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Developmental Aspects of Diabetes knowledge

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Developmental Aspects of Diabetes Knowledge

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

by

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Abstract

DEVELOPMENTAL ASPECTS OF DIABETES KNOWLEDGE

By Kari Lyn Morgan, B.A.

A Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

Virginia Commonwealth University, 2008

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The Test of Diabetes Knowledge (TDK) was studied to determine its appropriateness for children. Early onset diabetes was examined for residual effects on poorer adolescent understanding of diabetes and problem solving that could affect self-care behaviors.

Participant groups were created as children (<12) and adolescents (≥12). A second division created a group of adolescents with early onset disease (EOD < 12 years) and with late onset disease (LOD ≥12 years). Participants were predominantly Caucasian and from middle class families. 51% were boys with an average age of 12.95 years, disease duration of 4.35 years and onset age of 8.58 years.

Children scored significantly lower and responded "I don't know" significantly more often for all levels of knowledge when compared to adolescents. EOD and LOD group differences in problem-solving knowledge were not found for adolescents,

although duration accounted for a significant amount of variance in the model. *Post-hoc* regression indicated a significant negative relationship between duration and knowledge. EOD and LOD group differences were not found in self-care behaviors.

The TDK does not appear to be developmentally appropriate for children. EOD adolescents do not differ from LOD adolescents on problem solving questions; mean scores indicate the lack of abstract knowledge seen in children may be resolved with the transition into adolescence. Results indicate the longer a child has diabetes the less knowledge they appear to retain.

Introduction

According to the American Diabetes Association (ADA) about 1 in every 400-600 children and adolescents is diagnosed with Type 1 or insulin-dependent diabetes. While young people of any age can have Type 1 diabetes, it is most commonly diagnosed during puberty (Johnson, 1995). In 2005, over 176 thousand children and adolescents under the age of 20 had a diagnosis of Type 1 diabetes in the United States (National Institute of Diabetes and Digestive and Kidney Diseases, NIDDK, 2005). Type 1 diabetes, also called insulin-dependent mellitus (IDDM), is an autoimmune disease that affects the pancreas and causes the body to stop insulin production. The body's immune system attacks and destroys insulin producing cells in the pancreatic beta cells. Without these cells the body cannot create insulin, a naturally occurring hormone that helps breakdown and process the sugars from food. Without insulin, sugar accumulates in the blood stream and causes *hyper*glycemia, or too much sugar in the blood which can lead to ketoacidosis (diabetic coma). People with Type 1 diabetes also are susceptible to *hypo*glycemia, or insufficient sugar which can produce shakiness, dizziness, headaches, and seizures. (ADA, 2007; Johnson, 1995).

A diagnosis of Type 1 Diabetes (T1D) is a significant and life-changing event; not only for the patient but also for the entire family. Once diagnosed, a youth and parent(s) participate in an education program to learn disease management skills. These educational programs vary significantly depending on the institution of diagnosis; the most common options are an outpatient primary care office or a hospital. If hospitalized, a family may be offered inpatient education which is very intensive and costly or they may participate in an outpatient education program if their symptoms are not serious enough to warrant hospitalization at diagnosis. Outpatient programs have not been shown to be any less effective than intensive inpatient programs and are less costly and traumatic than an extended hospital stay (Siminerio, Charron-Prochownik, Banion, & Schreiner, 1999; Norris et al., 2002). Clinicians and researchers agree that this initial education is the "cornerstone" of appropriate daily diabetes management (Siminerio et al., 1999; Norris et al., 2002; Mensing et al., 2007). A basic understanding and knowledge of disease characteristics, symptoms, treatments and potential complications is necessary to appropriately manage the day-to-day challenges that accompany a diagnosis of T1D.

Type 1 diabetes is a serious concern for any adult who is diagnosed with the disease; however, the diagnosis of diabetes in children and adolescents creates a different set of problems for families. Youth and families have to learn how to balance a regimen of diabetes care that consists of diet, medication, and exercise management; a regimen that can be cumbersome to the carefree lifestyle of a child and to the independent lifestyle of an adolescent (LaGreca, Follansbee & Skyler, 1990; Siminerio et al., 1999). This regimen of diet, medication and exercise management is often referred to as self-care behaviors and is instituted to manage youth's blood sugar levels within a safe range. An average non-diabetic person's blood glucose ranges from 80 to 120 mg/dl; this is considered the normal and safe range. People with diabetes often fluctuate well above and below this range and utilize insulin therapy to help regulate their blood sugar level. Insulin therapy can take two forms, either multiple daily injections (MDI) of insulin, or insulin pump therapy. CSII (Continuous Subcutaneous Insulin Infusion) is one of the most recent advances in the diabetes field. CSII or “the pump” is an electronic device about the size of a pager; the patient receives a basal rate of insulin throughout the day via a catheter that is inserted underneath the skin. In addition to this basal rate of insulin the patient will bolus, or take an extra dose of insulin, for their level of food intake at each meal/snack. The pump is a very effective means to improve metabolic control in patients with Type 1 diabetes and to reduce the risk of hypoglycemia (Lenhard & Reeves, 2001). To monitor blood glucose levels throughout the day patients use a blood glucose monitor that requires a small drop of blood from a finger prick; this monitor provides your current blood sugar level and needs to be used on average 4-6 times a day. This method of blood glucose monitoring is very effective and essential for daily management; another measure of blood glucose levels is the glycosolated hemoglobin level (HbA1c). This assay provides an average blood glucose level for the previous three months and provides a global measure of overall diabetes management. If diabetes is not managed appropriately and youths undergo extended periods of hyperglycemia there can be significant long-term disease complications. These complications include retinopathy, nephropathy, neuropathy and cardiovascular disease (Nathan, 1993; Wysocki, 2006).

Cognitive Development

Unique to the challenges of people under the age of 21 diagnosed with T1D is the significant amount of physical and cognitive growth that occurs during childhood and adolescence. If an adult is diagnosed with diabetes after the age of 21 they have typically finished growing and are at the upper limits of their cognitive ability. However, if a child is diagnosed at the age of 5 or 6, they have several feet to grow, many stages of cognitive development to progress through, and years of education to complete. Their understanding and skills related to their diabetes will change significantly by the time they reach adulthood.

The stages of development hypothesized by Jean Piaget (1969) include the sensorimotor, preoperational, concrete operational and formal operational stages. The sensorimotor stage starts at birth and continues to about age 2. This period of development is marked by experiencing and learning about one's world through the senses. The preoperational stage starts at age 2 and lasts through ages 6-7. Preoperational children view the world from an egocentric perspective. Piaget's third developmental stage, the concrete operations stage, includes children from the age of 6-7 to 11-12. Concrete operations are marked by the initiation of logical thought and strict adherence to factual and very 'concrete' or tangible ideas and concepts guide their decision-making and an understanding of the world. Children in this stage are fairly rigid in their beliefs and make decisions base on strict ideals about what is right and what is wrong. Children progress from the concrete operational stage to formal operations around the age of 11 or 12. The formal operational stage is marked by higher-order thinking, or hypothetical thought. Adolescents are able to consider ideas and situations that are not directly observable; this stage marks a significant shift from concrete operations to abstract thought (Perrin & Gerrity, 1981; Vasta, Haith, & Miller, 1999).

Piaget's stages have been used extensively in the child health literature to track children's development in relation to their disease understanding and psychosocial adjustment. Hosek, Harper and Domancio (2005) utilized Piaget's stages of development to research medical adherence among HIV infected youth. Preformal operational children were inhibited in their ability to understand the complex medication regimen associated with HIV and did not have the foresight to adequately understand long-term disease complications. Youth with diabetes have similar illness management tasks including a cumbersome medication regimen and significant long term complications associated with their disease. Perrin and Gerrity (1981) studied children's understanding about the origin, symptoms and treatment of illness. They interviewed children in kindergarten, second, fourth, sixth and eighth grade. Children's responses were coded on a five point scale (0-4) following Piaget's stages ranging from no response scoring a zero, concrete rules a 2 and physiologic principles and mechanisms (formal operations) scoring a 4. Children's responses to health-related queries followed the established developmental progression associated with general development.

The development of disease understanding and illness concepts in children follows a linear progression that is in line with Piaget's proposed stages of development (Miller & Armstrong, 2006; Perrin & Gerrity, 1981). Bibace and Walsh (1981, as cited in Miller & Armstrong, 2006) completed what is considered the seminal study on children's developmental understanding of the progression of illness. They created a six stage scale of progression through Piaget's preoperational, concrete and formal operational stages. Stages 1 and 2 are the "associational" stages and are in line with Piaget's preoperational stage. In this stage children do not view illness as a cause and effect series; instead they report issues and symptoms that are associated with or external to the illness such as missing school as a symptom of illness. They attribute illness to external forces such as punishment for not obeying a specific set of rules or demands, or mystical or magical origins (Hansdottir & Malcarne, 1998). Lastly they understand recovery to simply happen or to come about by following another strict set of rules “such as staying in bed and eating chicken soup” (Perrin & Gerrity, p. 847). During the next stage of disease understanding, parallel to Piaget’s concrete operational stage, children have a more logical understanding of disease concepts. Attributions about infection and symptomology develop and a better understanding of how the body responds to external agents emerges. Children in this stage focus on potential contagions with a strong emphasis on germs. In this stage children still do not understand the physiological responses to germs, they simply subscribe to the concept that germs make you sick (Bibace & Walsh, 1980). However, in the formal operations stage children begin to understand how the body responds to external agents. When discussing how germs affect the body a child in the formal operations stage may be able to articulate how the immune system responds to germs and infection and how this process causes fever or illness (Perrin, Sayer & Willet, 1991).

However, some researchers assert that Piaget’s stages underestimate children’s ability to understand disease concepts. Hergenrather and Rabinowitz (as cited in Myant and Williams, 2005) argue that it is not appropriate to use Piaget’s stages to track disease conceptual development because the developmental stages track children’s logic and reasoning abilities rather than their capacity to understand. Despite these criticisms, Piaget's stages of development continue to be the cornerstone of developmental research (Bibace & Walsh, 1980; Miller & Armstrong, 2006; Travis & Schreiner, 1984).

Current literature in pediatric health care supports the use of a developmental framework to consider the needs of children and adolescents who have a chronic illness. While pediatric diabetes literature often suggests that a developmental perspective is important, the research surrounding diabetes knowledge has not always heeded this advice. Research has yielded ambiguous results regarding the effectiveness of diabetes education interventions on increasing diabetes care behaviors and decreasing HbA1c values. This may be explained by a lack of research that focuses on developmental differences in children (Band & Weisz, 1990). Research with other chronic illnesses confirms that children understand and retain knowledge differently at different developmental levels. Cremeens, Eiser & Blades (2006) studied the response patterns of children ages 5-9 as they answered questions on a generic quality of life measure. They asked children to use the "think aloud" method when responding to the questions and then coded a child's reasoning as 1 of 5 categories including social comparisons, character attributes, concrete examples, other responses or no response. Children across different age groups used different strategies to answer quality of life questions. Older children (7-9 yrs) used concrete examples and social comparisons to justify their answers; younger children (5-6 yrs) were less likely to use these strategies to justify their answers and were often unable to give any reason for their responses. These results indicate that children in different cognitive stages, concrete operational and preoperational respectively, contemplate and generate answers qualitatively differently from each other with some younger children lacking the cognitive ability to express how they reached their conclusions.

Similarly Johnson, et al. (1982) measured children's diabetes knowledge, specifically general knowledge, problem solving skills and urine testing with the Test of Diabetes Knowledge (TDK). Children, adolescents and their parents were given a multiple choice measure of diabetes knowledge developed for this study to assess knowledge and problem solving skill; an observational test of urine testing was used to assess skill in that area. General information items were based on a previous diabetes knowledge test by Etzwiler and colleagues (as cited in Johnson, et al.) and problem solving items were generated considering the tenets of this work as well as current educational programs. Once completed the measure was administered to 2 doctors and 1 nurse; only items that were answered the same by all 3 respondents were maintained. For this study youths and their families at a diabetes camp and a small number from a diabetes clinic completed these measures of diabetes knowledge. All respondents scored higher on general knowledge than problem-solving knowledge; girls performed better than boys; and adolescents scored significantly higher than younger children on all facets of diabetes knowledge. However, they suggest that is not simply a knowledge deficit in young children, but rather a developmental difference between the two groups and that diabetes education should be taught considering their developmental differences.

LaGreca, Follansbee and Skyler (1990) conducted a study that focused on youths' developmental level in the understanding of adherence, diabetes knowledge and metabolic control. Child (7-11 years), adolescent (12-17 years) and maternal diabetes knowledge was assessed with the TDK to test the relationship between knowledge and metabolic control for both the youth and their mother. Maternal knowledge was included due to the large role parents play in diabetes care especially in younger children. Adolescents had higher levels of diabetes knowledge than their younger counterparts as expected; however, there were no group differences in the metabolic control. Maternal diabetes knowledge was positively correlated with better preadolescent metabolic control but not adolescent metabolic control. Conversely, maternal diabetes knowledge had no relationship with adolescent metabolic control while higher adolescent knowledge was positively correlated with metabolic control. As adolescents aged and increased their level of knowledge and experience, maternal level of knowledge decreased with less involvement in daily care. However, the performance of adolescents and children was separated and all youth were tested with the same measure without consideration of developmental qualitative differences. Another cross-sectional analysis of diabetes knowledge replicated in the findings (O'Neil, Jonnalagadda, Hopkins, and Kicklighter, 2005) again showed that adolescents with Type 1 diabetes outscore their younger diabetic counterparts on the TDK.

Diabetes Knowledge

There are mixed findings in the literature regarding the relationship between diabetes knowledge, blood glucose control and disease care behaviors. There is dissent in the literature about the efficacy of diabetes education programs and if diabetes knowledge affects blood glucose levels and improves adherence behaviors (Grey, Kanner & Lacey, 1999). Many assert that diabetes knowledge, especially general knowledge, does not affect metabolic control, specifically HbA1c levels. La Greca et al., (1990) assert that knowledge is “necessary but not sufficient” (p. 133) to sustain appropriate levels of blood glucose control. However, Grey et al. (1999) assert that diabetes knowledge cannot directly affect blood glucose levels and that there are variables, such as self care behaviors or motivation, that moderate or mediate this relationship. Diabetes education programs that are designed to develop appropriate knowledge and target the improvement of disease management skills can be effective. Using HbA1c as an outcome variable would only be effective in a longitudinal study; immediate measures of change should be the direct targets of the program, knowledge and self-care behaviors. Along with the potential problems with reporting HbA1c as an outcome variable, another potential source for the discrepancy in diabetes education effectiveness is the lack of developmental focus and a developmentally sensitive measure of diabetes knowledge proposed in this study.

In contrast, some research has shown that diabetes education programs improve blood glucose control and adherence behaviors, especially in the short term (Colleran, Star & Burge, 2003; Stallwood, 2006; Wysocki, et al., 2007). Research has shown that greater diabetes knowledge is related to several aspects of metabolic control; Holmes et al. (2006) found that greater diabetes knowledge predicted better self-care behavior. Specifically, problem-solving knowledge was associated with greater self-efficacy and when combined with self-efficacy, knowledge predicts better adherence to dietary requirements. La Greca et al. (1990) showed that maternal diabetes knowledge was associated with better metabolic control in younger children and adolescents’ greater personal knowledge of diabetes predicted better metabolic control. In short, diabetes knowledge has been long considered a necessary component for good diabetes management.

The Task Force to Review and Revise the National Standards for Diabetes Self-Management Education Programs (2007) reviewed current educational programs and provided suggestions for future improvements and research. It asserts that "Diabetes Self-Management Education (DMSE) is the cornerstone of care for all individuals with diabetes who want to achieve successful health-related outcomes" (Mensing et al., 2007, p. S96). In their 2007 review of current educational standards, they emphasize the need to continue research on that the effects of education on diabetes management. This is due in part to the large number of patients that are not receiving adequate education about their disease.

The position of the Diabetes Education Task Force and the research that supports the need for a strong diabetes education indicates that diabetes knowledge is thought to be an important part of disease management, especially in the case of pediatric diabetes. In light of this, it is important for researchers and clinicians to understand what young people at different stages of development learn about diabetes knowledge. Currently a broad age range of children through adolescents are tested with the same diabetes knowledge questionnaire (Johnson et al., 1982; LaGreca et al., 1990; O'Neil et al., 2005); which is insensitive to developmental differences in cognitive stages. The most widely used measure of diabetes knowledge is Johnson et al.'s Test of Diabetes Knowledge (TDK). Johnson et al. (1982) developed this measure to assess diabetes knowledge of parents and youth, and to establish a reliable and valid measure that diabetes researchers could utilize to replace the many other unvalidated knowledge tests that were available. A single version of this measure was developed to be administered to youth of all ages with Type 1 diabetes and their parents. No rationale was given for the development of a single measure other than the need for the development of a transportable validated measure that could be widely utilized. However, with a single measure that covers multiple age groups, many questions do not apply to younger children; for example, one multiple choice question reads "You are at a school football game and begin to feel dizzy, shaky, and faint. What should you do?: a) Leave the game right away and go straight home; b) Buy a coke and a hot dog and eat them; c) Lie down, until you feel better; [or] d) I don't know" (Johnson et al., p. 709). It is unlikely that a young child would be in a social situation like this without their parent, nor is it likely they would be expected to fix the problem on their own through the purchase of food. In this situation a child who is dependent on their parents for care may choose the option of going home; while going and getting help is the "incorrect" answer, it may be the most developmentally appropriate answer for a younger child. Also, the TDK tests knowledge that is not developmentally sensitive. Children in the concrete stage are typically unable to consider hypothetical situations; many questions from Johnson et al.'s TDK are posed in this format:

> "You have a big test coming next period in your hardest subject. You are worried about it, because you feel unprepared. Thirty minutes before the test is to begin you start to feel weak, shaky, sweaty and your heart begins to beat fast. You drink some milk and eat some peanut butter crackers, but nothing happens. Fifteen minutes later you still feel weak, shaky, sweaty and your heart is beating faster. You should: (a) Test your blood glucose because your symptoms may be because you're worried about the test; (b) Eat some more; (c) Take some Regular insulin; or (d) I don't know" (Johnson et al., 1982).

This question has multiple layers of hypothetical thought; the child must imagine themselves at school, feeling worried, take into consideration time and physical symptoms and finally decide how to treat the situation. This question is more appropriate for a teen who often experiences and resolves situations of this nature. A child in the 5th or 6th grade may need to go to the nurse to get help with these symptoms and this more appropriate option is not an available choice. A more appropriate question for a younger child should focus on one aspect of their diabetes care, be concrete in nature and focus on physical symptomology, such as: “Insulin: a) Lowers the blood sugar level; b) Raises the blood sugar level; c) Increases sugar in urine; or d) I don’t know” (Johnson et al., 1982).

As adolescents move towards adulthood this may be an appropriate measure of their diabetes knowledge; they need to learn and understand the skills required to care for themselves and what to do in problematic health situations. However this type of knowledge is not necessary or developmentally appropriate for younger children who rely more on their parents for their disease management. Johnson et al. (1982) suggest that when a child is diagnosed with Type 1 diabetes it may be more appropriate to educate them utilizing “practical knowledge about diet and insulin reactions.” (p. 713). Once a child reaches adolescence, reeducate them to the “more sophisticated” aspects of diabetes management and care (p. 713). This suggestion supports the argument that young children need and retain different information to adequately manage their diabetes than adolescents.

Current Age, Onset Age and Disease Duration

Another important developmental aspect of diabetes knowledge to consider is how age of onset and duration of disease affects level of knowledge and skill. Research has overwhelmingly used current age as a means to separate youth into groups within a study (Johnson et al., 1982; Freund, Johnson, Silverstein & Thomas, 1991; LaGreca et al., 1990; O'Neil et al., 2005; Travis & Schreiner, 1984) However, separation into age groups may not be the most beneficial way to evaluate participants. A 14 year-old diagnosed at age 6 with a disease duration of 8 years will likely have different levels of knowledge and psychosocial development than a 14 year old diagnosed at age 13 with a disease duration of 1 year. However, these two teens would be grouped together solely on the basis of chronological age in an attempt to understand the disease knowledge of a youth with diabetes. Disease duration, age of onset, and current age have long been variables of interest to researchers who evaluate psychosocial variables and disease characteristics. However these three variables are highly correlated and it is often difficult to determine separate effects. Johnson and Meltzer (2002) attempted to address this problem by designing a study to disentangle the effects of disease duration, age of onset and current age. It can be difficult to discern specific effects because all three variables are so closely related; to determine effects for current age they ran two separate regression analyses controlling for disease duration in the first and age of onset in the second. Only outcomes that remained significant in both analyses were considered solely attributable to the original dependent variable of interest. Utilizing this method for each independent variable they discerned different effects for each of the three variables showing that age of onset best predicted family disruption associated with diagnosis, and maternal reports of ability to observe and detect diabetes symptoms. Disease duration best predicted maternal beliefs about diabetes as a "religious test," (Johnson & Meltzer, p. 82) and maternal attitudes towards medical staff. Lastly, current age best predicted rule orientation regarding diabetes care in youths and the desire for special treatment because of their diabetes. In the current study disease duration and age of onset will be utilized to help determine the effects of different age levels on diabetes knowledge.

Statement of Problem

The highest incidence of Type 1 diabetes occurs during preteen and teenage years. This time of life is typically filled with physical, mental and social changes, add the responsibilities associated with a diabetes care regimen and their lives can become significantly more complicated.

The initial diagnosis of a child with Type 1 diabetes is important because the family’s basic level of knowledge and new life routines are established at this time. Extensive education is typically only given once, either inpatient or outpatient, at the initial onset and diagnosis of the disease. Very rarely is reeducation offered to youths and their families unless the youth has to be hospitalized. This educational situation leads to several questions. If a child receives diabetes education in the concrete operational stage will they make the shift to a more abstract understanding of disease characteristics on their own? If youths do make the shift to abstract thought regarding their diabetes, will they have a knowledge deficit in relation to a peer of the same age who was educated during formal operations? Research in relation to diabetes knowledge has been largely focused comparing levels of diabetes knowledge between age groups as well as parent vs. youth. There are currently no studies that utilize age of onset and disease duration to determine how youths’ knowledge fluctuates as they get further away from their educational initiation. Two logical possibilities include: 1) decreased knowledge with time consistent with the concept of ‘if you don’t use it, you lose it’ or 2) increased knowledge and/or skill through experience with their disease that may replace rote memorized knowledge. With this increased experience youths and parents may be better equipped to answer questions correctly, specifically problem solving questions.

The proposed study will examine developmental differences in diabetes knowledge in childhood and adolescents. Children’s cognitive development will be considered within the stages of development hypothesized by Jean Piaget (1969), and will focus specifically on the transition from concrete and fact-based operations to formal operations and abstract cognitive ability. This developmental framework will be applied to children’s acquisition of diabetes knowledge. This study will not include Piaget’s sensorimotor or preoperational stages of birth to 6 years; during this time children are primarily reliant on their parents for their diabetes care and therefore not the focus of inquiry. Piagetian research suggests that concrete operational children (below age 12) are not able to learn the same information as formal operational adolescents (ages 12 and above). It is presently unknown how children with diabetes acquire or reformulate disease information as they age (Band & Weisz, 1990). Here we will consider how developmental level at time of diagnosis and initial diabetes education and disease duration affects an individual’s knowledge level and how this may generalize to diabetes management.

Specific hypotheses for this study are:

1) Adolescents (>/= 12) will score higher than children (< = 12) on measures of concrete, abstract and total diabetes knowledge.

2) Children will respond with the answer of “I don’t know” (IDK) more often than adolescents on all knowledge scales.

3) The discrepancy between adolescents and children’s response rate of IDK for questions in the abstract knowledge section will be significantly larger than the difference between their response rate of IDK for concrete knowledge questions.

4) Adolescents diagnosed with Type 1 diabetes prior to the age of 12 will have significantly lower abstract knowledge scores than their similar-age counterparts diagnosed after the age of 12 with disease duration as a covariate.

5) Adolescents diagnosed with Type 1 diabetes prior to the age of 12 will have significantly lower levels of self-care behavior than their similar-age counterparts diagnosed after the age of 12 with disease duration as a covariate.

Method

Participants

To recruit participants for this study, patients diagnosed with Type 1 diabetes were sent informational material detailing the purpose, requirements and potential benefits of a study of cognitive profiles in youths with diabetes. These families were affiliated with pediatric endocrinology clinics in two major metropolitan medical centers. After potential participants were identified, they were contacted by research staff via telephone to enroll them in the study.

Participants needed to be between 9 and 17 years of age to qualify for participation. They could not be taking any medications that affect their central nervous system other than insulin and cannot have another chronic illness or a traumatic brain injury.

Sample Characteristics

Previous research tapping patients in this region has yielded predominantly Caucasian and middle class samples. The current sample consisted of 77% Caucasian participants with the remaining 23% representing African Americans (37), Hispanics (5) and Other (1). The average socio-economic score (SES) on the Hollingshead Index (Hollingshead, 1973) for families indicated that the average family's SES was Class III; this score is based on several factors including education level and occupation and is synonymous with "middle class." A sample heavily weighted with Caucasian families may present generalizability issues; however, it would not be out of line with previous research and incidence rates of T1D. Studies have shown that Caucasian youth are more often diagnosed with Type 1 diabetes than their minority counterparts (Lorenzi, Cagliero & Schmidt, 1985; Delamater et al., 1999). With a 23% minority sample the current study generalizeability may not be as limited as with previously reported literature.

Procedures

Youth and their parents were typically given their psychological assessments with their already scheduled medical appointments. Sessions averaged two hours in duration and were administered by trained graduate students. Prior to completing the assessment measures, parents signed consent for themselves and for their children. At the same time, assent to participate was obtained from the youth participating in the study. After consent and assent were obtained the youth completed their neuropsychological and psychosocial testing (including the TDK) in a separate area while their parents completed psychosocial and medical history questionnaires.

Measures/Materials

Demographic Questionnaire – Parents were given a demographic questionnaire to complete during their initial assessment. Some questions included are: 1) age of the youth, 2) ethnicity, 3) marital status of parent, 4) socio-economic information, and 5) disease duration.

Test of Diabetes Knowledge – Youth diabetes knowledge was assessed by the Test of Diabetes Knowledge (TDK) developed by Johnson et al. in 1982. The TDK requires a youth to answer multiple choice questions relating to different aspects of diabetes knowledge and care. Four response options are given including three possible answers and a fourth response option of "I don't know." The multiple choice questions are divided into two subcategories of diabetes knowledge including 38 problem-solving questions and 36 general knowledge questions. The TDK has been shown to have good internal reliability with split-half Spearman-Brown reliability estimates of r = .90 for the general information questions (P<.0001) and $r = .84$ for the problem-solving questions (P<.0001) (Johnson et al., 1982).

The TDK is naturally divided into two scales: 1) general knowledge and 2) problem-solving. These subscales align well with Piaget's and Bibace & Walsh's stages of concrete and formal operations and disease understanding stages respectively. The general knowledge scale focuses on very specific aspects of diabetes such as food groups, how insulin affects your body and symptoms of high and low blood sugar. The problem-solving subscale consists of hypothetical situations that involve the correct application of several diabetes care behaviors in real life situations. Due to the hypothetical nature of the problem-solving questions they may only be appropriate for youths who have developed formal operations. For the purpose of this study, the general knowledge subscale will be included in the analyses as concrete operations and the problem-solving knowledge subscale will be included as formal operations; these terms will be used interchangeably throughout the paper.

Self Care Behaviors – 24 hour diabetes interview – Diabetes disease-care behaviors (blood glucose checking, insulin shots and bolusing) were assessed utilizing the 24 hour diabetes interview created by Johnson et al. (1982). The interview requires that the youth and parent recall their diabetic and meal related activities for the previous day. The initial administration of the interview was completed in person during the 2 hour assessment completed at the diabetes clinic. At some point during the next 10 days the family was contacted again by a trained graduate student to administer the second 24 hour interview; each interview takes approximately 10 to 15 minutes. Youth and parents were interviewed separately to provide two independent recollections of the previous day. If the interviewee neglected to offer information about diabetes care behaviors the administrator prompted them with questions about the omitted information. The administrators were trained to ask questions and respond in a non-judgmental way to information offered (e.g. not sounding disappointed if a child reports "sneaking" food). Reliability and validity for this measure have been well established (Johnson, Silverstein, Rosenbloom, Carter & Cunningham, 1986; Freund et al., 1991). Pearson product-moment correlations between parent and child report were significant for all 13 variables included in the interview. Correlations in Johnson et al.'s (1986) study ranged from $r = .42$ for "regularity of injection" and "meal timing" to $r = .78$ for "glucose testing frequency." These correlations were stable across time and dependent on age for 6 of the 13 variables (Johnson et al., 1986; Freund et al., 1991).

After information from both parent and youth was collected the decisions rules developed by Johnson et al. (1986) were be used to reconcile any differences between youth and parent reports of diet and self-care behaviors.

Data Analyses

The scores of youths were divided into two groups based on current age. Groups consisted of youths aged 12 and older and those under 12. This age was chosen using the general age guidelines provided by Piaget for transition into formal operations. Total, problem-solving, and general knowledge scores were compared with between group ANOVAs to determine if scores are significantly different for Hypothesis 1. A count function was completed to determine the number of IDK responses given by individual children and adolescents. Mean percentage scores were compared with ANOVAs to determine the difference in the IDK response rates between children and adolescents on general, problem-solving and total knowledge scores. The effect sizes obtained from the individual ANOVAs for abstract and concrete knowledge were compared to discuss the results of Hypothesis 3.

The high level of multicollinearity between onset age, current age and disease duration can complicate analyses and makes it difficult to tease apart the specific results associated with each variable. In the following analyses current age will be “controlled” for by reducing the variability associated with it. The goal of separating the participants into two developmentally grouped subsamples (children and adolescents) was to reduce the variance associated with current age. The previously discusses analyses compared between group differences on current age, and the following analyses will compare within group differences for the adolescent group. Youths ages 12 and above were divided into two groups by onset age diagnosed prior to age 12 or after. A between group ANCOVA was used to determine if adolescents diagnosed and educated about their disease during the concrete operational period have lower scores on abstract knowledge than their similar-aged counterparts diagnosed and educated during the formal operational period with disease duration included as a covariate. A second set of ANCOVAs was completed to determine if youths diagnosed and educated during concrete operations had significantly lower self-care behavior activity than their similar-aged counterparts with disease duration included as a covariate.

Results

The Test of Diabetes Knowledge (TDK) was completed by 192 participants. The sample included 100 boys (52.1%) with a mean age of 12.95 years (*SD* = 1.9), had a mean disease duration of 4.35 years (*SD* = 3.3), a mean onset age of 8.58 years (*SD* = 3.9) and a mean HbA1c of 8.2 (*SD* = 1.5). Participants were predominantly middle class, 77.6% Caucasian, 19.3% African American, and 3.1% Hispanic or Other. Table 1 includes detailed demographic information for the total sample divided by age into children (participants <12, N = 68) versus adolescents (participants ≥ 12, N = 124). Adolescents were further divided into groups with early disease onset (diagnosed <12, N = 79) and late onset (diagnosed ≥12, N = 43).

Table 1

Disease and Demographic Characteristics of the Sample: Mean scores reported with (SD)

		Total Sample by Age Group		**Adolescent Sample by Onset**	
	Total	*< 12 years*	*≥ 12 years*	*Early Onset*[1]	*Late Onset*[1]
N	192	68	124	79	43
Age (yrs)	12.95(1.9)	10.86(.68)	14.07(1.3)	13.68(1.2)	14.8(1.1)
Onset Age (yrs)	8.58(3.9)	6.13(3.1)	9.94(3.6)	8.04(3.1)	13.43(1.0)
Duration (yrs)	4.35(3.3)	4.73(3.1)	4.14(3.4)	5.64(3.3)	1.37(1.0)
HbA1c	8.2(1.5)	8.1(1.4)	8.2(1.6)	8.4(1.4)	7.9(1.9)
Gender					
Male	100	35	65	40	24
Female	92	33	59	39	19
Ethnicity					
Caucasian	149	51	98	62	34
African American	37	14	23	15	8
Hispanic	5	2	3	2	1
Other	1	1	-	-	-
Hollingshead SES Score	45.50(11.7)	45.31(12.9)	45.60(11.11)	46.62(11.0)	44.01(11.08)

[1] Early (<12 years) & Late Onset (≥ 12) groups are comprised of participants ≥12

Univariate Analyses of Variance (ANOVAs) were used to test knowledge differences between children and adolescents in percentage of correct answers for general, problem-solving and total knowledge scores. Response rates to diabetes knowledge questions with the option of "I don't know" also were evaluated. Univariate Analyses of Covariance (ANCOVAs) tested differences associated with age of onset in the adolescent group for both diabetes knowledge and self-care behaviors. Disease duration was included as a covariate in these analyses.

The required assumptions for ANOVA and ANCOVA tests include a normal distribution of the data, homogeneity of variance and equal sample sizes. Tests of normality were completed for each of the variables included in the statistical analyses; specifically data were checked for skewness, kurtosis and outliers. Two outliers identified as extreme cases by SPSS were found within the sample using box plots. Due to the large sample size (n = 194) single case deletion was utilized for both outliers without fear of impact on statistical power. The "I don't know" (IDK) variables, created by tallying the number of times a child responded with this option, were both mildly skewed and the general knowledge IDK variable was kurtotic. These statistics are not surprising however, because of the relatively low number of times this option was selected in relation to the total number of questions available. Chance indicates a participant will select the "I don't know" option at least 25% of the time; this potential response rate would result in positively skewed and kurtotic data. A square root transformation was employed to correct for the skew and kurtosis of these two variables; after transformation the normality indices for these variables were within normal limits. Both the transformed and original variables were entered into analyses; no differences were found in the results so for ease of interpretation the original variables were used.

Variables that utilized developmental level to compare children and adolescents (excluding problem-solving percentage correct) violated the assumption of homogeneity of variance indicated by a significant result using the Levene's Test of Equality of Variances provided by SPSS. Unequal groups, utilized in these analyses, can contribute to violations of the homogeneity of variance assumption. Several solutions are offered to deal with violations of homogeneity of variance, including comparing variances across cells and utilizing a more stringent test of main effects (e.g. $\alpha = .025$ instead of .05). Comparison of children to adolescents for all dependent variables revealed alpha levels at the $p < .01$ level conforming to this more stringent test of main effects. The tests for homogeneity of variance offered by SPSS are considered to be overly sensitive to violation of this assumption; the option of comparing variances across cells provides a less sensitive measure of equality of variances (Tabachnick & Fidell, 2006). A difference of less than 4 times between the largest and smallest error variance is considered to be acceptable. Comparison of the largest to smallest error variances for the results revealed a difference of 2.46 times indicating acceptable homogeneity of variance. This violation is more problematic when analyzing small samples sizes; generally a minimum of 10 subjects per predictor is suggested for adequate power. The present large N (approximately 14 subjects per predictor in the smaller group), coupled with a less stringent test of homogeneity of variance and the generally robust nature of ANOVA allows for interpretation of these results (Garson, 2008; Martin & Games, 1977).

Only the analysis that utilized exercise frequency in the adolescent group violated Levene's Homogeneity of Variance. Comparison of the largest to smallest error variance associated with this analysis revealed a difference of 1.94 times indicated an acceptable homogeneity of variance. The remaining variables that used age of onset to compare early onset to late onset adolescents did not violate the assumption of Homogeneity of Variance, so no additional analysis was warranted.

Performance of Children and Adolescents on the Test of Diabetes Knowledge

Based on a scale of 100, mean scores on the TDK revealed average to low average scores (M = 74.4%) for adolescents and lower scores for children (M = 67.3%). Of the respondents, 74 participants, more than 1/3 of the sample, scored less than 70% on the TDK. The TDK does not offer qualitative cutoffs for percentage scores; however, if these scores are considered in the context of a 7-point academic grading scale employed by many schools these scores may present cause for concern.

Developmental Differences in Concrete and Abstract Diabetes Knowledge by Current Age

Current literature continues to compare children and adolescents with ANOVA comparisons of total knowledge scores along with the subscales of general and problem-solving knowledge scales without consideration of important developmental differences. Often the primary findings reported from the TDK are significant differences between children and adolescents, which is an inherently a flawed comparison.

To replicate standard developmental differences and to show that this sample scores similarly, ANOVAs were conducted to compare younger and older groups of children. As expected, significant results indicate that adolescents score higher than children on general knowledge items, $F(1,190) = 9.512$, $p = .002$, on problem-solving items, $F(1, 190) = 18.851$, $p < .001$, and on total knowledge scores, $F(1,190) = 17.1$, $p < .001$. See Table 2.

Table 2

Outcomes from the Test of Diabetes Knowledge and Self-care Behaviors

		Total Sample by Age Group		**Adolescent Sample by Onset Age**	
Test of Diabetes Knowledge	*Total* *N* = 192	*< 12 years* *N* = 68	*≥ 12 years* *N* = 124	*Early Onset* *N* = 79	*Late Onset* *N* = 43
"I Don't Know" (IDK) Responses					
Problem Solving %	12.82(12.4)	17.97(13.8)	10.00(10.6)**	--	--
General Knowledge %	10.75(11.6)	13.66(14.3)	9.15(9.4)**	--	--
Total Knowledge %	11.75(12.4)	15.76(12.6)	9.56(9.0)**	--	--
Percentage Correct					
Problem Solving %	70.87(12.5)	65.80(11.9)	73.65(12.0)**	73.63(11.8)	73.25(12.6)[1]
General Knowledge %	72.85(14.2)	68.70(15.5)	75.14(13.0)**	--	--
Total Knowledge %	71.89(11.9)	67.27(12.2)	74.40(11.0)**	--	--
Self-Care Behaviors (#/per day)					
Eating Freq	4.1(.9)	--	--	4.2(.7)	4.1(.9)[1]
Exercise Freq	1.1(.7)	--	--	1.1(.6)	1.1(.8)[1]
Blood Glucose Testing	3.1(1.0)	--	--	3.2(1.0)	2.9(1.0)[1]

*p<.05
**p<.01
[1]Adjusted means from ANCOVA

ANOVA results revealed that children less than 12 years selected the response "I don't know" (IDK; *M* = 13.6%, *SD* = 14.29) significantly more often than adolescents age 12 and above (*M* = 9.1%, *SD* = 9.14) in the general knowledge section of the TDK, $F(1,190) = 6.894$, $p = .009$. Children also endorsed IDK answers (*M* = 18%, *SD* =13.79) more often than adolescents (*M* = 10%, *SD* = 10.64) in the problem-solving section, $F(1,190) = 19.936$, $p < .001$. Correspondingly, overall, children selected IDK (*M* = 15.8%, *SD* = 12.58) significantly more often than adolescents (*M* = 11.8%, *SD* = 10.8), $F(1,190) = 15.549$, $p < .001$. See Table 2. Comparison of effects sizes between general knowledge and problem-solving ANOVAs indicated a trend for children to answer IDK more often with problem-solving/abstract questions compared to general knowledge/concrete questions. For general knowledge 3.5% of the variance is attributed to developmental level ($\eta_p^2 = .035$) which constitutes a small effect, while for problem-solving questions 9.5% of the variance is attributed to developmental level ($\eta_p^2 = .095$), a medium effect (Cohen, 1988).

Onset Age and Its Relation to Adolescents' Diabetes Knowledge

Next, adolescent knowledge was examined in relation to age of disease onset. Early onset was operationalized as diagnosis before the age of 12; analyses were conducted to determine if early onset affected level of problem-solving in adolescents. Scores of participants ages 12 and older were included in a Univariate Analysis of Covariance (ANCOVA) in which onset age was used as a dichotomous variable to compare early onset adolescents to late onset adolescents. To control for shared variance between onset age and disease duration the latter variable was included as a covariate in the analysis. Results of the overall model neared significance, F (2,119) = 2.973, p = .055; however, the stronger continuous variable of disease duration accounted for a significant portion of variance, which rendered the categorical variable of onset age non-significant. See Table 2. An ANOVA compared the demographic characteristics of the two onset adolescent groups on the characteristics of SES and gender and revealed no significant differences.

A post-hoc analysis was completed to explore the significant covariate of disease duration identified in the previous analysis. A linear regression was completed with diabetes knowledge as the dependent variable and disease duration as the predictor variable. For adolescents, a significant negative relationship was identified between disease duration and diabetes knowledge F(1,188) = 5.321, β = -.166, p < .05. As disease duration increases, disease knowledge decreases.

Onset Age and Its Effect on Self-Care Behaviors for Adolescents

A second set of ANCOVAs were conducted to determine if the hypothesized knowledge differences between early and late onset adolescents would generalize to the self-care behaviors of exercise frequency, blood glucose monitoring and eating frequency. Again, disease duration was included as a covariate in the analyses because self-care behaviors generally worsen with longer disease duration. Due to the nonsignificant findings yielded by the previous analyses it was expected that the following analyses would also render nonsignificant results. Results of the ANCOVAs indicated that adolescents with early disease onset had similar self-care behaviors as those with late onset. See Table 2 for means and standard deviations.

A post-hoc analysis was completed to examine the relationship between diabetes knowledge and self-care behaviors. A linear regression indicated a trend towards a positive relationship between diabetes knowledge and blood glucose monitoring $F(1,119) = 3.662$, $\beta = .173$, $p = .058$. The relations between diabetes knowledge, exercise frequency and eating frequency were nonsignificant.

Discussion

Both children and adolescents in the present study obtained relatively low scores (67% and 74%, respectively) on the Test of Diabetes Knowledge (TDK). The following discussion will address how the TDK is inappropriate for children and how this may explain their low scores; however, the low adolescent scores are cause for concern and support the ADA's strong recommendation to focus on strong initial and continued education for pediatric patients diagnosed with diabetes. As hypothesized, children score lower on all knowledge domains than adolescents; consistent with the previous literature the present sample is developmentally representative of youth with diabetes. Further, as predicted, children endorsed a higher percentage of "I Don't Know" (IDK) responses than adolescents on both general items which are more concrete and problem-solving items which are more abstract. Children responded to abstract knowledge questions with IDK significantly more often than the concrete questions. These results provide support for the assertion that the Test of Diabetes Knowledge, specifically the problem-solving portion, may not appropriate for children who do not yet possess formal operational thought. Contrary to expectations, early onset adolescents did not score significantly lower on abstract level questions than late onset adolescent and did not have significantly lower self-care behaviors.

Developmental differences in total, concrete and abstract diabetes knowledge scores between adolescents and children may have several explanations. The first, and most obvious, reason is simply that children are inherently less knowledgeable than adolescents. Second, children have less experience, both in life and in managing their diabetes. Generally it is not until adolescence that one begins to take responsibility for oneself and individuate from parents (Soenens, et al., 2007). Lack of life experience undoubtedly generalizes to lack of experience caring for diabetes. The American Diabetes Association recommends early adolescence as a time to renegotiate diabetes care tasks and to let adolescents take greater responsibility for their disease regimen (Silverstein, et al., 2005). Children, whose parents are the primary providers of their daily diabetes care behavior, require less knowledge about disease characteristics and diabetes management; this reality is represented by their significantly lower scores on the TDK. These developmental differences support the need for ongoing education of children about diabetes management as they transition into adolescence. As disease care responsibility is transitioned from parent to adolescent, the provision of necessary knowledge and tools may help combat the well-established poorer metabolic control that frequently occurs in adolescence (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Ellis et al., 2007).

Beyond simple comparison of total and subscale scores, the TDK provides a unique way to examine hypothesized knowledge differences between children and adolescents by evaluation of “I don’t know” (IDK) responses. Children responded significantly more often with IDK than adolescents on both concrete and abstract diabetes knowledge questions. Effect sizes were compared; a small effect size was found for the developmental IDK difference for concrete questions and a medium effect size was found for abstract questions. Either an actual or perceived deficit in diabetes knowledge may explain this trend. An actual deficit could reflect children's inability to engage in the hypothetical thought required by the problem-solving questions; a perceived knowledge deficit could represent the poor applicability of the problem-solving scenarios to children.

The questions in the TDK, specifically the problem-solving questions, are worded for youths that are at least in middle school with questions that reference school dances, football games, the prom and parties with alcohol. These scenarios are used to determine if the youth can apply a general principle of diabetes in a hypothetical scenario, wherein lays the problem for concrete level children who may be incapable of hypothetical thought. When posed with a situation that does not apply to them or they have not experienced, such as attending a football game alone or attending the prom, the concrete child may not be able to envision themselves in the situation. This limits his/her ability to apply the answers provided and the child may perceive that they do not know the answer and could lead to an answer of "I don't know." However, if the questions were rephrased to ask the general principle, such as what should you do when your blood sugar is low or how does stress affect blood sugar, the child may be more likely to determine the appropriate answer.

For example, consider the question presented earlier:

"You are at a school football game and you begin to feel dizzy, shaky and faint. What should you do:

a) Leave the game right away and go straight home

b) Buy a Coke and hot dog and eat them

c) Lie down until you feel better

d) I don't know

It is unlikely that a child less than the age of 12 will attend a football game without a parent or be expected to go to the concession stand and purchase food to counteract a low blood sugar. In this case then, the more appropriate answer of "find a parent or adult to get help" is not included which may lead the child to respond with the closest option (option 'a') or IDK. Both of these answers would be counted as incorrect on the current TDK even though the appropriate answer for a child is not provided. This may misrepresent the child's knowledge of how to treat a low blood sugar or what the symptoms of a low blood sugar are. For concrete children asking them direct and specific questions would more accurately test their knowledge.

For example:

How do you treat a low blood sugar?

a) Lying down and resting

b) Eating something

c) I don't know

and/or

What are some symptoms of low blood sugar?

a) Dizziness and shakiness

b) Increased urination and ketones

c) I don't know

Rather than assert that the difference in IDK responses between children and adolescents is due either to an actual or perceived deficit in diabetes knowledge, it makes more sense that it is an outcome of the two combined. Due to the nature of substantial adult involvement in diabetes care prior to adolescence (specifically hands-on involvement and not simply monitoring) children will likely have less knowledge about their disease and how to handle it. This potential deficit is then enhanced by the wording of the TDK which seems not to apply, for the most part, to children and the situations they experience. If children had scored lower in a similar manner across subscales these low scores could be attributed to less experience and less knowledge; however, the larger difference found for abstract knowledge shows that developmental level and ability plays an important role and should be taken into consideration when creating a test intended for children and adolescents.

A unique contribution to the diabetes literature from this study is the in-depth examination of diabetes knowledge scores and self-care behaviors in adolescents. Researchers have struggled to find a way to examine the effects of onset age, current age and disease duration. Due to the mathematical relation among the variables (current age – onset age = disease duration) simply including both additional variables as covariates is not a statistically sound option. In this study, variability associated with current age was minimized by examining onset age within a single developmental subgroup. By controlling current age within the adolescent sample and disease duration statistically, any knowledge differences found should be attributable to the potential effect of onset age. Contrary to the hypothesized relation between onset age and diabetes knowledge, no significant differences were found between early and late onset adolescents in abstract knowledge. Alternatively, results show adolescents with early disease onset have similar problem solving skills as those with late disease onset. These findings suggest that as children transition into adolescence they appear to acquire diabetes problem-solving knowledge found in adolescents. When the average problem-solving score of children (*M* = 65.8%) is compared to the early onset adolescent group (*M* = 73.6%) a difference of nearly 8 points is seen between groups. An alternative explanation to this change could be the increased applicability of the problem-solving questions on the TDK as children transition into adolescence. Early onset adolescents are more likely to have experienced the scenarios posed in the TDK than the children with which they are being compared. Without a developmentally appropriate measure for children it is difficult to determine if this higher score reflects better problem-solving ability and abstract thinking or greater applicability of scenarios in the TDK to adolescents.

While onset age was not a significant predictor of problem solving knowledge, disease duration was a correlate of diabetes knowledge. The negative relationship between disease duration and diabetes knowledge may indicate that even though children appear to make-up the developmental difference in problem-solving ability, overall, longer disease duration is related to less diabetes knowledge. Potential contributors to the relation may be increased time from initial diabetes education and/or the documented cognitive difficulties associated with early onset diabetes which is highly correlated with longer disease duration (Gaudieri, Chen, Greer & Holmes, 2008). In light of the poorer metabolic control often seen during adolescence ongoing education to provide youths with the basic tools and information necessary to manage their diabetes is essential (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Ellis et al., 2007).

Finally, the effects of early versus later disease onset were evaluated in adolescents' self-care behaviors. Early versus later disease onset did not affect adolescents' level of self-care behaviors. If early onset adolescents were shown to have lower problem-solving knowledge this was expected to generalize into lower self-care behaviors; however, since no effects of onset age were found for problem-solving knowledge it was not surprising that no differences were found between groups for self-care behaviors.

Diabetes knowledge was hypothesized to have a positive effect on diabetes self-care behaviors. For the present sample it was found that higher diabetes knowledge predicted a strong trend for higher levels of blood glucose monitoring. This self-care behavior is a vital part of diabetes management to prevent hyper- and hypo-glycemic episodes and to calibrate insulin administration. Diabetes knowledge is often referred to as necessary but not sufficient for better self-care behavior and this trend strengthens this argument. Before secondary interventions to address poor regimen adherence and poor metabolic control are utilized it is important that youths have a base level of knowledge about their disease.

Limitations

A significant limitation of this study is the measure employed; the Test of Diabetes Knowledge (TDK) is a 26-year-old measure that has not kept pace with changes and advances in diabetes care. In spite of this issue, the TDK continues to be used; not because it is a good measure of diabetes knowledge, but because it's the only measure available for children and adolescents. Therefore it was used out of necessity, to try and provide support for the expansion and improvement of diabetes knowledge testing. However, the results of this study are based on a measure that is not a strong instrument.

A second limitation of the present study is the use of cross-sectional data and its inability to make causal inferences. Even though causal relations cannot be identified by cross-sectional research it can provide strong support for associations among variables and to inform future research and experimental studies (Kazdin, 2003). In this study, cross-sectional comparisons indicate that children appear to close the abstract knowledge gap as they transition into adolescence. Following the associational relation found here, a longitudinal study of 9-11 year olds diabetes knowledge trajectory is studied over time could better describe the developmental transition from concrete to formal operations.

A final limitation of the study is that only self-report data are included in the analyses. Self-report data are often criticized as prone to error, both measurement error as well as personal bias. However, especially in the case of medical data, self-report data are essential to get an accurate picture of the patient's history and current medical behaviors (Stone et al., 1999). In this study an interview method is used with the 24 hour interview to obtain information about self-care behaviors. The interview method, with a focus on the past 24 hours, minimizes the risk of halo effects that are often associated survey measures that cover larger or vaguer periods of time. To strengthen information about self-care behaviors future studies should include data from electronic medical equipment such as insulin pumps or blood glucose meters.

Future Directions

In light of the findings of this study, it is clear that there is a significant need to revisit and revise how diabetes knowledge is measured. This study has shown that the TDK in its current form is not appropriate for children on many levels; future researchers should create a measure that focuses on concrete facts about diabetes (Anderson, et al., 1982) and age appropriate problem-solving questions. This will help researchers determine if wording and/or the non-applicable hypothetical situations contribute to the developmental differences in the present study versus a true a difficulty in children's problem-solving ability. Due to the low scores obtained by both children and adolescents on the TDK it is important to develop a reliable and valid measure of diabetes knowledge to help guide researchers and clinicians as they educate their participants or patients about diabetes.

Finally, in this study early onset adolescents appear to make-up the developmental diabetes knowledge gap found between children and adolescents. However, even with this general increase in knowledge from childhood to adolescence, youths with T1D showed a significant decrease in diabetes knowledge with increased disease duration. These results along with the strong trend that indicates increased diabetes knowledge may contribute to increased blood glucose monitoring supports the assertion that an adequate level of diabetes knowledge is necessary for maintaining good metabolic control. Targeted and interactive strategies may be necessary to engage children and teenagers in educational programs since strict didactic programs have not been related to long-term improvements in metabolic control. Future studies should focus on the most effective way to provide continuing education to youths with T1D throughout childhood and adolescence.

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Vita

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