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# The Mediating Role Of Self-Efficacy Beliefs, Perceptions Of Diabetes Responsibility, And Their Impact On Treatment Adherence Among Adolescents With Type 1 Diabetes

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**THE MEDIATING ROLE OF SELF-EFFICACY BELIEFS, PERCEPTIONS OF  
DIABETES RESPONSIBILITY, AND THEIR IMPACT ON TREATMENT ADHERENCE  
AMONG ADOLESCENTS WITH TYPE 1 DIABETES**

by

**RICHARD W. WOOTEN**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

In fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

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MAJOR: EDUCATIONAL PSYCHOLOGY

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## **DEDICATION**

This entire work is dedicated to my wife Fay, and our five beautiful children: Anisa, Yasmeen, Sammer, Zayn, and Jad. Each one of you has given me the strength, focus, and determination to go on when times were difficult, and life's uncertainties tested us to the core. I hope that you all take pride in this accomplishment, because it was a team effort. It would never have happened without your encouragement, sacrifices, and unconditional support, for an undertaking that I know took valuable time from all of you. Thank-you for always being there, making me proud, and ensuring that I could see the forest through the trees. I love each of you with all of my heart.

With that being said, I want to say a few words about the person who inspired this mission to understand Type 1 diabetes, and by far, one of the most beautiful souls to grace my life, my daughter Yasmeen. I cannot begin to tell you how proud I am of you for taking charge of a condition that you never asked for, and for doing so with grace. As you said before, "I am not a diabetic, I am someone living with diabetes". Those words are eternally etched in my mind, because you have never allowed this ailment to define you, or interfere with your dreams and goals. Your strength of character speaks volumes and never ceases to amaze me, or those who have the privilege of being a part of your world. If all people with uncertain circumstances could adopt your reasoning and embrace your mantra, "Don't worry about me, I am bigger than this", then perhaps we have found the first step to better management of life's curve balls. You are my hero, and I love you for being you.

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## CHAPTER 1

### INTRODUCTION

#### **Background**

In the current body of work, the issue of treatment adherence in adolescents diagnosed with Type 1 diabetes mellitus was examined through the dissemination of the patient's personal self-efficacy beliefs, as well as the self-efficacy beliefs of the child's mother. Perceptions of parental responsibility for the adolescent's diabetes related care, as well as the adolescents' perceptions of how much responsibility the adult caregiver exerts in disease management, were also examined in an effort to determine correlations between these constructs. Demographic variables such as gender, age, parent marital status, socioeconomic status, and household income were included to observe possible correlations between individual levels of self-efficacy and parental involvement/responsibility and how these factors may influence treatment adherence.

#### **Defining and Understanding Type 1 Diabetes**

Type 1 diabetes is a chronic, autoimmune disease whose symptoms and onset are acute; offering little or no warning to the patient and family. Paradoxically, the lack of externalized symptomology in a Type 1 diabetes diagnosis also implies that the afflicted person's body has undergone a prolonged period of silent, internal, beta cell destruction in which the pancreas all but ceases normal insulin production. At the time of diagnosis, Type 1 diabetes patients and their families are presented with an overwhelming amount of information involving physical, behavioral, and psychological changes that are necessary to sustain the patient's health. These new challenges are driven by strict adherence to specific medical and behavioral directives that often leads to disruptions in daily routines that can adversely affect the entire family.

As is the case for people who live with Type 1 diabetes, the need for maximized glucose control to offset later complications mandates frequent monitoring that requires 24-hour maintenance. The need for continuous, regular blood glucose monitoring to avoid low blood glucose hypoglycemic episodes that can lead to coma, or high blood glucose readings which can lead to diabetic ketoacidosis, is taxing on all parties involved. The complex and demanding nature of the diabetes management regimen, which includes disruptions in meals and sleep, carbohydrate counting, and vigilant monitoring of symptom triggers such as tremors, dizziness, and other bodily effects, are primary contributors to the emotional rebellion, and familial conflict associated with Type 1 youth (Anderson, Svoren, and Laffel, 2007).

### **Etiology of Type 1 Diabetes**

A general explanation about the etiology of the illness is inconclusive at this point; however, there is consensus in the research community that a constellation of features including genetic markers, virus exposure, and environmental factors are responsible for the body's misalignment of healthy cell function. Among the many possible trajectories for the manifestation of the autoimmune response, stress has also been implicated in the genesis of the disease, citing a variety of scenarios that reduce immune functioning to include conflicted family interactions. Because warning signs are not readily present prior to diagnosis, the psychological impact of the disease on the patient and family is often overlooked to address the urgency of metabolic control that is necessary to offset life-threatening outcomes.

Through intensive meetings with diabetes professionals, the patient and family are educated about the challenges of strict management, as well as the necessity of committing to life-changing behaviors that serve to alter the structure of previously normal routines. In doing so, the psychological stress associated with these changes is often lost in translation in an effort

to optimize biological adherence. Strict blood glucose control in the first few years after diagnosis has been cited as the most important component to offset long-term health problems (American Diabetes Association, 2011).

### **The Importance of Treatment Adherence in Type 1 Diabetes**

Poor treatment adherence after initial diagnosis of Type 1 diabetes mellitus has been positively correlated with later onset complications such as kidney disease, cardiovascular illness, blindness, nerve disease, and a general decline in the quality of life (American Diabetes Association, 2011). In an effort to capture the constructs inherent in treatment adherence for those afflicted with Type 1 diabetes mellitus, the illness has been operationalized in current literature as a course of management that must include the continuous, dynamic, and specific behaviors which typify the population of those diagnosed with the illness (Kichler et al., 2011). Specific adherence to treatment protocols for Type 1 diabetics includes conventional management techniques (exercise, diet, stress reduction, and lifestyle change), multiple daily injections, the use of continuous subcutaneous insulin injection (via devices such as insulin pumps), ongoing glucose monitoring, and accurate carbohydrate counting (Kichler et al., 2011).

Current research also suggests that 30% of newly diagnosed patients with acute illnesses will fail to adhere to proper medical regimens that may prevent long-term complications, and additional research places the number at 50% or higher with those who suffer with chronic illnesses (DiMatteo, 1994; Rapoff, 2010). The multidimensional nature of adherence to Type 1 diabetes treatment as outlined by the American Diabetes Association makes the course of the illness challenging at best for the individual, and psychologically taxing at worst. In the case of patients who fail to adhere to proscribed treatment regimens, the families or parents of these individuals may also feel burdened and helpless. Taken a step further, the requirements of a Type

1diabetes regimen can place incalculable demands on the family; especially the adolescent who is attempting to address the complexities of a chronic illness, as well as the normal stressors encountered during this period of development.

### **Defining Adolescence**

Following the definition of adolescence used by contemporary scholars, the adolescent subjects in the current study were at least 11 years of age, and no older than 18 years of age, at the time data was obtained. The rationale in this classification stems in part from the onset of puberty that begins around the second decade of life, through the end of secondary education where many youths leave home for the first time to live independently. As research participants, adolescent patients who live with the rigors of Type 1 Diabetes face unique challenges related not only to disease management, but also with the overlapping demands of personal and social constructs that may be impeded as the adolescent attempts to foment an identity.

For the adolescent with Type 1 diabetes, strict adherence to treatment recommendations is the mitigating factor between hospitalization, disability, and even death. Like all children during this crucial stage of development, the adolescent with Type 1 diabetes is faced with the social demands of “fitting in” which also opens the possibility of conflicting choices that are not in tandem with a diabetes treatment regimen. These social exchanges can become confounded if the diabetic child alters health maintenance behaviors that are necessary to avoid negative health outcomes or risks for diabetes related complications. In a study of adolescent development, Harris (1998) found that 50% of adolescent decision-making can be accounted for through genetic influence, while the other 50% is primarily the influence of peer associations.

There is a broad base of research available filled with accounts of negative health behaviors during adolescence that play a pivotal role in treatment adherence and health outcomes

for teens with chronic illnesses (Anderson et al., 1997; Berg et al., 2007; Ellis et al., 2007; Ellis et al., 2008; Palmer et al., 2004; Patterson et al., 1989; Seiffge-Krenke et al., 2002; Wiebe et al., 2005). The notable presence of peers during this period act as an ever-present force who lend credibility to the adolescent's belief that they are not children, even though the majority of society refuses to view them as adults (Arnett, 2006; Jessor, 1991; Masten et al., 2006). Based on the work of Steinberg & Silverberg (1986), it is between the ages of 10-15 where the emergence of autonomy is initially recognized. Additional research by Anderson et al., (1997; 1999), and Hauser et al., (1990), suggests that this is also the period of development in which the diabetic child will begin to display a decline in his/her management of the illness. It is also important to recognize that reckless behaviors with the most negative outcomes gain strength through middle and late adolescence (15-18 years) when cognitive reasoning is still not fully developed. In addition, behavioral research shows a decrease in many (but not all) risk oriented behaviors as the individual enters the period of emerging adulthood between the ages of 18-25 years (Arnett, 2006).

The reciprocal exchange of social interactions during adolescence promotes the development of social skills that are critical for forming friendships and establishing bonds as the adolescent moves toward adulthood. In their work on adolescent development, Gardner & Steinberg (2005) indicate that teens and pre-teens are more susceptible to the influence of peers who guide much of this stage of development and social learning. Unfortunately, the peers who encourage and foster growth and exploration during this stage of life may also lack the insight and cognitive faculties to make sound decisions themselves. For the adolescent with Type1 diabetes, management of a chronic illness is something that may become secondary as they strive to define themselves and gain acceptance by those around them. Adding to the stress of the

demands that come with a chronic illness, it is during this period of development that many teens encounter intimate relationships for the first time, begin driving independently, spend more time away from family and parents, and are given the opportunity to navigate through an exciting new world of possibilities.

If the child's need to fit in with peers is also driven by the need for an ideal body image, then health risks become more likely as adolescence progresses and social interactions become more complex. This can be a complicated exchange for a child with Type 1 diabetes whose health is driven by strict dietary adherence. The current study examined the controlled management of the illness, which includes dietary and exercise factors through one of the subscales of the adherence measure. Furthermore, there are a number of studies which indicate that teens who adopt patterns of disordered eating during adolescence, will also experience more persistent and severe problems about eating in general as they move into young adulthood (Colton et al., 2004; Olmstead et al., 2008). Research in disordered eating indicates that adolescence is a time where males and females with or without Type 1 diabetes, may alter eating habits to conform to ideal body composition through excessive dieting, excessive exercise, or attempting to maintain the "ideal" standards of western society (Field et al, 1999; Neumark-Sztainer et al, 1998; Neumark-Sztainer et al, 1999; Stice, 2002). If the diabetic child is engaging in some form of disordered eating, they also increase the risk of negative outcomes in other areas where hyperglycemia, or hypoglycemia are more likely as they attempt to spend less time with their families, and more time on other social pursuits.

### **Defining Compliance**

Compliance constitutes an understanding that two parties are working toward a common goal, as is the case of the doctor/diabetes team who advises the patient about the necessary steps



to achieve optimum outcomes, and the patient actually completing the behavioral aspects of the doctor's suggestions. Compliance in diabetes literature is directly related to the patient's self-management of their illness. In the case of patients living with Type 1 diabetes, the primary goal of compliance is to *maintain strict blood glucose control* to offset later complications. When defining a compliance regimen in Type 1 diabetes care, compliance would consist of the patient's willingness to do the following tasks according to the American Diabetes Association's Standards of Care Guidelines 2011:

1.) adherence to regular glucose monitoring, at least three times per day, in an effort to maintain blood glucose levels of 80-120mg/dl for daytime glucose readings, and levels of 100-140mg/dl for bedtime numbers, 2.) continuous carbohydrate counting as a means of maintaining optimum glucose levels, 3.) controlled food intake, to include dietary guidelines as listed in the American Diabetes Association's Standard of Care Guidelines 2011, 4.) additional behavioral components such as refraining from harmful habits to include, a.) smoking, b.) consuming alcohol and 5.) engaging in healthy habits such as daily exercise of 15-30 minutes (minimum) and an adequate amount of sleep.

Because compliance with the diabetes related regimen is a multilayered task that focuses primarily on the behavioral aspects of disease management, it is sometimes easy to lose sight of other indirect processes such as the educational components that facilitate a better understanding of the outcomes of poor glycemic control (Hood et al., 2010). This is where the role of compliance is often misinterpreted by the patient as an issue of "doing what the doctors want," rather than viewing it as "doing something that I need to do to maintain health and wellness."

## The Role of Self-Efficacy in Treatment Adherence

Albert Bandura's Social-Cognitive Theory posits that the underlying self-efficacy beliefs that a person holds as true, will serve as buffers against anxiety or other psychopathologies and work independently of social contexts (Bandura, 1986). Self-efficacy is essentially the capacity of an individual to deal with the conditions experienced throughout life and make adjustments as necessary to meet those demands with decreased stress (Reber & Reber, 2001). Bandura suggested that individuals with strong self-efficacy beliefs would persevere in the face of a challenge, and respond with optimism about challenging life events (Bandura, 1986). On the contrary, those with negative efficacy beliefs would likely fall victim to their negative beliefs, and act in a more irrational or pessimistic manner about thoughts of possible death or disability (Cicerelli, 1998).

Self-regulatory processes used by a patient to offset the distress associated with a chronic illness could include positive self-efficacy beliefs. Although one's self-efficacy beliefs may not be entirely accurate when investigating an individual's ability to follow a proscribed course of action, Bandura (1977; 1986; 2001) suggests that people with high self-efficacy may be inclined to do things that lead to better psychological outcomes. In the case of those living with the demands of Type 1 diabetes, an understanding of the power of *one's perceived ability* to follow through with a demanding treatment regimen, may also contribute to factors that guide the course of a chronic illness. A thorough understanding of the self-efficacy components between children with Type 1 diabetes and their parents' self-efficacy beliefs has not been thoroughly addressed in diabetes education literature. Previous research with other chronically ill populations has shown the influence of self-efficacy beliefs, and the mediating effect that they impart on treatment adherence, and in turn, long-term outcomes.

## **The Role of the Parent**

There is a large body of information available which supports the idea that regimen adherence is increased in patients who feel that their social supports will be there to buffer the effects of the illness (Delamater, 2007). Because parental management of a child's daily diabetes regimen is consistent with the notion that the child is unable to maintain the rigors of strict treatment adherence independently, this position becomes problematic for the parent/child dynamic as the youth moves into adolescence and seeks greater autonomy. Parental behaviors; especially behaviors which are perceived by the adolescent as inconsistent with their own ideals, may cause them to move further away from treatment recommendations, and their parents, as new boundaries are explored and tested in the home setting (Pomerantz & Eaton, 2001; Ott et al., 2000; Williams et al., 2004).

An alternate explanation for this phenomenon is that the decline in adolescent adherence behaviors is related to the premature disengagement of the parental figure from the position of disease management (Anderson et al., 1997; Wysocki et al., 1996). Additional research in parent roles suggests that the premature withdrawal of adult responsibility is more a function of the child's age rather than true efficacy for successful management of the condition (Drotar & Ievers, 1994; Holmes et al., 2006). Furthermore, as the child attempts to balance the social, behavioral, and emotional ebb and flow of adolescence, parental self-efficacy may also influence the level of engagement that the child implements in his/her disease management.

## **Gender Differences in Adolescent Type 1 Diabetes Patients**

Aside from the typical physical, hormonal, social, and emotional challenges of adolescence, gender differences and expectations also become apparent during adolescence and can impact a young person with Type 1 diabetes. In the United States, adolescent boys are

socialized to be outgoing, and more athletically involved in daily affairs than their female counterparts. According to Grossman et al. (1987), females are expected to be more compliant in their demeanor and therefore more prone to seek out externalized feedback in their social settings. The compliance that Grossman and colleagues speak about, has also been assessed in behaviors that affect Type 1 diabetics such as disordered eating (Olmstead et al., 2008).

In an effort to measure compliance, Grossman, Brink, & Hauser, (1987) incorporated their Self-Efficacy for Diabetes Scale-SED, into studies which allowed them to assess sex differences which had previously been ignored in scholarly literature. Their findings indicated that sex differences are very likely the product of patterns of socialization that may vary from culture to culture. Their work solidified the idea that girls with Type 1 diabetes were more likely to retain a link between better glucose control and self-efficacy because societal standards expected them to be more compliant, and in turn, more self-evaluative (Grossman et al., 1987). To the contrary, boys were less likely to seek out externalized sources of support during adolescence, and therefore would present with less control of their illness. Grossman et al. (1987) go on to note that females personalize their conflicts and exert more energy into managing potential problem areas. On the other hand, males will distance themselves from the source of a problem, such as poor glucose control, and therefore externalize their behavior in other domains (Grossman et al., 1987).

Furthermore, low self-efficacy in the adult parent has been correlated with less glycemic control in their children. Delamater (2007) goes on to state that issues such as low socioeconomic status are also correlated with lower levels of adherence in Type 1 patients, therefore increasing the risk of later complications. Family relationships devoid of conflict are viewed as a positive attribute for adolescents who maintain better control of their illness

(Delamater, 2009). Unfortunately, the realities of divorce, separation in the marital home, removal from the primary care setting, or ongoing patterns of conflict, also appear to follow Delamater's definition of non-adherence promoting behaviors, which postulates that treatment success is compromised under such conditions.

### **Statement of the Problem**

The rationale behind the current study was to provide additional insight into the often-overlooked importance of self-efficacy beliefs, diabetes care responsibilities within families, and their relationships to treatment adherence. The psychologically relevant aspects of an individual living with Type 1 diabetes are often cited, but not practiced in diabetes education programs. Because the primary focus with Type 1 patients is to maintain control of an illness that emphasizes medically relevant behavioral changes, it is easy for the patient and family to become overwhelmed with the psychological stress of disease management. The current study sought to clarify the mediating role of self-efficacy in the management of a potentially life threatening illness, with the primary goal of contributing to a broader understanding of the psychological mechanisms that influence the difference between health and illness. By utilizing an adolescent population with a focus on patient and maternal self-efficacy, as well as the influence of diabetes care responsibilities and involvement, the diabetes educator was presented with concepts that are viewed in the current literature as critical to overall care with any chronic illness.

Current research in the area of treatment outcomes with Type 1 youth suggests that non-adherence in pediatric populations, is mediated in large part by parental involvement in the early course of the illness. Based on the assertion that parental involvement, especially in illness management, may wane as the adolescent begins to seek greater autonomy, the question then

arises as to the mediating roles of patient and parent self-efficacy on treatment adherence. There is a paucity of information available looking at these factors beyond initial diagnosis to gauge adherence to protocols which could prevent later onset problems such as kidney disease, blindness, neuropathies, as well as a general decline in the quality of life which is often experienced by those who undergo the effects of severe health problems associated with poor treatment adherence.

Based on the assertion that parental responsibilities may decrease when the child reaches adolescence and thus seeks more independence in personal matters, the question then arises as to the mediating role of adolescent vs. parent levels of self-efficacy when assessing compliance rates of the afflicted individual. The need for strict diabetes control on an ongoing basis without parental involvement, may also impact adherence levels if there is a perceived lack of control in situations where the child is expected to maintain strict diligence and attention to complicated treatment regimens, which are vital for positive health outcomes.

### **Variables**

The first independent variable in the current study was the self-efficacy beliefs of the adolescent and this score was derived from the Self-Efficacy for Diabetes Scale (SED). The second independent variable was the self-efficacy beliefs of the mother obtained from the same measure, but in a parent format. The third independent variable was the mother's perceived level of responsibility in diabetes related care based on data from the Diabetes Family Responsibility Questionnaire. The fourth independent variable was the perceived level of parental responsibility in diabetes related care by the adolescent based on data from the Diabetes Family Responsibility Questionnaire. The fifth independent variable was the gender of the adolescent respondent. The sixth independent variable was the age of the adolescent. The seventh independent variable

focused on parent marital status (single-parent, married, divorced, separated, or in committed adult relationship). The eighth independent variable was socioeconomic level. The ninth independent variable was family income level. The tenth independent variable took into consideration the frequency of blood glucose monitoring. The eleventh independent variable was the method of insulin administration, and the final independent variable was the HbA<sub>1c</sub> level of the adolescent.

The first dependent variable examined the adolescent's adherence to treatment through data taken from the Self-Care Inventory (SCI), Youth Form. The second dependent variable assessed the mother's perceptions of their child's adherence to treatment. This was accomplished by obtaining data from the Self-Care Inventory (SCI), Parent Version.

### **Assumptions**

It is assumed that the tests being used in the current proposal were valid and reliable measures of the variables under consideration. The second assumption was that the individuals recruited for the current study were not biased in any way due to statements made by, or through, the researcher's presentation during volunteer recruitment. The third assumption was that all participants were notified at the time of recruitment that participation was voluntary, and that all answers were to remain confidential. The fourth assumption was that all participating adolescent respondents were diagnosed as having Type 1 diabetes mellitus by a certified health care provider, and have received proper guidance in the treatment of their condition. The fifth assumption was that the parent has been involved with the adolescent in their diabetes treatment. The final assumption was that all respondents answered the questions in an honest and accurate manner according to the timelines outlined in the initial contact through the recruitment setting.

## Hypotheses

The current proposal tested the following hypotheses:

H<sub>1</sub>: HbA<sub>1c</sub> levels can be predicted from mothers' and adolescents' perceptions of treatment adherence.

H<sub>2</sub>: Self-efficacy will mediate the relationship between treatment adherence and HbA<sub>1c</sub> levels.

H<sub>2a</sub>: Maternal self-efficacy will mediate the relationship between mothers' perceptions of treatment adherence and HbA<sub>1c</sub> levels.

H<sub>2b</sub>: Adolescent self-efficacy will mediate the relationship between adolescent's self-report of treatment adherence and HbA<sub>1c</sub> levels.

H<sub>3</sub>: Mothers' perceptions of treatment adherence can be predicted from mothers self-efficacy, adolescent self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire.

H<sub>4</sub>: Adolescents' perceptions of treatment adherence can be predicted from mother self-efficacy, adolescent self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire.

H<sub>5</sub>: Mothers' perceptions of treatment adherence can be predicted from gender of adolescent, age of adolescent, marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and Hb A<sub>1c</sub> levels.

H<sub>6</sub>: Adolescents' self-report of treatment adherence can be predicted from gender of adolescent, age of adolescent, marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and Hb A<sub>1c</sub> levels.



## CHAPTER 2

### REVIEW OF THE LITERATURE

In the current study, all hypotheses were derived from literature that focused on the intensive management of Type 1 diabetes, which serves as the current standard of care for individuals with this illness. An explanation of relevant studies and treatment approaches has been incorporated in the formal review to address the intricacies of this management approach as the benchmark for improved glycemic control. Additional research sought to clarify the position that factors such as self-efficacy beliefs, parental involvement and responsibility, and socioeconomic factors play in the effective management of the illness. Furthermore, the current findings also highlight the importance of maintaining optimum management of Type 1 diabetes through outcomes derived from research findings that identify problematic behaviors, as well as their relationship to long-term complications.

#### **Introduction to Type 1 Diabetes and its Impact on the Patient**

Contrary to previous beliefs about the course of Type 1 diabetes, there is a consensus in the research community that the risk for diabetic complications begins at diagnosis (Donaghue et al., 2003; Donaghue et al., 1993; Olsen et al., 1999; Rosenbloom et al., 2000; Schultz et al., 1999; Sochett & Daneman, 1999). The treatment regimen for Type 1 diabetes, formerly referred to an “insulin dependent” or “juvenile diabetes”, consists of a number of critical steps to achieve optimum glucose control. Those who have had little, or no contact with someone who suffers with the physical and psychological problems associated with Type 1 diabetes, may find the course of the condition, including its complex treatment regimen, hard to understand or appreciate. The demanding, and often complex array of physical sensations that Type 1 patients may experience include lethargy, hyperactivity, excessive thirst, dizziness, sweating, blurred

vision, frequent urination, dry skin, slow healing wounds, and shaking just to name a few. Each of these occurrences requires the individual to understand, and address each symptom expediently and with accuracy to avoid negative outcomes (American Diabetes Association, 2011). When other factors such as the psychological effects of hypoglycemia, hyperglycemia, continuous dietary restrictions, and the grueling daily demands of treatment adherence are taken into consideration, a new level of complexity is added to an already difficult illness.

It is well established in the literature that glycemic control during adolescence becomes more problematic for Type 1 diabetics (Anderson et al., 1997; Hamilton & Daneman, 2002). Many follow-up, large scale longitudinal studies including the landmark Diabetes Control and Complications Trial (DCCT, 1993) and the Epidemiology of Diabetes Interventions and Complications Research Group (EDIC, 2001), contradicted earlier findings about practice standards in diabetes care and pushed for more intensive glycemic control. The reasoning here was that optimum glycemic control was necessary to offset later complications that resulted not only from hypoglycemia, but from hyperglycemia as well.

With the advent of new technologies and studies that highlight the role of adherence behavior in diabetes care, the demands placed on a Type 1 diabetic today are far more intense than in the past. Since the findings from the DCCT (1993) were released, the shift in treatment for Type 1 diabetes has focused on intensive management of the illness. Because the Type 1 diabetes management regimen requires constant diligence, it can alter and interfere with daily routines in several domains such as physical, social, employment, and academic to list a few. The DCCT (1993) provided the groundwork for standards of care that have been adopted globally for patients of all ages who live with the demands of Type 1 diabetes. Although the findings of the DCCT (1993) provided insight into the complexities of the illness, one drawback

was that patients would be forced to adhere to new demands of disease management that could increase stress. The stress in question could be exacerbated through a higher frequency of blood glucose monitoring, calculation of meals through carbohydrate counting, more intensive administration of insulin, and exercise requirements that make the disease more difficult on many levels.

### **Current Standard of Care for Pediatric Type 1 Diabetes**

The current standard of care for type I diabetes patients in pediatric populations is what is referred to as “intensive management” of the disease (American Diabetes Association, 2005; Craig et al., 2006). An important aspect of the intensive management model for children and adolescents includes treatment regimens that encompass on-going access to multidisciplinary teams of diabetes specialists such as pediatric endocrinologists, dieticians, diabetes nurses, and mental health professionals. (American Diabetes Association, 2005). The assumption inherent in these guidelines is that the patient and his/her family has participated in a structured diabetes education program which is an integral part of the treatment plan for all newly diagnosed Type 1 diabetes patients in the United States (American Diabetes Association, 2005). The importance of patient education and training in self-care cannot be over emphasized in diabetes treatment adherence, and this is due in large part to the ever changing and evolving nature of research in this area which promotes knowledge and self-care (Norris et al., 2000). Because self-efficacy relates to knowledge and skills that are necessary to achieve a desired result, the need for sufficient levels of self-efficacy in this case provides an important bridge between action and outcome (Bernal et al., 2000; Glasgow & Osteen, 1992).

## **The Role of the HbA<sub>1c</sub> Measure in Diabetes Care**

Newer techniques in diabetes care such as the HbA<sub>1c</sub>, also referred to as the glycosylated hemoglobin test or A1C test, offers a picture of “average” blood glucose readings that extends over a two to three month period. This simple blood test measures the concentration of hemoglobin molecules that have glucose attached to them (American Diabetes Association, 2011). The “percentage” measure utilized for this test is done to show how much of the hemoglobin molecules are “sugar” coated. For example, an HbA<sub>1c</sub> reading of 8% would mean that 8% of a person’s hemoglobin molecules are glycosylated, or covered with glucose.

In general, the HbA<sub>1c</sub> measure provides the patient and family with valuable information that allows the health care team to assess trends in treatment adherence, and make adjustments where necessary. The American Diabetes Association states that non-diabetic populations should maintain HbA<sub>1c</sub> readings between 4 and 6%, and that readings near 7% are often viewed as “pre-diabetes.” For adolescents with Type 1 diabetes, the American Diabetes Association (2011; 2005) recommends that levels should be less than 7.5%, but closer to 7%. This standard has also been adopted on an international level and recognized as the benchmark in the care of Type 1 diabetes (American Diabetes Association, 2011; 2007; Canadian Diabetes Association, 2003; National Institute for Clinical Excellence-London, 2005; Silverstein et al., 2005).

The necessity of the HbA<sub>1c</sub> test is rooted in the belief that later diabetic specific problems will arise if readings remain consistently above the target values. By remaining aware of HbA<sub>1c</sub> readings, the patient is also able to choose a corrective path to offset the possibility of later complications, which tend to be more subtle in the earlier phases of consistent hyperglycemia. Through the inclusion of the HbA<sub>1c</sub> test in routine diabetes care, the patient, family, and diabetes team are provided with valuable information to assess where modifications may be required to

achieve better management of the illness. Typical modifications to promote better glycemic readings might include changes in insulin administration throughout the day, or even dosing adjustments during the night that can be influenced by hormonal fluctuations as the body moves through the various stages of sleep. HbA<sub>1c</sub> readings during adolescence can also be affected because of the interplay between sex hormones, and growth hormones that can impact the body's ability to distribute insulin.

In order to keep up with the demands of Type 1 diabetes, the individual is required to pay constant attention to the physical and psychological cues that can be the difference between a visit to the hospital, or even life and death. Extraordinary discipline in maintaining glucose control is achieved through a combination of strict behavioral adherence to treatment, as well as the ability to problem solve in the face of new and unusual symptoms. The stress and constant demands of a disease that carries with it such an unpredictable course will often test the limits of all parties involved; including their abilities to cope with the illness (American Diabetes Association, 2011; 2005).

In a study by Kavanagh et al. (1993), HbA<sub>1c</sub> levels were classified as an indirect measure of treatment adherence, which is under the influence of the disease management regimen. Iannotti et al. (2006) contribute to the existing literature by confirming the association between higher than normal HbA<sub>1c</sub> readings and poor glycemic control. The Iannotti et al. (2006) study also found that there was no significant difference between male and female patients with Type 1 diabetes regarding self-management and glycemic readings. Although these findings are accepted to some degree in the general diabetes population, the study failed to account for gender related differences that may be the result of societal expectations. Those expectations could also

translate to familial influences in which the female may be seen as more structured and self-aware in specific cultural settings.

In a separate study by Haugstvedt et al. (2011), children in the 12-15 year age range showed higher overall HbA<sub>1c</sub> readings when compared to children in both younger and older cohorts. These findings are also supported in the work of Margeirsdottir et al. (2010) and Ziegler et al. (2011) which found that adolescents had higher incidences of elevated HbA<sub>1c</sub> levels than a cohort of Type 1 diabetic patients who were 12 years of age or younger. The theory here is that perceptions of diabetes related responsibility shifts as the child takes on the independence associated with adolescent development, therefore creating a greater opportunity for poorer glycemic control (Anderson et al., 1997; 1999; Hauser et al., 1990).

Another important component in better-controlled HbA<sub>1c</sub> values appears to be related to the frequency of monitoring (Haugstvedt, 2011). In this study, higher frequency of blood glucose monitoring, which was classified as seven or more times a day, and was significantly associated with better HbA<sub>1c</sub> values. In terms of caregiver needs that include blood glucose monitoring, Haugstvedt (2011) also found that older adolescents exhibited higher HbA<sub>1c</sub> readings that might be related to perceptions of lowered parental responsibility that often wanes as the child ages.

Regarding the notion that children are more likely to have irregular HbA<sub>1c</sub> readings within the first year of diagnosis, Haugstvedt (2011) argues that this may not be the case. In her sensitivity analyses, which were performed with a group of 115 adolescent, Type 1 diabetes patients, they found no substantial differences in those with the duration of more than one year. The findings in the study indicated that the 17 patients with disease duration of less than one year had average HbA<sub>1c</sub> values of 8.2%. The HbA<sub>1c</sub> values for the 98 respondents with disease duration longer than one year came back at 8.1%. In a separate study by Haugstvedt (2010),

findings went on to show that there were no significant differences in the glycemic readings of children who were on insulin pump regimens, versus basal-bolus injections with a syringe or insulin pen. Significant differences in the child's age were also found in relation to HbA<sub>1C</sub> values in the Haugstvedt (2005) study with younger children shown to maintain better overall numbers.

### **The Role of Insulin Pump Therapy and Type 1 Diabetes Treatment Adherence**

The current study included patients using multiple daily injections, and insulin pump therapy because both methods are still subject to the same treatment guidelines for intensive management of the illness. With the advent of precise insulin pump therapies in the new millennium, Type 1 diabetes patients are able for the first time to use an electronic device that is capable of administering the correct amount of insulin throughout the day minus the need to commit to multiple daily injections. The primary drawback for patients' who follow intensive management techniques with multiple daily injections, is that they must account for meal calculations independent of electronic means, which increases the burden on the individual for accuracy in food intake, thus putting them at risk for disordered eating.

McMahon et al. (2005) found that the use of insulin pump therapy improved overall glycemic control in a cohort of Type 1 diabetics' ages 3.9-19.6 years. Their findings were able to elucidate a decrease in HbA<sub>1c</sub> levels from  $8.3 \pm 0.1\%$  prior to the use of the pump, to  $7.8 \pm 0.1\%$ . Considering that the Standards of Care outlined by the American Diabetes Association require Type 1 diabetics to opt for HbA<sub>1c</sub> reading at or near 7%, this only adds to the encumbrance of a metabolic disorder that is sometimes hard to control.

Unlike the bulky and inaccurate predecessors to the current insulin pump technology, algorithms are now employed which gauge the amount of insulin needed based on a patient's individual carbohydrate requirements. Through the use of flexible management regimens, those

who opt out of insulin pump therapy also have the advantage of more freedom in food and activity as long as the carefully calculated insulin-carbohydrate ratios are adhered to without fail. Although these advances have curbed many of the worries that were associated in the “guesswork” of past diabetes methodologies including urine tests for acetone levels, and insulin administration based on pre-determined dosing, the stress of constant vigilance is sometimes too much for the patient to manage.

The McMahaon (2005) study concluded that insulin pump therapy also reduced the number of hypoglycemic episodes by approximately 1/3, or more specifically, from 32.9 to 11.4 per 100 patient years. The rationale presented by researchers for the promotion of subcutaneous insulin infusion treatments such as an insulin pump, is to promote a biological balance that offsets potentially life-threatening events such as hyperglycemia, and hypoglycemia (Bode et al., 2002; Linkeschova et al., 2002; Pickup & Kleen, 2002). Furthermore, the insulin pump is reported by patients and families alike to offer more flexibility and control in one’s life (McMahon et al., 2005).

### **Adherence to Diabetes Treatment**

It is well established in medical literature that a prominent obstacle in the management of chronic illness is low levels of treatment adherence (Epstien & Cluss, 1982). The research has been steadfast for a number of years, stating that patients with Type 1 diabetes must actively engage in controlled management of the illness through a process of behavioral modification that serves to enhance treatment adherence (Anderson et al., 2007; Anderson, et al., 1999; Anderson et al, 1997; Anderson et al., 2002; DiNicola & DiMatteo, 1982; Glasgow et al, 1987; Laffel et al., 2003). Among the more prominent constructs to predict behavioral changes over time, self-efficacy lends itself to a long-standing body of evidence across a variety of areas that includes



management and adherence to chronic illness (Condiotte & Lichenstein, 1981; Kavanagh et al, 1993; Kavanagh & Wilson, 1989; Sitharthan & Kavanagh, 1990).

McCaul et al. (1987) offered one of the first studies to measure the effects of self-efficacy on treatment adherence in Type 1 diabetes patients. In their sample of 107 participants, the findings indicated for the first time that self-efficacy predicted treatment adherence concurrently as well as prospectively. A shortcoming in the McCaul et al. (1987) by today's standards of care for Type 1 diabetes, is that their study was unable to measure self-efficacy expectations related to adherence in each of the currently proscribed treatment areas which includes diet, exercise, blood glucose monitoring, and intensive insulin management. Soon after the McCaul et al. (1987) study, Kavanagh et al. (1993) demonstrated that self-efficacy was the most powerful predictor of treatment adherence in adolescent patients when assessing diet and exercise regimens at that time. With the advent of intensive diabetes treatment and the need to monitor food intake and insulin distribution, the conflicting needs of an adolescent sets the stage for health concerns not previously touched upon before this period.

A more recent study by Palmer et al. (2009), which looked at the effect of self-efficacy as a facet of Type 1 diabetes treatment adherence, found that low self-efficacy beliefs in the adolescent patient were buffered by high parental involvement. This lends credibility to a multitude of diabetes literature that looks at the role of the family in general, and the parents in particular, as consistent contributors to better adherence and glycemic control (Berg et al., 2007; Ellis et al., 2007; Ellis et al., 2008; Palmer et al., 2004; Patterson et al., 1989; Seiffge-Krenke et al., 2002; Wiebe et al., 2005).

### **Measuring Adherence with the Self-Care Inventory (SCI)**

The Self-Care Inventory (SCI) has been recognized as one of the strongest predictors of HbA<sub>1c</sub> levels and has maintained this position since its inception, even when patient's demographic information is taken into consideration (Kichler et al., 2012). Annette La Greca and colleagues initially validated the instrument in 1988 when it was first utilized in a 13-question format. The measure was revised again in 1992 and another question was added to reflect updated research in the field of diabetes research. Dr. La Greca initiated the latest validation in 2004 and four conceptual factors were obtained by calculating a mean score. Blood glucose regulation, insulin in food regulation, exercise, and emergency precautions, were recognized on the original SCI, and confirmed in the revisions.

Unlike many measures of diabetes treatment adherence, the SCI offers a dual parent/youth format to assess perceptions of diabetes related care. The psychometric properties of the instrument were assessed by Lewin et al. (2009) with 164 adolescent Type 1 diabetes patients. The results of the study validated earlier findings by Quittner et al. (2008) that the SCI reported good psychometric properties regarding internal consistency and stability coefficients. The Quittner et al. (2008) study demonstrated a significant association between the patient's glycemic control and their adherence ratings. Furthermore, the SCI's adherence scores converged with other diabetes adherence measures including the 24-hour recall diary (a more time-consuming counterpart), as well as the measure for Health Beliefs and Problem Solving Skills (Bond et al., 1992; Quittner et al., 2008; Thomas et al, 1997).

Korbel et al., (2007) have also found that the SCI provides good internal consistency in adolescent populations. Internal consistency ratings in the Armstrong et al. (2011) study indicates that scores in preadolescent Type 1 diabetics was  $\alpha = .83$ . They also measured parents'

ratings of their child's self-care behaviors with the SCI and internal consistency was deemed adequate at  $\alpha = .78$ . Based on findings by La Greca (2004), the adjusted global score of the SCI provides the best predictor of glycemic control through the patient's HbA<sub>1c</sub> readings as it relates to self-care. The Kichler (2011) study utilized the original SCI rather than the revised version, and found that they were able to obtain internal consistency ratings of  $\alpha = .84$  for the adjusted total score. Furthermore, as an assessment tool for measuring adherence to self-care behaviors, the SCI has been shown to provide more robust interrelation to adherence levels than diary measures, electronic monitoring, and provider report (La Greca, 2004).

### **The Importance of the DCCT and EDIC in Diabetes Care**

The Diabetes Control and Complications Trial (DCCT, 1993) and the Epidemiology of Diabetes Interventions and Complications Research Group (EDIC, 2001) provided the wider public with new and improved guidelines to dictate the course of the illness. Prior to the research conducted in the DCCT (1993), there was no empirically validated study that looked at the long-term effects of glycemic control and its outcome. Early research in the diabetes literature offered conflicting information about the best methods to employ when addressing diabetes specific problems. Prior to the DCCT (1993) report, studies such as the one conducted by Kostraba et al. (1989) suggested that it was less important to be concerned about pre-pubertal hyperglycemia because it was considered a good practice to allow for high blood glucose readings. The rationale applied to this approach stemmed from behaviors that were meant to offset the possibility of life threatening low blood-glucose levels. On the contrary, and unbeknownst to researchers before the findings of the DCCT (1993), consistent hyperglycemia over an extended period of time also led to problems with blood vessels that acted as the precursor for later diabetic complications including blindness, stroke, heart attack, and kidney disease.

Over the ten year span that the DCCT (1993) was conducted in medical settings across North America, data collected from this study showed that early control of blood glucose levels through adherence to treatment recommendations, contributed to the delay, or even prevention, of diabetes related complications (Anderson et al, 2007). The DCCT (1993) also illustrated a lower incidence of microvascular complications by approximately 50% in patients who maintained blood glucose readings as close to normal as possible (Anderson et al., 2007). The philosophy that was born of the DCCT (1993) was a multifaceted approach that called for the utilization of highly trained specialists whose focus was on the patient, as well as the patient's ability to engage in self-care decisions (Brink et al., 2002).

The current study incorporated the findings of the DCCT (1993) by including measures which assess a patient's ability to talk with members of their multidisciplinary team as would be expected under the current guidelines for the treatment of Type 1 diabetes. Laron et al. (1979) were among the first in the field of Type 1 diabetes research to suggest that a team approach to disease management be adopted as a normal part of diabetes care. Because the researchers involved in this study felt that the metabolic issues of diabetes posed complexities beyond the scope of what many people could address on their own, they concluded that if teams were created, then patient stress and burnout could be mollified.

The EDIC study, which served as a follow-up to the DCCT (1993), used approximately 90% of the 1,441 participants in the original DCCT (1993) to provide additional insights into cardiovascular illness in Type 1 patients. Like the DCCT (1993), the EDIC (2001) project illustrated that patients with varying degrees of glycemic control were likely to experience predictable cardiovascular complications related to poor glucose maintenance, which included stroke, heart attack, and the need for cardiovascular surgeries. Data on other diabetes related

problems such as retinopathy, neuropathy, and kidney disease were also collected in the EDIC (2001) follow-up and found to be related to poor glycemic control, primarily as a result of non-adherence to treatment recommendations. The findings in the (2001) study signaled the public once again to the importance of strict adherence to treatment protocols when they released their findings and stated that significant cardiovascular events were reduced by 42%, and non-fatal heart attacks, stroke, and death from diabetes complications were reduced by 57% if glycemic control was utilized.

Although the results of studies such as the DCCT (1993) have provided data for a broad range of ages in regard to those afflicted with Type 1 Diabetes, the research has consistently shown that adolescents fail to maintain the same glycemic control as adults by nearly 1% of their recommended HbA<sub>1c</sub> levels. These findings are based on the ranges provided by the American Diabetes Association (2011; 2005), which indicates a significant difference between groups. Because rates of diagnosis for Type 1 diabetes are currently believed to be highest during adolescence when children are often handed the task of independent disease management, improper behavioral habits learned early could become long-standing obstacles that lead to long-term complications. Early measures and interventions need to be adopted that offer support to the patient before patterns of complacency or apathy lead to a negative shift in statistical outcomes for this population.

The DCCT (1993) and EDIC (2001), helped to highlight the importance of the multidisciplinary team approach in the treatment of diabetes. As a result of the findings from these studies, specialized diabetes teams are now viewed as a necessary component to aid the patient and their family toward better metabolic control of their diabetes. Included in the overall methodology to improved metabolic outcomes, increased monitoring of glucose levels, which

includes carbohydrate counting as part of a food-to-insulin ratio, helped to create a formula for better illness management (American Diabetes Association, 2011; 2007; 2005; Brink et al, 1997).

### **Problems in the Healthcare Setting that Affect Treatment Outcomes**

Contrary to the suggestions of early studies and best practice guidelines, to include the findings of the DCCT (1993), research in diabetes treatment often indicates deep theoretical and professional differences in health care providers' attitudes about the importance of medical treatment versus the role of professionals who provide behavioral health interventions (Delamater et al., 2001; Levinson & Roter, 1995). The current study utilized measures that assessed these ideological shifts in which the biological maintenance of the illness is often viewed as paramount to the emotional and psychological needs of the patient and family. Unfortunately, this approach is often encouraged to the detriment of psychological constructs that can be equally influential in treatment adherence.

In a study that was published on the heels of the DCCT (1993), Maguire et al., (1996) highlighted findings which show that variability rates among health care providers' ability to ask the appropriate questions, often creates a barrier in patient communication, and in turn, treatment adherence. The same findings also indicate that the provider's personal feelings of competence might impede positive outcomes that can have far reaching consequences for a patient; especially when that patient relies on his/her medical team for control of their illness. Although multidisciplinary approaches are the expected norm in diabetes treatment, these findings signal a problem in which internal struggles in the healthcare setting may interfere with the best interests of the patient.

The move to implement multidisciplinary teams allowed for closer follow-up care that helped re-align studies which focused on better illness management. With the advent of new clinical findings in the DCCT (1993), previously accepted forms of patient care methods were changed to meet the demands of increased day-to-day responsibilities for diabetic patients. The theoretical shift away from acute-care models which dominated Type 1 diabetes research prior to the DCCT (1993) and EDIC (2001), also meant that practitioners in this area would need to modify previously held notions that were incongruent with newer medical treatment methodologies (Brink et al., 2002). Those shifts are what led to the current best practice methods, which are accepted as the hallmark of proper treatment adherence in Type 1 diabetes care.

Schwarzer et al. (2011) pointed out that people with chronic illnesses are at a much higher risk of multiple behavioral risk factors that increase the likelihood of later health complications when compared to healthy members of the general population. As a result, patients with Type 1 diabetes are more likely to suffer the ill effects of treatment non-adherence unless proactive measures can be utilized in clinical settings to assess perceived abilities in a more systematic fashion. The trade-off for complying with treatment recommendation is the hope that the patient can live a longer, healthier life through proper metabolic control. Unlike many illnesses that may pass, or can be “cured”, the daily demands that Type 1 diabetics and their families face, requires around the clock care which at this point in time, is incurable.

### **Albert Bandura’s Social-Cognitive Theory: Relevance for Diabetics**

Albert Bandura’s Social-cognitive theory, and one of its core constructs, self-efficacy, is well established in diabetes literature. It is viewed as an influential force in overall treatment adherence, and a number of studies in self-efficacy, including its role in patient perceptions, have

offered insights into the mechanisms of this construct. The underlying feature in Bandura's theory is that it looks closely at one's motivation to pursue goals, and the processes needed to instill confidence to realize positive outcomes (Anderson et al., 2007; Bandura, 1977; Bandura, 1986; Bandura, 1997; Kavookjian, 2001; Kavookjian et al., 2005; Johnston, 1996; Schechter & Walker, 2002).

Bandura (1977) proposed that *perceived* self-efficacy refers to an individual's belief in his or her ability to successfully complete some course of action in order to produce given attainments. The effort, persistence, achievement, and task choices that a person undertakes are guided by their perceptions of personal capabilities (Bandura, 1997; Schunk & Meece, 1995). Even if the individual's true level of ability is not in tandem with the task at hand, those with high self-efficacy beliefs are more likely to work harder, persist longer, and achieve at higher levels than those with superior abilities who harbor feelings of low self-efficacy (Bandura, 1986; 1997).

Borkovec (1978) pointed out early criticisms of Bandura's social cognitive theory by noting that opponents viewed the attainment of skills as a better predictor of later behavior than self-efficacy alone (Kavanagh et al., 1993). Research studies conducted in chronic illness, as well as other problem areas in psychosocial functioning, lend support to the idea that self-efficacy is a better overall predictor of later behaviors than performance (Bandura, 1982; 1986; Condiotte & Lichtenstien, 1981; Kavanagh & Wilson, 1989; Kavanagh et al., 1993; Sitharthan & Kavanagh, 1990). Bandura helped solidify his position against his detractors by stating that the level of achievement attained by an individual is influenced by self-efficacy beliefs that serve to motivate the person (Bandura, 1977; 1986; 1997).



The manner in which self-efficacy is appraised is drawn from four sources which look at physiological reactions, actual performance, vicarious experiences, and various forms of persuasion from outside sources (Schunk & Meece, 2005). Equally important, the family structure helps to mold a young person's self-efficacy beginning at an early age. The literature is clear that experiences begin from the time that a child is brought into the home, and those experiences emanate from things such as material resources, human resources, and social resources which continue to shape their self-efficacy beliefs as they age (Bradley & Spight, 2002; Putnam, 2000). The greater the resources, the greater the likelihood the child will experience significant events that will bolster self-efficacy (Schunk & Meece, 2005). For a child with a chronic illness, living in an environment where self-efficacy is “put to the test,” the experiences that each member of the family incorporates into the home setting can have a profound impact on the patient. The literature generated from mainstream adolescent populations, indicates that domain specific measures of confidence in adolescent populations has shown that self-efficacy perceptions of confidence begin to regress in approximately grade seven, or 13 to 14 years of age (Eccles et al., 1998; Wigfield et al., 1992).

Iannotti et al. (2006) found that the outcome expectations and self-efficacy beliefs of adolescent Type 1 patients were independent of one another. They went on to note that a child, who understood the positive outcomes associated with proper treatment, but has low self-efficacy beliefs, will demonstrate poorer glycemic control (Iannotti et al., 2006). One of the more compelling points in Bandura's explanation of self-efficacy beliefs is how the perceived belief system works to modify behavior. In his overview of the concept, he surmises that a person's motivation, movement toward action, and their affective state, serve as better predictors of change than what the individual is truly capable of achieving in objective terms.

Self-efficacy is important in the behavior change process because it is a behavior specific construct that predicts an individual's future attempts, based on perceived abilities (Bandura, 1977; Johnston, 1996; Schechter & Walker, 2002). By measuring self-efficacy, one can predict the amount of effort that will be expended on a task, thus allowing for interventions that can be tailored to increase self-care behaviors (Kavookjian, 2001; Kavookjian et al., 2005). Mishali et al. (2011) found that patients who scored high on measures of treatment resistance also scored lower on measures of self-efficacy. In their work, Mishali et al. (2011) go on to suggest that self-efficacy could be implemented as part of the patient's intake process to assess where the individual may need support in the beginning, as well as when attempting to maintain behavioral change over time.

When a patient's self-efficacy beliefs are low and the demands of a chronic illness become overwhelming, stressors may consume the individual to the point where adherence is affected (Boardway et al., 1993). There are a number of studies, which illustrate the impact of stress, as well as its relationship to poor metabolic control which can act as precursor to dangerous patterns of noncompliance (Brand et al., 1986; Chase, 1981; Delamater et al, 1988; Hanson et al, 1989). Because stress is driven by feelings of internalized psychological stressors and low self-efficacy beliefs, it is believed that the self-efficacy construct also influences metabolic control through various other physiological pathways (Boardway et al., 1993).

The collateral effects of psychological problems that exacerbate stress, in turn affecting the patient's ability to cope with the demands of their illness, bear a direct relationship to a patient's perceived self-efficacy beliefs. Under these conditions, it is easy to understand why treatments such as biofeedback, anxiety management, relaxation training, and social skills

training, failed to show improvements in non-compliant diabetes related behaviors (Fowler et al., 1976; Gross et al., 1983; Rose et al., 1983; Seburg & DeBoer, 1980).

### **Goal Directed Behavior in Type 1 Diabetes Management**

To understand Albert Bandura's position on goal directed behavior, one must first realize that his theory is one whose focus is that of individual motivation. In this theory, there are three process mediators which Bandura states are essential for the *motivation of behavior*. The first area is referred to as *affective self-evaluation*, and this process states that people are motivated to achieve performance superiority. When dissatisfaction in this area occurs, we cognitively regulate our efforts to achieve maximum performance. It is also here where the anticipation of likely outcomes is formulated. The second area involves *personal goal setting* and deals with how an individual's personal challenges act as a means of motivating self-influence regulation. The third area, and by far the most critical component of treatment adherence, is the individual's *self-efficacy beliefs* (Bandura, 1986; 1997). After this process has begun and action is underway, it is then and only then, that the person will feel the force of their self-regulatory processes at work. Bandura (1986; 1997) suggests that we regulate our thoughts to choose goals that are smaller in scale, and pose less risk to the individual. These risks represent a variety of things from restricting oneself from more alluring future offers, protecting our own beliefs about what is socially important, or to ensure that our self-evaluative standards never contradict our notions of self-efficacy. In the pursuit of a goal, one could be disinterested in the topic or subject matter, but once they achieve the goal, their level of interest increases. When self-efficacy rises, so does interest in a given area. Self-regulation works to ensure that self-efficacy is not undermined in the attainment of an objective. In the pursuit of compliance with a diabetes treatment regimen, building interest in better health outcomes means a greater opportunity for positive personal

gains. This logic works in tandem with the theory posed by Masten (2006), which utilizes the existence of a potential challenge, which can be re-structured as a turning point opportunity that allows for growth. By having specific goal pursuits in mind, this serves as a vital function in effective cognitive regulation that inevitably leads to better self-efficacy beliefs.

Luszczynska et al. (2007) have stated that a sufficient sense of self-efficacy is required at the inception of an idea or goal, until the actual adaptation of a desired behavior. A systematic review of the literature by McLean et al. (2010) analyzed populations of chronically ill patients, and concluded that interventions tailored to address the improvement of motivational factors such as those found in self-efficacy beliefs, offer support to address potential barriers. This included potential obstacles related to healthcare providers and their respective organizations, which was noted as a key to improved outcomes.

When the healthcare provider and patient work together in setting small workable goals, this can prevent stress overload in which the involved parties become overwhelmed, in turn encouraging the use of avoidant behavior or dishonest interactions which can lead to negative feelings (Brink et al., 2002). The primary goal of treatment adherence, which is achieved through the successful attainment of smaller goals, is better glucose monitoring. Following the tenets of Bandura (1986; 1997), if the individual possesses low self-efficacy, but wants to present well to the healthcare team, the possibility exists that they may be induced to be dishonest about their care, further pushing their self-efficacy perceptions downward. In turn, this sort of interaction could aid in the creation of patterns of dysfunctional disease management (Brink et al., 2002). Through the implementation of realistic goals in diabetes treatment, the patient is more likely to achieve positive gains while bolstering their self-efficacy beliefs.

The theme here is that in order to create incentives for goal directed behavior, the goals must be specific. If a goal is specific, it lets you know how you will need to regulate your behavior to achieve the goal. Behaviors that are not in sync with the desired outcome, induce cognitive regulators to modify and redirect cognitive drives. If the goal is specific, this allows the individual the option of clearer self-evaluation regarding performance, as well as the tools to modify it if necessary. Specificity of goal choice also serves the function of motivating action plans to achieve the desired outcome (Bandura, 1986). When a goal is specific, but too large or unrealistic for the person to achieve, people will create smaller sub-goals to attain the desired outcome. These smaller sub-goals are what Bandura (1986) refers to as *proximal goals*. They are created to put us in closer proximity to a future goal, and will help keep a person motivated as long as some progress is being recognized. The purpose of proximal sub-goals is to make an impossible goal seem attainable by breaking it down into smaller units. As the patient begins to create patterns of better illness management, this leads to higher compliance rates, as well as the means to adapt to new information that becomes important for long-term health.

Because self-efficacy is often seen as a phase specific construct, the need to set realistic goals is of utmost importance to begin in the initiation of a desired outcome. Self-efficacy works within a larger self-regulatory system that aids the person to attain goals if the cognitive process works without impediment. For example, a person may harbor feelings of confidence in their ability to set goals and initiate the process, but exhibit little confidence in maintaining this position (Schwarzer, 1992; 1999). On the other hand, a person may display little confidence in setting goals, but will have high self-efficacy about their ability to resist temptation that may ultimately interfere with treatment outcomes. This aligns with an individual who is managing a chronic illness, and is inclined to recover from setbacks while maintaining positive gains in the

face of past failures (Schwarzer, 1992; 1999). When a patient with Type 1 diabetes is viewed within the framework of this methodology, both phases of self-efficacy, whether the action phase which focuses on intent, or the coping phase which relies on the ability to bounce back after problems arise, are necessary to offset negative health outcomes that are often irreversible.

In a general sense, the advantages of higher self-efficacy is that it allows the person to adapt their cognitive process to other behaviors which may lead to other health promoting plans of action (Bagozzi & Edwards, 1998). The consensus among theories of health behavior is that the best predictors for success center on the notion that the person must have a willingness to focus on an intention that drives the behavior (Schwarzer & Renner, 2000). Essentially, what this means is that self-efficacy must be fostered in the first phase of goal directed intent in order for the person to learn that an idea can produce a positive outcome through persistence and attention to task (Schwarzer et al., 2011).

### **Health Models Borrowing from Bandura's Social-Cognitive Theory**

Many programs that deal with the complexities of a chronic illness have also come to fruition as a result of Bandura's research in the area of self-efficacy. Among them, the Chronic Disease Self-Management Program is derived from Albert Bandura's self-efficacy theory and states that people with chronic illnesses, regardless of which chronic illness is being studied, will share common emotional and physical traits (Lorig et al., 2001). In research that examines the relationship between chronic illness and outcome, self-efficacy is positively correlated with lower HbA<sub>1C</sub> levels, as well as better adherence to self-care tasks in patients with Type 1 diabetes (Johston-Brooks et al., 2002; Mishali et al., 2007). If a patient believes that they can improve their adherence to treatment recommendations, and are able to execute this through the realization of small goals in a controlled and monitored manner, then screenings to assess self-

efficacy beliefs may be justified as part of routine treatment. Furthermore, self-efficacy as a diagnostic tool would allow members of a multidisciplinary team to see the problems inherent in the patient's and family's perceptions of the illness. This would encourage the use of early interventions to offset potential obstacles in treatment.

### **The Health Action Process Approach (HAPA)**

In general, theories of health behavior attempt to explain how and why an individual may, or may not, avoid risk behaviors in place of healthy alternatives (Conner & Norman, 1996). The overlapping feature found in such models points to the importance of the person's level of perceived self-efficacy, which is essentially their intention to engage in healthy behaviors, and the outcomes associated with those health expectations (Abraham et al., 1998). One such theory, the Health Action Process Approach (HAPA), which was developed by Ralf Schwarzer (1992), incorporated these components and borrows from Bandura's logic to explain the manner in which people are motivated, put an idea into action, and even possibly fail, to see their goals to fruition. Because it is believed that self-efficacy works best with general lifestyle changes to include things as diverse as physical exercise and the pursuit of reliable social supports, the HAPA model capitalizes on inherent processes that are necessary in successful disease control (Schwarzer & Renner, 2000).

According to HAPA, the person will initially develop an intention to act, or have a goal in mind that they would like to achieve. Once this occurs, the goal is then initiated by three separate cognitive processes that begin the motivation phase. Among the cognitive processes at work, self-efficacy acts in tandem with the individual's outcome expectancies and perceptions of the risk involved in a potential course of action. In order for the thought processes that formed the goal to become tangible, the person would then enter the second process (volitional), in

which planning takes place, and efforts are put forth to see the goal through to reality. Much like social-cognitive concepts, there is the intention that leads to the behavior that will eventually move the individual closer to the outcome. By focusing on a person's perceived level of self-efficacy, the primary difference between success and failure in this case, hinges on the idea that the patient's goals are not in conflict with their perceived abilities.

The strength of the HAPA theory is that it is flexible enough to work for those who may be suffering from a chronic illness and have reached a treatment plateau, or it can be used to encourage the individual to adopt preventative measures if they are currently healthy, but at risk for later complications. Schwarzer (1992) stresses this point by highlighting the role of self-efficacy and stating that there are three sets of cognitive processes at work in this theory that operate solely on the principals of the self-efficacy construct. In the first process, the person must feel that there is a risk of disease if they are healthy, or a risk for further complications if they are living with an illness. The second cognitive process states that the individual must believe that behavioral change would result in a reduced threat to their health. Finally, that person must possess the belief that he or she is “sufficiently” capable of controlling the behaviors inherent in the path to better health (Schwarzer, 1992; 1999; Schwarzer & Fuchs, 1996). Without self-efficacy, the individual will be unable to initiate, let alone maintain positive health behaviors that reduce the risk of later health complications.

A number of studies have been conducted to highlight the predictive quality of the HAPA model as a means of promoting behavioral change in individuals with health related challenges. For example, research in breast self-examination conducted by Luszczynska & Schwarzer (2003) showed that the HAPA model provided the intended effect of moving behavioral intentions into action, and eventually aiding in the maintenance of self-care behaviors. A follow-up study by



Luszczynska (2004) incorporated the HAPA model once again, and showed an increase in breast self-examination over a 15-week period. Other studies in areas such as binge eating and alcohol (Murgraff et al., 2003), as well as adherence to exercise regimens (Sniehotta et al., 2005), have all shown a correlation between the initiations of intention as a means of encouraging action through the HAPA model.

Unlike continuum models in which the person follows a path to foster explanation and prediction under diverse demographic conditions, stage models target homogeneous groups for interventions that are utilized to incorporate specific treatment plans within a narrow collection of individuals. Although both approaches have their benefits to health care, it is hard to separate the two without losing an important piece of patient progress and explanatory value in disease management. HAPA has created a marriage of both approaches that looks at health on a continuum, but also matches the treatment of the illness. The generalized nature of its core concepts can be tailored in healthcare settings where patient adherence has become problematic. The HAPA model also promotes the idea of social support as a protector of barriers to better adherence and positive health outcomes. It recognizes that the lack of support represents a missing resource that could be the difference between health and wellness, or long-term harm. Schwarzer et al. (2011) touts the importance of emotional supports that can be family or friends, and informative supports such as healthcare providers as part of multidisciplinary teams. It is believed that such measures act as catalysts for adaptation and continuation of positive health behaviors. Plotnikoff et al. (2008) illustrated the point of intact support systems as the glue that binds better health in diabetic patients.

Another way of looking at the idea of health and wellness among patients with Type 1 diabetes is to adopt a methodology that incorporates self-efficacy concepts that make them aware

of their ability to change. For example, instead of interventions that are designed to focus solely on awareness of health risks; techniques that have been traditionally unsuccessful because they promote action through defensive optimism (Schwarzer & Renner, 2000), newer techniques could also focus on resource availability that encourages the behaviors to be viewed as challenges that reinforce gains through personal strengths. Lending credibility to his line of reasoning, Iestra et al. (2005) found that for many chronic illnesses, mortality rates were reduced through behavior change.

### **Diabetes and its Impact on the Patient, Family, and Society**

Due to the intricate nature of the diabetes management regimen that involves significant disruptions in the daily lives of afflicted patients and their families, the home setting will often experience increased levels of conflict and burnout among its members (Anderson et al., 2007). Plotnik & Henderson (1998) have described diabetes as a “family disease” that tears into the fabric of the family on multiple levels. Simple behaviors that were taken for granted prior to a diagnosis of Type 1 diabetes within the family, now means that basic routines such as meals, vacations, holidays, and especially emergency situations, must be approached with a new strategy in mind.

A recent report by Rapoff (2010) confirms the earlier work of Dimatteo (1994), and suggests that non-adherence rates for children and youth with Type 1 diabetes averages approximately 50%. The total range of non-adherent behaviors paints a more troubling picture with estimates in the Type 1 diabetes population somewhere between 20% -93% (Kovacs et al., 1992; Rapoff, 2010; Wysocki et al., 2005). This is a stark difference from failure rates in acute care populations where non-adherence is reported to remain steady at approximately 30% (Rapoff, 2010). When taking into consideration the empirically validated treatments, which are

the accepted norm in clinics throughout the United States, the high non-adherence rates point to problems that have yet to be addressed in the literature. Additional studies correlate a reduced capacity to control the metabolic necessities of Type 1 diabetes with a higher risk for long-term health complications such as kidney disease, blindness, and non-traumatic lower limb amputations (Anderson et al., 2007; Rapoff, 2010; Wysocki et al, 2006).

The Centers for Disease Control and Prevention (2007) estimate that there are over 150,000 people under the age of 20 that live with the demands of Type I diabetes in the United States today. Many of those individuals are at an increased risk of multimorbid disabilities unless they maintain proper metabolic control of their illness. It is also estimated that one out of every 400-600 children the United States is living with the demands of Type 1 diabetes (SEARCH 2007), and that these demands are being placed on them at increasingly earlier points in development. Although the average age of onset for this disease is still primarily an adolescent phenomenon, newer data suggest that it is increasing most rapidly in the age range of four years or younger with no viable explanation behind this spike (Green & Patterson, 2001).

Aside from increased rates of morbidity and mortality from medically related complications, non-adherent behavior also results in 62% of mental health referrals for pediatric Type 1 diabetes patients (Gelfand et al., 2004). Furthermore, the long-term effects of non-adherence may cause a ripple effect in which inconclusive data collection resulting from non-adherent reporting populations, will adversely affect the clinical decisions of healthcare providers over time (Lewin et al., 2009). The likely fallout from misreported health data is that the costs will fall back into the laps of the general population in the form of increased health care expenditures such as inflated insurance premiums, as well as less efficient access to needed services.

## **The Role of the Parent in Disease Management**

It is well established in the literature that parents play a crucial role in their child's ability to manage a chronic illness (Follonsbee, 1989; Saucier & Clark, 1993). Studies in parental perceptions of child disease management found that fathers tended to see their children as more dependent than the mother, which can be problematic at best (Eiser et al., 1992). This places the burden of illness management in the hands of the mother more often than the father, which may also increase the rate of burnout for the primary caregiver. Results from the Leonard et al. (1997) study suggests that the father's role may be one of less involvement, as well as less realistic expectations regarding the child's behavior in relation to illness management. As a result of such findings, the current study chose to look only at the perceptions of the mother, and the manner in which the diabetic child views the mother's role in diabetes related care.

The role of the family and its influence on adolescent metabolic control has been studied extensively in the diabetes literature (Anderson et al., 1997; Berg et al., 2007; Ellis et al., 2007; Ellis et al., 2008; Harris et al., 1999; La Greca et al., 1995; Palmer et al., 2004; Patterson et al., 1989; Seiffge-Krenke et al., 2002; Wiebe et al., 2005). Parents have described the emotional distress that occurs as a result of poor metabolic control where it is often perceived as a barrier to positive outcomes in treatment (Leonard et al., 1997). Anderson et al. (2000) presented findings which show that blood glucose control and adherence to diabetic regimens often deteriorate during adolescence, which adds to the stress of an already complicated illness.

The beliefs of diabetic patients have been shown to act as predictors of disease management and health outcomes (Pattison et al., 2006). During the transitional period of adolescence, the parents are pulled between the demands of the child, and the demands of a chronic illness. In the event that the adolescent takes responsibility too soon for the management

of his/her illness, and their self-efficacy about personal abilities is not intact, the deterioration of adherent behaviors becomes a reality (Holmes et al., 2006). A delicate balance must be achieved during adolescence; especially when working with a child who wishes to take on an adult responsibility, but is also sensitive to treatment which they may perceive to be authoritarian in nature (Brink et al., 2004; Michaud et al., 2004). A study conducted in Germany with 89 adolescent patients, found that parents who stayed involved in their adolescent's care, also reported better glycemic control of the illness (Seiffge-Krenke et al., 2002).

It is also well documented that problems within the family structure, to include internal conflicts such as negative patterns of communication and ongoing disagreements about regimen compliance, inevitably leads to decreased treatment adherence and poorer glycemic control (Anderson et al., 1981; Anderson et al., 1997; Davis et al., 2001; Helgeson et al., 2008; La Greca et al., 1995; Miller-Johnson et al., 1994; Wysocki et al., 2008; Wysocki et al., 2009). The families of adolescent diabetics can also fall victim to the demanding nature of the illness, which can affect levels of motivation and efficacy beliefs in the home setting.

An important part of the parent's ability to maintain emotional stability as they work with their child to manage an illness is to have perceived control of the situation. Hummelinck & Pollock (2006) have shown that the parents who feel that their child's physician or care team listened to their concerns, and exhibited respect about the intricacies of their child's illness, reported higher commitment to the treatment recommendations. Furthermore, the same parents also reported a higher level of perceived control when it came to managing the day-to-day demands of the disease.

Parental self-efficacy has been reported as one of the primary constructs utilized by families to maintain normalization of a chronic health condition in the home (Bossert et al.,

1994; Knafel & Deatrick, 1986). It has been suggested that parents who feel pressured to meet the time constraints of short appointment schedules in medical settings, may appear competent on the surface, but may also lack appropriate self-efficacy beliefs to aid in the management of their child's illness (Pattison et al., 2006). In findings that would appear contradictory, the same study also noted that high parental self-efficacy was not associated with better glycemic control in their participant population (Pattison et al., 2006). A major drawback in the Pattison et al. (2006) study is that they looked only at younger children between the ages of 6 to 12 years-old; a time when the parent is generally the leader in illness care.

The literature recognizes that if the parents shift responsibility for self-care management prematurely, their child is more likely to experience poorer outcomes (Wysocki et al., 1996). Diabetes research is also clear about the importance of involved parents, and has found correlations to better patient outcomes with Type 1 diabetes if a parent aids in diabetes responsibilities (Anderson et al., 1997; Ellis et al., 2007; Wiebe et al., 2005). In order for this goal to be attainable, Vesco et al. (2010) found that responsibility must be clearly identified by the adolescent, and that direct management tasks are most influenced by the adolescent's perceptions in this area. In order to parcel out the unique contribution of parental responsibility to treatment adherence, Vesco et al. (2010) utilized the Diabetes Family Responsibility Questionnaire, along with the child's HbA1c readings, and frequency of blood glucose testing to observe possible correlations. They found that direct tasks such as blood glucose monitoring, responding to blood glucose fluctuations, as well as the changing and rotation of insulin injection sites, was related to explicit responsibility sharing by the adolescent and parent that resulted in better glycemic control. A similar approach was utilized in the current study to assess these

areas, as well as to understand the unique contribution of self-efficacy beliefs to adherence behaviors.

Britto et al. (2004) suggest that the need for autonomy in adolescence naturally follows a course where the patient will seize the opportunity to take control of personal healthcare. By empowering the adolescent to take charge of their autonomy, it has been positively correlated with increases in self-efficacy, as well as the patient's perceptions of confidence and control of their illness (Iannotti et al., 2006). Studies that have focused on the mediational value of patient empowerment related to treatment adherence and glycemic maintenance, illustrate the importance of a patient's perception of control when dealing with a chronic illness such as Type 1 diabetes (Griva et al., 2000; Grossman et al., 1987; Ott et al., 2000). The role of parents during adolescence cannot be downplayed, even in the midst of research that encourages autonomy. The fact remains that an adolescent's parents retain a vital role in management of the illness, as well as playing a part in the child's relationship with his/her physician.

In a review of the literature by Greening et al. (2006), a model was proposed which emphasized positive parental involvement as a means of promoting adherent behaviors and increasing self-efficacy. Prior to the review by Greening et al. (2006), Ott et al. (2000) recruited adolescent patients and their parents during a summer diabetes camp to assess the impact of self-efficacy and parental involvement on treatment adherence behaviors. Of the 119 families who participated in the Ott et al. (2000) study, results from the measure for self-efficacy, the Self-Efficacy for Diabetes Scale (SED), showed that self-efficacy served as a significant mediator between adherence and uninvolved parenting practices. One of the drawbacks to the Ott et al. (2000) study was that their research received a large number of children on the younger end of their 11-18 year-old population sample, primarily because older children were less likely to

spend time at a diabetes camp. Adding to the body of research, numerous studies in parental involvement showed that adolescents who perceive more parental involvement and responsibility in diabetes related care, were able to maintain adherence and report better outcomes with life satisfaction (Allen et al., 1983; Anderson et al., 1997; Ingersoll et al., 1986; Palmer et al., 2004; Wiebe et al., 2005).

Studies that observe the effects of child responsibility found that parents who report higher incidences of confidence in the patient's ability to administer insulin and check blood glucose readings, experience more success in treatment compliance (Allen et al., 1983; Leonard et al., 1997). The consensus in research which focuses on child responsibility for self-care behaviors is clear that parents must remain involved in their children's disease management until such time that the child is sufficiently able to be independent in task oriented procedures (Brink et al., 2002; Follonsbee, 1989; Frey & Fox, 1990).

It is further noted that social opportunities, such as events involving activities away from home to include spending the night out or going on a camping trip, were found to motivate parents to allow more freedom in the area of self-care. The findings here illustrate a trend in which parents will report feelings of less personal responsibility if the child is allowed to move toward treatment independence for social reasons. This reasoning runs in tandem with developmental theory in which parents are forced to cede the reins, and motivate the child to assume responsibility while maintaining a more peripheral role throughout adolescence.

### **Measuring Family Support: Diabetes Family Responsibility Questionnaire (DFRQ)**

The DFRQ was utilized by Anderson et al. (2009) to examine dyadic agreement on responsibility sharing, and they found that there were significant correlates in the age group 12 years or younger, but not with older adolescents when measuring glycemic control. The indirect



tasks identified in the subscales of the DFRQ, including telling others about the illness, or scheduling appointments, exhibited non-significant findings. In the case of indirect tasks, these findings may be related to tasks that are typically carried out by parents, and therefore a secondary concern for the adolescent patient that could not be accounted for in the Anderson et al. (2009) study.

In a study that was conducted to reassess the original factor analysis carried out by Anderson et al. (1990), Vesco et al. (2010) determined that a two factor solution was a better fit for the child and parent reports. This finding suggests that responsibility sharing is viewed in relation to direct, as well as indirect tasks. The Vesco et al. (2010) study also highlighted findings which showed that low parental education levels were correlated with poor blood glucose monitoring, and unmarried parents presented with children who had higher HbA<sub>1c</sub> values.

In a study by Leonard et al. (1998), the DFRQ was used to assess the child's level of responsibility for diabetes care using only the mother as a respondent. They found that mothers who rated themselves with higher self-efficacy, also rated their children higher in skill areas that corresponded to diabetes self-management on the subscales of the DFRQ. Furthermore, they found parental education level was also significantly related to a parent's view of diabetes responsibility behaviors in their offspring, lending support to the importance of demographic factors. One drawback to the Leonard et al. study was that the age groups examined covered three distinct periods that were shorter in chronology, and much younger than typical adolescent cohorts. The restrictive nature of the age groups prevented a thorough examination of the particular changes that often occur as a child eases through adolescence to independence from parental input. A separate study by Palmer et al. (2010) further validated the claim that the role

of parental involvement and responsibility for their offspring's care is an intricate array of factors which are easily parceled out by the subscales of the DFRQ.

### **Parenting Theories and Their Relevance to Treatment Compliance**

Today, research in the area of developmental psychology puts a greater emphasis on the role of parenting and its effects on children than any other area of published literature. The strength of developmental models and the role parents' play in the future of their children is evident by the proliferation of new research being published. This movement toward more family based strategies in dealing with youth problems has also been the impetus for more literature in the area of families coping with the demands of chronic illness. The once generalized notion of parenting skills as the causal nexus between good and bad kids has changed as parenting topics now cross lines into other research areas such as developmental psychopathology, criminology, addiction, forensic psychology, and illness management.

In the case of families who have a child who must address the demands of Type 1 diabetes, the parent-child bond is often at risk from problems that stem from disagreements about treatment behaviors. Other factors that may complicate a household where chronic illness is an ever-present phenomenon include marital distress, poor marital communication, and disagreements over child rearing practices that are shown to contribute to behavioral difficulties at home (Webster-Stratton, 1994). In general, deficits in the parents' perceived ability to effectively manage a disease which is often unpredictable, serves to enhance these problems and is frequently seen in the modeled behaviors of their children (Bandura, 1986).

Patterson (1982) describes the importance of familial communication patterns for positive child outcomes in his work on coercive parenting methods. In a coercive interaction, parent and child behave in a way that is meant to control the behavior of the other (Patterson, 1982). This

pattern of behavior then escalates in the following sequence: child irritates parent in an increasingly progressive manner, the parent then responds by trying to over-power the child with more coercive assertiveness, as the child continues to escalate the irritability with the parent, the parent gives in, unknowingly reinforcing the behavior that they seek to eliminate (Patterson, 1982). The effect of such dysfunctional parent-child interactions is that the child will become openly defiant without fear of recourse. If left unchecked, these interactions lead to the evolution of a self-perpetuating system where the child and parents pit themselves against one another in an effort to exert control (DeBaryshe et al., 1993). The risks inherent in this sort of interaction between the parent of a chronically ill adolescent and a parental figure, becomes more pronounced because it also increases the potential for negative health outcomes; not only in the short-term, but in the long-term as well. If the child retaliates from a coercive interaction by failing to comply with a disease that is already oppressive, defiance is likely to be exacerbated in turn increasing the risk for disease complications.

### **Supportive Parenting: The Role of the Child-Oriented Parent**

The question many people ask in response to the idea of supportive parenting is, “What exactly constitutes a supportive parent?” Supportive parenting alone could be a variety of things; all of them open to interpretation based on a number of factors. Some of those factors might include what is acceptable and supportive to a child’s environment in the context of cultural, religious, educational, and traditional values. For the purposes of disease management, supportive parenting is seen as that which promotes a sense of support and guidance with the child’s *immediate* interests or wants at the center of parental motivation (Dix et al., 2000).

Supportive parenting is a smaller component of what is commonly referred to as *sensitive parenting*. Although these terms may appear interchangeable, it should be recognized that they

represent two distinct areas of parental behavior that load on different parts of our larger cognitive regulatory systems (Dix et al., 2000). For instance, if an emotional behavior is viewed as warm, stimulating, or sensitive in the most accurate sense of the word, it may still fall short of being supportive if the child's *immediate* needs or wants are ignored, restricted, or criticized by the caregiver (Dix et al., 2000).

In contrast to being supportive, sensitivity is a purely emotional state that the parent projects while interacting with the child. This state of emotion which influences parental interaction with the child is only as effective as the child perceives it to be. In other words, if a parent receives an affective cue from the child in which he expects mom to respond, and mom responds in a manner that subverts attention from the immediate needs or wants of the child, the child is not receiving supportive parenting. It is a well-established principal in parenting literature that the sensitive, supportive, responsive parent promotes better long-term development and socialization skills in their children than the authoritarian, restrictive parent (Dix et al., 2004). Parents who succumb to the stress of contemporary parenting, which is often exacerbated in caregivers who deal with the daily demands of a child's chronic illness, could interpret the youth's problems as a reflection of their own competencies, and retaliate against the child when stress levels become heightened (Dix et al., 2004).

### **Parents as Buffers in Disease Management**

Because parents are also expected to help their children make transitions to self-management based on a number of factors including the child's age and psychological maturity, the responsibilities placed on both parties will increase as the child eases into adolescence (Palmer et al., 2004). Wiebe et al. (2005) demonstrated that the adolescent experienced greater metabolic control when the mother was seen as a "collaborator", rather than a demanding

parental figure. Due to the sensitivities imposed by the physical changes of puberty; coupled with the emotional aspects of this period, the onset of adolescence makes parental involvement challenging at best. Furthermore, when the physical and psychological nature of diabetes are added to the complexities of the diabetes regimen, it is not hard to conceptualize youth who may find themselves in a position where they are unclear about who is in charge of their diabetes care (Murphy, 1990).

The role of parents during adolescence cannot be downplayed, even in the midst of new research that encourages autonomy. Being the parent or the parent of a child or adolescent with Type 1 diabetes is an emotional struggle that can only be understood by those who live through the rigors of this illness. Much of the research to date has looked at the mother's role in helping the child deal with diabetes compliance, because in most households, the mother tends to be the primary executor of diabetes management (Gavin & Wysocki, 2006). Findings from the study conducted by Kaugars et al. (2011), suggests a relationship between high maternal self-efficacy and youth who report an increased motivation to shift the balance of responsibility away from the parent. Their study also highlighted the importance of the mother as a buffering agent in promoting more support for the diabetes patient from other members of the immediate family (Kaugars et al., 2011). Studies in parental involvement, prior to management independence with Type 1 diabetes youth, shows that monitoring and supervision of the child's daily activities, as well as consistent contact with their child, appears to safeguard better illness management which includes compliance, and better glycemic control (Berg et al., 2008; Grey et al., 2001). Furthermore, the diabetes literature is clear about two primary components that the parent-child dyad requires which includes emotional aspects of support, and the second which deals with

behavioral aspects of parent-child involvement (Berg et al., 2008; Ellis et al., 2007; Wysocki et al., 2006).

Patterson (1989) has identified the family as the primary social context for aiding a child with a disability. Interestingly enough, the cognitive domains seen as positive contributors to healthy development are also under the influence of learning mechanisms that are often orchestrated through adult supervision and guidance (Bandura, 2001). Research that examines the outcomes of positive personal gains argues that positive role models are the primary force behind optimum social and emotional development (Masten et al., 2006; Bandura, 2001).

Along with parental involvement, realistic medical goals should fit the youth's developmental age to bolster motivation, and work for a middle ground that steers away from overly permissive treatment "short-cuts" that may lead to hyperglycemia, or set the stage for psychopathology. Limitations in current diabetes research includes studies that look only at the child/adolescent perspective of the illness. This phenomenon fails to account for the multilayered, mediating role that parental involvement employs in disease management. Furthermore, it is well documented that problems within the family structure, whether it be an internal conflict between patient and parent, or ongoing issues regarding differences of opinion in regimen adherence, inevitably leads to decreased treatment compliance that contributes to poorer glycemic control (Anderson et al., 1981; Anderson et al., 1997; Davis et al., 2001; Helgeson et al., 2008; LaGreca et al., 1995; Miller-Johnson et al., 1994; Wysocki et al., 2008; and Wysocki et al., 2009). To further complicate matters, many parents of children and adolescents with Type 1 diabetes, may themselves meet criteria for psychiatric illness which bears a direct correlation to poor glycemic control in their children (Landolt et al., 2002). Anderson et al. (2007) have emphasized the importance of intervention programs that help

optimize control of the illness through improved family adjustment and psychological awareness that often serve as the catalysts for most psychosocial stressors.

Lending credibility to this idea, Delamater (2009) presented information from the International Society for Pediatric and Adolescent Diabetes in which their governing body attributes psychosocial factors, to include familial discord, as the primary influence of patient adherence to a diabetes management regimen. In the midst of many diabetes programs that prepare the patient and families for the rigors of daily monitoring and medical adherence, many patients with clinical levels of stress are not referred for psychological treatments that could aid in improved compliance (Delamater, 2009).

In terms of gender related differences, females with Type 1 diabetes are also more likely to experience psychiatric problems as a side effect of their illness; especially where poor glycemic control is a factor (Northam et al., 2004). Among the more common psychiatric diagnoses given to adolescent females with Type 1 diabetes, eating disorders appear at a rate that is nearly double the population of non-diabetic patients (Daneman et al., 2007; Jones et al., 2000; Neumark-Sztainer et al., 2002). Once this notion is coupled with the negative possibilities that abound from parental support that is compromised as a product of the child's chronological age, or mental health concerns of the parent, the need for early screening techniques at the family level becomes paramount. Unfortunately, brief screening methods, which look at familial factors in clinical settings, have yet to be utilized with Type 1 diabetes patients.

The mainstream research in developmental psychology for the past century has highlighted the importance of adolescence as a "testing ground" for adulthood. When the normal issues of adolescence are considered, along with the demands of a chronic illness, the need for early prevention and/or intervention techniques becomes vital. It is an accepted truth in diabetes

research that poor glycemic control during adolescence is a precursor for poor glycemic control into early adulthood (Bryden et al., 1999; Wysocki et al., 1992). Once a pattern of dysfunctional treatment adherence is started and then maintained over time, it becomes harder to modify with the prospect of later complications becoming more likely.

Unfortunately, the problems associated with poor glycemic control extend far beyond the reach of psychiatric illness or behavioral difficulties. Problems with learning, information processing, and memory have also been cited in the literature where poor metabolic control of the illness has been identified (Holmes et al., 1992; Holmes et al., 1985; Ryan et al., 1985; Ryan et al., 1984; and Schoenle et al., 2002). Unlike the female Type 1 patient who experiences a higher rate of general psychiatric illnesses related to poor metabolic control, findings with her male counterparts and non-diabetic female cohort, show that males with Type 1 diabetes will often exhibit a higher frequency of neuropsychological deficits (Holmes et al., 1992; Schoenle et al., 2002).

Overall, children and adolescents with Type 1 diabetes were shown to perform below their non-diabetic peers on measures of intelligence, long-term memory, and attentional issues (Delamater, 2007; Northam et al., 2004). The findings of the six-year study also looked closely at neuropsychological functioning, which included the speed that information is processed under normal conditions (Delamater, 2007; Northam et al., 2004). The findings suggest that diabetic children in general are more susceptible to cognitive deficits that result from glycemic challenges, and improper management of the illness.

### **Socioeconomic Status and Marital Status in Type 1 Diabetes Research**

Previous research with low SES families shows the children in Type 1 diabetes populations tend to exhibit poorer overall control of their illness. These findings focused on the



idea that poorer control is associated with competing needs and less than adequate resources in lower SES households (Harris et al., 1999; Overstreet et al., 1997). Research that examined the marital status of the parent, showed that parents who live together have children with lower HbA<sub>1C</sub> values (Hoey, 2001). Numerous studies also provide evidence that Type 1 diabetics from two-parent households have better health outcomes than their peers from single-parent living situations (Auslander et al., 1990; Hanson et al., 1988; Harris et al., 1999; Thompson et al., 2001). The other point found in relation to two-parent homes and better treatment outcomes is that the father is also likely to play a role in treatment, even if small compared to the mother's (Gavin & Wysocki, 2006).

A separate study by Lewin et al. (2006), showed that variables such as a family's adherence to diabetes treatment regimens, coupled with the child's age, and age of onset for the disease, accounted for 49% of the variation in HbA<sub>1C</sub> values. Urbach et al. (2005) also points out that more frequent blood glucose monitoring is equated to better treatment adherence, which is associated with perceptions of quality of care in the home. Furthermore, educational level of mothers and glycemic control appears to bear a modest relationship in the literature as well.

In a study of 103 mothers, Haugstvedt et al. (2011) found that higher levels of education, was significantly correlated with better glycemic control as measured by HbA<sub>1c</sub> levels. Dashiff et al. (2008) lends support to the idea that the mother is the most important parental source of input and support for diabetes related care in their offspring. Collaborative involvement between parents and the adolescent child is shown to be an effective means of promoting problem solving skills for better management, as well as outlining who is accountable for specific tasks and disease monitoring (Ellis et al., 2008; Wallender et al., 1989; Wysocki et al., 2008).

## **The demands of Adolescence and the Role of Type 1 Diabetes**

Early research in the area of Type 1 diabetes research, illustrated that most non-adherent behaviors in the management of the illness emerge at approximately 3-4 years after diagnosis (Kovac et al, 1992). Although a consensus has not been obtained on average age of onset for pediatric diabetes patients, it is suggested that the peak age for diagnosis in the United States is approximately 14 years of age, with the highest concentration of numbers occurring between the onset of adolescence and early adulthood. Considering the complexities encountered during these stages of development, a unique problem arises for patients and their families who are juggling the demands of a critical developmental period, while focusing on the increased risk of non-adherence to treatment which sets the stage for later complications.

An area that has received limited attention in the adolescent literature is the presence of psychopathology, which frequently develops after an individual has been diagnosed with Type 1 diabetes (Kovacs et al., 1992). Although psychopathology and the relationship to non-adherent behaviors appears to be independent of a person's age when considering the effects of chronic illness, Kovacs et al. (1992) found that the average age for the first onset of non-compliant behavior occurred at 14.8 years of age in patients with Type 1 diabetes. Studies conducted since the Kovacs et al. findings 20 years ago state that the non-compliant behavior has remained consistent and now emerge closer to 15 years of age. Non-compliance and psychopathology in the research are topics that deserve further attention; primarily because of the demands that mental illness alone places on the person. Psychopathology was not addressed in the current study, but the precursors to mental illness, which includes non-adherence, was examined across domains.

Aside from the data regarding non-adherent behaviors, the Kovacs et al. study was the first to offer a definition of “noncompliance with medical treatment” that was subsequently used in the DSM-III (American Psychiatric Association, 1980). They operationalized the definition to fit the strictures of diabetes disease management, and focused on the notion of “negligence” with treatment regimens. Negligence, according to Kovacs et al. (1992), was defined as a person's disregard for treatment in which the patient rarely, if ever, complied with recommended medical treatment. Although this definition offered a guide for medical practitioners to assess behaviors that were readily identifiable in poor HbA<sub>1c</sub> readings and clinical self-reports, it failed to look at the relevance of outside factors that could impact treatment adherence to include self-efficacy beliefs by the patient or parent, as well as the role of the family.

The work of Anderson et al. (2000) brought relevance to the notion that blood glucose control and adherence to diabetic regimens often deteriorate during adolescence as part of the normative process of the adolescent's need for autonomy. Britto et al. (2004) suggests that the need for autonomy in adolescence naturally follows a course where the patient will seize the opportunity to take control of personal health. While the adolescent attempts to forge an identity of their own and address the demands of the illness, the families of these individuals can also fall victim to the often-overwhelming nature of the disease. (Hohner et al., 2006) showed that the demands of the Type 1 diabetes regimen inadvertently affects levels of motivation and efficacy beliefs in the home. To make matters more complicated, the literature is replete with studies that warn of the dangers that can occur if parents prematurely shift the responsibility of illness management before the adolescent is ready to handle matters on his/her own (Berg et al., 2008; Ellis et al., 2007; Ellis et al., 2008; Kazak, 2006; Leonard et al., 1997; Palmer et al., 2004; Patterson et al., 1989; Seiffge-Krenke et al., 2002; Wiebe et al., 2005). This forces the patient

and family to engage in a “balancing act” in which the parties must reach a reasoned compromise on the issue of transition to self-care management.

On the opposite end of this debate, there is another camp that promotes empowerment as a means of encouraging the adolescent to take charge and become independent. Work in this area has been positively correlated with increases in self-efficacy to include the patient’s perceptions of confidence and control of the illness (Brink et al., 2002; Iannotti et al., 2006). Previous studies that have focused on the mediational value of patient empowerment; especially as it relates to treatment adherence and glycemic control, illustrate the importance of an individual’s health perceptions when dealing with a chronic illness (Griva et al., 2000; Ott et al., 2000).

### **Developmental Theories and Adolescence**

Regarding the developmental patterns that were once believed to be unchangeable when experienced early in development, adolescence, as well as emerging adulthood, offer opportunities of varying degrees for behaviors to occur again, or be avoided, based on past experience. Masten et.al (2006) characterized these “turning point” opportunities in emerging adulthood as a way of avoiding risky behaviors that may have been more appealing during an earlier phase of development. By adhering to the inhibition of action that is precipitated by a “turning point” opportunity, the individual is able to experience something that carries long-term importance, rather than short-term gratification (Masten et al., 2006). By applying this principal to the creation of goal-directed opportunities which capitalize on a person’s self-efficacy beliefs, current research in diabetes compliance has missed an opportunity to look at micro-level causality that could adversely affect treatment outcomes.

Diabetes research has consistently shown that the ability to face the demands of a chronic illness is more often than not, held in tandem with the individual’s perception of their ability to

manage the complexities of the disease. The negative effects levied on the developing brain as a result of exposure to the stress of a chronic illness, is incalculable; especially when long-term outcomes are taken into consideration. Based on the work of Arnett (2006), adaptive resources such as future orientation, coping skills, and the ability to plan seem to be the key contributors to success in the realm of transition to stable adult outcomes. Once again, these can be viewed as a constellation of traits, or environmental influences which include temperament, reactivity to a situation, and guidance by positive adult models such as those espoused in Albert Bandura's Social Cognitive Theory through modeling behavior.

Among the cognitive features that are indicative of success (or failure) during this stage of development, the concepts of exploration and instability appear to play an important role in transitional success (Arnett, 2006). Exploration encourages a healthy appraisal of one's environment, but can also lead to decisions that may be questionable at best such as experimentation with drugs, alcohol, or sexual activity. For patients with Type 1 diabetes, having a healthy appraisal of one's illness is fostered in the context of sufficient self-efficacy beliefs where the adolescent's perception of their abilities will render them capable of complying with the demands of the disease, while at the same time maintaining stability in their lives. Regarding instability in disease compliance, this is a personality characteristic which offers little positive valence, primarily because it hinders healthy cognitive appraisals of a situation.

### **Definitions of Adolescent Risk and Their Application to Patients with Type 1 Diabetes**

One of the reasons that research with adolescent populations has exploded in recent years is to explore the mechanisms that precede, and perpetuate behaviors that involve an element of risk. Taken under the assumption that non-compliance with treatment requirements is a risk factor for any patient diagnosed with a chronic illness, the normal tide of adolescent behavior

becomes more complicated with decisions that could be the difference between life and death. In order to appreciate the general complexity of adolescent risk-taking behavior outside of chronically ill populations, it is necessary to examine some of the definitions that breathe life into the behaviors under investigation. According to Jessor (1991), risk behaviors encompass the engagement of actions, which can compromise the health, or well-being of an individual, as well as to alter one's life course. Beyth-Marom et al. (1993) offer a more simplified explanation stating only that risk behavior is an action in which there is a probability of loss on some level. An alternative, more elaborate definition is proposed by Resnick & Burt (1996) in which four core components must be present to qualify as risky in nature. The component parts include 1.) the presence of risk antecedents which create the vulnerability, 2.) the presence of risk markers that combine with the antecedents to create an environment where negative earlier experiences can influence behavior, 3.) the presence of the problem behavior itself such as the opportunity to engage in risky behaviors, and 4.) the presence of risk-outcomes which relate to the long-term consequences of behaviors.

In tandem with research that emphasizes the importance of optimal glucose control to maintain positive gains and avoid the risk of later complications, it is at the discretion of the adolescent and his/her family to ensure that their illness is being monitored to achieve this end. The influence of peers in adolescence is well documented in developmental literature which means that access to risk related behaviors increases as a function of age, as well as the need for greater autonomy from family. Paradoxically, the need for independence, coupled with the need to maintain one's health in the face of a chronic illness, means that adolescents with Type 1 diabetes are more likely to experience domain impairments. The impairments which are more

likely to occur in relation to non-compliance, include physiological manifestations which can be life threatening, and which also inadvertently influence social, academic, and family factors.

General population studies of adolescent subjects indicates that areas of adaptive functioning such as poorer performance in academic settings, inadequate social performance, and health related problems resulting from a sedentary lifestyles pose risk factors for youth (1, 1998). The domain for health related impairment also encompasses the non-compliance aspects of diabetes related treatment that includes regular exercise and dietary control as a required part of a structured health plan. With that being said, the healthy nature of a domain extends beyond physical health to include all aspects of optimal mental health.

### **Dietary Concerns with Type 1 Diabetes: Metabolic Control vs. Disordered Eating**

The current study used information obtained from the proposed instruments to assess the dietary management of diabetes treatment which can act as a precursor to disordered eating. It should be noted that there is a theoretical divide between what is construed as disordered eating, and behaviors that constitute an eating disorder. The inclusion of dietary information in the proposed study served the purpose of assessing behaviors which could be problematic, and in turn affect adherence to treatment based on the guidelines set forth by the American Diabetes Association (2011). The intent of the examiner was to look at controlled management of the illness through the relationship between dietary adherence and exercise as prescribed by the Standards of Care Guidelines (American Diabetes Association, 2011). Due to the need for strict adherence to diet and exercise in a diabetes treatment regimen, positive health gains are much harder to obtain if deviations are present.

It is suggested that adolescent non-adherence to dietary recommendations may be explained by compensatory beliefs which allow the child to engage in one negative behavior,

while justifying it with something more akin to their treatment needs (Rabiau et al., 2006; Knaúper et al, 2004). For example, a Type 1 diabetic may skip insulin during a meal, then justify this behavior by indicating that they will exercise harder after the insulin has been administered. The justified behavior may be perceived by the adolescent as a means of maintaining adherence to the treatment regimen by attempting to regulate glucose levels through “extra” exercise. The problem with this approach is that the patient is unlikely to attain the desired amount of physical activity to moderate the effects of insulin substitution. Paradoxically, for the Type 1 diabetic, compensation becomes an important part of disease management that is done to maintain glycemic control (Rabiau et al., 2009). Patients who live with the demands of Type 1 diabetes, continuously make decisions that require them to compensate throughout the day in an effort to maintain near-normal blood glucose readings through food intake and levels of activity.

In a study comparing diabetic and non-diabetic adolescents, James et al. (2000) found that females with Type 1 diabetes were 2.4 times more likely to experience disordered eating behaviors than a similarly aged cohort without the disease. Goebel-Fabbri (2009) added to the previous findings by indicating that females were more likely to engage in disordered eating behaviors than their male counterparts (Colton et al., 2007; Olmstead et al., 2008; Peveler et al., 2005). Pinar (2005) reported that disordered eating behaviors were four times more common in adolescent diabetics than in their non-diabetic peers. Contrary to previous findings, the work of Helgeson et al. (2008) discovered that the need to be thin was more strongly related to decreases in metabolic control in male respondents. A separate study conducted by Ackard et al. (2008), contradicted the results of Helgeson et al. (2008) by noting that there were no difference in disordered eating behaviors when comparing youth with Type 1 diabetes to those without the



illness. A shortcoming in eating disorder research is that most studies fail to take into account the demands of metabolic disorders where food is the nexus between health and glucose control.

Studies which have examined disordered eating behaviors in Type 1 diabetics, show that without early interventions, these behaviors will persist and become more severe as the adolescent ages into young adulthood (Colton et al., 2004; Olmstead et al., 2008). Although the current study is not addressing the issue of eating disorders directly, it is duly noted that disordered eating behaviors act as the prerequisite for a formal diagnosis of an eating disorder (Olmstead et al., 2008).

Unlike non-diabetic populations, patients with Type 1 diabetes are predisposed to the risk factors which drive disorder eating behaviors, and in turn create a bridge to other negative health outcomes. Diabetes related health risk behaviors such as insulin aversion and restriction, place the individual at higher risk for acute, and even long-term diabetic complications (Goebel-Fabrizi, 2009). Among these behaviors, attempts to decrease weight gain due to the normal effects of insulin, also places the child at a higher risk for depressive symptoms (De Groot et al., 2001; Domargard et al., 1999). Aside from the weight gain that is associated with insulin disturbances, the Type 1 patient is also forced to pay constant attention to all aspects of food intake which can be disconcerting at best.

In two separate studies examining disordered eating behaviors, researchers found that the development of these behaviors is more likely in those with a higher BMI, higher ratings for shape and weight concerns, depressed mood, and lower self-image (Colton et al., 2007; Olmstead et al., 2008). The practice of insulin restriction to avoid weight gain, also places the patient at risk for long-term diabetes related complications, as well as being at risk for earlier mortality (Bryden et al., 1999; Polonsky et al., 1994; Rydall et al., 1997). The current study

addressed the issue of insulin administration to parcel out this phenomenon as it relates to overall treatment adherence.

### **The Importance of Self-Efficacy in Adolescent Patients with Type 1 Diabetes**

Research which has looked at the mediational role of self-efficacy beliefs in adolescent Type 1 populations, shows that the youth's self-efficacy beliefs may act as a positive influence on parental involvement in adherent behaviors (Skinner et al., 2001). This finding lends credibility to the work set forth by Kaugars et al. (2011) in which they state that maternal self-efficacy has a motivating effect on the child, and conversely, on the extended family to encourage better self-care behaviors. It can be surmised from these findings that a feedback loop may exist in families, where in the absence of high self-efficacy beliefs in others, may utilize a mother's self-efficacy beliefs to motivate members in the home.

In a study by (Beveridge et al., 2006) it was reported that high self-efficacy beliefs in parent-child populations are viewed as protective factors in adolescents with Type 1 diabetes, primarily because this construct appears to mediate decision making in the absence of parental input. These findings are important in the context of maternal self-efficacy beliefs because the mother is often viewed as the individual who "takes charge" of diabetes related care, and serves as the model for treatment adherence. Efforts have been made in Type 1 populations to incorporate self-efficacy techniques that include patient centered communication in which the patient and their multidisciplinary team focus on the collaborative nature of the patient's beliefs about the illness (Erikson et al., 2005). Through this collaborative environment, the patient is encouraged to take more control of their illness on his or her/her own by focusing on their personalized goals (Michie et al., 2003).

Self-efficacy is viewed as a key component in those areas which affect the ability to meet treatment goals, as well as adherence to prescribed daily regimens (Van der Ven et al., 2003). Van der Ven et al. (2003) also assert that it is necessary to have a sufficient sense of self-efficacy to remain compliant in the face of physical demands, which can at times be complex, as well as cumbersome. Unlike personality characteristics which may be harder to change, self-efficacy beliefs are malleable, and are often enhanced through behavioral interventions that affect levels of motivation in the adolescent (Maibach & Murphy, 1995; Bandura, 1997).

From a treatment standpoint, self-efficacy has been successfully modified through behavioral interventions that work to address the bulk of diabetes care where problems are more likely to arise. Without sufficient motivation to engage in the rigorous demands that must be adhered to on a daily basis, the patient who suffers with Type 1 diabetes, strengthens the possibility of negative outcomes through low self-efficacy beliefs. Earlier interventions that incorporated the use of behavioral techniques to enhance self-efficacy beliefs have been successful with adolescents, primarily because they are tailored to exploit the behavioral underpinnings which serve as motivators to change (Schlundt et al., 1999).

## CHAPTER 3

### METHODOLOGY

#### **Design**

A non-experimental correlational design was used in the current study. There was no control group in the current body of research, because all potential participants were given an equal opportunity to answer the questionnaires and participate at their discretion. Furthermore, random assignment was not used because an online format for answering questionnaires was implemented for data collection. The study consisted of a series of self-report questionnaires that were answered by the adolescent patient and their mothers. A personal information sheet was also utilized in the current study to obtain demographic and diabetes specific questions from the mothers. Because the respondents included minor children, all mother's participating in the study were required to provide consent for their child, as well as herself, before answering the questions in the online survey.

Consent to participate was accomplished through a consent form on the homepage of the survey website which stated that the mother understood the purpose of the research and that she willingly authorized the use of her data, as well as the data of her minor child to be used in the current study. By submitting, "yes, I accept these terms" on the homepage of the website, she gave permission for participation and was not able to enter the site until this step was completed. Those who took part in the study were also informed about the nature of the study on the homepage, which included information indicating that their participation was voluntary and could end at any point.

The minor child was also required to offer assent before entering the youth portion of the website. The assent on the homepage was worded according to the guidelines of the graduate

school in order to reflect age appropriate norms describing the nature of their participation in the study. Permissions were also obtained to use the survey instruments in an electronic format for purposes of collecting data in the present body of work.

### **Extraneous Variables**

Extraneous variables affecting the study included the mood of the respondents which could have an impact on answers. The fact that the information for voluntary participation was distributed in an environment where the patient's endocrinologists', group leaders in supportive settings, and others such as diabetes educators or dieticians were present, could also have imparted feelings of obligation to participate in the study. Furthermore, sources of error could also include the effects of the principal investigator's recruitment flyer (patient's contact from the referral setting) on the target audience. The study also recruited participants from mentoring groups, and community wide events associated with the Juvenile Diabetes Research Foundation, which could have influenced whether or not a potential participant decided to be a part of the study.

### **Recruitment of Participants**

The initial recruitment of respondents took place through the regional Juvenile Diabetes Foundation (JDRF) chapter in Southfield, MI. Paper and electronic copies of the flyer describing the study were then distributed to clinics, advocacy volunteers, and other interested parties. The advertisements were also transmitted to those on their mailing lists, posted on their Facebook page, and distributed to those who attended mentoring, coffee meetings, and organized events through the organization in the metro-Detroit area. Information regarding the nature of the proposed research project, the principal investigator's name and contact information, as well as information about how to gain access to the website was on the circular. A posting on the JDRF

Facebook page also brought attention to the study outside of the Detroit area as a means of recruiting potential participants who communicated in other locales. The flyer incorporated language that avoided judgments, bias, racially or spiritually charged words, as well as any phrases or material that could have been construed as misleading.

Those that chose to become test subjects were told that the online questionnaires would take approximately 15-25 minutes to complete in their entirety and that no respondent would be identified, or solicited for any purpose based on their submissions to the principal examiner. Furthermore, respondents were advised that the instruments should be answered when the respondent is not tired or rushed, and that the questionnaires should be finished in the same sitting. Potential participants were also advised to participate in the study only if they were sure that they would be able to answer all of the test materials without imposing any hardship upon themselves. The mothers were also informed that they would have to answer demographic and diabetes specific questions on a personal information sheet. All respondents were informed that their participation was completely voluntary, and that those who completed the questionnaires/surveys in their entirety, would have a donation paid by the principal investigator on their behalf to the Juvenile Diabetes Research Foundation. Participants were informed during the consent process that a total dollar amount will be posted on the JDRF website after all data has been collected over a period of months. see the money which was raised during the data collection process.

### **Population and Sample**

Participants in the study consisted of males and females with Type 1 diabetes who were at least 11 years of age, and no older than 18 years of age when they answered the online survey questions. The children's mothers were also required to answer the same questionnaires, which

were worded to reflect maternal perceptions of diabetes related care. The mother also filled out a brief personal information page on the research website to obtain demographic material, diabetes specific information, as well as data for socioeconomic status. A total sample of N=200 (adolescent and parent constituting one) was the minimum target for the current study. At the end of the data collection that lasted for approximately ten months, 314 mothers filled out the surveys, and 112 adolescents had participated in the study. The only stipulation for participation was that the adolescent respondent had to be at least 11 years of age and no older than 18 years of age when answering the surveys, and that he/she not have a Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV, TR) diagnosis of a pervasive developmental disorder, substance abuse disorder, and they had to be free of psychosis. Respondents, who were using a daily regimen of multiple insulin injections via insulin pen or syringe, or insulin pump therapy, were considered satisfactory candidates for the study. The mothers who participated could be single, married, divorced, widowed, or in a committed non-marital adult relationship.

### **Data Gathering Methods**

The method employed for data collection utilized an online survey format designed through Survey Monkey™, which was entered into a secure, encrypted URL that incorporated the assessment tools, demographic information, as well as the consent and assent forms. The name of the examiner and the attending university was prominent on the homepage. All data that was entered on the website was maintained in a secure, encrypted server through Wayne State University in an effort to avoid disclosure of data to outside sources. Data was downloaded at the end of the study into Excel spreadsheets to analyze the survey responses. Data collection proceeded in the following manner:

- 1.) Upon opening the website, the mother and child were introduced to information that stated the nature of the research, and that they were being asked to take a survey for Type 1 diabetes dissertation project.
- 4.) If they mother or child decided to continue, they were then introduced to the consent and assent agreements to participate on the homepage. Participants were notified at the time of consent/assent that their information would not be sold, reproduced, or otherwise used for any purposes outside of the current study.
- 5.) After reading the consent/assent forms, if they chose to continue, they were informed that by submitting “yes” that they were agreeing to participate in the study. This was the only the way that a respondent could gain access to the survey materials.
- 6.) The mothers’ consent agreement contained language which stated that they were aware that their child would be participating in the same study and that they were offering electronic consent to answer the survey questions.
- 7.) Once electronic consent/assent was obtained by the mother or child, they were then able to enter the site and begin answering the questions.
- 8.) Before they began each set of questions, they were told that they could change an answer at any time; however, once they pressed the “submit” button at the end of each measure, they would be unable to change those responses.

The decision to use separate hyperlinks for each participant was done in an effort to keep the answers of youth and mother separate and confidential. For those who wished to participate in the study, an introductory paragraph was presented on the homepage of the website which highlighted the nature of the study, as well as the participant’s ability to discontinue the study at any time if they chose to do so. The language in the opening paragraph also indicated that



participation constituted consent/assent for purposes of the research project. A unique identifier was utilized in which the mother was asked to insert her own, and the child's (mother-child dyad) birthdates by following the directions for two eight digit blocks that were separated by a hyphen. The identifier was found at the beginning of the personal information sheet, and was used to maintain the anonymity of the participant pool while ensuring that data entries matched one another.

### **Instrument for Adherence**

In the current study, the Self-Care Inventory (SCI) by LaGreca et al. (1992) was used to measure treatment adherence in patients with Type 1 diabetes. The SCI is a 14 item, self, and parent report measure which can be completed in less than five minutes. It uses a 5-point Likert scale that reflects the primary components of Type 1 diabetes treatment adherence to include regulation of meals, implementation of exercise, keeping appointments with the diabetes team, as well as the monitoring and recording of glucose levels. The scale looks at the child's and parent's perceptions of treatment adherence to self-care recommendations in the preceding month. It has been further shown that correlations between the SCI and the 24 hour recall interview; the latter of which is often used in larger clinical settings, that the SCI yields better predictive outcomes in terms of metabolic control and accounts for 36% of the variance in HbA<sub>1c</sub> values (the 2-3 month measure of overall metabolic control) versus 28% with the 24 hour report. Furthermore, the development of the assessment tool was done in collaboration with diabetes educators whose focus was on primary components found in a Type 1 diabetes treatment regimen, and it is ideally suited for research studies or brief office visits.

Scoring for the SCI allowed the examiner to group questions in a manner that allows for the analysis of data regarding constructs related to adherence, blood-glucose monitoring,

exercise and diet, as well as emergency situations. The current study utilized the scoring procedures recommended by the designer of the measure, Annette La Greca, Ph.D. She has suggested that all 14 items be administered to respondents, but only questions #1, 2, 5, 6, 7, 8, and 13 be calculated for an overall adherence score. The identified questions are viewed as the essential components of treatment adherence for patients with Type 1 diabetes. In order to obtain an adjusted total score, the mean of the seven endorsed items was used to replace the fourteen items in the full measure.

The treatment adherence scores will be used as criterion variables in each of the hypotheses presented in the proposed study. Internal consistencies with the endorsed items are 0.80 or higher in several studies of children and adolescents with Type 1 diabetes, and test-retest reliability scores of 0.77 have been obtained over a 2-4 week period (Delamater, 2007).

Aside from its ease of administration, the SCI also alleviates the need to engage in structured interviews with both parties which are often viewed as time consuming in the context of an office appointment. The items used in the SCI are broad enough to encompass Type 1 diabetics who are using regular injections during meal times, as well as those on insulin pump therapy. The tool has also been used with ethnically diverse samples, and is suited for a broad range of behaviors in the Type 1 diabetes treatment regimen minus the need for additional measures to address each domain.

### **Instrument for Self-Efficacy**

The Self-Efficacy for Diabetes Scale (SED) was developed by Grossman, Brink, & Hauser (1987) to measure an adolescent patient's perceived ability to exhibit control and resourceful management of Type 1 diabetes symptomology. It follows the tenets of Bandura's self-efficacy test construction by incorporating language that is meant to assess an individual's

perceived ability to complete a course of action. The 35 item instrument is comprised of three subscales which assess a patient's self-efficacy regarding diabetes specific concerns (24 items), general concerns (6 items), and medically specific scenarios (5 items). Each item is rated using a 6 point Likert scale with scoring for high self-efficacy represented as, "very sure I can" to the extreme for low self-efficacy which is defined as, "very sure I can't". In the current study, self-efficacy beliefs were assessed using only the diabetes specific scale which endorsed questions #1, 2, 4, 5, 6, 12, 13, 15-26, 28, 30, and 33-35.

The adolescent and maternal self-efficacy scores were used as mediating variables in hypothesis #2, and used as predictor variables in hypotheses #3 and 4. The SED in the current study was adapted to assess the perceived abilities of the mother. As in past studies, this was accomplished through restructuring of the original question format to reflect the mother's perceptions of her own ability to manage the child's diabetes related care. The wording for each possible response on the Likert scale remained essentially the same as it appeared in the adolescent version. Prior statistical analyses indicated that total scale scores for the SED were .90 using the Kuder-Richardson reliability coefficient, and .92 for the 24 items which make up the diabetes specific subscale. Cronbach's coefficient  $\alpha$  from earlier studies also provides good internal consistency for the adolescent measure at  $\alpha = .88$ . Internal consistency in the adapted version for parents has been as high as  $\alpha = .87$ , with most studies reporting .80 or greater.

The self-efficacy measure in the current study was chosen in an effort to follow Albert Bandura's recommendations for accurate assessment of the self-efficacy construct. Bandura (2006) addresses a common shortcoming in self-efficacy test construction by highlighting the way in which questions are often worded, therefore confounding the purpose of self-efficacy in behavioral or educational research. Because measures of self-efficacy should be concerned with

the individual's *perception of their abilities*, Bandura (2006) suggests that all questions in a measure of self-efficacy must use the words "can do" rather than "will do". According to Bandura (2006), the "can do" characterization indicates a person's judgment about their capabilities, hence their self-efficacy beliefs, whereas "will do" is more concerned with statements of intention. Bandura goes on to note that the distinction between what a person "can" and "will" do are empirically and conceptually different.

### **Measure for Family Involvement and Responsibility Regarding Diabetes Related Care**

In an effort to assess the importance of family factors as they relate to metabolic control in the current body of work, the principal investigator included the Diabetes Family Responsibility Questionnaire (DFRQ) by Anderson & Auslander (1990). The test consisted of 17 items, and the purpose of this scale was to assess family members' perceptions of their involvement or level of responsibility regarding diabetes related care. The DFRQ was comprised of three subscales which looked at the participant's general health maintenance, regimen tasks, as well as their social presentation of the disease (Anderson & Auslander, 1990). The use of the DFRQ allowed the researcher to look at differences between patient and parent responses through separate reporting's from each party. The 17 items examined in each protocol, assessed the extent to which each party's (parent or child) perceptions influence their role in behaviors that are directed at responsibility for diabetes related care.

Instructions for the DFRQ were easy to understand, and the test allowed the child and parent to rate their level of involvement or responsibility on a 3-point ordinal scale. The responses ranged from 1 (the adolescent takes or initiates responsibility for this almost all of the time), 2 (parent and adolescent sharing responsibility for this task almost equally), to 3 (the caregiver takes or initiates responsibility for this almost all of the time). The test can usually be

answered in approximately 5 minutes. Measures of test-retest reliability on the DFRQ showed internal consistency alphas ranging from .82 to .80. for adults and children respectively. Sufficient evidence also existed to indicate acceptable validity levels for the DFRQ when compared to the Family Environment Scale (FES) which has been used in clinical settings for 25 years.

The current study utilized all 17 items of the measure to obtain a full-scale score that encompasses a scoring range of 17-51. There were no individual subscale scores provided for this measure. A full scale score of 17 would indicate that the adolescent assumes all of the responsibility for diabetes care, and a score of 51 would mean that the caregiver assumes responsibility for all diabetes care (Vesco et al., 2010). A middle range score of 34 would indicate equal responsibility sharing between the child and parent. The parent and youth formats for the questionnaire were scored separately to determine individual perceptions about diabetes related care. The scores obtained from the DFRQ were used as predictor variables in hypotheses #3 and 4.

The management tasks addressed in the DFRQ are labeled as direct or indirect, and were broken down by factor analysis into a three-factor solution (Vesco et al., 2010). Two of the factors were categorized as direct management tasks and were correlated with behaviors such as diabetes regimen tasks, and general health maintenance. The third factor encompasses the indirect tasks which address the social presentation of diabetes. Issues such as the ability to confide in friends, family, and school personnel, are all labeled as indirect tasks according to the findings set forth by Anderson & Auslander (1990).

### **Measure for Socioeconomic Status**

The Hollingshead Four Factor Index of Social Status (1975) was utilized to measure education, occupation, and income. Information used in the Hollingshead Index was extracted from the Personal Information Sheet, and was utilized in hypotheses #4 and 5. Although the index has been used for a number of years in the behavioral science, the validity and reliability of the measure were established again by Cirino et al. (2002) who found it to be consistent with earlier studies which recognized the index as a suitable measure of socioeconomic status.

In a study by Hassan et al. (2006), the index was used in a population of adolescent Type 1 diabetics to determine whether or not poor glycemic control was the product of SES when looking at other factors such as depressive symptomology, and poorer quality of life. Their findings showed that patients that were in higher SES categories were also more likely to have better glycemic control. The study reasoned that the glycemic readings of higher SES participants was better controlled due to financial advantages that allow for luxuries such as the use of insulin pump therapy which acts as a mediator of blood glucose management in Type 1 diabetics (Hassan et al., 2006). Because the lower income groups were found to have poorer glycemic control, this would also make them unsuitable for insulin pump therapy. The assumption then becomes entrenched in the idea that decreased glycemic control means less attention to management of the disease. Due in large part to the increased demands placed on the user to maintain glycemic control with insulin pump therapy, the irony here is that the poorer family will also be less likely to gain the opportunity for pump therapy, thereby lessening the chance for better illness management over time.

## **Statistical Tests**

The current study used Pearson product moment correlations to determine the strength and direction of relationships between HbA<sub>1c</sub> levels, and mothers' and adolescents' perceptions of treatment adherence. Baron & Kenny's (1986) four-step mediation analysis was employed to determine if self-efficacy mediated the relationship between HbA<sub>1c</sub> levels and perceptions of treatment adherence. Stepwise multiple linear regression analysis was also incorporated in the current study to assess the predictive nature of the predictor variables on treatment adherence. The statistical tests that were utilized were appropriate in the current study because previous research has found that each method has been used successfully implemented with similar variables in related domains. Descriptive statistics are found in Tables 2, 6, and 7. Frequency distributions are found in Tables 3-5, and inferential statistics encompass Tables 8-13.

## **Power Analysis**

Through the utilization of the G\*Power software, calculations were used to indicate the sample size needed to find an effect of .15. The power analysis suggested a sample size of 55 participants with a power level of .80, a total of 73 participants would be required for a power level of .90, and 89 participants would be needed with a power level of .95. A significance value of  $\alpha = 0.05$  was also used in the power analysis.

## **Assumptions Related to Statistical Methodology**

Assumptions for the inclusion of stepwise multiple linear regression analysis and Baron & Kenny's four-step mediation analysis in the current study are broken down into three separate areas. The first assumption stated that the observations were independent of one another. The second assumption stated that there will be equal variance and covariance matrices across the groups. The final assumption indicated that there would be normality in the dependent measures.

An alpha level of .05 was used in the current study to control for Type I error. The rationale behind that decision was based on the idea that much of the previous research in health outcomes has used an alpha of .05 with significant results. All data was analyzed using SPSS for Windows. SPSS was used in the current project due in large part to its data analysis capabilities and comprehensive statistics software. The updated versions of SPSS also allowed the researcher to integrate tables more readily, and with greater explanatory value than in earlier versions of the software.



## CHAPTER 4

### RESULTS

The results of the data analysis that were used to describe the demographic characteristics of the sample, as well as address the research questions which includes associated hypotheses, are presented in this chapter. The chapter is divided into three sections. The first section uses descriptive statistics to provide a profile of the participants, while a description of the scaled variables is presented in the second section of the chapter. The results of the inferential statistical analyses used to test each of the hypotheses are presented in the third section of the chapter.

The purpose of this study is to examine treatment adherence in adolescents diagnosed with Type 1 diabetes mellitus through the dissemination of the patient's personal self-efficacy beliefs, as well as the self-efficacy beliefs of the child's mother. Perceptions of parental responsibility for the adolescent's diabetes related care, as well as the adolescents' perceptions of how much responsibility the adult caregiver exerts in disease management was also examined to determine the relationships between these constructs.

A link to the online surveys was provided through SurveyMonkey, and was sent to parents who were members of the Juvenile Diabetes Research Foundation. Flyers were then distributed to those members to pass along to others in the diabetes community who might be willing to participate in the study. The inclusion and exclusion criteria of the study were described in age appropriate language through the consent and assent forms on the opening page.

A total of 314 mothers initially participated in the study by completing and submitting survey responses. After examining the mothers' data, 81 surveys were eliminated because their children were out of the age range (11 to 18 years of age) specified for participation, or insufficient information was provided on the questionnaires. Information from the remaining 233

mothers was used to analyze demographic information that was provided by them as part of their participation in the study. The children were not asked to answer any questions except those in the surveys. Of the 233 maternal respondents who were not eliminated based on exclusion criteria, only 50 of those mothers could be definitively matched to their child with type 1 diabetes for inferential analyses.

In addition to the mothers' completing the surveys, there were a total of 112 adolescents diagnosed with type 1 diabetes who participated in the study. After eliminating the adolescent participants who failed to finish any of the three questionnaires in their entirety, a total of 50 adolescents were successfully identified for use in the current analyses. The 50 remaining adolescent participants were then matched with their mothers by cross-referencing the IP addresses found in each of their survey response lists. This provided a total of 50 mother-child pairs that were utilized in the analyses of the research questions. The demographic data is the only section that utilized all 233-mother respondents.

A missing values analysis was used to determine the extent to which the participants had missing values on the scaled variables. No missing values were found on the three measures, Diabetes Family Responsibility Questionnaire (DFRQ), Self-care Inventory (SCI), and Self-Efficacy for Diabetes Scale (SED). Complete data, which included three surveys for the mother, as well as three surveys for the children, were available for the 50 mother-child pairs used in the survey analyses.

### **Description of the Sample**

The mothers were required to complete a demographic/personal information survey that included diabetes specific questions about the family, as well as questions about their child diagnosed with the illness. The ages of both the mother and the adolescent, as well as the age of

the adolescent at diagnosis, was among the demographic data obtained. Descriptive statistics were used to evaluate the responses of the 233 mothers who offered responses to this portion of the demographic data. Table 2 provides the results from those findings.

Table 2

*Descriptive Statistics – Ages of Mother and Adolescent and Age of Adolescent at Diagnosis of Type 1 Diabetes*

	Number	Mean	SD	Median	Range	
					Minimum	Maximum
Age of mother	232	44.78	5.84	45	30	59
Age of adolescent	232	13.83	3.57	14	11	18
Age of adolescent at diagnosis	232	8.27	2.03	9	1	17

Missing 1

The results of age related data shows that the children in the survey were represented at the low, as well as high ends of the data set for inclusion in the study (11 -18 years of age). The data for age at diagnosis revealed a considerable gap between the youngest and oldest type 1 patients in the study. The earliest diagnosis was reported in infancy (age 1), while the latest diagnosis occurred at age 17.

The personal characteristics of the participants were also obtained in the demographic questionnaire that was filled out by the mother. The responses to these questions were summarized using frequency distributions. Table 3 presents the results of the personal characteristics analysis.

Table 3

*Frequency Distributions – Personal Characteristics*

Personal Characteristics	Frequency	Percent
Gender of adolescent diagnosed with diabetes		
Male	118	51.8
Female	110	48.2
Total	231	100.0
Missing	3	
Ethnicity		
African American	3	1.3
Asian/Pacific Islander	1	.4
Caucasian	203	88.7
Hispanic	8	3.5
Middle Eastern	3	1.3
Other	11	4.8
Total	229	100.0
Missing	4	
Mother's Marital Status		
Married	195	84.1
Single	14	6.0
Divorced	14	6.0
Separated	2	.9
In committed relationship	6	2.6
Other	1	.4
Total	232	100.0
Missing	1	
Relationship to child		
Biological mother	227	98.3
Stepmother	1	.4
Other	3	1.3
Total	231	100.0
Missing	2	

Three mothers did not provide a response to the gender question; however, the findings show that there were more males ( $n = 118$ , 51.8%) identified by the mothers as having type 1 diabetes, than there were females ( $n=110$ , 48.2%). Ethnic classifications among the participant population was skewed heavily toward respondents that identified as Caucasian ( $n = 203$ , 88.7%). Four participants did not report their ethnicity on the survey.

In terms of marital status, the majority of mothers who participated indicated that they were married ( $n = 195$ , 84.1%), while only 28 respondents listed their marital status as single ( $n$

= 14, 6.0%) or divorced (n= 14, 6.0%). Nine mothers indicated that they were either separated from their spouse, or in a committed relationship but not married. One mother listed her marital status as “other” to denote that she did not fit into any of the traditional categories, and another participant did not provide a response to this question.

Further analyses of the personal characteristic questions shows that 227 (98.3%) of the mothers indicated they were a biological parent, and 3 mothers (1.3%) classified themselves as “other” meaning that they could be an adoptive parent, foster parent, or legal guardian (family or non family member). There was 1 respondent who indicated that she was a stepmother, while two of the adult participants did not provide a response to this question.

The participants were also asked to provide their socioeconomic status by indicating their occupations and their educational levels. Using the formula developed by Hollingshead (1975), the socioeconomic statuses of the families was computed. Descriptive statistics were used to summarize the results. Table 4 presents the socioeconomic statuses and family income levels.

Table 4  
*Frequency Distributions – Family Socioeconomic Levels*

Family Socioeconomic Levels	Frequency	Percent
Socioeconomic status		
Lower socioeconomic status	3	1.3
Lower middle socioeconomic status	14	6.1
Middle socioeconomic status	52	22.6
Upper middle socioeconomic status	111	48.3
Upper socioeconomic status	50	21.7
Total	230	100.0
Missing	3	
Household Income Levels		
Under \$20,000	9	4.0
\$20,000 to \$49,999	29	12.8
\$50,000 to \$79,999	45	19.9
\$80,000 to \$109,000	51	22.6
\$110,000 and higher	92	40.7
Total	226	100.0
Missing	7	

The mothers were also asked to provide diabetes specific information regarding their families and their child with the illness. Their responses were summarized using frequency distributions for presentation in Table 5.

Table 5

*Frequency Distributions – Diabetes-related Questions*

Diabetes-related Questions	Frequency	Percent
Mother is only caregiver for child with diabetes		
Yes	58	25.7
No	168	74.3
Total	226	100.0
Missing	7	
Other family members in the home with chronic illnesses		
Yes	67	29.1
No	163	70.9
Total	230	100.0
Missing	3	
Child with diabetes has siblings		
Yes	208	90.0
No	23	10.0
Total	231	100.0
Missing	2	
Child has a history of diabetic ketoacidosis		
Yes	9	3.9
No	222	96.1
Total	231	100.0
Missing	2	
History of Hypoglycemia		
Yes	43	18.7
No	187	81.3
Total	230	100.0
Missing	3	
Child with diabetes has been hospitalized since initial diagnosis		
Yes	57	24.7
No	174	75.3
Total	231	100.0
Missing	2	

The majority of the mothers (n = 168, 74.3%) indicated that they were not the only caregivers for their child diagnosed with diabetes. Sixty-seven (29.1%) of the participants indicated that they had other family members in the home diagnosed with chronic illnesses. Most of the mothers (n = 208, 90.0%) reported their child with diabetes had siblings. Nine (3.9%) mothers indicated their child had a history of diabetic ketoacidosis, and 43 (18.7%) reported that their child with diabetes had a history of hypoglycemia. When asked if their child with diabetes had been hospitalized since initial diagnosis, 57 (24.7%) answered yes.

The mothers were asked to indicate their child's previous HbA<sub>1c</sub> numbers and their latest HbA<sub>1c</sub> readings. They were also asked to provide the number of years the child had been on an insulin pump (if applicable), as well as the number of times that their child tested his/her blood glucose levels each day. The most recent HbA<sub>1c</sub> readings represented numbers from the adolescents' last visit with their Endocrinologist. The previous HbA<sub>1c</sub> number represented the findings of the checkup that occurred immediately before the current readings. Descriptive statistics were used to summarize their responses in Table 6.

Table 6

*Descriptive Statistics – Diabetes-related Characteristics*

	Number	Mean	SD	Median	<u>Range</u>	
					Minimum	Maximum
HbA <sub>1c</sub> Previous	204	8.13	1.34	8.00	5.00	14.00
HbA <sub>1c</sub> Recent	207	8.07	1.40	7.90	5.20	14.00
Time on Insulin Pump	165	4.41	2.94	4.00	<.01	15.00
Number of Times Glucose Testing	148	6.66	2.52	6.00	0.00	14.00
Missing: HbA <sub>1c</sub> Previous		29				
HbA <sub>1c</sub> Recent		26				
Time on insulin therapy (years)		68				
Number of times glucose tested daily		85				

Because of the importance that is placed on continuous glucose monitoring throughout the day as part of a standard diabetes treatment regimen, the mothers were asked to provide the number of finger sticks that their child provided each day. Based on data from the demographic and personal information sheet, the number of times that the child's glucose levels were checked ranged from 0 to 14 times daily, with a median of 6 times per day. Sixty-eight mothers did not provide a response to this question. The mean number of times that glucose levels were tested daily was 6.66 (SD = 2.52) times which coincides with the range of 5-7 checks per day which is recommended by the American Diabetes Association. Eighty-five mothers did not provide a response to question.

### Description of the Scaled Variables

The scores on the three surveys (Diabetes Family Responsibility Questionnaire [DFRQ], Self-care Inventory [SCI], and Self-efficacy for Diabetes scale [SED]) completed by the mothers and their child were scored according to the authors' protocols. The mean scores for each of the surveys are presented and summarized in Table 7 through the use of descriptive statistics.

Table 7

#### Descriptive Statistics – Baseline Scores for Scaled Variables

Scale	N	Mean	SD	Median	Actual Range		Possible Range	
					Minimum	Maximum	Minimum	Maximum
DFRQ-M	233	2.11	.28	2.08	1.23	2.92	1.00	3.00
DFRQ-C	50	1.84	.41	1.77	1.08	3.00	1.00	3.00
SCI-M	233	3.58	.70	3.64	1.00	4.93	0.00	5.00
SCI-C	50	3.60	.81	3.75	.86	5.00	0.00	5.00
SED-M	233	4.33	.49	4.42	2.83	5.00	1.00	5.00
SED-C	50	4.04	.58	4.02	2.58	5.00	1.00	5.00
HbA <sub>1c</sub> E	204	8.13	1.34	8.00	5.00	14.00	4.00	14.00
HbA <sub>1c</sub> MR	207	8.07	1.39	7.90	5.20	14.00	4.00	14.00



The range of scores for the mothers' responses to the DFRQ was from 1.23 to 2.92, with a possible range from 1 to 3. Higher scores on this scale indicate that mothers' perceived greater responsibility for their child's diabetes care. In terms of the child respondents, scores for the youth version of the DFRQ ranged from 1.08 to 3.00, with a possible range of 1.00 to 3.00. Higher scores on the youth form indicated that the child perceived that he/she assumed greater responsibility for their diabetes care.

Regarding the findings on the SCI, possible scores could range from 0 to 5, with higher scores indicating greater adherence to self-care regimen for Type 1 diabetes. The SED scores had a possible range of 1.00 to 5.00, with higher scores indicating higher levels of self-efficacy in relation to Type 1 diabetes.

The possible range of HbA<sub>1c</sub> readings is based on the usual assay for this measurement, which can be as low as 4, and as high as 14 using the standard DCA 2000 Analyzer for such analyses. Although the high end of the HbA<sub>1c</sub> spectrum can exceed 14 where readings >20 have been recorded, current standards of practice commonly employ testing devices with a cutoff of 14 which indicates very poor control of the disease. HbA<sub>1c</sub> scores closer to 4 are often associated with anemia or other conditions affecting red blood cells, whereas higher scores are related to an individual's ability to control the metabolic processes of insulin secretion and glucose control. Generally, optimal HbA<sub>1c</sub> readings for patients with type 1 diabetes range from <7.00 to 8.00 (American Diabetes Association). Readings less than 7.00 indicate good control of the diabetes, while readings greater than 8.00 indicate poorer control. The mean HbA<sub>1c</sub> reading scores for earlier data were 8.13, and 8.07 for the most recent maternal responses.

An HbA<sub>1c</sub> score of 14 would indicate individual blood glucose readings of 380mg/dl if averaged over a 90-day period. The target range for pre-meal (at least 2-4 hours since last meal)

blood glucose readings in children and adolescents with type 1 diabetes should fall between 90-140mg/dl. In the 2-4 hours following a meal, patients with type 1 diabetes are advised to keep their blood glucose levels at <180. In a non-diabetic population, the ranges of pre-meal blood glucose readings should be between 70-100mg/dl. Readings taken 2-4 hours after a meal in non-diabetic individuals should stay between 70-139mg/dl.

Pearson product moment correlations were used to correlate the scaled variables and the HbA<sub>1c</sub> levels. The results of this analysis are presented in Table 8.

Table 8

*Pearson Product Moment Correlations – Scaled Variables and HbA<sub>1c</sub> Levels for the 50 mother-child pairs utilized in the study*

	1	2	3	4	5	6	7	8
1	—							
2	.07	—						
3	-.03	-.02	—					
4	.02	.15	.07	—				
5	.08	.12	.04	.14	—			
6	.17	-.05	-.15	-.17	-.18	—		
7	-.12	-.12	-.12	-.18	-.05	.07	—	
8	-.02	-.10	-.07	-.03	.01	.08	.82**	—

\*p < .05; \*\*p < .01

*Note:* 1 = Diabetes Family Responsibility Questionnaire – Mother; 2 = Self-care Inventory – Mother; 3 = Self-efficacy Diabetes – Mother; 4 = Diabetes Family Responsibility Questionnaire – Child; 5 = Self-care Inventory – Child; 6 = Self-efficacy Diabetes – Child; 7 = HbA<sub>1c</sub> E = Glucose Reading – Earlier; 8 = HbA<sub>1c</sub> MR = Glucose Reading Most Recent

One statistically significant correlation was obtained between HbA<sub>1c</sub> E and HbA<sub>1c</sub> MR ( $r = .82, p < .001$ ). The remainder of the correlations were not statistically significant.

## Hypotheses Testing

Six hypotheses were developed for the study. Each of the hypotheses was tested using inferential statistical analyses. All decisions on the statistical significance of the findings were made using a criterion alpha of .05.

H<sub>1</sub>: HbA<sub>1c</sub> levels can be predicted from mothers' and adolescents' perceptions of treatment adherence.

The *earlier* HbA<sub>1c</sub> results were correlated separately with the mean scores for the mothers' and adolescents' perceptions of treatment adherence using Pearson product moment correlations. The *later* HbA<sub>1c</sub> results were correlated using the same constructs and methodology. The correlations were separated categorically by date (earlier and recent) in an effort to provide a snapshot of two distinct HbA<sub>1c</sub> readings at different points in the patient's treatment history. The two HbA<sub>1c</sub> values were not correlated with one another. Table 9 presents the results of these analyses.

Table 9

*Pearson product moment correlations - HbA<sub>1c</sub> E and HbA<sub>1c</sub> MR with Mothers' and Adolescents' Perceptions of Treatment Adherence*

Perceptions of Treatment Adherence	N	HbA <sub>1c</sub>				
		Earlier	P	Most Recent	R	p
Mothers	204	-.12	.093	207	-.10	.151
Adolescents	42	-.05	.743	44	.01	.422

The correlations between mothers' and adolescents' perceptions of treatment adherence and earlier and most recent HbA<sub>1c</sub> levels were not statistically significant. The discrepancies in mother respondent numbers between the earlier and most recent HbA<sub>1c</sub> data is reflective of missing HbA<sub>1c</sub> information from the mothers' personal information sheets (missing: n = 29 for

earlier;  $n = 26$  for most recent) in which the mother did not provide a reading for one, or both, of the dates. The absence of HbA<sub>1c</sub> scores from some of the mothers' responses also resulted in discrepancies in the adolescent response data. The adolescent responses in Table 9 reflect the children who were successfully matched with their mothers; however, data was only presented for the youths whose mothers provided information for the requested HbA<sub>1c</sub> data points in time (earlier and most recent). Based on the lack of relationships among the variables, the null hypothesis of no relationship is retained.

H<sub>2</sub>: Self-efficacy will mediate the relationship between treatment adherence and HbA<sub>1c</sub> levels.

H<sub>2a</sub>: Maternal self-efficacy will mediate the relationship between mothers' perceptions of treatment adherence and HbA<sub>1c</sub> levels.

A mediation analysis was used to determine if maternal self-efficacy was mediating the relationship between mothers' perceptions of treatment adherence and HbA<sub>1c</sub> levels. The four-step mediation analysis (Baron & Kenny, 2013) was used for this analysis. Table 10 presents results of this analysis.

Table 10

*Mediation Analysis – The Mediating Effect of Maternal Self-efficacy on the Relationship between Mothers' Perceptions of Treatment Adherence and HbA<sub>1c</sub> Levels*

Predictor	Criterion	$R^2$	$F$	Standardized $\beta$
HbA <sub>1c</sub> (most recent)	Mother s' perceptions of treatment adherences	.01	2.08	-.10

The results of the multiple linear regression analysis using mother's perceptions of treatment adherence and HbA<sub>1c</sub> (most recent) was not statistically significant,  $r^2 = .01$ ,  $F(1, 205) = 2.08$ ,  $p = .151$ . Because of the nonsignificant result on the first step, the mediation analysis

could not be continued. Based on these findings, the null hypothesis that mothers' self-efficacy was not mediating the relationship between mother's perceptions of treatment adherence and HbA<sub>1c</sub> levels was retained.

H<sub>2b</sub>: Adolescent self-efficacy will mediate the relationship between adolescent's self-report of treatment adherence and HbA<sub>1c</sub> levels.

A mediation analysis was used to determine if adolescent self-efficacy was mediating the relationship between adolescents' self-report of treatment adherence and HbA<sub>1c</sub> levels. Table 11 presents the results of this analysis.

Table 11

*Mediation Analysis – The Mediating Effect of Adolescent Self-efficacy on the Relationship between Adolescents' Perceptions of Treatment Adherence and HbA<sub>1c</sub> Levels*

Predictor	Criterion	R <sup>2</sup>	F	Standardized $\beta$
HbA <sub>1c</sub> (most recent)	Adolescents' perceptions of treatment adherences	<.01	<.01	.01

On the first step of the mediation analysis, the adolescents' most recent HbA<sub>1c</sub> was regressed on adolescents' perceptions of treatment adherence. Because the results of this analysis were not statistically significant on step 1 of the mediation analysis, the null hypothesis that self-efficacy was not mediating the relationship between most recent HbA<sub>1c</sub> levels and adolescents' perceptions of treatment adherence was retained.

H<sub>3</sub>: Mothers' perceptions of treatment adherence can be predicted from mothers self-efficacy, adolescent self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire.

A stepwise multiple linear regression analysis was used to determine if mothers' perceptions of treatment adherence could be predicted from mothers' self-efficacy, mothers' perceptions of diabetes family responsibility, adolescents' self-efficacy, and adolescents' perceptions of diabetes family responsibility. None of the predictor variables entered the stepwise multiple linear regression equation, indicating they were not statistically significant predictors of mothers' perceptions of treatment adherence. As a result, the null hypothesis that mothers' perceptions of treatment adherence could not be predicted from mothers' and adolescents' self-efficacy or perceptions of diabetes family responsibility was retained.

H<sub>4</sub>: Adolescents' perceptions of treatment adherence can be predicted from mother self-efficacy, adolescent self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire.

Adolescents' perceptions of treatment adherence were used as the criterion variable in a stepwise multiple linear regression analysis, with mothers' self-efficacy, adolescent self-efficacy, mother's perceptions of diabetes family responsibilities, and adolescents' perceptions of diabetes family responsibilities. None of the predictor variables entered the stepwise multiple linear regression equation, indicating they were not statistically significant predictors of adolescents' perceptions of treatment adherence. As a result of the nonsignificant findings, the null hypothesis that adolescents' perceptions of treatment adherence could not be predicted from adolescents' and mothers' self-efficacy and diabetes family responsibilities was retained.

H<sub>5</sub>: Mothers' perceptions of treatment adherence can be predicted from gender of adolescent, age of adolescent, marital status, socioeconomic status, family income

level, frequency of blood glucose monitoring, type of insulin administration, and HbA<sub>1c</sub> levels.

A stepwise multiple linear regression analysis was planned to address the fifth hypothesis. Prior to conducting the stepwise multiple linear regression analysis, an intercorrelation matrix was completed to determine which of the predictor variables (gender of adolescent, age of adolescent, mothers' marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and HbA<sub>1c</sub> levels) were statistically significant predictors of the criterion variable, mothers' perceptions of treatment adherence. Table 12 presents results of this analysis.

Table 12

*Pearson Product Moment Correlations – Mothers' Perceptions of Treatment Adherence*

Predictor Variables	n	r	p
Gender of adolescent with diabetes	228	.12	.066
Age of adolescent with diabetes	232	-.40	<.001
Mothers' marital status	232	.02	.804
Family socioeconomic status	230	.04	.602
Household income	226	-.09	.199
Number of times glucose levels checked per day	148	.13	.121
Use an insulin pump	230	-.09	.168
HbA <sub>1c</sub> earlier	204	-.12	.099
HbA <sub>1c</sub> most recent	207	-.02	.731

One predictor variable, age of child with diabetes, was significantly correlated with mothers' perception of treatment adherence,  $r = -.40$ ,  $p < .001$ . The negative direction of this relationship indicated that mothers' perceptions of treatment adherence was higher when the child was younger. The remaining predictor variables were not significantly correlated with the criterion variable, mothers' perceptions of treatment adherence. Because only one predictor

variable was related to mothers' perceptions of treatment adherence, the planned stepwise multiple linear regression analysis was not completed.

H<sub>6</sub>: Adolescents' self-report of treatment adherence can be predicted from gender of adolescent, age of adolescent, marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and HbA<sub>1c</sub> levels

The sixth hypothesis was addressed using a stepwise multiple linear regression analysis. Prior to conducting the stepwise multiple linear regression analysis, a intercorrelation matrix was completed to determine which of the predictor variables (gender of adolescent, age of adolescent, mothers' marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and HbA<sub>1c</sub> levels) were statistically significant predictors of the criterion variable, adolescents' perceptions of treatment adherence. Table 13 presents results of this analysis.

Table 13

*Pearson Product Moment Correlations – Adolescents' Perceptions of Treatment Adherence*

Predictor Variables	n	r	p
Gender of adolescent with diabetes	50	-.36	.010
Age of adolescent with diabetes	50	-.13	.383
Mothers' marital status	47	-.02	.878
Family socioeconomic status	49	.02	.880
Household income	42	-.18	.264
Number of times glucose levels checked per day	44	-.03	.838
Use an insulin pump	50	-.17	.252
HbA <sub>1c</sub> earlier	50	-.04	.803
HbA <sub>1c</sub> most recent	32	.06	.744



One predictor variable, gender of child with diabetes, was significantly correlated with adolescents' perceptions of treatment adherences,  $r = -.36$ ,  $p = .010$ . The negative direction of the relationship between the gender of the adolescent and their perceptions of treatment adherence provided evidence that females (coded as a 1) were more likely to have higher scores for perceptions of treatment adherence. The remaining predictor variables were not significantly related to adolescents' perceptions of treatment adherence. As a result, the planned stepwise multiple linear regression analysis was not completed and the null hypothesis was retained.

### **Summary**

The results of the statistical analyses used to describe the sample and test the hypotheses have been presented in this chapter. A discussion of the findings, along with recommendations for practice and future research can be found in Chapter 5.

## CHAPTER 5

### DISCUSSION

The purpose of this chapter is to offer an interpretation of the results obtained from the data analyses. The results are presented in three sections to offer insight into the study's findings. Section one will discuss the results of the six hypotheses beginning with hypothesis one, and moving sequentially through hypothesis six. Each research question will be analyzed in an effort to explain the extent that the hypotheses did, or did not, support the findings. Section two looks at the limitations in the current study, and section three offers practical implications to address points of interests for future research with Type 1 populations.

#### **Section One – Discussion of Results**

The *first hypothesis* predicted a positive relationship between the mothers' and adolescents' perceptions of treatment adherence and HbA<sub>1c</sub> readings. Pearson Product Moment Correlations were used to test this premise and no statistically significant correlations were found based on HbA<sub>1c</sub> readings in the 50 mother-child pairs. Because HbA<sub>1c</sub> readings are used as an indirect measure of treatment adherence, the inclusion of the Self-Care Inventory (SCI) seemed the best fit in addressing this construct.

The expected outcome in hypothesis one was that adolescents would exhibit higher HbA<sub>1c</sub> levels as a product of development, and in turn, would focus less on adherence to their diabetes regimen. This assumption was supported in the work of Margeirsdottir et al. (2010) and Ziegler et al. (2011) which found that adolescents had higher incidences of elevated HbA<sub>1c</sub> levels than a cohort of Type 1 diabetic patients who were 12 years of age or younger. The decision to use the measure for self-adherence by mother and child, and then correlate those results with HbA<sub>1c</sub> readings, was predicated on a large body of literature that suggests that an

adolescent's pursuit of autonomy is often in conflict with the demands and expectations of the parent. The anticipated result was that differences in the children's and parent's views of adherence, would be related to poorer HbA<sub>1c</sub> readings. This line of reasoning was also highlighted in studies by Anderson et al. (1997 & 1999), as well as Hauser et al. (1990), in which they found that perceptions of diabetes related responsibility shifts as the child takes on the independence associated with adolescent development. The lack of significant findings in hypothesis one was likely the result of a homogeneous population sample which came from predominantly married, highly educated, upper-middle class, Caucasian families. The demographic itself elucidates an unexpected phenomenon in the current work that fails to account for the typical Type 1 population.

The *second hypothesis* was presented in two parts in an effort to obtain data related to the maternal and child aspects of the research question. In part one, the study looked at maternal self-efficacy and predicted that it would mediate the relationship between mothers' perceptions of treatment adherence and HbA<sub>1c</sub> levels. The second part predicted that adolescent self-efficacy would mediate the relationship between adolescent's self-report of treatment adherence and HbA<sub>1c</sub> levels.

A mediation analysis was planned for both parts of hypothesis two using Baron & Kenny's four-step mediation process to determine if a relationship existed between the constructs. The results of the multiple linear regression analysis, using mother's perceptions of treatment adherence and HbA<sub>1c</sub> from hypothesis 1, were not statistically significant therefore the nonsignificant findings on the first step meant that a mediation analysis could not be continued. Based on these findings, the null hypothesis that mothers' self-efficacy was not mediating the

relationship between mother's perceptions of treatment adherence and HbA<sub>1c</sub> levels was retained.

In the second part of hypothesis two, the adolescents' most recent HbA<sub>1c</sub> was regressed on adolescents' perceptions of treatment adherence to achieve the first step of the mediation analysis. The results of this analysis were also not statistically significant; therefore, the null hypothesis was again retained.

The decision to examine treatment adherence as a mediator of self-efficacy in hypothesis two, was to assess the impact of this construct based on contradictory findings in the literature. In Iannotti's (2006) overview of self-efficacy, he indicates that a person's motivation, movement toward action, and their affective state, serve as better predictors of change than what the individual is truly capable of achieving with self-efficacy alone. In other words, self-efficacy was not viewed as a powerful enough construct by itself to influence a change in outcome. Kavanagh et al. (1993) derived findings to the contrary which noted that self-efficacy was the most powerful predictor of treatment adherence in adolescent patients when assessing select components of the diabetes treatment regimen. A more recent study by Palmer et al. (2009) looked at the effect of self-efficacy on the individual, and found that low self-efficacy beliefs in an adolescent patient were buffered by high parental involvement. Studies, which have focused on the mediational value of patient empowerment in relation to treatment adherence and glycemic control, illustrate the importance of a patient's perception of control when dealing with a chronic illness such as Type 1 diabetes (Griva et al., 2000; Grossman et al., 1987; Ott et al., 2000). The findings in the aforementioned studies provided a reasoned justification for the use of the SCI in the mediation analyses in an effort to establish the power of parental input in disease management.

*Hypothesis three* expected to show that a mothers' perceptions of treatment adherence could be predicted from her self-efficacy beliefs, adolescent self-efficacy, her perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and her child's responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire. A stepwise multiple linear regression analysis was used to test the hypothesis, and none of the predictor variables entered the stepwise multiple linear regression equation, indicating they were not statistically significant predictors of the criterion variable.

*Hypothesis four* took the same approach as hypothesis three, except the role of mother and adolescent were switched and the adolescents' perceptions of treatment adherence was used as a criterion variable while the mothers' self-efficacy, adolescents' self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire were used as predictors. Much like the findings in hypothesis three, none of the predictor variables entered the stepwise multiple linear regression equation, indicating they were not statistically significant predictors of adolescents' perceptions of treatment adherence.

The inclusion of the DFRQ in hypotheses three and four was to provide a measure of parent/child perceptions that looked specifically at disease management. In a study by Leonard et al. (1998), the DFRQ was used to assess the child's level of responsibility for diabetes care using only the mother as a respondent. They found that mothers, who rated themselves with higher self-efficacy, also rated their children higher in skill areas that corresponded to diabetes self-management on the subscales of the DFRQ.

The present study sought to address a shortcoming in the Leonard et al. analyses by drawing from a participant pool that was older, and not broken down into distinct periods which were shorter in chronology, and much younger than other adolescent cohorts. The restrictive nature of the age groups in the Leonard et al. (1998) study prevented a thorough examination of the particular changes that often occur as a child eases through adolescence to independence from parental input. Although the present work was able to address the older cohort of adolescents that was absent in the Leonard study, the unintended effect of a homogeneous sample failed to illustrate the expected differences within the group.

In a separate study by Vesco et al. (2010), they found that questions imbedded in the DFRQ readily parceled out the influence of direct tasks such as blood glucose monitoring, response to blood glucose fluctuations, as well as the changing and rotation of insulin injection sites. Furthermore, their findings also illustrated the unique contribution of parental responsibility to treatment adherence that fit well with the research question. Once again, a homogeneous sample in the current study was an obstacle in accurately assessing the impact of diabetes specific behaviors that were addressed in the personal information/demographic sheet from the mothers' response set.

Palmer et al. (2010) also found the DFRQ to be an advantage in their research because it was able to operationalize parental involvement as a combination of three separate factors, which included the quality of the parent/child relationship, behavioral involvement, and amount of monitoring in disease management. Their results showed that the role of parental involvement and responsibility for their offspring's care is an intricate array of factors, which were easily determined by the subscales of the DFRQ. Furthermore, Holmes et al. (2006) provided input about the intersection of parental involvement and self-efficacy beliefs that was an underlying

them in hypotheses three and four in the current undertaking. They found that if an adolescent takes responsibility too soon for the management of his/her illness while their self-efficacy beliefs about personal abilities is not intact; the deterioration of adherent behaviors is inevitable. This phenomenon was not uncovered in the current group because the respondents lacked variability in demographic and diabetes specific characteristics, which is incongruent with the expected representation of Type 1 research populations.

*Hypothesis five* utilized the mothers' perceptions of treatment adherence as a criterion variable, and predicted that demographic variables such as gender of adolescent, age of adolescent, marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and HbA<sub>1c</sub> levels would provide significant results. A stepwise multiple linear regression analysis was planned to address the fifth hypothesis. Prior to conducting the stepwise multiple linear regression analysis, a intercorrelation matrix was completed to determine which of the predictor variables from the demographic information were statistically significant predictors of the criterion variable.

One predictor variable, age of child with diabetes, was significantly correlated with mothers' perception of treatment adherence. The negative direction of this relationship indicated that mothers' perceptions of treatment adherence was higher when the child was younger. The remaining predictor variables were not significantly correlated with the criterion variable, therefore, the planned stepwise multiple linear regression analysis was not completed.

The findings in the current study support previous research in which it has been noted that parents tend to be more "hands on" when the child is younger, and perceived adherence to treatment is rated higher by caregivers. The structure of the current study also responded to earlier literature in which it was found that most non-adherent behaviors in the management of

the illness emerge around the time a child reaches middle school. Significant differences based on age have also been recognized in studies where HbA<sub>1c</sub> with younger children were shown to be better than an older cohort of Type 1 patients (Haugstvedt, 2010). As was previously mentioned, HbA<sub>1c</sub> is considered an indirect gauge of illness specific adherent behaviors, which is more controlled when the child is younger and the parents take the helm for diabetes related care.

The work of Anderson et al. (2000) brought relevance to the notion that blood glucose control and adherence to diabetic regimens often deteriorate during adolescence as part of the normative process of the adolescent's need for autonomy. Britto et al. (2004) added to those findings by indicating that autonomy during adolescence follows a natural course in which the patient seizes the opportunity to take control of personal health.

Wysocki et al. (1996) urged caution when transitioning to maximal self-care in the management of diabetes, because their findings coincided with another study in which it noted that parents who stayed involved in their adolescent's care, also reported better glycemic control of the illness (Seiffge-Krenke et al., 2002). The consensus in diabetes research, where the focus is on child responsibility for self-care behaviors, suggests that parents remain involved in their children's disease management until such time that the child is sufficiently able to independently address task oriented procedures (Brink et al., 2002; Follonsbee, 1989; Frey & Fox, 1990). The significant finding in hypothesis five supports this line of reasoning.

The *sixth hypothesis* anticipated that adolescents' self-report of treatment adherence could be predicted from gender of adolescent, age of adolescent, marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and HbA<sub>1c</sub> levels. The research question was addressed using a stepwise multiple



linear regression analysis. One predictor variable, gender of child with diabetes, was significantly correlated with adolescents' perceptions of treatment adherences.

The decision to incorporate gender related constructs in hypotheses five and six aligned with the reasoning of the Grossman et al. (1987) study, which suggested that females are expected to be more compliant in their demeanor, and therefore more prone to seek out externalized feedback. This externalized feedback was interpreted as the individual's perception that in order to gain acceptability among family and peers, one would have to adhere to proscribed expectations. The expectation in this case was the ability to comply with the diabetes treatment regimen and maintain acceptable control of the illness. Grossman et al. (1987) also indicated that if gender differences exist, they are likely the product of patterns of socialization that vary from culture to culture. Their work solidified the idea that girls with Type 1 diabetes were more likely to retain a link between better glucose control and self-efficacy because societal standards expected them to be more compliant, and in turn, more self-evaluative.

The present study adopted the position that if females indeed pursued a more structured course during adolescence, their self-management perceptions would be higher than their male counterparts. To the contrary, boys would be less likely to seek out externalized sources of support during adolescence, and would therefore present with less perceptions indicative of disease control. Grossman et al. (1987) went on to note that females tended to personalize their conflicts and exert more energy into managing potential problem areas. The Grossman et al. study was contradicted by findings by Iannotti et al. (2006), in which they found that there were no significant differences between gender in terms of self-management and glycemic readings. The present study reinforced the findings of the earlier study and showed that females exhibit better control of the illness as a result of adherence beliefs.

## **Section Two - Limitations**

One of the limitations of the study, and an unexpected outcome in the current body of work, was the homogeneous make-up of the respondent population. The decision to recruit individuals from the Juvenile Diabetes Research Foundation (JDRF) was predicated on the ethnically diverse make-up of families who attend, and participate in the organization's functions. The findings in the present study illustrated a response set whose majority consisted of higher SES, married, Caucasian families. This alone constitutes a departure from the true household make-up of families who are touched by the effects of Type 1 diabetes.

To rectify this issue, future recruitment procedures would need to encompass not only the JDRF community, but also families who are living with a Type 1 diagnosis and have no contact with the organization. Researchers could offset this shortcoming by working in collaboration with endocrinology clinics, larger health care facilities, or unified health care systems to retrieve database information related to Type 1 patients. This would likely be a more time consuming process because of the challenges associated with access to HIPAA protected information; however, the advantage to this approach would mean that the researcher would have a diverse data set that would reflect the true make-up of affected families. Furthermore, because all newly diagnosed Type 1 patients will encounter at least a brief hospital stay after diagnosis which requires follow-up care, this means that the researcher who is able to access a patient database in clinical or larger hospital settings, would also acquire a complete list of all Type 1 patients from the identified facility.

A second limitation in the study was that the survey format was electronic. For families that were not connected to social media outlets where the research was advertised or shared with others, they would have been averted from the opportunity to participate. Because respondents in

the current study were obligated to participate through a web site and answer all of the questions online, those without a computer, limited access to a computer, or barriers to Internet access, would also have been presented with obstacles to participate. In the future, this could be offset with traditional pen and paper recruitment techniques in which the respondent mails their completed work back for analysis, or participation might be conducted in the course of a clinical, or hospital appointment providing consent/assent is obtained by the facility and the caregiver/patient.

Another important limitation in the study was the length of the survey. The low response rate among the adolescent population might have been attributed to the length of the three adolescent questionnaires. Although the surveys for the adolescents were arranged individually beginning with the SCI (14 questions), followed by the DFRQ (17 questions), and then the SED (35 questions), participation from this population still fell short of expectations. A review of the raw data indicated that many of the adolescents eliminated from the study, failed to answer the final survey, and many stopped before completing the second questionnaire. The simplest way to offset this occurrence in future research would be to incorporate shorter surveys that include language signifying that it will “only take...minutes to complete”. Another possible solution would be to offer the adolescent the choice of a modest financial compensation for their time, or the option to donate the money to a charity if the studies are longer in duration. This approach would incorporate the methodology adopted by the University of Michigan Hospital for diabetes research in which their response rates are very high.

### **Section Three - Considerations for Future Research with Type 1 Patients**

As Brink et al. (2002) point out in their analysis of education and multidisciplinary approaches to disease management, assessing patients and their families to guide diabetes

management has become the target of treatment in the United States and abroad. The effectiveness of such efforts would rely on a program's ability to offer interventions, such as those which could enhance self-efficacy beliefs, disease perceptions, and adherent behaviors. At the same time, such an undertaking would have to guide the patient and family through an integrated treatment plan that explains the identified risk areas that aid in decision making (Brink et al., 2002; Schwartz et al., 2011). From an educational standpoint, the ability to assess perceptions of the disease course in patients with chronic illness would be a beneficial tool in long-term treatment options. Information could then be used to inform families about the psychological problems associated with important constructs such as self-efficacy, perceptions of family involvement, and health related behaviors. In theory, the data could offer new insights that might also be used to streamline existing diabetes education programs for patient and family.

To date, there is no indication that the standards of care for persons with Type 1 diabetes has enforced, or encouraged this ideology in the way that traditional medical approaches have been viewed in the totality of disease management and compliance. The benefit here is that if a patient believes that they can improve their adherence to treatment recommendations, and are able to execute this through the realization of small goals in a controlled and monitored manner, then screenings to assess self-efficacy beliefs, or family perceptions of the illness may be justified as part of routine treatment. Patient and family perceptions of the illness would then allow members of a multidisciplinary team to see the problems inherent within the family, and could use those findings as a means of tailoring early intervention strategies.

The idea that the family should shift from staying in "survival mode" to adopting more structured behavioral strategies, is also a consideration that could improve the quality of life for Type 1 patients and their families. For those who care for a child with Type 1 diabetes, the

knowledge they obtain after receiving the diagnosis is more about process motivation to include learning how to use a glucometer, providing insulin injections, and understanding warning signs which are the essentials of “survival mode”. The daunting nature of the disease course where survival and adherence to medical protocols are the primary concern of most medical approaches, can sometimes interfere with more structured behaviors that are geared toward creating advanced patterns of positive outcomes to include treatment adherence and collaborative family involvement. Unlike other chronic illnesses, Type 1 diabetes requires that the patient and family engage in ongoing behavioral modifications, as well as information analysis to achieve proper metabolic control (Brink et al., 2002). Unfortunately, the need to monitor the fluctuations associated with Type 1 often takes precedence in illness management, and prevents the evolution of other processes such as collaboration and shared responsibility.

Type 1 diabetes is an illness where much of the learning takes place in the home, and this process can exact a huge emotional toll on all family members (Schwartz et al., 2011). Modifications to previously established routines have to be implemented in an effort to control a complicated disease course. In the midst of many diabetes programs, which prepare the patient and families for the rigors of daily monitoring and medical adherence, many patients with clinical levels of stress are not referred for psychological treatments that may aid improved compliance (Carter et al., 2001). Because the family is a vital source of support, they too need to be aware of their own stress when looking at the effects of the illness on their psychological well-being.

This phenomenon places attention on the need for improved screening methods with adolescent patients and their caregivers as was mentioned in the work of Mishali et al. (2011). These screening methods could be facilitated by the health care team at the direction of the

physician responsible for the patient's care, or a mental health professional who could assess the need for further testing or intervention strategies. A screening approach as part of routine visits has yet to be utilized in standardized treatment protocols with diabetic patients. Although parents are the primary source of support during this period, and often the ones who bear the burden of the stressors associated with disease "burnout", the focus of disease management with Type 1 diabetes often becomes centered on the immediate concerns, which are biological in nature rather than psychological. Taken at face value, this alone creates a significant barrier to information that could offer long-term changes in the perception of chronic disease management.

Because the management of Type 1 diabetes is a complicated, lifelong course that places demands on all parties involved, it is vital to establish proactive routines immediately after diagnosis to offset later complications. Among the most important barriers, which was illustrated in the work of Varni et al., (2005), is the need for services that run in tandem with other patient services that create continuity of care. Perhaps, the idea of integrated health care teams where medical staff collaborate with mental health professionals, will become standard protocol in the treatment of future diabetic populations. Although a noted shift has taken place in recent years, there is still a lot of work to be done if parity is to be achieved in the treatment of individuals and families suffering with chronic illnesses.

Table 1

Hypotheses	Variables	Statistical Analysis
H <sub>1</sub> : HbA <sub>1c</sub> levels can be predicted from mothers' and adolescents' perceptions of treatment adherence.	HbA <sub>1c</sub>  Mothers' perceptions of treatment adherence  Adolescents; perceptions of treatment adherence	Pearson product moment correlations will be used to determine the strength and direction of the relationship between HbA <sub>1c</sub> levels and mothers' and adolescents' perceptions of treatment adherence.
H <sub>2</sub> : Self-efficacy will mediate the relationship between treatment adherence and HbA <sub>1c</sub> levels. H <sub>2a</sub> : Maternal self-efficacy will mediate the relationship between mothers' perceptions of treatment adherence and HbA <sub>1c</sub> levels. H <sub>2b</sub> : Adolescent self-efficacy will mediate the relationship between adolescent's self-report of treatment adherence and HbA <sub>1c</sub> levels.	<u>Criterion Variable</u> ●Mothers' perceptions of treatment adherence ●Adolescent's self-report of treatment adherence  <u>Predictor Variable</u> HbA <sub>1c</sub> levels  <u>Mediating Variable</u> ●Maternal self-efficacy ●Adolescent self-efficacy	Baron & Kenny's four-step mediation analysis will be used to determine if self-efficacy mediates the relationship between HbA <sub>1c</sub> levels and perceptions/self-report of treatment adherence.  The four steps include: 1. Determine if the predictor variable is significantly related to the criterion variable. 2. Determine if the predictor variable is significantly related to the mediating variable. 3. Determine if the mediating variable is significantly related to the criterion variable. 4. Determine the change in the relationship between the predictor variable and the criterion variable while holding the mediating variable constant.
H <sub>3</sub> : Mothers' perceptions of treatment adherence can be predicted from mothers self-efficacy, adolescent self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire	<u>Criterion Variable</u> Mothers' perceptions of treatment adherence  <u>Predictor Variable</u> ●Mother self-efficacy ●Adolescent self-efficacy ●Mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire ●Adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire (DFRQ)	Stepwise multiple linear regression analysis will be used to determine which of the independent variables can be used to predict mothers' perceptions of treatment adherence.

<p>H<sub>4</sub>: Adolescents' perceptions of treatment adherence can be predicted from mother self-efficacy, adolescent self-efficacy, mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire, and adolescents' responses about diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire</p>	<p><u>Criterion Variable</u> Adolescents' perceptions of treatment adherence</p> <p><u>Predictor Variable</u></p> <ul style="list-style-type: none"> <li>●Mother self-efficacy</li> <li>●Adolescent self-efficacy</li> <li>●Mothers' perceptions of diabetes care responsibilities from the Diabetes Family Responsibility Questionnaire</li> <li>●Adolescents' responses about diabetes care responsibilities from the DFRQ</li> </ul>	<p>Stepwise multiple linear regression analysis will be used to determine which of the independent variables can be used to predict adolescent' perceptions of treatment adherence.</p>
<p>H<sub>5</sub>: Mothers' perceptions of treatment adherence can be predicted from gender of adolescent, age of adolescent, parent marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and Hb A<sub>1c</sub> levels</p>	<p><u>Criterion Variable</u> Mothers' perceptions of treatment adherence</p> <p><u>Predictor Variable</u></p> <ul style="list-style-type: none"> <li>●Gender of adolescent</li> <li>●Age of adolescent</li> <li>●Parent marital status</li> <li>●Socioeconomic level</li> <li>●Family income level</li> <li>●Frequency of blood glucose monitoring</li> <li>●Type of insulin administration</li> <li>●HbA<sub>1c</sub> levels</li> </ul>	<p>Stepwise multiple linear regression analysis will be used to determine which of the independent variables can be used to predict mothers' perceptions of treatment adherence.</p>
<p>H<sub>6</sub>: Adolescents' self-report of treatment adherence can be predicted from gender of adolescent, age of adolescent, parent marital status, socioeconomic status, family income level, frequency of blood glucose monitoring, type of insulin administration, and Hb A<sub>1c</sub> levels</p>	<p><u>Criterion Variable</u> Adolescents' self-report of treatment adherence</p> <p><u>Predictor Variable</u></p> <ul style="list-style-type: none"> <li>●Gender of adolescent</li> <li>●Age of adolescent</li> <li>●Parent marital status</li> <li>●Socioeconomic level</li> <li>●Family income level</li> <li>●Frequency of blood glucose monitoring</li> <li>●Type of insulin administration</li> <li>●HbA<sub>1c</sub> levels</li> </ul>	<p>Stepwise multiple linear regression analysis will be used to determine which of the independent variables can be used to predict adolescents' perceptions of treatment adherence.</p>



## APPENDIX A: DEMOGRAPHIC INFORMATION FORM

## Patient (Type 1 Diabetes) Personal Information Sheet

**\*\*\*to be filled out by Mother only\*\*\***

Please answer the following pieces of information to help us better understand the responses to the questionnaires contained within the packet. DO NOT include your name or other identifying information on this sheet. Simply select the response that best fits the question description?

In order to create a code which recognizes the contribution that will be made to the JDRF on your behalf, please enter the numeric birthdates, beginning with yourself, and then and your child, in the following format:  
MM/DD/YYYY---MM/DD/YYYY

---

1.) What is the patient's gender?

- Male  
 Female

2.) What is the patient's age? (please write your response on the line)

---

What is your age? (please write your response on the line)

---

3.) Which of the following best describes the ethnic group of the patient? Please place a check in the box next to the appropriate response.

- Caucasian/White                       Hispanic/Latino                       Asian-Pacific Islander  
 African-American/Black               Middle-Eastern/Arabic               Native American                       Other

4.) Which of the following best describes the household income of the patient's family? Please select the appropriate response.

- under \$20,000  
 \$20, 000-49,999  
 \$50, 000-79,999  
 \$80, 000-109,999  
 \$109, 000 or above

5.) Which of the following best describes the highest level of education attained by the parent completing the current survey? Please select the appropriate response.

- less than 7<sup>th</sup> grade                       High School Graduate                       Graduate degree  
 at least 9<sup>th</sup> grade                       at least 1 year of college/specialized training  
 at least 10<sup>th</sup> or 11<sup>th</sup> grade               Standard college or university degree

6.) Which of the following best describes the highest level of education attained by the father (if applicable). Please select the appropriate response.

- less than 7<sup>th</sup> grade                       High School Graduate                       Graduate degree  
 at least 9<sup>th</sup> grade                       at least 1 year of college/specialized training  
 at least 10<sup>th</sup> or 11<sup>th</sup> grade                       Standard college or university degree

7.) Please describe your employment role and what your job consists of (for example, if an employee of a corporation, what do you do there)

---

8.) Please describe your spouse/significant other's employment role and what their job consists of (for example, if an employee of a corporation, what does he/she do there)

---

9.) At what age was the patient diagnosed with diabetes? (please type in your response)

---

10.) What were the patient's last two HbA<sub>1c</sub> (A<sub>1c</sub>) readings and the dates? (please type in your responses on the lines below)

---

11.) Are you a 1.) single-parent, 2.) married, 3.) divorced, 4.) separated, or, 5.) in committed adult relationship (please select the appropriate response)

12.) Please select an answer for the following question:

What is your relationship to the patient with Type 1 diabetes?

- a.) biological parent  
 b.) step-parent  
 c.) foster parent

13.) Are you the only caregiver for the child with Type 1 diabetes (please select a response below)

- a.) Yes  
 b.) No

14.) Is there anyone else in the home that has been diagnosed with a chronic illness? (please select a response below)

- a.) Yes  
 No

If you answered yes to #8, please list what the illness is, relationship to client in current survey, and the age of the other patient below

Type of illness \_\_\_\_\_

Patient's age \_\_\_\_\_

Relationship to patient in current survey \_\_\_\_\_

15.) Does the patient in the current survey have any siblings? Please select an answer below

a.) Yes

b.) No

If you answered yes, please list the age (s) \_\_\_\_\_

16.) Does the patient in the current survey use an insulin pump? Please select an answer below

a.) Yes

b.) No

If you answered yes to #13, how long have they been on insulin pump therapy? \_\_\_\_\_

17.) Does the client in the current survey have a history of recurrent diabetic ketoacidosis? Please select the appropriate response

a.) Yes

b.) No

18.) Does the client in the current survey have a history of recurrent hypoglycemic episodes? Please circle the appropriate response

c.) Yes

d.) No

19.) Has the client in the current survey been hospitalized since being diagnosed with Type 1 diabetes for any diabetes related complications? Please select the appropriate response

a.) Yes

b.) No

20.) How many times per day does your child check his or her blood glucose levels (this includes readings during the night) Please type in your response on the line below

\_\_\_\_\_

APPENDIX B: DIABETES FAMILY RESPONSIBILITY QUESTIONNAIRE (DFRQ)-CHILD  
FORM

**DFRQ**  
**(Anderson & Auslander,1990)**

For each of the following parts of diabetes care, choose the number of the answer that best describes the way you have handled things at home over the past month.

- 1—Child takes or initiates responsibility for this almost all of the time.  
2—Parent(s) and child share responsibility for this about equally.  
3—Parent(s) take or initiate responsibility for this almost all of the time.

	Responsibility		
	Child	Equal	Parent
	1	2	3
1. Remembering day of clinic appointment.			
2. Telling teachers about diabetes.			
3. Remembering to take morning or evening injection or boluses (pump).			
4. Making appointments with dentists and other doctors.			
5. Telling relatives about diabetes.			
6. Taking more or less insulin according to results of blood sugar monitoring.			
7. Noticing differences in health, such as weight changes or signs of an infection.			
8. Deciding what to eat at meals or snacks.			
9. Telling friends about diabetes.			
10. Noticing the early signs of an insulin reaction.			
11. Giving insulin injections or boluses (pump).			
12. Deciding what should be eaten when family has meals out. (restaurants, friends' homes)			
13. Carrying some form of sugar in case of an insulin reaction.			
14. Explaining absences from school to teachers or other school personnel.			
15. Rotating injection sites or infusion set-ups (pump).			
16. Remembering times when blood sugar should be monitored.			
17. Checking expiration dates on medical supplies.			

APPENDIX C: DIABETES FAMILY RESPONSIBILITY QUESTIONNAIRE (DFRQ)-  
PARENT FORM

**DFRQ**  
**(Anderson & Auslander, 1990)**

For each of the following parts of your child's diabetes care, choose the number of the answer that best describes the way you handle things at home.

- 1—Child takes or initiates responsibility for this almost all of the time.**  
**2—Parent(s) and child share responsibility for this about equally.**  
**3—Parent(s) take or initiate responsibility for this almost all of the time.**

	Responsibility		
	Child	Equal	Parent
	1	2	3
1. Remembering day of clinic appointment.			
2. Telling teachers about diabetes.			
3. Remembering to take morning or evening insulin injection/bolus by pump.			
5. Making appointments with dentists and other doctors.			
5. Telling relatives about diabetes.			
6. Taking more or less insulin according to results of blood sugar monitoring.			
7. Noticing differences in health, such as weight changes or signs of an infection.			
8. Deciding what to eat at meals or snacks.			
9. Telling friends about diabetes.			
10. Noticing the early signs of an insulin reaction.			
11. Giving insulin injections or boluses by pump.			
13. Deciding what should be eaten when family has meals out. (restaurants, friends' homes)			
13. Carrying some form of sugar in case of an insulin reaction.			
14. Explaining absences from school to teachers or other school personnel.			
15. Rotating injection sites or infusion set-ups for pump.			
16. Remembering times when blood sugar should be monitored.			
17. Checking expiration dates on medical supplies.			

## APPENDIX D: SELF-CARE INVENTORY (SCI)-YOUTH FORM

*SCI-Youth Version*

Please rate each of the items according to HOW WELL YOU FOLLOWED YOUR **PRESCRIBED REGIMEN FOR DIABETES CARE** in the *past month*. Use the following scale:

- 1 = Never do it  
 2 = Sometimes follow recommendations; mostly not  
 3 = Follow recommendations about 50% of the time  
 4 = Usually do this as recommended; occasional lapses  
 5 = Always do this as recommended without fail  
 NA = Cannot rate this item/ Not applicable

In the *past month*, how well have you followed recommendations for:

1. Glucose testing	1	2	3	4	5	NA
2. Glucose recording	1	2	3	4	5	NA
3. Ketone testing	1	2	3	4	5	NA
4. Administering correct insulin dose	1	2	3	4	5	NA
5. Administering insulin at right time	1	2	3	4	5	NA
6. Adjusting insulin intake based on blood glucose values	1	2	3	4	5	NA
7. Eating the proper foods; sticking to meal plan	1	2	3	4	5	NA
8. Eating meals on time	1	2	3	4	5	NA
9. Eating regular snacks	1	2	3	4	5	NA
10. Carrying quick-acting sugar to treat reactions	1	2	3	4	5	NA
11. Coming in for appointments	1	2	3	4	5	NA
12. Wearing a medic alert ID	1	2	3	4	5	NA
13. Exercising regularly	1	2	3	4	5	NA
14. Exercising strenuously	1	2	3	4	5	NA

## APPENDIX E: SELF-CARE INVENTORY (SCI)-PARENT FORM

*SCI-Parent Version*

Please rate each of the items according to HOW WELL YOUR CHILD FOLLOWED HIS/HER **PRESCRIBED REGIMEN** FOR DIABETES CARE in the *past month*. Use the following scale:

- 1 = Never do it  
 2 = Sometimes follow recommendations; mostly not  
 3 = Follow recommendations about 50% of the time  
 4 = Usually do this as recommended; occasional lapses  
 5 = Always do this as recommended without fail  
 NA = Cannot rate this item/ Not applicable

In the *past month*, how well have you followed recommendations for:

1. Glucose testing	1	2	3	4	5	NA
2. Glucose recording	1	2	3	4	5	NA
3. Ketone testing	1	2	3	4	5	NA
4. Administering correct insulin dose	1	2	3	4	5	NA
5. Administering insulin at right time	1	2	3	4	5	NA
6. Adjusting insulin intake based on blood glucose values	1	2	3	4	5	NA
7. Eating the proper foods; sticking to meal plan	1	2	3	4	5	NA
8. Eating meals on time	1	2	3	4	5	NA
9. Eating regular snacks	1	2	3	4	5	NA
10. Carrying quick-acting sugar to treat reactions	1	2	3	4	5	NA
11. Coming in for appointments	1	2	3	4	5	NA
12. Wearing a medic alert ID	1	2	3	4	5	NA
13. Exercising regularly	1	2	3	4	5	NA
14. Exercising strenuously	1	2	3	4	5	NA

## APPENDIX F: SELF-EFFICACY FOR DIABETES SCALE (SED)-CHILD FORM

**SED Grossman, Brink & Hauser, 1987**

Instructions: Please read the following questions. After each question, please circle the appropriate number to show how much you believe you can or cannot do what is asked *now*.

	<i>Very sure I can't 1</i>	<i>Sure I can't 2</i>	<i>Maybe I can 3</i>	<i>Sure I can 4</i>	<i>Very sure I can 5</i>
1. Be the one in charge of giving insulin to myself with a needle or pump	1	2	3	4	5
2. Figure out my own meals and snacks at home	1	2	3	4	5
3. Figure out what foods to eat when I am away from home	1	2	3	4	5
4- Keep track of my own blood glucose readings	1	2	3	4	5
5. Watch my own blood glucose levels	1	2	3	4	5
6. Figure how much insulin to take when I get a lot of extra exercise	1	2	3	4	5
7. Judge the amount of food I should eat before activities	1	2	3	4	5
8. Figure out how much insulin to give myself when I am sick in bed	1	2	3	4	5
9. Prevent having reactions	1	2	3	4	5
10. Avoid, or get rid of dents, swelling, or redness of my skin where I get my shot, or place an injection port	1	2	3	4	5
11. Talk to my doctor on my own and ask for the things I need	1	2	3	4	5



	<i>Very sure I can't</i>	<i>Sure I can't</i>	<i>Maybe I can</i>	<i>Sure I can</i>	<i>Very sure I can</i>
12. Suggest to my parents changes in my insulin dose	1	2	3	4	5
13. Sleep away from home on a class trip or at a friend's house where no one knows about my diabetes	1	2	3	4	5
14. Keep myself free of high blood glucose levels	1	2	3	4	5
15. Know how to make my glucose readings look better or worse than they are	1	2	3	4	5
16. Avoid having ketones	1	2	3	4	5
17. Change my doctor if I don't like him/her	1	2	3	4	5
18. Feel able to stop a reaction when I am having one	1	2	3	4	5
19. Ask for help I need from other people when I feel sick	1	2	3	4	5
20. Tell a friend I have diabetes	1	2	3	4	5
21. Play sports that take a lot of energy	1	2	3	4	5
22. Argue with my doctor if I felt he/she were not being fair	1	2	3	4	5
23. Prevent blindness and other complications from my diabetes	1	2	3	4	5
24. Tell my boyfriend or girlfriend I have Type 1 diabetes	1	2	3	4	5

	<i>Very sure I can't</i>	<i>Sure I can't</i>	<i>Maybe I can</i>	<i>Sure I can</i>	<i>Very sure I can</i>
25. Do things I have been told not to, when I really want to do them	1	2	3	4	5
26. Get as much attention from others when my diabetes is under control, as when it isn't	1	2	3	4	5
27. Easily talk to a group of people at a party when I don't know them	1	2	3	4	5
28. Make a teacher see my point of view	1	2	3	4	5
29. Show my anger to a friend when he/she has done something to upset me	1	2	3	4	5
30. Take responsibility for getting my homework and chores done	1	2	3	4	5
31. Regularly wear a medical alert tag or bracelet which says I have diabetes	1	2	3	4	5
32. Sneak food not on my diet without getting caught	1	2	3	4	5
33. Believe that I have the ability to have control over my diabetes	1	2	3	4	5
34. Follow my doctor's orders for taking care of my diabetes	1	2	3	4	5
35. Run my life the same as I would if I didn't have diabetes	1	2	3	4	5

## APPENDIX G: SELF-EFFICACY FOR DIABETES SCALE (SED)-PARENT FORM

**SED Grossman, Brink & Hauser, 1987**

Instructions: Please read the following questions. After each question, please circle the appropriate number to show how much you believe you can or cannot do what is asked of you now in the care of your child with Type 1 diabetes.

	<i>Very sure I can't 1</i>	<i>Sure I can't 2</i>	<i>Maybe I can 3</i>	<i>Sure I can 4</i>	<i>Very sure I can 5</i>
1. Be the one in charge of giving insulin to my child with a needle or pump	1	2	3	4	5
2. Figure out meals and snacks at home for my child	1	2	3	4	5
3. Figure out what foods my child eats when they are away from home	1	2	3	4	5
4- Keep track of my child's blood glucose readings	1	2	3	4	5
5. Watch my child's blood glucose levels	1	2	3	4	5
6. Figure how much insulin My child should take when they get a lot of extra exercise	1	2	3	4	5
7. Judge the amount of food my child should eat before activities	1	2	3	4	5
8. Figure out how much insulin to give my child when they are sick in bed	1	2	3	4	5
9. Prevent my child from having negative diabetic reactions	1	2	3	4	5
10. Avoid, or get rid of dents, swelling, or redness on my child's skin where they get a shot, or place an injection port	1	2	3	4	5
11. Talk to my child's doctor and ask for the things they need	1	2	3	4	5

	<i>Very sure I can't</i>	<i>Sure I can't</i>	<i>Maybe I can</i>	<i>Sure I can</i>	<i>Very sure I can</i>
12. Suggest changes in insulin dosage to my child's doctor or member of their diabetes team	1	2	3	4	5
13. Allow my child to sleep away from home on a class trip, or at a friend's house where no one knows about their diabetes	1	2	3	4	5
14. Keep my child free of high blood glucose levels	1	2	3	4	5
15. Prevent my child from making their glucose readings look better or worse than they really are	1	2	3	4	5
16. Prevent my child from having ketones	1	2	3	4	5
17. Change my child's doctor if I don't like him/her	1	2	3	4	5
18. Feel able to stop a reaction when my child is having one	1	2	3	4	5
19. Ask others for the help my child needs when they feel sick	1	2	3	4	5
20. Tell another person that my child has diabetes	1	2	3	4	5
21. Let my child play sports that take a lot of energy	1	2	3	4	5
22. Argue with my child's doctor if I felt he/she were not being fair about diabetes related care	1	2	3	4	5
23. Help my child prevent blindness and other complications from their diabetes	1	2	3	4	5
24. Tell my child's friends that they have Type 1 diabetes	1	2	3	4	5

	<i>Very sure I can't</i>	<i>Sure I can't</i>	<i>Maybe I can</i>	<i>Sure I can</i>	<i>Very sure I can</i>
25. Prevent my child from doing things they have been told not to do, when they really want to do them	1	2	3	4	5
26. Give my child the same amount of attention when their diabetes is under control, as when it isn't	1	2	3	4	5
27. Easily talk to a group of people at a party, that I don't know, about my child's illness	1	2	3	4	5
28. Make a teacher see my point of view	1	2	3	4	5
29. Show anger toward another when he/she has done something to upset my child	1	2	3	4	5
30. Encourage them to take responsibility for getting homework and chores done	1	2	3	4	5
31. Encourage my child to wear a medical alert tag or bracelet which says they have Type 1 diabetes	1	2	3	4	5
32. Prevent my child from sneaking foods that they should avoid	1	2	3	4	5
33. Believe that my child has the ability to control their diabetes	1	2	3	4	5
34. Believe that my child can follow their doctor's orders for taking care of their diabetes	1	2	3	4	5
35. Believe that my child can run their life the same as if they didn't have diabetes	1	2	3	4	5

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**ABSTRACT****THE MEDIATING ROLE OF SELF-EFFICACY BELIEFS, PERCEPTIONS OF DIABETES RESPONSIBILITY, AND THEIR IMPACT ON TREATMENT ADHERENCE AMONG ADOLESCENTS WITH TYPE 1 DIABETES**

by

**RICHARD W. WOOTEN****May 2014****Advisor:** Dr. Barry S. Markman**Major:** Educational Psychology**Degree:** Doctor of Philosophy

Treatment non-adherence for Type 1 patients; especially during adolescence, is viewed as the precursor for healthy, or unhealthy patterns of self-care in adulthood. The risk for long-term health problems such as blindness, renal failure, heart attack, lower limb amputations, and stroke are exacerbated if healthy monitoring of the condition is not adhered to consistently, and early after diagnosis. The present study sought to examine theoretical constructs that are important to overall treatment adherence among adolescents with Type 1 diabetes and their maternal caregivers. Self-efficacy and perceptions of diabetes self care between child and mother were disseminated through the inclusion of three separate measures designed for adult caregivers, and their children with Type 1 diabetes. Despite the literature which has established significant findings in the treatment domains separately, the present study did not yield significant results across the domains, but was able to offer new insights into previously held findings in the Type 1 literature. The author concludes with an analysis of the barriers in conducting research with chronically ill populations, and offers suggestions for future research in this area.



## **AUTOBIOGRAPHICAL STATEMENT**

Richard W. Wooten is presently employed as a psychologist with the Third Circuit Court in Detroit, MI where he conducts custody, parenting time, and domiciling evaluations through the Family Assessment, Mediation, and Education Department. He serves as one of two full-time psychologists on staff, and acts as an expert witness involving legal issues with children that includes the psychological capacity of the parents or caregivers. Over his career, he has accumulated an extensive work history across the life span with severely and persistently mentally ill clients, as well as developmentally disabled children and adults. He has also served as an adjunct lecturer at Henry Ford Community College since 2008 where he has implemented a non-traditional approach to teaching psychology that has been met with great enthusiasm and positive student outcomes.

Richard completed his Bachelor's degrees at the University of Michigan, Dearborn campus in 1996, but shortly thereafter took a break from his educational pursuits to begin a family with his wife, Fay, with whom he will celebrate 20 years of marriage, and five beautiful children together in 2014. He has described Fay as his rock and the best soul mate, wife, mother, and friend that a person could wish for. Richard went on to complete his Master's degree in School and Community Psychology at Wayne State in 2004, at which point he also decided to pursue his doctoral studies. The rest as they say, is history. His passions are his family, music, travel, the outdoors, kickboxing, and bringing others to a better understanding of psychology and its applications across multiple domains.