



# Understanding Nutritional Knowledge and Experiences in Families With a Child Newly Diagnosed With Type 1 Diabetes

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Nutrition is an integral part of diabetes management. Caregiver nutritional knowledge has been implicated in glycemic management of youth with type 1 diabetes. This study assessed the nutritional knowledge of parents/caregivers of children newly diagnosed with type 1 diabetes. Findings suggest there is a need for more targeted support and training during the initial diagnosis and a desire for more technology-related resources such as virtual nutritionist-guided grocery shopping visits. Integrating these interventions into routine care for children with type 1 diabetes will help address the current gaps in caregiver nutritional literacy and their ability to provide appropriate care.

Type 1 diabetes makes up about 5.8% of all diagnosed cases of diabetes in the United States (1), and the prevalence of type 1 diabetes in youth is rising (2). By 2050, it is projected that 5 million people in the United States will have type 1 diabetes, including nearly 600,000 children and adolescents <20 years of age (3). This is an increasing burden on the U.S. health system, and novel ways to better manage and address the needs of this growing population will be warranted.

Nutritional therapy is a cornerstone of type 1 diabetes management and is best administered with the assistance of a registered dietitian nutritionist (4–6). Poor glycemic outcomes are known to contribute to acute complications such as diabetic ketoacidosis, chronic complications such as microvascular and macrovascular disease, and an increase in the risk of infections (6–8). Nutrition also directly influences cardiovascular health, which is important for children with type 1 diabetes, who are at higher risk of cardiovascular morbidity (8). Improved dietary quality is associated with better glycemic management in youth with type 1 diabetes; however, many parents/caregivers of children with type 1 diabetes have difficulty understanding their child's nutritional needs (9).

Nutritional literacy assesses the degree to which individuals have the capacity to obtain, process, and understand basic nutritional or food-related information and services

needed to provide effective nutrition therapy. Health literacy, general literacy, and numeracy are all related to nutritional literacy and have been found to correlate to skills necessary for eating healthfully, including seeking out and trusting nutrition information sources (10), properly understanding nutrition labels (11), and estimating portion sizes (12). Better nutrition literacy predicts better dietary habits in adults (13), and better parental nutrition literacy predicts better dietary habits in children (14).

Previous studies have identified the need to improve caregiver support and literacy for those caring for children with type 1 diabetes. Caregivers of children with type 1 diabetes suffer worse mental health as a result of their increased duties, and education and clinical services to relieve this stress are not always provided (15,16). Caregivers have been found to rely on each other through blog sites, but there is limited evidence for consistency and reliability of the advice given on these sites (17). Challenges associated with diagnosis vary widely depending on the family but often include time constraints, financial concerns, lack of support, and child cooperability with dietary changes.

Research that assesses parent/caregiver health literacy and the need for increased caregiver support is available; however, similar research assessing nutritional literacy and caregiver perspectives on their needs is limited. This study

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This article contains supplementary material online at <https://doi.org/10.2337/figshare.21200113>.

<https://doi.org/10.2337/ds22-0009>

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fills a gap in the literature by examining the relationship between parent/caregiver nutritional knowledge/literacy and glycemic management of children with type 1 diabetes and directly eliciting caregiver perspectives on desired resources. We hypothesized that parent/caregiver nutritional literacy would be positively associated with glycemic management of youth with type 1 diabetes. We also hypothesized that caregivers would describe deficits in their ability to provide nutritious meals for their child, such as time, finances, and knowledge, that negatively affect the quality of the care they provide.

## Research Design and Methods

### *Participants and Recruitment*

The study was approved by the institutional review board (STUDY #11299) at Penn State College of Medicine. Caregivers (parents, stepparents, grandparents, adult siblings, or guardians) of children diagnosed with type 1 diabetes were recruited from the online diabetes community (18), including websites such as blogs and social media accounts. Eligible participants were caregivers of a child aged 1–17 years who was diagnosed with type 1 diabetes within the past year, U.S. residents, and able to read, write, and communicate effectively in English. Eligible participants provided implied consent before accessing the survey, which was distributed through REDCap (Research Electronic Data Capture) (19), a secure data information portal. A summary explanation of the research was provided through REDCap, and each participant was required to check “yes” if they agreed to the summary explanation of the research before proceeding to the survey.

### *Survey*

The survey consisted of questions assessing nutritional literacy, as well as closed- and open-ended questions related to food preparation, dietary habits, food preferences, and grocery store information. Nutritional literacy was assessed using the Nutritional Knowledge Survey (NKS) (20), a validated survey of general and diabetes-specific nutrition knowledge for youth with type 1 diabetes and their parents, developed by a multidisciplinary pediatric team. The NKS includes questions regarding healthful eating, carbohydrate counting, blood glucose responses to food, and nutrition label reading. Sociodemographic questions and diabetes-specific measurements such as self-reported A1C were also included in the survey.

Participants were informed that they could skip/refuse to answer any question. The survey was estimated to take ~15–20 minutes to complete. Participants had the option

to enter into a drawing for a \$25 gift card as compensation for their time.

### *Interviews*

Those who agreed to be contacted for a telephone interview to further discuss their responses were recruited for the qualitative portion of the study. Interviews were conducted over the phone by study team members (F.S., S.R., and J.P.), using Health Insurance Portability and Accountability Act-compliant Zoom videoconferencing ~1 year after participants had completed the survey portion of the study. The interview guide was composed of nine open-ended questions about nutrition and type 1 diabetes (Supplementary Material), as well as additional questions as necessary to facilitate the flow of the interview. Interviews were recorded and later transcribed for analysis using Rev.com.

### *Analysis*

Scoring of the NKS was calculated as the percentage of correct responses. Participants who skipped any question on the NKS were removed from the analysis, although the creators of the assessment allow skipped questions to be counted as incorrect, if desired. Scores were divided based on the median score into two groups: low NKS score and high NKS score. NKS scores were analyzed vis-à-vis caregiver-reported youth A1C level using a nonparametric Mann-Whitney *U* test. Statistical analyses were conducted using R and compareGroups software packages (21).

Qualitative analysis was completed in Microsoft Word using the inductive thematic analysis method. Three coders (F.S., S.R., and J.P.) reviewed the interview transcripts and developed preliminary codes based on patterns and similarities in the data. A codebook containing these codes, their definitions, and representative quotes was used by the coders to independently code the transcripts. A consensus approach was used so that initial disagreements were identified and resolved until 100% agreement was reached. Themes were generated after the coding process was complete.

## Results

### *Survey*

A total of 421 eligible participants completed the survey, of which 139 had complete NKS responses that were scored and used for analysis (Table 1). Ages of parents/caregivers ranged from 26 to 50 years, with a mean age of 38.9 years (SD 7.2 years). Seventy-nine participants had a bachelor's degree or higher, and 49 had no bachelor's degree. Of the participants, 126 completed the questions

**TABLE 1** Caregiver Demographics (*N* = 139)

Factor	Value
<b>Sex</b>	
Female	124 (89.2)
Male	4 (2.9)
Chose not to answer	11 (7.9)
<b>Relationship to child</b>	
Mother	124 (89.2)
Father	3 (2.2)
Stepmother	1 (0.7)
Legal guardian	1 (0.7)
Grandmother	1 (0.7)
Chose not to answer	9 (6.5)
<b>Race</b>	
White	121 (87.1)
Black or African American	1 (0.7)
Asian or Asian American	2 (1.4)
American Indian/Native Alaskan	3 (2.2)
Native Hawaiian or Pacific Islander	0 (0.0)
Other or mixed race	11 (7.9)
Chose not to answer	1 (0.7)
<b>Ethnicity</b>	
Hispanic or Latino	5 (3.6)
Not Hispanic or Latino	120 (86.3)
Chose not to answer	14 (10.1)
<b>Marital status</b>	
Single (never married)	5 (3.6)
Married/partnership	108 (77.7)
Divorced	12 (8.6)
Separated	3 (2.2)
Chose not to answer	11 (7.9)
<b>Employment status</b>	
Full time ( $\geq 40$ hours/week)	65 (46.8)
Part time (up to 39 hours/week)	22 (15.8)
Unemployed, looking for work	3 (2.2)
Unemployed, not looking for work	2 (1.4)
Student	2 (1.4)
Retired	1 (0.7)
Homemaker	38 (27.4)
Self-employed	4 (2.9)
Chose not to answer	2 (1.4)
<b>Highest level of education</b>	
Less than a high school diploma	0 (0.0)
High school degree or equivalent	8 (5.8)
Some college, no degree	16 (11.5)
Trade/technical/vocational training	5 (3.6)
Associate's degree	20 (14.4)
Bachelor's degree	51 (36.7)
Master's degree	23 (16.5)
Professional degree (e.g., MD/DO, DDS, JD)	2 (1.4)
Doctorate (e.g., PhD, EdD)	3 (2.2)
Chose not to answer	11 (7.9)
<b>Household income</b>	
Less than \$20,000	6 (4.3)
\$20,000–34,999	7 (5.0)
\$35,000–49,999	7 (5.0)
\$50,000–74,999	25 (17.9)
\$75,000–99,999	26 (18.7)
>\$100,000	55 (39.7)
Chose not to answer	13 (9.4)

Data are *n* (%). DDS, doctor of dental surgery; DO, doctor of osteopathic medicine; JD, juris doctor, MD, doctor of medicine.

pertaining to household income: 43% had a household annual income >\$100,000 and 83.4% had an income >\$50,000. Self-reported A1C ranged from <6 to >10.5% (42.1–91.3 mmol/mol). The majority of participants (*n* = 86 [66.2%]) reported seeing a nutritionist/dietitian one to two times since their child's diagnosis. Most participants also self-reported that their grocery store did not have a nutritionist/dietitian (*n* = 94 [69.1%]), followed by those reporting that they were unsure about the availability of this resource (*n* = 40 [29.4%]).

NKS scores ranged from 58.5 to 93.7 out of 100, with a median score of 78.3. Seventy participants scored below the median NKS score and were categorized as low NKS scorers. Sixty-nine participants scored above the median and were categorized as high NKS scorers. Higher NKS scores of caregivers were significantly associated with better A1C levels in youth with type 1 diabetes (*P* = 0.003). Of the caregivers with high NKS scores, 38% reported their child's last A1C to be >7.5% (58.5 mmol/mol). Of the caregivers with a low NKS score, 67% reported their child's last A1C to be >7.5% (58.5 mmol/mol).

Table 2 shows information related to NKS question difficulty, with difficulty relating to the number of incorrect/correct responses. Questions with the highest percentage of correctness (least difficult) were related to healthful eating and nutrition label reading. Questions with the lowest percentage of correctness (most difficult) were related to carbohydrate counting and nutrition label reading. These results are similar to the difficulty ratings assessed by Rovner et al. (20).

### Interviews

All caregivers who participated in interviews were female, and the average age was 38.4 years (SD 6.3 years). Most participants (80%) were White. The average age of the children of caregivers was 10.4 years (SD 4.0 years), and these children had been diagnosed an average of 2.4 months (SD 2.2 months) before the caregivers completed surveys. The mean A1C of the caregivers' children was 6.4% (46 mmol/mol).

### Themes

Qualitative analysis identified three major themes associated with caring for children newly diagnosed with type 1 diabetes.

#### **Theme 1: Nutritional Challenges Were Identified During the First Year After Type 1 Diabetes Diagnosis, an Often-Overwhelming Experience for Caregivers**

The year after initial diagnosis, there are many challenges to providing care for a child with type 1 diabetes such as a

**TABLE 2** Accuracy of the Most and Least Difficult NKS Questions for the Study Population ( $N = 195$ )

Question	Topic	Participants Who Answered Correctly, $n$ (%)
Which of the following foods provides the most vitamins and minerals?	Healthful eating	194 (99.49)
How many grams of carbohydrate are in 1 serving of Gatorade?	Nutrition label reading	193 (98.97)
How many servings are in this bottle of Gatorade?	Nutrition label reading	193 (98.97)
How many cups are in this can of chili?	Nutrition label reading	192 (98.46)
Which of the following is NOT a whole-grain food?	Healthful eating	191 (97.95)
Which of the following is NOT an example of a free food? ("Free foods" are those foods or drinks that have <20 calories and no more than 5 g of carbohydrate per serving.)	Carbohydrate counting	64 (32.82)
How many grams of carbohydrate are in 1 cup of cooked green beans?	Carbohydrate counting	50 (25.64)
How many grams of carbohydrate would you use to calculate an insulin dose for 1 serving of chili?	Nutrition label reading	44 (22.56)

lack of time and resources to prepare meals, lack of nutritious meals offered at school, stigma, and feelings of being overwhelmed. One caregiver stated:

*"Those first few weeks are really hard to navigate. We'd go to the grocery store, and she'd want everything, and we were limited on how much she could have at that time. So, that first few weeks is a really hard window, and it would be nice to have more support."*

Caregivers also felt pressured by the stigma associated with having different needs for their child with type 1 diabetes. As one put it:

*"I know that it affected me in that I wanted her to still be a typical kid and be able to eat what she wanted. And, I didn't want her to resent the disease the first year. So, I didn't want to stop her from eating certain things."*

Based on feedback from caregivers, there is nutrition-specific difficulty and pressure in handling a child's new type 1 diabetes diagnosis.

## **Theme 2: Caregivers Gained Confidence and Ability in Preparing Healthful Meals for Their Child Through In-Person and Virtual Support, Practice, and Resources**

After their child's diagnosis, caregivers reported using helpful resources such as physicians and nutritionists and social support such as family, friends, or the online diabetes community to help them cope with the challenges of caring for a child with type 1 diabetes. Caregivers expressed their tendency to search the Internet for tips on diabetes care. One caregiver said:

*"After the hospital, I got online with a million different Facebook support groups and learned a lot of information."*

Another described using digital apps such as Pinterest, saying:

*"I'm dependent on the Internet or Pinterest or recipes that my friends might share with me, as far as [meal planning]."*

Through their use of the aforementioned resources and supports, as well as continued practice, caregivers learned to make necessary changes to take care of a child with type 1 diabetes and implemented these changes in their child's daily routine (e.g., counting carbohydrates without assistance). One caregiver noted how she came to appreciate the importance of good nutrition for her child:

*"So, for us, it definitely became a journey to . . . still keep her being like a 'regular kid,' but also kind of realizing [that] now it's even more important that we are careful with our nutrition, that we're watching the foods that we're eating."*

Additionally, it was evident that caregivers felt more confident in their ability to prepare nutritious meals after the adjustment period immediately after their child's diagnosis. As one caregiver said:

*"My cooking has definitely gotten better . . . maybe not taste-wise, but in terms of food . . . just knowing that it's a lot easier to figure out a carb count when I make it myself versus a restaurant."*

This increased confidence showed how vital caregiver motivation and dedication is to a child's type 1 diabetes management.

## **Theme 3: Caregivers Offered Recommendations Regarding Customization of Meal Plans and the Use of Real-Time Technology to Support for Improving Nutrition After a Child's Diagnosis of Type 1 Diabetes**

Many caregivers expressed a desire for more support during the nutrition learning process that takes place

in the first year after a child’s type 1 diabetes diagnosis, including more information on reading nutrition labels and custom meal recommendations for their child. Caregivers continually expressed a desire for increased engagement from nutritionists. As one caregiver said:

*“I think they should ask questions [about] what your kid likes and what your kid eats and then give you options based [on] each child. Because everybody is different, and they just kind of give you a generic run-through.”*

Additionally, some caregivers suggested using smartphone apps to facilitate meal preparation:

*“I think that it would be really cool to make something interactive, like an app . . . that could be customized to a child. So, you can kind of put the preferences—you know, your child doesn’t like these kinds of things or does like these kinds of things—and then it automatically generates an idea list of some meals that you could provide. Because I think that’s part of it is—that you’re like, ‘Oh, okay, now I’m at the grocery. What should I make?’ Trying to get to my ideas. I think that would be a wonderful tool.”*

Caregivers also communicated being unsure of themselves in selecting meals and made positive remarks about possibly having grocery selection assistance from nutritionists. One caregiver said:

*“Maybe having nutritionists at the grocery store would help because then, when one of those items comes up that might have a lot of fiber, they can kind of say, ‘Okay, this is what you would do’ in a situation where it has a lot of fiber or has a lot of protein . . . but still has the carbs and whether we should count those carbs. So, it . . . would be helpful.”*

More meaningful involvement of nutritionists and health care providers in caregiver education was desired across participants, and many were highly receptive to potentially participating in an intervention to increase interaction.

Table 3 outlines the various potential resources that parents desired to make the transition to preparing diabetes-friendly meals easier.

### Discussion

Our quantitative findings showed varying NKS scores among caregivers and identified factors that contribute to higher scores, including older age, higher education level, and higher household income. Our qualitative findings shed additional light on the quantitative findings by identifying caregivers’ challenges in providing care for their child with type 1 diabetes during the first year after diagnosis. These challenges

**TABLE 3** Potential Resources Suggested by Interview Subjects to Improve Care for Their Child

Category	Recommendations
Technology	<ul style="list-style-type: none"> <li>• Telehealth options</li> <li>• Phone apps</li> </ul>
Personalization	<ul style="list-style-type: none"> <li>• Meal planning assistance</li> <li>• Nutritionist-guided grocery shopping</li> <li>• Parent-to-parent “buddy system” programs</li> </ul>
Information	<ul style="list-style-type: none"> <li>• Better carbohydrate counting instruction</li> <li>• More widely available nutritional information (e.g., for foods at schools and restaurants)</li> </ul>

included a lack of time and resources to prepare meals, a lack of nutritious meals offered at school, stigma associated with having a disease, and an overall feeling of being overwhelmed by their child’s diagnosis.

However, caregivers also identified resources to help address these challenges. For example, they mentioned the availability of in-person and virtual resources that helped to provide support and how this support empowered them to prepare healthy meals for their child and better manage the disease. Caregivers also offered important recommendations such as increased engagement of nutritionists, customized meal recommendations for their child, and increased use of technology (e.g., smartphone apps) to facilitate meal preparation; such resources were seen as a way to increase support and improve their nutritional care and management of their child’s diabetes. It is important to note that the majority of the participants self-reported that their grocery store did not have a nutritionist/dietitian available or they were unsure whether ones was available at their store. This resource may already exist in grocery stores near participants without their knowledge, supporting the need to raise awareness of existing community programs to increased their use.

Overall, the results of our study align with previous literature associated with the nutritional knowledge and needs of caregivers for children with type 1 diabetes. For example, our study found nutrition label reading and carbohydrate counting to be the two lowest-scoring domains of the NKS, similar to a study by Ndahura et al. (22). These researchers also found that caregivers with low education levels were more likely to have poor nutrition knowledge, which also aligns with our findings. This finding is important because it emphasizes the potential utility of incorporating the NKS into type 1 diabetes nutrition education. Once nutrition knowledge is assessed, education can be tailored to individuals’ NKS score.

Our study identified many barriers caregivers face that have been described in previous literature. For example, Kimbell et al. (23) identified the challenge of caregivers’

desire to enable a “normal childhood” for their child and reduce the stigma associated with the disease. This barrier underscores the importance of how a child perceives the disease and how that perception can influence a child’s physical and mental health. Lu et al. (24) also emphasized the mental stress, worry, and feelings of being overwhelmed that caregivers face. The uncertainty of their child’s condition and future seems to be the driving cause of caregiver stress.

There were also some differences between barriers identified in our study and those found in previous literature. Earlier studies discussed the economic burden that caregivers face resulting from high costs of their child’s treatment and hospitalizations (24,25). Caregivers in our study did not identify cost as a burden, most likely because of the generally high household incomes of our participants. Our study did pinpoint unique barriers associated with meal preparation, as previous studies did not focus on this specific aspect of care.

Similar to our findings, Kimbell et al. (23) found that diabetes technologies could lessen caregivers’ burden and influence their diabetes management practices. However, these technologies were more focused on insulin and blood glucose management rather than meal preparation. These authors also described types of support that were effective and ineffective for caregivers, noting that encounters with health care professionals were generally helpful but also led to caregiver frustration and anxiety (23). They found that other caregivers of children with type 1 diabetes provided caregivers with valued emotional and practical support. Our study also identified other caregivers as an important source of support, but our participants also identified a need for increased involvement of nutritionists to help with meal preparation for their child.

### *Impact of COVID-19 Pandemic*

Although the survey portion of this study took place before the onset of the coronavirus disease 2019 (COVID-19) pandemic, the interviews took place before and during the onset of stay-at-home orders in the United States (January through May 2020). Seven of the 10 interviews were performed after the United States declared COVID-19 a national emergency. Given the timing of the interview portion of this study, it is important to consider its results in the context of the pandemic.

The COVID-19 pandemic created a new set of challenges for diabetes care. Because of stay-at-home orders, fear of contracting COVID-19, and inability to schedule medical care in a timely manner, there has been a delay in access

to medical providers and/or specialists for patients with new-onset type 1 diabetes and increased reports of presentation of severe diabetic ketoacidosis (26–28).

Although we have limited information on the medical effects of COVID-19 on the population of people with diabetes, an increase in the use of telehealth and online resources amid the pandemic has provided nutritional resources for families and individuals with type 1 diabetes, including options for online education and clinical management with diabetes specialists (29,30). These new options have allowed many families and patients to access telehealth platforms and receive more comprehensive care by uploading data on physical activity, diet, blood glucose, and insulin dosing to discuss with their health care providers during videoconference or telephone visits. Incorporation of telehealth into the routine care of diabetes could be an asset for better nutritional and glyce-mic management of children with type 1 diabetes.

### *Limitations*

Our study included some limitations. First, our study population was predominately White and female and had a relatively high household income, limiting the generalizability of our findings. Additionally, because we recruited participants from the online diabetes community, our sample may not represent the general population of caregivers of children with type 1 diabetes. Our study did not specify in recruitment that only primary caregivers should take the survey; therefore, it is possible that more than one caregiver per child could have taken the survey. We also did not assess affinity to math in this study; therefore, some caregivers may have had an advantage in answering the NKS questions. Having a more diverse population of caregivers would increase the validity of these results across broader socioeconomic and racial/ethnic domains.

### **FUNDING**

This study was funded by the Thomas L. and Jean L. Leaman Research Endowment, Department of Family & Community Medicine, Penn State College of Medicine.

### **DUALITY OF INTEREST**

T.O. has served on an advisory panel for Dexcom and as a consultant for Cecilia Health Diabetes. She is a media spokesperson for the Association of Diabetes Care & Education Specialists. No other potential conflicts of interest relevant to this article were reported.

### **AUTHOR CONTRIBUTIONS**

F.S. contributed to the qualitative data collection and analysis and writing of the manuscript. J.C.G. and A.B. contributed to the quantitative data analysis and writing of the manuscript. S.R. contributed to the design of the study and interview guide, qualitative data collection and analysis, and writing of the manuscript. J.P. contributed to the design and implementation of the study, recruitment, qualitative and

quantitative data collection and analysis, and writing of the manuscript. T.O. contributed to the design and implementation of the study, qualitative and quantitative data analysis, and writing of the manuscript. T.O. is the guarantor of this work and, as such, has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis reported in this manuscript.

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