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# DIABETES EDUCATION: SUPPORTING THE PRE-ADOLESCENT CHILD

by

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> An Independent Project Submitted to the Graduate Faculty

> > of the

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in partial fulfillment of the requirements

for the degree of

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## ABSTRACT

A diagnosis of Type 1 diabetes impacts every aspect of life for the pre-adolescent child. In order to successfully manage Type 1 diabetes, the child must learn the complex regimen of its care. The responsibility for diabetes self-care begins to transfer to the child at pre-adolescence. Controlling diabetes is difficult for the pre-adolescent, however, due to the lack of understanding the complex concepts of this disease and the unique developmental tasks associated with this age group. Diabetes education must support the cognitive level and developmental needs of the pre-adolescent. Literature emphasizes the need for age appropriate diabetes education, yet research is lacking in what constitutes age appropriate knowledge for diabetes care as well as what specific educational approach is most effective for the pre-adolescent age group. Pre-adolescents may benefit from learning about diabetes at school. In an independent project conducted by a school nurse, the Diabetes Quiz for Pre-Teens, a diabetes educational tool was developed, proposing to be developmentally appropriate for the pre-adolescent with Type 1 diabetes. Two pre-adolescents with Type 1 diabetes, utilized as having expertise, assisted with developing the content of the questions and answers for the quiz, revealing their knowledge of diabetes care. The diabetes knowledge presented in the content of the questions was found to be lower than what was anticipated, reinforcing that this age group lacks the knowledge and understanding to self-manage their diabetes. Experienced

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school nurses evaluating the quiz indicated that the quiz appears to be a method for developmentally appropriate diabetes education, may impact pre-adolescents learning about diabetes at school, and most intended to utilize the quiz for their educational efforts in diabetes education at school.

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#### INTRODUCTION

Type I diabetes is a chronic health condition that commonly occurs among children. In the United States, it is the third most common health condition among school-aged children (Gage et al., 2004). According to the Centers for Disease Control and Prevention (2009), approximately 15,000 children under 20 years of age are diagnosed annually with Type 1 diabetes. In 2007, about 186,300 children less than 20 years of age had diabetes (National Diabetes Education Program, 2008). According to Kaufman, Gallivan and Warren-Boulton (2009), this represents 0.2% of all people in this age group in the United States.

When a child is diagnosed with Type 1 diabetes, the routine activities of daily life are changed forever. It significantly impacts the daily life of not only the child, but the family, due to the need for complex daily care and lifestyle modifications (Faro, Ingersoll, Fiore, & Ippolito, 2005). Type 1 diabetes requires 24-hour care that includes a multi-faceted schedule of managing blood glucose, insulin therapy, nutritional intake, physical activity, and preventing episodes of hypoglycemia. In order for the preadolescent child to learn about diabetes care, a comprehensive educational approach must be utilized. According to Pélicand, Gagnayre, Sandrin-Berthon, and Aujoulat (2006), diabetes affects all dimensions of the child's life and no matter how young, the child must eventually learn how it is managed.

Parents are initially responsible for the care of the young child, however, at preadolescence, the responsibility of diabetes self-management begins to transfer to the child. For the pre-adolescent, however, managing diabetes is difficult. The plan for care is inconsistently followed at this age and thought to be attributed to the pre-adolescent's lack of knowledge about the complex concepts of diabetes care and the developmental tasks associated with pre-adolescence. In order for the pre-adolescent to begin to take responsibility for their diabetes, they must be given knowledge to fully understand its management. It is critically important to consider the age and developmental needs of the pre-adolescent child with regard to the content and educational approach (Silverstein et al., 2005).

Pre-adolescents spend time in numerous environments including home, school, playgrounds, shopping malls, etc. For the child with diabetes, management of their diabetes must occur in all circumstances of his or her life. It can never be overlooked. According to the American Diabetes Association (2009), diabetes education is essential and must be integrated into the child's daily life. Children spend a significant time at school, therefore, the school environment can potentially influence diabetes control (Faro et al., 2005). The role of the school nurse then becomes vital in the education and management of diabetes for the school-aged child. Schools nurses, though knowledgeable and willing to support diabetes self-management, are challenged as the pre-adolescent with diabetes inconsistently adheres to his or her diabetes management plan at school.

An independent project conducted by a school nurse working with pre-adolescent children diagnosed with Type 1 diabetes is discussed in this paper. A diabetes

educational tool was developed in the format of an on-line quiz proposing to provide age appropriate diabetes education for pre-adolescents with Type 1 diabetes. Two preadolescent children assisted in developing the content of the questions and answers for the quiz.

## Problem and Clinical Significance

Being diagnosed with diabetes is demanding, especially for children. Parents are initially educated and responsible for diabetes care of the young child at the time of diagnosis; however, the responsibility gradually transfers to the child as he or she reaches appropriate developmental age. For example, the focus of diabetes self-care turns toward the child at around 10-12 years of age (Lowes, 2008). Therefore, at pre-adolescence, education becomes critical in order to successfully self-manage diabetes.

Pre-adolescence creates a particularly demanding time in the shift of diabetes selfcare due to the diabetes knowledge and developmental tasks of this age group. Children in this age group are commonly regarded as young adults and are given responsibilities similar to those of adults. The pre-adolescents themselves prefer to be considered young adults, however, due to their developmental understanding are unable to fully comprehend the implications of decision making affecting diabetes control. This is particularly problematic as the tasks that are given may be above their capability, making it difficult for the pre-adolescent with diabetes to perform. The pre-adolescent, therefore, may appear to be non-compliant in his or her care, when in fact; is lacking knowledge. "Because children are not simply 'small adults,' it is appropriate to consider the unique aspects of care and management of children and adolescents with type 1 diabetes" (ADA, 2009, p. S37). Pre-adolescence also poses a particularly challenging time in the shift of diabetes care to self-care responsibilities due to the developmental tasks of this age group. Preadolescents may compromise their diabetes management (Grey et al., 2009). During preadolescence, peer pressure and the priorities of being independent may become more important for the child than diabetes control. As a result, poor decisions regarding diabetes care are often made. For example, the pre-adolescent, wanting to be the same as his or her peer, will neglect to monitor food intake as required for diabetes management. Research indicates that there is a significant worsening of metabolic control during adolescence (Gage et al., 2004). Teaching diabetes care to the pre-adolescent, therefore, not only requires the general knowledge of diabetes and its care but also an ability to identify and understand the developmental needs of the child. Pélicand et al. (2006) effectively stated that it is challenging to provide diabetes education that promotes independence and yet respects individual developmental stages.

Anderson (2007) clearly explained the conflict between normal child development and managing type 1 diabetes as being complex and interfering with optimal self-care behavior in children and adolescents:

Normal developmental tasks of school-aged children - between 7 and 12 years of age - include making a smooth adjustment from the home to the school environment, forming close relationships with other children, developing new intellectual, athletic and artistic skills and forming a positive sense of self as a unique person within the school and family settings. The primary developmental tasks for adolescents - from 13 to 18 years of age - involve adjusting to a physically maturing body, building strong relationships with peers, becoming an individual by separating from parents psychologically and developing personal goals, values and opinions. Thus, the tasks of normal school-aged and adolescent development often compete and conflict with the requirements of intensive diabetes management regiments (p. 39).

"Youth with diabetes spend six to ten hours a day in school and school-related activities" (Faro et al., 2005, p 302). Because children spend a significant time at school, school personnel working with the child can influence diabetes management. According to Nichols and Norris (2002), most children with diabetes depend upon school employees to help meet healthcare needs. It is imperative, therefore, that individuals working with the child at school be knowledgeable about developmental needs and diabetes care. The school nurse is typically designated to coordinate diabetes care and provide diabetes education for the pre-adolescent with Type 1 diabetes at school.

The literature clearly addresses the importance of diabetes education considering the individual and developmental needs of the pre-adolescent child, however, research is lacking in what knowledge is considered age appropriate, and no specific educational intervention is considered most effective for diabetes education for the pre-adolescent child. Providing an evidence-based approach for diabetes education for this age group, therefore, is difficult. The Diabetes Quiz for Pre-Teens developed in this project is intended to be a developmentally appropriate educational tool. Designed by a school nurse, this quiz can influence school nursing practice involving diabetes education for the pre-adolescent child.

## Purpose

The purpose of this independent project is to answer the key question: *For pre-adolescent children with diabetes, what diabetes education is most effective and developmentally appropriate?* The goal is to develop an educational program for pre-adolescent children with Type 1 diabetes that is age and developmentally appropriate, focused on increasing the child's self- knowledge and improving self-care practices.

## Conceptual / Theoretical Framework

Albert Bandura's Social Cognitive Theory (Bandura, 1989) provides a framework for diabetes education and was incorporated to guide the design of this project. Stemming from the Social Learning Theory, the Social Cognitive Theory describes a relationship between human thought and behavior and how the cognitive processes influence human behavior, motivation, and affect (Pajares, 2004).

This theory has several key concepts that can be linked to diabetes education. They include 1) self-reflective capability, 2) reciprocal determinism, 3) symbolizing capability, and 4) vicarious capability. Self-efficacy, a type of self-reflective capability, is the belief that a person will learn from his or her current level of knowledge and cognitive processing and is capable of behaving in a specific manner to achieve goals (Bandura, 1989). Relating to diabetes education, the pre-adolescent is capable of making decisions based on current knowledge and life experiences. When the pre-adolescent has appropriate and adequate knowledge, they will have the capability to manage diabetes age appropriately and therefore, have a high degree of self-efficacy. Individuals with high self-efficacy have better health outcomes. Self-efficacy, therefore, is directly related to diabetes education as the goal for diabetes management.

According to reciprocal determinism, a person's behavior is regulated through a complex interaction between the environment, personal factors, and the particular behavior itself. Personal factors such as individual expectations, beliefs, self-perceptions, goals and intentions shape behavior which affects thoughts and emotions (Stone, n.d.). In other words, a person's behavior interacts with the environment and the environment may modify the behavior. The environment, therefore, is an important component to be

considered for diabetes education. Because the pre-adolescent spends time at school, an effective environment for diabetes education may be the school. At school, school nurses can potentially influence the outcome of diabetes care for the pre-adolescent child.

Symbolizing capability addresses cognitive problem solving and engaging in purposeful action using symbols. According to Bandura (1989), symbols are created and give meaning to one's life experiences that result in the formation of images and words. This ability allows the individual to store information in his or her memory to be used to guide behavior. Symbolizing capability was demonstrated in the problem-solving module of the quiz. The pre-adolescents created simple scenarios that required a solution to a problem. The problem and its solution identified by the children were based on their life experiences. Bandura further explains that due to experiences and maturation, the cognitive skills change over time which allows the behavior to be understood and changed. Thus, as the cognitive skills for the pre-adolescent child change, the educational efforts regarding diabetes care must reflect his or her needs, resulting in individualized diabetes education.

Albert Bandura's (1989) Social Cognitive Theory also focuses on how individuals learn from one another and encompasses concepts such as observational learning, imitating, and modeling (McEwen & Wills, 2007). Bandura entitles this vicarious capability. Learning occurs by watching or listening to others but may not be demonstrated until later. Therefore, difficult skills associated with diabetes care and observed by the child may not be demonstrated until he or she is developmentally capable. Due to the developmental stage, pre-adolescent children may be unable to fully understand the implications of diabetes care. This effectively explains the importance of

developmentally appropriate diabetes education. The Social Cognitive Theory addresses multiple influences that concern learning, including the environment, cognitive factors, and behaviors that all interact and affect the way diabetes learning occurs.

## Definitions

Multiple definitions related to diabetes education and its management was discussed in the literature. Due to the numerous opinions of when a child is capable of independently performing the tasks of self-management, inconsistencies exist as to what constitutes self-management in adolescents with Type 1 diabetes (Schilling, Grey & Knafl, 2002). The use of uniform definitions, therefore, is beneficial to facilitate a fundamental understanding of the terms. The following definitions were utilized for this project:

Pre-adolescent Self-management of Type 1 diabetes: An active, daily, and flexible process in which the pre-adolescent and their parents "share responsibility and decision-making for achieving disease control, health, and well-being through a wide range of illness-related activities" (Schilling, Grey, & Knafl, 2002, p.92). Diabetes Education: The process of "providing the person with the knowledge and skills needed to perform diabetes self-care, manage crises and to make lifestyle changes to successfully manage the disease" (Swift, 2009, p. 51).

Both definitions reflect characteristics of diabetes education that are critical for the pre-adolescent with diabetes. Diabetes education and self-management is a process reflecting the progression of events being on-going and flexible. Modifications are made according to the assessment of the individual's cognitive and developmental level as well

as the diabetes plan for self-management. A supportive environment is critical for the pre-adolescent to begin to self-manage his or her diabetes and is demonstrated when the parent and child are actively involved, sharing the responsibility and decision-making of diabetes-related care.

REVIEW OF LITERATURE

## Search Strategies

A series of searches were conducted of electronic databases including the Cochrane Database, CINAHL and PubMed. The searches were directed at identifying references that met the following criteria: 1) published after 1990; 2) published in English; 3) published in a peer-reviewed journal; 4) the articles identified educational interventions; and 5) the research addressed age and developmentally appropriate diabetes education for children or adolescents. The keywords used were Diabetes, Type 1 Diabetes, Education, Children, Child Development and Teaching Strategies. Research related to diabetes education for adults with diabetes were excluded as well as studies related to diabetes education directed toward teachers and other school personnel.

The reference sections of the literature and research were examined for relevant publications. The Google Scholar and Yahoo Health websites were also utilized as well as professional websites for health information regarding diabetes and education. These included the American Diabetes Association (ADA), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Minnesota Department of Health (MDH), Center for Health and Health Care in Schools, National Diabetes Education Program (NDEP), Medscape, National Institute for Health and Clinical Excellence (NICE), International Society for Pediatric and Adolescent Diabetes (ISPAD), National Association of School Nurses (NASN), School Nurses of Minnesota (SNOM), and the American Association of Diabetes Educators (AADE).

#### Synopsis

Much research was found regarding diabetes education associated with children diagnosed with Type 1 diabetes, however, no research was found that specifically addressed diabetes education and the pre-adolescent age group. The perceptions of children and their parents regarding diabetes were discussed as being influential factors affecting diabetes education and care (Carroll & Marrero, 2006; Faulkner, 2003; Herrman, 2006; Ivey, Wright & Dashiff, 2009; Jacquez et al., 2008; Marshall, Carter, Rose, & Brotherton, 2009; Roper et al., 2009). Research found reflected the effectiveness of diabetes education in multiple instructional settings (Basso & Pelech, 2008a; Basso & Pelech, 2008b; Bloomfield et al., 1990; Christensen, King, & Prestwich, 2000; Delamater et al., 1990; Franklin, Greene, Waller, Greene, & Pagliari, 2008; Martin, Lively, & Whitehead, 2009; Murphy, Wadham, Rayman & Skinner, 2007; Pélicand et al., 2006; Siminerio, Charron-Prochownik, Banion & Schreiner, 1999; Vicklund, Rudberg, & Wikbald, 2007). Clinical guidelines and recommendations for treating pediatric diabetes were found in which diabetes education was associated with optimal service delivery (Auslander, Haire-Joshua, Rogge & Santiago, 1991; Bloomfield et al., 1990; Couch et al., 2008; Roper et al., 2009). The literature regarding diabetes education emphasized the importance of considering the age, developmental level, lifestyle, severity of diabetes, cultural needs, and individual and family needs (Anderson, 2007; Anderson, Svoren, & Laffel, 2007; Lowes, 2008; Pélicand et al., 2006; Schilling, Grey, & Knafl, 2002). Lastly, publications of professional and governmental organizations associated with

diabetes management emphasized the importance of diabetes education in the guidelines for diabetes care (AADE, 2006; ADA, 2009; Funnell et al., 2009; Matyka & Richards, 2009; Nabors, Lehmkuhl, Christos, & Andreone, 2003; NDEP, 2008; NDEP, NIH & CDC, 2003; Silverstein et al., 2005; Swift, 2009). Research was lacking, however, regarding what diabetes knowledge was considered age appropriate, and what educational intervention was considered most effective for diabetes education for the preadolescent child.

#### Perceptions of Children and Parents

Children diagnosed with Type 1 diabetes and their parents are forced to make significant lifestyle changes that affect their family system. As a result, their perceptions related to the diagnosis of diabetes and its care significantly impact the understanding, attitudes toward, and diabetes-related behaviors (Herrman, 2006). From the preadolescent's view, friendships are strongly influenced by peer pressure to feel the same and belong to a group. The difficulty occurs when the child with diabetes ignores his or her health needs in an attempt to be the same as everyone else. Silverstein et al. (2005) stated that the adolescent with type 1 diabetes is at risk for complications of diabetes that are exacerbated by the "drive for independence and peer acceptance" (p 190). Research conducted by Faulkner (2003) explained that teens with diabetes express a lower life satisfaction and health perception when compared to those not diagnosed. Because of the diabetes, the teens considered themselves as being less healthy. The impact of diabetes, therefore, not only affects physiological functioning, but social and psychological health as well.

Interviews with children conducted by Herrman (2006), Marshall et al. (2009), and Roper et al. (2009) reflected children's perceptions and identified prevailing themes related to diabetes care. In her research, Hermann discussed the costs and rewards of having diabetes with children which included the themes of 1) thinking and counting; 2) constant interruptions; 3) you just can't eat; 4) normal but not; 5) what can happen; 6) some good things; and 7) you have to deal with it. Marshall et al. depicted the central theme of 'being normal' and recognized four themes that incorporated 1) transition; 2) attachment; 3) loss; and 4) meaning. Lastly, in a qualitative study, Roper et al. identified six recurrent themes from interviews with children regarded what children and adolescents know and want to know about their diabetes. These included: 1) care; 2) physiology; 3) consequences; 4) cure; 5) effects on the family: and 6) experience at diagnosis. The studies indicated that the children's perceptions of their diabetes affected how well the diabetes was self-managed. The perceptions, therefore, should be considered in the efforts of diabetes education.

Considering the parent perspective, concerns regarding the child's ability to make good decisions are related to the nature of the developmental tasks of adolescence. Peer relationships, an important aspect of pre-adolescence, are commonly prioritized over other life issues. When the child prioritizes other activities as being more important than diabetes care, parents express difficulty in finding a balance between understanding and supporting the child in their effort to be independent and attempting to control the selfcare activities needed for the child's diabetes (Marshall et al., 2009).

Research conducted by Carroll and Marrero (2006), Ivey, Wright and Dashiff (2009), and Marshall et al. (2009) described themes related to the experiences and

perceptions of having a child diagnosed with Type 1 diabetes from the parent perspective. According to Carroll and Marrero, parents worry about the choices that their child makes related to diabetes self-care during pre-adolescence and tend to remain over-protective. As the child ages, parents typically find they have less control of where the child goes, what the child does, and even when and what the child eats. The parents, however, attempt to maintain control by monitoring food intake or restricting the child from attending social functions. The child, therefore, experiences a learned helplessness. In other words, when the parents persist in telling the child what to do, the child hesitates in independently making diabetes-related decisions. This complicates the task of the preadolescent psychologically separating from the parents.

Anderson et al. (2007) further explained that parental involvement puts the preadolescent at a higher risk for difficulties in diabetes care because he or she wants to be more independent. Ivey et al. (2009) discussed that it is difficult for the parent to trust the adolescent to manage the diabetes and identified common themes of 1) parental frustration, 2) fear, 3) normalizing, 4) trusting, and 5) discounting. Similarly, a central theme dominant among parents and recognized by Marshall et al. (2009) was the "belief of being 'normal' and the pursuit of being 'normal' in the lives of their children" (p. 1705). Being 'normal' was associated with wanting to be the same as non-diabetics; or not having diabetes. Living with Type 1 diabetes over time, however, became the norm for living. Overall, identifying the perceptions of the pre-adolescent and parent is valuable to establish how diabetes-related behaviors are influenced and to support educational needs.

## Diabetes Education Instructional Settings and Formats

Research considered for this independent project involved the effectiveness of diabetes education in multiple settings and are summarized in Appendix A. According to the studies, diabetes education is provided in diabetes clubs (Bloomfield et al., 1990), diabetes camps (Christensen et al., 2000), group diabetes education (Martin et al., 2009; Vicklund et al., 2007), and creative arts interventions such as skits (Basso & Pelech, 2008a; Basso & Pelech, 2008b), puppets (Pélicand et al., 2006), and family-based education (Delamater et al., 1990). Diabetes education for children is also integrated with clinical care (Murphy et al., 2007) and in-patient settings (Siminerio et al., 1999). Only one study addressed diabetes education specifically at school (Faro et al., 2005) and one investigation involved the use of text-messaging via a mobile phone support system (Franklin et al., 2008).

Additional formats for possible diabetes education such as play, face-to-face or 1:1 interaction, and interactive education using computers, videos and puzzles were discussed in the literature. Methods such as focus groups and interviews combined with child-friendly approaches and incorporating the child's life using games and prizes may provide an empowering environment for children to share their views (Nabors et al., 2003). Although the methods described may be effective for learning, no research was available regarding the measurement of the knowledge gained in the specific formats.

A systematic and comprehensive literature review compared multiple diabetes education interventions for children with Type 1 diabetes. Couch et al. (2008) concluded that the evidence is insufficient for recommending specific learning interventions to improve metabolic control due to the variability of the educational interventions, outcome

measures and methods used for follow-up. Overall, both quantitative and qualitative studies reviewed concluded that, an increase in the level of diabetes knowledge had occurred with all interventions, however, no specific educational intervention was considered most effective.

## Diabetes Education in Clinical Guidelines

For all ages, individual diabetes education initially occurs when the diagnosis is given, usually at the time of hospitalization. Although diabetes education is critical at the time of diagnosis, a survey conducted by Bloomfield et al. (1990) of adults who attended a pediatric diabetes clinic as a child identified that too much information is given at diagnosis and diabetes education occurs randomly rather than in an organized approach. Inconsistent diabetes education and information that is overwhelming, therefore, would significantly impact the outcome of successful diabetes management, especially for children. Auslander et al. (1991) found that, among children, better metabolic control was associated with higher levels of diabetes knowledge. In general, to enhance higher levels of diabetes knowledge, it is important to incorporate normal activities of childhood with diabetes education.

The findings of the Diabetes Control and Complications Trial (DCCT) resulted in clinical guidelines published for the medical management of diabetes that included the measurement of glycemic levels to determine overall diabetes control (NDEP, 2009). While many methods appeared to be beneficial in educating the child with diabetes, no specific educational approach was shown to be the most effective based on the medical markers that measure diabetes control. For instance, Roper et al. (2009) found that increased knowledge of diabetes may lead to more effective self-management practices

and adherence that resulted in fewer complications. On the other hand, in the systematic review conducted by Couch et al. (2008), when glycemic control was measured as an outcome for increased diabetes knowledge, minimal changes were observed in HbA1c levels. This was consistent with the studies reviewed for this project. Those that measured glycemic levels as an outcome for increased knowledge noted minimal effects on the HbA1c even though increased diabetes knowledge had occurred.

# Age Appropriate Diabetes Education

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The literature consistently addressed the importance of diabetes education being age and developmentally appropriate for children. For example, Anderson (2007) stated that diabetes education must be age appropriate in content as well as delivery. Roper et al. (2009) emphasized that besides being age appropriate, diabetes education for children must support existing knowledge. Lowes' (2008) view was that because needs change at different stages of growth and development, educational programs for children and adolescents must be individualized, structured and on-going. According to Schilling et al. (2002), the ability for self-management is related to the chronological age and developmental status of the child. Pélicand et al. (2006) reiterated these findings, explaining that "children's understanding of health and illness depends more on their age and developmental stage, than on their health status or duration of the disease" (p. 152). Additionally, a helpful explanation from ISPAD was cited in Martin et al. (2009):

Education is considered to be an essential part of the care package for children and young people with diabetes and information has to be explained in such a way that it can be understood. The method of delivering education and content should be appropriate for the age and level of development of the child or young person. (p.33)

Lastly, according to the AADE (2006) position paper, age appropriate information is that which matches the attention span and cognitive abilities of the child.

Reflecting the literature, diabetes education must consider multiple factors in order to benefit the child. To enhance knowledge acquisition, the daily activities of childhood must be incorporated into diabetes education. To ensure an individualized approach, the education must build upon previous knowledge and be presented in such a way that the child will understand the concepts. Educational efforts that build upon previous knowledge suggest an on-going process, thus the need for multiple learning sessions to occur. Learning the concepts of diabetes care does not occur in one single event. Lastly, because children in this age group commonly have shorter attention spans and are easily overwhelmed when too much information is given or not understood, the learning sessions must occur frequently, in short duration episodes, with knowledge delivered in small increments, and basic instructions given to prevent feeling inundated. The educational approach, therefore, must be organized to provide structure and prevent the random delivery of information.

An additional factor impacting diabetes education is utilizing a multidisciplinary approach. According to Anderson, Svoren, & Laffel (2007), a multidisciplinary approach benefits the child by receiving the same information from multiple sources, and repeatedly over time, thus increasing his or her level of knowledge through replication. Utilizing the school nurse as a resource for diabetes education incorporates and strengthens the multidisciplinary approach. For instance, the child may develop a foundation of diabetes knowledge from diabetes education provided by his or her primary healthcare provider; however, a diabetes educator, dietician, and school nurse can provide additional learning opportunities to reinforce what was learned and to attain further knowledge. This allows the child to learn the diabetes concepts from multiple sources,

according to individual educational needs, age appropriately, across multiple settings, and through various methods.

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Although the significance of diabetes education being age and developmentally appropriate was addressed in the literature, no research specifically described what diabetes knowledge was considered age appropriate. Some tasks of normal development for the pre-adolescent child were described. For example, Anderson et al. (2007) listed developmental tasks that included a smooth adjustment from the home to the school environment, forming peer relationships, and forming a positive sense of self. They stated "Continued parental involvement in diabetes care complicates the tasks of normal adolescent development which involve solidifying peer relationships and separating psychologically from parents" (p. 102). The pre-adolescent child is at a higher risk for challenges in diabetes care due to the developmental level and wanting to become more independent in his or her care.

Diabetes education can also be applied to the developmental stages of children described by Piaget:

Children at this age (7-12 years) have reached the concrete operational stage, which means that they are starting to develop logical thought. At this age, children can be taught about the physiopathology of their disease, whereas before 7 the focus is put on what they experience rather than on cognitive aspects. They also learn to do their injections by themselves, but do not go as far as deciding by themselves on how to adapt their insulin intake to their needs. This would be the goal of a program intended for patients over 12 years of age who have reached the formal operational period which means that they begin to think abstractly and can anticipate and reproduce a situation. (Pélicand et al., 2006, p153).

Although this explanation is helpful, more detailed information is needed to address the needs specific to the pre-adolescent. The question still remains: *What specific diabetes-related concepts are recommended to be taught at the pre-adolescent level of development and how should they be taught?* 

## Guidelines of Professional Organizations

For this project, diabetes education was also described in published guidelines of federal agencies and organizations within the diabetes education community. For example, the National Standards for Diabetes Self-Management Education emphasized that there is no one 'best' education program or approach; however, integrating behavioral and psychosocial strategies results in improved outcomes, group education is effective, and culturally and age appropriate programs are important as well (Funnell et al., 2009). The recommendations for diabetes education from the ADA (2009) explained that children have unique characteristics and needs in comparison to adults which dictate different standards of care including the provision of age appropriate diabetes education. The NDEP (2008) also emphasized special issues related to age appropriate diabetes care:

Children with diabetes can participate in nutritional decisions and administer their own insulin, however may be unable to draw up the dose accurately until a developmental age of 11 to 12 years. Adolescents have the motor and cognitive skills to perform all diabetes-related tasks, however, risk-taking behaviors are common related to peer acceptance, therefore, supervision is necessary (p.10).

The ISPAD Clinical Practice Consensus Guidelines 2009 Compendium clearly stated the importance of individualized diabetes education that addresses each child's age, stage of diabetes, maturity and lifestyle as well as being culturally sensitive and paced according to their needs (Swift, 2009). Finally, the focus of the position statement of the AADE (2006), Individualization of Diabetes Self-Management Education addressed the need for individualized diabetes education through a process of customizing the educational program which included age appropriate information. Silverstein et al. (2005) explained that, regardless of the setting, diabetes education should be personalized and gauged to the individual needs of the child and consider cultural sensitivity as well.

The guidelines of multiple professional organizations have clearly stated the need for diabetes education to include age appropriate concepts for self-care; however, the literature does not specifically address what constitutes age appropriate concepts. For example, no recommendations were found specifically stating when a child should be taught to calculate and self-administer the insulin dose. Each child, therefore, must dictate what concepts are appropriate according to his or her own individual needs. According to Nabors et al. (2003), facilitating diabetes management at younger ages may improve the child's ability to manage the condition when they are older. In other words, when a child has a better understanding of the concepts of diabetes management at preadolescence, it may lead to better diabetes control as a young adult. Additionally, many diabetes educational programs are available; however, there is no one evidence-based structured educational program recommended for children with diabetes (Matyka & Richards, 2009).

## Critique of the Literature

Research found for this independent study reported the effectiveness of diabetes education for children in multiple educational settings and formats. In addition, studies were found that described how the perceptions of children and their parents regarding diabetes impact diabetes education. No research, however, was found specifically addressing diabetes education that targeted the pre-adolescent age group.

Twelve studies regarding the effectiveness of diabetes education in multiple settings for children with diabetes were considered for this project and are summarized in Appendix A. The sample size in the research studies ranged from 5 - 92 participants. The ages of the participants in the studies varied, ranging from 3 - 18 years of age, none of which specifically targeted the pre-adolescents as a developmental age group. Five studies were quantitative and seven were qualitative in nature. Of the twelve, less than half were conducted in the United States (Delamater et al., 1990; Faro et al., 2005; Herrman, 2006; Roper et al., 2009; Siminerio et al., 1999). The remaining studies were conducted in England (Franklin et al., 2008; Martin et al., 2009: Murphy et al., 2007), France (Pélicand et al., 2006), Canada (Basso & Pelech, 2008a; Basso & Pelech, 2008b), Sweden (Vicklund, et al., 2007), and Scotland (Bloomfield et al., 1990). Due to the variability in the study locations, possible ethnic differences may limit the generalizability to the United States.

Overall, the results of the studies reviewed showed that although the children benefitted from the diabetes education that was provided in each instructional setting, the evidence was lacking to show that one specific educational format was consistently more effective or developmentally appropriate. Due to small sample size, non-standardized methods of evaluation, and inconsistent study designs, the results of the studies could not be generalized to the pre-adolescent population. For example, comparing group educational diabetes programs, Vicklund, Rudberg, and Wikblad (2007), using a sample size of 90 adolescents between the ages of 14-18 years, found an improvement in diabetes knowledge and a positive impact on attitude; however, no impact occurred toward self-care when measured with a validated questionnaire. On the other hand, the research of Martin, Lively, and Whitehead (2009) had a sample size of five children in the 9-11 age range and their parents that showed a positive change in the aspects of the child's perceptions and diabetes care, however, the pre and post questionnaire used for measurement was not standardized. Although both studies demonstrated an increase in diabetes knowledge, an accurate comparison could not be made due to the variability in sample size and ages and methods of evaluation. In addition, for the same reasons, the results of the studies could not be specifically applied to the pre-adolescent age group which was the focus of this independent project.

In some studies glycemic control was measured as an indicator of diabetic knowledge (Bloomfield et al., 1990; Delamater et al., 1990; Murphy et al., 2007). The hypotheses in the studies were that HbA1c levels would improve when increased diabetes knowledge occurred. Bloomfield et al. found that in a diabetes club, HbA1c levels stabilized but were not sustained one year following diabetes education. No correlation between glycemic measures and diabetes knowledge was found for the whole study period (p = < 0.003). Utilizing diabetes education in a clinical setting, similar results were also reported by Delamater et al. (p = < 0.0001) and Murphy et al. (p = 0.003). According to Murphy et al., current guidelines regarding diabetes treatment and children recommend control of glycemic levels within a specific range, however, "even in the Diabetes Control and Complications Trial (DCCT), achieving optimal glycemic control in the younger cohort proved difficult" (p. 1261). In meta-analyses and critical reviews regarding the impact of diabetes education on self-care and glycemic control is modest to moderate at best (Anderson et al., 2007). Strict glycemic control, considered the gold standard to optimize health outcomes for Type 1 diabetes, is difficult to achieve with adolescents even when diabetes education is provided. Although the children appeared to enjoy diabetes learning experiences, the research was inconsistent regarding retention of the learning and effectiveness of maintaining good metabolic control.

Literature described how the perceptions of children and their parents regarding diabetes impact diabetes education. For this independent project, four studies related to the children's and parent's beliefs and perceptions about diabetes and current wishes for diabetes education were found (Faulkner, 2003; Herrman, 2006; Marshall et al., 2009; Roper et al., 2009). In the studies reviewed, diabetes education commonly incorporated parental perception and level of knowledge and support when the child participating was very young. Parental knowledge was measured less often for the older child because of the increased ability for self-care skills in that population.

Faulkner (2003) addressed the impact of Type 1 diabetes on the psychological functioning of the adolescent and found that teens with diabetes indicated a lower satisfaction and quality of life compared to teens without diabetes. Even though they feel they are capable of participating in the same activities as their peers, teens with diabetes consider themselves as being less healthy and worry about their metabolic control. "Health perception and worries about diabetes that are associated with metabolic control may reflect the status of psychological quality of life" (Faulkner, 2003, p. 366). Diabetes education therefore, must consider the impact of the diabetes and the developmental and emotional needs of the teen with Type 1 diabetes.

Interviews with children conducted by Herrman (2006), Marshall et al. (2009), and Roper et al. (2008) reflected children's perceptions and identified prevailing themes related to diabetes care as was previously discussed. Overall, identifying the perceptions and how they influence diabetes-related behaviors is valuable when providing diabetes education. According to Marshall et al. (2009), developing a deeper understanding of the children's experiences related to the diabetes will enable the delivery of care to meet their specific needs. Therefore, knowing and understanding the perceptions that children and adolescents have regarding their diabetes is important to support the educational needs of the child.

In summary, appropriate diabetes education is essential for the successful selfmanagement of diabetes. The period of preadolescence brings unique challenges that impact the pre-adolescent's ability to self-manage his or her diabetes successfully. Multiple factors affecting diabetes self-management include the perceptions of the preadolescent and parent toward diabetes, age, cognitive level, and developmental stage, all of which must be addressed in the provision of diabetes education. Research indicates that diabetes education provided in multiple settings such as a clinical setting, a small group educational setting, or a diabetes club is helpful to increase diabetes knowledge, however, no specific educational setting is considered most effective. In addition, literature regarding diabetes education consistently addressed the need for age and developmentally appropriate diabetes education, however, does not specifically describe at what age certain diabetes concepts should be learned. For example, at what age should a child learn how to self administer their insulin? Diabetes education must be based upon the individual needs of the child and be built upon existing knowledge. Pre-adolescents with diabetes would benefit most from an educational approach that addresses the individual diabetes knowledge and developmental needs, occurs frequently, in short duration, in multiple settings, and incorporates the normal activities of childhood. In other words, a diabetes educational program with six lessons, each lasting 20 minutes may be more effective than one lesson lasting two hours. Additionally, educational sessions conducted by multiple educators may be beneficial. Sessions conducted

individually by a diabetes educator, a dietician, and a nurse providing similar information allows the knowledge to be reinforced by multiple sources. Lastly, by using a multidisciplinary approach, the school nurse may be effective in providing diabetes education at school.

## PROCEDURES

#### **Overview of Independent Project**

This independent project was prompted by the individual working experiences of a Licensed School Nurse in rural Minnesota challenged by pre-adolescents diagnosed with Type 1 diabetes that inconsistently adhered to their diabetes management plan while at school. To begin the project, an in-depth literature review was conducted to identify what diabetes education was most effective and developmentally appropriate. After consideration of the literature, the purpose identified for the independent project was to create a developmentally appropriate diabetes educational tool for the pre-adolescent child with Type 1 diabetes. Two pre-adolescent children with Type 1 diabetes met with the school nurse in individual sessions at school for approximately 1 1/2 hours each. The meetings occurred during the summer to minimize interruptions during the school year. Each child was first asked to develop a list of topics important for diabetes care. The list was then compared to a list developed by the school nurse. Topics not listed by the child were added to create a comprehensive list of topics of diabetes care. Each child was then asked to develop questions associated with each topic, based on his or her perception of what information is necessary for individual diabetes self-care. During this process, when questions regarding diabetes care were voiced by the child, diabetes education was provided in the context of 1:1 interaction with the school nurse. The content of the

questions developed by the children were categorized to create modules for the design of the Diabetes Quiz for Pre-Teens, an on-line diabetes educational quiz targeting preadolescents with Type 1 diabetes. The interventions of this independent project are the modules that constitute the quiz for diabetes education targeting the pre-adolescent child. Peer evaluation of the quiz was conducted by school nurses practicing in schools from the same region. The quiz was posted on the health page of the school web site of the school nurse at http://wp.sebeka.k12.mn.us/jmattson/diabetes-quiz-for-pre-teens/

## Institutional Review Board Approval

This independent project was submitted to the Institutional Review Board (IRB) of the University of North Dakota for approval. According to the IRB, the children participating in the project were not providing personal, identifiable information. The task of the children was only to provide input in the development of the questions. This project, therefore, did not meet the requirements for human research and IRB approval was not required. Parental consent and child assent were obtained, however, for participation. Examples of the consent forms are included as Appendix B and C. *Participants* 

The participants in this project attended the schools that were served by the school nurse. The criteria for participating in the project included being in the pre-adolescent age group of 10 to 13 years old and having Type 1 diabetes. Three pre-adolescent children with Type 1 diabetes were eligible and invited to participate. Two males and one female, recruited by the school nurse, were between the ages of 11 and 13 years old. All children were eager to participate, however, one child moved to another school prior to the end of the school year. Efforts to contact him were unsuccessful. Two children

remained; a 12 year old female and 11 year old male. Both were diagnosed with Type 1 diabetes for over five years.

Each child was given the option of having someone along to ensure that they felt comfortable meeting with the school nurse. One child requested that a parent be present. The other child stated that they preferred having no one else in the room. Both children were cooperative, appeared relaxed, and followed directions without difficulty.

For one child, the procedure was different than what was anticipated. Two weeks before the summer recess, one child asked for permission to start working on the project after school. Permission was granted. The student identified topics with the school nurse and began developing questions accordingly. The task was completed, however, with the school nurse during summer recess.

## Independent Project Design

This independent project can potentially generate a new insight and a deeper understanding for diabetes education targeting the pre-adolescent child. The qualitative study conducted by Roper et al. (2009), discussed 'what children and adolescents know and want to know about the disease' and was central to the design of this project and the basis for asking the children to develop the content for the questions in the quiz. Additionally, according to Lowes (2008), "A starting point for any diabetes education program is to establish a baseline or what the child believes or understands about diabetes" (p. 53). For this project, the baseline of diabetes knowledge was established when each child identified and listed the components important for diabetes care and assisted in developing the questions for the quiz.

To ensure that the independent project reflected an evidence-based approach, the school nurse first reviewed literature to determine what components of diabetes care constituted comprehensive diabetes education. Then, each child was asked to develop a list of topics they thought was important for their diabetes care which was compared to the list created by the school nurse. Topics that were not listed by the child were discussed with the school nurse and then added to the child's list so that each child's final list reflected a comprehensive approach and included the same topics.

After identifying the components for diabetes care, each child was asked to develop questions associated with each subject area with the guidance of the school nurse. The content of the questions developed by each child reflected their diabetes knowledge associated with each topic. The ability to accomplish this task was based upon each child's history and experience of having Type 1 diabetes. Both children were diagnosed with Type 1 diabetes in early childhood and have experience learning the concepts associated with its management for over five years. Each child's diabetes knowledge and expertise was demonstrated by the information they provided in each question. Having each child develop the content for the questions was central so that the individual diabetes knowledge of each child was presented. Lange, Sassmann, von Schultz, Kordonouri and Danne (2007) stated "School children (between 6 and 12 yr) depend on their daily life in own decision making already in several circumstances. They need age adapted information" (p.66). The questions, therefore, reflected the current knowledge and skills that the pre-adolescents had established and expected of themselves.

In addition to the questions related to diabetes knowledge, the children also developed problem solving questions, informally entitled the "what-ifs." These questions reflected problem solving skills. Problem solving, identified by the AADE as one of seven key behaviors to diabetes self-management, is defined as "a learned behavior that includes generating a set of potential strategies for problem resolution, selecting the most appropriate strategy, applying the strategy, and evaluating the effectiveness of the strategy" (Mulcahy et al., 2003, p.788). Problem solving is important to diabetes education as it can measure the ability for thinking and understanding concepts. Research conducted by Hill-Briggs and Gemmell (2007) involved diabetesrelated problem-solving interventions and reported an improvement in behaviors, specifically related to adherence in children and adolescents with Type 1 diabetes. Their research showed that given a diabetes- related problem and identifying its solution, the pre-adolescent achieves a better understanding for diabetes self-care, resulting in improved adherence of his or her management plan. According to Mulcahy et al. (2003), diabetes problem solving is an effective predictor of self-care and particularly important for managing hyperglycemic and hypoglycemic episodes and sick days because these situations require the problem solving skills of recognizing and responding to the unanticipated circumstances. Guided by the school nurse, both concepts of hypo/hyperglycemia and sick days were addressed in the questions of the quiz developed by the children. For example, at this age both children have made decisions whether to test their blood sugar based on their symptoms to determine whether or not treatment for hypoglycemia was required. The questions were centered on simple problem-solving scenarios experienced by the children when they had to make this decision.
During the activity of developing the questions for the quiz, if the child inquired about any concept regarding diabetes care, diabetes education was provided in the context of 1:1 interaction with the school nurse. Each child benefitted as they received individualized diabetes education through the discussion they had with the school nurse. This allowed the school nurse to identify and reinforce the child's current knowledge and to supplement with appropriate diabetes education.

### Format of Quiz

Many options were considered in determining the teaching strategies for the educational tool developed in this independent project. Developing a curriculum, creating a game, and writing a story were possible curricular avenues. A web-based quiz format was chosen because pre-adolescents may particularly enjoy interactive web based activities. The web-based quiz allows the pre-adolescent to be actively involved in the learning process. The more interactive the educational experience, the greater the likelihood of successful learning (DeYoung, 2009). Websites for developing quizzes were available and reviewed to determine their advantages, cost, and appearance. The overall appearance and quality, however, was thought to be adversely affected by the multiple advertising links associated with each website and therefore, not preferred. A sample of such a quiz was created at: http://www.proprofs.com/quiz-school/story.php?title=diabetes-education-preteens.

The final format for the quiz was determined after consulting with the Center for Instructional & Learning Technologies (CILT) personnel from the University of North Dakota. The College of Nursing utilizes Adobe Presenter, a plugin to Microsoft PowerPoint that involves PowerPoint slides and e-learning that is made available for

students of the College. A version of Adobe Presenter with a quiz portion was made available and utilized for this project. The program allowed the quiz to be published in a PDF format that enabled it to be easily posted on the school web page of the school nurse.

The type of questions in the quiz, determined by each child with guidance from the school nurse, included multiple choice and true/false questions. A PowerPoint slide was created from each question and categorized into a topic area. Modules were then created according to the content of the slides. Module topics included general information, insulin, nutrition, exercise, and problem solving. The content for each question was identified by each child and the question was written also with guidance of the school nurse. After completion, grammatical errors and misspelled words were corrected. Clipart was added to the slides to enhance the visual appeal of the quiz for a pre-adolescent child. Lastly, a printable Certificate of Completion was incorporated as the last slide. The quiz-taker can choose to complete all or some of the modules according to his or her individual educational needs. The Diabetes Quiz for Pre-Teens can be accessed on-line at: http://wp.sebeka.k12.mn.us/jmattson/diabetes-quiz-for-preteens/ The PowerPoint slides of the questions included in the quiz are also included as Appendix E.

#### Evaluation

To evaluate the Diabetes Quiz for Pre-Teens, an expert panel of school nurses from rural Minnesota reviewed the quiz to determine its effectiveness and value in school nurse practice. Approximately fifteen school nurses were present at a Regional School Nurse meeting where they were notified of the independent project and all were invited to

participate in the evaluation process. Ten school nurses agreed to review the quiz and provide evaluative feedback. The Evaluation Questionnaire for Diabetes Quiz is included as Appendix D.

The criteria for the evaluation of the quiz were determined by the school nurse initially reflecting upon identifying the purpose of evaluation and what knowledge was desired for the outcome of the evaluation. The purpose of evaluating the quiz was to identify its value to school nursing practice. Needs based evaluation judges the impact and program worth (Owen & Rogers, 1999). To evaluate the impact and worth of the Diabetes Quiz for Pre-Teens, an 11 item evaluation tool entitled The Evaluation Questionnaire for Diabetes Quiz was constructed by the school nurse conducting the independent project. A Google search was conducted using the words "evaluation form" and "sample evaluation forms" in an attempt to locate examples or templates of evaluation forms that reflected the criteria. An example of an evaluation form was found with the criteria of content, organization, language, use of online resources, effectiveness, and presentation skills listed (Peer Evaluation Form for IL in English Assignment, n.d.). The criteria incorporated in the final document for the evaluation of the quiz included 1) content, 2) organization, 3) language, 4) effectiveness, 5) presentation, 6) overall quality, and 7) value.

The Diabetes Quiz for Pre-Teens and Evaluation Questionnaire for Diabetes Quiz were sent to each school nurse via e-mail with the request that it be completed and returned in three weeks. A second e-mail was sent one week later reminding each school nurse to complete the questionnaire. Five school nurses returned the questionnaire, two school nurses were unable to complete the review due to personal reasons, no response

was received from one school nurse, and an automated message was returned from two school nurses stating that they were out of the office.

Five school nurses evaluated the Diabetes Quiz for Pre-Teens. The approach of the evaluation was to learn the relevance of the quiz for pre-adolescents with diabetes and its potential for future use by school nurses for diabetes education rather than the evaluation of each quiz question and its content. The criteria of content, organization, language, effectiveness, presentation, overall quality, and value were rated on a Likert scale of 1 being "Poor" and 5 being "Excellent." Overall, high ratings of "4" and "5" were received in all criteria.

The characteristics for content included whether the modules presented in the quiz were relevant to diabetes education and whether the content presented in the questions were age appropriate for the pre-adolescent. All school nurses rated Content at "5," suggesting that the modules were relevant to diabetes education and the content of the questions were age appropriate based on the perceptions of the school nurses. The modules reflected the lists of topics produced by the pre-adolescents and according to what was considered in the literature as important, therefore, were relevant to diabetes education. One school nurse stated "It was nice that some questions are more thought provoking and some are more fun with silly answers." No additional information was written to further explain the meaning of this comment.

The characteristic for organization was that the questions were organized in a neat and logical manner. Three school nurses rated Organization at "5" and two school nurses rated it at "4." Categorizing the questions into modules created a logical method of organizing the content of the quiz.

The language criterion, meaning the use of language and terms were appropriate for the pre-adolescent, was rated "5" by four school nurses and "4" by one. Comments included: "Unsure if a child would use the word proper" and "The reference to bumps and bruises in the muscle if the injection site is not changed because insulin isn't supposed to be injected in the muscle." The term "proper" was used by the child in question #11, referring to proper diet and exercise being important to stay healthy. The term, thought to be appropriate relating to a child with diabetes following correct nutritional guidelines for self-management, was not changed in the quiz.

The answer to question #35, referring to the importance of rotating injection sites, stated "To avoid getting bruises and bumps in your muscle." The viewpoint of the reviewer was because insulin is injected subcutaneously and not intramuscularly, the answer was confusing. To improve accuracy and decrease confusion, the terminology in the question was changed in the quiz to "avoid getting bruises and bumps in your skin."

Two questions were asked to address the effectiveness of the quiz. The first question targeted the pre-adolescent: "Will the information presented in the quiz be effective and helpful for the pre-adolescent?" The second question targeted the school nurse: "Will the information presented in the quiz be helpful in your efforts of diabetes education for the pre-adolescent?" Four school nurses rated the first question for effectiveness at a "5," believing that the information presented in the quiz would be helpful for the pre-adolescent learning about diabetes. One school nurses rated the first question at a "4" and added the comment, "Probably as effective as any one tool can be with this developmental age group." The second question was rated at a "5," by four school nurses indicating that the information presented in the quiz would be helpful for

the school nurse in providing diabetes education. One school nurse rated the second question at "3," stating "Gave this rating more as a function of MY time restraints than anything. I might give access to the tool to a family, but not necessarily have time to go through it with the student." The rating of "3" therefore, suggested that the quiz would not be utilized due to its quality, but rather to the limited time that the reviewer had in providing diabetes education to students. The reviewer indicated that, because of time restraints, the ability to complete the Diabetes Quiz for Pre-Teens with students was limited. Families, however, may be given access to the quiz. This quiz may be also be useful for parents to reinforce diabetes education with their pre-adolescent child. In addition, utilizing the home environment may enhance a less stressful atmosphere as well as allow the child to take the quiz according to their individual educational needs.

The characteristics for the presentation criterion included three questions: "Are the instructions clear and understandable and reasonably easy to follow/navigate?" "Is the appearance of the modules in the quiz age appropriate?" and "Is the overall length of each module appropriate for the pre-adolescent age group?" Four school nurses rated all three questions at "5" suggesting that the directions were easy to follow and the quiz was presented in a manner that was appropriate for the pre-adolescent. One school nurse rated the first question at "3," one school nurse rated the second question at "4" and one school nurse rated the third question at "3." Written comments included: "I think the phrase 'Click anywhere to continue' confused me. It may be easier to have a 'next' button or say 'click anywhere on the slide to continue', "Pictures are fun," "I think there may be a few too many questions in each module," and "I'd like to see the navigation a bit more clear. Perhaps a change of color once the module has been completed." These

comments were considered and a format change was made. In the navigation of the slides, the phrase on each question was changed to "click anywhere on the slide to continue." Due to the constraints of the format of the quiz, however, a change in the color was not made. The PowerPoint slides of the questions included a colorful theme and the ClipArt that was used also added color to each slide.

The overall quality, meaning the general worth or attributes of the quiz was rated by two school nurses at "4" and three at "5." The criterion of overall quality was considered a rating of a combination of the criterion included in the evaluation tool. Overall, the quality of the quiz was rated highly by all of the school nurses.

Four school nurses rated the value, or potential value of the modules as future reference material for diabetes education at "5," with one rating the Value at "4," indicating that the quiz would be used as future reference material in their work. Comments included "This would be a great tool to use with my students," and "Great to put the information in a fun format."

Additional feedback and comments were provided at the end of the questionnaire by three school nurses. The following comments were made: "One question I did not agree with was "Why is the AIC blood test important? I felt it could have been another answer could have been partially correct," "Overall this is a great tool and I would love to be able to use it at the school to educate diabetic students. Bravo," "I would also like to use a tool like this with my teachers and staff that are working with the diabetic students. Well done," and "In one slide you referred to the 'diabetic' instead of

'person/student with diabetes'. I prefer not naming a student based on their medical condition."

The comments made by the school nurses were reviewed to determine whether additional changes needed to be made to clarify a question or decrease confusion. Due to the syntax and sentence structure of the comment related to question #17 regarding the importance of A1C, it was difficult to ascertain its meaning. In an attempt to clarify possible confusion, however, the answer was adjusted to state: "It is how the doctor knows what your blood sugar is over time and can makes changes to your diabetes plan if needed." In addition, the comment regarding the term "diabetic" being used as referring to a person/student with diabetes was unclear as the term was not found in any of the questions in the quiz. The comments that were written asking for permission to use the quiz in the school nursing practice of the reviewers were also addressed. The Diabetes Quiz for Pre-Teens was sent via e-mail to school nurses who attended the Regional School Nurse meeting in rural Minnesota giving them permission to use the quiz in their efforts for diabetes education.

Although this quiz targets the pre-adolescent child with Type 1 diabetes, the school nurse asking to use this quiz for diabetes education for school personnel may find this quiz helpful because the information presented reflects a comprehensive approach of the concepts for diabetes education. In addition, the level of knowledge presented may be helpful for individuals having no medical background and are in need of basic diabetes knowledge. Additional diabetes information could be added by the school nurse during the presentation to reflect the educational needs of the school staff.

Overall, from the feedback of the school nurses conducting the review, the Diabetes Quiz for Pre-Teens received high ratings. The positive feedback in the evaluation of this quiz implies that the quiz can be an effective tool to impact preadolescents with diabetes learning about diabetes care at school. The knowledge presented in this quiz appears to be a method for developmentally appropriate diabetes education for the pre-adolescent. The results of the evaluation do not suggest that changes in learners' knowledge, skills and attitudes may occur as a result of the quiz; however, the quiz may be beneficial for the pre-adolescent in learning about diabetes care. Lastly, all of the school nurses indicated that the Diabetes Quiz for Pre-Teens would be helpful in diabetes educational efforts. Most reviewers intended to utilize the quiz in their school nurse practice.

After completion of the project, the Diabetes Quiz for Pre-Teens was posted on the school website home page of the school nurse. This quiz can be accessed at www.sebeka.k12.mn.us. Click on Faculty at the top of the page, then Mrs. Janet Mattson in the Staff section. Click the Diabetes Quiz for Pre-Teens link and then click the item "Diabetes Quiz for the Pre-Teen." The quiz can also be accessed at the following URL http://wp.sebeka.k12.mn.us/jmattson/diabetes-quiz-for-pre-teens/

#### DISCUSSION

The questions in the Diabetes Quiz for Pre-Teens revealed the diabetes knowledge of the pre-adolescents who participated in the independent project. As the project progressed, each child's understanding of diabetes concepts became increasingly evident as demonstrated by the content of the questions and answers. The diabetes knowledge exhibited by the children was at a lower level than was anticipated. This supports the premise that pre-adolescents may not consistently adhere to their diabetes plan because they do not fully understand the concepts and implications of decision making related to diabetes care. Yet, the responsibilities for diabetes self-care typically begins to transition to the child at this age. Diabetes education, therefore, is critical for the pre-adolescent child.

Due to their developmental stage and lack of understanding the concepts, the preadolescent is unable to fully understand the implications of decision making and self-care related to diabetes control. The Diabetes Quiz for Pre-Teens may be a developmentally appropriate tool for providing diabetes education for the pre-adolescent age group. *Analysis of the Quiz* 

The components of diabetes education identified and addressed in the quiz reflected what was found in the literature regarding what constitutes a comprehensive diabetes education al approach. For example, "The goals of diabetes education include blood glucose control, prevent chronic and potentially life-threatening complications and to optimize the quality of life" (Ozcań & Erol, 2007, p.23). An overview of managing diabetes written by Lowes (2008) stated that diabetes education should include the practical skills of insulin administration, blood glucose monitoring, as well as recognizing, avoiding , and managing hypoglycemic and hyperglycemic episodes, dietary management, the importance of optimal glycemic control, and managing exercise, illness, and special occasions. Swift (2009) included similar topics with the addition of simple explanations of the uncertain cause of diabetes, the need for immediate insulin, explanation of what is glucose and prevention of ketoacidosis. Lastly, according to Funnell et al. (2009), content areas of diabetes education include describing the diabetes process and treatment, incorporating nutritional management and physical activity, using medication safely, monitoring blood glucose, preventing, detecting and treating acute and chronic complications, and developing personal strategies to promote health and behavioral change. When meeting with the school nurse, each child was given no limit to the number

of topics or questions to develop regarding diabetes care. The topics suggested by the children were similar to those found in the literature by the school nurse. The topics identified by the children included: 1) blood sugar, 2) what the numbers mean, 3) insulin, 4) how to control blood sugar, 5) when to take insulin, 6) what insulin does, 7) food questions and how to count carbohydrates, 8) rotating sites, 9) what exercise does and why it's important, 10) how to use the pump, 11) right insulin dose, 12) care of the feet, 12) diabetes control, 13) symptoms of high/low blood sugar, 14) treatment of high/low blood sugar, 15) how to store insulin, and 16) what can go wrong. Both children quickly generated a list of topics they felt were important for diabetes care.

Topics not listed by the children and added to the list included 1) travel, 2) special occasions, and 3) injuries. When these topics were suggested by the school nurse, both children agreed they were important for diabetes care and had inadvertently overlooked them. In addition, the problem solving questions developed by the children with assistance of the school nurse were added as well.

The children developed a total of 70 questions related to diabetes care. Questions that duplicated content were omitted, leaving 61 unduplicated questions. The large number of questions led to a concern in the length of the quiz. Considering the research of Bloomfield et al. (1990), diabetes education may be overwhelming when too much

information is given, significantly impacting the outcome of successful knowledge retention and influencing diabetes self-management skills, particularly for the preadolescent. The sheer number of questions generated for this project, therefore, could be overwhelming for the pre-adolescent child. The content of each question was reexamined to determine if further questions could be omitted. Finding none, an alternative approach of categorizing the questions and developing modules was considered. Imbedding modules within the quiz allows the quiz taker to choose the sequence of modules when completing the quiz according to his or her individual educational needs. Organizing the quiz into modules is supported by the literature explaining the importance of educational sessions for children needing to be individualized, short in duration, and knowledge given in appropriate increments without being overwhelming. For this project, the pre-adolescent can choose to complete all or some of the modules, in short time increments, and according to his or her individual interests or educational needs. The numbers of questions included in each topic were: general information (25), insulin (15), nutrition (8), exercise (3), and problem solving (10). The number of questions in each module varied and was based on the scope of the content area. The PowerPoint slides for the quiz questions are included as Appendix E.

### Analysis of Diabetes Knowledge

Helping to create the quiz allowed each child to apply his or her knowledge of diabetes care to the content of the questions that were developed. The children were considered experts about their own experiences with diabetes. Utilizing the child's knowledge and "expertise" was an effective method of collecting age appropriate diabetes information and reflected characteristics reported to be important in the literature

regarding diabetes education. By considering the perspective of the pre-adolescents, their diabetes knowledge was demonstrated, helping to establish that the content was presented as being age appropriate.

This independent project provided insight into the perceived diabetes knowledge of the pre-adolescents who participated through the content of the questions and answers they developed. From observations of the school nurse and day-to-day conversations prior to the project, a high degree of diabetes knowledge of the pre-adolescents was perceived by the school nurse, reflecting the capability for self-management of their diabetes. For instance, at school the students test their blood sugars independently and know how to treat hypoglycemic reactions. In addition, the students accurately count carbohydrates in the foods that they plan to consume. However, according to the content in the answers for the questions, the diabetes knowledge was demonstrated to be lower then what was expected. For example, regarding the question, "What should you do if you get a cut or scrape on your skin?" the perception was that the child understood the concept of healing and the anticipated answer was that he or she would probably cleanse the area independently and tell the parent if the cut or scrape became reddened or sore. Independently cleansing the area and monitoring the cut was not considered an option as an answer by the child. The correct response identified by the child was "Tell your mom and dad so they can help you clean it." Additionally, the anticipated answer to the question "What can happen if you don't take your insulin" was that hyperglycemia or ketoacidosis would occur. The options identified by the child for this question included "You can get very sick," "You can die," "Your limbs may need to be amputated when you get older," and "All of the above" with "All of the above" being the correct answer.

Similar responses were noted for other questions and answers indicating that the children's understanding of the diabetes concepts was lower than what was anticipated. The lack of diabetes knowledge, therefore, may explain why the pre-adolescent inconsistently follows his or her diabetes management plan. When given a specific activity such as glucose testing or carbohydrate counting, they are able to execute the task. Due to their cognitive ability, however, they are unable to understand the process or implication of decisions that are made related to that task. For instance, they are able to test their blood and know how to treat hyperglycemia, but because they do not fully understand the long term implications of high blood glucose, are not concerned when high blood glucose levels consistently occur.

According to DeYoung (2009), the terminology used in a question reflects the level of cognitive activity in learning. DeYoung described Bloom's Taxonomy, a popular method of classification used to categorize educational objectives, but also explains cognitive levels of questions as well. Created by Benjamin Blood for categorizing and classifying levels of intellectual learning, Bloom's Taxonomy contains three domains - the cognitive, psychomotor and affective. Within the cognitive domain, six levels that elicit thinking are identified from lowest to highest that include 1) knowledge, 2) comprehension, 3) application, 4) analysis, 5) synthesis, and 6) evaluation (DeYoung, 2009). Utilizing the question classification of Bloom's Taxonomy, the questions developed by the children were in the level of knowledge, which requires the lower cognitive skill of memory. In order to answer the question, the child was required to retrieve information that was memorized. On the other hand, the problem solving questions would suggest a higher cognitive level of application. In order for the students

to solve the problem depicted in the scenario, identifying the solution required the child to apply their knowledge. The answers or solutions to the scenarios depicted by the children reflected their diabetes knowledge. For instance, the responses for the question "What should you do if you get sick?" were "You try to pretend you feel fine," "You check your blood sugar more often and check for ketones," "You don't take your insulin," and "You drink a whole bunch of water." The correct response was "You check your blood sugar more often and check for ketones." Although the response was correct, an answer reflecting the higher level of application explaining why blood sugar needed to be checked more often, such as "Check your blood sugar more often because you might not want to eat when you are sick" was expected. As the children applied their knowledge of diabetes care to life experiences through the problem solving questions, a lower level of comprehension was a consistent pattern indicating a lower level of diabetes knowledge noted among the responses. The children were able to comprehend that the concept was important; however, did not demonstrate application.

On the other hand, suggesting a higher level of diabetes knowledge reflected by Bloom's level of application, a question was developed that involved counting the carbohydrate content of specific foods to monitor dietary intake. The question required the application of current knowledge. Because of the children's daily experience with counting carbohydrates, the questions and answers were developed by the preadolescents accurately and without difficulty. The questions were consistent with the literature of Roper et al. (2009) regarding the need for diabetes education to support and build upon existing knowledge. Both children conduct carbohydrate counting multiple times each day and the questions they developed supported their current knowledge.

When the pre-adolescent is given the responsibility for diabetes self-care, the assumption is that he or she understands the concepts of diabetes management. Considering the questions developed by the children, their lack of knowledge may be demonstrated in relation to their developmental level of cognitive functioning. For instance, questions regarding insulin administration were offered by the children as a general component of diabetes care; however, a question that was anticipated regarding the technical skill of how to administer insulin was not suggested. This may reflect the children's current cognitive functioning. Both children understand that insulin is an important component for diabetes management; however, neither of them independently calculates the dose nor self-administers their insulin. The perception of the school nurse was that one child was capable of self-administering insulin, but needed close supervision to determine the correct dose. The other child had an insulin pump, which automatically calculates and administers the insulin; however, that child did not calculate the dose or administer the insulin prior to receiving the insulin pump. Considering their developmental level, both children may not be capable of making the mathematical computations, therefore, do not self-administer the insulin as well. Hence, the lack of questions in the quiz regarding how to give an insulin injection. Both children may be inconsistent in following their diabetes management plan, appear to be uninterested or even non-compliant, however, may truly be incapable of performing the task due to their cognitive level.

### Analysis of Educational Needs

The content of the questions for the quiz addressed the individual diabetes management plan of each child. For instance, the child with an insulin pump developed

questions specific to its use, while the child who receives insulin injections emphasized questions regarding the insulin pen. This supports the research of many authors regarding diabetes education including the work of Anderson (2007), who emphasized that diabetes education for children must be individualized, according to their plan and educational needs as well as to consider the normal tasks of child development. Thus, each child developed the questions based on his or her current diabetes management plan and knowledge received from his or her diabetes education.

The individual diabetes educational needs of each child were also addressed as they developed the questions for the quiz in this project. When questions or verification of knowledge were asked regarding diabetes care, diabetes education was provided through 1:1 interaction with the school nurse. This was beneficial for each child and was used mostly for reinforcement of the child's current knowledge. For instance, after stating the question "What is blood glucose," the child acknowledged that his own understanding of blood glucose may be incorrect. After the child gave an accurate response, however, the school nurse provided information which reinforced the child's knowledge. In addition, the development of the problem solving questions was helpful in determining the children's understanding of the concepts, specifically for situations that required a solution to a specific problem.

Pre-adolescent children may benefit from the Diabetes Quiz for Pre-Teens as the baseline for the content of diabetes education. When reinforcing and building on previous learning, more time is required to highlight the process of on-going educational efforts. To benefit most from this quiz, an adult, particularly the school nurse, should accompany the pre-adolescent to assess and reinforce current knowledge and provide diabetes education to enhance the learning process. For the school nurse, the quiz may be beneficial as a basis from which to discuss diabetes care and to supplement individualized information during 1:1 interaction with the child. Although the quiz does not ensure that diabetes knowledge will increase or that changes in self-care behaviors will occur, this independent project has the potential to positively affect a cohort of preadolescent children with Type 1 diabetes.

### IMPLICATIONS

This project has multiple implications focusing on school nurse practice, research, education, and policy. School nurses have a unique understanding of school health and issues that impact child development and education. Not only do they provide health care but school nurses also promote healthy behaviors and preventative care to children and families. The school nurse can significantly impact diabetes education for the preadolescent with Type 1 diabetes. In addition, school policies must reflect the care provided by the school nurse.

### Implications for School Nursing Practice

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School nurses must be knowledgeable about Type 1 diabetes and the issues regarding management and education for all children with diabetes. The pre-adolescent, however, presents with unique needs for diabetes education. The school nurse must be prepared to address the need for individualized teaching and learning as well as for developmentally appropriate diabetes education. The school nurse must also consider the developmental need to enhance self-confidence in relationships with peers which affect diabetes self-care decisions. To achieve efficacy in diabetes self-management at school, the school nurse must provide appropriate diabetes education. This independent project strengthens school nursing practice. It impacts the current practice of school nurses providing diabetes education by presenting an approach for diabetes education that may be considered age appropriate for the pre-adolescent child. School nurses may utilize the Diabetes Quiz for Pre-Teens as a baseline for an educational diabetes program and individualize it according to the needs for a particular child. School nurses may also appreciate the format of this educational program because it can be easily accessed on-line.

This project can influence the success for the transfer of responsibility for diabetes self-management skills to the pre-adolescent child. As school nurses provide developmentally appropriate information, it is expected that the pre-adolescent will increases his or her diabetes knowledge and better self-care decisions will be made. In addition, the knowledge of the issues related to the pre-adolescent's own perceptions can assist the school nurse in supporting the ability to achieve proficiency in self-care skills to attain positive diabetes-related behaviors. Other healthcare professionals providing diabetes education may also find this quiz helpful for diabetes education. In addition, because this quiz targets an age group that enjoys web-based activities, the format alone may pique the interest of the pre-adolescent.

# Implications for Research

The breadth and depth of the information gathered in this independent study has implications for those involved in diabetes research regarding continued educational efforts for pre-adolescents living with diabetes, parents of the children, and health care workers providing diabetes education to this age group. The diabetes knowledge demonstrated by the pre-adolescents in this project revealed a discrepancy between their

understanding of diabetes concepts and the diabetes knowledge that was anticipated. Using similar procedures as this independent study, but using a larger sample size, would be helpful to determine whether the pattern of diabetes knowledge demonstrated in this project is typical for this age group. This is particularly important to distinguish the accuracy of the knowledge of the children participating in this project compared to peers and to identify what continued diabetes educational efforts are needed specifically for the pre-adolescent with Type 1 diabetes. In addition, further research identifying what educational interventions are most effective for this age group is needed to increase diabetes knowledge for the ultimate goal of diabetes self-management. Lastly, by utilizing children from other age groups and their "knowledge" and "expertise," developmentally appropriate diabetes research would address the gap in the literature regarding what constitutes developmentally appropriate diabetes education for the preadolescent.

This project has implications for further research that may benefit the school nurse. To ensure that diabetes education provided at school is evidence-based, research targeting educational approaches at school may indicate what is most effective in the school setting.

Additional research is suggested to determine what changes in diabetes knowledge and self-care practices occur, if any, as a result of the Diabetes Quiz for Pre-Teens. Measuring self-care skills pre and post quiz may determine whether the quiz is associated with an improvement in self-care practices and may have an impact on determining the effectiveness of the quiz. Increased diabetes knowledge resulting in

improved self-care practices would positively impact the health outcome of diabetes management of the pre-adolescent with Type 1 diabetes.

### Implications for Education

This project has implications for school nurses, nursing education as well as for the education of the pre-adolescent with Type 1 diabetes. School nurses, though knowledgeable about how diabetes is managed in the school setting, may be lacking information regarding the unique educational and developmental needs of the preadolescent with Type 1 diabetes. Workshops or in-services that provide evidence-based knowledge regarding diabetes care and educational needs focusing on the pre-adolescent would benefit the school nurse, particularly those entering school nurse practice.

Nursing education curriculum may include child development courses that address the physical, social, emotional, and intellectual growth and development of children as well as the provision of nursing care to the acute and chronically ill child. For example, nursing curriculum may address normal growth and development of the child and the effect of acute and chronic illness on normal child development. Knowledge regarding the management of chronic conditions such as diabetes in the school setting, however, requires additional education. Students in undergraduate nursing programs would benefit by curriculum that not only addresses diabetes, but the provision of care in other settings such as school.

Education is an essential component for the progression of child development. For the pre-adolescent with Type 1 diabetes, diabetes education is the foundation for diabetes self-care. Every child must be given every opportunity to achieve his or her academic potential to succeed. Uncontrolled diabetes can result in poor school

performance, low self-esteem, significant stress, and behavioral difficulties as well as medical emergencies (NDEP, 2003). It is imperative; therefore, that every effort is given to provide appropriate and exemplary diabetes education for the pre-adolescent to minimize educational difficulties and to facilitate making the healthiest choices possible for improved health related behaviors and educational outcomes. The Diabetes Quiz for Pre-Teens may potentially impact the health outcome of pre-adolescents with Type 1 diabetes. The impact of appropriate diabetes education for the pre-adolescent may result in a positive health outcome.

### Implications for Policy

The care of the pre-adolescent with Type 1 diabetes at school must include diabetes education facilitating self-management. The school nurse is central in providing diabetes care at school and must advocate for the child to promote and maintain individual health. According to current recommendations for school health policies and procedures, a school diabetes management plan is essential for children with diabetes (NDEP, 2003). This plan commonly focuses on the medical needs involving diabetes care at school. Although diabetes education may be provided during interactions with the school nurse, structured diabetes education is commonly not addressed in the plan. The diabetes management plan, therefore, must include an educational component to ensure a comprehensive approach, particularly for the pre-adolescent child with diabetes. The Diabetes Quiz for Pre-Teens can be utilized as a method for diabetes education. The implications of this project may influence policy and showcase the contributions of school nursing to parents, school personnel and school administrators. This project increasingly emphasizes the need for diabetes education, specifically for the preperformance, low self-esteem, significant stress, and behavioral difficulties as well as medical emergencies (NDEP, 2003). It is imperative; therefore, that every effort is given to provide appropriate and exemplary diabetes education for the pre-adolescent to minimize educational difficulties and to facilitate making the healthiest choices possible for improved health related behaviors and educational outcomes. The Diabetes Quiz for Pre-Teens may potentially impact the health outcome of pre-adolescents with Type 1 diabetes. The impact of appropriate diabetes education for the pre-adolescent may result in a positive health outcome.

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adolescent child. School nurses must ensure that school health policies address the need for diabetes education within the diabetes management plan. A well designed and effectively implemented school health policy that includes diabetes education in its procedures may lead to improved health related behaviors and educational outcomes.

### CONCLUSION

The focus of this independent project was diabetes education for the preadolescent with Type 1 diabetes. At this age, the responsibility for diabetes self-care begins to transfer to the child. In order for the pre-adolescent to begin to take responsibility, however, appropriate diabetes education is critical. Unique characteristics of this age group influence the efforts of diabetes education. In addition to providing knowledge regarding diabetes and its care, the cognitive ability of the pre-adolescent in understanding the complex concepts for care, and the child's developmental needs must be addressed. The literature reviewed in this independent project clearly addressed the importance of diabetes education addressing the age and developmental needs of the child and research has shown that no specific diabetes education approach is most effective.

The quiz designed in the independent project presented a diabetes educational tool specifically for the pre-adolescent with Type 1 diabetes. The method utilized in its creation assisted in addressing the cognitive and developmental needs of the pre-adolescent. By involving pre-adolescents in developing the content of the questions, the Diabetes Quiz for Pre-Teens portrayed a developmentally appropriate approach for diabetes education and may potentially impact the outcome of diabetes self-management for the pre-adolescent. Lastly, because children spend a majority of time at school,

school nurse can contribute to a multidisciplinary approach in providing developmentally appropriately diabetes education helping the pre-adolescent fit diabetes into his or her lifestyle for normal growth and development.

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APPENDICES

## APPENDIX A

Literature Review Grid: Characteristics of Reviewed Studies

CHARACTERISTICS OF REVIEWED STUDIES						
Author/ Purpose	Design	Participants	Interventions	Outcome Measures	Results	Study Quality
Basso & Pelech, 2008 Demonstrate the benefits of group- based creative arts interventions, i.e. skits for children with diabetes	Non- Experimental Qualitative – Case Study Canada	35 children/ caregivers Age groups: 4-7 yrs old 8-12 yrs old	Hospital-based 1 week summer program that incorporated skits in diabetic education of children	Observations of children and analysis of skit content, interviews with caregivers, Goal attainment scaling scores, self-reported knowledge level	Overall, positive changes/influence. Qualitative data: Core themes of skits – Dependencies on caregivers, Anger and dependence issues, Poor or compromised health, succumbing to ill health, Guilt/shame, fear	Low Specific case descriptions may be limited and cannot be generalized Although this program showed positive results, continued research needed
Bloomfield, et al., 1990 Determine whether diabetic club could improve diabetic control and increase knowledge	Experimental -2 year, Randomized Crossover Controlled trial Edinburgh, Scotland	92 children ≤ 13 yrs old (48 families) 100% participants completed the study	Diabetic Club to improve knowledge & understanding of diabetes in children	HbA1, length of hospitalization, episodes of hyperglycemia, insulin dose, number of infections, growth, school absenteeism, diabetic knowledge	HbA1c î when NOT attending diabetic club, rest had no significant changes. Diabetic club may have advantages in HbA1 but not sustained. Social support	Medium Well organized. Some children very young – parent input for level of knowledge
		CHAR	ACTERISTICS (	OF REVIEWED STU	DIES, continued	
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Author/Purpose	Design	Participants	Interventions	Outcome Measures	Results	Study Quality
Delamater, et al.1990 To evaluate the effects of a family- based self- management training program in a clinical setting	Experimental - Randomized Prospective study for two years post- diagnosis St. Louis, MO	36 Children 3-16 yrs of age	Randomized into 3 treatment groups w/ educational sessions 1)Conventional 2)Conventional +SC (supportivecouns eling) 3)Conventional+ SMT (self-mgt training)	Metabolic control: HbA1c C-Peptide Incidents of hypoglycemia	SMT group maintained lower HbA1c levels than Conventional, but not statistically different from SC group. Recommend education and training in self-mgt early following diagnosis	Low Participants in all groups were equated demographically, SES, etc. Small sample size Further studies needed to determine whether this can be replicated
Faro, Ingersoll, Fiore, & Ippolito, 2005 Conduct periodic diabetes care visits in school to promote optimal management of diabetes	Non- Experimental - Qualitative New York, NY	27 Students 6 – High School 4-Middle School 11- Elementary	Monthly school visits of 20-30 minutes for one school year	Pre/Post intervention rating scales completed by students, parents, healthcare provider and results of blood glucose monitoring	No significant changes in scores of the pre/post rating scales, no changes in HbA1c. Overall – positive changes in diabetic management	Low Overall, helpful information. Small sample size limits generalizability. Nature of participants may have an effect on the overall outcome. Those who participated may have been highly motivated individuals.

		CHAR	ACTERISTICS (	OF REVIEWED STU	DIES, continued	
Author/Purpose	Design	Participants	Interventions	Outcome Measures	Results	Study Quality
Franklin, Greene, Waller, Greene, & Pagliari 2008 To explore how patients with type 1 diabetes interact with Sweet Talk system in order to understand its utility to this user group	Non- experimental - Randomized	64 Boys and Girls 8-18 yrs old	Text messages to and from Sweet Talk were recorded over 12 month study, transcribed and analyzed	Observational data on messaging patterns, message content, number of text messages sent	Content of text messages 8 broad categories: BG readings, diabetes ?, Diabetes info, personal hlth adm, social aspects, technical messages, message errors and message responses Positive effects: seen as a trusted medium for communicating with hlthcare provider, passive support also passive support.	Low Generalizabilty is limited, Messages were skewed – 5 patients contributed to 52% of messages
Herrman, 2006 To explore children's beliefs about the cost and rewards of Type 1 diabetes and its treatment.	Descriptive Qualitative United States	17 Children attending diabetes camp 8-15 yrs old 7 Boys 10 Girls	Interviews, lasting ½ hr. in length Audio taped and transcribed within 24 hours of interview	Analysis of interviews	Prevailing themes: Cost: Thinking & counting; Constant interruptions; You can't just eat; Normal but not; What can happen Reward: Some good things; You have to deal with it	Medium Questionnaire had a high degree of validity Low number of participants: Cannot generalize: Most families had higher incomes and high degree of family support Suggest repeating study for low-income

		CHAR	ACTERISTICS (	OF REVIEWED STU	DIES, continued	
Author/Purpose	Design	Participants	Interventions	Outcome Measures	Results	Study Quality
Martin, Lively & Whitehead 2009 Monitor the effectiveness of a group health education intervention utilizing a psychological approach	Non- Experimental - Pilot study: Pre- post intervention design - Comparative Staffordshire,	5 children and their parents were invited, 3 accepted and joined the group - 9-11 yrs old	Three group educational sessions to improve diabetic knowledge	Results of pre & post experimental questionnaires comprising of questions regarding diabetes knowledge	Positive change in aspects of the child's perceptions of their diabetic care and illness related knowledge	Low Evidence is insufficient: low number of participants, results cannot be generalized Questionnaires were not standardized Varied behaviors of children
Murphy, Wadham, Rayman & Skinner 2007 To investigate whether a structured group education program integrated with clinical care, using a team approach can be effective	Experimental - Randomized Wait-list Control Ipswich, England	78 Children 6-11 yrs of age 12-16 yrs of age	Small-group educational sessions with children & their parent, integrated with routine clinical diabetic care over a two- year study period	HbA1c measured every 3 months Changes to insulin regimen PedsQL, PAID, and DFRQ Questionnaires completed before and after intervention	HbA1c decreased in attendees vs. non- attendees. Increased number of daily insulin injections Overall - Beneficial effects in a multidisciplinary approach to patient- centered group education	Low Well organized. Wait list not conducive to participation. Although beneficial in parental responsibilities, differences in motivation may affect results Small sample size – cannot generalize Inconsistencies in study design Low number of educational sessions (4/yr)

		CHAR	ACTERISTICS	OF REVIEWED STU	DIES, continued	
Author/Purpose	Design	Participants	Interventions	Outcome Measures	Results	Study Quality
Pélicand, Gagnayre, Sandrin-Berthon, & Aujoulat 2006 To evaluate the impact of the use of recreational and creative activities (puppets) related to aspects of diabetes	Qualitative Study France	14 Children 10-11 yrs of age	7 Educational sessions held at diabetic camp, over a 3-week period of time, every 2 days, 1 hour in length. Grp A used puppets Grp B did not	Children interviewed before intervention, compared between groups. Objectives, interventions and evaluative criteria developed for educational sessions. All sessions were video-taped and analyzed for content	Children in Grp A (w/ puppets) expressed more positive feelings about having diabetes more frequently. Children in Grp B intervention gained positive experiences, but to a lesser degree. The use of puppets is beneficial	Low Small number of participants This study showed only a short-term impact of the program Suggest using both interventions during educational sessions followed by a focus group to gain most benefit.
Roper, et al. 2009 Describe what children and adolescents with diabetes know and want to know about the disease	Non- Experimental- Qualitative, Descriptive (Part of a larger study) Western USA	58 children and adolescents 8-18 yrs old	Interview conducted using 4 questions, audio taped and analyzed.	Analysis of interviews	6 major themes identified: Care, Physiology, Consequences, Cure, Effects of the Family, Experience at Diagnosis	Low Results cannot be generalized due to several limitations: social desirability of answers, predominantly White participants. Gaps in previous research identified. Need for on-going education

# APPENDIX B

Independent Project Consent Form

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#### INDEPENDENT PROJECT CONSENT FORM

Your child is invited to participate in a project about diabetes education and children. She/he qualifies to participate because they have Type 1 diabetes and are in the 10-13 year old age group. The purpose of this project is to develop a diabetes educational game to increase knowledge and self-care skills for children age 10-13 with Type 1 diabetes.

If you are interested, please read the Informed Consent form. If you agree that your child may participate please sign the bottom of the form and return it to the Health Office at school. Please take your time in making your decision as to whether your child may participate. If you have questions at any time, please ask.

#### INFORMED CONSENT

TITLE:	Diabetes Education at School: The Pre-adolescent Child
PROJECT DIRECTOR:	Janet Mattson BSN RN LSN
PHONE #	(218) 837-5101, Ext, 129
DEPARTMENT:	Sebeka and Menahga Public Schools, Health Service

#### WHAT IS THE PURPOSE OF THE PROJECT?

The purpose of this project is to develop an age-appropriate diabetes educational game to increase knowledge and self-care skills for the pre-adolescent child. \_\_\_\_\_\_\_\_ is invited to participate in the project about diabetes education because he/she has Type 1 diabetes and is in the age group for this project.

#### HOW MANY PEOPLE WILL PARTICIPATE?

Three people will be invited to participate in the project.

#### HOW LONG WILL I BE IN THE PROJECT?

The project is anticipated to be completed in the summer of 2010.

#### WHAT WILL HAPPEN DURING THIS PROJECT?

Each participant will visit individually with the School Nurse at school and talk about aspects of diabetic care. Questions will be developed to create a game for children to learn about diabetes. The time of each visit will be pre-arranged. It is anticipated that two visits lasting ½ hour each will occur. The game will be posted on the School Nurse area of the school's website when completed.

#### WHAT ARE THE RISKS OF PARTICIPATING IN THIS PROJECT?

There are no foreseeable risks to participating in this project

#### WHAT ARE THE BENEFITS OF THIS PROJECT?

By participating in this project, you may learn more about your diabetes. However, in the future, other children with diabetes might benefit because it could help them in learning about having diabetes.

#### WILL IT COST ME ANYTHING TO BE IN THIS PROJECT?

You will not have any costs for participating in this project.

#### WILL I BE PAID FOR PARTICIPATING?

You will not be paid for being in this project.

#### WHO IS FUNDING THE INDEPENDENT PROJECT?

The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this project.

#### CONFIDENTIALITY

The records of this project will be kept private to the extent permitted by law. In any report about this project that might be published, the children will not be identified. Any information that is obtained in this project and that can be identified will remain confidential and will be disclosed only with your permission or as required by law. If a report or article about this project is written, the results of the project will be summarized in a manner so that the child cannot be identified.

#### **IS THIS PROJECT VOLUNTARY?**

Your child's help with this project is voluntary. She/he may choose not to help or may stop participation at any time without any problem with the school or school nurse. The decision whether or not to help will not affect anything. There will be no penalty to those who do not participate.

#### CONTACTS AND QUESTIONS

The researcher conducting this project is Janet Mattson BSN RN LSN. You may ask any questions you have now. If you have questions, concerns, or complaints later about the project please contact Janet Mattson at (218) 837-5101, Ext. 129 during the day or at Janet.Mattson@und.nodak.edu. You may also contact Dr. Julie Anderson, Advisor at (701) 777-4543 or julieanderson@mail.und.edu.

Your signature indicates that this project has been explained to you, that your questions have been answered, and that you agree to help in this project. You will receive a copy of this form.

Subjects Name: \_

Signature of Parent

Date

#### APPENDIX C

#### Independent Project Assent Form

#### INDEPENDENT PROJECT ASSENT FORM

You are invited to help in a project about children and diabetes education. You qualify to participate because you have Type 1 diabetes and are in the 10-13 year old age group. If you want to participate, please sign the bottom of this form and return it to the School Nurse. Please take your time in making your decision. If you have any questions, please feel free to ask.

TITLE:	Diabetes Education and School: The Pre-Adolescent Child
PROJECT DIRECTOR:	Janet Mattson, School Nurse
PHONE#:	(218) 837-5101, Ext. 129
DEPARTMENT:	Sebeka and Menahga Public School, Health Service

WHAT IS THE PURPPOSE? The purpose of this project is to make a game for children with diabetes to learn more about diabetes and talking care of themselves. By helping in this project you may learn more about your diabetes and other children with diabetes may also learn more about their diabetes as well.

WHAT WILL I BE DOING? During the summer you will visit with the School Nurse two times for about ½ hour and talk about your diabetes. You will be asked to help write questions for a game about diabetes. The game with the questions will be posted on the School web page where the School Nurse health information is. Other children with diabetes will be able to play the game and learn about diabetes.

**DO I HAVE TO HELP WITH THIS PROJECT?** You may choose not to help with this project or may stop without any problem with the school or school nurse. Your decision whether or not to help will not affect anything and there will be no penalty to those who choose not to help.

WHAT IS THE COST? It will not cost you anything to help with this project and you will not be paid for helping.

WHAT IF I HAVE MORE QUESTIONS? If you have any questions about this project you may ask the School Nurse now at (218) 837-5101, Ext. 129 or Janet.Mattson@und.nodak.edu. If you have any questions, concerns or complaints later about the project you may contact Dr. Julie Anderson at (701) 777-4543 or julieanderson@mail.und.edu

I have read and understand the project explained above. Anything that wasn't clear to me was explained so I could understand it. If I have more questions later, I can have these answered too. I understand that I don't have to help with the project, even if my parent(s) or guardian says that it is all right, even if I decide to do the things I will be asked to do. I can also change my mind later and that will be OK. I have decided I want to help with the project.

Subi	ect's	Name:

(Print Name)

Signature of Subject

Date

# APPENDIX D

Evaluation Questionnaire for Diabetes Quiz

#### EVALUATION QUESTIONAIRE FOR DIABETES QUIZ

This quiz includes modules related to diabetes care specific for the pre-adolescent child. Completion of this evaluation will provide helpful feedback regarding the overall quality of the quiz and value as future reference material. You will need to save this document first before adding your information.

Please rate the following aspects of the quiz:

		1=Poc	or			5=	Excellent
	Criteria				Rating		
		1		2	3	4	5
	Content (Are the modules presented relevant to diabetes education for the pre-adolescent?)						
2. 0	Content (Is the content covered in the questions age-appropriate for the pre- adolescent?)						
3. 0	Organization (How well is the quiz organized/Are the questions organized in a neat and logical manner?)						
4. 1	Language (Are the terms/language used appropriate for the pre-adolescent?)						
5.	Effectiveness (Will the information presented in the quiz be effective and helpful for the pre-adolescent child?)						
6. 1	Effectiveness (Will the information presented in the quiz be helpful in <u>your</u> efforts of diabetes education for the pre-adolescent?)						
7.	Presentation (Are the instructions clear and understandable and reasonably easy to follow- i.e. easy to navigate?)						
8. 1	Presentation (Is the appearance of the modules in the quiz age-appropriate?						
9.	Presentation (Is the overall length of each module appropriate for the pre- adolescent age group?)						
10. 0	Overall quality (Please rate the overall quality of the modules included in the quiz)						
11.	Value (What is the overall potential value of the modules to you as a future reference material in your work?)						

Additional Feedback/Comments:\_

Thank you for your help. You may e-mail this to Janet Mattson, School Nurse at Janet.Mattson@und.nodak.edu or mail to 702 USHY 71 No., Sebeka, MN 56477 by July 31<sup>st</sup>.

# APPENDIX E

PowerPoint Slides of Diabetes Quiz Questions



# Question 2





# Question 4





# Question 6





Question 8

<ul> <li>A) 70 - 140</li> <li>B) 500 - 600</li> <li>C) 40 - 55</li> <li>D) All of the above</li> </ul>	What range is considered g	ood for blood sugar?
<ul> <li>в) 500 - 600</li> <li>с) 40 - 55</li> <li>D) All of the above</li> </ul>	• A) 70 - 140	0
<ul> <li>c) 40 - 55</li> <li>D) All of the above</li> </ul>	О в) 500 - 600	
○ D) All of the above	○ c) 40 - 55	J.S.
	$\odot$ D) All of the above	Contraction of the second seco
		Submit Clear



# Question 10

○ A) Every week	
о в) Every month	
• c) Every 3 months	
O D) Every year	



Question 12



1



# Question 14

When should you check your blood sugar?

Submit

Clear

- $\circ~$  A) When you feel low
- $\odot$  B) Before you eat
- C) When your parents tell you to
- D) All of the above



Question 18





Question 20





Question 22

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What is another name for	r high blood sugar?
<ul> <li>A) Hypoglycemia</li> <li>B) Hyperglycemia</li> <li>C) Extra Active</li> </ul>	
O D) Energetic	
	Submit Clear



Question 24





# Question 26

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# Question 28

<ul> <li>A) Dirt</li> <li>C) Sores</li> <li>D) Slippers</li> </ul>	A) Dirt C) Sores D) Slippers	O A) Dirt	
<ul> <li>D) Slippers</li> </ul>	D) Slippers		
		0 D) Slippers	
		o by suppers	

You have completed the General Information section. Choose another topic. When you have completed all of the topics, click on "Review Your Answers"
A) Insulin
B) Nutrition
C) Exercise
D) Problem Solving
E) Review Your Answers

## Question 30

о в) When you exercise	
	ξ
い c) When you dance	,
ာ) When you work စ	



# Question 32



What are some typ	es of Insulin?
• A) Humalog	<b>.</b>
⊖ в) Novalog	
O C) Lantus	
• D) All of the above	
	formation formation

Question 34





# Question 36





# Question 38



4



# Question 40





Question 44

When you swin stay on.	n your insulin pump can
О А) True ⊛ В) False	
	Submit



Question 52





#### Question 54





# Question 56





# Question 58

You have completed the Exercise section. Choose another topic. When you have completed all of the topics, click on "Review Your Answers"




### Question 60





#### Question 62





### Question 64

and a state of the state of the





## Question 66





### Question 68



You have completed the Problem Solving section. Choose another topic. When you have completed all of the topics, click on "Review Your Answers"

Insulin	66	
Nutrition		
Exercise	de	
Review Your Answers		
	Submit	Cloa
	Submi	t

# Question 70

Diabetes	Quiz for Pre-Teens
Questions Correct	(correct-questions)
Total Questions	{total-questions}
Number of Quiz Attempts	{total-attempts}
	Continue Review Quiz

Certificate of Completion I successfully completed the Diabetes Quiz for Pre-Teens Name:\_\_\_\_\_\_ Date:\_\_\_\_\_

College of Nursing-Mattson, Janet A.-CSC11283

