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Maternal Monitoring of Adolescent Type 1 Diabetes Management and Its Influence on
Adolescent Quality of Life and Adolescent Depressive Symptoms

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Abstract

While current literature identifies variables such as demographics, parental monitoring, and family functioning and their association with glycemic control in adolescents with type 1 diabetes mellitus, there has yet to be sufficient evidence identifying and supporting the relationships between the level of maternal monitoring and adolescent psychological wellbeing. The purpose of this scholarly project was to assess whether higher levels of maternal monitoring of diabetes management practices was associated with fewer adolescent depressive symptoms and higher adolescent quality of life. The study sample consisted of 117 adolescents between the ages of 10 and 16 with type 1 diabetes and their mothers. Each mother completed the PMDC scale to measure the level of monitoring. Adolescents completed the CDI and PedsQL to assess depression and quality of life respectively. Median splits were conducted on the PMDC and the PMDC subdomains for comparison to the adolescent CDI and PedsQL scores through Mann Whitney-U tests. The level of maternal involvement in adolescent diabetes care was significantly associated with adolescent CDI scores and only moderately associated with PedsQL scores. Adolescents whose mothers monitored more had significantly fewer depressive symptoms than those whose mothers monitored less. Specifically, the monitoring of nonadherence, supervision of availability of medical supplies/devices, and oversight of diet subdomains were associated with better CDI scores. The results suggest that maternal involvement in diabetes care is a critical component to both adolescent physical and psychological wellbeing. Employing collaborative involvement in diabetes care can help fulfill the adolescents' desire for autonomy while also maintaining the needed structure for appropriate diabetes control.

Keywords: Type 1 diabetes mellitus; Adolescents; Mothers; Parental monitoring; Adolescent depression; Adolescent quality of life; Collaborative involvement.

Maternal Monitoring of Adolescent Type 1 Diabetes Management and Its Influence on
Adolescent Quality of Life and Adolescent Depressive Symptoms

Type 1 diabetes mellitus is a chronic disease process predominantly diagnosed in youth populations around the world. According to Guariguata (2011) with the International Diabetes Federation, type 1 diabetes mellitus is the most common endocrine disease affecting the pediatric population. Type 1 diabetes mellitus is characterized by a destruction of the beta cells of the pancreas, which leads to an absolute lack of insulin production and an elevation of serum blood glucose levels. Within the United States of America, more than 18,000 individuals under the age of 20 are diagnosed with type 1 diabetes mellitus annually (Centers for Disease Control and Prevention, 2014). The diagnosis of type 1 diabetes mellitus comes with the requirement of significant modifications in health maintenance practices that must be followed to minimize disease complications. In order to properly maintain a healthy euglycemic state, individuals with type 1 diabetes mellitus must follow a complex regimen of diet modification, regular exercise, daily blood glucose monitoring, and daily insulin injections. With inappropriate disease maintenance, individuals with type 1 diabetes can develop a myriad of complications throughout life including diabetic ketoacidosis, hypoglycemia, primary hypertension, hyperlipidemia, heart disease, stroke, renal disease, and neuropathy. These complications can cause an increased risk of hospitalization and significant financial burden to not only the patient, but also society as a whole. It is estimated that approximately 14.4 billion dollars is spent annually in the United States on the direct and indirect costs related to type 1 diabetes mellitus (Tao, Pietropaolo, Atkinson, Schatz, & Taylor, 2010). In order to prevent these complications and the various repercussions, healthcare providers must work diligently to identify and diagnose type 1 diabetes early in the disease process and create a plan to achieve and maintain control. Additionally, the

healthcare team must identify individuals at risk for suboptimal glycemic control and vigilantly monitor for complications and intervene in a timely manner in order to prevent these negative health outcomes when possible (Ingerski, Laffel, Drotar, Repaske, & Hood, 2010; Svensson, Eriksson, & Dahlquist, 2004)

In the youth population, independent management of this complex disease can be exceedingly difficult to maintain. Parental monitoring of diabetes management practices plays a vital role in preventing direct and indirect diabetes-related complications and improving long-term health outcomes and is noted as a strong predictor of adherence (Ellis et al., 2008; Hillard et al., 2013; Palmer et al., 2011). Parental support in youth diabetes management positively influences glycemic control, quality of life, and overall diabetes outcomes (Hanson, Henggeler, & Burghen, 1994; La Greca & Bearman, 2002; Mlynarczyk, 2013; Mulvaney et al., 2011; Palmer et al., 2011). Silverstein et al. (2005) demonstrated that parental involvement in care should continue throughout childhood and adolescence, with increasing amounts of independence being assumed by the child as he or she develops. However, as children enter adolescence, a time in which they seek to obtain independence and a sense of autonomy, continued parental support and involvement in diabetes care can seem intrusive and controlling. The adolescent's perception of unwelcome parental involvement can contribute to many negative outcomes, including increased parental and adolescent stress, parent-child conflict, resistance to care, decreased regimen adherence, and worsening glycemic control (Hillard, et al., 2013; Jaser, 2010; Nansel et al., 2009). Additionally, these negative outcomes can lead to increased adolescent depressive symptoms and decreased perceived quality of life, which can promote uncontrolled diabetes management and the occurrence of diabetes-related complications (Costa & Vieira, 2015; Maas-van Schaaijk, Roeleveld-Versteegh, & van Barr, 2013). Based on this

evidence, level of parental disease monitoring may then be considered as a possible indicator for increased risk for negative outcomes in youth with diabetes. Thus, evaluation of the level of parental monitoring may be beneficial as a method for diabetes outcomes screening. Palmer et al. (2011) found that mothers of children with type 1 diabetes mellitus take on the primary caregiver role and are more likely than the fathers to assume a supportive, supervising position in the diabetes care regimen. While relationships between parental monitoring and glycemic control have been identified, few studies have assessed whether parental monitoring, and particularly maternal monitoring, affects adolescent quality of life and adolescent depressive symptoms. The purpose of this scholarly project is to assess whether higher levels of maternal monitoring of adolescent type 1 diabetes management is associated with improved adolescent quality of life and decreased adolescent depressive symptoms.

Review of Evidence

Type 1 diabetes mellitus is a chronic condition predominantly diagnosed in the pediatric and adolescent population. It is caused by an autoimmune response leading to beta-cell destruction in the pancreas, an absolute insulin deficiency, and an elevation of blood glucose levels. The incidence of type 1 diabetes mellitus is rapidly growing in the United States. The SEARCH for Diabetes in Youth Study identified that type 1 diabetes mellitus affected an estimated 191,000 youths in the United States in 2009 (Pettitt et al., 2014). According to Imperatore et al. (2012), the prevalence of diagnosed type 1 diabetes mellitus in the youth population is expected to rise approximately 23% in the next 40 years. Thus, it is expected that there will be a great need for quality diabetes care within the healthcare system by the year 2050 in order to address and prevent diabetes-related health complications in adolescents and young adults. The following section will review the current literature concerning factors known to

influence adolescent diabetes-related health including glycemic control, quality of life, and depression.

Demographic Risk Factors

While type 1 diabetes is seen in both genders and through all ethnic origins, numerous demographic variables influence diabetes-related outcomes in the adolescent population. The adolescent period is consistently seen as a time of increased risk and is associated with poorer glycemic control and a decline in self-management practices (Baucom et al., 2015; McGrady, Laffel, Drotar, Repaske, & Hood, 2009). Specifically, during adolescence, diabetic females present with higher glycosylated hemoglobin (HbA1c) levels than diabetic males, indicating worsening glycemic control (Neylon, O'Connell, Skinner, & Cameron, 2013; Osan et al., 2016). This could be associated with the fact that female adolescents are more likely to experience anxiety and depression at this age than their male counterparts (La Greca, Swales, Klemp, Madigan, & Skyler, 1995; Korbel, Wiebe, Berg, & Palmer, 2007). Socioeconomic status has also been found to influence glycemic control in the adolescent population, with a lower socioeconomic status being correlated with poorer glycemic control and higher HbA1c (Mackey et al., 2014; Neylon, O'Connell, Skinner, & Cameron, 2013). The incidence of major diabetes-related health complications is linked to race within the type 1 diabetes population. Non-Hispanic black youths on average have higher HbA1c, greater risk of impaired glycemic control, and more negative diabetes-related outcomes (Delamater et al., 1999). Additionally, Ethnic minority status is associated with poorer glycemic control (Neylon, O'Connell, Skinner, & Cameron, 2013). Generally, minority populations have the greatest risk of poor glycemic control and poor outcomes. In addition, minority parents are less involved in diabetes care than Caucasian parents of adolescents with type 1 diabetes. While keeping these demographic

variables in mind, it is important to pay special attention to these higher risk children to properly assess the risk of inadequate control and diabetes complications.

Parental Monitoring

Parental support and involvement in adolescent diabetes management is essential to maintaining proper glycemic control and ensuring successful transition to optimal disease management later in life. Particularly, maternal involvement in diabetes-related care is associated with better glycemic control, better treatment adherence, and improved outcomes in care (Jaser, Linsky, & Grey, 2014; King, Berg, Butner, Butler & Weibe, 2014; Palmer et al., 2011). Mothers are predominantly the primary caregivers and therefore spend more time with the child with diabetes than the fathers (Jaser, 2010). These increased amounts of maternal involvement and support in care are associated with improved glycemic control and improved diabetes-related outcomes (Ellis et al., 2007; Ellis et al., 2012). The concept of maternal involvement in care is multidimensional. Factors such as relationship quality, conflict, behavioral involvement, and monitoring all contribute to the general idea of parental involvement (Palmer et al., 2011). It can be increasingly demanding and challenging for the parent to maintain an appropriate level of involvement as a child matures into adolescence. As a child matures into adolescence, it is common for parents to decrease their involvement in care in relation to the child's desire for autonomy and independence. However, this decrease in parental involvement in diabetes care often contributes to a decrease in treatment adherence and poorer glycemic control (Ellis et al., 2008; King et al., 2014; Palmer et al., 2011). Yet, similar findings are identified in cases where parental involvement was perceived as overbearing or invasive by the diabetic adolescent (Duke et al., 2008). Parents should provide the child with ample opportunities for independent care while also monitoring diabetes care practices throughout adolescence (King et al., 2014; Young,

Lord, Patel, Gruhn, & Jaser, 2014). It is important for the parent to maintain positive, collaborative relationships with their children, as it leads to decreased conflict, better glycemic control, and better outcomes.

Family Functioning and Adolescent Quality of Life

Research indicates adolescent perceived quality of life does not differ between individuals with diabetes as compared to those without diabetes (Bas et al., 2011; Laffel et al., 2003; Nieuwesteeg et al., 2012). However, children with diabetes have a significant increase in stressors, which can lead to impaired coping strategies, decreased quality of life, and impaired health outcomes. The diagnosis of a lifelong chronic illness like type 1 diabetes mellitus can introduce great burden and strain on both the mother and the child. Studies have identified that mothers experience pronounced stress related to the diagnosis and care of a child with type 1 diabetes (Jaser, Linsky, & Grey, 2014; Moreira & Canavarro, 2016; Smith et al., 2014; Young et al., 2014). As maternal stress increases, the negative effects on the child become evident and can consequently lead to decreased perceived support, impaired relationships, increased conflict, and worsening glycemic control (Mlynarczyk, 2013). These negative impacts on the mother-child dyad are associated with decreased adolescent quality of life. Additionally, an adolescent's experiences of family conflict related to diabetes management play a more important role in quality of life than actual treatment intensity (Laffel et al., 2003). The evidence ultimately suggests that family functioning is a major influence on adolescent quality of life and can be a significant predictor of outcomes. Several sociodemographic factors directly influence adolescent quality of life. Generally, female adolescents report lower quality of life than male adolescents (Novato & Grossi, 2011). Furthermore, ethnic minorities tend to report a lower

quality of life than Caucasians. Decreased quality of life has also been found to be associated with depression and anxiety diagnoses (Jaser, 2010).

Depression

Adolescents with type 1 diabetes are at increased risk for various psychosocial disorders such as anxiety, depression, and eating disorders (Bernstein, Stockwell, Gallagher, Rosenthal, & Soren, 2013; Corathers et al., 2013). Adolescents with type 1 diabetes are two to three times more likely to develop depression than healthy adolescents. Moreover, the development of depressive symptoms in children with type 1 diabetes is multifactorial (Corathers et al., 2013). Parental stress is directly affected by the presence of depressive symptoms in children with type 1 diabetes. These symptoms lead to noncompliance, decreased treatment adherence, decreased glycemic control, and decreased quality of life. Evidence has shown that adolescents with diabetes who also have symptoms of depression check serum glucose levels less frequently. Decreased compliance with optimal treatment recommendations is associated with increased HbA1c and more frequent hospitalizations (Corathers et al., 2013; Mackey et al., 2014). It has also been noted that depression during adolescence can lead to elevated stress levels, prompting additional negative diabetes practices and less desirable outcomes (Baucom et al., 2015). Since depression rarely disappears without proper treatment, it is essential to identify and treat the disease early to prevent continued undiagnosed depression and subsequent decline in diabetes-related overall health (O'Connor et al., 2016). In recent years, the United States Preventative Services Task Force has recommended annual depression screenings starting in early adolescence to help identify the need for depression treatment before complications arise (Bernstein et al., 2013; Silverstein et al., 2005). It is suggested that implementing annual depression screening for high-risk adolescents such as those with type 1 diabetes is necessary for

improving the outcomes in the diabetic youth population (McGrady, Laffel, Drotar, Repaske, & Hood, 2009).

After review of the existing literature regarding demographic risk factors, parental monitoring, family functioning, adolescent quality of life, and depression, the identification and description of the present relationships between these variables could be useful. Type 1 diabetes is a prevalent chronic illness among the youth population affected by several factors. These factors can pose a major impact on the overall diabetes-related outcomes for adolescents with type 1 diabetes. While current literature identifies these variables and their association with glycemic control, there has yet to be sufficient evidence identifying and supporting the relationships between maternal monitoring and adolescent quality of life and depression symptoms. This project attempts to identify these relationships.

Theoretical Framework

The theoretical model guiding this scholarly project is called the transactional stress and coping model (TSC). The transactional stress and coping model was created by Thompson and Gustafson (1996) in order to understand how the diagnosis and management of chronic illness in children affects adaptation and adjustment to the disease. According to Davis, Brown, Bakeman, and Campbell (1998), the transactional stress and coping model attempts to identify the relationships between the illness parameters, demographic parameters, maternal and child adaptation processes, level of adjustment, and health-related outcomes. The transactional stress and coping model was based on two previously established models: Bronfenbrenner's (1979) ecological systems theory and Lazarus and Folkman's (1984) cognitive appraisal of stress and coping model (Hocking & Lochman, 2005). The transactional stress and coping model is loosely framed within Urie Bronfenbrenner's ecological systems theory. In Bronfenbrenner's theory, a

child's development is directly and indirectly influenced by the connections, interactions, and relationships occurring within four established environmental systems; Microsystem, mesosystem, exosystem, and macrosystem (Onwuegbuzie, Collins, & Frels, 2013). Various factors within these environmental systems work concurrently to shape and influence development. The transactional stress and coping model similarly follows Bronfenbrenner's assumptions in that factors from various systems influence the adaptation process and health outcomes in an individual with chronic illness. The primary foundation for the creation of the transactional stress and coping model is Lazarus and Folkman's (1984) cognitive appraisal of stress and coping model. While Lazarus and Folkman's model focuses on the general ideas of stress and the adaptation process towards this stress, the transactional stress and coping model looks specifically at chronic illness as the primary stressor that one must adapt to. Additionally, the transactional stress and coping model uses the primary and secondary appraisal processes identified and outlined in Lazarus and Folkman's work to guide the maternal adaptation processes (Hocking & Lochman, 2005).

The transactional stress and coping model provides a guiding framework to explain how a child with chronic illness copes and adapts to the disease. The model's fundamental tenants are based on the assumption that a chronic illness, such as type 1 diabetes mellitus, is a stressor that an individual must adapt to in order to adjust properly and produce positive outcomes. This adaptation process related to the chronic illness is not solely dependent on the illness itself (Hocking & Lochman, 2005). Illness parameters, such as disease type, disease severity, length of illness, and treatment regimen, all contribute to and impose stress on the chronically ill child and caregiving mother. Various demographic parameters such as the child's age, gender, race, ethnicity, developmental stage, and socioeconomic status transact with and exaggerate these

stressors. In order to deal with the stressors, both the child and mother must work through unique processes of adaptation. The adaptation process for the mother involves three components: cognitive processes, methods of coping, and family functioning (Hocking & Lochman, 2005). Primary and secondary appraisal of stress and expectations for treatment and health comprise the cognitive processes of adaptation. Primary appraisal identifies the presence and significance of a stressor while secondary appraisal evaluates one's ability to manage that stressor (McCuaig Edge & Ivey, 2012). Methods of coping are the ways in which the mother manages the stressors that are identified through appraisal. These coping mechanisms can be either adaptive or palliative. Adaptive coping strategies influence the stressors by producing physical changes within the environment or person. These strategies are seen as positive approaches to dealing with the stress. In contrast, palliative coping strategies, such as avoidance and disengagement, adversely affect adaptation. Family functioning is the third component of the adaptation process and looks at aspects of family functioning such as parental involvement in care and maternal-child conflict. The child's adaptation process differs somewhat from that of the mother's. The transactional stress and coping model identifies that only treatment and health expectations and coping strategies mediate the adaptation and adjustment process in the child. The disease outcomes are a direct product of both the mother and child's ability to adapt successfully and adjust to the stressors that originate from the chronic disease. Figure 1 provides a depiction of the transactional stress and coping model with emphasis on how it relates to this project. Measures that will be assessed in this project are bolded within figure 1.

The transactional stress and coping model has been used to address the complex coping processes for both the mother and child dealing with a childhood diagnosis of sickle cell disease, cystic fibrosis, and type 1 diabetes mellitus (Bennett Murphy, Thompson, & Morris, 1997; Gold,

Treadwell, Weissman, & Vichinsky, 2008; Hocking & Lochman, 2005; Thompson et al., 1994; Thompson, Gustafson, George, & Spock, 1994; Thompson, Gustafson, Gil, Kinney, & Spock, 1999). Hocking and Lochman (2005) investigated the literature in order to discuss and apply the transactional stress and coping model to diabetic children and their mothers in order to illustrate the psychosocial factors affecting the disease adjustment process. The transactional stress and coping model was also used by Bennett Murphy, Thompson, & Morris (1997) to discuss the role that the cognitive appraisal process has on diabetic adolescents' adherence to treatment regimens. While this model's use in describing the foundations of maternal and child adaptation and adjustment to type 1 diabetes mellitus is much less extensive than that of sickle cell disease and cystic fibrosis, the theory's assumptions and concepts make it an applicable model to explain the multifaceted process of adaptation and adjustment to various chronic illnesses including diabetes.

The transactional stress and coping model is an appropriate theoretical framework for this scholarly project as it is centered around maternal and child adjustment to type 1 diabetes mellitus, a chronic condition commonly affecting the adolescent population. According to the transactional stress and coping model, a diagnosis of type 1 diabetes mellitus in a child is appraised as a significant stressor for both the child and the mother. Because diabetes management requires long-term cooperation and participation from both the child and parent, these disease-related stressors are common. Demographic parameters such as patient and family characteristics further contribute to the severity of the stressors, appraisal of those stressors, and methods of adaptation that occur. The mother and adolescent must learn to properly adapt to the illness in order to achieve positive disease-related outcomes. For mothers, methods of adaptation include monitoring, which is an aspect of the family functioning adaptation process. If the

process towards adequate adaptation is impaired, adjustment to the disease will be compromised and negative outcomes such as decreased adolescent quality of life and increased depressive symptoms will follow. The adjustment of both the child and mother is interdependent. Both individuals must be able to appropriately adapt to the disease-related stressors and must achieve adequate adjustment to these stressors to prevent negative outcomes such as deterioration of diabetes-related health (Hocking & Lochman, 2005).

Project Design

A cross-sectional analysis of secondary data was used for this scholarly project. The original study's design was longitudinal, prospective, and descriptive in format. Analysis of the existing dataset was practical and feasible for the timeframe that was available. The data used for this scholarly project was collected between December 2009 and July 2012 at Yale University in New Haven, Connecticut and de-identified for patient protection. Institutional Review Board approval was granted at the time of the original study. Project exemption was verified by Belmont University's Institutional Review Board.

Clinical/Practice Setting

Original data was obtained from adolescent patients in the Yale Children's Diabetes Program at Yale School of Medicine in New Haven, Connecticut. Access to the dataset was provided by Vanderbilt University Psychologist, Dr. Sarah Jaser, who was a faculty member at Yale University at the time of data collection. The Yale Children's Diabetes Program is a nationally known, comprehensive diabetes care center for children and adolescents diagnosed with type 1 and type 2 diabetes mellitus. The Children's Diabetes Program at Yale provides comprehensive diabetes care, management, and education to pediatric diabetes patients of all ages. Furthermore, this clinical research-based program focuses on educating patients, family,

and the public regarding the innovative technology-based tools used for the management of diabetes (Yale School of Medicine, 2015).

Study Population

The study sample consisted of 117 adolescents with type 1 diabetes mellitus and their mothers. Convenience sampling method was utilized for participant participation. Participants were selected based on status as clinic patients and willingness to participate in the study. The contributing adolescents were patients at Yale's Children's Diabetes Program at the time of data collection. Adolescents were eligible to participate in the study if they (1) were age 10-16, (2) had no other major health issues other than type 1 diabetes mellitus or a related condition, (3) were living with their mothers, (4) were age-appropriate for their grade within one year, and (5) were literate in English. Eligibility requirements for their mothers included (1) currently living with the adolescent and (2) being literate in English. In order to obtain the most accurate data regarding ethnic prevalence of type 1 diabetes mellitus in the United States, a sampling goal of 74% Caucasian, 12% Hispanic, 10% Black, and 4% other ethnicities was established. Additionally, the sampling goal was to have an equal number of male to female participants.

Sources of Data/ Instruments/ Measures

Various tools and instruments were utilized in the original study to obtain data from both the participating adolescents and their mothers. The original dataset included measures for maternal anxiety, maternal depression, and maternal affect. The instruments used to obtain these measures were the State Trait Anxiety Inventory (STAI), Center for Epidemiologic Studies Depression Scale (CES-D), and the Positive and Negative Affect Schedule (PANAS), respectively. These specific measures were not included in this scholarly project but can be found in the original study.

Other measures used from the original dataset include diabetes clinical variables, demographics, maternal monitoring, glycemic control, adolescent quality of life, and adolescent depressive symptoms. This section discusses the methods or instruments used to obtain these aforementioned measures.

Diabetes Clinical Variables. Items such as the length of time since diabetes diagnosis and treatment type were obtained from each participating adolescent's medical records. It is shown that the length of time since diabetes diagnosis is important in assessing glycemic control in type 1 diabetes, as the body's glycemic control declines readily after disease onset (Boland, Grey, Oesterle, Frederickson, & Tamborlane, 1999). Additionally, the treatment modality, specifically regular insulin injections versus an insulin pump, can significantly influence glycemic control.

Demographics. Patient demographics were obtained using a questionnaire that was completed by each participating mother at the time of initial study participation to establish a baseline. This questionnaire included general demographic variables such as race/ethnicity, marital status, birth order and sex of the child with diabetes, mother figure's relationship to the child, adults living at home, and screening information regarding the diabetic child's health. Additional sociodemographic parameters such as parental income, occupation, and years of education were also collected in this questionnaire. The demographics questionnaire utilized in this project is included in appendix A.

Maternal monitoring. Maternal monitoring of adolescent diabetes practices was measured using the Parental Monitoring of Diabetes Care (PMDC) scale. This scale is depicted in appendix B at the end of this paper. This scale was used to assess parental supervision of diabetes management-related practices (Ellis et al., 2008). The PMDC consists of 18 questions

within five subdomain: supervision of the availability of medical supplies and devices, monitoring blood glucose checking, oversight of diet, monitoring of nonadherence, and direct oversight of diabetes management behaviors. The PMDC has shown appropriate internal consistency ($\alpha=0.81$) and test-retest reliability ($ICC=0.80$) (Ellis et al., 2008).

In the PMDC, the subdomain pertaining to the supervision of availability of medical supplies and devices relates to the parents' knowledge regarding the various necessary supplies for monitoring diabetes and maintaining glycemic control. Five questions comprise this subdomain and assess details such as parental knowledge of diabetes-related supply levels, meter functionality, and insulin expiration dates. The subdomain concerning monitoring of blood glucose checking contained two questions regarding how often the parent reviews readings in the blood glucose meter and how often the parent reviewed those readings with the child. The oversight of diet subdomain addressed items related to family meal times, eating out, and knowledge of a child's meal makeup. Three questions were included in this PMDC subdomain. The monitoring of nonadherence subdomain included four questions pertaining to a parents' knowledge of skipped blood glucose testing and skipped insulin injections. The direct oversight of diabetes management behaviors subdomain included four questions regarding the parent being present at home or in the room for blood glucose testing and insulin injections. PMDC questions were answered using a 5-point Likert scale scoring system. Lower scores on the PMDC indicated that mothers had greater knowledge of and involvement in diabetes management. This project focused directly on each mother's responses for the questions included in the subdomains of monitoring of blood glucose checking and direct oversight of diabetes management behaviors. These specific subdomains were strongly related to the monitoring construct (Ellis et al., 2008).

Glycemic control. Glycemic control was measured at each visit using Hemoglobin A1c (HbA1c) test. This physiologic measure provides information regarding long-term glycemic control by measuring the amount of glucose attached to the red blood cells. This measure provides an average blood glucose level over the most recent 8 to 12 weeks. This test is a standard of practice for routine diabetes monitoring at clinic visits. On average, HbA1c scores should be less than 7.5% for children and adolescents with type 1 diabetes (American Diabetes Association, 2014). HbA1c for this study was obtained using a blood sample collected via finger stick using a Bayer Diagnostics DCA2000® machine, which provides each HbA1c level in approximately six minutes.

Adolescent quality of life. Adolescent quality of life was measured at each visit using the Pediatric Quality of Life Inventory (PedsQL). The PedsQL tool is commonly used to assess health-related quality of life in children and adolescents with various chronic illnesses, including type 1 diabetes mellitus. The PedsQL assesses psychosocial health using 15 questions related to areas such as emotional, social, and school functioning. Additionally, the PedsQL provides a 28-item diabetes-specific module that assesses quality of life directly related to a diabetes diagnosis. This project utilizes the diabetes-specific module. According to Varni et al. (2003) the PedsQL has high internal consistency reliability ($\alpha=0.88$), as did the diabetes-specific model ($\alpha=0.71$). High scores on the PedsQL indicate higher levels of health-related quality of life. This tool is practical and easy use in any pediatric setting. Items were created to be developmentally appropriate and take individuals less than five minutes to complete. The PedsQL 3.0 Type 1 Diabetes Module that was used in this project is included in appendix C at the end of this paper.

Adolescent depressive symptoms. Adolescent depressive symptoms at the time of each visit were measured using the Child Depression Inventory (CDI). The CDI is a tool that is often

used to identify symptoms indicating a diagnosis of clinical depression (Kovacs, 1985). The CDI is a 27-item tool. A higher score on the CDI represents higher levels of depression, with any score over 13 suggesting a clinical depression diagnosis. The CDI is shown to have high internal consistency ($\alpha=0.80-0.88$) and validity ($\lambda=0.84$) (Carnevale, 2011). The CDI tool that was used in this project is included in appendix D at the end of this paper.

Data Collection Process/Procedures

The original dataset was collected and provided by Dr. Sarah Jaser of Vanderbilt University. Data was collected at three separate points in time: baseline, six months, and 12 months after agreeing to participate in the study. These time points corresponded with designated diabetes follow-up appointments at the Yale Children's Diabetes Program within the twelve-month period. All data collection took place between December 2009 and July 2012. At each visit, individual data, HbA1c, and other clinical data such as treatment type, height, and weight were collected from the patient and their medical records. All adolescent and mother-reported tools were completed during the office visit times. Completion of all adolescent and mother-reported measures added approximately 60 minutes to each routine visit.

This scholarly project analyzes only data collected at baseline, as the variables used in this project are being tested as predictors. All data collected for the original study was previously coded by Dr. Sarah Jaser and her research team. Specific variables from the original dataset were compiled to form the secondary dataset used for this scholarly project. All data analysis for this scholarly project was completed using the secondary dataset in order to preserve the original records. The new, concise dataset was stored and analyzed using IBM SPSS 23.0 statistical analysis software.

In order to assess the PMDC tool in its entirety, the five individual subdomain scores of the PMDC were summed. Baseline scores for the summed PMDC subdomains were used to assess the level of maternal knowledge and involvement in diabetes care. Descriptive statistics, such as measures of central tendency, measures of dispersion, and frequency were calculated for this summed PMDC variable. Tests of normality were also completed in order to determine if the data was normally distributed. A median split was used to dichotomize the PMDC sum scores into high and low scores. While there are challenges identified in utilizing median splits to dichotomize continuous variables, the project leader believed that its use was justified, as the developers of the original PMDC tool did not distinguish a threshold score for appropriate parental monitoring (Iacobucci, Posavac, Kardes, Schneider, & Popovich, 2015; Streiner, 2002; Toyama & Agras, 2016). All scores at or below the median (≤ 29) were categorized as low scores. These low scores translated to higher levels of maternal monitoring. All remaining scores (≥ 30) were categorized as high scores, which translated to lower levels of maternal monitoring. Mann-Whitney U tests were then utilized to compare the medians between the split PMDC sum variable and CDI and PedsQL scores.

To assess the individual subdomains of the PMDC and their relationship with adolescent depression and quality of life, a similar process was followed. Descriptive statistics and frequencies were obtained for each of the individual PMDC subdomain scores. A median split was completed to dichotomize subdomain scores into either high or low scores. All subdomain scores at or below the median for the subdomains were categorized as low scores. These scores corresponded with higher levels of maternal monitoring. All scores above the subdomain medians were categorized as high scores, or less maternal monitoring. Mann-Whitney U tests

were then completed for each median split created for the PMDC subdomains to compare with adolescent CDI and PedsQL scores.

Results

Demographics

Sociodemographic characteristics for the maternal and adolescent study population are presented in table 1. The age of participating mothers ranged from 28 to 58, with mothers having a mean age of 44. Among the 117 mothers who participated in the study, 89.7% (n=105) identified as Caucasian, 6% (n=7) identified as African American, 2.6% (n=3) identified as Islander, 0.9% (n=1) identified as Asian, and 0.9% (n=1) identified as Biracial. The majority of participating mothers were married or partnered (75.2%, n=88), while the remaining were single, divorced, or widowed (24.8%, n=29). Regarding household income status, 66.1% (n=74) of mothers identified as having a household income of \$80,000 or greater. Specifically, over half of the mothers identified as having a household income of greater than \$100,000 (54.0%, n=61). Only 33.9% (n=38) of mothers reported income of less than \$80,000.

Adolescents who participated in this study ranged from 10 to 16 years old, with an average age of 12.79 years old. Of the participating juveniles, 54.7% (n=64) were male, whereas 45.3% (n=53) were female. Reported race distribution of adolescents was 86.3% (n=101) Caucasian, 6.8% (n=8) African American, 6% (n=7) Biracial, and 0.9% (n=1) Asian. The average duration of diabetes diagnosis among participating adolescents was 5.05 years. A majority of adolescents utilized insulin pump therapy as his or her treatment modality (82.9%, n=97). Insulin injection therapy was the primary treatment modality for 17.1% (n=20) of participating adolescents. Average HbA1c for adolescents participating in this study was 7.65, slightly higher than the recommended goal of 7.5% for diabetic individuals at this age.

PMDC, CDI, and PedsQL Scores

Statistical analysis results for the PMDC scores are presented in tables 2 and 3. A median split of the PMDC scores dichotomized the variable into high and low scores. Of the 117 responses, 64 PMDC scores (54.7%) were categorized into the low scores, meaning the responses corresponded with higher levels of maternal monitoring. The remaining 53 PMDC scores (45.3%) were categorized into the high scores group. These responses corresponded with lower levels of maternal monitoring. Analysis of the PMDC split indicated that PMDC scores were significantly associated with adolescent CDI scores ($p < 0.001$). While PedsQL scores were higher in adolescents whose mothers monitored more, this was only moderately significant ($p < 0.060$).

PMDC Subdomains, CDI, and PedsQL Scores

When examining each of the individual PMDC subdomains in relation to adolescent CDI and PedsQL scores, several associations were noted. This project's original focus was on the direct oversight of diabetes management behaviors subdomain and the monitoring blood glucose checking subdomain. Data analysis showed no significant associations between these subdomains and adolescent CDI scores (Direct oversight: $p < 0.056$; Monitoring blood glucose checking: $p < 0.258$). However, scores for the monitoring of nonadherence subdomain ($p < 0.012$), supervision of availability of medical supplies/devices subdomain ($p < 0.002$), and oversight of diet subdomain ($p < 0.001$) were significantly associated with CDI scores.

It was noted that PedsQL scores were generally higher in adolescents whose mothers reported lower scores (more monitoring) for all subdomains. However, analysis of the direct oversight of diabetes management behaviors subdomain ($p < 0.984$), monitoring of blood glucose checking subdomain ($p < 0.751$), supervision of availability of supplies/devices subdomain

($p < 0.123$), and oversight of diet subdomain ($p < 0.126$) indicated that there were no significant associations between these subdomains and adolescent PedsQL. Associations were only moderately significant when analyzing the relationship between PedsQL scores and the monitoring of nonadherence subdomain ($p < 0.079$). Tables 4 and 5 depict the results of the statistical analysis for each of the individual PMDC subdomains.

Discussion

The purpose of the scholarly project was to identify whether increased levels of maternal monitoring of diabetes management behaviors decreased adolescent depressive symptoms and improved adolescent quality of life. Data analysis substantiated the notion that maternal involvement in diabetes care continues to be a critical component to adolescent wellbeing and mental health. Overall, adolescents had significantly lower CDI scores, indicating less depressive symptoms, when mothers participated more in diabetes care. Furthermore, increased levels of monitoring related to specific diabetes management subdomains such as diet, the availability of supplies/devices, and treatment nonadherence showed significant influence and reduced adolescent CDI scores. While adolescent quality of life scores were higher when mothers reported higher levels of monitoring, only moderate significance was noted through data analysis. Analysis also indicated only moderately significant associations between PedsQL scores and the monitoring of nonadherence subdomain. No other associations between individual subdomains and PedsQL were noted. Nevertheless, adolescent quality of life was higher when mothers reported higher monitoring within each subdomain.

The results from the current study support the existing literature related to family functioning and its influence on adolescent mental health. Mothers who are more involved and supportive in their adolescent's diabetes management regimen are likely to have more cohesive,

trusting, and balanced relationships with the diabetic adolescent. The adolescents will consequently have more confiding, open, and trusting relationships with the mothers. Research has indicated that a positive relationship between parent and adolescent is a key element in decreasing risky health behaviors and negative health outcomes (Ellis et al., 2008). A strong parent-child dyad in which both individuals work concomitantly to manage the diabetes also greatly reduces the burdens and stressors that derive from dealing with a chronic illness diagnosis alone (Berg et al., 2007; Jaser, Linsky, & Grey, 2014; Moreira & Canavarro, 2016; Smith et al., 2014; Young et al., 2014). The lower adolescent CDI scores in the study sample could be accredited to the fact that the mothers and adolescents had adequate relationships at the time of data collection. Therefore, it could be assumed that fewer stressors were present related to a fractured mother-child dyad. Furthermore, these scores could be attributed to the idea that neither the mother nor the adolescent was managing the chronic illness alone, as evidenced by the lower PMDC scores indicating more maternal monitoring activities. Future exploration of the data could attempt to identify if adolescent and maternal stress levels were, in fact, significantly associated with fewer adolescent depressive symptoms. While the results did indicate that adolescents whose mothers monitored less had greater depressive symptoms, the causative variable was not identified in the study. Were the adolescents who exhibited more depressive symptoms actually depressed because their mothers were less involved in diabetes management, or were these mothers less involved in care because the child was more depressed and consequently more withdrawn from the mother? It would be important for future research to attempt to elucidate this relationship.

The project originally aimed to identify whether maternal PMDC scores for the monitoring of blood glucose checking subdomain and the direct oversight of diabetes

management behaviors subdomain influenced adolescent depressive symptoms and adolescent quality of life. Data analysis revealed that neither subdomain was significantly associated with depression scores or quality of life scores. This was surprising because the developers of the PMDC indicated strong relationships between the two subdomains and the monitoring construct (Ellis et al., 2008). Specifically, their research identified a strong association between these subdomain scores and adolescent illness control and metabolic control. It is important to note that this study is not attempting to discount the importance of these two subdomains in predicting diabetes-related health outcomes. It could be assumed through the results gathered, however, that these two subdomains are more suggestive of adolescent physical wellbeing and less suggestive of adolescent psychological wellbeing. Supplementary analysis of the remaining three PMDC subdomains, which included supervision of availability of medical supplies/devices, oversight of diet, and monitoring of nonadherence, showed that all three were significantly associated with adolescent depression scores but not quality of life scores. Considering the questions included in each of the five subdomains, queries within the direct oversight of diabetes management behaviors subdomain and monitoring of blood glucose checking subdomain involved direct parental participation in which the parent judged performance or directly observed the adolescent during his or her management tasks. Inversely, questions comprised in the remaining three subdomains involved the parent being more supportive and knowledgeable of the adolescent's current status, but did not revolve around the parent being directly involved or authoritative in supervising the adolescent's diabetes management techniques. Previous literature has consistently recognized that overbearing and invasive monitoring practices negatively impacts the adolescent (Duke et al., 2008; Karlsson, Arman, & Wikblad, 2008; Nansel et al., 2009; Paterson & Brewer, 2009). Overbearing, authoritative monitoring can contribute to increased

conflict, loss of trust, rebellion, and subsequent decrease in treatment adherence and increase in diabetes-related complications (Paterson & Brewer, 2009; Sweenie, Mackey, & Streisand, 2014). Furthermore, these consequences can result in psychological instability, increased adolescent depression, and decreased quality of life related to the loss of sense of self-reliance and autonomy sought throughout adolescence (Karlsson, Arman, & Wikblad, 2008; Nansel et al., 2009).

While depression scores were significantly lower in adolescents whose mothers indicated more monitoring, quality of life scores were less significant. The relationship between adolescent PedsQL scores and PMDC scores was found to be only moderately significant through data analysis. Furthermore, only a moderately significant relationship was noted between PedsQL scores and the monitoring of nonadherence subdomain. No other subdomains were significantly associated with adolescent PedsQL scores. Past literature has identified that quality of life of adolescents with type 1 diabetes typically does not significantly differ from that of their healthy adolescent counterparts (Bas et al., 2011; Laffel et al., 2003; Nieuwesteeg et al., 2012). It could be speculated that the similarity of quality of life scores between adolescents whose mothers reported high monitoring and adolescents whose mothers reported low monitoring is related to the fact that quality of life scores in diabetics do not usually significantly differ in comparison to even healthy adolescents. Nevertheless, these findings do not indicate a need to disregard quality of life as an indicator of negative diabetes related outcomes. Similar to depression, quality of life is influenced by the presence of various factors including taxing family relations and the presence of disease-related stressors (Laffel et al., 2003; Mlynarczyk, 2013). Family functioning, disease-related stress, depression, and quality of life are all important interrelated aspects

influencing an adolescent's ability to appropriately manage his or her disease to prevent negative diabetes-related outcomes.

Demographic variables for the population should be taken into account when interpreting the results of the study. Various adolescent and maternal demographics, such as race, ethnicity, family makeup, and socioeconomic status have all been indicated as risk factors for negative diabetes-related outcomes due to elements including lack of availability of resources, financial constraints, and associated stresses (Delamater et al., 1999; Neylon, O'Connell, Skinner, & Cameron, 2013). A majority of the study participants reported adequate or above adequate income, with only approximately 9% of participants earning less than \$40,000 per year. Additionally, a majority of the mothers who participated identified themselves as either married or partnered and of Caucasian race. A strong majority of the children were also classified as Caucasian. Participant demographics could have played a vital role in influencing the level of maternal monitoring, the presence of adolescent depressive symptoms, and quality of life scores, as most of the participants in this study could not be classified as at-risk in regards to their demographic characteristics. Future studies could explore the demographic characteristics of this study sample and identify their associations with maternal monitoring, adolescent depression, and adolescent quality of life.

Clinical Implications

This study provides substantial evidence regarding the crucial characteristics that should exist to facilitate appropriate parental management and monitoring practices. Throughout adolescence, parent-adolescent relationships often become more cooperative and mutual, as the parent begins to understand and recognize the developmental need for adolescents to gain independence (Hanna & Guthrie, 2000). Rather than transferring total care directly to the

adolescent to manage independently, appropriate parental monitoring involves providing the adolescent with ample opportunities to manage his or her disease independently while the parent provides supportive, collaborative guidance rather than direct control (Berg et al., 2007; Hanna & Guthrie, 2001; Karlsson, Arman, & Wikblad, 2008; Nansel et al., 2009). This collaborative involvement in which both the mother and child participate cooperatively in the diabetes management process improves treatment adherence, glycemic control, and psychological adjustment (Ellis et al., 2008; Sweenie, Mackey, & Streisand, 2014; Wysocki et al., 2009). Parents should avoid strict, overbearing, and direct management during this time of needed autonomy and self-reliance and should strive to provide more nurturing and supportive assistance while the adolescent performs his or her daily diabetes management activities. Through this collaborative involvement, both parents and adolescents can improve interpersonal relationships, disease adjustment, and adaptation processes. Therefore, collaboration in care can help decrease the effects of disease-related stressors on coping, disease management, and psychological and physical wellbeing (Berg et al., 2007). Ultimately, collaborative involvement between the adolescent and parent can have a profound impact on the adolescent's ability to successfully and independently manage their diabetes once they transition into adulthood (Babler & Strickland, 2015).

The findings uncovered through this study could be employed to support the routine usage of the PMDC tool to identify diabetic adolescents who may be at risk for developing mental health issues related to ineffective parental monitoring practices. While depression screenings are a recommended and commonly used tool in adolescent diabetes clinic visits, the routine inclusion of the parent-reported PMDC tool could be a strategy for healthcare providers to identify at-risk adolescents before depressive symptoms develop. Additionally, regular PMDC

usage could facilitate better monitoring practices for parents by providing insight into appropriate monitoring and management strategies that will be inclusive of the developmental requirements of the adolescent.

Limitations

Several limitations to the study should be acknowledged. While the study sample size was adequate (n=117), the sample consisted of adolescents and only their mothers. While mothers have been found to be the primary caregivers for chronically ill children, it would have been more inclusive and generalizable to include fathers and other guardian figures in the study sample. The fact that the study sample only included current patients at one specific diabetes clinic in New Haven, Connecticut, could have also had a profound impact on the gathered results. The study sample was not particularly diverse, as a majority of the participants reported being of upper-middle class status and Caucasian race. Replication of this study at various clinics in different regions with a more diverse sample could yield dissimilar results.

This study only assessed baseline data regarding PMDC scores, CDI scores, and PedsQL scores. While this was done in an effort to ascertain PMDC scores as predictors of adolescent depression and adolescent quality of life, the investigation strategy caused much of the previously collected data to be omitted from the analysis. It would be beneficial for future studies to address and make associations between the baselines scores investigated in the present study with the data collected 6-months after baseline and 12-months after baseline. This comparison at two future points would provide insight into the predictive capabilities of the PMDC tool over time.

The use of a median split procedure to dichotomize PMDC scores into high and low scores could also be identified as a significant limitation. Various studies have identified the

risks of splitting continuous variables (Hunter & Schmidt, 1990; Iacobucci, Posavac, Kardes, Schneider, & Popovich, 2015; Streiner, 2002). At the time of data analysis, the project leader believed the use of a median split to dichotomize the PMDC scores into high and low scores was appropriate because the creators of the tool did not designate a benchmark PMDC score for appropriate parental monitoring. In future studies, PMDC scores could be assessed as a continuous variable in order to identify correlations with adolescent CDI and PedsQL scores.

Conclusion

Through this scholarly project, it has been affirmed that maternal monitoring plays an important role in the psychological wellbeing of adolescents with type 1 diabetes mellitus. Adolescents tended to have significantly fewer depressive symptoms when their mothers participated more in the diabetes management process. While adolescent quality of life was rather stable regardless of monitoring levels, adolescents whose mothers monitored more still had somewhat higher quality of life scores than those whose mothers reported less monitoring. With this being said, parents and caregivers of adolescents with type 1 diabetes mellitus should not only take into account the physical health implications that come with appropriate monitoring, but also the mental health implications that can occur when monitoring practices are suboptimal for the developmental stage of the adolescent. Employing monitoring techniques such as collaborative involvement when caring for adolescents with diabetes can have a profound impact on physical and psychological health, as it affords desired independence to the adolescent while also providing needed structure through nonintrusive monitoring techniques. Optimistically, the results from this scholarly project could be used to guide health practitioners in preemptively identifying adolescents who may be at risk for developing psychological health issues related to parental monitoring practices. Furthermore, the results could pave the way for

the routine use of the PMDC as an adequate evaluation tool to identify parents and caregivers who may need educational interventions to improve monitoring practices.

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Figure 1: Transactional Stress and Coping Model. Adapted from the Transactional Stress and Coping Model, Thompson & Gustafson, 1996.

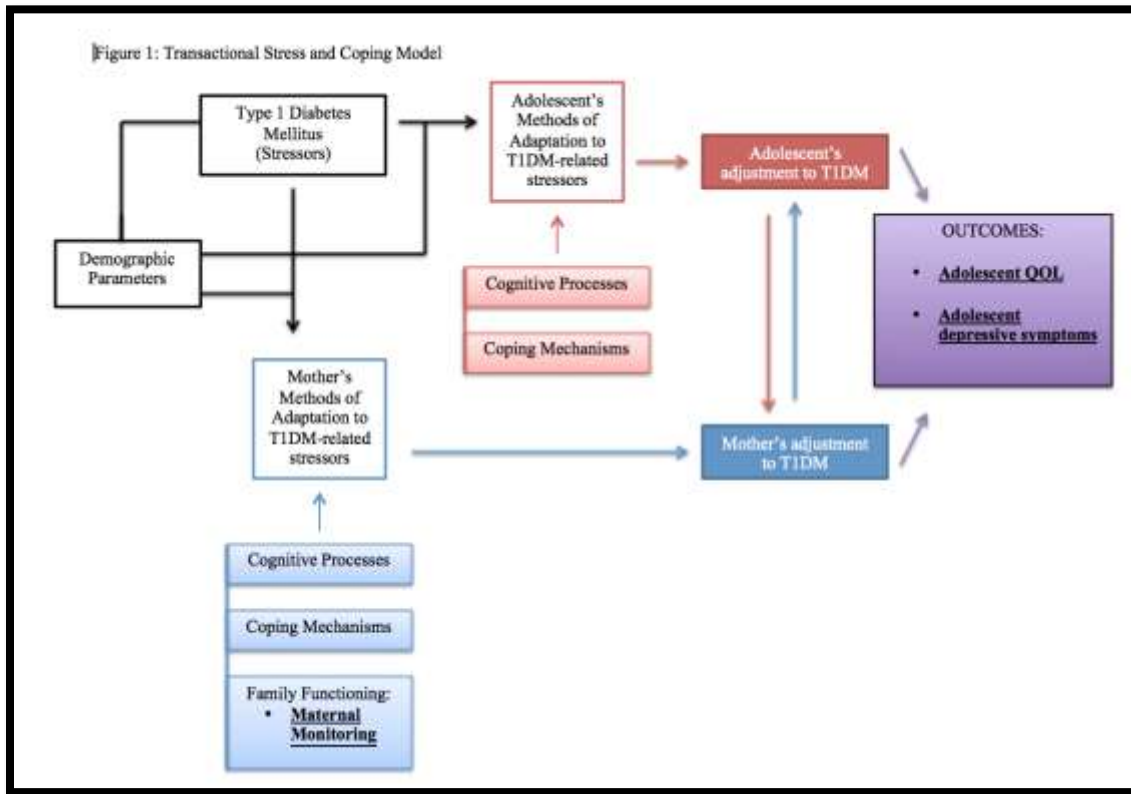


Table 1: Sociodemographic Characteristics of Study Sample

Variables - Mean (SD)	<i>N</i> (%)
<u>MATERNAL VARIABLES</u>	
Maternal Age - 44.23(5.782)	116
Maternal Race - 44.23(5.782)	117
Caucasian	105 (89.7%)
African American	7 (6.0%)
Asian	1 (0.9%)
Islander	3 (2.6%)
American Indian	0 (0%)
Biracial	1 (0.9%)
Other	0 (0%)
Marital Status	117
Single	10 (8.5%)
Married	87 (74.4%)
Divorced	19 (16.2%)
Widowed	0 (0%)
Common Law Partner	1 (0.9%)
Married/Non	117
Single/Divorced/Widowed	29 (24.8%)
Married/Partnered	88 (75.2%)
<u>CHILD VARIABLES</u>	
Child Age - 12.79(2.062)	117
Child Sex	117
Male	64 (54.7%)
Female	53 (45.3%)
Child Race	117
Caucasian	101 (86.3%)
African American	8 (6.8%)
Asian	1 (0.9%)
Islander	0 (0%)
American Indian	0 (0%)

Variables - Mean (SD)	<i>N (%)</i>
Biracial	7 (6.0%)
Other	0 (0%)
<u>DIABETES-RELATED VARIABLES</u>	
Diagnosis Duration-5.05(3.697)	117
Treatment Modality	117
Insulin Pump	97 (82.9%)
Insulin Injections	20 (17.1%)
HbA1c - 7.65(1.128)	117
<u>OTHER VARIABLES</u>	
Income	113
<\$20,000/year	3 (2.7%)
\$20,000-39,999/year	7 (6.2%)
\$40,000-59,999/year	11 (9.7%)
\$60,000-79,999/year	18 (15.9%)
\$80,000-99,999/year	13 (11.5%)
>\$100,000/year	61 (54.0%)
Income Category	112
<\$80,000/year	38 (33.9%)
\$80,000/year or more	74 (66.1%)

Table 2: PMDC and CDI

	MEAN RANK		<i>U</i>	<i>z</i>	<i>P value</i>
	Low PMDC	High PMDC			
PMDC	48.64	70.63	1033.00	-3.523	<0.001***

*Significant at $p < 0.1$; **Significant at $p < 0.05$; *** Significant at $p < 0.01$

Table 3: PMDC and PedsQL

	MEAN RANK		<i>U</i>	<i>z</i>	<i>P value</i>
	Low PMDC	High PMDC			
PMDC	62.25	50.62	1255.50	-1.879	0.060*

*Significant at $p < 0.1$; **Significant at $p < 0.05$; *** Significant at $p < 0.01$

Table 4: PMDC Subdomains and CDI

CDI - Subdomain	MEAN RANK		<i>U</i>	<i>z</i>	<i>P value</i>
	Low subdomain	High subdomain			
CDI - Supervision of Availability of Medical Supplies/Devices	39.89	57.34	683.00	-3.092	0.002***
CDI - Monitoring Blood Glucose Checking	54.69	61.81	1358.50	-1.131	0.258
CDI - Oversight of Diet	47.90	68.34	931.00	-3.293	0.001***
CDI - Monitoring of Nonadherence	47.39	62.44	1048.50	-2.506	0.012**
CDI - Direct Oversight of Diabetes Management Behaviors	50.53	62.41	1090.00	-1.931	0.056

*Significant at $p < 0.1$; **Significant at $p < 0.05$; *** Significant at $p < 0.01$

Table 5: PMDC Subdomains and PedsQL

PedsQL - Subdomain	MEAN RANK		<i>U</i>	<i>z</i>	<i>P value</i>
	Low subdomain	High subdomain			
PedsQL - Supervision of Availability of Medical Supplies/Devices	49.86	41.29	832.00	-1.541	0.123
PedsQL - Monitoring Blood Glucose Checking	55.22	57.19	1421.50	-0.317	0.751
PedsQL - Oversight of Diet	58.32	48.94	1163.50	-1.530	0.126
PedsQL - Monitoring of Nonadherence	57.97	47.53	1101.50	-1.756	0.079*
PedsQL - Direct Oversight of Diabetes Management Behaviors	53.46	53.58	1303.50	-0.020	0.984

*Significant at $p < 0.1$; **Significant at $p < 0.05$; *** Significant at $p < 0.01$

Appendix A.

Demographic Data Questionnaire

ID: _____

Child's birth date _____ Child's age _____

Child's date of diagnosis _____

Injections or Insulin pump _____ Date started pump _____

Gender: Male _____ Female _____

Grade in School: _____

Information to be obtained from parent:

How many children are in the family? _____

What is the birth order of this child?

- _____ (1) First born
- _____ (2) Second born
- _____ (3) Third born
- _____ (4) Fourth born
- _____ (5) Other

Ethnic Categories: Do you consider your child?

Hispanic or Latino _____

Not Hispanic or Latino _____

Racial Categories: Do you consider your child?

- American Indian/Alaskan Native _____
- Asian _____
- Black or African American _____
- Native Hawaiian or other Pacific Islander _____
- White _____
- More than one race of the races listed above _____
- Other _____

Does this child have any other problems with his or her health?

___ Yes If yes, what? _____

___ No

Your health problems (if any): _____

What is mother's occupation? _____

What is father's occupation? _____

How many years of education have each of the parents had?

___ Mother

___ Father

Your age: _____

(PLEASE CIRCLE YOUR ANSWERS)

What is the yearly household income (before taxes)?

- Less than \$19,999.....1
- \$20,000-39,999.....2
- \$40,000-59,999.....3
- \$60,000-79,999.....4
- \$80,000-99,999.....5
- More than or equal to \$100,000.....6

Your relationship to the child:

Mother Guardian Other (please specify): _____

Marital Status:

Single Married/Partnered Divorced Widowed

Other Adults living in Home:

Significant Other Grandparent Aunt/Uncle Other _____

Appendix B.

Parental Monitoring of Diabetes Care Scale (Developed by Ellis et al., 2008)

ID: _____
Date: _____

Parent-Teen Diabetes Behaviors – Parent Report

This questionnaire asks some questions about interactions that you may have with your child that have to do with their diabetes care. We would like to know how often you have done these things in the past MONTH. The past month is the period from _____(date) to _____(date).

Please answer in regard to yourself only, not including any other caregivers.

1. How often were you present at home when your child tested his/her blood glucose?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

2. How often were you present in the room when your child tested his/her blood glucose?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

3. When your child skips a blood glucose test, how often do you know?

All of the Time (1)	Most of the time (2)	Sometimes (3)	Hardly every (4)	Never (5)
------------------------	----------------------------	------------------	---------------------	--------------

4. When your child skips a blood glucose test, how quickly do you know?

Within a few hours (1)	Within a day (2)	Within a few days (3)	Within a week (4)	Within a few week (5)
------------------------------	---------------------	-----------------------------	----------------------	-----------------------------

5. How often do you look at the readings in your child's blood glucose meter?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

6. How often do you review or go over your child's blood glucose test readings with him/her?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

7. How often were you present at home when your child gave him/herself insulin?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

8. How often were you present in the same room when your child gave him/herself insulin?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

9. When your child skips his/her insulin, how often do you know?

All of the Time (1)	Most of the time (2)	Sometimes (3)	Hardly every (4)	Never (5)
------------------------	----------------------------	------------------	---------------------	--------------

10. When your child skips his/her insulin, how soon do you know?

Within a few hours (1)	Within a day (2)	Within a few days (3)	Within a week (4)	Within a few week (5)
------------------------------	---------------------	-----------------------------	----------------------	-----------------------------

11. How often do you check your child's insulin vials to see if the expected amount has been used?

Before it runs out (1)	Within a few hours (2)	Within a day (3)	Within a few days (4)	Within a week or more (5)
------------------------------	------------------------------	---------------------	-----------------------------	---------------------------------

12. How often do you eat meals with your child (sit down together and eat at the same time)?

More than once a day (1)	Once a day (2)	3-4 times a week (3)	Once a week (4)	Less than once a week (5)
--------------------------------	-------------------	----------------------------	--------------------	---------------------------------

13. When you do not eat meals with your child such as lunch at school) how often do you know what he/she ate?

All of the Time (1)	Most of the time (2)	Sometimes (3)	Hardly every (4)	Never (5)
------------------------	-------------------------	------------------	---------------------	--------------

14. How often does your child eat food (meals or snacks) outside of the home [including at school, neighbors, with relatives, at the mall, restaurants, stores, etc.]

More than 6 times a day (1)	5-6 times a day (2)	3-4 times a day (3)	2 times a day (4)	Once a day (5)
--------------------------------	------------------------	------------------------	----------------------	-------------------

15. When your child's blood glucose meter breaks or gets lost or misplaced, how quickly do you know?

Within a few hours (1)	Within a day (2)	Within a few days (3)	Within a week (4)	Within a few weeks (5)
---------------------------	---------------------	--------------------------	----------------------	---------------------------

16. When your child runs out of strips and lancets, how quickly do you know?

Within a few hours (1)	Within a day (2)	Within a few days (3)	Within a week (4)	Within a few weeks (5)
---------------------------	---------------------	--------------------------	----------------------	---------------------------

17. When your child runs out of insulin, how quickly do you know?


Within a few hours (1)	Within a day (2)	Within a few days (3)	Within a week (4)	Within a few weeks (5)
---------------------------	---------------------	--------------------------	----------------------	---------------------------

18. When your child's insulin is going to expire, how quickly do you know?


Before it expires (1)	Within a few hours (2)	Within a day (3)	Within a few days (4)	Within a week or more (5)
--------------------------	---------------------------	---------------------	--------------------------	------------------------------

Appendix C.

PedsQL 3.0 Type 1 Diabetes Module (Developed by Varni, 1998)


 11082

PedsQL Version 3.0
TEEN REPORT (ages 13-18)



Interview No:

Site ID:

Participant ID:

Date: / /

DIRECTIONS

Teenagers with diabetes sometimes have special problems. Please tell us *how much of a problem* each one has been for you during the past ONE month by filling in a bubble:

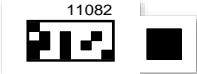
0 if it is never a problem
 1 if it is almost never a problem
 2 if it is sometimes a problem
 3 if it is often a problem
 4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past ONE month, how much of a problems has this been for you....

ABOUT DIABETES (<i>problems with...</i>)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel hungry	0	1	2	3	4
2. I feel thirsty	0	1	2	3	4
3. I have to go to the bathroom too often	0	1	2	3	4
4. I have stomach aches	0	1	2	3	4
5. I have headaches	0	1	2	3	4
6. I go "low"	0	1	2	3	4
7. I feel tired or fatigued	0	1	2	3	4
8. I get shaky	0	1	2	3	4
9. I get sweaty	0	1	2	3	4
10. I have trouble sleeping	0	1	2	3	4
11. I get irritable	0	1	2	3	4

Study ID:


 11082

Page 1 of 2



Interview No:

Participant ID:

TREATMENT-I (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It hurts to prick my finger or give insulin shots	0	1	2	3	4
2. I am embarrassed about having diabetes	0	1	2	3	4
3. My parents and I argue about my diabetes care	0	1	2	3	4
4. It is hard for me to stick to my diabetes care plan	0	1	2	3	4

Whether you do these things on your own or with the help of your parents, please answer how hard these things were to do in the past ONE month

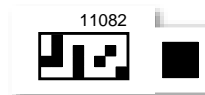
TREATMENT-II (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard for me to take blood glucose tests	0	1	2	3	4
2. It is hard for me to take insulin shots	0	1	2	3	4
3. It is hard for me to exercise	0	1	2	3	4
4. It is hard for me to keep track of carbohydrates or exchanges	0	1	2	3	4
5. It is hard for me to wear my ID bracelet	0	1	2	3	4
6. It is hard for me to carry a fast-acting carbohydrate	0	1	2	3	4
7. It is hard for me to eat snacks	0	1	2	3	4

In the past ONE month, how much of a problems has this been for you...

WORRY (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. I worry about "going low"	0	1	2	3	4
2. I worry about whether or not my medical treatments are working	0	1	2	3	4
3. I worry about long-term complications from diabetes	0	1	2	3	4


COMMUNICATION (problems with...)	Never	Almost Never	Sometimes	Often	Almost Always
1. It is hard for me to tell the doctors and nurses how I feel	0	1	2	3	4
2. It is hard for me to ask the doctors and nurses questions	0	1	2	3	4
3. It is hard for me to explain my illness to other people	0	1	2	3	4

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Appendix D.

CDI Tool (Developed by Kovacs, 1985)



35182

CD Inventory



Participant ID: X X

Interview No:

Date: / /

Study ID: 2 0 1 1

Site ID: X X

KIDS SOMETIMES HAVE DIFFERENT FEELINGS AND IDEAS.

THIS FORM LISTS THE FEELINGS AND IDEAS IN GROUPS. FROM EACH GROUP, PICK **ONE** SENTENCE THAT DESCRIBES YOU BEST FOR THE PAST TWO WEEKS. AFTER YOU PICK A SENTENCE FROM THE FIRST GROUP, GO ON TO THE NEXT GROUP.

THERE IS NO RIGHT ANSWER OR WRONG ANSWER. JUST PICK THE SENTENCE THAT BEST DESCRIBES THE WAY YOU HAVE BEEN RECENTLY. PUT A MARK LIKE THIS "X" NEXT TO YOUR ANSWER. PUT THE MARK IN THE BOX NEXT TO THE SENTENCE THAT YOU PICK.


HERE IS AN EXAMPLE OF HOW THIS FORM WORKS. TRY IT. PUT A MARK NEXT TO THE SENTENCE THAT DESCRIBES YOU **BEST**.

EXAMPLE:

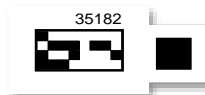
- I READ BOOKS ALL THE TIME
- I READ BOOKS ONCE IN A WHILE
- I NEVER READ BOOKS

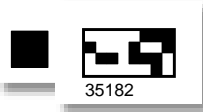
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Version 7/77 with format change 8/79



Page 1 of 5





CD Inventory

Participant ID: X X

Interview No:

REMEMBER, PICK OUT THE SENTENCES THAT DESCRIBE YOUR FEELINGS AND IDEAS IN THE PAST TWO WEEKS.

1. I AM SAD ONCE IN A WHILE
 I AM SAD MANY TIMES
 I AM SAD ALL THE TIME
2. NOTHING WILL EVER WORK OUT FOR ME
 I AM NOT SURE IF THINGS WILL WORK OUT FOR ME
 THINGS WILL WORK OUT FOR ME O.K.
3. I DO MOST THING O.K.
 I DO MANY THINGS WRONG
 I DO EVERYTHING WRONG
4. I HAVE FUN IN MANY THINGS
 I HAVE FUN IN SOME THINGS
 NOTHING IS FUN AT ALL
5. I AM BAD ALL THE TIME
 I AM BAD MANY TIMES
 I AM BAD ONCE IN A WHILE
6. I THINK ABOUT BAD THINGS HAPPENING TO ME ONCE IN A WHILE
 I WORRY THAT BAD THINGS WILL HAPPEN TO ME
 I AM SURE THAT TERRIBLE THINGS WILL HAPPEN TO ME
7. I HATE MYSELF
 I DO NOT LIKE MYSELF
 I LIKE MYSELF
8. ALL BAD THINGS ARE MY FAULT
 MANY BAD THINGS ARE MY FAULT
 BAD THINGS ARE NOT USUALLY MY FAULT





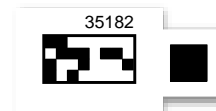
CD Inventory

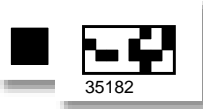


Participant ID:

Interview No:

9. I DO NOT THINK ABOUT KILLING MYSELF
 I THINK ABOUT KILLING MYSELF BUT I WOULD NOT DO IT
 I WANT TO KILL MYSELF
10. I FEEL LIKE CRYING EVERYDAY
 I FEEL LIKE CRYING MANY DAYS
 I FEEL LIKE CRYING ONCE IN A WHILE
11. THINGS BOTHER ME ALL THE TIME
 THINGS BOTHER ME MANY TIMES
 THINGS BOTHER ME ONCE IN A WHILE
12. I LIKE BEING WITH PEOPLE
 I DO NOT LIKE BEING WITH PEOPLE MANY TIMES
 I DO NOT WANT TO BE WITH PEOPLE AT ALL
13. I CANNOT MAKE UP MY MIND ABOUT THINGS
 IT IS HARD TO MAKE UP MY MIND ABOUT THINGS
 I MAKE UP MY MIND ABOUT THINGS EASILY
14. I LOOK O.K.
 THERE ARE SOME BAD THINGS ABOUT MY LOOKS
 I LOOK UGLY
15. I HAVE TO PUSH MYSELF ALL THE TIME TO DO MY SCHOOLWORK
 I HAVE TO PUSH MYSELF MANY TIMES TO DO MY SCHOOLWORK
 DOING SCHOOLWORK IS NOT A BIG PROBLEM
16. I HAVE TROUBLE SLEEPING EVERY NIGHT
 I HAVE TROUBLE SLEEPING MANY NIGHTS
 I SLEEP PRETTY WELL





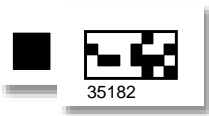
CD Inventory

Participant ID:

Interview No:

17. I AM TIRED ONCE IN A WHILE
 I AM TIRED MANY DAYS
 I AM TIRED ALL THE TIME
18. MOST DAYS I DO NOT FEEL LIKE EATING
 MANY DAYS I DO NOT FEEL LIKE EATING
 I EAT PRETTY WELL
19. I DO NOT WORRY ABOUT ACHES AND PAINS
 I WORRY ABOUT ACHES AND PAINS MANY TIMES
 I WORRY ABOUT ACHES AND PAINS ALL THE TIME
20. I DO NOT FEEL ALONE
 I FEEL ALONE MANY TIMES
 I FEEL ALONE ALL THE TIME
21. I NEVER HAVE FUN AT SCHOOL
 I HAVE FUN AT SCHOOL ONLY ONCE IN A WHILE
 I HAVE FUN AT SCHOOL MANY TIMES
22. I HAVE PLENTY OF FRIENDS
 I HAVE SOME FRIENDS BUT I WISH I HAD MORE
 I DO NOT HAVE ANY FRIENDS
23. MY SCHOOL WORK IS ALRIGHT
 MY SCHOOL WORK IS NOT AS GOOD AS BEFORE
 I DO VERY BADLY IN SUBJECTS I USED TO BE GOOD IN
24. I CAN NEVER BE AS GOOD AS OTHER KIDS
 I CAN BE AS GOOD AS OTHER KIDS IF I WANT TO
 I AM JUST AS GOOD AS OTHER KIDS





CD Inventory



Participant ID: X X

Interview No:

- 25. NOBODY REALLY LOVES ME
 I AM NOT SURE IF ANYBODY LOVES ME
 I AM SURE THAT SOMEBODY LOVES ME

- 26. I USUALLY DO WHAT I AM TOLD
 I DO NOT DO WHAT I AM TOLD MOST TIMES
 I NEVER DO WHAT I AM TOLD

- 27. I GET ALONG WITH PEOPLE
 I GET INTO FIGHTS MANY TIMES
 I GET INTO FIGHTS ALL THE TIME

THE END

THANK YOU FOR FILLING OUT THIS FORM

SUM

TYPE OF ADMINISTRATION: INDIVIDUAL
 GROUP

