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Experiences Managing Type 1 Diabetes Mellitus among Parents of African-American Youth

Sonya T. Strider
Walden University

Walden University

College of Health Sciences

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Sonya Strider

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Review Committee
Dr. Peter Anderson, Committee Chairperson, Public Health Faculty
Dr. Chester Jones, Committee Member, Public Health Faculty
Dr. Magdeline Aagard, University Reviewer, Public Health Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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MPH, Walden University, 2008

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Dissertation Submitted in Partial Fulfillment

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Abstract

Type 1 diabetes mellitus (T1DM) is one of the most frequently diagnosed endocrine and metabolic conditions that occur during childhood. This research study utilized a phenomenological study design to examine how the lived experiences of 20 African American (AA) parents of children with T1DM recruited using social media affects their management and control of the disease among AA youth age 5-17 years old. The interview questions were outlined in categories that tested key constructs of the health belief model (HBM) to determine the perceived barriers, seriousness, and susceptibility to maintaining good glycemic control for their children. Data from each interview was classified and coded to identify and categorize, and then used as codes. Themes were then developed in order to determine intent and importance of the responses. Three themes emerged: the disease's impact on the life of the parents, its impact on the life of the child, and its social impact. The impact on the parents' lives included financial burden and time management. The impact on the lives of the child included, the parent's beliefs and fears about their child's future with diabetes and their child's ability to successfully manage their diabetes. The impact on the socialization for both the parent and the child, included family socialization, how others perceived diabetes and diabetes management, teaching diabetes management to others, and the parent's trust in other's ability to manage their child's diabetes. The findings of this research study provides insight into population based needs for successful diabetes management, such as how to make healthier cultural and ethnic meals and the need for culturally-centered whole family diabetes education, to enhance family relationships and diabetes management.

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Dedication

Mommy,

I hope I have made you proud …

(RIP 12/3/15)

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Thank you to all the people who believed in me when I didn’t believe in myself.

To my sister, Michelle, for picking up all the slack left in my life by this process, so that I could devote all of my time to completing this dissertation.

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Chapter 1: Introduction to the Study

Introduction

Type 1 diabetes mellitus (T1DM) continues to be one of the most frequently diagnosed endocrine and metabolic conditions to occur during childhood (International Diabetes Federation, 2011). Affecting approximately 215,000 young people under the age of 20 years (American Diabetes Association [ADA], 2011) in the United States alone, it is also growing internationally. Noted as the most common chronic disease in children and adolescents by the Centers for Disease Control and Prevention (CDC), nearly 13,000 children are newly-diagnosed with this disease each year (CDC, 2011). This research proposal is a qualitative phenomenological study among 20 African American families with youth ages 5-17 who are diagnosed with T1DM for at least six months and reside in the Eastern region of the United States. This study is designed to elicit the factors in management and control of the disease as lived by these families. Telephone interviews were the primary source of data collection from parents of these children, who described their lived experience and lifestyle management issues. If parents were unavailable by telephone, questions were answered through e-mail.

There has been a notable increase in the incidence of Type 1 and Type 2 diabetes among children worldwide (Giannini, Mohn, Chiarelli , 2009). This includes a national incidence of type 1 diabetes of 19 per 100,000 cases among young people age 10-19 years (CDC, 2011). In a study conducted by Patterson, Dahlquist, Gyurus, Green, and Soltesz (2009) among European children, the researchers predicted that the incidence of type 1 diabetes among children younger than 5 years will double from 2005 to 2020. Researchers who conducted The Search for Diabetes in Youth multi-center study, found that there were 15,600 new cases of type1 diabetes each year (Atkinson, 2012). Over the last twenty years, the average increase of type 1 diabetes has been

5% annually (Maahs, West, Lawrence, Mayer-Davis, 2010). Increase in incidence of T1DM worldwide, along with associated complications, can help explain the economic burden of this disease (Giannini, Mohn, Chiarelli, 2009). The cost of medication and treatment of diabetes-related complications contribute to the rising cost of diabetes care. Children and teens with diabetes subsequently experience more hospital and doctor visits than children of the same age without diabetes (CDC, 2011). In a study published by CDC (2011), the cost of caring for a child with T1DM was reported to be six times higher than caring for a child without diabetes. The researchers determined that the cost of caring for a child with diabetes was as high as $9,061 annually as compared to $1,468 annually for caring for a child the same age without diabetes (CDC, 2011). Researchers showed that the cost of insulin therapy alone was more than $9,333 annually compared to the cost of caring for a child with diabetes who doesn’t require insulin therapy at $5,683 annually (CDC, 2011). The risk associated with uncontrolled diabetes management further adds to the increased cost of caring for a child that has diabetes. Dietary restrictions, more frequent visits to a physcian, the cost of specialists, and the cost of prescriptions contribute to the finacial burden associated with diabetes treatment and care for a child with diabetes. The ADA ,reports that the cost of diagnosed diabetes was $245 billion in 2013. This cost includes $176 billion associated with indirect costs, and another $69 billion in loss of productivity; representing a 41% increase over five years (ADA , 2015).

As the incidence of diabetes among the population increases, the cost of caring for a patient with diabetes is likely to rise to $336 billion by the year 2034 (Huang, Basu, O’Grady, & Capretta, 2009). Patients with T1DM experience the disease and its effects for a longer period of time than those diagnosed with diabetes at an earlier age; therefore, the cost assosciated with managing the disease reflects a life long expenditure (Tao, Pietropaolo, Atkinson, Schatz, &

Taylor, 2010). The long range effects of managing and controlling T1DM overlap into other areas of the patient's life; contributing to significant indirect costs as well (Tao et al., 2010). Patients with type 1 diabetes are likely to experience a more difficult time with employment or school (Milton, Holland, & Whitehead, 2006). The CDC (2011), estimates the medical costs for a person with diabetes to be as high as $15,000 annually, further supporting the claim that diabetes care poses a signifanct financial burden on families. Additionally, financial obstacles can prevent children from receiving necessary health care.

While there is an abundance of research that examines the influence of the parents of children with T1DM on maintaining glycemic control, there is little research that investigates the impact of T1DM in children on the African American family. Challenges in parenting children with T1DM are well documented in the research. Researchers such as Nurmi and Stieber-Roger (2012), explored the challenges of parenting children with T1DM using a qualitative study design. In that study, the reseachers explained the changes that having children with T1DM bring about to the parent-child relationship. The researchers pointed out that the presence of diabetes in children brings a new dynamic to parenting that influences the way parents respond to the needs of their T1DM child. There is little literature that focusses on the specific needs of parenting African American children with T1DM and the ability of the African American family to meet the needs of the T1DM child. In fact, in a study conducted by Lipman et al. (2012), the authors found that African American children with T1DM were at a clear disadvantage compared European American children living with T1DM in relation to their metabolic control and clinical care. The researchers noted that there are few studies that focus on the racial differences in the priorities of the family as they relate to the management of the children with diabetes. This research study focused on the influence of the parents and families of African American children with T1DM on managing their disease and the obstacles associated with diabetes managment. Distinguishing the factors that affect African American families in managing T1DM in their children can contribute to positive social change by identifying measures that can be utilized by this specific demographic in their efforts to develop tools to further aid in diabetes management of African-American children with T1DM. The purpose of this study was to examine the experiences of African American parents with managing T1DM in their children. I looked for common themes among parents that present as barriers to maintaning their children's glycemic control. The first chapter of this dissertation introduces the topic and need for the study. In this chapter I describe the background, purpose for the research, the research problem, and the nature of the study, and provide the research and interview questions, definitions used, assumptions, scope and deliminations, limitations, and significance of the.

Background

Diabetes is the result of the body's inability to produce sufficient insulin in the body, resulting in above-average glucose levels (CDC, 2011). Specifically, type 1 diabetes is the result of the body's inability to produce insulin in the pancreas (ADA, 2011). The difference between type 1diabetes and type 2 diabetes is that the pancreas does not produce any insulin in type 1 diabetes, and insulin production is decreased or inhibited in type 2 diabetes (ADA, 2011). The body requires energy in order to perform its daily functions and insulin is the hormone required to change sugar, starches, and other foods into daily energy (ADA, 2011); therefore, when insulin production is interrupted, diabetes results. The American Diabetes Association (ADA) defines normal glucose levels as 70 mg/dl-130mg/dl, and less than 180mg/dl two hours after beginning to eat a meal (ADA, 2011). In order to monitor long-term diabetes control, physicians often use the hemoglobin A1C test results to determine a patient's average glucose levels over a period of time. The hemoglobin A1C test result can provide the physician with a glimpse of diabetes management over 2-3 months (Mayo Clinic, 2011). A normal hemoglobin A1C level is defined as less than 6 %. A hemogloin A1C level of greater than 7% indicates poor diabetes control, thus increasing the risk of diabetes related complications (Mayo Clinic, 2011).

In 2010, diabetes was the seventh leading cause of death in the United States (CDC, 2011). According to the CDC (2011), diabetes decreases the life expectancy and doubles a person's risk of dying suddenly compared to a person of similiar characteristics without diabetes. Uncontrolled diabetes leads to a number of life threatening complications, and uncontrolled juvenile diabetes subjects a child to an extended period of disease status. Poor diabetes control can result in blindness, kidney failure, heart disease, and feet and leg amputations (CDC, 2011). Treating T1DM presents unique lifestyle altering requirements; necesitating commitment to maintain recommended glucose levels to prevent future complications. Successfully managing childhood diabetes requires a rigorous and complex treatment regimen demanding that the child adhere to strict diet, exercise, and glucose monitoring regimen that requires extensive time and effort eveyr day to maintain healthy glucose levels (ADA, 2015). In order to reduce the risk of diabetes related complications, it is imperative that children with diabetes maintain tight metabolic control of glucose levels by working closely with a health care provider specifically trained to work with endocrine diseases (Hatherly et al., 2011). Receiving care from a specialist has been demonstrated to result in better metabolic control while reducing the risk of diabetes related complications (Zgibor et al., 2000). However, the number of ethnic minority children being diagnosed with type 1 diabetes and showing up at outpatient pediatric clinics continues to grow. This group is reported to be at risk for unsatisfactory metabolic control, according to Vanelli et al., (2012). In a study conducted by Vanelli et al., the researchers set out to investigate the barriers that prevent minority children with type 1 diabetes from achieving equivalent glucose target ranges as their nonethnic minority peers with type 1 diabetes.

Support from the family unit is crucial in maintaining good metabolic control for an adolescent with diabetes. There are many factors that inflence glucose management in children, since they are heavily dependent on parents for meals and life activities. Seiffge-Krenke, Laursen, Dickson, & Hartl (2013), discuss the importance of the interaction between T1DM adolescents and their families in dealing with the various challenges presented in T1DM treatment. The authors note the challenges as dietary restrictions, exercising regularly, frequent monitoring of blood glucose levels, and daily insulin administration. Youth with diabetes require the support of parents and siblings with regard to their dietary requirments and diabetes management needs until they are able to follow this regimen independently (Wennick, Lundqvist, & Hallstrom, 2009). The special needs of a child with diabetes can affect family dynamics, including how the family members interact with each other as a family unit. Maintaining a regimented schedule is not only stressful for the child with diabetes but for parents and siblings as well. The growing autonomy of adolescents brings on new demands by adolescents with T1DM as they struggle for more independence in all aspects of their lives (Seiffge-Krenke, Laursen, Dickson, & Hartl, 2013). Some teens with T1DM feel that their parents have lost sight of them as individuals because they focus so much time and effort on their diabetes maintenance. In order to continue to maintain good glycemic control, parents of children with T1DM must attempt to balance their sense of responsibility for managing their child’s diabetes with allowing the youth more freedom to make appropriate choices. Parents must renegotiate their relationship with their child in order to fight against the potential of declining metabolic control (Seiffge-Krenke et al., 2013). In a study conducted by Carroll and

Marrero (2006), parents of children with diabetes express fear of turning over diabetes management to the affected child. Managing and understanding the necessary dietary and lifestyle adjustments requires a balance for both child and parent (Carroll and Marrero, 2006). Diabetes education is an important aspect of maintaining a healthy diabetes regimen. The entire family unit of a child with diabetes reportedly tends to feel some responsbility for the care and management of the diabetes regimen for that child (Wennick et al., 2009). Understanding the signs and symptoms of abnormal blood glucose levels empowers all parties with the knowledge of how to recognize diabetes metabolic reactions and how to make the appropriate adjustments. Wennick et al.,(2009) found that the parents of children with diabetes experience more stress from worrying about whether the affected child is following the prescribed regimen appropriately when the child is not in the presence or control of the parent than parents of other adolescent children.

Adherence to diabetes-specific diet and lifestyle modifications have been shown to have a significant impact on the life of the child and family due to high levels of behavior regulations that are a part of the everyday life of a juvenile with diabetes (Wennick et al., 2009). Juvenile diabetes not only adds stress to the affected child, it is stressful for the entire family. The basic lack of understanding about diabetes in children adds to the stress and frustration often felt by a child with diabetes. Children interviewed by Wennick et al., (2009), confided that they found it easier to simply ask to be excused to the restroom to treat low blood sugar, than to explain to others what was occurring and its implications. Trying to explain to others what it means to have diabetes, particularly in childhood, is tiresome and stressful, as noted by one study participant (Wennick et al., 2009). Many chidren have feelings of anxiety when it is time to take their insulin or treat low blood sugars; they fear being looked at as different or thought to be receiving special treatment. Knowledge of this phenomenon adds further stress to parents as they attempt to determine when or if they should inform other parents, teachers, or friends of the child's medical condition. Determining whom to confide in concerning the child's condition and medical needs is often an agonizing decision for parents. Great care must be taken to ensure that proper medical attention can be given to a child when needed, without making the child feel restricted . Ensuring that there are informed individuals with children when they are away from home and family will allow parents to feel more at ease when the child is away. However, Wennick et al., (2009) note that it is best to allow the child to decide with whom they feel comfortable enough to share this information.

Following a diabetes diet grows increasingly more difficult as children grow, make their own decisions, and struggle to not be singled out as "different." Maintaining the child's privacy while ensuring the parents' confidence that those who may need to help are willing and knowledgable adds to the stress of living with type 1 diabetes. Milton, Holland, Whitehead, 2006 conducted a review of studies about the consequences of type 1 diabetes and found that children with T1DM were more likely to miss school because of diabetes related difficulties than other children. When children have to be absent from school due to illnesses, a parent may also miss work. These factors, among others, have been relatively ignored by the research literature. Few studies have been published in recent years that examine the multiple barriers to good diabetes control and management among juveniles with type 1 diabetes. However, the historical perspectives of this issue show that there is still a need to address the barriers and subsequent consequenes of uncontrolled diabetes. The consequences of long term poor metabolic control are costly and detrimental to the development and quality of life of those with childhood onset T1DM. In 2006, Whittermore, Jaser, Guo, & Grey (2010) conducted research aimed at updating the childhood adaptation model to chronic illness: diabetes mellitus developed in 1991 by Grey & Thurber (1991). Whittermore et al.'s findings indicate that there are multiple characteristics that contribute to the level of adaptation to type 1 diabetes in youth. Among the most common characteristics noted are age, socioeconomic status, family support, social competence, and physiological and psychosocial aspects (Whittermore et al., 2010). These characteristics are noted as having the greatest impact on a child's adaptation to the lifestyle modifications necessary to live with diabetes.

In a study conducted by Patterson, Dahlquist, Gyurus, Anders, Soltesz (2009) among European children, the researchers predicted that the incidence of type 1 diabetes among children younger than 5 years will double from 2005-2020. The CDC (2011) reported a growing incidence of Type 1 diabetes of 19 per 100,000 cases among young people age 10-19 years. Adapting to a lifestyle with a chronic illness is both complex and tedious. The complications of diabetes have long-lasting effects; therefore, it is important to understand the obstacles that prevent youth from adhering to a diabetes regimen. The focus of this research study is to elicit the lived experiences of African American families with a child diagnosed with T1DM. Although studies about the lived experiences of families with youth diagnosed with T1DM exist, few studies have been conducted within the last ten years. Additionally, none have been found to focus primarily on the African American family and their lived experiences with children diagnosed with T1DM. For example, Wennick & Hallstrom (2007) conducted a hermeneutic phenomenological study in 2004 among 11 primarily Swedish speaking family members of children age 9-14 one year after the children had been diagnosed with T1DM. Telephone interviews were conducted with these families and they were asked to describe family life with their T1DM youth. A study conducted in 2013 by Spencer, Cooper, and Milton (2013), interviewed 20 youth with T1DM and 27 of their parents in North West England. The aim of this study was to explore the experiences of both the adolescents and their parents of living with T1DM from an interpretive phenomenological perspective. Despite the fact that African American youth are reported to have the second highest incidence (1 in 438) of T1DM among youth in the United States, few studies have been conducted that focus on the lived experiences of this particular demographic (CDC, 2013).

A convenience sample was gathered by soliciting participants from social media forums, using an open invitation to individuals that met specific criteria. The invitation to participate was posted on social media websites, message boards, and online forums designed for parents of African American youth diagnosed with T1DM for at least six months. Based on their responses to the initial solicitation invitation, parents were qualified as to their suitability to participate in this research study. Interviews were conducted via telephone for the convenience of the participants.

This study contributed to an understanding necessary to provide psychosocial support and education to these patients and their families. A phenomenological design can provide valuable insight into attitudes and behaviors among African American youth diagnosed with T1DM. The primary clinical purpose of this phenomenological research study was to assist the caregiver in determining an applicable plan for their T1DM youth's life experiences (Karlsson, Arman, &Wikblad, 2008).

In a study conducted by Sweenie, Mackey, and Streisand (2014), the researchers identified a lack of diversity in research of T1DM children and recognized that more diverse research could add to the generalizability of research related to the parent-child relationship of these children. This research study addressed this gap in the research by examining specific diabetes management variables from the African American parent's point of view. This assists in idenitfying postive attributes in managing diabetes and adds to the diversity of research on African American children with T1DM, leading to positive social change. As children with T1DM get older and progress towards the teenage years, being able to address the factors that impact the parent-child relationship is crucial (Sweenie, Mackey, and Streisand, 2014). Issues such as the child's behavior, the parent's behavior, and the stresses of parenting could all be addressed through clinical interventions and provide an avenue to preventing deterioration in T1DM management (Sweenie, Mackey, and Streisand, 2014). Therefore, I aimed to expand the research on African American children with T1DM and how best to address the family needs for diabetes management. Additionally, this study helped to fill the gap in literature identified by Sweenie, Mackey, and Streisand, (2014).

Problem Statement

Healthcare cost associated with diabetes care places an economic burden on families as well as on the national healthcare system. In 2010, diabetes care expenditures accounted for 11.6% of total healthcare expenditures worldwide (Zhang et al., 2009). It is estimated that by the year 2030, the cost to prevent and treat diabetes and its associated complications will reach as high as $490 billion dollars worldwide (Zhang et al., 2009). During adolescent years, glycemic levels tend to be less controlled in patients with type 1 diabetes; however, as these patients age, glycemic management tends to improve (Palta & LeCaire, 2009). Understanding the barriers that prevent adherence to the diabetes self-management regimen would allow new programs, educational tools, and tips to be developed that could promote adherence to diabetes control measures in African American youth.

Maintaining normal or near-normal blood glucose levels, particularly in very young children, requires watchfulness by the individual and their family. Research has shown that strict and rigid glucose management helps prevent or delay diabetes complications in later years (Palta & LeCaire, 2009). Adhering to a diabetes regimen is particularly difficult for young children, resulting in more frequent hospitalizations and medical complications among children less than 8 years old (Borus, J., Laffel, L., 2010). When children are very young, the parents most often closely supervise diabetes management; this requires that not only the parents but also the entire family be educated in diabetes management and that they understand the needs of the T1DM child as the child matures. Close parental participation with managing type 1 diabetes in youth, particularly in the younger years, is important and promotes positive disease adaptation to a diabetes regimen (Streisand, Swift, Wickman, Chen, & Holmes, 2005) in African American youth.

The general problem was that, although mortality associated with type 1 diabetes has declined from the 1950s due to advancements in technology, the risk of premature mortality as a result of a prolonged, uncontrolled disease state is still of great concern (Nishimura et al., 2001). The specific problem was that factors need to be explored as reported by African American families with adolescent patients with T1DM in order to manage and control T1DM in youth. Determining and finding solutions to the barriers to diabetes management that are confronted by patient's families and that may interfere with adherence to diabetes control recommendations are crucial for young patients with diabetes. This research study explored the lived experiences of the African American family in the Eastern region of the United States with youth who had been diagnosed with T1DM for at least six months using a qualitative methodology and phenomenological design.

The responsibility of caring for a child with a chronic health condition such as T1DM is stressful for the caregivers. However, parental involvement in the daily management of T1DM in youth is important in maintaining glycemic control (Oskouie, Mehrdad, & Ebrahimi, 2013). Parents must utilize various events or conditions to serve as their coping mechanisms to manage and cope with problems that are likely to arise from this disease (Oskouie, Mehrdad, & Ebrahimi, 2013). There have been numerous studies that focus on the parents' ability to cope with their children's diabetes that include all phases of coping and strategies to cope; however, few have addressed the special circumstances and needs of African American parents. In study conducted by Lipman et al., (2012), the researchers noted a scarcity of research that addresses the goals and priorities of diabetes care from the perspectives of those from racially diverse backgrounds. This research study addressed this gap in the current literature and attempted to provide valuable information in identifying the differences in perspectives of African American families in order to develop more diabetes programs that are sensitive to the cultural differences.

Purpose

The effects of uncontrolled diabetes can range from depression to more severe symptoms, including death. The CDC (2011) lists diabetes as the seventh most common cause of death in the United States. The purpose of this research study was to examine the lived experiences of African American parents of children with T1DM; and to determine whether or not there were common threads among participant families that support or hinder control and management of diabetes regimen compliance among African American youth with type 1 diabetes. Identifying the barriers to diabetes management can provide public health practitioners the tools necessary to develop educational and intervention programs to increase diabetes compliance among African American youth. This qualitative phenomenological study relied on participation and perceptions from the parents of African American children identified as having T1DM. The research study relied upon interviews with individual African American parents to further expand upon the lived experiences of the families in managing their T1DM children’s condition. From this data source common themes of the lived experiences were identified, and data analysis focused on the commonalities among family dynamics. This research study was designed to satisfy gaps in the research literature that had not provided sufficient focus on African American families and youth with T1DM. Identifying the barriers to diabetes management may provide public health practitioners the tools necessary to develop educational and intervention programs to increase diabetes regimen compliance. There have been few research studies that examine the effects of long-term uncontrolled diabetes among African American youth and provide solutions to issues of noncompliance to prescribed diabetes regimens. Additionally, even fewer studies address the specific challenges faced by African-American families in effectively managing their T1DM child.

The American Diabetes Association describes the benefits of diabetes control as crucial to preventing or slowing the progression of serious diabetes complications such as diabetic eye disease, kidney disease, nerve disease, diabetic retinopathy, and cardiovascular disease (ADA, 2011). Tight control is characterized by glucose levels near a normal range of nondiabetic levels of 70-130 mg/dl for glucose and less than 6 percent for HbA1C (ADA, 2011). The Diabetes Control and Complications Trial (DCCT) conducted from 1983 to 1993 was one of the first to explore the relationship of long-term glucose control and diabetes complications (National Diabetes Information Clearing House, 2011). The trial, using 1,441 volunteers age 13 to 39 diagnosed with Type 1 diabetes for at least one year but not more than 15 years, compared the effects of average control of blood glucose levels versus intensive control on diabetes complications (National Diabetes Information Clearing House, 2011). The researchers concluded that maintaining blood glucose levels as close to normal as possible results in decreasing the start and development of eye, kidney, and nerve damage in patients with type 1 diabetes. This study addressed the specific challenges of African American parents in providing care and guidance to their T1DM child in order to effectively manage their diabetes and symptoms.

Research Questions

Although strides have been made in glucose self- monitoring equipment and diabetes medications, adherence to diabetes management regimens continues to be a problem among children and adolescents with T1DM. Poor glycemic control leads to increased diabetes complications that over time can be associated with premature mortality. DCCT (1993), although conducted nearly twenty years ago, first revealed the link of poor glycemic control with increased diabetes complications. The factors that prevent patients with T1DM from obtaining and maintaining optimal glucose control are multiple. This qualitative phenomenological research study included semistructured interview questions that explored the barriers to diabetes management related to the family dynamics among families with adolescent African American patients with T1DM. The overarching question was: How do the lived experiences of parents of children with T1DM affect the successful management and control of T1DM among African American youth age 5-17 years old?

This study was guided by the following research objectives:

1. to use storytelling or narratives, gathered through a social media solicitation and telephone interviews to garner information regarding attitudes, knowledge, behaviors, and barriers that factor in preventing African-American youth with T1DM from maintaining glycemic control as detailed by their diabetes care provider;

2. to use feedback from the study to disseminate knowledge related to the successful management of diabetes to participants; and
3. to use storytelling or narratives to determine the underlying concerns of African American parents of youth with T1DM in accurately managing and controlling the disease based on their knowledge, beliefs, and behaviors.

The following questions were designed to answer the overarching research question: How do the lived experiences of parents of children with T1DM affect the successful management and control of T1DM among African American youth age 5-17 years old? The questions are outlined in categories that tested key constructs of the health belief model (HBM).

Perceived Barriers

1. What are the costs associated with managing your child's diabetes?
    a. How do those costs affect the way you manage your child's diabetes?
2. How is your everyday life affected by your child's diabetes?
3. What are the circumstances that interfere with your child's diabetes control?

Perceived Seriousness

4. How do you know if your child is experiencing a diabetes emergency (what are the symptoms)?
5. How do other family members react when your child is having a diabetes emergency?
6. How do you prepare others (friends, family, teachers, etc.) to recognize or handle a diabetes emergency?
7. How do you feel that your child's diabetes will impact their future goals and aspirations?

Perceived Susceptibility

8. How do you ensure that you follow your child's diabetes regimen (blood glucose testing, medication decisions, dietary needs, activities, etc)?
9. What do you feel are the limitations placed on your child due to their diabetes?
10. How much of your time do you feel is required to manage your child's diabetes?

Conceptual Framework

Despite advancements made in diabetes care and management, few patients with diabetes achieve optimal glycemic control (Wallace & Matthews, 2000); which leads to poor health outcomes and increased likelihood of developing complications. The cost of treating diabetes-related complications continues to increase, placing a burden on the health care system. There has been little research conducted on the lived experiences of families with adolescent T1DM patients, and on the barriers that prevent children and youth from complying with recommended and prescribed diabetes management regimens. McLeroy, Bibeau, Steckler & Glanz, (1988), assert that there must be a focus on changing the individual factors that influence health behaviors as well as a change in social and environmental factors that are beyond the control of the individual and may contribute to health outcomes. In order to increase diabetes regimen compliance, it is important to understand the factors that prevent optimal compliance.

The conceptual framework used in this study was the HBM. The premise of the HBM is that health behaviors are determined by personal beliefs and perceptions about a disease and the frequency of occurrences (Hochbaum, 1958). The four main perceptions include (a) perceived susceptibility, (b) perceived barriers, (c) perceived benefits, and (d) perceived seriousness. Coupled with the newly-added (a) cues to action, (b) motivating factors, and (c) self-efficacy (Hayden, 2009, Chapter 4), the perceptions assist in explaining the difficulties experienced by patients with type 1 diabetes in avoiding diabetes complications. Numerous factors determine compliance to the diabetes regimen; however, this research explored the lived experiences of African American families attempting to manage and control the effects of T1DM in adolescent patients. Few studies have been conducted that examine the health beliefs of the parents and caregivers of youth with T1DM. Compared to European American youth and Hispanic youth, African American youth have consistently been in greater jeopardy of poor glycemic control (Valenzuela, La Greca, Hsin, Taylor, & Delamater, 2011). Some of the disparities in glycemic control between racial and ethnic minorities can be explained by physiological differences. Valenzuela, La Greca, Hsin, Taylor, & Delamater (2011) further express that there are family factors that contribute to poor glycemic control. The authors purport that factors such as socioeconomic status, family structure, and parenting style can all be influential in glycemic control. The research questions are designed to elicit responses that address some of the key constructs of the HBM. The questions have been categorized so that there are questions that tested three of the seven perceptions of the HBM; the perceived barriers, perceived seriousness, and perceived susceptibility of T1DM were evaluated using the responses to the interview question.

Nature of the Study

This qualitative phenomenological research explored the lived experiences of African American families with an adolescent that has been diagnosed with T1DM for at least six months and lives in the Eastern region of the United States. African American parents were solicited using an online forum entitled “Children with Diabetes” and solicited from other social media sites (Facebook, Twitter, LinkedIn). Twenty parents were selected as a convenience sample from the replies to the request for participants. van Kaam’s interpretation of phenomenological research stated that 10 to 50 descriptions of a target experience is sufficient to distinguish the essential and ample elements of the research (Moustakas, 1994). The subjects were interviewed by telephone and asked to participate in open-ended questions designed to elicit the lived experience and lifestyle management issues related to family dynamics and diabetes management of adolescent T1DM patients. Participants who couldn’t be reached by telephone were asked to respond to the questions by completing an e-mail questionnaire.

Using the modified van Kaam method, this research study explored, explained, and experientially examined human behavior (Moustakas, 1994). Additionally, I analyzed the participants’ “lived” experiences (Phillips-Pula, Strunk, & Pickler, 2011). The modified van Kaam approach is a phenomenological tool that can be used to assist in investigating and interpreting the family’s experience living with a family member who has been diagnosed with T1DM (Moustakas, 1994). According to Finlay (2013), using research grounded in phenomenology displays a shift in methodological standards of using quantitative methods. Using a phenomenological research design allows the researcher to study the phenomenon being investigated on an individualized basis from those individuals who have encountered the experiences (Loidolt, 2009). Phenomenology is unique in its approach in that it emphasizes the importance of the individual study participant’s experiences. In a phenomenological study design, the researcher focuses on understanding the participants’ personal experiences, motivations, and actions. Loidolt (2009) explains that the content of a phenomenological research study is determined by the participants’ orientation and the research objective.

Phenomenological research seeks to explain the experiences of the participants by having them describe their encounters. These experiences drive how people are understood and the meaning of their experiences. Knaack (1984) explained the characteristics of phenomenology as previously described by Giorgi (1975) as the lived experience, to include both the experiences and behavior of a person: the experience within the world as lived, which includes perceptions and actions; and the descriptive style of those actions. Other characteristics include (a) how the situation is expressed from the viewpoint of those being studied; the lived situations being the basic units of research, assuming that the meanings given to the lived situation by the subjects and the researcher are the significant factors; (b) a historical, temporal, and personal biographical emphasis of the studied phenomenon, resulting in formulating the key terms after you have contacted the data; and (c) explicitly setting the presuppositions of the investigator. Lastly, the researchers attempt to search for meaning in the experiences of the participants are a vital characteristic of phenomenology. Keen (1975) explains the strategies used by the researcher in order to understand the phenomena to be studied in a phenomenological study. Phenomenological reduction is used by researchers, wherein researchers set aside their presuppositions and preconceptions about the phenomena so that they can better and more fully understand the phenomena being studied as it relates to the participants. Imaginative variation is another technique used by researchers to imagine the appearance of a phenomenon and determine its meaning. The last technique is interpretation, whereby the researcher articulates the meanings of the phenomenon that has emerged from the research.

This study uses a qualitative methodology with a phenomenological design to summarize the perceptions of managing youth with type 1 diabetes as experienced by the parents of the youth (Loidolt, 2009). Using the phenomenological approach, I was able to conduct an intense investigation of the experiences of African American parents of adolescent children with T1DM. The modified van Kaam method has been shown to be a suitable approach for capturing the broad range of inquiry necessary to achieve the desired objectives (Moustakas, 1994). A qualitative research method was more appropriate than a quantitative method for this study because the participants described their views and insights relating to the management of T1DM in their adolescent child. Mason (2010) and O’Reilly and Parker (2013) have conducted studies whose findings indicate that a 20 person participation pool is an appropriate sample size to establish a sufficient account perception while providing a practical sample size to study the experiences of participants of a phenomenological research study. The literature corroborates that there are very few qualitative studies that involve African American family members of youth with diabetes, specifically the parents of children with T1DMt. Boice (1998) stated that in order to fully understand the impact of chronic illnesses on family members, researchers would need to engage in more interviews and rely less on questionnaires.

Operational Definitions

This study aimed to elicit the lived experiences common among African American families with adolescent patients affected by T1DM and to identify the determinants that impede or delay the adaptation of a prescribed diabetes regimen that has been shown to reduce diabetes complications due to consistently high blood glucose readings. For the purpose of this study, the following definitions are provided:

Type 1 diabetes: a chronic condition in which the pancreas produces little or no insulin; once known as juvenile or insulin dependent diabetes (Mayo Clinic, 2011).

HbA1C: Blood test used to measure the average glucose value over 2-3 months (Mayo Clinic, 2011).

Diabetes Mellitus: a condition characterized by hyperglycemia resulting from the body's inability to use blood glucose for energy (American Diabetes Association, 2012).

Diabetic Retinopathy: diabetic eye disease; damage to the small blood vessels in the retina. Loss of vision may result (American Diabetes Association, 2012).

*Complications: h*armful effects of diabetes such as damage to the eyes, heart, blood vessels, nervous system, teeth and gums, feet and skin, or kidneys (American Diabetes Association, 2012).

Blood Glucose Monitoring: checking blood glucose level on a regular basis in order to manage diabetes (American Diabetes Association, 2012)

Insulin: a protein pancreatic hormone secreted by the beta cells of the islets of Langerhans that is essential especially for the metabolism of carbohydrates and the regulation of glucose levels in the blood (Merriam Webster, 2012).

Tight Control: a method of intensive diabetes self-management that involves keeping blood glucose levels as close as possible to normal without causing severe or frequent episodes of low blood sugar (Diabetes Self-Management, 2012).

Diabetic Ketoacidosis: a complication of diabetes that occurs when your body produces very high levels of blood acids called ketones.

Youth: For the purposes of this study, youth is defined as a child between the ages of 5 and 17 years old.

Assumptions

In this study I focused on evaluating the multifaceted issues faced by African-American parents raising children with T1DM. Attending to the needs of children with T1DM is challenging for parents and families in the best of circumstances; adding ethnic/cultural considerations to those challenges can make managing diabetes in children becomes even more daunting. I have made assumptions regarding the study and study design. As the confidentiality of the participant responses was expressed to the participants, I assumed that participants answered the interview questions honestly and openly. Furthermore, I assumed that the lived experiences, as reported by the participants, were adequate to corroborate the objectives of this research study. Additionally, I assumed that the phenomenological information collected from the interview responses provided information about the perceptions of diabetes management among African American parents of children with T1DM.

Scope and Delimitations of the Study

The goal of this study was to identify the lived experiences of African American families with adolescent patients affected by issues of diabetes management and control. Because this study focused on African American families, it provided valuable information on a population less studied. I provided the perceived barriers to management affecting African American parents in managing T1DM in their children. The research plan included African American parents of children who had been diagnosed with T1DM for at least six months. There were no educational or income requirements. In this study the construct variables of the HBM were examined, including perceived barriers, perceived benefits, and perceived susceptibility and motivating factors.

Delimitations assist in narrowing the scope of a research study by discovering those variables that can be excluded from the research study (Yang & Kenagy, 2011). The delimitations in this research study included: (a) the use of a convenience sample with a small number of participants, (b) a specific location range, (c) a targeted population of African American parents of children with T1DM, and (d) the selected problem. Generalization to other minority populations in other regions of the United States and outside of the United States should be made with caution because health factors and socioeconomic statuses can differ greatly.

Additionally, the small sample size and the inclusion of only African Americans raised issues of diversity. The inclusion of other minority populations could have added to the generalizability of the study; however, I chose not to include other minority populations at this time because of the difficulty identifying potential minority participants. Telephone interviews or e-mail inquiries were conducted with African American parents of T1DM children; therefore, the questions were subject to interpretation by the parents and the responses were subject to interpretation by the researcher.

Limitations of the Study

Investigating a phenomenon necessitates a thorough analysis of the data and that the participant data is able to be synthesized. Therefore, Neuman (2006) explains that all research has limitations because the research is unable to be exhaustive. The limitations of this study include: (a) convenience sampling, (b) the number of African American parents with children diagnosed with T1DM that can be identified and are willing to participate in the study, (c) the years of experience managing T1DM, and (d) the number of African American parents of children diagnosed with T1DM who are members of the online communities from which participants were solicited. The perceptions, experiences, and knowledge of each participant managing T1DM from those chosen from the online outlet versus those solicited from other sources, such as endocrinology practices, is a limitation of this research study resulting in selection bias. Although not limited to just mothers, the participants were all mothers of children with T1DM. This research could have benefitted from the perceptions, experiences, and knowledge of fathers as well. The exclusion of biracial families, the absence of consideration for noncustodial versus custodial parenting, and geographical location were all limitations to this research study. Additionally, I also have T1DM; therefore, there is the possibility that researcher bias could have been introduced due to my personal experiences.

Significance of the Study

This study may be used to fill the research gap identified in the problem statement by examining the lived experiences of African American parents of children with T1DM and the barriers to managing their child's diabetes. The results of this study can provide valuable insight into the barriers, beliefs, and experiences of African American parents of T1DM children in order to more effectively design educational programs and support systems that address the needs of this population.

Summary

Preventing chronic complications associated with uncontrolled diabetes is crucial in all types of diabetes but particularly in patients with T1DM. Chronic complications arise from long periods of elevated blood sugars (Cleveland Clinic, 2015); thus, making the patient with T1DM more susceptible to complications by virtue of the duration of the disease. The majority of illness and death associated with Type 1 diabetes is due to those chronic complications of the disease including heart disease, peripheral vascular disease, stroke, diabetic retinopathy, cataracts, glaucoma, neuropathy, and nephropathy (Cleveland Clinic, 2015.). DCCT (1993) researchers showed that by following the diabetes regimen of proper diet, exercise, and frequent monitoring glucose levels, tight glycemic control could be obtained. Research has shown that tight glycemic control prevents or reduces the likelihood of developing chronic diabetes complications (DCCT, 1993). Type 1 diabetes self-management is convoluted and rigorous, particularly for young children and adolescents. Maintaining tight glucose control for young people with type 1 diabetes, presents challenges for both the family and the health care system (Sullivan-Bolyai, Knafl, Deatrick, & Grey, 2003).

Despite advancements made in diabetes care and management, few patients with diabetes achieve optimal glycemic control (Wallace & Matthews, 2000), which leads to poor health outcomes and increased likelihood of developing complications. The cost of treating diabetes-related complications continues to increase, placing a burden on the healthcare system (ADA, 2011). There has been little research conducted on the lived experiences of families with adolescent patients and on the barriers that prevent children and youth from complying with recommended and prescribed diabetes management regimens. McLeroy, Bibeau, Steckler, Glanz,(1988), assert that there must be a focus on changing the individual factors that influence health behaviors as well as a change in social and environmental factors that are beyond the control of the individual and may contribute to health outcomes. In order to increase diabetes regimen compliance, it is important to understand the things that stand in the way of optimal compliance.

The effects of uncontrolled diabetes can range from depression to more severe symptoms including death. The CDC (2011) lists diabetes as the seventh most common cause of death in the United States. The purpose of this study was to elicit the lived experience of families with youth diagnosed with T1DM to determine the dynamics and outcomes of such experiences. This research was designed to examine the barriers associated with family support that could affect adherence to the recommended diabetes regimen and maintenance of tight glycemic control among African American T1DM youth. Identifying the barriers to control and management may provide public health practitioners with the tools necessary to develop educational and intervention programs to increase diabetes regimen compliance. There have been few research studies in recent years that examine the effects of long-term poor glycemic control among African American youth and provide solutions to issues of noncompliance to prescribed diabetes regimens.

This qualitative phenomenological research explored the lived experiences of families with youth who have been diagnosed with T1DM for at least six months. Twenty African American parents were solicited using an online forum entitled “Children with Diabetes” and from other social media sites (Facebook, Twitter, LinkedIn). The subjects were interviewed by telephone or through e-mail with open-ended questions designed to elicit the lived experience and lifestyle management issues related to family dynamics and diabetes management of T1DM youth patients.

Chapter 2: Literature Review

Introduction

The control and management of T1DM is a complex process that requires constant monitoring and attention to details. The medical costs associated with caring for a person with diabetes was estimated at $6.9 billion yearly by Tao et al. (2010). Understanding the burden of type 1 diabetes on an adolescent is crucial to identifying the causes of diabetes mismanagement among young patients with diabetes. Adhering to the strict diabetes regimen is far more difficult for younger patients. The growing pains of becoming a young adult coupled with the burden of managing their diabetes regimen often overwhelm young patients. The mental and physical strain can take its toll on youth and spiral into noncompliance of the necessary diabetes regimen; particularly as the patients approach adolescence. Coffen (2009) conducted a study that examined the magnitude of the diabetes regimen for youth. Coffen asserted that the list of knowledge and behaviors that must be learned and adopted by patients with diabetes totals more than 600 different items. The enormity of learning 600 plus items is alone a daunting task, but more important is children with diabetes being able to incorporate the steps into their daily lives (Coffen, 2009).

During the past decade, researchers, psychologists, and therapists have contributed to a growing body of literature focused on adolescent onset of type 1 diabetes. Two issues have been the primary focus of these discussions: psychosocial issues, especially patient self-efficacy, and family dynamics among those caring for an adolescent who is attempting to manage the disease. Skinner, John, & Hampson (2002) among others have led this discussion, establishing a framework for understanding the issues that must be dealt with by such patients and the possible trends to watch for in coming years as research boundaries are extended. This chapter discusses these two issues, the ways in which researchers have treated these topics, and the parameters that impinge upon the potential participants in the current research study. This chapter addresses these issues through the lens of the embedded research question and subsequent interview questions within this phenomenological study: How do African-American families with adolescent patients affected by type 1 diabetes, as defined by HbA1c, experience the issues of management and control of the disease? What commonly-reported issues of lived experience are present among African American families attempting to manage and control T1DM in youth?

Literature Search Strategy

In order to find literature on type 1 diabetes in African American youth and its management by parents, the following key words and phrases were used both separately and in combination: *diabetes, type 1 diabetes, control, management, parents, African-American, Health Belief Model, children, youth, phenomenological study, qualitative study, complications of diabetes, psychological effects of type 1 diabetes in youth, type 1 diabetes nutrition, type 1 diabetes management,* and *type 1 diabetes self-management*. The key electronic databases used were Medline, PubMed, Scopus, Cochrane Library, Google Scholar, and CINAHL in order to detect as many sources as possible regarding this dissertation topic. The most recent articles (2009 to present) received the most focus, and some textbooks (e.g., Creswell, 2009 and Moustakas, 1994) were reviewed to support methodological design in this study.

Theoretical Foundation

Determining the reasons for noncompliance of the prescribed diabetes regimen for youth can be linked to the perceived attitudes and beliefs about developing future diabetes complications. The HBM can help explain the lack of compliance with the diabetes regimen regardless of the patient’s education and awareness of the severity of diabetes complications. The

HBM is designed to focus on two aspects of a person’s perceived health status and health behavior: threat perception and behavioral evaluation (Sheeran & Abraham, 1996). This framework helps in understanding adherence or reluctance to follow prescribed health directives (Janz & Becker, 1984). Adolescents don’t perceive the same threats of illness and severity that adults may, nor do they have the same fears and perceived benefits of illness. Using the HBM, Patino, Sanchez, Eidson, & Delamater (2005) determined that there are five factors that influence those with T1DM to follow the prescribed diabetes regimen. These factors include susceptibility, severity, benefits, barriers, and cues. That is, a patient’s perception of their vulnerabilities and likelihood of developing complications; the severity of the condition; the effectiveness of the prescribed regimen; the cost and convenience of following the regimen; and the signs that prompt action are factors that influence the successful adherence to the necessary diabetes health behaviors.

There have been very few studies to appraise the relevance of the HBM to diabetes care among youth (Patino et al., 2005). However, the conceptual framework of the HBM has made way for the development of the Diabetes Health Belief Questionnaire (DHBQ), developed by Brownlee-Duffeck et al. (1987). This tool has been used to assess health beliefs of persons with diabetes as they pertain to the HBM and treatment compliance. Additionally, Brownlee-Duffeck et al. investigated how metabolic control and regimen adherence in adults and adolescents with diabetes mellitus are influenced by their health beliefs. The HBM was found to be a major contributor to the 52% variance detected in factors associated with self-reported adherence in the younger participants. Bond, Aiken, & Somerville (1992) repeated the Brownlee-Duffeck et al. study using younger adolescents with diabetes, with a mean age of approximately 14 years. This study linked poor metabolic control with high threats and cues: threats to diabetes and cues to take action on their diabetes. Using patients with diabetes of a much younger age (6-9 years), Charron-Prochownik, Becker, Brown, Liang, & Bennett (1993) further solidified that even at this young age, health beliefs were linked to regimen compliance and glycemic control.

Being compliant to prescribed health regimens is often determined by the individual's perception of their health risk related to their health condition. The cognitive skills of younger children can make it difficult for them to assess the risk of regimen noncompliance, particularly long term complications. Anticipating long term consequences requires a more advanced thinking process that adolescents and younger children may not possess, thus making it more difficult for youth to conceptualize the dangers and risk of not following through on their treatment regimen (Patino et al., 2005). Skinner, Hampson, & Fife-Schaw (2002), observed that adolescents' appreciation for the required treatment regimen was greatly affected by their short-term frame of reference and their inability to think farther than the present situation. Additionally, individuals will perceive their personal risk of developing adverse health effects as significantly less than their peers with the same condition (Frey, Guthrie, Loveland-Cherry, Park, & Foster, 1997).

Patino et al. (2005) examined the health beliefs and relationship to glycemic control among minority adolescents related to diabetes management. The authors developed the Diabetes-Related Health Problems (DRHP), a new measure of diabetes-specific risk perceptions, in order to assess the way that T1DM youth perceive their risk of developing complications. This allowed the authors to compare the perceptions of susceptibility to short-term and long-term complications in addition to examining the difference between the probability of complication taking place among the individual or another person with diabetes. This measure was used along with the DHBQ and the Self Care Inventory (SCI). The results reported by the authors showed that in general, adolescent patients believe that they only suffer from short-term risk, and conversely assign long-term risk to others rather than to themselves.

Using the DHBQ, the DRHP questionnaires, and the SCI, seventy-four youth were recruited to participate in a self-report survey about regimen adherence and glucose control. The DHBQ uses the constructs of the HBM as its framework and has 27 items of perceived thinking for assessment. The researchers further reported in concert with Glasgow and Anderson (1995) that particularly among adolescent patients, regimen adherence is low, is not unitary, and tends to vary widely across demographic profiles. By looking at two factors assessed by the DHBQ (Janz & Becker, 1984) that include threat perception or perceived susceptibility to increases in risk from disease, as well as barriers to retention of behavioral patterns post-inception of disease, Patino et al (2005) discovered low correlation between self-perception and actual risk occurrence.

Both type 1 and type 2 diabetes are expected to continue escalating over the next 50 years, contributing to an increase in the public health burden of the disease and an even greater financial cost of care (Butler, Kaiser, Johnson, Besse, & Horswell, 2010). While there has been some evidence to support that maintaining optimal glucose control decreases the probability of developing diabetes related complications, poor glycemic management continues to be the number one cause of developing subsequent diabetes related complications (DCCT, 1993). Increased blood glucose levels are associated with a variety of consequential complications placing the person with diabetes at greater risk for premature death as compared to the general population (Secrest, Becker, Kelsey, LaPorte, & Orchard, 2010). Despite advances in blood glucose monitoring technologies, premature death from diabetes complications continues to be one of the leading causes of mortality for persons with diabetes (Shankar, Klein, Klein, & Moss, 2007). Balancing diabetes regimens with daily activities is challenging for children with diabetes and their families. However, maintaining this balance is crucial to ensure a good quality of life, avoiding future diabetes complications (Hirose, Beverly, & Weinger, 2012).

Studies performed in Assuit-Egypt found that children with type 1 diabetes who have poor glycemic control tend to be older children and adolescents (Mohammad, Farghaly, Metwalley, Monazea, & Abd El-Hafeez, 2012). The authors discovered that as patients increased in age, they were less likely to be in good metabolic control of their diabetes. Of 415 children with type 1 diabetes participating in the study, 54.2% of them were in good glycemic control; while 45.8% of the participants were in poor glycemic control (Mohammad et al., 2012). Poor glycemic control was found among 67.9% of the children 15 years and older compared to only 25.6% of the children 10 years old and younger (Mohammad, Farghaly, Metwalley, Monazea, & Abd El-Hafeez, 2012).

While it is important to maintain good glycemic control, some researchers warn that concentrating solely on glycemic control leaves patients with T1DM at risk for other cardiovascular risk factors being ignored (Mann, Woodward, & Muntner, 2010). Therefore, it is important that physicians not only closely monitor their patient’s glucose management; they should also make certain that they closely monitor additional risk factors as well (Mann et al., 2010). Among the numerous obstacles which may inhibit good glycemic control among children and adolescents with diabetes, identifying those obstacles and developing interventions to assist in conquering them requires further research.

Maintaining ideal glucose control requires strict observance of specific diabetes regimen constraints including daily insulin injections, repeated glucose monitoring, nutritional requirements, and physical activity in order to decrease the risk of both short-term and long-term diabetes complications (Patino et al., 2005). Despite advances in the treatment of type 1 diabetes, there continue to be factors that prevent optimal glucose control among young patients with diabetes. Anderson and McKay (2011) outlined barriers to good glycemic control for children and adolescents with type 1 and type 2 diabetes in an attempt to design interventions for the specified barriers. The most critical and most frequently identified barriers to glycemic control are deep-rooted and broad spectrum. These factors—developmental, psychological, family, transition to adult care, SES/cultural, and nutrition (Anderson & McKay, 2011)—are complex dynamics that require a delicate balancing act for the patient and their family. As many patients experience more than one of these roadblocks at a time, making diabetes management more stressful, this chapter discusses the importance of glycemic management and the impact that these factors and others have on maintaining good glycemic control in order to prevent long-term diabetes complications.

Psychosocial Issues in Adolescent Patients

The developmental stages for adolescents are, among the human tasks of psychosocial evolution, perhaps the most challenging of all growth stages (McIntosh, Helms, & Smyth, 2003). Christie and Viner (2005) explain some of the tasks presented to adolescents during this important stage: psychological, biological, and social demands present task such as abstract thinking; self still seen as “bullet proof”; growing verbal abilities; identification of law with morality; start of fervent ideology (religious, political); emotional separation from parents; strong peer identification; increased health risk (smoking, alcohol, etc); sexual identification; peer group identification, among many others. Consequently, the jumble of demands on an adolescent, who may then suddenly be faced with the additional seemingly formidable task of managing a chronic disease as type 2 diabetes mellitus (T2DM), can be overwhelming (Christie & Viner, 2005). They catalog the evolutionary tasks as including:

- Challenging authority
- Taking risks
- Experimenting with drugs, alcohol, and sex
- Challenging the moral and social structure of society
- Demanding rights and taking responsibility for self and others
- Seeking spiritual paths (organized or cult religions)
- Getting a job
- Changing schools and educational environment
- Developing relationships
- Understanding sexuality
- Renegotiating rules at home

These stages are all subsumed under the developmental umbrella in Piagetian terms of moving from the concrete developmental stage to the abstract developmental stage; not all adolescents succeed in that transfer (Neinstein, 2002). Skinner, Hampson, and Fife-Schaw (2002) point out that the onset of a disease such as Type I Diabetes during adolescence generates concern for self-efficacy in disease management that extends beyond the individual and includes the entire family. These concerns also overlap into the social arena which the adolescent occupies: school trips, social gatherings, timing of medication, administration of other related personal needs, as well as mundane tasks such as sports participation, routine bathroom care, food and nutrition, all related to the burden of proper glycemic control. The trajectory of the research literature through the past decade points out that self-efficacy of patient management revolves around appropriate support, both intra-family as well as in terms of social capital. Skinner, John and Hampson (2000) derive from that research and posit that personality, self-efficacy, and personal beliefs about the disease as well as about self-management are supported by interpersonal and social relationships, which are especially dynamic among adolescents. In a longitudinal study which Skinner published in 2000, evidence of social support is the strongest predictor of success in disease management (Skinner, John, and Hampson, 2000). Additionally, Pendley, Kasmen, Miller, Donze, Swenson and Reeves (2002) contribute to that position, reporting that peer and family support mechanisms follow roughly the trajectories suggested by Skinner et al. Edgar and Skinner (2003) suggest that simplifying the nomenclature to ‘coping’ with a disease, is also a function of emotional well-being, further indicating that as youth develop the capacity of the patient is in part impinged by personal development and psychological well-being. A longitudinal study initiated by Helgeson, Siminerio, Escobar, and Becker (2009) indicates that self-efficacy and skill developed in metabolic control by adolescents can be predicted by presence of social capital indicators, chiefly, family support and non-family interpersonal relationships. Wilburn and Smith (2009) corroborate that assertion, and suggest that adolescent relationships tend to influence the self-efficacy of the patient along similar lines as general adolescent interpersonal relationships and the development of concomitant personality issues. Borus and Laffel (2010) conclude along with Wilburn and Smith (2009) that similarities in adolescent personality development can be traced along the lines necessitated by patient adherence and disease management regimens; as the adolescent matures into a personality development trajectory, the adolescent patient likewise gains disease management maturity as well.

Achieving optimal glycemic control affects every facet of life; therefore, making diabetes management more difficult for the young person with diabetes. The rigidly structured requirements are stressful for adults and even more so for children. Children with insulin dependent diabetes find themselves faced with major lifestyle changes, coupled with the fear of more serious diabetes complications, the patient can be left feeling overwhelmed and afraid (Jacobson, 1996). Patients with long term uncontrolled glucose has been found to have a greater prevalence of associated psychiatric illness (Jacobson, 1996). Among the most common of these related psychiatric illnesses are depression and eating disorders (Jacobson, 1996). The stress of managing a chronic disease can often lead to adverse health outcomes. Delamater, Patino-Fernandez, Smith, & Bubb (2012), have found stress to contribute significantly to the lack of metabolic control among persons with type 1 diabetes. Although significant impacts to glycemic control due to stress have not been widely found, there has been one study to show the effects of stress on blood glucose levels in adults. A study conducted by Gonder-Frederick, Carter, Cox, and Clarke in 1990 provides a reliable representation of the negative effects of stress on blood glucose control in adults; however, no such study of comparable observations among adolescents have been performed (Delamater et al., 2012). When children were asked to complete questionnaires about recent stressful situations and their glycemic control, an association between the stressful experience and poor glycemic control was found in two pediatric studies; stress and sugar control in children with insulin-dependent diabetes mellitus and life-stress and diabetes control in children and adolescents with insulin-dependent diabetes in 1981 and 1986 respectively (Delamater et al., 2012). These studies confirmed the need for advancements in measuring the effects of psychological stress on glycemic control in youth with TIDM.

Delamater et al. (2012) conducted a study intended to evaluate the various aspects of diabetes-related stress for youth with TIDM. The health related effects of stress has been proven to cause an increase in adverse health outcomes, including but not limited to; a weakened immune system (Kiecolt-Glaser, Mcguire, Robles, & Glaser, 2002) and decreased psychosocial functions (Kanner, Feldman, Weinberger, & Ford, 1987). Originally developed in the late 1980s, Delameter et al. developed the "Diabetes Stress Questionnaire" to evaluate the level of stress in older children and adolescents with TIDM (2012). Today the questionnaire has been updated and is now called the "Diabetes Stress Questionnaire for Youth". This tool was used in this study, not only to measure diabetes related stress but its correlation demographically and clinically as well. Four hundred-seventeen youth, with TIDM were recruited from three university diabetes outpatient clinics in various demographic locations, to complete the 65-question questionnaire. There were 211 males and 206 female participants ranging in age from 9.3-20.0 years, and having a mean duration of diabetes of 5.4±3.7 years (0.1 to 16.6 yrs.). Approximately 75.1% of the participants were Caucasian and 22.8% were minorities, with the majority of those being African American. The remaining 2.1% of the participants did not list their race; therefore, race was unknown for those participants. The socioeconomic status score was determined using the Four-factor Index of Social Status (Hollingshead, 1975). With scores ranging from 8 to 66, the participant population was determined to be primarily middle class. The parent's socioeconomic status was determined by using the highest educational grade completed and occupational status. The glycosylated hemoglobin (HbA1c), taken at the completion of the questionnaire, was used to evaluate glycemic control. The 65 question DSQY was used to collect self-reported responses about possible stressful situations experienced by youth. A four point scale was used to rate the responses to the questionnaire. Using the principal components in factor analysis, factors were sub-classed into an eight-factor categorization scale with questions about stresses to include, peer stress, parental stress, diet stresses, and self- care stresses, to name a few. When evaluating the effects of clinical and demographic variables on the identified stress, age and social-economic status were found to be impertinent to the DSQY factor scores. What was found to be significantly related to the DSQY factor scores was diabetes duration. When greater diabetes duration was noted, there was an increase in stress related to hyper and hypo-glycemic occurrences. Conversely, there was less stress noted about dietary factors, as diabetes duration increased. Additionally, instances of higher $HbA1_C$ were found to increase stress levels related to parental and dietary concerns. There were differences in stress related to gender and race/ethnicity for certain stress factors. Females reported greater stress about issues such as, distress-worry, adverse interpersonal effects, hyper and hypo-glycemia, and diet. Where ethnic minorities reported that distress-worry, and peer stress were of greatest concern to them.

The necessity of this study rests in the importance of managing diabetes related stress in older youth in order to obtain optimal glycemic control. It is long-standing knowledge that diabetes greatly affects those affected psychologically and negatively, in the form of depression, anxiety, and even eating disorders (Rubin & Peyrot, 1992). Factors that increase stress in youth may diminish or increase as diabetes duration increases. Researchers note that factors such as stress related to hyper and hypo-glycemia tend to increase with diabetes duration. The increase in stress could be due to a greater awareness of the adverse outcome of hyper or hypo-glycemia and there is a more rapid identification of the symptoms and understanding of the urgency in treating these symptoms. Additionally, youth with diabetes and greater disease longevity reported less feelings of stress pertaining to dietary issues. This could be due to the familiarity with diabetes dietary requirements; regardless to whether or not the recommendations are followed, there is a greater understanding and awareness so there is less stress over certain situations. Psychological studies measuring stress and anxiety between girls and boys have shown that females report greater stress than males. In this study, that phenomenon was shown to be true as well. Of the eight DSQY subscales used in this study, five revealed females experiencing greater stress than males.

The findings from this study offer compelling support for the use of the DSQY as a tool to access anxiety and stress, in older children, in relationship to type 1 diabetes self- management and its impact on their daily lives. Additionally, how youth respond and cope with stress is often closely related to glycemic control and adherence to diabetes regimen (Delamater & Cox, 1994). This study also revealed that there was greater distress, worry, and peer stress reported by ethnic minority groups. Ethnic minority groups are associated with lower SES. Additionally, youth in lower SES have other factors that affect their behavior and subsequently their management of chronic diseases. Lowry, Kann, Collins, & Kolbe, identify housing, nutrition, social support, access to healthcare, and life style behaviors as factors that fluctuate according to social class (1996). These factors individually or collectively can also be the cause of distress and worry for youth. Difficulty obtaining healthcare, lifestyle, and access to and understanding of good nutrition can all be sources of worry and distress for youth and adolescents, particularly.

Youth and adolescents with TIDM develop psychiatric, eating disorder, and substance abuse problems more frequently than their peers who do not have diabetes, at a rate of 10-20%, 8-30%, and 25-50% respectively, according to Kakleas, Kandyla, Karayianni and Karavanaki (2009). These issues are associated with declining glycemic control caused by non-conformity to diabetes management requirements. The complex requirements of diabetes management place a large responsibility on youth and adolescents, requiring consistent and constant glucose monitoring to maintain good glucose control. Managing these requirements place pressure on the youth and can be extremely stressful to deal with. Kakleas et al., conducted a review of the factors that contribute to the stress and development of psychosocial problems among adolescents and focused on specific goals in managing and preventing negative diabetes outcomes (2009). During adolescence, youth go through numerous attempts to define their identity and establish autonomy. This time of physiological and psychological change, coupled with the burden of diabetes management, is often when diabetes control begins to decline for adolescents (Kakleas et al., 2009). It is important to recognize that the psychosocial and behavior issues that occur during adolescence contribute significantly to the decline in glucose control due to failure to comply with the necessary diabetes regimen. An additional factor that is important to diabetes control during adolescence is better education and subsequent understanding of diabetes and its rigid requirements (Kakleas et al., 2009).

What is described as disturbed eating behaviors are of concern for many persons with type 1 diabetes. Bulimia nervosa (BN), binge-eating disorders (BED), and anorexia nervosa (AN), are among the most commonly observed eating disorders, in adolescents with TIDM. Behaviors such as purging, excessive exercise, self-induced vomiting, using laxatives, and omitting insulin are all behaviors associated with incongruously trying to inhibit weight gain (Takii et al., 2002). Youth with TIDM have a higher incidence of eating disorders than those without T1DM in the same age group; with an incidence ranging from 8% to 30% for patients with type 1 diabetes, and 1% to 4% for those without diabetes (Kakleas et al., 2009). Among adolescents with a mean age of 11.8 years, there is an incidence of eating disorders of 37.9% in girls and 15.9% in boys, with a greater persistence amid girls (Colton, Olmsted, Daneman, Rydall, & Rodin, 2007). During early adolescence, children with T1DM are monitored more closely by parents; thus, the frequency of eating disorders is considerably less (17%) amongst girls aged 9-13 years, with no instances of anorexia or bulimia detected in this age group of adolescent girls (Colton, Olmsted, Daneman, Rydall, & Rodin, 2007). Eating disorders lead to poor glycemic control; thus increasing the possibility of long-term diabetes complications, as noted by Rydall et al (1997). Diabetes complications such as retinopathy, was seen more often among adolescents with T1DM and a reported 5 year duration of eating disorders, at a rate of 86%, compared to a 24% of T1DM patients with comparable disease longevity and no reported eating abnormalities (Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997). Eating disorders can severely affect diabetes control, lending way for severe diabetes complications long range.

Kakleas et al., identify psychiatric and behavioral disorders, among adolescents, as a major contributing factor to poor glycemic control and a common phenomenon during adolescence (2009). Learning to cope with the demands of a rigorous diabetes regimen takes its toll on adolescents; leading to psychiatric and behavioral disorders. These disorders often manifest as unhappiness, isolation, and angst in the lives of youth with T1DM, contributing to more than 30% of youth and adolescents with T1DM developing clinical adjustment disorders within three months post-diagnosis (Kakleas et al., 2009). Depression, anxiety, and behavioral disorders are observed most often within the first ten years of T1DM diagnosis in more than 1/3 of children with diabetes. Failure to adapt completely to diabetes regimens in the beginning can result in children developing psychiatric difficulties later in life; as demonstrated in longitudinal studies of the 10-year period and lifetime prevalence rates assessing psychiatric conditions in juveniles with T1DM. At a rate of 47% and 37% respectively for developing psychiatric disorders, these numbers represent a two to three times higher prevalence of psychiatric disorders in juveniles with type 1 diabetes, than found in the general community of the same age group

(Kakleas et al., 2009). Kakleas et al., cited studies conducted by Goldston et al., (1997) and Hood et al., (2006) that identified depression in 10-26% of youth with T1DM, along with increased incidence of anxiety and disruptive behavior conditions on an average of 20% for each (2009). These conditions, often accompanied by other conditions, include approximately 60% of those with a diagnosed psychiatric condition to have more than one psychiatric condition (Northam, Matthews, Anderson, Cameron, & Werther, 2005).

While managing the day-to-day requirements of diabetes is a daunting task, there are predisposing circumstances that contribute to psychological and psychiatric conditions in juvenile persons with type 1 diabetes. Contributing factors related to gender, diabetes control and management, and family dynamics surrounding diabetes care and management are all contributors to feelings of depression and anxiety by youth with T1DM (Dantzer et al., 2003, Hood et al., 2006). Depression, anxiety, and low self-esteem are primarily seen in female patients, resulting in poor glucose monitoring, which in turn results in poor glycemic control and a greater feeling of depression (Hood et al., 2006). The pressures of adolescence contribute to the difficulty that youth with type 1 diabetes have with obtaining optimal glucose control. The pressure to fit in, struggles for greater independence, and the turbulence of self-discovery increase the likelihood of feelings of depression. The burden of navigating adolescence and feelings of depression, coupled with additional emotional conditions result in instances of uncontrolled glucose levels. Instances of frequent uncontrolled glucose lead to recurrent periods of hospital admission due to non-compliance with the prescribed diabetes regimen, to include diet, exercise, and medications (Kakleas et al., 2009). The desire to fit in or have a particular body type leads adolescents to make rash decisions to achieve certain goals. Adolescents with T1DM have an increased prevalence of eating disorders, insulin omission, and lack of self-care;

all linked to depression and anxiety, consequently resulting in diminished glucose control. Feelings of depression and anxiety often lead to thoughts of suicide among adolescents. Although only a few adolescents with diabetes have attempted suicide, they have reported more frequent thoughts of suicide than their peers who do not have diabetes have. The challenges of adolescent discoveries and the regimented routine of good diabetes management can leave adolescents with type 1 diabetes feeling helpless and hopeless. Adolescents with T1DM that suffer from depression have a tenfold increase in thoughts of suicide and suicide attempts than their peers who do not have diabetes.

Depression among this group is found to be extreme in nature and complex to treat, often with reoccurring symptoms, particularly for those children with longer duration of diabetes (Kakleas et al., 2009). Although youth with a longer duration of T1DM think about suicide, it is thought of no more than other youth their age entertain the idea of suicide. The difference in the ideas of suicide among youth with T1DM and other youth is that patient with diabetes have the option of using their diabetes medications to carry out the attempts. Adolescents with T1DM tend to misuse their diabetes medications to attempt suicide; often not administering insulin as directed or by administering too much insulin, causing severe hypoglycemia (Dahlquist & Kallen, 2005). Adolescent females are noted to have the highest incidence of secret self-administration of insulin as a form of attempted suicide; frequently resulting from difficulties in their home life and fearing impending diabetes complications. In order to detect early indications of psychological disorders, it is important for youth with diabetes to receive early screening for these possible conditions and receive treatment if necessary, to prevent possible attempts of suicide or harm to oneself. Paying close attention to youth with T1DM can be crucial in helping the child receive early interventions for diabetes coping and management, in addition to psychiatric treatment. These youth present to hospitals frequently with diabetic ketoacidosis and coincidentally are known to have extreme conflict with parents and authority. Younger patients with diabetes may have feelings of depression and anxiety, where adolescents may experience feelings of anger and rage that could result in poor diabetes management without proper psychological and psychiatric interventions (Kakleas et al., 2009).

Learning to cope with the requirements of diabetes management can leave youth frustrated and confused, resulting in a high rate of non-compliance to the prescribed diabetes regimen. Among the issues that plague youth with T1DM most often are maintaining glycemic control, coping with stress and anxiety related to diabetes management, and family issues surrounding independence in diabetes care. Children presumed to be at high risk for non-compliance of prescribed diabetes treatment often display emotional and behavioral attitudes that lead to more risk taking and failure to perform diabetes treatment required functions. Studies have shown that seeking psychiatric and psychological treatment for young patients with diabetes, early in their disease state, is the most beneficial to the child. Research has shown that measures such as behavioral contracts, enhancing problem solving skills, and regular therapy are effective with increasing compliance and easing the patient's anxiety, fears, and frustrations with the rigid diabetes management requirements. Further studies have shown that teaching social and coping skills, coupled with therapy to manage stress and anxiety improve treatment compliance tremendously (Kakleas et al., 2009). A longitudinal study conducted by Luyckx, Seiffge-Lrenke, & Hampson (2010), explores the correlation between glucose management and internal and external psychological symptoms among youth with type 1 diabetes. The demanding and complex regimen required to maintain good, stable glucose control places youth with diabetes at greater risk for developing psychological symptoms of depression, anxiety, eating disorders, and other self-destructive behaviors that can result in poor glucose management outcomes. The Luyckx et al., (2010) longitudinal study examined 109 adolescent patients with type 1 diabetes during a four wave-four year study to investigate how the stresses of everyday life with diabetes is managed by youth. Recognizing that the pressures of maintaining good glycemic control, coupled with the stresses of adolescent issues (peer pressure, developmental changes, social changes) make managing diabetes extremely stressful for youth, this study seeks to demonstrate how psychological symptoms of depression, anxiety, coping, and glycemic control influence each other over a four- year span. Taking into consideration the differences in glycemic control between boys and girls, forty- seven percent of the participants chosen from the Longitudinal Study on Juvenile Diabetes were females recruited from two German cities, among 17 pediatric outpatient health care services. At the beginning of the study, the mean participant age was 14; representative of the early years of youth, ranging in age from 12-16 years old. The average disease span was five years and the only relevance to other study variables was the positive association between disease length and hemoglobin A1C values, and the age of onset of psychological symptoms at the beginning of the study. Participants, along with their parents, were asked to complete questionnaires with their personal information to include, age, sex, disease duration, and parental educational level. Using the Coping across Situations Questionnaire (Seiffge-Krenke, Stemmler 2003), the participants were surveyed about their coping strategies in response to seven potential stressors, as outlined in the questionnaire. Further, internal and external behaviors were assessed using the Youth Self-Report (YSR) (Achenbach & Edelbrock, 1987). Consisting of 102 items for internalizing and externalizing symptoms, the YSR rates the symptoms from not true to very often true in order to calculate the overall symptomatology score. The participants of this study had low to moderate symptomatology, over the various time- periods that were outside of the clinical range. The patient's hemoglobin A1C was assessed at each period of the study. The patients completed questionnaires at each visit to their physician and the answers to the questionnaires were compared to the hemoglobin A1C results, to compare glucose control against reported stressors.

Retention of participants is a common concern with multi-year studies; however, this study had an 83% retention and completion rate. Over the four-year period, active coping was found to increase over time; resulting in a decrease in psychological symptoms. Even though active coping increased over time, indicating that youth found positive ways to deal with their stressors, glycemic control worsened over time. The worsening glycemic control indicated in this study has been seen in several studies of youth with diabetes. This phenomenon can be associated with hormonal changes that are common during puberty and adolescence, peer pressure, and a decrease in parental involvement with diabetes management (Helgeson, Siminerio, Escobar, & Becker, 2009). This longitudinal study illustrates the detrimental cyclic effect of psychological issues on glucose management and control. The deterioration of glucose control during time- period 1, led to an amplification of withdrawal behavior during time-period 2, and an increase of psychological symptoms at time-period 3. Lastly, an increase in psychological symptoms during time-period 3 was found to be a major contributing factor to lessening glucose control during time-period 4.

Difficulties maintaining glucose control and developing coping skills early in adolescence, lead to difficulties with glycemic control later in life. Adolescents could benefit from interventions that focus on improving coping skills and managing psychological issues, in order to improve glucose management during the difficult period of adolescence. Conversely, patients demonstrating active coping skills during time- period 1, showed better glycemic control during time- period 2. In turn, active coping at time-period 3 was increased; resulting in increased glycemic control at time-period 4. This reciprocal relationship between active coping and improved glycemic control suggests that learning active coping skills could be a major benefit to maintaining glycemic control and good glycemic control results in less use of withdrawal coping. This phenomenon, however, seems less associated with active coping skills to stress and anxiety and more associated with other factors associated with adolescent development, as children get older. As children enter adolescence, they are less dependent on their parents to help manage their diabetes and are more in charge of their own diabetes management. The effects of psychological symptoms (internalizing and externalizing symptoms) have impacts on glycemic control during adolescent and early adulthood, more than in younger persons with diabetes. Perhaps because these components adversely affect self-image, and adolescents are more affected by peer pressure, hormonal changes, and the need for independence, the authors suggests regularly screening for maladaptive coping behaviors and supply education and training in using active coping, focused directly on the problems, in order to maintain optimal glucose control. Although this study showed indications of a relationship between coping behaviors and glycemic control, it did not demonstrate the differences in glycemic control across sexes. There was also no delineation of diabetes duration about participants. Additionally, the small sample size may have added to some of the limitations in distinguishing factor impact. Nevertheless, it is clear that there is an association between psychological issues and successful management of glucose among youth with diabetes.

Studies show that depression and anxiety are cause for major concern among teenagers; however, teenagers with type 1 diabetes have a risk two times greater of developing depression and anxiety than teens that do not have diabetes (Hood et al., 2006). These disorders and other psychological disorders make diabetes management and proper glucose monitoring a much more complicated situation; often resulting in poor glycemic control (Herzer & Hood, 2010). A study conducted by Hilliard, Herzer, Dolan, & Hood, (2011), suggested that adolescents with type 1 diabetes can greatly benefit from systematic psychological screening for depression, anxiety, and other psychological issues, and the outcome of their glucose management can be predicted one year later by using the results of the screening. Using one hundred-fifty adolescents, 13-18 years old, with type 1 diabetes, who were fluent in English, and didn’t have any other severe psychiatric, neurocognitive, or chronic medical condition, the authors attempted to demonstrate that higher depression and anxiety screener scores would be an indication of increased HbA1C, infrequent glucose monitoring, and decrease in quality of life among adolescents, one year later. The increased risk and subsequent consequences of psychological issues among persons with type 1 diabetes has led to a universal recommendation to routinely screen adolescents for psychological disorders (United States Preventive Services Task Force, 2009). Although the need for psychological screening is evident, pediatric diabetes centers have been slow to adopt this practice. That study aimed to investigate how psychological screening could be a predictor of diabetes management and glycemic control after one year. Additionally, quality of life (QOL) was examined as an added outcome measure. During the baseline visit, adolescents completed two self-report psychological screeners, the Children’s Depression Inventory (CDI) and the State-Trait Anxiety Inventory for Children (STAIC). Consisting of 27 items about depression, adolescents were asked to rate their level of depression. With possible scores from 0-54, a clinical cutoff of 13 was used to determine levels of depression; scores higher than the cut-off were indicative of more depressive symptoms (Kovacs, 2003). Additionally, the state scale of the State-Trait Anxiety Inventory for Children (STAIC) was administered at baseline. This scale consists of 20 items, with a possible range of 0-40, and higher scores are indicative of anxiety that is more recent; however, the scale does not have a clinical cut-off (Spielberger, Edwards, Montuori, & Lushene, 1973). Medical records were reviewed at baseline and 12 months to obtain glucose readings downloaded from the patient's glucose meter. Using HbA1C test results obtained at each physician visit conducted over the 12 month period, glycemic control was assessed. Parents used three subscales of the PedsQL™ Diabetes Module (Varni, Seid, & Kurtin, 2001) to rate the quality of life of their children at each time point. Using treatment adherence, treatment barriers, and worry, parents used 14 diabetes specific behaviors and emotions as rating criteria. Scores were found to be linear, where higher scores were indications of a better quality of life. Additionally, background information was collected from parents using a questionnaire. Parents were asked about the patient's gender, age, ethnicity, caregiver marital status and educational level, duration of diabetes, insulin delivery method, and insurance coverage. Contact with mental health providers during the study period was tabulated by using electronic medical records to review past confirmed appointments.

Statistical analyses were performed, conducting a baseline correlation between screening tests and health behaviors and their associated outcomes. Multivariate models were tested to establish the capability of the scores to predict the outcomes, one year later. Additionally, the CDI score and the STAIC-state score were each entered as predictors in both models. Included in the analysis were all measured demographics and medical covariates were included to account for the theoretical association between adolescent demographics and the medical context and diabetes outcomes being investigated (Hilliard et al., 2011). The utilization of clinical cut-offs as opposed to using continuous raw scores as screening tools was evaluated by running each model an additional time, utilizing fictitious coded CDI and STAIC-state scores as predictors. Medical characteristics, demographics, screener scores, and diabetes outcomes from the baseline to the 12-month follow-up period revealed a decrease in blood glucose monitoring among all participants; however, there was no significant change in the quality of life and HbA1c levels amongst participants. Additionally, baseline CDI and STAIC-state scores were correlated with HbA1c, blood glucose monitoring, and quality of life to determine a direct relationship. Higher CDI and STAIC-state scores were associated with increased HbA1c values, decreased frequency of blood glucose monitoring, and a decrease in quality of life; as reported by parents.

As demonstrated in this study, psychological screener scores have been closely associated with diabetic behaviors and outcomes monitored over a one-year period. As predicted, higher levels of anxiety and stress in adolescents resulted in increased HbA1c values. Additionally, depression was predicted and proven an indicator of less frequent blood glucose monitoring and a decreased quality of life over time. Symptoms of depression and anxiety can cause disruptions to the commitment necessary to carry out successful glucose management. As demonstrated in the study, varying degrees of psychological distress; including increased depression and anxiety, and a reported decrease in quality of life, have various correlations with blood glucose monitoring and HbA1c values over a one-year period. These declines in blood glucose monitoring and reporting quality of life coupled with increased HbA1c values can be indicative of a decline in diabetes management and control. The results show the relationship between glucose control and insulin delivery methods. Adolescents whose insulin regimen includes multiple daily injections, as opposed to continuous subcutaneous insulin infusion (insulin pump, etc) reveal a greater risk for inadequate glucose control, resulting in poor outcomes over a 12-month span for all areas observed(Hilliard et al., 2011). Also revealed in this study were the association of parent’s marital status and the long range outcome of the associated factors. There were demographic and medical covariates that could have had an impact on blood glucose monitoring frequency and glycemic control. Adolescents from single parent homes were found to perform blood glucose monitoring less frequently and have higher HbA1c values; however, marital status was not a sole indicator of glycemic control, adherence, or quality of life for the participants.

There were limitations to this study that included the omission of baseline values for blood glucose monitoring frequency, HbA1c, and quality of life assessments in the multivariate model design. Including these variables at baseline would have provided a basis for correlation over time in order to adequately narrow the focus of investigational questions to be used during psychological screenings as predictors of health outcomes. Additionally, the demographic makeup of this study’s participants may lead to difficulty in applying these findings to populations with greater diversity. The need to carefully monitor the frequency of blood glucose monitoring, HbA1c levels, and quality of life in adolescents, using psychological screeners as a tool has demonstrated   a usefulness in diabetes management. The use of screening tools can help clinicians identify psychological issues that may be arising in adolescents; that prevent them from fully complying with prescribed diabetes management requirements.

Family Dynamics in Adolescent Patients

Pendley et al (2002) reported that peer relationships among adolescent patients in certain instances bears a stronger influence than do family relationships and cause or tend to create family dynamics that mitigate disease management. This thread of research was followed also by Lewandowski and Drotar (2007) who reported that families with adolescent patients report having a need for or an expectation for social capital. The presence or absence of social relationships helps to foster, or detract from the quality of family dynamics and the quality of intra-family relationships between parents and children in issues such as glycemic control, nutritional intake, appropriate weight management, self-image and self-efficacy, and self-managed social interaction. Williams, Sharpe, and Mullin (2013) agree that these developmental issues are common among this type of family where an adolescent patient and the needs of the patient seem to have tendencies to drive the agenda for family activity. Ayala and Murphy (2010) suggest that, along with Williams Sharpe and Mullin (2013), family dynamics ultimately bridge the concerns of psychosocial development, personality development, self-efficacy, and disease management, and concerns of parents in managing an adolescent patient grow over time in terms of efficacy, shared roles, maturation of the patient, and beneficial family relationships.

Haugstvedt, Wentzl-Larsen, Rockne, and Graue (2011) report the same dynamics among families with patients up to age 15, wherein general psychosocial development issues consistent with adolescent growth do not differ significantly except along disease management concerns. Likewise, family functioning among families with adolescent patients is a dynamic that adds less-than subtle stressors to parents; parents reported in a study by Moore, Hackworth, Hamilton, Northam, and Cameron, (2013) that family size, family socio-economic status, demographics, geographic location, and family cohesion all tend to migrate toward the central issue of patient management and add stress to the over-riding issue of family functioning. As a result of those family functioning concerns, some families as reported by Rearick, Sullivan-Bolyai, Bova, and Knafl, (2011) have turned to social capital and social networks and extended family relationships for support in appropriate functioning mechanisms.

Better diabetes management has been shown to occur when daily diabetes tasks and activities among adolescents are assisted and monitored by parents (Berg et al., 2013). In a study conducted by Berg et al., (2013), parents' daily involvement in influencing their adolescent in better diabetes management was investigated. Parents attempted to persuade their adolescent to maintain good glycemic control, as well as develop diabetes management skills; however, these efforts may be viewed as interfering by the maturing adolescent. According to Berg et al., (2013), a parent's natural response to the many issues related to blood glucose that occur during the day usually require parents to engage in persuasive behavior to get the adolescent to do more to manage their diabetes. This persuasive strategy could serve as an attempt to correct the problems in diabetes management among adolescents, but could undermine the youths' confidence in their ability to manage their diabetes independently (Berg et al., 2013). This study focused on parental involvement necessary in diabetes management and concentrates on the understanding of how parents use persuasive techniques to guide adolescents in diabetes management. This study examined daily diary entries of 180 adolescents, 176 mothers, and 139 fathers who made daily diary entries for 14 days about daily diabetes related variables. Each parent rated their parental persuasive strategies utilized to maintain daily diabetes management among their adolescent. The results of this study suggested that daily diabetes problems may be reduced with greater parental involvement; however, the persuasive strategies can lead to greater stress and strain on the parents and less self-efficacy for the adolescent with T1DM. Moore et al (2013) suggested that parent perceptions are as strong an indicator of the success in family functioning as any other more concrete symptom of how patient management develops.

Diabetes management and insulin therapy has progressed significantly; however, achieving metabolic success in diabetes management is limited by family conflict, family dysfunction, and problems with parenting (Sabmann, Hair, Danne, & Lange, 2012). The many issues already associated with the various developmental stages of children coupled with the requirements of diabetes management can be exacerbating for parents. Conversely, parents' wellbeing coupled with encouraging family functioning have shown some impact on maintaining better metabolic control among youth (Lange et al., 2011). The specific issues related to parental and family involvement of African American families in managing T1DM in African American youth is an area that has been scarcely investigated. This study seeks to identify the common factors among African American families that may influence diabetes management for T1DM.

Summary

Among adolescent-onset Type I Diabetes, two major components of medical care concern professionals and parents: psychosocial issues and family dynamics (Ayala & Murphy, 2010. Among psychosocial issues, adolescents respond to disease management along trajectories similar to general adolescent personality development, and require appropriate development of interpersonal relationship skills. Among family dynamics, concerns expressed by parents do not differ markedly from those expressed by parents of non-patient families, and seem to develop similarly to general adolescent attitudinal and maturation issues. A body of research developed over the recent two decades points out that social capital, appropriate interpersonal skill development, and individual maturity are among the factors which may mitigate disease management concerns among these patients and their families. The lived experiences of African American families, which was the focus of this qualitative phenomenological research study, could help develop an understanding of the issues which have been suggested by Williams, Sharpe, and Mullin (2013), Pendley et al (2002), and Rearick et al (2011) and identified the specific issues that African American families encounter when managing T1DM in youth. Management issues associated with T1DM patients among African American families has had little research that focuses on this demographic and its specific needs.

Chapter 3 details the qualitative methodology and phenomenological design that I propose to use to identify the lived experiences of African American families in managing T1DM. I used a qualitative methodology in order to investigate the common patterns among African American families and attempted to create an importance and theme from the specific phenomenon presented (Ryan & Bernard, 2003; Moustakas, 1994). Furthermore, the use of phenomenology as a research design is the methodical approach that I used to explore trends and patterns in diabetes management among African American parents. I examined the commonalities in diabetes management that influenced diabetes management in these families. Lastly, through the information gained during this qualitative study, I explored what measures could have been taken to assist this demographic with strategies for better diabetes management among African American youth.

Chapter 3: Research Methods

Introduction

The CDC (2011) lists diabetes as the seventh most common cause of death in the United States. Tight control is needed to reduce premature deaths among diabetes patients. Tight control is characterized by glucose levels near normal range of, nondiabetic levels of 70-130 mg/dl for glucose and less than 6% for HbA1C (ADA, 2011). DCCT, conducted from 1983 to 1993, was one of the first studies to explore the relationship of long-term glucose control and diabetes complications. The trial, using 1,441 volunteers age 13 to 39 with T1DM for at least one year but not more than 15 years, compared the effects of average control of blood glucose levels versus intensive control on diabetes complications (National Diabetes Information Clearing House, 2011). The researchers concluded that maintaining blood glucose levels as close to normal as possible results in decreasing the start and development of eye, kidney, and nerve damage in patients with type 1 diabetes.

This research study was designed to elicit the lived experience reported by African American families with children diagnosed with Type1 Diabetes (T1DM) for at least six months. The purpose of this research study was to evaluate the common threads among participant families that support or hinder control and management of diabetes regimen compliance among youth with type 1 diabetes. The long-term effects of poor diabetes management can lead to adverse health effects of much larger proportions. Ranging from psychological conditions, such as depression, anxiety, and eating disorder, to the loss of limbs and death, maintaining good diabetes control is crucial to preventing or delaying the onset of serious diabetes complications (ADA, 2011). Although there has been research conducted to examine the effects of long-term uncontrolled glucose, few studies have been conducted to examine the cause and effect of non-compliance to recommended diabetes regimens.

This chapter includes the research design and rationale, as well as the role of the researcher. It covers the methodology selected and the instrument used to collect the data. The process and procedures used to recruit participants and collect and analyze data is discussed in this chapter. Additionally, this chapter addresses issues of trustworthiness and ethical research procedures.

Research Design and Rationale

This study was designed to discover the patterns of lived experience reported by African American families with children diagnosed with Type I diabetes for at least six months who live in the Eastern region of the United States. The study utilized a qualitative methodology with a phenomenological design. The main purpose of this qualitative study was to identify specific factors and the relationships amongst those factors as they relate to diabetes control and management among African American youth. This research was conducted using subjects solicited from an online forum entitled “Children with Diabetes” and from online social media (Facebook, Twitter, LinkedIn). Walden University approved this research study and the IRB number is 03-12-15-0118727**.** The study participants consisted of a minimum of 20 African American parents with a child diagnosed with T1DM for at least six months who lived in the Eastern region of the United States. The primary source of data collection was interviews with parents of children diagnosed with T1DM for at least six months. These subjects were asked to participate in open-ended semistructured interviews using questions designed to elicit the lived experience of family dynamics surrounding patient management with T1DM youth. If unavailable by telephone, participants were able to complete the questionnaire via electronic mail.

This study was guided by the following research objectives:

1. to use storytelling or narratives, gathered through a social media solicitation and telephone interviews to garner information regarding attitudes, knowledge, behaviors, and barriers that factor in preventing African-American youth with T1DM from maintaining glycemic control as detailed by their diabetes care provider;
2. to use feedback from the study to disseminate knowledge related to the successful management of diabetes to participants; and
3. to use storytelling or narratives to determine the underlying concerns of African American parents of youth with T1DM in accurately managing and controlling the disease based on their knowledge, beliefs, and behaviors.

The following questions were designed to answer the overarching research question: How do the lived experiences of parents of children with T1DM affect the successful management and control of T1DM among African American youth age 5-17 years old? The questions were outlined in categories that related to the constructs of the HBM.

Perceived Barriers

1. What are the costs associated with managing your child’s diabetes?
    a. How do those costs affect the way you manage your child’s diabetes?
2. How is your everyday life affected by your child’s diabetes?
3. What are the circumstances that interfere with your child’s diabetes management?

Perceived Seriousness

4. How do you know if your child is experiencing a diabetes emergency (what are the symptoms?)
5. How do other family members react when your child is having a diabetes emergency?
6. How do you prepare others (friends, family, teachers, etc.) to recognize or handle a diabetes emergency?
7. How do you feel that your child's diabetes will change their future goals and aspirations?

Perceived Susceptibility

8. How do you ensure that you follow your child's diabetes regimen (blood glucose testing, medication decisions, dietary needs, activities, etc)?
9. What do you feel are the limitations placed on your child due to their diabetes?
10. How much time do you feel is required to manage your child's diabetes?

A phenomenological research design was chosen for this research study. As explained by Husserl, phenomenological research designs explore themes, the meaning of findings, and common experiences in the experiences of study participants. He further emphasized the importance of these qualitative design features (cited from Loidolt, 2009). This research design allowed me to gain a thorough understanding of the nature and cause of difficulties managing T1DM in African American youth related to their lived experiences from the perspective of the parents. Moustakas (1994) explained that phenomenological research studies individuals lived experiences and seeks to synthesize meaning from them. This research study explored commonalities in responses from study participants related to their experiences managing T1DM in their children and their views about these experiences.

There were other research designs considered, including narrative research, which explores ongoing associations between individuals and things. Those who adopt a narrative perspective will consider the past, present, and future to be all intertwined. According to Garud & Giuliani, (2013), in a narrative design, meaning is interfaced between space and time. Grounded theory was another research design that was considered. Gambetti, Graffigna, & Biraghi,(2012) explain that in grounded theory the elements of experience from specific groups and settings are scrutinized by the researcher. Additionally, ethnographic research makes cultural observations, studying the cultural phenomena over an extended period of time (Plinio, Young, & Lavery, 2010). Lastly, the case study research design requires the consideration and examination of multiple situations within a connected system (Dowlatshahi, 2010).

After careful consideration of other research designs, phenomenology was determined to be the most appropriate design to investigate the lived experiences of parents and families of youth with T1DM. The concepts of phenomenology are stressed by Mortari (2008) and include, intention, perception, lived experience, and subjectivity. Faÿ and Riot (2007) profess that phenomenology is the research design most effective for a study seeking to understand work, life, and responsibility; therefore this was the most appropriate design for my study. Moreover, Mortari uses phenomenological designs in the studies of human behavior. He argues that this type of epistemological approach is important to a researcher seeking knowledge and information related to lived experiences.

Role of the Researcher

Qualitative studies are used by researchers mainly to address questions of “how” and “what” in order to direct their research in a specific direction. These studies use general and broad wording in order to help the researcher better understand the experiences of the study participants. In this study, the qualitative research method served as the instrument used for data collection and analysis.

Moustakas (1994) explained the importance of a qualitative researcher’s ability to interpret what they have heard, seen, and understand. In essence, qualitative research relies on the observations and analysis of the researcher. For the purposes of this research study, I used a phenomenological research design to examine the lived experiences of African American parents of youth with T1DM. The analysis of phenomenological data utilized systematic approaches in order to investigate the psychological trends. Included in this type of analysis are data collections, comparing research questions, data analysis, and emphasizing trends and experiences in order to develop themes (Moustakas, 1994). This research methodology allowed me the opportunity to be an intimate part of the data collection and analysis process. Utilizing this research methodology required me to carefully select my study participants in order to maintain objectivity and validity.

In this research study, 20 African-American parents of youth diagnosed with T1DM were interviewed using semistructured telephone interviews or the participants responded to the research questions via electronic mail. The parents were asked 15 questions about their experiences managing their child’s diabetes. The questions were created to explore the perceived barriers, seriousness, and susceptibility of their child’s diabetes. The primary source of data for this research study was parent interviews. Participants for this study were solicited from online forms and social media sites, including Twitter, LinkedIn, and Facebook. They were required to meet specific criteria including living in the eastern region of the United States, being African American, and having a child with diabetes between the ages of 5-17years old, who had been diagnosed with diabetes for at least six months. This is a convenience sampling, and I had no prior relationship with the interviewees. I also had no power relationship with the participants that required consideration or mitigation.

This qualitative phenomenological research study explored the lived experiences of families with children who have had T1DM for at least six months. Twenty volunteer African American parents were solicited using an online forum entitled “Children with Diabetes” and solicited from other social media sites (Facebook, Twitter, LinkedIn). The subjects were interviewed by telephone and participated in open-ended semistructured interview questions designed to elicit their lived experience and lifestyle management issues related to family dynamics and their T1DM youth. If parents were unable to be contacted by telephone, they were able to respond to the interview questions by completing the questions via electronic mail.

Using the modified van Kaam method, this research study explored, explained, and experientially tested human behavior while discovering the participants’ lived experiences (Phillips-Pula et al., 2011). The modified van Kaam approach is a phenomenological tool that can be used to assist in investigating and interpreting the family’s experience living with a family member who has been diagnosed with T1DM. According to Finlay (2013), using research grounded in phenomenology displays a shift in methodological standards of using quantitative methods. Using a phenomenological research design allows the researcher to study the phenomenon being investigated on an individualized basis from those individuals who have encountered the experiences (Loidolt, 2009). Phenomenology is unique in its approach in that it emphasizes the importance of the individual study participant’s experiences. In a phenomenological study design, the researcher focuses on understanding the participants’ personal experiences, motivations, and actions (Loidolt 2009).

This study used a qualitative methodology with a phenomenological design to summarize the perceptions of managing T1DM in youth as experienced by the parents of these children (Loidolt, 2009). Using the phenomenological approach, the researcher was able to conduct an intense investigation into and create an account of the experiences of African American parents of adolescent children with T1DM. The modified van Kaam method has been shown to be a suitable approach for capturing the broad range of inquiry necessary to achieve the desired objective (Moustakas, 1994). A qualitative research method was more suitable than a quantitative method for this research study.

Participant Selection Logic

The target population for this study was African-American parents of youth (ages 5-17) diagnosed with T1DM for at least six months and living in the Eastern region of the United States. A convenience sample of 20 African-American parents was solicited using an online forum entitled Children with Diabetes (http://forums.childrenwithdiabetes.com/forum.php) and other social media sites (Facebook, Twitter, LinkedIn). Invitations to participate in the study were posted on the aforementioned cites (Appendix C). Once an interest in the research was expressed, a brief questionnaire (Appendix A) was emailed to the participants to determine eligibility to participate in the study. Open-ended, semi-structured interview questions, designed to elicit the lived experience and lifestyle management issues related to family dynamics and diabetes management of T1DM youth was administered. .

The participants described his or her views and insights relating to the management of T1DM in their youth. Mason (2010) and O’Reilly and Parker (2013) have all conducted studies whose findings indicate that a 20 person participation pool is an appropriate sample size to establish a sufficient account perception, while providing a practical sample size to study the experiences of participants of a phenomenological research study. Lasch et al. (2010) described this number of participants as adequate to ensure saturation. Furthermore, Lasch et al. recommends that this sample size includes a small collective of participants who have experience in or with the phenomenon. Twenty participants met this criterion. In order to develop a rich description of all of the phenomena occurring within the context of the setting, interviews were the primary data collection source that was used for this study.

Instrumentation

Moustakas,(1994) states that research questions must relate to the study design, in a phenomenological study. Moustaks described data collection as a formal and informal process; however, data collection and analysis are the foundation of a research study. This study utilized semi-structured interviews as the data collection method. Using semi-structured interviews allowed me to obtain a comprehensive understanding of each participant's experiences (Moustakas, 1994). The size of participant pools varies in qualitative phenomenological research studies. This research consisted of 20 participants. This number is adequate in size to ensure that saturation occurs, yet it is small enough to certify that participant's experiences are in line with the phenomenon. As suggested by Lasch, et al. (2010), this sample included a diminutive pool of participants who have experience with the phenomenon. Semi-structured interviews were the primary source of data collection for this research study. The study participants were asked for consent to record the interviews. From the recorded conversations, notes were transcribed to ensure accuracy and understanding. Moustakas (1994) suggests that semi-structured, informal, and open-ended questions be used to provoke responses that are meaningful and in depth in order to further explore certain phenomenon, if needed. Therefore, this research study employed that ideology.

Using a semi-structured interview format required that I was extremely careful not to insert any personal bias into the interviews or interview questions. As recommended by Moustakas (1994) a protocol was developed and followed to aid in recording responses. He further suggests that a table be used to outline the data collection types including, options, advantages, and limitations of the proposed questions. I followed these recommendations for data collection. This process, detailed by Moustakas, assisted with maintaining objectivity and ensured the integrity of the interview process; while fulfilling ethical requirements for this study.

Reliability and quality of data is a significant part of any research study; however, it is of particular significance in qualitative research studies. Qualitative studies strive to investigate and understand the attitudes, beliefs, and values of the phenomenon being investigated. All of the qualities previously mentioned are subjective qualities, so it was important for me to consider the study's internal and external validity. Husserl (as cited in Lodit, 2010) and Moustakas (1994) both warned that the researcher's inability to draw precise and adequate extrapolations from the data collected (external) or drawing inaccurate conclusions that relate to the participants (internal) can lead to threats to the validity of the research study. In order to address the quality and reliability of the data, I included an appropriate number of study participants to provide a foundation of analysis and one that is representative of the demographic population (Morrow, 2005).

Data Analysis Plan

The research was conducted and the data was analyzed using Moustakas' (1994) phenomenological strategy. This strategy includes classifying or coding the transcripts from the telephone interviews. Giorgi (2009) outlines the function of the descriptive phenomenology as one to address the complexity of the study as described in terms of the way the participants perceive their experiences and avoid biased ideas that can influence the study (Giorgi, 2009). In this study of how African-American parents of youth with T1DM manage their child's diabetes and the family influence of management of the disease, data analysis methods helped me stay focused on the data obtained from the interviews of this phenomenological study. Problem refinement-research was the first step of data analysis. In this phase, I developed a way to determine the influence of parental involvement and family dynamics on glycemic control in African-American families. This study design assisted in the exploration of perceptions that may influence glycemic control among African-American T1DM youth.

Each participant's interviews were transcribed verbatim. Using the modified van Kaam method, the collected data was analyzed through: (a) grouping, (b) reducing and eliminating, (c) clustering and thematizing, (d) validating, (e) textural describing, (f) structural describing, (g) and using themes for constructing textual-structural description (Loidolt, 2009). The final steps utilized for data analysis (evaluation and summary of the data findings) was to analyze all of the findings and develop summaries and conclusions that were appropriate for the findings. As outlined by Reiners,(2012), these methods were adequate for analyzing data in a phenomenological study. I used qualitative data analysis software (www.dedoose.com) to complete the grouping, coding and analysis of the data received. Using web-based software such as Dedoose, helped to manage and integrate the many changing themes that evolved in the data (Kilooma, 2010). Qualitative data analysis software is a tool that facilitates the classification, coding, and sorting of information. Each of the 20 study participants received a unique alphanumeric code in order to maintain confidentiality. Delattre et al.,(2009), maintains that the finding in qualitative research must answer the research questions. I collected the data and began a repetitive process of validation, categorization, codification, and tabulation that produced a comprehensive list of the views of the parents of T1DM youth and their issues with helping their youth adhere to prescribed diabetes guidelines. Data analyzed that did not uncover the hypothesized conclusions in this qualitative study may have been a testament that quantitative studies could be a more appropriate research method for future research (Mason, 2010; Thomas & Magilvy, 2011).

Issues of Trustworthiness

Quantitative methodology constructs its theory by testing the hypotheses of the studied phenomenon. However, in qualitative methodology, there is no judgment made until the study is complete and the data is incorporated, along with theory, in a way that the connection between the analyzed data, the theory, and the literature can be associated (Bansal & Corley, 2012). In the study of diabetes management, qualitative research can help clinicians explore the patients' motivators, perceptions, and expectations in how to effectively manage their diabetes (Ritholz, Beverly, & Weinger, 2011). Managing T1DM is crucial to the quality of life and overall good health, particularly in youth. Therefore, it is important that the data collected and analyzed be reliable and valid. The reliability and validity of a study address the transferability, trustworthiness, and credibility of data that has been collected (Lasch, e, 2010). Additionally, rigor and defining the process are also included in this procedure. As suggested by Bansal and Corley (2012), the problem statement began this process and continued through to the review of the literature, ending with data collection and analysis. This mutual dependency generated urgency for reliability and validity in qualitative studies.

Reliability

Evaluating the reliability of research results requires that the researcher ensures and verifies that the coding is repeatable by other researchers. According to Ryan and Bernard

(2003), reliability is established when themes that are based on judgment are developed and are explicitly clear. Coding the original data allows the researcher to assess the reliability of the qualitative research. As expressed by Delattre, Ocler, Moulette, and Rymeyko (2009), the reliability of a study is guaranteed by the structured methods of the codification and classification of the data collected. Delattre, et al., (2009) further explained that the use of themes, sub-themes and key ideas, allows the researcher to maintain the integrity of each piece of data. In this study, reliability was established by developing themes from the reoccurring codes of the participant comments, whereas, categories and themes can then arise.

Validity

The validity of the study relies on the agreement between codes and methods, and the examination performed by the researcher (Ryan and Bernard, 2003). Delattre, et al (2009), explain that testing the validity of a qualitative research study heavily depends on ensuring that the variables used evaluate and answer the research question/questions proposed. In order to establish internal validity of the research, the relevance and accuracy of the results obtained should be guaranteed. While external validity encompasses the capability of results to be generalized to other variables that occur in a different time and place (Delattre, et al, 2009). In order to ensure that the research questions are appropriate to elicit the level of response desired, I conducted a pilot study with two parents from the respective population. The pilot study helped me to assure validity and reliability of the research instrument and enabled me to be more aware of language and terminologies that may have been sensitive for this population. The pilot study is a succinct version of the proposed research intended to enhance the procedures of the proposed research project (O’Sullivan, Rassel, Berner, 2008). O’sullivan, Rassel, Berner (2008) explained the primary goal of a pilot study as not only collecting research data, but evaluating the research procedures so that the necessary adjustments can be made prior to the collection of actual study participant data. Furthermore, the pilot study data can assist with determining if the planned data analysis was adequate and sufficient. Issues that arose during the pilot study were corrected by altering the data collection procedures or data analyses. Participants in the pilot study were recruited from purposeful selection; meaning I selected persons to participate in the pilot study whom I already had a relationship with. I asked persons that I was already familiar, with who meet the criteria of having a child with T1DM. I asked the pilot test participants to review the questions for readability, understanding, relevance, and sensitivity of the language used. It is my desire to be sensitive to the feelings of the parents of these children and to ensure that no one is offended by the research questions; I asked the pilot test participants to pay special attention to this issue. Once the research questions were validated with the pilot testers and all necessary adjustments were made, I began to collect the data.

I conducted interviews with the participants. Their responses were audio recorded, as well as transcribed. This allowed me to assure the accuracy of the responses and allow me to recognize emerging themes and categories. I took the necessary steps to guarantee that the sample, setting, and context represent the population, setting, and context were appropriate to generalized data (Bansal & Corley, 2012; Golafshani, 2003; Homburg et al., 2012). Credibility was established by using triangulation of the recorded interview against the transcribed interviews for accuracy of comments, and member checking, as described by Whiteley (2012). Data triangulation was used to analyze whether or not the results are generalizable to a broad spectrum of the population by the results received and interpreted from the participant responses (Homburg et al., 2012). The creditability and transferability of qualitative research requires that responses be analyzed and themes be identified that are able to assist in the evaluation and response to the research questions (Delattre et al., 2009). Establishing creditability of the research consists of guaranteeing the significance and the accuracy of the results obtained in the study. Transferability includes the appropriateness of the results to be applied to other variables (generalization) in a different time and place (Delattre et al., 2009).

I verified the accuracy of the interviews through audio-recordings that ensured that my verbatim written responses accurate. Member checking is an additional validation and verification technique that was used. According to Bradbury-Jones et al., (2010) member checking or participant feedback enriches the reliability of qualitative research and is essential for establishing validity. Checking data collected with the participants of the study (member checking) in order to gauge accuracy and-or the reactions of the participants is a normal research follow-up verification step in the process (Reiners, 2012). I provided a transcript of the interview data to the participants for review. This allowed me to verify the accuracy of the data and findings from the participant, reader, and researcher perspective (Bradbury-Jones et al., 2010; Reiners, 2012). By eliminating my biases in the design and technique of the interview questions, I was able to establish the dependability of the study. The interview question script was consistent for each interview as a safeguard to ensuring the objectivity of the data, (Golafshani, 2003; Homburg, Klarmann, Reimann, & Schilke, 2012).

Ethical Procedures

In this study, I met all of the ethical requirements of research by following all ethical codes of conduct, legal requirements, and adhering to social responsibility expectations in order to ensure the utmost respect, justice, beneficence, and integrity to the participants and the process, as outlined by Bauman (2011). There was no anticipated opportunity for harm to the participants. The research consent form is located in Appendix C.

Prior to conducting this study, I submitted a confidentiality agreement (Appendix D), ensuring that the identity is kept private and confidential. I informed each study participant in writing of the criteria for participating in the study and how the data will be used, by providing the study participant invitation and the implied consent form (Appendix C). These forms allowed the participants to make an informed decision about their participation in this study. I required that each participant submit a signed consent via electronic confirmation. I ensured the confidentiality of the participants' responses by using unique identifiers for each participant.

Participants were free to withdraw from the study, if they so desired and they could decline to answer any questions that they feel uncomfortable answering during the interview process. I informed the participants that the records of this study are private and will remain confidential. All data was stored on an encrypted flash drive and the flash drive is stored in a locked filed cabinet at my home. I explained to the participants that all records from this study will be destroyed in 5 years from the date that the study is approved. This study did not offer any participation incentives. My documentation for this study was approved by Walden University Institutional Review Board (IRB). Walden IRB approval ensured that the research met all the ethical standards before the beginning of the study. There was no collection of data or contact with potential study participants, until the IRB forms had been approved.

Summary

The purpose and focus of the study were outlined in Chapter 1. The literature review in Chapter 2 set the foundation and philosophical framework for the study. Chapter 3 of this research study provided a detailed explanation of the research project. Additionally, the related headings provided an in-depth view of the role of the researcher, the research design, the methodology used, the participant selection logic, instrument used, and the data analysis plan.

Issues of trustworthiness, to include reliability and validity are further, discussed in chapter 3; along with the ethical procedures. The methodology employed in this study potentially provided evidence to determine a conclusion. The conclusion answered the overarching research question of the study: How do the lived experiences of parents of children with T1DM affect the successful management and control of T1DM among African-American youth age 5-17 years old?

Chapter 4 provided a detailed description of the setting, demographics, data collection, data analysis, the evidence of trustworthiness, and a discussion of the results. Chapter 5 discusses the findings, the study limitations, recommendations, implications, and conclusion.

Chapter 4: The Study

Introduction

The purpose of this study was to explore the lived experiences of a composite of 20 African American parents of children diagnosed with T1DM. This study was designed to explore the common experiences of African American parents of youth with T1DM that could affect the control and management of their child's diabetes. The findings presented in this chapter reveal the discovery of possible barriers faced by African American parents in managing their child's T1DM. Early diabetes management is essential to preventing diabetes complications (American Diabetes Association, 2011). When children are young, their parents play an important role in their diabetes management and diabetes' role in family life is significant (Whittemore, Jaser, Chao, Jang, & Grey, 2012). Therefore, understanding the barriers to diabetes management from the parent's perspective is crucial.

Study participants were asked questions intended to address the overarching research question: How do the lived experiences of parents of children with T1DM affect the successful management and control of T1DM among African American youth age 5-17 years old? The questions were outlined in categories to test constructs of the HBM.

Pilot Study

A pilot study was conducted using two participants from the target population. The purpose of this pilot study was to assure validity and reliability of the research instrument and enabled me to more carefully select language and terminology that was sensitive to the needs and concerns of the population. The participants were selected primarily for convenience. I asked people with whom I have a relationship and who met the criteria for study participation to participate in this pilot study. They were requested to review the interview questions provided to them via electronic mail prior to the scheduled meeting. After pilot test participants had an opportunity to review the original questions, a face to face meeting was scheduled with each participant. Participants were asked about the readability, understandability, relevance, and language used in the instrument. Participants were asked to give their overall feedback of the questions. Each question was discussed with the pilot test participants and revisions were made to the research questions according to their feedback.

The pilot test participants felt that the original instrument was too lengthy. They also thought that the length of the instrument would discourage participation; particularly for telephone interviews. They thought that the participants may not be able to give their undivided attention. Additionally, the pilot test participants thought that there were questions that were not relevant to the overarching research question and would not produce straight forward answers from respondents. They also thought that there was redundancy in the research questions. With the help of the pilot test participants, I was able to reduce the number of research questions from fifteen to ten. I was also able to remove the redundancy of questions and leave room for follow up questions.

Setting

At the time of the study, none of the study participants had recently experienced any adverse events managing their child's diabetes that could have hindered their participation in the study or their responses to the study questions. Managing diabetes is very unpredictable, as stated by all of the study participants; however, there were no experiences reported that were out of the ordinary. At the end of the interview process, I disclosed to study participants that I am a type 1 diabetic of 39 years. I did not, however, discuss my experience with diabetes or that of my family.

Demographics

African American parents of African American children with T1DM were recruited for this research study. Although there was no purposeful exclusion of fathers, all 20 respondents were mothers of children with T1DM. Inclusion criteria required that the children were diagnosed with T1DM for at least six months and were between the ages of 5-17 years old. Disease duration ranged from less than one year (eleven months) to eleven years. The children ranged in age from 5 years to 16 years old. Study participants were recruited from the Eastern region of the United States. Thirty-five percent of the respondents were from Georgia, twenty percent were from Virginia, fifteen percent from South Carolina, and ten percent from Maryland. Florida, New York, North Carolina, and the District of Columbia, each had five percent of the respondents.

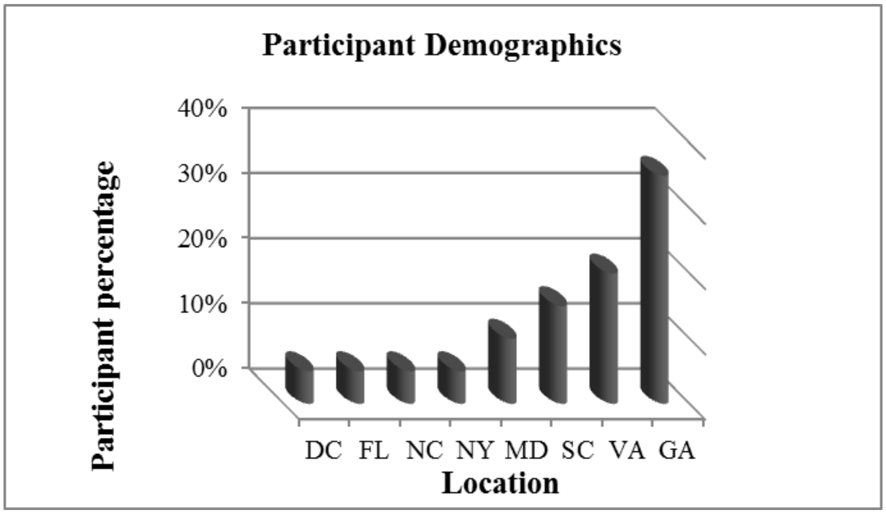

Figure 1. Bar graph depicting number of participants in each city.

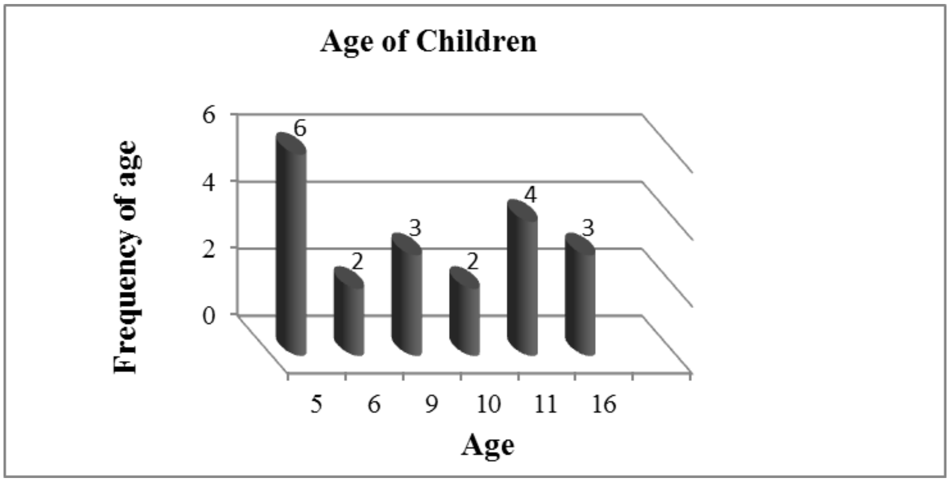

Figure 2. Bar graph depicting frequency of age of participant’s children.

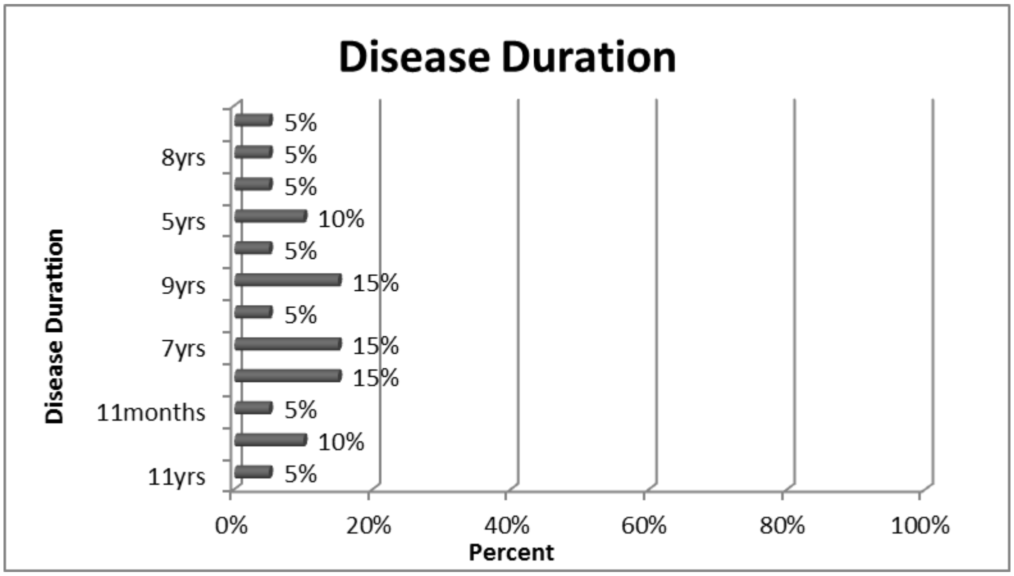

Figure 3. Bar graph illustrating length of disease duration vs. percent of participants with each duration.

Data Collection

A variety of media were used to solicit participation for this study. African American parents of children with T1DM were solicited to participate in this research study through a request for participation post via social media outlets (Facebook, LinkedIn, and Twitter) that included the nature of the study and the responsibilities of the participants,. Those who expressed an interest in participating in the study were e-mailed a qualifying questionnaire to determine their eligibility. The participants must have lived in the eastern region of the United States and been an African American parent of an African American child (both parents of the child must have been African- American). The child must have been diagnosed with T1DM for at least six months. Twenty-five people expressed an interest in participating in the survey. Twenty-three people completed the qualification questionnaire; three people did not meet the qualifying criteria. One child was turning eighteen and two others were biracial. The twenty people who met the qualifying criteria were selected to participate in the study. My choice to use 20 participants is supported by van Kaam’s theory that 10 to 50 descriptions who detail targeted experiences is sufficient to interpret phenomenological research and distinguish the essential elements of the research (Moustakas, 1994). Participants were sent the interview questions prior to the interview to allow them time to gather their thoughts or ask questions as needed.

As described by Loidolt (2009), in this phenomenological research I used the research questions to gain an understanding of the participants’ personal experiences, motivations, and actions in managing their children’s T1DM. The interview questions were open-ended and broad enough to stimulate extended dialogue with the participants about their children’s diabetes management and its effect on their lives. Each interview was completed uninterrupted, lasting approximately 30 minutes. As each question was asked, I wrote the responses verbatim during the interview. During the first interview, follow-up questions were found to be needed in order to create extended dialogue to ensure accuracy and enhance understanding and intent of the responses. The voice recorded interviews were saved as MP3 files on a micro secure digital (SD) card. The micro SD card is stored in a locked file cabinet, along with the composition notebook containing the interview notes and verbatim responses.

Upon completion of the telephone interviews, the verbatim written responses were checked against the corresponding voice recordings for accuracy. Member checking was performed as suggested by Reiners (2012). Each participant was emailed a written copy of their interview and interview responses to review for accuracy of information. Member checking or checking the collected data with the participants of the study is a routine research follow-up step and helped me gauge the accuracy of the data collected while enabling me to assess the reaction of the participants. After all interviews were completed and checked for accuracy, the data was placed in an excel spread sheet. The excel spreadsheet was uploaded into Dedoose.com, the statistical program that was used for data analysis.

Data Analysis

As suggested by Moustakas (1994), the data from the 30 minute interviews were classified and coded. This method allowed me to create a list of codes from my written responses to the interview questions. Phrases and words explaining the lived experiences of parents of children with T1DM were identified and used as codes. The codes were applied to the responses and the frequency of use was calculated; paying special attention to repetitive phrases and words. If words and phrases fell into more than one category, careful consideration was made to place them in the most appropriate section. The potential risk of researcher bias was taken into consideration in the development of themes and drawing conclusions because the interpretation of data and coding was my decision. The collected data was categorized and arranged into elements or codes (Moustakas, 1994). Codes were developed from the questions based on impact, affect, cost, and implications. Themes were then developed in order to determine intent and importance of the responses. Qualitative data analysis software (www.dedoose.com) was used to aid in data analysis, coding, and theme development. Kilooma

(2010) supports the use of computer software aided qualitative data analysis and purports that rigor can be applied and amalgamated using this tool. He further asserted that combinations of narrative analyses and coding using themes enable the researcher to relate empirical findings to theoretical dialogues. Following this process enabled me to give a more precise description of the views of the participants.

The interview questions were divided into three categories; perceived barriers, perceived seriousness, and perceived susceptibility, to test the constructs of the Health Belief Model. The research questions below; include the follow-up questions that were used in this study.

Perceived Barriers

1. What is the cost associated with managing your child’s diabetes?
   a. What are the things that contribute to your costs?
   b. What are the most challenging things about managing your child’s diabetes?
2. How is your everyday life affected by your child’s diabetes?
3. What are the things that interfere with your child’s diabetes?
   a. Based on your child's most recent endocrinologist visit, do you feel that your child is in good diabetes control, fair diabetes control, or poor diabetes control and why or why not?
   b. How does that affect the way you manage your child’s diabetes

Perceived Seriousness

4. Do you recognize when your child is experiencing a diabetes emergency?

    a. How do you know if your child is experiencing a diabetes emergency (what are the symptoms?)
    b. How many diabetes emergencies does your child have per day or per week and how disruptive are they to your day?

5. How do other family members react when your child is having a diabetes emergency?
    a. Do family members and friends feel prepared to handle a diabetes emergency, when your child is in their care?
    b. How comfortable do you feel leaving your child with friends or family?
    c. Do your friends, family, etc., feel that they can recognize a diabetes emergency and act on it?
    d. Do your friends, family, etc., follow your child's diabetes regimen when in their care?
6. How do you prepare others (friends, family, teachers, etc.) to recognize or handle a diabetes emergency?
7. How do you feel that your child's diabetes will change their future goals and aspirations?

Perceived Susceptibility

8. How do you ensure that you follow your child's diabetes regimen (blood glucose testing, medication decisions, dietary needs, activities, etc.)?

   a. What is the most difficult part of following your child’s diabetes regimen?

9. What do you feel are the limitations placed on your child due to their diabetes?

10. How much time do you feel is required to manage your child’s diabetes?

This study used a phenomenological methodology to gain understanding of the lived experiences among African American parents of children with T1DM and the impact of the disease on their lives. From these categories and questions, three categories emerged. The first category was the impact of T1DM on the lives of the parents. Two themes emerged from this category; financial impact and time management. The second category identified the parent’s perception of the impact of diabetes on their child’s future. The common themes within this category were the parent’s beliefs and fears about their child’s future with diabetes and their child’s ability to successfully manage their diabetes. The last category was the social aspects of disease management for the child and the parents. The themes in this category were how others perceived diabetes and diabetes management, teaching diabetes management to others, and the parent’s trust in other’s ability to manage their child’s diabetes, and how these things impacted their socialization. Themes were found to transfer from one category to another and to be included in more than one category.

Evidence of Trustworthiness

The theory of quantitative analysis is developed by analyzing hypotheses; while qualitative methodology reserves judgement until the completion of the study and incorporates data and theory (Bansal & Corley, 2012). This allows the researcher to express the connections between analyzed data, theory, and literature. The primary purpose of using qualitative data in this study was to understand the lived experiences of the parents of African American children with T1DM and produce approaches to understand, analyze, and explain organizational phenomenon at a social level (Delattre, Ocler, Moulette, & Rymeyko, 2009). Therefore, it was imperative that both the data and data analysis be reliable and valid. According to (Lasch, e, 2010), the reliability and validity of the data addressed transferability, trustworthiness, and credibility. Additionally, the reliability and validity of the data included rigor and procedures that explained the processes. The process of obtaining this information should begin with the problem statement and continued through the review of the literature, ending with data collection and analysis (Bansal and Corley, 2012). This linkage was essential in obtaining reliability and validity in this qualitative study. .

Credibility

In order to establish the credibility of this research, I triangulated the data by using the recorded interview responses, transcribed interview responses, and member checking to ensure accuracy of the responses; as suggested by Whiteley (2012). Authenticating the credibility of research involves ensuring that the results obtained in the study are relevant and thorough. To verify the accuracy of my verbatim written responses, I used the recordings of the interviews to verify my written responses and validate the data collection process to analyze the data. As suggested by Bradbury-Jones et al., (2010), member checking is a validation and verification technique that can be used to enrich the reliability of qualitative inquiries. I provided the participants with the recording and the verbatim written responses to the interview questions from their respective interviews, to review for accuracy. Reiners (2012), purports that this kind of process is a standard verification process in qualitative research and complies with routine member checking research protocols. Allowing the participants to review their interview recordings supports accuracy of the responses from the viewpoint of all stake holders; readers, participants, and the researcher (Bradbury-Jones et al., 2010; Reiners, 2012). I also conducted a pilot test of the original survey questions. From the pilot test, I was able to determine if the questions were reliable and accurate and would generate the desired information. I adjusted the survey questions based on feedback from the pilot testing process.

Dependability

Thomas & Magilvy, (2011) describe dependability as the benchmark for evaluating the constancy or consistency of the query processes of qualitative studies. Addressing preconceived notions, through the design of the interview questions and the interviewing technique, allowed me to maintain objectivity in the interview process. The dependability of a qualitative study can be assured by careful considerations by the researcher. The researcher must assure that there have been no inaccuracies in the process. Ihantola & Kihn (2011) stated that when performing qualitative research and data analysis, the researcher should ensure that errors have not occurred, and there have been no inaccuracies in (a) theorizing the study, (b) data collection, (c) results interpretation, and (d) results reporting. To ensure the integrity and dependability of the process, I used the same script when interviewing each participant and asked the questions in the same manner, with each interview. This technique is described by Golafshani(2003) and Homburg, et al., (2012) as a suitable method to ensure dependability of the data.

Developing themes based on clear and well defined judgement is the method that Ryan and Bernard (2003) state can establish reliability. When conducting qualitative research, coding the original data helps to assess reliability. Therefore, the reliability of the research results depends on the method of coding and the ability to be repeated by other researchers. Reliability can be obtained by utilizing the structured method of the codification and classification the data (Delattre, Ocler, Moulette, and Rymeyko, 2009). Delattre, et al., (2009) also believed that using themes, subthemes, and key ideas enables the researcher to preserve the character of each data point. Reliability was established in this study by the development of themes based on reoccurring participant comments and or codes. The study questions were organized into categories. From this process themes emerged. The reliability of the themes was confirmed and analyzed, and conclusions were drawn (Homburg, Klarmann, Reimann, & Schilke, 2012).

Transferability

Transferability includes the capability to utilize the results in the presence of other variables; making the results generalizable in another place and time (Delattre et al., 2009). Data triangulation was used to analyze whether or not the results were generalizable to a broad spectrum of the population. Comparing the responses from co-researchers/ other participants living in similar geographical locations allowed me to address issues of generalizability in the research study (Homburg et al., 2012).

Results

The interviews were coded for frequency of terms, expressions, and vocabulary. Initially there were 11 interview questions. After the pilot testing and initial interview, 6 follow-up questions were added to the interview in order to obtain a better understanding and get a more complete picture of the experiences of African-American parents of T1DM children. The responses to each question were grouped and combined into themes. Each theme was assigned a sub-code under its corresponding question. There were a total of 61 sub-codes. Some codes were found to be so similar that they were narrowed and combined into themes. Question 8a and its responses were found to be so similar to question 1a, that it was discarded. Three categorizes emerged; the disease’s impact on the life of the parents, the life of the child, and its social impact. The impact on the life of the parent included financial impact and time management. The

Impact on the life of the child included the effect that diabetes has on the child now and its effect on any future endeavors. Aspects of socialization for both the parent and the child, including family socialization, were included in the social impact.

There were study questions that lead way to quantitative responses; thus necessitating a mixed methods or mixed model approach. Johnson and Onwuegbuzie (2004), suggested that rather than identifying a study that blends both quantitative and qualitative approaches across research stages as a mixed methods research design, it should be identified as a mixed model research design. According to Johnson and Onwuegbuzie (2004), mixed model can be used to describe research studies that integrate both quantitative and qualitative data. Moreover, Caracelli and Green (1993) and Onwuegbuzie and Teddlie (2003), explained that transformative data designs exist whereas data forms can be transformed from one form to another and merged. The results of this research study followed a mixed model research design. As suggested by Caracelli and Green (1993) and Onwuegbuzie and Teddlie (2003), this research study utilized a transformative data design; whereas the results of the qualitative questions were presented both qualitatively and quantitatively and merged to allow for a more comprehensive picture of the experiences of the parents. Research questions 1, 3a, 4, 4b, 5a, 5c, 5d, yielded quantitative, results; however, the addition of the verbatim qualitative responses from participants helped to increase understanding of the experiences of the parents in managing their child's T1DM. Figures 1-19 provide the visual quantitative analysis of the experiences of parents managing their child's T1DM. While the verbatim written excerpts from the study interview are presented under each question, to provide a deeper understanding of the experiences of the parents. All data was analyzed both quantitatively and qualitatively. Creswell (2009) further explains that quantitative measures can be obtained from qualitative data; particularly from issues investigated less frequently in the literature. There is a scarcity in the literature that explores the lived experiences of African American parents of children with T1DM. Creswell further purports that quantitative data develops from qualitative data when data is not currently available, data does not exist on the population being studied; or there is scarcity in the exploration of the subject by others. The results of the study are outlined below and arranged in sections according to the categories that emerged.

Impact on Parental Life

The stress associated with parenting a child with diabetes is high (Whittemore, et al., 2012). Caring for a child with T1DM requires constant daily management, which contributes to the increased stress felt by parents (Jaser, et al., 2009). It is evident that diabetes management significantly affects the quality of life of parents with younger children. It has been reported that 22% of parents of young children experience high levels of anxiety and depression (Jaser,et al., 2009). Additionally, the financial impact on the family of a T1DM child is unsurmountable; adding additional stress to the parents and caregivers.

Financial Impact

Q: What is the cost associated with managing your child's diabetes?

Forty-five percent of parents interviewed reported spending upwards of $300 per month on costs associated with managing their child's T1DM. As noted by participants, the extra expense associated with diabetes management was often crippling to the household finances. "Diabetes management is very expensive. We spend around $250 extra per month on diabetes management", noted one parent. Another parent explained that "no matter how much we try not to, most months we spend more than $300." Noting the financial strain on the household budget, another parent stated "on average our diabetes management costs are about $350 per month. It is really causing a financial strain in our household.” Medical coverage varies; therefore, some parents did not feel the same financial strain that others with less comprehensive coverage felt. One parent noted “my husband is in the military, so we don’t have to spend money on medications and supplies. This makes our costs only about $100 extra per month; very minimal compared to what I have heard from other parents.” Other parents noted that costs associated with diabetes vary for their child, depending on how many visits to the doctor or emergency room. “Each month our costs vary from $50 to $200 for diabetes management. It just depends on what kind of month we are having; whether she has been sick or needs to see the doctor more often, stated one parent.

Juggling the family budget to accommodate the diabetes needs of their child, at times, left parents feeling inadequate. One parent expressed her despair about finances, stating, “We don’t have health insurance, so the medical bills are sinking us”. Another parent relayed her frustration about the financial strain, saying “diabetes needs take all of our extra money. I feel guilty because we have no extra money for extra activities. It feels so unfair to all the children”.

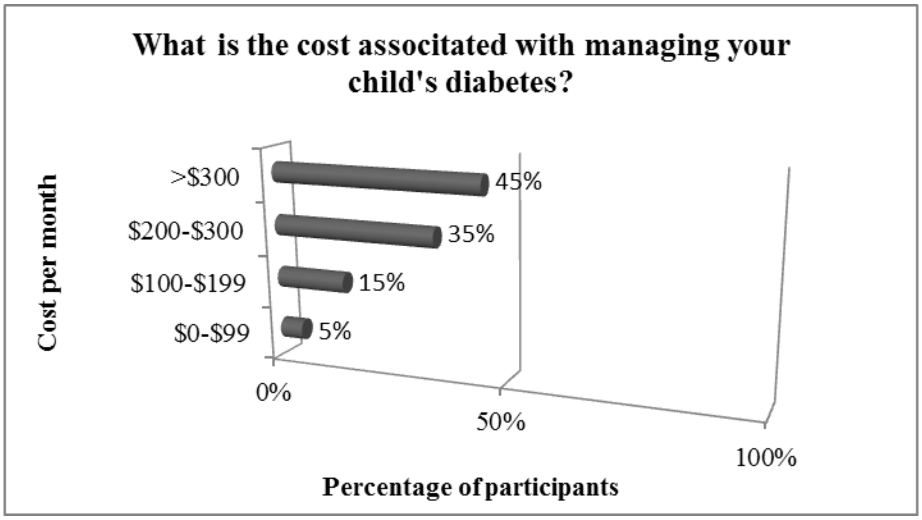

Figure 4. Bar graph illustrating monthly diabetes costs.

Q: What are the things that contribute to your costs?

Parents identified several expenses for their family, including diabetes supplies, medical bills, insurance premiums and co-payments, hospital stays, and time missed from work. Eighty percent of parents indicated that medical expenses cause a big strain on their family budget. One parent stated, “we spend a large part of our monthly budget on doctors’ visits, and diabetic supplies.” Another parent explained the extra expenditures that their family experiences in order to go to the endocrinologist. She stated, “we have to travel more than two hours away for our endocrinologist appointments, so those appointments cost us so much more than a regular visit to the pediatrician would. We have travel expenses, including gas, meals, and then sometimes we spend the night; so that is hotel expenses.” Some parents explained that their children’s issues of non-compliance lead to more hospital and doctor’s visits. One parent expressed “ we are still figuring out this diabetes thing and my daughter is pretty non-compliant, so we spend a lot of time in the emergency room.” Another parent explained, “ My son plays sports and he has begun to exert his independence, he doesn’t want to stick out in the crowd, so he neglects his diabetes care. This leads to us being in the doctor’s office or urgent care at least twice a month.”

Seventy percent of the parents interviewed indicated that purchasing diabetic supplies, including glucose monitoring supplies and prescription medications, significantly contributed to their increased expenses. One parent explained that even though we have very good health insurance, the co-payments for test strips, insulin, ointments and wipes run us a pretty penny, each month. Her infusion site sometimes needs special care too, so that’s an additional cost” Another parent explained how the cost of supplies affects their budget, stating “ my son takes 5 insulin shots a day; the cost of insulin alone is drastically affecting our budget. Not to mention the cost of syringes, and glucose monitoring test strips.” The cost of test strips is a major concern for parents. A parent described her experience with glucose monitoring supplies, explaining that "glucose monitoring test strips never seem to last the entire month, I find myself paying for them out of pocket to cover the month." Another parent discussed the cost of special products needed for her son; stating, "My son suffers from severely dry skin that they say diabetics gets. I find myself spending lots of money every month trying out different creams and lotions, to help his dry, itchy skin. Most of them are pretty expensive, considering."

Forty percent of those interviewed indicated that purchasing diabetic friendly foods not only cost them monetarily, but it also cost them in time. Parents indicated that dietetic items tended to increase their grocery bill and were not on sale as often as other items. This concern was expressed most frequently among parents of children diagnosed with diabetes for less than five years. "The items that I really should be buying him are not a part of the items that I used to purchase when grocery shopping. The items that I need to buy for my son are far more expensive than the usual items that I purchased for the kids," stated one parent. Another parent stated " my other children won't eat the kinds of snacks I buy for my child with diabetes. I try to get everyone eating healthy snacks(but it is very difficult) like the dietetic snacks that I purchase for my son. They won't eat what I buy for him, so that makes me have to purchase separate items for the other kids; doing so is very costly." One parent expressed her angst with grocery shopping since her son has had diabetes. She recounts her experience grocery shopping stating; "I spend so much more time in the grocery store now. I have to read every label and try to figure out how I will incorporate the needs of my diabetic child, with the desires of my other two children, when it comes to meals and snacks. I'd say that reading labels of everything that I buy to make sure the carb and sugar ratio is appropriate, is very taxing".

Fifteen percent of parents expressed concern about taking more time off of work with their T1DM child. For parents who either did not have paid time off for these incidences or who had taken a lot of time off, this was a major concern. The parents were concerned about possibly losing their jobs because of the needs of their children. One parent stated, “last year I was averaging taking off at least one day per week with my daughter. I got written up twice for attendance. I can’t afford to lose my job, so sometimes I have to leave her with a friend that works nights. I feel really guilty when I have to do that.” Another parent explained her issues with coworkers and her supervisor, stating “when I get a call from the school about my son’s glucose, often I feel like I need to leave. Neither my co-workers nor my supervisor really understand. It has caused major issues in work relations.” One parent expressed the importance of a supportive work environment and the economic impact of having to miss a lot of work. She states, “I have a very supportive work environment, so leaving work is not a problem for me; although it financially impacts us because I don’t get paid for the time I have missed from work.” Another parent further elaborated on the importance of a supportive work environment, stating “my coworkers are very supportive and sympathetic about my daughter. Usually, if it will not take me longer than an hour or so, I am able to leave without clocking out. I am able to make up the missed time anytime that week or by working from home.”

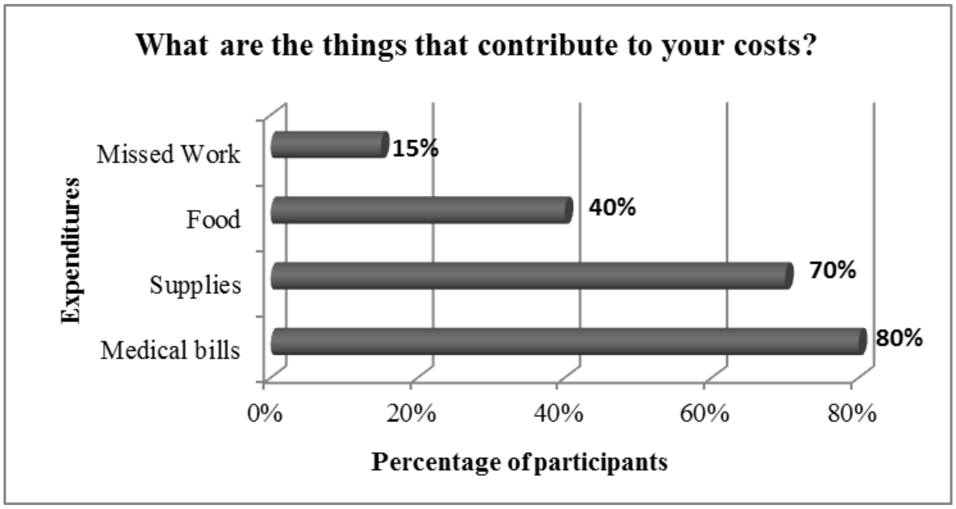

Figure 5. Bar graph illustrating sources of monthly expenditures.

Q: How do the costs affect the way you manage your child’s diabetes?

All 20 participants indicated that the increasing costs associated with diabetes management influence the way they follow their child’s diabetes management regimen. For those with health insurance, that covered all prescription medication and diabetes testing supplies, cost was not a factor. However, the overwhelming majority of the parents interviewed did not have insurance coverage that covered all of their expenses. As a result of the increased expense, parents took short cuts in diabetes management, where they felt it would have the least impact. Less frequent blood glucose monitoring was stated by 18 of the 20 parents, as a way of decreasing cost and ensuring that glucose test strips would last until the end of the month. Parents felt that doing fewer glucose tests would not significantly affect their child’s diabetes management. Most parents indicated that they saw no difference in testing 6 times per day and testing 3 times per day. One parent stated “test strips usually run out before the end of the month. If we were to test 6 times per day, we would have to purchase additional test strips out of pocket. The cost of test strips is a lot, so we just cut back to 3 to 4 times per day, I don’t think it hurts anything." Another parent admitted performing less frequent glucose tests, noting "I have not found a difference in testing 4 times per day and testing 6 times. We simply cannot afford to purchase the test strips out of pocket, so we do the best we can." Other parents indicated that they cut corners in other ways to make supplies last the whole month. One parent explained that "sometimes we use the infusion sets on her pump longer than 3 days. When she was on multiple injections, we would use the syringes more than once. These all seem like harmless adjustments and we have never seen any side effects from doing this." Another parent expressed feelings of angst for not following the diabetes regimen as prescribed; stating, "I feel so much like a bad parent, but we scrimp on everything; medication, supplies, and even miss doctor's appointments, all the time. We don't do glucose testing as prescribed. We have to miss appointments with her endocrinologist when we don't have the money to pay the co-pay, and sometimes we take fewer injections of insulin, in order to make it last longer." Other parents admitted missing doctor's appointments because they couldn't afford the co-pays. One parent stated, "Often times a visit to the endocrinologist's office requires a co-pay for the doctor and a co-pay to get her blood drawn for lab tests. Some months we really can't afford it, so we just don't go. I feel really bad, but I just can't afford it." Fifteen of the twenty parents interviewed indicated that they miss at least two endocrinologist appointments per year due to expenses. For one parent, traveling to the endocrinologist adds an additional cost. Recounting her experiences, she stated "our endocrinologist is 150 miles away, so we sometimes have to spend the night, which is an additional cost. The cost of gas, a hotel room, and eating out, are overwhelming, so sometimes I just cancel the appointment because it is not in the budget." Another parent explained her dilemmas, expressing "financially there are more doctor visits than normal children; resulting in more co-pays, and time away from work and school. I always feel bad about the decisions we have to make in order to cut costs, but it just can't be helped. In the beginning I felt like I was jeopardizing his life, but so far it has worked out. However, it is agonizing as a parent to have to make choices between a bill and a doctor's appointment or medications."

Parents also indicated that attempting to provide the proper nutrition, was a source of financial strain and worry. Purchasing items with the proper carbohydrate ratios, sugar and fat content, and portion size, presented as problematic for the parents interviewed for this study. Fourteen parents indicated that purchasing diabetes friendly foods and the cost of them, affected the way they manage their child's diabetes. Purchasing the right foods was not the only concern that parents had around food choices for their T1DM child. Parents also expressed concern about preparing their traditional meals in a healthier manner. One parent stated "I really want to know how to change my traditional recipes to be more carbohydrate friendly for my T1DM child and ultimately my whole family." Another parent explains her obstacles with changing how she cooks, stating "I want to prepare meals that are healthier and better for my T1DM child, but the rest of my family won't eat what they think are *diet* foods. I am not a real experienced cook, so I struggle with meals anyway. I struggle particularly with trying to make preserve the traditional flavor, with a better choice for my family." One parent expressed her frustration with grocery shopping, exclaiming "grocery shopping is always a challenge and a stressful experience for me. I always feel so defeated when trying to shop for the whole family." Parents felt restricted by the perceived nutritional demands. One parent expressed her exasperation with meal planning and preparation, stating, "I have issues with trying to find a healthy variety of quick and easy meals. I no longer feel that I have options for meal time. I sometimes feel like the bad guy during meal times. We rarely eat out anymore. I know home-cooking is best for us all, but it is really time consuming." "Grabbing a quick meal is no longer an option for meal time for us, at least not as often as we used to. We lead a busy lifestyle and often have to make choices of quick meals to grab in between practices and after school activities. It adds a lot more stress and work for me, stated another parent. One participant found grocery shopping frustrating and too expensive; stating, “trying to shop for food that the whole family would like and eat is draining, Reading labels, purchasing low carb and low calorie items, that my T1DM daughter won’t even eat, is expensive and frustrating.”

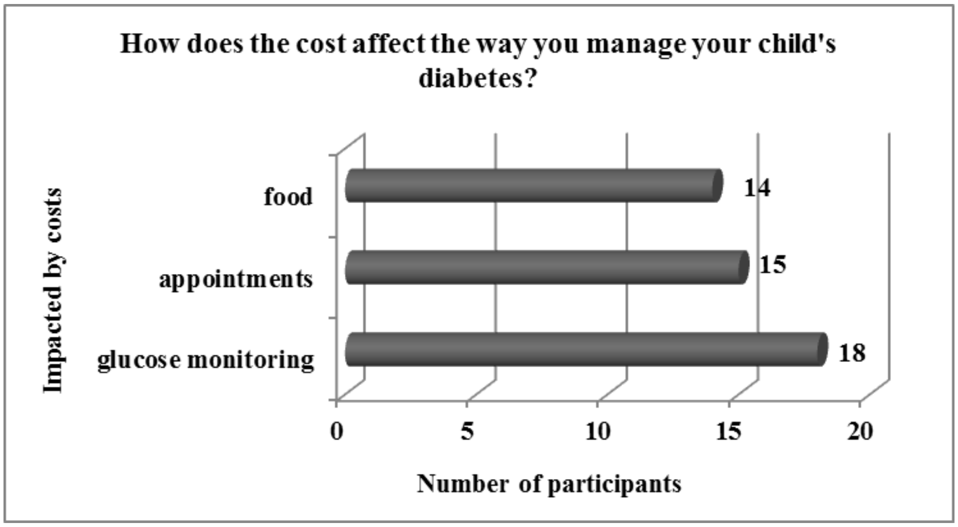

Figure 6. Bar graph illustrating how diabetes costs impact diabetes management.

The financial strain placed on families to provide adequate and proper diabetes management can hinder diabetes care; especially, if it results in missed appointments or less frequent blood glucose monitoring. Self-monitoring of blood glucose for those diagnosed with diabetes is an essential component of glycemic control (Diabetes Control and Complications Trial Research Group [DCCT], 1993). Proper and consistent blood glucose testing is believed to greatly enhance the management of diabetes by improving blood glucose levels to help reduce the occurrence of diabetes complications (Kirk & Stegner, 2010). From sleep, to grocery shopping, to frequent blood glucose checks, parents indicated that diabetes affects their lives in some way.

Time Management

Q: How is your everyday life affected by your child's diabetes?

Managing daily diabetes needs in children is a tedious and laborious process for parents, requiring alterations in family routines and plans (Whittemore et al., 2012). Regardless of how severe or how minimal, life with diabetes is never uneventful. All parents interviewed felt that their lives are changed in some way, small or large, by their child having T1DM. Whether it made them more watchful, more vigilant, and more protective; or whether it required more work for them during the day to check in with schools and coaches, diabetes affected their lives.

Seventy percent of parents stated that their lives were minimally affected by their child's diabetes. Parents felt that although there is no denying that diabetes has changed their daily routine, they did not allow diabetes to prohibit their children from doing the things they wanted to do. Although some parents experienced difficulty developing a daily routine that worked for their family, in the beginning, once they had a routine they were able to go about their daily lives with minimal interruptions. When there was an interruption, it generally required a few extra minutes to attend to blood sugar issues. Additionally, parents felt that diabetes introduced additional responsibilities to their routine; however, they were still able to manage those additional responsibilities and work them into their day in a way that didn't make it stressful. One parent explained, "In the beginning our lives were turned upside down. Now that we have begun to understand what things affect her glucose, we are able to manage better. It still causes us some unexpected turmoil sometimes, but we tend to be able to pick up the pieces and continue with our day. Another parent stated, "My son is very diligent with his diabetes, so he has few diabetes emergencies. Sometimes when he goes to a party or is with a new crowd of friends, he may slip or if he get a cold or flu or something; otherwise, we are fine. We have not had a diabetes emergency in a few months." The effect of diabetes on the lives of the children and their families can be intense; routines have to be altered and the new normal is difficult to adjust to. From changing the way you prepare meals, to the time that you prepare meals, to who you leave your child with, all have to change to adjust to life with diabetes. .

Twenty five percent of the participants felt that their lives were greatly affected by their child's diabetes. Participants felt that they had a difficult time managing their child's diabetes, and that managing diabetes was a full time job. Participants didn't feel comfortable that others would manage the diabetes correctly, so often felt that they had to do everything their selves. Learning to manage the disease, particularly in very young children and for those newly diagnosed lead to feelings of great anxiety and stress for participants. Participants felt that there was never a break from diabetes. With the demands of diabetes management always on their minds, participants felt they often neglected the needs of their other children and/or themselves. One parent stated, "I call the school many times a day checking in with the nurse. Sometimes this causes me problems on my job, since I don't get that many breaks at work." Another parent explained her desire to be less involved in diabetes management, but feared that her son would be non-compliant. She stated, "I am trying to be less of a helicopter parent pertaining to his diabetes, but it is really hard. I don't know if I can trust him to do the right thing. That really worries me." Another parent described the stress of going on outings and trips with her diabetic daughter. She explained "I am always nervous when going on outings. I check her bag many times when going on outings and trips. I am always afraid that I have left something." Another parent recounts their life before the diabetes diagnosis as very social and involved. Since diabetes, she describes a change in their lifestyle, by saying “Our family was very involved and active in all kinds of activities. Since she has been diabetic we hardly go anywhere. It has been so hard for her to follow her diabetes regimen, so I try to keep her out of unnecessary situations where she will be tempted. I no longer let her do sleepovers; not even with family. I just don’t trust it. We are a lot less social now.” While, another parent explained, “There is always something to think about with diabetes. As my son gets older, I am more afraid than ever as he transitions to managing his diabetes himself. I am always checking behind him. I probably check too much, but I just can’t leave it to chance.” One parent discussed her issues adjusting to life with diabetes, stating, “We have had a very difficult time adjusting to life with diabetes. I am hoping that this will get easier as we go along. I have had to quit my job so that I can ensure that I am available to go to the school if needed, chaperone field trips, and monitor his glucose throughout the day.” Another parent spoke of the stress of associated with day to day diabetes management, stating “Late night blood sugar checks leave me feeling exhausted the next day at work. Sometimes, this affects my performance at work. During sick times, especially, I struggle at work the next day.” While another parent explains the stress of diabetes management, coupled with the stress of her job, saying “My job is really stressful, and added to that, trying to find time to call the school nurse to check on my daughter, multiplies the stress factor. If I don’t get time to call, I worry that something may have occurred that I could have prevented.”

A small percentage of those interviewed (5%), felt that diabetes did not affect their lives much at all. Most of these participants have now been managing diabetes for a few years and have developed a very efficient routine. Additionally, these participants felt that it is all in their attitude as to how much they let diabetes rule their lives. One participant stated, “We try to allow diabetes to interrupt our lives as little as possible. We do what has to be done and continue doing all of what we want to do." Another parent noted, "I don't know if I feel that her diabetes is exceptionally life altering but I do know that our lives will never be the same. We just make the necessary adjustments and keep living." "Another parent describes their life with diabetes, recalling that "After about 4 years, life with diabetes got a little easier for us. We have almost a fail proof routine, if my son just adheres to it." After having dealt with this disease for five years, I am able to live as normal a life as possible". With time and experience, the stress and strain of diabetes management got easier for some parents and children, as expressed by one participant. One participant stated, "Now that my son is older, he is taking his diabetes management more seriously, so I am not as stressed. Measuring foods and knowing carbohydrate breakdowns are almost our specialty, now."

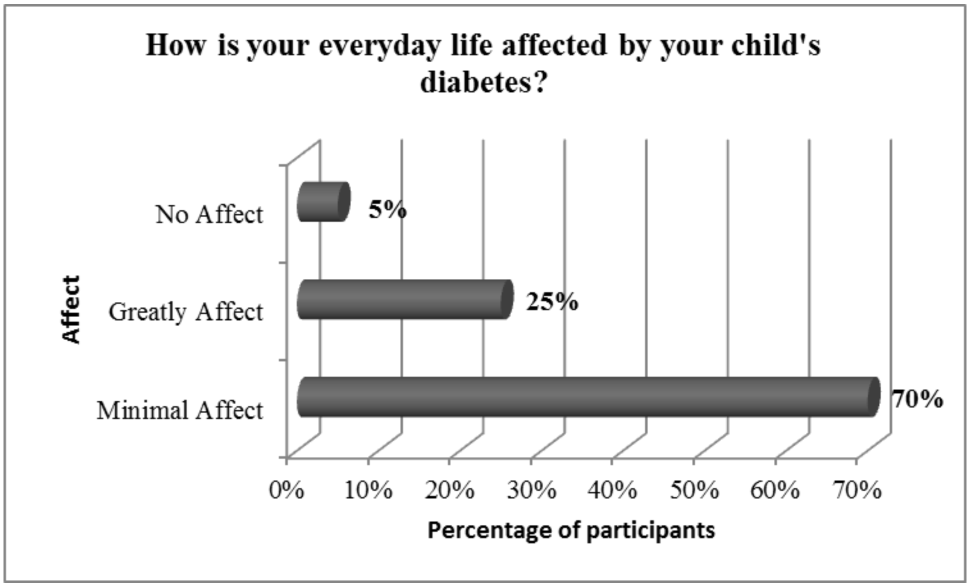

Figure 7. Bar graph illustrating the effect of diabetes.

Q: How much time do you feel is required to manage your child's diabetes?

Whittemore, et al.,(2012), noted that there is stress associated with parenting a child with T1DM. The participants of this study expressed that there is never a time that they don't think about their child's T1DM; however, the time required to manage the diabetes varied based on disease duration. Thirty percent of participants reported spending three to four hours per day consumed with diabetes management issues, activities, and thoughts about diabetes management issues. Those participants newer to diabetes management explained the demands of diabetes management on their lives. One parent stated, “Diabetes seems to consume so much of my day. I am always thinking about it. I would say that I spend about three hours a day packing lunches and snacks, and planning out their day.” Another parent explained, “My son has only had diabetes for about two years, so I feel like every waking and sleeping moment is consumed with thoughts about diabetes.” One parent told of the constant demands of diabetes management, stating, “There is never a break from diabetes; I feel like it is a job that never ends. There is always something to do. I even spend hours searching the internet trying to find ideas that will make this easier on the both of us. ” Although there was great anxiety with diabetes management among parents of newly diagnosed children, the anxiety decreased with time. Parents spent less time on diabetes management issues, with disease progression. Fifty-five percent of parents indicated that they spend one to two hours per day on diabetes related issues for their child. One parent stated, “Now that we have been dealing with diabetes for about four years, I don’t spend nearly as much time as I used to managing diabetes.” Another parent explained, “Diabetes management is never a breeze, but it is certainly less stressful after 10 years; we really have this down now.” Another parent recognized that with time diabetes management issues are less life altering, stating, “The more I work through some of the idiosyncrasies of diabetes management and my son, the less it changes our lives.” One participant recognized the importance of developing a routine for management, stating “I try not to let this disease consume our lives. We try to run this like a well-oiled machine so that we are able to enjoy life.” Another participant explained the reduction in her management duties, stating “I have two children with T1DM, they are old enough to look out for each other now and that makes my time much less.”

As children learned to handle their diabetes needs on their own and transitioned to independency, parents found that they spent less time with diabetes related issues. Fifteen percent of parents reported spending less than one hour per day with diabetes related issues. One parent explained her desire to have her daughter be more independent, stating, “I have tried to allow my daughter to do a lot of her own planning and preparation. This helps me a lot. I spend very little time doing it now.” Another parent noted, “The longer my son has diabetes, the better he gets at managing it and he is in a lot of activities that make him have to do his own prep and management. I still worry about him 24/7, but I do less of the work now.

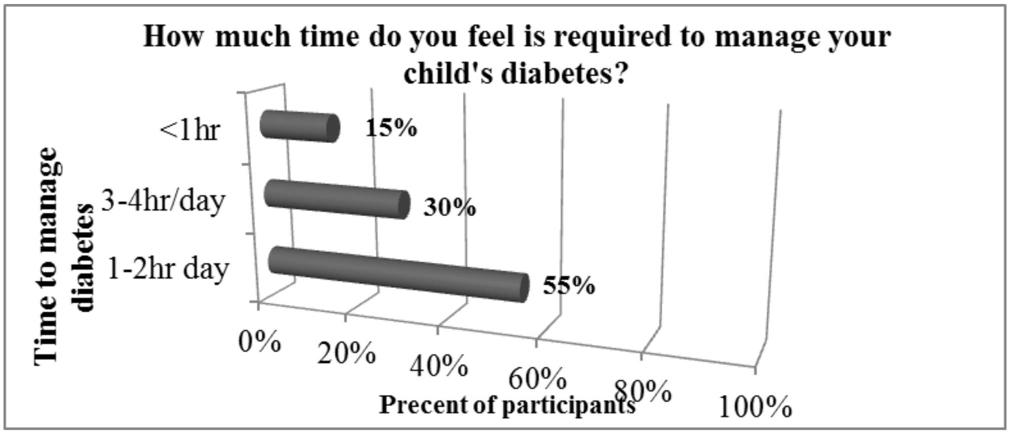

Figure 8. Bar graph illustrating time required to manage diabetes.

Parents reported, communicating with schools, coaches, care givers, and meal planning, as extra activities that require more time to perform. As disease duration increased, parents reported disease management time decreased, as they developed routines for managing the diabetes requirements. Ten percent of parents whose children have had diabetes for five years or more reported spending less than one hour per day managing diabetes needs for their children.

One parent boldly stated, “Whether actively or passively, diabetes is always on my mind; it’s hard to quantify the amount of time because even though managing it is a big part of our lives, it’s second nature now, so it doesn’t take me that long to do what I need to do. We have diabetes, but diabetes doesn’t have us.” Another parent shared her success to diabetes management, stating “The whole family participates, so diabetes planning goes swiftly in our house. Everyone knows what they have to do.” Another 40% of parents whose children have had diabetes for five years or more indicated that they spend one to two hours per day managing diabetes related issues. With experience comes lessons learned and parents have been able to adapt those lessons to make diabetes management more manageable. One parent shared, “My daughter takes her lunch, so we have to plan it out the night before. Then we make sure we pack snacks for the entire day; which includes after school. This takes us about an hour each night to do.” Another parent explained, “We review the school lunch menu for the next day; decide if he will have that for lunch and count out the carbs, if he will. Then we have to adjust the snacks and medication accordingly. Usually we can get that done in about an hour, if we are uninterrupted.”

Fifteen percent of participants with disease duration of one to five years reported spending one to two hours daily on diabetes management activities. Participants admitted that it took time to get used to the routine, but in time they were able to pick up and develop a routine that didn’t interfere with their lifestyle, as much. One participant commented, “The first year was a really hard adjustment. It seemed like everything we did was about diabetes. Now we can get it done in about an hour.” Another participant explained, “After five years we can do meal prep, back pack check, and snack prep very quickly.” Five percent of parents whose children have been diagnosed with diabetes between one and five years reported spending less than one hour and three to four hours, respectively, managing diabetes related requirements. Parents admitted that diabetes management was most difficult in the first two years, but as time went on it became easier with experience and education. One parent recalls the first two years being the worst time with diabetes management; stating, “During the first two years, I felt like a complete failure. We had a very difficult time gaining control and adjusting to lifestyle changes. It was difficult for both me and my daughter. It seems like we spent all day prepping, planning, and preparing. I easily spent four hours. Now in year four, it is much easier. We breeze through and probably spend around an hour getting everything together for the day. We certainly don’t stress as much about it.” Another parent noted, “Year one was the worse for me. It was harder for me to adjust than for my son. He took the diagnosis in stride, but I felt as though it was a death sentence. I believe I added to his stress. He has had it for three years now and I am much more at ease and it is second nature. We spend probably, maybe, an hour.” Another parent, whose daughter has only been diagnosed for thirteen months, indicated that it still takes her several hours to manage her daughter’s diabetes. She stated that “It takes me about four hours, but I don’t do everything at one time; but diabetes management is definitely equivalent to a part time job for me.”

Lastly, of parents whose children have had diabetes for less than one year, 25% reported spending three to four hours per day managing diabetes related issues. One parent noted the enormity of her daily routine; stating, “It takes me several hours to make sure that I have done everything for school the next day. I have to make sure I have everything packed. I am very meticulous about it too, so it takes me at least three hours or more. I am always afraid I will leave something at home that he will need.” Another parent noted “My daughter was diagnosed a little less than a year ago. I am still trying to figure things out. I am probably a little more anal about things than I have to be, so I spend at least three hours checking glucose, recording glucose, and prepping food for the next few days, so that she has meals and snacks.” Parents often referred to disease duration during their interviews; giving insight into how long their child has had diabetes. Statements such as, “in the beginning”, “not any more”, and “we used to”, when referring to time spent managing diabetes related issues were clues into their experiences with disease management and duration of disease.

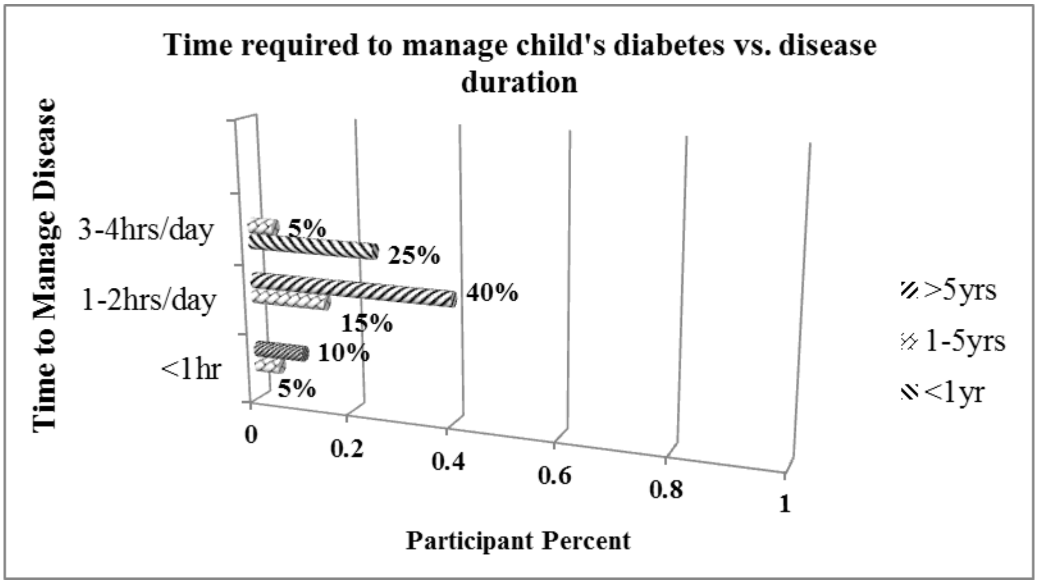

Figure 9. Bar graph illustrating management time vs. disease duration.

Q: Do you recognize when your child is experiencing a diabetes emergency?

Parents interviewed, particularly those with more recently diagnosed children, expressed feelings of angst over glucose checks, staying within range, affording proper food and medication, and potential diabetes complications for their children. Although diabetes management became an everyday part of life for the parents interviewed, there were still feelings of uneasiness. One parent stated, “Managing my daughter’s diabetes is the hardest thing I do all day. I wish I could keep her with me all day.” Another commented, “When I can’t stay home with her during her sick days, I feel so guilty. Parents reported feelings of worry about whether they were doing the “right thing”. This was particularly true in parents with children more recently diagnosed with T1DM. One reflected that, “I am never sure if I am making the right decisions. I hope that decisions that I make don’t cause her problems later in life.”

Ninety percent of parents were aware of the signs and symptoms of a diabetic emergency, such as shakiness, sweating, clamminess, irritability, and mood swings. However, ten percent of the parents admitted that they weren’t always sure if their child was experiencing a diabetic emergency. Depending on the age of the child and how their symptoms manifested, signs of high or low blood sugars can go undetected for a period of time. Small children are not always able to communicate their feelings of low or high blood sugars, so parents have to be vigilant in watching them, so they can recognize their changes quickly. Additionally, the signs and symptoms of a diabetic emergency can mimic those of other things. The only way to be sure would be to perform frequent glucose checks.

“I know the signs and symptoms of a diabetes emergency, but the symptoms sometimes mimic other things.”

“I struggle with whether I need to take her to the hospital for certain things, so I feel really bad when I don’t take her, but should have.”

“Whether I should act or not, is always iffy for me.”

All parents expressed feelings of anxiety about responding to a low blood sugar in time. *“I am always worried that I will not respond in time. I check on her all night, so that I don’t miss a low.”*

“I barely sleep at night anymore for fear of not recognizing or acting on a low glucose soon enough. In the beginning she slept in our room. Now she sleeps in her own room, but I check on her at least five times per night.”

“I think I probably make her nervous because I am constantly checking her glucose and policing what she eats and drinks. My fear for her is affecting our relationship; especially as she gets older. I am trying to back off some.”

“I know what a diabetic emergency is supposed to look like; however, I am always fearful because my son doesn’t always show usual signs of low glucose, until he is really low. He can go a really long time before he starts to feel shaky.”

“There never seems to be an in between for my son. There never seems to be a warning. He will be normal, and sometimes even high, and then in less than thirty minutes, he is at a very low number. He never feels it coming on, we just check and it is low.”

Some participants admitted not recognizing diabetes emergencies when their child was first diagnosed.

“It took some time to recognize it. After a few years, I can now spot it quicker, but sometimes they come on so quickly."

“Even after 5 years, I still am not sure by just looking at her; she has to be getting pretty low for there to be a behavior change, so it has always been difficult for me to recognize. Not because I am not paying attention, but because she doesn’t exhibit symptoms.”

“I am now very in tuned to her behavior changes, even slight ones; however, when she was first diagnosed, she would be very low before I knew it.”

“The first two years, I felt like such a failure. I never recognized when she was in trouble. Needless to say, I spent a lot of sleepless nights during those first few years.”

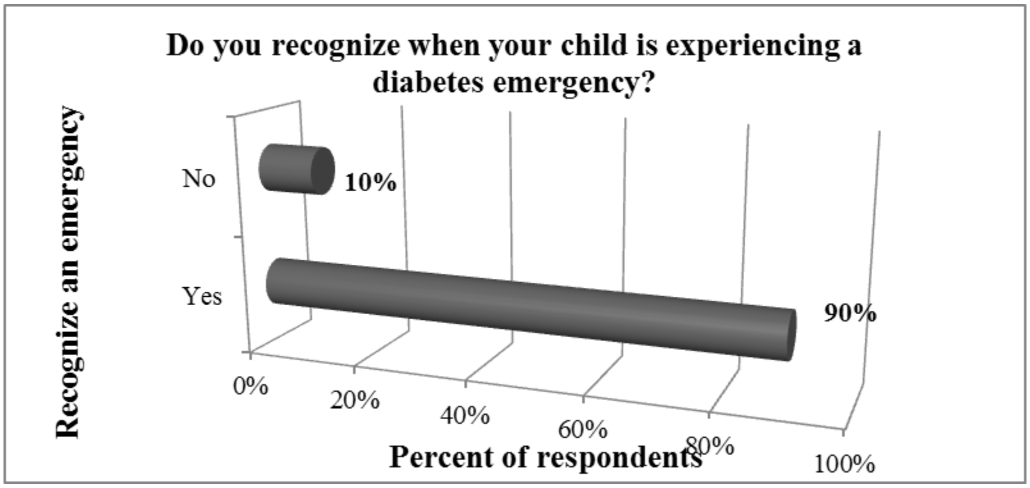

Figure 10. Bar graph illustrating emergency recognition.

Q: How do you know if your child is experiencing a diabetes emergency (what are the symptoms)?

The signs and symptoms of a diabetes emergency are easier to identify for a parent with more experience with diabetes management. The common signs and symptoms of a diabetes emergency can vary depending on the child and the circumstances. Hypoglycemia can happen very quickly and if left untreated can cause accidents, injury, coma, and death (ADA, 2015). Not always the same in each patient, symptoms of hypoglycemia include, shakiness, nervousness or anxiety, sweating, clamminess, chills, confusion, sleepiness, headache, weakness, and seizure; to name a few (ADA, 2015). There are also times when the child doesn’t know, or doesn’t exhibit any of these symptoms, but may be having a hypoglycemic episode. This is called hypoglycemia unawareness and when a person has this, they are less likely to notice signs of low. They are also less likely to be awakened out of their sleep for a low blood sugar (ADA, 2015).

All parents interviewed knew the signs of a diabetic emergency; however, parents did express concern about hypoglycemia unawareness. Parents feared that they would not recognize that their child was in trouble.

"Not only am I not sure when she is experiencing a hypoglycemic episode, sometimes she doesn't either."

"My son plays sports and sometimes the dehydrations masks the symptoms *of hypoglycemia."*

"I am afraid that I won't notice his hypoglycemia because he doesn't always slow down when he is low."

Without a Continuous Glucose Monitor (CGM), parents felt that it would be extremely difficult to monitor their children's lows. "I am thankful that our insurance covers the CGM, it relieves a lot of stress and worry about glucose, when my child is away from home." Those parent whose children do not have a CGM explained that "knowing the signs and symptoms of a low blood sugar are much harder to detect, if your child is not on a CGM." Another parent said, "I find myself second guessing the glucose readings and my daughter all day. She is so new in her diagnosis that sometimes she doesn't know when she is having a low, until it is really low. At other times she will think she is low and we will check it and she will have a very good glucose reading."

Q: How many diabetes emergencies does your child have per day or per week and how disruptive are they to your day?

It is important for parents to understand as much as possible about how to manage and treat their child's T1DM, in order to reduce the risk of diabetes related complications. It is imperative that children with diabetes maintain strict metabolic control, and parents work closely with a health care provider specifically trained to work with endocrine diseases (Hatherly et al., 2011). Parents indicated feelings of anxiety when their T1DM child experiences a diabetes emergency.

"I still get really nervous when my daughter has a low blood sugar. She can handle them herself for the most part, but I still get really nervous."

"Even though I know what to do, I feel really panicked when it happens. There is always the thought in my mind of, suppose this bring her glucose up enough or fast enough or suppose I give too much insulin to bring her glucose down."

"When I panic my daughter panics, so I try not to but it is really hard; especially if I don't have the things that she is supposed to have on me."

Eighty-five percent of participants stated that their children have between one and five diabetic emergencies per week, with an average of two per week. Parents with more experience (longer disease duration) expressed that, while it is not always easy handling a diabetic emergency, they try to allow as little disruption as possible into their normal lives. The unpredictable nature of diabetes has the potential to wreak havoc on your life. You can become a slave to the requirements of diabetes and stringent routine required to ensure that glucose stays stable and that lows or highs can be treated immediately. However, recognizing and quickly acting on diabetic emergencies can make a big difference in the daily lives of children and parents. Parents recognized that the demands of diabetes management leave them exhausted and fearful for their children. Nonetheless, parents desired to not let diabetes always be the main focus of their lives. There are considerations that have to be made; whether there is something readily available to treat a low, whether they have their glucose meter to measure their glucose, whether medication is onboard and available, these are all daily reminders of life with a person with diabetes. After adjusting to the initial shock of diabetes and its requirements, there were parents who focused on making sure that their child's diabetes didn't dictate their lives. Focusing on assuring their children that they are capable of doing anything they want, and learning to quickly adapt their situations so that they were in control are important adaptation tactics for parents of children with T1DM. Learning to recognize a diabetes emergency, being prepared to treat the emergency, and quickly returning to regular activity, was mentioned by parents as ways to try and minimize the effect of diabetes on the lives of their children. Parents recognize that there are days when diabetes will interfere and it won't be as easy to bounce back; however, their daily goal is to try and provide their children with normal childhoods. Parents identified being well organized as a mechanism to reduce the impact of diabetes on their daily routines. One parent explained her strategy, stating, "We stay pretty well stocked with carb appropriate items to treat lows, so that we are able to treat them quickly. We are able to just reach for the item, pass it on, and keep moving, as opposed to stopping to find things. Now I know what things may cause him to have highs or lows, so I am prepared just in case and able to act quickly." Another parent stated her strategy to minimal disruption as staying calm; noting, "I try not to make a big deal about it. Of course we act quickly, especially when she is having a low glucose, but I also make sure that we have items that will raise her glucose quickly on hand at all times. We make sure that we do glucose checks more often when participating in an activity that may lower her glucose or cause her glucose to rise."

Five percent of the participants stated that their children have more than five diabetes related emergencies per week. With almost one diabetic emergency every day, participants felt that it was a great disruption; particularly for parents with less experience with diabetes. Additionally, those parents whose children were getting older and responsible for more of their diabetes management and had more freedoms also noted the frequency of diabetic emergencies as a major disruption. One participant noted, "My daughter is in her teenage, experimental years; she doesn't check her glucose as she should and every day gets either a really high glucose or a really low. These teenage years are the worst for us." Another participant explained that her inexperience with diabetes management causes her to panic; stating that "We are still getting adjusted to this routine, but low glucoses really scares me, so I tend to let her get a little too high before I correct for it. I am trying to get better. This probably happens at least once a day, so our world is often in chaos."

Ten percent of participants said they have less than one emergency per week. These participants were the more experienced parents; thus they felt more equipped to handle a diabetic emergency. Many of these participants in this category had older children who were managing their own less severe diabetic emergencies. One parent stated, "I don't panic as I did when he first was diagnosed and had either a high or low glucose. Now I just treat accordingly and we keep it moving. Most times he is able to treat and get it where it needs to be himself. " Another participant admitted that she doesn't check as much as she should, since her son is older now. She explains, "He probably has more than I think, but since he manages a lot of them himself, I am not exactly sure how often he gets too high or too low." Another participant noted, "I think that since we have been doing this for about 12 years now, I don't even really count them in terms of how many per day or week, I just treat the glucose and we keep going."

Two of the themes that emerged from the analysis were that there are certain times of year that diabetes control was harder to maintain; one is holidays and the other is cold and flu season. Participants expressed that holidays were difficult to maintain diabetes control because there were more options and opportunities to tempt their children. With school parties, family dinners, outings and activities, holidays require parents to be much more vigilant in helping their children maintain diabetes control.

“I try very hard to keep the Halloween candy out of sight and don’t buy any at home; however, she always seems to find the candy and has an eating frenzy.”

“Holiday parties at school are the worse for us. She feels left out of the delectable treats that the other kids get. Even though the class always tries to get her sugar free treats. Who wants that?"

“The big family holiday meal is a very trying time for us. I know my family understands her restrictions and probably call themselves helping her sneak some of her favorite things,but that always lands us in the emergency room.”

“There are always so many delicious desserts at my mom’s and despite trying to make alternative items, my daughter always seems to sneak too much regular cake.”

“My daughter is on an insulin pump and she is a lot more responsible with her diabetes management, so that helps. However, sometimes she takes too much insulin for the “cheat” meal that she plans to have and then she doesn’t have all that she had planned. This usually leaves her with a low glucose and sometimes it drops too fast for her to catch.”

My daughter really likes hot chocolate in the winter and doesn’t like the sugar free kind. During the winter months she sneaks several packs to have and usually ends up with high blood sugars, a few times a week.”

Participants noted cold and flu season as another time of difficulty maintaining diabetes control. The symptoms of a common illness and medication to treat the illness can cause glucose fluctuations. Participants noted their difficulty with maintaining glucose control during these times..

“If she catches a cold or the flu that is the worse time for us. Her glucose will yo-yo all day. In any given day she will have several highs and several lows per day, during that time.

"When he catches a cold, it is very bad. He won't eat, even the sugar free cough syrups raise his glucose, and trying to keep him hydrated is problematic for us. It is always a really rough few days when he is sick."

"Last year she caught the flu and ended up in the hospital with ketoacidosis. I tried my best to keep that from happening, but I couldn't get her glucose under control."

"The worse time for her is cold, flu, allergy season. She is a really bad allergy sufferer and when it is allergy season there is no glucose control happening. No matter how hard we try, it just stays high. A cold really does her in too. We usually end up in the emergency room behind the common cold."

Another theme that emerged in the analysis that was of great concern for parents was the fact that their children are transitioning to managing their diabetes more independently and thus experiencing more highs and lows in the process.

"Now my daughter manages her own glucose, for the most part. She has been experiencing a lot of highs and lows. Sometimes she can't trace them back to a particular meal or event."

"Now that my daughter is older, she spends time going out with her friends, often she doesn't do as she should and in turn she has several highs or lows per week."

"My son is now at the age that he doesn't think he needs me to check his glucose and adjust his insulin. He is not as diligent as he should be, so he has a lot of highs."

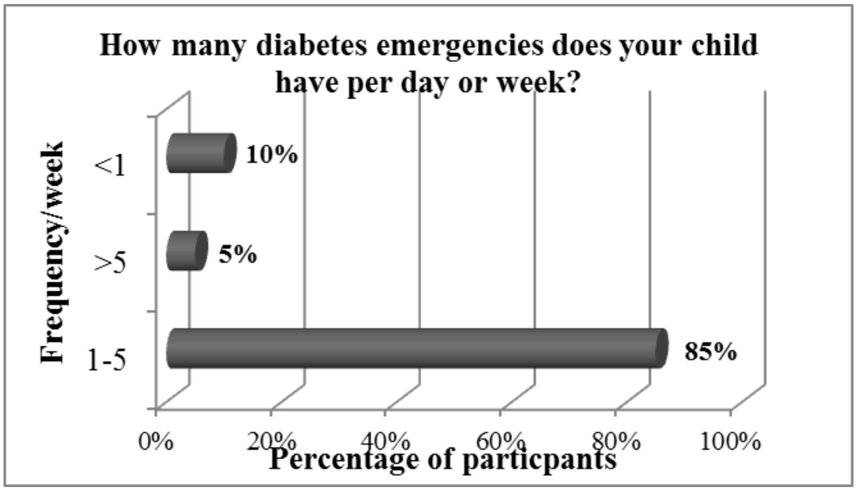

Figure 11. Bar graph illustrating diabetes emergencies per week.

Q: How do you ensure that you follow your child's diabetes regimen (blood glucose testing, medication decisions, dietary needs, activities, etc)?

Parents indicated that part of ensuring that they followed their child's diabetes regimen included a need to better understand the disease and how it affects their child. There were concerns about sick days, ensuring that they have given the right amount of medication, when to change the pump site, and how often to allow their child to eat sugar. Parents noted the importance of having a routine and following it to ensure that their child's diabetes stayed on track. Ninety-five percent of the parents interviewed indicated that they ensured that they follow their child's diabetes regimen by following a strict and well planned routine.

"In order to remain diligent with diabetes management, it requires that me and my husband split duties related to managing our son's diabetes. My husband is responsible for counting carbs, and mealtime medications. I monitor the glucose logs and blood sugars throughout the day. Without splitting it up, we would never be able to stay on top of all that needs to be done."

“I’m a single mom, but my 2 oldest children help me with diabetes management. They make sure that their brother checks his glucose and records his results. They also help him pack his lunch and snacks, so that he gets to feel a sense of independence without mom breathing down his neck all the time.”

“Everyone in our house has a position to play in helping with diabetes management. Everyone is vigilant in making sure that my daughter follows her diabetes regimen.”

“I have our daily routine posted on the refrigerator. It changes based on what is going on that week and what needs to be done.”

“We have a schedule of activities for all of our children posted in the home. I have a check list of things to check book bags and the car for every few days, to make sure that she never runs out of snacks. I go to the school every Monday to make sure that her snack container has everything she may need in it.”

Twenty percent of the parents indicated that they regularly consult their child’s diabetes education team, to include, dietician, endocrinologist, and nurses. The parents expressed that they heavily rely on their diabetes team.

“I call my son’s endocrinologist for everything.”

“I make sure to check in with my son’s diabetes education team at least once every two weeks. I fax blood sugar results to the office every week so that we can make adjustments as needed.”

“Whenever I am unsure about what is going on or what I should do, I call the nurse or diabetes educator at the office. They are very good with explaining everything and they will call back to check up and make sure that what they suggested is working.”

Fifteen percent of participants indicated that making sure they are aware of the most current diabetes treatments, advancements, and care aids, helps them stay informed of treatment options and antidotes.

"I make sure that I educate myself on new advances in treatment and technology."

"I take advantage of every opportunity to go to attend anything that offers diabetes education or talks about diabetes treatments. I want to be able to help my daughter make the best choice possible for her long term health."

There were no participants who indicated that they did not have a plan and course of action that they attempted to follow daily. However, parents did express difficulty in following the diabetes regimen, as their children transition to more independently monitoring glucose and taking medication. As previously mentioned, participants felt that as their children began to have more responsibility for their diabetes management, it was more difficult to ensure that the children followed the respective plans.

"I try to stay on top of what she is doing, even though she does much of it herself, but it is getting increasingly more difficult."

"I attempt to get her to follow the schedule and record what she is doing so that I can follow along to make sure she has what she needs, but she seldom does it."

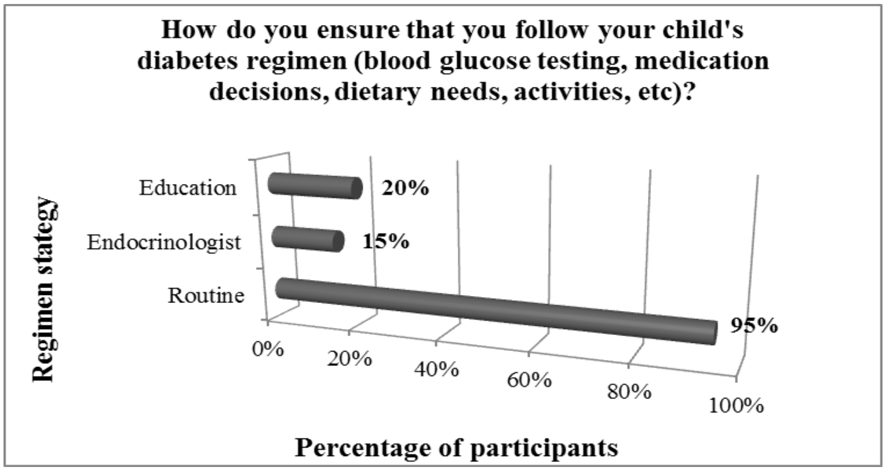

Figure 12. Bar graph illustrating methods used to ensure that diabetes regimen is followed.

Q: What is the most difficult part about following your child's diabetes regimen?

The day to day routine of caring for a child with T1DM can be very taxing on parents. The very rigorous and multifaceted daily activities consist of numerous finger sticks for blood glucose checks, injections, insulin pump adjustments, diet monitoring, and carbohydrate counting and adjustments (Doyle & Grey, 2010). The majority of the responsibility for these activities relies heavily on the parents. As children get older, some of the responsibilities of diabetes management are transitioned to the child. However, the level of anxiety and worry is still the same, as stated some of the parents interviewed for this research study. The unpredictable nature of diabetes management can cause a major interruption of the day to day activities and was noted as one of the most difficult parts of diabetes management by all participants.

Parents in this research study have consistently maintained their desire to have their children live a normal life. Parents realize that diabetes is something that their children will have to live with the rest of their lives; however, they stress the importance of leading as close to a normal life as possible. Busy parents with busy lives identified; glucose monitoring, challenges with meal planning and maintaining normalcy in their lives as the most difficult aspect of diabetes management.

Among the parents surveyed, meal planning was a big concern. Sixty percent of parents surveyed stated that meal planning was very challenging for them and often caused them great angst. Maintaining a good diet is an essential element to diabetes management and is fundamental to successful diabetes treatment (Patton, Dolan, Chen, & Powers, 2013). Parents expressed concern about making meals that would satisfy the entire family.

"I just don't know how to make sure I get her what she needs on the run. We have a busy schedule with evening activities and trying to plan for the entire day around diabetes is sometimes stressful. I can't afford to have forgotten something at home and be at the practice field."

"I am always concerned that I will not be able to get her a carbohydrate friendly meal on the run. Prior to diabetes, at least twice a week we would have quick meals at fast food restaurants. With my busy schedule and the kid's homework, practices, and other activities, I find it difficult to prepare home cooked meals."

"Trying to prepare his favorite meals so that they don't affect his glucose is the most difficult part of managing his diabetes. I have not figured out how to adapt and adjust recipes yet."

"I often have to prepare two meals because my family refuses to eat what they consider, diet, meals."

Parents expressed interest in learning how to prepare traditional "soul-food" in a way that would still be appetizing, yet carbohydrate friendly for their child. "I would really like to be able to adapt some of our favorite meals, so that they are still delicious, but are more carbohydrate friendly, state one parent" Another parent said, "I have problems carb counting and adjusting the insulin requirements for some of his favorite meals. I still don't understand what I am doing wrong."

Thirty percent of parents interviewed identified constant glucose checks or "finger sticks" as a very difficult and time consuming aspect of diabetes management and following the prescribed regimen. They identified timing of glucose checks, supplies, and treating adverse glucose results were difficult for them to keep up with. "Those 3 AM glucose checks are really disruptive. I have a hard time getting back to sleep, but I know they need to be done, stated one parent" "My daughter is not on a CGM and she is very active, making sure her glucose stays in range is a constant battle for us, explained another parent." Parents expressed fears of overnight hypoglycemia and monitoring glucose during times of illness. One parent expressed, "Every night that I go to bed, I sleep very lightly. I need to hear her if she cries out in the night." Another parent explained, "I am always afraid that she will have a low and I not hear the alarm. I always feel sleep deprived." Parents of children who are active in sports and other physical activities stated that during those times of activity, they are always fearful. One parent explained, "I attend every game, every practice, and I stay around even if they go out after games or practice. I don't want to hover so much, but I do." Another parent discussed how she deals with her fears about her daughter having a diabetic emergency. She stated, "I am always here. I attend every soccer practice, soccer game, band practice, band performance, and field trip, just in case my daughter has a diabetes emergency."

Ten percent of parents indicated that they just want to keep their lives as normal as possible. Parents admitted that since the diabetes diagnosis they have had to change the way they do a lot of things, both as a family and individually. The lifestyle changes have been life altering for these families. From not letting their T1DM child spend time alone with family and friends, to middle of the night glucose checks, to dealing with schools and teachers, parents admit that their lives are not the same. Parents stated, “no matter how much we try, life is not as it was before the diabetes diagnosis”. Another parent noted, “It is impossible to not think about some aspect of diabetes, every day.”

“There is really no way to plan with this disease. You have to be ready for a low or a high, even when you have done everything right. That is the most difficult part to me. We will be going along fine and BOOM; low blood sugar sneaks up.”

“My son’s blood sugar jumps all over the place. He is very susceptible to even light exercise, some sugar free products sends his glucose higher than regular sugar, and sometimes his glucose goes from 150 to 300 in a few hours, without him having done or eaten anything. It is very frustrating for him and me.”

“Even with all the unpredictability of diabetes, I try to make sure my daughter maintains as normal of a childhood as possible.”

“Sometimes she feels like an outcast, so we work really hard as a family to keep things normal. We don’t get all excited with high or low blood sugars, we just try to treat them and kep it moving. This actually helps her bounce back much more quickly and she doesn’t feel as embarrassed afterwards.”

“I worry that my daughter will suffer some diabetes complication that will drastically change her life.”

Another parent noted that they were a very active and social family prior to diabetes. However, she feels that since her son has been diagnosed, he does not attend as many social outings with his friends. Parents noted that although they have a desire for their children to maintain normal activities, they find it hard to let them go.

"Before diabetes, we were a very active and social family. We don't go on as many social events and outings with friends since her diagnosis."

"Sometimes my daughter would rather not go with her friends because she feels that her dietary restrictions will make her feel more uncomfortable."

"I don't let her spend the night with friends or even other family members. She has been diagnosed for 2 years now, but I am still very skeptical about letting her be with others overnight."

Impact on the Children

Diabetes management is a rigorous and complex task. The child diagnosed with T1DM must adhere to a strict diet, exercise, and glucose monitoring regimen in order to maintain healthy glucose control and decrease the likelihood of diabetes complications (Standards of care, 2009). With diabetes advancements, those with T1DM can look forward to newer insulin therapies, newer insulin delivery options, preventing hypoglycemia through monitoring technology, and hopefully a cure (Aathira & Jain, 2014). There are many options available to children with diabetes that help them lead seemingly "normal" lives, but those advancements only partially reduce the fear that parents have about their children's future.

Q: What do you feel are the limitations placed on your child due to their diabetes?

When asked about the limitations for their children due to diabetes, all 20 parents interviewed felt that there were no life altering limitations placed on their child because of their diabetes. However, they felt that there were things that must be done more cautiously in order for them to be successful. Parents identified possible diabetes related complications as an area of limitation. All parents expressed fears that if their child with TIDM did not work at maintaining good glucose control they would have serious diabetic complications that would affect their future aspirations. Maintaining good diabetes control requires vigilance on the part of the parent and the child and is paramount to preventing diabetes complications. Additionally, parents felt that as long as there was proper preparation, their children would be able to do anything they set their mind to.

"My daughter plays tennis, babysits, is a cheerleader, and on the dance team. She does everything she wants to do. We just make sure we do several glucose checks before, during, and after activity, to make sure that she is within range or won't get low."

"My son has no limitations. He can and does do everything he wants to do. However, I still prefer that there is an adult that knows how to handle his diabetes around. I still worry a lot."

"I feel that she can do anything she wants to. She is her own worst enemy because she doesn't manage her diabetes well. She doesn't take her insulin as she should and she eats whatever she wants when she is not around me or my husband."

"As she gets older, her diabetes control is not as good. I worry about her developing complications. I think avoiding diabetes complications will be her biggest challenge, if she doesn't start doing better."

"I just worry that he will lose a limb or his eyesight, that is the only thing that I think will hold him back."

Q: How do you feel that your child's diabetes will change their future goals and aspirations?

Similar to the question above, the overarching theme from the parents to this question was that they felt that diabetes would have no bearing on their child's future goals and aspirations. One parent commented that, "Diabetes can't stop my son from doing anything. We continue to encourage him to strive towards his dreams." Another felt that, "We won't let diabetes limit her. She can and will do and be whatever she wants to." Yet another expressed similar thoughts, "Staying in good glucose control is the key to doing and being everything that she wants to be."

A second theme the parents expressed was the importance of closely following the prescribed diabetes regimen and preventing illness and diabetic complications. They felt that developing diabetic complications was the only obstacle to their child living the life they dreamed of. All parents indicated that they continue to instill in their children that they can be anything they desire. Parents admitted that there may be professions that would be harder than others to excel in, due to diabetes; however they continue to encourage their children.

"My son wants to be a pilot. I am not sure that he will be able to achieve that dream because of regulations that may prohibit him from doing that."

"My daughter wants to go in the military; current criteria prevent her from enlisting. We are hoping that by the time she is old enough, there will be new regulations that will allow her to enlist."

"I encourage my daughter to make sure she follows her diabetes regimen so that she is in the best health to go into any profession that she chooses."

"I understand a lot of the rules against diabetic going into some professions. I know that if the diabetes regimen is not followed strictly, it could be hazardous for the person with diabetes and others."

"Diabetes is a difficult disease to control and is very unpredictable. If my son is a firefighter and he is in the middle of saving someone and his glucose gets low, that could be detrimental to my son, the person he is trying to save, and the entire squad. I understand that."

Many parents felt that their children could be role models for other children who are facing adversities. They felt that the independence, leadership, and responsibility needed for a child to live with T1DM requires strength and courage and they hoped that they could serve as examples of that for their peers. Additionally, some parents felt that the opportunity to inspire other children and be an example might help to ease the angst of having diabetes; helping their child be more diligent about glucose control.

"I hope that my daughter will inspire other children; showing them that anything is possible."

"My son can be a positive role model for other children with chronic diseases, he just doesn't embrace it. I am hoping that he realizes the influence he could have on other kids."

"Many kids look up to my son. The maturity that he displays in managing his diabetes, has helped other kids conquer some of their fears."

"My daughter has found her voice in diabetes advocacy and is often asked to talk about it to other children and adults. She really enjoys that and likes to be able to report that she has been having good numbers."

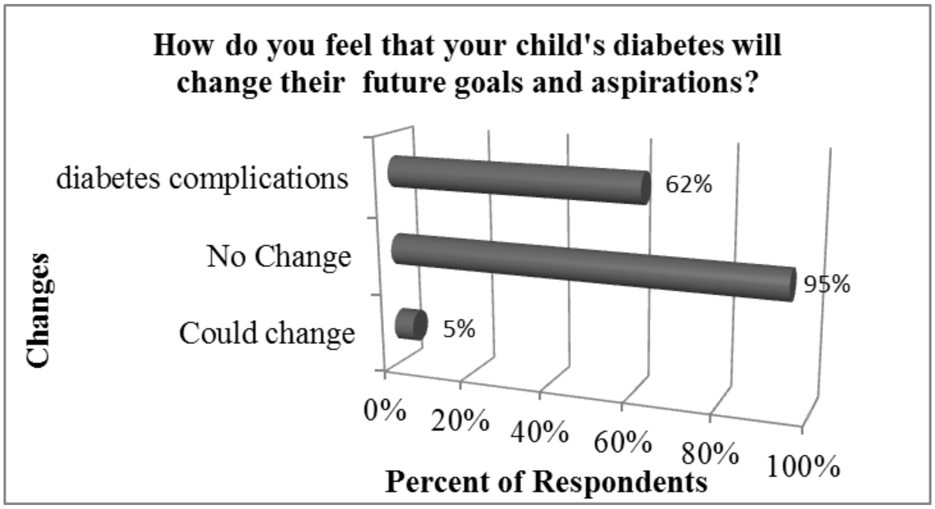

Figure 13. Bar graph illustrating how diabetes will change child's future goals.

Q: What are the things that interfere with your child's diabetes?

Although parents overwhelmingly felt that there was nothing that their child couldn't do, the reality that diabetes has an impact of their child's daily activities was evident and apparent in their responses. Parents were asked about the things that interfere or prohibited their child from maintaining optimal glucose control. Parents felt that there were many common things that impact their child's glucose control. Among those things considered to have an impact on glucose control were sick days (cold, flu, virus, etc.), physical activity, and diet non-compliance.

The majority of parents interviewed felt that diet non-compliance was the largest interference to their child's quality of life with diabetes. Not following the prescribed diabetes diet and properly counting carbohydrates pose the greatest risk to their children living productive lives with diabetes. One parent explained, "My son is very diligent about glucose testing, but he is not diligent with diet compliance. He will check his glucose, but he doesn't always follow his diet well and he doesn't adjust his insulin for cheat meals." A parent commented that, "My daughter doesn't always check her glucose and being on a pump, she sometimes doses before she eats; causing her to experience lows, quite often." Additionally, another parent explains about her son's struggles, "Even after 5 years, he has not gotten it into his head about candy. I almost have to strip search him every day. I find candy wrappers all the time. It is not so much that he eats the candy or other things, it is that he doesn't adjust his insulin accordingly."

Physical activity was noted as an area of concern related to maintaining glucose control. Physical activity can cause hyper or hypoglycemia and parents noted that during physical activity, they have to take extra precautions for their children. "Often after a track meet, his glucose will be as high as 500. His glucose rises quickly and drops quickly. We have to stay on top of his blood sugar at least for the first 2 hours after the track meet," stated one parent. Another parent said, "Before cheerleading practice I make sure that she checks her blood sugar and is at least at 200. If she starts at anything less than 200, she will start dropping before the game is over. This is the kind of delicate dance we do every time she cheers."

Other parents indicated that when their T1DM child experiences a cold, flu, allergy, or other common illnesses, it negatively affects their glucose readings. "He is very susceptible to colds and has very bad seasonal allergies. When he catches a cold or is suffering during allergy season, I am sure to be called to pick him up for a high glucose at least once during the week." Another participant noted that, "When my daughter gets a cold, she almost always runs high, very high. It doesn't matter what I do, she still runs high."

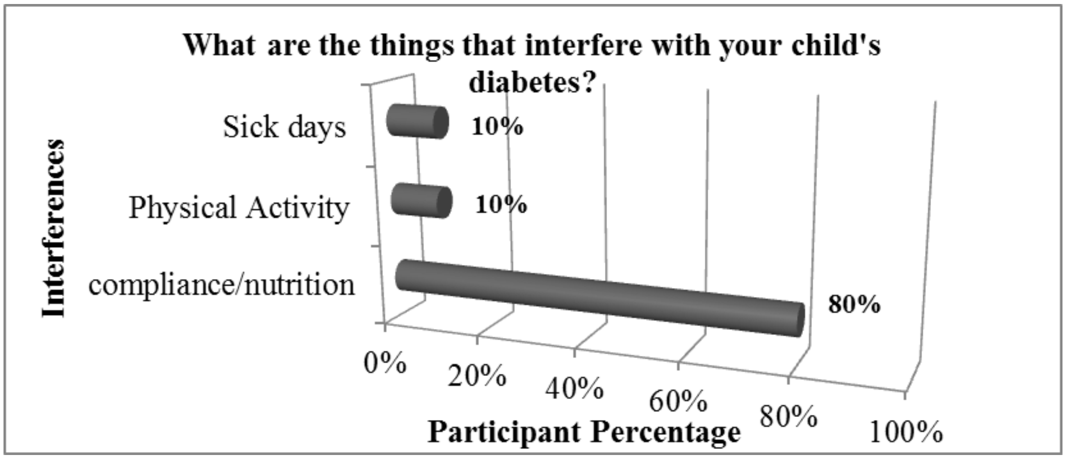

Figure 14. Bar graph illustrating the things that interfere with child's diabetes.

Q: Based on your child's most recent endocrinologist visit, do you feel that your child is in good diabetes control, fair diabetes control, or poor diabetes control and why?

Of the 20 parents interviewed, 40% feel that their T1DM child is in fair glycemic control. The parents who indicated that they felt their child was in fair glucose control were satisfied with that; stating that they are unsure if their child will ever reach "good" diabetes control.

"My daughter is probably in fair control. We are pretty diligent about medication and checking blood sugars. Her HbA1c is still not where her endocrinologist wants it, but hey…"

"I think we do the best we can. Her blood sugar runs a little high a few times a week, but her HbA1c is better than it has been, but not where her endocrinologist wants it. I think we are could be classified as fair control. I don't mind that either. I think we are improving."

"I would say fair control, but his endo doctor would probably say horrible control."

"I would say fair control, but we are working on getting better."

Thirty five percent of parents interviewed feel that their child is in good glycemic control.

"I say good control, his endo says differently. I think we do a good job trying to manage the blood sugar."

"I do the best that I can, so even when they are disappointed with his glucose results I still feel that we have done well."

"I think she is in good control. Of course there are always improvements, but I think she is in good control."

Twenty five percent of parents feel that their child is in poor glycemic control.

"I'm pretty sure her endo would classify her as in poor control. We have major problems with staying in control. She is older now and I have less control over what she eats and when she eats it. As a consequence her A1c has been running over 8 for a year now."

"I am so new to this. I feel so bad, but I know that he is way out of control. We are learning and working to get better."

"I am ashamed to say that he is in very poor control right now."

Parents rely on the advice of their diabetes care team to inform them of their child's progress in maintaining glycemic control. Of the parents interviewed, regardless of their diabetes care team's perspective, parents had their own perception of their child's diabetes status. Parents were reluctant to say that they felt that their child was in poor diabetes control; stating that poor diabetes control indicates that they have failed to manage the disease.

"I always feel like I have failed, when we go to the endocrinologist."

"I feel like the endo looks at me with disgust when he is reading my daughter's test results."

"I feel like I will never get this right. It is so frustrating trying to get their approval."

"I often feel like a failure when her lab results are high. It is my job to make sure that she does what she is supposed to do, but sometimes things fall through the crack".

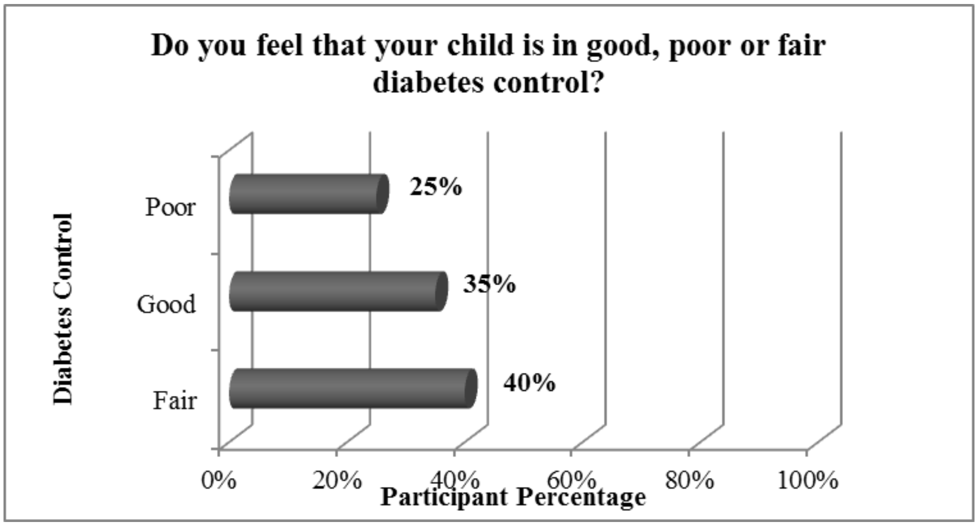

Figure 15. Bar graph illustrating feelings of child’s diabetes control.

Social Impact

Managing blood glucose control in children with T1DM is complex and time consuming (Spencer, Cooper, & Milton, 2014). The outcome of chronic illness is affected by psychological, emotional, and social factors (Oskouie, Mehrdad, & Ebrahimi, 2013). There are many barriers to successful management of T1DM and coping with the stresses of management include; low social support, financial stress, and lack of access to providers (Oskouie, Mehrdad, & Ebrahimi, 2013). In a study conducted by Wennick et al. (2009), children noted that it was tiresome and stressful to try and explain diabetes. Knowing that their children feel uneasy, parents are apprehensive about with whom to discuss their child’s diabetes.

Q: How do you prepare others (friends, family, teachers, etc.) to recognize or handle a diabetes emergency?

Study participants noted that when their children are young or newly diagnosed, they don’t allow them to stay with friends or even family. Participants recognized that eventually their children will have to stay with other people, but they were very apprehensive to allow them to be away from home.

"I have not left him with anyone other than his father, since his diagnosis; and I am skeptical about that."

"I want to make sure that everyone my daughter spends time with has information that they can readily go to, to help them figure out her needs."

"I want to make sure that everyone my son spends time with is comfortable with diabetes management and know what to do in case of a diabetes emergency."

"I don't want them feeling uneasy or not let him do things because they are not sure if he can because of his diabetes."

The overarching theme from the participants was that they would provide education to those with whom they would leave their child. This included personal training, books, pamphlets, websites, and other sources for self-education. When it comes to teachers and school officials, some participants indicate that they meet with teachers prior to the start of each school year and discuss the signs and symptoms of hypoglycemia.

"I make sure that everyone, family, friends, teachers, youth leaders, etc., know how to use the glucagon kit and know how to treat a high or low glucose. I provide them with information and training, so that they feel comfortable."

"I try to take the guess work out of what to do. Anyone that I leave him with will have carb counted meals and snacks already prepared for him. I provide all the supplies that he will need while he is in their care."

"I provide written instructions on what she be done and how to do it." "I make sure that I stay educated on all the new treatments and tricks of the trade, so that I can help others understand what they need to do."

"At the beginning of each school year, I meet with her teachers to explain her diabetes needs, signs, and symptoms."

"When she goes to summer or after school camps, I provide pamphlets and a brief training for those who will be interacting with her."

"I take a class and assessment yearly, so that I am up to date with the most recent treatments and products. I take this knowledge and inform others about her needs."

Q: Do your friends, family, etc., feel that they can recognize a diabetes emergency and act on it?

Although parents indicated that they provide training and information to those who their child is likely to spend time with, without them, they admit that there are still family, friends and teachers that do not fully recognize a diabetes emergency. Sixty percent of parents believe that their friends and family feel confident that they can recognize a diabetic emergency. Affirming their confidence one parent stated, .. "I think they recognize when there is a diabetes emergency." Another parent expressed, "I think they will recognize if she is in trouble."

There were 15% of the participants that believed their friends and family could not recognize a diabetes emergency at all. One participant stated, "I am confident that my parents would not recognize a diabetes emergency; therefore I only leave my son with them when there are no other options." Another participant commented, "I would love for my daughter to spend more time with my parents, but I know they do not know if she is in trouble, and I am afraid to take the chance." While another participant expressed, "I do not let my daughter participate in team sleepovers, etc. I know his team mates don’t understand and the coaches don’t seem to recognize when he is having a diabetes emergency.”

25% of parents felt that their friends, family, etc., were unsure of how to recognize a diabetes emergency. Parents felt uneasy about leaving their children with those that they had no confidence in their ability to handle a diabetic emergency. However, they admit that they would leave their child with family members anyway; for fear of hurting their feelings and recognizing the need for their child to keep family ties strong. Parents admitted that they did not want to offend friends or family members and often gave in to letting their children stay, even though they didn’t always feel comfortable. Providing the knowledge to act during a diabetic emergency was easy. However, ensuring that they were vigilant about following diabetes requirements was a much harder task.

“I am not totally convinced my parents know what to do, if my daughter has a diabetic emergency in their care, but they try so hard and plead so much that I let her spend the night sometime anyway. I find myself checking in every few hours and then that insults them. I know that they wouldn’t intentionally hurt her, but I am not confident in them making her watch her diet. They tend to let her cheat too much.”

“I think they know when he is experiencing a diabetic emergency, but I wouldn’t say they are confident that they can recognize it in the beginning. Because of that, it is a no for me with letting him stay away without me. Family and friends are often upset, but I just won’t do it.”

”*I am always uneasy, but my husband says let him go. I agonize and worry the whole time he is away.”*

“I have to trust that he will be OK when not in our care, so that I don’t smother him. I let him go with others, but I don’t want to.”

"I am always uneasy when she spends time away from us. I pray and ask God to protect her. That is the best thing I can do for her."

"I have lost a few friends because since diagnosis, I don't leave her with anyone because I am just too afraid. I know they are smart enough to handle it, and at least know how to call 911, but I won't do it. It never dawned on me that people would be offended by this."

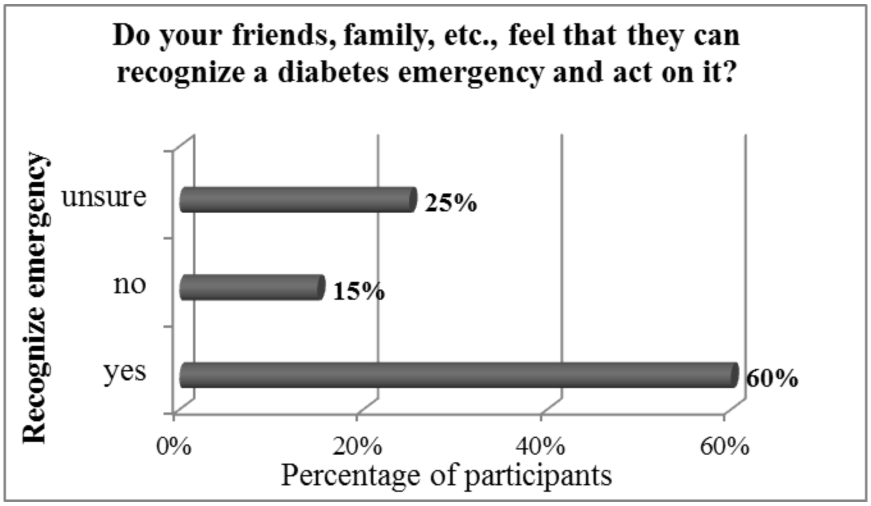

Figure 16. Bar graph illustrating feelings of recognizing a diabetes emergency.

Q: Do your friends, family, etc., follow your child's diabetes regimen when in their care?

Parental and family support is crucial to successful management of T1DM in children. Involvement in diabetes management from parents, friends and family; particularly in young children is important to maintain cohesion (Hilliard, Herzerb, Dolane, & Hood, 2011). Having confidence in the ability of caretakers to follow the diabetes regimen, in the parent's absence, was a major concern for many parents. Parents want to have confidence that those entrusted to care for their T1DM child will follow the diabetes regimen to prevent a diabetes emergency. Parents stated that they provide all who will be entrusted to care for their child, information and training needed to maintain glucose control, but admit that some do not follow the plan. Even though 75% of parents feel they can rely on friends and family to follow the diabetes regimen, 25% of the participants feel that their friends, family, etc., do not follow the regimen. The participants who could rely on family and friends said, “Her godparents are always very diligent when she is in their care. They have even taken classes on their own, so that they know how to administer medication, what to look out for, and how to treat;” and “Our friends and family are always very diligent about making sure that they know what she can and can’t have and how to compensate with medication if she is running high.” Whereas, those who couldn’t rely on family and friends stated that, “Some of my family refuse to do right, they just don’t act like he has diabetes;” and “I can’t trust my parents to not give him a lot of junk food, and then they don’t adjust his insulin accordingly. We pick him up and his blood sugar is always sky high.”

Parents’ spoke of the stress and fear experienced when their child is left with someone who does not make diabetes management a priority.

“It is stressful for me when I leave my daughter with her cousins. She doesn’t monitor her blood sugar, eats everything, and when I come back she is sky high.”

“I know that hanging with her friends is important, but they will help her sneak candy and junk food. She doesn’t like taking her insulin in front of them, so consequently she is very high when I pick her up.”

“Since diagnosis, I almost don’t want to even leave her at school. She occasionally stays with a neighbor after school. I am always worried until I pick her up. At the neighbors, she gets to eat what she wants. No matter how I have tried to stress the importance of the diet to her, she just is not diligent.”

“I am almost neurotic when he stays away from home. He is very close with one of my friends and her kids, so in an effort for him to maintain relationships he stays over occasionally.

She doesn't really enforce any limitations on him, so he has a smorgasbord while there and comes home with glucose out of this world; talk about stressful and frustrating.. "

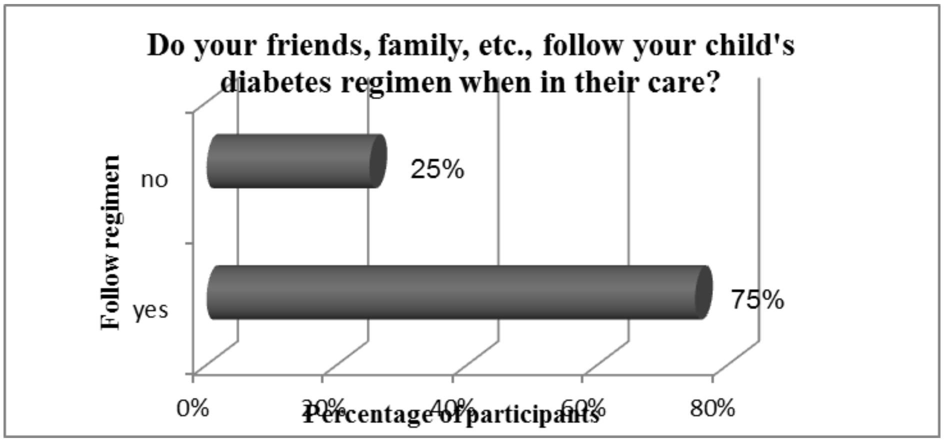

Figure 17. Bar graph depicting the number of people that follow the diabetes regimen.

Q: How do other family members react when your child is having a diabetes emergency?

Forty-five percent of the participants stated that their families are calm and helpful when their child is experiencing an adverse diabetes reaction.

"Everyone in my immediate family and in our household are calm and able to handle diabetes emergencies. Everyone jumps in and helps where needed, when he is having an emergency."

"We have all gone through extensive diabetes education, so everyone just moves into action when needed."

"Having the proper diabetes education really helps. Everyone has been educated, so they feel really comfortable and can react sometimes before me."

Fifteen percent of the parents interviewed expressed frustration, stating that their family acts hysterically and causes more uproar than necessary during a diabetes emergency.

"My parents are all over the place, hysterical. They don't know what to do because they don't take the training I've been trying to give them seriously."

"When she is having a low, especially, it sends the whole house in an uproar. Even though we have a plan of action and duties for everyone, they seem to go out the window when needed."

Forty percent of parents stated that their family was a little nervous. Despite their nervousness, however, participants stated that their family was helpful and knowledgeable.

"They act like they don't know what to do, but they spring into action when needed."

"My sister is always a little shaky, but she does what she knows what to do and has done it many times."

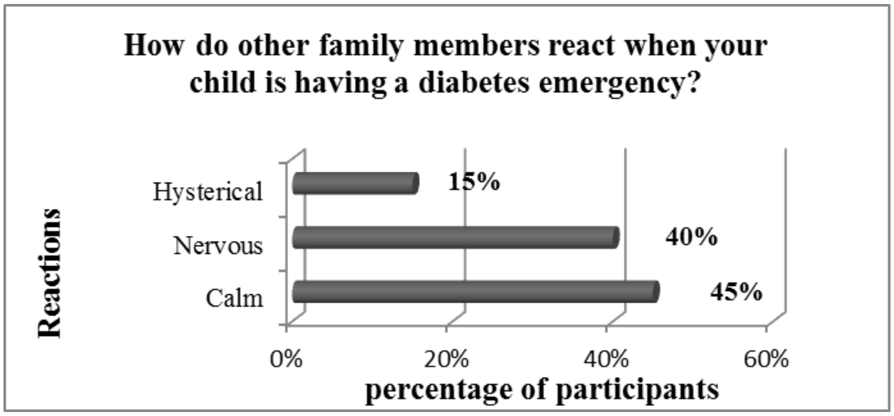

Figure 18. Bar graph illustrating reactions to a diabetes emergency.

Q: How comfortable do you feel leaving your child with friends or family?

Recognizing and reacting to a diabetic emergency, in a timely manner, can cause anxiety; especially if not trained to respond to diabetic emergencies. Parents expressed the need to feel comfortable leaving their child with friends or family, and knowing that their diabetes will be managed. Ensuring that their child stayed with someone who would take their diabetes needs seriously was of the utmost importance to the participants. Confidence in those that their children were left with was important to all of the participants. However, 20% of the parents interviewed indicated that they feel very uncomfortable leaving their child with family and friends. Feelings of anxiety and apprehension about leaving their child with someone who might not react in time was felt more during the early years of diagnosis.

"I am always worried the whole time we are out, when I leave my daughter with one of my best friends. She knows what to do; I just worry that she may miss something."

"I still don't let my son stay with anyone; maybe when he is older, but not now."

"I think when she gets older, I won't feel as nervous. Right now she is so young and it requires a lot of checking at night. I am not comfortable that other people will do 3am blood sugar checks."

"We are so new to this disease that honestly I just don't trust anyone. I am just not comfortable letting her spend the night away. I have tried doing it a few times and I don't sleep at all. I usually end up calling a lot."

"It has been almost a year and I have just started to feel like I might let her spend the night with my sister. I still worry that her late night glucose checks won't get done, though."

Forty-five percent of the parents felt comfortable leaving their children with family and friends. One parent stated, "Many of our family and friends have voluntarily taken training or try to make themselves very knowledgeable about the condition. I have the utmost confidence in their abilities". Another parent noted "In order for us to have a normal life, which includes him doing what kids do, I have to let him spend time with his friend. To ease my anxiety, his best friend's mom and dad have taken classes. I feel completely comfortable with them." Discussing her confidence in those she leaves her daughter with, one parent stated, "I feel OK about most of my family and friends watching my daughter. They are all very diligent about her diabetes management."

Thirty-five percent of parents felt slightly uncomfortable about leaving their child with family or friends; meaning they were not confident that the person could or would act in time or appropriately when faced with having to make diabetic related judgement calls. However, parents expressed feelings of relief when they were able to steal away. Parents confided that they long for the break from the rigorous schedule and stress of managing their child's diabetes and welcome the help from family and friends. Many parents admitted to just conceding to accepting the offers to help and decided that if their glucose was not in acceptable range, they would just "work it out" later. The daily routine of diabetes management in children is stressful and time consuming. No matter how parents focus on maintaining normalcy to their lives, diabetes management adds extra responsibilities that cannot be ignored.

"There is no break from diabetes, so I have learned to accept the times when she can get a break from us and we can get a semi-break from diabetes management. We just work out her glucose issues when she returns."

"*There are still only a very few people I will let him stay with, but boy do I appreciate those people. My sister is one of them. She does a good job with helping him stay on track, but sometimes they just go HAM and those times are really bad."*

"As it stands right now, my need to have some alone time, outweigh my fears of her staying away from me. I just send her on and pray real hard that everything will be OK. I close the door and welcome the opportunity to sleep through the night and not have a 3am glucose check."

“*I am so glad when she has somewhere to go. Sometimes we just need the break. She also needs the break from us. I am always a little nervous, but so far it has always been fine.”*

“We have not had any problems with her staying away, but I am still very nervous.”

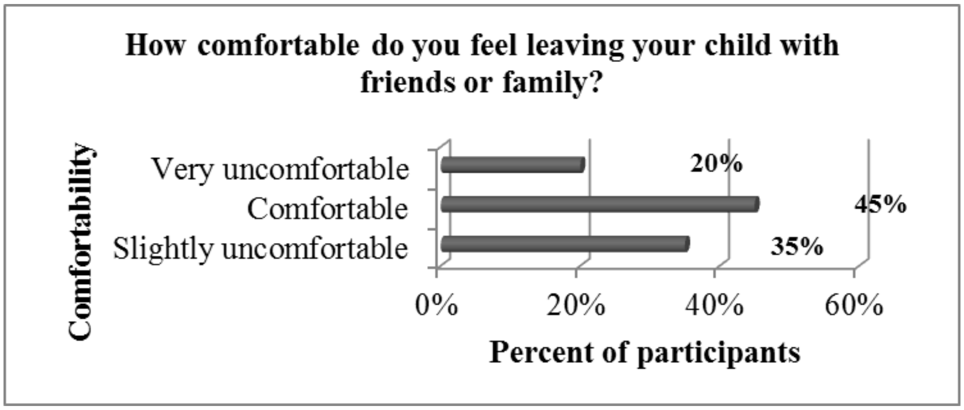

Figure 19. Bar graph illustrating comfortability leaving child.

Q: Do family members and friends feel prepared to handle a diabetes emergency, when your child is in their care?

Many parents worry that, although others may know how to handle a diabetes emergency, they may not act in time to sufficiently treat the need. The parents interviewed stressed the need to make sure that family and friends are properly trained and have resources to answer any questions they may have. Seventy percent of the parents interviewed indicated that their family and friends felt prepared to handle a diabetes emergency.

“All of my immediate family and close friends voluntarily took diabetes education classes. They are all prepared to handle anything that I am prepared to handle; some even more than me.”

“They want to know everything that I know, so they stay up on everything. They only want the best for him.”

"I love how my son's baseball coach, and scout leaders have taken diabetes education, so they are prepared and knowledgeable to handle anything that may come up."

Fifteen percent of parents feel that their friends and family felt unprepared and another fifteen percent felt that their friends and family were somewhat unprepared. Those who indicated that their friends and family were somewhat unprepared was because they felt they would panic.

"Even after all these years, my parents still are not comfortable with the finger sticks and insulin injections. They know the signs and symptoms of a high or low blood sugar, but they are still pretty frazzled when they have to act on something."

"My support team knows what to do, but they still get really nervous and feel unsure when they have to do it."

"They know when my daughter is having a low, but they will grab anything to treat it, so they often over shoot it. I leave things for them to treat a low, but they will grab anything."

"My mother knows what to do, but she always gets in a panic when she has to treat a low blood sugar."

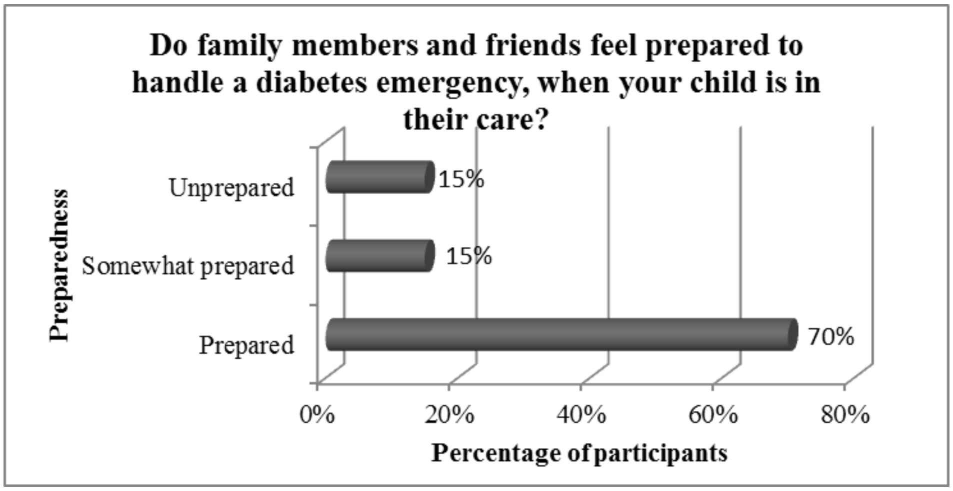

Figure 20. Bar graph illustrating preparedness to handle a diabetes emergency.

Summary

Each year the cost associated with T1DM is nearly $15 billion in the United States (Tao et al., 2010). Study participants emphasized the financial strain that T1DM places on their family. As reported by study participants, the costs associated with T1DM soars to more than $300 monthly. Common expenditures include medical bills and diabetes supplies. Among the monthly expenditures that contribute to the financial burden of diabetes are, medical bills, to include doctor visits and co-payments, and insurance premiums; along with diabetic supplies, including test strips and medications. As a result of the high cost of diabetic supplies, parents admitted to taking short cuts and altering the recommended diabetes regimen. Less frequent blood glucose checks, in order to use fewer test strips, was a common practice among all parents. Additionally, missing appointments was noted as a frequent occurrence because time, distance, or finances prevented them from keeping their appointments.

All participants felt that their lives were affected in some way by T1DM. The affect, great or small, has the potential for life threatening consequences, if not managed appropriately. The majority of participants identified one to five diabetic emergencies per week. The magnitude of the emergency varied and the time required to address the emergency differs; however, their lives are affected. Disease duration and experience managing diabetes seemed to play an important role in how these emergencies affected the everyday lives of parents. Parents, who indicated that diabetes greatly affected their everyday lives, noted that the rigorous demands of diabetes management sometimes get to them. Additionally, these parents indicated that they have a great deal of fear and experience stress and worry over the long term possibilities of diabetes mismanagement. Of the parents that indicated that diabetes greatly affected their everyday lives, therefore interfering with regular activity, those parents tended to be more recently diagnosed with all having five years or less experience with diabetes management. The manner, in which diabetes affects the lives of the participants, seemed to decrease as parents gained confidence and experience in managing diabetes and diabetic emergencies. Parents with five years or more experience managing diabetes indicated that diabetes on minimally affected their lives. Minimal effect, as indicated by parents, refers to parent’s ability to treat the adverse glucose reaction and continue with regularly scheduled plans. These parents leaned more towards continuing to live full, uninterrupted lives with diabetes. Their focus was not to let diabetes dictate the life paths of their children. The way that diabetes affects the lives of parents ‘decreases as children get older and the family gains experience with diabetes and its needs. As parents gained more experience with managing diabetes and children got older, some parents were able to deviate from the prescribed regimen. Parents admitted to not being as strict on certain aspects of management and care as they were in the beginning stages of diagnosis.

Diabetes management is a daunting task and can be very overwhelming to manage. The time required to perform diabetes related tasks decreased with experience. Thus, the longer the disease duration, the easier the management tasks become, according to participants in this research study. Parents with greater than five years disease duration found that performing tasks related to diabetes management and planning required less time than those with less than one year of experience. From checking in with teachers, school nurses, relatives, and day care providers; to planning, packing, and monitoring meals, parents can quickly get consumed with diabetes management activities. As parents gained more experience in managing diabetes and children began to be responsible for more of their own diabetes management, the time required to complete the daily tasks drastically diminished.

All parents agree that successfully managing T1DM has its challenges and they often feel in the dark about what is best for their child. High on the list of challenges for parents were, maintaining a sense of normalcy, multiple glucose checks, nutrition, and managing hypo-glycemia. Noted by all parents as challenging was performing the necessary number of blood glucose checks per day. All parents admitted taking short cuts to manual blood glucose checks, in order to cut cost on test glucose test strips. Maintaining a normal lifestyle for their child was noted as one of their greatest challenges. It was important to parents that their children not miss out on any of the normal activities available for children without T1DM. Parents found it especially challenging to ensure that they are preparing meals that contain the correct nutritional proportions. Counting carbohydrates and adapting their traditional meals to a more carbohydrate friendly make-up was noted as extremely difficult by parents. Parents admitted encountering challenges in preparing meals that would satisfy the entire family. Additionally, preventing instances of hypoglycemia were noted as difficult in managing their child's diabetes by an overwhelming number of the parents interviewed. Late night glucose checks, constant monitoring during physical activity and times of other illnesses were identified as sources of hindrance for diabetes management among parents.

The majority of parents confirmed that they knew the signs and symptoms of a diabetes emergency and were confident that they knew when their child was experiencing a diabetes emergency. However, there were some parents who knew the signs and symptoms, but were unsure that they could readily identify when their child was having an emergency, since sometimes the signs are not easily spotted. Parents feared that if their child didn't exhibit the usual signs and symptoms of hypo- glycemia or hyper-glycemia, they would not be able to react in time. This was mostly a concern for parents who had less than two years of experience managing diabetes. However, parents were confident that with more time and less worry, they would be able to identify a diabetes emergency with no problem. Participants reported that managing their child's diabetes could be time consuming; reporting less than one hour for diabetes management for more experienced parents, and up to three to four hours for parents with less experience with disease management. Participants noted preparing meals, counting carbs, and communicating daily with the schools and teachers, as activities that were the most time consuming.

Diabetes complications can include blindness, kidney failure, heart disease, and loss of limbs (ADA, 2015). These complications can gravely affect the quality of life for people with diabetes. Despite all the possibilities of diabetes complications, Parents had a positive outlook about their child's future and did not feel that diabetes would change their future goals and aspirations. However, even though they felt that having diabetes itself would not change their goals and aspirations, they felt that developing diabetes complications could drastically impede future goals and aspirations. Parents felt that the only thing that would hold their children back or change their planned course in life was developing diabetes complications brought on by not following the prescribed diabetes regimen. Parents recognize that there will be obstacles but were hopeful about their children's future, despite having diabetes. Almost all parents expressed that they didn't feel that having diabetes would hinder their child from doing anything that they wanted to do, and they encouraged them to do so.

Diabetes education is an important component in diabetes management; requiring knowledge of blood glucose monitoring, insulin therapy, diet, exercise, and problem solving skills to aid in diabetes management (Couch et al., 2008). Parents that allowed their children to spend time with family and friends, without them, stated that they provide training or written educational materials to those they entrust their child with. Additionally, parents stated that they continue to stay abreast of advances in diabetes management. Studies have shown a definitive and meaningful association between social support from family and friends and diabetes regimen adherence (Miller & DiMatteo, 2013). Recognizing that their children need to have as normal experiences as possible, parents expressed a desire to let their children have regular interactions with family and friends. Parents felt confident that they provided family and friends with all the essential tools and training to address a diabetic emergency, if the need arose. However, parents expressed fear and hesitation over leaving their child with family or friends, but admitted that they sometimes do in order to get the break that they need. Much of the concern surrounded compliance, not knowledge of the diabetes regimen. Parents felt that many of their friends and family knew what to do, but often intentionally did not follow the diabetes regimen. Being able to trust their children in the care of family, friends, or a babysitter, are necessary and essential to allow the parents to have a break from the demands of diabetes management. However, many parents expressed that they still felt fear and stress when leaving their children, but needed the break themselves; therefore, they let their children stay. Additionally parents acknowledged that they desire for their children to spend time with friends and family, without them. Parents realize that there is a time when they will have to trust others and many of them have begun to do that. They welcome the support and rely on faith and prayer to ease their apprehension.

In Chapter 4 the results of the in-depth analysis of the study were presented. The findings of the study, including themes, patterns, and relationships, were discussed in reference to the research questions. In Chapter 5, the findings will be interpreted and discussed in detail in respect to the lived experiences of African- American parents of African-American children with T1DM.

Chapter 5: The Findings

Introduction

This research study was designed to investigate the lived experiences of African-American parents of African American children with T1DM and the impact of the disease on their lives. Identifying the barriers to diabetes management could provide public health practitioners with the tools necessary to develop educational and intervention programs to increase or improve successful diabetes management among African American youth. This qualitative phenomenological study relied on participation and perceptions from the parents of African American youth with T1DM to satisfy the gaps in the research literature that have not provided sufficient focus on the challenges faced by African American families in effectively managing their child’s T1DM.

This qualitative phenomenological research study explored the lived experiences of African American families with a youth that has had T1DM for at least six months and who live in the Eastern region of the United States. African American parents were solicited using an online forum entitled “Children with Diabetes” and solicited from other social media sites (Facebook, Twitter, and LinkedIn). Twenty parents were selected as a convenience and purposeful sample from the replies to the request for participants on Facebook. According to van Kaam’s interpretation of phenomenological research, 10 to 50 descriptions of a target experience are sufficient to distinguish the essential and ample elements of the research (Moustakas, 1994); therefore, 20 participants was a sufficient sample size to describe the lived experiences. The subjects were interviewed by telephone and asked to participate in open-ended questions designed to elicit the lived experience and lifestyle management issues related to family dynamics and diabetes management of youth with T1DM.

All respondents expressed that T1DM places a financial strain on their family, sometimes causing them to have to deviate from the ideal management plan. Parents admitted to performing blood glucose testing less frequently than prescribed due to the cost of test strips. Additionally, purchasing food to prepare meals to maintain a balanced and diabetes-friendly diet was indicated as another source of financial strain. Insurance premium co-pays for doctor’s visits and medications, along with missed time from work by parents, were also noted as sources of financial and emotional pressures. Parents noted that these areas not only cause financial strain, but emotional and social pressure as well.

Support from family and friends were noted as essential to all participants. Those participants who indicated not having supportive networks expressed feelings of anger and hurt. Parents whose children have had diabetes for less than one year did not trust leaving their child with friends or even family. Participants also expressed frustration with friends and or family who were not diligent with their child’s diabetes management and refused to learn how to respond in a diabetes emergency. According to the respondents, their overall quality of life was greatly affected by their children’s diabetes. Participants, especially those whose children had been diagnosed for less than 5 years, felt more stress managing their child’s diabetes. Parents indicated that the increased stress affected the way they managed their child’s diabetes. Overall, finances and social interactions were the areas that were identified by parents as having the greatest effect on their ability to manage their child’s diabetes. Less frequent glucose monitoring along with distrust of others to be diligent with glucose testing and nutrition were perceived as major barriers to glucose management.

Interpretation of the Findings

This research study was designed to test the constructs of the HBM from the parent perspective. The HBM focuses on two aspects of a person’s perceived health status and health behavior: threat perception and behavioral evaluation (Sheeran & Abraham, 1996). This framework helps in understanding adherence or reluctance to following prescribed health directives (Janz & Becker, 1984). Although this research study utilized qualitative methodology with a phenomenological design, some quantitative data was generated. As suggested by Lobe (2008), quantitative data’s real power lies in its ability to answer questions numerically about frequency or quantity of behaviors.

Daily insulin injections, continual glucose monitoring, physical activity, and demanding nutritional requirements are all necessary in order to obtain optimal glucose control and decrease the risk of diabetes complications (Patino et al., 2005). It is a stressful and challenging task for the child with diabetes and their families to balance their diabetes regimen along with daily activities. However, maintaining this balance is essential to ensuring a good quality of life and avoiding future diabetes complications (Hirose et al., 2012). The stresses of managing T1DM by parents have shown to increase parental depression and affect parenting practices among parents of T1DM children, specifically, parental involvement and monitoring (Eckshtain, Ellis, Kolmodin, & Naar-King, 2010). Participants of this study indicated management was a stressor in their lives; however, they felt that T1DM only minimally affected their everyday routines. Managing their child’s T1DM had become such a routine that it was a subconscious part of everyday activities. Some of the participants of this study relied on their faith to sustain them, as opposed to other family members and friends. Many of the participants were uneasy with the level of commitment to the diabetes regimen demonstrated by their family and friends.

Recognizing that they and their children needed outlets and opportunities to interact with family and friends separately, these parents did not feel that they had the level of commitment needed for them to feel comfortable. Therefore, some parents mentioned prayer and faith as sustaining forces. From getting through late night glucose checks, the vigilance of nutrition monitoring, and the strain on finances, prayer was noted as a coping mechanism for parents.

The financial burden associated with diabetes supplies influenced the diabetes management regimen, primarily with blood glucose monitoring. Parents indicated that the high cost of glucose test strips forced them to perform testing less frequently than prescribed by their diabetes management team. As a result parents reported that, according to their child's endocrinologist, their child was considered in poor glucose control based on their current HbA1C results. The parents felt that their child's glucose was "pretty well controlled", but could use some "tweaking" to their regimen despite laboratory results that indicated otherwise. Parents did not express worry or great concern over reports that their child was in poor diabetes control. Instead they place great value on their children living as normal a life as possible. These outcomes are consistent with the findings of the study conducted by Edmonds-Myles, Tamborlane, & Grey, (2010) who looked at 21 patient- parent dyads of African American, Hispanic, and European American low income families to explore the psychosocial impact of T1DM on their family life. The authors discovered a reduction in the variability of HbA1c average values as diabetes regimens were intensified. Additionally, a decrease in HbA1c values by approximately 0.19% was noted, as the glucose testing frequency increased closer to the suggested five glucose measurements per day (Edmonds-Myles et al., 2010). This research study indicated that African American parents did not spend as much time worrying about their child's diabetes as European American and Hispanic parents did. Moreover, African American parents did not feel that diabetes greatly affected their family life, whereas most Hispanic parents felt it did.

While most parents felt that there was always something to do concerning diabetes management, few thought that it changed their lifestyle much. The parents that felt that diabetes dominated their lives were very new to managing the disease, usually less than one year into diagnosis. The perception of non-lifestyle interruptions due to T1DM by the participants of this study is consistent with Becker, Gates, & Newsom's (2004) conclusion that African Americans' self-care practices in chronic illnesses evolve from tactics for survival, self-preservation, and long-term struggles in order to overcome adversity. In this research study, African American parents believed that diabetes affected their daily life, but not to the extent of interfering with routine activities. They thought that the requirements for managing diabetes were not beyond their range of accomplishment.

Although Williams et al. (2013) explained that in a family setting, the needs of the patient with a chronic illness can have a propensity to propel the agenda for family activities, in this study, participants did not let T1DM interfere with the activities of the child or the family. These families focused on maintaining normalcy within their family in spite of the diabetes. In contrast to Ayala and Murphy (2010) and Williams et al., who reported on the importance of family and social support, study participants did not rely heavily on family and friends. Contrarily, although some felt that family and friends were capable of following the diabetes regimen and were vital to their children leading normal lives with T1DM, they did not feel that they would be vigilant concerning their children's diabetes needs. They were reluctant to leave them alone with family members, especially older family members. They felt that the approach of other family members to the needs of their T1DM child would compromise the child's health, even when left for a short time. Nonetheless, family and social support was important to the participants and the lack thereof was a major stressor.

HBM is regarded as the most widespread demonstrative model of health related behavior (Janz & Becker, 1984). The chances of morbidity caused by a disease or disorder (perceived susceptibility), the severity or the potential severity of the disease symptoms (perceived seriousness), and the perceptions of circumstances that would impede successful management of a disease (perceived barriers) were examined in this study. The perception of those affected by the disease, whether caretaker or patient, can influence the management of disease. Parents recognized that their children’s chances of developing diabetes complications are dependent on how well their diabetes is managed in younger years. Parents identified this as a source of stress and worry for them; however, they admitted to taking shortcuts in diabetes management, particularly in the area of glucose monitoring, and occasionally with doctor’s visits and nutrition. Despite awareness of the recommendations for glucose self-testing and nutrition, parents did not perceive their shortcuts as life threatening. They did perceive the disease as a serious illness; however, they refused to allow it to be a deterrent for their children living “normal” lives, participating in “normal” activities. They did not wish to allow their children to use T1DM as an excuse not to succeed. Parents regarded the symptoms of T1DM as serious and understood the repercussions; however, they were more persistent on living “normal” lives and did not let the fear overtake that goal. Additionally, there were barriers to disease management identified by parents, and many of them greatly affected disease management, according to the participants. The high cost of diabetes medications, blood glucose self-monitoring, and maintaining a proper diet were all identified as barriers to glucose management. However large or small the perception, the parents did not identify them as life altering but rather something they had to get used to and learn to work around.

Limitations of the Study

The limitations of this study included: (a) the number of African-American parents with children diagnosed with T1DM that were identified using social media, (b) the years of experience managing T1DM, and (c) the socioeconomic status and educational level of the parents of children diagnosed with T1DM that are members of the online communities from which participants were solicited. The perceptions, experiences, and knowledge of each participant managing T1DM from those chosen from the online outlet versus those solicited from other sources, such as endocrinology practices, could have resulted in selection bias. The participants selected to participate where members of the online parent communities; therefore, they are most likely actively engaged in diabetes management. The parents' active participation in the online communities, shows that they are likely to be interested in adhering to the prescribed regimen, even if not as closely as prescribed. The participants being able to opt in to participation themselves could lead to a sample make-up that is not likely representative of the parents who also meet participation criteria. The 20 participant sample size could be a limitation. Even though a 20 participant participation pool is sufficient for a qualitative study, the research could have benefitted from a larger participation pool that included more diversity. Including a larger sample size and a more diverse sample pool, to include; the perceptions, experiences, and knowledge of mothers and fathers, bi-racial families, non-custodial versus custodial parents, and a broader geographical region, could have made the results more generalizable and would have added to the body of discovery.

The study participants participated in telephone interviews. Although the telephone interviews were conducted at a time requested by the participants, it is possible that the fear of family members possibly overhearing the responses could have prevented open and honest conversation by parents. Telephone interviews could have resulted in a more guarded conversation. Qualitative research is accommodating; allowing for flexibility in the research format and the interview protocol (Debus, 1986; Ulin et al, 2005). This loose structure posed significant challenges when analyzing and interpreting the data. The subjectivity of qualitative research also produced limitations (Ulin et al, 2005). Additionally, there is the possibility of researcher bias, because I have T1DM. Remaining mindful of the possibility of introducing my own biases into the answers, I was careful to not react to any of the responses and attempted to keep all follow-up questions relevant to the responses given. Additionally, I did not inform the parents that I too, had T1DM until after the interviews had been completed.

Recommendations for Future Research

As a result of the qualitative nature of this study I was able to provide a closer look at the challenges encountered by parents in managing their children’s T1DM. The introduction of follow-up questions provided additional knowledge and ideas that could be helpful and relevant for future research. A study that addresses the knowledge, attitudes, and skills set of African American parents as caregivers could provide valuable knowledge to this topic in future research. Areas of future study could address the attitudes and perceptions of parents as disease duration increases. Additionally, examining a larger, more broad, sample population could uncover more challenges; as would making more direct inquiries about parents’ experiences and feelings about disease management.

The study was limited to African-American parents solicited from social media venues who reside in the eastern portion of the United States. Telephone interviews were conducted; therefore, the participants were at home and stood the risk of being overheard in their responses. A focus group setting could allow the parents to speak more freely among parents who understood their feelings. Focus groups would allow parents to meet each other and could possibly result in the formation of supportive system for parents. No consideration was given to socioeconomic status (SES) or educational level of the parents in this study; this could be another area of valuable future research. To understand the perceptions of disease and disease management by parents based on their SES could provide health care providers and health educators, valuable insight into how to best address the needs of varying African American demographics. Valuable considerations for future study include a broader solicitation base demographically. Soliciting study participants from endocrinologist offices and diabetes clinics can add a broader spectrum of perceptions and knowledge to this topic. The parents solicited for this study were members of a Facebook group for parents of children with T1DM, which implies that these parents are already seeking options, support, and advice for ways to manage their child's T1DM. Also, an examination of the feelings and perceptions of the entire family, would add knowledge on managing T1DM from a family perspective and the impact of the family unit on disease management. Examining the perceptions of fathers versus mothers, and bi-racial parenting could add valuable knowledge to this understudied population, as could examining the perceptions of disease management between custodial parents and non-custodial parents. Additionally, using a different theoretical model to examine this population could give a different perspective and elicit more comprehensive insight to the topic. Public health theoretical models such as the Theory of Reasoned Action, Social Cognitive Theory, Theory of Planned

Behavior, and Stages of Change, could all be used to examine behavior adaptations in this population.

Implications for Social Change

Determining the barriers to T1DM management in children and adolescents among African-American families is crucial to disease management among this understudied population. This study examined the lived experiences of African American parents of children with T1DM. Understanding the lived experiences of African-American parents could allow public health entities to make improvements to the delivery and design of services and programs for the management of T1DM in African-American children. The results of this study revealed two major concerns for this population. In order to maintain good glucose control, nutrition is an important aspect of the treatment regimen to manage diabetes (Patton, 2011). Learning to eat healthy and monitoring carbohydrates and diabetes medication has been linked to better glucose control (Patton, Dolan, Chen, & Powers, 2013). The participants of this study found it difficult to adjust family favorites to be more healthy, flavorful, and acceptable by their family. Meal time should include the entire family and being able to prepare meals for the entire family to enjoy was paramount to these parents. Providing education and instruction that focuses primarily on managing the diabetes dietary requirements is needed among this population. Adjusting traditional family favorites without compromising flavor is a necessary adaptation. Dieticians and nutritionist should incorporate these skills into diabetes education classes.

Although participants felt that their family and friends knew what to do in case of a diabetes emergency, there was still great trepidation about leaving their children; particularly with older relatives. Clinicians can develop new programs in diabetes education that would address the entire family and extended family. Programs could be designed to enhance the way that diabetes trainings are offered in order to better incorporate the entire family in diabetes education. Programs geared towards siblings and friends could aid in understanding the importance of adherence to the diabetes regimen and the consequences of not adhering to the regimen. Additionally, such programs could enhance the family's commitment to and understanding of the diabetes regimen; while helping the family to further adjust to the new "normal" of the family dynamics.

Lipman et al., (2012), addressed the necessity to fully understand the culturally specific needs of families faced with managing pediatric diabetes. The authors purport that there are major differences in the way that the well-being of diabetes in children is viewed, by race (Lipman et al., 2012). The findings of this research study could contribute to positive social change by providing insight into population based needs for successful diabetes management, such as how to make cultural and ethnic meals healthier. Additionally, providing culturally centered whole family diabetes education could enhance family relationships as well as diabetes management. These types of programs could reinforce the importance of the diabetes dietary nutrition requirements, and when or if exceptions can be made.

Conclusion

The results of the groundbreaking research of the Diabetes Control and Complications Trial (DCCT), revealed the importance of good diabetes control to decrease the risk of diabetes complications (Diabetes Control and Complications Trial Research Group [DCCT], 1993). African-American children with T1DM have been found to have poorer metabolic control than their counterparts of different ethnicities (Kamps, Hempe, & Chalew, 2010). Decreasing morbidity and mortality among African American adults with T1DM begins in childhood. How the parents and family units view the disease early in diagnosis is related to how the child deals with the disease later in life. Developing good diabetes management techniques in the early stages of disease can prevent debilitating complications later in life (Lipman et al., 2012). Parents are the primary caregivers of children with T1DM; therefore it is important to understand the elements that will assist them in managing their child's diabetes.

Few studies have examined the ethnic and cultural barriers of managing T1DM from the parents' perspective. The perceptions of chronic disease and disease outcomes have many variables. As previously expressed, Lipman et al., (2012) identified the need to address families and inquire about the methods of support needed to improve diabetes management. Key components to managing chronic disease in the African American community are centered on family and social support. African American communities heavily rely on extended family and friends to help provide care for ailing loved one (Lipman et al., 2012). However, the participants of this study did not rely on family or friends for support. They were untrusting of the abilities or willingness of family and friends to adhere to the diabetes regimen, if in their care alone. It is important to understand the most appropriate and effective forms of support, education, and information to meet the various needs of the demographic.

The African-American parents interviewed for this study all viewed diabetes as a constant in their lives. However, they did not feel that it was limiting or severely life altering for them or their children. The parents developed a coping mechanism centered on maintaining normalcy for them and their children. The necessary life style adjustments were made with little to no alteration of life's activities. Becker et al., (2004) reasoned that the African-American community has a different view of adversity and sickness; therefore creating a need to develop health education programs that are more culturally specific. As a people historically more accustomed to adversities, African-American people are inclined to be more optimistic about the potential outcomes and complications of illness (Spruill, Magwood, Nemeth, & Williams, 2015). The participants of this study chose to remain optimistic about their children's future with diabetes. Although, there is most likely fear and worry, for these participants, optimism was a coping mechanism.

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Appendix A: Qualifying Questionnaire

Date	Study ID:
Name	Telephone number
Age of Child	Email address

1. What race is your child?
2. Is your child the same race as the other members of your family?
3. How long has your child been diagnosed with diabetes?
4. At what age was your child diagnosed with type 1 diabetes mellitus?
5. In what state do you reside?

Appendix B: Research Questions

Date	Study ID:
Name	Telephone number
Age of Child	Email address

Perceived Barriers

1. What are the costs associated with managing your child's diabetes? How do those costs affect the way you manage your child's diabetes?
2. How is your everyday life affected by your child's diabetes?
3. What are the things that interfere with your child's diabetes?

Perceived Seriousness

4. How do you know if your child is experiencing a diabetes emergency (what are the symptoms?)
5. How do other family members react when your child is having a diabetes emergency?
6. How do you prepare others (friends, family, teachers, etc.) to recognize or handle a diabetes emergency?
7. How do you feel that your child's diabetes will change their future goals and aspirations?

Perceived Susceptibility

8. How do you ensure that you follow your child's diabetes regimen (blood glucose testing, medication decisions, dietary needs, activities, etc)?
9. What do you feel are the limitations placed on your child due to their diabetes?
10. How much time do you feel is required to manage your child's diabetes?

Appendix C: Solicitation Advertisement

Participants Needed for Research on the Family Life of African-American Youth with Type 1 Diabetes.

Are you the parent/guardian of an African- American youth age 5-17 with type 1 diabetes mellitus for at least six months?

If so…

Volunteers are needed to take part in a study to examine the issues associated with the management of type 1 diabetes mellitus in African-American youth, from a parental point of view.

What's involved?

You will be asked to participate in a telephone interview that will take approximately 20-30 minutes. You will be asked about the way that you help manage your child's T1DM and the challenges related to control and management of the disease that you experience. A sample of the study questions are below:

- What family members participate in decisions related to your child's diabetes management?
- How do you know that the decisions that you make related to your child's diabetes management are correct and effective?
- How has your child's diabetes affected family life?

Who can participate?

- Parents of African- American youth age 5-17 with type 1 diabetes for at least six months..
- Reside in the Eastern region of the United States.
- Have access to a telephone
- Able to speak, write and read English.
- Both parents are African-American

What are the Risks?

Being in this type of study does not involve any risk of discomfort other than those associated with the discussion of a challenging and thought provoking topic. However, you will be contributing to the body of knowledge used to help determine the factors that affect glycemic control and management of African-American youth with T1DM, as described by the parents of these children.

How can I participate?

If you have questions about this research study or are interested in participating, please contact Sonya Strider at Sonya.Strider@waldenu.edu