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# ATTENDANCE AT TYPE 1 DIABETES CAMP IMPROVES NUTRITION KNOWLEDGE IN CHILDREN AND ADOLESCENTS

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# ATTENDANCE AT TYPE 1 DIABETES CAMP IMPROVES NUTRITION KNOWLEDGE IN CHILDREN AND ADOLESCENTS

BY

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ABSTRACT

**Purpose:** The purpose of this study was to systematically assess nutrition knowledge in children and adolescents before and after attending a diabetes camp enhanced with a 45-minute education intervention. Knowledge was assessed using the Nutrition Knowledge Survey (NKS), a tool that has been validated in 10-18 year olds with Type 1 Diabetes (T1DM).

**Methods:** This study used a single group pre-post design. Campers completed the pre NKS at start of camp. The intervention was provided during camp, and campers completed the post NKS on the final day. Medical history and demographic data were collected from camp records. Changes in NKS score for all participants as well as separate analysis by age group was assessed using a paired t-test. Independent t-tests were used to assess the relationship between prior camp experience and NKS baseline score.

**Results:** Forty-seven eligible campers completed the Pre and Post NKS. There was a significant increase in NKS overall score (p = .002) and among those ages 13-17 (p=. 006) but not among those age 10-12 (p =. 155)

**Conclusions:** Attendance at a diabetes camp with a nutrition intervention as associated with a significant improvement in nutrition knowledge in children and adolescents with T1DM. Diabetes camps provide a safe and supportive environment for children and adolescents to improve nutrition knowledge.

KEYWORDS

Type 1 diabetes, glycemic control, nutrition education, diabetes camps, children and adolescents

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# PREFACE

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*To be submitted to The Diabetes Educator*

**Attendance at Type 1 Diabetes Camp Improves Nutrition Knowledge in Children and Adolescents**

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Type 1 Diabetes Mellitus (T1DM) currently affects over three million individuals in the United States with new diagnoses increasing at about 3% per year[1]. Diagnosis typically occurs during childhood and adolescence, age periods that can be challenging due to physiological and social changes that the individual is going through [2]. Daily management activities must be practiced to prevent acute hyper and hypoglycemia and the long-term complications of poorly managed T1DM that can be detrimental to health and quality of life [3, 4]. Skills for monitoring signs and symptoms of hyper and hypoglycemia, checking blood glucose, and accounting for carbohydrates with a highly individualized insulin regimen must be taught from point of diagnosis in conjunction with diabetes specific and general nutrition education [1, 5]. Nutrition education is provided at diabetes camps and previous studies have found nutrition knowledge improves after attendance at camp[6 7]. Diabetes camps provide a safe and supportive environment for children and adolescents with T1DM to strengthen nutrition knowledge and develop fundamental self-management skills[7-9].

In the few studies where nutrition knowledge was tested as a primary outcome, nutrition knowledge increased after attendance at a diabetes camp. However these studies failed to use validated instruments to assess nutrition knowledge. The Nutrition Knowledge Survey (NKS) was validated in the child and adolescent T1DM population[6]. The NKS is a 23 item questionnaire including seven questions on general nutrition knowledge such as the benefits of fruits, vegetables and whole grains, seven questions assessing carbohydrate counting, seven questions on nutrition label reading, and three questions assessing blood glucose response to foods[10]. Although the NKS is a validated instrument, it has not been used to assess change in knowledge, nor has it been used in the setting of a diabetes camp.

A strong understanding of general and diabetes specific nutrition knowledge is necessary to maintain optimal glycemic control and prevent long-term health complications in individuals with T1DM. Maintaining optimal glycemic control can be compromised by physical growth, hormonal state, physical activity and diet quality. Achieving optimal blood glucose control is particularly difficult in the child and adolescent due to physical and social maturation as well as diet quality [11-14]. Children and adolescents with T1DM typically consume a diet that does not include adequate amount of fruits, vegetables and whole grains but includes excessive amounts of total and saturated fat [13, 15, 16]. Most of the energy dense snacks that adolescents consume are processed foods that are high in added sugar and fat [13, 17]. Adolescents with T1DM may choose processed foods to facilitate counting carbohydrates from food labels[13, 14]. Another challenge facing this population is the commonality of the dual diagnosis of Celiac Disease (CD) [18-21]. Celiac disease affects between of 9.2 to 11.1% of individuals that have T1DM compared to the general population where about 1 in 100, or 1% of individuals are diagnosed with CD[22]. This dual diagnosis means greater dietary restrictions and a great need for nutrition education.

Providing general nutrition as well as diabetes specific nutrition education from point of diagnosis provides a foundation to help individuals self manage their diabetes[12]. A greater understanding of diabetes specific nutrition is related to better glycemic control, lower Hemoglobin A1c (A1C) and a reduced risk for developing cardiovascular disease[23, 24]. After completing diabetes specific nutrition education sessions, children and adolescents have improved carbohydrate-counting accuracy, which was maintained at follow-up [25] [26]. Nutrition education improves knowledge and management skills of children and adolescents with T1DM.

Physical activity is another factor that influences glycemic control. Regular physical activity provides a range of benefit especially in individuals with T1DM [27-30]. Despite the beneficial effects of physical activity, only 4.7% of children and adolescents with T1DM achieve the recommended 60 min of moderate to vigorous physical activity per day [28, 31, 32]. This may be due to a fear of hypoglycemia, which could prevent them from believing that they are able to participate, or reduce their exercise self efficacy [27]. Diabetes camps provide a safe setting for children and adolescents with T1DM to participate in physical activity, and therefore campers may have greater physical activity self-efficacy (PASE) in this setting compared to others[33, 34]. However PASE has not been assess in relationship to diabetes camps.

Attendance at diabetes camps improves nutrition knowledge and glycemic control in children and adolescents with T1DM in a safe supportive environment with a controlled, diet and exercise regimen [8] [33, 34]. However, the tools used to assess nutrition knowledge in previous research were not validated. The NKS was validated in the clinical setting in individuals age 10-17 with T1DM but has not been used to assess change or to assess knowledge in a diabetes camp[10]. The primary purpose of this study was to assess nutrition knowledge using the validated NKS after attending a diabetes camp with a 45-minute nutrition education. The secondary purpose is to analyze the relationship between previous camp experience physical activity self-efficacy.

**Methodology**:

Research design

This study used a single group pre post design. Participants attended a one-week summer camp at Camp Surefire, a camp specifically for children and adolescents with T1DM. Campers were exposed to standard nutrition and diabetes education from this staff. Campers also received an additional nutrition education session. Participants completed pre test of diabetes nutrition knowledge (Nutrition Knowledge Survey, NKS)[10] as well as a Physical Activity Self-Efficacy (PASE) questionnaire on the first day of camp and the post NKS at the end of camp [35]. The primary hypothesis was that campers would increase knowledge (NKS score) from pre to post-test. The University of Rhode Island Institutional Review Board approved this study.

Participants

A total 75 campers attended camp in the Summer 2014. Inclusion criteria for this study included 1) age 10 – 17 years, and 2) completion of parental consent form, camper assent form, and parental HIPAA release form. Only eligible participants completed the assessments. Forty-nine campers met eligibility criteria. Of the 49 eligible campers, two campers did not complete the post NKS leaving a final total study sample of 47 that completed the pre and post NKS.

Instruments

Data collection forms included medical history and demographic information developed by camp staff. The medical history form assesses gender, age of diagnosis, insulin regimen and administration technique, presence of celiac disease, most recent A1C, height weight, and prior attendance at Diabetes Camp. The parents of the campers filled out these forms. BMI percentile for age and gender were calculated based on the Center for Disease Control standards and BMI z-score was calculated using a validated online calculator [36].

Nutrition knowledge was assessed on the first and last day of camp. The NKS was developed by a multidisciplinary team and was validated after administration to 282 children and adolescents ages 8-18 years old with T1DM at a diabetes clinic[10]. Item discrimination (ID) (15-25%) and the Kuder- Richardson Formula 20 (KR-20) were used to determine a final set of 23 items (coefficient alpha >.70)[10]., Each of the 23 questions had four possible responses with one correct answer. In development of the instrument, it was found that adolescents 13-18 years (62.9 ± 14.1%) had higher score than children 10-12 years of age (49.4 ± 16.0%) and NKS scores were correlated with age (r=0.44, p=0.0001) suggesting that scores should be grouped by age[10] .

Physical activity self efficacy (PASE) was assessed at the beginning of camp by participants using a validated tool[37]. The instrument was validated in healthy third and fourth grade students by Parcel et al. [37]. The questionnaire includes 5 questions about physical activity with three options, “not sure” (score=1), “a little sure” (score=2) or “very sure” (score=3) [37] for a range of 5-15 points with higher scores associated with greater PASE. In the validation of this survey, the average PASE score was 12.25 ± 2.07 (KR-20 coefficient alpha = 0.569). Physical activity was closely monitored during camp and campers perception of physical activity may have changed after being exposed to it in a controlled setting, however PASE was only assessed at baseline because the intervention did not directly address physical activity.

Procedures

Prior to camp, a letter was sent out to all families attending camp introducing the project. In this letter they were made aware that upon arriving to camp they will visit a table where, if willing to participate, they will be asked for parental consent, camper assent forms, and HIPAA release forms. Standard demographic and medical history information were recorded in an online survey that all families fill out prior to camp. On the first day of camp, prior to their first meal, the participating campers completed the NKS and PASE questionnaire. Prior to this, no camper had been previously exposed to the NKS. Throughout the week campers attend standard nutrition education lessons as well as an enhanced nutrition education intervention described below. On the last day of camp, prior to their first meal, participating campers completed only the NKS survey. The answers to the NKS were not discussed at any point.

Intervention

The intervention was provided separately to younger campers age 10-12 and older campers age 13-17. The intervention for both age groups was exactly the same and lasted 45 minutes including a general nutrition lesson followed by a diabetes specific nutrition lesson including nutrition facts labeling, portion sizes, and insulin dose related to carbohydrate intake. The intervention was developed for this study but was not based directly off on the questions asked but rather the themes present in the NKS. Though the diabetes specific lesson was very similar to the format of the questions asked in this section of the NKS, the food examples were different and several portion sizes were discussed.

The general nutrition lesson used a lesson board with columns for each food group and two rows labeled “likes” for healthier options and “dislikes” for less healthy options. Campers were given food models and asked to get into groups based on the items that they had been provided. Once campers were in groups, they discussed why they chose their groups. The "Nutrition Likes and Dislikes" board was then presented to the group. Information about how important it is to eat foods from each food group every day was presented including how there are healthy "likes" and unhealthy "dislikes" in each food group depending on how the food was processed and prepared. Campers then placed their food model in the correct food group either as a "like" or "dislike" and explained to the group why they chose to place it where they did.

The next section used a large nutrition facts label with missing values, which was filled in during an interactive discussion about reading the food label, portion sizes and insulin dosages. Food models (including healthy and unhealthy items) with nutrition facts labels were printed and campers were responsible for filling out these on the nutrition facts label lesson board.

**Analysis**

Variables were assessed for normality using skewness and kurtosis and analyzed using SPSS (IBM 22.0. Armonk,NY). Demographic and medical data were compared between two age groups (10-12 years and 13-17 years) using independent t-tests and chi-squared tests. Changes in NKS score for all participants as well as separate analysis by age group was assessed using a paired t-test. Data was again split into prior camp experience and no prior camp experience. Independent t-tests were used to compare prior camp experience with baseline NKS score as well as prior camp experience and PASE. Based on the age effect found in the validation of the NKS, Analysis of Covariance

(ANCOVA) explored controlling for age. Nonparametric bivariate spearman correlation was used to assess the relationship between baseline NKS score and PASE.

**Results**

Demographic and medical history data are presented in table 1. There was a significant increase in NKS score from pre to post (t=3.2, p=.002). Table 2 presents NKS pre and post scores. Scores were first analyzed by total campers (N=47) and then by age group (age group 1 (10-12 years n=16) and age group 2 (13-17 years n=31)). There was no effect of age on change in NKS score (ANCOVA f=0.7, $t_{45}$=1, p=.724).

There was a significant correlation between baseline knowledge and PASE score (r=.363, p=.004). The four campers that did not have previous camp experience had a mean PASE score of 12.8 compared to the 40 campers with previous camp experience mean PASE score of 12.4, which was not significantly difference (t=.353, p=.676). There no difference between baseline NKS score and previous camp experience (t=.559, p=.653). Campers in the celiac group had significantly greater knowledge at baseline compared to campers that did not have celiac (t=2.2, p=.03), however there was no effect of celiac disease on change in NKS score (ANCOVA f=0.6, 1,45df, p=.45).

**Discussion:**

As hypothesized, there was a significant increase in knowledge from pre to post in campers but this appears to be primarily due to 13-17 year olds; there was not a significant change in knowledge in 10-12 year olds. This significant increase in knowledge in older campers reinforced previous finding that attendance at a diabetes camp improves nutrition knowledge and diabetes management. Physical activity self-efficacy was positivity correlated with baseline knowledge.

The significant increase in knowledge in campers age 13-17 years but not 10-12 years either be explained by differences in understanding the tool and intervention. The NKS has not previously been used as a pre post tool to measure change in nutrition knowledge. Younger campers may either truly have less nutrition knowledge than older campers or may have had difficulty with the NKS at baseline and therefore would have the same problems at post. The older children may have a better understanding of the NKS, making it a better measure of their baseline knowledge as well as their change in knowledge. The significant increase in knowledge in older children may also be a reflection the impact of nutrition intervention. The instructor noted they were attentive during the intervention and interactive. Some expressed how they had been exposed to the information presented to them before, but that it was presented in a different way, and the interactive lesson allowed them to learn and understand more. The younger campers viewed the intervention as more of a game then a learning opportunity. This may have caused the reduced increase in knowledge. Further research is needed on the sensitivity of the NKS to measure change in younger children.

Campers age 13-17 proved to have greater NKS scores at baseline compared to campers age 10-12. This was anticipated due to the age effect that was found during the validation of the NKS. The validation study found adolescents 13 years of age or older had higher score than children that 10-12 years, 62.9 ± 14.1% versus 49.4 ± 16.0%, respectively[10]. These results remained the same after controlling for age, family income, parent education, diabetes duration, and insulin regimen. The current study found similar results in those 13-17 years scored an average of 62.8 ± 17.6 compared to those 10-12 years who scored an average of 51.2 ± 14.9% at baseline. The validity of the baseline scores of campers is strong because the similarity of the results in the validation of the NKS.

Previous studies found significant effects of attendance at camp on nutrition knowledge. Tuchinda et al. using a non-validated instrument found average knowledge scores increased from 65% at the start of camp to 80% after camp, a 15% significant increase ($p < 0.001$)[6]. Bundak et al. also reported increase in knowledge from 69.5% pre-camp to 79.5% post-camp, a 10% significant increase ($p < .05$)[7] but they also used a non-validated instrument. This study found a 4.1% increase in knowledge was found in this study. Although this percent increase is not as large as reported in previous studies, the knowledge measurement tools used in other studies were developed for those studies and based on education given at camp. This may have made it easier for campers to translate what they learned onto the test. The intervention given in this study was based on the themes present in the NKS rather than the specific questions. For example, discussing the impact of processing of foods on the nutrient content compared to discussing specific examples from the NKS. This ensured that the campers were retaining more nutrition knowledge rather than answers to specific nutrition questions.

Greater PASE may lead to more participation in physical activity, which will lead to improved weight and glycemic control. Physical activity self-efficacy in the T1DM adolescent population was studied by Faulkner et al [39]. Adolescents age 12-19 years old who were not routinely active were given a 10-item questionnaire giving reasons as to why the individual would not exercise. On this scale, a lower score, meaning less perceived barriers, was associated with greater PASE[39]. The PASE mean was 3.792 ± 0.640[39]. This is a greater score than to be expected because this population does not typically participate in the recommended about of physical activity. These scores also may be better than predicted because of the safe environment and sense of support that they have. Physical activity self-efficacy was measured because fear of hypoglycemia may influence the individual's perception of their ability to participate in physical activity. Physical activity self-efficacy is dependent on past experience, familiarity, control over the situation, and support from peers [35]. The fear of hypoglycemia has been shown to be a barrier in children with T1DM[27]. Therefore, it is logical to theorize that individuals with T1DM would have less self-efficacy in their ability to participate in physical activity compared to their peers. Healthy individuals of about the same age as those involved in this study were used in the validation of the PASE questionnaire[37]. The average PASE score was 12.25 ± 2.07 in the healthy school children, which is similar to the PASE score for campers in this study, 12.3 ± 2.03. All of these studies were either completed in a school or other safe environment where participants were surrounded by support. Also, in the camp setting physical activity is a part of daily activities and about 89% of campers had previous camp experience. Although previous camp experience did not prove to have a statically significant relationship with PASE (t=.353, p=.676), with a larger sample size previous camp experience may have impacted PASE scores.

Those who reported celiac disease (CD) had higher NKS scores compared to those who did not. Individuals with CD must consume a gluten free diet in order to prevent inflammation and damage of the small intestine[22]. A dual diagnosis requires monitoring carbohydrate intake, while maintaining a gluten free diet that often contains high carbohydrate foods [22]. Parents of campers reported presence of CD. Thus, it is not possible to know if this report reflected a diagnosis of CD or parental perception of gluten sensitivity. Those with reported celiac disease do not have a confirmed diagnosis. Those reported to have celiac had an average baseline NKS score of 68.7% compared to an average score of 55.7% in those who did not identify with celiac disease. To the author's knowledge this is the first assessment of nutrition knowledge in children and adolescents with CD. Further research is needed to investigate the relationship between nutrition knowledge and CD in children and adolescents with T1DM.

A major strength of this study is the use of a validated knowledge instrument (NKS) to measure nutrition knowledge in a camp setting. The NKS is one of few nutrition knowledge surveys for children and adolescents with T1DM that measures diabetes specific as well as general nutrition knowledge [5]. To the author's knowledge, this is the first study to use this instrument to measure knowledge pre and post a diabetes camp. Another strength of this study is the setting and intervention. This camp provided an ideal, safe setting for learning, staffed by a multidisciplinary team of nurses and dietitians and led by the founder of the camp who is an endocrinologist. The campers receive around the clock medical care while enjoying the summer camp setting. The intervention found to be effective through a significant increase in knowledge in older children.

The major limitation of this study is a lack of a control camp. Without a control camp, it is impossible to separate the effects of camp from the effects of intervention. Future research is needed using an experimental design. Another limitation is the self-reporting of medical history data such as celiac disease. Medical data from primary care physicians office may be more accurate. The final limitation is that there was no follow-up. Previous studies found campers retained the knowledge learned at camp for 6-12 months after camp but these did not use a validated knowledge instrument[6].

The prevalence of T1DM is increasing rapidly in children and adolescents resulting in the need for additional research in nonclinical settings such as diabetes camps. Children and adolescents with greater nutrition knowledge have been shown to have greater glycemic control as well as better overall management of their T1DM. As individuals transition from childhood to adolescence, they begin to gain independence and make more of their own decisions and self manage their diabetes[12]. This study found a significant increase in knowledge post camp.

References


1. Y. L. Wu, Y. P. Ding, J. Gao, Y. Tanaka, and W. Zhang, "Risk factors and primary prevention trials for type 1 diabetes," International Journal of Biological Sciences, vol. 9, pp. 666–679, 2013.
2. Daneman D. Type 1 diabetes. *Lancet.* Mar 11 2006;367(9513):847-858.
3. Mitrovic M, Popovic DS, Naglic DT, Paro JN, Ilic T, Zavisic BK. Markers of inflammation and microvascular complications in type 1 diabetes. *Central European Journal of Medicine.* Dec 2014;9(6):748-753.
4. Nathan DM. Lifetime benefits and costs of intensive therapy as practiced in the diabetes control and complications trial (vol 276, pg 1409, 1996). *Jama-Journal of the American Medical Association.* Jul 2 1997;278(1):25-25.
5. American Diabetes A. Standards of medical care in diabetes--2013. *Diabetes Care.* Jan 2013;36 Suppl 1:S11-66.
6. Tuchinda C, Likitmaskul S, Unachak K, Panamonta O, Patarakijavanich N, Chetthakul T. The epidemiology of type 1 diabetes in Thai children. *J Med Assoc Thai.* Jun 2002;85(6):648-652.
7. Karaguzel G, Bircan I, Erisir S, Bundak R. Metabolic control and educational status in children with type 1 diabetes: effects of a summer camp and intensive insulin treatment. *Acta Diabetol.* Dec 2005;42(4):156-161.
8. Carlson KT, Carlson GW, Jr., Tolbert L, Demma LJ. Blood glucose levels in children with Type 1 diabetes attending a residential diabetes camp: a 2-year review. *Diabet Med.* Mar 2013;30(3):e123-126.
9. Wang YCA SS, Tuli E, White P. Improved glycemic control in adolescents with type 1 diabetes mellitus who attend diabetes camp. *Pediatric Diabetes* 2008;9:29-34.
10. Rovner AJ, Nansel TR, Mehta SN, Higgins LA, Haynie DL, Laffel LM. Development and validation of the type 1 diabetes nutrition knowledge survey. *Diabetes Care.* Aug 2012;35(8):1643-1647.
11. Snyder CK. Strategies to improve insulin adherence in adolescents with type 1 diabetes. *J Pediatr Nurs.* Jan-Feb 2015;30(1):278-280.
12. Silverstein J, Klingensmith G, Copeland K, et al. Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care.* Jan 2005;28(1):186-212.
13. Nansel TR, Lipsky LM, Liu A, Laffel LM, Mehta SN. Contextual factors are associated with diet quality in youth with type 1 diabetes mellitus. *J Acad Nutr Diet.* Aug 2014;114(8):1223-1229.
14. Lipsky LM, Nansel TR, Haynie DL, Mehta SN, Laffel LM. Associations of food preferences and household food availability with dietary intake and quality in youth with type 1 diabetes. *Appetite.* Oct 2012;59(2):218-223.
15. Rovner AJ, Nansel TR. Are children with type 1 diabetes consuming a healthful diet?: a review of the current evidence and strategies for dietary change. *Diabetes Educ.* Jan-Feb 2009;35(1):97-107.
16. Nansel TR, Haynie DL, Lipsky LM, Laffel LM, Mehta SN. Multiple indicators of poor diet quality in children and adolescents with type 1 diabetes are associated

with higher body mass index percentile but not glycemic control. *J Acad Nutr Diet.* Nov 2012;112(11):1728-1735.

**17.** Piernas C, Popkin BM. Trends In Snacking Among US Children. *Health Affairs.* Mar-Apr 2010;29(3):398-404.

**18.** Not T, Tommasini A, Tonini G, et al. Undiagnosed celiac disease and risk of autoimmune disorders in subjects with Type 1 diabetes mellitus. Diabetologia 2001;44:151–5.

**19.** Frohlich-Reiterer EE, Hofer S, Kaspers S, et al. Screening frequency for celiac disease and autoimmune thyroiditis in children and adolescents with type 1 diabetes mellitus - data from a German/Austrian multicentre survey. *Pediatric Diabetes.* Dec 2008;9(6):546-553.

**20.** Mackinder M, Allison G, Svolos V, et al. Nutritional status, growth and disease management in children with single and dual diagnosis of type 1 diabetes mellitus and coeliac disease. *Bmc Gastroenterology.* May 28 2014;14.

**21.** Cronin CC, Shanahan F. Insulin-dependent diabetes mellitus and coeliac disease. *Lancet.* Apr 12 1997;349(9058):1096-1097.

**22.** Erickson K, Freeborn D, Roper SO, Mandleco B, Anderson A, Dyches T. Parent experiences raising young people with type 1 diabetes and celiac disease. *J Pediatr Nurs.* Mar-Apr 2015;30(2):353-363.

**23.** Mehta SN, Volkening LK, Anderson BJ, et al. Dietary behaviors predict glycemic control in youth with type 1 diabetes. *Diabetes Care.* Jul 2008;31(7):1318-1320.

**24.** The NS, Crandell JL, Thomas J, et al. Correlates of medical nutrition therapy and cardiovascular outcomes in youth with type 1 diabetes. *J Nutr Educ Behav.* Nov-Dec 2013;45(6):661-668.

**25.** Spiegel G, Bortsov A, Bishop FK, et al. Randomized nutrition education intervention to improve carbohydrate counting in adolescents with type 1 diabetes study: is more intensive education needed? *J Acad Nutr Diet.* Nov 2012;112(11):1736-1746.

**26.** C.E. Smart, K. Ross, J.A. Edge, B.R. King, P. McElduff, C.E. Collins Can children with type 1 diabetes and their caregivers estimate the carbohydrate content of meals and snacks? Diabet Med, 27 (2010), pp. 348–353

**27.** Yardley J, Mollard R, MacIntosh A, et al. Vigorous intensity exercise for glycemic control in patients with type 1 diabetes. *Can J Diabetes.* Dec 2013;37(6):427-432.

**28.** Minges KE, Whittemore R, Grey M. Overweight and obesity in youth with type 1 diabetes. *Annu Rev Nurs Res.* 2013;31:47-69.

**29.** Janssen I, LeBlanc AG. Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *International Journal of Behavioral Nutrition and Physical Activity.* May 11 2010;7.

**30.** Warburton DER, Nicol CW, Bredin SSD. Health benefits of physical activity: the evidence. *Canadian Medical Association Journal.* Mar 14 2006;174(6):801-809.

**31.** Liese AD, Ma XG, Maahs DM, Trilk JL. Physical activity, sedentary behaviors, physical fitness, and their relation to health outcomes in youth with type 1 and type 2 diabetes: A review of the epidemiologic literature. *Journal of Sport and Health Science.* Mar 2013;2(1):21-38.

**32.** Schweiger B, Klingensmith G, Snell-Bergeon JK. Physical activity in adolescent females with type 1 diabetes. *Int J Pediatr.* 2010;2010:328318.
**33.** Botero D, Wolfsdorf JI. Diabetes mellitus in children and adolescents. *Arch Med Res.* May-Jun 2005;36(3):281-290.
**34.** Santiprabhob J, Likitmaskul S, Kiattisakthavee P, Weerakulwattana P, Chaichanwattanakul K, Nakavachara P, et al. Glycemic control and the psychosocial benefits gained by patients with type 1 diabetes mellitus attending the diabetes camp. Patient Educ Couns. 2008 Jul 5;73(1):60–6.
**35.** Edmundson E, Parcel GS, Feldman HA, et al. The effects of the child and adolescent trial for cardiovascular health upon psychosocial determinants of diet and physical activity behavior. *Preventive Medicine.* Jul-Aug 1996;25(4):442-454.
**36.** The Children's Hospital of Philidelphia. Pediatric Z-Score Calculator. http://stokes.chop.edu/web/zscore/. Accessed December 2014.
**37.** Parcel GS, Simons-Morton B, O'Hara NM, Baranowski T, Wilson B. School promotion of healthful diet and physical activity: impact on learning outcomes and self-reported behavior. *Health Educ Q.* Summer 1989;16(2):181-199.
**38.** Cohen J. Statistical Power Analysis for the Behavioral-Sciences *Perceptual and Motor Skills.* Dec 1988;67(3):1007-1007.
**39.** Faulkner MS, Michaliszyn SF, Hepworth JT. A personalized approach to exercise promotion in adolescents with type 1 diabetes. *Pediatric Diabetes.* May 2010;11(3):166-174.

| Table 1: Demographic data by age group | | | |
|---|---|---|---|
| | Age Group 1 (10-12 years) n=16 | Age Group 2 (13-17 years) n=31 | |
| | **(M ± SD) or %(n)** | **(M ± SD) or %(n)** | **p** |
| Age | 10.9 ± .75 | 14.3 ±1.1 | <.001 |
| Age of diagnosis | 6 ± 2.9 | 7.3 ±4.4 | .338 |
| Height (inches) | 58.9 ±4.1 | 65.1± 4.4 | .001 |
| Weight (pounds) | 100.6 ±18.9 | 132.9 ±24.7 | .001 |
| BMI | 21.2 ±4.1 | 22.3 ±3.35 | .430 |
| BMI Z-score | .78 ±1.1 | .54 ±1.1 | .569 |
| A1C (% (mmol/mol)) | 8.6% (70mmol/mol) ±1.3 | 8.2 (66mmol/mol) ±1.7 | .498 |
| Physical activity self efficacy (PASE)[1] | 11.5 ± 2.3 | 12.8 ± 1.7 | |
| Gender | | | |
| Males | 4 (25%) | 16 (52%) | |
| Females | 12 (75%) | 15 (48%) | .151 |
| Previous Camp Experience | | | |
| Yes | 13 (81%) | 28 (90%) | |
| No | 3 (19%) | 3 (10%) | .151 |
| Insulin Administration | | | |
| Pump | 10 (63%) | 22 (71%) | |
| Injections | 6 (37%) | 8 (29%) | .671 |
| Parent reported celiac (yes/no) | | | |
| Yes | 12 (75%) | 7 (23%) | |
| No | 4 (25%) | 24 (77%) | 1.00** |

[1] PASE scores are based out of a maximum score of 15 points. Higher scores are associated with greater PASE.

| Table 2: Total and by Age Group Pre and Post Nutrition Knowledge Survey (NKS) Scores[1] | | | | | |
|---|---|---|---|---|---|
| | Mean Pre x ± SD[2] | Mean Post x ± SD[2] | p | Average Score % (# correct/23total) | Increase % |
| Total N=47 | 13.53 ± 4.02 | 14.48 ± 3.99 | .002 | Pre 58.8<br>Post 62.9 | 4.1 |
| Age Group 1 (10-12 years) N=16 | 11.75 ± 3.43 | 12.62 ± 3.32 | >.05 | Pre 51.2<br>Post 54.9 | 3.7 |
| Age Group 2 (13-17 years) N=31 | 14.45 ± 4.04 | 15.45 ± 4.00 | <.05 | Pre 62.8<br>Post 67.2 | 4.4 |

[1]NKS total scores are scored out of 100% (correct out of 23 total questions)
[2] Mean ± standard deviation total number correct answers

APPENDIX A- Review of Literature

**Introduction:**

This literature review will discuss prevalence of T1DM, consequences if T1DM is not adequately managed, and techniques to improve management of T1DM in the child and adolescent population, the significance of nutrition education and physical activity and finally how attendance at a diabetes camp plays a role in management. For the purpose of this literature review, children are defined as individuals less than 12 years of age and adolescents as individuals ages 13-17 years[1]

Type 1 Diabetes Mellitus (T1DM) currently affects over three million individuals in the United States with new diagnoses increasing at about 3% per year[2]. In addition, the incidence of T1DM in several European countries and the US reportedly increased by 2-4% [3]. If this rate continues, the amount of T1DM diagnoses will be doubled within the next decade[3, 4]. Diagnosis typically occurs during childhood and adolescence, age periods that can be challenging due to physiological and social changes that the individual is going through [3]. Type 1 diabetes is the third most common chronic condition in children and adolescents[5]. Daily management activities must be practiced to prevent acute hyper and hypoglycemia and the long-term complications of unmanaged T1DM that can be extremely detrimental to health and quality of life [6, 7]. Skills for monitoring signs and symptoms of hyper and hypoglycemia, checking blood glucose, and accounting for carbohydrates with a highly individualized insulin regimen must be taught from point of diagnosis in conjunction with diabetes specific and general nutrition education [2, 8].

Type 1 Diabetes (T1DM): Diagnosis and Insulin Therapy

Symptoms of hyperglycemia and several blood glucose tests lead to diagnosis of T1DM and insulin therapy is then initiated. Diagnosis of T1DM typically occurs during the ages of childhood and adolescence and has historically been referred to as juvenile diabetes[3]. Diagnosis occurs due to an autoimmune response that impairs insulin production from the beta cells of the pancreas[2]. Beta cells both sense blood glucose levels and produce insulin to keep glucose levels in control. Without these cells producing insulin, there is an unregulated amount of glucose in the blood. Glucose can therefore not enter the red blood cell to be used for energy, and the cell becomes coated with excess glucose, or glycated, which leads to further health complications such as heart disease, nerve damage, blindness and other organ damage[2]. Prior to diagnosis and insulin therapy, the individual will experience hyperglycemia, which presents itself with the classic symptoms of polydipsia, polyphagia, and polyuria[9]. Diagnostic criteria for T1DM include a fasting blood glucose level of 126mg/dL, a post prandial blood glucose greater than 200mg/dL along with symptoms of hyperglycemia, or an abnormal glucose tolerance test [10, 11]. These results are combined with a hemoglobin A1C (HbA1c) test result, which is an average of blood glucose levels over the last 3 months[10, 11]. Normal HbA1c range is 4.5-6%, which is an average blood glucose level of about 95-126mg/dL. Pre-diabetes HbA1c range is 5.7-6.4%, which is an average blood glucose level of about 115-140mg/dL[10, 11]. An HbA1c of 6.5% or higher, a blood glucose of 140mg/dL or greater on two separate occasions is considered a diagnostic criterion for diabetes[10, 11]. In diabetes management, an HbA1c test should be administered every three months[10, 11]. As HbA1c increases, the risk of developing complications from diabetes also increases[10, 11]. Management of blood glucose levels and HbA1c is dependent on insulin injection therapy.

Insulin administration, through injection or pump, is the primary therapy for the delay and prevention of health complications such as cardiovascular disease, macular degeneration, and neuropathy[5]. Insulin regimens are individualized based on diet, physical activity, and physiology [8]. Blood glucose levels must be kept in control in order to prevent episodes of hyper or hypoglycemia. Without insulin therapy, the individual with T1DM will experience long-term help complications that will greatly affect quality of life and could lead to death.

Complications and challenges in the T1DM population

The increased risk of hyperglycemia, vascular complications, and excess weight can be eliminated with insulin therapy and a healthy diet[6, 12]. Though blood glucose ranges may be individualized to each individual with T1DM, normal fasting blood glucose range is 70-100mg/dL. Without insulin therapy, the individual with T1DM will experience chronic hyperglycemia, which leads to oxidative stress and increased inflammation due to the production of Advanced Glycosilation Endproducts (AGEs)[6]. This is the major cause of vascular complications responsible for damage to the blood vessels, causing retinopathy, neuropathy and nephropathy, most commonly [6]. These vascular complications put individuals with T1DM at an increased risk for blindness, kidney disease, lower limb amputations and cardiovascular disease[6]. Also adding to this increased risk is excess weight[13-15]. As the rate of T1DM increases in the child and adolescent population, the rate of overweight and obesity is simultaneously increasing in this population [4, 14]. As part of Medical Nutrition Therapy (MNT), the American Diabetes Association (ADA) and the International Society of Pediatric and Adolescent Diabetes (ISPAD) recommend a healthy overall diet along with exercise for the management of

T1DM [8, 16-18]. A healthy diet and exercise regimen will help maintain weight and glycemic control and reduce risk for cardiovascular disease and dyslipidemia [18, 19]. Therefore, children and adolescents with T1DM especially need nutrition education that stresses the importance of an overall healthful diet as well as physical activity.

An additional challenge facing this population is the commonality of the dual diagnosis of Celiac Disease (CD) [20-23]. Celiac disease affects 9.2 to 11.1% of individuals that have T1DM[24]. Celiac disease is defined by an immune response that causes inflammation and damage to the mucosal walls of the intestine following ingestion of gluten, a protein found in wheat, barley and rye [25]. Therefore, the primary therapy for those that have CD, is a gluten free diet [25]. The dual diagnosis of CD and T1DM requires greater dietary restrictions. If a strict gluten free diet is not followed, acute gastrointestinal symptoms as well as chronic poor linear growth malabsorption and nutritional deficiencies may result[22, 25]. This requires the individual with the dual diagnosis to have a greater understanding of nutrition as their diet must now be monitored for overall nutrition quality while counting carbohydrates and avoiding wheat, rye and barley products.

Maintaining Glycemic Control

Individuals with T1DM should establish and follow strict insulin and diet regimens from the point of diagnosis in order to maintain optimal glycemic control to prevent long-term health complications. Insulin therapy along with MNT should be used in conjunction to maintain optimal glycemic control. The Diabetes Control and Complications Trials followed two large cohorts, one receiving intensive insulin therapy and education and one receiving only two insulin injections per day without nutrition education over 6.5 years tracking disease complications [26]. Overall, the intensive therapy delayed complications of retinopathy, albuminuria and neuropathy compared to the conventional group [26]. Also, the intensive therapy group had an average of an additional 7.7 years of eye sight, 5.7 years free from renal disease, and 5.6 years free of lower extremity amputation compared to the conventional group [7]. This demonstrates the importance of not only consistent insulin therapy, either with Continuous Subcutaneous Insulin Infusion (CSII) or Multiple Daily Injections (MDI), but also nutrition education to maintain glycemic control and prevent health complications associated with T1DM.

Continuous subcutaneous insulin infusion, or pump therapy, is more common and preferred in this population to avoid MDI, which presents an additional challenge for adolescents with T1DM due to the diet flexibility that comes CSII [18]. Nutrition education, specifically carbohydrate counting, is fundamental in the management of T1DM especially if using CSII. Marigliano et al., explored the potential role of carbohydrate counting in combination with nutrition education and the impact on glycemic control [18]. Twenty-five Italian participants age 7-14 years using CSII were followed for 18 months. During this time, standard ADA and ISPAD education programs were delivered, participants checked blood glucose six times per day, and routinely met with a multidisciplinary team to manage their glycemic control [18]. Results at the end of the follow-up period, showed that in individuals with significant improvements in HbA1c, total carbohydrate intake was significantly higher while fat and protein intake significantly decreased compared to baseline [18]. Proper nutrition education on the overall healthful diet along with carbohydrate counting, will improve the food choices that children and adolescents make. This will improve glycemic control and promote a nutrient-rich and healthful diet.

Nutrition Education

There is a need for diabetes specific and general nutrition education for children and adolescents with T1DM from point of diagnosis. Clements et al. gathered longitudinal information on T1DM care from a children's hospital. Overall, average HbA1c increased with the age of diagnosis with the greatest increases occurring in individuals diagnosed at age 10 or older[12]. Patients that were diagnosed at younger ages had better glycemic control and less of a rise in HbA1c as they aged compared to the older individuals [12]. Across all age groups, there was a significant rise in HbA1c after the start of insulin therapy during the first one and a half years after diagnosis[12]. These results can be explained by the multifaceted ways that T1DM need to manage their diabetes. First, if diagnosed at a younger age, there may be more parental involvement in diet and insulin therapy, which would result in better glycemic control [12]. Children and adolescents are a high-risk population for poor glycemic due to peer pressure, lack of knowledge and rebellion. In addition, age of diagnosis may be related to blood glucose control[12].

If diagnosed earlier in life, individuals will be exposed to education and support to manage their diabetes for a longer period of time than those diagnosed later in life. Exposure to nutrition education as early as possible helps children and adolescents develop the skills and practices they need to best manage their diabetes. This population can be particularly challenging and the need for nutrition education is great.

T1DM: Childhood to Adolescence

Children and adolescents are particularly challenging age groups in terms of general health care due to physical and social changes[1]. Prior to reaching adolescence, children have limited management options and parents have primary involvement in treatment decisions. However, these children must receive multiple doses of insulin throughout the day, sometimes at school or other places without their parents. This requires an understanding of insulin administration from all of the child's caretakers. Transitioning from childhood to adolescence involves physical and social growth. This is a particularly challenging time for the adolescent with T1DM, especially during years of puberty when insulin dosages need to be constantly monitored. Insulin dosages will change daily and physiological response to the insulin may also vary greatly due to hormonal status affecting insulin sensitivity[27]. Monitoring blood glucose therefore proves to be frustrating, especially while the adolescent is developing social skills and wants to act as their peers do. However, it is during adolescence where self-management skills are developed and solidified to be carried into adulthood [27]. Adolescents begin to take responsibility for their health and are able to make their own decisions such as when, how, and how much insulin they are going to take as well as what foods they are going to eat. Information is easily attainable from sources that are unreliable and peers easily influence decisions[1]. Adolescents with T1DM need have access to reliable diabetes management information in order for them to make decisions that will benefit their health and to understand the short and long-term consequences of self-management behaviors. Aside from proper diabetes management techniques, these individuals also need to have general nutrition education to promote an overall healthful diet due to their consumption of a typically nutrition poor diet.

Despite the importance of dietary quality and diabetes education, individuals with T1DM typically have a diet of less nutritional quality then the general population of adolescents [28]. All children and adolescents are recommended to maintain calorie balance in order to support normal growth. The recommended macronutrient distribution ranges for individuals age 4-18 are 45-65% carbohydrate, 10-30% protein and 13-15% fat[29, 30]. In the general adolescent population, sodium, saturated fat, sugars and refined gains are all consumed in excess and replace nutrient dense foods, which increases risk of obesity and cardiovascular disease[29, 30]. Individuals T1DM should consume a diet similar to healthy individuals, rich in whole grains, fruits, vegetables, and low fat dairy while limiting trans and saturated fat consumption [31, 32]. The American Diabetes Association to prevent the progression of heart disease and vascular conditions that often result from unmanaged diabetes[32]. A diet that includes carbohydrates from fruits, vegetables, whole grains and low-fat milk is recommended for tight glycemic control[32]. Adolescents with T1DM typically do not consume adequate amount of fruits, vegetables and whole grains but consume excessive amount of total and saturated fat [33-35]. Most of the nutrient poor foods that adolescents eat are snacks in-between meals that are high in added sugar and fat [33, 36]. Snacking is important in order to maintain stable blood glucose levels, however snacks should be nutrient rich and add to the overall healthfulness of the diet. Nansel et al., conducted a study examining the diets of 8-18 year olds with T1DM and how the dietary quality differed depending on meal, location and time of the week [33]. The majority of participants used CSII. Meals eaten at home during the week were of higher nutritional quality then meals eaten on the weekend and away from home [33]. Breakfast was one of the most nutrient rich meals containing the highest amount of carbohydrate and whole grains with the lowest amount of saturated fat. Snacks were lowest in fruit and vegetable intake and contained the most added sugar. Nutrition and diet education is needed in this population so the adolescent has the knowledge to choose nutrient rich foods when they are away from home [33].

Another reason for poor diet in adolescents with T1DM is the perception that it is easier to count carbohydrates that are listed on the nutrition label of packaged food items rather than foods without a label [28]. Lipsky et al. conducted a study looking at food preference and availability related to dietary intake and quality in children and adolescents ages 8-18 years with T1DM[28]. Preferences were assessed using a survey with a rating scale and dietary intake was assessed using three-day food records. Availability of food items was assessed using a yes/no survey given to the parents. The results showed that mean preferences were overall higher for refined grains, fats and sweets than for whole grains and vegetables. Children and adolescents in this study were 2-6 times more likely to rate refined grains, fats and sweets higher than fruits, vegetables and whole grains [28]. This demonstrates the need for nutrition education for the individual to know the importance of choosing healthy food options. There was also a positive correlation between fruit and whole grain intake with preference and availability demonstrating that families and care takers of the children and adolescents with T1DM have the responsibility providing access to foods of high nutritional quality[28].

Children and adolescents with T1DM need exposure to fresh foods in order to become familiar with them and more easily count carbohydrates. If children and adolescents have access to these types of foods constantly, they are more likely to choose and prefer these items, which will decrease the stress of carbohydrate counting fresh food items. This may lead to a more healthful diet, and thus prevent detrimental health aliments in the future. In order to make these conscious decisions, individuals with T1DM must have access to education both in the clinical setting as well as in the non-clinical, less controlled setting amongst their peers.. Diabetes specific and general nutrition education is the foundation for achieving successful health-related outcomes[5].

Education Impact on Children and Adolescents with T1DM

Although there are many techniques, carbohydrate counting is the most common nutrition education incorporated into MNT for children and adolescents with T1DM. Individuals with a greater understanding of carbohydrate counting have better glycemic control, lower HbA1c and less of a risk for developing cardiovascular disease[31, 37]. The et al. found that 43% of individuals with T1DM were taught carbohydrate counting. Of the 43% that had been taught carbohydrate counting, 25% were also taught at least one other form of MNT[31]. Carbohydrate counting, glycemic index and food exchanges were the most common combination of nutrition strategies [31]. Individuals that frequently counted carbohydrates had significantly lower triglyceride, cholesterol and HbA1c values compared to those that did not count carbohydrates often [31].

Carbohydrate counting is the most common and effective diabetes specific nutrition education that is taught, however some foods are easier to carbohydrate count than others. One study tested the carbohydrate counting efficacy in children and adolescents ages 12-18 with T1DM using a carbohydrate counting accuracy test [38]. Participants counted the carbohydrate amount in 29 food items that were typical foods consumed during breakfast, lunch, dinner or snack. Participants were divided into an intervention group and a control group. The intervention group attended a carbohydrate counting class and kept 3-day food records. The accuracy test was given again three months later [38]. Results showed at baseline, more than half of the participants in the intervention group significantly over or underestimated carbohydrate amounts in foods such as milk, orange juice, carrots, broccoli, chicken nuggets, and mixed meals. Results also showed that individuals exposed to nutrition education who had assistance from their parents, had a significantly lower HbA1c ($r$ 0.264, $P$ 0.008)[38]. Another study showed similar results in the child and adolescent population[39]. Children and adolescents ages 8-18 with T1DM were asked to count the amount of carbohydrates in several different, common food items. Seventy-five percent of the study population over or underestimated the amount of carbohydrates by 10-15g. Prepared foods and foods that did not have a nutrition label were more likely to be incorrectly estimated, but foods that had a nutrition label were estimated with the most accuracy[39]. Both of these studies concluded there as a need for providing skills to estimate carbohydrates in foods without nutrition labels.

In order to facilitate monitoring the amount of carbohydrate in foods, children and adolescents tend to choose foods that have a nutrition label [37]. Foods that have nutrition labels are typically processed and have elevated amounts of fat, sodium and added sugar. Fresh fruits and vegetables such as apples, oranges, lettuce and peppers are not labeled[37]. A diet that includes more processed foods than fresh foods is easier for carbohydrate counting, but does not provide a healthful diet[4]. The focus on carbohydrates distracts from other macronutrients such as fat [18, 40]. Choosing foods that are low in carbohydrates but high in fat also has a negative effect on glycemic index and weight [18, 40]. Carbohydrate counting must be taught to the individual with T1DM and their parents or caregivers, however this should be taught in conjunction with general nutrition and how to properly count carbohydrates in foods that do not have a nutrition label.

Upon diagnosis, education should focus on "basic survival skills" such as carbohydrate counting to control blood glucose and prevent hyper and hypoglycemia, and progress to diabetes self-management education (DSME) [1]. Diabetes self-management education should be highly individualized, detail oriented, and constantly reinforced to have a positive effect on adolescents with T1DM[1]. A fundamental aspect of DSME is self-monitoring of blood glucose (SMBG) [8]. Understanding SMBG is essential for individuals with T1DM to recognize their specific normal blood glucose ranges and how their bodies react to meals and insulin therapy. Ideally, SMBG should occur before and after meals, prior to exercising or any activity where a low blood glucose would be especially dangerous such as driving or before bedtime, and at any time when the individual feels that they are experiencing a high or low blood glucose [8]. This extensive checking of blood glucose will help maintain blood glucose control and serve as a guide for the multidisciplinary care plan team to adjust insulin and diet regimens if necessary.

Along with DSME and SMBG, the individual with T1DM must also have diabetes self-management support (DSMS) from family, peers and a multidisciplinary team that specializes in diabetes to develop a management plan that takes into consideration all aspects of the individual's lifestyle: age, school, work, physical activity, and social situations[8]. Children and adolescents experience many changes, physically and socially, and tend to find managing their diabetes burdensome. Therefore, motivation and support are critical to prevent acute hyper and hypoglycemic events, which, if left untreated will lead to the long-term complications previously discussed [41]. All of these forms of education and support are necessary for individuals with T1DM to gain knowledge of the condition and develop the ability to self-manage, make informed decisions and actively collaborate with a medical support team[8]. Collectively, DSME, SMBG, and DSMS will improve diabetes self-care, given that medical care and daily management are consistent but flexible due to the demanding nature of insulin, glucose monitoring and diet regimens [41].

Physical Activity and T1DM

Regular physical activity provides a range of benefits that prevent against risk factors associated with access weight, especially in individuals with T1DM. Benefits of regular physical activity include but are not limited to decreased cardiovascular disease and obesity risk, improved endothelial function, lowered cholesterol and blood pressure as well as decreased risk of depression [14, 42-44]. Despite these beneficial effects of physical activity and T1DM management, data suggest only 4.7% of children and adolescents with T1DM achieve the recommended 60 min of moderate to vigorous physical activity per day [14, 45, 46]. Furthermore, children and adolescents with T1DM report an average of 110-140 min per day of television time and an average of 40-225 min of computer time per day. This amount of screen time promotes sedentary behavior, which is detrimental to health [47]. The greatest barrier to physical activity in adolescents with T1DM is hypoglycemia. Physical activity promotes an increase in glucose uptake into the cells as well as insulin sensitivity for up to 48 hours[42]. If insulin dose or carbohydrate intake is not modified for physical activity, the individual will experience hypoglycemia during or immediately following exercise or during the night, which is of the most concern[42]. Yardley and colleagues found that a day that included 75 minutes of moderate-intensity exercise at 55% of peak fitness (VO2peak) more than doubled the incidence of having a hypoglycemic event overnight[42]. Hypoglycemia is prevented by limiting pre-exercise insulin, providing carbohydrate during exercise, and reducing insulin dose at night[42].

In order to participate in physical activity, the individuals must believe that they are able, which is measured by self-efficacy. Self-efficacy is critical for the initiation of an activity in both adults and children[48]. Self-efficacy is dependent on past experience, familiarity, control over the situation, and support from peers [48]. Self-efficacy is typically measured on a numerical score where as score increases, self-efficacy increases. Parcel et al. developed and validated a self-efficacy instrument in healthy third and fourth grade students [49]. The questionnaire includes 5 questions about physical activity with three options, "not sure" for one point, "a little sure" for two points or "very sure" for three points [49]. The maximum score is 15 points, therefore, higher scores are associated with greater PASE. The average PASE score was 12.25 ± 2.07 (KR-20 coefficient alpha = 0.569). If the individual with T1DM has great physical activity self-efficacy and believes that they can participate in physical activity, such activity must be adequately monitored in order to have beneficial health effects. The potential hormone and stress response that physical activity evokes needs to be accounted for to prevent hypoglycemic events [50, 51]. These scores were observed in healthy children in a safe school environment. Scores of children and adolescents with T1DM may differ.

Faulkner et al., conducted a study to promote physical activity in the T1DM adolescent population [52]. Adolescents 12-19 years old who were not routinely active were recruited from a pediatric clinic and given individualized exercise plans. Perceived self-efficacy was measured using a 10-item questionnaire developed for the study assessing barriers to exercise. Each item was scored on a Likert scale from one (not true at all) to five (very true) [52] and means were calculated. Different from typical self-efficacy scales like the one validated by Parcel, on this scale, a lower score (less perceived barriers) was interpreted as greater self-efficacy[52]. The mean score of the self-efficacy was 3.79 ± 0.64[52]. This is greater self-efficacy than to be expected because this population does not typically participate in the recommended amount of physical activity. These scores also may be better than predicted because of the safe environment and sense of support the subjects had.

The optimal management of T1DM is multifaceted and an ideal setting to incorporate nutrition education, DSME, SMBG, DSMS and physical activity is a Diabetes camp. Diabetes camps offer a non-clinical setting where children and adolescents can find support from their peers as well as trained, specialized, health professionals [41]. A diabetes camp offers a safe environment to promote self-efficacy in management and physical activity as well as providing nutrition education to the child and adolescent campers.

Diabetes Camps

The first diabetes camp was founded in 1925, only three years after the discovery of insulin and they are no present worldwide [53]. As of 2011 diabetes camps were serving more than 30,000 campers per year in North America and 16,000 campers around the rest of the world[41, 53-55]. The mission of diabetes camps according to the ADA in 2012 is as follows, "The mission of camps specialized for children and youth with diabetes is to facilitate a traditional camping experience in a medically safe environment. An equally important goal is to enable children with diabetes to meet and share their experiences with one another while they learn to be more responsible for their condition"[55]. These camps are specifically tailored for children and adolescents with T1DM and provide a safe environment for the campers to enjoy themselves while being exposed to general and diabetes specific nutrition education. Diabetes camps are the ideal setting for campers to thrive with, DSME, SMBG and DSMS[41, 54]. The camp environment provides an environment for campers to learn how to control their blood glucose levels, carbohydrate intake and insulin regimens. Attendance at a diabetes camp allows the campers to become more independent in the management of their diabetes[41, 54]

In addition to providing nutrition education to improve knowledge and T1DM management, another goal during attendance at diabetes camp is to avoid blood glucose extremes in an environment where there is increased physical activity[55]. All diabetes camps are staffed by a multidisciplinary team that specialize in diabetes management as well as protocols for normal blood glucose ranges and how to treat signs and symptoms of hyper and hypoglycemia. [55] Repeated attendance at diabetes camps results in better control of blood glucose through improved HbA1c both after camp and at follow up[56]. Ruzic et al., evaluated the effects of a tightly controlled insulin regimen on the glycemic control of Croatian campers with T1DM ages 9-16[51]. Only campers that used MDI were used in the study. Physical activity programs were increased from low to moderate intensity throughout the day and blood glucose concentrations and hypoglycemic symptoms were monitored closely during activity. Measurements of HbA1c were taken at the beginning of the 15-day camp, 10 days after camp, and two months after camp [51]. At the beginning of camp, the mean HbA1c was 8.28mg/dL. This significantly decreased at the end of the 15 days to 7.92 [51]. Average blood glucose concentration was also recorded daily. The last day of camp showed significantly lower averages, closer to normal, than the first day of camp [51]. In the controlled environment of diabetes camps, glycemic control is improved through diet and blood glucose monitoring as well as physical activity. Diabetes camps also provide the individual with a safe environment that is full of support, which may increase self-efficacy.

Tuchinda and colleagues evaluated glycemic control and knowledge after attending a 5-day diabetes camp[57]. Campers attended lectures that covered topics such as insulin therapy, the importance of diabetes control, blood glucose monitoring, exercise and diabetes, diabetes nutrition and hyper and hypoglycemia. At the end of each lecture, campers participated in an activity involving the information of skills they had learned. Knowledge was tested using a survey on the first day of camp, last day of camp, 3 months, and 6 months after camp. This tool was developed based on the topics in the lectures that were provided at camp such as general nutrition and diabetes knowledge[57]. The tool included 20 questions on diabetes knowledge, such as insulin doses and treating hyper and hypoglycemia, and 20 questions on general nutrition knowledge. A paired T-test was used to compare pre and post camp levels of knowledge and the results were reported as mean standard deviations[57]. Total knowledge scores at baseline was $26 \pm 6$ and after camp was $32 \pm 6$, $p < 0.001$[57]. This study also found that HbA1c decreased significantly after camp[57].

Bundak assessed nutrition knowledge at a diabetes camp that focused on insulin regimens and glycemic control[58]. The insulin regimens of the campers were adjusted using rapid and short acting insulin. Campers were also exposed to nutrition and diabetes education. This study showed that there was a significant decrease in HbA1c at 6 and 12 months post-camp[58]. This study focused mainly on the improvement of glycemic control.

Knowledge was tested using a tool developed for the study that included 25 questions covering topics such as timing and composition of meals and snacks, and the food groups with each question worth four points[58]. There was a significant increase in knowledge between pre 69.5±20.0 and post 79.5±16.0, $p<0.05$[58]. Although education is provided at all diabetes camps, the studies reviewed above did not use a validated to assess knowledge after attendance at camp.

Nutrition Knowledge Survey

The Nutrition Knowledge Survey is a measurement of diabetes specific and general nutrition knowledge, validated in children and adolescents with T1DM. The NKS was developed by a multidisciplinary team that included registered dietitians, endocrinologists, pediatric diabetes nurses, nutrition scientists, certified diabetes educators, and behavioral scientists[16]. The survey addresses carbohydrate counting, healthful eating, blood glucose in response to foods, and nutrition labeling. Rovner and colleagues administered the NKS to 282 children and adolescents ages 8-18 years old, mean age 13.3 ± 2.9, that had been diagnosed with T1DM for at least 1 year, were on a daily insulin dose of at least 0.5 units per day, and did not have gastrointestinal conditions. Children and their parents were recruited through a pediatric clinic. Three-day dietary records were collected from the children and the dietary quality was analyzed using the Healthy Eating Index-2005 (HEI-2005). The parents of these subjects also completed the NKS[16].

Item discrimination and internal reliability were calculated to determine the impact of each question on the total measure and final result as well as how the subscale score of each section (carbohydrate counting, general nutrition, blood glucose in response to foods and nutrition nutrition labeling), affect the total score. Item discrimination (ID) was calculated using the index of discrimination (upper group % correct – lower group % correct), which reflects how an item differentiates between high and low scorers on the total measure[16]. Fifteen to twenty-five percent discrimination was determined to be acceptable. Next, the Kuder- Richardson Formula 20 (KR-20) was used to measure chonbach alpha, a measure of reliability of the instrument. Reliability of the NKS was determined through comparing the relationship of the sub score of each of the four domains to the total score. NKS score was compared to HbA1c and dietary intake through multiple linear regression analysis, controlling for youth age, family income, parent education, diabetes duration, and insulin regimen[16].

The original NKS was 39 questions in length. Item difficulty was determined by the percentage of participants that answered the question correctly. Any questions in which less than 20% or more than 90% of both adults and children answered correctly were eliminated which also improved discrimination (ID)[16]. Additionally, questions that had an ID <25% in adults and youth were eliminated. This resulted in a final NKS of 23 questions and item difficulty ranging from 19 to 86% for youth with an average of 73%; the KR-20 coefficient alpha = .70[16].

Parent but not youth NKS scores were inversely correlated to HbA1c ($r = -0.31$, P, <0.01, and $r = -0.04$, respectively) and both parent and youth NKS scores were positively correlated with HEI-2005 scores ($r=0.20$, $P= <0.01$ and $r=0.19$ $P= <0.01$, respectively)[16]. Youth 13 years of age or older had higher score than those that were younger than 13 years of age $62.9 \pm 14.1\%$ vs $49.4 \pm 16.0\%$. NKS scores were correlated with age (r=0.44, P 0.0001)[16]. The results remained the same after controlling for age, family income, parent education, diabetes duration, and insulin regimen.

Conclusion

The prevalence of T1DM is increasing rapidly in children and adolescents, resulting in the need for additional research specifically in a nonclinical setting such as a diabetes camp. Children and adolescents with greater nutrition knowledge have improved glycemic control as well as better overall management of their T1DM. The literature shows the importance of nutrition education and significant increase in knowledge after attending a diabetes camp however no studies have used a validated tool to assess knowledge change[5, 56, 58]. However, diabetes camps have not systematically assessed the nutrition knowledge association NKS, a validated measure of nutrition knowledge, which has only been used in clinical settings to date. Research is needed to assess knowledge change using this tool at a diabetes camp to assess the nutrition knowledge of children and adolescents with T1DM before and after attending camp.

# APPENDIX B: Nutrition Knowledge Survey

## NUTRITION KNOWLEDGE SURVEY

**The following questions are about general nutrition and nutrition related to diabetes.**
**For each question, choose what you think is the best answer. Select only ONE answer for each question.**

| Question | Ⓐ | Ⓑ | Ⓒ | Ⓓ |
|---|---|---|---|---|
| 1. Which of the following are benefits of eating fruits and vegetables? | Good source of fiber | Low in fat | Good source of vitamins and minerals | All of these |
| 2. Which of the following foods is high in fiber? | Corn flakes | Kidney beans | Pretzels | White bread |
| 3. Which of the following foods contains heart healthy fats? | Beef | Nuts | Cheese | Butter |
| 4. Which of the following contains more than 15 grams of carbohydrate? | 1 small (4 oz) apple | 12-15 grapes | 1 cup fresh strawberries | 1 cup (8 oz) orange juice |
| 5. Which of the following foods provides the most vitamins and minerals? | French fries | Baked sweet potato | White rice | Potato chips |
| 6. Which of the following is NOT a whole grain food? | Brown rice | White bread | Whole wheat bread | Oatmeal |
| 7. Whole grains are healthier than processed or refined grains because: | They are higher in fiber | They are naturally richer in nutrients | Blood sugars rise more slowly after eating them | All of these |
| 8. If you ate 15 grams carbohydrate of each of the following foods, which would cause your blood sugar to rise the slowest? | Oatmeal | Plain bagel | Graham crackers | All the same |
| 9. If you ate 15 grams carbohydrate of each of the following foods, which would cause your blood sugar to rise the fastest? | Apple | Apple juice | Applesauce | All the same |
| 10. A juice labeled "No added sugar": | Is a "free" food | Contains no sugar | Contains carbohydrate | None of these |
| 11. Which of the following is NOT an example of a "free" food? | 3 slices of American cheese | 12 oz can of diet soda | ½ cup broccoli | ½ cup sugar-free gelatin (Jell-O) |

*(continued on next page)*

**Use the Nutrition Facts label (right) for AMY'S KITCHEN CHILI to answer questions 12-15.**


**Nutrition Facts**
Serving Size **1 cup**
Servings Per Container **2**

| Amount Per Serving | |
|---|---|
| **Calories** 190 | Calories from Fat 50 |
| | **% Daily Value*** |
| **Total Fat** 6g | **9%** |
| Saturated Fat 0.5g | **3%** |
| Trans Fat 0g | |
| **Cholesterol** 0mg | **0%** |
| **Sodium** 680mg | **31%** |
| **Total Carbohydrate** 30g | **10%** |
| Dietary Fiber 8g | **30%** |
| Sugars 6g | |
| **Protein** 13g | |
| Vitamin A 70% | Vitamin C 30% |
| Calcium 4% | Iron 10% |

*Percent Daily Values are based on a 2,000 calorie diet.

| | Ⓐ | Ⓑ | Ⓒ | Ⓓ |
|---|---|---|---|---|
| 12. How many cups are in this can of chili? | ½ cup | 1 cup | 2 cups | 4 cups |
| 13. How many grams of fiber are in 1 cup of chili? | 6 grams | 8 grams | 16 grams | 30 grams |
| 14. How many total grams of carbohydrate are in 1 serving of chili? | 14 grams | 22 grams | 30 grams | 60 grams |
| 15. How many grams of carbohydrate would you use to calculate an insulin dose for 1 serving of chili? | 6 grams | 14 grams | 22 grams | 30 grams |

*(continued on next page)*

Use the Nutrition Facts label (right) for GATORADE to answer questions 16-18.


**Nutrition Facts**

Serving Size **8 oz (250 ml)**
Servings Per Container **2.5**

| Amount Per Serving | |
|---|---|
| **Calories** 50 | Calories from Fat 0 |
| | % Daily Value* |
| **Total Fat** 0g | **0%** |
| **Cholesterol** 0mg | **0%** |
| **Sodium** 110mg | **5%** |
| **Potassium** 30mg | **1%** |
| **Total Carbohydrate** 14g | **5%** |
| Sugars 14g | |
| **Protein** 0g | |

Not a significant source of calories from fat, saturated fat, cholesterol, dietary fiber, vitamin A, vitamin C, calcium, iron.
*Percent Daily Values are based on a 2,000 calorie diet.

| | Ⓐ | Ⓑ | Ⓒ | Ⓓ |
|---|---|---|---|---|
| 16. How many servings are in this bottle of Gatorade? | 1 serving | 2.5 servings | 5 servings | 8 servings |
| 17. How many grams of carbohydrate are in 1 serving of Gatorade? | 14 grams | 28 grams | 35 grams | 70 grams |
| 18. How many grams of carbohydrate are in this bottle of Gatorade? | 14 grams | 28 grams | 35 grams | 70 grams |

**Questions 19-23 are about the number of carbohydrate in different foods. For the food listed in each question, choose the ONE answer that best matches or is closest to the number of carbohydrate in that food.**

| | Ⓐ | Ⓑ | Ⓒ | Ⓓ |
|---|---|---|---|---|
| 19. 1 cup (8 oz) low-fat milk | 6 grams | 8 grams | 12 grams | 20 grams |
| 20. 1 cup cooked spaghetti (white, not whole wheat) | 20 grams | 30 grams | 45 grams | 65 grams |
| 21. ½ cup corn | Less than 5 grams | 5 grams | 20 grams | 30 grams |
| 22. Small lettuce salad (¾ cup) with carrots, cucumbers, tomatoes, onion (no dressing) | Less than 5 grams | 10 grams | 20 grams | 30 grams |
| 23. 1 cup cooked green beans | Less than 5 grams | 5 grams | 10 grams | 15 grams |

## APPENDIX C: Physical Activity Self- Efficacy Questionnaire

### SECTION J: PHYSICAL ACTIVITY

**INSTRUCTIONS**: The questions in this section ask how sure you are about being able to eat some of the foods below. Please answer by circling either Not Sure, A Little Sure, or Very Sure for each question.

| | | | | |
|---|---|---|---|---|
| 1. | How sure are you that you can choose to **jog during recess?** | 1. NOT SURE | 2. A LITTLE SURE | 3. VERY SURE |
| 2. | How sure are you that you can be **physically active 3-5 times a week?** | 1. NOT SURE | 2. A LITTLE SURE | 3. VERY SURE |
| 3. | How sure are you that you can **exercise and keep moving for most of the time in physical education class?** | 1. NOT SURE | 2. A LITTLE SURE | 3. VERY SURE |
| 4. | How sure are you that you can **improve your physical fitness by running or biking 3-5 times a week?** | 1. NOT SURE | 2. A LITTLE SURE | 3. VERY SURE |
| 5. | How sure are you that you can keep up a steady pace **without stopping for 15-20 minutes when you are physically active?** | 1. NOT SURE | 2. A LITTLE SURE | 3. VERY SURE |

**STOP HERE**

CATCH - Health Behavior Questionnaire - Version 10/12/93 (retyped in MS Word in Spring 2006) Page 21

APPENDIX D: Child Consent Form

**Impact of Nutrition Education at Diabetes Camp on Children and Adolescents with Type 1 Diabetes Mellitus**

We are asking if you want to take part in a study where you will fill out two short surveys at the beginning of camp and one at the end of camp so we can see if campers learned about nutrition during camp.

*What will be done:*
You will fill out a survey with a few questions about nutrition and another about physical activity at the beginning of camp. It should take you about 15 minutes to finish both. With your parents' permission, we will be collecting some information about you from the camp registration materials. During camp you will attend a 45 minute nutrition activity lead by Kaitlyn Whipple, a student at the University of Rhode Island

*Risks or discomfort:*
You are not at any risk by participating in the study. All you will have to do is fill out the surveys about nutrition and physical activity and attend the activity during camp.

*Benefits of this study:*
This will help Camp Surefire to see if campers learn more about nutrition at camp and provide the best nutrition education to campers in the future

*Confidentiality:*
None of the information we get from you and use will identify you by name.

*Decision to quit at any time:*
It is you and your parents or caretakers' decision to participate in this study. You have the right to choose not to answer any questions. Also you can quit at any time, by telling camp counselors that you no longer want to participate in the study. Nothing will happen if you quit and you can still participate in Camp Surefire if you are not part of the study.

Feel free to ask questions. If you have a question later that you didn't think of now, you can ask Kaitlyn Whipple 401-787-3036. If you have questions you or parents may call the person in charge of the study Dr. Greene at 401-874-4028.

By signing below, I agree to take part in this study.

________________________________________ _______________
My Signature Date

APPENDIX E: Parent Consent Form

**Title of Project: Impact of Nutrition Education at Diabetes Camp on Children and Adolescents with Type 1 Diabetes Mellitus**

PARENT/GUARDIAN INFORMED CONSENT TO PARTICIPATE AND PERMISSION FOR A MINOR CHILD TO PARTICIPATE IN RESEARCH

Your son/daughter has been invited to take part in the research project of the Department of Nutrition and Food Sciences of the University of Rhode Island described below. We are trying to see whether our nutritional education program given at Camp Surefire will improve the nutrition knowledge of your child. If you have questions you may contact Kaitlyn Whipple, the URI Nutritional Sciences graduate student who will be conducting the education session at 401-787-3086 or Dr. Geoffrey Greene, her advisor at 401-874-4028.

*Description of the Project:*
The purpose of the study is to evaluate the impact of nutrition education given at camp.

*My Participation as a Parent/Guardian*
A parent/guardian must sign a HIPPA form authorizing use, for research purposes, of the following private medical information from the camp forms: demographic information, height, weight, age, duration of diabetes, insulin regimen and administration, hemoglobin A1c level, gastrointestinal symptoms and other medical problems, prior nutrition education and prior attendance at camp. A parent/guardian must sign this Parental Consent/Child Permission form, and the study HIPPA release form. These forms will take about 10 minutes to complete.

*What will be done:*
If you agree to have your child participate, he/she will be asked if they are also willing to participate. If both you and your child agree, your son or daughter will take a short Nutrition Knowledge Survey (NKS) at the beginning and end of camp to determine their nutrition knowledge related to diabetes. Participants will also take a short Physical Activity Self-efficacy questionnaire at the beginning of camp. These forms should take about 15 minutes to complete both. All children will be receive a 45-minute nutrition education session at Camp Surefire presented by Kaitlyn Whipple, a Nutritional Sciences graduate student from the University of Rhode Island, but only participants will take NKS to see if the program was successful. After camp is over, you will not be asked for any further information or time commitment.

*Risks or discomfort:*
The knowledge survey and physical activity self-efficacy survey should take no more than 15 minutes to complete and contain no questions that should be a problem. There is no risk or discomfort.
*Benefits of this study:*

There are no direct benefits to you or your child by participating but information about the effectiveness of nutrition education should help other children with diabetes. If we find the educational program is associated with improved knowledge about nutrition, the educational program is likely to be repeated next year at Camp Surefire and may be used by other camps for children with diabetes.

*Confidentiality:*
Your son/daughter's part in this study is confidential. All information from the camp medical forms will be recorded on forms identified by code number only. Surveys will have the child's name listed during camp, but these names will be replaced by ID numbers after camp is over. None of the information collected for this study will identify you or your son/daughter by name. The consent forms will not be linked to identification numbers. These consent, child assent and HIPPA release forms will be maintained in a locked cabinet in Dr. Greene's office for five years as required by law. Similarly, survey and abstract forms with ID numbers and no names will be maintained in Dr. Greene's lab. All information used for data analysis will be identified by code numbers and will not include any link to your child's name.

*Decision to quit at any time:*
Your son/daughter will be given the opportunity to decide whether or not to participate in this study. His/her decision to participate will not affect your or his/her present or future relationship with Camp Surefire. S/he will have the right to stop participating at any time. You have the right to withdraw your permission for your son/daughter to participate at any time.

*Rights and Complaints:*
If you are not satisfied with the way this study is performed, you may discuss your complaints with Dr. Geoffrey Greene (401-874-4028) In addition, if you have questions about your son/daughter's rights, you can discuss your concerns with Dr. Greene or with the University of Rhode Island Office of Research Integrity at 401-874-4328, anonymously, if you choose, or you may contact the office of the Vice President for Research, 70 Lower College Road, Suite 2, University of Rhode Island, at 401-874-4576. You have read this Parental Consent/Child Permission Form. Your questions have been answered. Your signature on this form means that you understand the information and you agree to allow your son/daughter to participate in this study. Please note that we have provided two signature lines in case your child has two custodial parents or guardians. In such case, both must sign this form or the reason for a single parent/guardian must be listed on this form.

Print Child's Name: ______________________________________________

| | |
|---|---|
| _________________________________ | ______________________________ |
| Signature of Participant/Parent Guardian | Signature of Researcher |
| _________________________ | ___________________________ |
| Typed/printed Name | Date |

APPENDIX F: HIPAA Release

AUTHORIZATION FOR USE OR DISCLOSURE OF PROTECTED HEALTH INFORMATION FOR RESEARCH

**Title of Project: Impact of Nutrition Education at Camp in Children and Adolescents with Type 1 Diabetes Mellitus**

The privacy law, Health Insurance Portability & Accountability Act (HIPAA) protects individually identifiable health information. The privacy law requires that an investigator explain in detail what information will be obtained during a study and how that information will be used, and with whom it will be shared.

Your son/daughter has been asked to participate in the above named study which will be led by Dr. Geoffrey Greene PhD, RD, LDN and Kaitlyn Whipple a graduate student and dietetic intern at the University of Rhode Island. The protected health information that may be used and disclosed includes:

| | Prior to Camp or Day 1 |
|---|---|
| Demographics | ✓ |
| Duration of Diabetes Diagnosis | ✓ |
| Insulin Regimen and Administration technique | ✓ |
| Presence of Gastrointestinal Condition | ✓ |
| Most recent HbA1C | ✓ |
| Age | ✓ |
| Weight and Height | ✓ |
| Amount of Nutrition Education Received | ✓ |
| Attendance at a Diabetes Camp | ✓ |

The investigators may use and disclose your child's protected health information until the end of the study June 1, 2016. They will use and/or share this information with:

The University of Rhode Island Institutional Review Board
Government Agencies when required by law

You do not have to sign this authorization. If you do sign, you may end your child's participation by notifying the investigator Kaitlyn Whipple 401-787-3086 or Geoffrey Greene 401-874-4028. Withdrawal of authorization will not affect your child's participation in the program. When you withdraw authorization investigators may only use and disclose the protected health information already collected for this research study.

The investigator will respect the confidentiality of the health information, however, should the health information be disclosed by the investigator, to someone outside of this study, it may no longer be protected by the HIPAA regulation.

Signing your name at the bottom of this form means that you have read or listened to what it says and you understand it. Signing this form also means that you agree to authorize the use and disclosure of personal health information. You will be given a copy of this form after you have signed it.

| | |
|---|---|
| ______________________________<br>Signature of participant | ______________________________<br>Signature of Researcher |
| ______________________________<br>Typed/printed Name | ______________________________<br>Typed/printed Name |
| ____________________<br>Date | ____________________<br>Date |

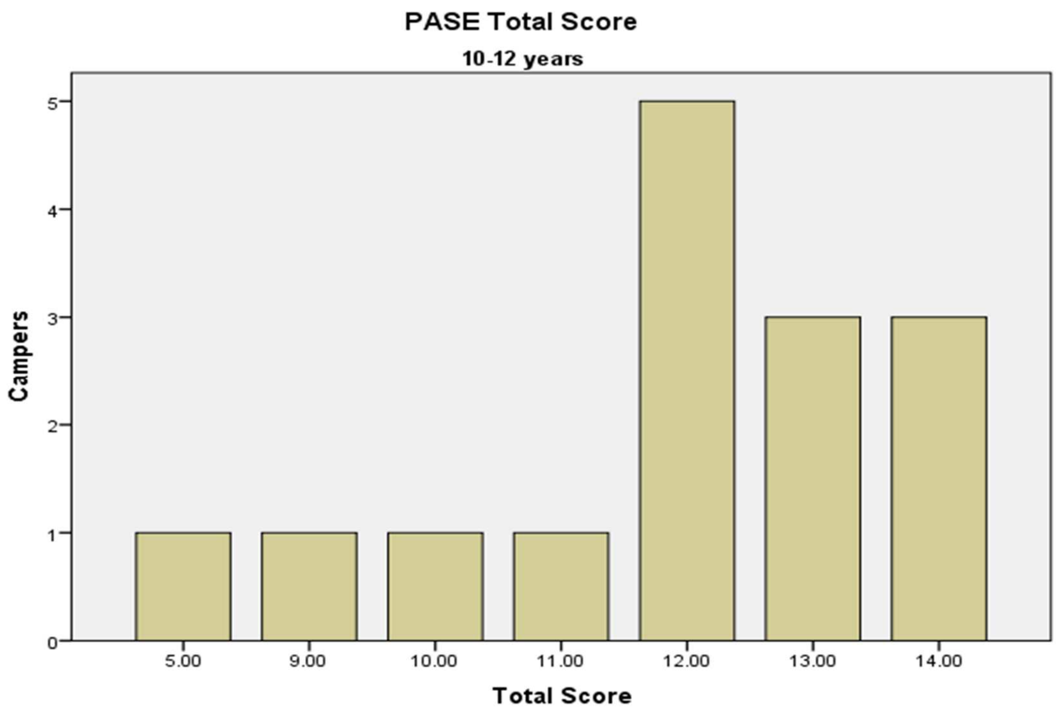
APPENDIX G: NUTRITION INTERVENTNION

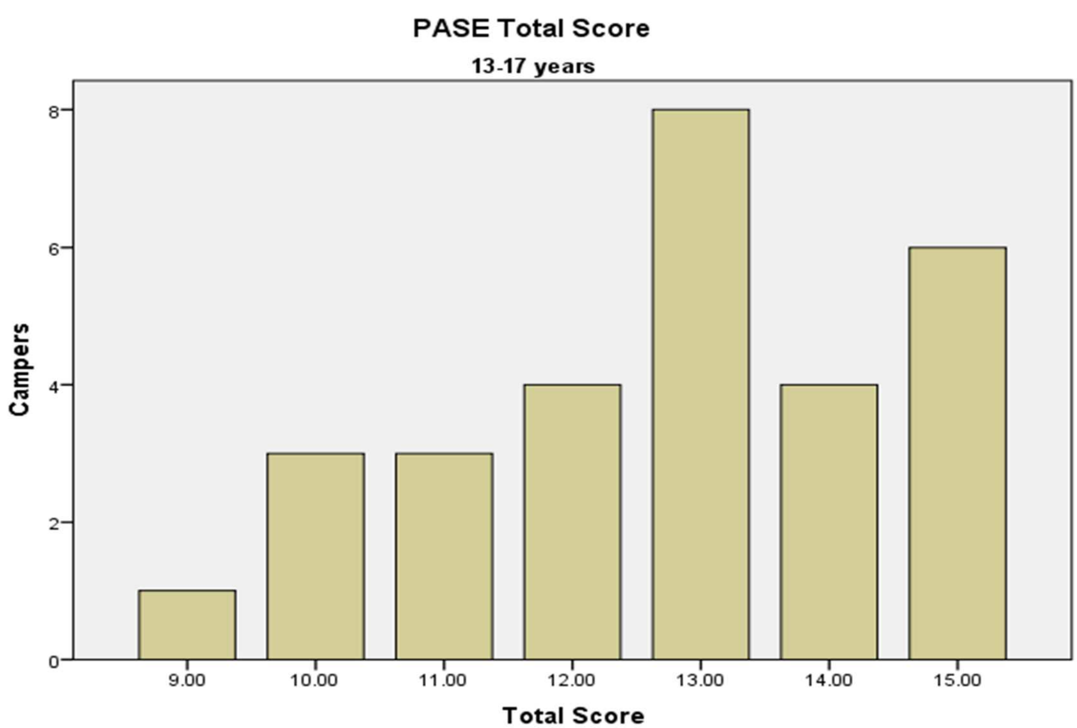
| Time | |
|---|---|
| 15min | General nutrition education: “Likes” and “Dislikes”. Pass out food models from each food group to the campers at random. Have campers get into groups based on the food models. Discuss the groups (should be 5 groups, one for each food group). Present the 5 food groups and talk about how it is important to have foods from every group every day but not every food in each group is healthy for us. Have the campers place their food models in the food group under “like” or “dislike” and talk about why they chose to put the food model where they did |
| 5min | Discussion |
| 15min | Diabetes specific education: Present the nutrition facts label board and have a discussion about portion sizes and insulin regimens. Have campers bring up their food models and fill out the nutrition facts label. |
| 5min | Discussion |
| 5min | Closing |

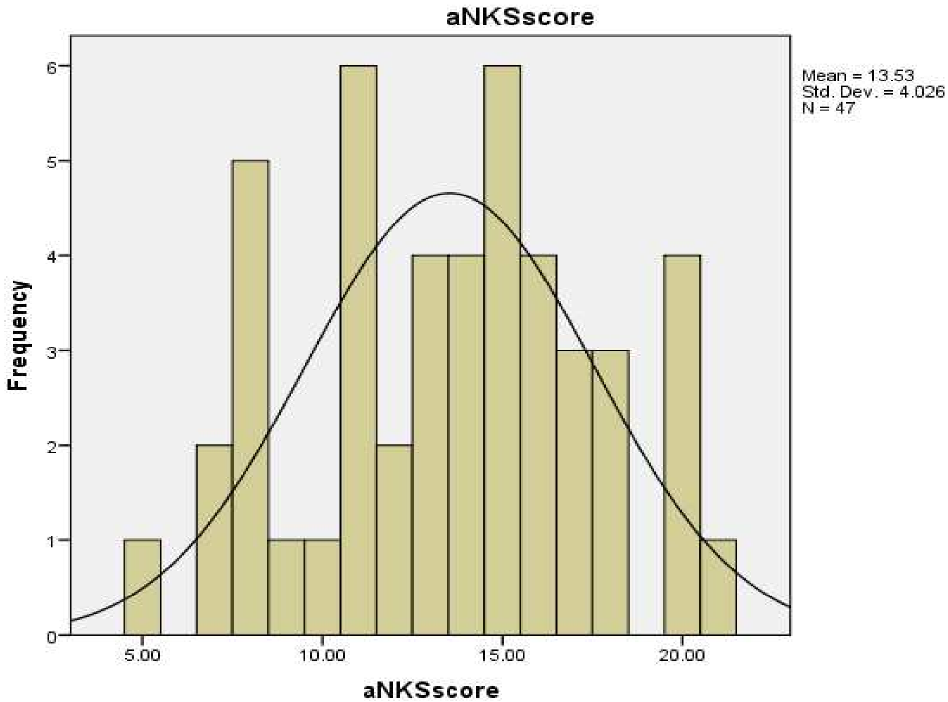
APPENDIX H: GENERAL NUTRITON LESSON PHOTOS


APPENDIX I: DIABETES SPECIFIC LESSON PHOTOS

# APPENDIX J: ADDITIONAL STATISTICAL ANALYSIS

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Frequency
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6
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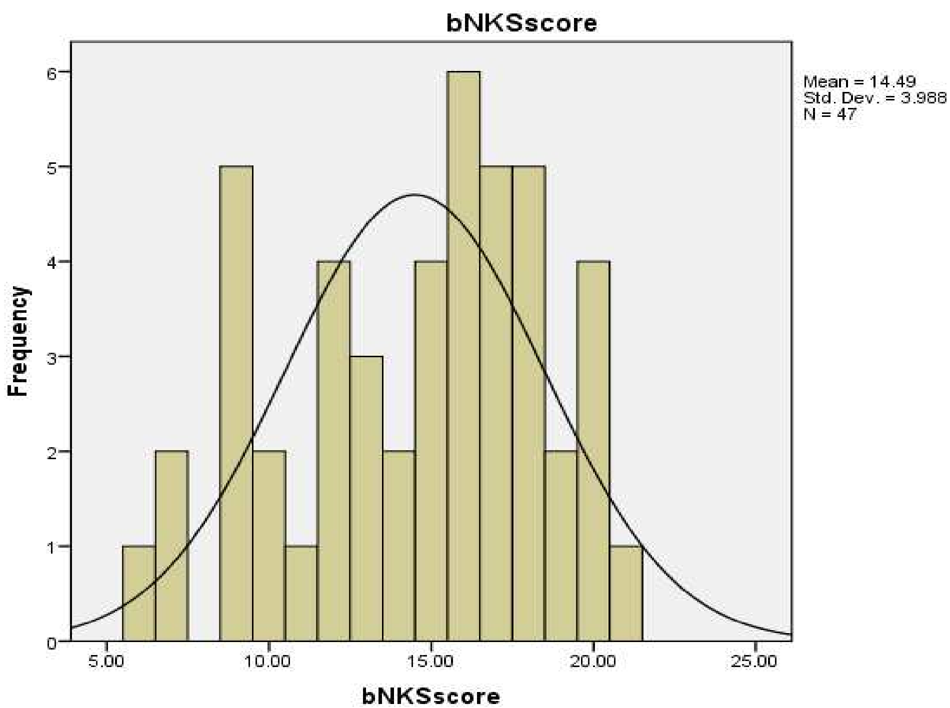
10.00
15.00
20.00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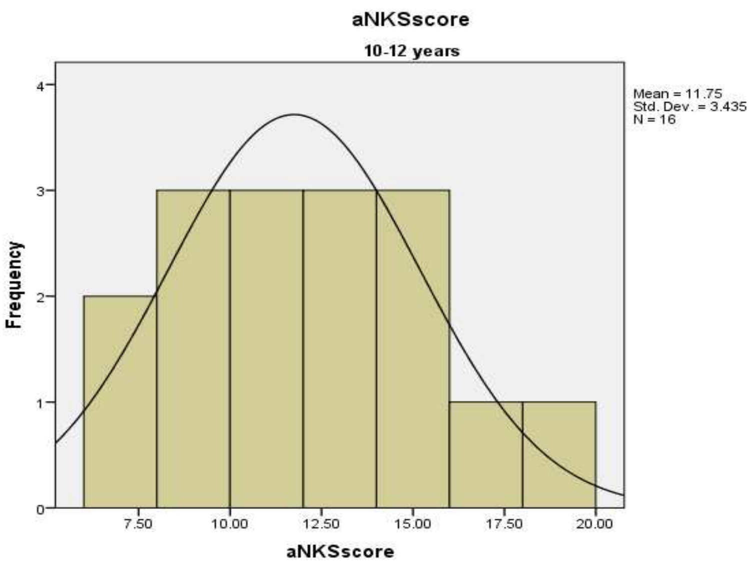
20.00
25.00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10-12 years
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Std. Dev. = 3.435
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Frequency
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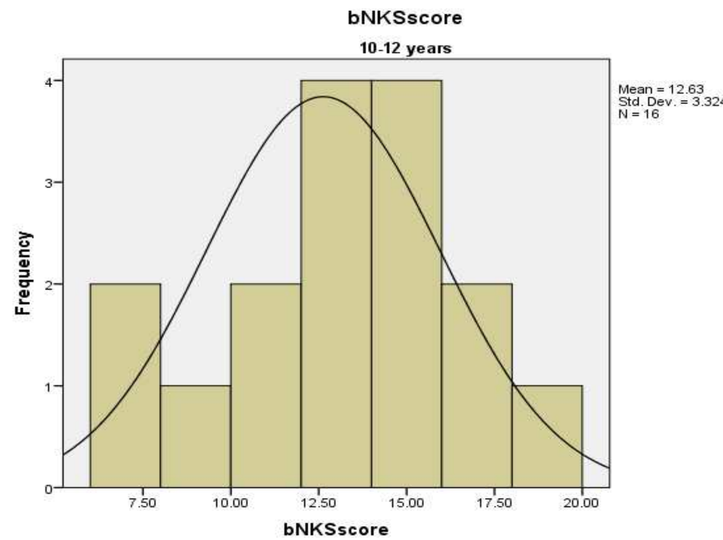
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10-12 years
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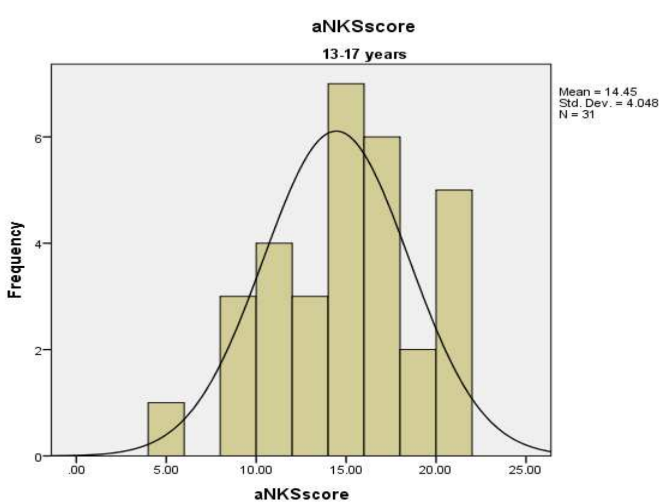
Std. Dev. = 3.324
N = 16
Frequency
bNKSscore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Frequency
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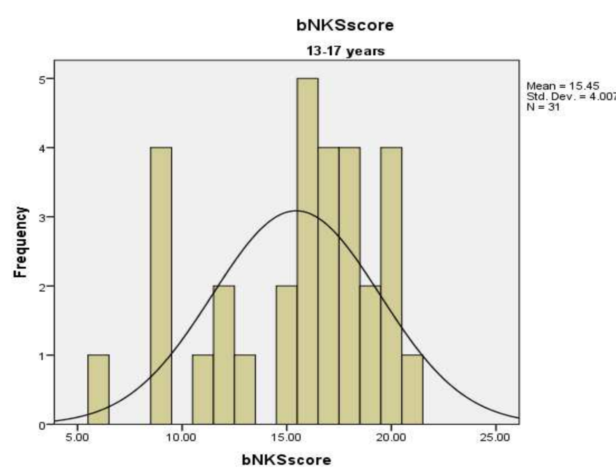
bNKSscore
13-17 years
Mean = 15.45
Std. Dev. = 4.007
N = 31
Frequency
bNKSscore

Bibliography


**1.** Y. L. Wu, Y. P. Ding, J. Gao, Y. Tanaka, and W. Zhang, “Risk factors and primary prevention trials for type 1 diabetes,” International Journal of Biological Sciences, vol. 9, pp. 666–679, 2013.

**2.** Daneman D. Type 1 diabetes. *Lancet.* Mar 11 2006;367(9513):847-858.

**3.** Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes: estimates for the year 2000 and projections for 2030. *Diabetes Care.* May 2004;27(5):1047-1053.

**4.** Wang YCA SS, Tuli E, White P. Improved glycemic control in adolescents with type 1 diabetes mellitus who attend diabetes camp. *Pediatric Diabetes* 2008;9:29-34.

**5.** Mitrovic M, Popovic DS, Naglic DT, Paro JN, Ilic T, Zavisic BK. Markers of inflammation and microvascular complications in type 1 diabetes. *Central European Journal of Medicine.* Dec 2014;9(6):748-753.

**6.** Nathan DM. Lifetime benefits and costs of intensive therapy as practiced in the diabetes control and complications trial (vol 276, pg 1409, 1996). *Jama-Journal of the American Medical Association.* Jul 2 1997;278(1):25-25.

**7.** American Diabetes A. Standards of medical care in diabetes--2013. *Diabetes Care.* Jan 2013;36 Suppl 1:S11-66.

**8.** Tuchinda C, Likitmaskul S, Unachak K, Panamonta O, Patarakijavanich N, Chetthakul T. The epidemiology of type 1 diabetes in Thai children. *J Med Assoc Thai.* Jun 2002;85(6):648-652.

**9.** Karaguzel G, Bircan I, Erisir S, Bundak R. Metabolic control and educational status in children with type 1 diabetes: effects of a summer camp and intensive insulin treatment. *Acta Diabetol.* Dec 2005;42(4):156-161.

**10.** Carlson KT, Carlson GW, Jr., Tolbert L, Demma LJ. Blood glucose levels in children with Type 1 diabetes attending a residential diabetes camp: a 2-year review. *Diabet Med.* Mar 2013;30(3):e123-126.

**11.** Snyder CK. Strategies to improve insulin adherence in adolescents with type 1 diabetes. *J Pediatr Nurs.* Jan-Feb 2015;30(1):278-280.

**12.** Silverstein J, Klingensmith G, Copeland K, et al. Care of children and adolescents with type 1 diabetes: a statement of the American Diabetes Association. *Diabetes Care.* Jan 2005;28(1):186-212.

**13.** Yardley J, Mollard R, MacIntosh A, et al. Vigorous intensity exercise for glycemic control in patients with type 1 diabetes. *Can J Diabetes.* Dec 2013;37(6):427-432.

**14.** Nansel TR, Lipsky LM, Liu A, Laffel LM, Mehta SN. Contextual factors are associated with diet quality in youth with type 1 diabetes mellitus. *J Acad Nutr Diet.* Aug 2014;114(8):1223-1229.

**15.** Lipsky LM, Nansel TR, Haynie DL, Mehta SN, Laffel LM. Associations of food preferences and household food availability with dietary intake and quality in youth with type 1 diabetes. *Appetite.* Oct 2012;59(2):218-223.

**16.** Mehta SN, Volkening LK, Anderson BJ, et al. Dietary behaviors predict glycemic control in youth with type 1 diabetes. *Diabetes Care.* Jul 2008;31(7):1318-1320.

17. The NS, Crandell JL, Thomas J, et al. Correlates of medical nutrition therapy and cardiovascular outcomes in youth with type 1 diabetes. *J Nutr Educ Behav.* Nov-Dec 2013;45(6):661-668.
18. Botero D, Wolfsdorf JI. Diabetes mellitus in children and adolescents. *Arch Med Res.* May-Jun 2005;36(3):281-290.
19. Santiprabhob J, Likitmaskul S, Kiattisakthavee P, Weerakulwattana P, Chaichanwattanakul K, Nakavachara P, et al. Glycemic control and the psychosocial benefits gained by patients with type 1 diabetes mellitus attending the diabetes camp. Patient Educ Couns. 2008 Jul 5;73(1):60–6.
20. Clinic M. Diabetes. http://www.mayoclinic.org/diseases-conditions/diabetes/basics/definition/con-20033091, Accessed: 2014.
21. The American Diabetes Association. A1c and eAg. http://www.diabetes.org/living-with-diabetes/treatment-and-care/blood-glucose-control/a1c/. Accessed2014.
22. Clinic M. A1C test. Available at: http://www.mayoclinic.org/tests-procedures/a1c-test/basics/definition/prc-20012585., 2014.
23. Clements MA, Lind M, Raman S, et al. Age at diagnosis predicts deterioration in glycaemic control among children and adolescents with type 1 diabetes. *BMJ Open Diabetes Res Care.* 2014;2(1):e000039.
24. Purnell JQ, Zinman B, Brunzell JD, Group DER. The effect of excess weight gain with intensive diabetes mellitus treatment on cardiovascular disease risk factors and atherosclerosis in type 1 diabetes mellitus: results from the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Study (DCCT/EDIC) study. *Circulation.* Jan 15 2013;127(2):180-187.
25. Minges KE, Whittemore R, Grey M. Overweight and obesity in youth with type 1 diabetes. *Annu Rev Nurs Res.* 2013;31:47-69.
26. van Vliet M, van der Heyden JC, Diamant M, et al. Overweight children with type 1 diabetes have a more favourable lipid profile than overweight non-diabetic children. *Eur J Pediatr.* Mar 2012;171(3):493-498.
27. Rovner AJ, Nansel TR, Mehta SN, Higgins LA, Haynie DL, Laffel LM. Development and validation of the type 1 diabetes nutrition knowledge survey. *Diabetes Care.* Aug 2012;35(8):1643-1647.
28. Bangstad HJ, Danne T, Deeb LC, et al. ISPAD Clinical Practice Consensus Guidelines 2006-2007. Insulin treatment. *Pediatr Diabetes.* Apr 2007;8(2):88-102.
29. Marigliano M, Morandi A, Maschio M, et al. Nutritional education and carbohydrate counting in children with type 1 diabetes treated with continuous subcutaneous insulin infusion: the effects on dietary habits, body composition and glycometabolic control. *Acta Diabetol.* Dec 2013;50(6):959-964.
30. Patton SR. Adherence to diet in youth with type 1 diabetes. *J Am Diet Assoc.* Apr 2011;111(4):550-555.
31. Not T, Tommasini A, Tonini G, et al. Undiagnosed coeliac disease and risk of autoimmune disorders in subjects with Type I diabetes mellitus. *Diabetologia.* Feb 2001;44(2):151-155.

**32.** Frohlich-Reiterer EE, Hofer S, Kaspers S, et al. Screening frequency for celiac disease and autoimmune thyroiditis in children and adolescents with type 1 diabetes mellitus - data from a German/Austrian multicentre survey. *Pediatric Diabetes.* Dec 2008;9(6):546-553.

**33.** Mackinder M, Allison G, Svolos V, et al. Nutritional status, growth and disease management in children with single and dual diagnosis of type 1 diabetes mellitus and coeliac disease. *Bmc Gastroenterology.* May 28 2014;14.

**34.** Cronin CC, Shanahan F. Insulin-dependent diabetes mellitus and coeliac disease. *Lancet.* Apr 12 1997;349(9058):1096-1097.

**35.** Erickson K, Freeborn D, Roper SO, Mandleco B, Anderson A, Dyches T. Parent experiences raising young people with type 1 diabetes and celiac disease. *J Pediatr Nurs.* Mar-Apr 2015;30(2):353-363.

**36.** Nadhem ON, Azeez G, Smalligan RD, Urban S. Review and practice guidelines for celiac disease in 2014. *Postgrad Med.* Feb 23 2015:1-7.

**37.** The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. The Diabetes Control and Complications Trial Research Group. *N Engl J Med.* Sep 30 1993;329(14):977-986.

**38.** Dietary Guidelines for Americans, 2010 7th Edition. *U.S. Department of Agriculture, U.S. Department of Health and Human Services.* . 2010;7th Edition.

**39.** Reedy J, Krebs-Smith SM. Dietary sources of energy, solid fats, and added sugars among children and adolescents in the United States. *J Am Diet Assoc.* Oct 2010;110(10):1477-1484.

**40.** American Diabetes A, Bantle JP, Wylie-Rosett J, et al. Nutrition recommendations and interventions for diabetes: a position statement of the American Diabetes Association. *Diabetes Care.* Jan 2008;31 Suppl 1:S61-78.

**41.** Rovner AJ, Nansel TR. Are children with type 1 diabetes consuming a healthful diet?: a review of the current evidence and strategies for dietary change. *Diabetes Educ.* Jan-Feb 2009;35(1):97-107.

**42.** Nansel TR, Haynie DL, Lipsky LM, Laffel LM, Mehta SN. Multiple indicators of poor diet quality in children and adolescents with type 1 diabetes are associated with higher body mass index percentile but not glycemic control. *J Acad Nutr Diet.* Nov 2012;112(11):1728-1735.

**43.** Piernas C, Popkin BM. Trends In Snacking Among US Children. *Health Affairs.* Mar-Apr 2010;29(3):398-404.

**44.** Spiegel G, Bortsov A, Bishop FK, et al. Randomized nutrition education intervention to improve carbohydrate counting in adolescents with type 1 diabetes study: is more intensive education needed? *J Acad Nutr Diet.* Nov 2012;112(11):1736-1746.

**45.** C.E. Smart, K. Ross, J.A. Edge, B.R. King, P. McElduff, C.E. Collins Can children with type 1 diabetes and their caregivers estimate the carbohydrate content of meals and snacks? Diabet Med, 27 (2010), pp. 348–353

**46.** Mehta SN, Haynie DL, Higgins LA, et al. Emphasis on Carbohydrates May Negatively Influence Dietary Patterns in Youth With Type 1 Diabetes. *Diabetes Care.* Dec 2009;32(12):2174-2176.

**47.** Janssen I, LeBlanc AG. Systematic review of the health benefits of physical activity and fitness in school-aged children and youth. *International Journal of Behavioral Nutrition and Physical Activity.* May 11 2010;7.
**48.** Warburton DER, Nicol CW, Bredin SSD. Health benefits of physical activity: the evidence. *Canadian Medical Association Journal.* Mar 14 2006;174(6):801-809.
**49.** Liese AD, Ma XG, Maahs DM, Trilk JL. Physical activity, sedentary behaviors, physical fitness, and their relation to health outcomes in youth with type 1 and type 2 diabetes: A review of the epidemiologic literature. *Journal of Sport and Health Science.* Mar 2013;2(1):21-38.
**50.** Schweiger B, Klingensmith G, Snell-Bergeon JK. Physical activity in adolescent females with type 1 diabetes. *Int J Pediatr.* 2010;2010:328318.
**51.** Galler A, Lindau M, Ernert A, Thalemann R, Raile K. Associations Between Media Consumption Habits, Physical Activity, Socioeconomic Status, and Glycemic Control in Children, Adolescents, and Young Adults With Type 1 Diabetes. *Diabetes Care.* Nov 2011;34(11):2356-2359.
**52.** Edmundson E, Parcel GS, Feldman HA, et al. The effects of the child and adolescent trial for cardiovascular health upon psychosocial determinants of diet and physical activity behavior. *Preventive Medicine.* Jul-Aug 1996;25(4):442-454.
**53.** Parcel GS, Simons-Morton B, O'Hara NM, Baranowski T, Wilson B. School promotion of healthful diet and physical activity: impact on learning outcomes and self-reported behavior. *Health Educ Q.* Summer 1989;16(2):181-199.
**54.** Riddell MC, Iscoe KE. Physical activity, sport, and pediatric diabetes. *Pediatr Diabetes.* Feb 2006;7(1):60-70.
**55.** Ruzic L, Sporis G, Matkovic BR. High volume-low intensity exercise camp and glycemic control in diabetic children. *J Paediatr Child Health.* Mar 2008;44(3):122-128.
**56.** Faulkner MS, Michaliszyn SF, Hepworth JT. A personalized approach to exercise promotion in adolescents with type 1 diabetes. *Pediatric Diabetes.* May 2010;11(3):166-174.
**57.** Maslow GR, Lobato D. Diabetes summer camps: history, safety, and outcomes. *Pediatr Diabetes.* Jun 2009;10(4):278-288.
**58.** American Diabetes A. Diabetes management at camps for children with diabetes. *Diabetes Care.* Jan 2012;35 Suppl 1:S72-75.