TYPE 1 DIABETES IN ADOLESCENCE: THE EFFECT OF DEPRESSION, PSYCHOSOCIAL ADJUSTMENT AND DURATION OF ILLNESS ON GLYCEMIC CONTROL

By

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TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION	1
Diabetes and Glycemic Control	
Adolescence, Duration of Illness, & Psychosocial Adjustment	
Purpose of the Study	6
II. REVIEW OF LITERATURE	9
Diabetes	9
Depression	14
Psychosocial Adjustment	
Adolescence	
III. METHODOLOGY	52
Participants	
Procedure	
Measures	
Demographic Questionnaire	
Duration of Illness	
HbA1C	
Beck Depression Inventory- Fast Screen for Medical Patients	
Psychosocial Adjustment to Illness Scale	

Chapter	Page
IV. FINDINGS	
V. CONCLUSION	
Limitations of the Study	
Implications for Future Studies	
Implications for Theory and Practice	
Summary	
REFERENCES	76
APPENDICES	

LIST OF TABLES

Tab	le	Page
1	Demographics of the Sample	62
2	Means & Standard Deviations of BDI-FS, PAIS-SR, Duration of Illness	
and	HbA1C	65
3	Correlation Matrix of BDI-FS, PAIS-SR, DI and HbA1C	66
4	Multiple Regressions of BDI-FS, PAIS-SR, DI and HbA1C	67

CHAPTER I

INTRODUCTION

Diabetes Mellitus (DM) is a widespread, chronic disease that affects approximately 18.2 million Americans and is ranked fifth among the leading causes of death within the United States in 2002 (American Diabetes Association). Overall, DM is a costly disease that has numerous physiological complications, such as increased morbidity, heart disease, blindness, and amputations. Research that contributes to methodology and strategies for improving the management of DM, therefore, has high public health significance (Stewart, Emslie, Klein, Haus, & White, 2005).

There are two common types of Diabetes, Type 1 Diabetes and Type 2 Diabetes. The onset of Type 1 Diabetes usually, but not always, occurs in childhood and appears to be caused by a susceptibility gene that renders an individual vulnerable to autoimmune-mediated destruction of the pancreatic beta cells (Gonder-Frederick, Cox & Ritterband, 2002). In individuals with Type 1 Diabetes, the pancreas produces little to no insulin, allowing glucose to accumulate in the bloodstream causing hyperglycemia. The body's inability to utilize glucose causes the breakdown of fat for use as metabolic fuel, which, in turn, leads to a buildup of ketone acids and can cause diabetic ketoacidosis (DKA).

The only way to promote sufficient glucose utilization and reduce hyperglycemia in individuals diagnosed with Type 1 Diabetes is by delivering insulin through subcutaneous injections or an insulin pump. Without exogenous insulin treatment, Type 1 Diabetes is fatal. It is associated with serious long-term health complications, including retinopathy, nephropathy, neuropathy, and cardiovascular disease. In fact, diabetes is the leading cause of blindness, nontraumatic lower limb amputation, physiological erectile dysfunction, and end-stage renal disease in the United States (Harris, Flegal, Cowie, Eberhardt, Goldstein, Little et al., 1998). The present study focuses on individuals diagnosed with Type 1 Diabetes.

There is no cure for Type 1 Diabetes. Consequently, individuals diagnosed with Type 1 Diabetes are typically placed on a strict and complex maintenance regimen that involves regular administration of insulin through injections, attention to diet and exercise, and monitoring glucose levels while making appropriate adjustments. Children and adolescents with Type 1 Diabetes must monitor their symptoms, test their blood sugar under the appropriate circumstances (when certain symptoms are present), and make adjustments in diet, physical activity, and insulin doses to maintain optimal glucose levels. Therefore, the proper management of Type 1 Diabetes, also called good glycemic control, requires an ongoing series of decisions that must be carried out on a daily basis by adolescents and their parents (Miller & Drotar, 2006).

Glycemic control refers to how well the individual controls their blood sugar on a day to day basis. In other words, it is a measure of the individual's medication and/or treatment adherence. Medication adherence is a complex issue involving the child, family members, and other caregivers. This process is dependent on the family's cultural beliefs, their perceptions of disease severity, and their understanding of the benefits of treatment. Patients often construct

their own versions of adherence according to their personal worldviews and social contexts (The Diabetes Control and Complications Trial Research Group, 1993).

Glycemic control is measured by obtaining an HbA1C value during regular doctor's appointments. HbA1C (glycosylated hemoglobin) is used in this study as a measurement of average blood glucose levels over the past 2 to 3 months. It is determined through an analysis of hemoglobin in red blood cells (Cameron, Young, & Weibe, 2007). Higher HbA1C levels represent higher blood glucose averages which indicate poor glycemic control.

Glycosylated hemoglobin, known in short as HbA1C, is an index of average blood glucose (blood sugar) over the past 2 to 3 months (ADA, 1998). It is measured using high performance liquid chromatography. This process is completed by taking a drop of blood (obtained by finger prick) from the patient at the specialty clinic. HbA1C is obtained every 3 months during a routine doctor's appointment at the children's hospital specialty clinic. The obtained number is a representation of the average 3 month blood sugar where an HbA1C of 6 equals an average blood glucose level of 120. For every 30 points above 120, a whole number is added. For example, an HbA1C of 7 equals an average blood glucose level of 180. HbA1C levels are measured to the nearest tenth of a point and the goal for individuals with Type 1 Diabetes is to maintain an average HbA1C under 8 to be considered having good metabolic control. Adherence rates are commonly over reported by parents and youths, so using a reliable measure such as HbA1C is important to get a clear picture of youths' glycemic control (Wysocki, 2006).

The factors that influence metabolic control of type 1 diabetes are important to identify because of the potential long-term physiological complications of poor metabolic control

(Diabetes Control and Complications Trial Research Group, 1993). Good glycemic control is important in children and adolescents with juvenile-onset diabetes for present well-being and normal development as well as reducing the risk of long-term complications. As mentioned above, good compliance is any HbA1C under 8.0 (The Diabetes Control and Complications Trial Research Group, 1993). Compliance with regular treatment, usually including at least three daily insulin injections, meal planning and evaluation of caloric intake, blood glucose tests, and daily physical exercise, usually stays reasonably good up to adolescence, as parents take partial or full care of the treatment until that time (Kokkonen, Taanila, & Kokkonen, 1997).

Therefore, Type 1 Diabetes management or glycemic control depends almost entirely on behavioral self-regulation. Although self-care is often challenging for all age groups, a significant number of children and adolescents fail to adhere to physician directives and do not receive adequate self-care (La Greca & Schuman, 1995). More specifically, Litt and Cuskey (1980) estimated that the overall adherence rate among pediatric populations (ages 0-18) is only approximately 50%. This low figure is troubling because the Diabetes Control and Complications Trial Research Group (1993) found that one's ability to maintain recommended blood glucose levels is paramount to an individual's overall health and well-being and significantly reduces the risk of damage to the kidneys, nerves, and visual system. Therefore, research that seeks to understand glycemic control is also paramount to an individual's overall health and well-being.

Adolescence, Duration of Illness, & Psychosocial Adjustment

For various reasons, about one-third of diabetics have significant problems in keeping proper glycemic control in adolescence. In adolescence, hormonal changes throughout physical

development, together with increased insulin need, provide one explanation for the increasing hemoglobin percentage values (HbA1C). However, social and psychological factors are also implicated through non-compliance with treatment, as strict adherence to treatment confronts the way of life at puberty. Finding a flexible approach to the treatment of the disease for adolescents with inadequate coping skills has important implications for multidisciplinary teams caring for adolescent diabetics (Drash, 1986).

Adolescents with Type 1 Diabetes may cope differently than their child and adult counterparts. Adolescence is a period that developmental specialists have described as stressful (Peterson, 1988). Adolescents face important developmental tasks including identity formation (Erikson, 1968), the development of social skills, autonomy, responsibility, and the development of a set of values (Irvin, 1996). Other developmental events that are significant to this period include increased cognitive development, development of a sexual identity, adjustment to a developing physical body, and the development of academic competence (Kegan, 1998). In other words, a sizeable majority of adolescents even without chronic disease are faced with turmoil during this period (Irvin, 1996). Therefore, the addition of a stressor such as a chronic illness, especially one like Type 1 Diabetes that requires daily tasks and continuous monitoring, may only add to the turmoil of this period making coping with the disease more difficult.

Another possible contributor to stress in adolescents with type 1 diabetes is the duration of illness. Duration of illness is the years and months that have passed since the adolescent was diagnosed with Type 1 Diabetes. Many children and adolescents display adjustment problems with the onset of diabetes; however, these reactions dissipate for most of them within approximately 1 year. Unfortunately, early psychological problems in response to diabetes persist over time for some youths and have clinically relevant consequences for later functioning,

adherence, and metabolic control (Jacobson et al., 1990). Grey, Whittemore, and Tamborlane, (2002) found that duration of diabetes was significantly correlated with depressive symptoms in a U-shaped distribution and that depressive symptoms were more common in the earlier years post diagnosis, less common between 4 and 9.9 years after diagnosis and rose again after 10 years. Prior research has demonstrated that the duration of illness may also moderate the association between family relationships and adherence to diabetes treatment, such that the relationship is stronger as the duration of illness lengthens (Hanson, De Guire, Schinkel, & Kolterman, 1995). Other salient findings included that the age of onset and diabetes duration were significantly associated with metabolic control and behavior problems (Nadeau, 1994).

Andreasen & Wasek (1980) have reported that stressors in the period of adolescence are more likely to be chronic than in adulthood. These symptoms and behaviors may look similar to an adjustment disorder, however, because psychological adjustment to diabetes is in constant flux (over the lifespan), adjustment disorder, by definition (Erk, 2008), does is not fit to name this phenomenon. The diagnosis of diabetes is a stressor that does not terminate and the psychological symptoms may be seen at many periods of life. Therefore, poor psychosocial adjustment as well as depressive symptoms may be better descriptions of the feelings of loss and adjustment experienced throughout the lifespan of one diagnosed with diabetes.

Purpose of the Study

The aim of this study is to address how depression and poor psychosocial adjustment, experienced as a result of the diagnosis of diabetes, as well as the length of time since diagnosis, may relate to glycemic control in adolescents diagnosed with Type 1 Diabetes. Overall, diabetes is a costly disease that has numerous physiological complications, such as increased morbidity, heart disease, blindness, and amputations. Litt & Cuskey (1980) estimated that the overall

adherence rate among pediatric populations is only approximately 50%. For adolescents, the challenge of diabetes is combined with the developmental tasks of adapting to puberty and a changing body image, peer group pressure, autonomy from the parents and identity formation (Delamater, 1986). Adherence is important to consider during adolescence as it is typically poorer during this period (Johnson et al., 1992) and because adolescence is a critical juncture in the adoption of health relevant behaviors (Santrock, 2004). Research has also demonstrated that age of onset and diabetes duration are significantly associated with metabolic control and behavior problems in children (Anderson et al., 1997).

Therefore, because of economical as well a physical costs to patients, research that contributes to methodology and strategies for improving the management of diabetes has high public health significance (Stewart, Emslie, Klein, Haus, & White, 2005) as the Diabetes Control and Complications Trial Research Group (1993) found that one's ability to maintain recommended blood glucose levels is paramount to an individual's overall health and well-being and significantly reduces the risk of damage to the kidneys, nerves, and visual system. Research that focuses on learning about the mechanism responsible for the relationship between diabetesrelated depression and diabetes in youth is needed. More specifically, research to more carefully characterize the nature of the depression in these youth and begin to understand why depression has a temporal relationship with diabetes duration in youth is of public importance.

The factors that influence metabolic control of type 1 diabetes are important to identify because of the potential long-term physiological complications of poor metabolic control (Diabetes Control and Complications Trial Research Group, 1993). Also, the optimal timing of preventive interventions, such as coping skills training and counseling, provided at high-risk times such as diagnosis and before 10 years of diabetes duration, and the impact of interventions

for diabetes on depression are important to aid patients and their families. No study has yet researched the link between the psychosocial adjustment process along with diabetes duration in adolescence, which may give insight into the processes responsible for the relationship between depression and diabetes as well as other psychological experiences that make daily management more difficult.

Geist (1979), even many years ago, encouraged closer collaboration between those involved with the emotional issues of chronically ill patients and those charged with their medical care. It was his opinion that only with this kind of collaboration will improve our present treatment techniques and illuminate more specifically the psychological patterns of chronic illness. This can be seen in hospitals and specialty clinics employing multidisciplinary teams for a greater overall quality of care. These teams may include a physician and/or physician's assistant, nurse, diabetes educator and a psychologist or counselor. Lastly, within the past 5 years, there has been an increase in the call for psychologists to conduct more research that could inform intervention with medical issues because of the lack of literature in that area (Ellis, Templin, & Cunningham, 2007).

CHAPTER II

REVIEW OF THE LITERATURE

Diabetes

Diabetes mellitus is one of the most common, serious, and costly chronic diseases, and is a leading cause of death in the United States. Currently, diabetes affects 6% of the U.S. population (Centers for Disease Control and Prevention, 2005). One in every 400 to 500 children is diagnosed with Type 1 Diabetes. Also, communities of color bear a disproportionate burden of diabetes risk, prevalence, complications, and mortality (Garvin, Cheadle, Chrisman, Chen, Brunson, 2004). Diabetes is a widespread, chronic disease that affected approximately 18.2 million Americans and is ranked fifth among the leading causes of death within the United States in 2002 (American Diabetes Association). Overall, diabetes is a costly disease that has numerous physiological complications, such as increased morbidity, heart disease, blindness, and amputations (Stewart, Emslie, Klein, Haus, & White, 2005).

There are two common types of Diabetes, Type 1 Diabetes and Type 2 Diabetes. The onset of Type 1 Diabetes, also called insulin-dependent diabetes, usually, but not always, occurs during childhood or adolescence and appears to be caused by a susceptibility gene that renders an individual vulnerable to autoimmune-mediated destruction of the pancreatic beta cells, also called islet cells (Bernard & Krupat, 1994; Gonder-Frederick, Cox, & Ritterband, 2002).

Although it can be diagnosed at any age, diabetes is one of the most common chronic illnesses diagnosed in childhood (Juvenile Diabetes Foundation, 2000). Despite modern health care treatment advances, the life expectancy for individuals diagnosed with Type 1 Diabetes is approximately 75% of that of the general population (Geffken et al., 2008).

The onset of diabetes is an insidious process as beta cells are gradually destroyed, which results in a deficiency of insulin (Leadbetter, 2002). Common symptoms of the onset of diabetes include excessive thirst, constant hunger, frequent urination, and sudden weight loss and fatigue. The causes of diabetes remain somewhat unknown, but it is thought that with Type 1 Diabetes, the pancreas produces little to no insulin, allowing glucose to accumulate in the bloodstream causing hyperglycemia. Hyperglycemia occurs when glucose levels are too high and insulin levels are too low. The body's inability to utilize glucose causes the breakdown of fat for use as metabolic fuel, which, in turn, leads to a buildup of ketone acids and can cause diabetic ketoacidosis (DKA). DKA may lead to loss of consciousness, coma, permanent damage to central nervous system functioning, or death (Leadbetter, 2002).

The only way to promote sufficient glucose utilization and reduce hyperglycemia in individuals with Type 1 Diabetes is by delivering insulin through subcutaneous injections or an insulin pump. However, insulin injections do not cure the disease and, many times, do not produce perfect levels of insulin as the body would do naturally. Without exogenous insulin treatment, Type 1 Diabetes is fatal. It is associated with serious long-term health complications, including retinopathy, nephropathy, neuropathy, and cardiovascular disease. In fact, diabetes is the leading cause of blindness, non-traumatic lower limb amputation, physiological erectile dysfunction, and end-stage renal disease in the United States (Harris, Flegal, Cowie, Eberhardt,

Goldstein, Little et al., 1998). Interestingly, there is not strong evidence of family history or twin concordance in Type 1 Diabetes.

Type 2 Diabetes, also called noninsulin-dependent diabetes, usually develops later in life and accounts for 90% of all cases of diabetes. It is more common in women, European Americans, and people from low socioeconomic status (Bernard & Krupat, 1994). In Type 2 Diabetes, the ability of islet cells to produce insulin or the insulin sensitivity of other cells is reduced. There is strong evidence of a genetic component in Type 2 Diabetes, and if one identical twin has it, the probability that the other will have it is 100%.

Because there is some insulin production in individuals with Type 2 Diabetes, injections are usually not a required part of medical treatment. However, weight control is a major problem as approximately 90% of persons with Type 2 Diabetes are overweight (Bernard & Krupat, 1994). Losing weight can often improve the sensitivity of insulin receptors and bring the disease under control. However, this is not the case with persons with Type 1 Diabetes. Type 2 Diabetes was uncommon in the pediatric age until recently. It now accounts for 10-20% of new cases of diabetes in youths. Interestingly, youths with either form of diabetes are prone to becoming overweight.

There is no cure for diabetes. Consequently, individuals with diabetes are typically placed on a strict and complex maintenance regimen that involves regular administration of insulin through injections, attention to diet and exercise, and monitoring glucose levels while making appropriate adjustments. Although self-care is often challenging for all age groups, a significant number of children and adolescents fail to adhere to physician directives and do not receive adequate self-care (LaGreca & Schuman, 1995). More specifically, Litt & Cuskey(1980)

estimated that the overall adherence rate among pediatric populations is only approximately 50%. This low figure is troubling, because the Diabetes Control and Complications Trial Research Group (1993) found that one's ability to maintain recommended blood glucose levels is paramount to an individual's overall health and well-being and significantly reduces the risk of damage to the kidneys, nerves, and visual system.

Because diabetes has no outward signs or symptoms, individuals with diabetes do not appear any different. Patients often simply forget to take their medication once they become symptom-free (Soutor et al., 2004). Also, because they do not usually undergo hospitalization or other painful procedures, it may be difficult for them to see themselves as ill. As a result, they may not understand diabetes and its long-term consequences and may have poor diabetes management (Bernard & Krupat, 1994).

Memory also plays a role in daily management of diabetes. Souter et al. (2004) found that memory is a significant predictor of some of the central self-care behaviors involved in diabetes management for older adolescents who have greater self-care responsibility. In short, there are several factors that may contribute to poor diabetes management.

Gonder-Frederick, Cox, and Ritterband (2002) created a psychosocial model that displays empirically identified variables influencing self-management and clinical outcomes in diabetes. Individual, social, and environmental variables are included. Individual variables include personal health beliefs, coping abilities, psychopathology (depression, anxiety, phobias, eating disorders), psychological distress (diabetes-specific, non-diabetes specific), personality (trait anxiety), and demographics (age, gender, etc.). The social variables include social support (family, friends, community), family characteristics (communication, cohesion), parental

responsibility, interactions with health care practitioners, impact of diabetes on significant others, and sociodemographic factors (ethnicity, socioeconomic status, number of parents in household). Lastly, environmental variables include the health care system, macro-environment (healthcare access, incentives, exercise, and healthy diet), work and/or school environment, community programs, and cultural factors.

Paterson & Thorne (2000) describe that becoming an expert in the self-management of a chronic illness such as diabetes may be a developmental process. Some research has demonstrated that children, adolescents, and adults may hold different personal models, including beliefs, attitudes, and emotional responses, about diabetes (Hampson, Glasgow, & Foster, 1995). Paterson & Thorne (2000) found that the development of expertise is age-related in that movement through the phases is often determined or influenced by the developmental age at the time as well as the person's age at the onset of the disease. Common phases in diabetes self-care put forth by Paterson & Thorn (2000) include passive compliance, naïve experimentation, rebellion, and active control. Most research on diabetes has been with the adult population; however, adolescents are often perceived by researchers as a high-risk group because of their tendency toward self-management neglect, and are increasingly becoming the focus of studies on diabetes management.

Diabetes may not only be a psychosocial transition for the person diagnosed with the illness, but also those around them including their parents. Lowes, Gregory, & Lyne (2005) found that parents of newly diagnosed children had extremely intense emotions. Their findings cast doubts that these parents ever fully accept the diagnosis because, even a year after diagnosis, their emotions resurfaced when discrepancies or triggers emphasized the reality that their

children were different in certain circumstances. So diabetes is a complicated chronic disease that not only affects the individual diagnosed, but also significant others in their lives.

Depression

Depression is the experience of deep sadness and loss of interest in nearly all normal activities. Depression is sometimes used as a common term to describe momentary periods of sadness and diminished interests, feeling down, and so on. However, the Diagnostic and Statistical Manual of Mental Disorders includes diagnoses describing more severe forms of depression affecting one's social and relational functioning that also include symptoms such as despair, hopelessness, helplessness, and worthlessness. Anyone may experience depression at one time or another, but not necessarily meet the DSM-IV criteria for a diagnosis of Major Depression or other related mood disorder diagnoses. Depression may be caused by a number of factors including triggering events, life circumstances, or genetics. It is treatable with psychotherapy and/or pharmacotherapy.

The likelihood of depression increases throughout adolescence with girls more likely than boys to experience depressive symptomatology and clinically significant levels of depression (Smith, Calam, & Bolton, 2009). In a study on depression in adolescence, attachment, cognitive style, relationship rating, live events, and depression inventories were given to 140 students ages 16-18 years. Alienation from parents and peers, helpless attributional style, gender, and perceived criticism from teachers contributed significantly to variance in scores for depressive symptoms. Negative self-inference and helpless attributions moderated the relationship between perceived criticism and depression in male participants. They concluded that different approaches to intervention may be more helpful for males and females.

Cullen et al. (2009) conducted a thorough review of the literature regarding pediatric depression. With a developmental perspective applied to integrate key neurobiological systems that are implicated in pediatric Major Depressive Disorder (MDD), they found that pediatric MDD is associated with chronicity and poor outcomes. On a positive note, since the biological systems implicated in MDD mature through adolescence, adolescents may be more susceptible to developing depression but also may be more amenable to treatment interventions. Additionally, early identification and treatment of pediatric MDD may be able to divert negative trajectories and lead to improved outcomes.

Sawyer, Pfeiffer, and Spence (2009) conducted a longitudinal study over one year of 5634 adolescents. They found that depression was found in those who had greater exposure to negative life events and who also use a negative coping strategy without the use of positive coping strategies. These authors emphasize that early adolescence is a time when the prevalence of depressive symptoms increases markedly, particularly among females. As a result, by late adolescence the prevalence of depressive disorders amongst males and females is comparable to that found among adults. One potential explanation for the increase in depressive symptoms among adolescents is the impact of greater exposure to negative life events in early adolescence, particularly those involving difficulties with peer and family relationships. An alternative explanation is that there is a positive interaction between exposure to negative life events and a tendency among some to young adolescents to attribute negative events to stable and global factors reflecting personal inadequacies (cognitive diathesis-stress model).

In another longitudinal study, Wroch & Miller (2009) surveyed adolescent girls in 4 waves over 19 months. Their findings suggest that depressive symptomatology may serve adaptive functions by facilitating the development of goal disengagement capacities. In their

publication, they mention that depressive symptomatology can manifest in the form of low mood or a pathological syndrome and is often accompanied by a state of helplessness that can adversely affect a person's motivation and behaviors. Additionally, depressive symptoms can also contribute to dysregulation of biological and to problems with physical health. In essence, they found that depressive mood may facilitate the abandonment of unattainable goals and thereby could promote quality of life, therefore suggesting that depressive symptoms in adolescence are not all bad as difficult as they may be.

Depression symptomatology is also seen in persons diagnosed with diabetes. Surridge et al. (1984) conducted a descriptive study of the psychiatric findings in 50 insulin-dependent diabetics. Among symptoms found were a marked reduction in energy level, increased fatigue and irritability, depression, and delayed psychosexual maturation. Diabetes is commonly considered to be a disease that, if properly controlled, allows the patient to lead a relatively normal life. They found that these symptoms often made the patients' lives uncomfortable, reduced their functional capacity, disrupted their family life, and disturbed the adolescence of those who were affected at an early age. The psychiatric changes may be due to the stresses of the diabetic way of life but it is rarely pointed out that psychiatric changes may also result from the direct effect of the disease on the nervous system.

In this study, depressive symptoms may be experienced in response to having been diagnosed with a chronic disease (It is important to note that we cannot attribute any depressive symptoms purely to the diagnosis as other factors may also be in play such as family conflict, genetic predisposition, and other life stressor variables). For children who are diagnosed with a chronic disease in late childhood, loss of their former "normal" life may be a triggering event and/or a constant struggle that may affect depressive symptoms.

Increased depressive symptoms may limit the individual's ability to cope with diabetes stressors and adhere to the medical regimen leading to problems in glycemic control. According the research by Ford et al. (2003), the likelihood of developing depression increases throughout adolescence even in the absence of chronic illness. Depression is just one symptom that an individual diagnosed with diabetes may experience as mentioned above. The common experiences that may facilitate depression in this population may include the loss of their former diabetes-free life (grief, mourning), isolation and feelings that they are different from their peers, being overwhelmed or tired due to the multiple daily tasks required for good glycemic control, belief that diabetes may keep them from life goals or knowledge that type 1 diabetes has no cure and the belief that they will die early.

Helgeson et al. (2009) interviewed 70 girls and 62 boys (mean age 12 years) annually for four years and found that eating disturbances, depression, and peer relations were related to poor metabolic control, whereas good family relations were related to better metabolic control for girls.

As previously mentioned, the diagnosis of diabetes in late childhood may introduce the loss of one's former "normal" life. Loss has been defined as the process of ending, terminating, or losing a relationship, person, or experience. Loss may require people to work through their feelings and come to resolution if they are to proceed developmentally (Gladding, 2001). There are two kinds of loss; physical (tangible) or symbolic (psychosocial), and yet, regardless of the type, it inevitably results in a deprivation of some kind (Rando, 1991).

Mourning can be defined as the expression of sorrow and grief that follows a loss. Mourning varies according to the person and the degree of loss. Prolonged mourning can lead to

pathological behavior (Gladding, 2001) including depression. Worden (1991) suggested that mourning is the process which occurs after a loss, while Rando (1991) recognized that mourning has two historically based meanings that result in an understanding based on cultural responses, implying that there is no style of grief, but that it is a reaction that, like other reactions, is socially and culturally influenced. Rando (1991) also recognized that mourning, derived from psychoanalytic theory, is a wide array of intrapsychic processes, conscious and unconscious, that are prompted by loss. Mourning refers not so much to the reaction to the loss, but to the process by which an individual integrates the loss into his or her ongoing life (DeSpelder & Strickland, 2002, p. 224). By entering into the mourning process after diagnosis through psychotherapy, teenagers may be less likely to experience depression or depressive symptomatology or other psychopathology.

Psychosocial Adjustment

Psychosocial adjustment is the process by which individuals adapt through change. It is a holistic view of adjustment involving both internal and external mechanisms such as emotions, behavior, and relationships. Psychosocial adjustment is a term used to describe the process of intrapsychic, social, and cultural environmental functioning of individuals in response to a life event, stage, or circumstance. These interactions between the individual and themselves, others, and their environment are usually achieved through roles (vocational, domestic, social, etc).So, psychosocial adjustment is composed of multiple domains. Coping is a term sometimes used in place of psychosocial adjustment. Coping is regarded as any attempt made to alter the mismatch between the person and his or her environment. More specifically, the concept of coping is generally defined as the cognitive and behavioral efforts made to master, tolerate, or reduce

demands that tax or exceed a person's resources. In this study, the term psychosocial adjustment is used to incorporate domains external as well as internal to the individual.

In adolescence, psychosocial adjustment is a part of normal development as it is a time of significant physical, mental, emotional, relational, and occupational change. In a study with 400 adolescents, Noom, Dekovic, and Meeus (1999) found that autonomy and attachment are positively related to psychosocial adjustment during adolescence. Autonomy is generally conceptualized in these reviews as the ability to regulate one's own behavior. Attachment is generally described as the quality of the relationship with significant others. These studies show how supportive relationships facilitate rather than inhibit autonomy.

Additionally, they found that attitudinal, emotional and functional autonomy were connected with attachment to father, mother and peers to predict indices of psychosocial adjustment (including social competence, academic competence, self-esteem, problems behavior and depressive mood). Only main effects of autonomy and attachment were found. There was no evidence for an extra positive effect of being both autonomous and strongly attached. Attachment to parents in adolescence has been found to be positively related to self-perceived competence and social competence and negatively related to feelings of depression. Attachment to both parents and peers was positively related to psychological well-being. A systematic comparison of attachment to parents and peers revealed that attachment to parents is a stronger positive predictor of school/work identity and a stronger negative predictor of problem behavior. Attachment to peers is a stronger predictor of relational identity and a stronger predictor of problem behavior.

Although many children with chronic physical health problems adjust well, as a group they have a 2-3 times increased risk of developing psychiatric and social difficulties compared with their healthy peers (Creswell, Christie & Boylan, 2001). Difficulties in adjustment may be exacerbated due to the competing demands of chronic illness and developmental tasks. An important, and sometimes overlooked difficulty facing adolescents with chronic illness, is the importance of peer relationships in successful adolescent developmental tasks. Adolescents with physical health problems have been found to be at greater risk of peer relationship problems (Ungerer, Horgan, Chaitow, & Champton, 1988). This may affect independence and autonomy. In addition, Hauser et al. (1992) found that adolescents with diabetes tended to be at a lower level of ego development than acutely ill peers.

Mackner and Crandall (2006) studied 50 adolescents with Irritable Bowel Disorder (IBD) and their parents, along with parents of 42 health comparison adolescents completed questionnaires assessing behavioral, emotional, social, and family functioning. Adolescents with IBD were reported to have worse anxious and/or depressed and social problems than healthy peers. Those diagnosed during adolescence were reported to have significantly worse social competence scores. In essence, adolescents with a chronic illness may be at higher risk for specific psychosocial difficulties than healthy peers. However, research on adjustment to pediatric chronic illness has focused primarily on children, and if adolescents are included, they are often grouped in the same sample with younger children. Adolescent adjustment to chronic illness has been neglected, and to Mackner and Crandall's knowledge at the time of publication, no previous research had examined the impact of chronic illness diagnosis during adolescence. Therefore, diagnosis of a chronic illness during adolescence may have a different impact on psychosocial functioning than childhood diagnosis, with specific implications for social

functioning. The authors suggest that, given the importance of social functioning in adolescence, psychologists and other health professionals should be alert to social difficulties among those with chronic illness, and these adolescents should be encouraged to participate in social activities.

Similarly to Mackner and Crandall's study, Meijer et al. (2002) studied the psychosocial adjustment of 84 adolescents ages, 13-16years, with a chronic illness. Psychosocial adjustment was assessed for with measures of social adjustment, global self-esteem and behavior problems. In this study, psychosocial functioning of chronically ill adolescents was significantly related to stress-processing factors. The coping style 'confrontation', characterized by active and purposeful problem-solving, seems to be the most important determinant for positive psychosocial functioning. A depressive reaction pattern was negatively associated with psychosocial functioning (adolescents who react to daily problems with depressive behavior reported low global self-esteem and high social anxiety). The 'seeking social support' style was also related with positive psychosocial functioning.

The authors emphasize that a chronic illness may interfere with the developmental tasks of adolescents by making them more vulnerable to psychological and social problems. However, resistance factors may act as a buffer against these problems. Resistance factors include intrapersonal factors (temperament, problem solving ability), social-ecological factors (family environment, family members' adaptation, social support) and stress processing factors (cognitive appraisal and coping strategies). Resistance factors are key parameters in preventing adjustment problems of chronically ill adolescents.

Also important to note from Meijer et al.'s study findings is that children with adjustment problems were more likely to use social withdrawal and wishful thinking than children without apparent adjustment problems were; that active coping is also associated with better illnessrelated adjustment; and that avoidance has been correlated with worse adjustment in children and adolescents with diabetes; and lastly, investigators have failed to find an association of psychosocial functioning with diagnosis (the chronicity of the condition appears to be the common factor associated with psychosocial maladjustment).

Creswell, Christie, and Boylan (2001) developed two groups designed to enhance the factors of self-esteem, social communication and stress management among inpatients on a specialist adolescent medicine ward. They mention in their publication that although many children with chronic physical health problems adjust well, as a group they have a 2-3 times increased risk of developing psychiatric and social difficulties compared with their healthy peers. They also include that difficulties with adjustment may be exacerbated in older children due to the conflicting demands of the developmental tasks of adolescence and the presence of a chronic illness.

Chassin, Presson, Sherman, and McConnell (1995) have described the primary developmental tasks that face adolescents: defining a sense of identity; establishing positive, intimate peer relationships; establishing independence and autonomy. Also, Carter (1990) has described a number of key changes that occur during adolescence. In particular self-concept is hypothesized to shift from being concrete to abstract, providing greater potential to distort views about the self by creating a greater reliance on social feedback for self-verification. Adolescents with physical health problems have been found to be at greater risk of peer relationship problems and hence are likely to experience difficulties with self-concept and establishing positive,

intimate peer relationships. Difficulties may also be likely with the third task, establishing independence and autonomy.

Hauser et al. (2002) found that adolescents with diabetes tended to be at a lower level of ego development than acutely ill peers. They hypothesized that the stress of having a chronic illness may lead to regression of maturity or that the demands of the illness may lead parents to be more restricting and reduce the adolescent's opportunities for independence. Perceived stress has been found to be associated with parent-reported behavior problems and self-esteem, and child-reported anxiety and depression among children with diabetes (Kovacs et al., 1990).

Berg et al. (2009) studied 252 adolescents with type 1 diabetes that completed stress and coping interviews where they appraised mothers' and fathers' involvement in stress ownership, in coping, and rated their effectiveness in coping and completed depressive symptoms, self-care behaviors, and efficacy of disease management assessments. HbA1c's were also obtained. They found that higher perceived coping effectiveness was associated with fewer depressive symptoms, self-care behaviors, and efficacy across age and, more strongly for older adolescents' metabolic control. Appraisals of support or collaboration from parents were more frequent when stressors were appraised as shared. Perceived coping effectiveness was enhanced when dyadic coping with mothers (but not fathers) was consistent with stress appraisals. Stress and coping is embedded within a relational context and this context is useful in understanding the coping effectiveness of adolescents.

Adolescents with chronic illnesses such as type 1 diabetes experience stressful events surrounding their illness and benefit from parental involvement. Adolescents with diabetes report stressful events such as regulating highs and lows in blood glucose and problems in food intake

and exercise. An assumption is that adolescents' ability to deal effectively with such stressors is associated with enhanced psychosocial and diabetes adjustment, an assumptions that has yet to be rigorously tested in the adolescent literature.

The child and adolescent literature largely excludes the measurement of perceived coping effectiveness defining effectiveness as psychosocial adjustment. For example, perceived coping effectiveness may be associated with better psychosocial adjustment (e.g., lower depressive symptoms) as well as diabetes management in adolescence.

In adolescents coping with diabetes, collaborative coping has been associated with fewer depressive symptoms, better glucose control, and adherence, greater parental involvement and greater parental acceptance. Families frequently appraise type 1 diabetes as shared within the family rather than as the adolescent's issue alone. Coping effectiveness is associated with better diabetes-related outcomes and perceived coping effectiveness was associated with adjustment.

While many adolescent patients diagnosed with type 1 diabetes display psychological symptoms similar to adjustment disorder, it many times simply does not fit by definition. Adjustment disorder is characterized by emotional or behavioral symptoms in response to an identifiable stressor occurring within 3 months of the onset of the stressor. These symptoms or behaviors are evidenced by marked distress that is in excess of what would be expected from exposure to the stressor as well as significant impairment in social or academic functioning (Erk, 2008). However, to meet the diagnostic criteria for adjustment disorder, once the stressor has terminated, the symptoms do not last for more than an additional six months. In the case of diabetes, psychological symptoms are seen much later than six months after diagnosis. Also, diabetes is a stressor that does not terminate since it is a chronic disease. Therefore psychosocial

adjustment and/or depression may be a better way to describe feelings of loss and adjustment throughout the life of an individual diagnosed with diabetes.

Depression, Psychosocial Adjustment & Diabetes

With individuals with medical issues, psychosocial adjustment may be significantly involved in etiology, course, or outcomes of the illness. In other words, within the contexts of many major diseases (Kaplan-deNour, 1982; Murawski, et al., 1978; Zyzanskil et al., 1981) that the nature of the patient's psychosocial adjustment can be just as important as the status of his/her physical disease in determining the quality of an illness experience. In the case of medical patients, there is not an extensive range of assessment methods available to measure psychosocial adjustment.

Since diabetes is a chronic illness, it forces the individual and their family to give up the idea of being cured, to adapt themselves to the incapacities and learn to live with the illness (Lefebvre & Levert, 2006). In addition, the daily tasks of managing diabetes can also serve as stressors that in turn lead to a rollercoaster of disbelief, anger, depression, and loss throughout the lifetime. Lefebvre (2006) mentions six interrelated phases that one may go through or feel simultaneously after a loss to highlight the dynamic and evolving nature of the grieving process. Those phases are shock, negotiation and denial, anger, guilt, depression, adaptation and transformation. In a chronic situation such as having Type 1 Diabetes, adjustment process is never complete, so individuals may continue to move from one phase to another (Lefebvre & Levert, 2006).

Stressors related to and beyond the illness are viewed as risk variables. Risk variables identified in the risk and resistance model by Siarkowski (1999) include gender, age,

socioeconomic status, developmental level, lack of social support, duration of illness, and the presence of depression and anxiety. Resistance variables can buffer the effect of risk on the individual's adaptation to chronic illness. Resistance variables include self perception or self-esteem, knowledge of the disease, and presence of social support. Factors that help with poor adaptation to a diagnosis include family environment, family support, family cohesion and adaptability, family knowledge of disease, and normalization.

Schwartz et al. (1991) found that psychosocial problems often occur after receiving a diagnosis of a chronic or terminal disease. Their study suggests that addressing the psychosocial aspects of long-term illness improves treatment outcome, but that the psychosocial needs of patients with various life-long illnesses have not been sufficiently met. Additionally, this study provided data showing that adjustment needs of the chronically ill differ from individual to individual. The knowledge that these differences exist and that ability to detect them is important in light of the literature that suggests that early intervention minimizes long-term maladjustment issues related to the changing course of the disease.

Laungani (2003) mentions that "yet the search for causes, primary or secondary, single or multiple, appears to be a universal quest." "They all want to know, "Why me? Why not Joe Blogs? What have I done to deserve this fate? There's got to be a reason."

He also mentions, commenting on his own chronic illness that, "Despite the fact that there may be another patient suffering from the same illness or disease, it does not follow that the disease, including the side effects of medication, will run through its course in the same manner in both cases. Your own subjective evaluations, your own approach to coping and combating the disease

have an important bearing on its outcome." While Laungani (2003) provides an adult perspective, children and adolescents may experience their illness much differently.

Children who are diagnosed with a chronic illness such as diabetes are more likely than children without illnesses to have psychosocial problems (Leadbetter, 2002). Jacobson (1996) identified common psychosocial difficulties associated with a diagnosis of diabetes, including initial feelings of anger, loss and bereavement on the part of the child and family. These psychosocial difficulties may lead to poorer academic achievement, lower self-esteem, and more psychological problems. Similarly, children with diabetes experience increased parental stress, parent-child conflicts, and continuous adaptation to ongoing stressors and crises (Floyd & Gallagher, 1997). In addition, Mullins, Hartman, Hoff, Balderson & Chaney (2003) found that children diagnosed with Type 1 Diabetes with higher levels of depressive symptomology were associated with increased health care utilization above and beyond demographic and illness variables.

Depression is two to three times more common among those with type 1 diabetes compared to normative populations (Anderson, Freedland, Clouse & Lustman, 2001) and girls with diabetes endorse more depressive symptoms than do boys. Similarly, Korbel et al. (2007) studied whether gender differences in adherence and metabolic control among adolescents with type 1 diabetes are mediated by depression. In a sample of 127 adolescents with type 1 diabetes (ages 10 to 15 years), gender interacted with age to predict symptoms of depression and adherence, but did not interact to predict metabolic control. Depression symptoms among adolescents are also associated with lower self-efficacy and perceptions of control over illness, reduced social support, and maladaptive coping in the face of stress (Korbel et al., 2007).

In a study by Ford (2004), 102 diabetic youth provided information on 2 occasions (10-20 months apart) on depressed mood, cognitions (self-efficacy, hopelessness, cognitive distortions), and adherence behaviors. HbA1c was also assessed. Hopelessness was found to predict diabetes-specific self-efficacy over time, and general self-efficacy was the only general cognitive concomitant that predicted depressed mood after one year. Cross-sectional data supported the indirect influence of depressive symptoms on metabolic control through cognitions. The findings provide support for additional areas that would benefit from further study and provide clinicians with insight into some of the most valuable points of intervention for diabetic adolescents. In other words, depressive symptoms have been found to associate with poor diabetes management (Littlefield et al., 1992); however, less information is available about the relationship between depressed mood, the cognitive concomitants of depressed mood, and the manner in which these variables related to diabetes care and outcomes in adolescence.

Dantzer et al. (2003) conducted a review of the literature on anxiety and depression in juvenile diabetes. While anxiety and depression appear to play an important and complex role in determining adaptation to the disease, their relationship to metabolic control does not yet appear clear. They found that several reviews of the literature have been published over the last 20 years concerning association of psychological disorders and diabetes. One of the earliest of these publications, a review of brittle diabetes (Greydanus & Hofmann, 1979), concluded that psychological factors appear to influence the course of diabetes, including metabolic control and the general management of the disease. Subsequent reviews have also underscored complexity of diabetes and the need to take into account patient variables, environmental factors, physiology, the role of stress, and the effects on health status into multifactorial models (Bennett Johnson, 1988). Among the most comprehensive reviews to date, Helz and Templeton (1990) examined

the role of psychological factors in precipitating diabetes or in affecting its course from six different perspectives: anecdotal case reports, epidemiologic studies, clinical studies of discordant twin pairs, physicological effects of artificially induced stress in humans and animals.

These authors (Dantzer et al., 2003) noted that psychological factors appear to play a very important role in diabetic control, a conclusion that is supported by other summaries of the literature showing that stress is reliably associated with changes in glucose regulation for a subset of diabetic patients. The most recent published review continues to observe greater psychiatric morbidity in diabetes patients than in the general population with depression being the most common psychiatric disturbance followed by anxiety, and to indicate that these disorders have a direct impact on metabolic control (Eiber, Berlin, Grimaldi, & Bisserbe, 1997). Despite these relatively consistent conclusions, past reviews have not been able to focus on the adolescent population.

Blanz, Rensch-Riemann, Fritz-Sigmund, and Schmidt (1993) found a significant association between psychological disorders and diabetes. They found a prevalence of psychological disorders of 33.3% in the diabetic group compared with 9.7% in the control group. No specific behavioral profile was found for the diabetic adolescents except that they suffered from significantly more internalizing symptoms than their healthy peers, especially somatic symptoms, sleeping disturbance, compulsions, and depressed mood.

Similarly, Grey, Cameron, Lipman & Thurber (1995) evaluated anxiety and depression over 2 years in newly diagnosed diabetic children compared with healthy peers and found that children with diabetes scored higher on the depression scale their peers at baseline and at 2 years post-diagnosis. Anxiety and depression in juvenile diabetes may be conceptualized both as

consequences of this chronic illness and as markers of maladjustment to the disease.Studies have shown that depressed subjects have different symptoms as a function of both age and gender. Still other research has underscored the interaction of these demographic variables in that the emerging gender difference for depression (with more girls being depressed than boys) generally appears after the age of 13 years. In light of these observations, studies of depression, anxiety, and metabolic control should include patients of similar age in order to have the most homogeneous sample as possible.

Grief-like behaviors and reactions are elicited in the individual and family recently diagnosed with diabetes (Edwards, 1987). During the days following diagnosis, a range of emotional reactions may be exhibited by the individual or family such as anxiety, despair, guilt, anger, sadness, depression, fear, concern, hope, disbelief, confusion, and helplessness. Grief occurs in response to a real or perceived loss and diabetes is associated with experiences of loss (Shepard, Sparkes & Hattersley, 2003). A diagnosis of diabetes may represent various and numerous losses such as loss of a trustworthy, functioning body, loss of lifestyle, loss of independence, loss of favorite foods, loss of social acceptance, loss of future career aspirations (Edwards, 1987), and loss of self (Shepard, Sparkes & Hattersley, 2003). The meaning of diabetes is in its consequences and significance for the individual and this meaning and significance may change over time (Shepard et al., 2000). So, psychosocial adjustment and depression in individuals diagnosed with diabetes may be ongoing with periods of remission.

Emotional and psychological reactions may affect the individual psychologically as seen above; however, it is also important in relation to the health of the individual. Delamater et al. (1987) found that coping style was found to be significantly correlated with the level of metabolic control in adolescents with diabetes. In addition, Jacobson et al. (1990) found a

significant correlation between children's coping strategies and diabetes-related compliance. Similarly, Edwards (1999), in studies examining adults with diabetes, found that the use of active coping strategies was associated with increased diabetic adherence; and Kvam and Lyons (1991) found that adults with diabetes who used a problem-solving coping style had better overall health than those who used a wish-fulfillment coping style. So, it has been demonstrated with individuals of all ages, that emotional and behavioral reactions to having diabetes can influence the individual on both a psychological and physical level.

Psychological consequences of the onset of diabetes are varying among type, intensity, and duration. There is a linkage between emotional arousal and diabetic metabolic instability among some insulin-dependent diabetics (Jacobson & Leibovich, 1984). Similarly, Edwards (1987) found that the initial psychosocial impact of the diagnosis of insulin-dependent diabetes mellitus is evidenced by grief responses and crisis reactions.

Emotional and psychological responses to the diagnosis of diabetes can also affect individuals close to the person with diabetes. Anderson et al. (1981) found that the parents of children diagnosed with diabetes also underwent the grief response. They found that successful coping is also important in parents to support their child in the treatment (Anderson, Miller, Auslander, Santiago, 1981). Other research on parents with children diagnosed with diabetes found that two-thirds of the parents reported having experienced considerable turmoil at the onset of their child's disease, and 40% of the mothers still reported continuous concern about their child's well-being (Kokkonen, Taanila, & Kokkonen, 1997).

Adolescence

Freud identified the adolescent years as puberty or the genital stage in his psychosexual stages of development. He thought that the task in this period of development is freeing oneself from ones

parents and characterized this period as one of dramatic physiological changes (Crain, 2005). Adolescents want more autonomy from their parents and more responsibility over their own life decisions, but still need a connection with their parents (Santrock, 2004). This sets up the parentchild relationship for a time of conflict. Freud also observed that sexual and aggressive drives are no longer dormant in this developmental period as in the latent stage before this period. Freud's daughter, Anna Freud, added that adolescent turmoil and the desperate strategies and defenses of this period are normal and to be expected (Crain, 2005).

Erikson agreed with Freud, but believed the turmoil in adolescence to be more complicated. He thought adolescence was also difficult because it was disturbed and confused by new social conflicts and demands. He thought the primary task for this period is establishing a new sense of identity. Both the rapid change in outward physical appearance as well as the surge in hormones make this task challenging.

Piaget hypothesized that adolescent cognitive abilities grow into formal operational capacities during this developmental period (Crain, 2005). They are able to think about the distant future and purely hypothetical situations. They can now entertain limitless possibilities about who they are and what they will become. This may contribute to the self-questioning of this period.

In other words, adolescents are developing expanding mental powers and realizing the many choices before them. Adolescents are no longer limited to concrete experiences as anchors for thought. They can think up make-believe situations, hypothetical events or possibilities and can try to reason logically when problem solving (Santrock, 2004). As this period produces more thought about oneself, accomplishments can be very important to developing a new identity. If positive experiences with accomplishments are met, than the self is seen positively; however if

challenges are met with failure, the self may be seen negatively without self-efficacy (Crain, 2005).

Commitment can be very difficult for adolescents because of the many choices they see before them. Because commitment can be so difficult, sometimes the adolescent may enter a "social moratorium", which is similar to taking a "time out" for finding oneself. This may lead the adolescent to be self-focused and very conscious of others' perceptions of them. This type of self focus has been called "adolescent egocentrisim". It is the heightened self-consciousness and can be put into two categories: imaginary audience and personal fable (Elkind, 1976). Imaginary audience involves the belief that others are as interested in the adolescent as they are in themselves as well as attention-seeking behavior and attempts to be noticed. The personal fable is the adolescent's sense of uniqueness and invincibility. For this reason, adolescents tend to be group-focused, but feel alone and isolated when they feel different.

Havighurst had a particular insight into adolescence. According to him, the following tasks defined his conceptualization of this period: accepting the uniqueness of one's body and using the body effectively; achieving a meaningful pattern of behavior in relation to masculine or feminine social roles; obtaining relationships with peers of both sexes that reflect greater maturity; achieving emotional independence from parents; preparing for the future in relation to work; preparing for an intimate relationship that reflects commitment; developing a higher level of social and community responsibility; establishing a value system that includes ethical considerations that are reliable guides to behavior; and achieving a level of physical maturity consistent with what is expected for adolescents maturation (Erk, 2008).

of rapid physical maturation involving hormonal and bodily changes. Hormones are powerful

chemicals secreted by the endocrine glands and carried through the body. The concentration of certain hormones increases dramatically during adolescence. Hormones affect physical as well as emotional development (Santrock, 2004). However, there is also a strong hormone-behavior link. For example, behavior and moods can affect hormones. Stress, eating patterns, exercise, sexual activity, tension, and depression can activate or suppress various aspects of the hormonal system as well.

The most noticeable physical changes in adolescence are height and weight increases. These rapid physical changes may lead to the adolescent being preoccupied with their body. In general, girls are less happy with their bodies during puberty while boys become more satisfied with their bodies during puberty (Santrock, 2004).

Adolescents have a heightened sensitivity that can lead them to respond to social situations more forcefully than expected. It is a time of mood swings, cycles of acting out followed by behavioral inhibition, and a period of preoccupation with oneself. Low self-esteem and mistrust of one's abilities to handle personal matters are also present (Erk, 2008).

Adolescence is also marked by an increase in experimentation and exposure to the culture at large and its potentially health-threatening aspects (Bernard & Krupat, 1994). Adolescence is a period in which the individual is exposed to changing health hazards and it is a critical transitional period for the development of health habits. Many of the factors linked to poor health habits and early death in the adult years begin during adolescence (Santrock, 2004). During adolescence many important health behaviors emerge, affecting future disease outcomes in adulthood (Williams, Holmbeck & Greenley, 2002). During this period of development lifelong patterns of self-management of and adjustment to chronic health conditions are established.

The literature on adolescence seems to spell out many of the same impressions of this period of development. While adolescence can be seen as a period of deviance, rebellion, and crisis, a better and more accurate description is that of a period of evaluation, decision making, and increasing cognitive, emotional, and physical abilities.

Diabetes in adolescence

Clinical experience indicates that poor adherence is common in patients with chronic illness (e.g., cystic fibrosis, epilepsy, asthma, diabetes). For parents and children, the daily hassles of living, stress, and typical family conflict are the biggest barriers to medication adherence. This is especially true in children with chronic diseases. Age, socioeconomic status, race, and family factors also can influence adherence to treatment, especially in children with asthma, epilepsy, and diabetes. Johnson, Perwien & Silverstein (2000) found that diabetes management transitions from childhood to adolescence. Adolescents are expected to monitor their own blood glucose levels and make management decisions on their own unlike their younger counterparts. Although adolescents many times have increased cognitive understanding of diabetes than do younger children, they experience less parental supervision and are many times less adherent with the numerous daily requirements of diabetes management (Johnson et al., 2000).

With the link between blood glucose control and the onset of complications clearly established, the problem of the decline in blood glucose control seen during adolescence is of even greater significance if later complications are to be delayed, reduced or possibly avoided (Skinner & Hampson, 1998). Adolescents diagnosed with diabetes are especially at risk for future complications because disease management and metabolic control typically begin to decline at the age of 12 or 13 years old when many youths assume more self-care responsibility

(Soutor et al., 2004). Although this decline in metabolic control is partly attributable to the physiological aspects of puberty such as rapid physical growth leading to a need for increased insulin or hormonal changes, research also indicates that adolescence is a period of reduced self-management (Anderson et al., 1990). However, a relatively consistent finding is that adolescents from more supportive cohesive families have better metabolic control and adherence (Burroughs et al., 1997).

For various reasons about one-third of diabetics have significant problems in keeping proper glycemic control in adolescence. Hormonal changes together with increased insulin need due to physical growth provide some explanation for the increasing hemoglobin percentage values in adolescence. Emotional reactions may also play a role. Many adolescents experience feelings of anger and being cheated (Holmes, 1986). Feeling different because of their rigid health regimen, adolescents may attempt to avoid rejection by their peers and may neglect careful management (Turk & Spears, 1983). Social and psychological factors are implicated through non-compliance with the treatment as strict adherence to treatment confronts the way of life at puberty. Among adolescents, girls display poorer overall metabolic control than do boys (Korbel et al., 2007).

Adolescents feel like they will live forever (Santrock, 2004) and at times they are sure they know everything. This may lead them to ignore or dislike physicians or parents telling them what to do. In practice, clinicians face coping problems in many adolescents, and about 1 in 10 has severe compliance problems. On the other hand, Hoff, Mullins, Chaney & Hartman (2002) found that increased illness uncertainty to be significantly associated with decreased perceived control of their illness as well as increased psychological distress in adolescents with Type 1 Diabetes. To find a flexible approach to the treatment of the disease for adolescents with

inadequate coping skills has important implications for teams taking care of adolescent diabetics (Drash, 1986).

Children with diabetes have a two-fold greater prevalence of depression, and adolescents up to three-fold greater, than youth without diabetes (Grey, Whittemore, & Tamborlane, 2002). According to Connell, Fisher & Houston (1992), several factors contribute to the increased prevalence of depression among those with a chronic illness, including the effect of the disease on physical functioning and activity, social relationships, quality of life and morale. Depression has a profound adverse influence on quality of life and overall functioning and has additional repercussions with individuals with diabetes because of its association with poor management (Mazze, Lucido & Shamoon, 1984). This association is poorly understood but has been hypothesized to operate through depression-induced abnormalities in neuroendocrine and neurotransmitter function, through decreased compliance with diabetes management, or because of as-yet-unknown complex behavioral-physiologic interaction.

For adolescents, the challenge of diabetes is combined with the developmental tasks of adapting to puberty and a changing body image, peer group pressure, autonomy from the parents and identity formation (Delamater, 1986). Adolescents with Type 1 Diabetes are known to be at increased risk to various forms of psychopathology (Law, 2002). Adolescent females with Type 1 Diabetes tend to define themselves in terms of their illness more so than males (Helgeson & Novak, 2006). Perceiving diabetes in negative terms is related to low self-esteem in females. This tendency is also related to poor psychological (anxiety, depression, and anger) well-being and poor metabolic control.

The combination of diabetes and depression in children, and especially adolescents, is important because it is associated with 10-fold increase in suicide and suicidal ideation. Also,

recurrence and course may be more severe than in adults, with some studies showing that depression tends to be more severe, take longer to resolve the initial episode and is more likely to recur compared with youth without diabetes. It may be associated with poorer metabolic control in diabetes, which may lead to complications and other poorer outcomes, and several studies have suggested that youth with diabetes and depression may be likely to have other comorbid conditions, such as eating disorders, adjustment disorders or anxiety disorders (Law, 2002).

Being diagnosed with diabetes as an adolescent is a stressful experience. Age of onset and diabetes duration was significantly associated with metabolic control and behavior problems (Nadeau, 1994). One study found that duration of diabetes was significantly correlated with depressive symptoms in a U-shaped distribution and that depressive symptoms were more common in the earlier years post diagnosis, less common between 4 and 9.9 years after diagnosis and rose again after 10 years. Other studies suggest that 20% of the variance in metabolic control is statistically explained by depression in youth. Hains et al. (2001) mention in their study that although many adolescents display adjustment problems with the onset of diabetes, most of them dissipate within 1 year; however, early psychological problems, such as depression, for some persist over time and have clinically relevant consequences for later functioning, adherence, and metabolic control.

Rates of depression may vary according to the duration of illness and age of onset. Delamater (1986) found that levels of depressive symptoms remained relatively stable, but the presence of depressive symptoms at diagnosis was associated with a higher prevalence of depression later. This second period of depression was characterized as being associated with the end of the physiologic honeymoon period and the necessity of learning to live with diabetes lifelong. The honeymoon period is the period just after the diagnosis of diabetes has been made

where insulin needs may be low and the blood glucose levels more consistent. This is a deceiving experience since, as time passes, the insulin needs will increase and the blood glucose levels will become more inconsistent. Male adolescents may find diabetes to have a more profound effect on work and social life than females, while females report more diabetes-related worries (Nadeau, 1994).

Delamater (1986) also found that those teens who reported lower family adaptability, lower family cohesion and less warmth and caring diabetes family behaviors were more likely to have depressive symptoms than those with higher family functioning. Youth who had a history of psychosocial difficulties either individually or in the family and who reported that they felt less warm and caring or adaptability from their families in their diabetes management were most likely to have higher depression scores.

In the literature on the influence of the family on adolescents with Type 1 Diabetes, it was also found that adolescents' perceptions of maternal psychological control were associated with greater depressed mood regardless of age and gender (Butler, Skinner, Gelfand, Berg & Wiebe, 2007). Firm control was strongly associated with greater depressed mood and poorer self-efficacy among older adolescents, less strongly among younger adolescents. Adolescents' perceptions of maternal acceptance were associated with less depressed mood, particularly for girls and with better self-efficacy for diabetes management, particularly for older adolescents and girls. During adolescence, the challenge for families is to maintain a level of involvement in diabetes management that supports the adolescent's growing independence and autonomy, while making certain that daily diabetes management tasks are completed competently.

Additionally, Skinner & Hampson (1998) examined social support in relation to self-care and well-being in adolescents with Type 1 Diabetes. They found that perceived impact of

diabetes and peer support were significant predictors of depression. Also, family support was a significant predictor of self-management. A chronic illness like diabetes creates ongoing stresses for the adolescent and their family (Brown, Krieg & Bulluck, 1995). As the adolescent transitions developmentally, physical and psychological issues consistently arise to be dealt with. Families that are more supportive may encourage and model the adoption of more adaptive attitudes and behaviors related to illness.

Better management of diabetes occurs when adolescents view parents as supportive and available as collaborators, but not as intrusive or controlling. Psychological control has been consistently associated with greater depression (Barber, Stolz & Olsen, 2005) whereas parenting styles characterized by high acceptance and moderate levels of firm control are associated with a range of positive child outcomes. Parenting styles characterized by high control but low acceptance, and those that are specifically low in firm control are associated with externalizing behaviors. During the adolescent years, older children may come to view psychological and/or firm control as intrusive and developmentally inappropriate relative to younger children; such perceptions are associated with poor psychosocial adjustment and adherence among adolescents with diabetes.

As one can see, multiple indicators of well-being have been identified in the literature that either limit or support the adolescent's ability to manage diabetes. Depressive symptoms frequently accompany childhood diabetes. Increased depressive symptoms may limit the child's ability to cope with diabetes stressors and adhere to the medical regimen leading to problems in glycemic control. Children with diabetes also experience lower levels of perceived competence and self-efficacy than healthy children, which may impair adherence to the medical treatment.

Adherence is important to consider during adolescence as it is typically poorer during this period (Johnson, Kelly, Henretta, Cunningham, Tomer & Silverstein, 1992).

Medication adherence is a complex issue involving the child, family members, and other caregivers. This process is dependent on the family's cultural beliefs, their perceptions of disease severity, and their understanding of the benefits of treatment. Patients often construct their own versions of adherence according to their personal worldviews and social contexts. Children with chronic illnesses often have more than one health care provider. Identification and communication among the parents, the various physicians, school nurses, pharmacists, teachers, and guidance counselors is essential, and the creation of a school management plan often in necessary. It is essential to inform parents and empower them to be an integral part of the team. Addressing family conflicts and introducing targeted interventions to build positive family involvement and interaction around disease management may have a positive effect on medication adherence.

The family context is important for understanding how children adjust to and manage chronic illnesses such as diabetes. Children with chronic illness benefit from a cohesive family environment where parents are responsive and accepting (Butler, Skinner, Gelfand, Berg, & Wiebe, 2007). Adolescents' perceptions of maternal psychological control were associated with greater depressed mood regardless of age and gender. Firm control was strongly associated with greater depressed mood and poorer self-efficacy among older adolescents, less strongly among younger adolescents. Adolescents' perceptions of maternal acceptance were associated with less depressed mood, particularly for girls and with better self-efficacy for diabetes management, particularly for older adolescents and girls (Butler et al., 2007). During adolescence, the challenge for families is to maintain a level of involvement in diabetes management that supports

the adolescent's growing independence and autonomy, while making certain that daily diabetes management tasks are completed competently.

During the adolescent years, older children may come to view psychological and/or firm control as intrusive and developmentally inappropriate relative to younger children; such perceptions are associated with poor psychosocial adjustment and adherence among adolescents with diabetes. When family communication is negative, adolescents are more likely to observe a family decision-making process characterized by pessimism, failure to take responsibility, and the inability to consider alternate perspectives. In this context, allocations of responsibility for diabetes decision-making may be unclear, making successful management of diabetes difficult to achieve.

Joint decision-making is likely to precede full adolescent autonomy for diabetes-related issues and has been identified as a significant component of diabetes management in prior research. In addition, joint decision-making may be crucial for the development of diabetes self-management skills in adolescents. It is possible for an adolescent to possess competent decision-making skills but fail to apply these skills in family and medical care contexts in such a way that adequate adherence is achieved. Diabetes-related decisions must be made on a daily basis, carry additional emotional significance compared with other types of decisions, and may have both short-term and long-term health consequences. It is possible that adolescents approach these decisions differently than they do other types of issues.

Leadbetter (2002) compared adolescents with diabetes to those without diabetes on several measures. Results from this study found significant associations between measures of family functioning and child outcomes for both groups. However, for families with a child

diagnosed with diabetes, it was found that greater parental involvement was associated with better glycemic control. It was also found that earlier diagnosis of diabetes was associated with greater parental supervision and ineffective parenting behaviors that were associated with more problematic child behaviors.

Geffken et al. (2008) found that not only did family support play a role in the management of type 1 diabetes in adolescents, but that parents who were perceived by their children as displaying more warmth and caring about the diabetes regimen have children who had a lower occurrence of DKA. Similarly, they found that children who reported more negativity related to their diabetes regimen were more likely to experience episodes of DKA. Also, Le Greca et al. found that preadolescents who assume greater responsibility for diabetes care were in poorer glycemic control as compared with peers who have more parental support.

Paterson & Thorne (2000), in a qualitative study of diabetes self-management phases, found that most of their participants went through a rebellion phase in learning how to manage their diabetes during adolescence. An excerpt from their study states, "I remember going through my adolescence thinking I can deny this whole thing. I can drink Cokes with the kids. So, I go drink all the Coke, go through the hyperglycemia, and suffer all the side effects rather than admit that I couldn't keep up with them. I didn't manage my diabetes during my adolescence. I denied it." Factors that brought on this stage may have been the individual's desire not to listen to what others were telling them to do and also wanting to fit in with the crowd, and experiencing anger as a reaction to having diabetes.

In another study comparing adolescents with diabetes to those without diabetes, Ryan, Vega, Longstreet & Drash (1984) found that adolescents with Type 1 Diabetes performed more

poorly on a number of tests known to be sensitive to brain damage. While Ryan and colleagues did not readily accept that diabetes causes brain damage, they did have the following explanations for their findings: adolescents with diabetes may miss more days of school, have motivational, academic, and social problems in the classroom, may have a more cautious response style, or may have had high or low blood glucose levels at the time of the testing.

Helgeson et al. (2008) interviewed 70 girls and 62 boys annually for 4 years where risk and resistance factors, including demographics, disease-related variable, self-care behavior, and psychosocial variables were assessed as well as HbA1c. Multilevel modeling showed metabolic control deteriorated with age. Self-care behavior interacted with age to predict the decline, such that self-care was more strongly related to poor metabolic control for older adolescents. Eating disturbances, depression, and peer relations were related to poor metabolic control, whereas good family relations were related to better metabolic control for girls.

Adolescents with diabetes are at increased risk for eating disorders and disturbed eating behavior because the diabetes regimen sets in motion a pattern of dietary restraint, and because intensive insulin therapy has been associated with weight gain. Adolescents with diabetes may purposely skip insulin injections or reduce their levels of insulin to lose weight.

A recent study concluded that children and adolescents with type I diabetes have nearly double the rate of depression of youth in general (Hood et al., 2006).Indicators of psychological distress, especially depression, have been linked to metabolic control among adults, but the relationship of depression to metabolic control among children is less clear. Actually, two narrative reviews of the literature reached different conclucions, one suggesting that depression is related to poor metabolic control among adolescents with a few exceptions (Grey, Whittemore,

& Tamborlane, 2002) and one concluding that relations are unclear (Dantzer, Swendsen, Maurice-Tison, & Salamon, 2003).More research is needed in this area to clarify the relation of depression to metabolic control and to determine if that relation changes over the course of adolescence.

To the extent that depression is associated with poor metabolic control, the relation may be direct or indirect. Depressive symptoms may have direct effects of metabolic control via counter regulatory hormones. Alternately, depression may indirectly affect metabolic control by detracting from self-care behavior.

A review article on children and chronic illness concluded that researchers have failed to incorporate gender into their models (Miller & Le Greca, 2005). Gender is especially relevant to this research, as several studies have found that girls have worse metabolic control than boys during adolescence (La Greca et al., 1995).

Davis, Anderson, Linkowski, Berger, & Feinstein (1985) conducted an exhaustive literature review and gave recommendations for rehabilitation counselors. They stated that poorly controlled juvenile diabetes may lead to slowed growth and delayed onset of puberty, and several investigators have found that diabetic adolescents have significant alterations in their body images (feeling that their bodies are damaged, feeling that internal organs are missing). Also, the few studies in which the peer relationships of chronically ill or disabled adolescents have been examined suggest that these adolescents express great concerns about their social relationships (Helgeson et al., 2008). Additionally, adolescents with disabilities may attempt to dissociate themselves from other disabled persons to avoid potential rejection from peers because disabled teenagers do not want to be identified as being different. This may be particularly true of

adolescents with nonvisible conditions, and their decisions to disclose that they have a chronic illness or disabling condition may be closely associated with their subjective perception of whether they are disabled.

The nature and severity of the illness or disabling condition also affects the autonomous functioning of the chronically ill or disabled adolescent. Parents may feel particularly overprotective toward their teenager if past attempts at independent functioning have resulted in exacerbations of the illness or disability. Another problem for disabled teenagers is that medical and allied health practitioners, as well as parents, often become concerned and preoccupied with the disabling condition that they forget that these children must simultaneously deal with the physical limitations of the disability but also with how these limitations affect their vocational interests and the development of vocational skills. Significant relationships between acceptance of disability and measures of personal competence have also been found such as acceptance and internal rather than external locus of control.

Grylli, Hafferl-Gattermayer, Wagner, Schober, & Karwautz (2005) enrolled199 adolescents that were screened and diagnosed with eating disorders. Adolescents with clinical eating disorders or subthreshold eating problems had significantly higher mean scores in harm avoidance and lower mean scores in self-directedness. Harm avoidance remained significant after controlling for depressive pathology. Among youths with type 1 diabetes, there is an association between low self-directedness, high harm avoidance, and the presence of eating, weight, and shape pathology. Adolescent girls and young women with type 1 diabetes have an increased risk for eating disorders as well as for milder, subthreshold eating problems. The presence of eating disorders meeting criteria of the DSM-IV was twice as common in adolescent females with type 1 diabetes as in peers without type 1 diabetes.

Hauser, DiPlacido, Jacobson, Willett, & Cole's (1993) literature review found that the administration of insulin by injection is taken on as an early task by the mother or father of the diabetic child. In adolescence, this practice frequently shifts to self-injection by the child. Parental involvement in the affairs of their adolescent's body, ordinarily diminishing in adolescence, is consequently often heightened, clearly differing from the kind of involvement that a parent might otherwise express in these early adolescent years. Other forms of increased parental attentiveness are also elicited by their adolescent's diabetes. There is the necessity to monitor their son or daughter's metabolic control, leading the parent to examine, or be sure that their adolescent has "tested" urine or blood products one or more times each day. Moreover, the conscientious parent who is following the best standards of medical management is also monitoring their child's physical activities outside the home, being sure that he or she is participating in enough exercise. To complicate matters even further, the parent must, with higher vigilance than usual, enforce restrictions about alcohol or other dietary pleasures, such as fast foods.

Ego development likely influences important health behaviors, such as compliance, adjustment to long- and short-term diabetes demands, and judgments of risk. Moreover, advanced levels of ego development may enhance the adolescent's tolerance of peer pressure toward noncompliance and changes in lifestyle.

For the adolescent with high compliance, her family's orientation of cohesiveness and interconnectedness as a family appeared to enhance their ability to competently deal with her diabetes. The family of the adolescent with less optimal compliance expressed anxious concerns about their family cohesiveness. The high compliant family also strongly relied on the appraisal coping strategy of "mastery" and less so on "helplessness." The low compliant family made

strong statements indicating their current feelings of helplessness and rarely spoke about family experiences of mastery.

Both families sought information and support; yet, the high compliant family employed these coping processes in active, positive, and progressive ways, whereas the low compliant family responded more passively, receiving information and support offered by others, yet not indicating any use of such assistance for their betterment; their emphasis was on routine and inaction rather than integration.

Because of the complexity of the disease as well as the interactions with daily life, academics, and social life it is not difficult to believe that youths with diabetes and their families are often referred by their physician to therapy (Wysocki, 2006). The most common referral issues in this population are problems with treatment adherence and diabetic control, problems with social and coping skills, and problems with diabetes-related anxiety and stress management. Demographic factors that increase risk for nonadherence with treatment include older age of the youth, single-parent family composition, and lower socioeconomic status. Behavioral factors that may predict poor treatment adherence are inordinate child responsibility for treatment tasks, high levels of family conflict and poor family communication and problems-solving skills, and deficient social skills and coping methods. Psychological stress can interfere with glycemic control indirectly by impeding treatment adherence and directly by inducing secretion of stress hormones that block insulin action and increase blood glucose levels.

Depression & Psychosocial Adjustment in Adolescence

In order to manage well one's diabetes, one must have the abilities and support to cope with this loss. Healthy coping requires a host of behavioral skills which may be just recently

developing in period of adolescence (Bernard & Krupat, 1994). Adolescents may not yet have the skills to cope with their growing challenges. They may tend to feel overwhelmed and stressed due to the daily stressors of being a teenager. Stress is related to depression in adolescence (Daniels & Moos, 1990) and depression is a serious health risk, especially for adolescents without proper social support. This may leave the adolescent unable to cope with the challenges they face. Female adolescents are especially susceptible to depression as Nolen-Hoeksema & Girgus (1994) found that across ages 10 to 15, the prevalence of depression among girls increases to twice that of boys.

Andreasen & Wasek (1980) have reported that stressors are more likely to be chronic in adolescents than in adults. A style of decision-making that is characterized by pessimism and indecisiveness may render the adolescent ineffective in making decisions about diabetes care, especially if the adolescent feels that the outcome will be negative regardless of what he or she decides. The end result may be that diabetes tasks do not get completed in a timely manner or that they do not get completed at all.

Venning et al. (2007) studied children diagnosed with chronic illness and their parents. At the onset of a child's chronic illness, hope levels are affected. Their study suggests that acquiring a chronic illness may be more devastating to the child's hopeful thinking than if they were born with it. The study explained that being diagnosed with an acquired chronic illness dashes a child's hopes after expectancies of a future without illness have already been formed.

A longitudinal study up to 9 years after diagnosis found that most children experienced some psychological symptoms (anxiety, depression, social withdrawal), with more than one third meeting criteria for clinical diagnosis. Similar symptoms occurred in parents, with mothers

experiencing significantly more distress than fathers (Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986).

Research on coping in adolescence proposes that significant changes may occur in coping practices between early and late adolescence (Williams & McGillicuddy-De Lisi, 2000; Broderick & Korteland, 2002; Plancherel & Bolognini, 1995). Williams & McGillicuddy-De Lisi (2000) found that older adolescents used a larger variety of coping strategies, used strategies that reduced the impact of the stressor, and used more cognitively-oriented strategies than did younger adolescents. However, even young adolescents use a variety of coping strategies including support seeking and using social relationships, rumination, venting, distraction, problem-solving, and humor.

There may be differences in the ways that adversity is dealt with in adolescence depending on the gender of the individual. Broderick & Korteland (2002) observed gender differences when gender role scripts impacted acceptability of coping strategies for both genders. For example, it may be socially acceptable for a female adolescent dealing with depression, adversity, or the like to cry in public, while this may not hold true for the male adolescent. However, Williams & McGillicuddy-De Lisi (2000) found no gender differences in their study of coping strategies in adolescence.

Children and their families who are devastated and overwhelmed by a chronic illness in the child may experience hopelessness, helplessness, disorganization, and numbness. Lewis & Vitulano (2003) describe diabetes stressors as the medical interventions themselves as well as parent-child control struggle over the medical regimen, adolescent rebellion, and pain of daily injections, fear of coma or insulin shock, and anxiety over long-term complications.

In conclusion, adolescence is a period of development marked with many changes.

Depression in adolescence may be different from depression experienced in childhood or adulthood. Although adolescents have more mental capacities to deal with stressors, they are also experiencing a myriad of other issues such as physical changes, hormonal changes, and trying to discover and solidify a personal sense of identity. The diagnosis of diabetes is a complicated stressor. It has both an immediate and long-lasting affect and can lead to a rollercoaster of grief reactions throughout the lifespan, but may be even more difficult in the developmental period of adolescence.

CHAPTER III

METHODOLOGY

Participants

Participants included a total of 23 adolescents (10 girls, 13 boys), ages 12 to 18 years, diagnosed with Type 1 Diabetes. The adolescents were volunteer patients at a pediatric diabetes and endocrinology clinic in a metropolitan children's hospital and were recruited during their regularly scheduled appointments within the clinic by the researcher. The sample includes adolescents with varying lengths of diagnosis as well as varying levels of glycemic control. Of the 85patients given the opportunity to participate in this study, 23 chose to do so.

Participants' average age was 14 years old (SD= 2.02). The average time since diagnosis was 6.6 years (SD= 4.95). The mean glycosylated hemoglobin (HbA1c) blood level in this sample was 8.5 (SD= 1.70) when they volunteered for the study. Participant's parental marital status varied: 14 married, 5 single, 4 divorced. The income and education levels also varied in this sample with a great number making less than \$25,000 annually. See Table 1 for complete demographic information.

Procedure

Data were collected for this study in order to explore of the influence of depression, psychosocial adjustment and duration of illness on glycemic control in adolescents with Type 1 Diabetes. During initial recruitment, adolescents and their parents were informed of the study by the researcher at their regularly scheduled doctor's appointment in the children's hospital diabetes and endocrinology specialty clinic. Parental informed consent as well as adolescent assent was obtained prior to the completion of any study-related measures (See appendices A and B).

After consent and assent were obtained, the parent or guardian completed a demographic questionnaire. The demographic questionnaire included information about the parent's and child's age, gender, education level, race/ethnicity, family income, parent marital status, child's date of diagnosis of Type 1 Diabetes as well as their most recent HbA1C measurement (See appendix C).

Following the completion of the demographic questionnaire, the adolescent alone then completed two inventories. The first inventory was the Beck Depression Inventory-Fast Screen for Medical Patients (BDI-FS) and was given to screen for depression in patients reporting somatic and behavioral symptoms that may be attributable to biological or medical issues. After the completion of the BDI-FS, the adolescent was given the second inventory on adjustment. The second inventory was the Psychosocial Adjustment to Illness Scale- Self Report (PAIS-SR) and was given to assess the quality of the patient's psychosocial adjustment to a current medical illness or its residual effects.

Together, the BDI-FS and the PAIS-SR were used in combination to give a more global picture of each participant's current psychosocial functioning as it relates to their diagnosis of Type 1 Diabetes.

As previously mentioned, the data collected in this study were collected as part of a study of the influence of depression, psychosocial adjustment and duration of illness on glycemic control in adolescents with Type 1 Diabetes. Research questions are as follows: Are the main study variables (depression, psychosocial adjustment, duration of illness, HbA1C) significantly related? Do any of the study variables (depression, psychosocial adjustment, duration of illness) significantly predict participants' HbA1C measure?

As there are a number of important questions this study attempted to answer, there were also hypotheses for these questions obtained from a combination of a review of the relevant literature and clinical experience. Hypothesis 1: As depression and poor psychosocial adjustment increase (higher scores on the BDI-FS and PAIS-SR), HbA1C also increases. Hypothesis 2: As duration of illness (time since diagnosis) increases, HbA1C decreases. Regression and correlational analyses were utilized to statistically obtain this information following data collection. Regression analyses were utilized to explore the predictive nature of the score on BDI-FS, score on PAIS-SR, and duration of illness on HbA1C (glycemic control). Pearson correlational analyses were conducted to explore the relationships between and among the main study variables: scores on BDI-FS (depression), scores on PAIS-SR (psychosocial adjustment), duration of illness, HbA1C.

Measures

Demographic Questionnaire

Demographic and disease information regarding child and family characteristics were obtained through the completion of a demographic questionnaire in this study. Many demographic factors have been shown to moderate youths' diabetes metabolic control (Swift, Chen, Hershberger & Holmes, 2006). Information included on the questionnaire were age, gender, grade in school, race/ethnicity, family income, parent marital status, date of diagnosis, and most recent HbA1C measurement (See appendix C).

Duration of Illness

Duration of illness describes the length of time since the adolescent was diagnosed with Type 1 Diabetes. The date of diagnosis was included on the demographic questionnaire. The number of years and months since diagnosis were then calculated and recorded.

A study on 103 children and adolescents less than 15 years old examined the child and parents response to the diagnosis of diabetes with symptoms of psychological distress and dysfunctional family functioning (Northan, Anderson, Adler, Werther, & Warne, 1996) at a 1 year follow-up. The results showed mixed results in the sense that at first assessment, significantly more of the children 4 to 11 years scored within the clinical range on internalizing, and total behavior problems measured by the Child Behavior Checklist, but these differences were no longer significant 1 year later.

In another study, self-reported diabetes adjustment (assessed in terms of attitudes and feelings about diabetes) appeared to have improved at 10-year follow-up. Such findings may indicate adaptation to the disease, as some authors have shown that onset of diabetes would be associated with psychological symptoms that would lessen but not disappear in the 12 months following diagnosis (Northam et al., 1996).

In another recent study aimed at investigating the longitudinal relationship between psychiatric diagnostic variables and metabolic control among youth with diabetes, psychiatric morbidity and duration of diabetes were found to have an interactive effect on metabolic control, with diabetes duration being more salient than age in this regard (Kovacs et al., 1996).

HbA1C

Glycosylated hemoglobin is an index of average blood glucose over the past 2 to 3 months (ADA, 1998). It is measured using high performance liquid chromatography. This process is completed by taking a drop of blood (obtained by finger prick) from the patient at the specialty clinic. HbA1C is obtained every 3 months during a routine doctor's appointment. The obtained number is a representation of the average blood sugar over the last three months. An HbA1C of 6 equals an average blood glucose level of 120. For every 30 points above 120, a whole number is added. For example, an HbA1C of 7 equals an average blood glucose level of 150 while an HbA1C of 8 equals an average blood glucose level of 180. HbA1C levels are measured to the nearest tenth of a point. For the purposes of this study, adolescents with HbA1Cs under 8 demonstrate good glycemic control while scores above 8 demonstrate poor glycemic control.

Adolescents are notoriously poor in adhering to diabetic regimens (Hoffman, 2002). However, objective measurement of self-care presents a challenge. There is little information in the literature on the reliability and validity of adolescents' reports of their self-management, therefore HbA1C is the most reliable measure for this. The most recent HbA1C measurement was included on the demographic questionnaire.

Beck Depression Inventory- Fast Screen for Medical Patients (BDI-FS)

Depression is the experience of deep sadness and loss of interest in nearly all normal activities. Depression is sometimes used as a common term to describe momentary periods of sadness and diminished interests, feeling down, and so on. However, the Diagnostic and Statistical Manual of Mental Disorders-IV-TR includes diagnoses describing more severe forms of depression affecting one's social and relational functioning that also include symptoms such as despair, hopelessness, helplessness, and worthlessness. Anyone may experience depression at one time or another, but not necessarily meet the DSM-IV-TR criteria for a diagnosis of Major Depression or other related mood disorder diagnoses. Depression may be caused by a number of factors including triggering events, life circumstances, or genetics. It is treatable with psychotherapy and/or pharmacotherapy.

It is possible to experience depression in response to receiving a chronic disease diagnosis. (It is important to note that we cannot attribute any depressive symptoms purely to the diagnosis as other factors may also be in play such as family conflict, genetic predisposition, and other life stressor variables). For children who are diagnosed

with a chronic disease in late childhood, loss of their former "normal" life may be a triggering event and/or a constant struggle that may affect depressive symptoms.

Instruments, such as the Beck Depression Inventory, are recommended for measuring the impact of non-death losses as is the case in this study. This inventory was following parental consent, participant assent, and the completion of the demographic questionnaire. The depression inventory was administered to the participant (the adolescent) only.

The BDI-FS is a 7-item self-report questionnaire used in adult and adolescent populations. The seven items were taken from the original 21-item Beck Depression Inventory-II. It was designed to screen for depression in patients reporting somatic and behavioral symptoms that may be attributable to biological, medical, alcohol, and/or substance abuse problems. It is used in place of the BDI-II with medical patients in order to reduce the number of false positives for depression.

The BDI-FS is scored by summing all of the highest rating for each of the seven items. Each item is rated on a 4-point scale ranging from 0 to 3. Total scores on the BDI-FS range from 0 to 21 with higher scores on the BDI-FS indicating poorer functioning. The cut-off score used should be based upon the clinical population for which the instrument is being used as well as the suspected underlying prevalence of clinical depression in the sample being screened. For this study, the cut-off score is 4 and above (scores of 4 and above in this population are used to identify patients with and without Major Depressive Disorder (MDD)). Winter, Steer, Jones-Hicks, and Beck (1999) screened 100 adolescents (12-17 years old) who were scheduled for health maintenance

exams with their physicians and found that a total cut-off score of 4 and above had 91% sensitivity and 91% specificity for differentiating adolescents with and without MDD.

The BDI-FS is made for use with individuals ages 12-82 and takes approximately five minutes to administer. This measure was formerly called *Beck Depression Inventory* for Primary Care. The internal consistency is .88 within outpatient populations being treated by physicians in family practice. In the area of construct validity, The BDI-FS was correlated with the Hospital Anxiety & Depression Scale (HDS), another depression screening tool widely used in medical settings. The correlation between the BDI-FS and HDS total scores was .62. As previously stated, the BDI-FS is composed of seven items from the BDI-II; the BDI-II was specifically developed to assess the depressive symptoms listed as criteria for depressive disorders in the DSM-IV, therefore suggesting high content validity. Mulrow et al. (1995) reviewed studies about the usage of nine widely used depression screenings for medical settings and found that the average rate of sensitivity was 84% while the average rate of specificity was only 72%. However, the average sensitivity rate for BDI-FS studies was 92% while the average specificity rate was 88%.

Psychosocial Adjustment to Illness Scale- Self Report (PAIS-SR)

Psychosocial adjustment is a term used to describe the process of intrapsychic, social, and cultural environmental functioning of individuals in response to a life event, stage, or circumstance. These interactions between the individual and themselves, others, and their environment are usually achieved through roles (vocational, domestic, social, etc). So, psychosocial adjustment is composed of multiple domains.

With individuals with medical issues, psychosocial adjustment may be significantly involved in etiology, course, or outcomes of the illness. In other words, within the contexts of many major diseases (Kaplan-deNour, 1982; Murawski, et al., 1978; Zyzanskil et al., 1981), the nature of the patient's psychosocial adjustment can be just as important as the status of his/her physical disease in determining the quality of an illness experience. In the case of medical patients, there is not an extensive range of assessment methods available to measure psychosocial adjustment.

The Psychosocial Adjustment to Illness Scale-SR is a 26-item questionnaire designed to assess the quality of a patient's psychosocial adjustment to a current medical illness or its residual effects. Higher scores indicate poorer functioning. This scale was given to the participant only (the adolescent) after the completion of the BDI-FS. It was made for use with adult or pediatric medical patients or their immediate relatives. This measure contains the following seven domains: Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationship, Extended Family, Social Environment, and Psychological Distress (Derogatis, 1986). This instrument has shown a good degree of reliability for both groups and individuals. (PAIS & PAIS-SR Administration, Scoring & Procedures Manual-II, Derogatis, L.R. and Derogatis, M.F., 1990). Internal consistency reliability for this instrument was derived by the domain sampling model (Nunnally, 1978) and relates to the consistency with which items comprising a particular scale measure the construct in question. The reliability coefficients for the PAIS-SR are as follows for its seven domains: Healthcare Orientation, 0.47; Vocational Environment, 0.76; Domestic Environment, 0.77; Sexual Relationship, 0.83; Extended Family, 0.62; Social Environment, 0.80; Psychological

Distress, 0.85. Interrater reliability for this instrument was also obtained. Interrater reliability coefficients for the PAIS-SR total score ranged from 0.83-0.86.

Construct validity for the PAIS-SR was measured by using factor analysis. Seven substantive dimensions are identified in the analysis, accounting for approximately 63% of the variance in the matrix. In the varimax solution Factor 1 accounted for 18% of the variance, with the remaining dimensions being associated with 10, 9, 8, 7, 7 and 5% respectively, therefore confirming the dimensional structure of the PAIS-SR. To measure convergent validity, the PAIS-SR was given to patients along with the Global Adjustment to Illness Scale (GAIS). The GAIS is also an adjustment scale in which higher scores reflect poor adjustment. The PAIS and the GAIS were positively correlated; the correlation coefficient between the two total scores was 0.81 (PAIS & PAIS-SR Manual. 1990. Derogatis, L.R. & Derogatis, M.F. Clinical Psychometric Research, INC.).

The PAIS-SR is designed to be interpreted at 3 distinct but related levels: the global level, the domain level, and the discrete item level. Data from each of the three levels of interpretation should converge to deliver an integrated picture of the participant's adjustment to his/her illness. The total score can provide a good indication of the participant's overall adjustment while the domain scores show areas of relative strengths and weaknesses, and discrete items communicate specifics about their illness experience. A total score equivalent to or greater than a T-score of 62 are positive for clinical levels of psychosocial adjustment.

CHAPTER IV

FINDINGS

Although the total number of participants (N=23) in this study is quite low, similar studies on adolescent diabetes produce similar participant numbers(Anderson et al., 2007; Hoffman, 2002; Kovacs et al., 1996; Northan et al., 1996; Stewart et al., 2005; Wysocki et al., 1993). The clinic utilized in this study has approximately 300 total patients of which only 85 met enrollment criteria. Therefore, the small participant pool from this specialty sample returned a small number of participants with 27% of patients approached consenting and completing the study. For this reason, this study's focus was exploratory in nature. See Table 1 below for sample demographics.

Table 1

Demographics of the Sample (n = 23)

Age	m =17.09	sd = 1.05	range = 14-19	
Gender		n		%
Male		13		56.5
Female		10		43.5
Race		n		%

	African American	2	8.7
	Hispanic	2	8.7
	Indian/Native American	4	17.4
	White/Caucasian	14	60.9
	Asian	0	0
Grade in School		n	%
	Fifth (5 th)	1	4.3
	Sixth (6 th)	3	13.0
	Seventh (7 th)	4	17.4
	Eighth (8 th)	5	21.7
	H.S. Freshman (9 th)	0	0
	H.S. Sophomore (10 th)	3	13.0
	H.S. Junior (11 th)	3	13.0
	H.S. Senior (12 th)	4	17.4
Family	/ Income	n	%
	<25,000	10	43.5
	25,000-50,000	5	21.7
	50,000-75,000	6	26.1
	75,000-100,000	2	8.7
	>100,000	0	0
Paren	t Marital Status	n	%
	Single	5	21.7

Married	14	60.9
Divorced	4	17.4
Parent Education	n	%
HS diploma/GED	10	43.5
Some College	6	26.1
Associate's Degree	3	13.0
Bachelor's Degree	4	17.4
Master's Degree	0	0
Doctoral Degree	0	0

There were many findings worthy of mention in this study. Of the 23 participants who completed the study, 30.3% met or exceeded the cut-off score on the Beck Depression Inventory- Fast Screen for Medical Patients (total score >/= 4) suggesting significant depressive symptoms present within the past month. In addition, 26.1% of participants met or exceeded the cut-off score on the Psychosocial Adjustment for Illness Scale (total score >/= 62) suggesting poor adjustment. In other words, roughly 1/3 of these adolescents were struggling with depression or poor psychosocial functioning at the time of the study. The average score on the BDI-FS was 2.6 (SD=3.6). The average score on the PAIS was 58.7 (SD=18.9). The average duration of illness in years was 5.8 (SD=5.1). And the average HbA1C was 8.5 (SD=1.7). See Table 2 below.

Table 2

Measure	Mean	Standard Deviation	Range
BDI-FS	2.6	3.6	0-14
PAIS-SR	58.7	18.9	43-132
Duration of Illness	5.8	5.1	0.5-17.1
HbA1C	8.5	1.7	6.7-12.5

Means and Standard Deviations for BDI-FS, PAIS-SR, Duration of Illness, and HbA1C

What are the bivariate relationships between BDI scores, PAIS scores, Duration of Illness and HbA1C ?

Pearson correlations were conducted to explore the bivariate relationships between and among the main study variables of depression, psychosocial adjustment, duration of illness and HbA1C. Two relationships were statistically significant, HbA1C with BDI scores, and BDI scores with PAIS scores. Participants' HbA1C measurements at the time of the study were negatively correlated to participants' scores on the Beck Depression Inventory (r=-0.24, p<.05). In this sample, those participants who scored higher on the depression measure actually reported lower HbA1C values (better glycemic control). Participants' scores on the Beck Depression Inventory were positively correlated with participants' scores on the Psychosocial Adjustment to Illness Scale (r=0.86, p< .05). This suggests that participants who experience depressive symptoms are also experiencing other symptoms characteristic of poor psychosocial adjustment to illness and that these two instruments are measuring somewhat similar constructs. Duration of Illness was not significantly correlated with any of the other study variables. See Table 3 below.

Table 3

Correlation Matrix of BDI-FS, PAIS-SR, Duration of Illness (DI), and HbA1C

	BDI-FS	PAIS-SR	DI	HbA1C	
BDI-FS 1.00					
PAIS-SR	.86 **	1.0	0		
DI	022	0	0	1.00	
HbA1C	24*	0	0	.09	1.00

*p<.05 ** p<.01

Do the study variables significantly predict the participants' HbA1C?

A multiple regression analysis was conducted to explore the linear relationship of depression, psychosocial adjustment and duration of illness with HbA1C. The model was not statistically significant, F (3,19) = 1.67, p> 0.05. Depression, psychosocial adjustment and duration of illness accounted for 37% of the variance in HbA1C scores in this sample; however, the R squared reduced that figure to only 14.7%. Even though the

overall model was not significant, the independent variable, BDI scores, is a significant predictor of HbA1C values (p < 0.05). See Table 4 below.

Table 4

Multiple Regressions of Depression, Psychosocial Adjustment and Duration of Illness as Predictors of HbA1C

Predictors	R	Rsq	F	β
	.37	.147	1.67	
Depression				880*
Psychosocial Adjustment				.749
Duration of Illness				.074

* p<.05 ** p<.01

CHAPTER V

CONCLUSION

Data were collected for this study in order to explore the influence of depression, psychosocial adjustment and duration of illness on glycemic control in adolescents with Type 1 Diabetes. In this sample, approximately 1/3 of the participants were currently experiencing depression or psychosocial adjustment related to their diabetes diagnosis. In addition, roughly half (10 of 23) of the participants' reported average blood sugars were in the poor range (HbA1C greater than 8.0), which is consistent with the literature. However, only depression, and not psychosocial adjustment or duration of illness was predictive of glycemic control.

Participants' HbA1C levels were negatively correlated to participants' scores on the Beck Depression Inventory. In this sample, those participants who scored higher on the depression measure actually reported lower HbA1C values (better glycemic control). It may be that participants who are compliant with medical advice are more burdened by the rigorous routine and therefore express more depressive symptoms. Participants who are not compliant and go about their daily lives without maintaining the rigorous routine score lower on the depression scale, even though they may be less physically healthy.

Participants' scores on the Beck Depression Inventory were positively correlated with participants' scores on the Psychosocial Adjustment to Illness Scale. This suggests that participants who experience depressive symptoms are also experiencing other symptoms characteristic of poor psychosocial adjustment to illness such as problems at home and school as well as a negative outlook on the future. This positive correlation is not surprising considering the instruments are measuring similar constructs.

Limitations of the Study

There were a number of limitations to this study. First, the number of participants is low. In addition, the environment in which participants were enrolled in the study is within a teaching hospital. These patients are all too familiar with being asked to participate in research and this may have contributed to only 23 of 85 approached patients consenting to this study. This population represents a small geographical area of the country and has limited diversity in areas such as ethnicity, parental education and annual household income. Also, this population is made up of adolescents in rural communities that may differ in many ways to adolescents living in urban environments. For example, a great number of participants' annual family income was at or under \$25,000.

In addition, the survey materials included in the study protocol took participants approximately 20-25 minutes to complete and may have contributed to patients choosing not to consent. Lastly, the survey materials in this study were only administered one time and therefore only give a snapshot look at the variables of interest in the lives of these adolescents.

Implications for Future Studies

In future studies, a larger number of participants would increase both the strength of the study as well as generalizability. Researchers, considering the specialty population, should aim to reach several clinics over a greater geographic area, including more diverse populations.

A longitudinal study with adolescents with Type 1 Diabetes may better capture the changing nature of chronic illness and its effects on the lives of those diagnosed. Similarly, longitudinal studies will better capture changes in HbA1c over a period of time as this study only took a one-time HbA1c reading. By better understanding how HbA1c changes over time in certain individuals, more specific contributing factors may become clear.

Additionally, future studies may incorporate treatment effectiveness for this population by using experimental design and randomizing participants into treatment and control groups utilizing psychoeducational groups, illness educational groups, and individual mental health treatment. Additional variables that may be of use in future studies include compliance with medical treatment, history of mental health treatment, and personality factors.

The depressive questionnaire used in the study, the BDI-FS, is a shortened version of the BDI-II and is comprised of the items focused on cognitive rather than vegetative depressive symptoms. Adolescents may vary in emotional and cognitive maturity and may not express depression in a purely cognitive manner that would be

detected by this instrument. In future studies, it would be interesting to use the BDI-II in order to assess for vegetative symptoms of depression in addition to cognitive symptoms.

Lastly, future studies should take into account grief experienced by these adolescents as not one study has yet to touch on this phenomenon in this population. The diagnosis of a chronic disease such as diabetes can serve as an extreme loss and life stressor. While grief has traditionally been understood as a bereavement-associated emotion, the construct has recently expanded to be included among the emotional reactions of living persons experiencing disability, illness or other life-altering events, as well as those caring for such persons (Marwit & Kaye, 2006).

Other implications for future research include taking into account other emotional experiences of adolescents with Type 1 Diabetes. For example, taking into consideration anger in this population may produce further insight as well as issues that could be treated in a therapeutic setting.

Implications for Theory and Practice

In summary, approximately one-third of adolescents diagnosed with Type 1 Diabetes who participated were experiencing depressive symptoms as well as poor psychosocial adjustment to illness at the time of this study. This has implications for both theory and practice. Practitioners should incorporate developmental perspectives into conceptualization and treatment of their clients with chronic medical conditions. It has been estimated that the overall adherence rate among pediatric populations is only approximately 50% (Litt, 1980). For adolescents, the challenge of diabetes is combined with the developmental tasks of adapting to puberty and a changing body image, peer

group pressure, autonomy from the parents and identity formation (Delamater, 1986). Adherence is important to consider during adolescence as it is typically poorer during this period (Johnson et al., 1992) and because adolescence is a critical juncture in the adoption of health relevant behaviors (Santrock, 2004).

In this study, depressive symptoms were higher in those adolescents who reported lower average blood sugars. This implies that even adolescents who may appear healthy regarding their diabetes care are still experiencing depressive symptoms. It is for this reason that every adolescent diagnosed with a chronic illness should be assessed for these symptoms even if they appear physically healthy. In other words, overall health incorporates both physical and psychological aspects of an individual.

Additionally, the BDI-FS is a shortened version of the BDI-II, as mentioned above. The items kept for the shortened version focus on cognitive depression symptoms rather than vegetative. Therefore, it can be more specifically explained that adolescents with good glycemic control in this study reported significantly higher levels of cognitive depressive symptoms. This can be best explained by the rigid lifestyle that must be maintained in order to obtain good glycemic control. Teens may not see their controlled blood sugar as rewarding, but rather experience the restrictive lifestyle as depressing and difficult to maintain over a lifetime. They may feel discouraged about the future or feel that no matter how hard they work, it is an exhausting task to succeed in medical compliance. Similarly, the internal validation they receive from good glycemic control may not offset the social costs associated with maintaining this lifestyle.

Considering overall health of adolescents with chronic illness such as Type 1 Diabetes is a complicated issue, there arise implications for practice. While physicians do not have time allotted to explore relationships, social involvement, school performance, emotional health, etc. with their medical patients, these are nevertheless important areas to explore in order to get a picture of overall health of an individual. Therefore, treatment teams with multidisciplinary professionals may provide better care for individuals increasing patients' quality of life.

Considering the significance of psychological symptoms in this study, psychotherapy may be a useful option for teens diagnosed with Type 1 Diabetes who are experiencing difficulties. Emphasis should be put on exploring how adolescents can feel rewarded by maintaining good glycemic control while not becoming overwhelmed or discouraged by the daily routine or small mistakes here and there. Another area of focus for therapy may be how teens can successfully navigate the task of independence common for this age group while also successfully managing their chronic illness. However, these are speculations and should be followed up with phenomenological studies exploring why adolescents diagnosed with Type 1 Diabetes are depressed.

Summary

It is clear that not all of the variables in this study were not predictive of glycemic control, but still provided important information. An implication for theory is that predicting glycemic control in adolescents is a highly individualized process and may involve many variables not included in this study.

Type 1 Diabetes is a chronic illness in which insulin must be given to an individual on a prescribed basis or the disease is fatal. It is associated with serious long-term health complications, including retinopathy, nephropathy, neuropathy, and cardiovascular disease (Harris, 1998). There is no cure for Type 1 Diabetes. Consequently, individuals diagnosed with Type 1 Diabetes are typically placed on a strict and complex maintenance regimen that involves regular administration of insulin through injections, attention to diet and exercise, and monitoring glucose levels while making appropriate adjustments. Individuals with Type 1 Diabetes must monitor their symptoms, test their blood sugar under the appropriate circumstances and make adjustments in diet, physical activity, and insulin doses to maintain optimal glucose levels. Therefore, the proper management of Type 1 Diabetes requires an ongoing series of decisions that must be carried out on a daily basis (Miller, 2006).

For various reasons, about one-third of diabetics have significant problems in keeping proper glycemic control in adolescence. Adolescents face important developmental tasks including identity formation (Erikson, 1968), the development of social skills, autonomy, responsibility, and the development of a set of values (Irvin, 1996). Other developmental events that are significant to this period include increased cognitive development, development of a sexual identity, adjustment to a developing physical body, and the development of academic competence (Kegan, 1998).

This study explored the relationships between depression, psychosocial adjustment, and duration of illness with participants average blood sugar levels. It was found that, of these variables, only depression was predictive of participants average blood sugar levels. In addition, there were statistically significant correlations between

variables. Participants' HbA1C was negatively correlated to participants' scores on the Beck Depression Inventory. Also, participants' scores on the Beck Depression Inventory were positively correlated with participants' scores on the Psychosocial Adjustment to Illness Scale.

In summary, this study found that depression affected approximately one-third of this adolescent population during the time of the study. Theoretical and practical implications for the study include more research exploring the variables affecting individuals' glycemic control and providing behavioral health professionals in addition to medical professionals for patient care. Geist (1979) encouraged closer collaboration between those involved with the emotional issues of chronically ill patients and those charged with their medical care. It was his opinion that only with this kind of collaboration will we improve our present treatment techniques and illuminate more specifically the psychological patterns of chronic illness.

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APPENDIX A

Informed Consent- Parent/Guardian

PARENT CONSENT/ PERMISSION FORM

Project Title: Type 1 Diabetes in Adolescence: The Effect of Psychosocial Adjustment, Depression and Duration of Illness on Glycemic Control

Investigators:

- 1) Barbara Stanfield, M.A., Oklahoma State University Counseling Psychology Doctoral Candidate
- 2) Don Boswell, Ph.D., Associate Professor, Oklahoma State University

Purpose:

The purpose of this research study is to gain better understanding of how psychological, emotional, and social adjustment to chronic illness, depression related to chronic illness and duration of chronic illness affect the average blood sugars in adolescents diagnosed with type 1 diabetes. It is estimated that approximately 1/3 of adolescents have poor blood sugar control and research aimed at identifying issues that may contribute to better understanding why are important in providing care and services for these adolescents.

You and your child are being asked to participate because your child is diagnosed with type 1 diabetes and is within the age range of 12-18 years old. Your child is invited to participate in this study to explore his/her experience with the diagnosis of Type 1 diabetes. This study involves approximately 5 minutes of your time to complete a demographics sheet, and 20-25 minutes of your child's time to complete two questionnaires. The information asked in this research study deals with emotions, relationships, and school and work activities and how they are affected in your child's life by having type 1 diabetes.

Procedures:

There are a total of three steps to this research study that require your participation after you consent to participate if you choose to do so. The first step is for the parent or guardian to complete a demographic questionnaire with six questions about your and your spouse's (if married) age, gender, ethnicity/race, marital status, yearly income, and level of education and six questions about the your child's age, gender, ethnicity/race, grade, date diagnosed with type 1 diabetes, and most recent A1C measurement. This first step takes less than five minutes.

The last two steps involve your child only. Your child will complete two questionnaires. The first questionnaire is called the Psychosocial Adjustment to Illness Scale and asks questions about emotions, relationships, and school and work activities and how they are affected by having type 1 diabetes. This questionnaire takes about 15 minutes to complete. The second questionnaire is called the Beck Depression Inventory-Fast Screen for Medical Patients and asks questions about emotions. This questionnaire takes less than five minutes to complete. Your child may feel more comfortable answering the questionnaires if you leave the room. This decision is up to your child.

During any of these steps, you or your child may ask questions of the researcher if you have any. You will also be provided with a list of referral services if you would like to talk with a mental health counselor.

Risks & Benefits of Participation:

There are potential benefits and risks from participating in this study. While there are no potential benefits for you, a potential risk may be discomfort felt by answering the questions on the Demographic Questionnaire. The potential benefit for your child is an increased awareness of how he/she has coped with this chronic illness as well as some of the barriers to good glycemic control (good control of blood sugars). The potential risk for your child is that thinking about these issues may bring up emotions that he/she may or may not have thought about since his/her diagnosis.

Confidentiality:

All information collected in this study is strictly confidential. However, if information obtained from your child's responses to the questionnaires signifies that your child is in danger of self harm, that piece of information allows the researcher to break confidentiality with your child and that information will be told to you. No individual participants will be identified. Your child's physician and/or other clinical staff will not know you or your child's individual responses on the demographic sheet or the questionnaires. The records of this study will be kept private. Any written results will discuss group findings and will not include information that will identify you or your child. Research records will be stored securely and only the researchers and individuals responsible for research oversight will have access to the records. Your participation in this study is greatly appreciated. If you or your child have questions, please feel free to ask at any time; please contact Barbara Terral, M.A. (405) 246-8201 or Don Boswell, Ph.D. (405) 744-9454. If you have questions about your rights as a research volunteer, you may contact Dr. Shelia Kennison, IRB Chair, 219 Cordell North, Stillwater, OK 74078, (405) 744-1676 or intb@okstate.edu.

Participant Rights:

Participation in this study is completely voluntary. There is no penalty for not participating and you have the right to withdraw your consent and participation at any time.

Signatures:

I have read and fully understand the consent form. As a parent or guardian I authorize my child ______ (print name) to participate in described research.

Parent/Guardian Name (printed)

Signature of Parent/Guardian

Date

I certify that I have personally explained this document before requesting that the participant sign it.

Signature of Researcher

Date

APPENDIX B

Child Assent Form

CHILD ASSENT FORM

The purpose of this research study is to gain better understanding of how teenagers' feelings, relationships and activities like school and work are affect by having type 1 diabetes. Many teenagers have difficulty with keeping their average blood sugar controlled and research to understand why this is will help provide care and services for teenagers with type 1 diabetes.

You are being asked to participate because you are diagnosed with type 1 diabetes and are between 12 and 18 years old. This research study involves approximately 5 minutes of your parent's time to complete a demographics sheet, and 20-25 minutes of your time to complete two questionnaires.

There are a total of three steps to this research study. The first step is for your parent or guardian to fill out a questionnaire questions about them and questions about you including when you were diagnosed with type 1 diabetes, and your last A1C measurement. The last two steps involve you only. You will complete two questionnaires about emotions, relationships, and school and work activities and how they are affected by having type 1 diabetes. The first questionnaire takes about 15 minutes to complete. The second questionnaire takes less than five minutes to complete. You may feel more comfortable answering the questionnaires if you parent or guardian leaves the room and if so, you may ask them to step outside while you complete both questionnaires. This decision is up to you.

You do not have to do this. You do not have to answer any questions that you do not want to. You may stop at any time. Your name will not be on the questionnaires you fill out, and you will be given a number that will be put on your answer sheet so no one will know whose answers they are. The only way anyone would know how you answered is if we are worried about you, and then we will talk to your parent or guardian. If you have any questions about the questionnaires or what you are doing, please ask at any time. Thank you for your help. Participant Name (printed)

Signature of Participant

Date

I certify that I have personally explained this document before requesting that the participant sign it.

Signature of Researcher

Date

APPENDIX C

Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

Parent/Guardian: Please answer the following information to the best of your ability. The first list of questions is information about you and your spouse (if applicable), while the second list of questions is about your child. Thank you.

Parent Information (parent/guardian):

1 a. Your age: _____

b. Your spouse's age: _____

2. Your Gender (circle one): male female

3. a. Which of the following best describes your ethnic/racial identity (circle one)?

3a.1 African American

3a.2 Hispanic

3a.3 Native American

3a.4 Asian

3a.5 Caucasian

3a.6 Other

b. Which of the following best describes your spouse's ethnic/racial identity (circle one)?

3b.1 African American
3b.2 Hispanic
3b.3 Native American
3b.4 Asian
3b.5 Caucasian
3b.6 Other

4. How would you best describe your marital Status (circle one)?

- 4.1 Married4.2 Single4.3 Divorced4.4 Widowed
- 5. Please circle the range that best fits an estimate of your yearly household income:
 - 5.1 Less than \$25,000
 5.2 \$25,000-\$50,000
 5.3 \$50,000-\$75,000
 5.4 \$75,000-\$100,000
 5.5 Greater than \$100,000

6a. How would you describe your highest level of education (circle one)?

6a.1 Less than a high school diploma or GED6a.2 High school diploma or GED

- - -

6a.3 Some college

6a.4 Associate's degree

6a.5 Bachelor's degree

6a.6 Master's degree

6a.7 Doctoral degree

b. How would you describe your spouse's highest level of education (circle one)?

6b.1 Less than a high school diploma or GED
6b.2 High school diploma or GED
6b.3 Some college
6b.4 Associate's degree
6b.5 Bachelor's degree
6b.6 Master's degree

6b.7 Doctoral degree

Patient Information (adolescent):

1. Your child's age: _____

- 2. Your child's Gender (circle one): male female
- 3. Which of the following best describes your child's ethnic/racial identity (circle one)?
 - 3.1 African American
 - 3.2 Hispanic
 - 3.3 Native American
 - 3.4 Asian
 - 3.5 Caucasian
 - 3.6 Other

4. What grade is your child currently enrolled?

For questions 5 and 6: If you are unsure of the correct answers or cannot recall them, you may ask the nurse to get this information for you.

5. Date of your child's Type 1 Diabetes Diagnosis (day/month/year) :_____

6. Your child's Most Recent HbA1C measurement:

VITA

Barbara Renee Merchant

Candidate for the Degree of

Doctor of Philosophy

Dissertation: TYPE 1 DIABETES IN ADOLESCENCE: THE EFFECT OF DEPRESSION, PSYCHOSOCIAL ADJUSTMENT AND DURATION OF ILLNESS ON GLYCEMIC CONTROL

Major Field: Counseling Psychology

Biographical:

Education:

Completed the requirements for Pre-doctoral Internship in Clinical Psychology at Brooke Army Medical Center in San Antonio, Texas in October 2010.

Completed the requirements for the Doctor of Philosophy in Counseling Psychology at Oklahoma State University, Stillwater, Oklahoma in May, 2011.

Completed the requirements for the Master of Arts in Counseling Psychology at University of Central Oklahoma, Edmond, Oklahoma in 2005.

Completed the requirements for the Bachelor of Arts in English Literature at Oklahoma State University, Stillwater, Oklahoma in 2003.

Experience:

Assistant Director: University of Oklahoma Health Sciences Center, Dept. of Pediatrics: Programs for Preventive Health (7/2006-6/2009)

OU Health Sciences Center, Dept. of Pediatrics, Diabetes & Endocrinology Section, therapist (8/2007-6/2009)

Graduate Assistantship: Assistant to the Training Director (8/2008-5/2009)

Adjunct Professor: University of Central Oklahoma, Oral Roberts University, University of Arts & Sciences of Oklahoma, The University of Oklahoma-Tulsa, Southwestern Oklahoma State University: (8/2006-5/2009)

Payne County Youth Services, therapist (6/2006-8/2007)

Professional Memberships: American Psychological Association

Name: Barbara Renee Merchant

Date of Degree: July, 2011

Institution: Oklahoma State University

Location: Stillwater, Oklahoma

Title of Study: TYPE 1 DIABETES IN ADOLESCENCE: THE EFFECT OF DEPRESSION, PSYCHOSOCIAL ADJUSTMENT AND DURATION OF ILLNESS ON GLYCEMIC CONTROL

Pages in Study: 105 Candidate for the Degree of Doctor of Philosophy

Major Field: Counseling Psychology

- Scope and Method of Study: This study used a sample of patients from a diabetes and endocrinology pediatric clinic in a metropolitan hospital to explore the influence of Type 1 Diabetes on adolescents in the areas of depression and psychosocial adjustment. Adolescents and their parent(s) were given a demographic questionnaire including information on their most recent HbA1C measurement as well as the date of their diagnosis. Then, adolescents alone were given the Beck Depression Inventory- Fast Screen for Medical Patients (BDI-FS) and the Psychosocial Adjustment to Illness Scale- Self-Report (PAIS-SR).
- Findings and Conclusions: One-third of the sample scored in the clinically significant range on the BDI-FS and approximately one-third of the sample scored in the clinically significant range on the PAIS-SR. Scores on the BDI-FS and the PAIS-SR were positively correlated. A multiple regression analysis revealed that BDI-FS scores were a significant predictor of HbA1C measurements. Adolescents who maintained their chronic illness with good control had significantly higher scores on the depression measure than did adolescents who maintained their chronic illness with poor control.