

Nutrition Knowledge in Children with Type 1 Diabetes and Their Parents

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Abstract

Aims: The purpose of this study is to investigate whether there is a relationship between the Nutritional Diabetes Knowledge Survey (NKS) score and the duration of Type 1 Diabetes in children.

Methods: All of the 200 children and adolescents with Type 1 Diabetes, aged < 18 years old, that we follow at our diabetes clinic, and their parents, were invited to complete a diabetes nutrition knowledge survey. The final score could range from 0 to 100%, with a higher percentage indicating better diabetes nutrition knowledge. Associations between NKS score and duration of diabetes, HbA1c, insulin administration mode, family income and parents' education were also analyzed.

Results: Of the 159 answers received, 129 surveys were valid for analysis. Median NKS score was 73.9% [60.9-82.6]. Most respondents were parents (43.4%), followed by children (40.3%) and by parents along with their child (16.3%). In this population, NKS score was inversely associated with diabetes duration ($\rho = -0.19$, $P = 0.029$) and even more so when we looked only at the parents' score ($\rho = -0.41$, $P = 0.002$). The further they were from the diagnosis, the less successful they were in the carbohydrate counting survey category ($\rho = -0.24$, $P = 0.006$). The score was also inversely associated with the HbA1c value ($\rho = -0.26$, $P = 0.003$) and was found to be better when factoring parent education level and insulin administration mode.

Conclusion: This study revealed a negative association between diabetes duration and diabetes nutrition knowledge, specifically in relation to carbohydrate counting.

Keywords: Education; Nutrition Knowledge; Type 1 Diabetes

Introduction

Day to day management of Type 1 Diabetes demands rigorous adjustments regarding meals and insulin as well as glucose monitoring and physical activity planning. The Diabetes Clinic team (nurse, doctor, nutritionist) is not directly involved in these daily adjustments. Therefore, structured education of patients with Type 1 Diabetes and their family is crucial to empowering them with the necessary skills at diagnosis and during follow up. Education steps are well described by many societies [1] and diabetes clinics usually adapt these recommendations with their own local tools [2] as there is no single internationally recognized education guide or booklet.

As part of this education 'Package', medical nutrition therapy has been demonstrated to be effective in diabetes outcomes in children and adults [3-10]. One of the main goals of this therapy

is to teach nutrition skills in order to improve knowledge of carbohydrate counting and to ensure the proper administration of insulin doses. Diabetes health-related quality of life in youth was also related to the strategy of 'carbohydrate counting' when compared to avoiding simple sugars' [11].

Despite all this knowledge transmission with age-adapted tools or technology (mobile applications can help with carbohydrate counting), therapeutic goals are not reached for most children with diabetes in North America [12]. This is probably multifactorial: Fear of hypoglycemia, or when family, personal and social burdens are present. But one can also question how knowledge is applied and retained in the long term. Accuracy of carbohydrate counting has been studied in adolescents using standardized meals: only 45% of participants could estimate the carbohydrate content of a meal or a snack within 10gr of the true amount [13,14]. In only one of these two studies, there was an association between counting accuracy, for the dinner meals, and glycemic control [13]. However, other factors than knowledge can affect glycemic control in this age

group, such as missed insulin injections for meals and regularity of meals. General diabetes knowledge has also been evaluated with questions related to several aspects of management. Parental knowledge correlates with glycemic control, whereas this is not always the case for children [15]. Two pediatric studies established their own questionnaire to assess knowledge about nutrition [16,17].

In order to meet ongoing nutrition education needs for children with Type 1 Diabetes followed at our clinic, we investigated whether there was a link between time since diagnosis and the score on a diabetes Nutrition Knowledge Survey (NKS) [16]. Rovner, et al found that youth but not parent NKS score was correlated to diabetes duration. However only families with children aged 8 to 18 years were included, and the convenience sample of participating families was not representing the real demographic (parents with higher education and few low-income families). Our hypothesis was that, given the children's or parents' experience, the longer the child has diabetes, the better his nutrition-related knowledge would be.

The secondary objective was to analyze associations between the NKS score and the socio-economic level of the family, HbA1c of the child, and the mode of insulin administration.

Methods

Subjects and Study Design

This cross-sectional study was conducted over a 15-month period at the CIUSSS de l'Estrie - CHUS, a tertiary hospital located in Sherbrooke, Québec, Canada. All children and adolescents with Type 1 Diabetes, aged < 18 years old (approximately 200 patients), followed at the Diabetes Clinic, and their parents were invited to participate in the study during a follow-up appointment. They were excluded if they couldn't speak either English or French, if another member of the family had already completed the survey, if they had severe gastrointestinal disease (excluding celiac disease), or if they refused to consent. We excluded all participants who were diagnosed less than 1 year prior to the survey (n=30). We feel that some families need 1 or 2 visits after diagnosis to get the complete information, for various reasons: adaptation to the shock of the diagnosis and readiness to learn in that context. Given the small number of participants, we could not explore in greater detail how much time was needed to reach the expected median scores on the survey. Therefore, we chose an arbitrary 1-year cut-off, as we felt this would be the necessary time for a family to receive the complete initial training on nutrition skills. In parallel, this same cut-off was used to interpret the HbA1c values after the honeymoon phase.

In our hospital, at diagnosis, all children with Type 1 Diabetes and their parents take part in a 2-hour standardized nutrition training session with a nutritionist. This training is

reinforced during the next outpatient visit, approximately 2 weeks after diagnosis. Children with diabetes referred from other centres also receive this training at their first visit. Although we were not audited, our education program follows the principles of nutrition therapy in ISPAD guidelines. All patients are monitored every 3 months at the Diabetes Clinic and meet with a nutritionist to review the nutrition plan (if a fixed plan is used) or the carbohydrates eaten during the day (type and estimated content). The nutritionist also provides nutrition counselling adapted to each patient's needs. Additionally, for patients moving to the insulin pump, a 4-day food diary is required. At this point, the nutritionist evaluates the child's or the family's knowledge of carbohydrate counting and discusses potential counting errors prior to using the pump. All participants or their parents signed the consent form. Prior to the beginning of this study, it was approved by an ethics committee, namely the Comité d'éthique de la recherche du CIUSSS de l'Estrie - CHUS.

Nutrition Knowledge Survey

The Type 1 Diabetes Nutrition Knowledge Survey (NKS) developed and validated by Rovner, et al. was used in this study with the consent of the author [16]. This survey, comprised of 23 multiple choice questions, is a tool used to measure specific and general diabetes nutrition knowledge. Each question has four response options and the whole survey contains four main categories: "Healthful eating, carbohydrate counting, blood glucose response to food and nutrition label reading" [16]. Each question of the NKS was worth one point. The score was calculated as the percentage of correctly answered questions and could range from 0 to 100%. A higher percentage indicating better nutrition knowledge. Questions skipped by participants in the paper version were counted as incorrect, as did Rovner, et al. [16].

This questionnaire was only available in English. We created a French counterpart by translating it to French, and then having it translated back to English by a professional translator to ensure that the meaning of each question was preserved. Even if children had more than one visit to the Diabetes Clinic during the recruitment period, they were allowed to complete the survey only once either on paper or online, on an electronic tablet under supervision. If the child was ≥ 12 years old and was managing his insulin himself, he was eligible to complete the questionnaire on his own. If children were < 12 years old, parents could complete the questionnaire by themselves or with their child. Participants whose first language was English completed the original survey.

Data Collection

For our main objective, time since diagnosis of diabetes was found in the patient Electronic Medical Record (EMR). For our secondary objective, Glycated Hemoglobin (HbA1c) was measured by high performance liquid chromatography (Tosoh G7, Somagen Diagnostics) on the day of the survey. Insulin administration mode (multiple injections or pump) was also found in the patient EMR.

Questions about family income and parents' education were added to the original survey for our study.

Statistical Analysis

Descriptive analyses are presented as a median with interquartile range as the variables were not normally distributed. The Spearman correlation coefficient was used between the NKS score and diabetes duration and other parameters such as survey categories, regimen and respondent type. A Kruskall-Wallis test was then performed to compare the score distribution between respondent type groups. Multiple comparisons were then made using the Mann-Whitney test, applying the Holm-Bonferroni correction to P values. To compare the distribution of scores between the regimen groups, a Mann-Whitney test was used. P values of less than 0.05 were considered statistically significant. Analyses were performed using SPSS version 24 (Québec, Canada).

Results

Not counting participants who were excluded, the total number of recruited children (n=159) represents nearly 80% of the children followed at our clinic. One family could not complete the survey because of their inability to understand French or English. Around 20 families did not give their consent. Median age of the 129 children included in the study was 13.2 years [9.8-15.3] and median duration since their diabetes diagnosis was 5.3 years [2.8-7.3]. Median HbA1c was 68 mmol/mol [61-78] (8.4% [7.7-9.3]) and 61% had an insulin pump (Table 1). The median and mean NKS scores were 73.9% [60.9-82.6] and 71.5 ± 14.7%. Most respondents were parents (43.4%), closely followed by children (40.3%) and only 16.3% of respondents were parents along with their child.

	Median (IQR) or n (%)
Age (years)	13.2 (9.8-15.3)
Sex	
Girl	59 (45.7)
Boy	70 (54.3)
Diabetes duration (years)	5.3 (2.8-7.3)

HbA1c (%)	68 mmol/mol (61-78) (8.4 (7.7-9.3))
Respondent	
Child	52 (40.3)
Parent	56 (43.4)
Parent and child	21 (16.3)
Regimen	
Insulin pump	79 (61.2)
Multiple daily injections	50 (38.8)
Parent education (n = 122)	
Less than High School	8 (6.2)
High school completed	34 (26.4)
College degree or equivalent	47 (36.4)
University degree	33 (25.6)
Family income (n = 116)	
< \$24,999	12 (9.3)
\$25,000 - \$49,999	20 (15.5)
\$50,000 - \$69,999	29 (22.5)
\$70,000 - \$99,999	40 (31.0)
\$100,000 - \$200,000	13 (10.1)
> \$200,000	2 (1.6)
IQR: interquartile range	

Table 1: Characteristics of study participants (n = 129).

In this population, NKS score was inversely associated with diabetes duration ($\rho = -0.19$, $P = 0.029$) and even more so when we looked only at the parents' score ($\rho = -0.41$, $P = 0.002$) (Figure 1). The further they were from the diagnosis, the less successful they were in the carbohydrate counting survey category ($\rho = -0.24$, $P = 0.006$). Regardless of whether children had an insulin pump or multiple daily injections, we observed that their NKS score got worse with duration of diagnosis (Table 2, Figures 2-3).

	Score (%) (median [IQR]) (mean \pm SD)	Correlation with diabetes duration	P value
Total (n = 129)	73.9 (60.9-82.6)	-0.19	0.029
	71.5 \pm 14.7		
Child (n = 52)	69.6 (57.6-78.2)	0.01	0.932
	67.4 \pm 15.0		
Parent (n = 56)	78.3 (69.6-82.6)	-0.41	0.002
	75.3 \pm 11.9		
Parent and child (n = 21)	78.2 (52.2-84.8)	-0.09	0.684
	71.4 \pm 18.4		
Survey categories			
Carbohydrate counting	66.7 (50.0-83.3)	-0.24	0.006
Healthful eating	71.4 (57.1-85.7)	-0.06	0.511
Blood glucose response to food	66.7 (66.7-100.0)	-0.17	0.058
Nutrition label reading	85.7 (71.4-100.0)	-0.09	0.339
Regimen			
Insulin pump (n = 79)	78.2 (69.6-82.6)	-0.28	0.011
Multiple daily injections (n = 50)	69.6 (51.2-79.3)	-0.32	0.024

IQR: Interquartile Range, MDI: Multiple Daily Injections, SD: Standard Deviation

Table 2: Association between nutrition knowledge survey score and diabetes duration depending on respondent, survey categories and regimen (n = 129).

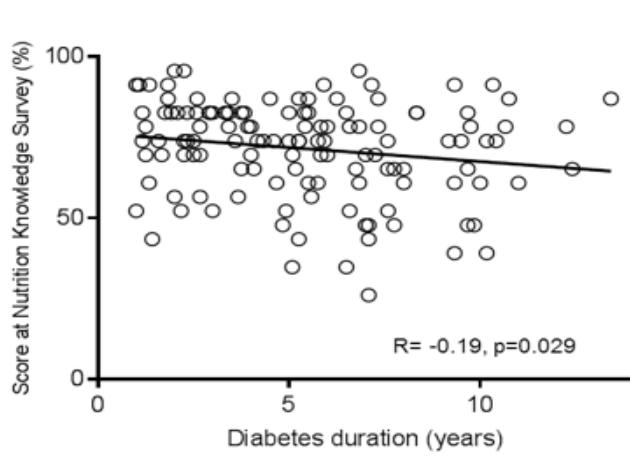


Figure 1: Association between nutrition knowledge survey score and diabetes duration.

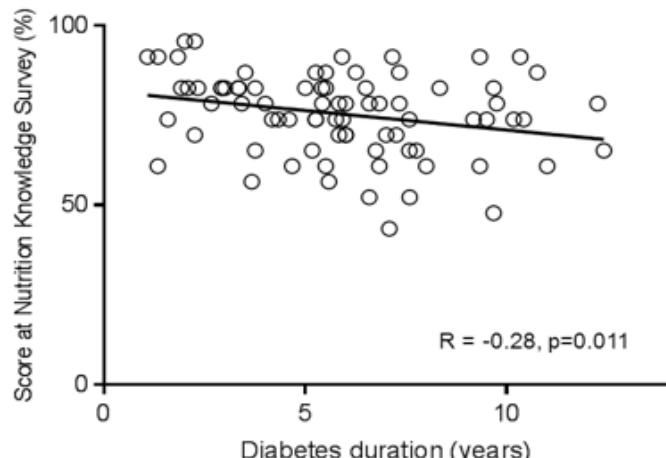


Figure 2: Association between nutrition knowledge survey score and diabetes duration in children with insulin pump.

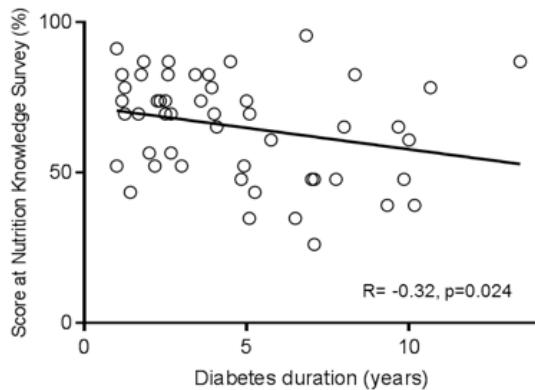


Figure 3: Association between nutrition knowledge survey score and diabetes duration in children with multiple daily injections.

NKS scores were inversely associated with HbA1c value ($\rho = -0.26$, $P = 0.003$) (Figure 4). Parents had a significantly better score than children alone (78.3% [69.6-82.6] vs. 69.6% [57.6-78.2], $P = 0.008$). Overall, the best score was obtained for the items related to “Healthful eating” (80% of correct responses). The scores for the next 2 categories were close: “Nutritional label reading” and “Blood glucose response to food” (79% and 75%, respectively). The category with the worst score was “carbohydrate counting” (54%). Participants who were on an insulin pump also had a significantly better score than those who had multiple daily injections (78.3% [69.6-82.6] vs. 69.6% [51.2-79.3], $P = 0.001$). However, the level of education of parents with children on a pump was also significantly higher than those on injections (73% had a postsecondary education compared to 52%, $P = 0.02$). Scores were found to be better based on the parents’ education level (Figure 5), but there was no correlation with family income.

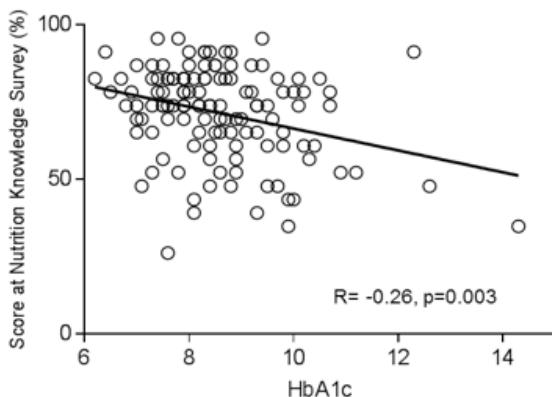


Figure 4: Association between nutrition knowledge survey score and HbA1c.

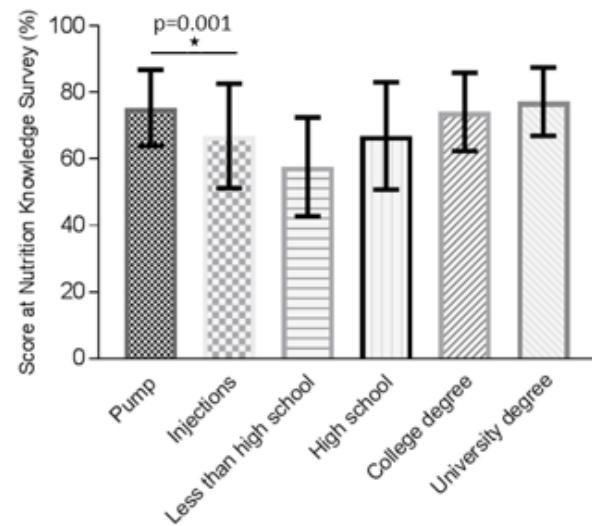


Figure 5: Nutrition knowledge score according to regimen and parent’s education.

Discussion

This cross-sectional study revealed that diabetes nutrition knowledge was inversely associated with diabetes duration. We were quite surprised to observe this, and, moreover, to see that this association was stronger with the parents’ score. In fact, it is the opposite of our initial hypothesis.

We also found that participants got worse in the carbohydrate counting category the longer they were from their diagnosis, which is new, rather interesting information for clinical practice. This could perhaps be explained by the hypothesis that, with time, people with diabetes count carbohydrates approximately and from memory rather than using their reference book, the scale or precise measuring tools. The same trend was found in the study evaluating the accuracy of carbohydrate counting in adolescents: the longer the child had been carbohydrate counting, the greater was the mean percentage error [14]. In their study, Rovner, et al. found a small positive correlation between the NKS score and diabetes duration only for youth (“ $\rho = 0.12$, $P = 0.04$ ” [16]). In another study assessing diabetes knowledge with a true or false survey, a small positive correlation between adolescent diabetes knowledge and diabetes duration has also been found [15]. However, this study was not specific to nutrition knowledge. We observed the same results with the children’s score ($\rho = 0.01$) but this was not statistically significant.

If we compare our mean scores with the ones found in the Rovner, et al. study (who originally developed the survey), we can see that our parents’ score ($75.3 \pm 11.9\%$) is quite similar (73.4

$\pm 12.5\%$). Our youth score ≥ 12 years old ($67.4 \pm 15.0\%$) is also fairly similar to their ≥ 13 years old score ($62.9 \pm 14.1\%$) [16].

This study also confirms that there is a positive association between diabetes nutrition knowledge and glycemic control (HbA1c) [16,17]. There was an association between NKS and education level, as shown previously in the recent French study evaluating general diabetes knowledge: the group even found that the highest association was related to social and familial factors and less to glycemic control [15].

Having 4 different question categories helps us to identify which areas we should focus on in relation to nutrition teaching. Patients have good skills when it comes to label reading. This suggests they are able to make an adequate carbohydrate calculation when consuming a commercial product because that information is readily available. The principal gap seems to be calculating carbohydrates of food that is unprocessed or not “ready to eat” because of the underutilization of measuring tools. In parallel to our findings, Smart et al. previously showed that the content of carbohydrates was underestimated in larger meals containing unlabelled food [14].

The NKS has shown us that basic knowledge about the carbohydrate content of some common foods is not optimal. The amount of carbohydrates contained in a given serving of a popular food is not acquired by all (questions about pasta, corn, milk). This tells us we should reinforce the idea that it is important to go back to reference documents when they don't know the carbohydrate content of a food. Everyone must acquire minimal knowledge relating to common foods.

In addition, analysis of the results demonstrates that not all participants are aware of the effect of food on blood glucose. Beyond the simple calculation of carbohydrates, some food choices (blood glucose response to food and healthful eating categories) can have a significant effect on glycemic control. Some basic nutrition concepts must be revisited with patients. In light of this, we must question ourselves as to whether our current nutritional teaching method is enough for children with diabetes and their family. We could perhaps try to improve the method by repeating this teaching in small interactive groups. This method was tried in asthmatic children and their families and seemed to be effective for managing asthma [18].

Given that this cross-sectional study only highlighted a trend in nutrition knowledge test score results compared to the time from diagnosis, a longitudinal cohort would have been an ideal study design to compare participants to themselves over time. Moreover, as the study sought a correlation, we were not able to assert a causal relationship between duration since diagnosis and the score on the nutrition knowledge test, but only to determine whether there was a link between these 2 variables.

The internal validity of the study was good because the sample from our study was representative of the target population under study. Also, as a monocentric study, the bias of nutrition education was very low. However, the results may not be applicable to other centres, given the possible difference in diabetes nutrition education provided.

Conclusion

In conclusion, this study showed that there is a negative association between diabetes nutrition knowledge and diabetes duration, specifically in carbohydrate counting. This has a clinical impact by demonstrating the importance of improving and repeating our nutrition teaching to children with diabetes and their families over time. Further prospective studies need to be done to corroborate the recurrence of our results and to assess nutritional knowledge and nutrition coaching over time.

What is already known? Medical nutrition therapy has been demonstrated to be effective in diabetes outcomes in children and adults.

What this study has found? This study showed that there is a negative association between diabetes nutrition knowledge and diabetes duration, specifically in carbohydrate counting.

What are the clinical implications of the study? This study has a clinical impact by demonstrating the importance of improving and repeating our nutrition teaching to children with diabetes and their families over time.

Conflicts of Interest: The authors have no conflict of interest to declare.

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