THE RELATIONSHIP BETWEEN PSYCHOSOCIAL FACTORS, SELF-CARE

BEHAVIORS, AND METABOLIC CONTROL IN ADOLESCENTS

WITH TYPE 1 DIABETES

By

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Dissertation

Submitted to the Faculty of the

Graduate School of Vanderbilt University

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

in

Psychology

August, 2008

Nashville, TN

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DEDICATION

To my parents, Clarence and Barbara Ann Franklin,
and to my grandparents,
Annie Mae & Lloyd Madison Arrington, Sr.
Isiah and Estell Franklin
It is upon your shoulders and my ancestors' shoulders that I stand.

ACKNOWLEDGMENTS

TABLE OF CONTENTS

Page

Chapter

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Many advances have been made in the care of children and adolescents diagnosed with a chronic illness. Due to these advances, there are increasingly greater numbers of youth with special health care needs and chronic illness living into adulthood. Factors such as medical and scientific improvements, shifts in patient education and support, changes in public knowledge of childhood chronic illnesses, as well as an improved understanding of the association between psychosocial factors and health, have contributed to an increased quality of life for youth living with a chronic illness. For these youth, a number of interventions targeted towards increased physical and emotional health have been designed, implemented and evaluated within the research literature (Blum, 1991; Blum et al., 1993; Myers, 1992).

Type 1 Diabetes affects 1.7 per 1,000 school-aged children and is one of the most common chronic illnesses among children in the United States. About 150,000 children under 18 years, or about one in every 400 to 500, have diabetes (Centers for Disease Control, 2005). Type 1 Diabetes is a metabolic disease which results from a deficiency of insulin, a hormone that aids in the metabolic process (Diabetes Control and Complications Trial Research Group (DCCT), 1993, 1994). Studies show that balancing dietary intake, insulin, and physical activity, helps to control blood glucose and prevent or delay diabetes complications. This balance is maintained through a daily therapeutic regimen of monitoring dietary intake (specifically carbohydrates), administering the

1

proper level of insulin, exercising regularly, and monitoring blood glucose levels. The prescription of these daily self-management tasks in most recommended treatment regimens is complex and often unpleasant. Patients must be mindful of dietary restrictions and monitor dietary intake and exercise, monitor and record blood glucose several times daily, administer insulin two to four times daily, make insulin dosage adjustments based on diet and exercise, and be prepared to respond to hyper or hypoglycemia (Hanson et al., 1996).

Lack of care in regards to the regimen can lead to both immediate and long-term physiological complications. Immediate complications include hypoglycemia or diabetic ketoacidosis. Long term complications include, among other things, damage to the autonomic nervous and vascular systems. In addition to controllable factors (i.e. diet, exercise), there are a number of uncontrollable factors that impact blood glucose. Therefore, even when following a regimen appropriately, blood glucose is expected to vary. Variance in diabetic control may be attributable to genetic, biologic, and demographic factors, as well as characteristics of the insulin, diet, and exercise regimens combined (Harris et al., 2000).

Studies have examined the impact of diabetes education programs, family systems, personality traits, coping skills, as well as other factors on health outcomes such as metabolic control, quality of life, and longevity (Glasgow, Toobert & Gilette, 2001; Hahl et al., 2002; Weinger & Jacobson, 2001). Within this population, knowledge about the complex associations between these factors and health outcomes can, in turn, lay the foundation for improved education, intervention, and support.

Typically, for adults, 98% of diabetes care is provided by the patient. Therefore, it is important that, eventually, children and adolescent patients become the locus of control and decision-makers in the daily treatment of their illness. Additionally, with the evolution of diabetes care toward a more intensified regimen, assessing self-management has become more complex (DCCT, 1993, 1994; Harris, 2000). Development of self-care behaviors should be a gradual process where, over time, children acquire an expertise in the everyday management of their disease (Anderson & Rubin, 2002). This development comes from an awareness of their bodies and how they typically respond to different behaviors. More important than an inflexible diabetes regimen, is the ability to adapt preventive and responsive self-care behaviors to dietary, physical, and emotional changes.

> "Self-management encompasses the behaviors displayed by a patient … that are directed at the establishment, maintenance, and monitoring of diabetic control, as well as the prevention or correction of deviations from targeted blood glucose levels. It, therefore, emphasizes the amount, precision, and regularity of these behaviors rather than the degree to which the patient's behavior conforms to the prescribed ideals." (Harris et al., 2000, pg. 1301)

This process is difficult for many adolescent patients (and parents), and they typically report becoming frustrated by a seeming lack of control even when adhering to the regimen (Dashiff, 2003; Rubin & Peyrot, 2001; Wysocki, 1992). This is one of many factors included in a large area of research focused on examining barriers to the shift from childhood dependency to adult autonomy. In addition to adjustments in health care

provision and the prescribed regimen, this shift includes developmental, emotional, and behavioral processes. Knowledge of the factors that impact the progression towards autonomy in health management for children and adolescents with diabetes, helps researchers and practitioners understand the influence of chronic illness on normative developmental processes (Anderson & Rubin, 2002; DCCT, 1993, 1994; Myers, 1992).

Self-management in children (as opposed to adolescents/young adults) has not been a significant topic of study, primarily because the underlying assumption of many researchers is that children simply follow the directive of their parent(s). Parents typically rearrange patterns of family life to accommodate the demands of diabetes and establish rules of conduct for their child which will prepare the child for life with diabetes. Adolescents, however, are often perceived by researchers as a high-risk group because of their tendency toward self-management neglect, mismanagement, and poor metabolic control (Anderson et al., 1990; Dashiff, 2003; LaGreca, 1990; Law, 2002; Paterson & Thorne, 2000; Stewart, Emslie, Klein, Haus & White, 2005; Weissberg-Benchell et al., 1995). Studies indicate that, during adolescence, metabolic control often deteriorates and the risk of developing long-term complications seems to accelerate (Anderson et al., 1997; Wysocki, Green & Huxtable, 1989).

Practitioners often attribute adolescents' poor metabolic control with a lack of compliance. However, behavioral issues are not the only factors that affect blood glucose control during this stage of development. Research shows that the physiological changes of puberty, such as insulin resistance, as well as individual psychological factors, are also related to poor control (DCCT, 1993, 1994; Hamilton, 2002; Wolfsdorf, 2002).

Health researchers have criticized the medical field for failing to recognize that adaptation to chronic illness, including learning to self-manage the disease, is a developmental process. As mentioned, there is question as to what point youth should be taking responsibility of their own health care regimen and how families and youth should work together to gradually adjust the expectations of self-care. (Dashiff, 2003; Kelly, Kratz, Bielski & Rinehart, 2002; LaGreca, 1998) Especially with diabetes self-care, daily self-management tasks must be carried out not only consistently, but also with consideration of important variables that impact acute and chronic health. There is often a misfit between the developmental demands of the early young adult period and the responsibilities of diabetes self-management. Learning to identify who (parent or adolescent) is responsible for which regimen requirements, as well as at what point the adolescent begins to assume responsibility for his/her care, is an important issue on which many parents and clinicians disagree (Dashiff, 2003).

Clinicians have been shown to report greater expectations of self-care for younger patients than those of parents. In a survey of diabetes professionals (Wysocki, Meinhold, Cox & Clarke, 1990), practitioners reported that all diabetes-related self-care behaviors should be mastered (fully understood) by the age of fourteen. The physicians' recommended age ranges were all below those endorsed by the American Diabetes Association. Researchers suggest that perhaps these expectations might be inappropriate for diabetes self-care autonomy. Metabolic control problems are more likely when children are given self-care responsibilities that they are not yet able to handle competently (Delameter, 2002; LaGreca, 1998). Some researchers feel that clinicians may expect the physically mature young adult to readily accept the demands of managing

diabetes without giving significant consideration to the developmental context that affects the patients' self-care behaviors (Wolpert, 2002).

Additionally, certain self-management behaviors (e.g. insulin adjustment) are highly dependent on maturity rather than age. Research studies which have examined motivations behind parents' transitioning of self-care responsibility to their children have found that the process of transition is not always based on cognitive maturity or demonstration of self-care behaviors, as would be expected, but rather the most common underlying motivation for transition is typically age, regardless of differences in level of maturity or knowledge of diabetes. Even more surprising is the finding that a withdrawal of the parents' responsibility for diabetes care is often not matched by an increase in adolescent self-care behaviors (Follansbee, 1989; Ingersoll, Orr, Herrold & Golden, 1986; Palmer et al., 2004). Studies have shown that adolescents with physical disabilities or chronic illness have a difficult time discussing or explaining their illness, providing the names of medications they are taking, and describing their long-term therapeutic goals (Dashiff, 2003; Wysocki, Taylor et al., 1996). Failure to make a smooth and gradual transition, especially during early adolescence, can have significant detrimental consequences.

Ideally, by the time a child reaches adolescence, he or she will have gradually assumed responsibility for primary self-care behaviors, such as insulin administration and glucose monitoring, with support from both the family and healthcare team. However, as mentioned, in families where maximal self-care autonomy is encouraged and expected, metabolic control may decrease (Wysocki, Taylor et al., 1996). Studies have examined various aspects of self-care behaviors for children and adolescents, seeking to understand

what hinders families from the idealism of gradual and appropriate transition. While researchers (Anderson, 1997; Wysocki, 2002; Wysocki, Taylor et al., 1996) caution families and practitioners from encouraging total independence on the part of the adolescent, they recognize that failure to support autonomy in the adolescent may constrain the adolescent from assuming developmentally appropriate responsibility and may have a negative emotional consequence for the adolescent (Wysocki, Meinhold et al., 1996).

Diabetes self-management behaviors are influenced by a number of personal and psychosocial factors. The timing and the success of the transition towards autonomy in self-care will depend on developmental readiness, complexity of the illness, characteristics of the adolescent and family, and the availability of health providers familiar with the unique issues of adolescence (Ahmed & Ahmed, 1985; Anderson & Rubin, 2002; Dashiff, 2003; Grey & Thurber, 1991; Hamp, 1984; Kelly, Kratz, Bielski, & Rinehart, 2002; Myers, 1992; Reis & Gibson, 2002; Tercyak, 2005; Thompson & Gustafson, 1996). It is this complex interrelationship of physical, interpersonal and social dimensions of childhood/adolescent diabetes that makes it difficult to manage, and it is important for adolescents, their families, and healthcare teams, to understand to what degree these factors affect successful transition to autonomy in their health management behaviors. The adoption of ideals for "optimal diabetes control," and acceptance of newly developed techniques for achieving and maintaining control, place great demands for adherence and responsible self-care on the child or adolescent with diabetes and his/her family (Ahmed & Ahmed, 1985). It is especially important for youth with Type 1 diabetes because of the dependence of their health on a constant monitoring of symptoms

and treatment. Researchers describe the important element of transition to be the "attitudes and abilities required to act as the primary causal agent in one's life and to make choices regarding one's actions free from undue external influence or interference" (Bremer, 2003, pg. 1). Accordingly, guidelines for independent self-care should take into account individual circumstances and traits. This process is not a universally consistent process and proceeds at differing rates for different individuals and families.

The importance of self-care as an independent health variable is that it has been linked, even in adolescents, to metabolic control (Hanson et al., 1996; Stewart, 2005). It is also clear that, over time, metabolic control is a significant predictor of diabetes-related complications (DCCT, 1993, 1994). Self-care and adherence have been measured traditionally as a single construct, however, patients may adhere to some aspects of the diabetic regimen more than others and certain aspects of the regimen (e.g. dietary compliance) may relate more closely to metabolic control than others (Burroughs, 1993; Hanson et al., 1996). As mentioned, the most important aspects of adherence may relate to the dynamic, rather than the static, aspects of self-care – the ability to respond to change in diet, exercise, and other aspects of the environment (Johnson, 1995; La Greca et al., 1995).

Capabilities needed to gain autonomy are most effectively learned through experience, which involves taking risks, making mistakes and reflecting on outcomes. These experiences help adolescents to become aware of and test their strengths and limitations and identify their short and long-term goals. The promotion of choice-making, risk-taking, problem-solving, self-advocacy skills, development of self-esteem and goal setting are all important factors in successful transition. Adolescents must be

8

permitted, and at times encouraged, to take an increasingly more active role in their health care and often require support and intervention to become independent managers of their health (Johnson, 1995; Kelly, Kratz, Bielski, & Rinehart, 2002; Streissand & Mednick, 2006).

Psychological Factors

All illnesses share some sources of psychological impact (Grey & Thurber, 1991; Thompson & Gustafson, 1996). Recent studies of illness in children suggest that the particular illness has less to do with the psychological reaction than do a number of psychological dimensions that cut across illnesses. Nevertheless, Type 1 Diabetes, as compared to some other illnesses, has unique characteristics which require sustained and systematic efforts, on the part of the patient, to monitor and manage the illness. At the time of diagnosis, and during the first few months of adjustment, the child and family typically need a lot of psychological support to deal with what is often seen as a medical crisis (Lazarus & Folkman, 1984; Rubin & Peyrot, 2001). The first year, especially, can be a considerably acute period when distress is at its highest. It is difficult for parents and children to learn to master new skills and figure out how to integrate diabetes management into their life (Delameter, 2002). In most cases, maladaptive reactions subside within the first year, however, if adjustment problems persist, there is a greater risk for later problems with psychosocial adjustment and metabolic control (Kovacs, 1990; Lernmark, 1999).

It is evident that psychosocial factors are considered an important component of, and have a great impact on, both metabolic control and appropriate development for

youth with Type 1 Diabetes. One of the primary goals of adolescence for all children is the gradual progression from dependence toward autonomy in all areas of life, including health management and self-care. This gradual progression can often be a difficult road with unexpected barriers and obstacles, especially for families and adolescents who have the additional burden of managing a chronic illness. It is to be expected that, often, the movement through this process (or the lack of movement) has significant behavioral and psychological impacts.

Without planning, guidance, and appropriate intervention, the intrusive and pervasive nature of diabetes and its impact on daily life may evoke maladaptive emotional or behavioral responses in the child and his family. These responses might vary, as clinical studies show that, compared to non-diabetic controls, diabetic adolescents report an increase of behavioral and adjustment problems (Ahmed & Ahmed, 1985) as well as an increase in depressive and anxious symptoms (Delemater, 2002). Studies have also shown that children with a chronic illness rate quality of life as significantly lower than community samples of healthy children (Sawyer et al., 2004). Psychiatric disorders have been shown, in some studies, to be more common in both adolescents and young adults with Type 1 diabetes than in healthy controls (Mayou, Peveler, Davies, Mann, & Fairburn, 1991; Moussa et al., 2005; Peyrot, 2002). Specifically, depression and adjustment disorders seem to be more common among adolescents with diabetes than among their peers. Appropriately, research shows that mental health services are increasingly available as a cornerstone of health services and intervention (Delameter, 2002; Scal, Evans, Blozis, Okinow & Blum, 1999).

There are also studies, however, (Bussing & Hillevi, 1996; Jacobson et al., 1987; Simonds, 1977) that have found no differences between the psychological well-being of adolescents with diabetes, healthy controls or children with other chronic illnesses. Some studies have also have found the psychological well-being of patients with diabetes to be within normal range even when scores on psychological measures are significantly higher than healthy controls (Tercyak, 2005). Some researchers suggest that, while Type 1 Diabetes is a risk factor for psychological disorders in adolescents, the majority of patients do "well" (Grey, Boland, Yu, Sullivan-Bolyai, & Tamboralane, 1998; Kovacs, 1990).

Adolescents who are having difficulty adjusting psychologically may find it nearly impossible to maintain active self-care, thus dramatically increasing the risk for acute and chronic complications. Studies show that resolving depression in individuals with diabetes generally improves metabolic control (Rubin, 2002). Since psychological distress increases the risk for future complications due to its association with metabolic control, studies have been conducted to identify characteristics of children with diabetes who are at risk for psychological distress, in order to provide preventive interventions at an early stage (Moussa et al., 2005). These studies have examined the relationship between psychological factors and long-term self-care adherence and metabolic control.

A study by Bryden (2001) examined the clinical and psychological course of diabetes from adolescence to young adulthood and the relationship between psychological state in adolescence and later diabetes outcomes. In this study, the authors found that there were associations between baseline psychological problems and follow-up metabolic control. They also found that adolescent behavioral problems of

aggression, delinquent behaviors, and attention problems were associated with poorer metabolic control (Bryden et al., 2001; Leonard, Jang, Savik, Plumbo & Christensen, 2002). Other studies (Van Tilburg et al., 2001) also show a significant positive correlation between depression and metabolic control for patients. Findings also show that one component of self-care, 'reported frequency of self-monitoring of blood glucose,' also contributed to the relationship between depression scores and HbA1c in patients with Type 1 Diabetes. This self-care behavior was a partial mediator between depressive symptoms and metabolic control. Another study (Jacobson et al, 1990) indicated that psychosocial variables, including patient coping, were associated with regimen adherence (diet, insulin adjustment and metabolic monitoring) four years after the initial assessment.

Although general psychological and individual factors have been examined, diabetes and depression, specifically, have become increasingly linked in both adult and pediatric populations, and in patients with both Type 1 and Type 2 diabetes (deGroot, 1999; Lustman et al., 2000). The incidence of depression in adolescents with diabetes is especially concerning (Kanner, 2003; Massengale, 2005). The significance of this link lies in the quality of life experienced by the adolescent patient, but also in the direct impact of depression on both short-term and long term health outcomes (Lernmark, 1999). Some studies suggest that, in youth, approximately 20% of the variance in metabolic control is statistically explained by depression (Grey, Whitmore & Tamborlane, 2002).

The mechanisms behind this link are still in debate. Many clinicians believe that compliance to the medical regimen is the important link between depression in youth

with diabetes and metabolic control, while others endorse various physiological explanations. Within the literature, a number of mechanisms have been examined. The increased incidence of depression in patients with diabetes has been attributed to hormonal changes, pubertal insulin resistance, the demand of increasing autonomy, adjustment and adaptation, neuropsychological impacts of depression on memory/diabetes self-care knowledge, persistent sub-threshold depression's effect on adherence, and the effect of negative attitudes associated with diabetes self-care (Grey, Davidson et al. 1998; Harris, 2003; Hamilton, 2002; Kanner, 2003; Massengale, 2005; Thomas, 1997). In adults, the hypothesis that self-care mediates the relationship between depression and hyperglycemia has been supported in some studies (McKellar, 2004), and not supported in others (Lustman, 2005). A number of studies have also examined the psychophysiological factors that have been shown to link certain aspects of depression and diabetes, including hormones and blood glucose responsiveness (Levenson, 2006; Sachs, 1993), hippocampbal formation and memory deficits (McEwan, 2002; Soutor, 2004) and neuroimmunologic mechanisms (Sabharwal, 2005). However, many of these studies have been done in adults.

Learned helplessness has also been investigated as a contributing factor in both metabolic control as well as regimen adherence (Kuttner, Delamater, and Santiago, 1990). Children and adolescents who experience repeated uncontrollable and non-contingent events and perceive few environmental contingencies are more likely to report depressive symptoms (Hoff, 2005). It is understandable that demands associated with diabetes may influence the personal salience of contingencies, however, little is known about how these beliefs affect the development of depressive symptoms in children with

diabetes. Results show that younger children may view outcomes as depending on their own behavior to a greater degree than older children. This may be because older children have more fully developed abstract reasoning skills, which may enable them to recognize more external factors. In studies of learned helplessness, although learned helplessness has been shown to be significantly associated with depression and metabolic control, it has not been associated with regimen adherence (Kuttner, Delameter & Santiago, 1990). Studies examining the mediating role of self-care in this association would help to clarify the relationships (Grey, Whittmore & Tamborlane, 2002).

The task of recognizing and diagnosing psychological disorders in patients with diabetes can be problematic. Bodily symptoms from negative emotions may intermingle with symptoms from physical illness, augmenting the experience of poor health. Many of the symptoms of hyperglycemia and hypoglycemia overlap with sensations that are frequently experienced as a part of anxiety and depression, such as fatigue, weakness, tenseness, pounding heart, fast pulse, queasy stomach, and changes in appetite (Lange & Piette, 2005; Peyrot, 2002). It is important to identify, at an earlier age, those patients and families at special risk, and to help them develop strategies which will optimize both physical and psychological health (Drash, 1979).

A number of psychological interventions have been utilized with adolescents with Type 1 diabetes, including peer group interventions, family interventions, nondirective supportive treatment, cognitive behavior therapy, and pharmacotherapy (Kanner, Hamrin, & Grey, 2003; Massengale, 2005). A meta-analysis of psychological intervention research in patients with Type 1 diabetes shows evidence that psychological interventions positively impact metabolic control in children and adolescents, although the effect is

small. However, psychological intervention, in this study, was found to have no impact on adults with Type 1 diabetes. The success of psychological intervention in children, as compared to adults, may be explained by higher levels of psychological distress in children and their families and the greater effectiveness of family therapies for children and adolescents as compared to individual therapies (Winkley, 2006).

Family Dynamic

Family dynamic is also an important part of understanding self-care and metabolic control for children and adolescents. Diabetes has been referred to as a "family disease" because of the importance of family support for disease management (LaGreca et al., 1995, 1998) and a number of studies have examined the significant influence of family dynamics on metabolic control, treatment adherence, as well as other factors, such as quality of life and psychosocial adaptation. Although a few studies (Gowers, 1995; Kovacs, 1989) do not report an association of family dynamic on adherence or metabolic control, the majority of studies, both cross-sectional and longitudinal, do indicate that the relationship between family dynamic, treatment adherence, and metabolic control is significant and stable across time (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Anderson, Miller, Auslander, & Santiago, 1981; Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004; Cohen, 1999; Dashiff, 2003; Dashiff, Bartolucci, Wallander, & Abdullatif, 2005; Drotar, 1997; Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998; Jacobson et al., 1994; LaGreca et al., 1995; Miller-Johnson et al., 1994). These studies highlight the importance of communication around diabetes responsibilities (Anderson, Auslander, Jung, Miller & Santiago, 1990),

supportive family functioning as it relates to the diabetes regimen (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998), and family cohesion (Cohen, Lumley, Naar-King, Partridge & Cakan, 2004).

As with any chronic illness, the individual's family may play an integral role in encouraging and providing support for treatment-related behaviors (LaGreca, 1998). Diabetes may require families to redistribute responsibilities, modify daily routines, and renegotiate family roles (Pendley et al., 2002). In addition to illness-specific behaviors, general family function factors, which covary with illness-specific behaviors, have also been shown to have a unique impact on health outcomes. These general family dynamic factors include both distal (e.g. parental marital satisfaction) and proximal (e.g., parent-child conflict) relations. Both general and illness-specific functioning are significantly associated with regimen adherence and psychosocial adaptation, two important health outcomes (Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992).

The quality of family relationships may influence adherence and the development or absence of coping skills in response to emotional distress. Family dysfunction has been found to negatively impact a child's metabolic control, likely mediated by poor adherence. In general, the literature suggests that children with more structured, cohesive, and supportive family environments are in better control of their diabetes (Cohen, Lumley, Naar-King, Partridge & Cakan, 2004; Hauser, 1990). However, certain studies also report that perceived family support is significantly positively correlated with parent-report of diabetes conflict. The authors explain that this is likely due to the fact that greater family involvement around diabetes tasks causes greater conflict simply because of the increased interaction. There may also be different interpretations between

parents and youth regarding what supportive vs. conflictual behaviors are (Pendley et al., 2002).

In a focus group analysis, adolescents reported parental worry and intrusive behaviors, parental lack of understanding and blaming behaviors, and the parent's focus on the future vs. the adolescent's focus on the present, as sources of diabetes related conflict (Weinger, 2001). However, adolescents vary substantially in their individual perceptions of what constitutes supportive behaviors. (La Greca et al., 1995). Although adolescents report that most supportive behaviors are 'emotional,' rather than behavioral, support related to daily management tasks has been shown to be most closely related to adherence (LaGreca & Bearman, 2002). Studies also indicate that older adolescents report less diabetes-specific support from their families than younger adolescents, even when accounting for diabetes duration (La Greca et al., 1995; LaGreca & Bearman, 2002). When considering the association of family dynamic with self-care and metabolic control, the implications of age differences are significant.

Summary

The passage from childhood to young adulthood can be a time of emotional and psychological turmoil, which, for the child with diabetes, is made even more overwhelming by the presence of a chronic illness. Research examining the impact of psychological factors on self-care in adolescents is rarely found in the literature. There is debate about whether the pathways are predominantly physiological or behavioral, whether this differs individually, and how these factors impact each other. Research on

psychological factors and self-care for adolescents is not as common as studies which examine metabolic control as the primary health outcome.

Metabolic control and self-care are undoubtedly linked, but should be examined distinctly. Self-care may be an important factor in the relationship between psychological adjustment and metabolic outcomes and may be impacted either by an increase in maladaptive care behaviors or a decrease in appropriate care behaviors for children and adolescents learning to assume responsibility for their illness. Additionally, family and healthcare provider responses to psychological factors might impact the level of responsibility that is recommended or expected of the adolescent. More research examining these dynamics will be necessary to form conclusions about these relationships. Independent disease management, for most youth, will come involuntarily with age. Regardless of the degree of metabolic control, youth with diabetes will become adults with diabetes, and the responsibility for self-care will shift. An understanding of how factors facilitate or impede the success of this developmental shift is essential.

Research Hypotheses

1.   Age/Maturity: Based on literature examining the shift in self-care with age, it is hypothesized that the level of self-care will increase with both age and maturity. However, it is also hypothesized that metabolic control will decrease with age due to the impact of physical, psychological, and behavioral changes during adolescence.

2.   Psychosocial Factors: It is hypothesized that significant associations will be found between psychological factors, family dynamic, self-care behaviors, and metabolic control. Specifically, it is hypothesized that higher levels of psychological distress and

lower levels of family supportiveness will be associated with decreased self-care and with a higher HbA1c.

3.   Self-care as a mediator: It is hypothesized that, after controlling for demographic variables and family dynamic, self-care behaviors will mediate the relationship between psychological factors and metabolic control.

4.   Age/Maturity as a moderator: It is hypothesized that, after controlling for demographic variables and family dynamic, there will be a significant difference in the association between psychological factors and both self-care behaviors and HbA1c, dependent upon age and maturity. It is expected that older patients, and more mature patients, will have a stronger association between psychological and health variables because of the increased developmental demands.

Theoretical Model

        The theoretical model that will be examined in this study (see Figure 1) depicts the hypothesized relationships. This model illustrates several important components which are based upon both previous research studies and current hypotheses. Psychological adjustment has been shown to be associated with metabolic control, but has less often been examined in the context of self-care. Here, it is hypothesized to impact metabolic control, however, this relationship is hypothesized to be mediated by self-care behaviors. The relationship between psychological adjustment and both self-care and metabolic control is also hypothesized to be moderated by age/maturity. It is hypothesized that psychological factors may have a more significant impact on older vs. younger adolescents and on more mature vs. less mature adolescents. Additionally,

although family dynamic is not examined as an independent/dependent variable of interest in this study, it is an important covariate in considering each of the associations and must be considered. The social/family context of child and adolescent patients has been shown to be highly correlated with both their psychological adjustment and with measures of self-care and metabolic control. This study controls for family dynamic to ensure that significant relationships are not due to its confounding effect on the variables of interest.
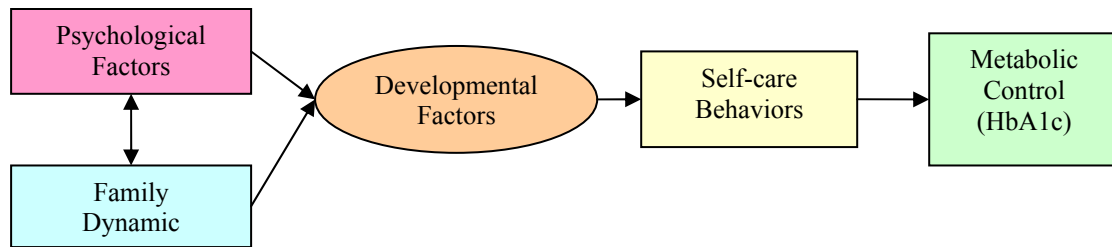
Figure 1: Theoretical Model

CHAPTER II

METHODS

Participants

Participants in this study included 102 adolescents diagnosed with Type 1 Diabetes and their parents/guardians. Adolescent participants were 10-18 years of age. The age range chosen for this study is optimal because it targets a lower bound age (10 years old) where adolescents may begin to take on a large part of their diabetes responsibilities as well as an upper bound age (18 years old) where most adolescents should be autonomous in their self-care. Additionally, it was thought that physicians and parents would be less comfortable with allowing younger children to participate in a research study examining psychosocial factors in a medical setting. Due to the nature and complexity of the research questions, younger children may have been at a higher risk of discomfort. Additionally, children below 10 years of age may have a limited understanding of the content of the questionnaires, and some of the measures included may not be appropriate for children under the age of 10. Including young adults (ages 19-25) in this study would also have been informative, however, patients in this age group typically experience a rapid amount of change in many areas of life (i.e. graduating high school or college, leaving home, gaining employment, etc.) and it would be difficult to compare the life and family environments of young adults who are developing and establishing lives independent of their families, to that of adolescents.

Adolescents were excluded if they had been diagnosed with Type 1 Diabetes for less than one year. Research shows (Rubin & Peyrot, 2001; Lazarus & Folkman, 1984) that the initial year following diagnosis of a chronic illness is a difficult one, and individuals who are still coping with adjustment issues may show disproportionately high rates of psychological distress, as well as self-care behaviors that are not consistent with the sample or age group. Other researchers have taken the same approach of excluding those with recent onset of illness from the study.

Adolescents were also excluded if either they, or their parents, were unable to read and speak English. Additionally, adolescents with other serious chronic illnesses were excluded from this study in order to eliminate the confounding influence of the effects of having multiple chronic illnesses. Patients with juvenile rheumatoid arthritis, cystic fibrosis, cancer, cerebral palsy, muscular dystrophy, sickle cell anemia, and any nervous system disorders were excluded. For the adolescent's participation, both parental informed consent and adolescent informed assent were obtained. Parents also gave informed consent for their own participation in the research study.

Recruitment and Data Collection

Recruitment of participants took place at the Vanderbilt University Medical Center - Eskind Pediatric Diabetes Clinic. Parents of patients were either presented with an information postcard upon check-in or were approached by the researcher and given a brief explanation of the study. Those willing to participate in the study were screened for inclusion/exclusion criteria. This process took place in the waiting area, prior to the

scheduled clinic appointment. Informed consent/assent information was presented

verbally, and in writing, to both the patient and his/her parent. It was explained to

participants that they were being asked to participate in a research study examining

"Emotions and Type 1 Diabetes" and that the study was targeted towards adolescents. It

was also explained that all information given remained confidential and would not be

provided to the physicians or staff of the diabetes clinic. Participants were asked to fill

out surveys (described below) addressing psychosocial factors and routine self-care

behaviors and also gave consent for the researcher to access their HbA1c, a measure of

metabolic control, from their medical chart.

Care was taken to ensure that data was handled confidentially. All

parent/guardian and adolescent measures were both administered and collected by the

primary investigator. Medical Center faculty and staff did not have access to data at any

time. The measures took approximately 5 to 20 minutes to complete. Both parent

participants and patient participants were compensated with a $5 gift card to Target

stores.

Measures

Specific measures used in this study included: the Reynolds's Adolescent

Depression Scale, 2nd edition (RADS-2), the Problem Areas in Diabetes Scale (PAID),

the Diabetes Family Behavior Checklist (DFBC), the Psychosocial Stage Inventory (PSI),

the Self-Care Inventory (SCI), the Diabetes Family Responsibility Questionnaire

(DFRQ), the Diabetes Independence Survey (DIS), and HbA1c, a measure of metabolic

control. Demographic information was also collected. Each of these measures is described below.

Adolescent-Report Measures

   Reynolds Adolescent Depression Scale – 2nd Edition. The Reynolds Adolescent Depression scale, 2nd edition, was developed to evaluate the severity of depressive symptoms in adolescents aged 11-18 years old. The RADS-2 is a 30-item scale with a Likert style response format ranging from "almost never" to "most of the time." Items assess somatic, motivational, cognitive, mood, and vegetative components of depression. The RADS-2 requires a 3rd grade reading level. Norms for the RADS-2 are based on samples of over 2,000 adolescents in grades 7-12 and have been determined to be robust based on similar mean scores in a number of research studies (Reynolds, 1994).

   Scores on the RADS-2 range from 30 to 120 with a score of 77 used as a cutoff to define a "clinically relevant" level of depressive symptomatology. This score has been validated in several studies, using both Hamilton Depression Rating Scale scores and formal diagnoses based on the Schedule for Affective Disorders and Schizophrenia (Reynolds, 2002; Reynolds & Evert, 1991). Reliability of the RADS-2 has been high with both normal and depressed adolescents.

   The validity of the RADS-2 has also been established in studies that examine relationships with other depression scales and measures of related constructs. The RADS-2 has been shown to be strongly correlated with the Beck Depression Inventory, the Center for Epidemioligic Studies - Depression Scale, several other self-report

depression measures, and semi-structured clinical interviews of depression (Reynolds, 1994, 2002; Reynolds & Evert, 1991).

Problem Areas in Diabetes Scale. The Problem Areas in Diabetes Scale was developed as a unique measurement of diabetes-related psychosocial distress (Polonsky et al., 1995). The survey includes 20 items rated on a five-point Likert scale, reflecting the degree to which the item is perceived as problematic and has been utilized with participants ranging from ages 13-60 years. Reliability and validity testing show that the PAID is positively associated with other relevant psychosocial measures of distress, including general emotional distress, disordered eating, fear of hypoglycemia, short and long-term diabetic complications and HbA1c. These studies also show that the PAID is negatively associated with self-care behaviors, and has been found to be a unique contributor to 'adherence to self-care behaviors' after adjustment for age, diabetes duration, and general emotional distress. The PAID is also associated with HbA1c even after adjustment for age, diabetes duration, general emotional distress, and adherence to self-care behaviors.

Psychometric reports have shown that the PAID has consistently high internal reliability ($\alpha = .95$), sound test-retest reliability ($r = .83$), correlates strongly with a wide range of theoretically related constructs such as general emotional distress, depression, diabetes self-care behaviors, diabetes coping, and health beliefs. It also significantly predicts metabolic control and shows responsiveness in studies assessing sensitivity of the measure to change across intervention studies (Welch, Jacobson & Polonsky, 1997; Welch, Weinger, Anderson & Polonsky, 2003).

Diabetes Family Behavior Checklist. The Diabetes Family Behavior Checklist is

an instrument designed to assess both supportive and non-supportive family behaviors

that may influence adherence to the treatment regimen (Schafer, McCaul & Glasgow,

1986). The scale was designed to be completed by individuals with Type 1 Diabetes

between the ages of 12 and 64, and their family members, but has been utilized in

adolescents as young as 8 years old (Lewin et al, 2005). This scale is distinguished from

other family environment scales because it assesses family interactions specific to the

diabetes self-care regimen. The DFBC assesses family behaviors that may support or

interfere with the appropriate conduct or timing of four regimen behaviors: insulin

injection, glucose testing, diet, and exercise.

The current version of the scale consists of 16 questions with 9 positive

(supportive) and 7 negative (non-supportive) items and approximately equal numbers of

items for each regimen component. Items are scored on a 5-point Likert scale. Internal

reliability of the measure for the adolescent sample was $\alpha = .63$ for the

positive/supportive items and $\alpha = .60$ for the negative/unsupportive items. The authors

state that the low level of internal consistency was due, in part, to two items (sleeping

late, eating different foods) that were conceptualized as being non-supportive, but were

actually considered by respondents as supportive. The authors also assert, however, that

the summary scores are comprised of family behaviors related to diverse aspects of the

diabetes self-care regimen, so a high internal consistency is not necessarily desirable.

Coefficient alphas reported for internal consistency using adolescent and parent reports

range from $\alpha = .63$ to .85 for the supportive scale and from $\alpha = .60$ to .82 for the non-

supportive scale. Test-retest reliability for the supportive scale was adequate for a 6-month interval across respondents in previous research (r = .60 & .75) (Ott, Greening, Palardy, Hoderby & DeBell, 2000; Schafer, McCaul & Glasgow, 1986).

Self-care Inventory. The Self-care Inventory (SCI) is a retrospective questionnaire which measures regimen adherence (LaGreca, 2004). This 14-item measure was developed to assess patients' perceptions of the degree to which they adhere to treatment recommendations for their diabetes self-care. Respondents rate adherence over the preceding 1-month period on a 5-point Likert scale, with higher scores indicating increased adherence to the self-care regimen. On the SCI, self-care is defined as the daily regimen tasks that the individual performs to manage diabetes. The SCI includes items that focus on blood glucose testing and monitoring, insulin and food regulation, exercise, and emergency precautions (e.g. carrying sugar to treat reactions).

The SCI, unlike measures that assess the frequency of certain adherence behaviors, is not based on a "presumed" or "ideal" regimen. The SCI allows for the possibility of varying treatment regimens across individuals and evaluates individuals' perceptions of how well they adhere to their individual treatment prescriptions. It has been demonstrated that high scorers on the SCI show significantly better metabolic control. Additionally, the SCI has been shown to predict levels of metabolic control independently from measures of anxiety and depression. Internal consistencies for the SCI items have been reported to be high (α = .80 or higher) in several studies of children and adolescents. Test-retest reliability has also been shown to be sufficient (r = .77) over a 2-4 week period (LaGreca, 2004). The author of this scale recommends that all 14

items of the questionnaire be administered but that seven items be used in calculating overall adherence scores (LaGreca, 2004). Items not included in the summary score are thought to be rarely reported (ketone testing) or almost uniformly endorsed (appointment keeping).

Erikson Psychosocial Stage Inventory. The Erikson Psychosocial Stage Inventory (PSI) is a self-report questionnaire developed to assess the first six of Erikson's psychosocial stages (Rosenthal, Gurney & Moore, 1981). Development of this measure arose from the need for a measure of Erikson's psychosocial stages suitable for administration to a large sample of participants in early and late adolescence. The PSI has six subscales based on the first six of Erikson's stages. Each subscale has 12 items, half of which reflect successful and half unsuccessful resolution of the "crisis" of the stage. Respondents are asked to mark each item (5-point scale) on a Likert scale ranging from "almost always true" to "hardly ever true." Although the PSI includes six total subscales, only three will be utilized in this study. These include the identity, autonomy, and industry subscales. These specific subscales have been utilized as measures of maturity that show a greater internal consistency than other similar measures (Galambos, 2003).

Internal reliability coefficients were uniformly high across all subscales on pilot samples (n = 97) with a range from α = .73 to .81. On test data (n = 622), the alpha coefficients were slightly lower but acceptable, ranging from α = .57 to .75. Subscales of this measure show significant positive correlations with other measures of psychosocial

maturity, such as the Greenberger Psychosocial Maturity Index (Greenberger &

Sorenson, 1974).

Parent-Report Measures

Demographic information, including the age and grade of the adolescent, family

income, racial/ethnic background of adolescent, length of illness, etc., was collected from

the parent/guardian.

Diabetes Independence Survey. The parent version of the Diabetes Independence

Survey (DIS) measures parents' perceptions of their children's mastery of 38 diabetes

self-care skills (Wysocki, Meinhold et al., 1996). It asks the parent to indicate "yes" or

"no" to questions asking "does or can your child…." carry out a variety of daily regimen

and self-care behaviors. It has been utilized with samples ages 3-18. It was developed to

assess diabetes knowledge and skill among children and adolescents and has been used as

a screening tool to help detect developmentally inappropriate levels of IDDM self-

management skills. Internal consistency was reported as $\alpha = .91$, and no differences were

observed in internal consistency between parents of younger (<11 years old) and older (>

11 years old) children. For children in the test sample that had measures from both

parents (n = 26) there was a .78 correlation between the two parents' scores. DIS scores

were also found to be positively correlated (r = .71) with age. Concurrent measure

analyses also showed significant positive associations (r = .79 to .82). The authors

suggest that the DIS could be used as a research tool in studies of maturation of diabetes

self-care autonomy and of the causes and correlates of deviation from age-appropriate self-management (Wysocki, Meinhold et al., 1996).

Diabetes Family Responsibility Questionnaire. The Diabetes Family Responsibility Questionnaire (DFRQ) measures family division of responsibility for 17 aspects of the diabetes regimen (Anderson, Auslander, Jung, Miller & Santiago, 1990). The DFRQ was developed to be used as a research tool for children with diabetes, ages 6-21, and their parents. The DFRQ can be used to highlight perceptions of the division of responsibility across a broad range of diabetes management tasks. Participants rate each treatment task on a three-point scale as a parent, child, or shared responsibility. Higher scores indicate greater child/adolescent responsibility.

The three subscales include regimen tasks (hypoglycemia-related and injection-related), general health maintenance, and social communication or presentation of diabetes. Internal reliability on normative test data ranged from $\alpha = .69$ to .78 on individual scales and $\alpha = .85$ for the total scale (Anderson, Auslander, Jung, Miller & Santiago, 1990; Wysocki, Taylor et al., 1996).

Metabolic Control. Good metabolic control is usually defined as having a normal glycosylated, or glycated, hemoglobin level. Glycated hemoglobin, or HbA1c, is considered the gold standard for long term metabolic control and is widely used for patients with diabetes. HbA1c reflects the average blood glucose level over the past two to three month period and is the primary indicator of whether an individual with diabetes is maintaining good control over their blood glucose level. HbA1c has been shown to be

linearly related to the development of severe short and long-term complications. Medical management of diabetes aims to keep HbA1c as close to the normal range as possible (4% - 7%), with lower levels reflecting better metabolic control. The DCCT showed that, in patients with Type 1 diabetes, the risk of long term complications was reduced significantly when patients maintained an average HbA1c of 7.2% (DCCT, 1993, 1994; Wdowik, 1998). Patients with diabetes typically have HbA1c measured at each clinic visit. With consent to access the patient's medical records, the HbA1c associated with the visit at which the questionnaires were completed was obtained.

Depression/Suicide Risk Plan

Because of the use of the RADS-2, a tool used to identify children at risk for depression, it was important to have a plan to identify and respond to indicators of depressive symptomatology for participants in this study. To identify depressive symptomatology, a cutoff score of 77 is often utilized to indicate significant depressive symptomatology. In this study, if an adolescent scored at or above the cutoff score of 77, the primary investigator sent a letter to the family with an explanation of the score results. The parent was encouraged, within the letter, to talk to his/her child about these symptoms and was advised that it might be helpful for the child to talk to a mental health professional. A list of mental health resources within the local community was also provided.

Measurement Model

The measurement model, illustrated below (see Figure 2), shows how each of the measures were hypothesized to fit into the theoretical model. Psychological factors were measured by the Problem Areas in Diabetes Scale (diabetes-related distress) and the Reynolds Adolescent Depression Scale-2 (adolescent depression). Family dynamic/supportiveness was measured by the Diabetes Family Behavior Checklist. In order to examine developmental factors, age was included as a variable, as well as psychosocial maturity, as measured by the Psychosocial Stage Inventory, an adolescent-report measure. Self-care behaviors were assessed by the Diabetes Independence Survey (self-care independence/ability), the Diabetes Family Responsibility Questionnaire (parent vs. adolescent responsibility) and the Self Care Inventory (regimen adherence). Finally, metabolic control was measured by HbA1c, which was retrieved from the patient's medical chart.
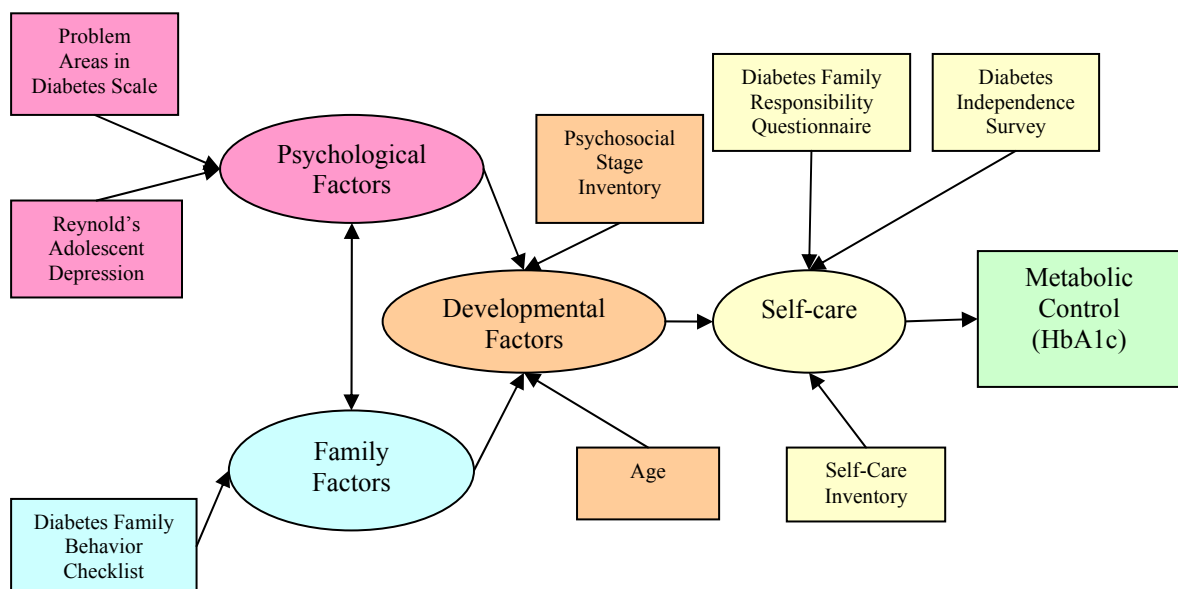

Figure 2: Measurement Model

Data Analysis

 Descriptive Tests. Mean scale scores for each of the measures were used in all data analyses. Initial data analyses examined descriptive statistics and sample characteristics, such as frequencies, means and cross-tabulations. Analyses also examined demographic group differences on each of the psychosocial and health outcome variables.

 Age/Maturity Analyses. The association of age and maturity with self-care behaviors and metabolic control were examined using bivariate correlation analyses.

 Psychosocial Factors Analyses. To test the hypothesis that psychosocial factors were related to the health outcomes examined in this study, partial correlation analyses, controlling for age, gender, race, and family income were conducted. Analyses examined the associations of adolescent depression, diabetes-related psychosocial distress, and family dynamic, with each of the three self-care variables and metabolic control.

 Mediating Effects. Several hierarchical regression models were examined to test the hypothesis that self-care behaviors mediate the relationship between psychological factors and HbA1c (Baron & Kenney, 1986). The initial step of each regression model included age, race/ethnicity, family income, gender, and family dynamic (DFBC). Categorical variables were coded as binary variables (dummy coded) when included in the regression analyses. The analyses aimed to test whether the association between psychological factors (RADS-2/PAID) and HbA1c was mediated by any of the self-care

variables (SCI/DFRQ/DIS). The first model tested the association between the

psychological variables and the self-care variables. The second model tested the

association between the psychological variables and HbA1c. The third model tested the

change in the association between psychological factors and HbA1c, while accounting for

self-care behaviors. Examining this change would indicate whether self-care was a

significant mediator. Each of the psychological factors was tested with each of the self-

care factors individually, creating six unique tests of mediation. Demographic

characteristics, mentioned above, were controlled for in each of these regression models.

Moderating Effects. Hierarchical regression was also used to test whether age or

maturity moderated the association of psychological factors with self-care and metabolic

control (Baron & Kenney, 1986). As in other regression analyses, demographic and

patient factors (age, gender, race/ethnicity, family income, and family dynamic (DFBC))

were included in the first step of the analyses and categorical variables were coded as

binary variables (dummy coded) when included in the regression analyses. Age was

included in the second step, as a main effect, instead of the first step, when testing age

interaction effects. The second step included the psychological factor (RADS-2 or

PAID) and the developmental factor (age or PSI), which were the main effects of interest.

The final step included a cross-product interaction term used to test moderation. Cross-

product interaction terms have been shown to be highly correlated with the corresponding

simple independent variables in the regression equation, creating problems with assessing

the relative importance of main effects and interaction effects. Therefore, each of the

continuous variables was mean-centered in order to control for multicolinearity (Cohen,

Cohen, West, & Aiken, 2003). A cross-product of the mean-centered values was used to create the interaction term (e.g. RADS-2 x age). Each of the psychological factor and age/maturity combinations were included in separate analyses for each the self-care (SCI/DFRQ/DIS) and HbA1c variables, which required eight unique tests for the age moderation hypothesis and eight unique tests for the maturity moderation hypothesis.

CHAPTER III

RESULTS

Sample Characteristics

A total of 102 adolescents were included in the study sample. Data from four participants was excluded due to diagnosis duration of less than one year. Therefore, the final total sample size was 98 participants. Of these participants, there were 51 females and 47 males. Eighty-seven percent of adolescents in the sample were Caucasian, 9.2% were African-American, and 2% were Native Hawaiian/Pacific Islander. The mean age for the sample was 14.32 ($\pm$ 2.29) and the mean duration of diagnosis was 6.26 ($\pm$ 3.83) years. The mean HbA1c was 8.93 ($\pm$ 1.88). The average family income was between $35,000 and $55,000 per year (see Table 1).

ANOVA and correlation analyses examined differences across socio-demographic variables (age, race/ethnicity, gender, family income) on each of the psychosocial variables, self-care variables, and HbA1c. In examining scores on the RADS-2, females scored significantly higher than males ($p < .05$). Females also showed a non-significant trend for increased scores on the PAID ($p < .07$). On the DFRQ, there were significant differences dependent upon both age and race. There was a significant positive relationship between age and DFRQ indicating that older adolescents were more responsible for their self-care behaviors ($p < .001$). African-Americans had lower scores on the DFRQ, compared to other racial/ethnic groups, indicating that the parent/family was taking more responsibility with their diabetes ($p < .05$). On the DIS, there was a

significant positive relationship with age (p < .001), indicating that older adolescents had

more independence or ability in their self-care behaviors. On HbA1c, there were

significant differences by race and income. African-Americans had a significantly higher

HbA1c than other ethnic groups (p < .001). Additionally, there was a significant negative

relationship between income and HbA1c, indicating that adolescents in lower family

income groups had significantly poorer metabolic control (p < .01). There were no

significant socio-demographic differences on the DFBC, which measures family

dynamic/supportiveness, or the SCI, which measures regimen adherence.

	Female		Male		Total	
	Mean	SD	Mean	SD	Mean	SD
Demographic Information						
Age	14.36	2.43	14.28	2.15	14.32	2.29
Grade	8.80	2.32	8.41	2.04	8.62	2.19
Years Diagnosed	6.49	3.61	6.02	4.08	6.27	3.83
Family Income [a]	51.1K	23.8K	50.1K	22.5K	50.6K	23.1K
HbA1c	8.73	1.72	9.16	2.05	8.94	1.89
Adolescent Report Measures						
Reynolds Adolescent Depression Scale - 2	1.70	0.51	1.52	0.36	1.61	0.45
Problem Areas in Diabetes Scale	1.98	0.77	1.71	0.63	1.85	0.72
Diabetes Family Behavior Checklist [b]	3.18	0.72	3.24	0.59	3.21	0.66
Psychosocial Stage Inventory	12.02	1.76	12.64	1.61	12.32	1.71
Self-Care Inventory	3.66	0.71	3.78	0.67	3.72	0.69
Parent Report Measures						
Diabetes Family Responsibility Questionnaire [c]	2.04	0.35	1.99	0.29	2.02	0.32
Diabetes Independence Survey	1.87	0.12	1.84	0.14	1.86	0.13

[a] family income ranked on Likert scale ranging from 1 to 5, with 1 < $15K, and 5 > $75K
[b] higher scores indicate a more supportive family environment
[c] higher scores indicate a greater level of adolescent autonomy

Age/Maturity Associations

Correlation analyses examined the relationships of age and maturity with each of the self-care variables, as well as HbA1c. Age was found to be positively associated with the DIS (p < .001) and DFRQ (p < .001) scores indicating that, for older patients, the parent reported a higher level of independence and ability in adolescent self-care activities and greater adolescent responsibility for these behaviors. There were no associations, however, with age and either the SCI or HbA1c. In examining PSI scores, which indicate a level of psychosocial maturity, higher scores on this scale were associated with increased SCI scores and DIS scores, indicating more regimen-adherent behaviors and more ability/independence in diabetes self-care. Psychosocial maturity was not associated with DFRQ scores but was negatively associated with HbA1c (p < .05), indicating that more mature adolescents reported better metabolic control (see Table 2).

Table 2: Bivariate Correlations for Age/Maturity Analyses

		Self-Care Inventory	Diabetes Family Responsibility	Diabetes Independence	HbA1c
Age		-0.13	**0.53****	**0.32****	-0.11
	Sig.	0.21	0.00	0.00	0.29
Psychosocial Stage Index (Maturity)		**0.50****	0.10	**0.28****	**-0.21***
	Sig.	0.00	0.32	0.01	0.04

** p ≤.005, *p ≤ .05

Psychosocial and Health Associations

Due to demographic group differences on psychosocial and health variables, demographic variables were controlled for in partial correlation analyses examining the

relationship of psychosocial variables with self-care variables and HbA1c. These analyses accounted for age, gender, race, and family income. The RADS-2 and PAID scores were found to be negatively associated with the SCI and the DIS, indicating that adolescents who reported higher depression scores and increased diabetes related distress were more likely to have less regimen-adherent behavior and less ability/independence in their diabetes care. There was no association of the RADS-2 or PAID with the DFRQ scores or HbA1c.

Scores on the DFBC, which indicate the level of family 'supportiveness' with regard to the diabetes regimen, were associated with higher scores on the SCI and the DIS. Additionally, as with the RADS-2 and the PAID, there was no association between DFRQ scores and HbA1c (see Table 3).

Table 3: Partial Correlations for Psychosocial and Health Outcome Variables†

		Self-Care Inventory	Diabetes Family Responsibility	Diabetes Independence	HbA1c
Reynolds Adolescent Depression Scale		**-0.45****	-0.02	**-0.29***	0.02
	Sig.	0.00	0.85	**0.01**	0.82
Problem Areas in Diabetes		**-0.52****	-0.07	**-0.27***	0.16
	Sig.	0.00	0.52	**0.01**	0.12
Diabetes Family Behavior Checklist [a]		**0.58****	-0.03	**0.27***	-0.03
	Sig.	0.00	0.82	**0.01**	0.76

[a] Higher scores indicate a greater degree of family supportiveness
†Partial correlations controlling for age, race, gender and family income
** $p \leq .005$, * $p \leq .05$

Self-care Mediation Hypothesis

Several hierarchical regression equations were conducted to test the association between psychosocial variables, self-care, and HbA1c, in order to determine whether

self-care was a significant mediator of the relationship between psychological factors and HbA1c. Each of the regression analyses controlled for age, race, gender, family income, and family dynamic (DFBC) in the first step of the regression model.

Initial results indicated that, after accounting for demographic/family variables, the RADS-2 and PAID were both significantly associated with only the SCI, and not with the DFRQ and the DIS. Additionally, neither psychological variable was significantly associated with HbA1c. Therefore, mediation of the relationship between psychological factors and HbA1c could not be examined within this study (see Table 4). Although not a direct step in testing mediation, another important result was the examination of the association between self-care and metabolic control, independent of psychological factors. Regression and correlation analyses indicated that independently, and after accounting for demographic variables and family dynamic, neither of the self-care variables was significantly associated with HbA1c.

Dependent Variable	Step 1 R^2 Change†	Sig.	Independent Variables	Step 2 R^2 change‡	Standardized Beta	Sig.
Psychological factors predicting Self-Care						
SCI	**.374**	**.000**	RADS-2	**.027**	**-.199***	**.050**
			PAID	**.058**	**-.294***	**.004**
DFRQ	**.361**	**.000**	RADS-2	.000	-.012	.909
			PAID	.000	-.003	.975
DIS	**.191**	**.003**	RADS-2	.027	-.199	.083
			PAID	.014	-.144	.220
Psychological factors predicting HbA1c						
HbA1c	**.405**	**.000**	RADS-2	.000	.006	.952
			PAID	.012	.132	.188
Psychological factors and self-care predicting HbA1c						
HbA1c	**.411**	**.000**	RADS-2	.019	.005	.958
			SCI		-.074	.494
			DFRQ		.089	.423
			DIS		. 101	.321
			PAID	.029	.128	.226
			SCI		-.037	.740
			DFRQ		.084	.448
			DIS		.110	.270

†Step 1: Includes race, gender, age, family income and family dynamic
‡Step 2: These values indicate the incremental R^2 change and Beta weights for the independent variables after controlling for age, race, gender, family income and family dynamic
** p $\leq$. 005, *p $\leq$ .05

Age/Maturity Moderation Hypothesis

Moderation hypotheses examined whether either age or psychosocial maturity was a significant moderator of the relationship between psychological factors and each of the health outcomes, including self-care variables and HbA1c. Results indicated that age was not a significant moderator between the psychological and health variables. Maturity, however, was a significant moderator for the relationship between the PAID, which measures diabetes-related psychosocial distress, and both HbA1c ($p < .05$) and DIS scores ($p < .05$).

In order to examine the significance of the associations between the PAID and the associated dependent variable, either HbA1c or DIS, at each level of the moderator, the simple slopes for each regression line were divided by its standard error and tested against the t-distribution (df = n-k-1 = 94; $\alpha = .05$, two tailed; $t_{critical} = 1.987$). For both the PAID/HbA1c analyses and the PAID/DIS analyses, there was not a significant relationship between the independent and dependent variables at any level of the moderator.

In examining HbA1c scores, examination of the regression lines for various levels of maturity indicate that, for "high" maturity scores, there is a stronger positive association between psychosocial distress and HbA1c than for "medium" scores. For "low" maturity scores, there is a slight negative relationship, indicating that, at this maturity level, higher scores on the PAID are associated with better metabolic control. In examining the moderating effect of maturity on DIS scores, the direction of the relationship between PAID and DIS scores changes from a negative relationship to a positive relationship as scores on the PSI increase (see Table 5, Figures 3 & 4).

43

It seems that the significant moderating effect of the PSI variable is more related to the changes in the strength and even the directions of the associations between the PAID and both HbA1c and DIS scores. However, it does not change the significance of the relationships, as there is not a particular maturity level group at which there was a significant relationship between the PAID and either HbA1c or DIS scores.

Table 5: Hierarchical Regression Testing Age/Maturity Moderation Hypotheses †

Dependent Variable	Independent Variable	Step 3 R^2 change	Standardized Beta	Sig.
SCI	RADS-2 x Age	.002	-.043	.673
	PAID x Age	.003	.063	.530
	RADS-2 x PSI	.007	.094	.322
	PAID x PSI	.005	.085	.365
DFRQ	RADS-2 x Age	.000	-.015	.871
	PAID x Age	.007	-.091	.339
	RADS-2 x PSI	.000	-.005	.961
	PAID x PSI	.000	.006	.955
DIS	RADS-2 x Age	.000	.003	.979
	PAID x Age	.003	-.066	.543
	RADS-2 x PSI	.024	.176	.102
	PAID x PSI	**.050**	**.258**	**.017***
HbA1c	RADS-2 x Age	.003	.063	.486
	PAID x Age	.001	-.030	.745
	RADS-2 x PSI	.021	.168	.074
	PAID x PSI	**.030**	**.202**	**.032***

†Step 1 of analysis controlled for gender, race/ethnicity, family income, and family dynamic (DFBC). Age was also included in Step 1 for maturity analyses, but was included in step 2 for age interaction analyses. Step 2 included tests of main effects. Step 3, indicated above, tested for interaction effects.
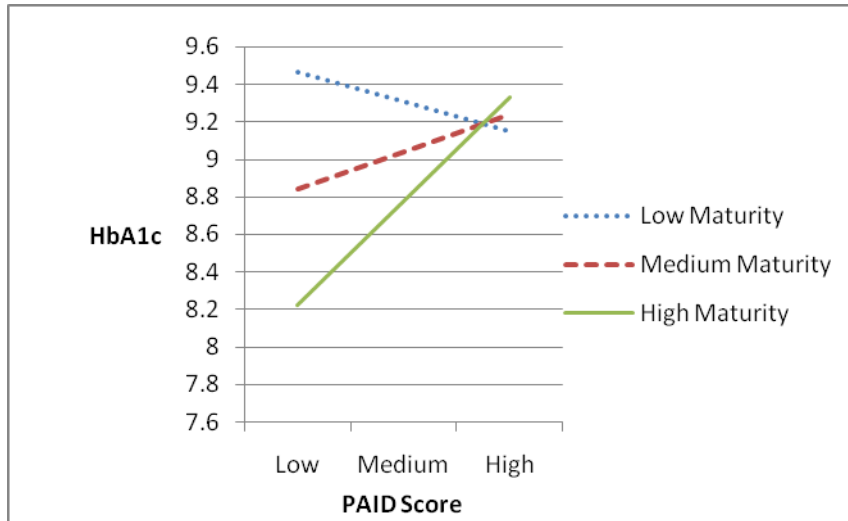**p<.005, *p<.05

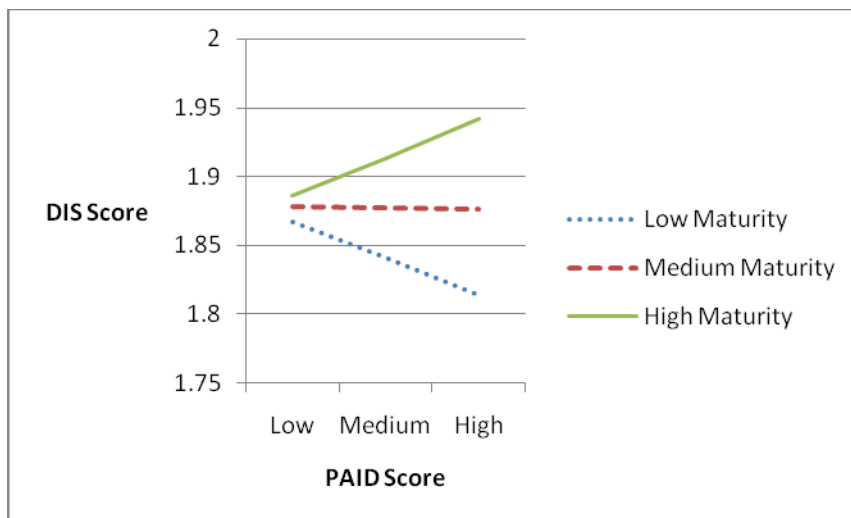**Figure 3: Maturity Moderates PAID/HbA1c Association**

Figure 4: Maturity Moderates PAID/DIS Association

CHAPTER IV

DISCUSSION

This research study focused on identifying and clarifying the relationship between psychosocial factors, self-care, and metabolic control for adolescents with Type 1 Diabetes. In order to analyze psychosocial factors, measures of depression, diabetes-related distress, and family dynamic were included in the study. Three different measures of self-care were also included. The SCI, an adolescent report measure, identified the level of regimen-adherent behaviors. The DFRQ and DIS, both parent report measures, identified adolescent vs. parent responsibility for regimen behavior and adolescent ability to perform self-care behaviors, respectively. HbA1c, which is a standard measure of metabolic control, indicating blood glucose levels for the past two to three months, was also included. Socio-demographic variables were reported by the parent. The PSI, an adolescent report measure of psychosocial maturity, was also included to provide information, in addition to age, related to the adolescent's level of development.

Hypothesis Testing

The first hypothesis addressed the relationship between age, maturity, self-care behaviors, and metabolic control. These hypotheses were partially confirmed. Age was found to be associated with both parent-report measures of self-care, including the DFRQ, which measures adolescent responsibility for self-care, and the DIS, which

46

measures self-care ability and independence. Age was not, however, associated with HbA1c or the SCI, a measure of regimen adherence. Maturity was associated with the DIS as well as with the SCI. Maturity was also, interestingly, shown to be negatively associated with HbA1c. Generally, it was found that age and maturity were associated with more regimen-adherent behavior, more adolescent responsibility, more self-care ability and lower HbA1c. However, it is of note that the age/maturity associations do not overlap entirely, indicating that these variables measure distinct constructs related to adolescent development. Additionally, post-hoc analyses examined the association between age and maturity. It was determined that age and maturity, in this sample, were not significantly correlated ($r = .024$, $p < .90$). Possible reasons for the lack of relationship between these theoretically related variables are discussed below.

The second hypothesis addressed the relationship between each of the psychosocial variables with self-care behaviors and HbA1c. Socio-demographic variables, including age, race, gender, and family income, were controlled for in partial correlation analyses. Generally, it was found that each of the psychosocial variables was associated with the SCI and the DIS, indicating that adolescents who were more depressed and more distressed about their diabetes exhibited less regimen adherent behaviors and fewer abilities in their self-care management. Adolescents who described their household as more supportive were also found to have more regimen-adherent behaviors and more self-care ability. There was no relationship between the psychosocial variables and either the DFRQ or HbA1c.

Due to the lack of relationship of either of the psychological factors (RADS-2/PAID) with HbA1c, the mediation hypotheses could not be tested. Regression analyses

did confirm that, after accounting for demographic variables and family dynamic, the RADS-2 and PAID were associated with the SCI, as also indicated in the correlation analyses. However, the relationships between these factors and HbA1c were not significant, which eliminated the possibility of testing the mediation analyses. It is important to note, however, that self-care may mediate the relationship between psychological factors and HbA1c in samples/studies in which this relationship is significant. It is interesting that, despite past evidence that psychological factors are related to metabolic control, this was not found in this sample. Although this may be due to a true lack of relationship between these factors, it is also likely that study limitations and sample characteristics, both discussed below, may have contributed to the lack of association in this study.

It is also interesting that self-care and HbA1c, independent of psychological variables, were found to be unassociated in this sample. For the DIS scores, this could be associated with the restricted range and ceiling effect, which is discussed in detail below. For the DFRQ, a strong association between these factors might not be expected since adolescent or parent responsibility might not necessarily be associated with better metabolic control, or even consistent self-care. If there was an association between DFRQ scores and HbA1c, based on previous research, it would be more likely that higher scores would be associated with poorer metabolic control since parent responsibility, rather than adolescent responsibility, is typically associated with better care. The fact that there is no association with the SCI and HbA1c is less expected and contradicts previous research. However, it does raise the question, again, of the impact of external factors and uncontrollable physiological factors occurring in adolescence that contribute

to metabolic control, and the significance of measuring self-care distinctly as an important health outcome.

In this study, maturity provides a different way of examining how developmental factors impact psychosocial and health variables, distinct from age. In testing moderation, it was found that maturity, but not age, was a significant moderator of the relationship between the PAID and both HbA1c and DIS scores. This finding indicates that the association between the PAID and health variables depends on the maturity level of the adolescent. In examining the relationship between PAID and HbA1c scores, there is a slight negative relationship between PAID and HbA1c scores for "low" scores on the PSI. The relationship between the PAID and HBA1c for "medium" and "high" scores are both positive, but stronger in the "high" maturity group. Although the negative relationship between PAID and HBA1c in the "low" maturity group was unexpected, the stronger positive relationship in the "high" compared to the "medium" maturity group was hypothesized. The mechanisms through which these associations occur, however, are still unclear. It is especially complex in light of the lack of association between self-care and HbA1c in this sample.

In examining the relationship between PAID and DIS scores, the change in the direction of the relationship as scores on the PSI increase, from a negative to a positive relationship, was not expected, and is somewhat counter-intuitive, especially for "high" scorers on the PSI measure. It was hypothesized that the strength of the relationship would increase with scores on the PSI, but a positive relationship between psychosocial distress and independence/ability was not expected. Despite the fact that DIS is the dependent variable in this analysis, the true direction of the association (and any bi-

49

directional impact) complicates the picture. It may be that psychosocial distress is

positively impacting increased ability/independence, which seems less likely, or that it is

the impact of increased ability/independence that is related to increased diabetes-related

distress. It is also important to note that, in both moderation analyses, although the

directions of the relationships change, the strength of the relationships are not statistically

significant at any level of maturity. Additionally, it should be noted that the PAID is a

measure of diabetes-related psychosocial distress, rather than depression. Therefore, it

could be that the distress experienced by these adolescents propels them to engage in

increased self-care.

Theoretical Model

In re-examining the hypothesized theoretical model, it is clear that while some

relationships have been supported within this study, many of the more significant

hypothesized relationships were not found. In examining psychological factors, it seems

that the diabetes-related measure of psychosocial distress (PAID) was a stronger

predictor of health outcomes and HbA1c than the depression measure (RADS-2).

Neither of these measures, however, was found to be associated with metabolic control.

In examining developmental factors, psychosocial maturity (PSI) was found to be more

strongly associated with each of the psychosocial and self-care measures than age. This

indicates the importance of independently examining individual aspects of development

in future studies rather than relying upon age as the only developmental variable. In

examining self-care measures, it was interesting that unique relationships were found

between each construct, indicating that it is important to examine various facets of

adolescent behavior when assessing self-care. It was also determined that self-care is not likely, at least in some adolescents, to be the primary pathway between psychological factors and metabolic control.

Limitations

There were several significant limitations of this study. First, as with all cross-sectional research, it is impossible to determine causality. This is especially important with these particular variables, which have been shown to be significantly inter-related. A longitudinal study would undoubtedly provide more insight into the direction of the relationship between psychosocial and health variables. A longitudinal design would also help to clarify the temporal relationship between these factors. Time may be a significant component in understanding the association between psychological factors and health outcomes. For example, there may be significant differences in the impact of psychological factors on health outcomes dependent upon the length of time that the adolescent has experienced symptoms of depression or distress. Additionally, if health outcomes, specifically metabolic control, impacts psychological distress, it may be that this occurs over a significant period of time.

Another limitation of this study, that was not anticipated, is the possible selective sample. This study was conducted within a specialty clinic at a teaching hospital. While the average family income was between $35-55,000, 33.7% (the modal response) of the families reported an average family income of over $75,000. This sample may not be reflective of the average income for most families of children with Type 1 Diabetes. Additionally, this specialty clinic was included within a medical center which has a

51

number of resources (social work and psychological consultation, dieticians, etc.) which may not be available for patients within a community setting, patients who are being seen through primary care/non-specialty clinics, or patients who are not receiving regular medical care. Patients who have been seen at this clinic for many years may have received, or be aware of, a variety of physical health, mental health and social resources.

In addition to limitations of the design and sample, there are also limitations related to the measures utilized within this study. Due to the age range selected for this study, it was difficult to find measures of interest that were appropriate for the full age range of adolescents included in this sample (10-18 years). The RADS-2 was created for 11-18 year olds, while the DFBC and the PAID had an age range beginning at 12-13 years old. Therefore, there could be some differences in scores for 10 and 11 year olds that are based on the appropriateness of these measures for these ages. Additionally, as mentioned earlier, in examining the PSI measure, it was found that age and maturity were not significantly correlated ($r = .024$, $p < .90$). This raises the question of whether the maturity measure is an accurate indication of the level of development. Because of the fact that this measure is a 'psychosocial' measure of maturity, it may have been more highly correlated with the corresponding measures of psychosocial factors than expected, rather than 'independent' developmental factors (although overlap is to be expected).

Some measures included in the study had restricted ranges or floor/ceiling effects that may have impacted the associations examined in the present study and resulting interpretations. The RADS-2 scores in this sample were approximately ten points lower for both males and females, when compared to the RADS-2 school-based normative sample ($n = 9, 052$ students) indicating that patients had lower scores and indicated fewer

depressive symptoms than their peers. In addition, DIS scores in this sample, were

comparatively high and had a small range. This may be due to the wide age range with

which the scale is typically used (3-18 years old) compared to the age range in this

sample. Normative data indicate age groups at which 25, 50 and 75% of parents respond

affirmatively to the item. Of the 38 items, 20 items have a 75% or higher response rate

for age groups of 10 or younger. Scores on each of the other measures was determined to

approximate normative scores, or scores indicated in other study samples.

Given unlimited resources, it would also have been helpful to have parent and

adolescent report data for each of the measures. Because the focus of the study was on

individual factors in the adolescent, the majority of the measures were adolescent report.

However, this raises questions regarding whether the associations, or lack of associations,

between some factors are due, in part, to consistency across measures or differences in

reporting that are due to the particular respondent (parent/adolescent).

Implications

Findings of this study are significant because they indicate that the expected

associations between depression, self-care, and HbA1c are not found in all samples.

Each of these independent relationships have been found in some studies and have been

absent in others. This confirms the findings of some researchers who assert that the link

between psychological distress and HbA1c is not easily understood or explained.

This study also indicates the importance of looking at many aspects of self-care.

For adolescents, their ability to perform self-care behaviors, their consistency in adhering

to their regimen and their responsibility for their self-care varies greatly. Each of these

factors is shown to have distinct associations with psychosocial and demographic variables. As mentioned, none of the self-care behaviors were associated with HbA1c. There were, however, associations between the self-care measures. The DIS was positively associated with the SCI ($r = .246$, $p < .05$) and the DFRQ ($r = .472$, $p < .001$). The DFRQ and SCI were not significantly correlated. Although certain self-care measures were associated, they allowed a closer investigation of various aspects of self-care and offer distinct contributions to understanding adolescent health behaviors.

This study also indicates the significance of considering socio-demographic variables, as well as family dynamic, in examining these relationships. For several variables, including gender, race, and income, there were significant differences in mental and physical health variables. Family income was, perhaps, the most significant demographic variable associated with health outcomes. Correlation analyses indicate a strong negative association between family income and Hba1c. Future research should focus on community populations or populations which represent a range of socio-economic status. In examining socio-demographic differences, it would be important to determine the mechanisms for the association between family income and HbA1c ($r = -.465$, $p < .001$)

Finally, future research should continue to focus on identifying, longitudinally, the causal agents that are related to the association between depression, diabetes-related psychosocial distress, and metabolic control. Many researchers have targeted self-care as the mediator, however, others have targeted physiological or external variables (family, peer group) as more significant correlates and predictors. The significance of understanding these relationships, considering both the strength and direction of these

associations, will impact treatment approaches. Most significantly it will determine

where treatment should begin, although treatment will undoubtedly consist of both

medical and psychological approaches. A better understanding of these corresponding

treatments will help to focus and target intervention on the most salient psychological,

social, and behavioral factors.

REFERENCES

Ahmed, P. I., & Ahmed, N. (Eds.). (1985). *Coping with juvenile diabetes*. Springfield: Charles C. Thomas.

Anderson, B., Ho, J., Brackett, J., Finkelstein, D., & Laffel, L. (1997). Parental involvement in diabetes management tasks: Relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *The Journal of Pediatrics, 130*(2), 257-265.

Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology, 15*(4), 477-492.

Anderson, B. J., Miller, J. P., Auslander, W. F., & Santiago, J. V. (1981). Family characteristics of diabetic adolescents: Relationship to metabolic control. *Diabetes Care, 4*(6), 586-594.

Anderson, B. J., & Rubin, R. R. (2002). *Practical psychology for diabetes clinicians* (2nd ed.). Alexandria, VA: American Diabetes Association.

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*(6), 1173-1182.

Blum, R. W. (1991). Overview of transition issues for youth with disabilities. *Pediatrician, 18*(2), 101-104.

Blum, R. W., Garell, D., Hodgman, C., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. *Journal of Adolescent Health, 14*(7), 570-576.

Bremer, C. D., Kachgal, M., & Schoeller, K. (2003). Self-determination: Supporting successful transition. *Research to Practice Brief: Improving Secondary Education and Transition Services through Research, 2*(1), 1-6, Retrieved August, 26, 2004 from http://www.ncset.org/publications/researchtopractice/ NCSETResearchBrief_2.1.pdf

Bryden, K., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood. *Diabetes Care, 24*(9), 1536-1540.

Burroughs, T. E., Pontious, S. L., & Santiago, J. V. (1993). The relationship among six psychosocial domains, age, health care adherence, and metabolic control in adolescents with IDDM. *Diabetes Educator, 19*(5), 396-402.

Bussing, R. A., & Hillevi, A. (1996). Youth with chronic conditions and thier transition to adulthood: Findings from a Finnish cohort study. *Archives of pediatrics and adolescent medicine, 150*(2), 181-186.

Centers for Disease Control - National Center for Chronic Disease Prevention and Health Promotion (2005). Diabetes public health resource. Retrieved April 5th, 2007, from http://www.cdc.gov/diabetes/projects/cda2.htm#5

Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3rd ed.). Mahwah, New Jersey: Lawrence Erlbaum Associates.

Cohen, D. M., Lumley, M. A., Naar King, S., Partridge, T., & Cakan, N. (2004). Child behavior problems and family functioning as predictors of adherence and glycemic control in economically disadvantaged children with Type 1 diabetes: A prospective study. *Journal of Pediatric Psychology, 29*(3), 171-184.

Cohen, M. S. (1999). Families coping with childhood chronic illness: A research review. *Family Systems and Health, 17*(2), 149-164.

Dashiff, C., Bartolucci, A., Wallander, J., & Abdullatif, H. (2005). The relationship of family structure, maternal employment, and family conflict with self-care adherence of adolescents with Type 1 diabetes. *Families, Systems, and Health, 23*(1), 66-79.

Dashiff, C. J. (2003). Self and dependent-care responsibility of adolescents with IDDM and their parents. *Journal of Family Nursing, 9*(2), 166-183.

deGroot, M., Anderson, R., Freedland, K. E., Clouse, R. E., & Lustman, P. J. (2001). Association of depression and diabetes complications: A meta-analysis. *Psychosomatic Medicine, 63*(4), 619-630.

Delamater, A. M. (2002). Working with children who have Type 1 diabetes. In B. J. Anderson & R. R. Rubin (Eds.), *Practical psychology for diabetes clinicians* (2nd ed., pp. 127-138). Alexandria, VA: American Diabetes Association.

Diabetes Control and Complications Trial Research Group. (1994). Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes control and complications trial. *The Journal of Pediatrics, 125*(2), 177-188.

Diabetes Control and Complications Trial Research Group (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *The New England Journal of Medicine, 329*(14), 977-986.

Drash, A. L. (1979). *The child with diabetes mellitus.* Paper presented at the Behavioral and Psychosocial Issues in Diabetes, Madison, WI.

Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology, 22*(2), 149-165.

Follansbee, D. S. (1989). Assuming responsibility for diabetes management: What age? What price? *The Diabetes Educator, 15*(4), 347-352.

Glasgow, R. E., Toobert, D. J., & Gillette, C. D. (2001). Psychosocial barriers to diabetes self-management and quality of life. *Diabetes Spectrum, 14*(1), 33-41.

Gowers, S. G., Jones, J. C., Kiana, S., North, C. D., & Price, D. A. (1995). Family functioning: A correlate of diabetic control? *Journal of child psychology and psychiatry, and allied disciplines, 36*(6), 993-1001.

Grey, M., Boland, E., Yu, C., Sullivan-Bolyai, S. and Tamborlane, W. (1998). Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care, 21*(6), 909-914.

Grey, M., Davidson, M., Boland, E.A., Davidson, M., Yu, C., Sullivan, Bolyai, S., & Tamborlane, W.V. (1998). Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care, 21*(6), 902-908.

Grey, M., & Thurber, F. W. (1991). Adaptation to chronic illness in childhood. *Journal of Pediatric Nursing, 6*(5), 302-309.

Grey, M., Whittemore, R., & Tamborlane, W. (2002). Depression in type 1 diabetes in children: natural history and correlates. *Journal of Psychosomatic Research, 53*(4), 907-911.

Hahl, J., Hamalainen, H., Sintonen, H., Simell, T., Arinen, S., & Simell, O. (2002). Health related quality of life in type 1 diabetes without or with symptoms of long-term complications. *Quality of Life Research, 11*(5), 427-436.

Hamilton, J., & Daneman, D. (2002). Deteriorating diabetes control during adolescence: Physiological or psychosocial? *Journal of pediatric endocrinology & metabolism, 15*(2), 115-126.

Hamp, M. (1984). The diabetic teenager. In R. W. Blum (Ed.), *Chronic illness and disabilities in childhood and adolescence* (pp. 217-238). Orlando, FL: Grune & Stratton.

Hanson, C. L., De Guire, M. J., Schinkel, A. M., Henggeler, S. W., & Burghen, G. A. (1992). Comparing social learning and family systems correlates of adaptation in youths with IDDM. *Journal of pediatric psychology, 17*(5), 555-572.

Hanson, C. L., De Guire, M. J., Schinkel, A. M., Kolterman, O. G., Goodman, J. P., & Buckingham, B. A. (1996). Self-care behaviors in insulin-dependent diabetes:

Evaluative tools and their associations with glycemic control. *Journal of Pediatric Psychology, 21*(4), 467-482.

Harris, M. A., Wysocki, T., Sadler, M., Wilkinson, K., Harvey, L. M., Buckloh, L. M., Mauras, N, & White, N.H. (2000). Validation of a structured interview for the assessment of diabetes self-management. *Diabetes Care, 23*(9), 1301-1304.

Harris, M. D. (2003). Psychosocial aspects of diabetes with an emphasis on depression. *Current Diabetes Reports, 3*(1), 49-55.

Hauser, S. T. (1990). Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: II. Immediate and long-term linkages with the family milieu. *Journal of Pediatric Psychology, 15*(4), 527-542.

Hoff, A. L., Mullins, L. L., Page, M. C., Carpentier, M. Y., Chaney, J. M., & Hommel, K. A. (2005). The relationship of control-related beliefs to depressive symptomatology among children with type 1 diabetes and asthma: A disease-specific approach. *Children's Health Care, 34*(4), 261-272.

Ingersoll, G., Orr, D. P., Herrold, A. J., & Golden, M. P. (1986). Cognitive maturity and self-management among adolescents with insulin-dependent diabetes mellitus. *The Journal of Pediatrics, 108*(4), 620-623.

Jacobson, A. M., Hauser, S. T., Lavori, P., Willett, J. B., Cole, C. F., Wolfsdorf, J. I., Dumont, R.H., & Wertlieb, D. (1994). Family environment and glycemic control: A four-year prospective study of children and adolescents with insulin-dependent diabetes mellitus. *Psychosomatic Medicine, 56*(5), 401-409.

Jacobson, A. M., Hauser, S. T., Wolfsdorf, J. I., Houlihan, J., Milley, J. E., Herskowitz, R. D., Wertlieb, D., Watt, E. (1987). Psychologic predictors of compliance in children with recent onset of diabetes mellitus. *The Journal of Pediatrics, 110*(5), 805-811.

Jacobson, A. M., Hauser, S.T., Lavori, P., Wolfsdorf, J.I., Herskowitz, R.D., Milley, J.E., Bliss, R. & Gelfant, E. (1990). Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: I. The influence of patient coping and adjustment. *Journal of Pediatric Psychology, 15*(4), 511-526.

Johnson, C. P. (1995). Transition into adulthood. *Pediatric Annals, 24*(5), 268-273.

Kanner, S., Hamrin, V., & Grey, M. (2003). Depression in adolescents with diabetes. *Journal of child and adolescent psychiatric nursing, 16*(1), 15-24.

Kelly, A. M., Kratz, B., Bielski, M., & Rinehart, P.M. (2002). Implementing transition for youth with complex chronic conditions using the medical home model. *Pediatrics, 110*(6), 1322-1327.

Kovacs, M., Iyengar, S., Goldston, D., Stewart, J., Obrosky, D. S., & Marsh, J. (1990). Psychological functioning of children with insulin-dependent diabetes mellitus: A longitudinal study. *Journal of Pediatric Psychology, 15*(5), 619-632.

Kovacs, M., Kass, R. E., Schnell, T. M., Goldston, D., & Marsh, J. (1989). Family functioning and metabolic control of school-aged children with IDDM. *Diabetes Care, 12*(6), 409-414.

Kuttner, M. J., Delamater, A. M., & Santiago, J. V. (1990). Learned helplessness in diabetic youths. *Journal of Pediatric Psychology, 15*(5), 581-594.

LaGreca, A. M. (1990). Developmental and behavioral aspects of diabetes management in youngsters. *Children's Health Care, 19*(3), 132-139.

La Greca, A. M. (1998). It's "all in the family": Responsibility for diabetes care. *Journal of Pediatric Endocrinology and Metabolism, 11*(2), 379-385.

La Greca, A. M., Auslander, W. F., Greco, P., Spetter, D., Fisher, E. B., Jr., & Santiago, J. V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology, 20*(4), 449-476.

La Greca, A. M., & Bearman, K. J. (2002). The diabetes social support questionnaire-family version: Evaluating adolescents' diabetes-specific support from family members. *Journal of Pediatric Psychology, 27*(8), 665-676.

Lange, L. J., & Piette, J. D. (2005). Perceived health status and perceived diabetes control: Psychological indicators and accuracy. *Journal of Psychosomatic Research, 58*(2), 129-137.

Law, G. U., Kelly, T. P., Huey, D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role? *Journal of Adolescent Health, 31*(4), 381-385.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Company.

Leonard, B. J., Jang, Y. P., Savik, K., Plumbo, P. M., & Christensen, R. (2002). Psychosocial factors associated with levels of metabolic control in youth with type 1 diabetes. *Journal of Pediatric Nursing, 17*(1), 28-37.

Lernmark, B., Persson, B., Fisher, L., & Rydelius, P. A. (1999). Symptoms of depression are important to psychological adaptation and metabolic control in children with diabetes mellitus. *Diabetic Medicine, 16*(1), 14-22.

Levenson, J. L. (2006). Psychiatric issues in endocrinology. *Primary Psychiatry, 13*(4), 27-30.

Lewin, A.B., Geffken, G.R., Heidgerken, A.D., Duke, D.C., Novoa, W., Williams, L.B., Storch, E.A. (2005). The Diabetes Family Behavior Checklist: A Psychometric Evaluation. *Journal of Clinical Psychology in Medical Settings, 12*(4), 315-322.

Lustman, P. J., Anderson, R. J., Freedland, K. E., de Groot, M., Carney, R. M., & Clouse, R. E. (2000). Depression and poor glycemic control: A meta-analytic review of the literature. *Diabetes Care, 23*(7), 934-942.

Lustman, P. J., Clouse, R. E., Ciechanowski, P. S., Hirsch, I. B., & Freedland, K. E. (2005). Depression-related hyperglycemia in type 1 diabetes: A mediational approach. *Psychosomatic Medicine, 67*(2), 195-199.

Massengale, J. (2005). Depression and the adolescent with type 1 diabetes: The covert comorbidity. *Issues in Mental Health Nursing, 26*(2), 137-148.

Mayou, R., Peveler, R., Davies, B., Mann, J., & Fairburn, C. (1991). Psychiatric morbidity in young adults with insulin-dependent diabetes mellitus. *Psychological Medicine, 21*(3), 639-645.

McEwen, B. S., Magarinos, A. M., & Reagan, L. P. (2002). Studies of hormone action in the hippocampal formation: Possible relevance to depression and diabetes. *Journal of Psychosomatic Research, 53*(4), 883-890.

McKellar, J. D., Humphreys, K., & Piette, J. D. (2004). Depression increases diabetes symptoms by complicating patients' self-care adherence. *Diabetes Educator, 30*(3), 485-492.

Miller-Johnson, S., Emery, R. E., Marvin, R. S., Clarke, W., Lovinger, R., & Martin, M. (1994). Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of Clinical and Consulting Psychology, 62*(3), 603-610.

Moussa, M. A. A., Alsacid, M., Abdella, N., Refai, T. M. K., Al Sheikh, N., & Gomez, J. E. (2005). Social and psychological characteristics of Kuwaiti children and adolescents with type 1 diabetes. *Social Science and Medicine, 60*(8), 1835-1844.

Myers, J. (1992). *Transition into adulthood with a chronic illness focus: Insulin-dependent diabetes mellitus.* Unpublished Dissertation, University of Michicgan.

Palmer, D. L., Berg, C. A., Wiebe, D. J., Beveridge, R. M., Korbel, C. D., Upchurch, R., Swinyard, M.T., Lindsay, R., & Donaldson, D.L. (2004). The role of autonomy and pubertal status in understanding age differences in maternal involvement in diabetes responsibility across adolescence. Journal of Pediatric Psychology, 29(1), 35-46.

Paterson, B., & Thorne, S. (2000). Developmental evolution of expertise in diabetes self-management. Clinical Nursing *Research, 9*(4), 402-419.

Pendley, J. S., Kasmen, L. J., Miller, D. L., Donze, J., Swenson, C., & Reeves, G. (2002). Peer and family support in children and adolescents with type 1 diabetes. *Journal of Pediatric Psychology, 27*(5), 429-438.

Peyrot, M. (2002). Recognizing emotional responses to diabetes. In B. J. Anderson & R. R. Rubin (Eds.), *Practical psychology for diabetes clinicians* (pp. 211-218): American Diabetes Association.

Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics, 110*(6), 1307-1314.

Reynolds, W. M. (1994). Assessment of depression in children and adolescents by self-report questionnaires. In W. M. Reynolds & H. F. Johnston (Eds.), *Handbook of depression in children and adolescents* (pp. 209-234). New York: Plenum Press.Reynolds, W. M. (2002). *Reynolds adolescent depression scale - 2nd edition professional manual*. Lutz, FL: Psychological Assessment Resources, Inc.

Reynolds, W.M., & Evert, T. (1991). Efficacy of a multiple-gate screening strategy for identification of clinical levels of depressive symptomatolgy in adolescents. Unpublished manuscript.

Rubin, R., & Peyrot, M. (2002). Helping patients develop diabetes coping skills. In B. J. Anderson, Rubin, R.R. (Ed.), *Practical psychology for diabetes clinicians* (2nd ed., pp. 63-71). Alexandria, VA: American Diabetes Assocation.

Rubin, R. R., & Peyrot, M. (2001). Psychological issues and treatments for people with diabetes. *Journal of Clinical Psychology, 57*(4), 457-478.

Sabharwal, P., Simen, B. B., & Sanacora, G. (2005). Depressed diabetics: A neuroimmunologic syndrome? *Primary Psychiatry, 12*(5), 42-46.

Sachs, G., Spiess, K., Moser, G., & Kautzky, A. (1993). Hormonal and blood glucose responsiveness as an indicator of specific emotional arousal in type 1 diabetics. *Journal of Psychosomatic Research, 37*(8), 831-841.

Sawyer, M. G., Reynolds, K. E., Couper, J. J., French, D. J., Kennedy, D., Martin, J., Staugas, R., Ziaian, T., & Baghurst, P.A. (2004). Health-related quality of life of children and adolescents with chronic illness - a two year prospective study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 13*(7), 1309-1319.

Scal, P., Evans, T., Blozis, S., Okinow, N., & Blum, R. (1999). Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *Journal of Adolescent Health, 24*(4), 259-264.

Simonds, J. F. (1977). Psychiatric status of diabetic children in good and poor control. *International Journal of Psychiatry in Medicine, 7*(2), 133-151.

Soutor, S. A., Chen, R., Streisand, R., Kaplowitz, P., & Holmes, C. S. (2004). Memory matters: Developmental differences in predictors of diabetes care behaviors. *Journal of Pediatric Psychology, 29*(7), 493-505.

Stewart, S. M., Emslie, G. J., Klein, D., Haus, S., & White, P. (2005). Self-care and glycemic control in adolescents with type 1 diabetes. *Children's Health Care, 34*(3), 239-244.

Streisand, R., & Mednick, L. (2006). Development of the diabetes education, counseling, information delivery and evaluation (decide) program: A health promotion intervention for preadolescents with type 1 diabetes. *Journal of Clinical Psychology in Medical Settings, 13*(2), 189-199.

Tercyak, K. P., Beville, K. W., Walker, L. R., Prahlad, S., Cogen, F. R., Sobel, D. O., & Streissand, R. (2005). Health attitudes, beliefs, and risk behaviors among adolescents and young adults with type 1 diabetes. *Children's Health Care, 34*(3), 165-180.

Thomas, A. M., Peterson, L., & Goldstein, D. (1997). Problem solving and diabetes regimen adherence by children and adolescents with IDDM in social pressure situations: A reflection of normal development. *Journal of Pediatric Psychology, 22*(4), 541-561.

Thompson, R. J., & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness*. Washington, D.C.: American Psychological Association.

Van Tilburg, M. A. L., McCaskill, C. C., Lane, J.D., Edwards, C. L., Bethel, A., Feinglos, M. N., & Surwitt, R. S. (2001). Depressed mood is a factor in glycemic control in type 1 diabetes. *Psychosomatic Medicine, 63*(4), 551-555.

Weinger, K., & Jacobson, A. M. (2001). Psychosocial and quality of life correlates of glycemic control during intensive treatment of type 1 diabetes. *Patient Education and Counseling, 42*(2), 123-131.

Weissberg-Benchell, J., Glasgow, A. M., Tynan, W. D., Wirtz, P., Turek, J., & Ward, J. (1995). Adolescent diabetes management and mismanagement. *Diabetes Care, 18*(1), 77-82.

Winkley, K., Landau, S., Eisler, I., & Ismail, K. (2006). Psychological interventions to improve glycaemic control in patients with type 1 diabetes: Systematic review and meta-analysis of randomised controlled trials. *British Medical Journal, 333*(7558), 65-68.

Wolfsdorf, J. I. (2002). Improving diabetes control in adolescents with type 1 diabetes. In B. J. Anderson & R. R. Rubin (Eds.), *Practical psychology for diabetes clinicians* (2nd ed., pp. 149-159). Alexandria, VA: American Diabetes Association.

Wolpert, H. A. (2002). Working with young adults who have type 1 diabetes. In B. J. Anderson & R. R. Rubin (Eds.), *Practical psychology for diabetes clinicians* (2nd ed., pp. 161-169). Alexandria, VA: American Diabetes Association.

Wysocki, T. (2002). Parents, teens and diabetes. *Diabetes Spectrum, 15*(1), 6-8.

Wysocki, T., Green, L., & Huxtable, K. (1989). Blood glucose monitoring by diabetic adolecents: Compliance and metabolic control. *Health Psychology, 8*(3), 267-284.

Wysocki, T., Hough, B., Ward, K.M., & Green, L.B. (1992). Diabetes mellitus in the transition to adulthood: Adjustment, self-care and health status. *Journal of Developmental and Behavioral Pediatrics, 13*(3), 194-201.

Wysocki, T., Meinhold, P., Cox, D., & Clarke, W. L. (1990). Survey of diabetes professionals regarding developmental changes in diabetes care. *Diabetes Care, 13*(1), 65-68.

Wysocki, T., Meinhold, P., Taylor, Al, Hough, B.S., Barnard, M.U., Clarke, W., Bellando, B.J., & Bourgeois, M.J. (1996). Psychometric properties and normative data for the parent version of the diabetes independence survey. *The Diabetes Educator, 22*(6), 587-591.

Wysocki, T., Taylor, Alexandra, Hough, Brenda, Linscheid, T.R., Yeates, K.O. & Naglieri, J.A. (1996). Deviation from developmentally appropriate self-care autonomy: Association with diabetes outcomes. *Diabetes Care, 19*(2), 119-125.