be amenable to change if identified and targeted in intervention curricula. None of the previously published literature identifies what parents of young children with T1DM understand to be a healthful diet for diabetes or their perceptions of factors which may impact their dietary management. Therefore, the purpose of this study

was to describe parents' perceptions of healthful eating for T1DM in families of young children and identify factors related to parents' dietary management in young children.

Materials and Methods

For this mixed-methods study, homogenous sampling was used to yield data specific to families of young children with T1DM.¹² Families receiving care at a Pediatric Diabetes Clinic in the Mid-western United States were invited to participate. Eligible families had a young child (1-6 years old) with T1DM duration of at least six months who followed an intensive insulin regimen (pump or basal/bolus). The parent who participated from each family reported having primary responsibility for managing their child's T1DM. Institutional Review Board approvals for Children's Mercy-Kansas City and the University of Kansas Medical Center were obtained prior to participant recruitment and all parents provided written informed consent. Study enrollment and data collection ran between February 2012 and April 2013. Families were recruited in person immediately following one of their child's routine diabetes clinic appointments by a trained research assistant. All families who were approached agreed to participate and to schedule the home study visit.

Data were collected through a home study visit and by mail. During the study visit, parents completed a demographic questionnaire and semi-structured interview administered by a research assistant who had completed training in qualitative interviewing. In the interviews, parents were asked about their knowledge and beliefs about healthy food items for their young child with T1DM and perceptions of any barriers to healthy eating. These interviews were the source for subsequent qualitative data. Parents also learned how to keep a three-day weighed food record of their child's food and beverage intake, and they completed a questionnaire to measure perceptions of mealtime behavior functioning; data which were subsequently used for the quantitative analyses. Parents received extensive training on how to weigh and measure their child's food and beverage intake using a standardized protocol.⁵ They were also given a complete set of measuring cups and spoons and a digital scale (Taylor model 3842) to use when keeping the food record. Parents were instructed to keep the three-day food record for two weekdays and one weekend day and to mail back the completed food record within two weeks of the study visit. Parents were reimbursed \$50 for their participation.

The semi-structured interviews were recorded and later transcribed verbatim. Two research staff independently coded each transcript to identify themes and subthemes. A third coder was used, as needed, to resolve any coding discrepancies. All diet records were reviewed by a research dietitian upon receipt from families. In cases where there were questionable data, the dietitian called families to clarify the data. Children's diet records were analyzed using the Nutrition Data System for Research (NDSR), version 2013, developed by the Nutrition Coordinating Center (NCC), University of Minnesota, Minneapolis, MN. Children's most recent glycated hemoglobin A1c (HbA1c) value was collected from their medical record. These values were obtained using the DCA 2000+ Analyzer (Bayer Corporation; normative reference range of 4.5-5.7%; 23-39 mmol/mol). For young children with T1DM the current HbA1c target for optimal clinical management is less than 7.5%.¹

Measures

Parents provided qualitative responses to open-ended questions about their knowledge and perceptions of a healthful diet for young children with T1DM, how they make choices related to meal planning and diet for their child, and their perceptions of any barriers to healthy eating (see Table 1). Questions developed for the semi-structured interview were based on previous research in adolescents with T1DM,¹³ the available data showing nutritional deficits among youths with T1DM,^{4,14,15} and guidelines for nutrition therapy for youths with T1DM.^{2,16} An underlying goal of the semi-structured questions was to understand the process by which parents go about feeding their child with T1DM rather than to identify specific foods in their child's diet or parents' accuracy or opinion of carbohydrate counting.

Parents completed the Behavioral Pediatric Feeding Assessment Scale (BPFAS),¹⁷ which assesses parents' perceptions of family mealtime problems using 35 items, 25 of which were specific to child behavior problems. Parents first used a Likert scale (1=never, 5=always) to rate the frequency of occurrence of each behavior. Then, they used a dichotomous scale (Yes or No) to identify the behaviors they perceived to be problems. For this study, the BPFAS was scored for all four component scores: Child and Parent Frequency and Child and Parent Problems. The BPFAS has previously demonstrated good psychometric properties and associations with young children's diet and glycemic control.¹⁸

To evaluate the quality of children's diet, the Healthy Eating Index (HEI-2010) was used.¹⁹ The HEI-2010 is a measure of diet quality that is based on 12 component scores which reflect intake of foods from different food groups.¹⁹ Because youth with T1DM are also recommended to follow the Dietary Guidelines for Americans, the HEI-2010 is an appropriate measure to use to evaluate their diet quality.³ Scoring instructions exist to calculate HEI-2005 scores using NDSR data.²⁰ These instructions were modified to score the HEI-2010 using NDSR data. Specifically, we used data from the Serving Count Food, Intake Properties, and Component-Ingredient Files of the NDSR to calculate servings per day for each component score based on the USDA Food Pattern guidelines for children 2-3 and 4-8 years old.³ Then, as appropriate, components were scored for servings per 1,000 kilocalories per day, percent of calories coming from solid fats and added sugars (Empty Calories), or ratio of unsaturated fatty acids to saturated fatty acids (Fatty Acids).¹⁹ Because children had three day records, numerators and denominators were summed over the three days and then single ratio scores were calculated and compared with the appropriate components' scoring standard.¹⁹ A list of the HEI-2010 components along with their maximum point values are found in Table 2. Across all components, higher scores reflect a more healthful diet.¹⁹ The HEI-2010 Total score can range from 0-100, with higher scores reflecting a more healthful diet. For this study, HEI-2010 Total and Component scores were reported.

Data Analyses

Descriptive statistics (mean scores, percentages) and Pearson product-moment correlations were calculated for the diet records and parent questionnaires using SPSS (IBM Corp, Released 2011, IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp).

Pearson product moment correlations are appropriate for small sample sizes ($\alpha = 0.05$). Effect sizes of the associations are presented as “r” and considered small (0.10), medium (0.30) or large (0.50) based on guidance from Cohen.²¹ Using NVivo 8 software, the identification of common themes from parent interviews was guided by a grounded theory approach.^{12,22}

Results

Family recruitment proceeded until interview responses reached saturation (i.e., no additional information was being found)²³, resulting in a final sample of 23 families (4 additional families gave informed consent, but did not complete the study). Tables 2-4 display a summary of the sample demographics as well as mean scores based on children's HEI-2010 scores and nutrient intake as gathered from the three day diet records, and the BPFAS. Based on the three day diet records, young children had a mean percent calories from fat intake ($M = 33$ (6%)) that fell within the recommended range of 30-35% as set by the American Diabetes Association.^{1,2} In contrast, children consumed a greater percent of calories from saturated fat ($M = 11$ (3%)) than the less than 10% benchmark recommended by the American Diabetes Association.² Children's mean Total HEI-2010 score was 63.5 (9), which was well below the optimal score of 100, suggesting children were generally not consuming a diet that meets nutritional guidelines. Specifically, children's mean component scores revealed lower than recommended intakes of fruit, vegetables, and lean protein and higher than recommended intake of empty calories (see Table 2).

Mean scores on the frequency subscales of the BPFAS were relatively low, suggesting that parents perceived many of the mealtime behaviors listed in the measure as occurring only some of the time. Likewise, scores on the problem subscales revealed that parents perceived few problems with family mealtime behavior (see Table 4). Consistent with a previous study, parents' Child Frequency Scores were negatively correlated with children's HEI-2010 Total Scores ($r = -0.48$, $p < 0.05$), suggesting child mealtime problems may be a barrier to healthful eating.²⁴

Qualitative Themes

As noted previously, qualitative data were gathered from interview transcriptions. Key themes and sub-themes were identified as well as supporting examples for each theme. The three key themes identified suggest that parents: 1) believe that there are differences in a healthful diet for a child with or without T1DM, 2) perceive significant barriers to healthful eating for children with T1DM, and 3) plan meals based on the nutritional education they have received. Below, these key themes (*in italics*) are expanded upon with additional information and brief in-text quotes. Longer parent quotes are provided in Table 5.

There are differences in a healthful diet for children with or without T1DM—

Despite food record evidence to the contrary, all parents perceived their child's diet as healthful and few parents ($n = 4$) mentioned specific changes that they made to their child's diet following his/her T1DM diagnosis. However, among the parents who did feel like their child's diet changed post-diagnosis, the most common changes included a restriction of sugar-sweetened beverages, emerging use of packaged sugar-free foods, restriction of foods

high in sugar or refined grains (e.g., rice, white bread, cookies), and greater offering of proteins, such as lunchmeats, beef sticks, cheese, ham, or turkey. Most parents (n= 20) expressed the belief that their young child with T1DM should not consume some foods because of the effect these foods can have on their child's blood glucose levels. For example, several parents (n=14) identified fruit snacks, fruit roll-ups, white rice, potatoes, pizza, and pasta as foods that they try to avoid because of their impact on blood glucose levels. Similarly, parents described a healthful diet for their child with T1DM to be one that is high in protein, includes fruits, vegetables, and dairy, avoids “high carbohydrate” foods, and balances carbohydrate intake with protein “to help sustain carbohydrates (Table 5, quote 12).” Interestingly, while all parents discussed the impact of specific foods on their child's blood glucose levels, many (n=17) also emphasized the importance of not restricting their child's diet. For parents who had other children without T1DM, this created a unique challenge; and parents said that they either have all of their children following the same diet or make exceptions allowing their child with T1DM to consume sweets, candy, and other “high-carbohydrate” foods when these are offered to a sibling who does not have T1DM (Table 5, quotes 95 and 119). Parents also discussed making exceptions to their child's diet because of school events, parties, or play dates (Table 5, quote 64). Some parents (n=8) discussed differences in how they manage mealtimes for their child with T1DM. Specifically, parents noted “pushing the carbohydrates” with their child with T1DM and making alternate meals for their child with T1DM if he/she refuses the family meal or his/her blood glucose levels are above the target level (Table 5, quotes 77 and 81). A few parents (n=5) mentioned having “backup foods,” which were described as preferred foods containing “a bunch of carbs in them,” available to offer their child if the “whole meal was a flop” and they were concerned about their child's glucose levels (Table 5, quote 84).

Parents perceive barriers to healthful eating for children with T1DM—Parents identified a number of barriers to healthful eating. For example, all parents emphasized the impact lack of time had on their ability to plan, shop, and make homemade meals for their young child. Similarly, there was a resounding theme across parents that pre-packaged foods are easier and more convenient than preparing homemade meals and snacks (Table 5, quotes 72 and 69). Although the BPFAS scores did not suggest that parents perceived problems with child mealtime behaviors, several parents identified problems in feeding their child a healthful diet because of picky eating (Table 5, quote 58). A few parents (n=4) also mentioned the relative higher cost of healthy foods, such as fresh fruits and vegetables, compared to pre-packaged foods as a barrier to healthful eating. Among parents of young children in day care and school, they identified friends and school as a barrier to healthful eating. Specifically, these parents described their young child as being influenced by what their peers eat for snacks and lunch. These parents also said that their child requests less healthful foods because they are seeing their peers eating these foods or even refuse some more healthful foods because of peer influence (Table 5, quotes 63). This barrier turned out to be a source of significant stress for some parents who worried that their child could be left out or perceived as different because of his/her diet. These parents said they would often give in to their child's request for less healthful foods if their child's request comes about because of contact with peers (Table 5, quotes 67, 124, 136, 142, and 143).

How parents practice meal planning based on the nutritional education they have received—All parents mentioned meeting with a dietitian for education at the time of diagnosis, but most (n=19) described it as being brief, focused primarily on carbohydrate counting, and inadequate to prepare them to meet the challenges of caring for their child (Table 5, quote 122). Few parents (n=5) said that they had participated in any follow-up or advanced nutrition classes. Parents said that they learned how to read labels, identify foods containing carbohydrates, and weigh and measure foods from their nutrition education classes. As for meal planning, most parents (n=21) described themselves as “self-taught,” and some parents (n=7) also said that they learned meal planning by asking other parents about what they do. All parents emphasized the importance of serving as a role model for their child and modeling healthy eating (Table 5, quote 127). In this way, many parents (n=14) discussed how their own diet has changed as a result of their child's T1DM diagnosis (Table 5, quote 131). Parents identified early childhood as a period to focus on helping their child to establish good dietary habits. They also noted the value of introducing new and healthful foods to their child as a part of helping their child to establish a healthful diet. However, here again, many parents (n=14) emphasized teaching their children to recognize how the new and healthy foods impact his/her blood glucose levels (Table 5, quote 134). Most parents (n=21) identified themselves as primarily responsible for deciding what their child will eat for meals and snacks, but a few parents (n=6) said they plan meals and snacks jointly with their child. Many parents (n=14) also said they decide how much their child will eat at meals and snacks and try to limit their child from consuming very large portions (Table 5, quote 107).

Discussion

Existing research has identified perceptions of healthful eating among adolescents with T1DM,¹³ but no study has examined parent-reported perceptions of healthful eating in young children with T1DM. Because young childhood is a period of developing food preferences and habits,⁸ establishing a healthful diet during this period may help to prevent the development of poor eating habits in later childhood and adolescence.²⁵ Moreover, because young children are nearly completely dependent on their parents to provide their meals and snacks, this is a period when parents may exert the greatest influence over children's food preference and diet, making it important to know how parents may perceive healthful eating practices.^{25,26}

The mixed methods design of this study integrated parents' qualitative perceptions of healthful eating and a quantitative assessment of their child's diet and mealtime behavior to identify specific targets for nutrition-focused components of diabetes education programs for families of young children. Notably, our results identify that while parents may believe they know what constitutes a healthful diet, they do not always feed their child a healthful diet. For example, a review of children's HEI-2010 suggests that children consumed a diet that was far from ideal based on the Dietary Guidelines for Americans.³ These results are consistent with previous studies,^{4,5} as are parents' report of limited food preparation time²⁷, the expense of healthful foods,²⁷⁻²⁹ and problems with child picky eating and neophobia.^{27,30} Yet, while parents of young children with T1DM report some common barriers to healthful eating, the daily tasks of diabetes care may impact how families will

relate to these barriers. For example, while it may be common for all young children to have an unpredictable appetite, in the context of diabetes, this is more problematic because of the recommendation that parents dose for carbohydrates at the start of meals versus the end.¹ Likewise, in the context of diabetes, challenging a young child to try a new food may seem harder to do because of the requirement to match insulin to youths' carbohydrate intake. We also identified several themes unique to parents of young children with T1DM which may also be appropriate targets for behavioral nutrition therapy. For example, unlike previous research in adolescents,¹³ parents of young children discussed the importance of modeling healthful eating for their child and not limiting their child's diet. Several parents discussed ways that their diet has changed since their child's T1DM diagnosis, namely a decrease in sugar-sweetened beverages and other sweets, and a few parents shared that this had been a difficult change for them to make. Parents who discussed feeling distress in limiting their child's diet also highlighted another concern, namely the dilemma between allowing their child to eat less healthful foods versus strictly enforcing their child's diet and risking that their child may feel different from his/her peers. Universally, parents said that they did not want their child to feel different because of his or her T1DM. Thus, many parents said that they often give in to their child's requests for less healthful food options, suggesting a parent's desire for their child to "fit in" may be another barrier to healthy eating.

In this sample, parents' reporting on the BPFAS identified few behavior problems. However, picky eating was commonly identified as a barrier to healthful eating during interviews. In attempting to reconcile these findings, we took a closer look at individual items on the BPFAS and found that more than half of parents (56%) reported that their child will rarely to sometimes "try new foods" and about half (48%) reported that their child will "try to negotiate what he/she will eat," both items that are characteristic of picky eaters. Effective strategies are needed to assist parents in adopting evidence-based feeding practices to support children in expanding their food repertoire to include more helpful foods.³¹

A significant contribution of this study is its presentation of both quantitative and qualitative data, allowing for integration of parents' reported beliefs and behaviors and their personal narratives, perceptions, and opinions related to diet and mealtimes. Importantly, our results suggest that nutrition education programs should place more emphasis on addressing parents' perceived barriers to healthy eating and skill development versus knowledge of healthful eating. This is consistent with years of behavioral nutrition research that demonstrates that increased knowledge does not itself lead to behavior change.^{9,10} Specifically, programs should focus on teaching parents strategies (e.g., meal planners, recipes) to speed up food preparation and how to work around family-specific budget limitations. Programs should emphasize that the foods that are healthy for a young child with T1DM are also healthy for the entire family, thereby addressing any concern that a special diet may add to household food expenses. Likewise, there are less expensive alternatives to produce, including canned, frozen, and dried fruits and vegetables.³² Programs should also be teaching parents behavioral parenting approaches, such as contingent attention and shaping, to introduce new foods and encourage greater child acceptance of healthful foods.^{33,34,35} Finally, our results suggest that programs for families of young children include addressing parents' concerns related to peer or social influences on their child's eating. Parents of young children may need to learn strategies to help them to

manage their own negative feelings about “their child being different” because of T1DM. Likewise, depending on their child's own feelings and age, parents may benefit from learning strategies to help their child cope with “feeling different.” This could be accomplished by inviting their child to talk about his/her feelings, using statements to normalize their child's feelings, empowering their child by highlighting their strengths, setting limits for their child's behavior to ensure a consistent message, and using role playing to build their child's confidence in managing peer situations competently. It is unlikely these topics have been a focus of most existing nutrition-focused components of diabetes education programs for families of young children, and our results suggest that this may be an oversight.

On a broader scale, our findings may provide a direction for diabetes education programs to take in supporting a healthier food environment for all youths. Consistent with recommendations from the Dietary Guidelines for Americans 2010,³ diabetes education programs and the hospitals where these programs reside may be uniquely positioned to support local or regional strategic plans to increase youths’ access to healthful foods and safe places for physical activity, to create and support policies promoting health surveillance among youths, and to provide guidance in how to disseminate general nutrition and physical activity programs to youths and families.³ A focus on strengthening the food environment in which families of young children with T1DM live can also play an important role in facilitating individual behavior change.

Despite making a significant contribution to the literature in this area, this study is not without its limitations. The sample was relatively small and homogeneous. While recruitment continued until saturation for the qualitative themes was met, this left limited power for the quantitative analyses. Thus, the presentation of these data was limited to primarily descriptive outcomes and simple correlations. Likewise, though the sample had a racial and ethnic diversity similar to the clinic composition from which it was drawn and to the U.S. population of young children with T1DM at large,³⁶ it was predominantly White so the results may not generalize to young children from other socioeconomic, racial, or ethnic backgrounds. Specific to the sample, there were four families who withdrew before completing the study. However, in post-hoc analyses, no differences were found in child and family demographics for the families who completed or withdrew from the study. A study design limitation was the researchers’ use of parent-reported three-day diet diaries and self-report questionnaires which may be vulnerable to reporter bias. However, parents’ three-day diet diaries ultimately yielded HEI-2010 scores which suggested diets that did not meet USDA guidelines for healthy eating,¹⁹ thus minimizing a concern that parents may have misrepresented their child's diet. Another limitation was the study's cross-sectional design. Families diet records were only collected at one time point eliminating the opportunity to assess for reliability.

Conclusions

The results of this study identify several new key areas that care teams may want to address as part of nutrition education for T1DM, including minimizing parent-perceived barriers to healthful eating, parents’ concerns related to peer or social influences on their child's eating,

and any negative feelings parents may have related to “their child being different” because of T1DM. Providing on-going skill development in these new areas will enhance nutrition education programs and may also increase their perceived relevance to parents, who seem to desire more than just “nutrition facts” and strategies for counting carbohydrates. As one mother commented, “I think my message is, that it's a difficult disease, it's hard to manage. I think sometimes the medical professionals think ‘oh just make this certain change and you'll be fine.’ That's not how it always works, because you're dealing with a human being [who] has thoughts and feelings and may not want to eat how, you know, the medical professional is telling us to feed [our] children.”

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Practice Implications

What is the current knowledge on this topic?

Research has examined dietary beliefs and management practices in families of adolescents with type 1 diabetes mellitus (T1DM), revealing that these families hold some misconceptions as to what constitutes a healthful diet for T1DM.

How does this study add to the current knowledge on this topic?

There are many ways that young children are different from adolescents. We add new information by revealing the dietary beliefs and management practices of parents of young children with T1DM specifically.

Based on the study results, what are the implications for treatment?

To bridge the gap between what parents perceive to be a healthful diet and what they feed their young child, programs should offer personalized nutrition education and teach behavioral management and better coping strategies for T1DM.

Table 1

Open-ended questions for 23 parents of young children with type 1 diabetes participating in semi-structured interviews regarding healthful eating for young children with type 1 diabetes

	Questions
1	What is a healthful diet for a child with diabetes?
2	Think back to after your child was diagnosed with type 1 diabetes. What messages did you hear about diet and meal planning?
3	As a parent, what are important things you can do to help your child with diabetes eat a healthful diet?
4	How has the diet of your child with diabetes changed with his/her diagnosis?
5	Who or what influences your food shopping and meal planning?
6	What are things that can make it harder for your child with diabetes to eat healthful foods? (prompt to include personal barriers that parents perceive)
7	How have you changed how your family eats because of type 1 diabetes?
8	Suppose that you could talk to another family of a child with diabetes about diet and meal planning. What would you talk about?

Table 2

Summary scores on the Healthy Eating Index- 2010, a measure of diet quality for young children with type 1 diabetes in 23 families

Variable	Mean (Standard Deviation)	Range	Maximum Points	Number of children achieving maximum points
Total Score	63.5 (9.0)	53-91	100	0
<i>Adequacy:</i>				
Total fruit	3.8 (1.1)	2.0-5.0	5	7
Whole fruit	4.7 (0.7)	3.0-5.0	5	16
Total vegetables	1.8 (0.8)	1.0-3.0	5	0
Greens and beans	0.9 (1.2)	0.0-4.0	5	0
Dairy	7.7 (2.3)	2.0-10.0	10	6
Total Protein foods	3.7 (1.1)	2.0-5.0	5	7
Seafood and Plant Proteins	1.9 (1.7)	0.0-5.0	5	2
Whole grains	6.3 (2.6)	2.0-10.0	10	5
Fatty acids	4.6 (2.6)	1.0-10.0	10	1
<i>Moderation^a:</i>				
Refined grains	8.6 (1.7)	3.0-10.0	10	6
Sodium	7.2 (3.0)	0.0-10.0	10	7
Empty calories	12.2 (3.8)	5.0-20.0	20	1

Note:

^a Moderation component scores are reverse scored so higher values represent more healthful intake.

Table 3

Sample demographics and average percent energy from macronutrients in young children with type 1 diabetes for 23 families

Sample Demographics			
Variable	n (%)	Mean (Standard Deviation)	Range
Child age, years		4.6 (1.3)	2-6.9
Child sex, male	13 (56)		
Child race/ethnicity			
Hispanic	3 (13)		
Non-Hispanic White	18 (78)		
Black	2 (9)		
Parent age, years		35.7 (5.1)	27-49
Parent role, mother	21 (91)		
Parent marital status, married	19 (83)		
Parent education, some college	20 (87)		
Child HbA1c, %		7.8 (1.0)	
Child HbA1c, mmol/mol		62 (10.9)	
Child diabetes duration, years		2.0 (1.5)	
Child insulin regimen, pump	20 (87)		
Children's percent energy intake from macronutrients			
% energy from fat		33 (6)	22-41
% energy from saturated fat		11 (3)	6-15
% energy from protein		15 (3)	10-25
% energy from carbohydrates		54 (6)	44-68

Table 4

Summary scores on the Behavioral Pediatric Feeding Assessment Scale, a measure of mealtime behaviors, for 23 families of young children with type 1 diabetes

Variable	Mean (Standard Deviation)	Range	Possible Range
Child Frequency ^a	44.2 (9.0)	30-64	25-125
Parent Frequency ^a	16.3 (4.2)	10-28	10-50
Child Problem ^b	1.6 (2.3)	0-7	0-25
Parent Problem ^b	0.5 (1.3)	0-5	0-10

Note.

^a Frequency scores for the BPFAS measure parents' perceptions of how often a behavior occurs from never to always

^b Problem scores for the BPFAS reflect the number of behaviors that parents perceive to be problematic

Table 5

Parent quotes from interviews illustrating the qualitative themes regarding healthful eating for children with type 1 diabetes

Quote no.	Respondent/age	Youth age (yrs), sex, HbA1c (%)	Quotes
<i>There are differences in a healthful diet for children with or without T1DM</i>			
12	Mother, 32	5, boy, 8.7%	"One that has a good balance of like the fruits and vegetables, but also for him specifically we try to make sure there's a good ratio of carbs and protein to help sustain the carbs. Obviously, you can't avoid carbs, but it's nice to limit high carb foods- breads and crackers."
95	Mother, 32	3, boy, 6.9%	"The rest of the family has conformed to eating like him, so that he is not singled out; everyone is on the same page."
119	Mother, 27	6, girl, 7.7%	"And so she eats what her sister eats [because otherwise it's not fair to her sister...or it's not fair to her that her sister gets to eat sweets and she doesn't.]"
64	Mother, 34	5, boy, 8.3%	"I don't know if you're at other people's houses or other, you know, I guess when they see the way other people eat, but they get to have donuts and fruit roll-ups and this and that, you know, and so like I said, we have it for special times and if we're somewhere they definitely can have it at somebody else's house."
77	Mother, 32	6, girl, 8.7%	"Yeah, it's always been her choice and, you know, my other kids, I would have never allowed that, you know, what I serve for supper that's what we're having and if you don't eat you're just...that's it. But with her, obviously, I didn't feel like that's a good alternative. Why battle it. But when she doesn't eat her supper and she has a peanut butter sandwich, she doesn't get a snack."
81	Mother, 33	5, girl, 7.8%	"If she is extremely high and the rest of us are having spaghetti she's in the 300s or even pizza or something and she's in the 300s, we will sometimes vary what she's having for dinner because of that."
84	Mother, 40	3, boy, 7.9%	"I mean you say I'm not going to cook special food for the kids, but bottom line I always make sure that I have something that I know the kids are going to eat. And I think one of the things that was a real comfort, kind of gave me some comfort feeding meals, especially when they were a little younger and I just was worried, you know, I think when you first start dosing and, you know, you're like punching in that we're going to eat 30 grams of carbohydrates and are they really going to eat it and it made me feel good if I had one of those chocolate whips in the fridge because they've got a bunch of carbs in them and the kids love them and so I would know that if the whole meal was a flop, I could also be like, and I would always try to be kind of subtle about it so they wouldn't realize, 'oh, you didn't eat my new rice dish that I made, you know, so you get a chocolate yogurt in place.' I know I can be aggressive with my dosing because I've got a high carb thing as back up."
<i>Parents perceive barriers to healthful eating for children with T1DM</i>			
72	Mother, 29	3, girl, 7.1%	"It's easier to do stuff prepackaged because it has the carbs already figured for you. Even recipes online and stuff now have all of that info. However, you never know if it's true and you never know who came up with that and that sort of thing."
69	Mother, 35	5, boy, 8.3%	"I think the biggest barrier is the time. Because being a single parent on the go, it's hard to have the time, you know, adequate time to really plan, really shop, and really think about those meals and what would be best to serve me son."
58	Mother, 42	5, girl, 6.8%	"The fact that she just doesn't like certain... she doesn't like vegetables. That's our biggest challenge."
63	Mother, 32	6, boy, 8.3%	"Um, school. School and day care and just like the standard child diet. And like just the type of stuff that people bring in for parties or for just their school lunches are so unhealthy. I would never let him eat a school lunch, but that's like the standard that everybody expects."
67	Mother, 36	4, boy, 8.3%	"The world. School. Birthday parties. But he doesn't want to feel left out. And we don't want him to be and we don't want him to ever resent what he has."
124	Mother, 35	5, boy, 8.3%	"He sees his classmates eating other foods that he wants to eat, or drinking other juices and he feels, at times, left out. So really trying to balance that between letting him be a kid and still experience the joys of childhood, but then also managing his diabetes at the same time."
136	Mother, 32	5, girl, 7.6%	"She probably gets more sugar now and just for emotional reasons. I don't want her to feel left out and me saying no, she thinks it's... I don't want her to think it's because of her diabetes that I say no. Because it's not true."

Quote no.	Respondent/age	Youth age (yrs), sex, HbA1c (%)	Quotes
142	Mother, 43	5, girl, 7.6%	"It's tough though because we want her to feel like a normal kid, number one."
143	Mother, 42	3, girl, 6.8%	"So that everyone can have the same thing, that's really really important. I think more important to me than it is to her, but I don't want there to be any kind of questioning or different... you know, like well why is this kid getting to have something and I'm not getting to have that."
<i>How parents practice meal planning based on the nutritional education they have received</i>			
122	Mother, 40	3, boy, 7.9%	"We learned in the hospital, when [child] was diagnosed, just kind of the general idea that you need to count carbs and then there was a one hour class, maybe a couple, 2 or 3 weeks after that I went to that, you know, further told you about label reading. And then really a lot of stuff that I'm doing I was not taught in class or I just had to teach myself."
127	Mother, 42	3, girl, 6.8%	"I think being a good role model. Like the healthier I eat, if she sees me eating things and enjoy eating things that maybe she doesn't particularly like, it will encourage her to continue to try them, because maybe someday she'll like that."
131	Mother, 34	5, girl, 8.3%	"I think that I have changed what I eat because once she was diagnosed I realized that everything that I do she's going to copy and so I made an effort to be healthier and so I'm especially conscious of what I'm doing in front of her and what I'm eating in front of her. I find that I don't drink soda anymore. I drink water or hot tea or coffee or, you know, Diet Coke now. Never drank Diet Coke in my entire life, ever. But we don't keep any sugared drinks in our house anymore, so that was a big change."
134	Mother, 35	5, boy, 8.3%	"Educating him on what healthy foods are, what healthy foods are not, what that looks like, why he shouldn't eat it and then if he does eat an unhealthy food letting him talk about, you know, how is it making you feel? You know, showing him the high blood sugars that may result and so he can understand and see the consequences of his meal choices and from the things that he eats."
107	Mother, 40	3, boy, 7.9%	"When we're dosing he usually gets to decide for meals how much he eats. Are you hungry for 25 carbs or is it more of a, you know, I'll usually try to give a guideline, like I think it's about a 36 carb meal, but you know, do you want a whole bunch of noodles or a little bit because that might make us go back to 30 or it might make us go up to 45. And so with meals, I kind of talk, but with snacks, I kind of dictate what he needs to eat."