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# MATERNAL DEPRESSIVE SYMPTOMS AND HEALTH OUTCOMES IN YOUTHS WITH TYPE 1 DIABETES: A MEDIATIONAL MODEL

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MATERNAL DEPRESSIVE SYMPTOMS AND HEALTH OUTCOMES IN YOUTHS WITH  
TYPE 1 DIABETES: A MEDIATIONAL MODEL

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

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“Make it a habit to tell people thank you. To express your appreciation, sincerely and without the expectation of anything in return. Truly appreciate those around you, and you’ll soon find many others around you. Truly appreciate life, and you’ll find that you have more of it.”

*Ralph Marston*

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## Table of Contents

	Page
Acknowledgements .....	ii
List of Tables .....	.vi
List of Figures .....	.vii
Abstract .....	.viii
Introduction .....	1
Clinical Disorders.....	2
Measurement Strategies.....	5
Diathesis-Stress Model of Depression.....	6
General Effects of Maternal Depression on Children.....	14
Depression and Effects in Mothers of Children with Chronic Illness.....	18
Diabetes Management.....	20
Disease-care Behaviors.....	22
Insulin Therapy.....	22
Blood Glucose Monitoring.....	24
Diet Management.....	25
Physical Activity.....	25
The Diabetes Team.....	26
Parental Involvement and Monitoring.....	27
Statement of Purpose.....	31
Method .....	34
Participants.....	34
Procedures.....	35
Measures/Materials.....	35
Disease Care Behaviors.....	36
Maternal Depressive Symptoms.....	37
Parental Monitoring and Involvement.....	38
Diabetes Conflict.....	38
Statistical Analysis Plan.....	39
Data Preparation.....	41
Results .....	43
Hypothesis 1.....	49
Hypothesis 2.....	49

Hypothesis 3.....	52
Discussion .....	53
Maternal Depressive Symptoms.....	53
Potential Mediators between Maternal Depressive Symptoms and Disease-care Behaviors.....	58
Treatment Implications for Reduced Parental Involvement.....	62
Diabetes Specific Family Conflict.....	63
Summary, Limitations, & Future Directions.....	64
List of References .....	67
Vita .....	79

**List of Tables**

	Page
Table 1. Symptoms Categories of Depression.....	4
Table 2. Developmental Stages of Parental Involvement and Diabetes Management.	28
Table 3. Descriptive Statistics.....	45
Table 4. Correlation Table.....	48
Table 5. Mediational Effects of Parental Involvement.....	51
Table 6. Mediational Effects of Diabetes Specific Family Conflict.....	52

**List of Figures**

	Page
Figure 1. Bidirectional Relationship of Maternal Depression.....	17
Figure 2. Parental Involvement and Monitoring Mediation Model.....	39
Figure 3. Diabetes Conflict Mediation Model.....	40
Figure 4. Mediational Model of Maternal Involvement.....	50

## **Abstract**

### **MATERNAL DEPRESSIVE SYMPTOMS AND DISEASE CARE BEHAVIORS IN YOUTHS WITH TYPE 1 DIABETES: A MEDIATIONAL MODEL.**

By Kari Lyn Struempf, M.S.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2012

Major Director: Clarissa S. Holmes, Ph.D., Professor, Clinical Psychology

**Objectives:** The rate and impact of depressive symptoms were examined with two models based on known effects of depression on variables related to diabetes management, parental involvement and diabetes conflict. The proposed models will measure potential effects high maternal depressive symptoms may have on parental monitoring and involvement and diabetes specific conflict and how these variables may in turn relate to poor regimen adherence.

**Methods:** Participants included 225 mothers and young adolescents (aged 11-14) with T1D.

Diabetes self-care behaviors were measured with the 24 Hour Recall Interview, parental involvement and monitoring were measured with the Parent Management of Diabetes Scale, and diabetes specific conflict was measured with the Diabetes Family Conflict Scale.

**Results:** A significant portion of mothers (21%) reported clinically elevated levels of depressive symptoms. These high levels of depressive symptoms were related to low levels of parental involvement with diabetes care ( $r = -.19, p < .01$ ). Depressive symptoms were indirectly related

to lower frequency of blood glucose monitoring ( $C_{.95} = -.03, -.002$ ), insulin use ( $C_{.95} = -.01, -.0007$ ), and meals ( $C_{.95} = -.02, -.002$ ) through low levels of parental involvement. Higher levels of depressive symptoms were also related to higher levels of diabetes specific conflict ( $r = .16, p < .01$ ), however, this relationship did not have a significant indirect effect on frequency of self-care behaviors.

Conclusions: A significant portion of mothers in the current sample reported symptoms of depression above the clinical cutoff. Mothers that reported higher levels of depressive symptoms also reported lower levels of parental involvement in management of disease-care behaviors. Low levels of parental involvement mediated a significant relation between depressive symptoms and less frequent disease-care behaviors. Diabetes conflict did not mediate a relation between depressive symptoms and disease-care behaviors. These findings suggest that the reported high levels of maternal depressive symptoms among mothers of children with T1D may interfere with good diabetes management through low parental involvement. Individual treatment for depressive symptoms and interventions targeted at increasing parental involvement without increasing diabetes conflict could help improve regimen adherence.

## Maternal Depressive Symptoms and Disease Care Behaviors in Youths with Type 1 Diabetes: A Mediational Model

Depression is the most common mental health disorder and leading cause of disability among adults in the United States (Murray & Lopez, 1997) and has consistently been found to affect women at a significantly higher rate than men (American Psychiatric Association [APA], 2000; Kessler 2003). Women are twice as likely to experience a major depressive episode (MDE) in their lifetime, and have a higher 12-month prevalence rate, 6.87%, of major depressive disorder (MDD) compared to 3.56% identified in men (Hasin, Goodwin, Stinson & Grant, 2005; Ingram, Scott, & Siegle, 1999; Kessler, 2003). This higher rate of depression in women has been translated into research on how higher rates of maternal depression can have a significant effect on children. Higher levels of maternal depression have been linked to higher levels of child depression (Klein, Lewinsohn, Rohde, Seeley, & Olino, 2005), anxiety (Lim, Wood, & Miller, 2008) and behavioral problems (Koverola et al., 2005). Generalization of these effects on child health outcomes has been studied in some children affected by chronic illnesses such as asthma (Klein et al., 2005), type 1 diabetes (Cameron, Young, & Wiebe, 2007; Eckshtain, Ellis, Komodin, & Naar-King, 2009), cystic fibrosis (Driscoll et al., 2010), and juvenile rheumatoid arthritis (Frank et al., 1998; Wagner et al., 2003).

Some research studies have identified higher rates of clinically elevated symptoms of depression among mothers of children with type 1 diabetes (T1D) than the 6.87% point prevalence of depression identified in women in the general population (Eckshtain et al., 2009; Horsch, McManus, Kennedy, & Edge, 2007; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2008). This study will look in depth at the potential negative outcomes associated with

higher levels of maternal depressive symptoms on health outcomes for children and adolescents with T1D. Previous research has identified many variables that can negatively affect health outcomes for youths with T1D such as family conflict (Anderson et al., 2009, Anderson, Vangness et al, 2002), lower parental monitoring and involvement (Wysocki et al., 2009), and youth psychosocial adjustment problems (Hood et al., 2006). It is possible that poor maternal mental health may be a driving or contributing factor for any these issues or may negatively impact metabolic control in other ways. Mothers are most often the primary caregiver for children with diabetes and are regularly responsible for the extensive disease care regimen (Kovacs et al., 1990; Jaser et al., 2008). In light of this significant responsibility, it is important to consider any potential risk factors that may affect these mothers and the diabetes regimen. Two potential models of how maternal depression may impact health outcomes will be explored: 1) lower parental monitoring and involvement in the day-to-day tasks of diabetes management, and 2) higher levels of diabetes specific conflict. The goal is to identify specific mechanisms through which maternal depression might impact diabetes outcomes and potential areas to target clinical intervention.

### **Clinical Disorders**

The term “depression” is widely used in society as a general descriptor for feelings of sadness or dissatisfaction with a person’s life or situation. For this reason, it is important for the construct of depression to be well defined when used clinically and in research. The DSM-IV TR (American Psychiatric Association, [APA], 2000) includes Dysthymia, a Major Depressive Episode (MDE), and Major Depressive Disorder (MDD), as three subtypes of depressive disorders.

Dysthymia is a chronic experience of mild depressive symptoms in which an individual experiences depressed mood for more days than not over a period of 2 years. Individuals also need to experience two of the following symptoms: poor appetite or overeating, hypo- or hypersomnia, low energy or fatigue, low self-esteem, poor concentration, and feelings of hopelessness. Women and individuals with a first-degree relative with depression are at a 2 to 3 times greater risk of developing dysthymia compared to men (APA, 2000).

A major depressive episode (MDE) is defined as a period of at least two weeks in which an individual experiences depressed mood or loss of interest in nearly all life's activities. The individual also must experience 3-4 of the following symptoms: significant disturbance in weight or eating habits, insomnia or hypersomnia, either increased or decreased activity, daily fatigue, feelings of worthlessness or inappropriate guilt, difficulty concentrating, and/or recurrent thoughts or suicidal ideation. These symptoms must occur on a daily or near daily basis and be newly onset. Women are at a significantly increased risk of experiencing a MDE during their lifetime (APA, 2000). Some research has linked the increased risk of a MDE to hormonal fluctuations or menses in women. Individuals may experience a period of subthreshold symptoms of depression prior to the onset of the MDE; these symptoms can serve as a warning sign to friends and family members and provide opportunities for early intervention. Researchers tend to study these increased yet subclinical levels of "depressive symptoms" that are associated with MDD and MDE rather than focusing on actual clinical disorders. This research is also critical since these symptoms can be preeminent to the development of a full onset clinical disorder (APA, 2000).

Major depressive disorder (MDD) is characterized by one or more MDEs and can be characterized as mild, moderate or severe. The presence of one MDE in the absence of a manic, hypomanic or mixed episode is indicative of MDD, Single Episode; the presence of two more MDEs in the absence of the aforementioned episodes is indicative of MDD, Recurrent. The most common symptoms of depression fall into four larger categories: emotional, cognitive, motivational and vegetative/somatic symptom manifestations (Table 1).

Table 1.

*Symptom Categories of Depression* (Beck & Alford, 2009)

<b>Emotional</b>	Dejected Mood Negative Feelings Toward Self Reduction in Gratification Loss of Emotional Attachments Crying Spells Loss of Mirth Response
<b>Cognitive</b>	Low Self-Evaluation Negative Expectations Self-Blame and Self-Criticism Indecisiveness Distortion of Body Image
<b>Motivational</b>	Paralysis of Will Avoidance, Escapist, and Withdrawal Wishes Suicidal Wishes Increased Dependency
<b>Vegetative/Physical</b>	Loss of Appetite Sleep Disturbance Loss of Libido Fatigability

The constellation, duration, and severity of these symptoms can vary widely from person to person. While these symptoms occur within the individual with depression, the effects are not limited to the self. Symptoms of depression are pervasive and affect those closest to someone with depression such as spouses, children and friends (Goodman & Gotlib, 1999).

The 12 month incidence rate of MDD is 6.87% in women compared to 3.56% in men and the lifetime prevalence rate is 17.10% in women compared to 9.01% in men (Hasin et al., 2005; Kessler, 2003). Other sources have identified point prevalence rates of MDD in women ranging from 5-9% and lifetime prevalence rates from 10-25% in women (APA, 2000). Being female is one of several risk factors for MDD; others include a genetic risk and age. Individuals with a first-degree relative with MDD are 1.5 to 3 times more likely to develop MDD and 50% of depression is developed before the age of 40 (APA, 2000; Kessler, 2003). These risk factors along with the introduction of a major life stressor (diagnosis of a child with T1D) may partially explain why mothers of children with diabetes appear to be at greater risk depressive symptomology.

### **Measurement Strategies**

Depression is a complex mental health disorder whose constellation of symptoms can present in countless variations (Beck & Alford, 2009). Due to this variability, consistent and accurate measurement strategies must be employed by researchers and clinicians to assess levels of depressive symptoms and make appropriate diagnoses. The two most frequent types of symptom assessment are self-report measures and clinician interview. Self-report measures of depression typically assess the level and severity of symptoms associated with a MDE or MDD. These symptoms include physical symptoms, such as sleep disruption and changes in weight, and cognitive symptoms such as feelings of sadness, guilt, and a loss of enjoyment related to daily activities. These measures are subject to the same limitations as most self-report measures, without outside corroboration conclusions about depressive symptoms are drawn from what could be biased report. Individuals may be less likely to report symptoms to seem more socially

desirable or may over-report if they have a flawed view of reality. A single measure of depression from one reporter should never be used to decide clinical diagnoses, however this method is regularly used in research because the ease of administration and the minimal resources required of research staff. In research studies self-report measures have provided good indications of potential problems and the direction of severity (Lovejoy, Graczyk, O'Hare, & Neuman, 2000).

An alternative to self-report measures are clinical interviews of depressive symptoms. Interviews can be structured, semi-structured, or free-form. Clinicians have the opportunity to ask about the presence, duration and severity of symptoms which can help inform diagnosis decisions. One significant benefit of interview versus self-report measures is the ability of the clinician to query further into areas of concern. Unfortunately, clinical interviews are rarely used in larger randomized control trials due to the time and resources that must be allocated to such an interview. Self-report measures and interviews have previously revealed similar effect sizes, thus provide a good enough indication about symptoms and potential relationships (Lovejoy et al., 2000). However, due to the aforementioned limitations researchers must interpret results with caution.

### **Diathesis – Stress Model of Depression**

There is little consensus among psychologists, doctors and researchers about the pathogenesis of major depression among men and/or women. Previously, research tended to focus on identifying a singular causal factor or model to explain the development of depression. These have included a negative life events model, biochemical explanations, social skills deficits, negative interpersonal interactions and maladaptive cognitive processes (Beck, &

Alford, 2009; Goldberg, 2006; Ingram et al., 1999). Currently more integrative models of genetic, intraindividual and exogenous variables as contributors to depression are supported (Ingram, Scott, & Hamill, 2009). The diathesis-stress (DS) model of depression has gained popularity as a fully integrative model of depression. It includes biological, cognitive, behavioral, social, and environment factors that may contribute to the activation of a predisposition or diathesis towards depression (Burke & Elliot, 1999; Monroe & Simons, 1991). The DS model posits that individuals that develop depression have a diathesis (predisposition) towards depression that was activated by a combination of the above factors. The model is flexible and focuses on individual differences for each person's specific diathesis and how different factors might bring about the onset of depression in one person and not have the same impact on another person (Burke & Elliot, 1999). This paper will focus on multiple potential factors that could contribute to diathesis activation for depression.

Risk factors within the genetic/biochemical category include individual genetic makeup, heritability factors, being female, and potential biochemical imbalances (Beck & Alford, 2009). Research indicates that individuals with a first-degree relative with depression are more likely to develop depression themselves with a heritability risk of about 38% for the general population (Ball, et al., 2009; Beck & Alford, 2009; Goldberg, 2006; Kendler, Gatz, Gardner, & Pedersen, 2006; Levinson 2006). More recently, twin studies have identified a greater liability of heritability in women, 42% than men 29% (Kendler et al., 2006). Greater genetic liability in women is one explanation for the higher lifetime rate of depression experienced by women.

One genetic pathway that appears to contribute to diathesis activation is the 5-HT transporter gene (5-HTT). This particular pathway is salient to the current study because of the

potential link between 5-HTT and the life stressors model of depression. The life stressors model posits that MDEs and MDD are triggered by stressful major life events, for example, a child's diagnosis with a chronic illness. There is a relationship between the length of the 5-HTT homozygote and an individual's reaction to stressful life events. Individuals with the longer homozygote tend to be resistant to life stressors while individuals with the short homozygote are highly sensitive to life stressors and in turn are more likely to develop depression after such an event (Goldberg, 2006). This genetic liability can contribute to an individual diathesis towards depression. Certain mothers may be better genetically equipped to handle a diagnosis of T1D than others with particular genetic risk factors.

The catecholamine hypothesis is the biochemical theory of how depression is caused by chemical deficits in the brain. Research has identified that in some individuals with depression there is a reduced availability of active norepinephrine that leads to depressed mood. MAO inhibitors, SSRIs, and tricyclic compounds have been found to be effective means of treating this imbalance in norepinephrine availability and absorption. However, the medical model cannot account for all occurrences and aspects of depression and depression medication does not improve everyone's symptoms (Beck & Alford, 2009).

The DS model also includes psychosocial variables that can contribute to the activation of an individual's predisposition for depression. This study will focus on three areas of risk that can contribute to the activation of depression, stressful life events (acute and chronic), cognitive distortions and behavioral reinforcement. The potential impact of negative or stressful life events on the activation of depression may be the most applicable to the high levels of depressive symptoms among mothers of children with diabetes. Previous research shows that individuals

who experience a major stressful life event (SLE) are more likely to develop depression than others that did not. Researchers have worked to answer the question “do stressful life events cause depression” however due to the non-experimental nature of research in this area, that question cannot truly be answered. Rather, consistent links have been drawn between negative and stressful life events and depressive symptomology (Kessler, 1997).

There are three different scenarios in which a negative or stressful life event(s) can serve as a precipitant to depression: 1) accrued stressful events over time, 2) individual events, and 3) chronic stressors (Kessler, 1997). The accrued life events model focuses on the potential additive effect of multiple stressors over a period of time. Studies that assess the potential relation between SLEs and depression find that not only is there a strong and consistent relationship but also a dose dependent relationship. More frequent and serious SLEs are related to higher rates of depression (Kessler, 1997). There are however, methodological concerns about the relation identified between these two variables. Research about cumulative SLEs is often retrospective in nature and is regularly measured through self-report checklists. The problems with this method are two-fold, potentially biased reporting and the inability to determine the direction of the relation. Typically, the retrospective reports are provided by individuals with depression; how they view the events in their life may be more negatively skewed than if reported by a nondepressed individual. Additionally, it is often difficult to determine the directionality of the relationship between SLEs and depression. Individuals with depression are also more likely to experience stressful life events in general (Kessler, 1997); without the ability to experimentally introduce multiple consecutive SLEs to determine if they activate an

individual's diathesis for depression, researchers cannot be sure of causal direction between these two variables.

To combat the problem of directionality, researchers have focused on acute, naturally occurring events that can be treated as meta-experiments. The diagnosis of a child with diabetes could serve as a discrete naturally occurring event to measure the development of clinically depressive symptoms in a specific timeline to determine directionality of the relationship. Previous research has looked at the relation between depression and other acute major negative life events like divorce (Bruce & Kim, 1992; Coryell, Endicott, & Keller, 1992), the loss of a spouse (Zisook & Shuchter, 1991), or the loss of a job (Kendler, Karkowski, & Prescott, 1999). Results of these studies indicate that there is a strong relationship between the occurrence of acute negative events and the activation of depressive symptoms and depression (Kendler, et al., 1999).

Finally, recent research has focused on the impact of a chronic life stressor on the activation of depression. Chronic role-related stress, such as job stress (Magnusson et al., 2009) or marital difficulties (Kendler et al., 1999), is linked to higher levels of depression. The impact of role-related stress may generalize to the significant levels of parental stress that are experienced by mothers of children with diabetes. The role of primary caregiver for another human being, in this case a child, imposes significant responsibility on a parent even in the case of a healthy child. Parents caring for children with chronic illnesses have the added responsibility of health care tasks and fears associated illness outcomes in addition to the regular parenting tasks and worries. Another study found that wives were more likely to experience episodes of depression after a significant negative life event than their husbands. This greater

experience of depression was related to stricter social roles for women including being the primary caregiver for children and responsibility for household tasks (Nazroo, Edwards, & Brown, 1997). Given that mothers of children with diabetes are primarily identified as responsible for diabetes management, this may put them at greater risk of experiencing depressive symptoms or syndromes. T1D is a chronic condition that parents and children must consider 24 hours a day, 7 days a week, 365 days a year. This high level of responsibility and stress likely affects mothers in the same way marital stress affects husbands and wives, and chronic job related stress increases the risk of depression in the employee. The DS model theorizes that individuals can experience varying levels of stress depending on their diathesis for depression. This may explain why some mothers can manage the stress associated with care of a child with T1D and for others the stress can lead to elevated levels of depressive symptoms.

Behavioral and cognitive factors can contribute to an individual's predisposition to develop depression. The behavioral theory of depression was first introduced in early 1970s by Lewinsohn (1974), Ferster (1974), and Seligman (1974). Behavioral principles such as "learned helplessness" and operant conditioning are used to describe the cause and trajectory of depressive experiences. Learned helplessness is best described as the decision that every experience one might have will be negative. Despite any effort to change circumstances, a person ultimately submits to these negative experiences with no perceived ability or intention to change their circumstances. For example, consider a mother of an adolescent with diabetes that is in poor metabolic control. If the adolescent continues to bring home poor blood glucose numbers on a daily basis a mother might feel that no matter what she tries, the bloods sugars numbers will

never improve. She may begin to feel helpless and simply accept that the blood glucose numbers are going to be high rather than making efforts to change or improve the situation.

Similarly, operant conditioning and behavioral reinforcement theories can be used to explain the activation and maintenance of depressive symptoms or MDD (Beck & Alford, 2009). Individuals with depression may have negative experiences in their lives that they do not have the skills (i.e. motivation, problem-solving, energy, self-worth) to manage. Rather than work to make improvements to negative situations, they escape or avoid the situation altogether. The escape is rewarding because the individual is no longer exposed to the aversive stimuli; therefore, an individual is reinforced for avoidant behavior. Because an individual avoids, rather than works to make changes to negative situations, he or she does not receive the same rewarding benefits that come from making positive change. Avoidance, particularly when managing a chronic illness, can result in a severe negative cycle. For example, it is recommended that youths with diabetes visit their endocrinologist on a quarterly basis. Mothers with depression may not have the necessary tools to help their child manage diabetes appropriately, which may lead to poor feedback at medical appointments. If a mother finds negative feedback aversive or views it as punitive, she may use avoidance as a learned coping mechanism. This may lead to missed appointments or longer time between appointments. Without the regular guidance and feedback from the endocrinologist a youth's diabetes will likely deteriorate, which will contribute to the negative situation that initiated the cycle, poorer metabolic control.

While the behavioral theory of depression focuses on flawed interactions and behavioral coping strategies, cognitive theory (Beck, 1961) focuses on flawed internal thought processes.

According to cognitive theory, negatively based views of the self, the environment and the future are three core processes at work in depression. An inherently negative interpretation of life can lead an individual to feel hopeless, worthless, and unable to change their circumstances. Additionally, an individual with depression may have a distorted view of reality or events that happen in their life; they may view positive or neutral events as negative to support their negative life view. Negative views may originate from early maladaptive self schemas. A schema is the way an individual processes and encodes information about a certain subject. Schemas are often based on past experiences that lead us to judge current situations and stimuli through historical information. Negative schemas can be developed in childhood (e.g. a child believes he or she cannot do anything right) can contribute to an individual's personal diathesis for depression. Then, when negative experiences occur in adulthood (e.g. this individual loses a job) the negative self-schema is activated and the content of the person's thoughts about their abilities become negatively distorted such as: 'I am a failure and will never be able to keep a job again' (Young, Weinberger, & Beck, 2001).

Diabetes management can be a difficult and stressful task for both children and mothers from which the family receives no reprieve. If a mother experiences this higher level of negative thinking it may have a significant impact on how she views diabetes outcomes (e.g. blood glucose numbers, HbA1c levels, food choices, etc.) and lead to negative or critical parenting which is related to poorer metabolic control. These mothers may also feel hopeless about their ability to manage the day-to-day demands of diabetes and withdrawal from diabetes care tasks leaving her child to manage the daunting regimen on their own.

## **General Effects of Maternal Depression on Children**

When a mother is diagnosed with depression it can have a multifaceted effect on her family, particularly her children. As discussed earlier, the symptoms of depression can manifest in many ways including cognitive/emotional symptoms such as negative affect, a negative outlook on life and the self, self-blame, and inappropriate levels of guilt. Additionally a mother might experience vegetative/somatic symptoms such as low activity levels, disturbed sleep, and diminished involvement with others (Beck & Alford, 2009). Children of mothers with depression are at a significantly higher risk for depression (Klein et al., 2005), generalized internalizing symptoms (Lim, Wood, & Miller, 2008), and/or behavioral oppositional problems (Goodman & Gotlib, 1999; Klein et al., 2005; Koverola et al., 2005). An early review of relevant research studies revealed that approximately 40 to 45% of children and adolescents of mothers with depression develop a psychiatric disorder (Beardslee, Bemporad, Keller, & Klerman, 1983). The links between maternal depression and child psychological functioning are strong. In a study about the potential effects of maternal depression on child internalizing symptoms and asthma, results indicate that 12.6% of the variance associated with child internalizing problems is explained by the effects of maternal depression (Lim, Wood, & Miller, 2008).

While the genetic component to depression between first-degree adult relatives has been well established with family and twin studies the heritability connection between parent and child is not as clear. Adults with a first degree relative diagnosed with an affective (depression or anxiety) disorder have a significantly higher lifetime prevalence rate of affective disorders (20-25%) than the general population (7%) (Goodman & Gotlib, 1999). The heritability

component between parent and child has proven to be more difficult to delineate due to the entanglement of genetic and environmental influences. To isolate the genetic component Bergemann and Boles (2010) analyzed mitochondrial DNA of mothers and children to determine if there was a matrilineal inheritance of depression. Data from 672 participants in the Genetics of Recurrent Early Onset Depression were analyzed and compared to matched nondepressed healthy controls. Participants were screened for MDD using DSM-IV criteria of an episode MDD lasting 3 years with onset prior to the age of 31. Results indicated that matrilineal relatives were significantly more likely (odds ratio = 2.0) to suffer from a mood disorder than those with nondepressed mothers. Additionally Todd, Neuman, Geller, Fox and Hickok (1993) worked to support the heritability of depression and other affective disorders by reversing the typical approach. Instead of tracking the effects of depression from mother to child, researchers started with children diagnosed with an affective disorder and worked up the family tree, looking at older relatives including parents, aunts and uncles, and grandparents to identify individuals that may have also been diagnosed with an affective disorder. First degree relatives of children with an affective disorder were diagnosed with MDD (~40%) more often than relatives of 'normal' children (7.9%). Approximately 26% of second degree relatives and 13% of third degree relatives of children with an affective disorder were diagnosed with MDD compared to 17.1% and 3.5% respectively for relatives of 'normal' children.

Family environment also plays a significant role in the increased risk of psychopathology in children (Burke, 2003). Children may live in environments marked by high levels of family conflict (Rice, Harold, Shelton, & Thapar, 2006), higher maternal negativity and parenting (Nelson, Hammen, Brennan, & Ullman, 2003), and poorer parent-child attachment (Burke 2003;

Lovejoy et al., 2000). Higher levels of child psychopathology are linked to negative expressed emotion towards and criticism of adolescents by mothers with depression (Nelson et al., 2003). Adolescents with diabetes and their parents are in a constant state of appraisal about diabetes care behavior and metabolic control; the impact of negative emotion and critical parenting is also linked to higher levels of externalizing symptoms in youths with T1D (Duke et al., 2008). High levels of externalizing symptoms can interfere with adherence behaviors and lead to poorer metabolic control. Family environments that are affected by maternal depression also have higher levels of conflict that are related to higher levels of maladaptive functioning in children. This relationship is moderated by genetic liability; children who have a greater genetic risk to develop depression are more likely to be impacted by this high level of conflict than children without the increased genetic risk (Koblinsky, Kuvalanka, & Randolph, 2006; Rice et al., 2006).

As discussed above, environmental and genetic factors are important to consider in the transmission of risk from a parent with depression to their child (Rice et al., 2006). Most research however, indicates that neither environment nor genes work in isolation. Rather, the combination of genetic and environmental effects have been identified as ways in which maternal depression may influence child/adolescent depression. In a study comparing adopted versus biological children, strong links between maternal depression and child psychological functioning were identified. Adopted children of a mother with depression are almost twice as likely than children of healthy mothers to experience MDD, general externalizing disorders, oppositional defiant disorder (ODD), conduct disorder (CD) and attention deficit hyper-active disorder (ADHD). Similarly, biological children of a mother with depression are also at an increased risk for these disorders; however, the cumulative genetic and

environmental effects make the risk even greater. These biological offspring are three times more likely to develop MDD and CD compared to children of a non-depressed mother (Tully, Iacono, & McGue, 2008).

However, the direction of effect from mother to child does not occur in a vacuum. The transactional theory describes the circular nature of the parent-child relationship, and how individual attributes and behaviors for each person contribute to the negative cycle (Goodman & Gotlib, 1999). Not only do parent issues affect children, but the problems associated with childhood psychopathology (depression, behavioral problems, anxiety, etc) can also serve to exacerbate the mother’s depression. This can lead to a negative cycle where poor outcomes exacerbate and ultimately lead to further difficulties for the mother (Figure 1).

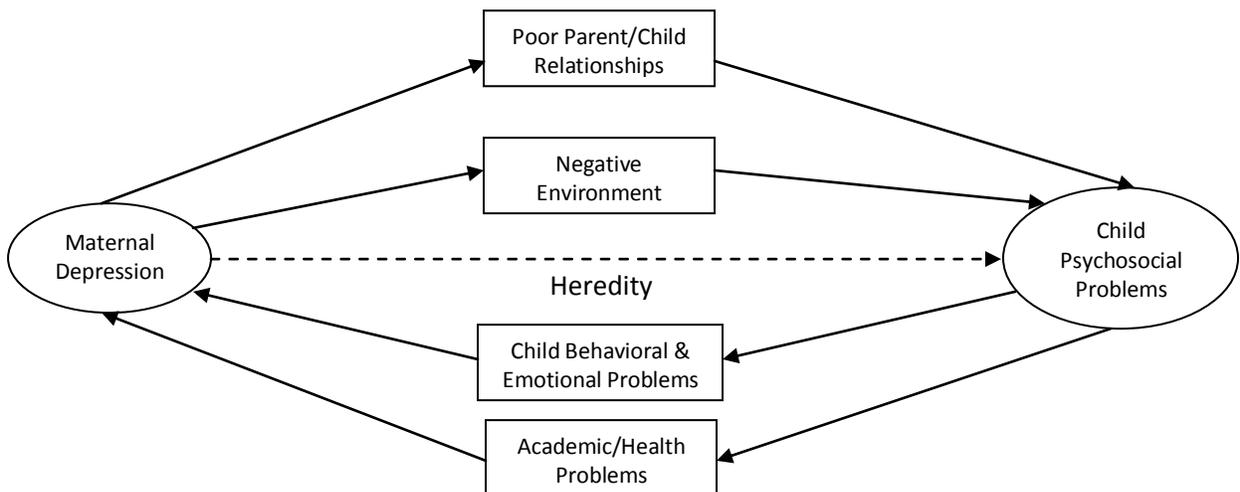


Figure 1. Bidirectional relationship of maternal depression

It can also be difficult to obtain appropriate treatment for children believed to be experiencing psychosocial difficulties. Mothers who are depressed are more likely to overestimate their child’s symptoms of depression compared to the child’s ratings of their own depression when compared to healthy controls (Hood, 2009). This can be problematic for the

measurement of childhood depression and other symptoms of psychopathology because parents often provide reports of symptoms to health care workers. In the context of providing care of chronic mental illness, mothers affected by depression may not be the most reliable reporters of symptoms or management because of this tendency to overestimate.

### **Depression and Effects in Mothers of Children with Chronic Illness**

As would be expected with the diathesis-stress model, mothers of children with chronic illness have higher rates of depression and depressive symptoms compared to mothers of healthy children. A survey of sixty mothers of children with T1D revealed high rates of anxiety, depressive symptoms and symptoms of post traumatic stress disorder (PTSD) (Horsch et al., 2007). These mothers were interviewed with the Structured Clinical Interview for DSM-IV PTSD module (SCID-PTSD) and completed the Hospital Anxiety and Depression Scale (HADS) a self-report measure of anxiety and depressive symptoms. Mothers in this study experienced higher rates of PTSD (10%) than the general populations and even more mothers experienced levels of PTSD and clinically significant symptoms of anxiety (43.3%) symptoms that are likely to have an impact on their daily functioning (Horsch et al., 2007). This higher level of maternal anxiety is related to poorer metabolic control in young adolescents (Cameron et al., 2007). Approximately 16% of these mothers also reported clinically significant levels of depression. Across studies, high levels clinically significant depressive symptoms ranging from 10-37% have been identified in mothers of youths with T1D. Eckshtain, Ellis, Kolmodin, & Naar-King (2009) surveyed 61 parents (92% mothers) to examine relationships between depressive symptoms and parenting practices and metabolic control. Of these 61 parents, 10% endorsed clinically significant levels of depressive symptoms. Even higher levels have been identified including

24% in a study of psychosocial adjustment in mothers of young children with T1D (Jaser et al., 2008), 29% in a study about the quality of life in mothers and children using intensive regimens (Whittemore, Urban, Tamborlane, & Grey, 2003), and most recently 37% in a study of mothers of children with T1D compared to mothers of children with CF (Driscoll et al., 2010). Clinically significant symptoms indicate that while mothers were not screened specifically for MDD or an MDE via DSM-IV TR criteria, they are experiencing levels of depressive symptoms that are likely impacting their day-to-day life and should be evaluated for a clinical diagnosis of depression (Horsch et al., 2007).

Despite the high levels of clinically elevated symptoms of maternal psychopathology (e.g. depression and anxiety) in mothers of children with T1D than the general population, (Cameron et al., 2007; Horsch et al., 2007; Jaser et al., 2008) minimal research has been done on the potential effects of maternal psychopathology on child diabetes health and adjustment outcomes. Of the few studies that have attempted to link maternal depression to metabolic control, no direct significant relations were found between maternal depression and HbA1c levels (Azar & Kanaan, 1999; Kovacs et al., 1990; Jaser et al., 2008). Indirect effects of maternal depression on metabolic control have been identified through parenting factors such as low parental involvement, monitoring and harsher discipline (Eckshtain et al., 2009).

Similar indirect effects and negative impact of maternal depression on secondary aspects of disease management have been identified among children with asthma. (Bartlett, et al., 2001; Bartlett et al., 2004; Kozyrsky et al., 2008; Leao et al., 2009; Perry, 2008; Shalowitz, Berry, Quinn, & Wolf, 2001; Shalowitz et al., 2006; Waxmonsky et al., 2006.) Mothers that score above the clinical cutoff for depressive symptoms are more likely to utilize the emergency department

(ED) for symptoms of asthma than non-depressed mothers (Flynn, Davis, Marcus, Cunningham & Blow, 2004). Mothers with clinically elevated symptoms of depression also report lower self-efficacy to manage their children's asthma and have less understanding about their children's medications (Bartlett, et al., 2004). A mother's depression may limit her ability to cope with stressful issues and lower her self-image about dealing with the day to day symptoms of her child's asthma (Bartlett et al., 2004). If these deficits identified in the asthma literature generalize to mothers of children with T1D, such as misunderstanding medication management, using emergency services to provide care and a lower self-efficacy to help with diabetes management, there could be significant and detrimental impacts on their children's health.

### **Diabetes Management**

Type 1 diabetes (T1D) is a chronic illness characterized by the body's inability to metabolize glucose in the blood. This inability comes from a lack of natural insulin production by the pancreas. T1D has a strong genetic component and is an autoimmune response against the pancreatic beta cells thought to be triggered by environmental stimuli. Diagnosis generally occurs during childhood and affects approximately 2 to 3 out of every 1,000 youths (Cooke & Plotnick, 2008). Diabetes management is a 24 hour a day, 7 day a week, 365 day a year job; many parents constantly worry about their child's blood sugar levels, what they eat, their activity level, and the long-term consequences of poor metabolic control. Anecdotally, many parents wake up several times in the night to check their children's blood sugars fearing that they will go low. Imagine then, the extreme difficulty a parent suffering from a mental health disorder may have trying to manage this significant responsibility. Type 1 diabetes can be a difficult disease to manage because of the demanding disease-care regimen as well as many exogenous factors

that can be beyond a family's control. Many factors are identified in the literature that put youths at risk for poorer metabolic control. Intra-individual factors, such as higher levels of depression along with general psychosocial distress, are related to disruption in metabolic control (Helgeson, Siminerio, Escobar & Becker, 2009.) Demographic variables, such as age, have also been shown to be a strong predictor of diabetes health outcomes. The increase in hormones during puberty has been shown to negatively impact insulin absorption and can lead to blood glucose fluctuations (Silverstein et al., 2005). Other biological factors such as growth and changes in eating habits can also lead to negative outcomes (Silverstein et al., 2005).

The lifestyle of these families is forever altered because of the complexity of the disease care regimen. Parental vigilance and involvement often begins even prior to diagnosis. Initial symptoms of T1D include a significant increase in thirst, urination, weight loss, and re-emergence of issues such as nocturnal bedwetting. Without prior knowledge of symptoms of T1D these issues are often noticed but attributed to other illnesses such as influenza. Diagnosis often occurs in either a primary care or urgent care setting and is confirmed by a blood glucose level above 200 mg/dL or a fasting glucose above 126 mg/dL (Cooke & Plotnick, 2008).

There are significant short and long term implications for health outcomes for a child or adolescent diagnosed with T1D. Fluctuations outside the normoglycemic range put youths at risk for hypoglycemia (too little sugar in the blood) and hyperglycemia (too much sugar in the blood). Hypoglycemia is an immediate risk that can result in dizziness, shaking, headache, confusion and if untreated, can deteriorate into coma and/or seizures (Daneman, 2008; Silverstein et al., 2005). The risk of hypoglycemia is often a source of concern and distress for parents, particularly parents of young children who cannot communicate their physical

symptoms (Jaser, et al., 2008). Alternatively hyperglycemia is associated with longer-term risks. Poorer metabolic control marked by high blood sugar levels can lead to microvascular damage to the central nervous system. This damage can lead to kidney disease, blindness, and neuropathy. Uncontrolled diabetes is also linked to macrovascular damage that can lead to heart attack and stroke. Isolated periods of extremely high blood sugar can lead to diabetic ketoacidosis (DKA) which can result in nausea, lethargy, dehydration and vomiting. DKA is the leading cause of death in children with T1D. Frequent episodes of DKA increase the risk of the long-term complications associated with poorer metabolic control (Cooke & Plotnick, 2008).

### **Disease-care Behaviors**

To prevent disease complications, youth and families have to learn how to balance a regimen of diabetes care that consists of diet, monitoring, medication, and exercise management. This regimen can be cumbersome to the carefree lifestyle of a child and to the independent lifestyle of an adolescent and may lead to conflict between parents and their children. This regimen is often referred to as disease-care behaviors and is instituted to manage youths' blood sugar levels within a safe range. An average non-diabetic person's blood glucose ranges from 80 to 120 mg/dl; this is considered the normal and safe range. People with diabetes often fluctuate well above and below this range and utilize insulin therapy to help regulate their blood sugar level (Cooke & Plotnick, 2008).

### **Insulin Therapy**

Type 1 diabetes occurs when the pancreas ceases to produce insulin to aid the body in processing glucose in the blood. Insulin analogs are used by patients with diabetes to compensate for their lack of insulin production. Several treatment options are currently available

for the administration of insulin to manage glucose levels in individuals with type 1 diabetes. Conventional insulin therapy consists of scheduled daily injections of long acting insulin and is the method of insulin administration used most often historically. However, it is the least intensive insulin regimen and is often reserved for patients who do not comply with more rigorous insulin schedules. Patients who use conventional therapy must follow more strict dietary restrictions including meal schedules and specific guidelines for nutritional intake (Cooke & Plotnick, 2008; Daneman, 2008; Silverstein et al., 2005).

Basal/bolus or multiple daily injection (MDI) therapy is another insulin option in which a patient receives a basal level of insulin via scheduled long acting insulin injections. Supplemental short-acting insulin is injected prior to meals. The amount of insulin is either based on a sliding scale as determined by a physician or the nutritional content of a meal, with a specific focus on carbohydrate intake. This technique is called “carb counting” and is necessary for both the intensive basal/bolus regimen as well as insulin pump therapy (Cooke & Plotnick, 2008).

Continuous Subcutaneous Insulin Infusion (CSII) is the most recent treatment advance in the diabetes field. “The pump” or CSII is an electronic device about the size of a pager; a patient receives a basal rate of insulin throughout the day via a catheter underneath the skin. In addition to this basal rate of insulin a patient will bolus, or take an extra dose of insulin, to correspond to the level of food intake at each meal/snack. The amount of additional insulin needed is determined by carb counting, entered into the insulin pump and delivered via the subcutaneous catheter (Cooke & Plotnick, 2008). The pump is a very effective means to improve metabolic

control in patients with T1D and to reduce the risk of hyperglycemia (Lenhard & Reeves, 2001; The Diabetes Control and Complications Trial Research Group, [DCCT], 1993).

### **Blood Glucose Monitoring**

In addition to insulin replacement therapy, youths with T1D need to monitor their blood glucose levels on a consistent basis. To monitor blood glucose levels patients use a blood glucose (BG) monitor that requires a small drop of blood from a finger prick. The BG monitor provides a current indication of blood sugar level and typically is used 4-6 times a day (Cooke & Plotnick, 2008). Blood glucose monitoring is essential to the maintenance of proper metabolic control. Despite this fact, it is one of the more difficult aspects of the diabetes regimen to regularly maintain. Several barriers can impede the completion of blood glucose monitoring including inadequate supplies, poor schedule management, and most often low motivation. Past research has also shown a significant positive relationship between parental involvement and average number of blood glucose checks (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Anderson et al., 2002). Parents who stay closely involved in their child's care can help remediate or prevent these issues by ensuring that appropriate supplies are available, that time and attention are paid to the completion of checks, and that support is provided to youths with low motivation. An alternative to the traditional method of blood glucose monitoring is a newer technology that continuously monitors BG levels. A sensor patch is worn all day that provides continuous feedback about the patient's blood glucose level. Current research is focused on the feasibility of this technique in both adult and child populations (Edelman & Bailey, 2009).

Traditional and continuous blood glucose monitoring provide immediate feedback about youths' current blood glucose levels and are used to monitor and manage symptoms. Another

method to monitor blood glucose levels is the glycosolated hemoglobin assay (HbA1c). This assay provides an average blood glucose level for the previous three months and is used as a global measure of overall diabetes management. This information is used to inform youths' health care and any regimen changes needed improve metabolic control (Cooke & Plotnick, 2008; Daneman, 2008). One major drawback of the HbA1c assay is that a moderate or controlled number could actually represent the average of significantly fluctuating levels. For example, a youth with an average of 200 BG level over the last 3 months could have numbers ranging from 150 to 250 (relatively low fluctuations) or they could range from 100 to 300 or 50 to 350 (higher fluctuations) and could have similar "average" 3 month HbA1c levels. Therefore, fluctuations in glucose ranges should also be monitored as part of good diabetes management.

### **Diet Management**

Diet management is another complicated, yet important aspect of good metabolic control. Historically individuals with diabetes adhered to strict diets low in sugar and carbohydrates. While those still on conventional insulin regimens have to adhere to this stricter dietary regimen, the introduction of the basal/bolus and insulin pump regimens have given youths more freedom in their dietary choices. Rather than restricting certain foods from their diet, youths who use supplemental insulin consider the nutritional value of the food they plan to eat, calculate the carb intake, and inject or bolus the appropriate amount of insulin. Carb counting is intensive and can be daunting to families trying to manage the already heavy load associated with diabetes management (Cooke & Plotnick, 2008).

### **Physical Activity**

Youths with diabetes and their parents must also monitor and manage levels of physical

activity. For youths with diabetes there is a delicate balance between too much and too little physical activity. Highly active children and adolescents have difficulty managing blood glucose levels and insulin administration around their activity. High activity can place youths at risk for hypoglycemia. However youths do not have to restrict their activity, rather they and their family must pay close attention to diabetes management needs such as more frequent BG checks and having snacks available for lows. A healthy level of physical activity can significantly help improve metabolic control by naturally helping the body use and absorb glucose that can lead to hyperglycemia (Cooke & Plotnick, 2008).

### **The Diabetes Team**

A final aspect of diabetes management is the responsibility of the parent to coordinate their child's care with multiple medical providers such as their endocrinologist, primary care physician, nutritionist, and any additional supports they might need. These relationships are crucial for families to obtain the support they need to facilitate diabetes tasks. Regular endocrinology appointments should occur approximately every 3 months; nutritionist appointments are recommended every year. The purpose of these visits is to monitor progress and make any regimen adjustments needed to address difficulties that families may experience. While these appointments and supports are intended to be helpful, the additional responsibility of maintaining regular appointments or the possibility of negative feedback may have a significant impact on mothers with depression. Mothers of children with asthma that are experiencing depression have difficulty utilizing these necessary supports, and instead rely on emergency services to manage out of control symptoms (Bartlett, et al., 2001; Flynn et al., 2004). This

pattern of ED usage in lieu of routine medical care could put youths with T1D at serious risk of complications such as DKA or hypoglycemic seizures or coma.

### **Parental Involvement and Monitoring**

Parents, most often mothers, play a central role in the day-to-day management of disease care behaviors, particularly for children in early and middle childhood (Jaser et al., 2008). Research has shown that due to the complexity of the diabetes regimen, parental involvement in diabetes management is necessary to maintain good metabolic control (Dashiff, Hardeman, & McClain, 2008; Wiebe et al., 2005). However as youths move from young childhood to adolescence, the components of when and how parents are involved in diabetes management changes. During childhood, parents are responsible for many actual diabetes tasks such as checking blood sugar, administering insulin, and preparing meals. However, as youths mature into adolescents this relationship changes and parents continue to remain involved in diabetes care but less in a hands-on fashion and more in a supervisory role. Due to the age and developmental level of the young adolescents in the current study parental involvement will be conceptualized as supervision and monitoring rather than actual parental completion of diabetes tasks. Fluctuations in several aspects of the diabetes management regimen such as insulin administration, blood glucose monitoring (Anderson et al., 2002), food choices (Gellar, Schrader, & Nansel, 2007) and physical activity (Mackey & Streisand, 2008) are linked to parental involvement and support. More frequent and supportive involvement is linked to better outcomes in these areas.

Table 2.

*Developmental Stages of Parental Involvement and Diabetes Management* (Anderson et al., 2002; Jaser et al., 2008; Silverstein et al., 2005)

<b>Young Childhood</b>	<ul style="list-style-type: none"> <li>• High parental involvement in all aspects of diabetes care</li> <li>• Low child communication of symptoms of hypo- or hyperglycemia</li> <li>• High levels of active vigilance and monitoring needed</li> <li>• Risk of high parental stress</li> </ul>
<b>Middle Childhood</b>	<ul style="list-style-type: none"> <li>• Children begin to participate in developmentally appropriate aspects of management</li> <li>• Parents balance active and passive involvement in diabetes management</li> <li>• Children and parents begin to manage school and after school activities</li> </ul>
<b>Late Childhood /Adolescence</b>	<ul style="list-style-type: none"> <li>• Adolescents begin to complete the active aspects of diabetes management (e.g. blood glucose checks, injections/boluses, diet management)</li> <li>• Parents take a more passive/supervisory role</li> <li>• Conflict can increase</li> </ul>

Level and type of parental involvement follows a natural developmental progression as children mature and age independent of disease duration (Anderson et al., 2002) as seen in Table 2. During young childhood (approximately 7 and below) parental involvement is very high; caregivers are responsible for virtually all aspects of diabetes management. At this stage children may not have the cognitive ability to recognize symptoms of hypo- or hyperglycemia or be able to communicate appropriately about them. This child dependence necessitates high levels of parental responsibility, vigilance, and monitoring that can often be a source of distress for parents (Jaser et al., 2008; Silverstein et al., 2005).

During middle childhood (approximately 8-11 years) youths begin to participate in developmentally appropriate aspects of the disease-care regimen such as blood glucose monitoring and diet management. These youths are better able to communicate about and to understand the physical symptoms related to high and low blood sugars. During this

developmental stage children and parents also begin the process of managing diabetes during school and after school activities (Silverstein et al., 2005).

Late childhood and adolescence is typically the most difficult time to manage diabetes and balance parent/child involvement. Adolescents have busy lifestyles that are centered around social and peer relationships rather than family involvement. Parents are encouraged to develop a collaborative and supervisory relationship with their teenagers to maintain involvement at the same time as encouraging more independent disease-care (Wiebe et al., 2005). During this time parent/child conflict and disagreement can increase which can negatively impact diabetes care behaviors and metabolic control (Silverstein et al., 2005).

Quality and level of parental involvement can have a significant effect on child health outcomes. In A study of parental involvement with different age groups (older [13-15] and younger [10-12] children) Anderson et al. (1997) identified significant differences in the level of parental involvement between the two groups. Parents are significantly less involved with the management of older youth's diabetes than their younger counterparts, as would be expected. However, this lower involvement was related to lower rates of blood glucose monitoring; younger children whose parents were more involved checked significantly more often than members of the older group. Monitoring was indirectly related to metabolic control through BGM when potential confounding variables (gender, disease duration and Tanner stage) were included as covariates. If youths checked more often their HbA1c levels were significantly lower ( $R^2 = 0.19$ ;  $p < 0.02$ ), indicating better metabolic control (Anderson et al., 1997). Additionally, adolescents may be at higher risk of less parental involvement compared to younger children regardless of disease duration. Due to perceived maturity, youths diagnosed

with T1D during adolescence may receive less support overall even after initial diagnosis when parental involvement may be the most effective and necessary (Anderson et al., 2002).

Blood glucose monitoring and insulin administration are considered the essential pieces of day-to-day management. However, the more overarching elements of healthy eating and good physical health are also necessary for good metabolic control. Gellar, Schrader, & Nansel (2007) reviewed the available literature of factors that contribute to healthy food choices in youths with diabetes. They identified a dearth of research related to this important aspect of diabetes management. To address this issue the authors conducted multiple focus groups at a diabetes camp directed at learning about contributors and detriments to healthy eating. One hundred and forty participants ages 7 to 16 completed surveys and identified multiple factors that affected their food choices including parental guidance and involvement. Youths most often endorsed parental involvement and support as an important component of healthy eating. Many children endorsed healthy eating as an important contributor to good metabolic control. However, other youths indicated that food choices are not important. Rather, matching insulin dose to food intake is an acceptable substitute for dietary restrictions (Gellar et al., 2007).

Similar to diet adherence, little research has been conducted about the importance of parental involvement in encouraging healthy levels of physical activity in children and adolescents with T1D. Mackey and Streisand (2008) addressed this deficit in the literature through exploratory research that combined and analyzed physical activity items from multiple self-report scales related to physical activity. Greater parental support related to higher levels of youth physical activity, and more conflict was related to lower levels of activity (Mackey & Streisand, 2008).

When one considers the research results related to parental involvement and monitoring in all of the aforementioned areas of diabetes management, the general conclusion is that greater levels of parental involvement and monitoring will likely result in better diabetes care. However, research has also shown that the quality of involvement is just as, if not more important than the quantity of involvement. Increased parental involvement without the appropriate guidance and coping skills can lead to increased conflict between parent and child that can negatively impact metabolic control (Anderson et al., 2002). Supportive and positive parental involvement is key for regimen adherence, better emotional adjustment (Berg, Schindler, & Maharajh, 2008) and improved metabolic control; whereas negative and/or conflictual involvement can lead to poorer metabolic control.

Both quality and quantity of maternal involvement in diabetes tasks are at risk when a mother is struggling with a mental health disorder as disabling as depression. Mothers experiencing cognitive/emotional symptoms of depression may have a negative view about their own or their child's ability to manage the T1D regimen. This could lead to higher negative or critical parenting, greater conflict, or a more negative family environment altogether. As discussed earlier these family and parent/child level variables have consistently been linked to poorer metabolic control. Alternatively, mothers may experience a constellation of vegetative/motivational symptoms such as avoidance, escape, fatigue or increased dependency. These mothers may withdrawal from the daunting and regularly unrewarding task of diabetes management, or may simply not have the energy to help manage, leaving their child to manage the daunting diabetes regimen on their own.

## **Statement of Purpose**

Type 1 diabetes is a complex chronic illness that in 2005 affected approximately 176 thousand children and adolescents under the age of 20 (Cooke & Plotnick, 2008). Clinicians and researchers are aware of the high demands of the T1D regimen, and that parental involvement is essential for good metabolic control. However, these demands may be related to higher symptoms of parental psychopathology including symptoms of depression, anxiety and rates of PTSD. The focus of the present study was exploration of the higher rates of reported clinically significant symptoms of depression in mothers of children with T1D, and disease management correlates.

Several mechanisms associated with biological and psychological theories of the pathogenesis of depression may account for higher rates of depressive symptomology found in mothers of youths with T1D. Mothers may view their child's diagnosis as a traumatic event (Horsch et al., 2007). According to the stressful life events theory mothers of children with T1D may be at a much greater risk to develop depression compared to mothers of healthy children. Biological factors also may predispose certain mothers to be less equipped to handle a traumatic event than other mothers (Goldberg, 2006). Traditional psychological theories of depression may explain the ongoing risk and/or maintenance of depression beyond initial diagnosis. Diabetes management is an inherently difficult task and "perfect" management is next to impossible. Difficulties and/or perceived failures are likely to occur at some point. The behavioral model of depression highlights how mothers with depression might learn avoidant and/or unhealthy mechanisms to cope with these perceived failures. Alternatively, mothers that are predisposed to

negative and or flawed reasoning, as constructed within the cognitive model of depression, may aggrandize these failures or may not be able to view any outcomes as successes.

Several family and parent/child factors have been found to be associated with greater maternal depression. Higher levels of family conflict, negative expressed emotion, critical parenting, and low parental involvement are related to poorer youth psychosocial adjustment, lower levels of disease-care behaviors and indirectly related poorer metabolic control (Anderson et al., 2002; Anderson, Brackett, Ho, & Laffel, 1999). The proposed study examined potential relations between high maternal depressive symptoms, parental monitoring and involvement and diabetes specific conflict. Mothers with higher levels of depressive symptoms likely have fewer cognitive and psychological resources to allocate to the complex regimen of T1D. Mothers may be able to manage certain aspects of the diabetes regimen, but may not have the time, mental energy or emotional resources to manage all the necessary components for healthy child adjustment, regimen adherence, and good metabolic control. The goal of this study was to identify areas of the diabetes care regimen that may be negatively related to clinically elevated levels of maternal depressive symptoms and potential mediators of this relation.

Specific hypotheses:

- 1) Ratings of depressive symptoms for mothers of children with T1D are higher than the point prevalence for women in the general population.
- 2) Higher levels of maternal depressive symptoms will have an indirect effect on disease-care behaviors (frequency of blood glucose monitoring, frequency of insulin use, meal frequency, exercise frequency and blood glucose range) mediated by lower parental involvement.

- 3) Higher levels of maternal depressive symptoms will have an indirect effect on disease-care behaviors (frequency of blood glucose monitoring, frequency of insulin use, meal frequency, exercise frequency and blood glucose range) mediated by higher diabetes specific conflict.

### **Method**

This research study was completed with baseline data from a larger randomized clinical trial (RCT), an intervention study currently in progress. Baseline recruitment for this study ended in June 2010.

### **Participants**

Eligible participants with T1D were identified by trained research assistants from patient profiles provided by clinic staff. After potential participants were identified, they were sent a letter detailing the purpose, requirements and potential benefits of a study designed to provide support and assistance to families during a youth's transition into adolescence. A follow-up informational phone call by research staff occurred approximately 1 week after letters were mailed. Families were affiliated with pediatric endocrinology clinics in two major mid-Atlantic metropolitan medical centers.

Participants were between 11 and 14 years of age when recruited for participation. All were free from any medications that affected the central nervous system other than insulin and could not be diagnosed with another major chronic illness, such as a seizure disorder, or traumatic brain injury. Additionally patients had been diagnosed with T1D for at least one year prior to enrollment.

## **Procedures**

After families agreed to participate in the research study, a baseline assessment was scheduled to coincide with a quarterly endocrinology appointment. Participants agreed either to come in prior to their medical appointment or to stay after to complete study questionnaires. A member of the research staff met with families at the clinic and obtained informed consent (parents) and assent (young adolescents) to participate in the study. After consent was obtained, both parent and child completed baseline psychosocial questionnaires and research staff interviewed parent and child individually about the previous day's diabetes care behaviors with the 24 hour diabetes interview (Holmes et al., 2006). The baseline questionnaires took approximately 90 to 120 minutes to complete and included measures of diabetes care, family environment, parental involvement and monitoring, psychosocial health, and diabetes adjustment. A family then provided potential times during the following two weeks in which the family could be reached for an additional 24 hour diabetes interview. This second interview is protocol for the diabetes 24 hour diabetes interview and provides additional information about disease-care behaviors (Holmes et al., 2006). Upon completion of the interviews and questionnaires, participants were reimbursed for their time with a \$25 gift card.

## **Measures/Materials**

Medical Information and Demographic Questionnaires – Parents were given a medical information and demographic questionnaire to complete during their initial assessment. Some questions included were: 1) age of the youth and parent, 2) ethnicity, 3) marital status of parent, 4) socio-economic information, 5) employment status for both parents, and 6) disease duration.

Additional medical and demographic information was obtained from patient medical history after the families provided consent to access these records.

### **Disease Care Behaviors**

24 hour Diabetes Interview – Diabetes disease-care behaviors (blood glucose monitoring, insulin administration, diet, and exercise) were assessed with the 24 hour diabetes interview created by Johnson et al. (1982) and adapted by Holmes et al, (2006). The interview requires that the youth and parent recall diabetic and meal related activities for the previous day. The initial administration of the interview was completed in person during the two hour baseline assessment at the diabetes clinic. During the next 7-14 days the family was contacted again by a trained graduate student to administer the second 24 hour interview; each interview takes approximately 10 to 15 minutes. Youth and parents were interviewed separately to provide two independent records of the previous day. If an interviewee neglected to offer information about diabetes care behaviors the administrator prompted them with questions about omitted information. The administrators were trained to ask questions and respond in a non-judgmental way to information offered (e.g. not to sound disappointed if a child reported “sneaking” food). Reliability and validity for this measure have been well established (Freund, Johnson, Silverstein, & Thomas, 1991; Holmes et al., 2006; Johnson, Silverstein, Rosenbloom, Carter & Cunningham, 1986). Pearson product-moment correlations between parent and child report were significant for all 13 variables included in the interview. Correlations in Johnson et al.’s (1986) study ranged from  $r = .42$  for “regularity of injection” and “meal timing” to  $r = .78$  for “glucose testing frequency.” Additionally Holmes et al., 2006 conducted a factor analysis that revealed a three factor model including exercise duration, frequency of meals and blood glucose checks,

and diet composition (Freund et al., 1991; Holmes et al., 2006; Johnson et al., 1986). For the current study insulin frequency was also used with insulin regimen included as a control variable to attenuate the inherent different insulin usage between conventional versus intensive regimens.

Information from both interviews was consolidated into a single score of diabetes adherence for each disease-care behavior. The 24 hour decisions rules developed by Johnson et al. (1986) were used to reconcile any differences between youth and parent reports of diet and disease-care behaviors. Potential differences include discrepancies in amount of food eaten, type of food eaten, and whether or not a meal occurred.

### **Maternal Depressive Symptoms**

Beck Depression Inventory-II (BDI-II) – This measure of depressive symptoms was developed by Beck, Steer & Brown (1996) as a revision of their earlier well-established measure of depression the Beck Depression Inventory (BDI). The BDI-II provides a measure of depressive severity for individuals age 13 and older. It is a 21-item measure with each question providing a range of answers from 0-3 to indicate symptom severity. Two subscales comprise the BDI-II: a cognitive-affective symptom scale and a somatic-vegetative scale. Possible scores on this questionnaire range from 0 to 63 with scores above 14 indicative of clinically elevated symptoms of depression. Scores ranging from 14 to 19 indicate mild symptoms of depression, 20 to 28 moderate levels, and a score 29 to 63 indicate severe symptoms of depression are reported. Mothers in the current study who scored above a 29 on the BDI-II were approached by research staff and provided referral information for psychological counseling. Follow-up telephone contact was made after the clinic appointment by a clinical psychologist to further assess mothers' well being.

The BDI-II is widely used and accepted as a screening measure of state depressive symptomology and is shown to have high reliability and validity. Excellent internal consistency is found, Cronbach's alphas of .92 to .93 and test-retest reliability of .93 (Beck et al., Dozois, Dobson, & Ahnberg, 1998).

### **Parental Monitoring and Involvement**

Parent Monitoring of Diabetes Scale (PMDS) – Parental monitoring related to diabetes disease-care behaviors was developed by Ellis et al. in 2007. The PMDS is a 19 item scale with 18 items in a 5 point Likert response format and 1 open ended item to provide parents a space to indicate any additional behaviors they regularly monitor. Several potential subscales were identified including: 1) Supervision of the availability of medical supplies, 2) monitoring of blood glucose checks, 3) oversight of diet, 4) monitoring of non-adherence, and 5) direct oversight of diabetes management behaviors (Ellis et al., 2008). Higher scores indicate higher levels of parental monitoring with lower scores indicate less frequent monitoring. Good internal consistency ( $\alpha = .81$ ) and test-retest reliability ( $r = .80$ ) were established in by Ellis et al. (2008).

### **Diabetes Conflict**

Diabetes Family Conflict Sale (DFCS) – The DFCS (Hood, Butler, Anderson, & Laffel, 2007) is a self-report measure of conflict between child and parent related to diabetes disease-care behaviors and other indirect aspects of diabetes management. There are two versions of the DFCS, one for parents to complete and one for children. Respondents describe the extent to which they have argued with parent or child about a particular diabetes situation over the past month. Choices are presented in a 5 point Likert scale where 1 indicates “Never Argue” and 5 indicates “Always Argue.” The most recent update of the DFCS was completed in 2007 by

Hood et al. Results of this study supported the reliability of the revised DFCS with good internal consistency Cronbach's  $\alpha = .85$  for the child version and  $\alpha = .81$  for the parent version.

### Statistical Analysis Plan

All variables were entered into a correlation table to determine potential significant relations and paths between variables. Hypothesized relationships were then entered into a path analysis (PA) to test indirect effects using Preacher and Hayes' (2008) distribution of products approach to mediation analyses with bootstrapping for SPSS. They hypothesized path models are illustrated in Figure 2 and Figure 3.

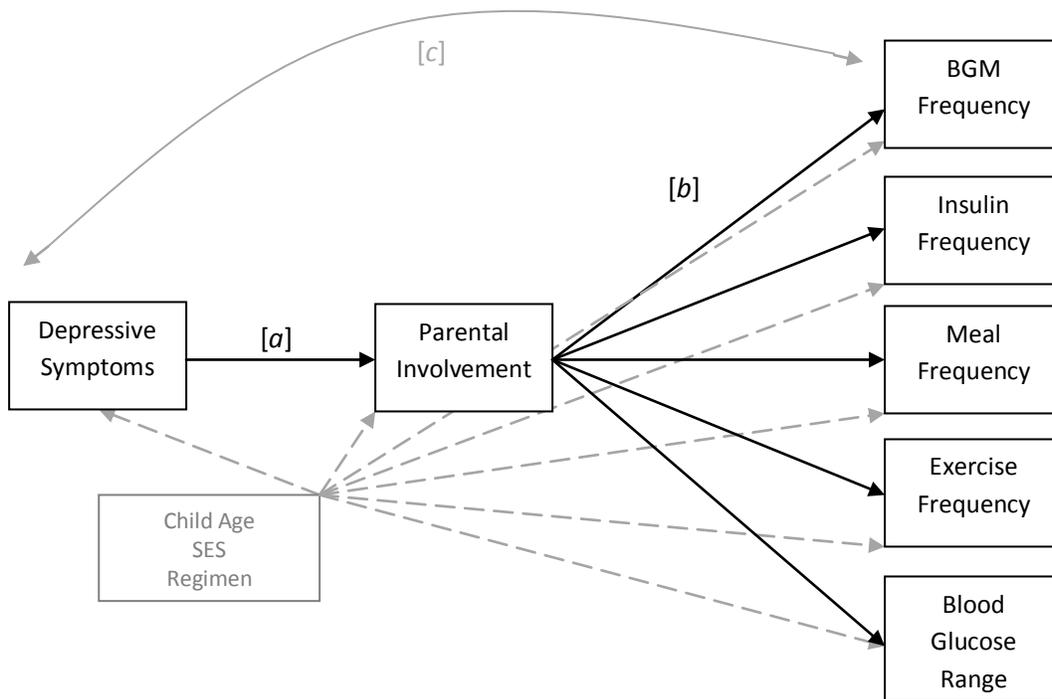


Figure 2. Parental Involvement and Monitoring Mediation Model

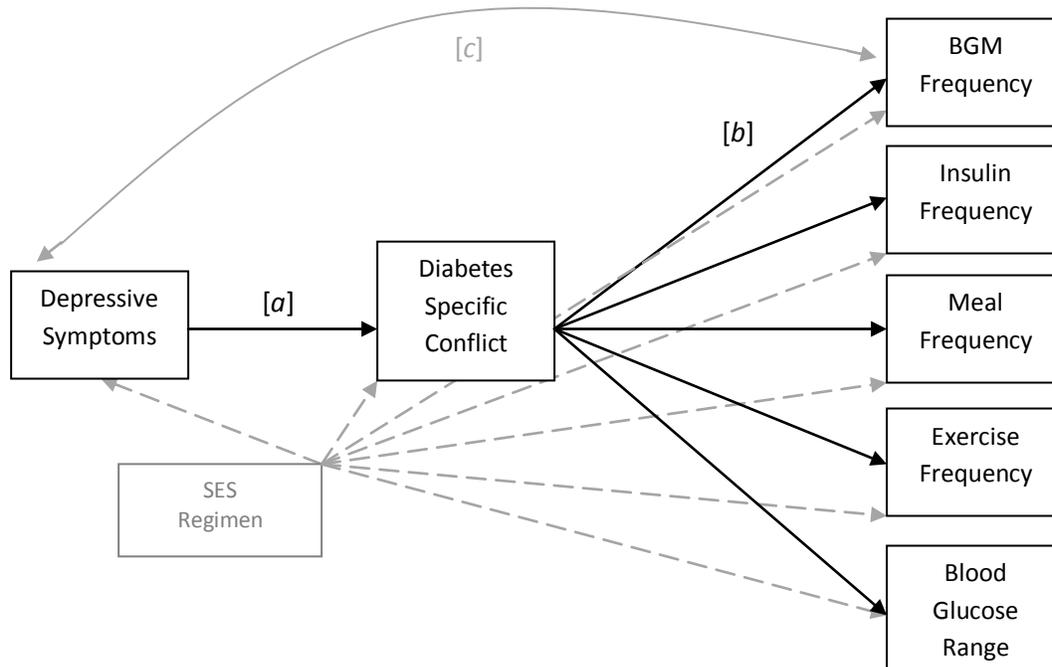


Figure 3. Diabetes Conflict Mediation Model

Within the PA model the  $c$  path is defined as the direct relation between the independent variable (IV) and the dependent variables (DV) of interest. The total relation between those variables is denoted as  $c'$  once the potential mediator variable (MV) is included in the model. The  $a$  path is defined as the relation between the independent variable and the mediator variable, and the  $b$  path is the relation between the mediator variable and the dependent variable. In the current study, higher levels of maternal depressive symptoms (IV) were analyzed to determine if there was an indirect effect on frequency of disease-care behaviors (DV) and blood glucose range (DV) through either parental involvement (MV) and/or diabetes specific family conflict (MV). Preacher and Hayes (2008) propose an updated statistical process to test indirect effects of mediator variables with bootstrapping for statistical software regularly used in the social sciences, SPSS, SAS and R. Bootstrapping is a statistical strategy designed to remedy common

problems encountered non-normal data distributions. An empirical representation of the sample distribution is created through repeatedly resampling of data with replacement during the analyses. After a resample is created the  $a$  and  $b$  paths are estimated and the product of the coefficients is recorded. This process is repeated for a  $k$  number of times, and after the process is completed, there are  $k$  estimates of the indirect effect. These estimates are used to generate a 95% confidence interval to create a percentile-based bootstrap confidence interval. If zero does not fall within the confidence interval than it is determined that the indirect effect is not zero with 95% confidence (Hayes, 2009; Preacher & Hayes, 2008).

### **Data Preparation**

The final sample used for data analysis was comprised of 225 mothers of children with type 1 diabetes. An initial pool of 228 potential participants was available at the time of these data analyses. Three participants without scores on the Beck Depression Inventory II were excluded. Mean substitution was used to replace missing data for disease-care behaviors, demographic variables and diabetes specific family conflict when all other data were available. Mean substitution is often utilized by researchers for its ease and the desire to maintain all participants for higher power. However, when substituting the sample mean for individual scores the variance associated with that variable is reduced and this reduction in variance may attenuate covariance estimates. Mean substitution is generally accepted when the percentage of data missing for a particular variable is less than 10% because it will likely have minimal impact (Roth, 1994). For the current sample, no more than four percent of the sample was missing for variables in which mean substitution was utilized.

Simple correlations were completed between demographic, independent, mediator, and outcome variables to determine important bivariate relations. See Table 4. Frequency of disease-care behaviors was strongly related to type of insulin regimen thus regimen (intensive,  $\geq 3$  injections or pump, versus conventional) was used as a control variable in all models. Several demographic variables were also significantly related to depression and disease-care behaviors including socioeconomic status and years of education. Because highest level of education is used to calculate the SES variable both were not included as control variables, rather SES, which is representative of both educational and occupational status, was included as a more comprehensive control variable in all models.

Frequency of blood glucose monitoring, insulin injection/bolus, meals, and exercise was determined for each participant using an average of child and parent report from the 24 hour interview. Blood glucose range was determined by blood glucose numbers obtained from the 24 hour diabetes interview. The lowest number from the two available interviews was subtracted from the highest number determine the range across the two interviews.

Diabetes related conflict scores from the DFCS were available for all but one participant; mean substitution was used to replace this missing score. Parent and child report were combined and then divided by two to obtain an average conflict score. Average scores were used to reduce any effects of reporter bias by either parent or child. The highest levels of conflict were reported for remembering to rotate injections sites or infusion sets and remembering to check blood glucose numbers.

Parental involvement scores taken from the PMDS disease monitoring scale were available for 156 of the 225 participants. This measure of parental involvement was added 12

months after data collection began. Mothers without PMDS scores were compared to those with scores and the only significant differences identified were for child age,  $F(1,223) = 10.44, p < .01$ , and disease duration  $F(1,223) = 3.93, p < .05$ . These differences are likely due to early recruitment strategies to bring eligible 14 year olds into the research study before they would no longer be eligible to participate. Because the only significant difference was due to study design and not participant characteristics pairwise deletion was selected to manage missing data. This strategy allows for the retention of the 69 participants without the PMDS for analyses in which they have full data, primarily the second model (Figure 3) with diabetes conflict as a mediator. To be conservative, child age was used as a control variable for the analyses that include PMDS scores.

## Results

Table 3 summarizes the descriptive statistics for sociodemographic and diabetes variables. On average, mothers were 42.17 years of age and their children were 12.73 years of age. The majority of youths included in the study were Caucasian (68.4%); information for parent ethnicity was not available. Families generally were middle class (SES = 46.3) and most children came from homes that contained both biological parents (66.7%). Both the socioeconomic and ethnic distribution were in line with previously reported samples of youths with diabetes from major metropolitan medical centers (Glasgow et al., 1991; Holmes et al., 2006). Parents and children reported low overall levels of conflict ( $M = 27, SD = 7.1$ ) where a score of 19 indicates no conflict and 95 indicates conflict is always present for all items. Parents and children reported relatively high parental involvement ( $M = 78.3, SD = 6.3$ ) in diabetes care where a score of 18 indicates little to no involvement and 90 indicates high involvement with all

aspects of diabetes care. Youths checked their blood sugar on average four times per day which is within the suggested range from the ADA ( $M = 4.4$ ,  $SD = 1.4$ ), ate approximately four meals per day ( $M = 4.2$ ,  $SD = .8$ ), exercised at least once a day ( $M = 1.06$ ,  $SD = .7$ ) and utilized insulin injections or boluses three to four times per day ( $M = 3.5$ ,  $SD = 1.0$ ). The average blood glucose range for participants was fairly large and variable ( $M = 238.8$  mg/dl,  $SD = 105.7$ ). The majority of participants used an intensive regimen ( $n = 144$ ) versus a conventional regimen ( $n = 81$ ).

Approximately 21% of mothers ( $n = 47$ ) reported clinically elevated ( $\geq 14$ ) symptoms of depression on the BDI-II. Of this 21%, five mothers endorsed suicidal ideation. The most frequently endorsed physical symptoms of depression were loss of energy ( $n = 144$ ) and fatigue ( $n = 124$ ). In relation to loss of energy, 58% endorsed an intensity rating of one, "I have less energy than I used to have" and 13% endorsed an intensity rating of two "I don't have enough energy to do very much." For higher levels of fatigue 33% of mothers endorsed a rating of one, "I get tired or fatigued more easily than usual," 3% endorsed a two, "I am too tired or fatigued to do a lot of the things I used to do," and 2% endorsed a three, "I am too tired or fatigued to do most of the things I want to do." The most frequently endorsed cognitive symptoms were feelings of guilt ( $n = 85$ ) and loss of pleasure in everyday activities ( $n = 84$ ). Of the mothers that reported feelings of guilt, 33% endorsed an intensity rating of one "I feel guilty over many things I have done or should have done," 4% endorsed a two "I feel quite guilty most of the time," and < 1% endorsed a three "I feel guilty all of the time." For loss of pleasure 33% of mothers endorsed a one "I don't enjoy things as much as I used to," 3% endorsed a two, "I get very little pleasure from the things I used to enjoy," and 2% endorsed a three "I can't get any pleasure from the things I used to enjoy."

Table 3.

*Descriptive Statistics*

	<i>M (SD) or % (n)</i>	<i>Range</i>
Mother age	42.17 (6.6)	28 - 64
Years of education	14.67 (2.5)	5 - 22
Depressive symptoms	8.24 (7.8)	0 - 44
Marital status Married to bio parent	65.7% (195)	
Employment status Full time	52.4% (118)	
SES <sup>a</sup>	46.31 (11.7)	12 - 66
Youth age	12.73 (1.2)	11 - 14.99
Youth gender Female	50.2% (113)	
Youth race/ethnicity Caucasian	66.7% (150)	
Disease duration	5.20 (3.2)	1.02 - 13.63
Diabetes conflict	26.91 (7.1)	19 - 51.5
Parental involvement	78.31 (6.3)	59.5 - 89.5
BGM frequency	4.38 (1.4)	1.25 - 9.25
Insulin frequency	3.53 (0.1)	1.5 - 6.75
Meal frequency	4.17 (.8)	2 - 6.25
Exercise frequency	1.07 (.7)	0 - 3
BG range	238.84 (105.7)	7 - 522

<sup>a</sup>SES assessed by Hollingshead, lower scores indicate lower SES and higher scores indicate higher SES

Table 4 provides bivariate correlations between sociodemographic, predictor, mediator, and outcome variables. The relations identified through these correlations are generally consistent with the literature and with the study's hypotheses. Significant relations between several sociodemographic variables were identified. SES was related to maternal education ( $r = .64, p < .01$ ), HbA1c ( $r = -.36, p < .01$ ), maternal depression ( $r = -.13, p < .05$ ), marital status ( $r = .44, p < .01$ ), race ( $r = .36, p < .01$ ), regimen ( $r = .27, p < .01$ ), and conflict ( $r = -.32, p < .01$ ). Due to the significant impact of SES on several variables of interest, it was included as a control variable in all models.

Simple correlations revealed negative relations between maternal depressive symptoms and blood glucose monitoring frequency ( $r = -.09, p = .18$ ), insulin frequency ( $r = -.17, p = .03$ ), eating frequency ( $r = -.07, p = .20$ ), exercise frequency ( $r = -.04, p = .58$ ) and blood glucose range ( $r = -.01, p = .88$ ). While only the relation between depressive symptoms and insulin frequency reached statistical significance, the direction of all relations except BG range was as hypothesized. These correlations allowed for further investigation of potential indirect effects through the proposed mediator variables except for BG range (Preacher & Hayes, 2008). In the absence of a significant relation, directionality is the key factor in determining indirect effects in mediation analysis. The correlation for BG range was not in the hypothesized direction (higher depressive symptoms relate to higher BG range) and was very small ( $r = -.01, p = .88$ ) thus it was not included in further analyses.

Aggregate child/parent report of parental monitoring on the PMDS was related to child age, ( $r = -.18, p < .05$ ), HbA1c ( $r = -.18, p < .05$ ) maternal depressive symptoms ( $r = -.26, p < .01$ ), blood glucose monitoring behavior from the 24 hour diabetes interview ( $r = .31, p < .01$ ), as

well as insulin utilization frequency ( $r = .25, p < .01$ ), and meal frequency ( $r = .26, p < .01$ ).

These correlations support the hypothesis that parental involvement may be an important variable in the relation between maternal depressive symptoms and disease management behaviors.

Diabetes specific conflict was related to more sociodemographic variables than diabetes variables of interest. Conflict was related to parent education ( $r = -.30, p < .01$ ), SES ( $r = -.32, p < .01$ ), HbA1c ( $r = .34, p < .01$ ), marital status ( $r = -.20, p < .01$ ), race ( $r = -.24, p < .01$ ), regimen ( $r = -.14, p < .05$ ), maternal depressive symptoms ( $r = .22, p < .01$ ), and insulin frequency ( $r = -.14, p < .05$ ). These correlations indicate that while conflict is related to some variables of interest (maternal depressive symptoms and insulin frequency) there may be a complex relation between the identified significant socioeconomic variables, conflict, and maternal depressive symptoms.

Table 4

*Correlation Table*

	BDI	Child Age	Gender	Onset Age	Dis. Dur.	Mat. Educ.	SES	HbA1c	Mar. Status	Work Status	Race	Reg.	BGM Freq.	Insulin Freq.	Ex. Freq.	Meal Freq.	Diab. Con.	Parent Involv	BG Range
BDI	1																		
Child Age	.05	1																	
Gender	.06	-.02	1																
Onset Age	.08	.35**	.02	1															
Disease Dur.	-.07	.02	-.03	-.93**	1														
Mat. Educ.	-.11	.04	.13	.09	-.09	1													
SES	-.13*	.06	.14*	.05	-.03	.64**	1												
HbA1c	.07	.13*	-.03	-.03	.08	-.30**	-.36**	1											
Marital Status <sup>a</sup>	-.15*	-.01	.01	-.15	.12	.34**	.44**	-.34**	1										
Work Status <sup>b</sup>	.08	-.04	-.01	.13	-.14*	-.04	-.02	.05	-.16*	1									
Race <sup>c</sup>	-.11	.03	.03	-.03	.04	.14*	.36**	-.24**	.31**	-.11	1								
Reg. <sup>d</sup>	-.15*	-.09	.09	-.28**	.25**	.17**	.27**	-.19**	.28**	-.19**	.31**	1							
BGM Freq.	-.09	-.19**	-.03	-.17*	.11	.19**	.32**	-.30**	.22**	-.13	.21**	.28**	1						
Insulin Freq.	-.15*	-.08	.06	-.25**	.24**	.17**	.26**	-.20**	.24**	-.18**	.32**	.37**	.55**	1					
Ex. Freq.	-.04	-.11	-.04	-.07	.04	.10	.10	-.12	-.03	.02	.07	-.06	.12	.01	1				
Meal Freq.	-.09	-.16*	-.04	.03	-.09	-.12	-.05	-.23**	.00	-.07	.02	-.03	.25**	.18**	.15*	1			
Conflict	.22**	-.03	.01	-.12	.11	-.30**	-.32**	.34**	-.20**	.03	-.24**	-.15*	-.10	-.14*	.04	-.10	1		
Parent Involv.	-.26**	-.18*	-.09	-.09	.02	.05	.10	-.18*	.05	-.11	.14	.13	.31**	.26**	.08	.26**	-.10	1	
BG Range	-.01	-.14*	.01	-.20**	.16*	-.13	-.12	.16*	-.04	-.03	-.01	.03	.19**	.24**	-.05	-.05	.11	.07	1

Note: <sup>a</sup>0=Not Married, 1=Married; <sup>b</sup>0=Not Full Time 1=Full Time; <sup>c</sup>0=Minority, 1=Caucasian; <sup>d</sup>0=Conventional, 1=Intensive; \* $p < .05$ ; \*\* $p < .01$

## **Hypothesis 1: Mothers of Youths with Type 1 Diabetes Will Report High Levels of Depressive Symptoms**

The literature supports the hypothesis that a substantial proportion of mothers of children with T1D report higher than expected rates of depressive symptoms (Cameron et al., 2007; Driscoll, et al., 2010; Horsch et al., 2007; Jaser et al., 2008). Results for the current study revealed a similar proportion of mother of children with T1D that endorsed clinically elevated depressive symptoms; 21% of the sample reported symptoms levels above what is broadly defined as the clinical range of symptoms for the BDI-II. Levels of symptoms fall into one of three clinical categories determined by the test developers: mild, moderate and severe. Mild symptoms were reported by 11.1% of the sample, 7.6% reported moderate symptoms and 2.2% reported severe symptoms. These prevalence rates of depressive symptoms are higher than the point prevalence of depression in women in the general population (6.87%).

## **Hypothesis 2: Higher Levels of Maternal Depressive Symptoms Will Have an Indirect Effect on Disease-Care Behaviors mediated by Lower Parental Involvement**

Figure 4 reveals the overall model for the indirect relation of maternal depressive symptoms to disease-care behaviors through parental involvement. This model was significant for BGM, insulin utilization, and meal frequency. Blood glucose range was not included within the model because the simple correlation was negative, thus did not conform to the hypothesized direction. The inclusion of blood glucose variability as a research outcome has gained popularity due to the increasing availability of blood glucose numbers either from meter downloads or continuous BG monitoring. However, there is still no gold standard of how to measure BG variability such as use of BG averages, standard deviations, and interquartile ranges. However,

these proposed techniques may be overly influenced by variability associated with hyperglycemia and not hypoglycemia (Kovatchev, Gonder-Frederick, Otto, Clarke, & Cox, 2006). In the current study, the relation between BG range and depressive symptoms was negative and very small ( $r = .01, p = .91$ ).

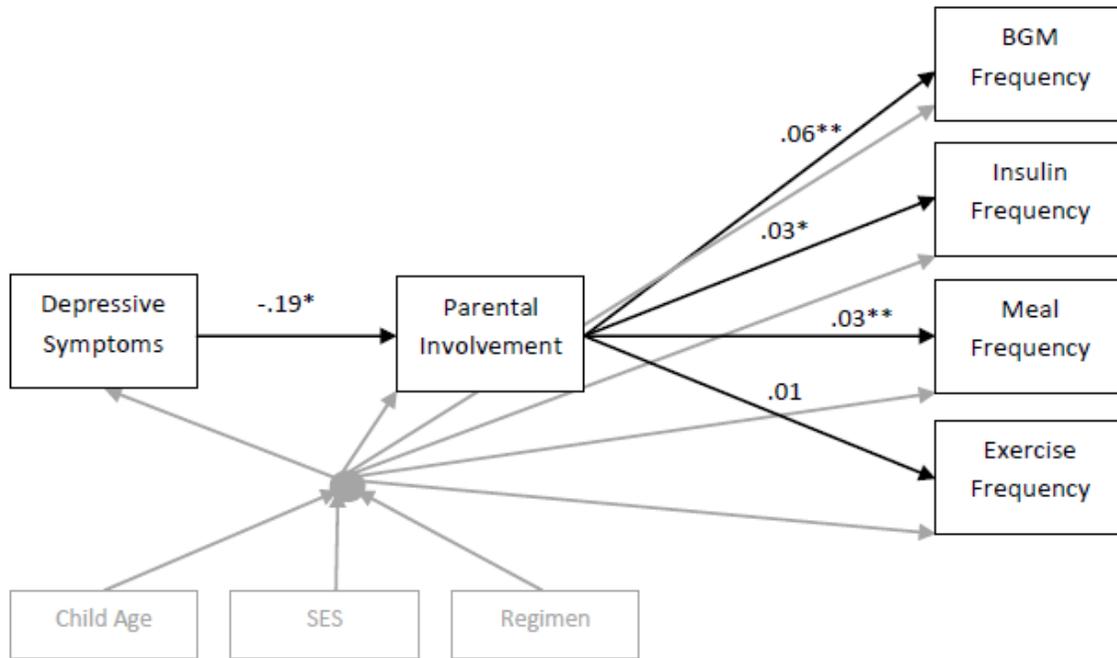


Figure 4. Mediation Model for Maternal Involvement

Additional results of the mediation model with bootstrapping are presented in Table 5. Depressive symptoms were negatively related to BG, insulin, and meal frequency ( $c$ ); these relations did not reach statistical significance. Depressive symptoms were negatively and significantly related to parental involvement ( $a$ ). The mediator variable of parental involvement was positively and significantly related to BGM, insulin utilization, and meal frequency; the relation between parental involvement and exercise frequency was also positive but not statistically significant ( $b$ ). Mediation is determined either by a reduction from significance to non-significance in the  $c$  to  $c'$  paths or statistical significance from the product of the  $a$  and  $b$

paths. In this case, the indirect effect ( $a \times b$ ) was statistically significant for depressive symptoms to BGM, insulin utilization, and meal frequency through the mediator variable of parental involvement.

Table 5.

*Mediational Effects of Parental Involvement*

	Independent variable (IV)	Mediating variable (M)	Dependent variable (DV)	Effect of IV on M ( $a$ )	Effect of M on DV ( $b$ )	Direct effects ( $c'$ )	Indirect effect ( $a \times b$ )	Total effects ( $c$ )
1.	Depressive Symptoms	Parental Involvement	BGM Frequency	-.19**	.06**	.00	-.01*	-.01
2.	Depressive Symptoms	Parental Involvement	Insulin Frequency	-.19**	.03**	-.00	-.01*	-.01
3.	Depressive Symptoms	Parental Involvement	Meal Frequency	-.19**	.03**	-.00	-.01*	-.01
4.	Depressive Symptoms	Parental Involvement	Exercise Frequency	-.19**	.01	-.00	-.00	-.00

These results indicate that mothers who report higher levels of depressive symptoms also report lower levels of parental involvement. Lower levels of parental involvement are related to less frequent blood glucose checks, fewer insulin injections, and fewer meals. When combined, the significance of these two paths indicate that higher levels of maternal depressive symptoms are indirectly related to poorer disease-care behaviors through the mechanism of lower parental involvement.

**Hypothesis 3: Higher Levels of Maternal Depressive Symptoms Will Have an Indirect Effect on Disease-Care Behaviors through Diabetes Specific Family Conflict**

Results of the bootstrapping model for diabetes conflict are presented in Table 6. As before, depressive symptoms were negatively related to BG, insulin, and meal frequency (*c*); these relations did not reach statistical significance. Depressive symptoms were positively and significantly related to diabetes conflict (*a*). However, the mediator variable of diabetes conflict was not significantly related to BGM, insulin utilization, meal frequency or exercise frequency (*b*).

Table 6.

*Mediational Effects of Diabetes Specific Family Conflict*

	Independent variable (IV)	Mediating variable (M)	Dependent variable (DV)	Effect of IV on M ( <i>a</i> )	Effect of M on DV ( <i>b</i> )	Direct effects ( <i>c'</i> )	Indirect effect ( <i>a x b</i> )	Total effects ( <i>c</i> )
1.	Depressive Symptoms	Diabetes Conflict	BGM Frequency	.16**	.003	-.01	.0006	-.004
2.	Depressive Symptoms	Diabetes Conflict	Insulin Frequency	.16**	-.004	-.01	-.0007	-.01
3.	Depressive Symptoms	Diabetes Conflict	Meal Frequency	.16**	-.01	-.01	-.002	-.01
4.	Depressive Symptoms	Diabetes Conflict	Exercise Frequency	.16**	.01	-.004	.001	-.003

These results indicate that while higher reports of maternal depressive symptoms are related to more diabetes specific conflict as expected, there is no indirect or mediational effect on disease-care variables.

## **Discussion**

The rate and impact of depressive symptoms experienced by mothers of children with type 1 diabetes was examined with two models based on psychological depression theory. The proposed models assessed two factors known to be related to both depressive symptoms and diabetes outcomes, parental involvement and conflict; and how each may mediate the relation between maternal depressive symptoms and regimen adherence. Results showed that a significant portion of mothers (21%) reported clinically elevated levels of depressive symptoms. Higher levels of depressive symptoms were indirectly related to less frequent disease-care behaviors through lower levels of parental involvement. While higher levels of depressive symptoms also were related to higher levels of diabetes specific conflict, this relationship did not have an indirect effect on frequency of disease-care behaviors. Higher levels of depressive symptoms were not related to blood glucose range in the hypothesized direction, thus it was not included in the model. This may indicate that maternal depressive symptoms are not related to BG range. Alternatively it may indicate that the method used to create BG range in the current study did not employ methods sophisticated enough to capture the potential relation between the two variables. Future researchers may consider more sophisticated algorithms available to synthesize large amounts of BG data into a more meaningful construct.

### **Maternal Depressive Symptoms**

Across previous studies, rates of clinically elevated maternal depressive symptoms have been high, with ranges from 10 – 37% on the Beck Depression Inventory - II (Driscoll et al., 2010; Eckstain et. al., 2009; Jaser et al., 2008; Whittemore et al., 2003). In this study, 21% of mothers reported clinically elevated symptoms that fell within the range established by previous research.

The current study used depressive symptoms as a proxy for the experience of depression. While the 21% of mothers who endorsed depressive symptoms cannot be directly compared to the point prevalence of 6.87% in the general population, the discrepancy between the two numbers is large enough to warrant concern and further consideration.

Several theories may explain the higher than average proportion of mothers with depressive symptoms in the present investigation. Review of literature related to maternal adjustment to other chronic illnesses (e.g. childhood cancer, juvenile rheumatoid arthritis, cystic fibrosis, and asthma) suggests that youth diagnosis and corresponding chronic stressors of a chronic illness are likely important contributors to high rates of maternal depressive symptoms. In a recent study, mothers of children with cystic fibrosis (CF) reported comparable levels of elevated depressive symptoms at 32.9% (Driscoll et al., 2010) to mothers of children with T1D. Similar to diabetes, CF requires high levels of parental involvement in day-to-day disease management. Daily disease management demands may create a diathesis for depression. Mothers of children with cancer had higher depressive symptoms at youth diagnosis, three months, and six months post diagnosis (Dolgin et al., 2007): Time 1 BDI-II:  $M = 13.2$ , Time 2:  $M = 12.0$ , Time 3:  $M = 10.6$ ) than the mean score of mothers in the current study ( $M = 8.24$ ). However, it may not be appropriate to compare depressive symptoms measured during the first year after diagnosis to more long-term depressive symptoms potentially associated with the chronic experience of illness. Children in the current study had been diagnosed for at least one year and an average of five years. For mothers of children with newly diagnosed cancer the mean score of depressive symptoms decreased significantly at each time point. This may indicate that the initial symptoms reported were attributable to the acute event of diagnosis of cancer rather than the

chronic experience of stress related to disease management. Alternatively, more mothers may experience depressive symptoms related to the acute stressor of diagnosis; this would also explain the higher initial mean. The reduction in mean scores over time could then represent healthy adaptation of certain mothers while others continue to experience the elevated levels of depression. Future research should assess depressive symptoms in mothers of children with T1D immediately post-diagnosis. This would help clarify if initially symptoms are higher and level out over time, or if initially more mothers experience depressive symptoms and a certain subset are at risk of developing long-term depressive symptoms.

In the context of the diathesis-stress model of depression, certain mothers likely have a combination of factors that predispose them to develop depression. Potential biological and genetic risk factors include being female, having a shorter 5-HTT gene, and/or having a family history of depression. Certain mothers may have pre-existing negative cognitive schemas about their own abilities, which may lead to low self-efficacy for diabetes management, or they may get caught in a behavioral reinforcement cycle that encourages withdrawal from stress or negative stimuli. Any of the above factors combined with the chronic stress of managing T1D may contribute to the high rates of depressive symptoms reported by mothers of children with T1D. The trajectory of depressive symptoms across multiple illnesses appears to support the contribution chronic stressful life events to the high rates of depression rather than the acute impact of diagnosis.

Physicians and their teams have a unique opportunity to intervene with mothers to help address, treat, and potentially even prevent the onset of depressive feelings in mothers of children with chronic illness, particularly mothers of children with T1D. Careful parent

screening at youth diagnosis for personal or family history of depression could be an effective first step. Mothers with either personal or family history of depression, or risk factors known to be associated with depression (e.g. low SES, single parent, less education) should be monitored and referred for additional help. Lack of physician awareness or time may prevent routine maternal screenings (Borowsky, 2010; Brown & Wissow, 2010). To increase awareness and comfort physicians should be trained in the use of specific mental health screeners (Brown & Wissow, 2010). The increase of electronically administered and scored measures of mental health can reduce the burden of both administration and interpretation on physicians. Physician training in the monitoring of maternal adjustment does not need to be intensive. Previous research showed that even brief training in physician-parent communication had a positive impact on parental mental health (Wissow et al., 2008).

Mothers report that they would be open to pediatrician involvement in the identification of their mental health risks. Mothers that were surveyed about pediatrician involvement indicated that they “would not mind” or “would welcome” screening and referral for mental health symptoms in the pediatric health setting (Kahn, et. al, 1999). Prevention and interventions strategies do not need to be intensive to be successful. A brief audiotape and workbook intervention for mothers of children admitted to a pediatric ICU was effective in reducing parent distress and increasing parental involvement (Melnik et. al, 2004). A program like this could easily be adapted for post-diagnosis of T1D to address stress and life management post-diabetes and empower parents to remain involved in disease care tasks throughout childhood and adolescence. Both psychological treatments and pharmacotherapy have been shown to be effective in reducing symptoms of depression. The use of pharmacological treatments both alone

(Dimidjian, et al., 2006) and in combination with psychological treatments (Rupke, Blecke, & Renfrow, 2006) have been shown to be effective in reducing symptoms of depression. However, many individuals prefer not to take antidepressant medications due to potential side effects and choose psychological treatments instead (Krupnick et al., 2006). Three common and effective psychological treatment modalities for depression are cognitive therapy (CT), behavioral activation (BA), and interpersonal therapy (IPT). The availability of brief intervention strategies may be particularly important for mothers of children with T1D. IPT-MOMS is a targeted short-term form of interpersonal therapy for depression (IPT-D) that was compared to treatment as usual for mothers of children with severe psychological illness. Mothers in the IPT-MOMS condition reported significantly reduced symptoms of depression immediately after treatment and at two follow-up time points. The reduction in maternal depressive symptoms was significantly related to reduction in reported child psychological symptoms (Swartz et al., 2008).

The current study confirmed the previously reported high levels of maternal depressive symptoms among mothers of children with T1D. This consistent poor psychosocial adjustment among some mothers warrants action on the part of the medical community to identify effective prevention and treatment strategies. Individual treatment to address the specific stressors that may have activated a mother's predisposition for depressive symptoms is important so that any family level variables affected by the mother's poor psychosocial adjustment can then be addressed.

## **Potential Mediators Between Maternal Depressive Symptoms and Disease-care Behaviors**

### **Parental Involvement**

Maternal depressive symptoms related to lower disease-care behaviors through lower parental involvement in frequency of blood glucose monitoring, insulin use, and meals. This relation was significant above and beyond the identified impact of SES, insulin regimen, and child age. The flexibility of the bootstrap mediation model allowed for data analysis with non-parametric data and the inclusion of control variables. The present study appears to be the first to quantify the impact of parental involvement as a mediator of the negative effects on regimen adherence associated with maternal depressive symptoms. Consistent parental involvement in diabetes management has regularly been identified as a necessary component for good metabolic control, particularly during adolescence (Anderson et al., 1997; Helgeson et al., 2010; Vesco et al., 2010). The relation between parental involvement and depressive symptoms in the current study has significant implications due to the 21% of mothers that report clinically elevated levels of depressive symptoms. This means that more than 1 out of 5 youths' may be less adherent to their diabetes regimen due to lower parental involvement related to depressive symptoms. Due to the cross-sectional nature of the data, causality or directionality cannot be confirmed. However, similar longitudinal research with mothers of children with asthma supported the theory that depressive symptoms contribute to greater disease morbidity. Caregiver depressive symptoms at time one predicted asthma morbidity at time two, however, morbidity at time one did not predict depressive symptoms at time two (Otsuki et al., 2010). Future research should apply this longitudinal model to mothers of children with T1D diabetes to confirm the causal hypothesis

that maternal depressive symptoms lead to poorer disease-care behaviors rather than poorer regimen adherence leads to higher depressive symptoms.

What specifically about the experience of depressive symptoms may relate to lower levels of parental involvement? The experience of depressive symptoms may be very individualized (Beck & Alford, 2009). Mothers in this study most frequently identified fatigue and sleep disruption as their symptomatic expression of depression. The overnight sleep period is regularly identified as a stressful time of day for parents because they fear their child may not feel the symptoms of low or high blood sugar while they are asleep. Many parents awaken during the night to check their child's BG level due to this fear (Juvenile Diabetes Research Foundation International, 2006). Increased exhaustion and sleep disruption, which could impact level of parental involvement during the day. Continuous blood glucose monitors (CGM), which are more recently in use can provide reductions in nocturnal hypoglycemia and hypoglycemic related fear in parents (Cemeroglu et al., 2010). An alarm sounds when there is the possibility of a low blood sugar. Other recent advances have developed an algorithm that is effective in predicting low blood sugars and subsequently halts basal insulin infusion from the insulin pump to avoid the low (Dassau et al., 2010). CGM is generally not accepted as a replacement for traditional BG monitoring in children and adolescents; however, it can provide useful supplementary information (Wilson et al., 2007).

Mothers in this study also reported high levels of cognitive symptoms of depression, most frequently reporting feelings of guilt. A study of 131 parents of children with diabetes identified specific areas that induce guilt feelings related to diabetes care. Parents most often reported feelings of guilt about meal and food related decisions and an inability to achieve "good control"

(Betschart, 1987). Healthy mothers may channel these feelings into greater involvement in different aspects of diabetes management. However, mothers that experience sleep disruption and fatigue may have less energy to optimally execute all aspects of diabetes care. Feelings of guilt may lead to negative distortions and learned helplessness and further exacerbate depressive symptoms, although this chain of events is speculative and awaits confirmation.

In the current study, lower parental involvement mediated the relation between maternal depressive symptoms and lower frequency of BGM, insulin use and meals. These results support previous research that identified relations between parental involvement and different aspects of the diabetes adherence regimen. In a study of children and teenagers aged 10 to 15 parental involvement was strongly related to blood glucose management. Lower parental involvement was related to less frequent blood glucose management, which in turn was related to poorer metabolic control (Anderson et al., 1997). Parental involvement has also been shown to moderate the relationship between length of pump use and metabolic control. For children whose parents were highly involved in diabetes management, how long the youth used the pump was related to better metabolic control. For children whose parents are less involved in diabetes management, having the pump actually contributes to poorer metabolic control over time (Wiebe et al., 2010).

Less research has been done on variables that may impact meal frequency, which is also an important aspect of diabetes management (Gellar et al., 2007). Results from this study provide unique insight into variables that may impact meal frequency, parental involvement and maternal depressive symptoms. Less frequent meals may lead to increased low blood sugars for children of mothers experiencing depressive symptoms. Appetite disturbance is a frequent

symptom of depression and may contribute to the lower meal frequency for children of mothers with elevated levels of depressive symptoms (Beck & Alford, 2009). Mothers may be less involved in meals for their child with T1D simply because their own eating habits are disrupted related to loss of appetite as a symptom of depression.

Similar to meal frequency, exercise frequency also is not regularly addressed in the literature. Mackey and Streisand (2008) conducted exploratory analyses and found that greater parental support related to higher levels of physical activity. Conversely, family conflict related to lower levels of physical activity. Results from the current study do not support the significant relation between parental involvement and level of physical activity. However, between studies the measurement of physical activity was different so the results are not comparable. Mackey and Streisand (2008) measured duration of physical activity in minutes rather than frequency of physical activity and this may contribute to the discrepant findings. Additionally the sample was approximately 2 years younger than the current sample. It is possible that as children get older and are making personal choices about participation in sports versus other activities parental input becomes less important. This may explain why parental involvement did not mediate a relation between maternal depressive symptoms and exercise frequency.

Results of the current study confirm a significant problem, elevated levels of depressive symptoms, which may impact 1 out of 5 children with T1D. These elevated symptoms of depression are related to lower parental involvement, which is related to poorer disease-care behaviors. Future research would benefit from an in depth study of depressive symptoms experienced by mothers of children with T1D. Qualitative research directed at determining specific triggers and stressors for mothers of T1D would provide further information about how

these symptoms may impact parental involvement. This research would help identify specific areas for intervention.

### **Treatment Implications for Reduced Parental Involvement**

Several randomized clinical trials have tested different intervention strategies to promote parental involvement and regimen adherence. Two programs include the Teamwork Program (Anderson et al., 1999) and Behavioral Family Systems Therapy (BFST; Wysocki, Greco, Harris, Bubb, & White, 2001). The Teamwork program was an evidence based intervention targeted at increasing parent-child involvement without increasing diabetes specific conflict. Participants in this study had similar disease duration to participants in the current study and were also in late childhood/early adolescence. The Teamwork group did not experience the deterioration in parental involvement that typically occurs during late childhood/early adolescence while education and standard care control groups did show an 11% decline in parental involvement in blood glucose monitoring and a 16% decline for involvement in insulin administration (Anderson et al., 1999). BFST utilizes four treatment components including problem-solving training, communication skills training, cognitive restructuring, and functional and structural family therapy to address parent-child relationships and adherence issues. When compared to educational support and current therapy control groups BFST resulted in improved in parent-adolescent relationships and reduced diabetes specific conflict. Improvements in regimen adherence were also seen in the BFST group at 6 and 12 month follow-up time points (Wysocki et al., 2001). In light of this typical reduction in parental involvement during adolescence, the findings in the current study indicate that adolescents of mothers that report elevated levels of depressive symptoms may be at an even higher risk of low parental

involvement. Once maternal mental health issues are addressed enrollment in a program such as Teamwork or BFST could help increase parental involvement that may be lacking in families where the mother endorses high levels of depressive symptoms.

### **Diabetes Specific Family Conflict**

Research consistently supports the relation between diabetes specific conflict and poorer health outcomes including less frequent disease-care behaviors (Anderson et al., 2002) and higher HbA1c levels (Anderson et al., 2009; Leonard, Garwick, & Adwan, 2005). The current study hypothesized a link between maternal depressive symptoms and disease-care behaviors as mediated by diabetes specific conflict. However, this hypothesized relation was not supported. In the present study, higher maternal depressive symptoms were related to more diabetes specific conflict but conflict did not mediate a relation between depressive symptoms and disease-care behaviors. However, in light of the significant findings related to parental involvement these findings were not surprising. If mothers who experience elevated levels of depressive symptoms have lower involvement in their children's diabetes care, there will likely be fewer opportunities for conflict to arise. Future researchers may choose to include a universal measure of family conflict to determine if general family conflict remains, and may impact health outcomes in spite the non-significant findings related to diabetes specific conflict.

Interventions targeted to increase parental involvement may inadvertently increase diabetes conflict. Past research has identified a significant positive relation between increased parental involvement and diabetes conflict after intervention (Anderson et al., 2002).

Interventions intended to increase parental involvement should provide appropriate guidance and

coping skills to contribute to positive involvement and interactions and to reduce any conflict related to diabetes care (Anderson et al., 2002).

### **Summary, Limitations, & Future Directions**

The present study used an innovative statistical method, mediation analysis with bootstrapping, to examine factors associated with high levels of depressive symptoms among mothers of children with type 1 diabetes. First, the prevalence of clinically elevated maternal depressive symptoms was determined within this sample. More than 1 in 5 mothers reported clinically elevated symptoms of depression on the BDI-II. This report is similar to other reports for mothers of children with T1D and across illness groups. These results highlight an area of child chronic illness that warrants significant attention and intervention, caregiver mental health. The field of pediatric psychology is currently growing and is still defining its place within the greater field of psychology. Due to the potential impact poor maternal/caregiver mental health can have on a child's physical and emotional health it is imperative that pediatric psychologists move forward in addressing the high levels of depressive symptoms among mothers of children with chronic illness.

Second, this study examined the potential relation between maternal depressive symptoms and health outcomes in a unique model posing two potential mediators, parental involvement and diabetes conflict. After controlling for pertinent sociodemographic variables, higher maternal depressive symptoms related to less frequency disease-care behaviors and this relation was mediated by lower parental involvement. The same model was non-significant for all disease-care behaviors when diabetes conflict was included as the mediator. That is, if mothers report higher levels of depressive symptoms they are less likely to be involved in the

day-to-day management of diabetes. With this lower level of parental involvement, parents and children report a lower frequency of blood glucose monitoring and insulin use, and eating fewer meals. Diabetes specific conflict was not significant in this model, likely due to the lower levels of parental involvement. These findings suggest that both maternal adjustment and parental involvement need to be addressed by health care providers to facilitate comprehensive care for diabetes management.

The current study had several limitations that could inform future research. Longitudinal research will be important to confirm directionality within this model. The present cross-sectional data do not allow causal inferences. While the path from maternal depressive symptoms through parental involvement to disease-care behaviors follows previous research and theory, the possibility exists that poorer regimen adherence could precede maternal depressive symptoms. Time of youth diagnosis could also provide a definitive start point for longitudinal research on maternal depressive sequelae. Personal and family history of depression could be assessed as well as current symptoms.

The present study also uses newer statistical methods with the Preacher and Hayes (2008) mediation program with bootstrapping in SPSS. Designers of the program offer it as an alternative to more traditional mediation models including Baron and Kenny's (1986) causal steps approach and the Sobel (1982) test. Bootstrapping has been used in statistical methods since the 1990s and is used in some SEM modeling programs, only recently has it been applied to mediation analyses (Hayes, 2009). Preacher and Hayes' (2008) method addresses weaknesses in previous mediation analyses and may be more powerful in detecting specific indirect effects. However, any new statistical method must be subjected to further scrutiny. Both time and future

research will determine if this statistical method is a viable alternative to traditionally used models.

A final limitation of the current study is the use of depressive symptoms as a proxy for the experience of depression among mothers of children with T1D. Based on consistent results across studies of a roughly 25% prevalence rate of clinically elevated depressive symptoms, future research studies should focus on more in depth research about the severity of these symptoms. Following screening with questionnaires, clinical interviews could definitively determine the prevalence of major depressive disorder among mothers of children with T1D. Further investigation of this depressive phenomenon would also aid in identifying specific areas for clinical intervention.

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## Vita

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