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CHAPTER I

INTRODUCTION

Elvia* sits quietly in her living room awaiting the return of her mother from the General Medical dialysis center. She lives in a two bedroom house along with her mother, father, and three younger siblings. Elvia Gonzalez is a 16 year old Hispanic female in the 10th grade at General High School. Her father, Miguel Gonzalez, is a construction worker who works 13-hour days, six days a week. Mr. Gonzalez dropped out of high school in the 9th grade to help support his parents and siblings. Elvia's mother, Juana Gonzalez, stays at home. She dropped out of school after the 6th grade to stay at home and help raise her 5 younger siblings. Elvia's siblings are Maria, Carlos and Daniela, whom are in the 6th, 4th, and 2nd grades respectively.

Elvia's mother, Mrs. Gonzalez, has been receiving treatment at a nearby dialysis center for over two years for kidney failure secondary to complications of type 2 diabetes (T2DM). Mrs. Gonzalez was diagnosed with T2DM five years ago. She reports a loss of feeling in her toes, problems with her vision, and problems with her concentration. Additionally, she reports feeling sad most of the time and not caring about her health. When asked about adhering to her medication and treatment, she mentions that she cannot afford her medications and being more active (i.e., exercising) is difficult for her because of her toes. Sadly, Mrs. Gonzalez's health has deteriorated in recent years.

This dissertation follows the style of *Journal of Pediatric Psychology*.

*The names in the introduction are fictional and the stories a sum of anecdotal information of various adolescents with type 2 diabetes.

Unfortunately, Mrs. Gonzalez is not the only person with T2DM in her family; Elvia was diagnosed with T2DM two years ago. Mrs. Gonzalez took Elvia to see her pediatrician because she complained of feeling tired most of the time, out of breath, and appeared to have difficulty focusing. In addition, Mrs. Gonzalez was concerned over Elvia's weight; which was 187 pounds at a height of 5'1". Mrs. Gonzalez was also concerned by dark brown areas that she noticed on the back of Elvia's neck and armpits. Elvia mentioned to her pediatrician that she drank 3 to 5 cans of soda a day, her favorite food was fast food preferably hamburgers and fries, and that she kept several candy bars in her bedroom. Elvia stated that she did not like any sports and all the walking she did was from the bus stop to her home. After the medical visit, Elvia was diagnosed with T2DM.

Elvia's diagnosis of T2DM has increased the strain within her family. Mr. and Mrs. Gonzalez report that they have difficulty ensuring that Elvia takes her medication at night. Elvia spends most of her time at home on her computer. Although she gets along with her siblings, she does not engage in any physical activity with them. Her school counselor reports that Elvia feels sad most of the time and is easily irritable. Elvia also reports having had suicidal thoughts. Her school counselor referred Elvia for counseling at a nearby community health center, but Elvia does not want to attend.

One of Elvia's schoolmates, Cyrus Johnson is an 18 year old African-American male at General High School. Cyrus lives at home with his mother, grandmother, and two siblings. Cyrus's mother, Mrs. Jones, is 47 years old. She completed the 10th grade and currently stays at home. She is disabled and receives disability payments. Cyrus'

sisters are 15 years old and 11 years old. Cyrus is now in the 12th grade. He has been on the football team since the 10th grade. At 6'1" and 230 lbs., his coaches thought he would be a great addition to the team's offensive line.

Ms. Jones ambulates using a wheelchair as her left foot was amputated six months ago. Approximately one year ago, Ms. Jones stepped on a broken piece of glass. Generally, wounds such as these heal quite rapidly, but Ms. Jones' poorly-controlled T2DM stagnated the healing process. Therefore, six months after her foot injury, Ms. Jones' doctors decided to amputate her foot.

Cyrus too has a diagnosis of T2DM; he was diagnosed when he was 15 years old. He reports that he tries to eat healthy during football season. However, it is important for him to keep his weight up to play first team, and he loves to eat fried foods, potato chips, and pizza. Yesterday, for instance, Cyrus had four fried eggs, three bacon strips, and two slices of toast for breakfast. He had lunch at school, and when he arrived home after school, he had fried chicken, macaroni and cheese, mashed potatoes, a side of cornbread, and fruit-flavored drink for dinner.

Although initially Elvia and Cyrus appear very different, they share many characteristics of adolescents with T2DM. First, they are members of an ever growing group of children and adolescents diagnosed with T2DM. They also are members of an ethnically diverse group. Both adolescents share a family history of T2DM and show the signs acanthosis nigricans, a biological markers of insulin resistance. Finally both youngsters are overweight, which is a risk factor for T2DM (American Diabetes

Association [ADA], 2000; Alberti, et al., 2004; Copeland, Chalmers, & Brown, 2005; Nadeau & Dabelea, 2008).

The recent increase in T2DM in children and adolescents worldwide is alarming (Pinhas-Hamiel, 2005; Fagot-Campagna et al., 2000). In the past, this illness was most often associated with adults. It is now increasingly being diagnosed in children and adolescents, especially in youth of diverse ethnic backgrounds. Adolescents with T2DM and their families face many challenges associated with the illness and its frequent complications. The impact of T2DM on youth is physical, emotional, and cognitive. As the age of onset decreases, more young people can expect to live many years with diabetes and its complications, which will affect their quality of life and that of their families.'

Given that youth are being diagnosed with T2DM now more often and much earlier, it is imperative to study how psychosocial factors relevant to this diagnosis affect them. The purpose of this project is to study the relationships among psychosocial factors identified in the literature as affecting the functioning of many adolescents with T2DM. Literature on psychosocial factors to date has primarily examined their relationship in youth with type 1 diabetes mellitus (T1DM), also known as insulin dependent diabetes, and/or adults with T2DM. Therefore, the unique contribution of this study is that it examines these relationships in adolescents with T2DM. Understanding the relationships between emotional factors and physical outcomes associated with T2DM will help increase the knowledge and understanding among social scientists who work with children and adolescents diagnosed with T2DM.

CHAPTER II

REVIEW OF LITERATURE

This review is divided into seven sections. The first section presents prevalence and incidence data of T2DM, mostly in youth. The second describes risk factors for T2DM. The third section illustrates complications of T2DM. These complications are divided into physical, cognitive, and emotional aspects. The fourth section describes health related quality of life. The fifth section depicts the role of family sharing of diabetes related responsibilities. The sixth section explains glycemic control and its association with psychosocial factors. The last section describes the purpose of the study.

Prevalence/Estimates of Type 2 Diabetes Mellitus in Youth

T2DM, formerly known as non-insulin-dependent diabetes mellitus or adult-onset diabetes mellitus, is the most common form of diabetes in the general population. T2DM accounts for about 90% to 95% of all diagnosed cases of diabetes in adults and youth (Centers for Disease Control and Prevention [CDC], 2008). Approximately 23.6 million Americans (7.8% of the United States population) have T2DM. Conservatively, it is estimated to be the seventh leading cause of death in the U.S. (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDKD], 2005).

In the past, diabetes in youth was almost entirely type 1 diabetes mellitus (T1DM), previously known as juvenile diabetes, or insulin-dependent diabetes mellitus (IDDM). T1DM occurs in about 1 in 400-600 children or adolescents. Onset peaks in

middle childhood, but initial diagnosis can occur through middle adulthood. T1DM develops when the body's immune system destroys pancreatic beta cells; these are the only cells in the body that manufacture insulin. Insulin regulates blood glucose and is needed to convert sugar (glucose), starches and other food into energy needed for growth, activity, healing and many other daily life functions. Conditions associated with T1DM include hyperglycemia, hypoglycemia, ketoacidosis and celiac disease. Individuals diagnosed with T1DM are treated with either multiple daily insulin injections or the use of an insulin pump. T1DM accounts for 5% to 10% of all diagnosed cases of diabetes. Risk factors include autoimmune, genetic, or environmental factors. There is at present no known way to prevent T1DM. With glucose control and attentive self-care, individuals with T1DM have a slightly shorter life expectancy than healthy individuals.

The pathophysiology of T2DM is different. In a healthy human, the body breaks down all of the sugars and starches consumed in food into glucose, which is the basic fuel for the cells in the body. Insulin takes the sugar from the blood into the cells. In T2DM, either the body does not produce enough insulin or the cells are resistant to the insulin resulting in conditions such as hyperglycemia and hypoglycemia. In addition, having T2DM increases the risk for many serious complications including heart disease, blindness, nerve damage, and kidney damage due to increased levels of excessive levels of glucose in the blood.

Recently, the rates of T2DM among children and adolescents have been found to be rising, necessitating more research on T2DM in youth. Pinhas-Hamiel and Zeitler

(2005) examined the trends in T2DM diagnosis across the globe by reviewing peer-reviewed articles on T2DM in children and adolescents published between September 1978 and May 2004 in all languages. They found that before 1990, there were only 2 reports; between 1990 and 1994, 4 reports; between 1995 and 1999, 12 reports; and between 2000 and 2003, 53 reports. As expected, T2DM was reported earliest in those countries with the highest rates of adult T2DM in the world, such as in Hong Kong, Singapore, and Taiwan. This demonstrates the close relation between rates of T2DM in adults and the eventual appearance of the disorder in adolescents. Interestingly, there was also an increase in obesity in the general population and, specifically among children in each of the regions affected. Consequently, the increase of T2DM in adolescents parallels the rise in obesity prevalence rates in adolescents, and the correlation between obesity and T2DM in this population of patients is consistently strong across studies (Fagot-Campagna, et al., 2000; Ogden, Flegal, Carrol, & Johnson, 2002).

Clinical reports and regional studies suggest that T2DM is being diagnosed more frequently in the United States among non-white children and adolescents, particularly among Native Americans, African-Americans, and Hispanic/Latino Americans (CDC, 2008). Fifteen to twenty years ago, the prevalence of T2DM at pediatric centers in the U.S. was between 2% and 4%. However, by 1999, the prevalence had increased to between 8% and 45% (Bloomgarden, 2004). This form of diabetes accounted for 46% of all newly diagnosed cases of childhood diabetes in the year 2000 (Nesmith, 2001).

SEARCH for Diabetes in Youth is a multi-center study funded by the U. S. Center for Disease Control and Prevention (CDC) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDKD). The study focuses on children and youth at six clinical centers in the US who have diabetes. SEARCH identified 769 youth (ages < 20) with T2DM in 2001 (SEARCH for Diabetes in Youth Study Group, 2006). Although T2DM was found in all ethnic groups (i.e., American Indian, Asian/Pacific Islander, Black, Hispanic, and non-Hispanic White), the prevalence of T2DM was disproportionately higher among non-white or underrepresented ethnic groups. It is reported that nearly one half of all Hispanic children born in 2000 will develop diabetes (Narayan, Boyle, Thompson, Sorensen, & Williamson, 2003).

The prevalence of T2DM in youth may be underestimated due to its previous relative rarity, the unavailability of comprehensive registries, and the small number of appropriate population-based studies. The true magnitude of T2DM in youth may be underestimated because most available data come from reviews of diabetes clinics, not population-based studies (Nadeau & Dabelea, 2008). Nadeau & Dabela (2008) suggest that population-based studies, where all individuals within a geographical area undergo diabetes screening, would be ideal to determine prevalence as they would capture even undiagnosed cases. The long-term economic burden of youth with T2DM is currently unknown because the likelihood of long-term complications and associated health care costs are unknown (Oza-Frank, Zhang, Imperatore, & Narayan, 2008). However, as the age of onset becomes much lower, the health costs associated with the complications of T2DM in youth, such as neuropathy, are likely to rise.

Risk Factors for T2DM

Youth diagnosed with T2DM are usually between 8 and 19 years of age, are overweight or at risk for being overweight, have a family history of diabetes, and are either African-American, Hispanic, or Native-American (ADA, 2000). The literature agrees on four general risk factors associated with youth developing T2DM: a family history, minority ethnic background, obesity, and biological markers of insulin resistance (e.g., acanthosis nigricans) (ADA, 2000; Alberti, et al., 2004; Copeland, et al., 2005; Nadeau & Dabelea, 2008).

Having a family history of diabetes is strongly associated with the development of T2DM in youth (ADA, 2000). The prevalence of T2DM in first-degree relatives of a child with T2DM is greater than 90% (Anderson & McKay, 2009).

Membership in an underrepresented ethnic group appears to be a strong risk factor for T2DM. Native American, Hispanic, African-American, and Asian/Pacific Islander ethnic groups are known to be at higher risk than others for developing T2DM (Fagot-Campagna, et al., 2000; SEARCH for Diabetes in Youth Study Group, 2006; Lawrence, et al., 2009). In a review of medical records of 18 Mexican-American children and adolescents, Glasser and Jones (1998) found the mean age of onset to be 12.8 years. A family history of at least one affected first-degree relative with T2DM was 87%, with 47% having three or more generations affected. The SEARCH for Diabetes in Youth Study Group examined the prevalence of T1DM and T2DM in African-American Youth between 2002 and 2005 (Mayer-Davies, et al. 2009). Among their conclusions they included the following related to youth with T2DM: a) girls had substantially

greater incidence of T2DM than boys (29.8/100,000 among girls compared with 12.2/100,000 among boys), b) about 60% of youth with T2DM lived in households with an annual income <\$25,000, and c) over 90% of youth with T2DM reported a family history of diabetes.

Another risk factor for youth developing T2DM is obesity. Obesity is a hallmark of T2DM, with up to 85% of affected children either overweight or obese at diagnosis (ADA, 2000). A similar pattern of obesity is also found between youth and their parents. There is a 66% chance that a child will be obese if both parents are obese (Rowell, Evans, Quarry-Horn, & Kerrigan, 2002). Weight is often measured by body mass index (BMI), which is defined as the individual's body weight divided by the square of his or her height. BMI is used by the National Institutes of Health (NIH) and the World Health Organization (WHO) as a way to help define obesity. A BMI of 18.5 to 25 generally indicates optimal weight; a BMI above 25 may indicate the person is overweight, and a number above 30 suggests the person is obese. Youth who are overweight tend to also have other health comorbidities such as hypertension and dyslipidemia. Hypertension refers to a high blood pressure, while dyslipidemia refers to high lipids (blood fats) that can cause heart attacks and strokes. Both hypertension and dyslipidemia can be present at the time of diagnosis of overweight or T2DM in adults or adolescents (Crimmins & Dolan, 2008).

Lastly, biological markers of insulin resistance (e.g., acanthosis nigricans, polycystic ovarian syndrome) are another risk factor. Insulin resistance is a condition in which the cells of the body become resistant to the effects of insulin. As a result, higher

levels of insulin are needed in order for insulin to have its effects. Acanthosis nigricans, a skin disorder characterized by brown to black, thick, velvety skin in folds and creases in the body (usually around the neck or armpits), is indicative of insulin resistance. It is seen in as many as 90% of children and adolescents with T2DM (ADA, 2000). In females, polycystic ovarian syndrome (PCOS) is another risk factor for T2DM. PCOS usually presents with signs of hyperandrogenism (excessive production and/or secretion of androgens) including acne, menstrual irregularities, or infertility. Additional research suggests that being female and pubertal appear to be additional risk factors for T2DM in youth (SEARCH for Diabetes in Youth Study Group [SEARCH], 2006).

Complications of T2DM

Youth with T2DM and their families face many challenges due to complications related to their disease. T2DM not only affects the youth physically, but also has emotional and cognitive ramifications (Anderson & McKay, 2009). As the age of onset becomes earlier, more young people can expect to live many years with diabetes and its complications, which will affect their quality of life and that of their families.

Physical Complications of T2DM. There are few reports of the complications of T2DM in adolescents, but studies comparing complications in T1DM and T2DM are emerging (Donaghue, Mohsin, & Stone, 2008). Physical long-term complications for T2DM are classified into two categories, a) complications involving small blood vessels (microvascular) and b) complications involving large blood vessels (macrovascular)

(Norris & Svoren, 2005). Microvascular complications of diabetes include damage to the small blood vessels, such as in the retina (retinopathy), kidneys (nephropathy), and peripheral nerves (neuropathy). Damage to these organs can cause permanent changes in behavior and cognitive abilities (Donaghue, et al., 2008). Limited joint mobility is another chronic complication of diabetes which is associated with increased risk of microvascular complications (Norris & Svoren, 2005). Studies in adults with T2DM have established two modifiable risk factors for the development of microvascular disease: hyperglycemia and hypertension. Having good control of blood sugars and blood pressure reduces the risk of developing future complications due to T2DM.

Macrovascular (large blood vessels) complications of diabetes include coronary artery, peripheral vascular, and cerebral vascular diseases. These complications are the greatest overall cause of morbidity and mortality in people with T2DM. The relative risk of macrovascular events is much higher in those who developed T2DM at a younger age than in individuals who developed the illness in later adulthood (ADA, 2000). Research on the complications and comorbidities of youth with T2DM is scarce, mostly due to the recent appearance of the disease in this population age. However, it is safe to assume that most of the complications of T2DM in adults will be prevalent in youth with T2DM although it is likely that the onset of these complications will be earlier and therefore more devastating to the life of the patient.

Cognitive Ability and Executive Function

The majority of studies examining the cognitive and neuropsychological abilities of individuals with diabetes focus on adults with T2DM or youth with T1DM. There is very little research examining executive functioning in youth with T2DM specifically. Executive function may include: cognitive control, ability to sustain or flexibly redirect attention, the inhibition of inappropriate behavioral responses, initiation and execution of strategies, and the ability to switch among strategies (Robbins, 1998). People use executive functions to perform activities such as planning, organizing, strategizing, and to maintain attention. Executive function impairments may include poor impulse control, inability to maintain attention, and disinhibition of inappropriate responses, which can have effects on an individual's treatment adherence. .

Studies in adults with T2DM have reported that this medical condition is associated with moderate reductions in overall cognitive performance and specifically with accelerated cognitive decline, impaired speed of information processing, decreased working memory, and difficulties with some aspects of attention (Biessels, Kerssen, de Hann, & Kappelle, 2007; Sommerfield, Deary, & Frier, 2004).

A literature review by Stewart and Liolitsa (1999) examined the evidence for an association between cognitive impairment and the presence of T2DM. Cross-sectional and prospective methodologies found associations between T2DM and cognitive impairment (both for memory and executive function). The majority of studies investigating cognitive impairment associated with T2DM indicated that older diabetic adults perform more poorly than controls on a variety of cognitive functioning tests.

Vascular disease, a frequent comorbidity of T2DM, and its principal risk factors were also recognized as important associations of cognitive impairment and cognitive decline (Breteler, Clause, Grobbee, & Hofman, 1994; Kalmijn, Freskens, Launer, & Kromhout, 1996).

The Utrecht Diabetic Encephalopathy Study (UDES) is a cross-sectional population-based study on determinants of impaired cognition in T2DM in Germany (Manschot, Brands, van der Grond, Kessels, Algra, et al. et al., 2006). The study included 113 patients (mean age 66.1 years old) with T2DM and 51 control subjects (mean age 65.1 years old). In this study, executive functioning was assessed using the Trail Making Test Part B, the Stroop Color-Word Test (Part III), the Brixton Spatial Anticipation Test, a verbal fluency test using the letters N and A, and category fluency using animal names. The aforementioned tests specifically measure task switching, response inhibition and abstraction of logical rules. The study found that the performance of adult patients with T2DM on neuropsychological examinations was significantly lower, particularly affecting the domains of attention, executive functioning, information processing speed, and memory.

Similar findings were reported in a study by Yeung, Fischer, and Dixon (2009) who examined whether T2DM was associated with exacerbated aging-related declines in cognitive/neuropsychological performance. Using both cognitive and neuropsychological tests, the researchers examined performance differences by diabetes status (T2DM group and health control group) and age (young-old group 53-70 years old and old-old group 71-90 years old). Areas of executive functioning that were tested were

initiation (begin a task or activity), shifting (move from one activity or aspect of a problem to another), response inhibition (appropriately stop own behavior at the proper time), and abstraction of logical rules. Two measures produced significant performance differences in favor of the controls: the Hayling (involving speed and inhibition) and Color Trails 2 (involving speed and shifting). Additionally, the group means were non-significant but in the same direction for the Brixton (involving rule attainment and planning) and the Stroop interference index (involving inhibition of response).

Given the fluctuations in sugar levels associated with T2DM, adolescents with T2DM frequently experience mild and moderate hypoglycemic or hyperglycemic episodes throughout their lives. These episodes can cause short-term and transient or even long-term cognitive impairments (Rovet, 2000). Olsson, Hulting & Montgomery (2008) assessed the cognitive function of youth at age 11 years with tests administered at school for general ability (both verbal and nonverbal) and reading comprehension. Their findings suggested that poorer cognitive function at age 11 years was associated with an increased risk of T2DM by age 42.

When considering the effects of T2DM and its correlates in youth, it is valuable to examine the relationship between obesity and executive functioning. This is particularly important given that obesity is a common comorbid characteristic of youth with T2DM. Note that although obesity is a risk factor for T2DM, findings should be regarded with caution. Nonetheless, we can examine this relationship further. Previous studies have examined obesity and attention (Cserjesi, Luminet, Poncelet, & Lenard, 2009), impulsivity (Braet, Claus, Verbeken, & Van Vlierberghe, 2007), cognitive

shifting (Cserjesi, Molnar, Luminet, & Lenard, 2007), and delay of gratification (Seeyave, et al., 2009); all of these areas directly related to a person's executive functioning.

In summary, research has reported an association between T2DM and cognitive impairments in adults as well as deficits in executive functioning. Comorbidities of T2DM such as hyperglycemia and hypertension have been shown to have a negative impact on cognitive and neurological capabilities in adults. However, cognitive and neurological skills such as executive functioning have not yet been studied extensively in youth with T2DM to determine how prolonged episodes of hyper/hypoglycemia can affect a young person's ability to adapt and respond to life's expectations.

Depression and Youth with T2DM

There appears to be a strong relationship between depression and health related conditions not only among adults, but also among chronically ill children and adolescents. A large majority of research associated with the comorbidity of depression and T2DM again has been done with adults, but several significant studies have looked at children with T2DM and depression. There is evidence to suggest that depression and T2DM are associated, but the direction of the association is unclear.

Results from the World Mental Health Surveys revealed that mood and anxiety disorders occurred with somewhat greater frequency among youth with diabetes than those without diabetes (Lin & Von Korff, 2008). Anderson, Clouse, Freedland, & Lustman (2001) conducted a meta-analysis of the prevalence of comorbid depression in

adults with T1DM and T2DM. They concluded that the presence of diabetes doubles the odds of comorbid depression; moreover, these odds of elevated depression were significantly higher in women than in men.

Knol et al. (2006) examined the association between depression and T2DM by reviewing the adult literature and conducting a meta-analysis of longitudinal studies published up to January 2005. Studies that longitudinally examined the relationships between depression and onset of T2DM were included in the meta-analysis. Nine studies met inclusion criteria. The researchers found that adults with depression or high-depressive symptoms have a 37% increased risk of developing T2DM compared to those who are not depressed or have low-depressive symptoms and have otherwise the same risk factors. However, Talbot and Nouwen (2000) report that initial onset of major depressive disorder typically precedes the diagnosis of T2DM by many years and seems to be independent of the onset of T2DM.

In a large population based study, Brown, Majumdar, Newman, and Johnson, (2005) observed an increased risk of developing diabetes in adults with a previous episode of depression. This relationship remained after controlling for potential confounding variables such as age, sex, and number of physician visits before study index date. Their analysis indicated that this increased risk lies mainly in the population segment aged 20-50 years. According to their results, depression appears to increase the risk of developing diabetes by 23% in younger adults.

In a meta-analysis looking at depression and diabetes treatment nonadherence, Gonzalez, Peyrot, McCarl, Collins, Serpa et al., (2008) found that depression was

significantly associated with non adherence to diabetes self-care. Studies were limited to those: 1) involving children, adolescents, or adults with T1DM or T2DM where findings were reported in English; 2) reporting sufficient data on the strength of the relationship between depression and treatment nonadherence to calculate an effect size; and 3) not involving any intervention. Depression was operationalized to include studies that used any measure that had been developed specifically to assess current depressive symptoms or diagnosis. The researchers concluded that non adherence to treatment may represent an important pathway between depression and non adherence and may lead to worse diabetes outcomes based on the results of 47 independent samples. In a study involving 367 patients with T1DM and T2DM, Ciechanowski, Katon, and Russon (2000) found that depressive symptom severity was associated with poorer diet and less medication regimen adherence, functional impairment, and higher health care costs among primary care adult patients with T2DM.

Children and youth who suffer a chronic illness, in addition to suffering cognitive impairments, are more likely to exhibit internalizing problems such as depression than the general population of children (Boekaerts & Roder, 1999). Studies have demonstrated increased levels of depression in adults with T2DM (Ali, Stone, Peters, Davies, & Khunti, 2006; Brown, Newman, Majumdar, Johnson, 2005; Li, Ford, Strine, & Mokdad, 2008; Sommerfield, et al., 2004). Furthermore, evidence indicates that depression is linked to the development and worsening of diabetes in adults, but the mechanisms underlying this link are not well understood (Sacco, et al., 2007).

Jaser, Holl, Jefferson, and Grey (2009) examined correlates of depressive symptoms in urban youth at risk for T2DM. Results of the study indicated that approximately 21% of urban youth at risk for T2DM were experiencing clinically significant levels of depression. Greater depressive symptoms were related to reports of poorer dietary intent and choice, less perceived support from healthy eating, poorer self-efficacy for physical activity, higher levels of BMI and insulin, and less self-reported physical activity, all of which are significant risk factors for poor outcomes of T2DM.

Correlates of depressed mood among youth with T1DM and T2DM were examined by the SEARCH for Diabetes in Youth Study (Lawrence, et al., 2006). A sample of 2,672 youth ages 10-21 years who had T1DM or T2DM for a mean duration of five years completed a SEARCH study visit. During the visit, youth who were at least 10 years of age also completed a Center for Epidemiologic Studies Depression (CES-D) scale to measure depressive symptomatology. SEARCH stratified depression severity as “minimally,” “mildly,” and “moderate/severely.” According to their clinical diagnosis, youth were placed in three groups; T1DM, T2DM and an “other or unknown” group. Compared with participants with T1DM, youth with T2DM or other types of diabetes were significantly ($p < .05$) more likely to be of a race/ethnicity other than non-Hispanic white, to have a shorter time since diabetes diagnosis, and to be overweight. They were less likely to have private insurance. Demographic factors associated with higher prevalence of depressed mood in the total sample were female gender, higher current age (females only), race/ethnicity other than non-Hispanic white, lower parental education, lower household income, not having private insurance, being overweight, and being

from a 1-parent family (females only). After adjusting for demographic factors and time since diagnosis of diabetes, they found the prevalence of depressed mood to be higher among males with T2DM than those with T1DM and to be higher among females with comorbidities than those without comorbidities. They also found that males with T2DM were almost 3.5 times more likely to have “moderately/severely” depressed mood than were males with T1DM, and that females with comorbidities were 1.5 times more likely to have “mildly” depressed mood and 2.3 times more likely to have “moderately/severely” depressed mood than were females without comorbidities.

At this time, although extensive research has been conducted exploring the demographic factors associated with youth with T2DM, less is known about the direct relationship between depression and youth with T2DM and the outcomes for children suffering both these conditions. However, it is possible that some of the correlates and outcomes between these diagnoses are similar for youth and adults with T2DM. One of the few studies examining depressive symptoms in youth with T2DM (Anderson, Edelstein, Walders-Abramson, Levitt-Katz, Yasuda, et al., 2011) found that the rates of significant depressive symptoms were similar to those of healthy adolescents. More research investigating the relationship between depressive symptoms and psychosocial factors, such as health related quality of life (HRQOL), needs to be conducted.

Health Related Quality of Life and T2DM

HRQOL includes aspects of general health, physical, emotional, cognitive and role functioning, as well as social well-being, sexual functioning and existential issues

(Fayers & Machin, 2000). HRQOL is an important health outcome in clinical trials and health care. Pediatric HRQOL assessments have important uses in research and the care of children and adolescents with chronic illnesses by: a) providing useful descriptive information regarding the health status of children with chronic health conditions, b) facilitating the identification of children with different levels of morbidity, and c) having the potential to improve the clinical decision-making process by increasing understanding of the consequences and experiences associated with different illnesses from children's and adolescent's perspective (Levi & Drotar, 1998).

T2DM complications have been found to be related to a reduced quality of life in adults (Bradley & Speight, 2002). Goldney, Fisher, Phillips & Wilson (2004) assessed the prevalence of diabetes and depression and their associations with quality of life in individuals with T2DM living in South Australia. The lowest quality of life scores were by those participants diagnosed concurrently with diabetes and depression. Depression was highly significantly associated with a negative impact on quality of life.

Scant research exists in the area of HRQOL and youth with T2DM. Prior to 2005, Anderson, Cullen, & McKay (2005) identified only one published report of HRQOL in children and adolescents with T2DM. Published in 2003, Varni, Gottschalk, Burwinkle, Kaufman, Jacobs, et al., examined HRQOL in youth with T1DM and T2DM and a healthy sample. They reported that youth with T2DM scored significantly lower on HRQOL than healthy children on all subscales (i.e., psychosocial health, emotional functioning, social functioning, and school functioning) except physical functioning.

The SEARCH for Diabetes in Youth Study examined associations between demographic and diabetes management variables and the HRQOL of youths with T1DM and T2DM (Naughton, et al., 2008). HRQOL was measured using the Pediatric Quality of Life Inventory (PedsQL) (Varni, et al, 2003). The PedsQL contains 5 subscales: physical health, psychosocial health, emotional functioning, social functioning, and school functioning. The major finding of this study indicated that youths with T2DM had a significantly lower HRQOL compared to those with T1DM. The interaction between age and gender indicated that the HRQOL of girls was lower in older groups, whereas the boys' HRQOL was higher in older groups. Interestingly, time since diabetes diagnosis was the only variable significantly associated with overall HRQOL for the boys with T2DM. The TODAY study data examining depression and quality of life demonstrated similar findings to the SEARCH study and found that depression and quality of life were significantly correlated (Anderson et al, 2011).

Understandably, further research on HRQOL in youth with T2DM is necessary given the fact that T2DM in youth is a relatively recent phenomenon. More research in this area should focus on the interaction between depression, diabetes and HRQOL. Also of importance, no studies have addressed youth's HRQOL and the family's role in sharing the tasks of diabetes management with their adolescents with T2DM.

Family's Role in Sharing Responsibility Management Tasks

Parents of youth with T2DM are usually of a minority ethnic group background, belong to a lower socioeconomic status, and are very likely dealing with their own

challenges associated with having T2DM in addition to other life's stressors. It is imperative however, that the parents of an adolescent with T2DM be involved in the management of the youth's T2DM. Parent involvement has been clearly linked to improved health outcomes in youth with T1DM, as well as in pediatric weight loss interventions for obese youth (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Wrotniak, Epstein, Paluch, & Roemmich, 2004). It is important to involve the whole family in the youth's management of T2DM since treatment usually consists of changing lifestyle routines, which affect the entire family, such as improving the youth's diet and increasing the amount of physical activity.

Anderson, et al., (2005) examined parental involvement in the management of T2DM in 75 youth receiving care for T2DM. The youth were divided into two groups to examine the relationship between glycemic control and parent involvement: 39 had acceptable glycemic control (HbA1c levels less than 8%), and 36 had unacceptable glycemic control (HbA1c \geq 8%). Parents of children in the unacceptable control group reported that children took more responsibility for the more social and proactive diabetes care actions than did the parents of children in the acceptable control group. Maternal involvement in managing diabetes outside the home was associated with better glycemic control, which leads to better life outcomes (Anderson, et al., 2005).

Glycemic Control

Glycemic control refers to the typical levels of blood sugar in a person with diabetes mellitus and is often assessed using the level of glycosylated hemoglobin

(HbA1c). The HbA1c level is proportional to the average blood glucose concentration over the previous two to three months (Chase, 2006). The American Diabetes Association provides blood glucose goals only for youths with T1DM; however, because vascular damage may be mediated by glycated end-products, it appears reasonable to use these same goals for the management of T2DM. A normal HbA1c value is between 3.9% and 6.1%. Optimal goals for HbA1c in youth with T1DM are <8.0% for 6 to 12-year-olds, <7.5% for 13 to 19-year-olds, and <7.0% for individuals older than 19 years old (ADA, 2009).

Again, most studies examining glycemic control in individuals with T2DM are with adults (Awad, Gagnon, & Messier, 2004; Cosway, Strachan, Dougall, & Frier, 2001; Sommerfield et al., 2004). Cognitive deficits are observed in older adults with glucose intolerance or untreated diabetes, but these deficits appear to be eased by treatments that improve glycemic control (Awad, et al., 2004). Speed of information processing, working memory, and some aspects of attention were impaired during acute hyperglycemia (as measured by HbA1c) in 20 adult subjects with T2DM aged 53 years to 72 years old (Sommerfield, et al., 2004). Interestingly, performance of tests measuring cognitive ability was not associated with recent measures of glycemic control (measured by HbA1c) in a study of 38 adults with uncomplicated T2DM. There were no significant differences found between the cognitive function or information processing of a group of adults with T2DM and their control group in this study. Perhaps this is due to the fact that all of the participants with diabetes were free of diabetic complications. At this time,

there are no available studies examining the relationship between cognitive ability or executive function and the glycemic control of youth with T2DM.

When looking at research conducted specifically with adolescents, similar findings were obtained. Rothman et al., (2008) examined self-management behaviors and glycemic control among 103 adolescents with T2DM through a telephone survey and medical chart reviews. Their analysis compared youth's demographic characteristics and self-report management behaviors to recent HbA1c levels. Higher HbA1c levels were significantly associated with older age, non-Anglo race, longer duration of diabetes and being on insulin. Nonwhite youths had higher HbA1c levels and more hospitalizations per year when compared with white youth. Nonwhite race was significantly associated with higher HbA1c levels even after adjusting for age, gender, BMI, insurance status, and other demographic factors.

Studies have examined the relationship between glycemic control and psychosocial factors in youth and adults (Nozaki, et al., 2009; Lane, et al., 2000; Lustman, et al., 2000). Lustman et al. (2000) identified studies that measured the association of depression with glycemic control. This research suggests that increases in depressive symptoms are incrementally associated with decreases in self-care that may lead to negative medical outcomes. A more recent study (Nozaki et al., 2009) examined the relationship between psychosocial variables and glycemic control of 304 adult patients with T2DM in Japan. A measure of participants' HbA1c was obtained as well as self-report using several psychological inventories. HbA1c was again measured one year later. A person's satisfaction with their diabetes treatment was measured by the Diabetes

Treatment Satisfaction Questionnaire (DTSQ) and diabetes-specific emotional distress was measured by the Problem Areas in Diabetes Scale (PAID). It was found that both the DTSQ and the PAID predicted both current and future HbA1c to similar and significant degree in adults with T2DM. That is, greater satisfaction with diabetes treatment was associated with better HbA1c values, while greater distress with diabetes treatment was associated with worse HbA1c levels.

These findings were supported by Lawrence et al. (2006), who reported that depressed mood is associated with poor glycemic control and more frequent emergency room visits in a study of 2,672 youth ages 10 to 21-years old with T1DM and T2DM. A higher mean HbA1c and high frequency of emergency room visits were associated with more depressed mood. In this cohort of youth with T2DM, males and females with mildly depressed mood and males with moderately/severely depressed mood also had higher mean HbA1c levels than males and females with minimal depressed mood.

A few studies have examined the relationship between glycemic control and quality of life (Naughton, et al., 2008; Paddison, Alpass, & Stephens, 2008). A study examined metabolic control (measured by HbA1c) and perceived quality of life among 615 adults with T2DM in New Zealand (Paddison, et al., 2008). A significant negative correlation was found between HbA1c and perceived quality of life. That is, a poorer HbA1c value was correlated with a low perceived quality of life. However, in a similar study conducted with youth suffering from T2DM, HbA1c levels were not significantly associated with HRQOL (Paddison, et al., 2008).

Purpose of the Study

Given the increasing prevalence of T2DM in youth and the lack of sound research in this area, it is imperative to continue to explore the different variables that contribute to positive and negative outcomes. Therefore, examining psychosocial factors relevant to this population, especially in non-white minority groups and their relevance to the treatment and outcomes of youth with T2DM is of the utmost importance. The purpose of this study is to explore the inter-relationships between certain psychosocial factors (e.g., depression and health related quality of life) that affect adolescents with T2DM.

Research Questions

The research questions are:

1) Does the youth participant's Behavioral Ratings Inventory of Executive Function (BRIEF) composite and indices scores, as rated by self and parent, predict the youth's HbA1c or their BMI? Based on the discussed literature, it is hypothesized that the relationship between the BRIEF composite and index scores and the youth's HbA1c will be positively correlated.

2) Does HbA1c mediate the relationship between depression and HRQOL?

Previous studies have demonstrated a significant relationship between depression and HRQOL however, HbA1c has not been evaluated as a mediator for this relationship.

3) Does HbA1c mediate the relationship between family responsibility sharing of the tasks of diabetes management and HRQOL? Few studies have examined the

relationship between family sharing of tasks of diabetes management and HRQOL, but HbA1c has not been evaluated as a mediator between this relationship.

At this time, most of the literature that relates to these factors has examined their relationship in youth with T1DM and/or adults with T2DM; therefore, the unique contribution of this current study is that it examines the relationships among these variables in adolescents with T2DM. Understanding these relationships will help increase knowledge and understanding among social scientists that study T2DM among adolescents and will have clinical implications for pediatric diabetes clinicians.

CHAPTER III

METHOD

Participants

Participants were recruited from a large pediatric hospital in an urban setting. The total number of participants was 50 pairs of youth and their parent/guardian. A previous study in this setting showed the sample population to be 38% male and 62% female; ethnic makeup was 45% Hispanic, 42% African-American, 12% Caucasian (Anderson, et al., 2005). Participants were from mostly urban households. Participant's ethnicity, parental level of education and family composition was obtained from participants or parental self report. The youth's BMI, weight, height, and clinical data was collected from their medical records.

Inclusion Criteria. For inclusion, youth had to be in the age range of 13.0 to 17.11 years old and have had a T2DM diagnosis for at least 3 months. In addition, participants were not to be involved in another research project, were literate (reading/writing) in English or Spanish at least at the 2nd grade level, and willing to provide assent.

The adult caregiver of the youth that accompanied them to their scheduled clinic visit had to meet the following criteria: have the primary responsibility for the youth's care and diabetes monitoring and agreed to participate in all aspects of the protocol.

Additionally, the parent/caregiver must have been literate (reading/writing) in English or Spanish at least at a 2nd grade level and has to be willing to provide informed consent.

Exclusion Criteria. Exclusion criteria for the youth included any major chronic illness other than diabetes (except well-controlled thyroid disease, asthma, celiac disease). Additionally, youth with major visual/auditory impairments that impeded them from completing the required questionnaires, current diagnosis of an eating disorder, or a moderate or severe diagnosis of mental retardation were not included in this study. Finally, youth who were in any other trial of a behavioral, psychological, or psycho-educational intervention specifically designed for youth with T2DM and who concluded their follow up within the past 6 months were excluded.

Adult caretakers who did not have primary custody of the youth with T2DM were not considered for participation in the study. In addition, caretakers with a visual or hearing disability that impeded them from completing the interview and questionnaires required by the study will were not included. Finally, caregivers with moderate to severe mental retardation that impeded them from completing written questionnaires were excluded.

Parent Measures

Executive Function. Participants' parents completed the Behavior Rating Inventory of Executive Function – Parent Form (BRIEF-Parent Form). The BRIEF-Parent Form is an 86-item questionnaire for parents of children 5 to 18 years, which

enables professionals to assess executive function behaviors in the home environment (Gioia, Isquith, Guy, & Kenworthy, 2000). The BRIEF-Parent Form contains 86 items within eight theoretically and empirically derived clinical scales that measure different aspects of executive functioning: 1) Inhibit - appropriately stop own behavior at the proper time, 2) Shift - move freely from one situation, activity, or aspect of a problem to another as the situation demands; transition; solve problems flexibly, 3) Emotional Control - modulate emotional responses appropriately, 4) Initiate - begin a task or activity; independently generate ideas, 5) Working Memory - hold information in the mind for the purpose of completing a task; stay with, or stick to, an activity, 6) Plan/Organize - anticipate future events; set goals; develop appropriate steps ahead of time to carry out an associated task or action; carry out tasks in a systematic manner; understand and communicate main ideas or key concepts, 7) Organization of Materials - keep workspace, play areas, and materials in an orderly manner, and 8) Monitor - check work; assess performance during or after finishing a task to ensure attainment of goal; keep track of the effect of own behavior on others.

These theoretically and statistically derived scales are added to create two broader Indices: 1) Behavioral Regulation Index (BRI) - Inhibit, Shift, and Emotional Control and 2) Metacognition Index (MI) - Initiate, Working Memory, Plan/Organize, Organization of Materials, and Monitor. These are added to create a composite score - Global Executive Composite (GEC). The BRI represents a child's ability to shift cognitive set and modulate emotions and behavior via appropriate inhibitory control as rated by the parent. The MI represents the child's ability to initiate, plan, organize, and

sustain future-oriented problem solving in working memory as indicated by the parent. This index is interpreted as the ability to cognitively self-manage tasks and reflects the child's ability to monitor his or her performance and relates directly to a child's ability to actively problem solve in a variety of contexts. The GEC is a summary score that incorporates all eight clinical scales of the BRIEF.

Additionally, the BRIEF contains two validity scales (Inconsistency and Negativity). The inconsistency scale describes the extent to which the respondent answers similar BRIEF items in a consistent manner. Negativity describes the extent to which the respondent answers selected BRIEF items in an unusually negative manner. Internal consistency for the BRIEF –Parent Form was high, ranging from .80 to .98 (Gioia, et al., 2000). Within the parent normative subsample, the mean test-retest correlation across the clinical scales was .81 (range = .76-.85) (Gioia et al., 2000).

Family Sharing of Responsibility. The Diabetes Family Responsibility Questionnaire – Type 2 Diabetes (DFRQ-T2) (Anderson, et al., 2005) was used to assess the family's responsibility sharing related to the child's/adolescent's diabetes management tasks. The DFRQ-T2 includes 15 items describing a range of diabetes management situations that occur at home and away from the home. Both parents and children were asked to respond to these questions on a 3-point scale and to check the box that best describes the way each diabetes-related task or situation had been handled in their family during the previous month. A high score indicated that parents had less involvement. The DFRQ-T2 provides a Task Subscale, Social and Proactive Diabetes

Care Subscale, and a Total Responsibility Scale. The internal consistency of the Total DFRQ-T2 was .85 for parents and .74 for children (Anderson et al., 2005).

Health Related Quality of Life. The Pediatric Quality of Life Inventory – Diabetes Module (PedsQL 3.0 Diabetes Module) (Varni, Burminkle, Jacobs, et al., 2003) was completed by the participants to obtain a measure of health related quality of life. The PedsQL 3.0 Diabetes Module consists of 28 items that encompass five scales: a) diabetes symptoms (11 items), b) treatment barriers (4 items), c) treatment adherence (7 items), d) worry (3 items), and e) communication (3 items). Child self-report is designed for children and adolescents ages 5-18 years, and parent proxy-report is designed for parents of children ages 2-18. The instructions ask how problematic each item has been during the past 1 month. A five point response scale is used (0 = never a problem to 4 = almost always a problem). Items are reverse-scored and linearly transformed to a 0 – 100 scale; higher scores indicate better health related quality of life (HQRL). Internal consistency (reliability) for most Diabetes Module average $\alpha = 0.71$ for the child and 0.77 for the parent-report (Varni, et al., 2003). The diabetes symptoms scale of the PedsQL 3.0 Diabetes Module will be used as the measure of health related quality of life, given that there is not a composite score for all five subscales of the PedsQL 3.0 Diabetes Module.

Youth Measures

Executive Function. Youth completed the Behavior Rating Inventory of Executive Function – Self-Report Version (BRIEF-SR). The BRIEF-SR is a standardized self-report measure that captures older children's and adolescents' (5-18 years) views of their own executive functions, or self-regulation, in their everyday environment (Guy, Isquith, & Gioia, 2004). The BRIEF-SR questionnaire contains 80 items in the same eight non-overlapping clinical scales and two validity scales as the BRIEF-Parent Form. Factor analytic studies and structural equation modeling provide support for the two-factor model of executive functioning as encompassed by the two indices (Gioia, et al., 2000).

The internal consistency for the BRIEF – SR was moderate to high, with alpha coefficients ranging from .72 for those scales with fewer items to .96 for the full 80-item scale. The test-retest correlations across the clinical scales and subscales ranged from .59 to .85 over an average interval of 4.91 weeks for the BRIEF-SR. The BRIEF and the BRIEF-SR were developed to have a strong content validity (Gioia, et al., 2000); items were selected from clinical interviews with parents to capture common descriptions and complaints that reflect behavioral expressions of executive functions (BRIEF). These were modified in order for the instrument to be a self-report measure and to make the items age-appropriate for adolescent respondents (Guy, et al., 2004).

Depressive Symptoms. The Children's Depression Inventory (CDI) Short Form (Kovacs, 1992) was used to assess depressive symptoms. The CDI Short Form was

developed to provide an easily measured, empirical assessment of the extent to which a child exhibits depressive symptoms (Kovacs, 1992). The CDI short form contains 10 items and is usually used as a depression screening instrument. The short form was developed from a backward stepwise internal reliability analysis to maximize the internal consistency of the items retained (Kovacs, 1992). The CDI short form has been demonstrated to be internally consistent and highly correlated with full CDI ($r=0.89$) in a normative sample of 1266 children aged 7 through 15 years.

Health Related Quality of Life. Youth completed the PedsQL 3.0 Diabetes Module to obtain a measure of their health related quality of life. The PedsQL 3.0 Diabetes Module is explained in further details in the previous section. The diabetes symptoms scale of the Peds QL 3.0 Diabetes Module will be used as the measure of health related quality of life.

Glycemic Control

The participant's glycosylated hemoglobin (HbA1c) was used as a measure of glycemic control. The HbA1c level is indicated in the youth's medical record. The HbA1c level is obtained from participants using a finger-stick blood sample at their regular diabetes clinic visit, using the Bayer DCA 2000+ GlycoHemoglobin Analyzer (Bayer Corporation, Elkhart, IN).

Demographic Variables

Youth demographic variables that will be collected include age, duration of diabetes diagnosis, weight, height, and body mass index. Race/ethnicity and gender will be collected from both the youth and parent. In addition to these parent variables, the number of people in the household and highest parental educational level will be collected. Highest parental education level will be used as a measure of SES.

Procedures

Participants were identified by examining the patient list in the Texas Children's Hospital clinic schedule calendar. Once possible participants were identified using exclusion/inclusion criteria, project staff called to speak with the parent one week prior to their scheduled visit at the Diabetes Clinic at Texas Children's Hospital. Staff invited them to learn more about the study at their upcoming adolescent's clinic visit. If the parent agreed to meet with the research staff to learn more about the project, he/she was to arrive 10 minutes prior to their scheduled visit and to plan to stay 20 minutes after.

Once the youth and their guardian arrived at the Diabetes Care Center, Texas Children's Hospital, project staff informed the parent and youth about the study in further detail in order to obtain informed consent from the parent and written assent from the teen. The parent was also given a Health Insurance Portability and Accountability Act (HIPAA) form to sign to give access to the youth's medical record. Both the parent and teen were assigned an identification number that will be placed on their demographic sheet and on their questionnaires once informed consent and assent was

collected. At this point, both parents and adolescents were given instructions and were handed a demographic sheet and three psychosocial questionnaires to complete after their medical visit. Once parents and youth returned the completed questionnaires, they were given \$10 in cash. Additional pertinent medical data (e.g., body mass index, weight, height, etc.) will be obtained from the participants' medical records with their consent. A total of 56 participants were approached to participate in the study. Of the participants approached, 50 youth/parent agreed to participate in the study.

Analysis

Data analyses were conducted using SPSS16.0 for Windows (SPSS Inc., Chicago, IL, USA). Detailed descriptions of analyses for each question are below.

Question 1: Regression analysis was calculated to examine a) the association among the youth's obtained scores on the Behavioral Regulation Index (BRI), Metacognition Index (MI), and the General Executive Composite (GEC) of the BRIEF-SR, and their relationship with the youth's HbA1c and BMI and b) the relationship among the youth's obtained scores on the BRI, MI, and GEC, as rated by their parent, and their relationship with the youth's HbA1c and their BMI.

Question 2: As recommended by Judd and Kenny (1981), a series of regression models was estimated to assess mediation. HbA1c will be examined as a

mediator. To test for mediation, the following regression equations were estimated. First, Pearson's r will be calculated to examine the correlation between depression and HbA1c. Second, Pearson's r was calculated to examine the correlation between depression and HRQOL. Third, Pearson's r was calculated to examine the correlation between HRQOL and both depression and HbA1c. This question examined if the relationship depression and HRQOL is mediated by HbA1c.

Question 3: A series of regression models was estimated to test for mediation (Judd & Kenny, 1981). HbA1c was examined as a mediator. To test for mediation, the following regression equations were estimated. First, Pearson's r was calculated to examine the correlation between HbA1c and family sharing of responsibilities of diabetes. Second, Pearson's r was calculated to examine the correlation between family sharing of responsibilities of diabetes and HRQOL. Third, Pearson's r was calculated to examine the correlation between HRQOL and both family sharing of responsibilities of diabetes and HbA1c. This question examined if the relationship between DFRQ-T2 and HRQOL is mediated by HbA1c.

The three regression equations employed in question 2 provide the tests of the linkages of the mediational model (Baron & Kenny, 1986). To establish mediation, the following conditions must hold: 1) the independent variable (i.e., depression) must affect

the mediator (i.e., glycemic control) in the first equation, 2) the independent variable (i.e., depression) must be shown to affect the dependent variable (i.e., HRQOL) in the second question, and 3) the mediator (i.e., glycemic control) must affect the dependent variable (i.e., HRQOL) in the third question. If these conditions hold in the predicted direction, then the effect of the independent variable (i.e., depression) on the dependent variable (i.e., HRQOL) must be less in the third equation than in the second. Perfect mediation holds if the independent variable has no effect when the mediator is controlled. The same holds true for question 3. In either analysis, if the primary conditions hold, a Sobel test and bootstrapped estimation of the mediation (Preacher & Hayes, 2004) will be completed.

CHAPTER IV

RESULTS

This chapter presents the results of the study organized around the initial three research questions.

Descriptive Characteristics

In this section a summary of the descriptive variables is presented. Participant specific descriptive variables such as gender, age, grade, and ethnicity were collected. Additionally, participant biological data, such as height, weight, and Body Mass Index were also collected. Parental/family related variables were also collected, because these variables can be important explanatory factors in the results of this study. The following family-wide variables were collected: familial relationship to the participant, parental level of education, number of people living in the home, as well as any history of family members with diabetes.

A total of 50 youth and their primary caregiver participated in this study. The sample was female 72% female. The gender make-up of this sample represents the gender population of youth with T2DM in that the population is mostly female, as evidenced in previous studies related to youth with T2DM (Copeland, K. C., Zeitler, P., Geffner, M., Guandalini, C., Higgins, J., et al., 2011; Lawrence et al., 2009). The ages of the participants ranged from 12 to 17 years old, with an average age of 14.6 years old. Regarding education, 54% of the participants were enrolled in high school while 46%

were enrolled in 5th through 8th grades. The ethnic make-up of the sample was as follows: 58% Hispanic, 30% African American, and 8% Caucasian, with 4% indicating Other. Table 1 summarizes the demographic characteristics of youth participants.

Table 1

Participant Demographic Variables for Sample

Variable	Number of participants	Percent (%)
Gender		
Female	36	72
Male	14	28
Age		
12 – 13	16	32
14 – 15	17	34
16 – 17	17	34
Grade		
5 – 6	4	8
7 – 8	19	38
9 – 10	19	38
11 – 12	8	16
Ethnicity		
Caucasian	4	8
African Am.	15	30
Hispanic/Latino	29	58
Other	2	4

Biological descriptive data of youth participants are given below. The time since the initial diagnosis of diabetes for the youth participants, ranged from 3 months to 98 months, with an average time since initial diagnosis of 26 months. The glycosylated hemoglobin (HbA1c) levels for the youth ranged from 4.9 to over 14, with a mean of 7.9 and a standard deviation of 2.56. The average HbA1c level for a youth without diabetes is below 7. Nearly half (n=24) of the participants had an HbA1c level of 7 or higher. See Table 2 for participants' biological data.

Table 2

Clinical Characteristics of Youth

Variable	Mean	SD	Range
Males			
Disease duration (months)	22.86	17.01	3 – 49
HbA1c level	7.45	2.03	4.9 – 11.5
Height (centimeters)	169.94	9.30	147.0 – 183.0
Weight (kilograms)	96.78	22.39	66.0 – 128.2
BMI	35.03	7.46	24.7 – 50.8
Females			
Disease duration (months)	24.97	21.33	3 – 98
HbA1c level	8.09	2.74	5.30 – 14.0
Height (centimeters)	160.25	7.90	140.1 – 174.2
Weight (kilograms)	93.82	27.00	53.4 – 150.5
BMI	37.82	8.99	22.9 – 68.0

The youth were accompanied to their medical visit primarily by their mothers (78%), while 10% were accompanied by a father and 12% were accompanied by a grandparent. Of the adults accompanying the participants, 64% had an educational level of high school or less. Of the overall sample reported, 95% had a history of diabetes in their family. Participant report indicated 62% either a mother or father with T2DM, 30% with a grandparent with T2DM and 8% with an extended relative with T2DM. The average number of people living in the home was 4.54 with a SD of 1.28. For more information on youth's and parents' demographic information, see Table 3.

Table 3

Family Demographic Variables

Variable	Number of participants	Percent
Parent Completing Questionnaire		
Mother	39	78
Father	4	8
Grandparent	6	12
Other	1	2
Parental Level of Education		
Less than High School	19	38
High School Completion	13	26
Some College	8	16
College Degree	8	16
People Living in Home		
2 – 3	12	24
4 – 5	26	52
6 – 7	12	24
Family History of Diabetes		
Yes	46	92
No	4	8
Relationship of History of Diabetes to Youth		
Mother	21	45.7
Father	10	21.7
Grandparent or Other	15	32.6

Power Analysis

A power analysis was conducted to determine the number of participants necessary given that the study contains three dependent variables and one independent or predictor and the goal was to obtain at least a medium effect size. A priori power analysis using G Power 3.1.3 revealed that on the basis of a medium effect size of 0.15, approximately 77 participants would be needed to obtain power at .80.

Research Question # 1

Does the youth participant's BRIEF composite and indices scores predict their HbA1c or their BMI?

The first question examined: a) the association among the youth's obtained scores on the Behavioral Regulation Index (BRI), Metacognition Index (MI), and the General Executive Composite (GEC) of the BRIEF-SR (self-report), and their relationship with the youth's HbA1c, and b) the relationship among the youth's obtained scores on the BRI, MI, and GEC of the BRIEF-SR, with their relationship with the youth's BMI. It was hypothesized that higher BRI, MI, and GEC scores would correlate with a higher HbA1c and with a higher BMI. These predictive relationships were examined by utilizing a regression analysis on the youth's score on the two broader indices (BRI and MI), and composite (GEC) score on the BRIEF-SR with their HbA1c and BMI.

Results indicate that for the youth neither index nor composite score of the BRIEF-SR is significantly associated with their HbA1c or their BMI. Of note, the youth's score on GEC, although not significant at the .05 level, it is in the right direction and represents a likelihood of meaningfulness. Refer to Table 4 and Table 5 for more details.

Table 4

Regression Analysis – Youth – HbA1c as Dependent Variable

Variable	B	SE(B)	β	<i>t</i>	Sig. (d)
Behavioral Regulation	.046	.047	.231	.968	.338
Index					
Metacognition Index	-.061	.054	-.270	-1.132	.263
General Executive Comp.	-.009	.030	-.042	-.289	.774

Table 5

Regression Analysis – Youth – BMI as Dependent Variable

Variable	B	SE(B)	β	<i>t</i>	Sig. (d)
Behavioral Regulation	.159	.153	.242	1.040	.304
Index					
Metacognition Index	.023	.173	.031	.133	.894
General Executive Comp	.180	.097	.262	1.859	.069

The second part of question 1 examined: a) the association among the youth's obtained scores on the BRI, MI, and GEC of the BRIEF (as reported by the parent), and their relationship with the youth's HbA1c, and b) the relationship among the youth's obtained scores on the BRI, MI, and GEC of the BRIEF, and their relationship with the youth's BMI. These predictive relationships were examined by utilizing a regression analysis on the youth's score on the two broader indices (BRI and MI) and the composite (GEC) score on the BRIEF with the youth's HbA1c and their BMI. More information on

the relationship among the parent's ratings of youth on the BRIEF (BRI, MI and GEC) can be found in the tables below with HbA1c as the dependent variable (Table 6) and with BMI as the dependent variable (Table 7).

Results indicate that for the youth neither index nor composite score of the BRIEF (parent report) is significantly associated with their HbA1c or their BMI.

Table 6

Regression Analysis – Parent – HbA1c as Dependent Variable

Variable	B	SE(B)	β	<i>t</i>	Sig. (d)
Behavioral Regulation Index	-.024	.044	-.118	-.538	.593
Metacognition Index	.034	.052	.143	.651	.518
General Executive Comp.	.008	.031	.038	.262	.795

Table 7

Regression Analysis – Parent – BMI as Dependent Variable

Variable	B	SE(B)	β	<i>t</i>	Sig. (d)
Behavioral Regulation	.062	.147	.092	.423	.674
Index					
Metacognition Index	.042	.172	.053	.242	.810
General Executive Comp.	.091	.105	.125	.872	.388

Post-hoc Analysis. Given the lack of significant findings in the regression analysis, a post-hoc analysis was conducted to examine the relationship among the eight scales of the BRIEF, in addition to the two index scores and the composite with the youth's HbA1c and their BMI. It was hypothesized that difficulties in executive functioning (higher scores, particularly the metacognitive skills and behavioral components of executive functioning), would correlate with higher HbA1c and higher BMI indicating a positive relationship between executive functioning and HbA1c and between executive functioning and BMI. Table 8 provides the mean scores and standard deviations for the BRIEF and Table 9 provides the mean and standard deviations for the BRIEF-SR.

Table 8

Mean and SD Scores on the BRIEF

Scale/Subscale	Mean (T Score)	SD
Inhibit	54.8	13.0
Shift	56.0	13.2
Emotional Control	56.3	11.0
Behavioral Regulation Index	56.4	12.8
Initiate	53.0	11.5
Working Memory	55.5	11.9
Planning/Organizing	52.8	9.72
Organization of Materials	50.8	10.8
Monitor	53.7	9.83
Metacognition Index	53.9	10.9
General Executive Composite	55.1	11.8

Table 9

Mean and SD Scores on the BRIEF-SR

Scale/Subscale	Mean (T Score)	SD
Inhibit	49.9	12.0
Shift	52.7	12.6
Emotional Control	53.7	11.3
Monitor	53.0	10.4
Behavioral Regulation Index	52.8	12.9
Working Memory	51.9	12.2
Planning/Organizing	50.0	9.97
Organization of Materials	49.6	9.49
Task Completion	50.4	11.9
Metacognition Index	50.6	11.4
General Executive Composite	51.8	12.3

Youths' Ratings of Executive Functioning. A correlation analysis revealed that there is not a significant correlation between HbA1c and any subscale or composite score on the BRIEF-SR (Table 10). Although HbA1c did not correlate with any subscale or composite score on the BRIEF-SR, a significant positive correlation between the Shift subscale of the BRIEF-SR and the youth's BMI ($p = .307$; $p < 0.05$) was found. Additionally, a significant positive correlation between the Emotional Control subscale of the youth's ratings on the BRIEF-SR and their BMI ($p = .295$; $p < 0.05$) was also found. See Table 10 for more information.

Table 10

Correlation of Youths' BRIEF-SR Ratings with HbA1c and BMI

Variable	HbA1c	BMI
Inhibit	.034	.175
Shift	-.019	.307*
Emotional Control	-.018	.295*
Monitor	.040	.143
Working Memory	-.124	.195
Planning/Organizing	-.047	.229
Organization of Materials	.036	.165
Task Completion	-.115	.233
Behavioral Regulation Index	.017	.267
Metacognition Index	-.087	.223
General Executive Composite	-.042	.262

* Significant at the 0.05 level (1-tailed).

Parents' Ratings of Youths' Executive Functioning. The parents' ratings of the youths' executive functioning did not correlate with either the youths' HbA1c or with their BMI. See Table 11 for more information.

Table 11

Correlation of Parents' BRIEF Ratings with Youth's HbA1c and BMI

Variable	HbA1c	BMI
Inhibit	-.031	.142
Shift	-.004	.130
Emotional Control	.014	.078
Initiate	.102	.137
Working Memory	.089	.122
Planning/Organizing	.019	.148
Organization of Materials	.001	-.001
Monitor	-.010	.066
Behavioral Regulation Index	-.011	.132
Metacognition Index	.054	.122
General Executive Composite	.038	.125

Research Question # 2

Does HbA1c mediate the relationship between depression and health related quality of life?

The second question examined whether the youth's HbA1c mediates the relationship between depression and health related quality of life. Youth's average T-Score on the CDI-Short form was 50.49, indicating an average level. The standard deviation was 14.16.

A mediation model using regression analysis was used to determine if HbA1c affects the relationship between depressive symptoms and health related quality of life. To test for mediation the following regression equations were estimated: first, Pearson's r was calculated to examine the correlation between depression and HbA1c. Second, Pearson's r was calculated to examine the correlation between depression, as measured

by the CDI-S, and HRQOL, as measured by the Diabetes Problems of the PedsQL Diabetes Module. Third, Pearson's r was calculated to examine the correlation between HRQOL and both depression and HbA1c.

A series of regression analyses indicated that Baron and Kenny's (1986) required conditions to establish mediation were not met using the youth's ratings of their HRQOL. First, depressive symptoms were significantly associated with HRQOL, ($r = 0.436$; $p < 0.05$). However, depressive symptoms were not significantly associated with HbA1c, ($r = 0.067$; $p > 0.05$) indicated that there is no mediation. In conclusion, while there was a significant relationship between depression and HRQOL, there was not a significant relationship between depression and HbA1c, suggesting that the participant's average blood sugar for the last three months did not mediate the relationship between their depression and their quality of life. Consequently, the Sobel test was not conducted. Table 12 reports parents' and youths' mean scores and standard deviations on the PedsQL 3.0 Diabetes Module. Table 13 lists the youth's scores on the CDI-Short Form and the DFRQ-T2 scores by parents.

Table 12

Mean and SD Scores on the PedsQL3.0 Diabetes Module

Variable	Mean	SD
Parent Report		
Diabetes Symptoms	63.8	20.9
Treatment Barriers	65.6	25.5
Treatment Adherence	70.9	22.9
Worry	72.6	25.4
Communication	69.7	31.0
Self-Report		
Diabetes Symptoms	63.5	18.5
Treatment Barriers	66.4	27.0
Treatment Adherence	78.1	17.8
Worry	67.7	23.2
Communication	71.3	26.0

Table 13

Mean and SD Scores on the CDI-Short Form and the DFRQ-T2

Variable	Mean	SD
CDI-Short Form	50.5 (t-score)	14.2
DFRQ-T2	25.4	4.45

Research Question # 3

Does HbA1c mediate the relationships between family responsibility sharing of tasks of diabetes management and health related quality of life?

The third set of questions examined if the youth's HbA1c mediates the relationship among family responsibility sharing of tasks of diabetes management and HRQOL, as rated by the parents.

A mediation model was used to determine if HbA1c mediates the relationship between the family sharing of tasks of diabetes and the parent's ratings of the youth's health related quality of life. Similarly to the youth's model, a series of regression analyses revealed that Baron and Kenny's (1986) required conditions to establish mediation were not met. The association between the parent's ratings of sharing of tasks and their ratings of the youth's health related quality of life was not significant ($r = 0.100; p > 0.05$). Consequently, the Sobel test was not conducted.

CHAPTER V

DISCUSSION

This study investigated the psychological, such as depressive symptoms and health related quality of life (HRQOL), and family characteristics of youth with type 2 diabetes (T2DM). The study expands the research on demographic and clinical information of youth with T2DM and provides a better understanding of how these interact. Specifically, the study examined the relationship among executive functioning and glycosylated hemoglobin (HbA1c) and body mass index (BMI). In addition, this study examined whether HbA1c mediated the relationship between depressive symptoms and HRQOL. Lastly, the study also endeavored to examine whether HbA1c mediated the relationship between family sharing of task responsibility of diabetes and HRQOL.

Summary of Results

The study examined three main questions. The first explored whether the youth's indices and composite scores on the BRIEF, as rated by youth and by their parent, predict the youth's HbA1c and/or BMI. It was hypothesized that higher scores on the BRIEF, suggesting greater difficulties with executive functioning, would have a positively related influence on HbA1c and BMI. The second question examined if HbA1c mediated the relationship between depressive symptoms and HRQOL. The current study hypothesized HbA1c would mediate the relationship between depressive symptoms and HRQOL. Lastly, the third question investigated whether HbA1c mediated

the relationship between family responsibility sharing of tasks of diabetes management and HRQOL. It was hypothesized that HbA1c would mediate this relationship.

Results for the first question indicated that neither the BRIEF individual indices nor the composite scores, as rated by youth and parent, predicted the youth's HbA1c levels. These results were also insignificant when the youths' BMI was used as a predictor variable. These findings are somewhat surprising, given the findings in previous research examining relationship between executive functioning, glycemic control and BMI, which has found significant positively related correlations between these (Gold et al., 2007; Munshi et al., 2006; Raeven, Thompson, Nahum, & Haskins, 1990).

A noteworthy difference between this study and the previous research however, is that most studies examining these relationships are comprised of adults with T2DM, and exclude youth with T2DM. There may be youth specific characteristics that could be contributing to the non-significant findings, such as the youth's the short amount of onset of diabetes. Furthermore, no previous studies have examined the relationship among these variables using behavioral rating scales to assess executive function. In previous studies, executive function have been assessed in various ways, including using the Stroop Color-Word Test, Mini Mental State Examination, and the Trail Making Test (Gold et al., 2007; Manschot et al., 2006; Munshi 2006), which are more objective than behavioral rating scales. Results of this current study may not be significant because executive functions are measured as a distal variable, rather than directly. The accuracy of response might be impaired since it is based on opinions of people who might have a

conscious or unconscious bias. Furthermore, parents may view the youth's age and their perspective developmental levels and have different expectations for their behaviors.

Although the initially stated hypothesis was not supported, additional post hoc analyses did reveal some interesting findings regarding the relationship among certain clinical scales of the BRIEF-SR and the youth's BMI. These analyses identified that the youth's ratings regarding their ability to adjust to changes in routine or task demands (Shift) significantly correlates positively with their BMI. Difficulties in adjusting to changes in routine or to task demands can greatly influence the adherence to any treatment that is geared to reducing BMI, by developing or changing diet, exercise, or general treatment protocols.

Another important finding was that the youth's rating of their ability to modulate emotions (Emotional Control) also significantly correlates positively with their BMI. Difficulties with modulating emotions can be related to emotional or situational eating. Overeating can then lead to an increase in youth's BMI.

It was hypothesized HbA1c would be mediate the relationship between depressive symptoms and health related quality of life, but no significant results were demonstrated. Analysis demonstrated that depressive symptoms were significantly correlated with HRQOL, but depressive symptoms were not significantly correlated with HbA1c, therefore indicating that HbA1c does not mediate the relationship between depressive symptoms and HRQOL. Several studies have reported on the correlation between depression and quality of life in youth with T2DM (Anderson et al., 2011; Lawrence et al., 2006) and in adults with T2DM (Wexler et al., 2006; Lustman et al.,

2000). In the adult population, a higher mean HbA1c has been found to be associated with increased depressed mood (Lawrence et al., 2006). The relationship between quality of life and glycemic control has also been studied in adults (Testa & Simonson, 1998). The present study found that even though a significant correlation between depressive symptoms and quality of life in youth exists, this relationship is not mediated by HbA1c.

Data addressing the third question in this study demonstrated that HbA1c did not mediate the relationship between family sharing of responsibility related to diabetes care and HRQOL. Specifically, the first step of the mediation analysis indicated no correlation the family sharing of responsibility and HRQOL, hence indicating no mediation. Few studies have assessed specific parenting practices or parenting behaviors with respect to the diabetes management of their youth with T2DM (Anderson & McKay, 2009). Research studying the parents' role in helping youth with T2DM is emerging.

General Limitations

A number of important limitations in this study need to be considered. The most important limitation lies in the small sample size. A power analysis indicated a need for 77 participants for a power at .80, but the study used 50 due to the slow data collection process and a naturally small pool of potential participants. The data collection process also took a long time due to frequent cancellations and no shows by participants to their clinic visit. Another limitation of the study was the use of self-reported data, specifically

the behavioral rating scales. Self-reported data is limited by the fact that it cannot be independently verified and it is subject to a response bias where the participant has a need to portray themselves as being more positive or negative than the reality would show. An important limitation exists in the manner by which we measure executive functions. Studies on diabetes outcomes in the past have obtained scores of executive function through various ways, which may not make it possible to generalize findings to other studies. When looking further into question 2, which addresses depressive symptoms, there appears to be a lack of variance in the scores obtained. The CDI Short Form was used to minimize the time commitment from the youth but it may have not been sensitive enough to pick up differences in the youth's depressive symptoms, which is another limitation of the study. Additionally, the sampling design may be another limitation of the study. We used a convenience sample that was available through the already established diabetes clinic. The availability of this convenience sample also assisted in making data collection more streamlined and efficient, however, this process still took approximately 6 months.

Implications

Despite the aforementioned limitations, the findings from this study contribute useful information to the understanding of the psychological and family factors of youth with T2DM, such as valuable clinical information and data pertaining to executive functions and BMI. Implications for future research and clinical care are discussed in light of the limits of this particular study.

Future Research

In general, future research is needed to increase and improve the overall understanding of the psychological and emotional issues of youth with T2DM and their families that can directly affect their treatment adherence and long-term outcomes. More research is needed to understand the relationship between executive function and HbA1c in youth with T2DM. Knowledge in this area can help in the development of treatment programs for diabetes management or prevention based on youth's executive function abilities. Although some studies have examined the relationship between depression and HRQOL in youth with T2DM, further research is needed to clarify the underlying mechanisms that support this association between HbA1c, depression, and quality of life. Additionally, research should focus on understanding the family's division of tasks related to T2DM to obtain insight into what is helpful when working with youth with T2DM.

Conclusions

The present study was designed to investigate psychological and family characteristics of youth with type 2 diabetes. This study demonstrated that executive function does not predict a youth's HbA1c, nor their BMI. Interestingly, one of the more significant findings to emerge from this study is that the youth's rating of their ability to adjust to changes in routine or task demands and their ability to modulate emotions also significantly correlates with their BMI. Future research examining the relationship

among psychological and family characteristics can aid the development of diabetes prevention and treatment management.

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